

**Get Your Coat: Examining the Development of Independent Dressing Skills in  
Young Children with Visual Impairment in comparison with Young Children  
with Down syndrome and Typically Developing Children**

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### Declaration

I, Jessica Hayton, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I can confirm that this has been indicated in the thesis.

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Jessica Hayton

## Abstract

The ability to independently dress is a fundamental skill for children. Vision is an integrative sense. Sight affords the opportunity for individuals to learn independence skills via observation. The absence of vision, or a reduced visual capacity, restricts access to this form of learning (Lewis & Iselin, 2002). As a result of this restricted access, children with visual impairment (VI) and conditions where VI is a component (e.g. Down syndrome (DS)) require systematic and structured support. This is to facilitate the development of independent dressing skills. There has been little research to date relating to strategies for successful dressing, or the effectiveness of such strategies in children (as most of the research has been based around the re-habilitation of adults: e.g. Klein, 1983).

This thesis reports an observationally based pre-test, intervention, post-test study. It examines the effectiveness of novel intervention materials and systematic strategies to support independent dressing abilities in young children. The sample consisted of three groups of children. Namely, children with VI ( $n=9$ ; age range: 5;06-10;02 years), children with DS ( $n=9$ ; age range: 5;04-10;00 years) and typically developing children ( $n=9$ ; age range: 6;05-8;00 years) ( $N=27$ ; age range: 5-10 years). The effectiveness of the structured intervention was examined over a 10 week period. The longevity of skill development was assessed 1 month and 3 months post-intervention. In addition to the development of novel resources, a supporting document for teachers, parents and carers was developed in order to further support the delivery of the intervention.

The thesis reported that VI, DS and TD children benefited from the intervention and dressing strategies to support their development of independent dressing skills. Clear systematic instruction combined with motor activities were found to be useful in the development of dressing skills. The findings from this thesis inform future research regarding the development of independent dressing skills, and could also form a model for future work regarding other skill areas such as personal care and eating in relation to other clinical groups e.g. William's Syndrome.

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## List of Terms and Abbreviations

ASD. *Autistic Spectrum Disorder*

BPS. *British Psychological Society*

CA. *Chronological Age*

CVA. *Clinical Vision Assessment*

CVI. *Cerebral Visual Impairment*

CYP. *Children and Young People*

DS. *Down Syndrome*

DSB. *Digit Span Backward*

DSF. *Digit Span Forward*

DVA. *Distance Visual Acuity*

EYFS. *Early Years Foundation Stage*

FVA. *Functional Vision Assessment*

HAB-VI. *Habilitation for Visually Impaired*

H-O-H. *Hand over Hand*

H-U-H. *Hand under Hand*

ILS. *Independent Living Skills*

ILSD. *Independent Living Skill of Dressing*

IPG. *Interactive Puzzle Game*

IQ. *Intelligence Quotient*

LDSB. *Longest Digit Span Backward*

LDSF. *Longest Digit Span Forward*

LSA. *Learning Support Assistant*

MA. *Mental Age*

PE. *Physical Education*

RNIB. *Royal National Institute for the Blind*

SEN. *Special Educational Needs*

SENCO. *Special Educational Needs Coordinator*

SEND. *Special Educational Needs and Disabilities*

SENDA. *Special Educational Needs and Disability Act*

TA. *Teaching Assistant*

TD. *Typically Developing*

UK. *United Kingdom*

USA. *United States of America*

UNCRPD. *United Nations Convention on the Rights of Persons with Disabilities*

VI. *Visual impairment*

VI+SEN. *Visual impairment and an additional Special Educational Need*

WISC-IV. *Wechsler Intelligence Scale for Children 4<sup>th</sup> Edition*

ZPD. *Zone of Proximal Development*

## Glossary of Definitions

*Developmental Delay:* The difference between standardised test scores of individuals with a developmental disorder, when compared to typically developing, chronological age-matched groups.

*Developmental delay (relating to atypicality):* The difference in performance on standardised test scores in individuals with developmental disabilities when compared to TD groups, matched on chronological age and mental age.

*Habilitation:* The development and teaching of independent living skills in children with developmental disabilities who are moving toward independence.

*Haptic perception:* the information directly perceived through the hands and fingers.

*Incidental learning:* an acquisition of skills and knowledge as a by-product of an activity.

*Learning:* an approximate permanent change in behaviour, resulting from practise.

*Mobility:* The safe, efficient, focused and directed movement of an individual throughout the environment.

*Orientation:* An individual's ability to understand their position in space, both relating to their body and their environment.

*Reflexes:* temporary, innate survival instincts (present from birth to 1 year, dependant on the reflex) which reflect the infant's ability to respond to sensory stimulation.

*Theory:* a set of observation based parsimonious principles that describe change over time

*Theorisation:* the process of formulating a theory

*Visual Impairment:* A diagnosed optical condition at birth or early infancy which denies or restricts access to typical development in relation to motor skill acquisition and most likely atypical developmental pathways of other domains.

## **Thesis Overview**

The main aim of this thesis was to develop novel intervention materials to aid development of independent dressing abilities. Dressing skills were examined in children with visual impairment (VI), Down syndrome (DS) and typically developing (TD) children.

This thesis is divided into ten chapters and is presented in APA formatting. Chapter 1 provides a conceptualisation of the thesis as a whole. Chapter 2 reviews the current theories of habilitation and dressing abilities. This leads to Chapter 3 which discusses the literature regarding developmental disorders, namely VI and DS, and domains such as motor development, vision and motion as well as issues surrounding incidental learning. Following on from this Chapter 4 examines the history of habilitation, the importance of play, types of schooling and governmental policy. After the examination of the relevant literature, Chapter 5 presents a survey on the types of clothing fastenings that children (aged 0-14 years) are likely to be exposed to. Then, Chapter 6 presents a brief overview of the methods, including the issue regarding heterogeneity of variance used in this thesis. Taking the general methodology into account, Chapter 7 describes the pilot study which influenced the development of the intervention resources. The results of the pilot study subsequently informs Chapter 8, which includes the methods employed in the main study, including standardised measures, the apparatus and the intervention procedure. Chapter 9 then presents the results of the main study. Finally, Chapter 10 discusses the findings of the main study in light of the results, the established research questions and the examined literature. Chapter 10 also addresses limitations, implications and highlights the contribution to knowledge.

## 1. Introduction

This thesis concerns the development of the independent living skill of dressing (ILSD) in three distinct but related groups of children. These children are identified as young children with visual impairment (VI), young children with Down syndrome (DS) and typically developing (TD) children.

It might be supposed that as dressing is an integral part of everyday life, regardless of needs, previous research would have been undertaken in terms of finding the most effective ways of developing ways of dressing in developing children with a range of needs. Every day an individual has a need to get dressed. Whether the act of dressing is carried out independently or not, society dictates that an individual should be dressed, despite the fact that we were all born naked. It is considered socially unacceptable for an individual to walk around naked. If an individual does not or cannot dress themselves, somebody else takes responsibility for dressing the individual. This means that we either dress ourselves or are dressed by others.

The concept of dressing represents a developmental process in which parents and carers are the first dressers. They make the decisions and the choices about what we wear and when we wear it. Through social interactions with parents/caregivers (because there is very little formal, explicit, school based type teaching) the question is how do children acquire dressing skills? This thesis will argue that this acquisition of ILSD (viewed from a social-constructivist perspective) is through sighted observation and incidental learning. This process of acquired learning expertise is done experientially through practising. This process of practise is extensive and gradually built up over time.

The developing child progresses by the parents' instruction and the child's active participation in the dressing routine. This development occurs to the point of which, in optimal conditions, that the child is increasingly able to dress themselves over their development, transitioning from dependence to independence. This incremental development leading to independent dressing skills is usually attained by the time the child enters a formal schooling environment.

For those with identified needs, the developmental trajectory of the child may be interrupted. This is due to physical, sensory or coordination reasons which may delay or impact the acquisition of independent dressing skills. We might therefore expect to see this issue raised in the available literature, however as the literature search demonstrated, this is not the case. In actuality, a detailed investigation of the best strategies to support independent dressing appears not to have been investigated systematically since the early 1950s.

In the absence of literature, investigating or identifying the need for the development of such dressing strategies has been acknowledged anecdotally and is alluded to but not explicitly mentioned in certain literatures. This is done in relation to a barrier to developing adaptive behaviour, of which dressing is a sort (Sugden & Wade, 2013; Herbert, 2003). There is a suggestion therefore that there is an issue surrounding the development of dressing skills in particular population of need, and it is argued here that this is perhaps most pertinent in the VI population for the following reasons:

- Children with VI have an inability or reduced capacity to learn incidentally through sighted observation
- Children with VI have an inability or reduced capacity to use the visual modality to refine and control hand-eye and body coordination (Sugden & Wade, 2013),
- Children with VI are less likely to move around and explore their environment, subsequently restricting incidental haptic learning experiences (Bowman, Bowman & Dutton, 2001)

With an awareness of these reasons, and aware of the absence of literature, the rationale for this project arose as a result of a desire to create a systematic intervention protocol. The development of such protocol would enable the dressing process to be more carefully understood and executed within the schooling environment, and, incidentally, with parents. The schooling environment was chosen as attaining independence is a curriculum entitlement, and also, affords the opportunity for children to work in groups which could encourage peer learning through social interaction. Social interaction and its link to learning will be explored later in this chapter.

By developing a systematic protocol to support ILSD, the current project also sought to gather empirical evidence via task analysis. This was done to better understand the nuanced development of dressing skills over the intervention period, as the whole task (e.g. fastening a zip) was split into smaller, yet observable, sequences (e.g. pinching the zip). This sequential approach to developing ISLD could be indicative of skill development and acquisition in children with children with VI and/or DS and TD children. Much of the published literature which may inform this is based around rehabilitation techniques that remain to be used to develop ILSD in children with disabilities including children with VI (Klein, 1983). The existing literature is outdated, prescriptive and not based on habilitation techniques.

Habilitation techniques are methods (informed by task analysis) used to aid the development of independence in individuals who have an impairment from birth (Miller, Wall & Garner, 2011). The concept of habilitation is not a new idea. The concept was discussed in the 1970s,

however the term '*inclusion*' became more popular within the literature. The conceptualisation of habilitation receded until the early 2000s when the term re-emerged largely due to the publication of the Quality Standards (Miller, Wall & Garner, 2011). Despite the reconceptualization of habilitation, there remains to be an appropriate, coherent, unifiable theory underpinning habilitation. Currently, the concept of habilitation has sought to begin to unify the previously distinct three components: orientation, mobility and independent living skills (ILS).

As the investigation of relevant literature will make apparent, ILS development is, in a sense an emergent field, and not one that currently exists in a formal theorised way. This begs the question of how one develops a theory in an emergent, practice based field. One way of addressing this is to examine theories in the relevant literature, and to examine direct interactions between theories and practice. This examination involves developing an understanding of their utility, their interrelationships and their appropriateness in relation to the methodological processes that are being used. From this, a process of theorisation and theory development can occur.

In the current thesis it was necessary to examine the literatures from related fields that would make a contribution to the development and discrimination of ILS as a distinct field. The literature review suggests that there is not currently a concrete, direct relationship between theory and practice in terms of the development of ILS. A key part which became apparent in the literature review is that there are many divergent theorisations in place informing the current thesis. To that end, this thesis has to undertake a process of theorisation. Theorisation was considered appropriate given the nature of the thesis, as the thesis begins to draw parallels between theory and practice.

The contributing theories to the overall theorisation include: Vygotsky's Zone of Proximal Development (Vygotsky, 1978), Neuroconstructivism (Karmiloff-Smith, 1998) and Baddeley's Working Memory Model (Baddeley, 2003). These theories were brought into focus in relation to the purpose of the project (the development of ILSD in 3 groups). The theories examined, however, were inconsistent in demonstrating the ability to directly link theory to practice. As a result of this, a theorisation was adopted in the current thesis which moves toward the creation of a theoretical underpinning for the project in terms of epistemology, phenomenology and ontology. By systematically examining literature in relation to the project, social-constructivism is a theoretical perspective that is used both implicitly and explicitly in the related literature. Arguably all three chosen theories are related to the broader theoretical perspective of social-constructivism.

The examined literature across the next three literature based chapters suggest that learning and development occur through implicit and explicit interactions between an individual and their environment over time. This is broadly conceptualised by Vygotsky's theory of social-constructivism (Vygotsky, 1978). The theory of social-constructivism as proposed by Vygotsky (1978) postulated that the development of an individual occurs via interactions between an individual and their environment. However, processes underlying development and learning are conceptualised differently in relation to typical and atypical populations. Within a typical population it was argued that learning and development of motor skills (for example) occurred incidentally, through sighted observation. In atypical populations such as VI, access to incidental learning is restricted or denied as a result of an impaired visual sensory modality.

The inability to learn through sighted observation, therefore has an impact on accessibility to learning experientially. A method of which to overcome the restriction to incidental learning is by appealing to the intact, available sensory modalities to promote optimal development. In the absence of any centralised theory unifying the components of habilitation, the current project broadly drew upon and was informed by the theory of social-constructivism. As the nature of the current project is to develop ILSD in young children, it is arguable that the development of such skills has a reliance on the interaction between an individual and the objects (including people) within their environment that facilitate the development of ILSD. There is an issue in adopting this broad theoretical stance, however. This is largely due to an inability to generalise theoretical claims that are based on typically developing, normative samples (Warren, 1984).

The application of typically derived developmental theories to atypically developing populations is problematic. This is because the theories are largely based on the observation of "typical" behaviour. Therefore the boundaries of any theoretical perspective do not necessarily extend to populations that are atypical. This is due to theoretical claims being drawn from homogeneous typically developing samples in order to make generalizable claims. Warren (1984) acknowledged that there was a need to develop theoretical frameworks to encompass heterogeneous atypical populations. He also noted that the majority of research in developmental disability at the time of writing was isolated and could not be generalised to a broader theoretical framework (Warren, 1984).

Although the aforementioned are established theories that relate to the project, there is no clear or established relationship between theory and practice. The theories may be applied to the project however fall short as a result of their application to atypical populations and their link to practice. The current project is heavily practice based and although guided by phenomenology, ontology and epistemology, the project can only seek bridges between

existing theoretical ideas and the current understanding of practice. This is because the bridges between theory and practice have not yet been established. The current thesis is an attempt to begin to engage in and initiate a more comprehensive theorisation than has previously been explored in relation to habilitation and ILS. After systematically reviewing related literatures, the thesis is the first literature source to attempt this.

From the issue of the application of typically derived theories to atypical populations, the relationship between atypical populations and their environment needs to be explored. It could be argued that the most effective way of examining the relationship between atypical populations and their environment is by bringing to focus the Ecological systems theory of development (Bronfenbrenner, 1994). This is because the model is flexible enough to accommodate atypicality such as VI. However, the adoption of this theory is problematic within itself.

In the most conventional sense, the Ecological systems theory (Bronfenbrenner, 1994) posits a focus on the individual (usually a child) typically within a 5 layer model, where the individual is the epicentre. Each surrounding layer of the model represents environments of which the child has exposure to. The most proximal environments (such as home and school) are in the layer closest to the individual. The model then extends outward to encapsulate factors within environments that may have influence or be influenced by the individual. It is important to note that what the individual does influences the system, and vice versa. Within the Ecological systems theory, key figures can also have an impact on the development of the individual. For the purpose of the current argument, the individual will be the child. Examples of key figures in the child's system are parents, teachers, siblings and peers. The role of key figures is problematic in the model. This is because the model applies only to the child in focus. In this instance, if the child is the focus of the model, parents, teachers and professionals may occupy different layers of the model or remain in the same layer and interact with each other. This interaction between occupants of the layers is not acknowledged in the model as the focus is on the individual in the epicentre.

McLinden, Douglas, Cobb, Hewett & Ravenscroft (2016) adopted the Ecosystems theory to examine the role of specialist teachers for the visually impaired in supporting access to the curriculum. Within this, it is mentioned that one role of the specialist teacher was to "contribute to" assessing SEND for each child. This application appears to conflate interactions between the child and the teacher which then shifts the paradigm from the focus of the child, to the focus of the teacher. The teacher and their role should hypothetically become the focus of the system, and the pupil should then become an interactant. This is because the child's access to the curriculum is based around interactions with the teacher,

who is also interacting with other professionals, practitioners, parents and such in order to then make an appropriate decision for enabling the child to access the curriculum, including ILS provision.

One way to account for ILS in the school context is that teachers, teaching assistants and, to an extent, researchers play a part in the development of the skills, but they are not the sole descriptor. Not least because at the centre of the ecosystem is the child. The child would remain to be the focus of the application of Ecosystems theory (Bronfenbrenner, 1994) in this thesis because the project concerns what is happening to the child in terms of ILSD development. Key elements toward developing ILSD, however include the teacher, teaching assistant (TA) and the researcher (who would also be developing within their own Ecosystems). However the researcher is only present in the layer when the research is being undertaken. The role of the researcher is more transient than that of a teacher or TA. In normal school based ILSD learning (i.e. when research is not being undertaken), the researcher would not be present. The presence of the researcher in this case is directly due to the project, not the overall entitlement to ILSD development. When the researcher becomes apparent in the child's Ecosystem, another interactant is present within the layer most proximal to the child.

In the general development of ILSD there would also be an influence from the home environment. In the case of the current thesis, this influence is not explicit or investigated as the project was entirely school-based. There is, however, a route for input in a home-school link so that would be facilitating ILSD for the child, yet is outside the area of investigation for the project. What unifies and underpins the Ecological Systems theory is social constructivism. The Ecological theory (Bronfenbrenner, 1994) is a particular instantiation of the way in which accumulated social interactions can lead to learning. The prior theory on which the Ecological systems theory is based is actually social constructivism. Within that prior theory is Vygotsky who advocated "tool based" instruction in terms of language, and also postulated an understanding of skills developed through social interactions.

The Ecological systems theory could have been adopted within the current project, however due to associated issues with the focus of the model, it was considered unsuitable. The project could have examined the development of the child as the centre of the Ecosystem, but by adopting this approach, the interactions between the child and others, and also the interactions between the others (e.g. between parents and teachers) would have also had to have been accounted for. This would conflate the research aims. In order to effectively adopt the Ecological systems theory, the focus would have had to have been the researcher. This was not the purpose of the project. The aim of the project was to develop ILSD in children.

By shifting focus in the Ecological model, the dynamics of the project would have been altered.

Furthermore, the research was conducted within a school context, which did involve interactions between teachers, TAs and the researcher, yet parental involvement was still required. This was because of consent and background measures that needed to be collected. Although there was not a direct interaction between the researcher and the parents, they were still involved within the development of ILSD. This means that the researcher was not an influence on the parent, however the child did have influence the parent, for example going home and practicing ILSD. This raises the question of the utility of the Ecological systems theory. When applying the theory to practice as in the case of the current thesis, there are many limitations. Although it is acknowledged in the literature that there are weaknesses within the model, they have yet to have been overcome.

It is argued that theorisation is needed to help drive the focus of the current thesis and also inform the research questions, but the theorisation needs to accurately represent the practical reality and should not distort it. By examining the Ecological Systems theory, the distortion of the aims of the project is demonstrated by shifting the focus of the model. To overcome this issue, the recommendation of a theory has to be clear enough to act on. It has been made clear that the underpinning theory of the Ecological model is Vygotsky's theory of social constructivism. As aforementioned the ZPD is one aspect of the theory. The ZPD is understood to be the difference between an individual's actual state of skill and their potential (Vygotsky, 1978). It is argued that the difference can be lessened by a "more experienced other". In the current thesis, a "more experienced other" is an adult (either the researcher or the TA) who work with the children to support the transition to independent dressing.

An "adult" is a subset of "more experienced others". This is because the term "more experienced others" extends further beyond "adults" as it may be found that some adults cannot support the development of ILSD. To this end, "more experienced others" are different categories of people who take you through the ZPD. They can be parents, teachers, siblings and/or peers. The term is not governed by chronological age, it is governed by experience. As the intervention in the current thesis was group based, it meant that there was opportunity for the participants to support each other, this means that there are multiple levels to the degree of more experienced other. Although the children were participating in the intervention due to their ability, some children supported their peers and helped them with the process of developing ILSD. Vision, for example, also better facilitated the role of more experienced other, as the children could visually observe their peers struggling and so

offered support. It is subsequently identified that there are two broad sorts of more experienced others: peers and adults. The current thesis is focussed on adults, however infiltration from the peers could not be stopped during the intervention procedure.

The models of training that have been previously developed relied heavily on repetition and were grounded in task analysis (Klein, 1983). Task analysis is a process by which tasks are broken down into sequential stages to support skill development. Task analysis is an approach used in the current thesis to support the development of ILSD. As a result of task analysis, developing individuals are required to learn a sequence of stages to facilitate task completion. This is reliant upon memory. In relation to the two clinical samples (VI and DS), memory issues may well be problematic in terms of the intervention procedure and training as a result of their diagnoses. In light of this, a key contemporary theory in relation to theory is Baddeley's Working Memory Model (Baddeley, 2003).

The working memory model demonstrated the role of attention and rehearsal in order to encode items into either a short term- or long term- memory store. Baddeley's working memory model is applicable to both typical and atypical population, without the need for substantial modification (A. Baddeley, personal communication, 2016). This is because it is argued that access to each component to the model can be accessed, even if an individual has a sensory impairment such as VI (A. Baddeley, personal communication, 2016). This means that the application of the working memory model is not restricted to typical development, as compensation can occur within the components of the model.

The premise of social-constructivism and the issue of working memory, come together in the theory of Neuroconstructivism (Karmiloff-Smith, 1998). Neuroconstructivism is a theory of which cognitive functioning is explained in terms of "domain-relevance". This is useful given the current study as the thesis had to necessarily address memory and how information is made available in terms of sensory and motor experiences for example. This, however is only a starting point, there may well be other elements which can contribute towards the theorisation for the current thesis. The current theorisation, for example, does not directly address the roles of different individuals such as peers or siblings it only characterises adults as a more experienced other. From this, it could be argued that teachers are a different form of more experienced other. This is because they have undergone formal teaching qualifications and have qualified teacher status (QTS). This means that there is a difference between a Teacher (a person with formal training and QTS), and a teacher who teaches without formal training but their methods may be effective for incidental reasons.

McLinden, Douglas, Cobb, Hewett & Ravenscroft (2016) drew upon an ecological systems theory in order to better understand curriculum access for children and young people with VI

(CYPVI) by focusing on the Qualified Teacher for Visual Impairment (QTVI). They argued that conceptualisation was needed in order to understand how children with VI access the curriculum, and adopted a dual-model approach. Within this dual-model approach, the researchers investigated: the QTVI structuring an environment to promoting learning in CYPVI (“access to learning”); and, the QTVI supporting CYPVI to learn distinctive independence skills (“learning to access”) (McLinden, Douglas, Cobb, Hewett & Ravenscroft, 2016).

The work by McLinden, Douglas, Cobb, Hewett & Ravenscroft (2016) raised important issues in relation to the role of the QTVI to support CYP access to the curriculum. Whilst important to acknowledge that the role of the specialist teacher does play an important role in the accessibility to the core curriculum and the additional curriculum (e.g. ILS and mobility) for a CYPVI, it is important to note, however, that the implications of this paper are somewhat restricted in relation to the current project. This is because the focus of the paper by McLinden et al., (2016) is directly related to the role of the QTVI or specialist teacher. The focus of the current thesis, however, is in relation to the actual and physical development ILSD in three groups of children (VI, DS and TD). This means that although the researcher (acting as a specialist or “more experienced other”) played a role in the teaching and developing of ILSD, the focus of the project was directly related to the children developing ISLD within the schooling environment. This was done through structured intervention activities designed to compensate for restricted access to incidental learning (detailed further in Chapter 2).

One of the issues about more experienced other is that these interactions occur in different environmental contexts: home and school for example. Those contexts are not merely about the physical nature of the environment, other factors that have an influence on the environment are the cultural nature, knowledge nature, and the legislative nature. In the case of ILS in relation to SEND, the broader environmental context is framed by the Code of Practice in England (Department for Education & Department of Health England, 2015). The SEND Code of Practice 0-25 Years frames the legal entitlement and the availability of support for those with diagnosed and identified needs, but also extends to those who require support but await a formal diagnosis. Given the context of the current study, it was considered necessary to consider the Code of Practice but also have an awareness of its limitations. The most apparent limitation of the SEND Code of Practice in England is that it appears to have a reliance on the good practice of schools. This means that although habilitation provisions are included within the legislation, the utility is dependent on the schools acknowledging the importance of it, and sourcing appropriate provisions for children to develop from it.

The Code of Practice provided the legislative framework which had implications for practice in relation to SEND and the current thesis. As the research was done in a schooling environment that is subject to the legislation, we need to take account of it.

The provision of interventions to support ILS in young children is advocated within the SEND Code of Practice: 0-25 Years (Department for Education & Department of Health England, 2015). The SEND Code of Practice: 0-25 Years (Department for Education & Department of Health England, 2015) applied to all children (including TD, as some provisions may not be currently identified) provided the legal, health and educational context. This supported the work of the current thesis with regard to the development of ILS in order to prepare children for adulthood. Chapter 8 in the SEND Code of Practice: 0-25 Years (Department for Education & Department of Health England, 2015) states that the Early Years providers, schools and colleges should enable and encourage CYP to develop independence skills. This means that in educational settings (such as schools and nurseries) the developing of skills such as independence begins with Early Years providers in order to support a developing child's transition into adulthood (Department for Education & Department of Health England, 2015; Tutt & Williams, 2015).

The underlying principles supporting a child's transition into adulthood concern (but as not exclusive to): the general well-being and decision making abilities of the child and their parents; the dissemination of appropriate information concerning the provisional entitlement for the child (including specialist support and intervention); encouraging the "best possible" educational, social, physical and psychological outcomes in order to prepare the child for adulthood (McLinden, Douglas, Cobb, Hewett & Ravenscroft, 2016; Department for Education & Department of Health England, 2015; Tutt & Williams, 2015). McLinden, Douglas, Cobb, Hewett & Ravenscroft (2016) used the underlying principles of the SEND Code of Practice in England in order to examine the role of the QTVI for CYPVI. This was done to support the balance between "access to learning" and "learning to access". These principles do resonate with the current project in terms of provisional entitlement such as structured interventions, contact with parents and the choice of the child, however with regard to the current thesis, the focus is child-centred. This means that although the researcher (acting as a specialist) does play a role in the development of ILSD, the research addressed the development of ILSD in relation to the outcome of preparedness for adulthood presented in Chapter 8 of the SEND Code of Practice: 0-25 Years (Department for Education & Department of Health England, 2015).

Taking this chapter into account, the current research aims to address the following research question:

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1) 'To what extent can novel intervention materials support the development of gross and fine motor skills suitable for independent dressing in children with VI in a range of needs and contexts?'

To explore this question, more specific research questions focus on:

- 2) How do children with VI compare to DS and TD children in relation to ILSD development?
- 3) To what extent do novel and systematic intervention activities support the development of ILSD?
- 4) Can a novel observation schedule reliably and validly assess the development of ILSD in these groups?
- 5) Is there a need for a training manual designed for parents/caregivers and professionals to support the development of ILSD?

This project has involved a re-assessment of previous research and practice in the light of current and contemporary understandings of sensory and motor development in children. The research has also taken into account the historical background that has led to the changes of our understanding of sensory and motor development in children. This also involves developing novel interventions for habilitation programmes, rather than adapting previous interventions which are largely based on rehabilitation techniques (Miller, Wall & Garner, 2011; Klein, 1983).

The current project is the first of its kind to explicitly and empirically assess the immediate and longer-term impact of a novel intervention targeted at increasing ILSD in young children with VI, young children with DS and TD children. As aforementioned there is a lack of literature in relation to this topic. To overcome this, the thesis synthesises relevant literatures in order to provide a basis for exploring the development of ILSD in three groups (VI, DS and TD). To this end, the thesis is not presented in a "typical" format. Rather, the thesis draws upon relevant literatures (as there remains to be an established literature base) that explore three broad themes that are considered important in the development of ILSD. These themes are: Independent Living Skills; the relationship between vision and movement; and, habilitation in principle and practice. Each theme is contextualised in three separate chapters, however these chapters link together in order to contextualise the variety of different factors that might affect the development of ILSD in the three distinct, yet related groups.

The next three literature based chapters explore available research and theories in order to understand the context and existing literature base from which we can understand ILSD development. Each chapter explores a different theme which is related to the focus of enquiry

and the rationale of the current thesis. The first theme (explored in Chapter 2) is the development of ILS. The second theme (explored in Chapter 3) is typical and atypical development. The third theme (explored in Chapter 4) is the relationship between habilitation and ILS.

## 2. The Development of Independent Dressing Skills

### 2.0 Introduction

Chapter 2 is focused around the first theme of the thesis: Independent Living Skills (ILS). This chapter explores ILS as a broad term, and explores the issue of terminology in relation to relevant literatures. The role of visual impairment (VI) is examined in relation to ILS. This is because visual functioning is considered to substantially contribute to physical, psychological and social development in individuals. Within this context, the chapter then examines relevant literatures that explore the development of ILS in children with VI. The chapter then narrows focus to the independent living skill of dressing (ILSD) as this is the identified focus of the thesis. The role of the caregiver is examined in relation to the development of ILSD and then the chapter identifies the general, transferable skills that are required for successful dressing/undressing. Time is acknowledged as a major component in the development of ILSD, and it is argued that for speed and ease, an adult may take control of a dressing routine which reduces a child's access to developing emerging dressing skills.

The development of ILSD is then explored in relation to developmental disabilities. As the focus of the thesis is on the development of ILSD in two clinically defined groups (VI and DS), it is considered important to explore the impact that developmental delay (resultant from developmental disabilities) may have on the emerging skills. Time is acknowledged as a potential barrier or facilitator for the development of ILSD. It is argued in the thesis that children with developmental disabilities (such as VI and DS) develop in the same manner as TD children, however the development takes a longer period of time.

As the field of ISLD is limited in relation to available literature, the chapter then explores two available texts that remain to be used in practice. It is argued that these literatures are outdated, lack systematic and empirical evaluation and are based on rehabilitation work. It is acknowledged, however, that as they remain to be used in practice based setting, they provide a foundation for which the development of ILSD is understood. The thesis aimed to create an empirically based project which would support the development of ILSD in young children, and also update the literature in the field.

After exploring the "core" texts, the chapter then outlines the dressing sequence that is prescribed in the available literatures. The dressing sequence is based on "standard" and "adapted" techniques which remain to be used in a practical session. Based on these

approaches to dressing, the chapter then explores pre-requisite skills for dressing. The chapter notes that these skills are transferable across ILS, and argues that the ability to transfer skills is necessary in order to demonstrate a child's readiness and suitability to participate within a specialised intervention programme.

The current state of dressing practice is then explored as far as the literature will permit. The current thesis is the most recent understanding of the development of ILSD. The section mentions the SEND Code of Practice: 0-25 Years (Department for Education & Department of Health England, 2015), however this is later detailed in the fourth chapter which synthesises government policy, schooling and play in focus of the development of ILSD. This section also explores the main rationale for the thesis: the case for early intervention to support independent dressing skill development in young children with VI, young children with DS and young TD children.

Incidental learning is then explored in relation to the development of ILSD. This is because sighted children have the ability to visually observe and subsequently mimic and learn the skills and behaviours of others. A child with VI however has a reduced access to incidental learning and subsequently this must be compensated for in order to facilitate optimal development. It is argued in the chapter that compensation can occur by using clear and systematic instructions. The thesis drew upon the Montessori Method to illustrate this claim. This was because Montessori advocated the use of systematic instruction to facilitate learning in children. The first theorisation then emerged from the synthesis of relevant literature in relation to the development of ILSD. This was Vygotsky's Zone of Proximal Development (ZPD). The ZPD illustrates how adult support (termed as scaffolding) supports the development and task mastery in children. This theoretical approach is applied practically in the thesis. This is because the ZPD directly links to the intervention practice as the researcher provides hand over/under hand support and applies the concept of chaining to support task mastery in the child subjects. After outlining the ZPD and its importance within the context of developing ILSD, the chapter concludes with a short summary.

## **2.1 Independent Living Skills**

Independent living skills (ILS) is an umbrella term referring to a number of skills and their underpinning strategies. ILS skills such as 'mealtimes' and 'dressing' are considered to be essential for autonomous living (Miller, Wall & Garner, 2011). The underpinning strategies for these tasks support ILS skill development. This is because they refer to a specific and systematic order for successful task completion, for example to remove a front-buttoned shirt, you must first unfasten the buttons, then remove one arm at a time. Each aspect of this ILS

task is systematically broken down into meaningful stages and has accompanying strategies (e.g. unbuttoning top to bottom or bottom to top) to support task completion (Klein, 1983). The systematic strategies support the development of independence and mobility skills.

The development of independence and mobility (movement) skills are considered essential for active participation and safety in daily activity (Miller, Wall & Garner 2011; Pavey, Douglas, McLinden & McCall, 2003; Franks, 2000). Pavey et al., (2003) investigated the mobility and independence needs of children with visual impairment (VI) in mainstream schools. The research analysed: literature reviews; mobility and independence policy and curriculum documentation. The policy and curriculum documentation was sent to 156 Local Education Authorities (47% response rate;  $n=83$ ). From the sample, semi-structured interviews ( $n=72$ ); and focus groups (6 focus groups;  $n=36$ ) were conducted with professionals and people involved in the provision of mobility and independence needs.

One outcome of the focus group sessions indicated that better terminology was needed. Specifically, the term 'mobility' was favoured as an encapsulating term for 'orientation and mobility'. This was because the term 'mobility' arguably accounted for the broader issues within the development of mobility and independence skills such as communication skills and spatial and directional awareness (Pavey, Douglas, McLinden & McCall, 2003). In addition to this, as Mobility Specialists deal with a broader age range of children (from birth to 16+ years), the term was also considered suitable for encapsulating the wider age range. This was due to children having different provisional requirements within mainstream schooling during different stages of their development.

Although the term 'mobility' was arguably suitable terminology for the development of young children with VI, Aplin (2001, as reported in Pavey, Douglas, McLinden & McCall, 2003) proposed that the terminology was too generalised and in fact over simplified the nature of the necessary provision. Aplin (2001) suggested that as the same concepts underpin mobility and ILS, dividing the broader aspects of mobility and ILS into smaller stages (for learning and practice) would arguably benefit development of the skills. This division highlighted the common underlying concepts (such as body awareness and spatial awareness) which were postulated to contribute to the optimal development of mobility and independence (Aplin, 2001, in Pavey, Douglas, McLinden & McCall, 2003).

A merger of the two propositions suggests an overarching terminology to encapsulate the development of 'mobility' across the ages and stages of development of children and young people (CYP). This umbrella term would be consistently used with professionals and people

within the field. After establishing this umbrella term for 'mobility', the splitting of the contributing areas (such as ILS and social/emotional development) in relation to learning and practice could benefit the general understanding of the area. This is because 'mobility' is multi-faceted and so the splitting of underlying areas may explicitly identify areas that contribute toward the global 'mobility'. This split may also support the identification of specific provision for specific areas for development of 'mobility' skills within the mainstream schooling environment. This proposition suggests that the combination of the general and more specific aspects of mobility may benefit the inclusion of children with VI within a mainstream school. As the term 'mobility' encapsulated a number of areas, consistency and specificity in terminology could be considered crucial for understanding the development of CYP with VI. This is to ensure that appropriate provisions are made to support the general and specific mobility needs of CYP with VI.

Research regarding the needs of children with VI and sighted children has shown that visual functioning substantively contributes to physical, psychological and social development (Pavey, Douglas, McLinden & McCall, 2003). The development of a sighted child is facilitated by their ability to observe the activity of others. The observation of the *actions* of others underpins modelling and imitative behaviours which support motor skill development. These behaviours and/or abilities are often delayed or impaired in clinical conditions where VI is a component (Lewis, 1987). This is due to limitations in observation associated with VI. Through independence training (*habilitation*, which is the development of mobility, orientation and ILS), children with VI are encouraged to actively and independently engage with their surrounding environment and the other people in it. One aspect of the habilitation framework is to encourage children with VI to socially engage with typically developing (TD) children within the mainstream school environment (Pavey, Douglas, McLinden & McCall, 2003; Franks, 2000).

It is argued that vision is a facilitator for learning and so aids children's natural process toward independence (Pavey, Douglas, McLinden & McCall, 2003; Lewis & Iselin, 2002). Lewis and Iselin (2002) interviewed the parents of children with VI and the parents of children who were sighted peers of the VI sample. The interview was conducted in order to determine each child's mastery of 101 daily living skills (referred to in this thesis as ILS). The authors found that children with VI ( $n=10$ ; age range not specified) completed 44% of daily living tasks independently, whereas sighted children ( $n=10$ ; age range not specified) completed 84% of these tasks independently.

The findings of Lewis and Iselin (2002) demonstrated that sighted children are more “independent” in terms of completing daily living skill tasks. However sighted children still had an opportunity to further develop ILS skills. Children with VI were less able to complete daily living tasks independently. This finding may indicate the need for structured support and guidance in order to optimise their ILS development. One reason for the findings of Lewis and Iselin (2002) may be that sighted children are arguably able to achieve many forms of independence without structured guidance or instruction. This means that independence occurs incidentally, as a by-product of their sighted observation of others. A sighted child is able to copy or mimic observed adult behaviour. Children with VI do not develop or have delayed access to incidental learning abilities (if an action or behaviour is not visible to the child). This suggests a need for specific interventions designed to teach independence skills through systematic instruction. Children with VI and/or VI with other special educational needs (VI+SEN) use other available sensory routes such as touch (haptic perception) in order to access the learning of independence skills (McLinden, 2012; McLinden & McCall, 2010 as referenced in McLinden, 2012).

McLinden (2012) evidenced this through a systematic literature exploration regarding haptic exploratory strategies in children with VI and intellectual disabilities. It was noted that due to a reduced visual modality, practitioners promote tactile symbolic communication in order to appeal to the haptic sense. However for young children, resources used to support this type of communication need to appeal to the less experienced haptic sense. This is arguably because humans learn to use haptic exploratory strategies in order to understand the physical properties of an object. Limited experiences of handling and haptic exploration may have an effect on the CYP’s concept formation regarding objects. McLinden (2012) explored three developmental theories regarding haptic perception (Piaget, Gibson and Bushnell & Boudreau). Although the theories were distinct, there was a degree of overlap in relation to the CYP *actively* engaging in haptic exploration. Furthermore, McLinden (2012) reported that although vision aids haptic exploration (as the hand is directed to an object as a result of visual observation), it is not essential for haptic perception. It was concluded that haptic perception is *guided* by vision in sighted children. The role of a supporting adult was brought into question regarding haptic perception in CYP with VI and intellectual disabilities. This was because an issue was identified relating to the development of a framework regarding adult-structured haptic learning experiences. It was concluded that the development of a framework was needed in order to understand the role of the adult and ultimately maximise independence in CYP with VI. The current project views the role of the adult as key in supporting the transition between dependence to independence, however the focus remained on the children achieving independence.

### **2.1.1 The development of dressing skills**

Dressing is one aspect of a broader framework of ILS. Dressing is an adaptive human behaviour which is predominantly purposive for protection from the environment, for example regulating body temperature (Stolwijk & Hardy, 1977). Initially babies and infants are suitably clothed by their caregivers, in order to appropriately protect the infant e.g. from the weather. Elements of independent and successful dressing skills and strategies include: making an appropriate choice of clothing (suitable for the environment); the actions of putting on and removing items of clothing; the ordering of this process (a key aspect e.g. understanding that underwear is to be put on before trousers); and the ability to fasten items of clothing in order to secure the garments in place.

Dressing is a fundamental, everyday task that is often taken for granted hence we often fail to recognise the complex skills and strategies needed for successful development of this ability (Kellegrew, 2000; Klein, 1983). Klein (1983) developed a self-teaching workbook to support the development of dressing skills in children with disabilities. The workbook was practice based and provided standard and adapted dressing approaches (detailed in Chapter 3). This was provided for clothing items such as trousers, shirts, socks, t-shirts. In addition to the items of clothing, specific fastenings; zips, buttons, poppers, laces, buckles were also identified and fastening techniques were provided. The work of Klein (1983) was supported by rehabilitation for adults (Hofmeister & Gallery, 1977; Lowman, 1959) and also the Oregon project (Brown, Simmons & Methvin, 1986). The Oregon project developed a manual (containing instructions and procedures) and a skills inventory (consisting of 693 skills, organised into 6 developmental areas; cognitive, language, self-help, socialisation, fine and gross motor development). The sample sizes and methodology for Hofmeister & Gallery, (1977), Lowman (1959) and the Oregon project are not currently available. This is due to the literature being out of press and arguably outdated.

### **2.1.2 The role of caregivers in developing dressing skills**

Caregivers usually dress infants and young children. This may predominantly be for convenience but also potentially due to the judgement and decision making required when choosing clothing appropriate for a child in an environment or activity. As chronological age increases so does the need to learn to dress independently. This is arguably an expected transition projected from caregivers onto children as well as a possible societal expectation by the immediate family and schools. As the child enters this transitional expectation, the

caregiver transfers some responsibility onto the child e.g. allowing the child to put on underwear.

It can be argued that all children naturally aspire to reach independence (Shields, 2014; Fairham, Johnston, Kain, Kain, McCauley & Steele, 2002). In order to achieve independence, developing children must learn from their interactions with their caregivers indicating an initial dependence on their caregiver (Winnicott, 2013). Daily dressing routines provide an opportunity to allow refinement of a child's emerging dressing skills (Kellegrew, 2000). Infants and children depend upon their caregivers to provide the clothing they are to wear and appropriately dress them. The clothing provided is based on availability and parental choice. This means that what a child wears relies upon what a parent/caregiver feels is appropriate, not necessarily what the child wants. When a child is dressed by a caregiver s/he may make an attempt to put on or take off clothing when provided with an opportunity to do so.

Kellegrew (2000) conducted a qualitative study examining the daily routines of mothers with young children ( $N=7$ ; age range 2;02-2;08 years) with disabilities in California. Each child participant was observed and videotaped between 1 and 4 occasions over a 2 month period. The observations were made during dressing and meal-time routines. Caregivers were also interviewed over the 2 month period. The generated data consisted of 72 observations and 15 detailed interviews. It was reported that dressing routines for 4 participants occurred on the floor. The remaining 3 participants' dressing routines occurred on a high platform such as a changing table. Kellegrew (2000) observed that children were more active in a dressing routine that occurred on the floor. Children who were dressed on a changing table were not observed to participate in the routine unless prompted by the mother. These findings suggest that infants and children display an increase in independence in dressing activities when provided with an opportunity to participate (Kellegrew, 2000). It is important to note that the research by Kellegrew (2000) is limited by the small sample size. Although the work is the only currently available paper regarding the influence of participation in dressing activities, the findings are not generalizable to the broader population. From the findings of Kellegrew (2000), it is argued in the current thesis that in order to participate effectively in a dressing routine, children must develop general and transferable skills. This is needed in order to begin to appropriately learn dressing practice.

### **2.1.3 General skills needed for successful dressing**

Successful dressing and undressing require a mastery of gross and fine motor skills. Balance, co-ordination, orientation and mobility are pre-requisites for any independence skill and are

important facilitators for play, exploration and adaptation to the surrounding environment. Furthermore, motor skill acquisition is fundamental for physical, psychological and social development in children as well as allowing and encouraging safe participation in tasks (Pavey, Douglas, McLinden & McCall, 2003; Franks, 2000). The development of ILS and associated refinement of gross and fine motor skills in childhood affects participation in activities and successful employment in adulthood (Luftig & Muthert, 2005; Fairnham, Johnston, Kain, Kain, McCauley & Steele, 2002). The concept of dressing and how dressing skills develop has somewhat been overlooked in the habilitation literature as currently the focus surrounds other skills for example those involved in mealtimes and toileting (Miller, Wall & Garner, 2011).

Time, however, plays an important role in any dressing schedule and subsequent opportunities for independence. A hectic morning routine, for example, does not provide an appropriate opportunity to develop emerging dressing skills (Kellegrew, 2000). This is because a child does not have the opportunity or time to learn the skill at their own pace based on their current skill ability due to a busy morning schedule. The caregiver will tend to dress the infant or child for their convenience, rather than to teach dressing skills. The dressing of the infant/child by the caregiver subsequently eliminates participation. In turn, this reduces the opportunity to rehearse and refine dressing skills which are essential for independence. Time also has an impact upon the varying ability of infants and children. For example, a child may be able to independently dress themselves, but do so slowly. This means that when under time constraint, the caregiver will dress the child speedily for efficiency, even though the child may have the ability to dress themselves successfully and independently. If, however, the child can complete the dressing task in a timely fashion, this can be accounted for within a rushed morning routine. The variability between individual children and their caregivers reflects upon the skill acquisition of each child (Kellegrew, 2000). It is thus speculated that the different environmental contexts may have an effect on skill acquisition. For example, a single caregiver versus two caregivers or the presence of an au pair/nanny may have an effect on ILSD based on time available to support the emerging ILSD. There is a lack of available literature regarding the role of time and parenting strategies in the development of ILSD, however it appears to be acknowledged in McLinden, Douglass, Cobb, Hewett & Ravenscroft (2016) that limited time over the course of a day has an impact on development and curriculum access.

#### **2.1.4 Dressing and developmental disabilities**

Many TD children overlook the motor skills that are required to put on a hat or coat. This is because they complete the task with ease based on the observation and mimicking of others

(Klein, 1983). For children with a disability, however, completing these tasks is an achievement. This is due to the internalisation of the sensory-motor co-ordination that facilitates task completion. This means that a child with VI, for example, is required to integrate the remaining senses and internalise physical and task-appropriate properties (sequences) in memory to successfully dress (Johansson & Cole, 1992). So what may appear skilled and effortless in a TD child may be more difficult and demanding for a child with disability, despite sensory-motor co-ordination occurring in both groups.

The ability to dress and undress is crucial for independence and becomes increasingly important with developmental age. This is because earlier experiences underpin later practice e.g. learning how to choose clothing and independently dress aids in preparing for job interviews. The transition from dependence to independence over time needs to occur for both TD children and children with developmental disabilities if they are to maximise their independence. However, the development of independence skills is believed to occur at a slower rate in children with developmental disabilities. This is due to developmental delays and/or impairments in different cognitive and social domains (Government of South Australia, 2013; Warren, 1984). Warren (1984) argued that children with developmental disabilities (and associated developmental delay) develop in the same way as their TD peers, however their development occurs at a later chronological age (Warren, 1984). This means that, theoretically, children with VI and/or DS (the focus of the current research), should follow the same motor developmental trajectory, but this will occur at a slower rate when compared to their TD peers. This is based on an assumption that there were no intervening additional motor difficulties or needs (Warren, 1984). In contrast, other empirically driven theories, suggest that impairments or delays in one domain such as the visual system will have a knock on effect on other domains which subsequently results in delayed or atypical developmental trajectories.

In a detailed literature review Karmiloff-Smith (2009) argued that cognitive development is not as modular as first assumed. Rather, the cognitive systems become specialised in relation to specific input. This means that specific cognitive modules adopt specific functions over the course of development. It is also argued that an impairment in one module may have an effect on the development of another. This theory was termed 'neuroconstructivism' (later examined in Chapter 3) and contributed to the theorisation of the current thesis. The effect of sensory input and developmental delay is also evidenced by Annaz (2006) who examined face processing abilities in TD children and children with Williams syndrome (WS) and DS (age range; 5-12 years). Annaz (2006) reported that the ability to recognise faces appeared to be one aspect of a broader cognitive system, and so in genetic disorders such as WS and DS cognitive abilities are limited from the beginning of life, due to the nature of the disabilities.

The findings of Warren (1984), Karmiloff-Smith (2009) and Annaz (2006) suggested that developmental delay may have an impact on the development of dressing skills due to limited cognitive capacity, directly resultant of clinical diagnosis. The extent of this in the 3 recruited participant groups (VI, DS and TD) may become apparent in the current thesis.

### **2.1.5 Available dressing literature**

Available ILS literature provides examples of step-by-step instructions as well as methods for successful dressing. These instructions are based on established historical practices rather than as a result of having undergone a systematic evaluation (Fairham, Johnston, Kain, Kain, McCauley & Steele, 2002; Klein, 1983). Fairham et al., (2002) conducted a survey in Australia ( $N=122$  families; child age range: 5-12 years) regarding parental concerns over their children's ability to cope with all aspects of daily living (ILS) (including dressing skills). Some outcomes of the study were arguably constrained by the environmental context (such as the impracticalities of travelling up to 1000km for a home visit, and the ensuing cost). However, the study revealed that children better learn ILS in naturalistic settings and parents/caregivers hold the main responsibility for teaching and developing ILS. In a response to the outcomes, Fairham et al., (2002) devised a practice based training manual entitled "*Do It Yourself*" which was primarily aimed at parents/caregivers in order to support the development of ILS in children with VI. The package was also designed to support "generic professionals" in rural and remote areas who conduct interventions to support ILS (Fairham et al., 2002). The package broadly covers: (a) Domestic and Community Activities, (b) Dressing, (c) Mealtimes, and (d) Personal Care. Each section is split into further, more detailed subsections with step-by-step instructions. The dressing section includes: managing buttons and zips; putting on a jumper, trousers, shoes and socks; and tying shoelaces. Although the "*Do It Yourself*" package remains to be used in practice (e.g. by Habilitation Specialists in the UK), the existing literature supporting dressing skill development is brief, prescriptive and outdated. Much of the available literature is designed for teaching rehabilitation techniques to *adult* individuals who required systematic training activities after losing their independence skill/s due to sickness or domestic injury (Miller, Wall & Garner, 2011).

### **2.1.6 The dressing sequence**

It is postulated that the development of ILS in relation to dressing skills (ILSD) is sequential in nature. The development of ILSD progresses from transferable skills such as pinching and directional movement (e.g. left and right) to more specific and directed skills such as putting on and fastening an outdoor coat or putting a fork to the mouth (Fairham, Johnston, Kain, Kain, McCauley & Steele, 2002; Swallow & Huebner, 1987). Development of ILSD commences with a "standard approach" e.g. removing a coat one sleeve at a time and pulling

the coat around off the arm. The person supporting the child then uses the least possible adaptations to the standard technique if the child has difficulty with the standard method. Adaptations are first made to the training approach itself (e.g. using different verbal instructions). If this is not effective, the person supporting the child makes adaptations to the training technique (e.g. using a different method to teach the same task). If the adapted training technique does not suffice, adaptations are then made to the training device, for instance the items of clothing being used (e.g. using a bigger shirt to support buttoning/unbuttoning). Finally, adaptations can be made to the equipment itself (e.g. laced shoes with a zip on the side, so that shoes can be put on/taken off without unfastening/fastening laces) (Klein, 1983). The use of standard and adapted techniques support the development of ILSD based on the current skill ability of the child. This means that the development of ILSD is optimised in an individual based through differing approaches to teaching the same skill (e.g. buttoning a shirt).

The availability of different approaches appeared to be beneficial in the development of ILSD. The development of directional and spatial awareness are transferable skills that can be applied to any area of ILS including dressing. In addition to the aforementioned skills, there are further transferable and pre-requisite skills which aid the development of ILSD.

### **2.1.7 Pre-requisite skills for independent dressing**

Before independence can be achieved in an ILSD context, there are some transferable pre-requisite skills that each child must demonstrate (Fairnham, Johnston, Kain, Kain, McCauley, & Steele, 2002; Klein, 1983):

- Body awareness – understand the position and shape of the body, how the body is moving, balance, co-ordination and directional concepts (e.g. left/right/up/down)
- Spatial awareness – understand objects in space and the relationship between them
- Finger and hand strength – pinching and holding objects, co-ordination when using two hands together
- The ability to differentiate between the fastening holding the garment together and the material of the item of clothing
- Time as a concept – the length of time is relative to the numbers on a clock and understanding appropriate times for dressing/undressing e.g. play time

The pre-requisite skill of finger strength could be demonstrated by taking a lid off of a paint pot, the ability to pinch together the index finger and the thumb can be demonstrated by holding a crayon, and also the ability to co-ordinate both hands at the same time can be

demonstrated by using modelling clay to make an object. The ability to discriminate between the fastening and the material can vary based on visual need. For children with partial sight who are using residual vision, the distinction could be made by using contrasting colours in order to highlight the difference (Bishop, 2004). For children with blindness, using materials with contrasting textures would tactually highlight the difference between material and fastening (Bishop, 2004; Fairnham, Johnston, Kain, Kain, McCauley & Steele, 2002).

The distinction between partial sightedness and blindness has been drawn here to appropriately illustrate different strategies (based upon visual need) that are explored within the current thesis. Bishop (2004), however, does not draw the distinction in the definition of VI. VI in her context is understood to be the damage to, or malfunctioning of the visual system (Bishop, 2004; Bishop, 1996). The “*Do It Yourself*” package (Fairnham, Johnston, Kain, Kain, McCauley & Steele, 2002) used the term VI to mean “blind”. This lack of consistency in defining VI creates issues when designing and understanding the general development of children with VI. It is also important to note that these outlined abilities are drawn from literatures which are training and support manuals, informed by observations and practice. This means that the effects of the suggestions remain to be systematically supported and evaluated within the area of research.

The ability to demonstrate pre-requisite skills is not governed by chronological age. Rather, the demonstration emerges and occurs at a time suitable for each individual child. Once a pre-requisite skill is acquired, it must be demonstrated and included within the child’s daily routine in order to retain, practice and apply the developed skill. The demonstration of these pre-requisite skills indicate the child’s readiness for independence tasks (Baker & Brightman, 2004; Fairnham, Johnston, Kain, Kain, McCauley & Steele, 2002). Once a child has demonstrated these pre-requisite skills and recognised them as transferable they will then begin to incorporate the skill informally. This could be done within their daily routine, e.g. using the pincer grasp to pick up or manipulate objects such as pens and forks (Fairnham, Kain, Kain, McCauley & Steele, 2002).

Mobility and orientation skills are also essential for successful participation in activities (Keppens, De Pourcq, Dewerchin & Standaert, 2015). In relation to the current thesis, *mobility is defined as*:

‘The safe, efficient, focused and directed movement of an individual throughout the environment’ (LaGrow, 2010; Jansson, 2000; Berube, 1991).

*Orientation, is defined as*:

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‘An individual’s ability to understand their position in space, both relating to their body and their environment’ (LaGrow, 2010; Jansson, 2000; Berube, 1991).

Mobility and orientation work together allowing a child with VI to navigate and demonstrate focused, purposeful movement around their environment and the objects it contains (LaGrow, 2010; Jansson, 2000; Berube, 1991).

As a result of this understanding of orientation and mobility, children are able to attentively establish a safe base for exploration of the surrounding environment (Berube, 1991; LaGrow, 2010). Mobility links to orientation as it concerns the child’s physical movement around their surrounding environment. Balance is required for both orientation and mobility. It is important for stability, as it controls posture and strengthens the muscles which in turn provides a safe and stable base for exploration object manipulation (Sharma & Cockerill, 2014). Orientation and mobility work together with the other senses such as balance, for both gross and fine motor skill activities, from navigating and travelling between areas within the class room to applying the fine motor skills necessary for fastening a zip for example.

By examining the pre-requisite skills for independence, an understanding of the essential nature of these skills emerge. If the child does not demonstrate the pre-requisite skills outlined, a child could not participate in an intervention programme that develops ILSD. This means that development of pre-requisite skills must occur before participation in an ILSD intervention programme.

### **2.1.8 The current state of dressing practice**

Independent living skills and habilitation are now acknowledged within the SEND: 0-25 Code of Practice (Department for Education & Department of Health England, 2015). There is yet to be an appropriate bridge between the theoretical and the practical elements that optimises the development of independence skills in the educational setting. The current project addresses the cognitive, behavioural and physical development of children (both typically and atypically developing). Using research evidence as a base, the current project systematically developed strategies and intervention materials to reduce the gap between the theoretical and practical elements of habilitation in relation to dressing skills.

The suite of novel intervention materials developed within the current research used the examined habilitation literature as its foundation. However, in order to fully inform the design of the novel intervention materials, an exploration of further relevant literature was considered necessary.

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The main rationale of the current research therefore supports the implementation of early intervention targeted at the independent living skill of dressing in children with VI and DS. Fazzi, Signorini, Bova, Ondei, & Bianchi (2005) explored the effects of early intervention in children with Cerebral Visual Impairment (CVI – where a VI is resultant from brain damage). The authors examined 50 children from 2 years old (upper age not specified) with CVI. 30 children participated in an intervention programme which was designed to: (a) optimise residual vision; (b) improve perceptual processes; (c) develop adaptive functioning (as a response to VI); (d) prevent effects which may be secondary to the CVI; and (e) promote the overall development of the participants. The intervention programme consisted of 2-3 sessions per week over a period ranging from 1-3 years. Of the recruited participants,  $n=20$  did not receive intervention “treatment” for a variety of reasons including distance to travel (Fazzi, Signorini, Bova, Ondei & Bianchi, 2005). It was reported that the children who participated in the intervention programme displayed a better visual performance (in relation to fixation, visual attention and acuity, saccades and pursuit) when compared to the untreated group. In light of these findings, Fazzi et al., (2005) argued the case for the importance of early intervention for young children with CVI.

It is also argued that the majority of developmental changes occur until approximately age six (Shonkoff & Meisels, 2000). This is demonstrated by the rapid development in social, physical, cognitive and emotional domains (Shonkoff & Meisels, 2000). The previous research on which this thesis was initiated examined TD children and children with VI ( $N=16$ ) aged between 4 and 6 years old (Hayton, 2012). The age range specifically targeted children before reaching the ‘critical age’ of six years old. It was observed, however, that there was a need for TD children and children with VI to learn dressing skills above the age of six years (Hayton, 2012). This means that although it has previously been advised that early intervention leads to longer lasting effects (DfE, 2012; Skellenger & Sapp, 2010), it can be argued that it is necessary to include children older than 6 years old in an intervention programme, if they seek to benefit from developing ILS such as dressing.

## **2.2 The Role of Incidental Learning**

Understanding the behavioural and clinical characteristics of children with VI may reveal the importance of vision in the typical development of different cognitive and behavioural domains (Herbert, 2003), and vice versa. This is because the presence of a VI may deny or reduce access to incidental learning. *Incidental learning is defined as:*

‘an acquisition of skills and knowledge as a by-product of an activity’  
(Marsick & Watkins, 2001).

Incidental learning is usually facilitated by visual observation. Incidental learning is an informal approach to learning and can occur at any age. Learning is achieved without the learner being consciously aware that learning is taking place. Within the context of children's development and learning, many skills are acquired through visual observation, by mimicking and copying adult behaviour (Marsick & Watkins, 2001).

In contrast to 'formal' learning which is understood to be purposive and occurs within a classroom environment, for example, incidental learning is more haphazard and less structured in nature. Incidental learning is more of an unconscious process that occurs through play, and other everyday activities involving the child or young person. For example, a child does not necessarily realise that during playtime they are learning social skills and developing gross and fine motor control. In contrast, in a formal learning environment, such as a classroom, an individual is more aware that learning is taking place. This is because they associate a particular environment with the 'task' of learning (Marsick & Watkins, 2001; Marsick & Watkins, 1990).

It is postulated that motivation relates to incidental learning. This is because an individual is more likely to engage with a stimulus if they have the incentive to do so (Marsick & Watkins, 2001). For example, in the current research project, a participant may be more willing to engage in dressing tasks if they have the motivation to become an independent dresser. It is also argued that incidental learning occurs in an environment where an individual has the opportunity to learn (Marsick & Watkins, 2001). With specific regard to adult learning (aged 18 years and upward), conditions were outlined by Marsick & Watkins (2001) that would facilitate incidental learning:

1. Incorporation into a daily routine
2. Triggering from an internal or outward desire
3. The learning is unconscious
4. Learning occurred through chance
5. Learning is a result of personal reflection
6. Has a link to the learning

It is important to note that these conditions are applicable to individuals who have the capacity and opportunity to learn this way *and are 'adults'*. There is currently a lack of evidence supporting these specific conditions for children and young people. The adult approach outlined is used as a means to understand how incidental learning may be applied in the context of the current thesis. It could also be argued that further application of this model

suggests that sensory deprivation may have an effect on an individual's capacity to learn incidentally. As vision is a facilitator for incidental learning, partial vision or the complete absence of vision does not allow for learning to occur through visual observation alone. Children with VI (including children with Down syndrome (DS) where VI is a component) cannot copy adult behaviour in the same way as a sighted child. This makes it difficult for the child to develop and optimise their physical skills such as dressing (Rosen, 2010). Overcoming the absence or restriction to incidental learning is one purpose of the current research.

### **2.2.1 Compensating for restricted access to incidental learning**

The current research is an intervention study designed to compensate for restricted access, or complete absence of access to incidental learning in children with VI and children with DS. This is done in relation to ILSD. It is believed that the lack of incidental learning in this context can be compensated for through training involving systematic strategies. These strategies include structured interventions which develop and refine skills which may have otherwise, for a sighted child, been learned through observation and mimicking. It is argued that this form of structured intervention needs to be conducted at an appropriate time of day for dressing; e.g. before the children go out to play (Swallow & Huebner, 1987; Fairham, Johnston, Kain, Kain, McCauley, & Steele, 2002). This means that the intervention activity is timed to be appropriate to the typical context of the activity and subsequently bears most relevance for the child.

In addition to the structured intervention programme, the natural desire for a child to attain independence is also a contributing factor to motor skill acquisition (Shields, 2014; Perez-Pereira & Conti-Ramsden, 2013; Fairham, Johnston, Kain, Kain, McCauley & Steele, 2002). Although children have a natural desire to attain independence, it is not identified as to whether this is an intrinsic desire or if the environment acts as a catalyst (Perez-Pereira & Conti-Ramsden, 2013). This desire can also be unconscious in nature, for example, a child may be unable to formally identify the difference between active and passive learning. This means that when engaging in an activity where learning is a by-product (e.g. dressing a doll indirectly develops the skills required for independent dressing of themselves) the child is not necessarily aware that completing the task will lead them to a more independent state. This is how incidental learning can occur within day-to-day activity.

The inaccessibility or reduced accessibility of incidental learning in several clinical populations may affect concept formation. This means that the individual's development of frameworks of understanding, vocabulary and reason may be impaired. These impairments subsequently reduce access to Gibson's affordances (Gibson, 1954). Gibson suggested that individual perception and action was reliant on an individual's interactions with their surrounding

environment. 'Affordances' refer to how an individual responds to their environment, taking into account accessibility and constraints within the given environment (Greeno, 1994). If there is a limited or complete denial of incidental learning through visual observation, the perception and action of an individual is reduced. This is due to an impaired sensory modality. This means that task performance of an individual with sensory impairment within an environment is reduced (Grèzes & Decety, 2002; Greeno, 1994).

### **2.2.2 Restricted access to incidental learning and social implications**

As well as the effect on physical responses to the surrounding environment, children with VI may also be affected socially (Munro, Garza, Hayes & Watt, 2016). The study by Munro et al., (2016) found that parental overprotection of children with VI could interfere with the practice of social skills and the ability to initiate social interactions (Munro, Garza, Hayes & Watt, 2016). Furthermore, the child with VI is unable to observe non-verbal responses (e.g. facial expressions or shaking of the head) or read body language (e.g. folded arms) and so they may be unable to act appropriately in a social context (Bowman, Bowman & Dutton, 2001). This means that external cues or guidance from a key supporting adult (e.g. teacher, parent/caregiver) is necessary (Massachusetts Department of Elementary and Secondary Education, 2012; Bowman, Bowman & Dutton, 2001).

In an attempt to overcome the absence of incidental learning in children with VI or DS, structured step-by-step interventions combined with simple and reliable instructions may begin to account for the deficit (Bowman, Bowman & Dutton, 2001; Swallow & Huebner, 1987). The suite of intervention materials used in the current project have been developed alongside clear instructions (both verbally and in Makaton) in an attempt to optimise the learning environment for the children concerned.

### **2.2.3 Montessori and the importance of instructions**

Montessori in theory and subsequent practice highlights the importance of clear and explicit instructions. The Montessori Method also notes that children need to have practise and experience in following instructions as well as the capacity to concentrate on the task in hand (Wentworth & Wentworth, 1999). Montessori is considered to have supported human development by providing opportunities for exploration within a learning environment (Montessori, 2013). The innovative techniques used by Montessori adapted existing educational frameworks. Her novel methods provided freedom for exploration within a schooling environment. Although this was not accepted within a 'formal' educational

environment, her methods revolutionised education for children who could not thrive within a traditional environment (Montessori, 2013).

The Montessori Method may not, however, be suitable for all children. Lopata, Wallace & Finn (2005) conducted a comparison study in America which examined academic achievement in Montessori and traditional school settings. Participants were drawn from 4<sup>th</sup> grade ( $n=291$ ; age range: 9-10 years) and 8<sup>th</sup> grade ( $n=252$ ; age range: 13-14 years) classes. All 543 participants were recruited from an urban setting whereby 53% were “minority students” and 67% were considered “low income” (Lopata, Wallace & Finn, 2005). The comparisons were drawn from standardised measures of maths and language arts (e.g. reading, writing and listening). The study revealed that there was not a link between attendance at a Montessori school and higher academic achievement (Lopata, Wallace & Finn, 2005). This suggests that a Montessori schooling environment may not be conducive to academic attainment in children.

As the Montessori Method is based around the choice of the child, some children may not feel comfortable with this seeming lack of structure. Some children may prefer to have a more structured, teacher-guided learning environment. This means that the Montessori Method may not be of benefit, or have a negative effect on their participation and learning. In addition to this, attending a Montessori school may hinder the transition to mainstream schooling. As the mainstream timetable is more rigid and teacher-directed, children who have previously been exposed to the Montessori approach may have difficulty integrating into this dynamic.

Montessori (2013) established three points for the delivery of any lesson:

1. Simplicity: use only words that are an absolute truth
2. Objectivity: the lesson must be presented so that the personality of the teacher must disappear – meaning that the child is uninfluenced by the teacher
3. Method of observation: the teacher observes the child’s interest in the materials, including their body language and verbal responses. The teacher must not provoke the child into making an unnatural effort. This is because the spontaneous activity of the child is being observed. Furthermore, the child must not know that they have made a mistake.

The delivery of the Montessori lessons encouraged the natural instincts of the child and discouraged direction from the teacher. It was considered important for the natural state of the child to remain intact (Montessori, 2013).

The current research was informed by the Montessori Method. The intervention programme addresses the three established points for the delivery of the lesson, although does not necessarily strictly follow the prescriptive procedure. Simplicity was addressed by using words that are specific to successful fastening, for example 'open/unfasten', 'close/fasten', and 'pull/push'. Within the intervention environment, the language that was used was specific to fastening and unfastening and also praise (positive reinforcement) for the children. Objectivity was addressed by framing the intervention session (lesson) around the needs and personalities of each child.

With regard to 'method of observation' the children were encouraged to behave naturally and spontaneously. However due to the tactile nature of the task, some children asked for help to complete a fastening stage. Assistance provided during the intervention could have therefore be considered to be unnatural in the context of a Montessori lesson. However, if the child requested assistance, this could be considered to be a natural occurrence. Further to this, as a result of the limited time within the session, the children may not have had the opportunity to manipulate all fastenings due to their natural behaviour. In the current project the children were encouraged to naturally explore their environment. However they were guided towards attempting to fasten and unfasten all types of fastening according to the established intervention schedule outlined in Chapter 8.

Clear and explicit instructions suggest a more accurate execution of a task (Klein, 1983). For example in the context of a drawing exercise, children who are given the most explicit instructions produce the most accurate drawings (Barrett & Bridson, 1983). It is also important to split the task into smaller, more manageable steps, for example to unfasten a zip, you must first pinch the slider, hold the material at the top of the zip, and then pull the slider down to the base. By asking the child to complete these smaller tasks, they can feel a sense of achievement for each stage accomplished (i.e. pinching the slider), rather than waiting to complete the entire task (unfasten the zip). This strategy is supported by the Zone of Proximal Development (ZPD) (Vygotsky, 1978). The ZPD refers to the 'gap' between the actual development of problem solving in a child when executing a task independently and the potential development of problem solving (Vygotsky, 1978) in a child when supported by a teacher/parent/caregiver (Millar, 2011).

The ZPD postulates that efficient skill development occurs when an individual learner is supported by an expert in the area (for example, motor skill development). The expert uses 'scaffolding' (language or physical support in this case) to support the learner. As the learner

increases in confidence and proficiency, the expert gradually removes the support. This occurs until the learner can independently complete the task.

The ZPD outlines the influence of person to person interactions regarding the development of skills and supporting the transition from dependence to independence. The ZPD is useful in terms of supporting the development of skill acquisition. However the concept is vague regarding skill abilities of children. It is possible that, for example, a low functioning child may not benefit from scaffolding or a high functioning child may rely on adult (e.g. teacher/parent/caregiver) support as they lack the motivation to complete the task independently (Miller, 2011). Furthermore, there is no real benefit to knowing the width of individual zones as this may not reflect the individual's learning capacity (Millar, 2011).

It is important to attend to the individual needs of each child and structure the intervention accordingly. Furthermore, the task needs to correctly and accurately teach the individual the appropriate constituents to the step, for example, using the pincer grasp rather than holding the parts in a fist (Klein, 1983). With support, rehearsal and adequate time, the child will gradually improve and refine the skill for each step until the task is completed independently (Swallow & Huebner, 1987).

### **2.3 Chapter summary**

Chapter 2 explored the relevant literature regarding the development of ILSD. The chapter started with ILS as an umbrella term, outlining that dressing is one aspect of a range of skills that are required for independence. The role of caregivers, the notion of time and current practice were examined in relation to ILSD. In addition to this, the chapter also explored pre-requisite skills and strategies which need to be demonstrated in an individual child in order to develop ISLD. Incidental learning was introduced as a method by which typically developing, sighted children learn independence skills.

As the project also explored ILSD development in two clinically defined groups where VI is either a diagnosis or component, methods of compensating for incidental learning were also explored. This compensation concerned the development of an intervention which appealed to the preserved senses. Following on from this, the chapter drew upon the Montessori Method and highlighted the importance of clear and systematic instruction to support task completion. This linked to the ZPD as splitting the motor tasks of dressing into smaller and more manageable achievable stages supported task mastery. "Scaffolding" was introduced as a

method to facilitate ILSD development. This is where a more experienced adult supports the emerging skill in developing individuals.

The following chapter examines typical and atypical development and the relationship between vision and movement. This is done to examine the physical and cognitive development of children with VI, children with DS and TD children, in order to understand and contextualise the development of a dressing intervention.

### **3. Vision, Motor Skills in Typical and Atypical Development, and Developmental Delay**

Chapter 3 concerns the second outlined theme which broadly concerns typical and atypical development. Within this theme, seven specific areas are explored. These are: the impact of visual impairment (VI) on movement, social skills and neurological compensations for VI; VI (including: definitions, prevalence, comorbidities and visual assessment measures); Down syndrome (DS) (including: history, diagnosis, prevalence comorbidities, cognitive phenotype and behavioural characteristics); Developmental Delay; Typical and atypical development from birth (including: prematurity, gross and fine motor skill development, stages of motor skill development and the relationship between cognition and motor skill development (examined from the neuroconstructivist position); multi-sensory learning and haptic perception; the Working Memory Model (Baddeley, 2003) (including: chaining as a method for developing gross and fine motor skills suitable to develop the independent living skill of dressing (ILSD)).

First, the chapter explores the role of vision and the role of visual impairment in relation to movement and social skills. In order to demonstrate the distinction between sighted children and children with VI a study is presented (Khadka, Ryan, Margrain & Woodhouse, 2012) to show how environmental restrictions can occur as a direct association with VI. The same study is used to illustrate the importance of the presence of a parent/caregiver which may impose restrictions on a child with visual impairment out of the parent/caregiver's concerns over the child's safe participation in activities. The comparison between available vision and a restriction of vision is important within the context of the current study as it may have had an influence on child participation within the intervention activity and the ability to learn incidentally. In the absence of sight-derived learning, some children with VI use tactile perception and/or echolocation to safely move around the environment. Echolocation requires a refined auditory sense. An exploratory neurological study (Bedny, Richardson & Saxe, 2015) is presented to illustrate how the visual cortex may develop to respond to auditory stimulation (specifically spoken language) in children who were born blind. In the current study, this development may support the use of verbal instruction to support the development of ILSD in children with VI. As this phenomena was only present in children who were born blind, the varying definitions and diagnoses of VI are next explored.

Second, the chapter then explores the complex nature of defining 'visual impairment'. For the purpose of the thesis, VI refers to both partial sightedness (uncorrected by glasses or prescribed lenses) and complete blindness. Due to the low prevalence rates of VI within the UK, the conditions and comorbidities which were apparent within the VI sample for the main

study in this research are presented. This is in order to contextualise the types of conditions which are present within the UK VI population. As the definition covers a wide range of VIs visual assessment measures are presented in order to illustrate the difference between a clinical diagnosis and functional vision. Functional vision is arguably more important given the context of the current study as it concerns how children use their vision in everyday tasks. Functional vision assessments and clinical vision assessments aid an understanding of a child with VI, however within the VI population there is a high level of variability even when a diagnosis is shared (Warren, 1994) and this variability extends to typically developing (TD) children, and children with a genetic disorder such as Williams Syndrome or Down syndrome (DS) (Van Herwegen, Rundblad, Davelaar & Annaz, 2011).

Down syndrome (DS) is the third element of the chapter detailed in the first paragraph. The chapter explores the historical perspective of DS, and examines how non-disjunction from conception is a cause for the disorder. Prevalence rates, physical and medical characteristics and associated comorbidities (including VI) are explored in relation to DS. The chapter explores how DS affects cognition in relation to processing speed, language and memory (Jarrod, Baddeley & Hewes, 2000). Within the context of this study, the procedure used verbal instructions which require an individual to comprehend, encode, rehearse and recall task relevant instructions. This means that the DS sample recruited in the current study may have an issue with working memory and so may need additional support (such as Makaton sign language) in order to support the retention of instructions and skills acquisition. Behavioural characteristics of DS are also explored, this is to contextualise the types of behaviours that may be elicited from the DS sample in the current study.

As variation is acknowledged within and between the three recruited groups in the current study, developmental delay is the fourth element to be explored. It is acknowledged that most of the published works on developmental delay relate to language development and comprehension, however the studies comparatively explore genetic conditions (specifically William's syndrome) and typically developing children (Van Herwegen, Dimitriou & Rundblad, 2013). The study offers insights in the three examined populations in the current study in relation to the two "forms" of developmental delay: 'persisting' and 'resolving' (Thomas, 2014).

Developmental delay can also be apparent in relation to motor skill development. The fifth element of the chapter explores typical and atypical development from birth. Within this, 5 components are presented. These are: reflexes, the effects of prematurity, the development of gross and fine motor skills, the stages of early motor development, and the relationship between cognition and motor skill development (viewed from a neuroconstructivist lens).

Reflexes are the first indication of neurological health of an infant and form the basis of more refined movements. Retained or a delayed disappearance of reflexes may suggest problems with an individual's central nervous system. Central nervous system issues may also be resultant from prematurity. In addition to neurological conditions that may arise from prematurity, a premature infant may be subject to medical treatment (Herbert, 2003) which may lead to physical complications such as retinopathy of prematurity (outlined in Table 3.1).

The sequential development of gross and fine motor skills is then examined in the chapter. It is argued that children appear to develop such skills from the midline out towards the fingers and toes (Herbert, 2003; Klein, 1983). Motor development is typically recorded by the use of developmental milestones. These are markers based on chronological age (CA) which suggest the minimum, maximum and average age of motor skill acquisition e.g. sitting to standing, reaching and grasping. It is acknowledged that the developmental milestones presented in a text-book format may not appropriately represent all children, but the milestones presented are based on averages. Within the chapter, Figure 3.6 demonstrates developmental delay in TD and VI children. This illustrates how a VI may have an impact on the reaching of developmental milestones.

Cognition in relation to motor skill development is then explored. Neuroconstructivism informed the theorisation of the current research. The rationale for this choice is because the theory of neuroconstructivism links to the different elements of the current study: the role of memory, the interactions between an individual and their environment, and the role of cognition between sensory and motor experiences. In summary this was because it appeared to be the most appropriate developmental theory for explaining the observed phenomena in all three recruited samples. The theoretical argument underpinning this perspective and adopted in the current study postulates that cognitive systems are gradually refined through physical brain maturation and the individual's response to and interaction with, their environment (Ward, 2010; Karmiloff-Smith, 1998). It is therefore proposed that the development of ILSD in a developing child may be a product of brain maturation and the child's individual exposure to dressing and fastenings. This means that a stimulating and relevant learning environment (in relation to dressing) would, in theory, enhance synaptic connections and subsequently support the development of ILSD in all three groups (VI, DS & TD).

The sixth element of the chapter demonstrates that there is a difference between typical and atypical development, whereby atypically developing children require structured support to assist development. It is argued next in the chapter that creating a learning environment that is tactile and stimulating may optimise development in atypical populations such as VI and DS

(Warren, 1984). Two approaches that may support this development within the context of the current study are: Multi-sensory learning and Haptic Perception.

Multi-sensory learning uses two or more available senses to assist learning. A study by Rains, Kelly & Durham (2008) is presented to illustrate the potential benefits of applying multi-sensory learning techniques. The multi-sensory approach is useful within the context of the current study as it accommodates all three groups (VI, DS and TD). The procedure for the current study uses tactile methods combined with auditory instructions to provide dyadic sensory experiences which could be individualised to help to support ILSD development.

As touch was a shared available sensory modality within and between the three recruited groups in the current study, haptic perception is characterised in this chapter. Haptic perception for the purpose of the thesis is defined as the information directly perceived through the hands and fingers. This excluded passive haptic perception in relation to temperature and pressure because the study concerns a child's purposive manipulation and control of the intervention materials. The definition adopted informed the nature of the intervention procedure (actively touching the intervention materials) and alerted the researcher to issues that may arise as a result of needing to apply pressure – for example in order to encourage a child to push “harder”, verbal instruction must be used. Verbal instruction is auditory information, not haptic, so this demonstrates an appeal to multi-sensory learning techniques.

The chapter then develops further two main approaches toward understanding haptic perception apparent in the current literature. The *'differentiation approach'* (Warren, 1984) argues that the senses are interconnected and so one sense (vision) cannot “teach” the other (touch). The *'integrated approach'* (Warren, 1982) argues that sight guides the hand to attend to an object and then as the gross/fine motor skills develop, the touch sensory modality does not need visual support in order to attend to a stimulus (e.g. touch typing).

Proprioception is defined as an automated motor response to the environment (Boisgontier & Swinnen, 2014). In this chapter, proprioception is explored within the context of haptic perception, which supports the integration approach to haptic perception. It is argued that an individual can develop and train their proprioceptive sense in order to appropriately respond to the external environment (Rosenkrantz & Rothwell, 2012). It is also argued that the novel intervention materials created for the study, could gradually refine the participant's proprioceptive sense over the intervention period. This assumed that each of the senses were compartmentalised into separate sensory modalities and subsequently have a unique input to the brain for processing. In this sense, the development of materials which appeal to the haptic

sense would, it is posited, be beneficial for children with VI and children with DS who have sensory loss in other modalities. As touch is a preserved sense in all three recruited groups, it could be argued that appealing to the haptic modality is beneficial for all.

The concept of synaesthesia (Cytowic & Eagleman, 2011) however, may jeopardise the position of the sense being compartmentalised. This is because some children can experience 'joined sensation' meaning that sensory input cannot be perceived and interpreted according to sense e.g. colour can be tasted, holding something can be smelt. If any recruited participants had synaesthesia the processing of haptic input may have been clouded by the other senses. As synaesthesia suggests that senses are not domain-specific, multi-sensory learning techniques and the theory of neuroconstructivism illustrate that synaesthesia is not a barrier to learning ILSD.

The chapter continues by noting that much of the literature on haptic perception is specific to the development of children with VI. This means that it is too bold to conclude that children with other disabilities such as DS or indeed TD children would experience/benefit from haptic strategies. Although a link had been established regarding haptic stimulation and working memory (Harris, Harris & Diamond, 2001). The repetitive nature of the intervention task proposed in the current study may mean that the working memory system would benefit from repeated stimulation as per the nature of the intervention task. If this is the case, haptic methods may support children with DS who have an issue with working memory as a characteristic of their clinical condition. As there is an established link between tactile perception and working memory, the chapter then explores the nature of working memory and how the system can be enhanced in populations that may have a restricted access/poorer working memory in comparison to TD peers.

Last, the components of the working memory model (Baddeley, 2003) are presented within the thesis (see Figure 3.7) to illustrate the role of memory in relation to the current study. The illustration shows how inputs are processed, encoded, rehearsed and retrieved within an individuals' short term and long term memory capacity. It is argued that repetitive rehearsal and retrieval supports encoding of a task (for example) within a long term memory store. Although the Working Memory Model is a typically derived theory, the current study demonstrates how the model can be applied to VI and DS populations. It is posited that although the developmental disabilities may have an impact on the input for processing, compensations can be made through the available senses (A. Baddeley, personal communication, 2016). The Working Memory Model informs the intervention procedure, as a participant rehearses and retrieves the fastening information. If this is effective it might be

supposed that the intervention would have longer term effects on skill retention. If this is the case, the working memory model and the neuroconstructivist approach may work symbiotically in developing ILSD in relation to memory and domain-relevance.

The working memory model also links to Vygotsky's Zone of Proximal Development (ZPD) (see Chapter 2) and the overall theorisation of the current study. The link between the Working Memory Model and the ZPD is made apparent through the concept of chaining.

Through scaffolded support (Chapter 2), areas of the working memory model are also supported through the rehearsal and retrieval of the motor skills to be learned e.g. fastening zips, buttons, poppers and shoe laces. The following section of the chapter details the concepts of forward and backward chaining and its implication for the working memory model as described in the present study. Time is once again a common theme within this process, and it is acknowledged that the concept of time plays a crucial role in the development of a child's understanding of the skill that is to be taught, and the mastery of the skill itself. It is understood that chronological age (CA) acts as a marker for understanding developmental progression, however the CA does not define when a skill emerges or is mastered – it is simply a marker for understanding development.

### **3.1 The Relationship between Vision and Movement**

Vision is an essential, integral sense, providing vast amounts of input for processing (Sugden & Wade, 2013). Sighted individuals have an immediate and synchronised representation of their environment; seeing individuals and objects which are static or moving, that are located within their environment (Sugden & Wade, 2013). The information provided by sight allows us to safely and smoothly navigate our way through our environment. Information regarding obstacles is processed quickly, and correction of potential movement errors are executed swiftly (Sugden & Wade, 2013). Furthermore, vision allows individuals to examine and recognise objects from varying angles and distances, as well as confirming perception through other visual clues. Vision also allows individuals to predict events, and socially respond to stimuli, for example smiling when greeting somebody or protecting an individual from danger (Sugden & Wade, 2013). It is apparent that with regards to movement, vision is essential for perception and subsequent action. This is demonstrated by hand-eye coordination, temporal and spatial pairing of eyes, body and limb coordination (Sugden & Wade, 2013).

Consider, then, the absence or impairment of vision and the implications this has on the moving individual. Arguably, if vision is impaired or lost, there are negative effects on the individual's capacity for movement. This, however, is not necessarily the case. Compensation for the impairment is typically made by other senses (e.g. echolocation) and achievement in

completing everyday skills is possible with effort and time (Sugden & Wade, 2013). CYP with VI have the ability to participate in sporting and leisure activities. Arguably, CYP with VI require more systematic instruction in order to participate. However research suggests that participation in sporting and leisure activities is affected by something other than physical constraints (Khadka, Ryan, Margrain & Woodhouse, 2012).

The research required children with VI to compare themselves with their sighted peers (Khadka, Ryan, Margrain & Woodhouse, 2012). The study followed 13 focus groups containing school aged children. It was found that children with VI lead similar lives to those of their sighted peers but experienced restrictions in certain areas. The children reported that the restrictions imposed were not a product of their skill ability rather that the restrictions were in place as a result of a parent/caregiver making the decision for them. The results suggested that participation in activities was not always limited as a result of the individual child's physical ability. The research indicated that parents and key supporting adults (e.g. teachers and teaching support assistants) have to take a step back and allow the child with VI to engage in activities that are suited to, and perhaps challenge their abilities (Khadka, Ryan, Margrain & Woodhouse, 2012).

The research conducted by Khadka, Ryan, Margrain & Woodhouse (2012) is important given the context of the current study. This is because the parents of the participants in the current study gave consent on behalf of their child. This meant that for the children involved in the current study, parents were not a barrier to the development of ILSD.

It can be argued that although vision is not essential for movement, blind children are less likely to move around their surrounding environment due to a lack of visual stimulation (Sugden & Wade, 2013; Bowman, Bowman & Dutton, 2001). Sighted children are more inclined to move toward a visual stimuli (Sugden & Wade, 2013). This inclination could be because the earliest form of communication at a distance (in the typical context) is visual in nature. This means that development is facilitated by the access to visual stimuli (Bowman, Bowman, & Dutton, 2001). Lack of visual stimulation is one reason why children with VI are less likely to move around their environment, but also a fear of injury and parental overprotection are reasonable arguments (Munro, Garza, Hayes & Watt, 2016; Warren, 1994). For example, in an unfamiliar environment a child with VI may be unwilling to explore because of unknown risks which could cause injury (Sugden & Wade, 2013; Bowman, Bowman & Dutton, 2001). It is important to understand however, that movement is not facilitated by vision. This means that we do not need sight in order to move.

Individuals with VI are able to manage the majority of motor skill demands with appropriate adaptations to their learning environment (Miller, Wall & Garner, 2011). Individuals with partial

sight are able to use residual vision to guide their movement. Individuals who have a complete absence of sight are able to move and navigate using tactile methods e.g. the use of a long cane, and auditory methods e.g., echolocation (Sugden & Wade, 2013). Tactile methods can involve using feet, arms and hands directly as a guide. Indirect tactile methods include changes in the air around the individual, suggesting the presence of a wall or gap between buildings (Sugden & Wade, 2013). These indirect tactile methods are supported by the use of a long cane, for example. Further to this, auditory stimulation through active and passive echolocation are also suitable methods for facilitating safe movement. Individuals develop a distinct competency in echolocation as a result of VI (Sugden & Wade, 2013).

Adults whose blindness is a result of injury or disease have the benefit of previously using their sight-derived understanding and experience of the environment to guide their movement. Children who have been blind from birth or infancy have to develop their dorsal stream (to improve mobility and safety when navigating through an environment) and their visual cortex in order to account for the loss (Sugden & Wade, 2013). Bedny, Richardson & Saxe (2015) found that in young children with blindness ( $n=19$ ; age range 4-17 years) the visual cortex developed by response to auditory input (spoken language, music or foreign speech). Blindness in this study was categorised as a pathology in or anterior to the optic chiasm and was not a result of brain damage (Bedny, Richardson, & Saxe, 2015). 18 of the blind participants had minimal light perception from the age of 2 months or earlier. The blind participants were compared to a sighted sample ( $n=40$ ; age range 4-17 years). Half of the sighted sample ( $n=20$ ) were blindfolded for the study, and the remaining half ( $n=20$ ) remained sighted. It was found that the visual cortex in sighted children (across both groups) did not respond to auditory stimulation. The findings of this study suggested that in the absence of visual input, the visual cortex of young children with blindness becomes occupied with auditory input, particularly that of spoken language (Bedny, Richardson & Saxe, 2015).

## **3.2 Visual Impairment/s**

### **3.2.1 Defining visual impairment**

There is no single agreed definition of VI. It is accepted that VI is an umbrella term ranging from partial sightedness to blindness (Herbert, 2003). Blindness is the complete absence of sight. 'Low vision' refers to moderate and severe partial sightedness. An individual is considered partially sighted if their vision cannot be corrected with prescribed glasses or lenses (NHS Choices, 2013). An individual with partial sight has a degree of residual vision which they can rely on to complete certain tasks (Tobin, 1997). Blindness does not prevent an individual from completing tasks that involve vision, however adaptations to the environment and/or equipment may be necessary to accommodate the absence of sight (Miller, Wall & Garner, 2011). Taking this into account, VI, in the context of the current thesis,

refers to those collectively referred to as having ‘low vision’ (moderate to severe partial sightedness) and blindness (Dandona & Dandona, 2006).

### 3.2.2. Classification and causes of visual impairment

There are many classifications and causes of blindness in infancy and childhood. This section focuses only on optical conditions and diagnoses that occurred within the recruited sample for the project. Table 3.1 names each condition, providing the cause and description. Table 3.1 aids contextualisation for the findings of the VI sample in later chapters.

Table 3.1

#### *Clinical diagnoses of visual impairment (VI)*

<u>VI</u>	<u>Cause and Description</u>
Pilocytic Astrocytoma (PA) in chiasmatic/posterior fossa and PA in the optic pathway	A type of CVI. Slowly growing cyst like tumours that occur in the astrocytes in the brain. The astrocytes are cells which make up the supportive tissue in the brain. PA is considered to be a benign (noncancerous) condition. In the cases outlined, these tumours are based in the back of the brain (posterior fossa) and the optic pathway, causing severe VI (American Brain Tumor Association, 2014).
Congenital Glaucoma (CG)	A condition which may be inherited. CG causes abnormal development in the drainage system of the eye. This leads to a build-up of pressure within the eye, damaging the optic nerve causing VI (Glaucoma Research Foundation, 2015).
Septo-optic Dysplasia	Diagnosis occurs when 2 or more of the following criteria are met: optic nerve hypoplasia (underdeveloped fibres in the optic nerve); midline brain abnormalities in the septum pellucidum and/or corpus callosum (abnormalities in these areas can result in developmental delay in language/speech and motor skill abilities/movement/coordination); pituitary gland abnormalities (where the pituitary gland does not produce a sufficient amount of hormones e.g. growth hormones). Other issues surrounding pituitary gland problems include hypoglycaemia (low blood sugar levels), hypernatraemia (high salt levels) and diabetes insipidus (excessive thirst and production of urine) (Great Ormond Street Hospital for Children, 2015).
Rod/cone retinal dystrophy (tunnel vision)	This diagnosis covers a wide range of eye conditions that are related to issues with rod cone photoreceptors. Dystrophy refers to a condition present since birth. Rod cone dystrophy can have a genetic cause.

Common rod cone dystrophies include Leber's Amarois, Retinitis Pigmentosa, Usher's syndrome and Batten's disease. Tunnel vision refers to a type of rod cone dystrophy which causes blurred peripheral vision. This type of dystrophy suggests a problem with the rod photoreceptors (Blaikie, 2016).

Leber's hereditary optic neuropathy (LHON)	An inherited condition. Rare cases appear in childhood. It is a progressive condition that affects visual acuity and colour vision. Typically it affects central vision. Loss of vision results from cell death in the optic nerve. VI is typically the only symptom, but "LHON-plus" refers to movement disorders, tremors and cardiac conduction defects which are present in addition to the VI (Genetics Home Reference, 2013).
Retinopathy of Prematurity (ROP)	Underdeveloped retinal blood vessels which is directly correlated with prematurity (where a child is born before being carried to full-term). As a result of the underdeveloped blood vessels, the retina does not receive sufficient oxygen and so the retina attempts to grow new blood vessels. The new vessels are sensitive and cause scarring on the retina. The most severe forms of ROP lead to retinal detachment and blindness (RNIB, 2016).
Juvenile Batten Disease (JBD)	An inherited disorder affecting the nervous system. The condition is associated with rapid progressive vision loss (resulting in blindness), intellectual disability, speech difficulty, and seizures. VI is usually the first symptom at between 4 and 8 years of age. Individuals with JBD will also experience developmental regression, a loss of motor skills and a difficulty in learning new information (Genetics Home Reference, 2016).

Within the context of the current research project, it was estimated that the most frequent causes of blindness would concern perinatal, intrauterine or hereditary problems due to the early onset of VI in the young sample of children.

### **3.2.3 Prevalence of visual impairment**

Within the United Kingdom (UK), 0.2% of children and young people (CYP) aged between 0-16 meet the VI classification criteria outlined by the WHO (Keil, 2014). It is estimated that over 25,000 children and young people are classified as blind or partially sighted within the UK (Keil, 2014). It is important to note, however, that the prevalence rates are not always accurately reported in statistics. This is a result of varying definitions of VI (outlined in section 3.2.2), the difficulty of diagnosing certain optical conditions (e.g. CVI) and varying methods of collecting data (Keil, 2014).

### 3.2.4. Prevalence of comorbidity and visual impairment

Keil (2014) also reported the prevalence of VI and comorbid conditions. She estimated that in the UK, 19,000 children have a learning disability and VI, and 4,000 children have a learning disability and are classified as blind. This was supported by the findings of Emerson & Robertson (2011). These statistics were based on the assumption that all children were known to the education services within the UK (Emerson & Robertson, 2011). Table 3.2 shows nine comorbid conditions. These include Tourette's syndrome, Autism Spectrum Disorder and Growth Hormone deficiency. All nine conditions were associated with the VI sample in the context of the current thesis.

Table 3.2

#### *Additional disabilities characterised in the VI sample*

<u>Additional Disability</u>	<u>Description</u>
Autism Spectrum Disorders (ASD)	Developmental disability which affects communication and concept formation for the external environment. It is a spectrum condition and varies in severity. A characteristic of ASD is hyper- or hypo-sensitivity of the senses e.g. touch and sound (The National Autistic Society, 2016).
Tourette's syndrome (TS)	A neurological disorder where an individual presents with repetitive and involuntary movements and/or vocalisations. Average onset occurs between 3 and 9 years of age (National Institute of Neurological Disorders and Stroke, 2012).
Precocious Puberty	Where the characteristics of puberty occur earlier than the average age of onset e.g. before the age of 8 years in girls and 9 years in boys (Boyse & Phelps, 2012).
Growth Hormone Deficiency	Where the pituitary gland does not make a sufficient amount of growth hormone. The cause is currently unknown but it may be present at birth or resultant of a traumatic brain injury (U.S. National Library of Medicine, 2016; Kaneshiro, 2015).
Cardiac Ebstein Anomaly	A rare heart defect characterised by an abnormal tricuspid valve. This means that the separation of the 2 chambers (right lower and right upper heart chambers) is abnormal (Schumacher, 2014).
Diabetes Insipidus	Excessive urination caused by an antidiuretic (water balancing) hormone called vasopressin (Diabetes.co.uk, 2016).

Attention Deficit Disorder (ADHD)	A neurological disorder with an unknown cause. Arguments postulate that the condition could be genetic, resultant of a hormone deficit or a neurotransmitter deficiency. The condition is associated with inattentiveness, impulsivity and hyperactivity (Optometrists Network, 2016).
Cohens syndrome	A genetic disorder which affects motor skill development, cognitive development and also behavioural problems. Other characteristics include poor muscle tone, high flexibility and a difficulty gaining weight (Counsyl, 2016).
Gastroesophageal reflux of prematurity (GRP)	Direct result of prematurity. Immature muscles and abnormal breathing can cause GRP. If the lower oesophageal sphincter is underdeveloped or weak it can remain open when it should be closed. This means that the stomach acid and undigested food can flow back up the oesophagus. If the infant also has problems breathing, this can also pull on the oesophagus, keeping it open (Maroney, 2016).

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Taking the outlined diagnoses of VI and other comorbid developmental disorders into account, for the purpose of this thesis *VI is defined as:*

‘A diagnosed optical condition at birth or early infancy which denies or restricts access to typical development in relation to motor skill acquisition and most likely atypical developmental pathways of other domains’.

This umbrella term for VI employed for the current research foregrounds motor skill development in the VI population.

### 3.2.5 Visual assessment measures

Vision is assessed by using two measures: clinical vision assessments (CVAs) and functional vision assessments (FVAs). A CVA is conducted by a medical professional in a controlled setting. The CVA can measure the constraints of vision (e.g. colour vision, contrast sensitivity, CVI, control of eye movement, and distance visual acuity (DVA)). The CVA can also diagnose optical conditions and provide information regarding the nature of the diagnosis. The DVA is one form of a CVA. The DVA clinically assesses the degree of vision loss. It is based on the smallest object which can be recognised by the individual when unaided by a corrective device such as a lens. There are a wide range of DVA assessment tools to use. The tools are adaptable for age, objects and formats. Figure 3.1 shows two forms of a DVA; the Snellen chart and the Tumbling E chart.

(a) The Snellen Chart



(b) The Tumbling E Chart

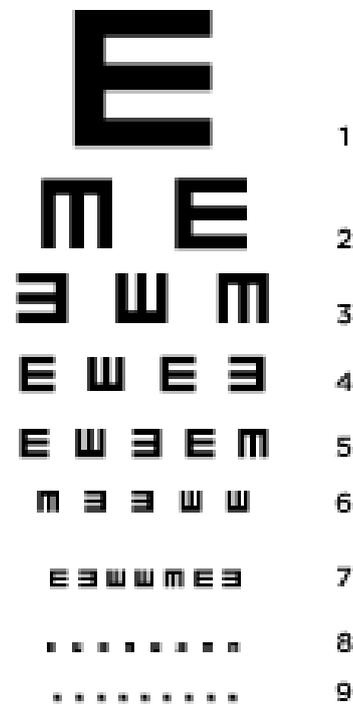


Figure 3.1. The Snellen Chart (Uveitis Information Group (Scotland), 2007). The Tumbling E Chart (Segre, 2015).

The CVA however is limited for everyday practical purposes as the assessments are made in “ideal” conditions, for example adequate lighting. This means that the CVA does not appropriately assess the individual’s vision in a “real-life” situation. The CVA is perfectly adequate for prescribing spectacles or lenses.

FVAs assess how an individual uses their available vision (Topor, 2015). These assessments are carried out in uncontrolled settings – usually familiar environments with varying light conditions for example. The purpose of a FVA is to assess an individual’s functional (useful) vision, by how they use the vision they have available to them for a range of tasks when carrying out their usual daily activities. This provides insight to how *they* use the vision available to them of their vision. The FVA can be used for individuals with single/dual sensory loss and individuals with multiple disabilities and needs.

The FVA should be carried out in a systematic manner and continually reassessed to examine changes in an individual’s useful vision. The necessity of continual monitoring could have

significance for a child with VI's performance in everyday settings and tasks. The FVA provides information as to how the child with VI uses their vision in everyday tasks, but also assesses what skills a child may need to develop or develop further.

The CVA and the FVA work together in order to fully understand the nature of the VI for an individual. This is because the CVA and FVA results demonstrate an understanding of the clinical aspects of the VI and also how the individual uses their residual vision in real-life situations. The results of CVA and FVA together with Habilitation Specialists and Qualified Teachers for Visual Impairment can subsequently suggest necessary adaptations to an individual's environment. In addition to this, the collaboration between the results of CVA, FVA and supporting adults (e.g. class teachers and teaching assistants) can provide indications for certain provisions for learning equipment, such as documents provided in large print (Miller, Wall & Garner, 2011, page 18).

### **3.2.6. Variability and cognition in children with VI**

It is understood that individual differences within the VI population can have an effect on child development (Herbert, 2003; Warren, 1994). For example, a child may use their residual vision more effectively than another child with the same diagnosis, indicating an apparently higher intellectual ability (Herbert, 2003). This means that a shared diagnosis of VI *does not* lead to shared characteristics between individuals (Warren, 1994). The individual differences could arguably be due to developmental delay resulting from VI.

Developmental delay can be explained in terms of developmental trajectory (Thomas, Annaz, Ansari, Scerif, Jarrold & Karmiloff-Smith, 2009). This means that to examine the effects of developmental disorders, participants are matched with TD participants and grouped according to chronological age (CA) and mental age (MA). The 3 groups are then tested on standardised measures. If the developmental disorder group displays an impairment compared to the CA group but not the MA group, it is postulated that the disorder group show a developmental delay on the specific measure (Thomas, Annaz, Ansari, Scerif, Jarrold & Karmiloff-Smith, 2009). If the developmental disorder group display an impairment in comparison to both MA and CA matched groups, they are then assumed to have atypical development (Thomas, Annaz, Ansari, Scerif, Jarrold & Karmiloff-Smith, 2009).

There has been very little research regarding this phenomenon in children with VI. This is arguably a result of a somewhat lacking battery of standardised tests suitable for use with a VI population. Warren (1994), assumed that children with VI develop in the same way as their

sighted peers (i.e. following the same trajectory), yet the achievement of developmental milestones (such as standing, for example) takes a longer period of time (Warren, 1994).

It is important to note that tests of individuals with VI are usually based on TD norms (Warren, 1984). The use of TD norms as a basis for understanding VI or DS can be considered inappropriate due to the great degree of variation found within clinical populations (Van Herwegen, Dimitriou & Rundblad, 2013). However, it has been noted that there is arguably also a great degree of variance within the TD population (Van Herwegen, Dimitriou & Rundblad, 2013; Van Herwegen, Rundblad, Davelaar & Annaz, 2011). Van Herwegen, Rundblad, Davelaar & Annaz (2011) conducted a study regarding cognitive task performance. The study examined the variability in children with Williams Syndrome (WS) ( $n=33$ ) and TD children ( $n=33$ ). It was found that when CA was controlled for, there was no reported statistical significance between group performances. Furthermore, it was found that there was significantly less variability in WS group performance on a Pattern Construction task when compared to the TD group. The findings of Van Herwegen, Rundblad, Davelaar & Annaz (2011) supports the notion of a high variability within a TD sample, which previously has been considered to be homogenous.

In relation to individual variation within the development of children with VI, it is postulated that a child has more access to learning if the nature of the impairment allows a reliance on residual vision (Warren, 1994). *Learning is defined as:*

‘an approximate permanent change in behaviour, resulting from practise’  
(Millar, 2011; Kimble, 1961).

The use of residual vision for learning however may be limited. This means that certain provisions (such as large print books) within the school environment have to be made (Miller, Wall & Garner, 2011). These provisions aid and support the development of independence and mobility in children and young people with VI (Miller, Wall & Garner, 2011).

### **3.3 Down Syndrome**

#### **3.3.1 Historical perspective**

The characteristics of DS were first documented in 1838 by Jean-Étienne Dominique Esquirol (Scorza, Scorza, Arida & Cavalheiro, 2011). The report described individuals who suffered from intellectual and developmental disabilities. At this time, the individuals were considered to be ‘idiots’ and separate from individuals who were labelled as ‘insane’ (Rosen, Clark & Kivitz, 1977). DS was not termed so until 1866 (Scorza, Scorza, Arida & Cavalheiro, 2011;

Ward, 1999), when the distinctive facial characteristics described by John Langdon Down were linked with a lower intellectual ability (Ward, 1999). Down referred to the patients as “Mongoloids” as he understood the facial characteristics (notably the eyes), to be similar to native Mongolians (Ward, 1999).

In 1932, Davenport first suggested a failure of cell division as a possible cause for DS (Patterson & Costa, 2005; Davenport, 1932). Support for the nondisjunction hypothesis and also the discovery that DS is a result of a triplication of chromosome 21 occurred in 1951 (Lejeune, 1951). As a result of this, the term ‘Trisomy 21’ was then used in medical journals to describe the condition (Lejeune, 1959). Translocation was discovered in 1960 (Polani et al, 1960) which is understood to be a permanent attachment of one chromosome to another, in this case, an additional portion of chromosome 21 to another chromosome. This is believed to occur in 4-5% of DS cases (Fidler & Daunhauer, 2011). Mosaicism (the rarest form of DS) was identified in 1961 (Allen et al, 2009; Sherman et al, 2005; Gomez et al, 2000).

### **3.3.2 Genetics and diagnostics**

Through mitosis and meiosis, cells divide and adopt particular functions. Variation within the genetic makeup of chromosomes occur through meiosis. This occurs before the cell divides, as the chromosomes are split and pulled to the polar side of the cell. The random nature of the split results in a random mixture of genes. From conception the unique genetic makeup contains the foundations that govern genetic traits of growth and development throughout the lifespan (Herbert, 2003).

For a child with DS, the extra genetic material arises from an atypical cell division (nondisjunction) before conception, and is typically passed on from the mother (O’Day, 2010). Figure 2.4 displays how nondisjunction can occur during both meiosis 1 and meiosis 2. Nondisjunction is apparent in the right hand side of the image during meiosis 1. Figure 3.2 shows how the chromosomes have not been pulled apart which has led to an abnormal distribution of chromosomes. The left hand image of meiosis 1 illustrates normal cell division for comparison. Nondisjunction can also occur during meiosis 2. Figure 3.2 shows how a nondisjunction can occur after ‘normal’ cell division during meiosis 1. This is illustrated in the bottom left corner of the image. It is apparent that the chromosomes have not split during meiosis 2 in this case.

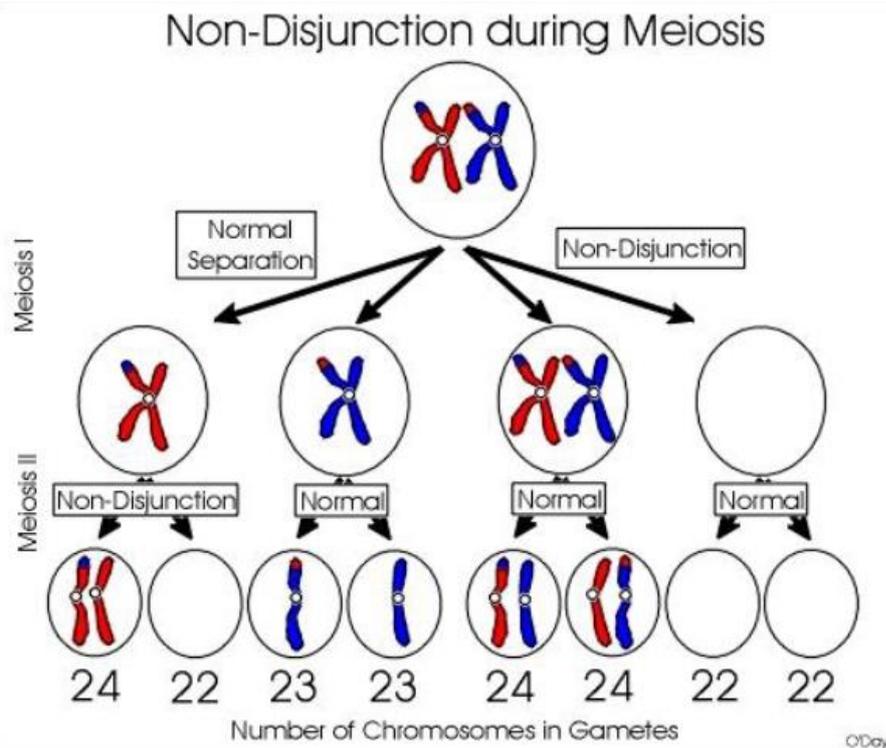


Figure 3.2. Non-disjunction during meiosis (O'Day, 2010).

DS is a condition associated with the presence of three copies of chromosome 21 (trisomy 21). This is caused by non-disjunction (a failure of cell division) of chromosome 21 (Patterson & Costa, 2005; Davenport, 1932). The exact relationship between trisomy 21 and DS, however, is not fully established. Some studies suggest a link between the syndrome and mitochondrial dysfunction at the cellular level (Roizen & Patterson, 2003). There are three identified forms of the syndrome; trisomy 21, translocation trisomy 21, and mosaicism. Approximately 94% of all people with DS are diagnosed with trisomy 21 (where all their cells have an extra chromosome 21) (Patterson & Costa, 2005; Davenport, 1932). Translocation trisomy 21 (or Robertsonian translocation), results from the permanent attachment of chromosome 21 to another chromosome (mainly chromosome 14, hence the use of the signifier 't(14;21)' in the relevant literature) (Fidler & Daunhauer, 2011; Scriven, Flinter, Braude & Ogilvie, 2001).

The prevalence of translocation trisomy 21 occurs in about 3-4% of DS cases or one in every 1,000 births (Fidler & Daunhauer, 2011; Polani et al., 1960). Mosaicism is the least prevalent form of DS. It was previously understood to be prevalent in 2-4% of the DS population (Benke, Carver & Donahue, 1995), but is now believed to occur in approximately <1% of DS cases (Sherman, Freeman, Allen & Lamb, 2005). Mosaicism is characterised by a mixed population of cells (trisomy 21 and normal cell population) which contain extra genetic material believed to be passed on by the mother in approximately 90% of cases (Allen et al, 2009; Sherman et

al, 2005; Gomez et al, 2000). It is understood that older women have a higher incidence rate of abnormal chromosome numbers in their eggs due to a meiotic block for an extended period of time. Older men can also produce sperm with this abnormal chromosome effect but this is not a result of a meiotic block.

In order to diagnose DS, non-invasive prenatal testing (NIPT) is used. NIPT can detect DS by examining the foetal DNA found in the maternal blood stream (Morris, Karlsen, Chung, Hill & Chitty, 2014).

### **3.3.3. Prevalence rates**

The National Down Syndrome Cytogenetic Register for England and Wales reported the prevalence for DS across the UK in the year 2012 (Morris & Springett, 2014). This is the most recent record for the UK. In 2012, the prevalence rate for DS was 2.7 per 1,000 births, and a live birth rate of 1.1 per 1,000 live births (Morris & Springett, 2014). This means that there is a high level of pre-birth fatality associated with DS. Out of 1,982 diagnoses of DS (made across England and Wales in 2012, where 64% of diagnoses were made prenatally), it was estimated that there were 775 (39%) live births (Morris & Springett, 2014). This suggests that approximately 61% of DS pregnancies end through miscarriage, still birth or termination (Morris & Springett, 2012). In 2012, 92% of DS pregnancies were terminated (Morris & Springett, 2012).

### **3.3.4 Physical and medical characteristics**

The physical features of DS vary depending on the extent of the trisomy population. Individuals with trisomy 21 have 3 full copies of chromosome 21 which is replicated in each cell of the body (National Down Syndrome Society, 2012). This may lead to more distinctive physical characteristics associated with DS. For individuals with mosaicism the characteristics tend to be milder compared to trisomy 21 (National Down Syndrome Society, 2012; Benke, Carver & Donahue, 1995). This is based on a larger proportion of normal cells containing 46 chromosomes (National Down Syndrome Society, 2012; Benke, Carver & Donahue, 1995). Individuals with translocation have a full or partial presence of an extra chromosome 21, and this is related to the physical characteristics associated with DS (National Down Syndrome Society, 2012). This means that although there are distinctive physical characteristics associated with DS, not all characteristics may be present in each case, as this is dependent on the DS diagnosis (National Down Syndrome Society, 2012; Roizen & Patterson, 2003; Benke, Carver & Donahue, 1995).

Physical facial characteristics associated with DS include: almond shaped eyes which slant upwards; a flattened nose; small ears and mouth; a single palmar crease; and in some cases,

white spots on the iris (the coloured part of the eye) (Percy & Schormans, 2005). Further physical characteristics include: hypotonia (decreased muscle tone at birth which is believed to be present in almost all cases of DS (Freeman et al., 1998)); an excess of skin at the nape of the neck; small, wide hands with short fingers; and a separation of joints between the bones of the skull (Freeman et al., 1998). Furthermore, children with DS are generally short in stature, meaning that they are unlikely to reach an average adult height. This is due to a delay in physical development which is also associated with DS.



*Figure 3.3. Images of children with Down syndrome. (Osman, 2016; Jones, 2013).*

### **3.3.5 Prevalence of DS and comorbidity**

Medical conditions that arise from DS include: cardiovascular (heart) problems; VI (such as cataracts and glaucoma); gastrointestinal problems (such as vomiting and constipation); auditory problems (usually caused by their susceptibility to ear infections); problems with the pelvis (an increased risk of dislocation of the hip); an underactive thyroid (leading to weight problems); and a delay in the development of teeth, which could impact chewing. Further to these outlined conditions there is also an established link between DS and Autism Spectrum Disorder (ASD) (Capone, Grados, Kaufmann, Bernad-Ripoll & Jewell, 2005). The comorbidity of DS and ASD is estimated at 5-10% (Capone, Grados, Kaufmann, Bernad-Ripoll & Jewell, 2005). There is a lack of available literature regarding the sensory and visual implications for children with DS and ASD, arguably due to the difficulty in differentiating between the two conditions in younger children (Reilly, 2009). However, Bregman and Volkmar (1998) reported a case study of a 12 year old female with DS and ASD. They found that she engaged in

repetitive behaviours and was engrossed with details of objects. She would also use smell and taste to “feel” objects such as toys (Reilly, 2009; Bregman & Volkmar, 1988). It is also reported that the comorbidity between DS and ASD has: a negative effect on social relationships and communication; an association with negative behaviour such as aggression and resistance; poor eye contact and gesticulation (Reilly, 2009; Howlin et al., 1995). Although these findings are not generalizable, if a participant in the current study is diagnosed with DS and ASD, these types of behaviours may be displayed and so impact upon the presence of additional support of teaching assistants if necessary.

The Atlanta Down Syndrome Project found that cardiac diagnoses were identified in 93% of DS cases. It is important to note that these data included investigations from echocardiography, cardiac catheterization, surgery or autopsy. This meant that the prevalence of 93% included both live subjects and subjects who had died (Freeman et al, 1998). The project analysed 227 infants of which 44% had congenital heart defects. Of this sample, 45% of participants had an atrioventricular septal defect (which could have included other congenital heart defects), 35% had a ventricular septal defect (either with or without other congenital heart defects), 8% had an isolated secundum atrial septal defect, 7% had isolated persistent patent ductus arteriosus, 4% isolated tetralogy of Fallot, and the remaining 1% were classified as ‘other’ (Freeman, 1998). Although congenital heart defects are prevalent in the DS population, they are surgically corrected if possible (Percy & Schormans, 2005). Gastro-intestinal blockages are also highly prevalent in individuals with DS. Although these are usually corrected through surgical intervention, they can impact the potential movement of the child due to the pain and discomfort associated with the condition (Percy & Schormans, 2005; Hyman, Milla, Benninga, Davidson, Fleisher, Taminiau, 2005).

### **3.3.6 DS and comorbid VI**

Children with DS usually have a VI in association with their disorder (Määttä, Kaski, Taanila, Keinänen-Kiukaanniemi, & Iivanainen, 2006). In addition to VI, children with DS are also reported to have developmental delay which has an impact on motor skill acquisition, as well as other developmental milestones (Pereira, Basso, Lindquist, da Silva & Tudella, 2013).

### **3.3.7 Cognitive phenotype**

Chromosomal abnormalities are reported to explain 15% of intellectual disability (Vissers, Gilissen & Veltman, 2015). Within this, DS is estimated to account for 6-8%. This means that DS identified as the main genetic cause of learning difficulties (Vissers, Gilissen & Veltman, 2015; Bittles, Bower, Hussain & Glasson, 2006). It is argued that intellectual impairment is

present in almost all cases of DS (Freeman et al, 1998). However the extent of the cognitive impairment is based on the severity of the individual's condition (Silverman, 2007). In this thesis, *cognition is understood as:*

‘The conscious or unconscious transformation of sensory input into meaningful and accessible experiences in order for an individual to make sense of the world’ (Silverman, 2007).

It is important to note that cognitive impairments (average IQ of 50-60 points in DS cases (Henry Spink Foundation, 2016)) are present in cases of DS. This is due to the variability of the effect of chromosome 21. Also, cognitive profiles of individuals with DS can vary over the lifespan. This is due to maturation effects and neurodegeneration (Grieco, Pulsifer, Seligsohn, Skotko & Schwartz, 2015; Silverman, 2007; Zigman & Lott, 2007).

Research evidence supports an association between DS and cognitive impairments in the following areas: processing speed; language; and memory (Jarrold, Baddeley & Hewes, 2000). The impairment in auditory processing is believed to arise from an impairment in the phonological loop area of working memory (Jarrold, Baddeley & Hewes, 2000). This means that individuals cannot effectively rehearse the auditory information they are processing (Jarrold, Baddeley & Hewes, 2000). However, the research evidence for this claim is somewhat lacking. This means that the impairment could be due to problems in encoding auditory information or for reasons not yet understood (Jarrold, Baddeley & Hewes, 2000).

Processing speed is also relative to the time it takes to successfully complete tasks and reaction time. However much of the literature explored lacks clarity and is outdated (Silverman, 2007; Gibson, 1978; Nettlebeck & Brewer, 1976; Berkson, 1960). The available research identifies that there is a delayed response in DS individuals' reaction time. The reasons for the delay could be due to a multitude of variables ranging from intellectual delay, to the participant not realising that the test was to be completed as soon as they could (Silverman, 2007; Nettlebeck & Brewer, 1976). This lack of substantiated evidence suggests that there is a possible processing disorder that is associated with DS, however there are many confounding variables making the cause currently unknown.

A further association between DS and working memory problems concerns the retention of information. This is because children with DS can only retain such information for short periods of time (Jarrold, Baddeley & Hewes, 2000). Jarrold, Baddeley & Hewes (2000) investigated the premise that children with DS have a poorer short term memory when compared to verbal

and mentally matched controls. The study examined children with DS ( $n=14$ ; mean CA: 166.43 months; mean verbal and mental age: 54.93 months) and children with moderate learning difficulties ( $n=14$ ; mean CA: 116.93 months; mean verbal and mental age: 56.50 months) (Jarrold, Baddeley & Hewes, 2000). During a single session, the participants were tested on their short term memory span and their articulation rate. Short words such as 'bee', 'lamp' and 'shoe' were chosen for the testing and long words such as 'caterpillar', 'grandmother', and 'policeman' were also chosen. The chosen words were matched on word frequency.

Short term memory span was assessed by verbally presenting lists of words that increased in size. Participants were required to listen to the word lists and verbally recall them. The assessment continued until the participant was unable to recall the words in the correct order. Articulation was measured by asking the participants to repeat pairs of words as fast as possible. If a participant hesitated or failed to repeat, they were prompted by the examiner who modelled the response.

The study reported that children with DS perform more poorly than the controls. The DS group performed better when asked to recall short words. The results of the study supported previous findings regarding impaired short term memory ability in DS individuals (Jarrold, Baddeley & Hewes, 2000). The findings presented by Jarrold, Baddeley & Hewes (2000) suggests that children with DS have a difficulty in retaining auditory input. In order to aid the retaining of this input, it is advised that prompted rehearsal is important to aid encoding and memory (Sigman, 1999; Seung & Chapman, 2004). A phonological loop problem could explain the difference in speech pattern and also elocution of words and phonemes, however as previously explained, there is insufficient research evidence to substantiate this claim.

To further support encoding and memory, the use of gestures (and Makaton, Signalong or British Sign Language where appropriate) are also common. Makaton is a type of language that uses simple signs and symbols alongside and in order with speech to aid communication (The Makaton Charity, 2016). Makaton sign language is typically used in school and at home in order to support language development in young children with DS (All Party Parliamentary Group on Down Syndrome, 2012).

These forms of gestured communication are believed to be governed by the phonological loop system in verbal memory (A. Baddeley, personal communication, 2016). This means that although DS is associated with phonological processing problems, the main form of communication (e.g. Makaton) also relies on this form of processing. Despite this, the use of sign language is still prevalent in communicating with children with DS. One study reported

that after cochlea implant surgery (to correct a hearing impairment) a child participant reported the preference for using Makaton (Phelan, Pal, Henderson, Green & Bruce, 2016).

Although this is one reported instance of communication preference, the use of Makaton to support communication between adults and children with DS is also considered good practice (Oulton, Sell, Kerry & Gibson, 2015). Within the context of the current study, it was understood that language comprehension and expression may be difficult for participants with DS. However as the researcher used basic Makaton, this effect was reduced in order to ensure meaningful communicative interactions between the children with DS and the researcher.

### **3.3.8 Behavioural characteristics**

Positive behavioural characteristics of children with DS can include being placid, good-natured and affectionate. More negative behavioural traits include (but are not exclusive to) temper tantrums, disobeying instructions, stubbornness and a poor attention span (Pueschel, Bernier & Pezzullo, 1991). Arguably these behavioural traits are non-specific to the condition, as TD children also display these behavioural traits. Research has found that on the Child Behaviour Checklist, children with DS had less behavioural problems when compared to their TD peers (Eisenhower, Baker & Blacher, 2005). The Child Behaviour Checklist is for use with children between 1;05 years and 5 years old. Although the Child Behaviour Checklist does not account for children older than 5 years, the information reported by Eisenhower, Baker & Blacher (2005) can be used as a predictor for behaviours of the older children with DS. This may be of use within the current project as it may influence the need for the additional presence of teaching assistants within the intervention sessions.

Although children with DS can elicit behavioural problems, their behaviour is reported to “fit in” with societal expectations (Buckley, Bird & Sacks, 2002). There is, however, varying evidence for this claim. Buckley, Bird & Sacks (2002) reported that 16-30% of teenagers with DS ( $n$ =not specified) had significant behavioural problems, but this was dependent of the types of behaviours that were assessed. This was compared to 5% of reported behavioural issues in TD teenagers. In the same paper, Buckley, Bird & Sacks (2002) reported that children with DS could elicit particular behaviours e.g. throwing items, which are not accounted for within the general questionnaire which was “suitable” for all. This means that TD derived anti-social behaviours are not characteristic of the DS population. The findings also suggested that the design of questionnaires ought to be representative of all possible behaviours, not only those characterised by a TD sample.

Sloper, Cunningham, Knussen and Turner (1988) investigated behavioural issues in children with DS ( $n=120$ ; age range 5-10 years) and compared the findings with a similar study regarding TD children. The comparison yielded the result that 12% of mothers of children with DS reported their children as having behavioural difficulties. 14% of mothers of the TD children reported behavioural problems in their children. Across both TD and DS groups, 40% of mothers reported their concerns over their children's behaviour. Furthermore, some reports have found that children with DS who have TD siblings, tend to behave in a way similar to them (Dykens & Kasari, 1997; Pueschel, Bernier & Pezzullo, 1991).

A longevity study by McCarthy (2008) investigated early risk markers and later behavioural disorders to unpack whether childhood risk factors had an effect on negative behavioural conduct in young adults. 50 participants with DS were recruited and tested on the same measures in childhood (age range 6-17 years) and early adulthood (age range 22-33 years) (McCarthy, 2008). Aspects measured for behaviour included childhood functioning and the quality of the parental marriage. The research reported that impaired functioning of DS children may predict short- and long-term behaviour disorders (McCarthy, 2008). The reports regarding the behavioural traits of the DS population suggest that behavioural characteristics tend to be similar to the TD population. In saying this, functioning may be a predictor of negative behaviour in children with DS.

### **3.4 Developmental delay**

Taking individual variation into account, it is important to note that an atypical sample may require more methodological and systematic instruction compared to a TD sample (Van Herwegen, Dimitriou & Rundblad, 2013). This is due to developmental delay (Van Herwegen, Dimitriou & Rundblad, 2013). Van Herwegen et al., (2013) investigated whether CA or MA (represented by word knowledge) related to the comprehension of novel metaphor and metonym. The sample consisted of TD individuals ( $n=34$ ; age range 7;01-44 years) and individuals with Williams syndrome (WS) ( $n=31$ ; age range 3;09-17;01 years). The results of the study found that an increase in CA did not affect comprehension in the WS sample. This finding was in contrast to the TD sample. Furthermore, developmental delay was apparent in the WS group regarding the development of novel metonymy. The comprehension of the novel metaphor was both delayed and atypical within the WS group.

The findings of Van Herwegen et al., (2013) demonstrated that language development and comprehension occurs early in life, however the effect of genetic conditions (such as WS) and the associated developmental delay may impact task performance in language tasks.

Defining developmental delay in any sense, for example language or motor skill delay is more difficult than it may seem. *Developmental delay is defined as:*

‘The difference between standardised test scores of individuals with a developmental disorder, when compared to TD CA-matched groups’ (Thomas, Annaz, Ansari, Scerif, Jarrold & Karmiloff-Smith, 2009).

Developmental delay is distinguished from atypicality. *Developmental delay in relation to atypicality is defined as:*

‘The difference in performance on standardised test scores in individuals with developmental disabilities when compared to TD groups, matched on CA and MA’ (Thomas, Annaz, Ansari, Scerif, Jarrold & Karmiloff-Smith, 2009).

Some research has attempted to distinguish between developmentally delayed individuals and atypical individuals (Thomas, Annaz, Ansari, Scerif, Jarrold et al., 2009). This is because it is argued that a TD child can also experience a developmental delay. This means that developmental delay and atypicality can be mutually exclusive, as one does not depend upon the other (Thomas, Annaz, Ansari, Scerif, Jarrold et al., 2009). Taking this into account, the TD, VI and DS groups examined in the current study have the potential to display developmental delay. The research is informed by this and so treats VI, DS and developmental delay as separate, distinct entities, although it is understood that developmental delay can be related to sensory impairment such as VI because of a reduced or complete inaccessibility to learn incidentally through the observation of others, and the need for systematic strategies to support learning.

Thomas (2014) outlined two different types of developmental delay: ‘persisting’ and ‘resolving’. Thomas and Knowland (2014) conducted a study which adopted a population modelling approach. They studied individual rates of development in 1000 simulated individuals. This was done to examine if there was a basis for establishing the difference between persisting and resolving delay. The variation of the sample was elicited through computer programming for neurocomputational learning parameters. The parameters included the richness of the language environment which was considered to be representative of the effects of socio-economic status (Thomas & Knowland, 2014). The study reported that there were quantitative variations within the simulated learning mechanisms. This meant that persisting delay and resolving delay subgroups were apparent in the analysis.

The findings of Thomas and Knowland (2014) support the theory of persisting and resolving developmental delay through computation. The study, like other studies regarding developmental delay (i.e. Thomas, Annaz, Ansari, Scerif, Jarrold & Karmiloff-Smith, 2009), explore developmental delay within the context of language development. This means that the general findings support the notion of delayed/atypical development in children, but they do not examine other developmental domains such as motor skill development.

It is argued that the individual participant with persisting developmental delay will always perform lower when compared to a TD trajectory (Thomas, 2014; Thomas & Knowland, 2014). Resolving developmental delay has three aspects; low, good and high. Low resolving developmental delay suggests that there is a minimal transition toward a typical trajectory, but the delay remains present. Good resolving developmental delay refers to a moderate transition toward a typical trajectory. High resolving developmental delay refers to the transition toward a typical trajectory which falls within the normal, typical range (Thomas, 2014; Thomas & Knowland, 2014). These three aspects suggest that developmental delay can be compensated for, to an extent, depending upon the individual participant (M. Thomas, personal communication, October 6, 2014).

Some individuals may experience a compensation for developmental delay e.g. through structured interventions. This means that their subsequent developmental pattern will become similar to the TD trajectory (in the case of good and high resolving developmental delay). In contrast, individuals with low resolving developmental delay may experience some resolution but still perform lower than the typical trajectory (M. Thomas, personal communication, October 6, 2014).

There are many contributing factors for developmental delay. Three examples of these are; hereditary conditions, problems in utero and problems after birth (Pietrangelo, 2013). It is argued that a developing child with sensory impairments such as blindness has to maximise the use of the remaining senses in order to compensate for developmental delay (Winnick, 1979). Three types of aid for children with developmental delay are outlined below (Winnick 1979):

1. Adapted: encouraging the modification of activities ensuring that individuals can participate safely and successfully
2. Developmental: emphasise development through specialised habilitation techniques to reduce physical, cognitive and emotional developmental delay
3. Corrective: correcting bad habits to ensure good practice of movement skills for example. This must only be used with guidance of a medical professional.

The current research acknowledges the three outlined methods for support, and used them as a basis for the development of the suite of intervention materials. To further refine the intervention materials, an examination of the relationship between vision and movement was necessary. This was because it has been previously established that a reduced capacity or complete inaccessibility to incidental learning has an effect on the development of motor skills. This means that movement can be facilitated by observation, or compromised by the inability to observe (Lewis & Iselin, 2002). The following section further explores this relationship between vision, movement and motor development in both atypical and typical contexts.

### **3.5 Typical and Atypical Motor Development**

Human development begins at conception, ceasing only in death. Individual humans follow different developmental trajectories based on genetic influences and environmental factors. The following section examines human development from conception through to childhood, and how this relates to the development of the suite of intervention materials used in the current research.

According to the Equality Act (2010) an individual is considered disabled if:

- “(a) A person (P) has a physical or mental impairment,  
and
- (b) The impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities” (Equality Act, 2010, page 4).

The genetic makeup of an individual plays an important role in determining what the individual may become (Herbert, 2003). Genes may demonstrate their effects early on in life, and so it is also postulated that genetic information may have an influence on the cognitive abilities of individuals, although this is under debate (Herbert, 2003; Plomin & Kosslyn, 2001; Plomin, 1990). Variation within the genetic makeup of chromosomes governs genetic traits of growth and development throughout the lifespan (Herbert, 2003).

#### **3.5.1 Infant development from birth**

Amongst other criteria, the Apgar test is used to measure the reflexes of the new-born infant. Bodily movements in new-born infants initially appear uncontrolled and predominantly reflexive in nature. These movements however, are the basis of development of postural control and locomotion. Locomotion is understood as a voluntary movement of the whole body from one place to another (Anderson et al, 2013). *Reflexes are defined as:*

'temporary, innate survival instincts (present from birth to 1 year, dependant on the reflex) which reflect the infant's ability to respond to sensory stimulation' (Herbert, 2003).

Reflexes are considered important, as if they were not present at birth or if they lasted long into infancy, concerns would be raised regarding the neurological health of the infant (Herbert, 2003). The concerns regarding the absence or continued existence of reflexes relate to neuro-developmental delay. This is because reflexes occur from the lower brain areas which are the first to develop in infancy. As the brain develops, movements become more controlled and refined, moving away from the primitive reflexes present at birth.

The Palmar Grasp is an example of a reflex present at birth, where physical contact to the palm of the baby's hand elicits a grasping response. It is thought to be an evolutionary trait from primitive times, whereby a new-born would have to hold onto the mother after birth for safety. The Palmar Grasp is thought to be important due to an association between the reflex and grip strength; and also the development of fine motor control and stereognosis (identification of an object through touch alone) (Retained Neonatal Reflexes, 2015). This reflex typically disappears at 4 months of age, and is replaced by voluntary grasping specifically, the pincer grasp which is a refined and controlled movement (Herbert, 2003).

It is believed that approximately 12% of infants who score less than 4 on the Apgar Test are at greater risk of developing disabilities such as Cerebral Palsy (Herbert, 2003). However, more recent research suggests that the use of the Apgar measure is inconsistent when predicting neurological dysfunction (American Academy of Paediatrics, 2006). The general consensus suggests that the Apgar score is relevant for use as a *predictor* of infant mortality, yet is inconsistent when predicting neurological dysfunction (American Academy of Paediatrics, 2006). It is argued here that reflexes and the retention of reflexes, however, can be a predictor of atypicality (Zafeiriou, 2004). This is because they are representative of the functioning of the central nervous system (Zafeiriou, 2004). Retained reflexes or a delayed disappearance of reflexes suggest that there is a dysfunction of the central nervous system, and could be symptomatic of conditions such as cerebral palsy (Zafeiriou, 2014).

### **3.5.1.1 The effects of prematurity**

Prematurity is a large cause of neurological complications and developmental problems in children which can manifest in different ways. If a child is born prematurely it is at an immediate developmental disadvantage. This is due to reduced development in utero, as the foetus does not reach the full gestation period. Premature infants also have atypical crying patterns involving piercing sounds. This type of crying pattern appears to be characteristic of infants

with neurological complications and so could be an indicator of developmental problems in infancy (Herbert, 2003). Neurological damage associated with prematurity has been identified as the cause of certain disabilities such as Cerebral Palsy from birth (Marret, Marchand-Martin, Picaud, Hascoët, Arnaud, et al., 2013).

A premature infant may also be subject to medical treatment which can be prolonged for extended periods of time (Herbert, 2003). Prematurity can lead to cognitive and physical developmental complications such as intellectual problems and body size, for example, a premature child has a smaller stature when compared to a child who reached full term gestation in utero. It has been found that children who are born prematurely remain physically small in size throughout childhood and also perform poorly in tests of intelligence (Herbert, 2003; Goldenberg, 1995; Lin, 1993). The following physical complications may also arise as a result of prematurity due to lack of development in utero:

- Intracerebral haemorrhages lead to effects of leg movements as well as contributing to the child's risk of spastic diplegia which is one form of cerebral palsy
- Retrolental fibroplasia (also known as retinopathy of prematurity)
- Sudden Infant Death Syndrome ('cot death') is where a child unexpectedly dies and a post-mortem cannot conclude the cause
- Behavioural difficulties such as hyperactivity, audio hypersensitivity and lack of attention (Herbert, 2003; Shirley, 1938).

Any child may develop typically in utero. However the birthing process is considered to be the most dangerous event in any individual's life (Herbert, 2003). Although most babies arrive at the birthing position in the womb (head pointing down), some babies are delivered feet or bottom first in a breech delivery. This in itself is risky as the umbilical cord can easily become tangled or restricted, thus limiting the amount of oxygen supplied to the baby and ensuing brain damage. It is now commonplace for breech babies to be delivered via caesarean section to avoid potential damage (Herbert, 2003; Lin, 1993).

Prechtl, Cioni, Enspieler, Bos & Ferrari (2001) conducted a ten year study which investigated movements from in utero to 30 weeks after birth (Prechtl et al., 2001). The participants ( $N=14$ ; 13 born prematurely, 1 born at full term) were recruited from Italy, Austria and the Netherlands. The study identified three distinct categories of movement; writhing, fidgeting and voluntary movements. According to the research these movements develop from the tenth week in utero to the twentieth week after birth (Prechtl et al., 2001). However there appear to be no noticeable motor development differences between TD children and children with total blindness (without additional neurological dysfunction) until around 2 months after term age

(accounting for babies that were premature) (Prechtel et al., 2001). This meant that initially newborn babies who were later diagnosed with total blindness appeared to develop and behave typically (as movements were indistinguishable from the TD sample). This was observed during the first 2 months of life. This suggested a need to examine the role of vision in developing infants, although is problematic due to an inability to communicate and a lack of measurement tools suitable for infants of this age.

Although blindness may not have an immediate effect on the development of the new-born, it is argued that vision relays information back to proprioceptive and vestibular (balance) systems, to support general development (Prechtel et al., 2001). Blindness affects this development, which subsequently delays motor skill development. For example, the child with VI produces more exaggerated fidgeting movements (Prechtel et al., 2001). It was concluded however, that this delay in motor development can partially be compensated for with early intervention specifically targeted at the proprioceptive and vestibular systems (Prechtel et al., 2001). Prechtel et al., (2001) concluded that the three movements identified (fidgeting, writhing and voluntary movements), demonstrated differences between typical and atypical development but this was evidenced in the third month after birth (Prechtel et al., 2001). Subsequently these movements were identified as a predictor of neurological dysfunction in young children aged between 3 and 4 years old.

After birth, infants continue to develop physically, socially and emotionally. By 2 years of age, the TD infant has developed sufficient postural control to manage postural demands demonstrated by the ability to walk, for example, on average at 18 months old (age range 8-18 months) (Herbert, 2003). By the age of 2 years, the TD infant is able to walk and explore, grasp and manipulate objects of various sizes and shapes as well as play an active role in their environment (Sugden & Wade, 2013).

### **3.5.2 The development of gross and fine motor skills**

The ability to explore, grasp and manipulate objects independently is fundamental for the development of ILS (Sugden & Wade, 2013). The ability to control fast bodily movement and spatial awareness is not yet refined at the age of 2. This means that children often require a degree of adult support (e.g. from teachers, parents/caregivers), for example verbal and physical hand-over-hand assistance. Research regarding infant development 'post term' is a firm foundation for developing an understanding of gross and fine motor skill ability and acquisition. This understanding is essential for the development of the suite of interventions which promote independent dressing skills in children in the present study. This ensures that the activities are pitched at an appropriate level in order to match the activity to the individual's motor skill ability.

Children appear to develop sequentially (Herbert, 2003). This means that skill 'B' can only *usually* be achieved after successfully mastering skill 'A' (Warren, 1984). This bottom up approach suggests that the complexity of tasks increase as the mastery of the previous skill develops; for example, we do not run before we can walk (Swallow & Huebner, 1987). Within the TD context this approach seems to be appropriate as it is an observed and recorded progression in developmental literature (Herbert, 2003). The development from gross to fine motor skills form an observable progression: TD children develop gross motor skills such as walking before developing fine motor skills such as writing.

However, it is also argued that infants can develop motor skills simultaneously (Keenan & Evans, 2009; Cheatum & Hammond, 2000). For example the ability to balance while sitting, as well as being able to stand with support are both abilities that tend to occur at the age of 5 to 7 months (Keenan & Evans, 2009; Cheatum & Hammond, 2000). It is important to note that the time of which the skills were acquired as well as the nature and extent of these acquired skills are different for each infant (Keenan & Evans, 2009). The existing literature largely indicates an *average CA* for motor skill acquisition alongside the range for minimum and maximum CAs for acquisition (Keenan & Evans, 2009; Herbert, 2003; Bayley, 1969).

The variance in minimum and maximum CA for skill acquisition suggests that developmental milestones are achieved at a time which is appropriate for the infant. This can arguably be influenced by a variety of factors including height, weight, and the presence or absence of disability and possible co-morbid conditions. The difference in these factors may predict high individual variance. However this variance in CA could also be a result of developmental delay – where the MA of the child may not be representative of their CA. This suggests a difference between variation in skill acquisition as a result of physical development, and variation in skill acquisition as a result of developmental delay. Although both types of variation have the capacity to “resolve”, true developmental delay persists after the physical development of the individual has resolved to fall within typical norms. Figure 3.4 displays an example of the minimum and maximum CA range also demonstrates a difference between typically and atypically developing infants (Sugden & Wade, 2013).

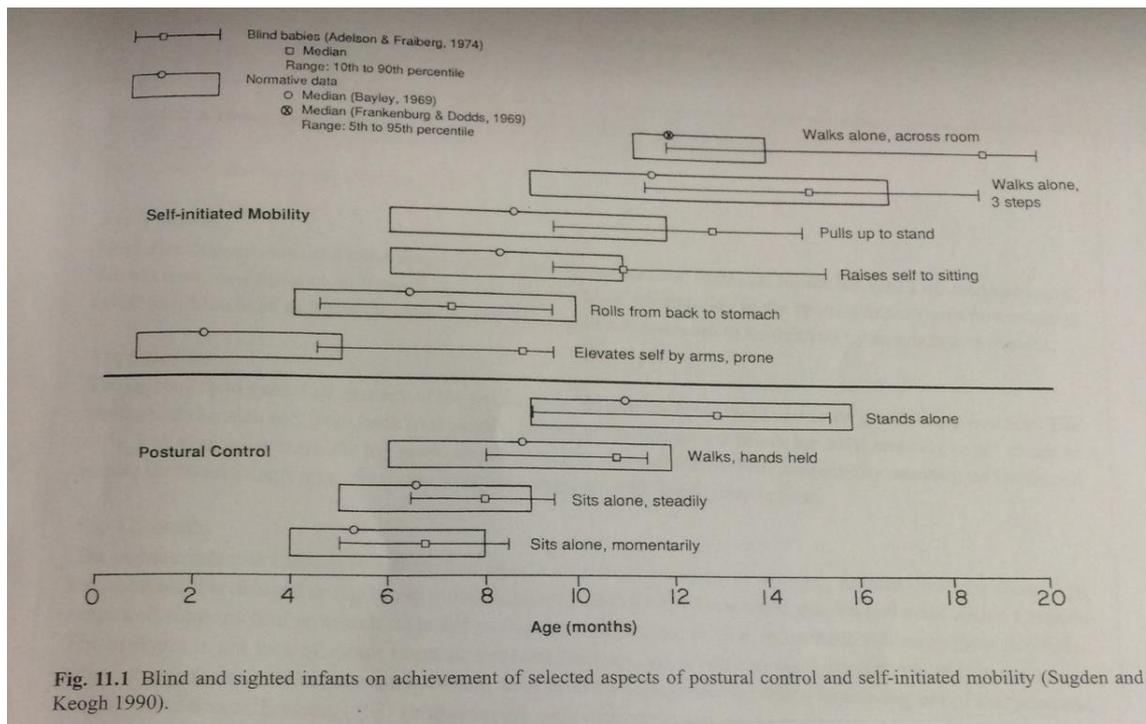


Fig. 11.1 Blind and sighted infants on achievement of selected aspects of postural control and self-initiated mobility (Sugden and Keogh 1990).

Figure 3.4. Developmental milestone differences between VI and TD infants (Sugden & Wade, 2013).

Developmental milestones identified in textbooks and journals (e.g. Figure 3.4) are merely guidelines based on the assessment of large samples of infants and children, supporting the notion that there is variance between individuals (Herbert, 2003). It is important to record developmental milestones of infants and children as they provide information regarding developmental age in comparison to CA. This is useful for the current research as one established aim of the research is to examine the inter-relationships in motor skill acquisition, CA and MA.

### 3.5.3 Stages of early development

There are three outlined stages of early development: cephalo-caudal, medial-lateral and proximal distal (Klein, 1983). These early stages of development reflect three dimensions of increasing control. The first (cephalo-caudal), refers to the direction of body growth from the head (cephalic) to bottom (caudal). The second (medial-lateral), refers to the development from the centre of the body to its periphery at the midpoint of the body plan, including the arms and hands. Finally, proximal-distal development refers to the increase of control over the limbs and associated joints moving out from the torso of the body to the limb extremities (e.g. fingers and toes) (Klein, 1983).

Cephalo-caudal development relates to the overall direction of motor development along the long axis of the body (head to hips), and is understood to begin and develop in utero (Keenan,

2008; Klein, 1983). Cephalo-caudal development is also marked by the infant's ability to sit and reach for objects at the average age of 3 months (Keenan & Evans, 2009). Observations show that the development of the hands and torso occur before similar control of the legs and feet. As a result it is considered easier for an infant to learn how to put on a hat before learning how to put on socks. This is due to the greater experience of spatial targeting needed to put on socks rather than put on a hat (Klein, 1983). One aspect of the suite of intervention materials required the participant to sit and reach for the fastening which would then be manipulated. The ability to sit and reach for the intervention material observationally demonstrates, on this basis, the cephalo-caudal development of the participant.

Proximal-distal development is the second major stage of motor development. It is noted that a child initially has more control over joints that are closer to the midline of the body (proximal joints) for example hips and shoulders. Control over the distal joints, such as those of the wrists and ankles develop later (Klein, 1983). Control over hips and shoulders are used for activities such as crawling; a milestone typically achieved at 7 months of age (Herbert, 2003). Using dressing as an example, it is important that a child is able to complete gross motor skill tasks such as putting arms through sleeves before they can accomplish fine motor skills, like fastening buttons (Klein, 1983). This is because gross motor skills (like those required to put arms through sleeves) are directly emergent from the primitive reflexes. Fine motor skills are arguably more difficult to develop due to the dexterity, balance and co-ordination required (Herbert, 2003). In addition to this, the sequence of dressing requires putting clothes on before fastening.

Further to this, the fine motor control in the fingers, for example, is a product of strength and skill developed in the whole arm, including the shoulders (Herbert, 2003; Klein, 1983). Similarly, control of the legs progresses from the hips down through the knees, continuing to the ankles and finally reaching the toes. It is important to note however that the wrist skill develops sooner than the ankles despite the fact that ankles have fewer degrees of movement. For example, the child also has to develop the aim in the ankle when putting on trousers to avoid getting their ankle stuck (Klein, 1983).

Medial-lateral development is observed to be the final stage of movement development. This is marked by the individual's ability in performing tasks that require fine motor control, particularly dexterity in the hands and fingers. Medial-lateral development is demonstrated by the pincer grasp, typically present at 9 months of age (Herbert, 2003). The fastenings used in the current research all require fine motor control – particularly the use of the pincer grasp for successful fastening. In order to gradually refine participant's use of fastenings, over-sized large fastenings were used in the intervention to support the gradual refinement of the motor

skill required to manipulate fastenings that were commensurate to the size of fastening the children were likely to be exposed to.

Smaller fastenings are also available within the intervention for two reasons; first children may choose smaller fastenings at a later stage of the intervention as they may find the larger fastenings “too easy”; second, smaller fastenings will be more representative of the clothing available to the children. It is predicted that as the intervention progresses, the children will feel more comfortable with the smaller fastenings and their fine motor control will become more refined (Fairnham, Johnston, Kain, Kain, McCauley & Steele, 2002). It is important to note that each participant was offered the choice of small, medium or large fastenings. The preference of each participant was recorded as the size of the fastening chosen may have demonstrated floor or ceiling effects in terms of their motor skill progression. This choice might have been predictive of their motor skill development over the course of the intervention period.

Herbert (2003) supported the notion that development occurs from the core of the body outwards (Fairnham, Johnson, Kain, Kain, McCauley & Steele, 2002; Klein, 1983). Establishing a framework for understanding the sequence of physical development was considered important when designing intervention materials. This is so that the intervention works in accordance with observed developmental progression (Herbert, 2003). Initially the participant is asked to sit and reach (gross motor control) for the intervention material before fastening/unfastening the piece (fine motor control). Arguably, as the participants in the current research are aged between 4 and 11 years, the children should have already achieved the gross (movement of arms, legs, wrists and ankles) and fine (finger movements e.g. pincer grasp) developmental milestones necessary for successful, independent dressing. In the context of the current thesis, it is important to establish whether or not this assumption is valid for each child. This will be done by conducting a pre-intervention assessment, which is part of the study protocol. Although it is understood that these movements may need refinement in relation to dressing skills, especially for children experiencing developmental delay. Therefore, one aim of the current research project is that participants will be able to refine gross and fine motor control within the context of fastening items of clothing. This refinement of skills will be supported, it is anticipated, by the use of the novel suite of intervention materials developed in the study.

#### **3.5.4 The relationship between cognition and motor skill development**

It is also important to understand the role of cognition in relation to motor development. The neuroconstructivist approach is believed to be the mid-line between nativism and behaviourism. The nativist approach argues that within the brain there are specialised

'domain-specific' regions for processing particular inputs, whereas behaviourism postulates a 'domain-general' approach (Ward, 2010). The 'domain-general' approach refers to a global structure informed by experience (Ward, 2010). Neuroconstructivism argues domain-relevance; arguing that a brain mechanism may be domain-relevant for many different types of input processing, yet is most efficient for a particular type of processing. This process, in turn, becomes domain-specific over time (Annaz, Karmiloff-Smith & Thomas, 2008; Karmiloff-Smith, 1998).

The neuroconstructivist approach argues that a mature cognitive system emerges from the transformation of earlier cognitive systems. These cognitive systems are influenced by the environment and brain based constraints (for example, synapse formation) (Ward, 2010). Neuroconstructivism argues that the development of cognitive systems are gradually refined in infancy and childhood through a combination of physical brain maturation and environmental influences (Ward, 2010). Therefore neuroconstructivism assumes that there is a constant interaction between genetics, individual action and the environment.

A probabilistic approach to childhood development argued that the structure and functions of the brain can be influenced by the environment and vice versa (Ward, 2010; Gottlieb, 1992). It was argued that the environmental influence on brain development and subsequent function can even occur in utero. This can be resultant of maternal diet, for example, which have an effect on the developing foetus (Ward, 2010; Gottlieb, 1992).

After birth, it is argued that all internal and external experiences, including actions on and in the environment by an individual have an effect on brain structure as they alter synaptic connections. The effect of the environment on infant development, however, is believed to increase with brain plasticity (Ward, 2010). Plasticity relates to the change in neural functioning as a result of experience. It is argued that plasticity reduces with CA, and that there are 'sensitive' periods (within specific brain regions) for optimal development to occur (Ward, 2010). It is postulated that high plasticity in infancy enables the environment to rapidly alter the developmental trajectory of particular circuits within the infant's brain (Murgatroyd & Spengler, 2011). This means that motor development in particular, may be optimised through stimulating learning environments, as this increases synaptic connections in the developing child's brain.

The neuroconstructivist approach argues that typical infant development is a result of indirect genetic interactions combined with environmental interactions that the infant chooses, and how the infant processes such inputs (Karmiloff-Smith, 1998). It is not yet understood whether the interconnectivity of the atypical developing infant is the same as the TD infant. If

interconnectivity was similar in atypical infants it could be assumed that an impairment could initially affect all brain regions (domain-general), but as a result of domain-relevance and subsequent domain-specificity it is postulated that some brain regions would be more affected by the impairment than others (Annaz, Karmiloff-Smith & Thomas, 2008). In order to increase domain-relevant development in infancy and childhood, multi-sensory learning approaches could appeal to the 'preserved' brain regions which are not considered to be affected by the sensory impairment of the child with VI, for example

### **3.5.5 Optimising development in atypical children**

The development of atypical infants and children is similar to that outlined for TD with regard to cephalo-caudal, proximal-distal and medial-lateral development (Section 3.5.3). However, for an atypical child to reach optimal development, the surrounding environment must be tactile and stimulating thus allowing the children to appropriately engage within the environment. The understanding of access to incidental learning is important there, as a reduced or complete denial of access to incidental learning can be compensated for through structured learning in a stimulating environment.

TD children and children with developmental delay are understood to follow a systematic developmental pattern. This includes reaching developmental milestones at a particular age. Individual variation needs to be taken into account. A developmental milestone such as pulling to stand may develop spontaneously in one TD child, however more guidance or structure may be needed for another TD child, or a child with a developmental disorder (Warren, 1984). Motor development in children with a developmental disorder is believed to occur in a similar nature to the development of TD children, but over a longer period of time (Warren, 1984).

### **3.6 Multi-sensory Learning and Haptic Perception**

Multi-sensory learning is a process in which children learn through using two or more available senses. These could be audio-kinaesthetic, visual-audio or sometimes olfactory (Rains, Kelly & Durham, 2008). Multi-sensory development uses the integration of the multiple available senses (including the vestibular sense responsible for balance) to support individual development (Bremner, Lewkowicz, & Spence, 2012). Rains, Kerry and Durham (2008) examined children's performance in elementary school level mathematics ( $n$ =unknown; age range; 4-11 years). They conducted a detailed literature review regarding developmental theories (e.g. Piaget and Vygotsky) in order to address the issues that class teachers may face when teaching mathematical concepts. The research argued for the suitability of multi-sensory learning techniques (specifically for children in kindergarten; aged 5 years). It was further argued that due to the variation between TD and SEND children, multi-sensory routes to learning may enable many students to assimilate to, and subsequently grasp mathematical

concepts which helps the children 'keep up' with their peers (Rains, Kelly & Durham, 2008). The research conducted by Rains, Kelly and Durham (2008) suggests that multi-sensory learning routes can be beneficial for 'academic' subjects. By appealing to multi-sensory pathways, the study suggests that individual differences between children can be compensated for to support learning.

Multi-sensory learning draws on historical theories of development as it concerns an individual child's skill ability, and individual preferences for learning. Furthermore, multi-sensory learning uses the available senses to maximise environmental influences that may impact on development (Rains, Kelly & Durham, 2008). The multi-sensory approach attempts to encompass different aspects and types of learning, through stimulating different senses in order for the individual to achieve developmental milestones associated with their CA (Rains, Kelly & Durham, 2008). In this view, the multi-sensory approach encompasses all types of learning to ensure that the individual has a full education.

The multi-sensory approach accommodates both TD and atypical children. This supports the current research framework, especially as the intended sample have a sensory impairment or disability which may impact on this observational, incidental learning. This means that the use of different sensory modalities to support development and learning will be required for the appropriate teaching of independence skills. Furthermore, the suite of interventions will need to accommodate the needs of the children, ensuring that the surrounding environment is accessible for them as participants.

To further accommodate individual needs, the multi-sensory approach to learning suggests that additional resources may be required in order to fulfil the individual needs of children and boost their understanding of concepts (Rains, Kelly & Durham, 2008). It is believed that the multi-sensory approach is more effective in facilitating and enhancing learning. This is because it uses dyadic sensory relationships to solidify and contextualise the content of any lesson, for example auditory instructions combined with physical, motor tasks.

The effects of multi-sensory learning on atypical children therefore appear to be beneficial (Rains, Kelly & Durham, 2008). With regard to the VI population, the ability to use two routes i.e. auditory and tactile is beneficial for task mastery (Rains, Kelly & Durham, 2008). For example verbal instructions supported by manually manipulating objects aid learning as the audible instructions directly relate to the motor skill task (Rains, Kelly & Durham, 2008). Children with sensory impairment stand to benefit from multi-sensory learning as they are able to rely on their remaining and available senses in order to optimise learning. The current

proposed novel intervention programme does not rely on a singular sensory modality as it incorporates both audible (verbal instructions) and tactile (interactive games) stimulation.

Humans have evolved to gather information from the environment through all their senses (Rains, Kelly & Durham, 2008). Therefore, the individual has the capacity to engage in a variety of sensory experiences which occur naturally and without formal or pre-mediated consciousness. It is therefore postulated that multi-sensory learning environments are highly beneficial in order for an individual to engage within an optimal learning environment (Rains, Kelly & Durham, 2008). This means that a multi-sensory environment influences the learning of the developing individual. Humans appear to learn through multi-sensory routes (Rains, Kelly & Durham, 2008). This means that the use of multi-sensory routes in formal learning environments are arguably beneficial, especially for individuals who have a sensory impairment. This is because the formal learning environment can direct the individual to using the remaining available senses.

The suite of intervention materials proposed in the current study used mainly audio-kinaesthetic stimulation (without over emphasizing residual vision). This was done by using clear verbal instructions and interactive, tactile games which require the use of the hands and fingers. As the intervention programme required participants to manipulate the fastenings using their hands and fingers, theories of haptic perception and the role of proprioception are explored next. It is important to note that for the purpose of this section the *definition of haptic perception* is limited to the information directly perceived through the hands and fingers. This excludes passive touch such as temperature and pressure and also hand and finger movements that are directed by the gross movement of the arm (Warren, 1984). This definition is fitting as the current research focuses on the development of fine motor control in the hands and fingers, which are required for fastening zips for example.

There are two research approaches toward the development of haptic perception in the literature: the development integration view and the development differentiation view (Warren, 1984). The development of integration view postulates that vision gradually influences the movement of the hand. It is suggested that this is a result of the hand becoming increasingly 'present' in the visual field. The integration approach suggests that the hands initially work independently of vision, meaning that an individual does not need to visually attend to an object, for example, in order to explore it haptically. Over time the independent movements of the hands reduce and become more refined in relation to the increase of visual perception and ultimately visual behaviour (Warren, 1982).

The integration approach is linear in nature. Kalagher and Jones (2011) examined 72 children (age range 2;06-5 years) and 20 adults in a haptic exploration task. Participants were asked

to either visually or haptically explore objects. They were then asked to visually match these objects. The research found that 5 year old children and adults performed well on the matching task. The younger participants, however, had issues with matching objects. It was argued that this was a result of the child's inability to use their hands appropriately in order to obtain reliable haptic information.

The research by Kalagher and Jones (2008) supports the notion that the haptic and visual modalities integrate. Initially the hand has random movements, the hand then becomes directed by vision (when the hand/s are present in the visual field). Vision then becomes dominant in hand-eye co-ordination, but only when the hand is present in the visual field. Finally, if the hand is out of sight and a visual stimulus is present, the hand will be brought into the visual field and directed to the object to be held (Warren, 1982). This means that the co-ordination between the hand and visual sense become integrated as development occurs. Subsequently, the movements of the hands are initially independent from the visual sense, providing different (tactual) information regarding the object. This is done until the integration with vision occurs (Warren, 1982). This theory could explain the development of haptic perception in a TD context, however this approach does not account for the development of haptic perception in individuals with VI. This is because the hand may not be clear or present in the visual field.

The differentiation view postulates that neither vision nor movement of the hands are a facilitator or teacher of the other (Warren, 1982). The differentiation view argues that the senses are interconnected rather than hierarchical, as suggested by the integration view. The differentiation approach suggests that initially the senses are united and equal, however as development occurs, the senses differentiate (Bower, 1974). This means that visual modality (if available) becomes more dominant within the child, but this does not suggest that other senses become subservient.

Studies have suggested that there is an association between the learning of motor skills and systematic changes to proprioception (Ostry & Gribble, 2016; Rosenkranz & Rothwell, 2012). Rosenkranz & Rothwell (2012) tested whether attending to proprioceptive input during a completely sensory task would influence the later learning of a novel motor task. This was done by applying a low-amplitude vibration to participant's muscle which controls the thumb ( $n=8$  females; age range 33-37 years) for 15 minutes. It was found that sensory attention does have an effect on subsequent motor learning (Rosenkranz & Rothwell, 2012). Proprioception is understood to be a kinaesthetic sense which is essential for orientation and mobility.

Proprioception is considered to be an automatic response to internal information processing which causes an individual to move, stretch the muscles and exert the correct amount of

strength for successful manipulation of objects in the environment (Boisgontier & Swinnen, 2014). It is important to note that proprioception does not rely on vision as it is haptic in nature. It is believed that motor skill activity supports the refinement of proprioception for specific tasks/activities such as targeted reaching and so continual proprioceptive feedback arguably optimises the learning of motor skills (Ostry & Gribble, 2016; Rosenkranz & Rothwell, 2012).

In the context of the current research project, individual experience in relation to the manipulation and exploration of the fastenings, it will be argued, refine the proprioceptive sense, subsequently supporting motor skill acquisition for successful fastening. The delineation of the process of proprioception is not yet fully understood, however, it is argued that the external experience of objects in the environment shapes the motor cortex through practice and rehearsal (Rosenkranz & Rothwell, 2012).

It is understood that the proprioceptive sense can be trained and improved upon with individual experience (Rosenkranz & Rothwell, 2012). It is argued that if the proprioceptive sense is well regulated, individuals are more likely to engage in activities that involve movement, such as sports. If the proprioceptive sense is impaired, this could result in proprioceptive defensiveness. Proprioceptive defensiveness is characterised by an individual's unwillingness or discomfort in moving or being moved. Individuals with proprioceptive defensiveness are less likely to participate in tasks which involve movement; this includes sports and also everyday activities like dressing and travelling on public transport.

Proprioceptive defensiveness, arguably, may be more apparent in children with VI and developmental delay due to reduced ability or complete inability to access visual sensory information. However, as aforementioned, vision is not essential for proprioception. Research evidence for this claim is mixed. Some research suggests that, for example, individuals with CVI use the senses of proprioception and audition in order to support their motor movements (Goodale, 2013).

Haptic perception is believed to be a derivative of the combination of external tactile and proprioceptive feedback and an internal predicted sensory feedback (Gori et al., 2012). Internal feedback is based on an internal copy of the signal created by motor commands that enable exploratory commands (which may appeal to the working memory model outlined in Section 3.7) (Gori, et al., 2012). Gori et al., (2012) explored haptic perception of objects in children ( $N=33$ ; age range: 6-14 years). They found that in children, haptic precision was lower in active exploration when compared to passive exploration. This supports the integration assumption. Only in early adolescence, did haptic acuity reach adult levels. Younger children, therefore experience difficulty when making sense of haptic input. This sensory "noise" can only be compensated for with maturation. The findings of Gori et al., (2012) suggest that an

increase in CA supports the relationship between haptic perception and proprioception. This means that the nervous system is able to predict a response to a particular stimulus and then adjust the response according to the external environmental input (afferent signals). By adjusting the response appropriately, for example gripping an object tighter, the individual can obtain an accurate representation of the external object and/or environment (reafferent signals) (Gori, et al., 2012). This is one example of how the proprioceptive sense can be trained in order to respond to external stimuli.

As an individual can arguably develop and optimise their proprioceptive sense through training, the current suite of intervention materials should aid this development. It is argued that kinaesthetic information is faster to process, and so for efficient motor skill training, proprioception and haptic perception is a faster route compared to vision (Haptics Technologies, 2011). However in a detailed literature review, Eimer (2004) reported that the visual processing of sighted individuals is considered to be faster and can substantially alter the perception of tactile information.

The aforementioned studies regarding haptic perception and proprioception assumed that the senses are compartmentalised into separate sensory modalities e.g. touch and vision. This means that each sense provides a unique input for processing (Eimer, 2004). Synaesthesia (meaning "joined sensation") is a condition where the senses are not separated and compartmentalised into the five identified senses (vision, hearing, smell, taste and touch) (Cytowic & Eagleman, 2011). This means that auditory stimulation, for example, can also be seen or tasted (Cytowic & Eagleman, 2011). Synaesthesia typically occurs in young children and the effects reduce over time through maturation. Synaesthesia can be present in children with VI who, for example, see colours when reading Braille (Cytowic & Eagleman, 2011). The concept of synaesthesia suggests that the senses may differentiate but they are not domain specific. Synaesthesia therefore contradicts the domain specific, modular approach to the senses which is adopted by cognitive psychology and argues that personal experiences are (perhaps superficially) a culmination of the interaction of the senses (Cytowic & Eagleman, 2011).

There is a body of research evidencing that children with VI use touch in order to explore the surrounding environment, for example using tactile reading strategies (McLinden, 2004; Millar, 1997; Warren, 1994). Although TD children also use touch to explore their environment, the tactile input can be substantially altered and subsequently distorted by the visual sense (Eimer, 2004). It is argued that children with VI have the capacity to perceive haptically through adapted tactile tasks, but the development of haptic perception is believed to be delayed due to the lack of vision (McLinden, 2004).

The existing literature, however, does not inform the research as to the development of haptic perception in children with other disabilities where VI may be an element (McLinden, 2004). This meant that within the current research, the tactile tasks were adapted further to accommodate the needs of children with additional disability (for example placing the object in the participant's hand as they cannot sit and reach). The children with disabilities were given appropriate opportunity to interact with the materials (either independently or with support) in order to access Gibson's affordances (how a child interacts with the environment) via touch (McLinden, 2004). This suggested a need for the intervention materials to be of a size commensurate with the child's hand to aid manipulation of the materials (McLinden, 2004). This enabled the participant to gather as much information as possible, encouraging independent control of affordances.

Further research is required in the field of haptic perception, especially regarding children with VI and additional disabilities as little is known about the process (McLinden, 2004). Approaches toward haptic perception are important to understand as, arguably, the participant will be influenced by the external environment through tactile stimulation and vision (if accessible) or another sensory modality. Tactile stimulation appeals to the working memory system in terms of proprioception. It could be argued that in the absence of tactile stimulation, the previous experience/s of an object would temporarily remain within the working memory system (Kaas, Stoeckel & Goebel, 2008). Harris, Harris & Diamond (2001) tested the role of working memory and tactile stimulation. 31 adult participants (age range 24-45 years) took part in the experiment. The participants were exposed to vibrations (differing between 14 and 24Hz) either on the same fingertip or different fingertips. The exposure to vibrations were separated by a timed break (<1 seconds or 1-2 seconds). It was found that participants who had an interval of <1 seconds were more accurate in reporting the frequency of vibrations (whether the frequencies were the same or different) when they were applied to the same finger (Harris, Harris & Diamond, 2001). Participants who had a greater break between trials (1-2 seconds) displayed equal performance when vibrations were applied to either the same finger, or the corresponding finger on the opposite hand. Performance was poorer in the group with the longer retention period when vibrations were applied to distant fingers on either hand (Harris, Harris & Diamond, 2001). The research concluded that tactile working memory appealed primarily (but not exclusively) to the somatosensory cortex region. Although the study by Harris, Harris & Diamond (2001) was related to adults, arguably, tactile stimulation may appeal to the working memory system in children. The following section explores the role of the working memory model in relation to children and the current research focus.

### 3.7. The role of Working Memory

Allowing rehearsal and time for skill acquisition may benefit the working memory system, as some sensory information can be retained through practice (Kaas, Stoeckel & Goebel, 2008). Working memory is understood to be a temporary, short-term memory system that is responsible for encoding and storing sensory input (Baddeley, 1997). The working memory model remains to be relevant in developmental psychology, as it demonstrates the role of attention and the importance of rehearsal for encoding short-term memory and how this sensory information can be transformed to long-term memory. It is argued that the working memory system has a limited capacity which is used for the temporary storage of sensory input and also manipulates such input to allow learning to occur (Baddeley, 2000).

The traditional working memory system was comprised of three parts: the central executive, the phonological loop and the visuospatial sketchpad (Baddeley, 1997; Baddeley, 2000; Baddeley, 2003). However, after further research into the phenomena, the fourth component, the 'episodic buffer', was included as it was believed to be an area responsible for integrating all sensory input, but relies upon conscious awareness for information to be retrieved (Baddeley, 2000; Baddeley, 2003).

It is believed that the central executive is limited to attention, however is responsible for controlling the working memory system (Baddeley, 2003). The phonological loop is responsible for verbal and auditory input, and the visuospatial sketchpad is believed to be the visual equivalent of the phonological loop, responsible for visual, spatial and possibly kinaesthetic (movement) sensory inputs (Baddeley, 2000). It is argued that the phonological loop and the visuospatial sketchpad are 'slave systems' to the central executive, meaning that the central executive governs these two systems (Baddeley, 2003; Baddeley, 2000).

Figure 3.5 shows how the components of the current model of working memory work together in order to encode short term memory (STM) and long term memory (LTM). In Figure 3.5 the dashed line represents knowledge that is 'crystallised' into long term stores. The straight lines indicate a 'fluid' capacities which include attention. In addition, the direction for encoding moves from the Central Executive down towards the Episodic LTM. Figure 3.5 illustrates the process of retrieval. This process works from STM/LTM back towards the Central Executive but this process requires conscious attention.

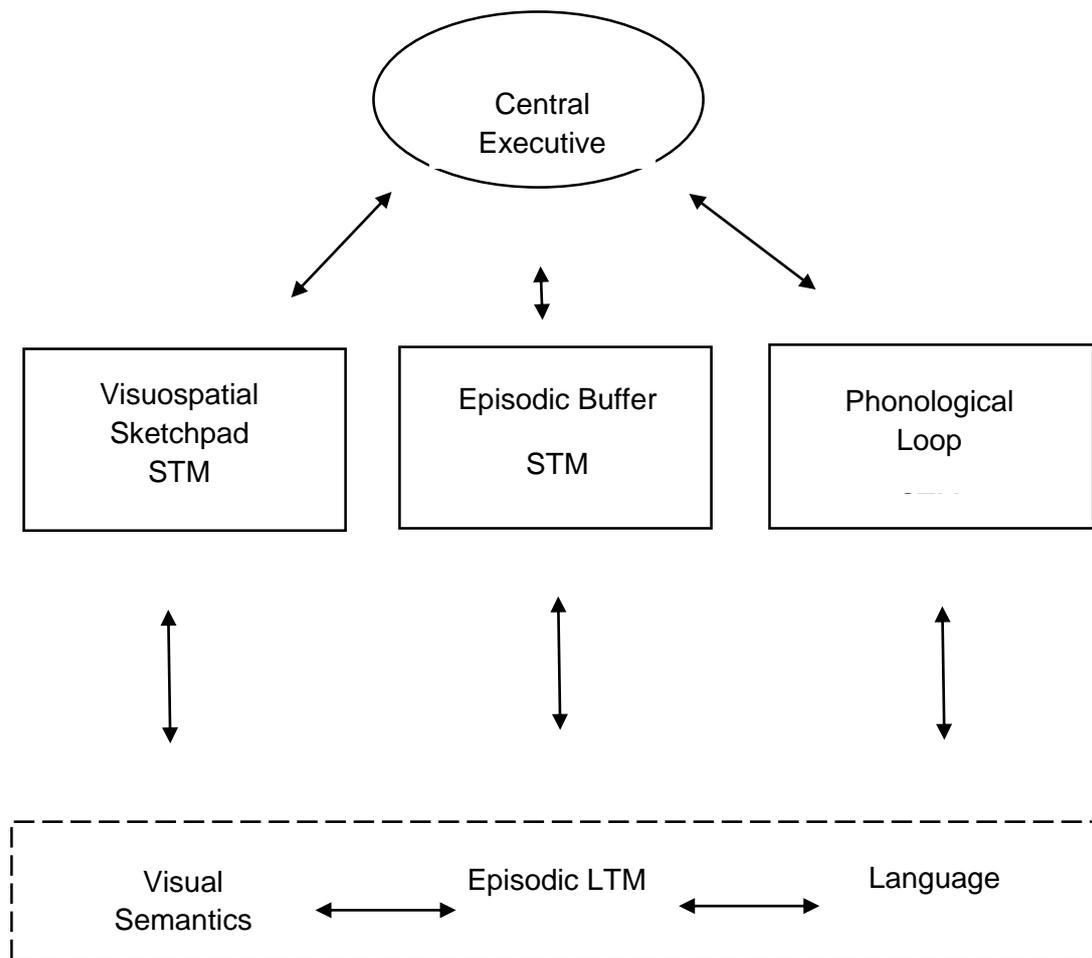


Figure 3.5. Working Memory Model (Baddeley, 2003).

The working memory system outlined in Figure 3.5 is considered to be a fundamental aspect of the intervention procedure within the current research. This is because the auditory instructions provided for fastening completion are repeated to the participant in order to enhance skill development. As the instructions are provided verbally, the phonological loop is responsible for the holding of such information. Research suggests that there is a link between phonological loop performance and an enhancement in language skill acquisition (Baddeley, 2000; Baddeley, 1998).

Furthermore, research also suggests that verbal retrieval performance increases when the words provided have meaning, as there is a sequential element to successful phonological loop processing (Baddeley, 2000). This, combined with the physical manipulation of the

fastenings may increase task performance, as the ability to recall sequential verbal instructions may support the motor skill aspect of the intervention. However this is based on an implication that there is interconnectivity between the audio and tactile senses (Cytowic & Eagleman, 2011). Yet there remains to be research evidence supporting the compartmentalisation of the senses, suggesting that the interconnectivity may be superficial (Eimer, 2004).

The application of the working memory model to children with VI may at first appear problematic, however the model is adaptable. The current thesis argues that in the case of VI the phonological loop could (hypothetically) compensate for the restricted visual access to the visuo-spatial sketchpad but also, the visuo-spatial sketchpad is still accessible via haptic perception. This means that VI is not necessarily be a barrier to accessing the working memory system (A. Baddeley, personal communication, 2016). Subsequently, this suggests that sensory input from any available sense could still be processed via the working memory model. This would also be the case for dual sensory loss such as deaf-blindness, where the visuo-spatial sketchpad and/or phonological loop would compensate to account for the sensory impairment.

The novel intervention materials proposed in the current research acknowledge and accommodate the role of instructions. This is done by splitting the task into manageable steps whilst remaining adaptable to the needs of the children. For example, regarding verbal instructions, one child may understand the terms 'fasten' and 'unfasten', whereas another child may refer to this as 'close' and 'open'. Verbal instructions are more variable than physical guidance, due to the range of language that can be used. Physical hand-over-hand guidance is more rigid in nature, the physical actions remain the same (for manipulating the fastenings). However, this guidance can be varied by applying different pressure. For example, if the participant requires support in applying the correct amount of finger strength, more pressure would be applied. In contrast, if the participant was close to reaching independence but still asking for physical support, a lighter pressure would be applied in order to reassure the child rather than support task completion.

'Chaining' is an example of this. Chaining is sequential completion of a task and can be done either forwards or backwards. Forward and backward chaining involves both children and adults (teachers or parents/carers) who work together to achieve the task goal. In the process of forward chaining the child begins the sequence of dressing, for example holding the base of a zip and then the adult demonstrates the rest of the task (inserting the tail into the slider and pulling up to fasten). 'Scaffolded support' is another form of chaining. This is where the child completes the stages of a task that they are currently able to achieve, and receives adult

support with the remaining steps. Over time, the adult support is reduced as the child increases in task mastery.

For successful forward chaining a child must firstly have the motivation to begin the task and be clear about its goals and purpose, for example being given the instruction that a coat must be worn before going outside to play. The child will then begin the task by putting one arm through the sleeve of the coat, for example, and then the supporting adult physically completes the remainder of the task. The adult support includes providing verbal instructions detailing the further stages to completion (Hertfordshire Community NHS, 2011). The adult may also intervene by providing physical hand-over-hand guidance, supporting the child by physically guiding and manipulating their hands for successful completion of the task. The concept of backward chaining allows the child to complete the final stage of the task, for example pulling the zip up to the top of the coat. The adult begins the sequence until the final stage with verbal or physical hand-over-hand support where necessary (Hertfordshire Community NHS, 2011).

The key difference between forward and backward chaining is the point at which the child is actively engaged in the task. In forward chaining, the child works from the start of the task without help, and then would receive adult support for the latter stages in the task. Contrastingly, in backward chaining, the child begins at the last stage of the task, and works increasingly backwards with adult support to the earlier stages of the task.

In both forward and backward chaining procedures the adult provides support, guidance and methodological instruction (physical, verbal (through instruction or motivational speech) or both) aiding the child in task completion. As the child increases in confidence and skill ability, the adult removes the next stage (in both forward and backward chaining). The child is encouraged to complete further stages until the skill is acquired and achieved independently. The gradual removal of adult assistance allows the development of independence in the child.

At the end of the chaining process the responsibility of the child increases and the adult involvement decreases. The novel intervention materials in the current research are inspired by this idea of the gradual removal of adult assistance ensuring successful and independent fastening and unfastening skills in the child.

Forward and backward chaining are beneficial for motor skill development as they split the task into manageable stages for the child. Slocum and Tiger (2011) assessed children's sensitivity to forward and backward chaining. The participants ( $n=4$ ) were aged between 10 and 12 years old, and were diagnosed with SEN. The participants engaged in multiple learning tasks of differing complexity yet similar content. It was found that individual children did not show preference for either forward or backward chaining. However, performance on tasks

which used chaining strategies were better when compared to the baseline condition. The research by Slocum and Tiger (2011) supports the role of chaining and adult guided support when learning new skills. One reason for this finding may be that the processes of chaining split up the task into smaller stages and allows children to work at their own pace. Smaller manageable stages are also beneficial for the working memory system, as it splits the action into meaningful chunks which are processed more easily. This means that the confidence and independence of the child increases through time, rehearsal and support, where necessary.

It is important to allow time for the child to practise the emerging skill, and encourage the child to rehearse independently. Often, supporting adults do not provide sufficient time for the child to develop, expecting that the training provided is adequate, or the child will inevitably 'pick up' the skill in their own time. Time has been observed to be a large component of a child's successful skill acquisition, and plays a large role in child development as a whole. This is because infant and child development appears to involve a series of steps. Each of these steps require motivation and practice if a particular skill is to be mastered e.g. small children will assemble a tower of blocks and then knock them down. The child may then repeat this process many times in any one play session. Each successful building of the tower will have allowed the child's body and brain to practice, refine and hone, its control of the child's hand, spatial-targeting and perception of the environment in which the blocks are being balanced. This repetition *is time consuming* but aids the general, cognitive and motor skill development of the child.

The progression between these phases of skill mastery (achieved after prolonged repeated practice) may be represented chronologically as a series of chronological stages. CA acts as a marker for the development of infants and children in these stages as it is defined by the child being increasingly able to achieve particular identified motor tasks successfully within a particular age range. This is problematic in nature as CA may not be representative of the MA of the child – this is particularly apparent in children with developmental disorders. However, within the field of developmental psychology, it remains to be accepted that the achievement of developmental milestones is related to CA, even though the foundations for this belief are arguably outdated (Gesell & Ilg, 1949).

### **3.8 Summary**

In summary, the examination of the relevant literature shows how VI, genetic dysfunctions (in the case of DS) and resulting developmental delay can have an impact on motor skill acquisition. As VI denies or restricts access to visual observation and subsequent visually derived incidental learning, structured interventions are considered to be the most appropriate method for attempting to compensate for developmental delay and increase independence.

Taking the examined literature into account, the current research aimed to aid the development of independent dressing skills in young children with VI and DS. It has been established that VI and DS have an impact on orientation, mobility and independence. This is partially due to the sensory impairment associated with the conditions. As vision is also an integrative sense, the absence or restriction of vision has an impact on physical, cognitive, social and emotional development.

Developmental delay is associated with both VI and DS. Developmental delay is the marked time between the skill acquisition of a child with a developmental disorder and the average age of skill acquisition in TD children. Habilitation techniques aim to integrate a child's functioning senses with their motor development in order to optimise development. This can be done through multi-sensory techniques, for example combining auditory instructions with haptic (touch)-based strategies.

The theories examined earlier inform the research questions and draw focus on the interactions and influences of the external environment on the developing child. In addition, the theories outlined suggest different sensory routes to optimise the learning environment. Understanding the influences of the environment on the developing individual are fundamental to the research topic. It is argued that external influences help to conceptualise the developmental profile of an individual. This is important within the current research as the adaptability of the suite of interventions should not be bound by environmental restrictions.

The outlined theories acknowledge the role of the environment on the developing individual and accept the inseparability of an individual from their environment, and so by adapting the resources according to individual need rather than environmental restriction, development is optimised. This optimisation occurs as the individual may not have previously had the resources to optimise independence skill development, and so by introducing these resources to their environment, they are afforded the opportunity to develop further develop their motor skills in relation to independent dressing.

Furthermore, the explored theories outlined in this chapter support the need for the development of activities suitable for accessing available sensory modalities in a developing individual. The current research addresses this by developing a suite of intervention materials which accommodate the needs of children with sensory impairment and enhance person-person/object interactions. The following chapter presents the third theme of the thesis: the relationship between habilitation and independent living skills.

## **4. Habilitation and Independent Living Skills**

Chapter 4 explores the third theme of the thesis which is the relationship between habilitation and independent living skills (ILS). This chapter explores three aspects of this theme: the history of habilitation, the distinction between habilitation and re-habilitation, and finally the importance of play which is contextualised in terms of school based learning grounded in government policy.

In this chapter the history of habilitation will be explored in relation to the attitude and treatment of habilitation practitioners, and individuals participating in habilitation programmes. The chapter draws on the historical habilitation techniques first outlined in the USA, due to an unavailability of historical literature in the UK context.

The distinction between habilitation and rehabilitation is then made. The chapter draws upon legislation and available literature in the field to illustrate the difference between the two. This is done to aid contextualisation of the rationale of the project which is to support and develop the independent living skill of dressing (ILSD) three distinct yet related groups (VI, DS and TD) in accordance with Special Educational Needs and Disability (SEND) provisions.

Finally, the chapter will examine the importance of play to support learning and how this position is viewed in terms of government policy and school based learning. In this current study play based, multi-sensory learning is advocated in order to develop ILSD and attempt to compensate for incidental learning (see Chapter 2). Play is typically facilitated by the environment which links to the Zone of Proximal Development (Vygotsky, 1978) and the Neuroconstructivist approach (Karmiloff-Smith, 1998) (see Chapters 2 and 3). Play is also considered to be a useful medium to facilitate movement which supports ILS in general (see Chapter 3). The chapter explores three main approaches to learning (Winnick, 1979) in order to inform the current study as to the most appropriate approach to take when developing a habilitation programme such as the intervention presented in later chapters.

### **4.1 The History of Habilitation**

Habilitation was a concept first identified in the mid nineteenth century (Rosen, Clark & Kivitz, 1977). It was a term used in reference to the optimisation of the development of individuals with developmental disabilities (Rosen, Clark & Kivitz, 1977). The available historical literature is largely based in the USA (Rosen, Clark & Kivitz, 1977). This means that the historical account presented in this section is largely based on this contextual understanding.

The concept of habilitation was arguably ahead of its time. This is because during the nineteenth century, the public attitude toward disability was sceptical. This was because individuals with disabilities were considered to be 'idiots' and were ostracised (Rosen, Clark & Kivitz, 1977). Individuals who supported those with disability were considered to be missionaries, hence the public attitude towards the practitioners was largely positive (Rosen, Clark & Kivitz, 1977). Arguably, this positive attitude was due to habilitation techniques which promoted inclusion and employment opportunities to those previously considered to be unemployable (Rosen, Clark & Kivitz, 1977). Inclusion, for the purpose of this thesis refers to the participation of an individual with disability within a TD group setting. An example of this would be a child with disability participating in a mainstream schooling environment.

A negative shift of opinion occurred when it was observed that children were not attaining as highly as was initially predicted (Rosen, Clark & Kivitz, 1977). With hindsight, it would appear that there was a misconception between compensating for, what we would now term as developmental delay, and the understanding that individuals with disability would likely require lifelong support. Habilitation techniques are designed to be practiced, utilised in everyday situations and developed as the individual transitions across developmental stages (Miller, Wall & Garner, 2011). The continual support required for those with disability then led to an educational divide within North America (Rosen, Clark & Kivitz, 1977). This divide created the "School Department" and the "Custodial Department" (Rosen, Clark & Kivitz, 1977).

Individuals in the School Department engaged in literacy, numeracy and practical skills workshops, for example. Individuals with developmental disability were placed alongside criminals within the Custodial Department (Rosen, Clark & Kivitz, 1977). This was because delinquency was considered to be a genetic trait, and it was argued that around 50% of criminals were "mentally deficient" (Rosen, Clark & Kivitz, 1977; page 7). Both individuals with developmental disability and criminals were considered to be incapable of daily function. This meant that they were restricted to developing independence skills and obedience (Rosen, Clark & Kivitz, 1977). This work was considered to be the antithesis of habilitation, despite the encouragement of developing independence.

In both the UK and USA context, the turn of the twentieth century appeared to acknowledge that intellectual disabilities could not be fully compensated for, despite specialist schooling (Rosen, Clark & Kivitz, 1977). This meant that the institutionalisation of individuals with developmental disabilities was the seemingly viable option. However, between 1920 and 1960, optimism toward helping individuals with developmental disability prevailed once again. Inclusion, was once again in vogue, and educational and training opportunities were provided

for individuals with developmental disability. Deinstitutionalisation in the early twentieth century laid the ground work for half-way houses and shared accommodation in order to support those living with disability. This became popular in the UK and USA in the 1960s and 1970s (Rosen, Clark & Kivitz, 1977).

This shift toward deinstitutionalisation coincided with Post-World War One and Two veterans, and the Vietnam War where it was reported that 153, 303 American soldiers suffered non-mortal wounding (a debilitating condition that does not kill) and subsequently required rehabilitation support (Department of Veterans Affairs, 2015). In the USA, the Civic Vocational Rehabilitation Act (1920) provided rehabilitation techniques for those who had suffered an impairment as a result of the war. The rehabilitation techniques were designed to aid the return of veterans to employment (Rosen, Clark & Kivitz, 1977). The amendment of this Act in 1943 incorporated those with developmental disability into re/habilitation programmes. It was now legislation (in the USA) to support individuals with developmental disability and encourage their inclusion (Rosen, Clark & Kivitz, 1977).

It appears that in both the UK and USA contexts, positive social attitudes towards habilitation and rehabilitation, coincided with impairments and disabilities associated with warfare. Disability was becoming to be disassociated with intellectual impairment, and strategies towards support and inclusion were becoming more apparent both in the public and legislative domains.

A public shift toward the inclusion of all minority groups in the USA occurred in the 1960s. The publication of the "Rights of Mentally Retarded Persons" (1973) advocated the rights for those with developmental disability. This included the right to family membership, employment training, education and marriage (Rosen, Clark & Kivitz, 1977). Scepticism surrounding the involvement of individuals with developmental disability in 'normal' life occurred. Throne (1975) postulated that it was not appropriate to treat individuals with disability as 'normal'. Throne (1975) argued that specialised support for individuals with developmental disability was more appropriate than attempting to subject the individuals to a 'normal' life.

Rather, Throne (1975) suggested that the means of supporting individuals with developmental disability to living a 'normal' life was more important than actually achieving the ends of 'normality'. Arguably, Throne (1975) was correct in his assumption. As is currently understood, individuals with developmental disabilities require specialist support, provisions (such as lighting and specialist equipment) and habilitation training in order to maximise independence

and facilitate inclusion in day-to-day living (Department for Education & Department of Health England, 2015; Miller, Wall & Garner, 2011).

Taking the history of habilitation into account, the concept, techniques and legislation have had time to evolve and embrace new technology. Society has also had the opportunity to evolve. In the UK, current understandings of disability and impairment are far more advanced due to medical progressions and a reduced social stigma associated with disability. Support for individuals with developmental disability has always been evident in the habilitation literature. Additionally, due to the advancements in technology and the sciences, society is far more equipped to support individuals with disabilities and impairments. Habilitation work appeared to subside again after the 1970s, and appeared to emerge in the UK in the early 2000s. The definition of habilitation still incorporated the development of independence skills in individuals with disability (Miller, Wall & Garner, 2011). However, the focus of the habilitation techniques surrounded children and young people with VI (CYPVI) (Miller, Wall & Garner, 2011).

#### **4.1.1 Habilitation and re-habilitation**

Habilitation is understood to be training which occurs when an individual has suffered impairment before, during or after birth or during early childhood. It is different to rehabilitation which is understood to be the training that occurs when an individual has suffered an impairment later on in life e.g. veterans (Miller, Wall & Garner, 2011). For the purpose of this thesis, *the definition of habilitation* refers to:

‘the development and teaching of independent living skills in children with developmental disabilities who are moving toward independence’ (Miller, Wall & Garner, 2011).

The Quality Standards publication (Miller, Wall & Garner, 2011) was designed to support Qualified Habilitation Workers who assist CYPVI. One focus of the standards was to identify how practitioners could support the delivery of habilitation techniques supporting mobility (movement) and ILS in CYPVI. The Quality Standards worked in accordance with the then active Equality Act (2010) which defined disability as a mental or physical illness that substantially affects daily living (Equality Act, 2010), and also the Special Educational Needs and Disability Act (SENDA, 2001). The SENDA (2001) outlined that all children with special educational needs and disabilities (SEND) were entitled to the same standard of education as their TD peers (SENDA, 2001). The SENDA was applicable to all schools and local authorities within the UK (SENDA, 2001).

The Quality Standards (Miller, Wall & Garner, 2011) and the SENDA (2001) supported the use of special provisions within educational environments in order to make the then active national curriculum as accessible as possible. Examples of accessibility include the use of Braille worksheets, lighting provision (i.e. anti-glare), and handrails to aid independent movement. The Equality Act, the SENDA and the Quality Standards all encouraged maximum independence for each individual child with SEND. Further to this, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) of which the UK is a part, states that all individuals with SEND are entitled to achieve and maintain the maximum level of independence possible (EBU, 2014). In addition, individuals with disability are also entitled to achieve their full mental, physical, social and vocational capacity, and through inclusion, participate fully in everyday life (EBU, 2014). It is important to note that the UK ratified the UNCRPD in 2010. The UNCRPD offered funding in order to supporting the training of specialists in the UK (K. Wall, personal communication, April 3, 2016).

The Quality Standards (Miller, Wall & Garner, 2011), also worked in accordance with the 'Every Child Matters' (Every Child Matters, 2003). This initiative placed emphasis on early intervention and learning which were considered fundamental for aiding mobility and independence in children with disability. Although it has been revoked, some aspects of the initiative are apparent in the Children and Families Bill (2013), and subsequent Children and Families Act (2014) which outlined a new "birth-25" regime considered to support vulnerable children and children with special educational needs and disabilities (SEND). The Children and Families Bill (2013), the Children and Families Act (2014) and the new SEND: 0-25 Years (Department for Education & Department of Health England, 2015) were designed to maximise and extend the support and provision for children with SEND and their families. It is important to note that the Children and Families Act (2014) provided the legal basis for the SEND: 0-25 years Code of Practice for England.

The SEND: 0-25 years (Department for Education & Department of Health England, 2015) and the UNCRPD (EBU, 2014) recognised habilitation as a means to support CYP with SEND. It is important to note that the SEND: 0-25 years (2015) is relevant only to England, not to the rest of the UK (Scotland, Northern Ireland and Wales). Habilitation support is outlined in the health outcomes of the SEND: 0-25 years (Department for Education & Department of Health England, 2015). Habilitation is identified as a provision for CYP with SEND, alongside other healthcare and educational provisions such as occupational therapy and assistive technology (Department for Education & Department of Health England, 2015; page 39) and specialised support from Qualified Teachers of Visual Impairment. For the first time in England, habilitation training for children and young people with SEND has been legislatively recognised as a means for special educational support.

The existing habilitation literature outlines the importance of ILS, however it does not fully inform the field as to ways in which this development can be optimised. By recognising this gap in the previous literature and examining current government legislation, the aim of the current thesis was to develop novel systematic intervention resources to support the development of independent dressing skills in young children with VI and children with DS.

#### **4.2 The Importance of Play and UK Government Policy**

The shifting standards of government initiatives, however, have somewhat clouded the role of play in development and learning. In 2007, the Statutory Framework for the Early Years Foundation Stage (EYFS) stage stated that play supported learning and development of children (aged between birth and 3 years) and was also the key to the successful delivery of the EYFS curriculum (Moyles, 2015). However, due to the formation of the coalition government in 2010, educational ideologies shifted towards the 'traditional' forms of subject centred learning. This came to fruition in 2014 when a new National Curriculum was introduced which appeared to scorn the use of play based learning. This element was subsequently substituted for a detailed curriculum that itemised academic development (Moyles, 2015).

The prescriptive EYFS curriculum (Department for Education England, 2014b) outlined three 'prime' areas of learning; Communication and Language, Physical Development and Personal, Social and Emotional Development. Also four 'specific' areas of learning were outlined; Literacy, Mathematics, Understanding of the World and Expressive Arts and Design (Moyles, 2015; Department for Education England, 2014b). Play based learning was arguably substituted for 'golden time' or 'choosing time' in which children particularly in Key Stage 1 (KS1) 'earned' their time to play for around 30 minutes, typically on a Friday afternoon. This meant that the children participated in structured lessons throughout the week and were subsequently rewarded with an additional 'play time' at the end of the week. As golden time is a reward based system, it means that some children may not participate due to behavioural problems, for example.

In addition to the reduced opportunities to learn through play at school, social anxieties from parents and caregivers appears to restrict unsupervised playing external to the educational setting (Moyles, 2015). This reduction in opportunity means that children are perhaps more likely to participate in structured extra-curricular activities such as dance classes, or sports teams which are arguably safer and more organised due to the presence of teachers (Moyles, 2015). In addition to this, there also appears to be an increase in the availability of tablets, smartphones and computer games specifically targeted for the young population (De Aguilera & Mendiz, 2003). Arguably, in the context of the current research, the children who are using

tablets, computers and smartphones are refining their gross and fine motor control. This is due to the dexterity required to engage with the technology (De Aguilera & Mendiz, 2003). Although the use of tablets and smartphones are no substitute for the benefits of physical exercise and play.

Play is an important component in the learning and development of children as it facilitates movement in children. Play also increases sociability, self-regulating behaviours, language, multi-modality and developing a theory of mind (Moyles, 2015). Although it is not formally accepted within an educational context for ideological reasons, children naturally explore their environment through play and informally learn the skills that are considered necessary for optimal development (Moyles, 2015). Self-initiated play is considered a medium for learning as children have a tendency to set themselves challenges and overcome them. This type of play is naturally controlled by the child alone, and so adult guidance cannot structure or predict the nature of the play outcome (Moyles, 2015).

In a socio-cultural context, play is determined by the environment and societal norms. This is further structured by the adults present (e.g. parents/carers), including the environments children physically play in e.g. parks and also the type of play they can engage in e.g. group or sibling interactions. This means that parents and carers are shaping the 'affordances' of the play space which has a bearing on the type of play they engage in). This adult directed structure is arguably useful in order for the child to develop their social self, and also their theory of mind (Moyles, 2015).

For all children, audible and visual stimuli should be presented by the caregivers and other adults (e.g. health professionals) soon after birth, providing that the sensory modalities are intact. If the child has a sensory impairment, the remaining senses should be appealed to. This is done in order to aid the social development of the child. Infants attend to patterned sounds as opposed to sounds that are monotone. They turn their heads particularly in response to human speech patterns. Furthermore infants with vision are attracted to stimuli that are mobile rather than static, and the expression of human faces.

The attention to these aspects aid the child socially and act as preparatory activities to support future social orientation (Herbert, 2003). This implies that children actively seek interaction with objects (within their visual field) that could provide social benefits, and further assumes that the child has the ability to recognise their social potential. However for atypical children, especially children with VI, they are denied access to these visual social learning cues and so different routes must be taken to achieve sociability.

Multi-modality in play is characterised by children manipulating objects around them and becoming engrossed in play using both their mind and body. Children construct their own 'worlds' and interact within it, for example a cardboard box turns into a rocket ship, and also turns the child into an astronaut (provided that the child has had prior exposure to this as a concept). This engagement of both the mind and the body demonstrates how play has an effect on both the physical and mental aspects of development (Moyles, 2015). However, there is a debate surrounding the use of play in infancy and childhood. For some it is considered an acceptable and necessary means for exploring and engaging with the environment as well as reaping social benefits (Winnick, 1979). Samuelsson and Johansson (2004) found play and learning to be indivisible dimensions in the pre-school environment. Although play and learning situations have different characteristics, incorporating the entities, the children involved demonstrated creativity, created meaning and formed goals (Samuelsson & Johansson, 2004).

Time also plays an important role for the engagement in play. Amounts of time are usually allocated by adults (teachers and parents/carers alike) towards activities that are considered to be most important for a child's development (Moyles, 2015). Taking into account the new National Curriculum (Department for Education England, 2014a) and EYFS Curriculum (Department for Education England, 2014b), arguably, the majority of time allocated is dedicated to the prime and specific areas of learning as aforementioned. This means that 'play time' is confined to break time (usually 20 minutes), lunch time (approximately 1 hour) and golden time (around 30 minutes in total, but is dependent on sanction and rewards), unless the Class Teacher incorporates play activities into lessons. This allocation of time was apparent in the schools recruited for the study. This means that within the typical educational context in England, opportunities to play are prescribed by adults. This means that the amount of time allocated is dependent on how the adult perceives the value of play.

The ability to play and navigate through the environment –physically *and* socially allows the child to improve learning and development. In the early years a child is almost continuously moving, exploring their immediate and surrounding environment. It therefore seems logical that the majority of development and learning lies in the ability to move (Winnick, 1979). As the child grows, so does the extent of their movement capacity. Movements develop from gross to fine (Chapter 3), the environment extends from the proximal and immediate to the distal and as yet uncontacted, and experience contexts change from those at home to going to school for example. Observation suggests that as maturation occurs, movements become more structured; moving away from reflex into more self-directed and initiated movement. The occurrence of this is linked to participation in games and sporting activities (Winnick, 1979).

Movement experiences and play in school are predominantly found in Physical Education (PE) lessons in England. This is compulsory across the curriculum from age 5-16 years (Key Stages 1-5) (Department for Education England, 2014a). In the new curricula however, teachers have a responsibility for learning and play in the classroom (Samuelsson & Johansson, 2004). Opportunities for movement and play can be found in Performing Arts lessons, through dance or choreographed movement, for example. Performing Arts lessons are available as a curriculum entitlement but it is not a compulsory subject in the Key Stage 4 Framework (age 14-16 years) (Department for Education England, 2014a). Although this is not compulsory, arguably, movement can be incorporated into any aspect of the curricula across the Key Stage Framework. For example using movement to explain particle structure in Science. In PE lessons, physical and motor development are targeted and addressed through activities designed to improve motor skill objectives (Winnick, 1979), but movement opportunities are not confined to PE lessons.

The engagement in play activity in structured or unstructured environments (educational settings versus home settings for example) supports the development of gross and fine motor control. Within the schooling environment, it is currently advised that children should engage in two hours of physical education per week, however the Education Act (gov.co.uk, 2002), states that the Secretary of State does not hold responsibility for timetabling, or dedicating certain amounts of time to any subject. This means that the target of 2 hours of physical education per week is a guideline, and not controlled by government policy. However, by affording the opportunity of participation in sporting or physical activities for longer periods of time, children have a greater opportunity to develop and refine motor skill control suitable for independent living.

Children are afforded the opportunity to learn, practise and rehearse motor skills over a period of time both directly (through structured lessons directed by a teacher) and indirectly (through incidental learning, play and the observation of others). Time dedicated to rehearsing and developing physical motor skills are considered crucial for the development of independence in children. It appears that play is a useful and fundamental tool for children to actively engage in their environment, and develop socially and physically. Ultimately, however, it is the role of the teacher to formally incorporate such activity into lessons, and also permit the child to engage in a variety of play activities. In order for a child with an impairment to engage in play activities, the teacher must both incorporate play into a lesson, and also reduce parental overprotection which can be a barrier to development.

In order to incorporate play into education, it is important to understand the different approaches to learning to optimise child development. There are three main approaches to

educating children evidenced in the explored literature, these are: (a) the child-centred approach, (b) the subject-centred approach and (c) the teacher-centred approach. Although these approaches are described separately below, they are not mutually exclusive. This means that teachers can incorporate all into the learning environment (Winnick, 1979).

*Child-Centred Approach:* The child centred approach examines and meets the individual needs of each child and the emphasis is based around the child's personal interests and targets (Winnick, 1979). The child centred approach is commonly used with children with special educational needs and disabilities (SEND). A child is identified with SEND if they require specific learning provisions to support their education (Department for Education & Department of Health England, 2015). To detail this, a child is considered to have SEN if they fall into one of two categories, either;

1. They demonstrate a level of developmental delay meaning that their learning is not representative of children who are the same CA
2. They have a 'disability' meaning that their education environment needs to be adapted and make provisions for their needs. Put simply, the child cannot function as other TD children do, within the educational facility provided and so structural changes, such as handrails, wheelchair ramps and lighting have to be made to optimise the individual's access to learning (Department for Education and Department of Health England, 2015).

*Subject-Centred Approach:* Subject centred teaching involves the construction of experiences around the particular aspects of a subject area (Winnick, 1979). In this approach most children are taught similar content, but the content and activities are adapted to suit the needs of the group. A group is formed by splitting the class, usually in accordance with ability (Winnick, 1979).

*Teacher-Centred Approach:* the teacher determines the needs of the children through standardised assessment techniques, for example phonics assessments. The combination of subject and teacher centred approaches are common in UK mainstream schools (Winnick, 1979).

By examining these approaches, it appears that the current research focus and approach combines both the child-centred and the teacher-centred approaches. This is because assessments will be used to inform the teacher (researcher), however the suite of intervention materials and instructions provided are adapted to suit the individual needs of the child (for example using Makaton sign language in order to communicate with a child with partial sight or DS).

### 4.3 Summary

Chapter 4 explored the concept of habilitation in relation to the development of ILSD. The examination of the historical perspective demonstrated how the concept has evolved over time to its present format. Contextually, the history of habilitation showed that despite provisional requirements being needed, acknowledgement of this in relation to education and adequate provision is fairly recent. The work of Throne (1975) supported the rationale for the current study in relation to maximising independence, whilst maintaining an awareness that support and specialist provisions would possibly be necessary for the duration of the individual's life.

This history of habitation also demonstrated how little research has been done in the field until recently. By understanding that through the centuries there has been a dichotomy between what has been done and what is needed to be done, the gap in the literature is evidenced regarding ILS and habilitation as a concept. Between the 1970s and early 2000s habilitation had somewhat been overlooked. When habilitation re-merged as a concept in 2005, it largely applied to children and young people with VI until the publication of the SEND Code of Practice (2015).

The difference between habilitation and re-habilitation is essential. This is because the participants in the current study have not suffered a loss of visual functioning later in life. The strategies that are developed are based on a different baseline as the participants had never previously mastered ILSD. It was noted that although the existing habilitation literature recognises the need to develop ILS, the current available existing literature does not systematically evaluate practical techniques within a research environment. The current study is the first since the 1950s to systematically evaluate the impact of a dressing intervention. To this end, the current thesis is updating the field in relation to habilitation techniques and strategies suitable for independent dressing.

As habilitation is now recognised within the SEND Code of Practice (2015), and the intervention procedure in the current study is based on play the chapter examined the role of play in relation to government policy. This was because the opinions toward incorporating play based learning could have an impact on the effectiveness of delivering a play-based intervention programme. The explored literature indicated that play was not commonly incorporated within a traditional schooling environment. In addition, opportunities for play during the school day were based on adult directives and specific times (e.g. playtime/lunchtime). The chapter suggested that play based learning appears to be effective in terms of appealing to incidental learning (Chapter 2) and also the physical, social and psychological development of children (Chapter 3).

Finally, the multi-dimensional aspect of play facilitates movement, which facilitates exploration, which facilitates learning. By providing movement opportunities within the classroom environment it may be possible that children learn through different experiences. This supports the neuroconstructivist theory and multi-sensory learning (Chapter 3). In summary, this chapter explained the concept of habilitation, and how habilitation techniques can be informed by play and government policy.

## 5. Fastenings Survey

This chapter presents a fastenings survey in order to contextualise types of clothing and fastenings that children aged between birth-14 years have exposure to. This survey is based on the previous chapters in relation to the role that a parent/caregiver may take when clothing a child (Chapters 1-3). The fastenings survey presented in this chapter may serve as a platform for understanding real-life applications when designing an intervention suitable for teaching the independent living skill of dressing (ILSD).

### 5.1 Introduction

The purpose of this study was to contextualise the types of clothing available for infants and children (aged between birth and 14 years). The investigation of the availability and use of clothing fastenings was considered important in contextualising the gross and fine motor control needed to carry out independent dressing. This was done on the basis that the children do not usually choose the clothes that they wear, as clothing is determined by caregivers. The choice of clothing determined by the caregiver has an effect on the child's affordances and opportunities for fastening. This means that a child may be limited to fastening experiences as a result of clothing choice determined by caregivers, and also the availability of fastenings on clothing targeted at specific chronological ages (determined by clothing designers).

The examination of the range and commercial availability of children's clothing (and the fastenings that are used) reported here provided insight into the resources that are currently available for children and predicted the likelihood of fastening exposure at particular chronological ages (for example a high exposure to 'popper' fastenings during infancy might be anticipated if these are a dominant form of fastening available on clothes for this age group). This, combined with accessible online information regarding 'most popular' items of clothing, reflected the consumer habits of parents and caregivers who actively chose the types of clothing for their children.

Humans are clothed from birth for warmth, protection and functional purposes (for example, the use of nappies for children who are not yet toilet trained). As infants begin to develop and mature, the complexity and availability of different types of clothing increases. Typically, infants (aged between premature and 3 months), are dressed in all-in-one body suits (also known as baby-grows) that are designed for both indoor and outdoor wear. Figure 5.1 displays examples of all-in-one body suits:



*Figure 5.1: All-in-one body suits*

(Left image from an online shop: 'Not on the High Street', 2016; right image from an online shop: SSR Fashions Ltd., 2015).

Initially all-in-one body suits are used for both day-time and night-time. However after approximately 3 months of age, baby-grows are primarily used only at night-time. The sizes of the fastenings available on items of clothing are commensurate to the size of the infant; however, in the case of baby-grows, they are arguably too small for the developing child to manipulate. Infants do not have the necessary motor skills to carry out this task, and so this assumes that clothing and fastening is dependent on a competent parent/caregiver and also, presumably on the assumed motor skills of the caregiver.

As the child matures, the range of clothing items increases to trousers, shirts/blouses, skirts, dresses and t-shirts, for example. Similarly, the sizes of fastenings are representative of the size of the child, however some children may remain to have a dependence on adult support for dressing and fastening. Throughout these developmental phases, parents/caregivers have a responsibility to provide appropriate clothing for their child. An assumption was then made that the availability and types of children's clothing is targeted at parents rather than children. This means that although the choice of clothing is determined by the commercial availability, purchasing of these items is ultimately prescribed by the judgement and decision making of parents/caregivers.

The current fastenings survey provided a basis for understanding whether an increased exposure to (and availability of) particular clothing fastenings lead to knowledge of fastenings (physical and verbal identification) and subsequently the ability to fasten and unfasten. The aim of the survey was to predominantly identify the most popular items of children's clothing and the fastenings available. The results of the survey therefore served to inform the field

about: the likelihood of exposure to particular fastenings from birth to the middle childhood which will aid intervention studies; and the development of systematic dressing strategies to support habilitation training in young children with VI.

## 5.2 Method

A sample of the full spectrum of items of children's clothing were examined ( $N=1,569$ ). The sample was drawn from the most popular children's clothing stores in the United Kingdom (UK), based on an internet search. This search was then supported by an online forum for parents, where the mention of the particular stores were tallied against the original internet search. The online forum is a global platform, however the results were refined to posts which specified clothing stores within the UK, as this is the national context of the current study and in particular England. This ensured that the results would be representative of the clothing likely to be worn by children within the UK. The purpose for the cross-referencing was to ensure that the stores chosen were representative of consumer habits and preferences. 5 online clothing stores were established as the most popular for purchasing children's clothing based on an internet search, and so these websites formed the basis for the survey sample.

The overall clothing items (across all age groups) were split into two categories based on CA. These categories were predetermined by the filtering options on the websites, and were consistent across all stores examined. The two categories were identified as: 'premature – 2 years' and '2 years – 14 years'. As the websites covered the UK, it is assumed that they remain constant within the 4 devolved nations of the UK (England, Northern Ireland, Scotland, and Wales) even if these divisions are not consistent with physical shopping outlets in the respective nations.

Within the age defined categories (premature – 2 years and 2 years – 14 years), all identified forms of available clothing items for babies, boys and girls (listed in Figure 5.2) were refined to 'most popular' (determined by the 'sort/filter' option on each website) as this reflected consumer habits and preferences. After this search refinement, 30% of each identified type of clothing on each online store was recorded (see Figure 5.2). Duplicates of the same item were excluded, for example the same item in a different colour. This was because the style of the item and fastenings (if present) remained the same. If an item was duplicated, the duplicate was overlooked and the next item was recorded.

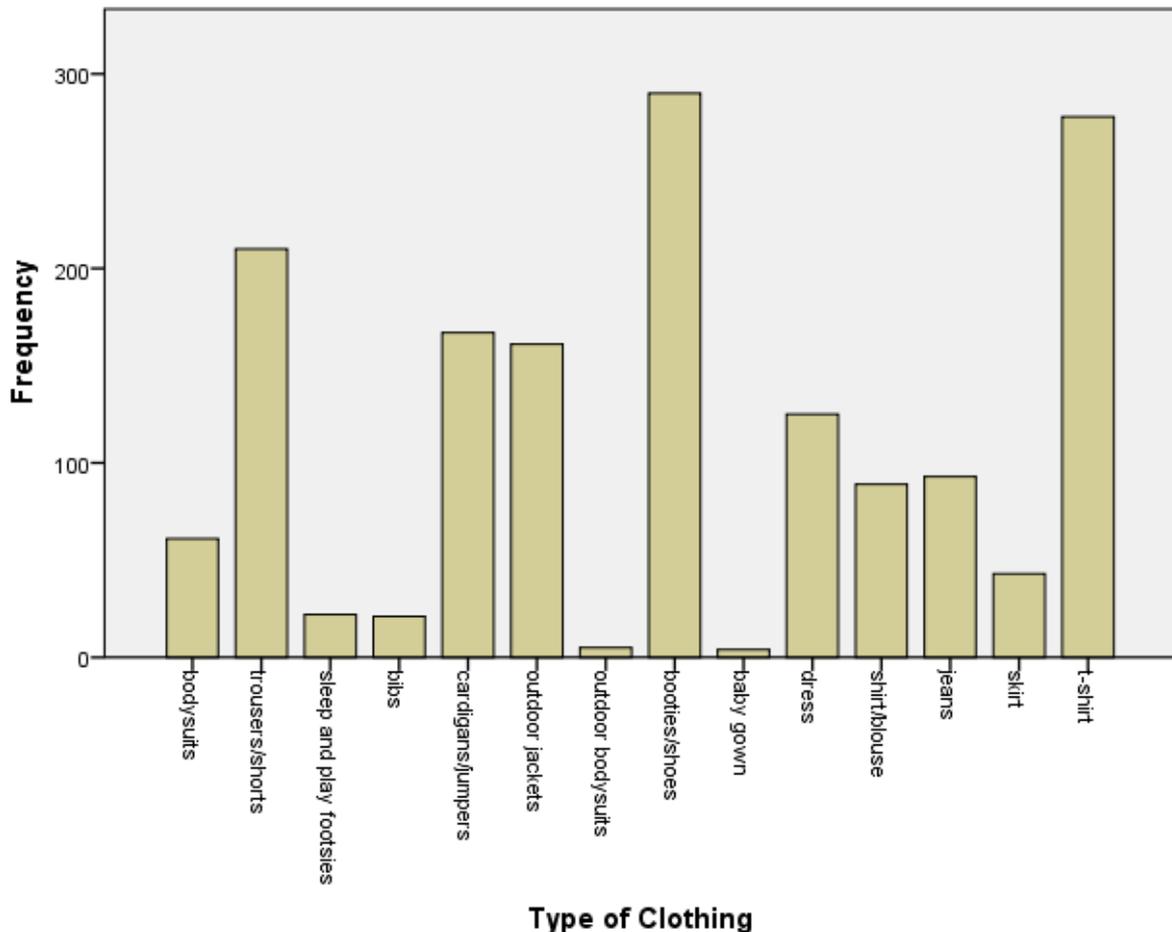


Figure 5.2. Histogram showing the frequencies and types of surveyed clothing.

The advantage of using an internet based search meant that the total number of items available was easily recorded. The items were split into clothing types (Figure 5.2) and the total number of each type available on the website. From this total number, 30% could be calculated. This is an aspect of the survey that would be more difficult in a physical shopping outlet, as the availability may be restricted in particular stores. Ultimately failing to provide an accurate representation of the range available. An additional advantage of an internet based search was the ability to filter the items of clothing to 'most popular' - something that could not necessarily be achieved in a physical clothing store without examining order requests and stock taking documents. The disadvantage of using a web based search was the variability of quality of product images and product descriptions. The survey relied upon the quality of images and product descriptions in order to identify fastening types. It was found that where one aspect of the recording failed (e.g. product description), the other aspect (e.g. product images) provided sufficient, recordable information.

The survey assessed functional fastenings only. Functional fastenings are classified as fastenings that need to be unfastened and fastened in order to put on and secure or take off the item of clothing. Fastenings that were used for aesthetic purposes only (i.e. buttons used for decoration that could not be fastened/unfastened), were not recorded. This was because an infant or child would not be able to manipulate the 'aesthetic' fastening in the same manner as a functional fastening. At most, it was understood that the infant or child would only be able to hold the 'aesthetic' fastening, and not appropriately manipulate it. But on the basis of Gibson's theory of affordances, one might argue that, nonetheless, finding and playing with the button will provide the child an understanding of the affordances of the button.

Some items of clothing were gender specific in the search matrix, for example skirts and dresses are only available within the 'baby' and 'girl' categories. The clothing fastenings identified in the refined (30%) sample were: zips, buttons, poppers, Velcro, shoe buckles, shoelaces and elastic/slip on. Tables 5.1 and 5.2 provides descriptions of these identified fastenings. Table 5.1 describes zip, button, popper and shoe lace fastenings. These are representative of the fastenings later used in the main study. Table 5.2 provides descriptions for Velcro, shoe buckles and slip on clothing. These fastenings were not tested within the main study.

Table 5.1.

*Descriptions of identified fastenings on children's clothes that are used in the current research.*

Name of fastening	Description
<p data-bbox="199 423 248 456">Zip</p> 	<p data-bbox="528 423 1481 506">Two rows of 'teeth' (plastic or metal) that interlock by pulling a slider mechanism. Commonly used on outdoor coats and the trouser fly.</p>
<p data-bbox="199 656 293 689">Button</p> 	<p data-bbox="528 656 1481 790">Typically a circular plastic object (although other sizes and materials are used) which is pushed through a button hole relative to the size of the button. Commonly used on cardigans and shirts.</p>
<p data-bbox="199 887 304 920">Popper</p> 	<p data-bbox="528 887 1481 1070">Also known as 'press studs' or 'snap fastenings', the popper consists of two pieces (typically metal or plastic) that 'pop' together by inserting the convex 'stud' into a matching concave hole. Frequently used for baby-wear due to speed and ease of fastening.</p>
<p data-bbox="199 1115 363 1149">Shoe Laces</p> 	<p data-bbox="528 1115 1481 1249">A long string that is fed through eyelets from the throat line of the shoe upwards, following the length of the tongue. Typically made from cotton, however are also available in elastic for ease.</p>

*Note: Images taken by author*

Table 5.2.

*Descriptions of identified fastenings on children's clothes that are not used in the current research.*

Velcro		A fabric form of 'hook and loop' fastening. Typically produced in Nylon due to variability and durability of the material (e.g. thickness of loops) (Suddath, 2010)
Shoe Buckle		Typically on the quarter part of a shoe. A length of leather is taken across the foot and fed through the metal buckle frame and over the bar of the buckle. The leather length contains holes, and so a buckle pin is inserted through a hole to keep the shoe in place
Elastic (slip-on)		Stretchy fabric that is manipulated over the body and revert to a fitting size. Used in t-shirts and athletic clothing where fastenings are not required/pose a risk.

*Note:* Images taken by author

'Slip on' clothing is also recorded in the current survey. Although, it is not technically considered a fastening as it does not require the joining of material to secure an item of clothing in place. Slip on clothing does require the gross motor skill of pulling, and arguably the gross/fine motor skill of pinching and holding the material in order to secure the clothing item. However, as the clothes are pulled on and then stay in place, different skills are employed when carrying out this activity. An item of clothing with a zip for example, requires further stages of fastening completion in order for the item to stay in place (i.e. trousers are pulled on, like a slip on item of clothing however the fly fastening on trousers is used to tighten the waist and secure the item on the body).

Slip on was recorded for the purposes of a selection of t-shirts and trousers, which did not have fastenings which secured the item in place, but were part of the 30% of most popular items. Omission of the slip on category would not reflect the availability of children's clothing or the shopping habits of consumers. This means that the inclusion of the slip on category more accurately reflected the most popular items of clothing bought, and subsequently the

types of clothing that the children were exposed to. The recording of the frequency and availability of slip on items could be useful in understanding why some children may struggle with fastenings. This is because slip on only clothing *reduces* exposure to fastenings, and potentially may hinder the development of gross and fine motor fastening skills. This is because children do not need to complete additional stages in order to independently dress and secure their clothing. This means that the gross motor skill of pulling on or pushing off clothing may be better developed than the fine motor skill of fastening which requires more dexterity and control.

The method used for the current survey was effective in encompassing a wide range of children's clothing, covering the ages of 0-14 years. By recording all methods for securing clothes in place (i.e. the identified fastenings and slip on items), an understanding of exposure to fastenings was developed. Furthermore, refining the items to the most popular represented the purchasing preferences of parents/caregivers, although it of course did not explain the basis of caregivers' decisions to purchase the items (and so types of fastening).

### **5.3 Results**

The current study provided a clear basis for designing the novel intervention materials suitable for the development of independent dressing skills. It demonstrated a developmental approach to motor skill acquisition based on CA. As a result of this, systematic dressing protocols can be developed based on fastening availability and CA. By recording the frequencies of fastenings on the most popular items of children's clothing, it can be assumed that the data represents the types of fastenings that infants and children are exposed to from birth to 14 years of age, across the UK. The splitting of the age groups at 2 years, demonstrated the variability and progression of fastening exposure during infant and child development. The split of the age in the online sorting filters did show an overlap between the two groups, however this cannot be controlled for within the filtering option on the website.

The survey revealed that overall the most common fastening for the 'premature-2 years' range was poppers (frequency of 100). This suggested that exposure to 'popper' fastenings is greatest in the 'premature - 2years' range. For the overall range of '2-14 years' the most frequent fastening was zips (frequency of 318), suggesting that children of this age are more exposed to zip fastenings. Despite the high frequency of zip fastenings, it can be argued that children who remain to be in nappies (with Velcro-like tabs) may be more likely to be exposed to Velcro rather than zips. Children who have been reared with cotton nappies affixed with safety pins, will also have a different exposure to clothing fastenings and may not have had the opportunity to attempt Velcro fastenings. This means that although the survey is a record of the availability of fastenings on children's clothing, it may not be holistically representative

of each child's individual experiences of clothing. The frequency of fastenings across both age groups were recorded and are displayed in Figure 5.3 and 5.4 (data tables presented in Appendix 11.1).

Figure 5.3. Histogram showing the types and frequency of clothing fastenings for children aged premature-2 years.

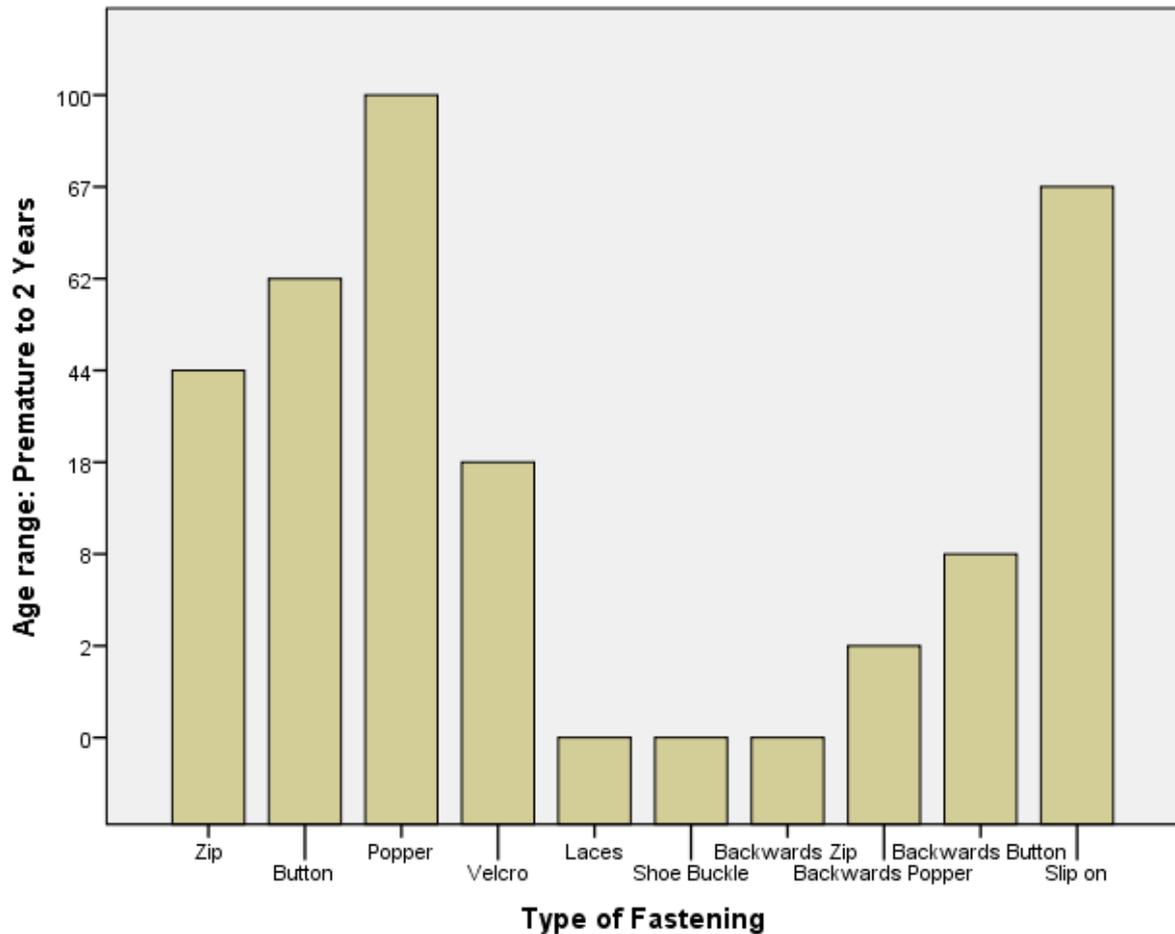


Figure 5.3 shows that in the age range 'premature – 2 years', popper fastenings have the highest frequency of use on clothing. Slip on clothing was also identified as having a higher frequency. The frequencies of fastenings displayed in Figure 5.3 therefore suggest that children aged between premature-2 years should have a greater exposure to popper fastening and slip on clothing when compared to other forms of fastening. Figure 5.4 displays the frequency of clothing fastenings for the age group '2-14 years'.

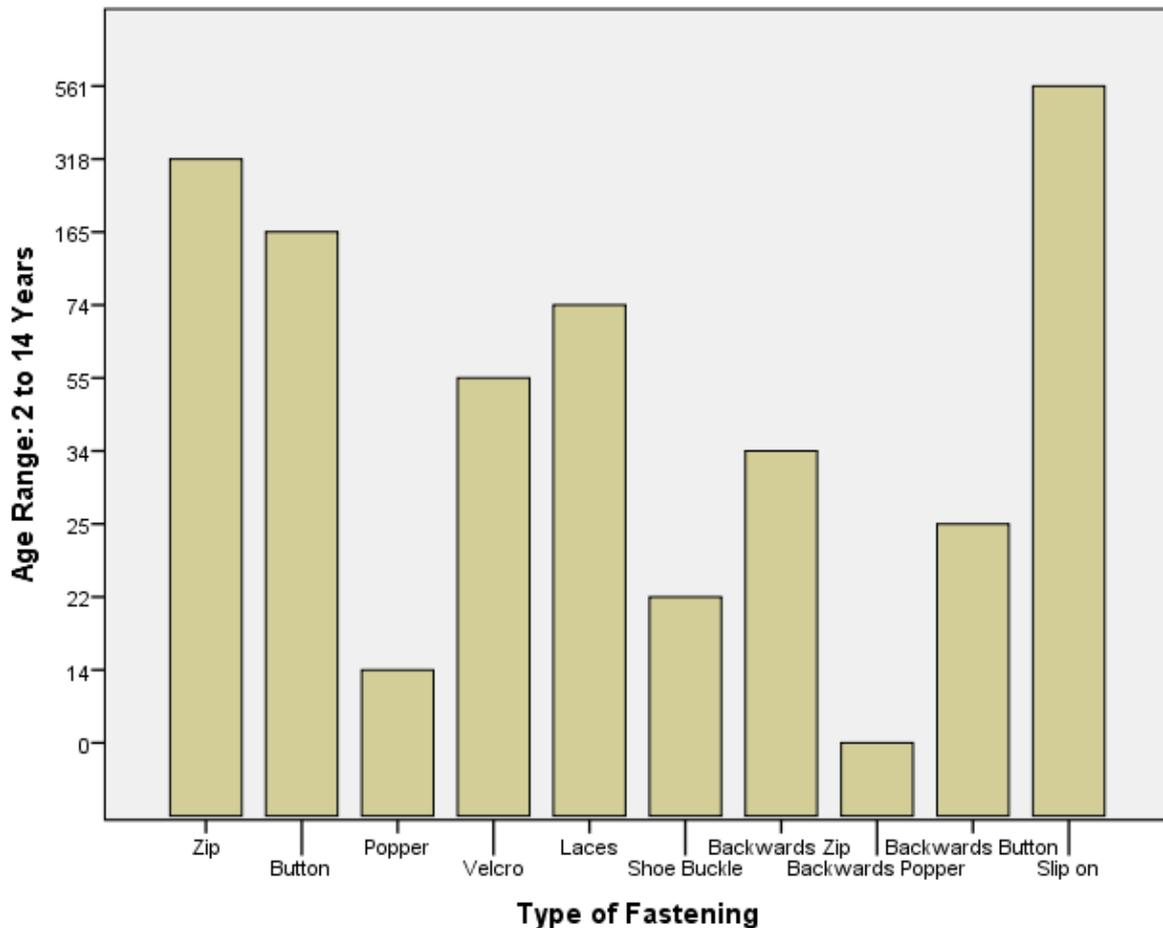


Figure 5.4. Histogram showing the types and frequency of clothing fastenings for children aged 2-14 years.

Figure 5.4 shows that there is a high frequency of slip on clothing for children aged between 2-14 years. Zip fastenings are the most frequent form of clothing fastening within this age range. This suggests that children aged between 2-14 years should have a higher exposure to forward fastening zip fastenings. In contrast to Figure 5.3, children ages between 2-14 years have a substantially lower exposure to popper fastenings.

Figures 5.3 and 5.4 identified the different types of clothing fastening available, and revealed an overall difference in fastening availability between the two identified groups. Figures 5.3 and 5.4 showed that there was more variance in the types of fastenings available in the '2-14 years' range. The difference in the total numbers of surveyed items was representative of the wider range of clothing available in the '2-14 years' category.

The data were then split into primary, secondary and tertiary fastenings in order to determine children's exposure to multiple fastenings on one item of clothing. A primary fastening was identified as the most important fastening to secure the item. For example, a button at the top of a zip fly would count as the primary fastening because the trousers are not secure without fastening the zip. The zip fly would therefore be considered as a secondary fastening, as it still needs to be fastened to successfully complete the task of putting on and fastening trousers. An example of a tertiary fastening is the popper at the top of an outdoor coat (after completion of the primary zip and the secondary Velcro, for example). The raw data are presented in Appendix 11.1. The following figures show the frequency of primary, secondary and tertiary fastenings found across the combined age range.

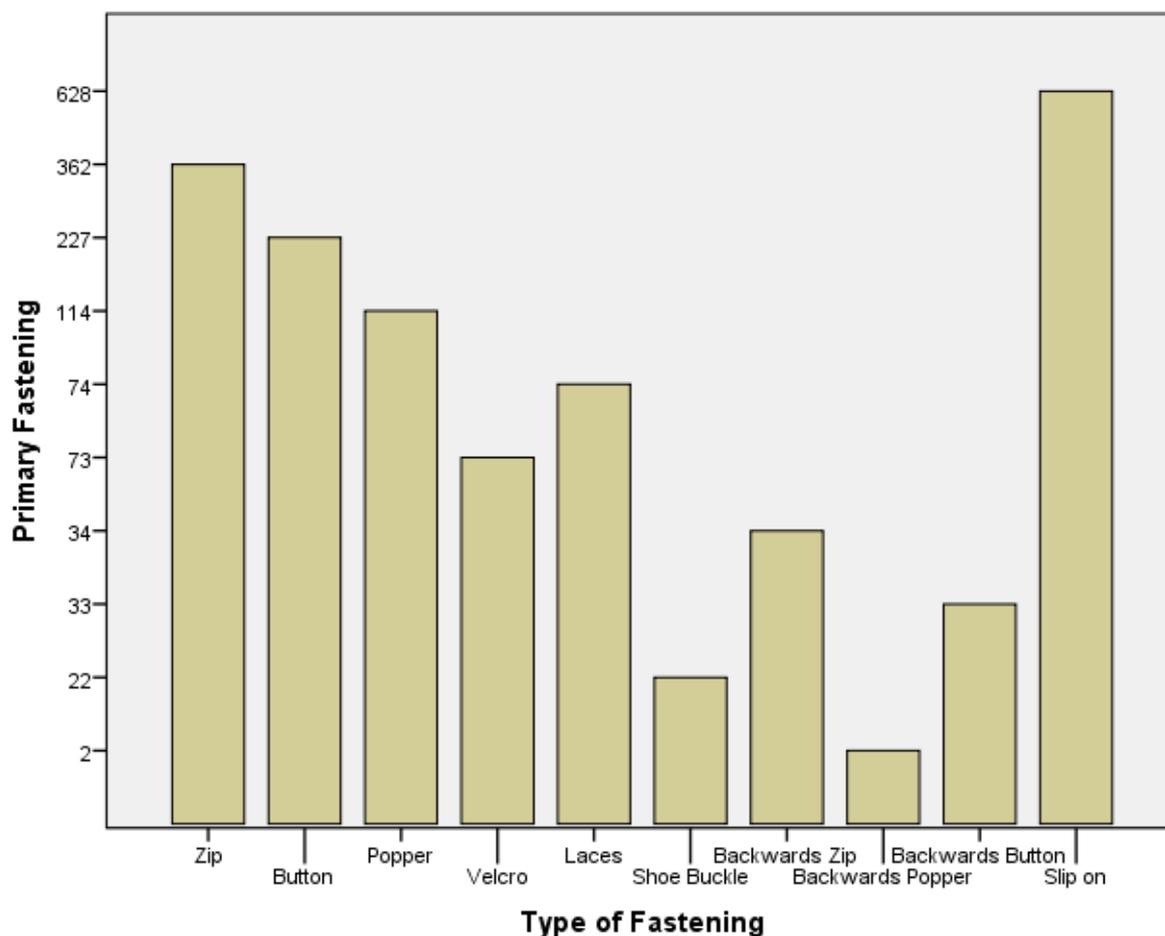


Figure 5.5. Histograms showing the frequency and type of primary fastenings across premature-2 years and 2-14 years combined.

Figure 5.5 shows that zip fastenings were the most frequent form of primary fastening on children's clothing across the age range of premature-14 years. The histogram also displays the variety of fastenings that are available on children's clothing over the age range of premature-14 years.

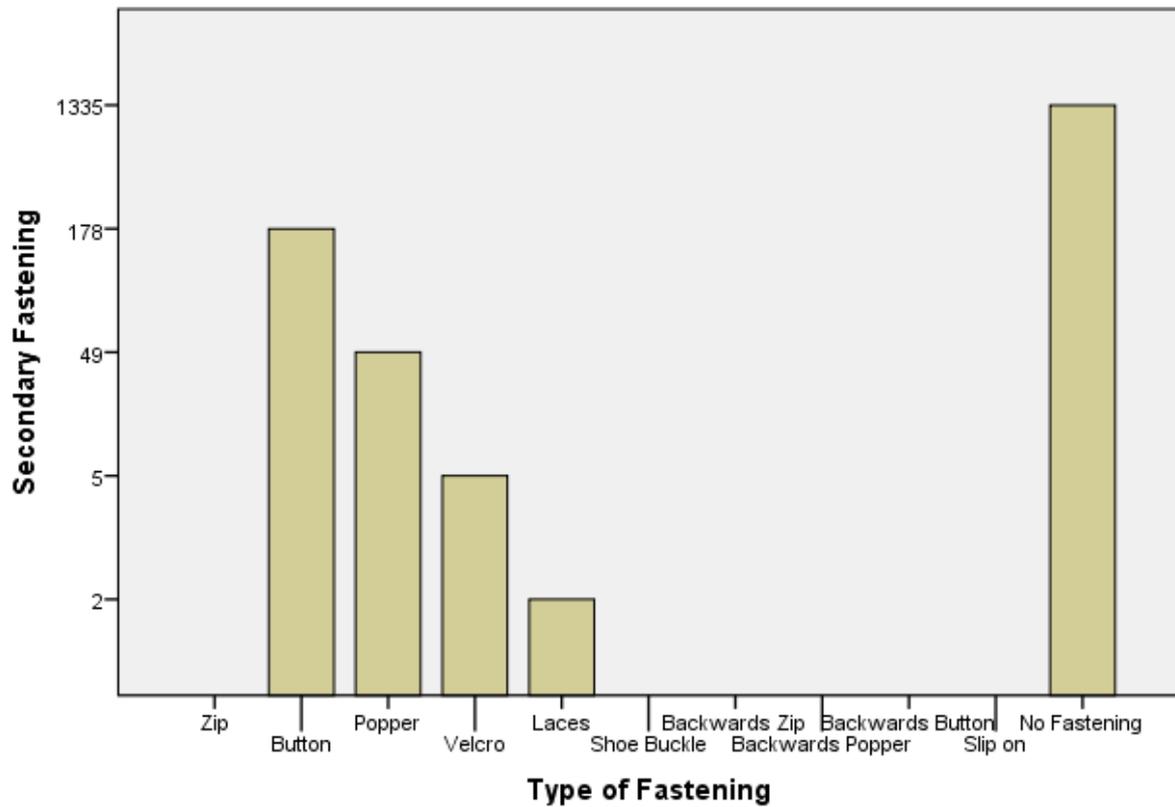


Figure 5.6. Histograms showing the frequency and type of secondary fastenings across premature-2 years and 2-14 years combined.

Figure 5.6 shows that the majority of items of children's clothing do not have a secondary fastening. There were only four identified forms of secondary fastening. They were identified as: buttons, poppers, Velcro and shoelaces. Buttons were observed the most frequent secondary fastening for items of children's clothing across the age range of premature-14 years.

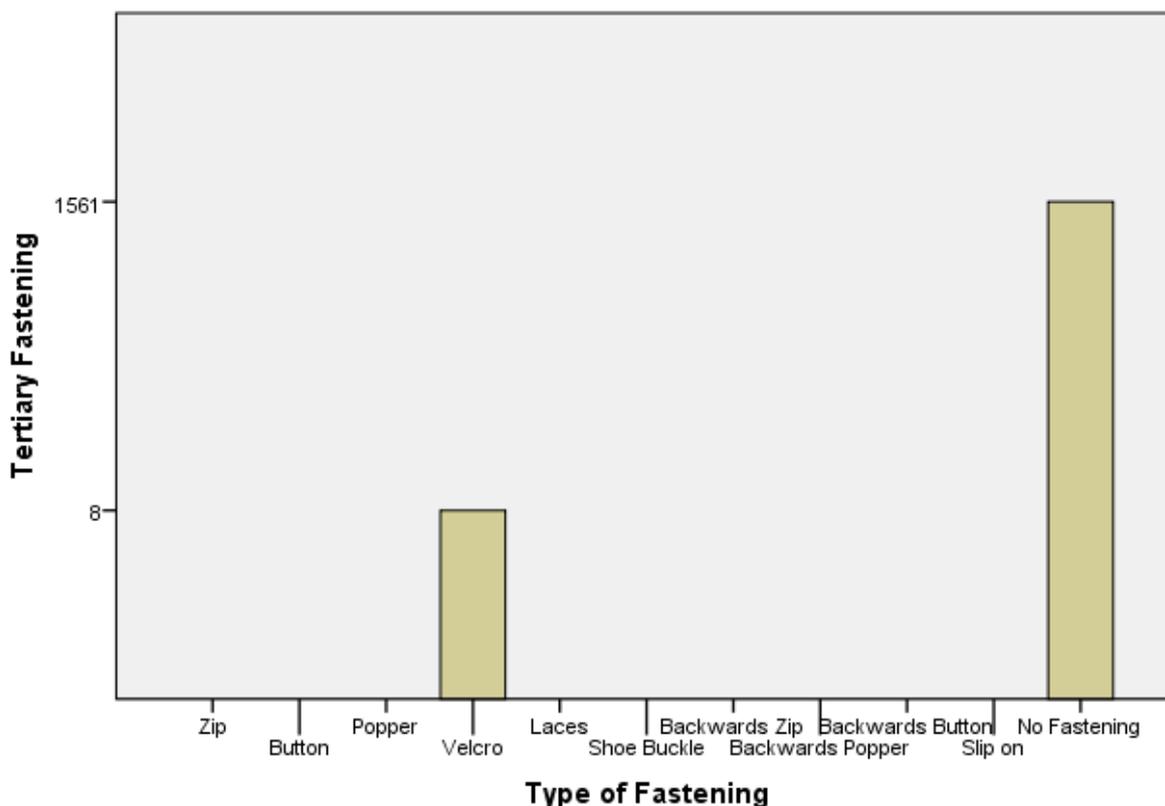


Figure 5.7. Histograms showing the frequency and type of tertiary fastenings across premature-2 years and 2-14 years combined.

Figure 5.7 shows that the majority of children's clothing do not have a tertiary form of fastening. It is apparent from the histogram, that the only observed form of tertiary fastening is Velcro.

The results of the fastenings survey (as demonstrated in Figures 5.5, 5.6 and 5.7) indicate that items of children's clothing tend to have only one functional, primary fastening. In this instance (and with the exception of slip-on) the most frequent primary fastening were zips (frequency of 362). Buttons were identified as the most frequent secondary fastening (frequency of 178). Velcro was the only identified tertiary fastening (frequency of 8). This indicated that children's exposure to fastenings are usually one fastening per item of clothing, meaning that they have a reduced exposure to items with multiple fastenings.

An exception to this finding is that for an outdoor coat, for example. An outdoor coat usually has three types of fastening e.g. zip, Velcro, button/popper. This suggested that in some instances, one frequently used item of clothing with multiple fastenings may support fastening skill ability. However this does not presuppose that the children are fastening all possible types of fastening on the item (e.g. children may just fasten the Velcro and ignore the other available fastenings on the item). This means that although *exposure* may play a role in fastening

ability, high exposure to items with multiple fastenings *does not necessarily* lead to high fastening ability.

The current results demonstrated that infants aged between premature-2 years have most exposure to popper fastenings. As infants move into childhood, the availability of different types of fastenings increase, yet the availability of popper fastenings decrease. Zips and buttons are identified as the most frequently used type of fastening within this survey. This frequency is evident in the 2-14 years context, and arguably this is due to the wider range of clothing available within this age range. Rapid social, emotional, cognitive and motor skill development occurs within this age range (particularly until the age of 6) (Shonkoff & Meisels, 2000) and so emerging independent fastening skills may surround fastenings that the child has high exposure to. The development of dressing skills may also be resultant of a conscious awareness of dressing procedure and the strategies employed.

#### **5.4 Discussion**

The current fastenings study has highlighted the types of fastenings that children aged between 'premature-2 years' and '2-14 years' would have greater exposure to. By contextualising availability in this manner, the likelihood of exposure to particular fastenings at particular ages was evident. The current results indicated that a child of 6 years old (for example) would have had higher exposure to zip fastenings when compared to other fastenings. It was then causally assumed, that the greater exposure to particular fastenings linked to a better ability to identify and manipulate zip and button fastenings because they were the most frequent fastenings within the '2-14 years' sample. Within this age range of '2-14 years' there was a reduced exposure to poppers when compared to the 'premature-2 years' category. However, it was assumed that all children over 2 years of age would have previously been exposed to popper fastenings (for example) and should, theoretically, demonstrate a knowledge of fastening and unfastening poppers. The survey also reported that popper fastenings were still available (albeit in a reduced capacity) in the '2-14 category', and so children in this category may still have had experiences with this type of fastening in early childhood. This is understood in a similar vein to the aforementioned experiences of infants wearing nappies and exposure to Velcro.

It could be argued that a child's exposure to particular fastenings could be a direct result of parental choice for clothing items. Slip on items were very common in both commercial availability and in relation to consumer habits (previously outlined in Figures 5.3-5.5). If slip-on items were preferred by parents, this could limit a child's exposure to fastenings such as zips and buttons, and arguably reduce individual skill ability in fastening tasks. If a child has

had a limited exposure to clothing items with functional fastenings, their ability to practise and refine fine motor skills for fastening would also be reduced.

If a child is not afforded the opportunity to fasten and unfasten, for example in an instance of high exposure to slip on clothing, it is unlikely that fastening skills will develop due to inaccessibility to appropriate resources. If an individual's exposure to clothing fastenings is very limited, further exposure and opportunities to manipulate fastenings would be restricted to non-clothing items such as backpacks/bags, sleeping bags, and bed clothes, for example. These additional items do require a type of fastening for security, however availability and exposure to these items are not recorded in the current survey.

The current survey data cannot account for individual levels of exposure to fastenings, as this was beyond the scope of the survey. However the results do reflect the consumer habits of purchasing clothes which could indicate the likelihood of exposure. Although, a high exposure to fastenings does not necessarily mean a high experience of fastening. Further information that could inform the main study as to exposure to fastenings is the gathering of participants fastening 'history' from birth onwards and also sibling data.

Recording participant's siblings and their ages can inform the research as to different types of fastenings that the participant may be exposed to within the home environment. For example, if the participant has younger siblings aged between 'premature to 2 years', it can be assumed that the participant will have a greater exposure to popper fastenings and possibly Velcro, as well as the popular fastenings associated with participant age. If the participant has older siblings, aged up to 14 years, it can be assumed that the participant has a higher exposure to – and so greater awareness of the affordances of, the fastenings most common within this age group. If the participant has both younger and older siblings (that cover the spectrum of the survey) it can be argued that they have the most exposure to the widest variety of fastenings. This exposure may suggest a correlation between the frequency of exposure to fastenings and also the skill ability associated with fastening and unfastening.

There are limitations to the current study. Firstly, the study only assesses items of clothing from stores within the UK. This means that the results are not generalizable to countries outside of this context. Also, the items examined were based on popular clothing stores and correlated with an online forum for parents. This means that the sample was limited as it does not account for differences in socio-economic status. Families who have higher or lower incomes may choose different stores which may supply different items. This could then shift the likelihood of exposure to different fastening types. Future research could account for this by using questionnaires and interviews with families to fully assess environmental influences which could contribute to clothing choice.

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A further limitation is that the current study does not examine the differences of clothing availability within the context of gender. This means that assumptions cannot be made regarding fastening exposure and fastening availability between genders. The current study is limited as gender differences are only highlighted within the context of dresses and skirts.

### **5.5 Conclusion**

In conclusion, the survey cannot determine the exposure or experience of fastenings within the personal environment. The fastening survey does, however, provide a foundation and possible steer for establishing a dressing protocol. This is because the survey is arguably representative of the consumer habits within the top 5 children's clothing outlets in the UK. Future work could explore and contextualise fastening use and availability across Europe (for example) in order to examine trends. This would add to the existing survey, providing a cross-cultural approach to fastening exposure and the potential link to the development of gross and fine motor control.

The current survey could also be useful for establishing a consolidated parent/caregiver information sheet. This is because parents and caregivers have a responsibility for clothing their children. The development and dissemination of an information sheet could act as an aid for parents and caregivers (specifically those who have children with VI). The information sheet would serve to highlight the importance of clothing choice in order to optimise the development of independent dressing skills. To distribute this information, supporting organisations such as the Royal National Institute for the Blind, HAB-VI and Blind Children UK will be contacted.

## 6. General Methodology

### 6.1 Introduction

Two separate groups that were clinically defined as visually impaired (VI) and Down syndrome (DS), participated in this research project. Their performance throughout the 10 week intervention procedure was compared to typically developing (TD) children. This chapter first details: participants, recruitment and diagnosis, ethics, age range and response rates. The chapter then explores characteristics of each group. The characteristics of the VI sample are presented in Table 6.1 to show the relationship between VI and comorbidities within the recruited sample. By using mini vignettes, the chapter then illustrates participant characteristics of the VI ( $n=9$ ) and DS ( $n=9$ ) samples. The exclusion criteria for the current study is then presented, followed by the incorporation of heterogeneity within the current research design. Next, general methodological issues will be presented. These issues include: a lack of standardised measures suitable for use with a VI population, ceiling/floor effects, the screening procedure and the methodological approach to be employed within the current thesis design. Finally, three further issues which may have implications for the project are presented. These are in relation to: recruitment; matching a typical group with atypical groups; and testing children with developmental disabilities.

In this chapter, the participants' characteristics, general data collection methods and methods of analysis will be described and evaluated. Last, some methodological issues surrounding participant matching strategies are identified and evaluated.

It is important to acknowledge that the prevalence rate for VI in the UK is low (Keil, 2014). This means that sample recruitment can prove difficult if recruitment occurs in one specific place. It is preferable to recruit a randomised sample in order to increase the chance of the sample being representative of the chosen population, taking into consideration any characteristic that could have an effect on the outcome of the experiment (Warren, 1984). While randomised selection is arguably preferable for working within the clinical groups the low prevalence in the VI condition has meant that this was not possible in the current study.

In the current study, the clinical sample was an availability sample. This meant that recruitment for the current study was based upon minimal exclusion criteria and the availability of the participants. The impracticality of recruiting a randomised clinical sample leads to the importance of detailing individual characteristics and reporting a full background of the participants involved. Although the detailed characteristics are beneficial for the report itself, it

is highly unlikely that the results of one study will be generalizable to the VI population (Warren, 1984).

## **6.2 General Methods Adopted in this Thesis**

### **6.2.1 Participants**

The current sample was drawn from three distinct yet related populations; VI, DS and TD. The clinical samples (VI and DS) were recruited from a specialist school/voluntary organisation in London, UK. Due to a difficulty in recruiting TD participants from London, the TD sample were recruited from a mainstream setting in Cumbria, UK. Matching participants based on location was originally designed in the research, however due to the issues with TD recruitment (mentioned later in this chapter) this was not possible. For the purpose of this chapter and subsequent chapters, VI and DS groups will collectively be referred to as the clinical group unless otherwise specified.

#### **6.2.1.1 Recruitment and diagnosis**

A pre-requisite of the VI sample was that all children were clinically diagnosed with a VI (ranging from total blindness to partial sightedness). The clinical diagnosis for both VI and DS groups was obtained via the educational setting (either a specialist school or a voluntary organisation) and a medical history questionnaire was completed by the parents/caregivers.

Initial contact with the schools/organisations was made in order to recruit the sample. This was because the intervention was to take place within these settings. The child participants were identified by the school (in the case of VI and TD) or by the parents (in the case of DS). The respective parents/caregivers were provided with a consent form outlining the project, the role the parents/caregivers would play and the activities that their child would participate in. The consent form was an 'opt in' form which required written consent from the parents/caregivers for their child to participate in the study. Verbal assent from the child participants was also considered appropriate at the beginning of each session as the proposed intervention was based on participant cooperation.

The consent form (Appendix 11.2) also outlined that responses to the questionnaires were confidential and the information would only be viewed by the researcher and her research supervisors. It also acknowledged that video/audio/photographic recordings might be used in order to support inter-rater validity for the observation schedule. All parents/caregivers understood that the information that they provided would be anonymised, meaning that the participants could not be identified within the thesis and future publications. Parents/caregivers were also advised that they and their children could withdraw from the study at any point without explanation and that any data relating to them would then be destroyed. They were

also given assurances that their individual child's voice would be listened to throughout the intervention. This made it clear that a duty of care was occurring throughout the testing period.

### **6.2.2 Ethical procedure**

The research reported here worked in accordance with the BPS Code of Ethics and was approved by the UCL-Institute of Education Research Ethics Committee. The child participants were informed of the nature of the study and asked before every session if they wished to participate. Child assent was verbally provided at the start of every session. All adult (teacher/parent/carer) and child participants were informed of their right to withdraw from the study at any time, and also that their data would be treated as 100% confidential. The children were openly informed about the aims and purpose of the study and were not misled in any way about its protocols.

The ethical procedure (Appendix 11.3) considered all aspects of the research project, including: the piloting and the main study procedures; recruitment; and, the longer term assessment of impact of the intervention. In relation to the planned 'ideal' sample for the project, the ethics form stated that 40 participants were to be recruited. This consisted of 20 TD participants, and 20 participants who were considered to have developmental delay. The sample of participants with developmental delay was originally conceptualised as 4 distinct clinical groups: Visually Impaired, Down syndrome, Cerebral Palsy and Williams Syndrome. Drop-out rates were also accounted for within the ethics form. It was predicted that 15% of the recruited sample would drop out due to the threat of mortality. Mortality referred to dropping out over the course of the intervention period, and actual mortality which is an issue when working with children with profound and complex disabilities.

Exclusion criteria were established within the ethics form, as were the background measures that we considered to be most appropriate for use within the clinical samples. The ethical procedure also illustrated how the child participants were not blinded to the aims of the research. This was because it was not considered necessary, appropriate or indeed possible to disguise the true aims of the intervention due to its very nature. There were 5 main ethical issues that were identified and subsequently resolved within the ethical procedure. These were: working with vulnerable children; dressing and undressing; general risks; access to medical records; safeguarding. For details on the resolutions see Appendix 11.3. There was one instance of an amendment to the approved ethics form. Within this instance, and after receiving advice from the RNIB, the method of consent was changed from 'opt-out' to 'opt-in'. The high level of detail in the ethics form (Appendix 11.3) was purposeful in order to ensure the protection of the participants and ensure the integrity of the research undertaken.

### 6.2.3 Age Range

The age range for the study was 5;04-10;02 years. The choice of this age range was two-fold: the first reason being that in relation to types of schooling, all participants would be representative of a primary school setting; the second reason being that previous work (Hayton, 2012) had suggested a possible observed ceiling effect in fastening skill ability (in all fastening conditions) in TD children above 11 years of age. This meant that there would be a lack of comparison between TD and clinical participants. Furthermore, as previous research has suggested that there is a 'critical period' for child development (up to the age of 6 years) (Van Herwegen, Rundblad, Davelaar, & Annaz, 2011; Warren, 1984), the research accommodated this position, while providing the opportunity to investigate children who have exceeded this age but still appear to require systematic formal teaching strategies in order to increase independence.

### 6.2.4 Response Rates

Taking into account the outlined exclusion criteria, the total number of participants  $N=27$  was drawn from 2 schools and 1 voluntary organisation across England. The VI sample ( $n=9$ : age range: 5;06-10;02 years) was drawn from a specialist school in London, UK. The TD sample ( $n=9$ : age range: 6;05-8;00 years) was drawn from a mainstream primary school in Cumbria, UK. The DS sample ( $n=9$ : age range: 5;04-10;00 years) was drawn from a voluntary organisation in London, UK. The distance between testing areas was a direct result of the inability to recruit a TD sample from London. In total, 60 mainstream schools were contacted across London, 3 made contact declining access.

Furthermore, in order to increase the awareness of the project, contact was made with the Royal National Institute for the Blind (RNIB) in order to aid recruitment for the VI sample. Although awareness of the project was raised, this advertising did not increase the sample size for the VI group.

Contact was also made to specialist and mainstream schools and charitable organisations regarding the DS sample, however only one voluntary organisation agreed to be associated with the project. As a result of the poor response rate, the sample size was smaller than anticipated.

The VI and DS samples were matched on CA with a plus/minus 2 month margin. Matching of the TD group to the clinical group was not based on CA however. This was because older TD children had already mastered successful fastening/unfastening. The match of the TD participants to the clinical participants was therefore based on need to develop fastening skills.

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#### **6.2.4.1 Typically Developing Sample**

Nine TD children (male,  $n=6$ ; female,  $n=3$ ; age range = 6;05-8;00 years old;  $M = 6:09$ ) participated in the intervention study. These children were recruited from a mainstream primary school located in Cumbria, UK. The TD children all had English as a first language and were undiagnosed with a learning disability. All TD participants were recruited based on an inability to fasten zips, buttons, poppers and laces, as determined by the class teacher.

#### **6.2.4.2 Visually Impaired Sample**

Nine VI children (male,  $n=6$ ; female,  $n=3$ ; age range = 5;06-10;02 years old;  $M = 8:03$ ) participated in the intervention study. These children were recruited from a specialist school in London, UK. The children with VI had English as a first language (although some were bilingual). Eight children were clinically diagnosed as VI, one child was clinically undiagnosed but was reported to have partial sightedness.

The types of diagnosis varied between the participants with VI, although some shared the same diagnosis. Table 6.1 shows the characteristics of the children with VI who participated in the study. The visual status was confirmed by the class teacher, and the cause of impairment and additional health problems are recorded based on information provided by the parents in the medical history questionnaire.

Table 6.1

*Characteristics of the VI sample*

PP*	CA  (Year; Months)	Gender	Visual Status	Cause of impairment	Additional Disability/Problem
1	8;10	Male	Registered severely sight impaired	Pilocytic astrocytoma brain tumour in chiasmatic/posterior fossa	Autism, Tourette's Syndrome, precocious puberty, growth hormone deficiency
2	10;02	Male	Registered severely sight impaired	Glaucoma	Cardiac (Ebstein anomaly)
3	7;11	Male	Registered severely sight impaired	Not recorded	No
4	8;08	Male	Registered severely sight impaired	Optic pathway pilocytic astrocytoma	No
5	5;06	Female	Registered severely sight impaired	Septo-optic dysplasia	Autism, Diabetes insipidus
6	8;05	Female	Undiagnosed partially sighted	Not recorded	Attention Deficit Disorder, communication difficulties
7	8;00	Female	Registered partially sighted	Rod cone retinal dystrophy (tunnel vision)	Cohens Syndrome
8	7;11	Male	Registered blind with light perception	Leber's Syndrome	Autism, Behavioural problems
9	7;00	Male	Registered blind, no light perception	Retinopathy of prematurity	Reflux, problems associated with prematurity

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\*PP = participant

All VI participants were recruited based on an inability to fasten zips, buttons, poppers and laces in the pre-intervention screening activity.

#### **6.2.4.3 Down syndrome sample**

Nine DS children (male,  $n=4$ ; female,  $n=5$ ; age range = 5;04-10;00;  $M = 7;05$ ) participated in the intervention study. The participants were recruited from a voluntary organisation in London, UK, which specialised in support for children with DS. The children with DS had English as a first language, but also used Makaton/British Sign Language to support their communication. All participants with DS were clinically diagnosed with the condition. This was supported by staff reports within the organisation and the medical history questionnaire completed by the parents/caregivers. The participants with DS did not have additional need diagnoses.

#### **6.2.4.4 Individual participant characteristics of the clinical sample**

To further detail the characteristics of the clinical sample recruited for the current study a series of vignette excerpts are presented. This is to aid understanding of the individual characteristics displayed by the recruited participants. More detailed vignettes are presented in Appendix 11.4.

Table 6.2

*Vignettes: Children with VI*

Participant Number	Diagnosis, characteristics and behaviour
1	P1 was an 8 year old male. P1 had pilocytic astrocytoma in the posterior fossa brain region. This form of CVI means that P1 had some residual vision which he used to complete particular tasks (by moving objects closer) but was registered severely sight impaired. In addition to his VI, P1 had Autistic Spectrum Disorder, Tourette's Syndrome, Precocious Puberty and a Growth Hormone Deficiency. He did not have any language or communication problems. P1 was regularly admitted to hospital for chemotherapy and shunt breakdown/revision. During the intervention period, P1 began attending a mainstream school one day per week.
2	P2 was a 10 year old male who had glaucoma and retinal detachment. In addition to his VI, P2 had a Cardiac Ebstein Anomaly. P2 had regular hospital admissions regarding corneal transplants, retinal surgery and cyst removal. P2 was very inquisitive and initiated conversations very easily with familiar people. He was recruited for the study based on a need to independently put on and take off an outdoor coat. P2 did

also 'parrot' words/phrases that were used in the session, and he became fixated on certain concepts. P2 was very responsive to clear instructions and boundaries, and refocussed when prompted.

- 3 P3 was a 7 year old male who had Juvenile Onset Batters Disease causing severe sight impairment. In addition to the VI, P3 also experienced developmental regression and attentional problems. P3 had no additional reported comorbidities, however was last hospitalised in 2015. He had language difficulties as a result of his condition.
- 4 P4 was an 8 year old male who had a pilocytic astrocytoma in the optic pathway and was registered severely sight impaired. In addition to his VI, P4 also had chronic hypomagnesaemia which he took supplements for. P4 was regularly hospitalised for chemotherapy, radiotherapy and the insertion of a shunt, however hospital admissions have reduced since 2013. P4 was a friendly and talkative child, he was very motivated to independently fasten and unfasten in the sessions as well as motivated to practice lace tying at home.
- 5 P5 was a 5 year old female who had septo-optic dysplasia and was registered blind. In addition to her VI, P5 also had Autistic Spectrum Disorder and diabetes insipidus which she took medication for. P5 was regularly hospitalised as an infant as she experienced neonatal abstinence syndrome (withdrawal). She now lives at home with her grandparents and does not have any siblings. P5 had some difficulty engaging in social situations and had a sensitivity to sound - specifically social sounds such as other children crying, shouting and squealing. She became easily distressed and frightened in loud environments and covered her ears to reduce the impact of these sounds.
- 6 P6 was an 8 year old female who had an undiagnosed VI and was registered as partially sighted. Her distance vision was between 1 and 2 metres and so she would bring objects close to her face to see them. In addition to her VI, P6 also had attention deficit hyperactivity disorder and communication problems. She used Makaton to support her communication and understanding. P6 had not been regularly hospitalised, however did undergo surgery to correct her legs and hips.
- 7 P7 was an 8 year old female who had Cohen's Syndrome, Rod Cone Retinal Dystrophy and Myopia. She was registered partially sighted. In addition to her VI, Cohen's syndrome also affected her motor skill development and behaviour. She was also prone to mouth ulcers and nose bleeds. P6 used Makaton to support her communication, and was a very friendly and chatty girl.

- 8 P8 was a 7 year old male who was diagnosed with Autosomal Recessive Congenital Leber's Amaurosis (Leber's Syndrome). He was registered as blind and had light perception. In addition to his VI, P8 was diagnosed with Autistic Spectrum Disorder which had a significant impact on his behaviour. He was reported as high functioning and displayed very challenging, repetitive and obsessive behaviour and was also manipulative at points.
- 9 P9 was a 7 year old male with retinopathy of prematurity. He was registered blind and had no light perception. His birthweight was very low at 3lbs (1.36kg) and he was the only surviving child from a set of triplets. His weight is now 20.1kg and he is 113.5cm tall. In addition to his VI, P9 also had gastroesophageal reflux associated with prematurity. He did not have any language or communication difficulties.

Table 6.3

*Vignettes: Children with DS*

Participant Number	Diagnosis, characteristics and behaviour
19	P19 was a 9 year old female diagnosed with DS. She did not have any comorbid conditions in addition to her diagnosis. She was a very outgoing and confident child, but preferred to work alone rather than in a group. Her behaviour reflected this as she would snatch resources from other children who were engaged in the session. She was co-operative with the researcher, but she had a short attention span and could be heavy-handed. She was verbal but used Makaton to support her communication and understanding.
20	P20 was a 5 year old female diagnosed with DS. She did not have any comorbid conditions in addition to her diagnosis. She was verbal but used Makaton to support her communication and understanding.
21	P21 was a 6 year old male diagnosed with DS. He did not have any additional diagnoses. He was very interested in the activities and the resources however had a very short attention span. P21 used Makaton to support his communication and understanding.

- 22 P22 was a 6 year old female diagnosed with DS. In addition to DS she also was diagnosed with a cataract in one eye and was awaiting surgery. She was a quiet and shy child, and she needed to be encouraged to engage in the session.
- 23 P23 was a 9 year old male diagnosed with DS. He was not diagnosed with a comorbid condition. He was very wary of new people, especially those he perceived to be “professionals” helping him. This meant that he was often uncooperative. He could get frustrated very easily and so needed to be eased in to the sessions more informally than with the other children. He preferred to work alone and did not speak very much despite being verbal. He used Makaton to support his communication and understanding.
- 24 P24 was a 7 year old female diagnosed with DS. She did not have any additional comorbidities. She was a softly spoken girl, very quiet but interested in the session. She had a short attention span and so needed regular breaks between practising to keep her concentration and focus.
- 25 P25 was a 9 year old male diagnosed with DS. He did not have any additional diagnoses. He was a very verbal child and very headstrong. P25 appeared to be fearful of new experiences and his mother would often sit with him during sessions. He used Makaton to support his communication and understanding.
- 26 P26 was a 5 year old male diagnosed with DS. He did not have any comorbid conditions. He lived at home with his mothers and younger sibling. He was a very quiet child but eager to try new things. He used Makaton to support his communication and understanding.
- 27 P27 was a 7 year old female diagnosed with DS. She did not have any additional diagnoses. She was very interested to engage with the intervention materials. She had a short attention span and became easily distracted. She used Makaton to support her communication and understanding.
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The vignettes detailed in Table 6.2 and 6.3 are indicative of both the clinical and behavioural aspects of the recruited participants. The detailing of the characteristics here provide a basis for understanding the individual participants as a whole, rather than merely understanding their diagnoses. The mini vignettes presented here also inform the case studies that are later presented in Chapter 9 which reports the results of the main study.

### **6.2.5 Exclusion Criteria**

In the current thesis, the exclusion criteria altered based on the real-world nature of conducting research. Originally, the design excluded participants with VI with an additional special educational need (VI+SEN). This criteria was revoked however, as the exclusion of such participants meant that the data collected would not be representative of the VI population. This is because within the UK many children with VI also have an additional disability or special educational need (Keil, 2014). One issue with the incorporation of VI+SEN is controlling for the effect of the additional disability. In order to overcome this issue, individual participant characteristics (including additional disabilities) were reported.

It was acknowledged that a potential issue for the undertaking of the project might have been individuals who experienced emotional and behavioural problems. This was accounted for in the ethical procedure (Appendix 11.3). In order to minimise the effects of this, it was planned that if a participant displayed these types of behaviours there was a likelihood of the participant being removed from the session. This was planned for two reasons: first, to safeguard the participant as per the conditions of the ethical procedure; second, to ensure the safeguarding of the other participants, including the researcher. To further account for this, an additional adult (a Teaching Assistant/Learning Support Assistant) was present in every session. The inclusion of an additional familiar adult supported the researcher and the students in relation to behaviour management and safety. Planning for this issue was incorporated into the research design, however exclusion based on emotional/behavioural problems did not occur in the project.

As a result of the transition from the original research design into the actual, the only exclusion criteria for participation in the intervention programme was 'English as a first language'. Due to the verbal aspect of the study, it was a requirement for all children to have English as a first language. This is because the intervention relies heavily on language comprehension and response to verbal instruction.

In order to recruit a sample which corresponded to the outlined criteria, communication with research supervisors, parents/carers, class teachers, teaching assistants and Special Educational Needs Co-Ordinators (SENCOs) was essential. Strong communication links were considered necessary to safeguard the children and conduct the research within ethical boundaries.

### **6.3 Incorporation of Heterogeneity in the Research Design**

Heterogeneity has previously been explored in this thesis (see Chapter 3). It is subsequently understood that variation is likely to be a characteristic relative to the recruited clinical and typical groups (Van Herwegen, Dimitriou & Rundblad, 2013). Heterogeneity in a sample is not usually ideal, however, consideration of heterogeneity is important in order to understand such highly variable populations. Some heterogeneous issues are inherent and so cannot be completely controlled for, however the effects can arguably be minimised within the research model in order to provide meaningful results (Warren, 1984).

In the current study, the effects of heterogeneity are arguably minimised by the specific reporting of the individual characteristics of participants within the clinical group. These characteristics or variables include; CA, IQ or MA, gender, disability, the nature and cause of the VI, age of onset, for example. These characteristics are identified as variables that may have an effect on motor skill acquisition suitable for successful independent dressing (Warren, 1984). These listed variables are individualised to the participant and are not able to be controlled by the researcher or the research setting (Warren, 1984). Although these variables cannot be controlled for within the research project, detailed reporting and the inclusion of the individual characteristics are necessary in order to provide insight toward developmental changes over the course of the intervention period.

In order to further account for the heterogeneity within the clinical sample, the variables identified above were incorporated into the research design of the current study and its data analysis. It is possible to assess the variation in the results over the intervention period in terms of motor skill acquisition and in terms of the aforementioned characteristics (e.g. using background measures). In the context of the current thesis, this meant that the characteristics of the individual participants, and any change in these characteristics (e.g. a change in diagnosis) were reported in a similar fashion to the reporting of the results of the intervention procedure itself (Warren, 1984). There are three advantages to this approach.

The first advantage of incorporating variation was that the potential sample size could have been increased. This is because the incorporation of variation and minimal exclusion criteria arguably created more opportunity for participation. There is one outlined exclusion criterion within the current research design, (i.e. the children having English as a first language), however, medical variables such as onset of blindness, for example, can be incorporated into the research design. This means that the exclusion of participants due to medical history is not an issue within the context of the current research, as additional medical diagnoses (e.g. Autism Spectrum Disorders) are quite prevalent in the VI population (Keil, 2014). Despite this

advantage, the real-world nature of conducting research led to a smaller-than-hoped-for sample of recruited participants in the current thesis.

A second advantage was that the effects of the variables can also be evaluated over the intervention period and in the results section. By incorporating and evaluating this individual variation the research can track changes or recognise patterns in behaviour over the course of the intervention (Warren, 1984). The ability to evaluate these particular variables allows comparisons between and within subgroups of the experimental design. These comparisons (e.g. between the VI and the DS group) then allow conclusions to be drawn for samples with are not just homogeneous.

The third advantage was the ability to generalise conclusions more freely than if a restricted homogeneous sample was chosen (Warren, 1984). If a situation arose within the research design where these individualised variables display no effect on the dependent variables, it could be suggested that the intervention period itself had an effect on the dependent variable (fastening ability), as opposed to individual variation. The 'no effect' of the outlined variables will remain to be reported within the research as it is important to report the results as fully as possible (Warren, 1984). The consideration of the implications of this are also important.

#### **6.4 General Methodological Issues Relating to Previous Studies Regarding Visual Impairment**

Previous studies regarding children with VI appear to fall short when it comes to the methods employed to gather data (Warren, 1994). Some studies use assessments designed for the TD child, usually with little or no modification to the instruments. As a result of this the instruments that are used are not designed for scarce populations that are heterogeneous and display high variability. This could be considered problematic when undertaking a comparative research project such as the current thesis.

The current research aims to address this fundamental issue in the VI literature, using assessment tools that are suitable for children with VI, children with DS and TD children. Through doing this, we may have the ability to understand individual responses by taking into account between subjects variance, as well as understand recorded scores between populations such as those that are VI, DS or TD. The results of these measures however could perhaps only yield indicative results, as the adapted measures may not have validity within the VI population, for example.

One of the main issues when working with children with VI is ensuring that the instruments used have validity within the VI population. Any instrument chosen must be able to

appropriately record the chosen characteristic. As there are very few standardised measures for the VI population, the validity of chosen instruments may be questionable. This will be explored further in Chapter 8.

Further issues when designing a research intervention programme include 'ceiling effects'. Ceiling effects usually occur when a task is too easy for the participants to complete and so it is not possible to have effective differentiation of task performance for the samples. 'Floor effects' can also occur when the task is too difficult for participants to complete. Within the current study, ceiling effects naturally occur due to the nature of task demands. Successfully unfastening and fastening zips, buttons, poppers and laces leave no room for further progression – the task ends when the fastening or unfastening is complete. As a result of this, unfastening and fastening ability was recorded at weekly intervals to see how gross and fine motor skills developed within and between the 3 participant groups (VI, DS or TD). By examining the effects weekly, it might be possible to evaluate the average time it takes for both the clinical group and TD group of a particular chronological age (CA) to develop gross and fine motor skills suitable for successful fastening and unfastening.

The fastenings survey (Chapter 5) and the pilot study (later presented in Chapter 7), aided the development of the resources, suggesting that the fastening activities within the suite of intervention materials may be appropriate for use with TD children. Also as a result of the pilot study for the current research further refinements were made in order to accommodate children with VI.

In addition, all child participants experienced a screening procedure before taking part in the intervention programme. This screening procedure assessed each child's fastening ability for each item of fastening (zips, buttons, poppers and laces). If the child demonstrated a need for the intervention programme (characterised by the need for support in fastening and unfastening tasks), they were chosen as participants. If the child did not demonstrate a need (characterised by ceiling effects at the screening level), they were excluded from the research. Given the time-constraints of the project, the screening procedure was arguably effective in identifying each child's ability. However, performance in the screening activity may not be truly representative of an everyday situation, for example, a child may have demonstrated ceiling effects toward the researcher yet remained to be dressed by a parent/caregiver within the home context (e.g. buttoning a shirt may be demonstrated to the researcher but this ability may not necessarily be replicated at home).

The screening procedure also indirectly assessed hearing acuity. As a hearing assessment could not be formally made, the screening procedure required participants to respond to verbal

instruction. The researcher observed participant response to verbal instruction. If the response was suitable and functional, the participant was recruited for the main study.

The assessment of task performance was based on the individual's independent accomplishment. This was measured by physical motor skill ability or speech/vocalisations which demonstrated a knowledge of the stage if the stage could not be physically completed. This was measured for each stage of fastening for each item of fastening, and each size of fastening (where applicable). It is already acknowledged that ceiling effects were likely to occur due to the nature of the study, however it must also be acknowledged that 'floor effects' or poor performance could have occurred in relation to stages of fastening that required fine motor control. This, may have been dependent upon individual preference for gross or fine motor skill tasks, and so the preference was also recorded on the individual's observation schedule.

Further to this, as the observation schedule, and the suite of intervention materials recorded and used both auditory and kinaesthetic resources in order to teach the independent living skill of dressing, measuring independent components (i.e. auditory or kinaesthetic) is not possible due to the integration of the inter-modality within the research design. This means that within the scope of the study, it was not possible to separate the audible from the tactile. This may suggest that poor performance could be a result of poor comprehension of verbal instructions rather than a misunderstanding of the tactile task. This, however, could not be controlled for. Poor performance could have been due to an individual's problem in completing integrative tasks. As this effect could not be controlled for, it was considered essential to maintain participant recordings (in the form of observations and notes) which provided evidence for or against an individual's performance when compared with integrative tasks.

Taking the established methodological issues into account, the results will be analysed by using single subject experimental interventions within the broader frame of a multiple case study. This strategy has been chosen due to heterogeneity within each of the 3 recruited samples. Reporting the data in this manner allowed a more detailed explanation of the outcomes and effects (taking into account the varying backgrounds from each individual participant) (Van Herwegen, Dimitriou & Rundblad, 2013).

By treating each case as individual we are able to take into account individual cases even when the participants share the same diagnosis and also, participants act as their own controls. As aforementioned there is a great degree of variance in the DS population and the VI population even when the diagnosis is the same. This variability is also apparent in TD individuals, although the effects of variance are not as great as their VI peers. Even though TD individuals share the same characteristics of typical development, we cannot treat a group

as identical, but the heterogeneity is more amenable to statistical analysis on the samples. Furthermore, we cannot generalise the characteristics of the TD individuals because it is important to take into account the variability of each individual's background. By analysing the results in the same manner, implications for shared characteristics arguably may begin to be made.

A single-subject intervention design is also suitable for comparing individual scores for pre- and post-intervention. As the participant acts as their own control, the effectiveness of an intervention programme can be monitored by comparing the motor skill ability pre-intervention, to their motor skill ability post-intervention. The pre-intervention ability serves as the individual's baseline score, from which comparisons can be made with other assessments throughout the course of the intervention procedure (Warren, 1984). In this instance, score 'A' would reflect the participant's score at pre-intervention level and score 'B' would show the difference after the intervention has been employed.

This A-B design is not without flaws however, and so a repeat assessment of impact over the duration of the intervention period must be made.

The current research employs an A1-Bn-A2-A3-A4 design, where the participant is measured at baseline/pre-intervention level (A1) and then repeatedly over the course of the intervention period (Bn). The participant is then measured again immediately after the intervention period (A2), and then again after 1 month (A3) and 3 months (A4). This is illustrated in Figure 6.1.

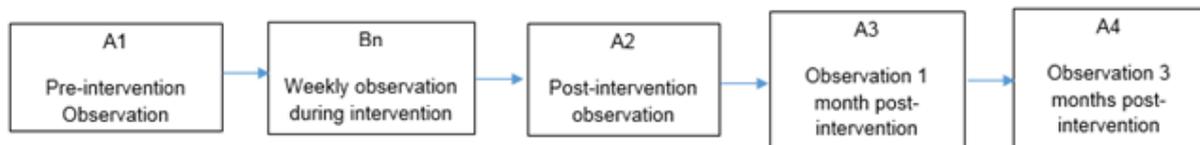


Figure 6.1. The repeated measures design of the current project.

The repeat of the assessment after 1 month and 3 months demonstrated the transiency or permanence of the intervention procedure. If, after 1 and/or 3 months the participant reverts to A1 it could be assumed that the intervention has no lasting impact upon the motor skill development of the children. If the immediate A2 score reverts to the A1 score, it could also be assumed that the intervention had no effect on the development of motor skill ability. If however, the A2 score shows an improvement from A1, it could be assumed that, at least on a transient level, there has been some effect of the intervention on the development of motor skill acquisition.

It is important to note that it may not be clear as to whether or not the intervention actually caused the effects, or if maturity, for example, played a role in skill acquisition. If, the score

improves between A2 and A3 and/or A4 after the removal of the intervention at A2, it can be assumed that the intervention programme had a longer lasting effect – however, again it may not be clear as to whether this effect was a direct result of the intervention or a process of maturation effects combined with the intervention programme.

This ‘extraneous variable’ effect on the A2, A3 or A4 score can be reduced with the replication of the study on other participants. This is the case for the current study. The participants were assessed based on their individual ability, however scores will be compared according to A2, A3 and A4 levels to examine the possibility of transient and permanent effects of the intervention on the development of children from the same group (VI, DS or TD). In order to have more confidence regarding the observation scores, replicability is highly desirable. However, it is understood that within the context of the current study, children within the same group may have high variability and this could affect the A2, A3 and A4 scores.

By using single subject experimental interventions within the context of a multiple case study we are able to cross reference between and within the sample groups (VI, DS and TD) and aim to highlight consistent patterns of behaviour that may aid our understanding of gross and fine motor skill development in relation to dressing.

When conducting a research project with a highly variable population, it is difficult to account for all of the variables that may have an effect on the sample. The current research project identifies and attempts to account for these issues in relation to research design, but also in relation to participant recruitment.

### **6.5 Methodological Issues in Participant Recruitment**

There are two main methodological issues to take into account regarding the recruitment of participants. The first issue concerned the matching of TD with atypical groups. In the previous chapters and in the current chapter it is acknowledged that there is a difficulty when conducting comparative research between typical and atypical populations. Initially it appeared inappropriate to compare children with VI and/or DS to TD children due to a distinct heterogeneity within the clinical samples. However, as already outlined there is also a great degree of variation within a TD sample (Van Herwegen, Dimitriou & Rundblad, 2013).

The second issue concerned the issue of testing children with developmental disorders. A consideration when working with children with VI is the timing onset of blindness. A child who has been blind from birth will have different environmental experiences. In addition a child will also have a different understanding of the affordances offered by particular environments compared to children who lost their sight shortly after birth or in early infancy. The child who initially had full or partial sight will have had experiences of visual stimuli. Therefore even if

the children share a common diagnosis, due to the timing of onset of blindness or VI, their early childhood experiences will differ greatly.

Other factors which may affect each of the three recruited groups include: prematurity, degree of residual vision, educational experiences and the home environment also play a role in the development of the individual. In the current research these background factors were accessed via parental questionnaires, medical records and retrospective recordings of developmental milestones (detailed in Chapter 8). These instruments added further meaning to the results gathered, potentially alerting the researcher to any external influences that may have had an effect on the intervention and subsequently, a child's development.

### **6.6 Summary**

This chapter explored the general methodology that was used in the current study. Participant and group characteristics were explored in relation to the recruited sample between and within the 3 recruited groups (VI, DS and TD). In addition, the potential issues that could have had an effect on the project (such as heterogeneity of variance, ceiling/floor effects, recruitment, matching and working with developmental disabilities) were identified and subsequently incorporated within the research design in order to minimise their potential effects.

The general methodology is used to inform the next three chapters: Pilot Study (Chapter 7), Methods (Chapter 8) and the Main Study (Chapter 9).

## 7. Pilot Study

Chapter 7 presents the pilot study for the current thesis. The pilot study was conducted with the existing resources which were based on the fastenings survey (Chapter 5) and previous research (Hayton, 2013; Hayton, 2012). The aim of the pilot study was to test the reliability and validity of the interactive puzzle game (IPG) and the observation materials in relation to the development of the independent living skill of dressing (ILSD). A re-test after the previous project (Hayton, 2012) was deemed necessary, as particular adaptations had been made in order to further account for children with VI. The adaptations included; the incorporation of different sized fastenings where available (e.g. buttons and poppers in sizes small, medium, and large); the inclusion of a shoelace condition.

The pilot study was also an opportunity to revise the verbal instructions that were provided to the participants, and refine the observation schedule that had previously been used (Hayton, 2012). The utilisation of this measure within the pilot study might indicate whether a refinement of the measure was necessary.

Within this chapter, six sections are presented. The first section details the participants that were recruited for the pilot study. Due to an unavailability of children with VI or children with DS, the recruited participants were TD. Although this was not ideal in relation to the main study, given the real-world nature of research, the recruitment for the pilot study was an availability sample.

The second section of this chapter details the piloting procedure. The nature of the pilot was to systematically split the fastenings tasks (zips, buttons, poppers and shoelaces) into smaller, more manageable, and arguably achievable stages. This includes how the IPG was utilised to support these stages and also to demonstrate the progression of the procedure from the abstract (e.g. fastening an IPG piece in front) into the actual (e.g. fastening an IPG piece on the stomach as this is more representative of a real-life fastening situation). This section also explores the observation schedule, participant scoring and previously observed behaviours which may impact the re-development of the resources.

The third section details the results of the pilot study. Two tables are presented, the first shows the raw scores of the participants' improvement. The second shows mean scores and standard deviations which represent participant improvement for each fastening condition (e.g. zips, buttons, poppers and laces).

The discussion of the pilot results are then presented in the fourth section. This is followed by the implications of the pilot results in section five. The implications emerged based on the

results of the pilot study and also the examined relevant literature in relation to the development of children with visual impairment (VI) and children with Down syndrome (DS). As these samples were not recruited for the pilot study, by examining literature relating to the development of these two groups, implications for re-development of the main study materials could begin to be made. The chapter concludes with a short summary of the pilot study and the implications for the main study.

## 7.1 Participants

Pilot data were gathered to test the outlined adaptations made to the IPG (Hayton, 2012). A small sample of TD children ( $N=4$ ; male; 4; age range 3;05-7;09 years;  $M=5;04$  years) were recruited for the pilot. The sample was an availability sample drawn from Cumbria, UK. The participant data for CA are shown in Table 7.1.

Table 7.1

*Means and Standard Deviations for Pilot Sample*

<u>Statistic</u>	<u>CA (months)</u>
Mean	65*
SD	22
Min	39
Max	93

*Note:* \* rounded up to whole months

## 7.2 Procedure

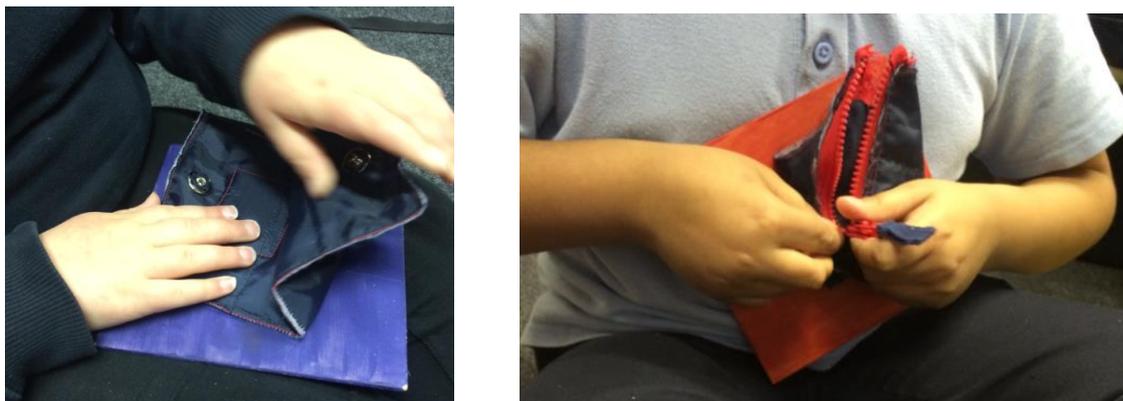
This section details the procedure for the pilot study. First the section introduces the interactive puzzle game (IPG). This was a novel resource designed specifically for developing ILSD. The section then explores the instructions that were provided to the participants, and how encouragement was used to ensure all participants attempted all fastenings (i.e. zips, buttons, poppers and laces). Next, the section explores how the IPG was used to develop ILSD from the abstract to the actual. Scoring and assessment is also explored within this section. Last, the section ends with detail from previous research which demonstrates how a physical inability to execute the task does not necessarily mean that a participant does not know what to do. This was considered important to acknowledge as it is suggestive that verbal and motor

skill abilities are distinct from each other, and so ought to be recorded as such on the observation schedule which accompanied the novel intervention resources.

The IPG was a 16 piece puzzle game which had zips, buttons, poppers and shoes with laces affixed to each piece. The IPG introduced the child participants to the different types of fastenings that they were considered to have the highest exposure to without confining the children within items of clothing (e.g. shirts and shoes). The IPG was designed to promote and develop fastening ability in an abstract form and then develop the skills which were to be applied in the actual. The IPG was played for 10 minutes daily over three days in each participant's home after the school day had ended.

The participants in the pilot group were instructed to choose the fastening type and the size of fastening that they preferred (this does not assume that the choice was made on the basis of type or size of fastening). When the participants had successfully fasten/unfastened the first fastening (with or without verbal or hand-over-hand assistance) they were instructed to attempt the second size (if appropriate). As aforementioned, only the button and popper conditions contained two sizes of fastening. The choice of fastening (either large to small, or small to large) may be an indicator of the linear development of motor skills. Once the participants had fastened/unfastened one type of fastening, they were encouraged to try the remaining types of fastenings. This meant that recordings could be taken for all types of fastening.

The IPG required the participants to initially manipulate the fastening whilst holding the puzzle piece in front of them (on a table or on the floor depending on the comfort of the participant). Once the participant successfully fastened/unfastened the piece in front of them, they were instructed to hold the piece on their stomach and fasten/unfasten while keeping the piece on their stomach. Participants could complete this lying down, sitting or standing, depending on their preference (preference relates to the position which was most comfortable for the participant). The use of the pieces either in front of participants or on the stomach is demonstrated in Figure 7.1.



*Figure 7.1.* Participants using the IPG materials in front of them/on their stomach (image authors own).

The progression between fastening/unfastening in front and on the stomach represented the abstract ability to fasten (in front) and moved toward the actual position for fastening (the stomach area). It is important to note that rotation of the puzzle piece was required when manipulating the piece on the stomach and so hand dominance or preference may affect successful fastening. This progression from the table to the stomach bridged the gap between the abstract intervention procedure and the practical application in a real-life situation. However the task was still bound within the context of a controlled environment.

Each participant was individually assessed using a previously piloted observation schedule (Hayton, 2012). The observation schedule recorded the participant's fastening ability at pre- and post-intervention level. Each type of fastening process had its own continuous sequence of stages which split the fastening task into steps. Each step was categorised 'gross' or 'fine' in relation to the kind of motor skill required for task completion, for example 'holding the base of the zip (fine)' is one stage of fastening a zip which required fine motor control.

Participants were also scored on the indications of their vocalisations (sounds/speech), their observed motor skill associated with fastening and the type/extent of any support given (speech or physical hand-over-hand). The vocalisations were noted, and whether or not the participant independently used appropriate speech for the task, for example if the participant could verbally identify a button or explain the next stage of fastening using words.

In the previous research (Hayton, 2013; Hayton, 2012) participants had a tendency to use to describe the stage of fastening when they could not physically complete the stage e.g. saying "now the tail goes in the slider" when they could not physically insert the tail into the slider, but had an understanding of what needed to be done. The 'fastening skill ability' recorded whether or not the participant could physically complete each fastening stage independently. The adult help given (speech/physical) was also scored. Assistance was only given if the participant

either asked for support or responded 'yes' (through vocalisation or movement of the head) when they were asked if they needed help.

Each participant's ability was recorded on the aforementioned observation schedule and the number of ticks representing 'yes' for independent motor skills were totalled.

### **7.3 Results of Pilot Study**

The participant data were explored in the context of a single-subject experimental design where the individuals act as their own control. This means that pre-test observations were used as the individual's baseline and then compared with post-test observations which demonstrate the effectiveness of the IPG. Table 7.2 shows the individual participant's scores pre- and post-intervention and the difference between scores.

Table 7.2

*Results of Pilot Data*

<u>Participant</u>	<u>CA</u> <u>(months)</u>	<u>Fastening</u> <u>Type</u>	<u>Score Pre-</u> <u>Test</u>	<u>Score Post-</u> <u>Test</u>	<u>Difference</u>
1	93	Zip	7*	7*	0
		Button	7*	7*	0
		Popper	6*	6*	0
		Lace	9*	9*	0
2	58	Zip	5	7*	2
		Button	7*	7*	0
		Popper	2	6*	4
		Lace	5	7*	2
3	68	Zip	4	7*	3
		Button	5	7*	2
		Popper	2	6*	4
		Lace	3	5	2
4	39	Zip	5	7*	2
		Button	3	7*	4
		Popper	2	6*	4
		Lace	5	9*	4

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*Note:* \* indicates independent fastening for all stages of fastening

From these results, three key findings can be identified. First, Participant 1 (Table 7.2) demonstrated ceiling effects at pre-intervention level. Although accepted for the pilot, as the focus was on the intervention materials, this was unacceptable for the main study as a direct result of the project aim (development of ILSD).

Second, with the exception of Participant 1, all other participants demonstrated a reduction in verbal instruction and physical hand-over-hand assistance over the three day testing period. This implies that fastening skill development was emerging in the group.

Third, participants demonstrated a level of variability in task performance. Participant 3, for example, would have required a longer intervention period in order to develop the ability to independently fasten shoelaces. This was because the 3 day intervention period was insufficient for the participant to master this skill.

As the sample was small, assessment of frequencies was used to allow changes in the overall means of the types of fastening to be apparent. There was an increase in all of the means for each types of fastening (zips, buttons, poppers and laces). Table 7.3 displays the means and standard deviations (SD) for pre- and post-test observations in relation to the independent motor skills demonstrated by the participants.

Table 7.3

*Means and Standard Deviations for Fastening ability*

	<u>Zip</u>	<u>Button</u>	<u>Popper</u>	<u>Shoelace</u>
Mean pre-test*	5.25	5.50	2.50	5.50
SD	1.258	1.915	1.000	2.517
Mean post-test*	7.00	7.00	6.00	7.50
SD	.000	.000	.000	1.915

*Note:* \* Means for independent motor skills only.

The pilot data shows that noticeable improvements were found in the zip, button and popper conditions, however, with a fixed alpha of .05, the results of a paired-samples t-test showed significance in the popper condition only:  $t(3) = -7.00$ ,  $p = .006$ . Although there was an improvement in the means of the remaining conditions, the results for the zip condition  $t(3) =$

-2.79,  $p = .07$ , the button condition  $t(3) = -1.57$ ,  $p = .22$  and the lace condition  $t(3) = -2.45$ ,  $p = .09$  were not noteworthy.

In summary, all participants (except participant 1) demonstrated some improvement over the 3 day intervention period. Verbal instruction and physical hand-over-hand assistance was reduced over the three day period, which demonstrated the gradual removal of adult support toward as the participant gained task mastery of the skills suitable for ILSD. The results of this small scale study are not generalizable to the TD population. However the pilot study informed the main research in relation to potential adaptations to the suite of intervention materials and observation schedule.

#### **7.4 Discussion of Pilot Results**

The results of the paired sample t-test were expected to show little difference because of the small sample size recruited and the brief three day intervention period. The implications of the results were arguably compromised by the small sample size and the possibility of ceiling effects of the fastening task.

By examining the means in Table 7.3, a suggested reason behind the non-significant result of the zip and button conditions may be that pre-intervention mean ability, being relatively high, combined with a ceiling effect (brought about by the nature of the task). The ceiling effect occurred upon successful fastening, thus fulfilling the aim of the research identified as independent fastening. This meant that although the participants could successfully fasten and unfasten zips and buttons at post-intervention level, the difference in means between pre- and post-intervention observations were too small for statistical significance.

Task difficulty could also have an effect on general fastening ability, due to the gross and fine motor skill demands for each type of fastening. A suggested reason for the smaller difference in means for the lace condition may be due to the difficulty of gross and fine manipulation required for successful fastening. The laces used in the pilot study are not sturdy, they are floppy. This difficulty in handling combined with the high fine motor skill demand, dexterity and co-ordination necessary for fastening shoelaces indicated that laces were harder to manipulate.

The zips, button and popper fastenings used in the IPG are rigid and sturdy, meaning that the solidity of the fastening could make the fastening easier to manipulate. This means that the difference in fastening ability may be due to the rigidity of the type of fastening as it is easier to control a solid object as opposed to a limp object. Furthermore, compared with zips, buttons and poppers, the fastenings survey showed that children have the least exposure to lace

fastenings (Chapter 5). This means that lack of exposure to lace fastenings may also have an impact on fastening ability.

The participants in the pilot study were given a choice as to which type and size of fastening they preferred. The chosen size (small or large) may be an indicator of a preference for gross or fine motor tasks which could possibly reflect the motor development of the individual. The difference in the size of the fastenings may have had an effect on the individual's ability to fasten and unfasten due to the difference in motor skill demands (gross or fine). Size preference therefore questions the role of linearity in motor skill development. If a child displays a preference for fine motor tasks or is more successful in fine motor tasks as opposed to gross motor tasks, this suggests that the refinement from the gross to fine is not as previously described in the literature.

Both younger participants (aged 3;05 and 5;01 years) chose the large fastenings first because they looked easier. The remaining (older) participants chose the smaller fastenings first because they found the larger fastenings. This verbalised choice (small or large) could also be due to the dexterity of the participants hands and fingers suggesting that the younger participants found the larger fastenings easier to manipulate. Also, the participant's choice could be influenced by previous experience of small or large fastenings, for example the older participants may have had more experience using smaller fastenings. The size of the fastenings may have an effect on the ability to fasten because of the fine motor control needed to manipulate smaller objects for successful fastening. The main study will record the reasons why children choose a particular size first, as this could support an understanding of motivation to the task and particular fastenings.

The main study subsequently recorded the size preference of each participant during the intervention as well as ask the participant why they chose the particular piece. This informed the research as to the decision making of each participant, and whether choice was made on the basis of the size of the fastening or other variables such as type of fastening or a prior experience of fastenings or motivation towards independence.

The oldest child in the pilot study (aged 7;09 years) was able to fasten and unfasten all of the items at pre-intervention level. This suggested that there may not be a need for TD children of this age and above to participate in the intervention. The observation of this phenomenon suggested a need for screening individuals based on fastening ability, before participation in the intervention programme (see section 8.6.2).

An atypical sample was not included in the pilot due to recruitment issues. It was not clear whether atypical children aged 7 years and over would benefit from the intervention in the

main study, however based on the results of Hayton (2012) it was assumed that there would be a need to participate in the intervention programme. This is due to the developmental delay that is associated with both VI and DS groups.

### 7.5 Implications of Pilot Results

Although an atypical sample was not recruited for the pilot study, the pilot data and the characteristics of the atypical sample (Chapter 3) highlighted a need for further adaptations for the IPG. The researched literature and the pilot study indicated a need for an ecologically valid intervention programme which addressed the following confounding variables: fastening colour; fabric used; tactile avoidance; partial sight; ceiling effects; preference for size of fastenings; and observational issues (Table 7.4).

Table 7.4

#### *Identification of confounding variables and resolutions from the Pilot Study*

<u>Confounding Variable</u>	<u>Resolution</u>
Fastening colour	Ensured all of the fastenings used are of the same colour. This reduced the colour variable for participants who were likely to make decisions based on colour preference
Fabric used	Ensured the fabric used for the zip, button and popper conditions are the same outdoor coat material and the same colour – avoiding fastening choice based on the material/colour of material used. This meant that the same outdoor coat material was used, and shoes will be the same type/colour for the lace condition
Tactile Avoidance	Used fabric/materials that the children were most familiar with thus reducing tactile avoidance, specifically in children with VI
Partial Sight	Used contrasting colours for the material and the fastening so that participants could distinguish between the fastening and the material
Ceiling effects	Developed a screening process to account for ceiling effects at pre-intervention level
Preference for size of fastenings	Recorded the size preference of the participants in relation to fastening size

Observational issues Used video recordings of the hands to accurately review individual participant's fastening. The video recordings were used with the refined observation schedule in order to assess for inter-rater validity.

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Further to the outlined confounding variables (Table 7.4) it was also acknowledged that the sample size for the main study had to be larger, and incorporate VI and DS groups. The adaptations made to the IPG in relation to fastening colour and material for example were made and then re-tested on a VI sample in order to test for reliability and validity.

The intervention period was also lengthened for the main study. Previous research established an intervention period of 5 weeks, however this was not considered long enough for task mastery in the VI condition (Hayton, 2012; Hayton, 2013). The main study increased the intervention period to 10 weeks in order to account for this. To overcome boredom/fatigue effects in the longer intervention period, the suite of intervention materials increased in complexity as the programme progressed. An example of this is teaching fastening/unfastening strategies for zips and buttons, followed by poppers and laces. This was chosen to take into account the apparent fastening trend for children in the study, as zips and buttons were considered easier to fasten compared to poppers and laces. In addition to this, the modified suite of intervention materials included more resources than the previous study (Hayton, 2012). The additions included: a standardised outdoor coat and the inclusion of a shoelace condition. Further details regarding additional materials are included in Chapter 8.

## **7.6 Conclusion/Chapter Summary**

In conclusion, there appears to be a distinct gap in the existing habilitation literature with regard to the development of dressing skills in children with VI. The development of the novel intervention materials in the pilot study may begin to account for this gap. The materials provided a systematic strategy for the development of gross and fine motor skills which were considered necessary for successful, independent dressing in children. The multi-sensory approach to learning informed the development of the suite of intervention materials which, arguably, better facilitates learning and motor skill development in children with VI and DS.

The pilot study explained here led to further developments in the intervention programme, particularly the IPG. In light of the TD pilot data and a better understanding of VI and DS drawn from the previous literature based chapters, the outlined adaptations to the puzzle were made. These are evidenced in Chapter 8.

## 8. Methods

It is acknowledged that there is a difficulty in conducting a comparative research project when comparing a VI sample to a TD sample. The previous chapters, (see Chapter 6), have addressed the issues that were perceived to be the most challenging for the current research design. As a result of the recognition of the potential flaws in the design of the current research, the methods employed to conduct the intervention programme were rigorous and highly detailed.

Chapter 8 is split into two sections. The first section (comprised of subsections 8.1-8.4) presents five background measures that were used in the current study. These were: a medical history questionnaire, a measure of socio-economic status, the Digit Span Test and semantic and phonemic verbal fluency tests. A summary is then provided in relation to the background measures presented.

The second section, (comprised of subsections 8.5-8.6), details the six materials that were used in the intervention procedure. These were: the starter game 'Simon Says', the interactive puzzle game, the interactive story, the standardised coat, the commercially available soft toy, and the accompanying observation schedules. Each resource is detailed in the relevant subsections. The section then details the seven procedural points used during the intervention period. The first two procedural points relate to the familiarisation period and the screening activity. The next four procedural points relate to (and include): the intervention schedule, pre-intervention communication, general procedural points, and the detailed intervention procedure. The final procedural point relates to the post-intervention follow up. The follow up was carried out in order to examine the impact of the intervention after one month and three months without intervention. The chapter then concludes with a short summary.

### 8.1 Section 1: Background Measures

As outlined in the general methodology, the incorporation of background measures was essential for controlling for the differences between the TD and the clinical group. It is important to record detailed participant histories in order to incorporate potential background variables for each participant. Through this similarities and differences in participant backgrounds (e.g. socio-economic status, nature of disability) were identified that may have had an effect on the data gathered. The background data enabled the researcher to understand the development of the child prior to the commencement of the intervention. Background data was considered crucial within the context of this research as it informed the research of the individual history of the participants, such as prematurity and birth weight for example, which may have had an impact on the effectiveness of the intervention. A limitation

of background data, however, was the reliance on retrospective accounts; that it is usually self-reported and relied on the level of detail provided by parents/caregivers.

By recording pre-existing variables such as CA and MA in addition to the onset, cause and nature of the impairment, the research is informed by the characteristics of an individual which cannot be 'controlled for'. These characteristics however, have to be recorded and acknowledged as they are likely to have an impact upon the individual's performance through the intervention period.

Furthermore, the recording of these characteristics may be crucial when analysing and interpreting the data. It is considered good practise to record background data and include such data in the final report. Omitting the background data may jeopardise the research, as some characteristics may play a crucial role in the data gathered. Collecting and using the individual background data is a form of accepting that the sample is heterogeneous. This means that it is known that a sample of children with VI or DS varies greatly. However, rather than forcing homogeneity by controlling for each independent variable, the variance is incorporated into the research design and data analysis. The integration of variance means that the potential sample size would be larger than the enforced homogeneous sample. This is a further benefit to using a heterogeneous sample.

Background data were collected from the parents/caregivers of the recruited participants, and also the educational setting where appropriate. Parental background data informs the research about socio-economic status, ethnicity and income for example, as well as the medical history of the child and the mother during and after pregnancy. The data provides a deeper understanding of the child participant and their environment which could also have an impact on their results. Background data from the schools involved is also important as it informs the research to interventions that may have taken place within the school context.

The lack of background data in the previous research (Hayton, 2012) meant that full participant profiles could not be established and subsequently the discussion of the results was limited. The current research aims to address this issue by gathering sufficient background data in order to yield more robust results.

## **8.2. Questionnaires**

The parental questionnaires informed the research of the history of each child participant; something that the child may not have had the ability to provide. Parents were asked to complete each questionnaire truthfully and as fully as possible in order to gather the most accurate representation of the child's situation. Each element of the questionnaires was considered purposeful for the current research.

Jessica Hayton

### 8.2.1 Medical Questionnaire

The medical questionnaire addressed the pregnancy, birth and early years of the child taking into account a variety of factors. These were factors that may have been relevant to the study. The questionnaire asked about aspects of the pregnancy as well as habits of the mother including maternal health, drinking and smoking. The questions also addressed complications (if any) surrounding the birth of the child. Prematurity was also an item on the questionnaire as there is existing research evidence supporting a link between prematurity, low birth weight, VI and cognitive functioning (Cioni, Fazzi, Coluccini, Boldrini & Duin, 1997; Powls, Botting, Cooke, Stephenson & Marlow, 1996).

The medical questionnaire also included the amount of hospital admissions of the child were recorded as they were considered relevant to the study. In addition, the onset, nature and cause of VI, ear, nose and throat problems, any interventions that the child has already engaged with, home life and any extra-curricular activities that the child is involved with were considered relevant.

Recording hospital admissions was considered notable for two reasons. First, the frequency of such may have revealed the likelihood of participant absence over the course of the intervention period. Second, the regularity of hospital admission may be indicative of the severity of clinical diagnosis. This means that if a participant was hospitalised regularly, this may have implications toward further adaptations to the intervention resources in order to appropriately support the participant.

Ear, nose and throat problems were considered noteworthy as any previous issues could have had an impact on the development of the auditory system and the development of language. This includes verbal fluency, production and comprehension of speech. The effects of previous ear, nose and throat problems would in turn, have potential impacts upon subsequent standardised measures as well as the comprehension of instructions during the intervention period in the current study.

Any previous interventions (carried out in the school/playgroup/home setting) and extra-curricular activities (e.g. horse riding, swimming) that the child had engaged could also impact on the child's skill ability. Even if the intervention/extra-curricular activity did not target dressing skills specifically, these activities could indirectly have had an effect on the development and refinement of gross and fine motor skills. As a result of participating in other activities, it is argued that there could be an effect on the individual's motor skill ability during the intervention

period. By recording an individual's participation in particular interventions and activities, it can inform the research as to any extra support the child may have had which could have increased and refined gross and fine motor skills.

How the child engages with their home environment is also important. The use of technology (e.g. smartphones and tablets), are considered indirect ways of developing and refining motor control and dexterity in the hands. The amount of time a child spends on these technological activities could also have an impact on their gross and fine motor skill development over the intervention period. The child's engagement in home life may also have an impact on orientation and mobility. Typically the home environment is a safe and accessible place for a child meaning that they would more frequently explore and navigate around this environment thus increasing orientation and mobility skills.

Developmental milestones were also recorded on the medical history questionnaire. The incorporation of this recording was based on the inaccessibility and unavailability of the 'Developmental Journal' within the typical context. The Developmental Journal marked developmental milestones which in turn informed the research of the child's developmental history - where a child has or is suspected of, developing a special educational need or disability.

Parents/caregivers were asked for retrospective milestone information prior to the intervention. The questions regarding developmental milestones were specific to dressing ability. As it was considered a lengthy (and arguably irrelevant) task for the parents to complete a full assessment, select items were chosen in order to gather the relevant information. The information regarding the developmental milestones was used in the current study in order to aid the understanding of individual developmental trajectories. The reported information regarding the chronological age (CA) of milestone development was compared with TD norms and used as an indicator of developmental delay.

By collecting these data outlined on the medical history questionnaire, it was possible to create a more complete participant profile in relation to the activities that they engage in, which could affect development. This data was incorporated into the analysis to examine whether or not a participant's history could have an impact on their performance over the 10 week intervention. An example of the medical history questionnaire can be found in Appendix 11.5.

### **8.2.2 Measure of Socio-Economic Status**

The socio-economic status (SES) questionnaire was used to establish socio-economic status. Items included annual household income, dependents, housing type (e.g. rented or bought),

ethnicity and marital status. The questions were used and adapted from the Census questionnaire (Office for National Statistics, 2011).

The questionnaire was designed to contextualise the environment of the child participant. The 'dependents' item within the questionnaire plays two important roles. First, it is an indicator of SES which is considered to have a potential impact on the prevalence of VI and also the development of motor skills based on environmental restrictions because it has an impact on the types of clothing available due to levels of familial income. Second it plays an important role with regard to dressing skills. However, one issue with using measures of SES is that they rely on personal report, and so the information provided may not actually be a true representation of a family's circumstance. This is because some families may have issues with disclosing such personal information.

One of the outlined research questions regarded the number of siblings, as it was thought that the presence and age of siblings might have had an impact on the child participant's ability to dress. This was discussed earlier in relation to the results of the fastenings survey (Chapter 5). For example, a child with a younger sibling might display more knowledge of baby clothes and popper fastenings, whereas a child with an older sibling may have more knowledge of fastening laces. An example of the Socio-Economic Status questionnaire can be found in Appendix 11.6.

### **8.3 Standardised Measures of General Cognitive Functioning**

In addition to the suite of intervention materials, the observation protocol and the collection of individual participant background data, standardised measures were also used. There are very few standardised measures that are suitable for use with a VI population, and the suitable measures are yet to be standardised for the norms of the VI population. This is an acknowledged limitation as it meant that although the chosen measures of cognitive functioning were suitable for use within the clinical group, the scores can only be compared to a TD norm.

Chapter 6 outlined the limitations of testing a VI sample with measures designed for TD individuals, however by incorporation into the research design, the use of such measures are justified. It is important to note that the justification does not condone the use of adapted or non-adapted measures for VI samples, however they were the only measures available that could assess general cognitive functioning of both clinical and TD groups.

The instruments selected for the current research address different areas of psychological and physical development. The instruments used were considered the most appropriate for use

with children with VI, as well as most suitable for answering the established research questions. Instruments for use with children with VI are scarce. Researchers tend to use measures for TD children then make minimal adaptations (Warren, 1984). The reason behind making minimal adaptations could result from an attempt to maintain the reliability and validity of the original measure, and keep the scores within the pre-established norm. Perhaps one reason behind the lack of tests for the VI population is a result of an inability to standardise results from this heterogeneous population. This being said, literature within the field suggests that the Wechsler Intelligence Scale for Children with adaptations is the most suitable for use with children with VI (Tillman, 1973; Begum, 2003) in relation to IQ.

The current thesis is not the first body of writing to call for suitable tests for measuring children with VI. Warren (1984) raised this issue 30 years previous to the current research. It is understood by the research community in this field that there is a need for such measures but, to date, there is not a measure specifically for use with children with VI. This meant that adaptations could be made to pre-existing assessments, but caution must be used when scoring and reporting results. This distinct gap in the research means that until a standardised assessment for the VI population is available, the only way to assess cognitive functioning is through adaptations to pre-existing instruments. Although this is not an ideal solution, currently it is the only option. This meant that the assessment tools chosen in the current research are considered to be the most adaptable and subsequently suitable for use with both clinical and TD groups.

### **8.3.1 Digit Span (from WISC-IV)**

As outlined in Chapter 3, working memory appears to play a role in the development of learning in children. In order to measure declarative memory and working memory, the digit span test was chosen. There are many available versions of the digit span test, however the version chosen for the current research was taken as a sub-test from the Wechsler Intelligence Scale for Children: Fourth Edition (WISC-IV, 2003). Although the test was first used in the United States of America (USA), the scores have been standardised for the population of the United Kingdom (UK). Small modifications were made to the USA version in order for the battery to apply to the UK population. The Anglicisation of some subsections of the test are applicable on both sides of the Atlantic (Wechsler, 2003). The digit span test was unaffected by the modifications.

The digit span test was considered the only standardised measure of intelligence suitable for use with a VI sample, as the remaining battery of tests required vision in order to complete. It is important to note that the standardisation of the WISC-IV was used on a TD sample and also on a sample with learning difficulties (Wechsler, 2003). Children who have physical,

learning or sensory impairments can still engage with the battery of tests but the administrator involved in the actual assessments may need to deviate from the standardised procedure in order to compensate for the impairment. The battery has not yet been tested on a VI population, and even though compensation can occur, the majority of the battery relies on visual stimulation. This meant that the scores of the digit span in the current research could not be transposed into a standardised score as there is not currently a normative distribution for the VI population.

Digit span was considered the most appropriate test for declarative and working memory. The digit span test determines an individual's declarative and working memory based on auditory stimulus and the child's ability to relay/recall the information back to the administrator (Wechsler, 2003). The digit span test used in the current project records digit span forwards (DSF) and digit span backwards (DSB). The DSF requires the participant to recall the information as presented by the researcher. This part of the test measures auditory short-term declarative memory (Wechsler, 2003), the ability to sequence information and also measures attention (Hale, Hoepfner & Fiorello, 2002) and concentration (Sattler, 2001). The ability to complete the DSF task is also dependent on rote learning (learning by repetition) and auditory processing (Groth-Marnat, 1997; Kaufman, 1994). The DSB, however, requires the participant to manipulate the auditory information, transform the information and then recall the sequence of numbers backwards (Wechsler, 2003). This means that DSB involves working memory, the ability to transfer and manipulate auditory information, and also visuo-spatial imaging (Reynolds, 1997; Kaufman, 1994). It is believed that the transition from the DSF task to the DSB task requires mental attentiveness and cognitive flexibility (Wechsler, 2003). Put simply, it is argued that the DSB task places more demand on the participant, and so the difference between the DSF and DSB scores reflect performance on a relatively simple (DSF) task, and a more complex cognitive task (DSB) in turn (Wechsler, 2003).

In one stage of the test a series of number lengths were read out to the participant at an even pace (1 second intervals). It was the participant's task to recall the numbers that they heard in the correct order. Number lengths began with two digits (for example; 2 - 9) and gradually increased by one digit to lengths containing 10 digits (i.e. 5-3-8-7-1-2-4-6-9). Both the DSF and DSB tests contained 8 items which contained 2 trials (16 trials in total). However the DSB trials also included a 'practice' trial whereby the participant had an opportunity to practice backward recall before the actual trial commenced. Each trial (from 2 digits to 10 digits) contained two number lengths. The participant must correctly recall at least 1 out of the 2 number lengths (assigned to the digit span length) in order to proceed to the next digit length. The procedure was repeated until the participant could not recall two lengths in a row. The

digit span was recorded in terms of the largest length of digits successfully recalled within the trials.

As the individual's performance on the DSF and DSB tasks may produce similar scores, two additional process scores were added to the digit span test in order to allow for further evaluation of an individual's differential performance. These additional scores are 'longest digit span forwards' (LDSF) and 'longest digit span backwards' (LDSB). The LDSF and LDSB scores are raw scores which record the largest number of digits recalled on the last successful trial where the participant scored 1 point (Wechsler, 2003). For example, a LDSF score of 6 would show that the longest successful number length recalled was 6 digits long.

As aforementioned, there is currently a lack of standardisation of digit span performance in children with VI and so within the context of the current research, the raw scores were used as an indicator of working memory capacity. This meant that higher digit span scores could be used to predict higher levels of independence in the fastening tasks. This is because participants with higher digit span scores display better declarative and working memory, and so this combined with the auditory instructions and kinaesthetic actions may predict the independent skill ability over the course of the 10 week intervention period. Furthermore, it would be expected that due to repetition of instructions and physical manipulation, there could be a lasting effect after a break of one and three months without intervention. This is because the repetition of meaningful instructions could be encoded into the long term memory store.

### **8.3.2 Verbal Fluency**

Verbal fluency tasks (Appendix 11.7) were also considered to be an appropriate measure of cognitive functioning for the current research. This was because vocabulary is an essential communicative tool, especially for a child with VI. However it was also acknowledged that due to the clinical characteristics of DS, an assessment of verbal fluency may not be effective. This is due to comprehension hearing problems associated with the condition.

All children use language to make sense and understand the world, as well as using it as a compulsory tool for accurately and appropriately conveying their personal thoughts and ideas (Begum, 2003). By having an understanding of each child's verbal capacity, the intervention instructions could be adjusted according to the comprehension level of the child. If the child did not understand the verbal instructions provided, the child cannot be expected to complete the task without physical assistance. Therefore, using the assessment of verbal fluency and language comprehension we can, to a degree, ensure that the child has an understanding of the task they will engage in. It is essential that the instructions were pitched at the correct level for each child so as not to confuse or frustrate the participant.

The current research examined semantic verbal fluency and phonemic verbal fluency (Strauss, Sherman & Spreen, 2006). The semantic verbal fluency test (Strauss, Sherman & Spreen, 2006) required each participant to recall as many animals as they could as fast as possible. Scoring of semantic verbal fluency was based on the number of acceptable words for the category.

The phonemic verbal fluency test required the participant to orally produce as many words as possible in one minute beginning with a particular letter. In the current study, the letters chosen were “F”, “A” and “S” as there are arguably the most commonly used letters in the English language (Strauss, Sherman & Spreen, 2006). Scoring of the phonemic verbal fluency test relates to the amount of acceptable words for each letter.

In both semantic and phonemic tests, words were omitted from the score if they were proper names, wrong words, variations of the same word or a repetition (Strauss, Sherman & Spreen, 2006). One potential issue of using these measures is that children may not understand what is required from them in these tests, despite being provided with verbal instruction. For children with developmental disorder such as DS, comprehension of such instruction may be difficult due to issues previously outlined in Chapter 3.

#### **8.4 Summary**

Section 1 of this chapter has outlined the participants recruited for the current study and has also presented the measures for collecting background data. The measures chosen are based on existing standardised measures and have been adapted where appropriate. The standardised measures of general cognitive functioning were chosen as a direct result of their compatibility with the VI sample, however the limitation of using such measures in clinical populations have been stated.

As the measures did not rely upon visual functioning (but did rely on auditory functioning), they were considered to be the most appropriate for use across the clinical and TD groups. The following section outlines the apparatus used in the current study, ranging from the novel suite of intervention materials, a commercially available material and also the observation protocol.

### **8.5 Section 2: Novel Intervention Study**

#### **8.5.1 Apparatus**

Within the apparatus used in the current study, three of the materials are novel, specifically designed for the purpose of developing gross and fine motor skills in relation to dressing. The novel materials include: the interactive puzzle game (IPG), and interactive rhyming story (‘Just

Joey'), and a standardised outdoor coat which was adaptable to a child of any height and size. The following section details both the novel resources used within the suite of intervention materials, and also existing resources that have been adapted for incorporation within the intervention procedure.

## **8.5.2 Intervention Materials**

### **8.5.2.1 Starter game: 'Simon Says'**

In order to warm the children up at the start of a session, 'Simon Says' was played (full script in Appendix 11.8). The game was used to welcome the children into the session and was considered to be an ice breaker. 'Simon says' is an instructional game, where participants are required to follow the verbal instructions given by the caller ("Simon"), for example, "Simon says touch your nose". The body parts chosen for the Simon says warm up were based on the limbs that are used most frequently during the intervention procedure. Furthermore, the directional awareness is also demonstrated by the use of the left/right hand and up/down directions.

There are two implications of this task in relation to responding to verbal instruction. First, the ability to respond correctly demonstrated a functional level of hearing acuity and language comprehension. This suggested a suitability for participation in the intervention procedure. Second, the ability to correctly respond to instruction demonstrated body/directional awareness, orientation and mobility. All of which are pre-requisites for partaking in a dressing intervention (e.g. Chapter 2).

### **8.5.2.2 Interactive puzzle game**

The interactive puzzle game (IPG) was created after an extensive search of commercially available resources for the development of dressing skills proved unsuccessful (See Chapter 7). As a result of this, the IPG was designed and developed in order to address the lack of resources suitable for the development of such skills.

As outlined in Chapter 7, the IPG was specifically designed for the purpose of teaching the most common fastenings on an outdoor coat (zips, buttons and popper fastenings). The original design was used to support previous research which examined the effectiveness of a dressing intervention for children with VI and with TD children (Hayton, 2012).

The initial design of the IPG was mainly targeted for the VI population: the pieces were large, and the fastenings used were representative of the size used on children's outdoor coats, with the exception of large buttons. The size of the affixed fastenings on the IPG were a size

commensurate with a child's hand over the age ranges being investigated in order to make fastening and unfastening more accessible. The fastenings were attached to different types of coat material, also representative of the wide availability of children's clothing. However the type and texture of the materials were not consistent (i.e. some fastenings were attached to fleece, and the others attached to outdoor coat material). Furthermore, where possible, the colour of the fastenings used were in high contrast to the colour of the material (e.g. bright red buttons on lime green material). However, this high contrast was not always possible and so some fastenings were the same colour as the material (e.g. red zips on red fleece). Although the target group for the IPG were children with VI, the colours, size and versatility were also designed to interest TD children aged 4-6 years. Figure 8.1 shows the initial IPG design.



Figure 8.1. MSc initial IPG design.

The IPG pieces are cut as squares, this means that the pieces could be placed in different areas around the board, and so do not follow the traditional jigsaw puzzle pattern (where the pieces fit in a certain order). By making the pieces square it meant that further versatility was available when playing different games with the participants. In addition to this, the square design meant that if the children were eager to complete the puzzle, rather than do the task, they could be frustrated in this activity as other participants would have the puzzle pieces meaning that puzzle completion would be problematic. If this occurred, the children were informed that they could complete the puzzle after the session had finished. This was done by asking the child/ren to place the puzzle pieces on the board to mark the end of the session.

The IPG was further adapted after the completion of the previous research (Hayton, 2013) and the pilot study (Chapter 7). It was evident that adaptations to the puzzle were necessary in order to standardise the measure and also further accommodate the needs of the children with VI. This was because the participants still required some adult assistance at the end of the intervention period. Assistance was categorised into 'verbal assistance' and 'motor assistance'. Verbal assistance consisted of: (a) the child requiring verbal instructions to support their motor skill tasks, and (b) the child being verbally informed of the noun of the fastening (e.g. zip, button, popper). Motor skill assistance consisted of physical hand-over-hand guidance from the researcher (or supporting adult) in order to aid the child when physically fastening or unfastening the materials.

Assistance (either physical or verbal) was only provided if the child specifically asked for support, or if they were seen to be struggling. If the child asked for support, they would be asked if they required verbal or physical support e.g. "would you like me to help with my hands?" or "shall I tell you the next step?" The child would then inform the researcher as to how they would like support and this was provided accordingly. It is important to note that when providing physical assistance to children with VI, verbal instructions were also given in order to synchronise the tactile with the audible. Sighted, TD children were able to see how their hands were guided and so did not always require both types of support.

As the intended outcome of the study was for participants to complete motor skill independence for unfastening and fastening at the post-intervention level, adaptations were made to the IPG to support this aim. This was noted from the previous research where the children with VI required adult assistance at the end of the 5 week intervention period (Hayton, 2012), and also evidenced in the pilot study for the current research (Chapter 7).

There were 3 main adaptations to the initial IPG design:

1. The incorporation of a lace condition as some participants in the previous research (Hayton, 2012 page 69) expressed a verbal interest in fastening laces and the existing IPG did not accommodate a lace condition. The initial exclusion of laces was as a result of time constraints, as the participant's successful fastening of zips, buttons and poppers was not expected to occur so rapidly, over such a short period of time due to the relative complexity of lace tying. The incorporation of laces into the adapted puzzle was also informed by the results of a survey of which fastenings were used on children's clothing aged between premature-14 years (N=1569 items) (Chapter 5). The survey revealed that lace fastenings were present on shoes designed for children aged 2-14 years. The participants for the main study were to be

aged between 3 and 11 years old, meaning that they would likely have been exposed to lace fastenings, although not necessarily on their own shoes.

2. The inclusion of popper and button fastenings in three sizes. This adaptation was made in order to further refine the identification of fine motor skill, as manipulating smaller objects generally requires more fine motor control and dexterity. The three sizes were:

- large (button: 3.7cm, popper: 2.1cm),
- medium (button and popper: 1.5cm)
- small (button and popper: 1cm).

This adaptation was also made in light of the availability of fastenings of this size within children's clothing, as noted in the fastenings survey (Chapter 5). The availability of fastenings were examined in a systematic survey of children's clothing and this was represented in the adaptations to the IPG.

The survey found that medium and larger popper and button fastenings were present on cardigans and outdoor coats, and the use of smaller popper and button fastenings on baby-grows and shirts respectively. The medium sized buttons were used throughout the range of available clothing. Lace length appeared to vary in comparison to the size of the shoe, however for the purpose of standardisation of the lace condition in the IPG, different sized laces were not used. This was because longer laces are harder to manipulate and successfully fasten, arguably due to the limpness of the laces, and manipulation of an excess of material.

Longer laces are apparent on adult shoes, and the size of lace is relative to the size of the shoe – the larger the shoe, the longer the lace. Smaller laces were also not used on the IPG as the pieces are representative of the length of laces that the children would be exposed to in a real-life situation. Smaller laces are also more difficult to fasten, as there is a reduced length of material to manipulate, thus requiring a greater level of fine motor control, as shorter laces have to be manipulated closer to the tongue of the shoe and require more dexterity and precision when fastening. The size of zips on the IPG were not altered because of a commercial non-availability at the time of the pilot and testing period.

3. The addition of Velcro on the wooden puzzle pieces and the materials containing the fastenings. This was because the adapted IPG offers 4 fastening conditions and the intended use of the IPG is with a group of 4 participants (equating to 16 puzzle pieces). However the base for the IPG would have been too large to accommodate 16 pieces, and also

would have been out of scale for the participants' experience if it contained 16 spaces (Hayton, 2012). It is argued that the existing 12 space board was more accessible. In order to ensure that all participants can choose the same item (e.g. a zip) the pieces were made interchangeable (meaning that the fastenings can be removed and attached to the wooden square pieces). Extra IPG pieces were also made as a back-up for two reasons: the first being in case any piece was damaged beyond repair, and the second reason was if a group of children exceeded 4 participants. The interchangeable aspect meant that the pieces could no longer be glued to the puzzle boards. To overcome this, Velcro substituted the glue in order to increase the flexibility of the instrument.

Furthermore, the ability to remove the fastenings from the puzzle board meant that there was an increase in the handling opportunity of the fastenings (separated from the board) for participants. The inclusion of the Velcro as an adhesive does afford the opportunity for children with sight/residual vision to observe fastening/unfastening of Velcro. This means that although unintentional, the presence of the Velcro may be identified as a further, albeit indirect, source of training for fastening. The adaptations to the jigsaw piece are illustrated in three parts (Figures 8.2, 8.3 and 8.4).



*Figure 8.2.* The IPG used in the previous MSc study (Hayton, 2012).

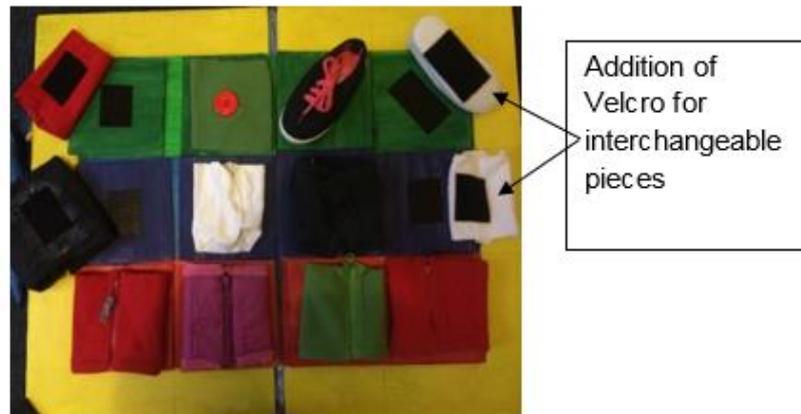
Figure 8.2 shows the initial design of the IPG that was used in the previous study (Hayton, 2012). The image identifies the three types of fastening that were previously used. These were zips, buttons and popper fastenings. Each fastening was sewn onto fleece or outdoor coat material, and were glued onto the wooden squares. The 12 fastenings were placed on a large, foldable backboard for ease of use within the intervention sessions. Figure 8.3 shows the first

form of adaptations that were made for use in the pilot study for the current thesis (Chapter 7).



Figure 8.3. Initial IPG adaptations (image authors own).

Figure 8.3 shows initial adaptations that were made to the IPG in preparation for the pilot study (Chapter 7). Figure 8.3 includes the incorporation of a lace condition. The laces have a fixed length and are commensurate to the size of children's feet. Figure 8.3 also displays the incorporation of large and small buttons and popper fastenings. The zip condition remains to be in one size, due to an unavailability of different sized zips at the time of design. The materials used differed slightly from Figure 8.2. The zips remained to be on outdoor coat material as did two of the popper fastenings. The other two popper fastenings were on a cotton material, this was because at the time of design, smaller popper fastenings were difficult to source. This meant that the use of the cotton material was the only way at the time to present smaller popper fastenings. Similarly, for the button condition, a cotton material was also used. This was because the material was elasticated and so may have supported children pulling the button through the button hole. A further adaptation to the design of the IPG presented in Figure 8.3 was the incorporation of Velcro on the back of the material, so that the pieces could be interchangeable. Figure 8.4 illustrates how Velcro was used.



*Figure 8.4.* Initial IPG adaptations displaying Velcro (image authors own).

The pieces displayed in Figures 8.3 and 8.4 were used in the pilot study (Chapter 7). Further adaptations to the IPG pieces had to be made in light of the findings outlined in Chapter 7 in order to standardise the material. The IPG pieces were subsequently standardised in relation to the colour and texture of the fastenings. Figure 8.3 shows the final version of the IPG which was used in the main study.



*Figure 8.5.* Final version of IPG (image authors own).

Figures 8.2- 8.5 show the development of the IPG from the initial design to the standardised measure that was used in the current study. The use of standardised material and colour reduced the variable of colour or material preference, therefore indicating the participant's choice of fastening was based on the fastening itself and not the material/colour.

The IPG is considered to be the most important resource within the suite of intervention materials, based on the practical aspect of fastening and unfastening, and also transferring the skills from the abstract to the actual. The IPG affords the opportunity to practise fastening and unfastening without being constricted in clothing or reducing movement. The skills of fastening and unfastening are gradually refined over the course of the intervention and then the learned skills are transferred on to actual items of clothing. Although the IPG is classed as the most important resource used in the intervention, there are other novel materials which further support skill development in relation to dressing.

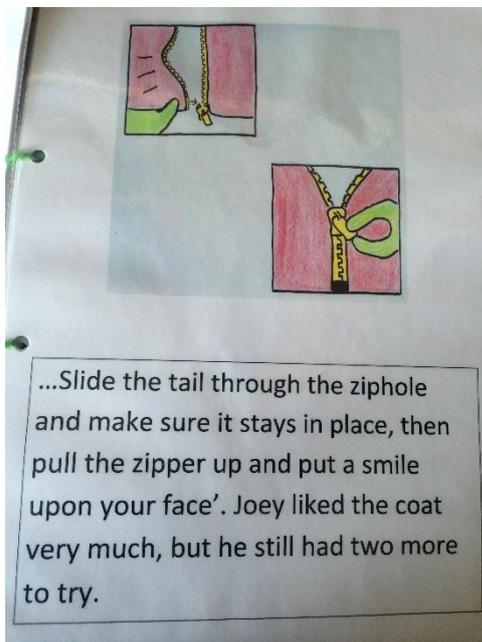
### **8.5.2.3 Interactive Story**

The novel interactive story ('Just Joey') was written by the researcher to accompany the IPG and the commercially available soft toy. The 'Just Joey' story was used in the previous research (Hayton, 2012) and also in the pilot study (Chapter 7). The previous work (Hayton, 2012) suggested that the story had some suitability in accompanying the IPG as it arguably supported participant engagement and accessibility. The story was originally created to provide verbal rhyming instructions to the participants to support their fastening abilities. The rhyming element of the intervention, may however be a confounding variable for the processing of the instructional information as it supports memory encoding. This cannot be controlled for within the context of this study, however it is acknowledged that the rhyming strategies used, may have an effect on motor skill development.

For the purpose of the research, the toy was named 'Joey'. The story follows Joey on a trip to the shops to buy himself a new coat. In the story Joey tries on many coats using different fastenings, and the story used rhymes to describe how the coat was put on and fastened for button, zip and popper conditions. The story was read to the children in order to familiarise them with the terminology and instructions for fastening, and the children were also able to manipulate the IPG fastenings along alongside the story.

The language chosen in the story is representative of the types of language used for fastening. The rhymes label the parts of the fastenings so that the children can learn specific parts of the fastenings, for example the tail of a zip. In order to support the learning and teaching of the words, the children manipulated the IPG whilst listening to the story thus combining tactile and auditory stimulation. Figure 8.6 shows an example of the rhyming strategies that are used in the story book.

(a) Rhyme for zips



(b) Rhyme for buttons

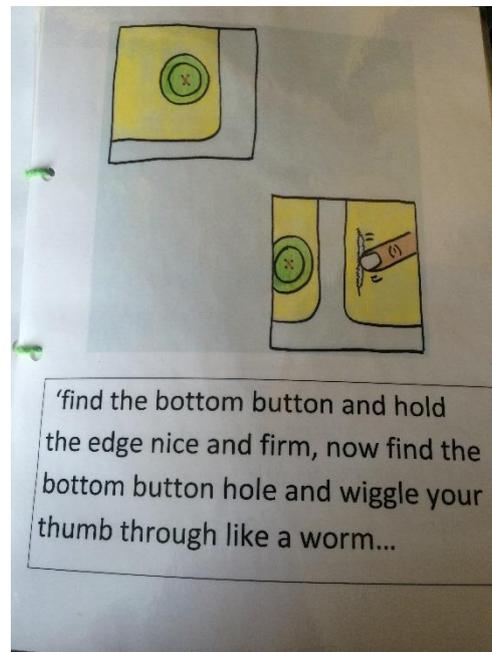


Figure 8.6. Examples of rhyming strategies used in 'Just Joey' (image authors own).

The rhyming strategies combined with the visual images were used in order to access all available sensory routes. Furthermore, the story was read to the children whilst handling IPG pieces, in an attempt to maximise the meaning of the story. The full 'Just Joey' story is presented in Appendix 11.9

#### **8.5.2.4 Standardised Coat**

In order to control for and support the transference of skill ability from the IPG to real-life situations, a standardised outdoor coat was created. The coat contained zips, button and popper fastenings which aided the participant's progression from the IPG resources to their own outdoor coat. The standardised coat was adapted from a small adult coat.

The sleeves were removed as they were considered too long for use with smaller children, and due to participant's having different body sizes, the inclusion of sleeves on a standardised measure was not possible. Figure 8.7 displays the front of the standardised coat.



*Figure 8.7.* The front of the standardised outdoor coat (image authors own).

Furthermore, three-quarters of the back of the coat was removed. This was done in order to make the front of the coat adjustable in order to accommodate the different sizes of each participant. Figure 8.8 illustrates the back of the standardised coat.



*Figure 8.8.* The back of the standardised outdoor coat (image authors own).

By pulling down the back panel, the base of the zip on the front of the coat was made accessible to smaller children.

The coat was worn around the neck like a scarf, and the researcher adjusted the size of the coat in accordance with the size of each participant. The adjustment was made so that the base of the zip was in proportion to the participant's hips. This meant that the zip rested at the same point that it would if the child was wearing their own coat. Once the standardised coat was adjusted, the participant was then asked to fasten and unfasten the zip, buttons and poppers accordingly.

The creation of the standardised outdoor coat aided the transference of fastening and unfastening zips, buttons and poppers. As the standardised coat contained all of the fastenings that the children were working with on the IPG (with the exception of laces), it was considered to be a more consistent measure for skill ability. This was because their own personal outdoor coats had different characteristics, for example, one participant's coat had only buttons and another participant's coat had a zip and buttons. The standardised coat was the final stage in the intervention before transferring the skill onto their own individual items of clothing.

#### **8.5.2.5. Commercially Available Resource: ‘Joey’**

A commercially available resource was also incorporated into the suite of intervention materials. The commercially available soft toy (“Learn to dress with Alex”, who for the purposes of this study is referred to as ‘Joey’) was used as a different method for teaching dressing strategies. The toy is a monkey who wears human clothes and shoes. The clothes are fully removable and the fastenings available on the toy cover the range of the current research, excluding Velcro.

There are two available sizes of the soft toy; a large version (standing approx. 1.23metres tall) and a small version (standing 58cm tall). The fastening sizes therefore are comparative to the size of the toy. The large toy uses oversized fastenings (arguably suitable for children who prefer gross motor tasks) and the small toy has smaller fastenings of which the buttons, zips and poppers are representative of the sizes of fastenings that the children are exposed to. However, as the shoes were smaller, this meant that the laces were shorter. Although two sizes of the toy were available for use, the current study used only the smaller version of the toy (Figure 8.9). This was because the children had exposure to the larger fastenings on the IPG game, and also due to an inability to transport all of the materials for the intervention period. Therefore the smaller ‘Joey’ was used, as the children had the opportunity to manipulate smaller fastenings in a different context, and also for the easy transporting of the resource. As ‘Joey’ was used at a later stage in the intervention procedure, it was also considered a more appropriate resource to use as the participants were refining their gross and fine motor control in relation to fastening sizes of zips, buttons and poppers that they were likely to be exposed to.



*Figure 8.9.* “Learn to dress with Alex” (Joey) – a commercially available soft toy (image authors own).

### **8.5.2.6 Observation schedule**

The observation schedule was required in order to formally assess individual performance on fastening and unfastening tasks from the pre-intervention stage, throughout the 10 week intervention period and post-intervention follow ups (1 month and 3 month post-intervention). The schedule recorded observable and individual stages of fastening for each individual type of clothing fastening – for example matching a button to the button hole. The observation schedule used in the previous study (Hayton, 2012), and the pilot study (Chapter 7) was considered to be too complicated for practitioner use and so was simplified and subjected to inter-rater validity for the purpose of the current study.

The observation schedule was issued to 65 adult participants to examine inter-rater validity. The participants were students within the UCL-Institute of Education, and completed the task as part of a seminar. They were fully informed as to the nature of the task, and briefed as to how to use the observation schedule. Participants were shown a total of 8 videos which was a simulation of the intervention procedure. Due to ethical regulations in terms of anonymity, videos from the actual intervention sessions were not shown. In order to compensate for this, a script from one session was used with a student also at UCL Institute of Education. The simulated intervention environment, was, therefore representative of genuine occurrences from the intervention procedure (albeit with an adult playing the role of the child). The videos used in the session were split into two categories: the first category showed the ceiling conditions for each of the 4 fastenings (zip, buttons, poppers and shoelaces). The second category of video showed each fastening condition where the participant needed hand-over-hand assistance to complete the task.

In the first video condition (all fastenings at ceiling effect) all participants' observations were the same as the researcher. This meant that a kappa score for inter-rater validity could not be obtained due to a 100% agreement rate. In the second video condition, kappa values could not be obtained for the button and lace score as there was a 100% agreement rate. For the zip condition, however, there was a 98% agreement rate, as one participant scored the observation schedule 1 point less than the researcher, and the remainder of the student sample. The results of the popper condition displayed a 95% agreement rate, this was based on 3 participants scoring the observation schedule on one point less than the researcher. Kappa values could not be obtained due to the researcher's observations remaining constant, and so the error rate could not be appropriately calculated.

Based on the previous observation schedule, key stages of fastening were identified in addition to the type of motor control (either gross or fine) that would be necessary for skill

development. The choice of fastenings reflected the most popular fastenings that are currently used on children's clothing (Chapter 5).

Table 8.1 shows the observable key stages for fastening zip, button, popper and shoelace conditions. Each stage is then labelled in Table 8.1 as 'gross' or 'fine'. This indicated the type of motor skill needed to accomplish each stage. The majority of the stages outlined in Table 8.1 demonstrate the use of fine motor control for fastening and unfastening across zips, buttons, poppers and shoe lace fastenings. Table 8.1 is continuum based, meaning that each observable stage follows on from the previous.

Table: 8.1

## Observable fastening stages for each item (zips, buttons, poppers and shoelaces)

Item	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6	Stage 7	Stage 8	Stage 9	Stage 10
Zip	Can identify zip (Gross)	Can unfasten zip (Gross)	Can identify top and bottom of zip (Gross)	Can pull the slider to the bottom (Fine)	Can pinch the tail correctly (Fine)	Can slide the tail into the bottom of the slider (Fine)	Can hold the tail in place (Gross)	Can pull the slider up to fasten (Fine)	X	X
Button	Can identify buttons (Gross)	Can unfasten buttons (Fine)	Can grasp button (Fine)	Can find corresponding hole (Fine)	Can match button to hole (Fine)	Can put button ½ through (Fine)	Can push button fully through (Fine)	X	X	X

Popper	Can identify poppers (Gross)	Can unfasten poppers (Fine)	Can find popper and its corresponding piece (Fine)	Can grasp both pieces (Fine)	Can match both pieces (Fine)	Can pop them together to fasten (Fine)	X	X	X
Laces	Can identify a lace (Gross)	Can unfasten laces (Fine)	Can fold lace over left lace (Fine)	Can push right lace under left lace (Fine)	Can pull laces tight to form a knot (Gross/Fine)	Can make 1 loop (bunny ear) with left lace (Fine)	Can make a second loop (bunny ear) with right lace (Fine)	Can push 1 loop underneath the other loop (Fine)	Can pull both loops apart to tighten the laces (Fine)

Note: Although Velcro was used on the IPG to allow the pieces to be moved, a schedule for Velcro was not established in the current project as a result of observed ceiling effect at pre-intervention level in the previous research (Hayton, 2012).

Using the information outlined in Table 8.1 as a basis, the development and refinement of a manageable observation schedule occurred. This was done by observing children successfully and unsuccessfully fastening and unfastening zips, buttons, poppers and shoelaces. As a result of these observations, the stages in Table 8.1 were then further refined into more nuanced sub-stages for fastening.

The outlined stages are continuum based, meaning that stage 4 can only be completed after stage 3, for example. Once the sub-stages for fastening were developed they were then numbered accordingly. The first stage for fastening each condition is the ability to identify (by pointing or picking up) any of the fastening conditions. Although identification is arguably not necessarily for motor skill development, the ability to correctly identify a fastening suggests the participant's awareness and understanding of the task that they are undertaking.

After identification, the schedule progressed to the unfastening of the conditions (zip, button, popper and shoelace). Unfastening was considered the next appropriate stage in the schedule. This was arguably due to the nature of the development of the human body (Chapter 3). It has been suggested that it is easier for a child to unfasten than to fasten e.g. in the case of zips, unfastening occurs when the tag on the slider is pinched between the index finger and the thumb, and then the slider is pulled down to release the tail. This is largely a gross motor movement (with the exception of pinching). However, when fastening, there were more criteria to meet (in the case of the observable stages) and greater fine motor control and dexterity required in order to be successful.

After the stages of unfastening are completed, the continuum based observation schedule continued to the fastening process. Each stage identified on the schedule was an observed behaviour. However it is acknowledged that there are 'transitional' stages that can occur between each stage which are not necessarily observable (in the sense of establishing a scale point) nor consistent, for example, the movement of the hands or the wrist to ensure an appropriate grip. As these transitional stages were not consistently observed, they were omitted from the schedule.

The main stages of fastening were then broken down into smaller, more manageable (yet observable) stages for the children to access. The breaking down of the main stages of fastening into achievable sub-stages supported task completion as children were praised, based on their attempt or achievement of each smaller stage. This was opposed to attempting or achievement of 'fastening a zip' as it was observed that children are more daunted by a larger task, but are more willing to engage in smaller ones which eventually lead to the same outcome i.e. a fastened zip.

Figure 8.10 displays an example of the finalised observation schedule used for the popper condition. The complete observation schedule (including zips, buttons, poppers and shoelaces) can be found in Appendix 11.10.

<p style="text-align: center;">1</p> 	<p style="text-align: center;">2</p> 	<p style="text-align: center;">3</p> 	<p style="text-align: center;">4</p> 	<p style="text-align: center;">5</p> 
<p>Can find popper on IPG/material and can say 'popper'</p> <p>VI* VE*</p>	<p>Holds popper parts in a fist</p> <p>VI* VE*</p>	<p>Can pinch the popper parts using appropriate strength*</p> <p>VI* VE*</p>	<p>Can pull pieces apart to unfasten</p> <p>VI* VE*</p>	<p>Sweeps hand across the material to scan for pieces</p> <p>VI* VE*</p>
<p style="text-align: center;">6</p> 	<p style="text-align: center;">7</p> 	<p style="text-align: center;">8</p> 	<p style="text-align: center;">9</p> 	<p style="text-align: center;">10</p> 
<p>Sweeps hand across the material and finds one piece</p> <p>VI* VE*</p>	<p>Holds found piece in one hand and uses the other hand to scan for the other</p> <p>VI* VE*</p>	<p>Finds corresponding piece with other hand</p> <p>VI* VE*</p>	<p>Holds both unfastened pieces in a fist</p> <p>VI* VE*</p>	<p>Pinches both unfastened pieces with appropriate strength*</p> <p>VI* VE*</p>
<p style="text-align: center;">11</p> 	<p style="text-align: center;">12</p> 	<p style="text-align: center;">13</p> 	<p style="text-align: center;">14</p> 	
<p>Uses palm of hand to rest one piece on top of the other horizontally</p> <p>VI* VE*</p>	<p>Uses palms of the hand to match pieces vertically</p> <p>VI* VE*</p>	<p>Uses pincer grasp to match pieces vertically placing popper in the hole</p> <p>VI* VE*</p>	<p>Uses appropriate strength to push the pieces together to fasten</p> <p>VI* VE*</p>	

Figure 8.10. Excerpt from popper observation schedule (VI\* = verbal instruction; VE\* = verbal encouragement – for the observer to circle as appropriate).

Figure 8.10 shows the progression from identification of the popper piece, then the observable stages of unfastening and finally the observable stages of fastening. The observation schedules in Appendix 11.10 illustrate the major stages of the fastening task in order to support the overall intervention procedure. The identified stages were supported with pictorial evidence in order to further support the observer. The pictorial support is used throughout the remaining observation schedules (zips, buttons and shoelaces). The pictures assist the observer by displaying the behaviours/actions that are required to fulfil the stages. This is important as some of the stages are quite nuanced and so it takes time to develop effective observation.

Each observable stage on the schedule has its numerical value, which can be transformed into a participant's score. The scoring of the observation schedule is based on independent ability. This means that a score of 4 on the schedule outlined in Figure 8.10 represents that the child can independently achieve all stages including stage 4. The remaining stages (5-14) represent the child's dependence on physical hand-over-hand support by an assisting adult.

It is argued that a child may independently achieve stages 1-4, then require hand-over-hand assistance for stages 5-10, then revert back to independent fastening for the remainder of the schedule. Although this is an observed behaviour and arguably logical due to that variation of task difficulty (i.e. it is easier to pull a zip up to complete fastening than inserting the tail into the slider), the schedule represents the individual's transition from dependence (the need for hand-over-hand assistance) to complete independence (the child physically completing the task independently). So for simplicity for scoring and in order to track individual progression in independence, the scores represented are based on the stage the child can independently physically achieve from stage 1.

Verbal support was also identified on the observation schedule. Verbal support was split into two types: instructions and encouragement. Verbal instructions were provided when the child asked for assistance but did not want hand-over-hand assistance, but were also used to support hand-over-hand assistance where necessary (for example the VI condition). The use of verbal instructions supported fastening and unfastening activities. Encouragement, however, did not facilitate fastening behaviour as it was not considered instructive. Verbal encouragement did not direct the children toward task completion, rather it served as motivation for the children to continue attempting the fastening activity. Encouragement was used to support and reassure the participants that they were doing well in the task. This could have an effect on fastening ability however, as it boosts confidence and increases motivation for task completion.

The observation schedule was subjected to inter-rater validity for reliability and validity. The piloting of the schedule was completed by using video recordings of the zip, button, popper and shoelace conditions. The schedule was explained to the observers (N = 62) who were all consenting students at the UCL Institute of Education. After the explanation, videos showing successful identification, unfastening and fastening were presented. The purpose of presenting the successful condition first was to demonstrate the continuum of the schedule. After the successful videos were observed, the observers then viewed videos in which the participant displayed difficulty and asked for either physical hand-over-hand assistance or verbal instruction. The observers were then asked to score the participant on the observation schedule. Across the sample of observers, the scoring was consistent (between 95% and 100%). This suggested that the instructions for use of the observation schedule are useful as a training material, and also that the observation schedule itself appropriately represents fastening and unfastening behaviour.

## **8.6 Procedure**

As indicated earlier in the chapter, this section details seven procedural points for the intervention. The first 2 subsections detail the familiarisation and the screening periods. Then the outline of the intervention procedure is provided, illustrating the structure and timing of each session. Next, the pre-intervention communication is detailed in relation to timetabling sessions and maintaining strong communication links with teachers/organisers. General procedural points are then detailed in relation to classroom layout. A detailed intervention procedure is then presented. This details the activities used in each session, and also demonstrates the transition from the abstract to the actual as ILSD developed. Finally, the post-intervention procedure is presented. This was done in order to examine the longer-term impact of the intervention 1 and 3 months post-intervention period.

Once participant and parent/caregiver consent was obtained the background measures were distributed accordingly. With regard to the medical questionnaire and the socio-economic questionnaire it was politely requested that the information was completed and submitted within two weeks. The deadline for the background questionnaires was provided so that the data could be inputted as soon as possible, in accordance with the research timetable.

Once the background measures and the developmental assessments were complete, the intervention procedure began. The support staff (TA/LSA) for each school was briefed on how the intervention worked and participated in sessions.

### **8.6.1 Familiarisation Period**

A familiarisation period with the child participants was requested. This was considered important due to the nature of the intervention, where the children would in effect be working with someone who they considered to be a stranger. The familiarisation period eased the children into working with the researcher, thus enabling the children to feel more relaxed and at ease with the situation. The digit span and verbal fluency measures were completed after familiarisation had occurred, in order to make the children feel more at ease with the researcher and the novel materials.

All recruited participants participated in a familiarisation period (mean time: 65 minutes). For TD children and children with VI the familiarisation period consisted of the researcher being introduced to the child participants by the Class Teacher. This was a brief interaction (mean time: 10 minutes) where the children were informed about the project. The familiarisation period with the DS sample, however, was done over 2 sessions (2 hours) within the context of the voluntary organisation. This was done at the request of the group organiser, in order to support the transition of children working with another researcher, as the children could become distressed with the presence of additional, unfamiliar adults.

### **8.6.2 Screening**

In order to ensure that all participants could benefit from the intervention procedure, a screening activity was used. The use of a screening procedure was identified as an outcome of the TD pilot study (Chapter 7) which included a participant who could successfully fasten all fastenings at pre-intervention level. The successful completion at pre-intervention level meant that an accurate report of the effects of the intervention during the pilot study was not possible.

The screening activity used the standardised coat to measure whether the individuals could fasten the fastenings in the context of wearing an outdoor coat. If the children were able to fasten the standardised coat they were omitted from the sample as they had reached a ceiling effect for the zip, button and popper conditions and did not demonstrate a need for a fastening intervention. If children struggled or needed assistance during the screening procedure (either verbal or physical hand-over-hand) they were included in the intervention sample. This was because they had demonstrated a need for a fastening intervention.

### **8.6.3 Intervention Schedule**

The intervention procedure was pre-intervention observations, intervention and post-intervention observations. During the pre-intervention observations, the children were

provided with the IPG puzzle pieces containing zip, button, popper and shoelace fastenings. They were asked whether they could name the fastening or demonstrate how the fastening worked (see Appendix 11.8 for intervention script as part of the training manual). This was to establish a baseline for each individual child. Once the scores for each child were recorded the intervention could begin.

It was important that support staff from the respective school/organisation were present during the intervention process. This was because the support staff were also learning how to conduct the intervention, so that they could apply the procedure to other students who did not participate in the research project. In addition to the development for the support staff, their inclusion in the procedure meant that the research could take place in the most naturalistic of environments for the children, as they were working with people that they were already familiar with.

The intervention was conducted twice a week for 10 weeks. Each intervention session lasted for 20 minutes in order to hold the attention of the participants. Although the timing of the intervention sessions appears short when taking into account the types of activities that the children were engaging with, it was preferred in order to keep the children engaged in the task. The sessions ran at a pace suitable for each individual child. This means that there is not a deadline for task completion, nor is there a set time for the intervention to be completed.

Progress over the 10 week intervention period was recorded individually, and the participants were aware that they were under no pressure to successfully fasten/unfasten all fastenings. In addition to this, within a real-life context, if a child had not successfully managed to put on a coat within a 20 minute time-frame, it is very possibly that either a teacher or parent/caregiver would support them through this task.

Within the context of this research, an understanding of time constraint is essential, but this did not dictate the course of the intervention. The sessions are pitched at a general and standardized level where specific resources were used in each session. Each participant had the opportunity to engage with all resources and were advised to attempt all tasks. If a child did not wish to engage in a particular task, they were asked what they would like to engage with, within the context of the availability of the resources of the particular session. If the child does not physically progress in terms of motor skills, this is demonstrated by their weekly observation schedule score. Table 8.2 illustrates the overall 10 week intervention procedure.

Table 8.2

*Outline of intervention schedule*

Week	Session 1	Session 2
1	1) Play 'Simon Says' 2) Read 'Just Joey' with IPG	1) IPG
2	1) 'Just Joey' with IPG	1) IPG
3	1) IPG	1) IPG
4	1) IPG	1) IPG
5	1) IPG	1) IPG 2) Joey
6	1) IPG	1) IPG 2) Standardised coat
7	1) IPG 2) Standardised coat	1) IPG 2) Standardised coat 3) Joey
8	1) Joey 2) IPG	1) IPG 2) Standardised coat 3) Joey
9	1) IPG 2) Joey 3) standardised coat	1) IPG 2) Standardised Coat 3)Joey
10	1) IPG 2) Joey 3) standardised coat	2) Transference session onto personal items

Using Table 8.2 as a basis, the following section details the intervention procedure on a weekly basis. The procedure outlines preparatory work which needs to be accounted for before the commencement of the intervention procedure.

#### **8.6.3.1 Pre-intervention communication**

Prior to the commencement of the intervention, meetings with the respective Class Teachers was made. This was to allow familiarisation to occur between the researcher and the teacher, as well as provide an introduction to the child participants and their individual needs.

The intervention procedure was explained to the class teacher/organiser. This was done via email communication and then solidified upon a face-to-face meeting. This meeting was also utilised to organise a consistent room for use, and synchronise calendars. In the case of the specialist school within this research project, the 'Dark Room' (a multi-sensory learning environment) was booked for all sessions for the duration of the intervention programme. This room did not have chairs for the children to sit, and so the teachers were asked whether or not the children would be able to sit on the floor. In this instance, the individual needs of the children did not require them to be seated in a chair. If this was the case, however, chairs and a table would be brought into the room for each session. In the case of the TD participants, two classrooms were used due to an unavailability of either class at certain times based on the existing school timetable. The DS group worked in the "Stay and Play" room as this was the only space available for the duration of the intervention procedure. This meant that a section of the room was dedicated to the intervention, however other children and adults were also present in this room.

Timetables were discussed between the class teachers/organiser and the researcher. Times and dates were agreed based on the best fit for the children and the teachers. In the VI group, the intervention ran on Wednesday between 13:30 and 14:15, and Friday 10:30 to 11:15. The times and days were consistent throughout the intervention procedure. The TD sessions ran before playtime (10:15am), and the DS sessions ran every Saturday between 9am and 12pm, based on the availability of the participants and dependent on the timings of their speech and language therapy sessions.

All child participants were introduced to the researcher prior to the intervention and were informed that they would be participating in 'Fastening Group with Jess'. This meant that the children knew where they were going, who they were going with and the activity that they were participating in. The general procedural points outlined below are consistent for all participating groups.

### 8.6.3.2 General procedural points

For all sessions the room was appropriately prepared, prior to the children entering the room. The resources were placed in the centre of the room with sufficient space for the children to sit around the resources comfortably. Materials that may already be inside the room were moved to one side in order to reduce distraction.

### 8.6.3.3 Detailed intervention procedure

Table 8.3 shows the detailed procedure that was used for the overall 10 week intervention period. It was based on the pre-intervention communication and the 10 week procedure (outlined in 8.6.3)

Table 8.3

#### Detailed intervention procedure

Week	Session	Procedure
1	1	<p>(a) Simon says warm-up activity. Following script in Appendix 10.8). Observational notes were taken if a participant struggled with body/directional awareness. Children said that they did not want to play this game again so the comment was taken on board</p> <p>(b) Read 'Just Joey', each child given 3 puzzle pieces (1 x zip, 1 x button, 1 x popper) so that the children could fasten along with the story, helping to establish a link between the language and the materials</p> <p>(c) End of the session, each child was asked what their favourite piece was and why</p>
	2	<p>(a) Children welcomed into room and reminded that they were doing 'Fastenings with Jess' and "today we will practice unfastening"</p> <p>(b) Each participant was asked what piece they would like to play with first and were given all of the options (e.g. large, medium or small button) – children with communication problems were asked if they wanted to try a 'big popper' first and they would either nod or shake their head until the piece they wanted was mentioned. Offering pieces was done in the manner of perceived increasing complexity e.g. poppers first, laces last.</p> <p>(c) Children asked to unfasten first. Help was given if the children asked or if they were perceived by the researcher to be struggling. They were offered physical assistance e.g. "would you like me to help you with my hands?" or verbal assistance "would you like me to help you with my words?" (The latter meaning instruction giving). The children were encouraged to manipulate different fastenings, and assistance was provided as necessary.</p>

- (d) End of the session, each child was asked what their favourite piece was and why
- 2      1      (a) Researcher introduces the session, participants were asked if they could remember what fastenings we use. If they could not, the researcher reminded them of the names of the fastening e.g. zip.
- (b) Read 'Just Joey', participants given relevant pieces and join in with the story
- (c) Assistance (physical/verbal) provided as and when needed
- (d) End of the session, the children were asked what their favourite piece was and why
- 2      2      (a) Researcher introduces the session, participants were asked if they could remember what fastenings we use. If they could not, the researcher reminded them of the names of the fastening e.g. zip.
- (b) In turn each child is asked what piece they would like to try first. All children were encouraged to try every piece in the session – assistance (physical/verbal) offered accordingly
- (c) End of the session, the children were asked what their favourite piece was and why
- 3      1      (a) Same procedure as week 2, session 2
- 2      2      (a) Same procedure as week 2, session 2, however laces were introduced in this session. Children were also encouraged to attempt the lace fastening condition
- 4      1      (a) Same procedure as week 3, session 2
- 2      2      (a) Same procedure as week 3, session 2
- 5      1      (a) Same procedure as week 3, session 2
- 2      2      (a) Same general procedure as Week 3, session 2 however 'Joey' (the educational soft toy) was introduced in this session as a special guest.
- 6      1      (a) Same procedure as week 3, session 2
- 2      2      (a) Children were introduced to the standardised coat and asked in turn if they would like to try and fasten it up. Each child took a turn (if they wanted to). The children who did not want to try followed the same procedure as week 3 session 2.
- 7      1      (a) Same procedure as week 6, session 2
- 2      2      (a) Joey (the soft toy) was used in this session, but session followed the same procedure as week 6, session 2
- 8      1      (a) Same procedure as week 5, session 2
- 2      2      (a) Same procedure as week 7, session 2
- 9      1      (a) Same procedure as week 7, session 2
- 2      2      (a) Same procedure as week 7, session 2
- 10     1      (a) Same procedure as week 7, session 2

- 2 (a) Transference session. The children were able to manipulate the pieces of the IPG as well as provided with the opportunity to attempt fastening/unfastening shoes and outdoor coats of different sizes. This is done to observe the ability of the children to generalise their learnt skills to items of clothing and materials that have not been standardised
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The detailed intervention procedure in Table 8.3 shows the gradual progression and exposure to unfastening/fastening. The weekly procedure follows the same principles: introduction to the session, the practising of unfastening/fastening skills, and ending the session by asking children what their favourite pieces were and why. The repetitive structure of the sessions was purposeful in order to maintain a structured learning environment which could optimise the development of unfastening/fastening skills.

#### **8.6.4 Post-Intervention**

After the 10 week intervention period a post-intervention observation was made for each individual child (in the TD and VI groups) for each type of fastening after a 1 month and 3 month period. The 1 month and 3 month follow-up was not possible for the DS group due to time restrictions. The follow up sessions enabled a comparison of pre-intervention observations to immediate post-intervention observations, and follow up intervention observations at set intervals after the 10 week intervention period had ended. By repeating post-intervention observations at the same intervals, the research assessed the longevity impact of skill development. The weekly observations provided more detail as to the child's development over the course of the intervention, but the follow up assessments allow an evaluation of fastening skills after the structured intervention has ceased. The routine follow up sessions examine each participant's skill ability and also take into account participant reports of practise since the structured in-school intervention had stopped. Follow up observations were not possible in the previous research due to time constraint, however, it had the potential to be included in the scope of the current research.

Once the structured intervention period was over, all participant data was collated in accordance to participant number, and organised into three groups: VI, DS and TD. The full participant profiles were then coded and inputted into SPSS 22 for analysis. The following chapter (Chapter 9) examines the participant data and the results of the intervention procedure.

## 8.7 Chapter Summary

This chapter detailed the methods that were used within the current study. The background measures detailed in section one of this chapter are essential when incorporating variance into a research design (Chapter 6). Also the collection of such background measures may also inform the project as to ways in which a participant may be incidentally refining their gross and fine motor skills (e.g. video games, or extra-curricular activities). The chosen standardised measures of cognitive functioning was directly due to the compatibility with the VI group. This is because there are very few standardised measures that are suitable for the VI population. The chosen measures did not require vision to complete and so were considered most appropriate for use with the VI group.

The second section of this chapter presented the apparatus and procedure of the novel intervention study. The materials were presented in detail according to design and purpose within the intervention schedule and protocol. The IPG was considered to be the most prominent resource in the intervention schedule as it is consistently used over the 10 week intervention period. As a result of this, the refinements and adaptations to this resource were also presented in order to demonstrate the suitability of this resource for the recruited participants. The interactive story, standardised coat and the commercially available resources were then detailed according to use within the intervention study.

The observation schedule was detailed. The observation schedule was developed alongside the IPG in order to record the development of ILSD in participants. The observation schedule comprised of 4 scales (1 scale for each fastening) that were based on tsk analysis for successfully fastening/unfastening the IPG pieces. The observation schedule was tested for inter-rater validity, and there was an agreement rate of 95% or more for each fastening condition.

The second section of this chapter also demonstrated the procedure of the current study. The procedure began with initial contact and familiarisation periods (within and between each group) and ended either at the end of the 10 week intervention (in the case of the DS group) or after 3 months post-intervention (in the cases of the VI and TD groups). The next Chapter (9) reports the results of the main intervention study.

## 9. Results

Chapter 9 reports the results of the main intervention study (see Chapter 8). First, the chapter explores participant absence as this was apparent in the recruited clinical groups. Then, in a series of sections, the chapter reports the effects of the intervention across the 4 fastening conditions (zips, buttons, poppers and laces) within and between groups. Then, the chapter reports the main effects (illustrated with 4 figures) of the intervention across all fastening conditions. This is to illustrate the effect of the intervention on task performance across the clinical and TD groups at particular times over the intervention period. The potential longer-term impact of the intervention is then explored. This is based on the data gathered from 1 month and 3 month post-intervention observations. To illustrate the potential impact of confounding factors (such as diagnoses and behaviour), six case studies are presented. The case studies are organised in accordance with two themes that emerged from data collection. One main theme concerned clinical diagnosis, the second main theme concerned participant behaviour. At intervals during this chapter, summaries are provided to aid contextualisation.

### 9.1 Participant Absences

Participant absences were recorded during the intervention procedure. Absence was considered important to report, as an absent participant could not contribute data to the project. Participant absence was only apparent within the clinical groups. This was because most children in the clinical groups had a number of medical problems which resulted in a large number of absences. Table 9.1 shows the global percentage of absences of the clinical groups. Table 9.1 shows that there was a higher number of absences in the DS group compared to the VI group. Reasons for this are discussed in Chapter 10.

Table 9.1

*Percentage of absences for clinical groups over 10 week intervention period*

<u>Group</u>	<u>VI (n=9)</u>	<u>DS (n=9)</u>
	<u>%</u>	<u>%</u>
Total Number of Absences	14 (15.5)	19 (21.1)

Due to the high number of absences in the clinical groups demonstrated in Table 9.1, it was thus decided to carry out a partial analyses of the scores. The effect of this partial analysis

was to examine weekly performance where most participants were present and so could contribute the most data. Most participants were present during weeks 4, 7, 10 and pre-intervention (baseline). The differences between scores over these weeks were then transformed into a percentage against the ceiling score for independence. This means that the scores reported in this chapter are indicative of the percentage change (toward independence) between the identified weekly scores over the 10 week intervention period.

The conversion of the scores was done to directly demonstrate the difference between dependence (on adult support) and independence. This means that a score of 100% indicated maximum dependence, as the children required physical hand-over/under-hand assistance to support their fastening ability. A score of 0% indicated maximum independence. This was because participants had reached the ceiling effect brought about by the nature of the fastening task (e.g. independently unfastening/fastening a zip). A score of 0%\* was indicative of a participant reaching their own ceiling effect (as there was no change between their weekly scores). In depth analyses of the fastening conditions are presented in the following sections.

## **9.2 Zip Condition**

Examination of the intervention effects were done using ANOVA. The ANOVA revealed a noteworthy effect of the intervention on zip fastening ability; Wilks' Lambda = .117,  $F(3, 13) = 37.57$ ,  $p < .001$ . This meant that the intervention procedure appeared to support independent zip fastening abilities. In addition, there was a further interesting result between the zip improvement score and group, Wilks' Lambda = .116,  $F(6, 26) = 8.37$ ,  $p < .001$ . This meant that VI, DS and TD participants increased in independent zip fastening over the intervention period. Overall, the ANOVA revealed that the intervention appeared to aid the development of independent zip fastening ability both across 10 weeks of the intervention, between all examined groups. To further detail the effects of the intervention between groups paired samples t-tests were conducted to examine group performance.

### **9.2.1 Paired samples t-test: VI**

Table 9.2 shows VI participants' transition from dependence to independence. The decrease in percentage directly corresponds to an increase in independence. This means that 0% represents a participant completing the zip fastening task independently. This is because the participant/s did not need physical hand-over/under-hand (H-O/U-H) support from an adult. A score of 100% would be indicative of a participant requiring complete H-O/U-H support, and subsequently having maximum dependence.

Table 9.2

*Percentage change demonstrating the development of independent zip fastening ability in children with VI (%)*

Participant Number	CA (month)	Zip Pre-Wk10 (n=9) %	Zip Wk1-Wk10 (n=7) %	Zip Wk4-Wk10 (n=8) %	Zip Wk7-Wk10 (n=8) %
1	106	86	36	A	25
2	122	68	A	21	14
3	95	86	43	21	<b>0</b>
4	104	86	39	<b>0</b>	<b>0</b>
5	66	18	18	14	11
6	101	54	46	18	A
7	96	46	39	29	11
8	95	82	A	39	<b>0</b>
9	84	68	68	25	21
<i>Mean</i>		66	41	21	10

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

A = absent

Table 9.2 shows that the intervention supported independence skills in the zip condition. As expected however, there is a great deal of variance between individual scores. Participant 4 reached the ceiling score (maximum independence) for the zip condition by week 4, and participants 3 and 8 reached the ceiling score by week 7.

A paired samples t-test was used to examine the effect of the percentage change. Within the VI group, an interesting result was reported between baseline (pre) and week 1 scores;  $t(6)=3.31$ ,  $p = .016$ . This indicated that after 1 week of intervention, the participants had somewhat increased in independent skill ability. No notable difference was found between week 1 and week 4 scores. This may have resulted from a need for H-O/U-H support to insert the tail into the slider. The results of the t-test revealed an important change between week 4

and week 7 scores;  $t(4)=2.92$ ,  $p = .027$ . This result indicated that the intervention somewhat increased independent zip fastening ability between week 4 and week 7. This noteworthy result between week 4 and week 7 arguably represents the task mastery of this “tricky” aspect of zip fastening. This is because the percentage change represented an increase in independent zip fastening ability.

### 9.2.2 Paired samples t-test: DS

Table 9.3 shows the DS participants’ percentage changes over the 10 week intervention period. As before (Table 9.2), a decrease in percentage directly corresponds to an increase in independence.

Table 9.3.

*Percentage change demonstrating the development of independent zip fastening ability in children with DS (%)*

Participant Number	CA (month)	Zip Pre-Wk10 (n=9) %	Zip Wk1-Wk10 (n=7) %	Zip Wk4-Wk10 (n=8) %	Zip Wk7-Wk10 (n=6) %
19	108	57	50	36	36
20	66	61	61	43	14
21	82	61	46	4	4
22	82	54	43	14	0*
23	120	54	46	14	A
24	84	57	54	A	7
25	108	50	39	4	0*
26	64	50	A	11	A
27	93	54	A	0*	A
<i>Mean</i>		55	48	16	10

*Note:* 0\* equates to a participant reaching their own ceiling effect

A = absent

Table 9.3 presents data which suggests that children with DS did increase in independent zip fastening over the intervention period. The difference in baseline to Week 10 scores (range 50-61%;  $M=55\%$ ) suggest that DS required H-O/U-H assistance for approximately half of the zip fastening task. Table 8.3 shows an increase in independent zip fastening ability, but DS participants do not reach the natural ceiling effect brought about by the task. Rather, the scores show that participants (P) 27, 25 and 22 do reach their own ceiling effect (0%\*). This

is because their scores did not change between week 4 and week 10 (in the case of P27); and week 7 and week 10 (P25 and P26).

A paired samples t-test was used to examine the effects of the intervention. Within the DS group, a noteworthy result was found between pre and week 1 scores;  $t(6)=4.01$ ,  $p = .007$ . This meant that DS participants somewhat improved in independent zip fastening after 1 week of intervention. Further interesting results were found between week 1 and week 4 scores;  $t(4)=6.57$ ,  $p = .001$ . This suggested that the intervention appeared to support independent skill development over 4 weeks. There was no noteworthy difference between week 4 and week 7 scores. This may be a result of the DS sample appearing to reach their own ceiling effect.

### 9.2.3 Paired samples t-test: TD

Table 9.4 shows the TD participants' percentage changes over the 10 week intervention period. As before, a decrease in percentage directly corresponds to an increase in independence. Table 8.4 shows that TD participants reached ceiling effects for the zip condition by week 4 of the intervention procedure.

Table 9.4

*Percentage change demonstrating the development of independent zip fastening ability in TD children (%)*

Participant Number	CA (month)	Zip pre-Wk10 (n=9) %	Zip Wk1-Wk10 (n=9) %	Zip Wk4-Wk10 (n=9) %	Zip Wk7-Wk10 (n=9) %
10	80	46	25	0	0
11	80	43	25	0	0
12	77	57	46	0	0
13	86	46	25	0	0
14	93	46	25	0	0
15	83	75	43	0	0
16	84	43	29	0	0
17	82	46	25	0	0
18	96	89	79	32	0
<i>Mean</i>		55	36	4	0

*Note: 0 equates to a participant reaching ceiling effects for the fastening condition*

Table 9.4 shows that TD participants commenced the intervention at a similar fastening ability. The similarities between the participants appear throughout the intervention period. All TD participants had reached the natural ceiling effect prescribed by the fastening task by week 4. This shows that the intervention for zip fastening was beneficial for TD participants.

Within the TD group, revealed a change between pre and week 1 scores;  $t(8)=8.45$ ,  $p = <.001$  and week 1 and week 4 scores;  $t(8)=9.69$ ,  $p = <.001$ . As TD participants had reached the ceiling effect for the zip condition by week 4, there were no data to report for the comparison between week 4 and week 7.

#### **9.2.4 Summary of zip condition**

The results of the ANOVA and accompanying t-tests indicated an increase in independent zip fastening ability within each group (VI, DS and TD). This meant that the intervention may have been effective in developing ILSD, specifically after 1 week of intervention. This was demonstrated by the noteworthy t-test results for each group in the comparison between baseline and week one scores.

Tables 9.2, 9.3 and 9.4 illustrate a degree of variability in independent zip fastening ability within and between all three groups (VI, DS and TD). The quantitative data revealed that between the clinical groups, the minority of VI participants achieved the natural ceiling effect brought about by the nature of the zip fastening task. All participants with DS did not reach the ceiling effect for the task. Rather, participants with DS appeared to reach their own ceiling effects. This is evidenced by the lack of percentage change (represented by 0%\*). The quantitative findings of the zip condition suggested that the intervention may have been suitable for increasing independent zip fastening skills in VI, DS and TD groups.

#### **9.3 Button Condition**

To examine the effects of the intervention on button fastening ability a one way repeated measures ANOVA was used. There was an interesting effect of the intervention on button fastening ability, Wilks' Lambda = .016,  $F(3, 14) = 281.93$ ,  $p <.001$ . This finding suggested the potential suitability of the intervention in developing independent button fastening skills. There was a further noteworthy finding between the button improvement score and group, Wilks' Lambda = .020,  $F(6, 28) = 28.71$ ,  $p <.001$ . This finding suggested that the intervention was arguably beneficial in developing independent button fastening skills in VI, DS and TD groups.

### 9.3.1 Paired samples t-test: VI

Table 9.5 shows VI participants' transition from dependent to independent button fastening. As before, the decrease in percentage directly corresponds to an increase in independence. Table 9.5 shows that most VI participants had reached the natural ceiling effect for independent button fastening by week 4.

Table 9.5

*Percentage change demonstrating the development of independent button fastening ability in children with VI (%)*

Participant Number	CA (month)	Button Pre-Wk10 (n=9) %	Button Wk1-Wk10 (n=7) %	Button Wk4-Wk10 (n=8) %	Button Wk7-Wk10 (n=8) %
1	106	81	<b>0</b>	A	<b>0</b>
2	122	81	A	33	14
3	95	81	14	<b>0</b>	<b>0</b>
4	104	81	5	<b>0</b>	<b>0</b>
5	66	62	62	48	0*
6	101	95	76	<b>0</b>	A
7	96	95	52	<b>0</b>	<b>0</b>
8	95	86	A	<b>0</b>	<b>0</b>
9	84	90	52	<b>0</b>	<b>0</b>
<i>Mean</i>		84	37	10	2

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

0\* equates to a participant reaching their own ceiling effect

A = absent

Table 9.5 shows the increasing independence of the VI sample over the intervention period. The pre-intervention scores indicate a high level on dependence on physical H-O/U-H support. Individual variation is better demonstrated by week 1. This is evidenced by P1 reaching the natural ceiling effect for this condition by week 1. By week 4, the majority of VI participants had reached the natural ceiling effects brought about by the fastening task. The observation at week 7 demonstrated that 6 VI participants had reached the prescribed ceiling effects. P5, however appeared to have reached her own ceiling effect as there was no difference between her score at Week 7-Week 10 score.

The result of the paired samples t-test revealed a difference between the baseline and week 1 scores;  $t(6)=4.05$ ,  $p = .007$ . This indicated that after 1 week of intervention, independent button fastening ability increased. A further interesting difference was reported between week 1 and week 4 scores;  $t(5)=2.93$ ,  $p = .001$ . This indicated that the intervention continued to increase independent button fastening abilities. No notable difference was found between week 4 and week 7 scores. This was due to participants reaching either; (a) the natural ceiling effect of the fastening task, or (b) a personal ceiling effect for each participant.

### 9.3.2 Paired samples t-test: DS

Improvement in independent button fastening was calculated using percentages. Table 9.6 shows the DS participants' percentage changes over the 10 week intervention period.

Table 9.6

*Percentage change demonstrating the development of independent button fastening ability in children with DS (%)*

Participant number	CA (month)	Button Pre-Wk10 (n=9) %	Button Wk1-Wk10 (n=7) %	Button Wk4-Wk10 (n=8) %	Button Wk7-Wk10 (n=6) %
19	108	95	81	<b>0</b>	<b>0</b>
20	66	95	81	<b>0</b>	<b>0</b>
21	82	95	81	19	<b>0</b>
22	82	95	62	19	<b>0</b>
23	120	95	52	<b>0</b>	A
24	84	95	57	A	<b>0</b>
25	108	95	33	<b>0</b>	<b>0</b>
26	64	95	A	33	A
27	93	95	A	19	A
<i>Mean</i>		95	64	11	0

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

A = absent

Table 9.6 shows that within the DS group, the baseline percentages were the same. This suggested that all DS participants commenced the intervention at the same level. From Week 1, individual variation within the group became apparent, and this is revealed in week 4 and week 7 scores. During week 4, a total of 4 DS participants were observed to have independently unfasten/fasten buttons. All DS participants who were present during week 7

had also reached the natural ceiling effects brought about by the nature of the fastening task at this stage.

Within the DS group, a noteworthy result was reported between pre and week 1 ( $t(6)=4.49$ ,  $p = .004$ ) and week 1 and week 4 ( $t(5)=7.26$ ,  $p = .001$ ). There was not an apparent difference between week 4 and week 7 scores. This was anticipated due to participants reaching either: (a) the natural ceiling effect of the fastening task, or (b) a personal ceiling effect

### 9.3.3 Paired samples t-test: TD

Improvement in independent button fastening was calculated using percentages. Table 9.7 shows the TD participants' percentage changes over the 10 week intervention period.

Table 9.7

*Percentage change demonstrating the development of independent button fastening ability in TD children (%)*

Participant Number	CA (month)	Button pre-Wk10 (n=9) %	Button Wk1-Wk10 (n=9) %	Button Wk4-Wk10 (n=9) %	Button Wk7-Wk10 (n=9) %
10	80	0	0	0	0
11	80	0	0	0	0
12	77	0	0	0	0
13	86	0	0	0	0
14	93	0	0	0	0
15	83	0	0	0	0
16	84	0	0	0	0
17	82	0	0	0	0
18	96	33	19	0	0
<i>Mean</i>		4	2	0	0

*Note: 0 equates to a participant reaching ceiling effects for the fastening condition*

Table 9.7 shows that P18 was the only TD participant who was unable to independently fasten buttons at pre-intervention level. Task mastery, however, was achieved by week 4 and this is evidence by the natural ceiling effect for the fastening task (0%).

A paired samples comparison could not be achieved in this condition. This was a direct result of 8 participants reaching ceiling at the pre-intervention level.

### **9.3.4 Summary of button results**

The quantitative results yielded by the ANOVA and t-tests indicated that only VI and DS groups demonstrated an improvement in independent button fastening. This was evidenced by the results for the paired samples t-test ran for both VI and DS groups.

The majority of participants with VI were observed to have reached ceiling effects for buttons by week 4 of the intervention (Table 9.5). Four participants with DS had also reached ceiling effects for the button fastenings by week 4 of the intervention (Table 9.6).

All DS participants had reached the natural ceiling effect occurring from task completion by week 7. T-tests were not possible for the TD group. This was because the majority of TD participants were observed to be at the ceiling effect during the baseline observation (Table 9.7).

### **9.4 Popper condition**

To examine the effects of the intervention on popper fastening ability a one way repeated measures ANOVA was used. The ANOVA revealed an interesting effect of the intervention on popper fastening ability, Wilks' Lambda= .003,  $F(3, 14) = 1587.69$ ,  $p = <.001$ . This was indicative of the potential effectiveness of the intervention over the 10 week period. There was no noteworthy difference between popper fastening ability and group.

#### **9.4.1 Paired samples t-test: VI**

Improvement in independent popper fastening was calculated using percentages. Table 9.8 shows the VI participants' percentage changes over the 10 week intervention period. As before, a percentage decrease directly corresponded with an increase in independent popper fastening skills.

Table 9.8

*Percentage change demonstrating the development of independent popper fastening ability in children with VI (%)*

Participant Number	CA (month)	Poppers Pre-Wk10 (n=9) %	Poppers Wk1-Wk10 (n=7) %	Poppers Wk4-Wk10 (n=8) %	Poppers Wk7-Wk10 (n=8) %
1	106	100	93	A	7
2	122	100	A	43	<b>0</b>
3	95	100	93	<b>0</b>	<b>0</b>
4	104	100	93	<b>0</b>	<b>0</b>
5	66	100	86	71	29
6	101	100	93	71	A
7	96	100	92	54	31
8	95	100	A	29	<b>0</b>
9	84	100	93	<b>0</b>	<b>0</b>
<i>Mean</i>		100	92	34	8

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

100 equates to total dependence on adult physical adult support

A = absent

Table 9.8 indicated that children with VI were observed to be totally dependent on adult support at the baseline observation. By week 1, the participants with VI had begun to develop independence in this skill, however were still highly dependent on adult support. This was demonstrated by the mean score of 92%. By week 4, three VI participants (P3, P4 and P9) had reached the natural ceiling effect of independently unfastening/fastening poppers (represented by **0**). P2 and P8 were able to independently unfasten/fasten poppers by week 7.

Within the VI group, noteworthy results were reported for all three interactions examined by the paired samples t-test. The first was reported for baseline and week 1 scores where,  $t(6)=8.26$ ,  $p = <.001$ . This meant that independence had appeared to increase after the first week of the intervention procedure. The second noteworthy result was reported between week 1 and week 4, where  $t(5)=3.81$ ,  $p = .013$ . This meant that the intervention appeared to remain effective in developing independent popper fastening abilities during week 4. An interesting result was reported between week 4 and week 7 scores where  $t(6)=2.64$ ,  $p = .038$ . This result

indicated the apparent increase in independence over the intervention period. By week 7 of the intervention, 5 participants with VI had reached the natural ceiling effect brought about by the nature of the popper task (Table 9.8.). This began to demonstrate the utility of the intervention procedure for popper fastening ability.

#### 9.4.2 Paired samples t-test: DS

Improvement in independent popper fastening was calculated using percentages. Table 9.9 shows the DS participants' percentage changes over the 10 week intervention period. As before, a percentage decrease represented an increase in independent fastening ability.

Table 9.9

*Percentage change demonstrating the development of independent popper fastening ability in children with DS (%)*

Participant Number	CA (month)	Popper Pre-Wk10 (n=9) %	Popper Wk1-Wk10 (n=7) %	Popper Wk4-Wk10 (n=8) %	Popper Wk7-Wk10 (n=6) %
19	108	100	93	7	29
20	66	100	93	14	<b>0</b>
21	82	100	93	21	<b>0</b>
22	82	100	93	21	<b>0</b>
23	120	100	93	7	A
24	84	100	92	A	31
25	108	100	93	7	<b>0</b>
26	64	100	A	71	A
27	93	100	A	71	A
<i>Mean</i>		100	93	28	10

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

100 equates to total dependence on adult physical adult support

A = absent

Table 9.9 indicated that participants with DS had maximum dependence on adult support during the baseline observation. This is demonstrated by the score of 100. During week 1 of the intervention, participants with DS demonstrated an increase in independence, yet still required a high level of adult support. This is demonstrated by the 7% change in group mean between baseline ( $M=100\%$ ) and week one ( $M=93\%$ ). There was a considerable increase in independent abilities between week 1 and week 4. This was characterised by the change in

group mean (week 1:  $M=93\%$ ; week 4:  $M=28\%$ ). Although week 4 showed a higher variability between independent popper fastening ability. Independence popper fastening continued to increase between week 4 and week 7. This is demonstrated by the change of 18% between mean scores. Further to this, 4 participants with DS had reached the ceiling effect for poppers by week 7 (as represented by **0**).

The paired samples t-test did not reveal any noteworthy result between baseline and week 1 scores. This is supported by the mean scores presented in Table 8.9. The t-test did reveal a difference between week 1 and week 4 where,  $t(5)=28.53$ ,  $p= <.001$ . This represented a quantitative increase in independence scores as the participants moved toward independence. The t-test did not reveal any difference between week 4 and week 7 scores in the DS group.

#### 9.4.3 Paired samples t-test: TD

Table 9.10 shows the TD participants' percentage changes over the 10 week intervention period. As before, percentage decrease represented an increase in independent fastening abilities.

Table 9.10

*Percentage change demonstrating the development of independent popper fastening ability in TD children (%)*

Participant Number	CA (month)	Popper Pre-Wk10 ( $n=9$ ) %	Popper Wk1-Wk10 ( $n=9$ ) %	Popper Wk4-Wk10 ( $n=9$ ) %	Popper Wk7-Wk10 ( $n=9$ ) %
10	80	100	93	<b>0</b>	<b>0</b>
11	80	100	93	<b>0</b>	<b>0</b>
12	77	100	93	<b>0</b>	<b>0</b>
13	86	100	93	<b>0</b>	<b>0</b>
14	93	100	93	<b>0</b>	<b>0</b>
15	83	100	93	<b>0</b>	<b>0</b>
16	84	100	93	<b>0</b>	<b>0</b>
17	82	100	93	<b>0</b>	<b>0</b>
18	96	100	93	<b>0</b>	<b>0</b>
<i>Mean</i>		100	93	0	0

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

100 equates to total dependence on adult physical adult support

The percentage changes in TD scores show that at the pre-intervention observation, TD participants required maximum adult support (as represented by the score of 100). Independence had increased after the first week of intervention but not substantially. This is demonstrated by the mean score of 93, which represented high dependence. By week 4, all TD participants had reached the natural ceiling effect of independently fastening poppers. This effect was consistent throughout the remainder of the intervention period.

As all TD participants were observed to have the same skill ability over the intervention period, a paired samples t-test could not be carried out due to a lack of standard deviation.

#### **9.4.4 Summary of popper results**

The quantitative results for the popper condition revealed a need for all participants to learn popper fastening skills. This was demonstrated by the maximum dependence scores within all three groups (VI, DS and TD) at the baseline observation. This was not appropriately represented in the findings of the ANOVA due to the lack of variance within each group. The noteworthy finding from the ANOVA indicated that the intervention appeared to be beneficial in developing independent popper fastening abilities.

Within all three groups (VI, DS and TD) the independent fastening ability rapidly developed between week 1 and week 4 observations. This was supported by the ceiling effect. At week 4, three participants with VI and all of the TD participants had reached ceiling effects. By week 7, the majority of VI participants had reached ceiling effects for the popper condition (Table 9.8), and 4 participants with DS had also reached this effect (Table 9.9).

#### **9.5 Lace Condition**

To examine the effects of the intervention on lace fastening ability a one way repeated measures ANOVA was used. The ANOVA reported two noteworthy effects. The first demonstrated an interesting effect of the intervention on lace fastening ability, Wilks' Lambda = .088,  $F(3, 14) = 48.10$ ,  $p < .001$ . This meant that the 10 week intervention period appeared to support the development of independent lace fastening. There was also an interesting finding between the lace improvement score and group, Wilks' Lambda = .124,  $F(6, 28) = 8.60$ ,  $p < .001$ . This meant that the intervention appeared to have had an impact on independent lace fastening ability between groups (VI, DS and TD).

### 9.5.1 Paired samples t-test: VI

Table 9.11 shows the VI participants' percentage changes over the 10 week intervention period. As before, a percentage decrease corresponded with an increase in independence.

Table 9.11

*Percentage change demonstrating the development of independent lace fastening ability in children with VI (%)*

Participant Number	CA (month)	Lace Pre-Wk10 (n=9) %	Lace Wk1-Wk10 (n=7) %	Lace Wk4-Wk10 (n=8) %	Lace Wk7-Wk10 (n=8) %
1	106	85	81	A	-4
2	122	67	A	41	7
3	95	89	85	22	<b>0</b>
4	104	89	81	<b>0</b>	<b>0</b>
5	66	15	15	4	4
6	101	26	19	11	A
7	96	30	22	11	7
8	95	89	A	78	11
9	84	56	52	-7	<b>0</b>
<i>Mean</i>		60	51	20	3

*Note:* **0** equates to a participant reaching ceiling effects for the fastening condition

- indicated a decrease in skill ability

A = absent

The results of the paired samples t-test in the VI condition demonstrated an interesting difference between pre and week 1 scores;  $t(6)=4.58$ ,  $p = .004$ . This meant that 1 week (30 minutes) of intervention appeared to improve independent lace fastening abilities. A noteworthy effect was also found and week 1 and week 4 scores;  $t(5)=2.93$ ,  $p = .033$ . This demonstrated that the intervention apparently continued to develop independent lace fastening ability over 4 weeks of intervention. There was not a reported difference between VI participants' scores at week 4 and week 7. Table 9.11 supports this, as there was an increase in dependence in week 4 (for P9) and in week 7 (for P1). This was demonstrated by the negative percentages which affected the t-test.

### 9.5.2 Paired samples t-test: DS

Improvement in independent lace fastening was calculated using percentages. Table 9.12 shows the DS participants' percentage changes over the 10 week intervention period. As before a decrease in percentage related to an increase in independent lace fastening ability.

Table 9.12

*Percentage change demonstrating the development of independent lace fastening ability in children with DS (%)*

Participant Number	CA (month)	Lace Pre-Wk10 (n=9) %	Lace Wk1-Wk10 (n=7) %	Lace Wk4-Wk10 (n=8) %	Lace Wk7-Wk10 (n=6) %
19	108	59	48	48	4
20	66	59	59	44	30
21	82	93	81	63	22
22	82	30	30	19	15
23	120	56	44	26	A
24	84	30	26	A	-7
25	108	85	74	59	22
26	64	30	A	15	A
27	93	56	A	26	A
<i>Mean</i>		55	52	38	14

*Note:* '-' indicated a decrease in skill ability

A = absent

The results of the paired samples t-test for lace tying in the DS group yielded interesting results for all three time intervals. The first interesting result was found between baseline and week 1,  $t(6)=3.37$ ,  $p = .015$ . This illustrated that the first week of intervention appeared to increase lace tying abilities. The second noteworthy result was reported between week 1 and week 4,  $t(5)=4.63$ ,  $p = .006$ . The result indicated how the intervention procedure continued to develop independent lace fastening ability. The third revealing result was reported between and week 4 and week 7,  $t(4)=3.50$ ,  $p = .025$ . This suggests that lace tying performance in the DS group improved across the whole intervention period. Table 9.12 also showed that the DS participants did not reach the natural ceiling effect brought about by the fastening tasks. The negative percentage score for participant 24 during week 7, shows an increase in dependence for the lace fastening task.

### 9.5.3 Paired samples t-test: TD

Table 9.13 shows the TD participants' percentage changes over the 10 week intervention period. As before, the decrease in percentage related to an increase in independent lace fastening abilities.

Table 9.13

*Percentage change demonstrating the development of independent lace fastening ability in TD children (%)*

Participant Number	CA (month)	Lace Pre-Wk10 (n=9) %	Lace Wk1-Wk10 (n=9) %	Lace Wk4-Wk10 (n=9) %	Lace Wk7-Wk10 (n=9) %
10	80	89	85	0	0
11	80	89	85	0	0
12	77	89	85	0	11
13	86	89	85	0	0
14	93	89	85	0	0
15	83	89	85	0	0
16	84	89	85	0	0
17	82	85	81	0	0
18	96	96	85	0	0
<i>Mean</i>		89	85	0	1

*Note:* 0 equates to a participant reaching ceiling effects for the fastening condition

The TD paired samples t-test yielded two noteworthy results. The first was found between baseline and week 1 where  $t(8)=6.14$ ,  $p = <.001$ . This indicated that the first week on intervention increased independent lace fastening abilities. The second noteworthy result was reported between week 1 and week 4 where  $t(8)=190.25$ ,  $p = <.001$ . This meant that the intervention continued to support TD children in developing independent lace fastening abilities. There was not a noteworthy difference between week 4 and week 7 scores as the majority of TD children (with the exception of participant 12 whose performance had fluctuated) had reached the natural ceiling effect brought about by the intervention procedure. The results show that the TD mastered lace fastening by week 4 of the intervention procedure.

#### **9.5.4 Summary of lace results**

The results of the lace condition support the use for the intervention to increase independent fastening ability in all three groups (VI, DS and TD). All groups appeared to benefit from the intervention procedure and this is supported by the results of the ANOVA and the paired samples t-tests.

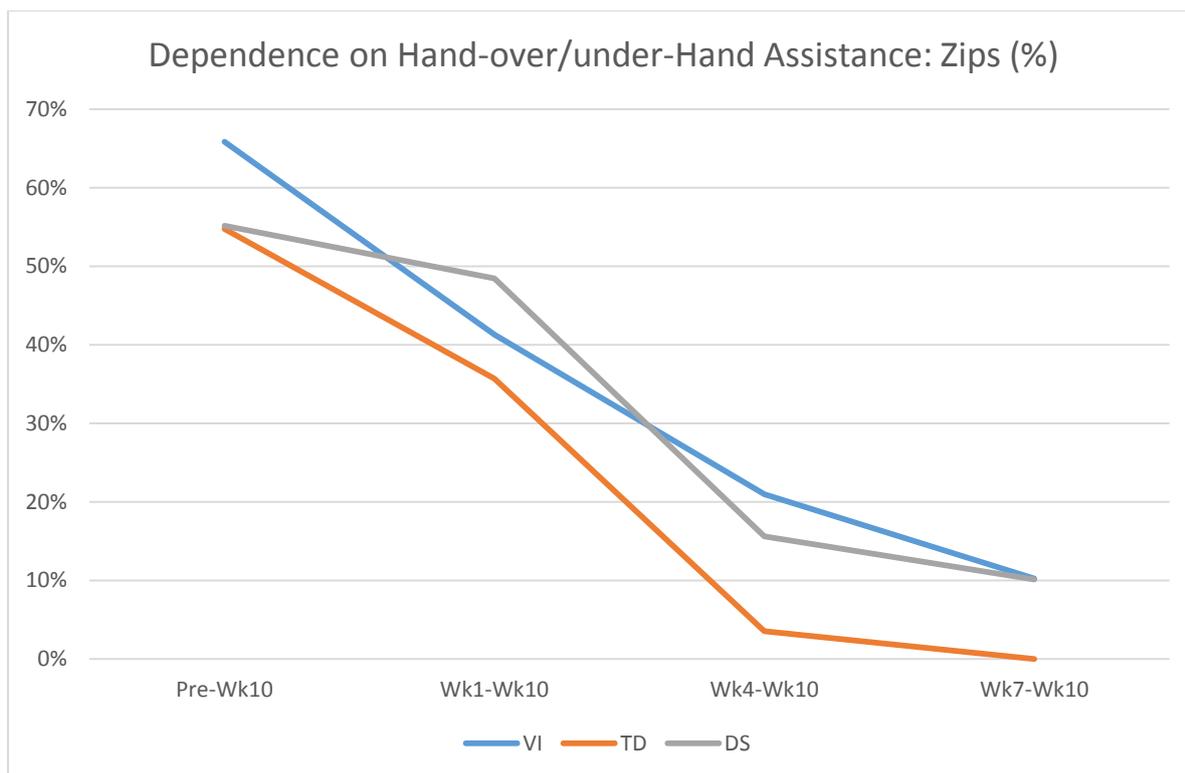
TD participants demonstrated more rapid acquisition of independent lace fastening ability. This was characterised by all TD participants being observed as completely independent in their lace fastening ability by week 4.

Although DS participants did improve over the intervention period, the ceiling effect brought about by the nature of the task was not reached. VI participants demonstrated considerable improvement over the intervention period (Table 9.11). Three participants with VI displayed ceiling effects in the lace condition during week 7. By examining the mean scores of the VI and DS (Table 9.11 and Table 9.12 respectively) groups in relation to task performance it appeared that the VI sample responded better to the lace fastening intervention.

#### **9.6 Overview of the Main Effects of the Intervention**

The main effects of the intervention are presented in this section. Over a series of four line graphs (for each fastening condition), the mean reduction in dependence scores are presented.

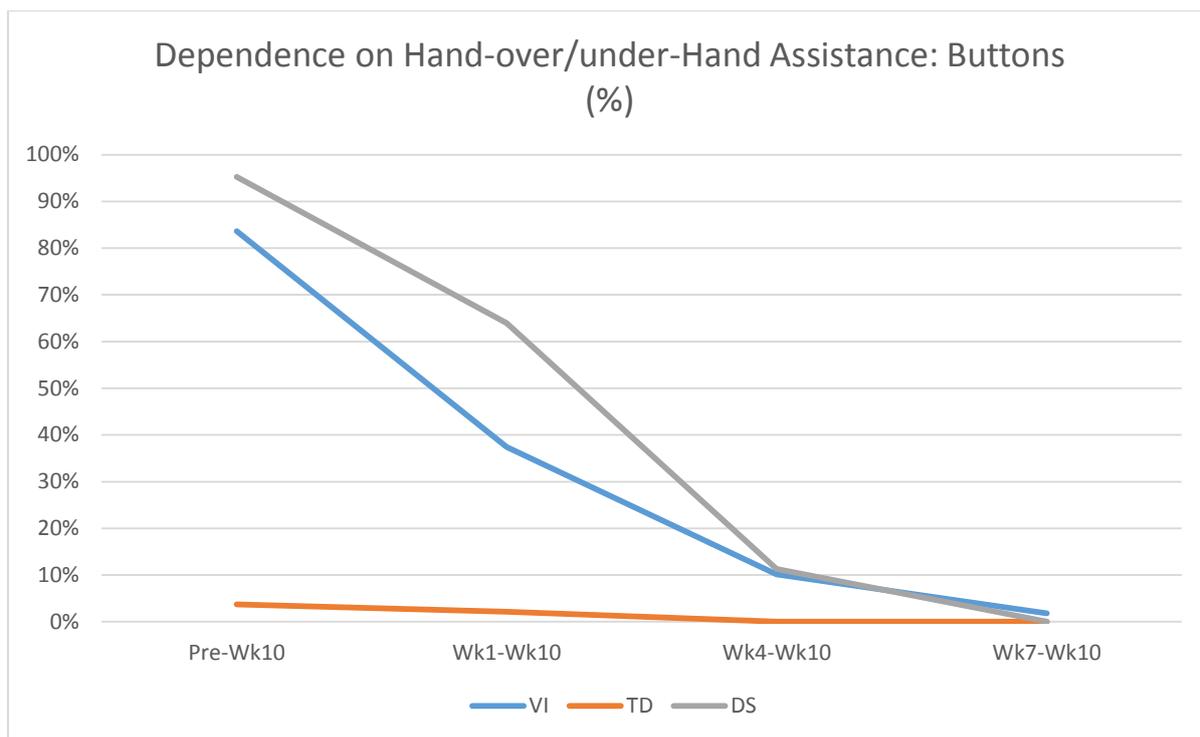
Figure 9.1 shows the mean percentage scores for zip fastening for each group over the intervention period. It is important to note that a decrease in percentage score is representative of an increase in independence.



*Figure 9.1.* The mean reduction in zip dependence scores over the 10 week intervention period for each fastening condition.

Figure 9.1 shows that over the 10 week intervention period, all 3 groups decreased in dependence. This decrease in dependence is directly related to an increase in independent fastening ability. The TD and DS groups commenced the intervention at a similar percentage level. The VI group displayed the greatest need for assistance at the start of the intervention procedure. As the intervention progressed, the difference between the TD group and the VI and DS groups became clear. TD participants had reached ceiling effects by week 7. DS and VI groups displayed an increase in independent zip fastening ability, yet the mean group scores did not represent ceiling effects.

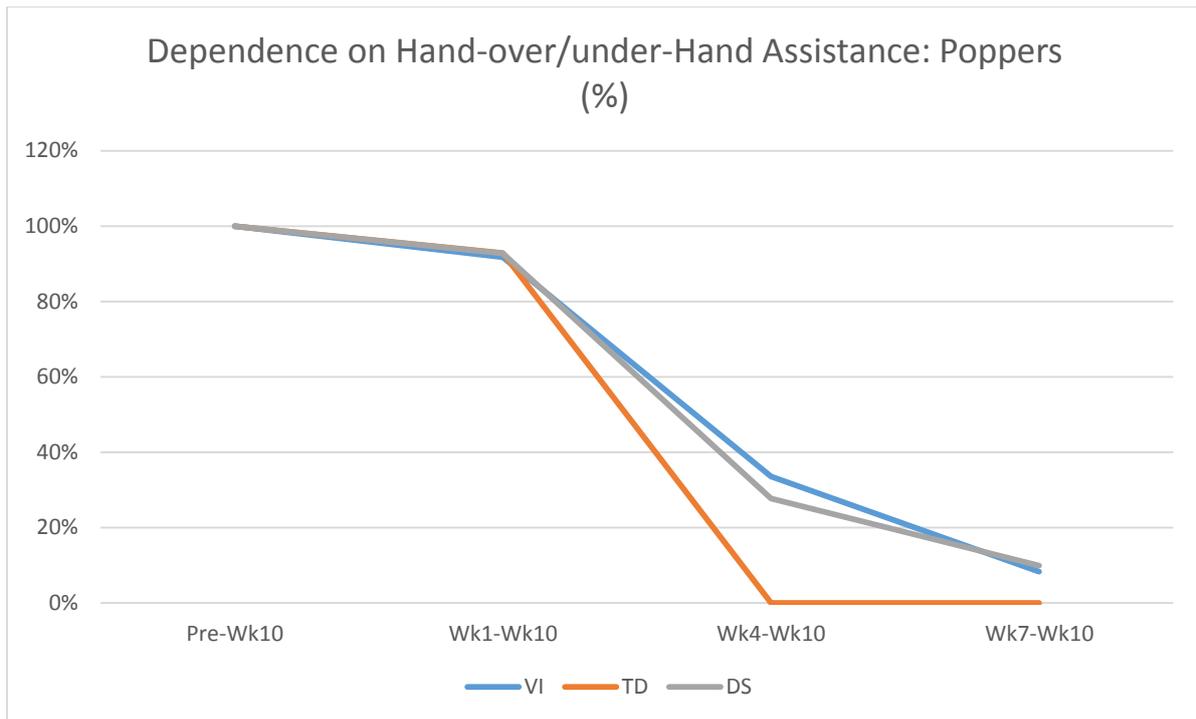
Figure 9.2 displays the mean group performance in the button fastening condition for all three groups.



*Figure 9.2.* The mean reduction in button dependence scores over the 10 week intervention period for each fastening condition.

Figure 9.2 shows that the TD group were close to independent button fastening at the pre-intervention level. By week 4, the TD group had reached ceiling effects for this condition. The DS and VI groups began the intervention with a high dependence level. At week 4 of the intervention, VI and DS participants appeared to follow a similar trajectory in relation to independent button fastening. By week 7 of the intervention procedure, both the VI and DS groups had increased greatly in independent button fastening ability.

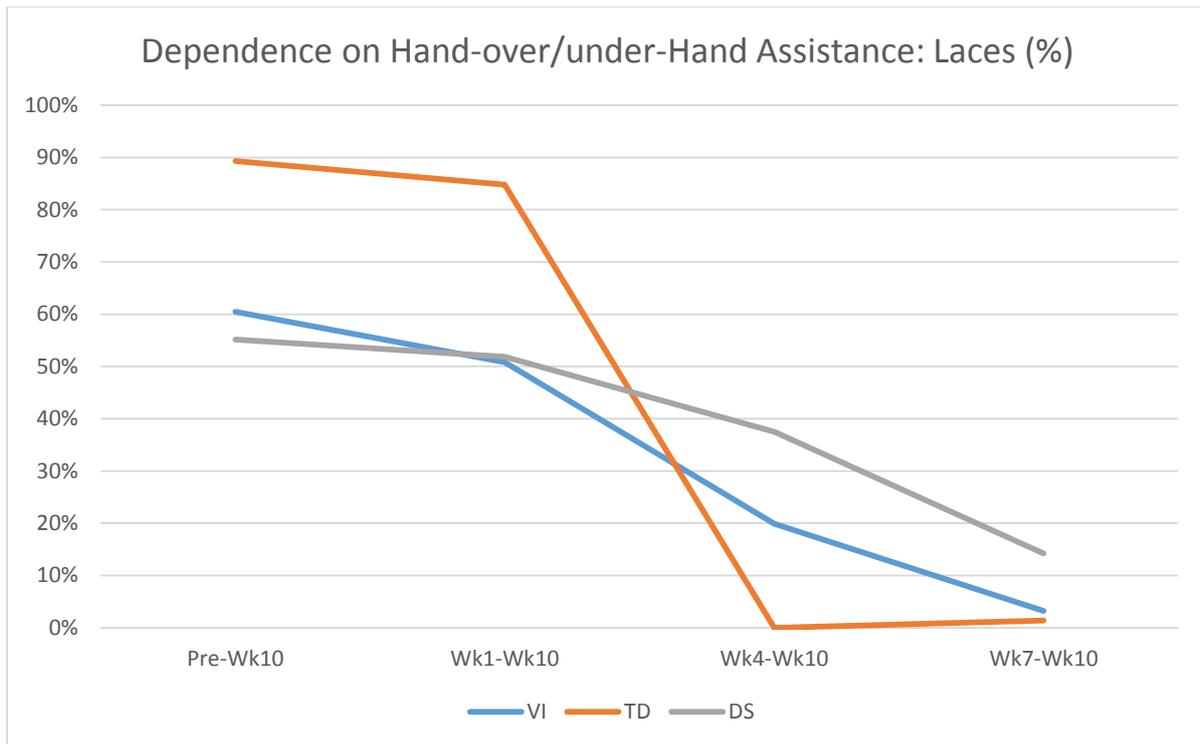
Figure 9.3 shows the mean group performance in the popper fastening condition for all three groups.



*Figure 9.3.* The mean reduction in button dependence scores over the 10 week intervention period for each fastening condition.

Figure 9.3 shows that within the popper condition, all three groups (VI, DS and TD) commenced the intervention with total dependence on adult support. A high dependence on adult support was observed during week 1 of the intervention. By week 4 of the intervention, the TD group had reached ceiling effects for the popper condition. VI and DS groups showed a similar progression over the remainder of the intervention.

Figure 9.4 displays the mean group performance in the lace fastening condition for all three groups.



*Figure 9.4.* The mean reduction in lace dependence scores over the 10 week intervention period for each fastening condition.

Figure 9.4 indicated a difference between baseline observations between the TD group and the clinical groups. The TD group appeared more dependent at the pre-intervention observation. Rapid skill acquisition occurred in the TD group between week 1 and week 4 of the intervention. This is demonstrated by the steep gradient in Figure 9.4.

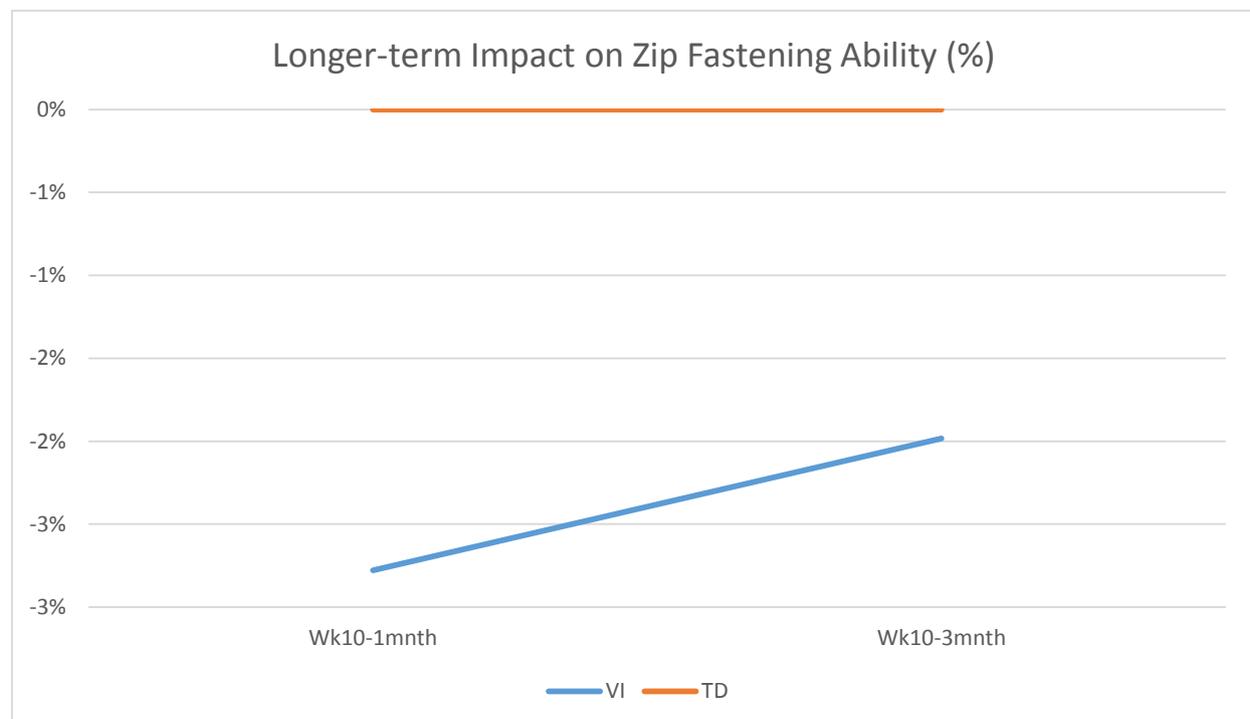
VI and DS groups commenced the intervention at a similar stage. Observable differences in task performance between the VI and DS groups are indicated from week 1. The DS group required the greatest amount of adult support by week 10. Although performance of the VI group was initially similar to that of the DS group, by week 7 of the intervention, the VI group performance was more similar to the TD group.

Figures 9.1 to 9.4 indicate that the TD group acquired independent fastening skills more quickly than the clinical groups. This is demonstrated by the observed ceiling effects that occur around Week 4. The finding was expected due to the nature of the sample. The clear difference between the clinical groups' performance and the performance of the TD group. This could be resultant of developmental delay associated with the clinical diagnoses. Although the TD children developed the skills faster, the clinical groups' baseline scores indicated a higher dependence on adult assistance. This means that over the course of the intervention, the clinical groups arguably benefited more from the intervention as they initially

required most adult support, but their final scores are close to the ceiling score for independence. Figure 9.1 also indicated that the clinical groups developed independent fastening skills over a similar trajectory, as there appeared to be marginal differences in the group mean score performance over the intervention procedure. Figure 9.1 indicated that over the intervention procedure, all groups increased in independent fastening ability, suggesting that the intervention has a positive effect on the development of independent fastening skills.

### 9.7 Long-term Impact of the Intervention

The 10 week intervention period supported independent fastening skill ability of all three groups. Observations of the TD and VI participants were repeated across all four fastening conditions after 1 month post-intervention and 3 months post intervention. Figures 9.5 to 9.8 display the mean group scores at these time points.



*Figure 9.5.* The impact of the intervention on zip fastening ability 1 month and 3 months post-intervention for VI and TD groups (mean scores).

Figure 9.5 shows that the effects of the intervention appeared to remain constant for the TD group. This is demonstrated by the straight line at 0%. The VI group mean, however showed an increase in dependence 1 month after the intervention had ceased. This is represented by the negative percentage. The VI group did increase in independent ability between 1 and 3 month observations. This is represented by the gradient moving up toward 0%.

Figure 9.6 displays the longer-term impact of the intervention on button fastening ability for VI and TD groups.

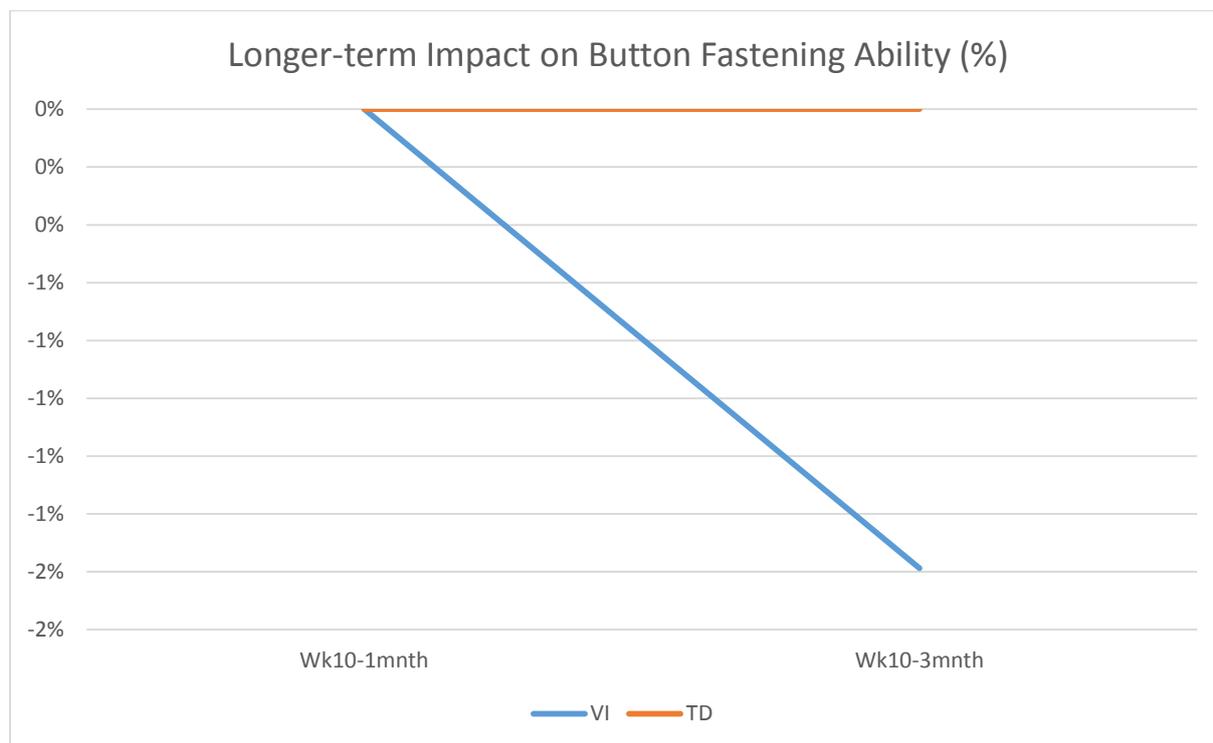
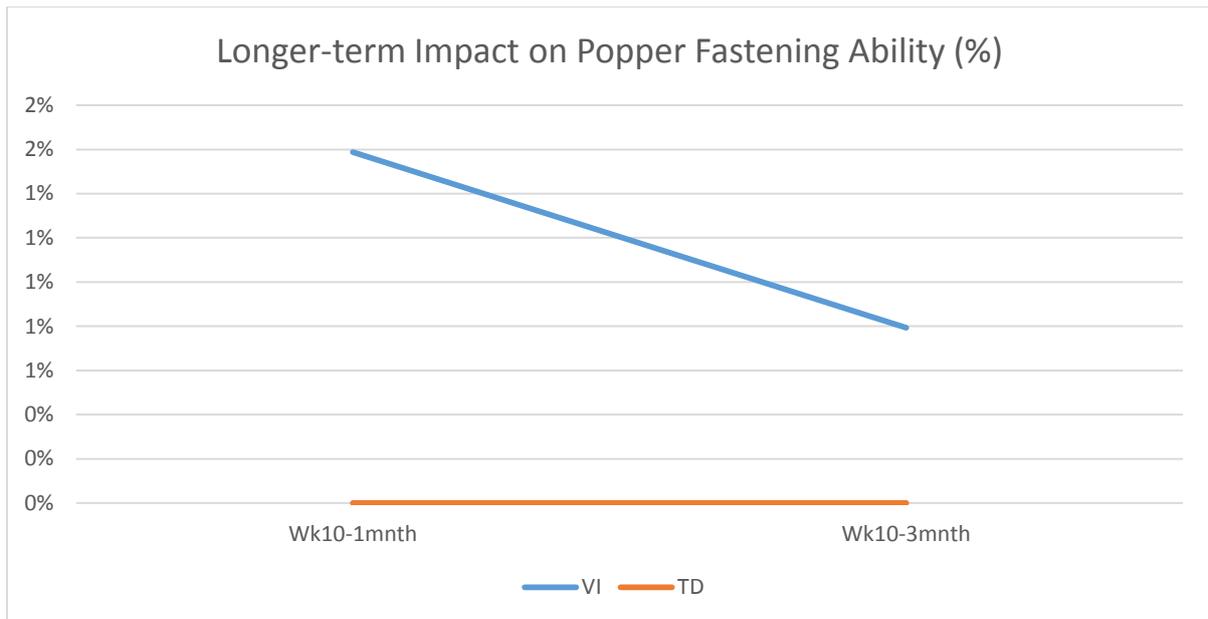


Figure 9.6. The impact of the intervention on button fastening ability 1 month and 3 months post-intervention for VI and TD groups (mean scores).

Figure 9.6 shows that the TD group remained to be at ceiling effects both 1 month and 3 months post-intervention. The VI group were observed to be at ceiling 1 month post-intervention.

Three months after the intervention had ceased, the VI group mean dropped to -2%. This represented an increase in dependence for button fastening.

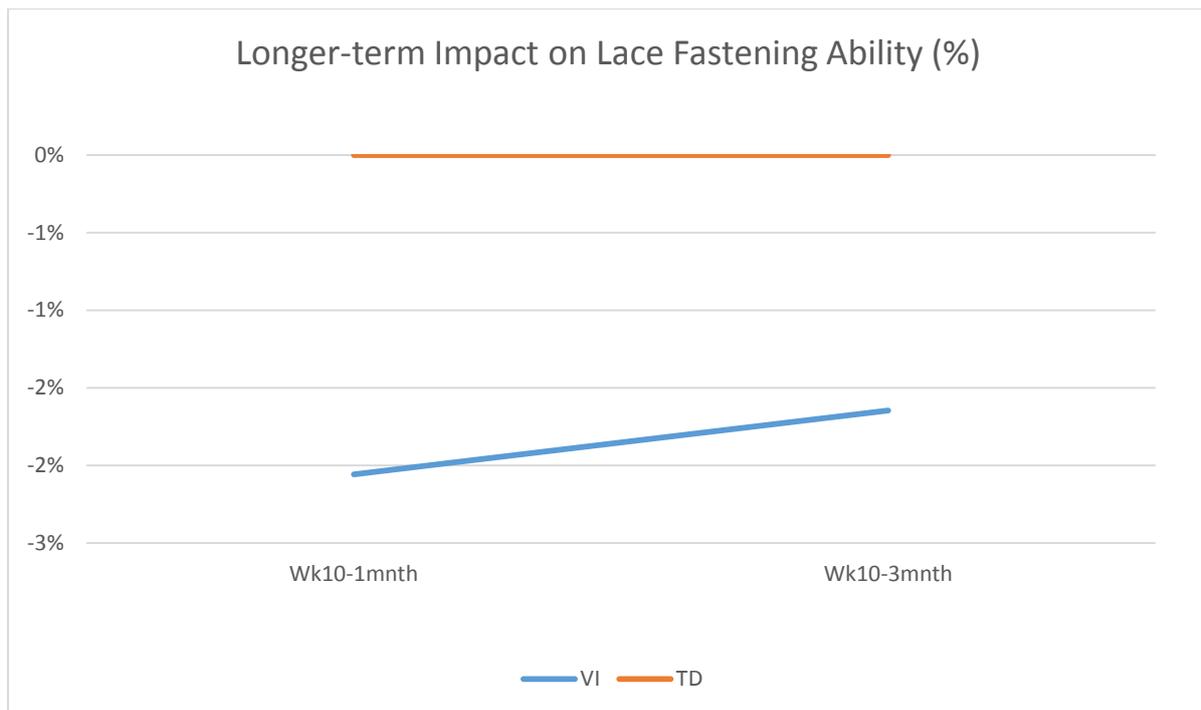
Figure 9.7 shows the longer-term impact of the intervention on popper fastening ability for the TD and VI groups.



*Figure 9.7.* The impact of the intervention on popper fastening ability 1 month and 3 months post-intervention for VI and TD groups (mean scores).

Figure 9.7 shows that the TD group remained to be at ceiling effects both 1 month and 3 months post-intervention. Interestingly, the VI group continued to show an increase in independent popper fastening ability both 1 month and 3 months post-intervention. This is the only example of consistent participant improvement post-intervention.

Figure 9.8 shows the longer-term impact of the intervention on lace fastening ability for the VI and TD groups.



*Figure 9.8.* The impact of the intervention on zip fastening ability 1 month and 3 months post-intervention for VI and TD groups (mean scores).

Figure 9.8 shows that the TD group remained to be at ceiling effects both 1 month and 3 months post-intervention. The VI group increased in dependence 1 month post-intervention. This is demonstrated by the negative percentage. The VI group did show a slight increase in independence after 3 months post-intervention.

Figures 9.5 to 9.8 show that the intervention appeared to have potential lasting effects on participants' performance. The fluctuations are marginal (by 1 or 2 points on the observation scale). The results show that participants who had either reached the natural ceiling effects of the fastening task, or their own ceiling effect, largely maintained the fastening ability that was achieved at week 10. TD children remained at ceiling scores for both the 1 month and 3 month post-intervention follow up sessions. In the VI group, 1 participant decreased in button fastening ability (meaning they became more dependent on physical adult support) which affected the group mean. The VI group slightly increased in independence for zip, popper and lace scores during the 3 month post-intervention period.

### 9.8 Case Studies

The indicative case studies presented in this section are used to aid contextualisation of the quantitative data previously explored. They are considered indicative because they offer a

series of aspects which will be further discussed in Chapter 10. Two broad themes emerged from the observation of participants with VI and DS. These were apparent in relation to clinical diagnoses and behaviour (participant/parent). Detailed vignettes for all participants can be found in Appendix 11.4. Six case studies are presented in this section. They are organised in accordance with the apparent themes. Two case studies are related to medical conditions. Four case studies are related to behaviour.

### **9.8.1 Participant 3 (VI)**

Participant 3 (P3) was identified as a suitable case for exploration due to the severity his medical condition and his performance over the intervention period.

P3 was a 7 year old boy who had been diagnosed with Juvenile Onset Batten's Disease (see section 3.2.2 for details of the condition). VI is a characteristic of this condition, as well as developmental regression (including motor skills) and loss of speech. He was not diagnosed with any additional comorbidities. P3 was quiet and reserved in the sessions. However, he would say 'yes' or 'no' and also ask for assistance when he needed it. This demonstrated that despite his condition, he was still able to efficiently communicate with the researcher and his peers.

P3 preferred to work alone and did not ask for much assistance throughout the intervention period. He reached ceiling for the zip condition by week 5, the button and popper condition by week 4 and the lace condition by week 5. This was considered remarkable taking into account the severity of his diagnosis. P3 would collect as many pieces as he could and unfasten/fasten as fast as he could and place them to his side (creating a tower). He would repeat this behaviour throughout the sessions and was very focused toward attempting every piece available.

The performance of P3 over the intervention period did not seem to correspond with the severity of his diagnoses. Theoretically P3 should have performed worse than was observed over the intervention period.

Furthermore, P3 maintained ceiling effects in all fastening conditions 1 month and 3 month post-intervention. The case of P3 suggests that at the time the research was conducted, P3 was still able to acquire new motor skills suitable for ILSD.

The next case study also relates to the clinical diagnoses and task performance, and indicates that task performance may not entirely be predicted based on clinical diagnoses.

### **9.8.2 Participant 5 (VI)**

Participant 5 (P5), was identified as a suitable case due to her medical conditions and her performance over the intervention period. In contrast to P3, P5 was not diagnosed developmental motor skill regression, and so her poor performance could not necessarily be explicitly related to her diagnosis in the same manner as P3. This is not to say that P5's performance was unrelated to diagnoses as developmental delay is characteristic of VI, yet in comparison to P3, P5 should have (albeit theoretically) performed better than P3.

P5 was a 5 year old girl, who was diagnosed with septo-optic dysplasia, and was registered blind (see Section 3.2.2). In addition to her VI, P5 was also diagnosed with ASD and diabetes insipidus (see Section 3.2.4). P5 had also suffered from neonatal abstinence syndrome (withdrawal) as an infant and as a result, she now resided with her grandparents. P5 was a very polite and softly spoken child. She enjoyed working in a group, but would get frightened if there were any loud or unexpected noises which occurred inside/outside the workroom.

P5 required the most adult support over the intervention period, and so a teaching assistant would sit beside her and support her (by mimicking the researcher's behaviour). This was done in order to maximise the opportunity for P5's fastening abilities. P5 did not reach the prescribed ceiling effect for the fastening conditions,

however she did appear to reach her own ceiling effect during the intervention period. P5 preferred the button condition as opposed to the others, and so had to be encouraged to try the other fastenings in every session. She would attempt the other conditions once or twice and then request a big button because she liked the feel of it. P5 was the youngest recruited participant in the VI condition, and this may have had more of an effect on her performance through the intervention period than her medical diagnoses.

The cases of P3 and P5 indicate that despite clinical diagnoses, performance in the fastening activities were variable.

It is arguable that CA may also have an effect on task performance, but from the observations, the performance of the two identified participants did not appear to correspond with the characteristics of their diagnoses.

The following case studies examine different behaviours which may have had an impact on task performance.

### **9.8.3 Participant 2 (VI)**

It was initially thought that the development of ILSD in relation to fastening would have required participants to specifically focus on the task alone. This was not always the case.

Participant 2 (P2) exhibited multi-tasking behaviour and arguably this may have supported his motor skill development over the intervention procedure.

P2 was a 10 year old male who was diagnosed with glaucoma and retinal detachment (for details see section 3.2). P2 did not have verbal communication difficulties, but would often mimic or 'parrot' words or phrases that were said throughout the sessions.

He was a very inquisitive and chatty child and would often tell jokes within the sessions whilst unfastening/fastening to make the participants and the

researcher laugh. He was very motivated toward task completion and would often ask if fastening a coat was like fastening a seatbelt, because he had recently learned how to do that. He would ask such questions whilst attempting to unfasten/fasten different materials.

P2 had reached the ceiling effect for buttons by week 8 and poppers by week 6 of the intervention period. He became so comfortable with the button and popper conditions that he would hold detailed conversations about 'wanting to be a dentist' and warning the researcher about the risks of eating too many Easter eggs. He would maintain these conversations whilst continually and successfully unfastening and fastening buttons and poppers. This ability to do two arguably complex things at once with such ease demonstrated multi-tasking behaviour.

P2 struggled with the lace and zip condition. He was motivated toward fastening zips, due to an awareness that the other members of his group could fasten them. He would become frustrated and say "silly zip" frequently throughout sessions. For fastenings that he struggled with (i.e. zips and laces) he would start conversations about how to successfully unfasten/fasten while attempting the pieces.

It was observed that when attempting to insert the tail into the slider, P2 would turn his hands in toward his stomach, which meant that he could not insert the tail due to approaching from the wrong angle. In order to attempt to correct him, he was asked to hold his hands in the correct position for 3 repetitions of 10 seconds.

P2 would then ask questions and talk about the task whilst he was doing this. As he could be easily distracted, focusing on the action for 10 seconds would

sometimes make him laugh, and so we would start again in order for him to remember where to position his hands. Although P2 did not reach ceiling effects for the zip and lace condition, he continued to attempt these fastenings, and hold conversations about them. P2 was not demotivated toward the tasks.

The case of P2 demonstrated that engaging with the intervention materials did not mean a singular focus on the task in hand. He was able to develop unfastening/fastening skills whilst speaking about related or unrelated concepts.

In contrast, the following case studies further examine different aspects of behaviour, where all participants have limited language and communication difficulties.

#### **9.8.4 Participant 19 (DS)**

The intervention procedure was group based. This meant that participants would sit and work together, and the researcher would divide attention accordingly. The majority of participants were content with this, and would request help when they needed support. This attitude however was not always shared.

Participant 19 (P19) is used here to illustrate how behaviours can manifest in order to gain the attention of the researcher, and the potential negative impact that this may have on a group dynamic.

P19 was a 9 year old girl who was diagnosed with DS. Additional comorbidities were not reported, as the background questionnaires were not completed. She did have communication problems, and used Makaton to support her limited speech. P19 was a very confident girl who preferred to work directly with the researcher, and would exhibit behaviours in an attempt to make this happen.

P19 was present in group settings, however would snatch the materials out of the other participant's hands or push them out of the way in order to have the researcher's attention. The researcher explicitly

informed P19 that this was unacceptable behaviour. She was cooperative with the researcher, however had a very limited attention span and would then sit back down with the group and exhibit the same negative behaviours.

She could be very heavy handed with other participants and also the researcher. If she wanted attention and perceived to be ignored P19 would grab the researcher's arm or hand and try to drag the researcher away. The researcher would remain in the same position, inform P19 that the behaviour was unacceptable and continue assisting the other participants.

P19 mostly responded well to verbal instructions provided by the researcher regarding her behaviour, but would not respond to additional adults (including her mother). She would physically push these people away and move to position herself directly next to the researcher.

She often needed to be reminded of her behaviour and 'kind hands' in order to participate in the sessions. She responded to this and so was present in the full 10 week intervention, yet due to her disruptive behaviour sessions were interrupted. Despite this, P19 reached the ceiling effect for buttons by week 3 and poppers by week 9. She did not reach ceiling effects for the zip and lace condition, however appeared to reach her own by week 6 for the lace condition.

The case of P19 demonstrated that some children may exhibit negative behavioural strategies in order to gain attention of a supporting adult. Had the sessions have been uninterrupted, the performance of P19 may have been better.

The following case study demonstrates how avoidant behaviour and wariness of supporting adults may have an effect on task performance.

Jessica Hayton

### 9.8.5 Participant 23 (DS)

As a familiarisation period was incorporated into the research design, it was thought that this would aid to ease the participants into the intervention procedure. The case of Participant 23 (P23) suggests otherwise.

P23 was a 9 year old boy who was diagnosed with DS. He did not have any additional comorbidities. P23 was very wary of new people, especially those who he considered to be professionals or teachers who were there to help him. He was very reserved and would spend most of his time interacting with his mother rather than the supporting adults or his peers. He would actively avoid any adult who he perceived to be 'support'. As a result of this, when present, P23 would often be uncooperative in the sessions and had to be gently introduced to the fastenings. He appeared suspicious of the tasks, as if he was aware that he was being assessed on task performance, and so he would mainly attempt unfastening/fastening when he felt comfortable.

Over the 10 week period, he was absent for 4 sessions, meaning that in total he only had 6 weeks of intervention. Despite this, he reached ceiling effects for buttons and poppers by week 7.

He showed improvement over the intervention period for the zip and lace condition, however did not reach the natural ceiling effects. His mum was very encouraging for the development of ILSD however, would frequently explain that he was not keen on people helping him specifically.

The avoidant behaviour of P23 could be examined in two ways. The first is that his avoidance is related to shyness, and perhaps anxiety as the voluntary organisation was specifically targeted at different forms of supporting therapy for children with DS, and assessing the impact

of these therapies. Yet, framing P23's behaviour in a different light may suggest that due to a motivation toward independence, being surrounded by 'supporting' adults may not be conducive to attaining it. The following case examines the link between participant behaviour (wariness and anxiety) and the potential impact of parental presence in the sessions.

#### **9.8.6 Participant 25 (DS)**

The previous case study reported that anxious or wary behaviours may have had an impact on fastening skill development. This case study illustrates how similar participant behaviour combined with a parental influence may impact the effectiveness of the intervention procedure.

Participant 25 (P25) was a 9 year old boy diagnosed with DS. Comorbidities were not reported due to the background questionnaires not being completed. He had language difficulties but used Makaton frequently to support his communication. His mother sat with him for every session.

He was very wary and anxious toward new activities and initially when offered IPG pieces he would say that he could not do it because it was too difficult or he was scared. He would say this before he had attempted unfastening/fastening. In order to account for this, the researcher verbally encouraged him to try and then physically showed him how the fastenings worked. He would then engage with the task, overcome his anxiety and then became excited with his attempts.

If P25's mother perceived him to be slow or unsuccessful she would take his hands and complete the task for him (similar to H-O-H but without verbal instruction). The researcher advised that the mother removed her assistance until P25 asked for help, as this was the nature of the intervention. This was usually effective until P25 attempted another piece. When attempting different pieces, the mother would then complete the task for P25, until reminded otherwise. Then, when P25 asked for help, the researcher assisted with hand-over-hand

support and systematic verbal instruction to support. This modelled the behaviour to both P25 and his mother so that she would be able to assist if/when necessary.

Once P25 became more comfortable with the researcher, he would move away from his mother (who was still present) and toward the researcher. He preferred the button condition because he found this easier to achieve, and reached ceiling effects for this condition at week 3. For the remaining conditions, P25 achieved ceiling effect for the popper condition by week 5. He did not reach ceiling effects for the lace and zip condition.

The case of P25 illustrated how initial anxiety toward a task can be overcome with gentle guidance and listening to the voice of the child. In addition, the case of P25 demonstrated how parental presence may have had an impact on the effectiveness of the intervention procedure.

### **9.9 Chapter Summary**

The quantitative data revealed that the intervention did appear to have an effect on the development of independent fastening skills for all four fastening conditions (zips, buttons, poppers and shoelaces). This was supported particularly by the noteworthy findings between baseline and week 1 scores for all three groups (VI, DS and TD) for zip and lace fastening abilities.

The quantitative data also revealed that as the intervention progressed, the values of the t-results decreased. This was indicative of an increase in independent fastening abilities (movement toward ceiling effect) which reduced variation within the groups. The quantitative data was then contextualised by the use of qualitative case studies. The case studies identified aspects of the intervention that were not necessarily quantifiable in the same manner as fastening ability, but may have had an impact on the quantitative score. The behaviours exhibited and the role of the clinical diagnosis could have affected task performance.

In summary, the 10 week intervention period appeared to aid the development of independent fastening abilities. TD children acquired independent skills more rapidly than the clinical groups, which was expected due to the nature of the sample. Although TD acquired the skills faster, the clinical groups displayed the largest improvement in independent fastening abilities

over the 10 week intervention period (Hayton, 2015). This is because the baseline for the clinical groups was smaller (with the exception of the lace fastening condition). The results also indicate that the 10 week intervention period has a lasting impact on motor skill acquisition.

There was not a noteworthy difference between week 10 scores and 1 and 3 month post-intervention follow ups. This suggested that a 10 week intervention period may potentially be suitable in developing independent fastening skills for children with VI (Hayton, 2015). Post-intervention follow up sessions were not possible for the DS groups as a direct result of time constraints.

It is important to note that all missing values in the data were a direct result of absence from the session, not through participant refusal. Absence may play a crucial role in the development of ILSD and affect the effectiveness of the intervention procedure. Absence is arguably a characteristic of the clinical groups explored (see Chapter 8). As a result of the high number of absences in the DS group, it was considered reasonable to conduct partial-analysis to comparatively explore scores where most participants were present.

The results presented in this chapter will be discussed in the following chapter. The discussion will explore the results in terms of the previously established research questions and also in terms of the literature explored in previous chapters.

## 10. Discussion

The data presented in Chapter 9 provided support toward the potential impact of the intervention in relation to ILSD. This chapter explores the noteworthy findings from (Chapter 9) and the examined literature (Chapters 1-3) in the context of the five established research questions (RQs). The findings are then explored in relation to the fastenings survey (Chapter 5) and the pilot study (Chapter 7). The discussion chapter then identifies and explores the limitations and implications of the current study. Future directions for the field are then presented, followed by the conclusion to the thesis.

The current thesis was based on previous literatures which were largely based on rehabilitation techniques (e.g. Klein, 1983; Fairnham et al., 2002). The pilot and main study presented in the current thesis (Chapter 7 and Chapter 9) have drawn upon these literatures, and as a result offered a contribution toward the updating of the field. This is because the intervention materials and procedures presented here were based on the development of children with disabilities rather than the development of adults who had previously developed typically, yet due to injury, have to develop new techniques to support independent living. By using the work of Klein (1983) as a basis, a systematic, detailed and refined dressing protocol has been established for zips, buttons, poppers and shoelaces.

The current research has examined the rehabilitation-based techniques used by Klein (1983) however has examined their utility within a child-centred, habilitative context. This is because one aspect of the current research focused on gross and fine motor skill development in children. This child-first approach to the development of ILSD means that one contribution to knowledge from the current thesis is identified as an evidence based intervention task which is based on habilitation techniques. This is identified as a contribution to knowledge, as previous related work (e.g. Klein, 1983) developed techniques to support children based on the rehabilitation approaches used for adults, as opposed to the current research which developed techniques based on child development.

The current thesis also worked in accordance with established UK government policies in relation to children with SEND. The main study directly addressed habilitation provisions as outlined in the SEND Code of Practice (Department for Education & Department of Health England, 2015) as the intervention protocol worked to achieved the outcome of preparedness for adulthood (Chapter 8, Department for Education & Department of Health England, 2015) in relation to independence training. The suite of intervention materials have in effect

attempted to bridge the gap between the theoretical concept of habilitation and the practice of habilitation. This is due to the evidence based study (namely Chapter 9) which could inform later practice in relation to employing habilitation strategies within mainstream and specialist schooling. The current thesis arguably extends knowledge and understanding of habilitation as a concept that could later inform theory and subsequent practise in relation to the development of ILS within educational contexts.

### **10.1 Discussion of the Main Study Results**

The quantitative and qualitative results of the main study are discussed here in relation to the five research questions (RQs) established for the current thesis. These questions were:

- 1) 'To what extent can novel intervention materials support the development of gross and fine motor skills suitable for independent dressing in children with VI in a range of needs and contexts?'
- 2) How do children with VI compare to DS and TD children in relation to ILSD development?
- 3) To what extent do novel and systematic intervention activities support the development of ILSD?
- 4) Can a novel observation schedule reliably and validly assess the development of ILSD in these groups?
- 5) Is there a need for a training manual designed for parents/caregivers and professionals to support the development of ILSD?

In the subsequent sections, each RQ is addressed in turn, in relation to the noteworthy findings from Chapter 9 and the previously examined literature (Chapters 1-3).

#### **10.1.1. Discussion of Findings in Relation to RQ1**

This section explores the findings of the main study in relation to RQ1:

'to what extent can novel intervention materials support the development of gross and fine motor skills suitable for independent dressing in children with VI in a range of needs and contexts?'

The noteworthy findings (Chapter 9) appeared to support the suitability of the use of novel intervention materials in the development of gross and fine motor skills suitable for ILSD in children with VI in a range of needs and contexts. The t-test results demonstrating the

difference between week 4 and week 7 zip scores yielded interesting results. Within the VI paired samples t-test a difference was found at this stage for the zip fastening condition. The noteworthy result indicated that the intervention appeared to increase independence in the VI group over this period of time thus suggesting the suitability of a 10 week intervention period for children with VI.

A suggested reason for the noteworthy result for VI participants at this stage of the intervention (week 4 – week 7, rather than between week 1 and week 4 scores) may have been due to the complexity of the zip fastening task. This is because in order to successfully fasten a zip, one must insert the tail into the slider. This aspect of the task demands fine motor control, co-ordination of the hands and the ability to pinch the fingers together. This is arguably the most complex stage of zip fastening, and so the noteworthy result that occurred between week 4 and week 7 may have been representative of the VI participants beginning to overcome these more complex stages of zip fastening. This difference was not apparent in the DS nor TD groups for the zip condition.

Arguably, the lack of difference between these scores in the DS group may have been due to DS participants failing to reach the ceiling scores for the condition. The desired outcome of the intervention was for participants to reach the ceiling scores within the intervention period. This was because the reaching of ceiling scores represented the ability to independently fasten/unfasten each fastening condition, which could have been suggestive of the effectiveness of the intervention procedure. Although the ceiling effects for the zip condition were not reached by the DS group, it is posited that a 10 week intervention may also be reasonable for this group. This is because of the initial similar performance between the VI and DS groups and the high absence rates of the DS group.

In the current study, ceiling effects reflected a participant's independent skill ability in each fastening condition. This was considered important as the nature of the intervention task was to support each participant in reaching ceiling effects for each fastening condition. A ceiling score represented an individual's ability to independently fasten/unfasten a fastening condition. Ceiling effects over a number of weeks arguably demonstrated that the skill lasted for a longer period of time which may have been suggestive of the effectiveness of the intervention tasks.

An interesting finding was also noted between the week 4 and week 7 t-test scores in the popper condition within the VI group. This was due to an apparent increase in independent popper fastening skills over this time. The result could be further characterised by participants

reaching the ceiling effect brought about by the fastening task. During week 4, three participants with VI had reached ceiling effects for the popper condition compared to five participants with VI reaching ceiling by week 7. This arguably demonstrated that the 10 week intervention period was suitable for developing independent popper fastening abilities within the recruited VI group.

The noteworthy findings relative to the extent of which the intervention materials/procedure supported ILSD development are also explored in terms of the examined literature. The intervention procedure was based on the literature of Klein (1983) and Fairham et al., (2002). This was because the procedure had a standard approach to teaching ILSD and an adapted approach if a participant required adaptations to support their ILSD development. The participants were encouraged to find the most suitable way for them to complete the task independently. This meant that although the children were taught a particular method to support task completion, the participants were encouraged to complete the task however they saw fit i.e. in a manner that made sense and worked for them. The children developed their own strategy for fastening which they found easier, but the skills remained grounded in the 'taught method', for example buttoning from bottom to top, rather than top to bottom. As long as the outcome was achieved (e.g. a fastened button), the method for doing so was flexible. If the steps for task completion were initially followed, the participants could adapt their strategies according to their preference e.g. left handedness or right handedness. This is because there is not one particular prescribed method for ILSD. The conditions for completing the task were: that it was performed in a safe environment; the task was performed successfully; and also, the task was performed independently. The outcome being that the coat ends up either fastened or unfastened (Swallow & Huebner, 1987).

The findings of the main study in relation to RQ1 may begin to address the issue raised by McLinden (2004) regarding the development of haptic perception in children with disabilities where VI is a component. The main study presented in the current thesis (Chapter 9) examined the development of ILSD in children with DS, where VI is an element of the diagnosis. The results of the main study suggested that the haptic tasks (in the form of the novel intervention materials) were sufficient to begin to develop the haptic sense in relation to ILSD.

The novel intervention materials developed for the current thesis were specifically designed to appeal to the haptic sense. This was done based on the results of the fastenings survey (Chapter 5), the pilot study (Chapter 7) and also in light of the explored literature (McLinden, 2012), whereby vision supports but is not essential for developing haptic perception strategies.

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The materials chosen for the novel intervention resources were based on an understanding of the types of material that children would have previously experienced. This was done to reduce the likelihood of tactile avoidance. Also, the novel materials were standardised to reduce confounding variables such as texture or colour preference. The standardisation of the materials meant that there was a limited choice for children with partial sight or full sight who may have otherwise been influenced by colour rather than fastening.

The haptic task combined with verbal instructions arguably further complimented the development of ILSD, yet a further adaptation needed to be made for the DS sample. This was the use of Makaton sign language. Makaton was used to support verbal communication with the DS sample, as impaired hearing was also a characteristic of the diagnosis. It is arguable that as Makaton is typically taught from approximately 3 years old, the DS participants' performance may have been affected by a hearing impairment which may not yet have been medically treated (e.g. a cochlear implant). This means that although Makaton was used to compensate for hearing impairments and to support verbal communication, the effectiveness of Makaton arguably cannot compensate for up to 3 years of hearing impairment and the associated language delay.

Furthermore, the use of systematic verbal instruction was designed to appeal to the development of haptic perception. This was done to aid children with blindness as their haptic perception was not arguably influenced by the visual modality. The performance of participants with partial/full sight may have been influenced by the interaction between the visual and auditory modalities to better develop their haptic sense. This means that on a theoretical level (supported by the overarching theorisation of the current thesis (Chapter 1)), in-tact/preserved senses arguably better facilitate the development of ILSD. This is supported by the results of the TD sample as independence was at ceiling effects by week 4 for all fastening conditions.

The design of the intervention procedure and materials attempted to compensate for this. Although the use of the materials supported ILSD development, it only began to address the issue raised by McLinden (2004) in teaching haptic strategies to children with DS.

The longer-term impact of the intervention was also a surprising result. TD independence scores remained at a constant ceiling effect over 1 month and 3 months post-intervention. The retention of the skills could arguably be a result of the rapid independent skill acquisition evidenced in the t-test and percentage change tables. A more surprising result was found when examining the longer-term impact of the intervention of the VI group. Most VI participants retained the same independence score as the week 10 observation. Some participant abilities

dropped by 1 point which was not considered to be a substantial difference. This was because the participants had developed the appropriate fastening techniques, had previously demonstrated ceiling effects and arguably the fastening was already secure. The drop in score therefore was not considered to be meaningful, as the independent ability remained high. The findings of the assessment of the potential longer-term impact of the intervention suggested that a 10 week intervention period is arguably suitable for task performance within the VI sample.

The exploration of the results of the main study (Chapter 9) showed that the novel intervention materials did appear to increase independent fastening skills in the VI group who were characterised as having different needs and personal contexts (as indicated by the background measures). The novel intervention materials also appeared to support the development of ILSD in DS and TD groups who also had different needs and contexts. The results suggested that the intervention materials and the length of time prescribed to the development of fastening ability were arguably effective in the development of ILSD in the specific recruited participant groups (VI, DS and TD). Furthermore, the assessment of the longer-term impact revealed that the retention of ILSD skills were apparent in the TD and VI group.

The intervention materials used in the current thesis were designed to appeal to multi-sensory learning strategies and also to develop the haptic sense. The results of the pilot study and the main study (chapters 7 and 9) offered some support to the study conducted by Rains, Kelly & Durham (2008). In their study, Rains, Kelly and Durham (2008) reported that multi-sensory learning techniques supported task performance in 'academic' subjects, mathematics in particular. The current thesis arguably provided some evidence that multi-sensory learning can also be effective in increasing task performance in motor skill tasks. The current thesis provides some support toward the effectiveness of multi-sensory learning relative to increasing task performance in motor skill tasks. The current intervention procedure appealed to multi-sensory routes as the intervention combined sequential auditory instruction, the visual modality (where available) and motor skill (kinaesthetic) activity to develop ILSD. The intervention procedure optimised the development of ILSD by appealing to as many in-tact senses as possible. The combination of the use of the interactive rhyming story with the IPG materials may have also have enhanced the development of ILSD by appealing to dyadic sensory relationships as suggested by Rains, Kelly and Durham (2008).

In addition to potentially offering a contribution to the field of multi-sensory development, the current study also attempted to appeal to participants proprioceptive senses. This was

because the repetitive nature of the intervention procedure may have appealed to the participants proprioceptive sense as the body adjusts itself accordingly to the repeated tactile sensory input (Boisgontier and Swinnen, 2014). Also the nature of the intervention tasks arguably afforded participants the opportunity to continually reach for and manipulate IPG pieces subsequently gaining a vast amount of proprioceptive feedback (Ostry and Gribble, 2016) which incidentally optimised the development of ILSD.

Time also played a fundamental role in the development of ILSD. The results of the main study (Chapter 9) demonstrated that TD children benefited from time to rehearse and practice ILSD skills. Although the time needed for TD children to develop and maintain such skills was shorter than the 10 week intervention period. In contrast, participants in the clinical groups did appear to need the full intervention period to develop and maintain ILSD skills, and arguably some participants (namely children with DS) may have benefited from a prolonged intervention period – longer than 10 weeks. Time can be understood in this context as the time of the intervention period (10 weeks) and also the length of time of the intervention sessions (15 minutes).

In the current study, all participants were provided with the opportunity to develop ILSD for 30 minutes per week over a 10 week period. This meant that the total time dedicated to develop ILSD was 5 hours. The results of the main study indicated that this was an ample amount of time for TD participants and some participants in the VI group. This was demonstrated by the observed ceiling effect brought about by the nature of the intervention. Other participants may have benefited from an extended intervention period, rather than an extension of the time of the sessions. This was because 15 minutes appeared to be beneficial in relation to the attention span of VI and DS participants. A short attention span is characteristic of the DS sample and so prolonging the time of the session may not have been of benefit.

The explored literature promoted the case for early intervention before children reached the “critical age” of 6 years old (Shonkoff & Meisels, 2000). The results from the main study showed that children over the age of 6 years old benefited from the intervention study, and the effects remained over a 3 month period. This showed that although there is a research base evidencing rapid social, cognitive and physical development up until the age of 6 (Shonkoff & Meisels, 2000) this did not have a negative effect on the development of ILSD in children over the age of 6 years. This meant that the results of the main study has suggestively illustrated that the development of ILSD is arguably quite rapid (over the 10 week intervention period) for children over the age of 6 years old.

It could be argued that the rapid development of ILSD skills may have been a cumulative result of plasticity, time allocated to development, adult support, and, motivation toward the task. The older participants in the main study, specifically P1, P2, P3 and P4 all vocalised their desire to be independent. Despite being over the critical age of 6 years old, it is arguable that motivation was a component in the development of ILSD skills.

Although it was outlined in the examined literature that children have a natural desire to attain independence (Shields, 2014; Perez-Pereira & Conti-Ramsden, 2013), the main study revealed that this was not the case for *all* children. Motivation appeared to play an important role for participant co-operation within the fastening tasks. If a participant was motivated toward fastening and independence they would continue to attempt the fastenings until successful. This was more evident in the VI group as P1, P2, P3, P4 and P9 who vocalised their desire to independently fasten performed better than VI participants who were less motivated toward the task (e.g. P6 and P7).

The motivation exhibited by participants had two themes: personal motivation and group motivation. Personal motivation was demonstrated by a participant saying “I want to do my zips” (as mentioned by P2). Group motivation was more competitive in nature e.g. “I want to do better than P4” (as mentioned by P1). It may be the case that over time all participants may become motivated toward ILSD but their current cognitive state was arguably too immature to fully understand the nature of the intervention tasks and the future implications for developing such skills.

The intervention procedure was, to an extent, informed by the Montessori Method (Chapter 2). The main similarity between the intervention procedure detailed in this thesis (Chapter 8) and the Montessori Method was the child’s ability to choose. Participants were encouraged to choose the pieces that they wished to play with. This was done in order for the child to have a sense of freedom within the sessions yet also to examine if their choice reflected subsequent fastening skill ability, e.g. did a preference for buttons lead to better button fastening ability. Although participants had a degree of choice within the sessions, they were also encouraged by the researcher to attempt every fastening in every session. This was done in an attempt to increase independence for all fastenings.

It appeared that giving the children a level of choice worked in two ways: firstly, children who were motivated toward ILSD as a whole would attempt every fastening piece without verbal prompt from the researcher. Secondly, children who appeared to be less motivated would focus on their preferred piece and only attempt other fastenings with verbal prompt from the

researcher. This observation illustrated how the Montessori Method may be influenced by personal motivation. The effectiveness of the Montessori approach may be influenced by motivation toward the task and the confidence required to attempt and develop new skills. It is arguable that the Montessori Method may not be as suitable for children who require structure and direction from an adult in order to develop new skills. Furthermore, motivation toward a task may have an effect on task performance.

The examined literature also related to the potential impact that VI may have on a developing child. In relation to the effect of VI on mobility, the current thesis supported the notion that vision is not essential for movement (Sugden & Wade, 2013). The intervention procedure began with participants entering a room and encouraging the participants to find a space on the floor. All participants were able to do this independently, and did not need adult support to find a suitable space. The action of the children finding a space and sitting down on the carpet arguably reduced the potential for movement around the room, especially as the activities were floor based. The floor based nature of the intervention task was to reduce potential health and safety risks which could have occurred if the child was sat on a chair and may have fallen off.

The restriction of movement was however illusory, as the participants were not necessarily encouraged to move around the room, yet they were permitted to do so. During the sessions all participants were encouraged to find the IPG which was placed on the floor in the middle of the group. Participants would sit and reach for the pieces, or get up and move toward them if necessary. Participants were encouraged to pick up the pieces that they wanted to play with and once they had attempted one fastening, they were further encouraged to return the piece to the board and choose a different one. With the exception of P5 (who had VI), all participants (across all 3 groups) actively moved towards the IPG to choose the fastening that they wanted to play with. This meant that movement in the sessions was largely focussed toward the task in hand. Some participants, (e.g. P9 (VI) and P19 (DS)) would stand up and move toward the researcher and sit beside her. The motive toward this movement could be identified as attention seeking behaviour. P6 (VI) and P7 (VI) would also independently stand up and move around the room to find different spaces to work. These observations begin to illustrate that VI does not necessarily hinder movement, as long as the children have a motive to move. This follows from the point made by Bowman, Bowman and Dutton (2001) as the children with VI did not necessarily have the same visual input as the TD sample, yet moved around the room in response to verbal instruction e.g. "can you find a button?" As the children were initially exploring 'unfamiliar' objects within a familiar environment, their comfort and ease with the space around them may have further facilitated their movements.

In this section, the results from Chapter 9 and the examined literature do appear to support the RQ1 regarding the extent to which the novel intervention materials supported the development of gross and fine motor skills suitable for ILSD development in children with VI with a range of needs and contexts. This is because the novel intervention materials appeared to support ILSD during the 10 week intervention period, and also the effects of the intervention appeared to last up to 3 months after the intervention had ceased. In order to further understand the impact of the intervention, the next section explores RQ2 which comparatively explores the results in terms of skill development in the 3 distinct yet related groups (VI, DS and TD).

### **10.1.2. Discussion of Findings in Relation to RQ2**

This section explores the noteworthy findings in relation to RQ2:

‘How do children with VI compare to DS and TD children in relation to ILSD development?’

RQ2 is first addressed in relation to absence from intervention/training sessions. Absence was explored in relation to a comparison between VI, DS and TD groups based on the observed ILSD development over the course of the intervention period. It is arguable that the high rate of absence may have affected the quantitative results. Children with DS had the highest rate of absence, and the lowest independence scores (supported by the poor achievement of ceiling scores for all fastening conditions). Absences were also recorded in the VI group. The rate of absence in the VI group was lower in comparison to the DS group (Table 9.1). Although children with VI had a lower absence rate, the results indicated that ILSD development in children with DS and children with VI was initially similar over the intervention period. However, the differences in ILSD development within the two groups emerged toward the end of the intervention period. This was characterised by more children in the VI group reaching the ceiling effects brought about by the nature of the fastening task when compared to participants with DS.

There were not any reported absences in the TD group, and so a comparison between the clinical groups (VI and DS) and the TD group in terms of attendance could not be made. As the TD group were observed to have reached the ceiling effects for all four fastening conditions by week 4 of the intervention, this is suggestive that attendance may be important when developing ILSD. In relation to the clinical groups (VI and DS), the record of absence is indicative that a higher absence rate may lead to slower skill development within the recruited

clinical groups. However it is arguable that medical diagnosis and associated developmental delay (Chapter 3) may have contributed further. The qualitative data presented in the case studies are indicative of how performance in ILSD tasks may be related to clinical diagnoses and/or affected by behavioural issues.

The qualitative data indicated that confounding variables such as clinical diagnosis and behaviour may have an impact on the development of ILSD. As the recruited clinical groups (VI and DS) had profound and complex medical histories, it is posited that there could be a link between medical condition and absence. This is because the children with VI and DS required more medical intervention and/or were more frequently ill and so this had an impact on attendance rates. In addition, clinical diagnoses may have an association with the development of ILSD. The results of the main study illustrated that the clinical groups demonstrated a slower rate of motor skill acquisition in relation to ILSD when compared to the TD group. As chronological age (CA) was controlled for in the current study (recruitment of participants based on a CA of plus/minus 2 months) it could be assumed that the results of the main study may have potentially been influenced by the developmental delay apparent as a part of the clinical diagnoses.

This finding potentially offers support to the studies by Annaz (2006) and Karmiloff-Smith (2009). This is because it is arguable that the impairment/s of the visual system appeared to have an effect on motor skill acquisition. This does not assume, however that VI was solely responsible for the delay in ILSD but VI was at least one aspect which could have affected performance in the clinical groups. The results from the main study therefore support but do not logically entail the argument for neuroconstructivism nor domain-relevance, yet the results of the clinical groups support the notion that VI and/or cognitive impairments appear to have an effect on motor skill acquisition.

This finding regarding the comparison between the three participant groups (VI, DS and TD) may also bear relevance to the different aspects/characteristics of developmental delay. Resolving developmental delay (i.e. a participant's transition toward a typical developmental trajectory (Chapter 3)) may have been apparent to an extent in participants whose ILSD scores continued to improve (but not reach ceiling effects) over the intervention period. The scores of these participants (from VI and DS groups) appeared to follow the same trajectory of motor skill acquisition as the TD group but at a slower rate. Persisting developmental delay may have been characterised by participants who had reached their own ceiling effect over the 10 week intervention period.

The main study effects as demonstrated in Figures 9.1 to 9.4 indicated that DS and VI groups performed similarly in relation to the trajectory for fastening skill development. This shows that although there was a high level of variation within the VI and DS groups, the task performance developed at a similar rate. This similarity was also evident between DS and VI groups in relation to popper fastenings between baseline and week 4 (Figure 9.3). This may have been reflective of all participants' initial inability to identify and manipulate this type of fastening. Taking into account the results of the fastenings survey (Chapter 5) this finding was surprising. This is because arguably all participants had previously had an extensive exposure to popper fastenings, yet could not identify or manipulate the piece at baseline level.

In order to further examine the effects of the intervention within the 3 participant groups (VI, DS and TD), paired-samples t-tests were conducted. Within all three groups (VI, DS and TD) the individual t-tests yielded an interesting result between baseline and week 1 scores for zip and lace conditions. This result (i.e. the difference between baseline and week 1 scores) was indicative of a need for all three participant groups to develop ILSD in relation to zip and lace fastening conditions. Furthermore, noteworthy results were found in the button condition between baseline and week 1 scores, but this was only found within DS and VI groups. This suggests that comparatively, VI and DS participants displayed a need to learn button fastening, whereas TD children did not demonstrate this need.

This finding also adds weight to the findings relating to the first research question in relation to the intervention supporting skill development to a great extent for children with VI (including DS). Only the VI group showed significance at this stage for the popper condition. These noteworthy results in these conditions for each group suggested that 1 week of intervention appeared to increase independent fastening ability. One reason for this may simply be due to the participants being formally introduced to the fastenings and the techniques required to successfully manipulate them. This may also have been apparent within: the VI and DS groups for button fastening; and the VI group for popper fastenings. The combination of physical activity with verbal instruction and rhyming strategies during the first week of intervention may have helped to consolidate information pertaining to the fastening function and how to successfully unfasten/fasten.

The results of the DS group suggested that the intervention materials supported ILSD development to a lesser extent when compared to the VI and TD group. This is supported by some participants with DS only reaching ceiling for the button and popper conditions. The ceiling effects brought about by the nature of the fastening tasks were not observed for any DS participant for the zip and lace condition. This may be because participants in the DS

condition appeared to reach their own ceiling effect in the zip condition (reported as 0%\* (page 196)). This meant that although the novel and systematic intervention materials supported ILSD development (as supported by the t-tests and ANOVA results), the extent of the impact varied between groups. Absence may have played a role in this, as the intervention could only impact ILSD development if participants were physically present in the sessions.

Within the DS and TD groups, a noteworthy result was found in participant performance in zip fastening between week 1 and week 4 of the intervention. Within the DS group, this effect demonstrated the suitability of the intervention in dramatically increasing independence over a 4 week period. Further to this, one participant (P27) has reached their own ceiling effect by week 4. This personal ceiling effect was identified due to the participant score of 0%\* - as there was no percentage change in individual score between week 1 and week 4. The noteworthy result reported between week 1 and week 4 in the TD group showed how the intervention appeared to arguably increase task performance over a 4 week period. With the exception of (P18) all TD children had reached the natural ceiling score at week 4. This suggested that a minimum of 4 weeks of intervention was a suitable amount of time for TD children to reach maximum independence in zip fastening abilities. This effect was not found within the VI group.

Additional interesting findings were reported as a result of the t-tests between week 1 and week 4 scores in the button and popper conditions within the VI and DS groups. These noteworthy findings could be interpreted to say that VI and DS fastening abilities were continuing to develop over the intervention period. It is arguable that this result was not found in the TD group for the button condition due to the majority of participants achieving the ceiling effect at the baseline observation. The lack of effect between the week 1-week 4 popper scores for the TD participants may have been a result of the lack of variation between participant scores.

An interesting finding was also noted arising from the t-tests within all three groups (VI, DS and TD) for the lace condition in the week 1 – week 4 comparison. This notable result was arguably due to the complexity of the lace fastening task. The complexity of the observation schedule (Appendix 11.10) associated with this task supports this claim. This was because there were considerably more observable stages which constituted the lace fastening task. In addition, the outlined stages required fine motor skills (e.g. the ability to pinch the laces between the index finger and the thumb), and also coordination of the hands. This noteworthy result therefore may relate to the task complexity in addition to the progression toward independent lace fastening. A noteworthy result was also reported within the DS group for

lace fastening abilities between week 4 and week 7. This was demonstrated by a considerable improvement of lace fastening scores but interpreting the result found in the t-test may also indicate an effect of the high number of absences during the week 7 observation score.

The within group t-tests results revealed that the intervention fluctuated in effectiveness between groups. There was a greater number of noteworthy scores for the VI group. This suggested that the intervention continued to support fastening skill development in VI participants for each condition over the intervention period. The noteworthy findings from the t-test in relation to the TD sample also reveal that there was a need for TD participants to specifically learn zip and lace fastening over a 4 week period. The lack of difference in the results of week 4 – week 7 scores were arguably a result of the participants reaching the ceiling effect for the fastening conditions. The results of the t-test within the DS group may have been affected by the high rate of absence and also the observed personal ceiling effect for the individual participants.

The results presented in Chapter 9 indicated that both clinical groups (VI and DS) and the TD group required physical and verbal support in the development of ILSD. The extent and type of this support, however varied based on individual participant needs. This was indicated by the results of the ANOVAs which indicated that the intervention had a noticeable impact on ILSD across all four fastening conditions (see Chapter 9). The noteworthy findings arising from the ANOVA calculations suggested that the novel intervention materials were useful in developing ILSD in the recruited sample of children with VI, despite varying clinical diagnoses which may have had impact on each individual's needs and contexts.

Further, the noteworthy ANOVA results suggested that there was an apparent need for such intervention to develop fastening abilities in both typical and atypical contexts. However, there was no noticeable effect reported for the intervention and group interaction for the popper condition. This is suggestive that within the popper condition, there was no considerable difference in group performance over the intervention period. This could be explained in terms of all participants having the same baseline score, and the majority of participants reaching the ceiling effect by week 7 of the intervention. As all participants scored similarly over the popper condition, this result may be due to a lack of variation in performance in this fastening condition.

Another factor in support of the noteworthy results after only one week of intervention was the participant's opportunity to freely explore and manipulate the fastenings. Arguably, the intervention session may have been the first opportunity that the participants of each group

were afforded that was completely dedicated to developing fastening skills and so this may have had an effect on fastening ability at such an early stage of the intervention. This may be because the intervention procedure offered an exclusive and targeted attention to the development of fastening skills. It is important to note that the noteworthy results showing the difference between baseline and week 1 was not representative of the ceiling effect brought about by the task. Rather, it is argued, it was representative of an increase toward independence after 1 week (30 minutes) of intervention. This demonstrated that 2 sessions of 15 minutes per week appeared to considerably alter participant performance in each group (VI, DS and TD) for zip and lace conditions, buttons for the VI and DS group, and poppers for the VI group.

The exploration of the results presented in Chapter 9 in relation to RQ2 suggested that the performance of children with VI and children with DS was similar in terms of the trajectory of skill acquisition for all four fastening conditions. The most noticeable difference between the VI and DS groups became apparent in the lace fastening condition and this was represented by the week 7-week 10 scores. At this point of the intervention period, the VI and the TD group performed more similarly (Figure 9.4), and the DS group appeared to lag. This may be because of the high absence rate reported in the DS group.

The longer-term impact of the intervention in the VI and the TD groups indicated that the effects of the intervention appeared to last up to 3 months after the intervention had ceased. The longer-term impact suggested that the separate group scores (VI and TD) appeared to remain relative to the week 10 scores for each group. This meant that there was still a noticeable difference between skill development between the TD and VI groups. As a result of the time constraints of the project, reassessment of the DS sample was not possible, and so comparisons between the 3 groups could not be made. This will be discussed in the limitations section of this chapter (see Section 10.2).

In light of the findings summarised above and the difference between group performances, the next section explores the results of Chapter 9 in terms of the extent of support of the novel intervention materials in terms of ILSD in general.

### **10.1.3. Discussion of Findings in Relation to RQ3**

This section explores the findings of the main study in relation to RQ3:

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'To what extent do novel and systematic dressing activities support the development of ILSD?'

This section first explores the findings in relation to the ANOVA results presented in Chapter 9. Then the section explores the extent of the impact of the novel and systematic dressing activities in relation to the longer-term impact of the intervention. Last, the section explores the extent of support of the intervention materials in relation to participant absence.

The noteworthy results from the ANOVAs indicated that the novel intervention materials appeared to support ILSD to a reasonable extent in relation to type of fastening (zip, button, popper and shoelaces). The ANOVA results for fastening ability for each fastening condition (zips, buttons, poppers and shoelaces) illustrated two points. First, the interesting results (apparent in all four ANOVAs) regarding the intervention task and independent fastening ability suggested that the 10 week intervention appeared to increase ILSD (within and between each of the three participant groups). This observed increase in independent fastening abilities appeared to occur at different rates for each fastening type. This suggested that the 10 week intervention period was adequate enough to develop and increase independent fastening abilities, but there was variation between the intervention procedure and mean scores. Second, the noteworthy ANOVA results suggested that the intervention appeared to be effective for all three participant groups (VI, DS and TD) in zip, button and lace conditions. The notable results suggested that the effectiveness of the suite of novel intervention materials varied between group means for each fastening condition.

In relation to the VI sample, the intervention appeared to support recruited participants to a varying extent. This was indicated by the variation within the VI group whereby some participants with VI reached the observable ceiling effects for all four fastening conditions, where others did not. It is arguable that a higher attendance rate may have increased ILSD (within the VI group) brought about by the use of the novel and systematic intervention activities. It is posited that higher attendance rates may have also increased the impact of the development of ILSD in the case of participants with DS.

The 1 and 3 month follow up for the TD and VI samples indicated that the intervention appeared to have a longer-term impact on the development and retention of ILSD within the examined contexts. This is suggestive that the extent of the impact of the intervention may potentially last up to 3 months post-intervention.

The quantitative results presented in Chapter 9 also suggested that attendance may have an impact on the extent of the effectiveness of the intervention activities. In the TD group (where no absences occurred) the intervention activities appeared to fully support the development of ILSD. This is represented by the observed ceiling effects for all participants in the recruited TD sample.

Absence was considered to be an important factor in the development of ILSD as there were differences in attendance rates within the clinical groups (VI and DS). It was noted (Table 9.1) that children with DS had a higher rate of absence when compared to the VI group. One reason for this may have been the additional medical complications (Chapter 3) that were associated with the diagnosis of the recruited participants. Arguably, a contributing factor toward the high level of absence may be due to the context in which the intervention was carried out. As the DS sample were recruited from a voluntary organisation, attendance was not compulsory. The sessions were ran outside of standardised schooling hours and over a weekend, which may have had a considerable effect on attendance rates. This is in contrast to the VI and TD participants, whose sessions ran within schooling hours, and attendance was expected and well-regulated in order to fit government policy. The absence of VI participants, however, was often a direct result of illness. It is important to note that the recorded absences evidenced in the current thesis were directly a result of physical absence from the sessions. If the participants were present in the respective educational contexts, they would always participate in the sessions. This means that absence was not a result of a refusal to participate, rather, the participants were not physically present.

In relation to RQ3, the results demonstrate that the extent of support toward ILSD differed within and between the 3 participant groups (VI, DS and TD). The TD group were observed to reach maximum independence for all four fastening conditions by week 4 of the intervention. This indicated that the intervention supported ILSD to a great extent as independence occurred quite rapidly. Arguably, the intervention supported ILSD in the VI group to a reasonable extent. This is indicated by the mean increase in independence scores over the intervention period, and also represented by some participants with VI reaching ceiling effects for all four fastening conditions. It is posited that although the intervention did increase independence scores in the DS group, this was to a lesser extent compared to that of the VI and TD group. As outlined in this section, this could be resultant of a high number of recorded absences compared to the VI and TD group.

From this comparison between VI and TD groups, the current thesis somewhat supported the claims of Lewis and Iselin (2002). Their study reported that sighted children were more

independent in completing ILS tasks when compared to children with VI (Lewis & Iselin, 2002). In the current study, the TD group displayed better task performance and achieved ceiling effects more rapidly than the clinical group over the intervention period. In saying this, the current thesis illustrated that there was a need for TD children to master ILSD. This means that although sighted children performed better, the recruited TD participants *did* benefit from the structured and systematic intervention procedure. This is not to say that TD children may not have learned ILSD incidentally over the 10 week intervention period, in the absence of the intervention. Yet it was apparent by the results presented in Chapter 9 that the intervention procedure appeared to maximise ILSD (demonstrated by all TD participants reaching the ceiling effect) by the fourth week of intervention.

Incidental learning in all three recruited groups (VI, DS and TD) has arguably been compensated for, to a certain extent, through systematic verbal instruction and the novel intervention materials developed to support ILSD. This is supported by the findings presented in Chapter 9 and the examination of results relative to RQ3. A further issue presented by Lewis and Iselin (2002) was also somewhat addressed in the current thesis. The issue they raised regarded incorporating systematic teaching activities within children's daily routines. The procedure used in the current thesis addressed this issue and actively chose timings where participants would normally put on an outdoor coat and shoes. This was considered to be useful in the transference of an "abstract" skill development session into the actual daily routine of the participants.

The independence scores that were used to assess and record participant progression over the intervention period were part of the observation schedules (Chapter 8/Appendix 11.10). The independence scores were arguably representative of observable fastening behaviours for all fastening conditions (zips, buttons, poppers and shoelaces). The scores from the observation schedules were used in the current thesis in order to examine the impact of the intervention on the 3 participant groups. The reliability and validity of this measure is outlined next in relation to RQ4.

#### **10.1.4. Discussion of Findings in Relation to RQ4**

This section explores the findings of the main study in relation to RQ4:

'Can a novel observation schedule reliably and validly assess the development of ILSD in these groups?'

The results of inter-rater validity investigation (Chapter 8) appeared to support the reliability and validity of the data regarding the observation schedules for each fastening condition (zips, buttons, poppers and shoelaces). This meant that each outlined stage of unfastening and fastening was considered observable and measurable from an outside perspective. The detailed and nuanced observation schedules for each fastening condition are the first of its kind in the literature. They draw on the established literature (Fairnham et al., 2002; Klein, 1983) but split fastening activities into smaller more manageable and observable steps which are arguably beneficial to the concept of chaining (Chapter 3). Arguably, the nature of the observation schedules also support adults who may be delivering the intervention. This is done by providing detailed guidance on verbal instructions to support children with their fastening (e.g. “pinch the button”). By labelling the multiple stages of fastening and linking each stage with a photograph, it is argued that supporting adults (e.g. teachers and parents/carers) can more fully understand the nature of the task and what is to be achieved. It is hoped that this further supports the task development in children due to the clearly defined stages of unfastening and fastening.

The preliminary findings supporting the reliability and validity of the observation schedule may be indicative of the need to appropriately train key supporting adults in relation to delivering the intervention tasks. The following section explores this in relation to RQ5.

#### **10.1.5. Discussion of Findings in Relation to RQ5**

This section explores the findings of the main study in relation to RQ5:

‘is there a need for a training manual designed for parents/caregivers and professionals to support the development of ILSD?’

As a direct result of the intervention and appropriate recording of the intervention procedure, the development of a training manual to accompany the intervention was made possible. The training manual (Appendix 11.8) included strategies for using the IPG and also warm up activities which enabled the observation of pre-requisite skills for ILSD (outlined in section 2.1). Due to time constraints of the project, the development and testing of a full training protocol for key supporting adults was not possible. However, the training manual demonstrates the simple, systematic and clear verbal instructions which were used to aid the development of ILSD in the three participant groups recruited for the current study. The training manual also details the instructions as to how to use the suite of novel intervention materials to further support the development of ILSD.

The current research was, to an extent, informed by the research by Fairnham et al., (2002). Their project culminated in the publication and dissemination of a training package which was designed to support parents and practitioners in the development of ILS in children with VI in Australia. The package, although arguably beneficial and suitable for addressing parent and child needs, was brief and lacked identification of the nuances revealed in the current study, that are apparent in developing ILS. The current thesis developed a systematic, nuanced and detailed novel intervention protocol, accompanying observation schedules and guidance for parents and professionals (Appendix 11.8). The current work is evidence based and is grounded in habilitation. The current study has incorporated elements of the published work by Klein (1983) and Fairnham et al., (2002) such as the incorporation of pre-requisite skills that are essential for ILSD (e.g. pinching the index finger and the thumb together) and also the concept of body awareness (as demonstrated by playing the game Simon says). The current thesis brings together previously established works and has updated an approach to developing ILSD in children with VI and DS.

Supporting parental involvement was also indicative of the need to develop a training manual as presented in the case of P25 (Section 9.8.6). This is because the parents involved within the DS group, and also the presence of teaching assistants within the VI group showed an interest in the development and utility of the intervention. This suggests that in order to appropriately and efficiently deliver the intervention protocol, parents and professionals ought to be provided with the appropriate training and information regarding the delivery of the intervention. This means that, arguably, the development of the training manual (Appendix 11.8) designed for supporting adults could potentially support ILSD development to a great extent. Although this has not been quantified within the current thesis, the expression of interest from supporting adults begins to demonstrate a need for such materials to support the delivery of the intervention. Future work (discussed later in this chapter) is intended to address the need for a complete training package to support the development of ILSD in young children with developmental disabilities.

The role of supporting adults was also an apparent theme in the explored literature, the underpinning theorisation and the main study. There were arguably many different dimensions to this theme, such as the role of the professional and also the role of the parent/caregiver. Although it can be posited that both groups of adults supported the participants, their roles were arguably different. McLinden (2012) noted some aspects (e.g. practitioners supporting tactile symbolic communication) in relation to the role of the professional and suggested ideas for future work in relation to this.

In the examined literature, there was an identified need for a framework to better understand the role of the adult (McLinden, 2012) in relation to maximising child independence. Although a specific framework has not been established within the current thesis, the role of the adult has been considered and action was taken through the development of the training manual (Appendix 11.8). The role of the professional/practitioner is acknowledged within the training manual and the current thesis has established that arguably simple, systematic instruction and physical hand-over/under-hand assistance appeared to support independence in the three recruited groups (VI, DS and TD). The current thesis has also illustrated that providing the opportunity to ask for assistance was beneficial for the development of ILSD. This implies that the presence of a supporting practitioner is useful in maximising independence, however the children must be afforded an opportunity to develop themselves, albeit through trial and error.

The role of the practitioner in this thesis arguably provided a safe environment for participants to facilitate haptic exploration through the use of verbal instructions and physical assistance. The use of scaffolding and chaining (Chapter 2) to support task performance was also beneficial. The intervention overall used scaffolded support in order to assist the development of ILSD in the recruited participants. The support provided was physical hand-over/under-hand and verbal instruction.

The adult involvement was reduced over the intervention period in accordance with the development of ILSD in the sample. This is evidenced by the percentage decrease in all fastenings presented in Chapter 9. The use of scaffolded activity supports the notion of the zone of proximal development presented in Section 2.2.3. The results presented in Chapter 9 illustrate how independence can be maximised by the gradual removal of structure and guidance provided by a practitioner. From this, a foundation to appropriately explore McLinden's (2012) point in terms of practitioners and professionals may begin to be established.

Developing the role of the practitioner/professional may appeal to McLinden's (2012) point regarding the development of a framework, however the role of the parent/caregiver must also be considered. The evidence accumulated from the current thesis noted that the role of the parent/caregiver was also important. The obtained parental consent toward child participation in the current study demonstrated that parents were keen for their child to learn ILSD. This meant that parental overprotection (as suggested by Kellegrew, 2000 and Khadka et al., 2002) may be a less apparent issue in the general recruitment for the sample. In contrast to this, the behaviour of some parents of the DS group may have had an effect on the effectiveness of the intervention.

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As illustrated in Chapter 9, in the case of P25, parental influence may have reduced the effect of the intervention on participant development of ILSD. It was observed that parents would often complete the fastening task for their child, if the participant was seen to be struggling or taking too long. By “taking over” the fastening task, parents were effectively reducing the opportunity for their child to develop ILSD. This provided some evidence for the assumption made by Kellegrew (2000) whereby children develop ILSD more when they are provided the opportunity to do so.

Parental involvement and arguably overprotection (as noted by Khadka et al., 2002) may have restricted access to developing maximum independence. Linking the literature of Kellegrew (2000) and Khadka et al (2002) to the issue raised by McLinden (2012) it is suggested that the role of the adult as a parent/caregiver must be accounted for when developing a framework to maximise independence. Arguably, from a parental point of view, the framework and subsequent practices should relate to day-to-day practices in the home environment (e.g. Lewis & Iselin, 2002).

From this understanding of the role of an adult (e.g. parent/professional), it was considered important to make the training manual accessible (e.g. using appropriate language for parents), meaningful (so parents/caregivers can understand the utility of the task), and also have elements of transference which converts the abstract (intervention) into the actual (independent dressing). The intervention materials, observation schedules and training manual were all designed to be accessible to supporting adults ranging from professionals to parents. This was considered important as it accommodated the needs of adults in addition to supporting the needs of the children.

The previous sections have explored the results of the main study within the context of the five established research questions. The next two sub-sections discuss the findings of the main study in relation to the fastenings survey (presented in Chapter 5), and the pilot study (presented in Chapter 7). This was done in order to explore the potential impact of the novel intervention materials in relation to the previous work undertaken in this thesis (Chapter 5 and Chapter 7).

#### **10.1.6 Discussion of main study in relation to fastenings survey**

The preceding sections discussed the findings of the main study (Chapter 9) in relation to the five established RQs for the thesis. The next two sections explore the findings of the main study in relation to the fastenings survey (Chapter 5) and the Pilot study (Chapter 7). This is done as potential perspectives and further insight may be drawn from these chapters which may add to the main discussion.

The results of the fastenings survey (Chapter 5) did not predict intervention score performance. This meant that although participants arguably would have had a greater exposure to zip fastenings (due to their chronological age (CA)), it did not entail that the participants were able to successfully fasten them. This was supported by the results of the main study (Chapter 9) where 12 participants (VI  $n=3$ ; TD,  $n=9$ ) reached the ceiling effect for fastening. This suggested that independent fastening ability may not be directly linked to fastening exposure. This finding was unexpected in relation to the findings of the fastenings survey. To add to this point, as participants arguably had a high exposure to popper fastenings from birth, not one participant could not identify or manipulate this fastening at baseline level. This supports the notion that high exposure does not necessarily lead to independent fastening ability. However, another explanation may be resultant of the lack of gross and fine motor control required in order to successfully manipulate the fastenings at the time of their exposure to the fastening in question. As high exposure to popper fastenings (for example) occurred early on in the participant's development, their gross and fine motor skills are emerging and largely unrefined. As CA increases and the child develops, the refinement of these skills gradually occur. This has been somewhat evidenced in the results of the main study, where baseline scores for popper fastenings were poor, however the gross and fine motor skills required for successful, independent fastening occurred quite rapidly between week 1 and week 4 for all three groups (VI, DS and TD) (Section 9.4).

As suggested by the discussion of the survey results (Section 5.4), the survey was unable to record the exposure to particular fastenings for each individual participant. It is arguable that the collection of this data would not have any substantial bearing on the results of the main study. This means that the results of the fastenings survey may have been indicative of fastening ability for some participants, yet the results were not necessarily applicable to the experiences of the three recruited samples (VI, DS and TD).

The findings of the fastenings survey did inform the development of the IPG materials. The fastenings chosen (zips, buttons, poppers and shoelaces) were indicative of the types of fastening that children (aged between 4-11 years) would likely to be exposed to. Arguably, shoelaces were less prevalent when compared to zips, buttons and poppers, yet they were

included on the design as tying shoelaces was considered to be an essential component for ILSD when the participants transitioned into adolescence and adulthood.

### **10.1.7 Discussion of main study in relation to piloting**

This section explores the findings of the main study in relation to the pilot study (Chapter 7). As outlined in Chapter 7, a number of adaptations to the IPG were required for the main study. These adaptations included: standardising the materials in terms of colour and material; recording fastening preference; and video recording sessions to aid inter-rater validity for the observation schedules. In light of the results of the main study, these adaptations seemingly supported the effectiveness of the intervention materials and procedures.

Participants largely chose fastenings based on their preference. Colour and texture were not mentioned by the participants throughout the intervention procedure. This meant that controlling for colour and texture was a necessary adaptation to avoid bias based on those attributes. Affording the participants the opportunity to try fastenings of different sizes however, did have an impact on fastening choice. Participants who struggled with fastening (particularly P5) had a tendency to prefer the big button when given the choice of fastening. In addition to this, participants who had the motivation to independently fasten and unfasten (e.g. P3, P4 and P1) had a tendency to choose the smallest size of fastening as they thought that it was “trickier”. By controlling for size, recording participant preference and ILSD scores (on the observation schedule), the research has been informed as to the types of choices children may make based on motivation and arguably their perception of “easier” tasks.

Video recordings were made during the intervention procedure. The videos were taken of participants hands when manipulating the pieces. As a result of this “up-close” form of videoing, it was difficult to both video and assist participants during tasks. A fixed camera was not a feasible option to preserve the anonymity of participants and to also film the movement of the hands, and so this arguably limited the capacity to use the videos for an interrater process (Chapter 8). In order to compensate for this, an actor was used to create the videos to support the inter-rater process. The inter-rater process was carried out in order to support the reliability and validity of the observation schedules. This process yielded a minimum of 95% confidence of observation scores (Chapter 8). This finding supported RQ4 as it appeared that the novel observation schedule did reliably and validly assess the development of ILSD within the context of the main study (Chapter 9).

The adaptations that were made as a result of the pilot study arguably benefited the main study. The materials used were more refined, and the observation schedules became more nuanced and detailed (Chapter 8). Controlling for as many confounding variables as possible arguably aided the effectiveness of the materials used in the main study. This is demonstrated by the results of the main study for each group (VI, DS and TD), across all four fastening conditions (zip, buttons, poppers and shoelaces).

The findings of the main study have been explored in relation to the outlined research questions, the fastenings survey and the pilot study. The following section offers a critical reflection of the thesis. Within the next section, the limitations of the current study are presented.

## **10.2 Critical Reflection of the Thesis**

The previous sections in this chapter explored the main study and literatures related to the five RQs established for the current study. The results of the fastening survey and the pilot study in relation to the main study also offered different perspectives for the thesis. Overall, having looked at the RQs, the fastenings survey and the pilot study (and the perspectives they offered), it has been argued that the current thesis has addressed all five RQs. However on the grounds of practicality and transparency it is important to acknowledge the limitations of the work. This section explores five identified limitations to the current work. These are: the original conceptualisation of the work compared to the actual work undertaken; the small sample size; issues with matching the three groups; participant absence; and, the division of the researcher's attention within a group based setting. These limitations are addressed in turn, and commence with the issues surrounding the original conceptualisation of the project.

The first identified limitation regarded the original conceptualisation of the project. As outlined in Chapter 6, the study was originally conceptualised on a larger scale. The intended populations for recruitment were: children with VI, children with DS, children with Cerebral Palsy, children with Williams Syndrome and TD children. This meant that the sample was intended to be drawn from 4 clinical populations with associated developmental delay. The ideal sample size for the project was conceptualised as 40 where  $n=20$  were TD and  $n=20$  were drawn from the 4 clinically defined populations. However, due to the real-world applications of research (including issues with recruitment and time constraints of the project), examining 5 groups (4 clinically defined; 1 TD) was not feasible. The project was subsequently downsized to two clinically defined groups (VI and DS) and TD children. Although the project was originally designed as a larger project, the current thesis provides the first empirically

based intervention for the outlined groups, and subsequently provides a basis for further exploration in groups where developmental delay is a characteristic.

Although the current project was downsized in order to focus recruitment toward three participant groups (as this was more realistic given the time frame for completion), the second limitation of the current thesis was the small sample size of recruited participants. As outlined in Chapter 6 there were a number of issues relating to participant recruitment. Some of these issues pertained to general access issues (particularly noted for the TD sample), and other issues related to the recruitment of participants with VI and DS. In order to recruit VI participants, contact with the RNIB was made to publicise the project. An information sheet was disseminated via email to parents/caregivers, specialist and mainstream schools to explain the research aims and procedure. Unfortunately, this publicising of the research project did not in practice, materially aid in the recruitment of further participants.

The recruitment of the DS was also difficult. Initial contact was made to a number of specialist schools and volunteering organisations. This contact was made at a similar time to that for the VI and TD groups. This attempt to recruit participants with DS was unsuccessful, possibly because children with DS may attend mainstream schools and this was not factored into the recruitment approach for participants with DS. Ten months after the initial attempt to recruit DS participants was made, a final attempt was successful from an organisation that had initially declined to participate. This was within the context of a voluntary organisation, which was dedicated to support children with DS. This was the only organisation who permitted access for the research project, and due to the limited students in attendance, this also affected the nature of and sample size of the current study.

Although every effort was made to recruit a substantial sample for each group (VI, DS and TD) due to access problems and the nature of real-world research this was not possible. This limitation does have an effect on the practical application of the results presented) and effectively precludes any claims for generalizability) in the current study, yet serves to provide an arguably indicative basis for further examination of ILSD progression.

The third limitation also pertained to recruitment. As there were issues in the recruitment of a TD sample from London meaning that matching the VI, DS and TD groups based on location was not possible. The TD group were recruited from a mainstream school setting in Cumbria, UK. This was considered a limitation as the difference in physical location may have had an effect on ILSD development. This is because there may potentially be a difference in skill development and provision between urban areas (e.g. London) and rural areas (e.g. Cumbria).

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This meant that there may have been a confounding variable (location) which may also have affected the development of ILSD which could not have been controlled for in the current study.

The absence of recruited participants was identified as the fourth limitation to the study. Absence arguably played a crucial role in the development of ILSD and could not be controlled for. Although absence is considered to be a characteristic of the recruited clinical groups (e.g. due to sickness and hospital admissions), it could be argued that a prolonged intervention period may support the reaching of ceiling effects in the clinical samples. To elaborate on this, it was evidenced that the DS group did not engage in the full 10 week intervention. Although the intervention was conducted within a 10 week time-frame, due to the high number of absences, the children with DS did not engage in 10 *full* weeks of intervention. This meant that the observed impact of the intervention was dependent on participants attending the sessions, and so extending the allocated time available (e.g. 20 weeks) may ensure that participants would receive the full 10 week of structured and systematic intervention.

The fifth limitation to the study concerned the division of the researcher's attention during the intervention sessions. This was because the intervention was conducted in a group based setting. This is considered to be a limitation as the researcher's attention was divided across the children within the groups. This meant that although the intervention session ran for 15 minutes, each child did not necessarily receive 15 minutes of continual support. The TD group and some children with VI (e.g. participants 1, 3 and 4) did not need continual adult support, and did not vocalise this in the sessions. This suggests that not all children may need the full 15 minutes allocated for the session, and this may be a result of motivation toward independence and task completion. Other participants with VI (e.g. participants 2 and 5) and the DS participants were more dependent on physical assistance (as demonstrated in Chapter 9) and also verbal instruction and encouragement to support task completion. Arguably, this means that some children may prefer to work 1:1 with an adult. The development of ILSD for these participants may not have been optimised as a result of shared attention, and the children may have benefitted from the full 15 minute session working 1:1.

The five outlined limitations to the current study reflect the real-world nature of conducting research within educational settings. Although every effort was made in order to minimise the effects of these limitations, they were considered to be unavoidable given the nature of the project. Acknowledging the limitations of the current study does aid in contextualising the findings of the thesis and also sheds light on the implications that the current study may have.

The next section explores the implications of the thesis and also outlines the original contribution to knowledge that this thesis may offer.

### **10.3 Implications and Contribution to Knowledge**

This section first explores three arguably important implications of the current thesis. This is in relation to the research findings (presented in Chapter 9 and discussed in the current chapter). The section then identifies six areas of which the current thesis offers original contributions to knowledge.

The first possible implication pertains to participant performance in relation to clinical diagnosis. The individual participant performance in this study were indicative of the high level of variation within clinical samples. Taking into account the clinical diagnoses of Participant 3, for example, the nature of his condition (Juvenile Onset Batten's Disease), his acquisition of fastening skills and additionally his ability to reach the ceiling effects (brought about by the nature of fastening, not a personal ceiling effect), were not predicted based on his clinical diagnosis. This was diagnosed as a result of developmental regression associated with the condition. Participant 3 however, appeared to benefit greatly from the intervention period and was able to complete all fastenings independently by week 10. In addition, Participant 5, (who was clinically diagnosed with septo-optic dysplasia) appeared to reach her own ceiling effects as opposed to the ones occasioned by the fastening tasks. This pattern was consistent throughout the clinical sample, whereby the participant's individual scores, when they did not reach the fastening ceiling effect, appeared to reach their own. This was evidenced by the lack of percentage change between particular weeks. This result may be due to the developmental issues informing the clinical diagnoses and associated developmental delay, whereby progression was not possible beyond a certain point.

The first implication related to the need to fully understand the complexities that may be informing a specific clinical diagnosis. This means that the background measures (medical history and socio-economic status questionnaires) and the standardised measures of cognitive functioning used in this thesis contributed toward understanding these complexities. By gathering these forms of data, it meant that the intervention procedure could then potentially be adaptable to support the development of ILSD in relation to individual needs. It was found that some participants with severe diagnoses performed "better" than some participants who had less severe diagnoses. By understanding the nature of diagnoses in

general, in addition to understanding how the diagnoses affects the participant physically and behaviourally the intervention was structured accordingly.

The second implication related to participant motivation. Participant motivation also appeared to influence task performance. Participants who appeared motivated toward independence, or engaged in competition with their peers appeared to perform better within the VI and TD groups. Arguably, due to participants' communication problems within the DS group, and their reduced verbal fluency, this motivation was not expressed in the same way as the other groups. The performance scores on the standardised tests (digit span and phonemic/semantic verbal fluency) were not predictive of the outcome of the intervention. This meant that modes of meaningful communication (e.g. speech and Makaton) needed to be explored to support participant motivation. In order to meaningfully communicate the instructions for the intervention, the person delivering the intervention must have knowledge and understanding of methods of non-verbal communication (e.g. Makaton). This is to understand participant's expression of emotion and also to communicate effectively with participants who may have communication problems.

The third implication of the current thesis related to the role of the professional who would be delivering the intervention. Good record keeping is essential, and the gathering of robust background information assists in developing full participant profiles to fully understand the effects of the intervention. Although there were limitations to this implication in the pilot study, the information gathered helped to better understand the individual participants. In the current thesis, parents/carers were encouraged to complete medical history questionnaires (including developmental milestones) and socio-economic status questionnaires, the response rate was poor. As a result of this, more detailed participant profiles, and the relationship between the effects of the intervention and participant background could not be appropriately investigated. Further research may benefit from a higher level of detail regarding participant histories, as there may be a link between task performance and participant background/age of reaching developmental milestones which may be predictive of ILSD development.

In addition to addressing the five research questions, the current thesis contributes to knowledge in a number of ways. First, the development, refinement and standardisation of the IPG and standardised coat have contributed to the field of habilitation. This is because the resources were developed with a child-centred approach, unlike resources which have previously been used from a rehabilitation perspective. The effectiveness of these resources and impact on the development of ILSD have arguably and positively contributed to the field of developmental psychology and theories of multi-sensory learning, including haptic

perception. This is supported by the noteworthy quantitative findings reported in Chapter 8, as the intervention procedure and the use of the novel suite of intervention materials have appeared to increase ILSD development in children with VI, DS and also TD children. These findings have also contributed to the field in relation to the discovery that TD children also required structured and systematic support in ILSD development.

This links to the second contribution to knowledge which the development of the intervention-related observation schedules. The schedules were designed to support the suite of novel intervention materials, by splitting the unfastening and fastening tasks into smaller, systematic and meaningful chunks. These detailed and nuanced continuum-based observation schedules have identified the many stages required to successfully unfasten and fasten zips, buttons, poppers and lace fastenings. The inter-rater validity results also demonstrated a high confidence rate in the reliability and validity of the observation measure. This means that the observation schedules may serve to provide a meaningful base for the observation of task mastery across all four fastening conditions, and may also be used as an assessment measure by supporting adults (e.g. parents/carers and professionals).

Third, the current thesis is the first cross-developmental comparison of clinically defined populations which has explored novel habilitation techniques for ILSD (i.e. the novel resources created for the study). Thus one contribution to knowledge that the current thesis offers, is the innovative application of novel systematic strategies within a habilitation context which extends beyond children with VI. Professionals can use the novel materials, observation schedules and training manuals presented in this thesis. These can be used in order to structure interventions which are appropriate for children with VI and also children with clinical diagnoses where VI is a characteristic.

The development of the training manual to support parents and professionals offers the fourth novel contribution to knowledge. The manual has consolidated the intervention procedure, the use of the novel suite of intervention materials and the observation schedules in order to support adults who would be teaching such strategies to children with VI and DS in particular. The training manual also serves to support the teaching of ILSD within a typical context. The training manual was purposefully written to be as accessible as possible for a range of supporting adults, and so the dissemination of this resource is not specific to practitioners. This is because it is arguably useable and accessible for parents and carers too.

In addition to the physical materials that offer a novel contribution to the fields of habilitation, developmental and educational psychology, the fifth contribution to knowledge, arguably, was the emerging underpinning theorisation of the development of ILS. This concerned the examination of aspects of related theories that arguably support the link between the practical and theoretical aspects of the current study. It was also posited that the related theories may possibly support the development and discrimination of ILS as a distinct field. As outlined in Chapter 1, there is yet to be a unifiable theory underpinning habilitation and the development of ILS. The current thesis offers a theorisation which may begin to form a suitable underpinning theory for future work in relation to habilitation and the development of ILS. Arguably, the current research has contributed to updating the field of habilitation by providing an intervention approach based on the needs of children with VI in a range of needs and contexts.

Finally, the literature based chapters illustrated that research regarding the development of ILSD in children with VI has been somewhat lacking. As habilitation is now identified within English legislation (Department for Education & Department for Health England, 2015) it is imperative that an understanding of techniques and practice is understood as fully as possible. The findings of the current thesis may begin to form a foundation for further areas of ILS and habilitation in practice.

The implications and contributions to knowledge illustrated how the current study may begin to support understandings of the development of ILSD in the three participant groups. From these understandings future directions for the work can emerge. The future directions are explored in the next section.

#### **10.4 Future Directions**

In light of the points previously discussed, the current thesis offers potential for future work in the area of ILSD. In direct relation to the results yielded from the main study, future work could examine the effectiveness of 10 full weeks of intervention (over a longer period of time e.g. 15 weeks) rather than offering a limited 10 week period where participants with clinical diagnoses may have a high absence rate. Also, as the 10 weeks condensed into 5 hours of training, further work could also examine the effectiveness of a more intense intervention period, which ensures that participants have the full 5 hours of intervention but over a shorter period of time. The assessment of the impact over an intensive period may also reveal more about the development of ILSD and the development of gross and fine motor control trajectories.

The qualitative results as demonstrated by the case studies (presented in section 9.8) also revealed that some children may have a preference for 1:1 learning, as opposed to group

based activities. Further research could comparatively analyse individual ILSD development between 1:1 sessional teaching and group teaching. This may reveal the effectiveness of the intervention procedure in different contexts which may optimise the development of ILSD.

In a similar vein, the findings of the main study (Chapter 9) may also have been affected by the educational setting of which the intervention was ran. As VI and TD sessions were school based, the development of ILSD may have also been affected by the participants understanding that the intervention was school based. If participants had an association with the school setting and learning, they may have been more prepared to learn. The sessions for the DS participants were ran within an educational environment, however as this was non-compulsory education, this may have affected the ILSD scores. This is because participants with DS may have understood the sessional context as purely play, rather than play based learning.

The educational context of which the sessions were ran may have affected performance, and so a future direction may be to conduct the intervention procedure within the same education setting (i.e. compulsory school based settings). To further expand this context-based assessment, a further future direction may also be to examine the development of ILSD within a home based context – using the same materials and procedure.

A further direction for the research is to investigate the role that parents/caregivers play in the development of ILS and ILSD in particular. As the VI and TD groups were based in a school setting, parents were not present during the intervention procedure. However, parents were present in the DS setting. This arguably had an impact on the development of ILSD, as evidenced in section 9.8 and also the vignettes (Appendix 11.4), as parents would complete the task for their child instead of allowing the child to attempt to unfasten/fasten. This could arguably be a result of parental overprotection, as the parents involved appeared uncomfortable witnessing their child struggling.

Furthermore, it draws on the evidenced literature where parents complete the task for the child within a given time frame. As the research focus was on the development of ILSD, it could be argued that parental presence may have limited fastening skill development. By exploring the role of supporting adults, the effectiveness of the training manual (Appendix 11.8) could also be systematically examined.

Finally, the initial research design and ethical procedure included children with Cerebral Palsy and Williams Syndrome. Due to time constraints associated with the project, the recruitment

and subsequent testing of these groups were not possible. Future work in this field would benefit from the examination of additional groups with disabilities, in order to understand the developmental progression of ILSD within a range of clinical diagnoses. The additional impairments associated with these conditions ought to be measured and controlled for. Given the time constraints of the current project, the hearing impairment/s associated with the DS diagnosis were not measured.

## **10.5 Conclusion**

The current thesis aimed to answer 5 research questions relative to the development of the independent living skill of dressing in 3 participant groups (VI, DS and TD). The previous sections in this chapter have indicated the extent to which the research questions were answered and also provided: a critical reflection of the project, the implications of the project, the contributions to knowledge and potential future directions of the research.

The main findings of the current thesis appeared to support the suitability of the novel intervention materials in relation to the development of ILSD in young children with developmental disabilities, namely VI and DS. Remarkably, the findings also supported the materials' use in the development of ILSD within a TD context. The results of the project indicated that there were notable benefits for using the novel intervention materials to support ILSD development over a 10 week intervention period. A longer-term impact was also found which suggested that, ILSD skills could be retained after 3 months after the intervention ceased. Although there are limitations to the current study, they provide opportunity for further research within the broader area of ILS, not just the development of ILSD skills.

In conclusion, the thesis presented a novel and innovative approach to understanding ILSD. This was done through the design and development of novel intervention materials to support ILSD. The thesis is the first literature source to attempt to provide a theorisation in the emergent, practice-based field of habilitation and ILS. The current study is also the first to offer a contribution to dressing strategies since the early 1950s, and also the first to comparatively explore the development of ILSD in 3 distinct, yet related, participant groups (VI, DS and TD). As the current study is the first of its kind, there is a great potential toward future directions of such research in other areas of ILS, and also in relation to other clinical groups such as Williams Syndrome and Autism.

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## Appendices

### 11.1. Raw data to support Chapter 4: Fastenings Survey

Table 5.2.

*Combined frequency table of items of clothing surveyed.*

<u>Clothing Type</u>	<u>Frequency (% of total items*)</u>
Bodysuits/onesies	61 3.9%*
Trousers/Shorts	210 13.4%*
Sleep and play footsies	22 1.4%*
Bibs	21 1.3%*
Cardigans/jumpers	167 10.6%*
Outdoor jackets	161 10.3%*
Outdoor bodysuits	5 0.3%*
Booties/shoes	290 18.5%*
Baby gown	4 0.3%*
Dress	125 7.9%*
Shirt/blouse	89 5.7%*
Jeans	93 6.0%*
Skirt	43 2.7%*
T-shirt	278 17.7%*
Total	1569 100%

Note: \* percentage rounded to nearest decimal point.

\*\* Bibs are identified as an item of clothing on the search matrices on all websites, and so were included in the survey.

Table 5.3.

*Frequency of clothing fastenings for children aged between premature-2 years and 2-14 years.*

<u>Type of Fastening</u>	<u>Frequency</u>	<u>Frequency</u>
	<u>Prem-2 years (% of total items*)</u>	<u>2-14 years (% of total items*)</u>
Zip	44 2.8%*	318 20.3%*
Button	62 4.0%*	165 10.5%*
Popper	100 6.4%*	14 0.9%*
Velcro	18 1.1%*	55 3.5%*
Shoe Laces	-	74 4.7%*
Shoe Buckle	-	22 1.4%*
Backwards Zip	-	34 2.2%*
Backwards Popper	2 0.1%*	-
Backwards Button	8 0.5%*	25 1.6%*
Slip on	67 4.3%*	561 35.8%*
Total	301 19.2%*	1268 80.9%*

Note: '-' represents no data gathered for these conditions.

\* percentages rounded to nearest decimal point.

Table 5.3.

*Frequency of primary fastenings across both age ranges.*

<u>Type of Fastening</u>	<u>Frequency (% of total items*)</u>
Zip	362 23.1%*
Button	227 14.5%*
Popper	114 7.3%*
Velcro	73 4.7%*
Laces	74 4.7%*
Buckle	22 1.4%*
Backwards Zip	34 2.2%*
Backwards Popper	2 0.1%*
Backwards Button	33 2.1%*
Slip on	628 40.0%*
Total	1569 100%

Note: \* percentage rounded to nearest decimal point.

Table 5.4. *Frequency of secondary fastenings across both age ranges.*

<u>Type of fastening</u>	<u>Frequency (% of total items*)</u>
No fastening	1335 85.1%*
Button	178 11.3%*
Popper	49 3.1%*
Velcro	5 0.3%*
Laces	2 0.1%*
Total	1569 100%

Note: \* percentage rounded to nearest decimal point.

Table 4.5. *Frequency of tertiary fastenings across both age ranges.*

<u>Type of fastening</u>	<u>Frequency (% of total items*)</u>
No fastening	1561 99.5%*
Velcro	8 0.5%*
Total	1569 100%

Note: \* percentage rounded to nearest decimal point.

## 11.2. Participant consent form

Dear Parent/Guardian,

My name is Jessica Hayton, I am a PhD student at the Institute of Education, University of London. I am writing to you regarding my research, entitled:

*Developing the Independent Living Skill of Dressing in Children with Visual Impairments, matched with Typically Developing Children aged 4-11 years.*

My research focus involves comparing children with visual impairment, Down Syndrome and non-visually impaired children, by observing them carrying out independent living skills, such as putting on an outdoor coat. I will carry out my research through an interactive dressing game story, and will be working with the children for 10 weeks. All of my research will take place during school hours.

The aim of my study is to develop the skill of putting on an outdoor coat. Although this seems like a simple task, the development of the gross and fine motor skills required to successfully put on a coat promotes independent living skills. If my research is effective, it could encourage much needed further development in this area, especially for visually impaired children.

I will be conducting the study in four parts, as follows:

- Part One – Collecting background medical data for your child, asking you the parent/carer to complete a medical questionnaire and provide a retrospective record of the age that your child reached certain developmental milestones. Assessing your child's developmental age by using memory tasks and problem solving tasks. Asking you the parent/carer to complete a quick questionnaire on socio-economic status
- Part Two - an initial assessment of the child's gross and fine motor skills
- Part Three – an interactive dressing game story, where the children will take part in a role play activity in which 'Joey the monkey' goes out for the day, putting on and taking off their coats in line with the places Joey goes as part of his daily routine
- Part Four – a final assessment of the child's gross and fine motor skills, to see if anything has changed after the role play activity

I expect to spend 8-10 weeks with your child. This will allow me to carry out fair research, and will also ensure that I am familiar with the children with whom I am working. Your child is still entitled to any support they usually receive at school, but the teaching assistant's ability to help with the dressing activity will be limited, as it is important for the children to independently complete as much of the task as possible.

I have ethical approval from the Institute of Education's Ethics Committee and permission from your child's school. I am asking for your permission on behalf of your child. Please fill in the form below and return it by **5<sup>th</sup> June 2015** if you **do** wish your child to participate in this study; this includes audio, video and photographic recordings used for the observation phase.

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You and your child are guaranteed 100% confidentiality and anonymity and also have the right to withdraw from the study at any point. Your child's voice will be listened to throughout the study and if your child wishes to withdraw, their file will be destroyed immediately and data will not be used. All files will be destroyed in September 2016, upon completion of the thesis. There is a chance that parts of the thesis will be published which includes the results section and scoring. As each child's result is anonymous your child will not be identifiable in the write-up. I, the researcher, have a full enhanced DBS check, as do my supervisors, who will be the only other people who have access to the data.

If you have any questions or queries, please do not hesitate to contact me on the email address above.

Yours sincerely,



Jessica Hayton

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**I give permission for my child \_\_\_\_\_ to  
participate in the study.**

**Signed \_\_\_\_\_ (parent/guardian) Date \_\_\_\_\_**

Jessica Hayton

### 11.3. Ethical procedure

## Ethics Application Form: Research Degree Students



Leading education  
and social research  
Institute of Education  
University of London

All student research that use research methods to collect data from human participants is required to gain ethical approval before starting. Please answer all relevant questions. Your form may be returned if incomplete. Please write your responses in terms that can be understood by a lay person.

For further support and guidance please see Ethics Review Procedures for Student Research <http://www.ioe.ac.uk/studentethics/> or contact your supervisor or [researchethics@ioe.ac.uk](mailto:researchethics@ioe.ac.uk).

### Section 1 Project details

a.	Project title	<i>Developing the Independent Living Skill of Dressing in Atypical Children with Visual Impairments, matched with Typically Developing Children aged 3-11 years.</i>
b.	Student name	Jessica Antonia Hayton
c.	Supervisor	Dr. Karl Wall. and Dr. Dagmara Dimitriou
d.	Advisory committee members	
e.	Department	Psychology and Human Development
f.	Faculty	Policy and Society
g.	Intended research start date	10/2014
h.	Intended research end date	05/2016
i.	Funder (if applicable)	

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j.	Funding confirmed?	
k.	Country fieldwork will be conducted in  <i>If research to be conducted abroad please check <a href="http://www.fco.gov.uk">www.fco.gov.uk</a> If the FCO advice against travel a full travel risk assessment form should also be completed and submitted:</i>  <a href="http://intranet.ioead/ioe/cms/get.asp?cid=14460&amp;14460_0=22640">http://intranet.ioead/ioe/cms/get.asp?cid=14460&amp;14460_0=22640</a>	UK
l.	All research projects at the Institute of Education are required to specify a professional code of ethics according to which the research will be conducted. Which organisation's research code will be used?	BPS
	<i>If your research is based in another institution then you may be required to submit your research to that institution's ethics review process. If your research involves patients recruited through the NHS then you will need to apply for ethics approval through an NHS Local Research Ethics Committee. In either of these cases, you don't need ethics approval from the Institute of Education.</i>	
m.	Has this project been considered by another (external) Research Ethics Committee?	<b>No</b> ⇒ go to Section 2
	<i>If so, please insert the name of the committee, the date on which the project was considered, and attach the approval letter in either hard or electronic format with this form.</i>	
	External Committee Name:	Date of Approval:
⇒ <i>If your project has been externally approved please go to <b>Section 9 Attachments</b>.</i>		

## Section 2 Research Summary

Please provide an overview of your research. This can include some or all of the following: purpose of the research, aims, main research questions, research design, participants, sampling, data collection, reporting and dissemination. *It is expected that this will take approximately 200-300 words, and you may write more if you feel it is necessary.*

The research referred to below concerns the habilitation of children with visual impairment. Habilitation refers to the teaching and developing of independent living skills in children as they move towards independence (Miller, Wall & Garner, 2011).

Dressing is considered an essential independent living skill, fundamental for everyday day life yet quite often taken for granted (Klein, 1983). The ability to dress oneself is crucial for independence and becomes increasingly important with age. Pre-requisites for successful dressing such as balance, hand-eye co-ordination of both hands, and transferable skills, such as pinching together the index finger and the thumb have all been identified (Fairnam, Johnston, Kain, Kain, McCauley & Steele, 2002).

There is a distinct lack of literature in the field of visual impairment in relation to dressing skills in relation to children. The majority of current practice being based on Klein's work, with disabled soldiers and veterans in the 1950s and 1960s. The available literature highlights methods for successful dressing but does not provide supporting resources, except in the limited case of some recent Australian materials which have not been assessed in the UK. It is also important to note that the majority of published materials around independent dressing are targeted at adults meaning that there are very little published materials relating to children and children's clothes. The current research aims to develop the independent living skill of dressing, through a programme of 4 novel intervention materials developed in this project- these will constitute the 'intervention suite'.

The intended participants are children with visual impairment, and children who have a disability with visual impairment as a characteristic or component of their needs; Down syndrome (DS), Williams Syndrome (WS), Cerebral Palsy (CP). The reason for including children with visual impairment as a characteristic is because it is considered important to provide all children, regardless of type of disability, with a means of acquiring independence (as noted by Wall (Wall, 2014). Also, the testing of the suite of instruments on different populations may indicate its effectiveness and offer insights into how they might work over a range of visual needs. This is important because of the very high levels of within-person variation found among those with visual impairments within and across different diagnosed needs. Furthermore, within the context of general disability, it is postulated that children with a disability of the types indicated here may experience developmental delay in motor skill acquisition. As visual impairment is a characteristic of DS, WS and CP it is understood that these children will not be able to observe and copy adult behaviour. This is because visual impairment denies access to incidental learning, and so optimizing their learning requires additional systematic instructions using their other senses to access practical experiences. The resources to be used in the study have been developed in order to attempt to compensate for the developmental delay by using systematic dressing activities and using multi-sensory and motor routes (tactile, audible, motor manipulation) in order to provide an optimal learning environment.

The novel interventions to be used were initially designed for my MSc research. During the first year of my MPhil/PhD the interactive puzzle game was adapted in order to include a wider range of fastenings and sizes of fastening available. The adapted game will be piloted before the main study is completed.

*Pilot:* The pilot will involve children playing the interactive puzzle game at their own home. The sample will be an availability sample recruited from family friends of the researcher. The reason behind the recruitment is due to the familiarity between the children and the researcher, meaning that a familiarisation period would not be necessary. The parents will be informed (verbally and also provided with an information sheet/consent form) of the game that the children will be playing and also that their child will be observed on motor skill ability in relation to fastening activities. Once the aims of the pilot have been explained to the parents they will provide verbal and written consent. The small sample will contain 6 typically developing (TD) children, aged between 3 and 11 years. The pilot will take place over three days including two 10 minute sessions with the puzzle. Motor skills will be recorded on a previously piloted observation schedule for both pre- and post-intervention.

*Main Study:* The recruited participants will be aged 3-11 years, matched with a (TD) sample. The sample will be taken from a range of locations around the UK. The 'suite of instruments' (previously piloted) were created specifically for the purpose of this research and will run for 12 weeks. Post-intervention an assessment of impact of the resources will be made.

*Participants:* The sample will consist of individuals aged 3-11 years with Visual Impairments, Cerebral Palsy, Down Syndrome and Williams syndrome. Within the developmental disorder (DD) groups all participants must have also have been diagnosed with a form of visual impairment. This includes conditions like strabismus (commonly referred to as a squint), which has a high incidence in the WS sample for example. Relevant information regarding impairments will be passed on by the Qualified Teacher for Visual Impairment (QTVI) or the Special Educational Needs Co-Ordination (SENCO) in the child's school setting. The age range for recruitment is 3-11 years old in order to provide a natural cut-off point between junior and secondary school. The TD sample will be matched to the DD sample with age and geographical location. Recruitment will be made from both specialist and mainstream schools. There will be an attempt to match schools within the immediate area, but if this is not possible, within the Local Authority. As the incidence level of VI is so small and the nature of a visually impaired sample is so complex, a large sample is not expected. Ideally, the maximum number of participants will be 40; 20 for the DD Group matched with 20 TD children. A 15% drop out rate is expected due to a threat of mortality; this means participants dropping out over the course of the intervention and unfortunately actual mortality which is a risk when working with children with disabilities of the types mentioned here. This threat to the sample has already been

factored into the sample size. The research is a single-subject, repeated measure in a multiple-case study framework.

*Recruitment:* to recruit the sample, initial contact with schools across the UK will be made via email and/or telephone and information sheets will be provided. Potential child participants will be identified and then information sheets/consent forms will be sent to the respective parents/caregivers. Parents/carers will be given an information sheet which also acts as a consent form. This will detail the research, and explain the roles of the children and the parents. The consent form also informs the carers that data collected is 100% confidential and that participants have the right to withdraw at any time without giving reason. Geographical location will also be taken in account with regard to recruitment from inner city areas in comparison to rural areas. This is because literature supports an earlier development of motor skills in children from rural areas compared to children raised in an inner city, on the basis of their being more opportunities for early motor experiences in rural settings.

Exclusion criteria are also established for the participants; the recruitment of the children will take place and then a screening for emotional and behavioural problems will be undertaken to establish whether or not a child would be suitable for the intervention programme. It is understood that children with disabilities such as DS have a wide spectrum of emotional and behavioural problems, however the screening processes is intended to safeguard the children in relation to their participation, by identifying those who might have an emotional response to the suite activities (see ethics section). Screening for emotional and behavioural problems will be done through discipline/incident records of the child held at the school (if available) and also brief teacher/teaching assistant reports regarding the emotional and behavioural manner of the child participants.

*Background Measures:* The gathering of background data are essential to provide full participant profiles. The background measures intended to be used are

- Medical Questionnaire: to be completed by the parents, informing the researcher of the medical history of the child participants in both the developmental disorder group (DD) and the TD group. The history is relevant to the research project. The medical questionnaire also informs the research of any medical issues the mother encountered (if any) during pregnancy and birth. Prematurity for example is important as there is research evidence suggesting a link between visual impairment and prematurity. Appendix 1
- Developmental Journals: tracking developmental milestones of the children in both the DD and TD groups. Parents of children in the DD group may already have a Developmental Journal. If the parent/caregiver from either the DD or TD group does not have a Developmental Journal, they will be provided with one and asked to complete it retrospectively and as accurately as possible. The purpose of the journal is to record developmental milestones over the intervention period. Appendix 2
- Habilitation VI UK Assessment (Previously Mobility and Independence Specialists in Education, MISE) framework will be used as a framework to develop a profile for children with visual impairment. If this is not available, the QTVI will be asked to assess the children. Appendix 3

- Socio-Economic Status Questionnaire: to be completed by the parents in order to inform the research of the social and economic status of the child participants. This is because the literature suggests a strong link between SES and visual impairment. Appendix 4

*Measures:* Developmental trajectory of each individual will be measured using digit span and verbal fluency tasks, suitable for both children with disability and TD children. Motor functioning will be assessed through the finger tapping test and a grip strength test. This is because of the relation between finger strength and hand co-ordination and the skill of dressing. It is noted that children with CP may struggle with the finger tapping and grip strength tests due to the nature of their disability and may produce a ceiling effect. These tests will be repeated post-intervention. The measures are non-invasive, and short in length to maintain attention span in children. An adaptation of Raven's Matrices to use with Visually Impaired children is being explored. If this is possible, this may be considered to be an appropriate predictor for IQ. See examples in Appendix 5

*Suite of Instruments:*

- Novel puzzle game: (previously piloted) containing zips, button, popper, Velcro and lace fastenings. The children fasten and unfasten the pieces of various sizes according to their preferences with verbal support and hand-over-hand assistance (an established habilitation practice strategy) if necessary.
- Interactive Rhyming Story: a story teaching rhyming strategies for successful dressing for children. The children listen to the story to become familiar with the rhymes and then as the intervention programme progresses they put on their coats and fasten them along with the story.
- 'We're going on a Joey Hunt': an adaptation of the familiar story 'We're Going on a Bear Hunt'. The children have to put on and fasten their outdoor coats in order to find Joey, a soft toy, who is hidden.
- Learn to Dress with Alex: a commercially available soft toy designed to aid dressing skills. Brightly coloured and with large fastenings and fully removable clothes, the children can fasten and unfasten, dress and undress the toy applying the skills that they will personally use.

The suite of instruments is fully adaptable to individual or group needs.

*Procedure:* The procedure is pre-intervention(assessment) – intervention – post-intervention(assessment); 'assessment' taking the form of a sequence of observation, skills and developmental maturity/progress instruments. 'Observation' will be repeated thrice in one week, to observe frequencies of behaviours. The game will be played for 15 minutes, twice a week for three months as part of participants' daytime curriculum. Appendix 6 shows an outline of the progression of the materials used, based on the previous MSc study on the same topic. The procedure for the current study will be lengthier and subject to change based on the needs of the individual participants. The table is to highlight the roles of the different materials used and how the complexity increases over time. During the first and last sessions with the interactive puzzle game, video documentation of the children's hands will be taken in order to ensure that the

observation schedule is completed as accurately as possible. The documentation will be subject to parental consent and will not identify any child in any group.

The participants are not blinded from the research aims in pre- and post-testing due to the demands of the resources. This may lead to demand characteristics but is not considered a threat to the experimental results due to the longevity of the intervention period and the likelihood of practise effects (this will be reflected upon in the thesis). Blinded participation will not be used as the participants are required to understand that the skills learned are relevant to dressing strategies (demonstrated in the verbal aspect of the observation schedule).

Once the intervention programme is complete, the recorded data will be analysed and reported anonymously to ensure the confidentiality of the participants. An assessment of impact of the intervention procedure will be made approximately 6 months after the intervention procedure has finished. It is expected that the drop-out rate will increase by approximately 20% from the end of the intervention procedure to the re-assessment after 6 months.

### Section 3 Security-sensitive material

Security sensitive research includes: commissioned by the military; commissioned under an EU security call; involves the acquisition of security clearances; concerns terrorist or extreme groups.

a.	Will your project consider or encounter security-sensitive material?		No
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⇒ If you have answered **Yes** please give further details in **Section 8 Ethical Issues**.

Will you be visiting websites associated with extreme or terrorist organisations?

*Will you be storing or transmitting any materials that could be interpreted as promoting or endorsing terrorist acts?*

#### Section 4 Research participants Tick all that apply

- |  |   |
|--|---|
| <input checked="" type="checkbox"/> <b>Early years/pre-school</b><br><input checked="" type="checkbox"/> <b>Primary School age 5-11</b><br><input type="checkbox"/> Secondary School age 12-16<br><input type="checkbox"/> Young people aged 17-18 | <input type="checkbox"/> Unknown<br><input type="checkbox"/> Advisory/consultation groups<br><input type="checkbox"/> No participants<br><input checked="" type="checkbox"/> <b>Adults please specify below</b><br><input checked="" type="checkbox"/> Parents/Carers, Teachers & QTVI/SENCOs |
|--|---|

#### Section 5 Research methods Tick all that apply

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Interviews<br><input type="checkbox"/> Focus groups<br><input checked="" type="checkbox"/> <b>Questionnaire</b><br><input type="checkbox"/> Action research<br><input checked="" type="checkbox"/> <b>Observation</b><br><input type="checkbox"/> Literature review | <input checked="" type="checkbox"/> intervention study<br><input checked="" type="checkbox"/> <b>Use of personal records summarised by parent</b><br><input type="checkbox"/> Systematic review<br><input type="checkbox"/> Secondary data analysis<br><input type="checkbox"/> Other, give details: |
|---|--|

#### Section 6 Systematic reviews Only complete if systematic reviews will be used

a.	Will you be collecting any new data from participants?	<b>Yes</b>	
b.	Will you be analysing any secondary data?		<b>No</b>

#### Section 7 Secondary data analysis Only complete if secondary data analysis will be used

a.	Name of dataset/s		
b.	Owner of dataset/s		
c.	Are the data in the public domain?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
		<i>If no, do you have the owner's permission/license?</i>	
		Yes <input type="checkbox"/>	No* <input type="checkbox"/>
d.	Are the data anonymised?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
		<i>Do you plan to anonymise the data? Yes <input type="checkbox"/> No* <input type="checkbox"/></i>	
		<i>Do you plan to use individual level data? Yes* <input type="checkbox"/> No <input type="checkbox"/></i>	
		<i>Will you be linking data to individuals? Yes* <input type="checkbox"/> No <input type="checkbox"/></i>	
e.	Are the data sensitive (DPA definition)?	Yes* <input type="checkbox"/>	No <input type="checkbox"/>
f.	Will you be conducting analysis within the remit it was originally collected for?	Yes <input type="checkbox"/>	No* <input type="checkbox"/>
		<i>Was consent gained from participants for subsequent/future analysis?</i>	
		Yes <input type="checkbox"/>	No* <input type="checkbox"/>
<i>⇒ If you have ticked any asterisked responses, this indicates possible increased ethical issues for your research please give further details in <b>Section 8 Ethical Issues</b></i>			

## Section 8 Ethical issues

What are the ethical issues which may arise in the course of your research, and how will they be addressed?

It is important that you demonstrate your awareness of potential risks or harm that may arise as a result of your research. You should then demonstrate that you have considered ways to minimise the likelihood and impact of each potential harm that you have identified. Please be as specific as possible in describing the ethical issues you will have to address. Please consider / address ALL issues that may apply.

*A minimum of 200 words is required. Less than this and your application may be returned to you.*

*Ethical concerns may include, but not be limited to, the following areas:*

<ul style="list-style-type: none"> <li>• Potentially vulnerable participants</li> <li>• Safeguarding/child protection</li> <li>• Risks to participants and/or researchers</li> <li>• International research</li> <li>• Sensitive topics</li> <li>• Sampling</li> <li>• Gatekeepers</li> </ul>	<ul style="list-style-type: none"> <li>• Informed consent</li> <li>• Assent</li> <li>• Methods</li> <li>• Confidentiality</li> <li>• Anonymity</li> <li>• Data storage/security</li> <li>• Data transfer/transmission</li> </ul>	<ul style="list-style-type: none"> <li>• Data sharing/encryption</li> <li>• Data documentation</li> <li>• Data management plan</li> <li>• Data protection</li> <li>• Reporting</li> <li>• Dissemination and use of findings</li> </ul>
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**Issue 1:** Working with vulnerable children

**Resolution:**

- a) The researcher has a full and enhanced DBS check
- b) The intervention will be delivered at school by the researcher following previous familiarisation visits with participating children. The child will have the option of having another familiar adult present during the intervention.
- c) Informed parental consent as well as participant consent will be obtained for these initial visits, the interventions, participation in the study and assessment phases (consent will have been previously obtained from the school)
- d) All data remains strictly confidential, participants are anonymised and data stored in a safe place: inaccessible by others except the researcher, supervisors and a person/s external to the research project who will inter-rate the observation protocol using anonymised video recordings (who also hold DBS clearance at enhanced level)
- e) Audio, video and photographic recordings of participants will only be made with the permission of the participant and their parent/guardian/school and will be destroyed upon completion of the research. The children's faces will not be present in the video/photographs – just their hands whilst the children are using the resources. Video recordings will be viewed and analysed by an individuals external to the research project, in the presence of the researcher who has the videos stored on an encrypted hard drive.
- f) Permission to include anonymised data from the research in the research, subsequent presentations and publication will also be sought.
- g) The IOE ethics committee will be notified of any changes in the methodology.

**Issue 2:** Dressing and Undressing

**Resolution:** The children will not be required to undress in any way. The intervention involves dressing over their school uniform/day time clothes. Practice will be in accordance with the Quality Standards for habilitation (Miller, Wall and Garner, 2011): The Special Educational Needs and Disability Code of Practice: 0 to 25 years (2014'): (Dfe: HMSO, 2014): the professional Practice Guidelines of Habilitation VI UK.

**Issue 3:** Risks

**Resolution:** Participants could experience psychological distress due to frustration or worry. This should be alleviated by the familiarity engendered by pre-assessment professional contact. At first sign of distress, participants will be told that they can 'stop now' and the activity will be stopped. It may be restarted if the participant indicates that they wish this to happen. Participants retain the right to withdraw from the activity at the participant's request (or their parents). If a child or their parent chooses to withdraw before the end of the study, they shall be debriefed if they wish: their data will be destroyed and not used in the study. Participants will be advised to contact the researcher if they experience any problems.

**Issue 3:** Access to medical records

**Resolution:** Parents of the child participants in the developmental disorder group will be asked to provide information regarding their child's impairment in order to inform the research. This information will be treated as 100% confidential, anonymous and destroyed upon completion of the research project.

**Issue 4:** Safeguarding

**Resolution:** Strong communication links between parents, teachers and medical professionals were considered necessary to safeguard the children and conduct the research within ethical boundaries. Links with medical professionals (associated with the DD children) would be via the parents, and would ensure that the child participant is considered medically well enough to participate within the intervention. Verbal communication links between parents and teachers are considered necessary for: understanding the overall well-being of the child in relation to the intervention and general schooling; to ensure that the intervention is not having a negative impact on other areas of schooling/home-life; and to answer any procedural questions that the teachers/parents may have. Teachers and parents will be provided with an email address and telephone number in order to contact the researcher to discuss any queries.

**Section 9 Attachments** Please attach the following items to this form, or explain if not attached

a.	Information sheet and other materials to be used to inform potential participants about the research.	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
b.	Consent form	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
c.	The proposal for the project, if applicable	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
d.	Approval letter from external Research Ethics Committee, if applicable	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>

**Section 10 Declaration**

I confirm that to the best of my knowledge this is a full description of the ethics issues that may arise in the course of this project

Name	Jessica Hayton
Date	6/10/2014 *Amended 7/09/2015

Please submit your completed ethics forms to your supervisor/course administrator.

## 11.4. Detailed vignettes

Vignettes: Children with VI

Participant Number	Diagnosis, characteristics and behaviour
1	<p>P1 was an 8 year old male who has a complex medical history. P1 has pilocytic astrocytoma in the posterior fossa brain region. This form of CVI means that P1 has some residual vision which he uses to complete particular tasks (by moving objects closer) but is registered severely sight impaired. In addition to his VI, P1 has Autistic Spectrum Disorder, Tourette's Syndrome, Precocious Puberty and a Growth Hormone Deficiency. P1 is regularly admitted to hospital for chemotherapy and shunt breakdown/revision. P1 has between 8-9 hours of sleep per night but does wake up between 2 and 3 times per night due to Tourette's episodes and restlessness.</p> <p>P1 spends between 0-2 hours on school days watching TV or using a computer/video games. During the weekends P1 spends 4-6 hours on these activities. P1 has a younger sibling which means that he is likely to be exposed to popper and button fastenings at home. During the intervention period, P1 began attending a mainstream school one day per week.</p> <p>P1 is a chatty and bubbly child. He was recruited for the study based on his personal school-based targets for independent dressing. He was very engaged in the fastening activities and motivated toward independent fastening and unfastening. He engaged in competition with the other members of his group (P2, P3 and P4) as to who could independently fasten first. He preferred the lace condition because he liked the challenge. Over the intervention period, P1 was absent for 3 sessions (week 4, 5 and 6).</p>
2	<p>P2 was a 10 year old male who has glaucoma and retinal detachment. In addition to his VI, P2 has a Cardiac Ebstein Anomaly. P2 has had regular hospital admissions regarding corneal transplants, retinal surgery and cyst removal. P2 averages between 7 and 8 hours of sleep per night, and is not reported to have disturbed sleep. P2 uses a tablet between 0 and 2 hours on a school day and between 4 and 6 hours on a weekend day. P2 has an older sibling and lives at home with both his mother and father.</p> <p>P2 is very inquisitive and initiates conversations very easily with familiar people. He was recruited for the study based on a need to independently put on and take off an outdoor coat. He likes to tell jokes in the sessions to make everybody laugh, and this encourages the other members of his group to join in. In addition to this, P2 can also 'parrot' words and/or phrases that are used in the session, and he can become fixated on certain concepts. P2 is very responsive to clear instructions and boundaries however, and will refocus when prompted. He liked the popper condition because the fastenings make a "pop" sound, but would attempt zip fastening the most throughout the intervention period. Over the intervention period, P2 was absent for 1 session.</p>
3	<p>P3 was a 7 year old male who had Juvenile Onset Batters Disease causing severe sight impairment. In addition to the VI, P3 also experienced developmental regression and attentional problems. P3 had no additional reported comorbidities,</p>

however was last hospitalised in 2015. P3 had 4 siblings, 3 older and 1 younger, and so may have exposure to the full range of clothing fastenings.

P3 was very quiet in the sessions, and predominantly focused on the task that he was completing rather than engaging in conversation. He only accepts assistance after he has attempted fastening for a few minutes.

P3 was recruited for the study based on a need to independently dress. He did not display any particular preference for any fastening piece, with the exception of week 10 where he said that he preferred laces. Over the course of the intervention period, P3 was absent once.

- 4 P4 was an 8 year old male who had a pilocytic astrocytoma in the optic pathway and was registered severely sight impaired. In addition to his VI, P4 also has chronic hypomagnesaemia which he takes supplements for. P4 was regularly hospitalised for chemotherapy, radiotherapy and the insertion of a shunt, however hospital admissions have reduced since 2013. P4 is an only child, and lives at home with his mother and father. He averages between 7 and 8 hours of undisturbed sleep per evening and spends between 0 and 2 hours per week watching TV or using a tablet/smartphone.

P4 is a friendly and talkative child, he was very motivated to independently fasten and unfasten in the sessions as well as motivated to practice lace tying at home. He was recruited for the study based on a target to independently dress. The first time P4 independently fastened laces in the sessions was a result of him practicing at home with his father. The dip afterward was a result of him not being able to practice at home that week. As P4 is severely sight impaired, he can get tired and grumpy quite quickly, and so it was important not to push him too hard when he did not feel motivated. He would practice in his own time and become slightly less social in the group dynamic but was still able to complete fastening/unfastening tasks independently. P4 preferred the lace condition throughout the intervention period because he liked the challenge. P4 was not absent for any of the intervention sessions.

- 5 P5 was a 5 year old female who had septo-optic dysplasia and was registered blind. In addition to her VI, P5 also has Autistic Spectrum Disorder and diabetes insipidus which she takes medication for. P5 was regularly hospitalised as an infant as she experienced neonatal abstinence syndrome (withdrawal). She now lives at home with her grandparents and does not have any siblings.

P5 had some difficulty engaging in social situations and has a sensitivity to sound specifically social sounds such as other children crying, shouting and squealing. She can become easily distressed and frightened in loud environments and will cover her ears to reduce the impact of these sounds. Unfamiliar people made P5 nervous although she warmed to me and the session very quickly. She would ask for help if she needed any, but would easily become distressed if the other members in the group became too loud.

P5 was recruited for the study based on a need to learn independent dressing. Her favourite piece was a big button, because it was large. This was consistent over the intervention period. She was not absent during the intervention period.

- 6 P6 was an 8 year old female who had an undiagnosed VI and was registered as partially sighted. Her distance vision was between 1 and 2 metres and so she would bring objects close to her face to see them. In addition to her VI, P6 also had attention deficit hyperactivity disorder and communication problems. She was developing her verbalisations however in the sessions she was not very verbal and used Makaton to support her communication and understanding. P6 had not been regularly hospitalised, however did undergo surgery to correct her legs and hips. P6 lives with her parents and 2 older sisters, both of which have a SEND. P6 participated in extra-curricular activities such as horse-riding and swimming. She has between 5 and 8 hours of sleep per night.

P6 is quite a sociable child in the classroom however she is wary of unfamiliar people. She was keen to start the fastening sessions, however sometimes she was not allowed to participate for behavioural issues which would have had an impact on the other members of the group. Further to this, P6 would sometimes use the sessions as a way to get out of class, and so she had to be heavily encouraged to participate in the fastening sessions. P6 was recruited for the study based on a need to independently dress. Her favourite piece was the popper because she thought it was easy. This was consistent over the sessions. P6 was absent for 3 of the intervention sessions.

- 7 P7 was an 8 year old female who had Cohen's Syndrome, Rod Cone Retinal Dystrophy and Myopia. She is registered as partially sighted. In addition to her VI, Cohen's syndrome also affects her motor skill development and behaviour. She was also prone to mouth ulcers and nose bleeds. She had some weakness in her legs which meant that she sometimes used a wheelchair, and also had a high pain threshold which meant that extra care was needed to ensure her safety e.g. she wore shoes that had badly blistered her feet and she was unaware. P6 lives with her mother, father and a younger sibling. She has approximately 8 hours of undisturbed sleep per night.

P6 uses Makaton to support her communication, and was a very friendly and chatty girl. She was very softly spoken and so sometimes had to repeat herself when she was asking for assistance. She was very keen to help other members of the group rather than focus on her own skills and also had a great preference for Joey the monkey above all other resources. She liked to cuddle Joey and look after him. P7 was recruited for the study based on her need to independently dress. She preferred the buttons on Joey, and this was consistent over the sessions. P7 was absent for 1 session over the intervention period.

- 8 P8 was a 7 year old male who was diagnosed with Autosomal Recessive Congenital Leber's Amaurosis (Leber's Syndrome). He was registered as blind and had light perception. In addition to his VI, P8 was diagnosed with Autistic Spectrum Disorder which has a significant impact on his behaviour. He was reported as high functioning and displayed very challenging, repetitive and obsessive behaviour and was also manipulative at points. He lived at home with his parents and an older brother. He also had an older sister who was diagnosed with the same condition.

P8 was a very confident and curious child and was very keen to engage in the fastening/unfastening activities. He was recruited for the study as he had a target for independent dressing. He had a preference for zips and laces during the sessions because he liked the challenge, however in week 8 he mentioned that he could not complete the tasks saying "I'm blind. I can't do it". This was the first and only time

that P8 had mentioned his condition and displayed an awareness for a need for extra support. This was dealt with accordingly, and disclosed to the relevant supporting adults. Over the intervention period, P8 was absent for 3 sessions.

- 9 P9 was a 7 year old male with retinopathy of prematurity. He was registered blind and had no light perception. His birthweight was very low at 3lbs (1.36kg) and he was the only surviving child from a set of triplets. His weight is now 20.1kg and he is 113.5cm tall. In addition to his VI, P9 also has gastroesophageal reflux associated with prematurity. P9 lives at home with his mother, grandmother and younger sibling. On average P9 has 6 hours of undisturbed sleep per night, but shares a room with his sibling.

P9 was an inquisitive child who was very keen to learn fastening and unfastening. He was recruited for the study to support his target to increase independence. He was very verbal and would often help the other children in his group once he could independently fasten a fastening. He would sometimes display attention seeking behaviour such as licking in order to shift the focus from a group member to himself. P9 vocalised a preference for the popper condition because he liked the noise that they made and he thought they were easy. Over the intervention period, P9 was absent once.

---

## Vignettes: TD children

Participant Number	Characteristics and behaviour
10	P10 was a 6 year old typically developing male. He lives with his mother, her partner, 2 older siblings and 1 younger sibling. He was an eager boy who wanted to be able to tie his shoe laces so that he could have a pair of football boots. P10 was recruited for the study to support independent fastening, particularly of shoelaces. He had a preference for the zip fastening as he liked to pull the slider up and down. He was not absent for any session over the intervention period.
11	P11 was a 6 year old typically developing male. He lives with his mother, father and 3 older siblings. P11 was recruited for the study because he was struggling with fastening his coat. He was initially quite quiet but over the intervention period he became more comfortable with his environment and the resources. His favourite piece was the button because they were easy. He was not absent for any session of the intervention period.
12	P12 was a 6 year old typically developing female. She lived at home with her mother, father, 3 older siblings and 2 younger siblings. She was softly spoken and verbally fluent, but could come across shy in particular sessions. She would often wait to be asked if she required assistance rather than speak up. P12 was recruited for the session to support her independent dressing. She preferred the popper condition because she liked the sound that they made. She was not absent for any session of the intervention period.
13	P13 was a 7 year old typically developing male. He lived at home with his mother, father and older sibling. He was very keen to start unfastening/fastening and mastered the skills very quickly. He was very motivated to the tasks and when he had reached ceiling effects for the fastenings he would extend the tasks to tying double knots/triple knots in the laces and also began practicing tying shoelaces behind his back. P13 was recruited to support his independent fastening, particularly for shoelaces. His favourite piece was the lace condition as he initially liked the challenge and then found fastening and unfastening easy. P13 was not absent for any session during the intervention period.
14	P14 was a 7 year old typically developing female. She lived at home with her mother, father, an older sibling and a younger sibling. She was very reserved throughout the intervention procedure, however remained to be motivated for task completion. When she had reached ceiling effects across conditions her confidence increased and she began to speak more in the sessions. P14 was recruited for the study due to a need to independently put on and fasten her outdoor coat. She initially preferred the zip condition because she found it easy, but after reaching ceiling effects for laces she then preferred that condition. She was not absent for any session during the intervention period.

- 15 P15 was a 6 year old typically developing male. He lived at home with his mother, father and 4 older siblings. He was motivated toward shoe laces because he wanted to wear “grown up” shoes. He was quite a chatty child and eager to independently fasten/unfasten. P15 was recruited for the study based on a need to put on and fasten his outdoor coat. He preferred the lace condition because he liked the challenge of fastening them. P15 was present for all sessions over the intervention period.
- 16 P16 was a 7 year old typically developing male. He lived at home with his mother, father and 2 older siblings. He was quite verbal in the sessions, however when he realised that other children were successfully fastening/unfastening he became more focused and driven to do the same. He found laces the trickiest but persevered to independent fastening/unfastening. P16 was recruited based on a need to independently dress. He preferred the button condition because he found it easier than the others. P16 was present for all sessions over the intervention period.
- 17 P17 was a 6 year old typically developing female. She lived at home with her mother, father and 1 younger sibling. She was very verbally fluent and switched on. She struggled with the 2 bunny ear method of fastening shoe laces because she naturally preferred the other method. Despite being told that she could choose any way of fastening, she wanted to learn the different way and she was motivated to do so. She was a very mature child and keen to independently fasten/unfasten. P17 was recruited based on a need to maximise her independence. She preferred the lace condition because she found it tricky and was motivated to succeed. She was present in every session over the intervention period.
- 18 P18 was a 5 year old typically developing male. He lived at home with his mother and father and was an only child. He was very shy and reserved in the sessions despite being encouraged by his peers and the researcher. He lacked confidence but persevered to independent fastening and unfastening. P18 was recruited for the study to support independent dressing, particularly for fastening an outdoor coat. He preferred the buttons and poppers because he found them easier. He was present for all sessions during the intervention period.
-

## Vignettes: Children with DS

Participant Number	Diagnosis, characteristics and behaviour
19	P19 was a 9 year old female diagnosed with DS. She did not have any comorbid conditions in addition to her diagnosis. She was a very outgoing and confident child, however preferred to work alone rather than in a group setting. Her behaviour reflected this as she would snatch resources from other children who were engaging in the session. She was co-operative with the researcher, but she had a short attention span and could be heavy-handed. This meant that she needed to be reminded of the task or her behaviour. She was verbal but used Makaton to support her communication and understanding. P19 was recruited for the study based on a need to independently dress. She preferred the button condition, but only when she could manipulate the piece on her stomach. P19 was present for the pre-intervention observation and every session during the 10 week intervention period. 1 month and 3 month post-intervention sessions were not possible due to time constraints.
20	P20 was a 5 year old female diagnosed with DS. She did not have any comorbid conditions in addition to her diagnosis. She lived at home with her mother and father and was an only child. She was vibrant and co-operative and was interested in fastening and unfastening buttons and zips. She was verbal but used Makaton to support her communication and understanding. She worked well in the group setting and could share the materials with the group. P20 was recruited for the study based on a need to learn independent dressing. Her favourite piece was the button condition because she liked the circles. P20 was present for the pre-intervention observation and the whole 10 week intervention period. 1 month and 3 month post-intervention sessions were not possible due to time constraints.
21	P21 was a 6 year old male diagnosed with DS. He did not have any additional diagnoses. He was very interested in the activities and the resources however had a very short attention span. This meant that in between attempting/practising fastening and unfastening he would spend 1 minute in the ball pool. This supported his co-operation in the sessions. P21 used Makaton to support his communication and understanding. P21 was recruited for the study based on a target for independent dressing. His favourite piece was the popper because he liked the noise that they made. P21 was present for the pre-intervention observations and the duration of the 10 week intervention period. 1 month and 3 month post-intervention sessions were not possible due to time constraints.
22	P22 was a 6 year old female diagnosed with DS. In addition to DS she also was diagnosed with a cataract in one eye and was waiting for surgery. She was a quiet and shy child, and she needed to be encouraged to engage in the session. Her mother was often close by when P22 was participating in the intervention and this may have improved her confidence. She had a very short attention span and did not like not being able to successfully and independently fasten/unfasten. This meant that she would try to avoid materials which she thought were too difficult. P22 was recruited as she required support to develop independent dressing. Her favourite piece was the button and this was consistent over the intervention period. P22 was present for the pre-intervention observation, however was absent for 1 intervention session over the 10 weeks. 1 month and 3 month post-intervention observations were not possible due to time constraints.

- 23 P23 was a 9 year old male diagnosed with DS. He was not diagnosed with a comorbid condition. He was very wary of new people, especially those he perceived to be “professionals” helping him. This meant that he was often uncooperative. He could get frustrated very easily and so needed to be eased in to the sessions more informally than with the other children. He preferred to work alone and did not speak very much despite being verbal. He used Makaton to support his communication and understanding. P23 was recruited based on a need to develop independent dressing skills. He did not display any fastening preference even when prompted. Over the intervention period, P23 was absent from 4 sessions. 1 month and 3 month post-intervention observations were not possible due to time constraints.
- 24 P24 was a 7 year old female diagnosed with DS. She did not have any additional comorbidities. She was a softly spoken girl, very quiet but interested in the session. She had a short attention span and so needed regular breaks between practising to keep her concentration and focus. She was very sociable and would try and help the other children in the session. P24 was recruited for the study to support her putting on and fastening her outdoor coat. She preferred the zip condition because she liked pulling the slider up and down. Over the intervention period, P24 was absent from 4 sessions. 1 month and 3 month post-intervention observations were not possible due to time constraints.
- 25 P25 was a 9 year old male diagnosed with DS. He did not have any additional diagnoses. He was a very verbal child and very headstrong. He tried to take the lead in sessions and tried to make the other children do things his way. He was initially avoidant of the materials saying that they were too difficult and that he couldn't do it. However, after observing the researcher untie shoelaces for example, he would then copy and try for himself. P25 appeared to be fearful of new experiences and his mother would often sit with him during sessions. Once P25 had become more comfortable with the researcher, he would move away from his mother and engage in the sessions more independently. He used Makaton to support his communication and understanding. P25 was recruited for the study based on a need to support his independence. P25 preferred the button condition because he liked pushing the button through the hole. Over the intervention period, P25 was absent on one occasion. 1 month and 3 month post-intervention observations were not possible due to time constraints.
- 26 P26 was a 5 year old male diagnosed with DS. He did not have any comorbid conditions. He lived at home with his mothers and younger sibling. He was a very quiet child but eager to try new things. He preferred the poppers because they were easy. He needed encouragement to support him to try “harder” fastenings. He used Makaton to support his communication and understanding. P26 was recruited for the study as he needed support with fastening his outdoor coat. P26 did not display any preference for a fastening piece even when prompted. Over the intervention period, P26 was absent for 4 sessions. 1 month and 3 month post-intervention observations were not possible due to time constraints.
- 27 P27 was a 7 year old female diagnosed with DS. She did not have any additional diagnoses. She was very interested to engage with the intervention materials. She had a short attention span and became easily distracted. She used Makaton to support her communication and understanding. P27 was recruited for the study mainly to support her shoe lace fastening. She did not display any preference for a fastening piece even when prompted. Over the intervention period, P27 was absent

on 5 occasions. 1 month and 3 month post-intervention observations were not possible due to time constraints.

## 11.5. Medical history questionnaire

**MEDICAL HISTORY QUESTIONNAIRE**

To be completed by the parent/carer(s) of the child participant. Please be assured that the information provided is fully confidential

1. Your name: .....
2. Your child's full name: .....
3. Gender: M  F
4. Your child's date of birth: .....
5. Were there any problems with this pregnancy or delivery (prematurity, high blood pressure, etc.)?  
.....  
.....  
.....
6. What was the birth weight? .....
7. What is your child's weight and height now?  
Weight...../height.....
8. Is your child: right handed  left handed  don't know
9. Has your child been officially diagnosed with a developmental disorder such as ADHD/ ADD/Autism/ Asperger's/ other? Yes  No   
If yes, please specify:  
.....
10. Does your child have any health problems? Yes  No   
If yes, please  
describe:.....  
.....
11. Has your child ever been hospitalized?  
If yes, when:..... What for?  
.....  
.....  
.....

12. Has your child ever had any operations (other than tonsils/adenoids removal)?

Yes  No

If yes, type of operation? ..... Year.....

..... Year.....

..... Year.....

13. Have your child's tonsils or adenoids been removed?

a. Tonsils: Yes  At what age? .....

For what reason:

.....

b. Adenoids: Yes  At what age?.....

For what reason:

.....

14. If NO, do you think the tonsils or adenoids are a problem? Yes  No  Don't know

15. Does your child have allergies? Yes  No  Possibly

If yes, please specify?

.....

16. List any prescription or over-the counter medications your child has taken in the last month:

Type:.....Reason for

medication.....

Type:.....Reason for

medication.....

Type:.....Reason for

medication.....

17. Does your child take part in any extracurricular sport activities? Yes  No

If yes, how many hours a week and what kind of sport?

Type:

.....Hours/week.....

..

Type:

.....Hours/week.....

..

Type:

.....Hours/week.....

..

18. Does your child have any sleep problems?

If yes, please specify:

.....  
.....

19. How many hours (on average) does your child sleep per night?

\_\_\_\_\_ hours per night.

20. Do you have any additional comments about your child's medical history?

.....  
.....  
.....  
.....

## HEALTH HABITS

21. How much television and/or videos did your child watch on school days?

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> 0-2 hours per day | <input type="checkbox"/> 4-6 hours per day | <input type="checkbox"/> More than 8 hours per day |
| <input type="checkbox"/> 2-4 hours per day | <input type="checkbox"/> 6-8 hours per day | <input type="checkbox"/> Don't know                |

22. How much time does your child spend on the computer on school days?

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> 0-2 hours per day | <input type="checkbox"/> 4-6 hours per day | <input type="checkbox"/> More than 8 hours per day |
| <input type="checkbox"/> 2-4 hours per day | <input type="checkbox"/> 6-8 hours per day | <input type="checkbox"/> Don't know                |

23. How often does your child use a tablet and/or smartphone on school days?

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> 0-2 hours per day | <input type="checkbox"/> 4-6 hours per day | <input type="checkbox"/> More than 8 hours per day |
| <input type="checkbox"/> 2-4 hours per day | <input type="checkbox"/> 6-8 hours per day | <input type="checkbox"/> Don't know                |

24. How often does your child play video games on school days?

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> 0-2 hours per day | <input type="checkbox"/> 4-6 hours per day | <input type="checkbox"/> More than 8 hours per day |
| <input type="checkbox"/> 2-4 hours per day | <input type="checkbox"/> 6-8 hours per day | <input type="checkbox"/> Don't know                |

25. How much television and/or videos did your child watch on weekend days?

- 0-2 hours per day       4-6 hours per day       More than 8 hours per day  
 2-4 hours per day       6-8 hours per day       Don't know

26. How much time does your child spend on the computer on weekend days?

- 0-2 hours per day       4-6 hours per day       More than 8 hours per day  
 2-4 hours per day       6-8 hours per day       Don't know

27. How often does your child use a tablet and/or smartphone on weekend days?

- 0-2 hours per day       4-6 hours per day       More than 8 hours per day  
 2-4 hours per day       6-8 hours per day       Don't know

28. How often does your child play video games on weekend days?

- 0-2 hours per day       4-6 hours per day       More than 8 hours per day  
 2-4 hours per day       6-8 hours per day       Don't know

## DEVELOPMENTAL MILESTONES

In this section, if possible, please write the age that your child was able to do the following: If you are unsure, or if your child does not do one of the following, please leave the space blank.

Milestone	Age
Sitting without support	.....
Standing with assistance	.....
Crawling on hands and knees	.....
Walking with assistance	.....
Standing alone	.....
Walking alone	.....
Reaching and grasping an object when sitting	.....
Holding an object in the hand	.....
Picks up an object with thumb and finger	.....

Takes off clothes .....

Dresses themselves .....

First word .....

Two word phrases .....

---

If you have any further comments or anything that you would like me to know, please use the space below:

.....  
.....

**Many thanks for filling out this questionnaire. Your answers will be treated in the strictest confidence and will be used only for this research project.**

**11.6. Socio-economic status questionnaire****SOCIO-ECONOMIC STATUS QUESTIONNAIRE\***

To be completed by the parent/carer(s) of the child participants. Where necessary, please write in BLOCK CAPITALS. Your response is 100% confidential.

Your name: .....

Your child's full name: .....

Gender: M  F

Your child's date of birth: .....

**HOUSEHOLD INFORMATION**

List the names, ages and relationships of all of the individuals in your household

Name	Age (Years/Months)	Relationship to person completing questionnaire (e.g. partner/child/sibling/foster child)

29. What type of accommodation do you live in?

a. A whole house/bungalow that is:

Detached       semi-detached       terrace

b. A flat/apartment/maisonette that is:

block of flats/tenement       Converted/shared house       Commercial building

c. A mobile or temporary structure

Caravan or other temporary structure

30. Does your household own or rent this accommodation?

Owns outright     own with mortgage/loan part own and part rent  
 Rent (with or without household benefit)     lives here rent free

31. If applicable, who is your landlord?

Housing association, housing co-operative, charitable trust, registered social landlord  
 Council (local authority)  
 Private Landlord or letting agency  
 Employer of a household member  
 Relative or friend of a household member  
 Other – Please state.....

32. In total, how many cars or vans are available for use by members of your household?

1     2     3     4     4 or more - please write .....

33. What is your average household income? £..... Per year

THE FOLLOWING QUESTIONS ASK FOR DETAILS FOR EACH PARENT/CARER OF THE CHILD PARTICIPANT.

PARENT/CARER 1:

Name: .....

Sex: Male     Female

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

1. What is your Marital Status?

Single     married     separated but still married     divorced  
 Widowed     civil partnership

2. Are you in full-time education?

Yes     No

3. Do you look after or give support to family members, friends or others because of illness or old age?

No     Yes 1-19 hours per week     Yes 20-49 hours per week  
 Yes 50+ hours per week

4. Please write your ethnic group: .....

5. What is your highest qualification (e.g. GCSE, NVQ, Apprenticeship, Degree/Higher Degree)?  
 .....

6. If appropriate, what is your full and specific job title?  
 .....

I am not currently in employment

7. Do you supervise employees?

Yes No

## END OF QUESTIONS FOR PARENT/CARER 1

## PARENT/CARER 2:

Name: .....

Sex: Male Female 

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

1. What is your Marital Status?

 Single  married  separated but still married  divorced Widowed  civil partnership

2. Are you in full-time education?

 Yes  No

3. Do you look after or give support to family members, friends or others because of illness or old age?

 No  Yes 1-19 hours per week  Yes 20-49 hours per week Yes 50+ hours per week

4. Please write your ethnic group: .....

5. What is your highest qualification (e.g. GCSE, NVQ, Apprenticeship, Degree/Higher Degree)?

.....

6. If appropriate, what is your full and specific job title?

.....

 I am not currently in employment

7. Do you supervise employees?

 Yes No

## END OF QUESTIONS FOR PARENT/CARER 2

**Thank you for taking the time to complete this questionnaire. Responses are completely confidential and will only be used for this research project.**

### 11.7. Phonemic and semantic verbal fluency

#### Phonemic Fluency

Instructions: (aloud) I will say a letter of the alphabet. Then I want you to give me as many words that begin with that letter as quickly as you can. For example if I say “b” you might give me “bad, battle, bed...” I do not want you to use words that are proper names such as “Boston, Bob or Brad”. Also, do not use the same word with a different ending such as “eat” and “eating”. Any questions? (pause). Begin when I say the letter. The first letter is F. Go ahead. (Begin timing immediately).

.....

The second letter is A. Go ahead.

.....

The third letter is S. Go ahead.

.....

Notes: if repetitions occur ask what was meant by each word at the end of the 1 minute

If there is a silence of 15 seconds repeat the instructions. If the participant stops before the end of the 1 minute encourage them to think of more

#### Semantic Fluency:

Instructions: (aloud) I am going to tell you the names of some things you can find in the kitchen: spoons, knives, forks, plates, faucet. Can you think of other things in the kitchen?

Allow the participant to name other things, and correct if they produces incorrect responses, explaining the task once again. Then say: Now tell me the names of as many animals as you can. Name them as quickly as possible.

Begin timing 1 minute. If there is a pause of 15 seconds repeat the instructions and give the starting word “dog”.

Start timing immediately after instructions have been given, but allow extra time in the period if instructions are repeated. Write down actual words in the order in which they are produced

.....

## 11.8. Training manual

# Learn to Dress with Success:

Using novel intervention materials to teach dressing strategies and skills to children with visual impairment.



## Contents

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## Overview

This training manual has been completed in order to aid supporting adults in the teaching of dressing skills to young children with disabilities. The manual works alongside the intervention materials to support the development of dressing skills in children. The materials in this manual have been developed from previous research regarding the development of independent dressing skills in children with visual impairment (VI). This manual has been written in order to provide guidelines for those who work with children with VI who need support with the independence skill of dressing. The current manual specifically targets the skills of putting on, fastening and unfastening an outdoor coat and shoelaces. The skills developed in this programme are transferable to other items of clothing such as shirts and trousers for example.

The aims of this manual are:

- To provide strategies for dressing to support the child with visual impairment
- To explain the previously tested resources and how they can be used to support the development of dressing skills
- To provide ideas for supporting adults to promote dressing skill development in children with visual impairment
- 

The manual works in accordance with the Quality Standards: Delivery of Habilitation Training (Mobility and Independent Living Skills) (Miller, Wall & Garner, 2011), the Special Educational Needs and Disabilities Code of Practice: 0 to 25 years (2014), and the United Nations Convention for the Rights of People with Disabilities (2006).

## 1. Materials

The novel suite of intervention materials include:

- a) 'Zip, Button and Pop' – interactive puzzle game (IPG) introducing the fastenings and materials used on an outdoor coat (zips, buttons, poppers and Velcro). The IPG also contains shoes with laces in order to support the development of putting on and fastening laces
- b) 'Just Joey' – an interactive dressing up story, supporting the IPG and also the commercially available soft toy. The story uses rhyming strategies in order to establish systematic dressing activities.

These materials are used alongside known and established materials which have been adapted for the purpose of developing dressing skills:

- a) 'Simon Says...' – a familiar game to children involving the naming and pointing to body parts. This game demonstrates body awareness, spatial awareness and sense of direction.
- b) 'We're going on a Joey hunt' – an adapted version of Michael Rosen's classic 'We're going on a bear hunt'. The adaptation regards putting on and fastening coats and shoes in order to go on a search for Joey
- c) 'Learn to dress with Alex' – a commercially available soft toy designed to supported dressing and fastening skills. For the purpose of this document this material will be referred to as 'Joey'

## 2. Intervention Period

The suggested intervention period is 10 weeks, depending on the skill acquisition of each child. Within this period, children should engage in at least 2x 15 minute sessions each week. Some children may complete the intervention and manage to transfer the skills faster than others. This needs to be taken into account when conducting the intervention as a whole. It is the responsibility of the deliverer of this intervention to decide the activities and the progression in task difficulty for each individual child. The following table is a guideline as to the order of activity completion over the period.

Table 1: Outline of intervention schedule

Week	Session 1	Session 2
1	1) Play 'Simon Says' 2) Read 'Just Joey' with IPG	1) IPG
2	1) 'Just Joey' with IPG	1) IPG
3	1) IPG	1) IPG
4	1) IPG	1) IPG
5	1) IPG	1) IPG 2) Joey
6	1) IPG	1) IPG 2) Standardised coat
7	1) IPG 2) Standardised coat	1) IPG 2) Standardised coat 3) Joey
8	1) Joey 2) IPG	1) IPG 2) Standardised coat 3) Joey
9	1) IPG 2) Joey 3) standardised coat	1) IPG 2) Standardised Coat 3)Joey
10	1) IPG 2) Joey 3) standardised coat	2) Transference session onto personal items

### 3. Getting Started...

A warm up activity generally lightens the mood and encourages participation and familiarisation with the person delivering the intervention and also other group members (if applicable). 'Simon Says' is a perfect starter activity especially if the children take it in turns to be 'Simon'. The adult should start the game, and play for 5 minutes as a warm up using the following instructions:

- Put your hands on your head
- Put your hands on your knees
- Put your hands on your stomach
- Put your right hand up in the air
- Put your left hand down on the floor

This activity will also provide the adult with a basic understanding of each child's body and spatial awareness. The body parts have been chosen for the adult directed aspect as they are the parts which will be used most frequently during the intervention.

Practicing hand shapes are also useful such as pinching together the index finger and the thumb, opening and closing a fist and wiggling wrists and fingers.

#### 3.1 The IPG

The interactive puzzle game (IPG) is designed to familiarise the children with the following clothing fastenings: zips, buttons, poppers, Velcro and laces. The following section provides examples of uses for the IPG and increase in task complexity. These examples can be modified according to each individual child. It is important to note that the examples provided are for children with visual impairment – this includes both children with partial sight and children with blindness. Some examples may not be suitable for children with blindness, however alternatives are provided.

##### Activity 1: Say what you see/feel

This is the first activity that should be carried out with the IPG. The adult asks the participant(s) to say what they can see or feel. This includes colours, textures, temperature and the names of the fastenings. For example, a child with partial sight may see the colour blue but may not know the name of a zip. The role of the adult throughout this activity is to

support and guide the children regarding the names of the fastenings and explain the function of each one. For example:

Adult: "Can you tell me what you have there?" (in reference to the puzzle piece in the child's hand)

Child: "Um, it's soft with a circle"

Adult: "Do you know what the circle could be?"

Child: "No."

Adult: "It is called a button. Do you know what buttons are for?"

Child: "No."

Adult: "Buttons are used to keep some clothes together. Do you know what else we could use to keep our clothes together?"

And so on until the child has experienced all fastenings on the IPG. Please note that this activity should be played at the start of each session, until you are comfortable with the child's knowledge of the names and functions of the fastenings used. Record the answers/ability of the child on the observation schedule.

#### Activity 2: Unfastening

As counterintuitive as it may seem it is important that the child can unfasten before fastening. This is because the child should be able to firstly free themselves from clothing. If a child cannot unfasten there is a chance that they may feel stuck in an item of clothing, this could lead to frustration or panic.

Using the IPG pieces, ask the child which one they would like to try first. Record this on the observation schedule. When the child has chosen ask them why they chose that piece. Record this also on the schedule. Once happy, ask the child to unfasten the piece that they have chosen, in front of them. Continue on until the child has attempted all fastenings of all sizes. Record the child's ability for each on the observation schedule.

If the child experiences difficulty with unfastening, the adult can offer two types of help: verbal and physical. Verbal help is the use of verbal instructions to guide the child in task completion e.g. "would you like me to help you unfasten with my words?" Physical help is hand-over-hand assistance from the adult to help the child e.g. "would you like me to help you with my hands?" NOTE: assistance should only be given if the child has asked for help, or replies 'yes' when asked by an adult.

### Activity 3: Fastening

Once the child is able to unfasten pieces they can then fasten them back up again. Ask the child which piece they would like to fasten and record the choice on the observation schedule. If the piece needs unfastened first, ask the child if they can do this also. Follow the same steps as in task 2, and record everything on the observation schedule. Ensure that the fastening is occurring in front of the child.

### Activity 4: Tummy Time

Once the child has mastered fastening and unfastening with the puzzle pieces in front of them, ask the child to place the wooden piece on their tummy (stomach/belly) and attempt to unfasten/fasten whilst keeping the puzzle piece on their stomach. The child can sit up, lean back or lie on their back for this activity – whichever is most comfortable.

The aim of this activity is to begin to apply the abstract puzzle fastening to a real-life situation – fastenings are usually done around the torso. Of course, this does not apply to shoe laces!

### Activity 5: Fastening Relay

As the children become more confident with the puzzle pieces you can introduce a relay session (if working in a group). Split the children into two teams and divide the puzzle pieces equally. The team who can unfasten/fasten and fill their half of the jigsaw first is the winner. This activity should only be played if the children are confident in their fastening ability. The purpose of the intervention is to encourage fastening, not discourage the children.

### Activity 6: Applying to their own coat

Once the children become confident with the IPG pieces, fastening and unfastening can then be applied to the real-life situation of putting on their outdoor coats. To accompany this, the use of 'We're Going on a Joey Hunt' is recommended as it provides the children with an incentive to put on and fasten their coat. Depending on the time of the activity, this could always be done before break-time or home-time for example.

Bear in mind that the children may still require assistance when applying the fastening to their own coat – this is due to the increase in length of fastenings, the added activity of putting arms through correct sleeves etc. It is the role of the adult to maintain support (verbal/physical) within this activity.

### Activity 7: Lovely laces

Once the child has mastered the previous fastenings or would like to progress/try something new, move on to lace fastenings. Lace fastening is quite a complex task and the motor skill demands placed upon the children can be tiring. Lace learning can also be confusing and frustrating, and so the children will learn this last as they will have developed the sufficient finger control needed for laces whilst mastering zips, buttons and poppers.

Laces are not included in the Just Joey story, and so the commonly used 'bunny ears' method will be used. Demonstrated below:

Step 1: Tie the knot. To tie the knot you need to pinch the laces between the index finger and the thumb. Then cross over the laces, so that the lace on your right crosses underneath the lace on the left. Bring the lace at the bottom over the top of the other lace. Push the lace through the gap, and pull each lace through to tighten.

Step 2: Bunny ears. Make loop either lace to make bunny ears. The fold one loop over the other like you were tying a knot. Pull the loops through, like the knot and you have your laces tied

An alternative method:

Step 1: Tie the knot. As above.

Step 2: Make a loop with the left lace.

Step 3: Bring the right lace towards you, and wrap it around the loop. Your left hand is still holding the left loop. The right lace will go around your thumb, making a gap in the lace

Step 4: Push the right lace through the gap you have just made

Step 5: Pinch the left loop with your right hand and the right lace with your left hand.

Step 6: Pull the either loop to the left/right, like tying the knot.

### 3.2 Just Joey

This is a rhyming story which details how to put on and fasten a coat with zips, buttons and poppers. The children should be read this story at least once per week – depending on your intervention schedule. The story supports the fastening of the IPG pieces, and also supports fastening when applying the fastening skills to real-life situations. This is because the story also details how to put arms through sleeves and pull the coat around. The children become familiar with the rhymes in the story and then repeat them when attempting to put on their coats.

### 3.3 Joey

Joey is the commercially available soft toy suitable for aiding dressing skills. A progression from the IPG is to unfasten and fasten the fastenings on the Joey doll – this includes laces when the child is ready

### 3.4 'We're going on a Joey Hunt'

This activity requires the book: 'we're going on a bear hunt'. The children have to put on their coats and shoes (if necessary) and follow the story to find Joey – remember you need to place him somewhere e.g. in the classroom, in the corridor etc.

#### 4. Observation schedules

Observation schedules are also part of the intervention procedure. These are used to record the individual progress of each child. An example of the observation schedule is attached at the end of this document. There is one schedule for each type of fastening. An example for each fastening schedule is provided at the end of this manual.

Each schedule lists different stages of unfastening and fastening, for each fastening type (zips, buttons, poppers and laces). The observation schedule begins with the identification of the fastening piece. This is done so that you and the child are aware of the fastenings that they choose. The observation schedule then progresses from the unfastening of the piece to the fastening. This progression follows on a continuum based scale – but do not worry if a child misses a step! Some children may skip over some steps that identify holding pieces in a fist as they know to us the pinching technique. Each stage is supported by a picture, so that you can observe the hand positions and fully understand the stage descriptions.

The observation schedules are scored based on the stage that a child can reach independently. “Independently” means that you as the supporting adult do not need to provide physical hand-over-hand assistance to support the child in stage completion. It is important to note that a child can still “independently” unfasten/fasten if you provide verbal instruction or encouragement.

For example:

1	2	3	4	5	6	7	8	9
								
Can find zip on IPG/material and say 'zip'	Holds zip parts in fist	Holds top part of the material	Holds top of the zip with appropriate strength*	Pinches zip slider with appropriate strength*	Pulls slider down 100%	Removes the tail from the slider so zip is fully open	Finds the unfastened slider if it has moved from the base of the zip	Holds the slider in a fist
VI* VE*	VI* VE*	VI* VE*						

Ideally observation schedules should be completed at pre-intervention level, then once at the end of every week for the duration of the intervention period. The observation should be repeated once again at the end of the intervention period, and if the child's performance is assessed after a period of time (e.g. 1 month or 3 months) the observation schedules should also be completed.

## 5. Things to remember

Before you start you need to have all of the intervention materials and the observation schedules. Ideally you should have a rough plan of your intervention schedule, in order to plan for your weekly sessions. Remember that the intervention period can vary depending on the skill acquisition of each child – it can be shorter or longer than the recommended 10 weeks.

The suite of intervention materials are easily adapted based on the needs of the individual child.

An example of a script to use for a session:

When the children enter the room, ask them to find a space around the IPG and to sit on their bottoms. Then introduce the session: “Good morning! Today we are going to do our fastenings, like we did last week. Who can tell me the fastenings that we do?”

Give the children an opportunity to speak – if nobody can remember, the researcher reminds them that they have done zips, buttons, poppers and shoelaces. The researcher then says, “Today we are going to do our fastenings with the Joey story/puzzle pieces”. Each child is handed the relevant pieces (1 zip, 1 popper and 1 button)

The story begins. Once the story reaches the fastenings, 3 minutes are spent on each fastening. The instructions are read and the children have the opportunity to manipulate the fastenings

Physical or verbal assistance is provided if a child asks for help – see week 1 stage 2

Once all fastenings have been attempted, the children are asked what their favourite piece was and why. Some children may not have the ability to say why, but all children will indicate a preference – even superficially.

## 11.9. Just Joey Story

# Just



# Joey

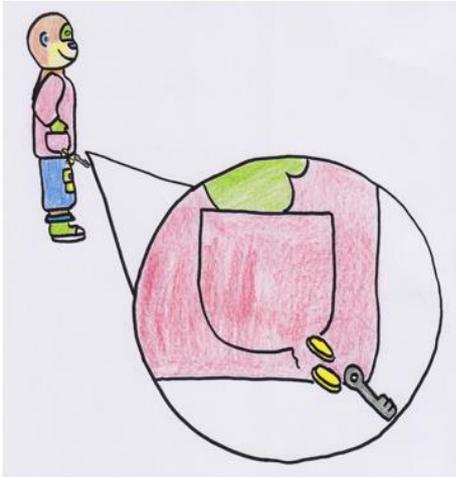


This is a story about Joey the monkey.



One day Joey decided to go to the shops to buy his friend Alice a birthday present.

He put on his favourite coat and put his keys and money into his pocket.



'Cling, clang, clink'. "Oh no!" cried Joey, "There's a big hole in my pocket. I'm going to need a new coat!"



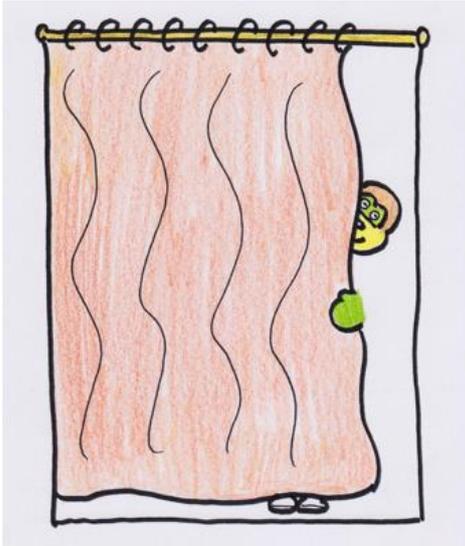
So Joey went to town to buy himself a new coat.



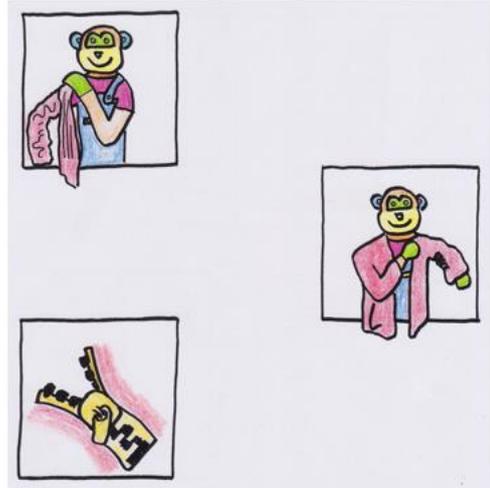
"Wow" said Joey, "So many choices". There were poppers and zippers and buttons and studs, Velcro and laces and jackets with hoods.



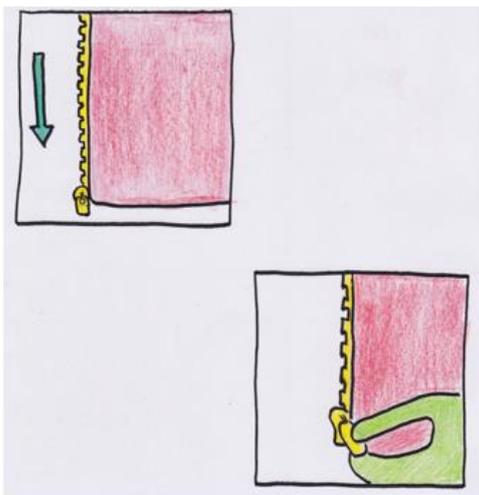
First Joey found a big red coat with a shiny gold zip. Then Joey found a light blue coat with shimmering poppers. Then Joey found a soft yellow coat with big buttons



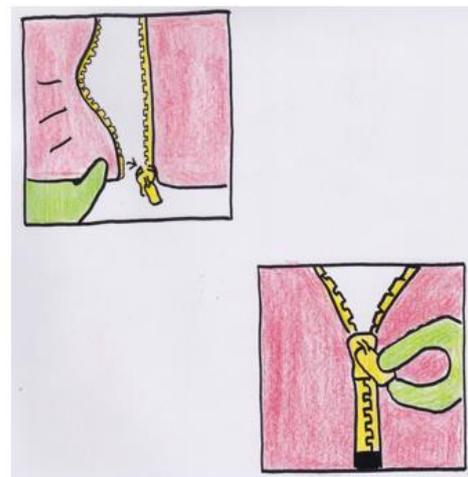
He decided to try them all on. "Excuse me," said Joey to the shop keeper, "Please may I try these on?" "Of course said the shop keeper and she hung them on the peg in the dressing room



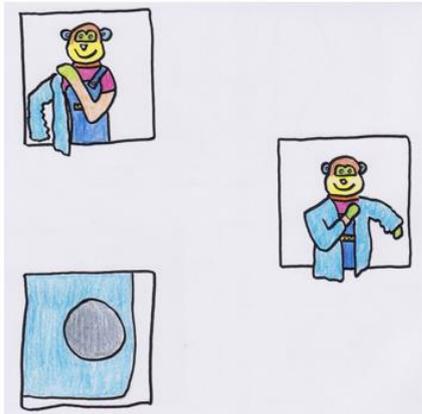
First he tried on the red coat. He took it from the peg and put his left arm through the sleeve. The he pulled the coat around his back and put his right arm through the other sleeve. "Now to fasten the zip" thought Joey.



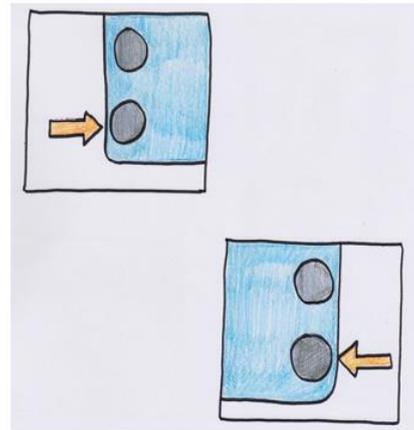
He remembered a rhyme from school; 'pull the zipper to the bottom so it goes down past your tum, and hold it at the base with your finger and your thumb...



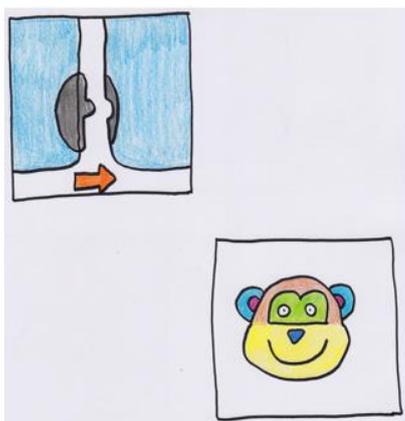
...Slide the tail through the ziphole and make sure it stays in place, then pull the zipper up and put a smile upon your face'. Joey liked the coat very much, but he still had two more to try.



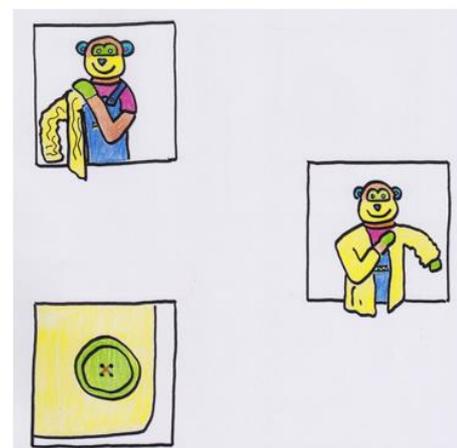
Next Joey tried the coat with poppers. Like the first, Joey put his left arm through the sleeve, pulled the coat around his back and put his right arm through the other sleeve.



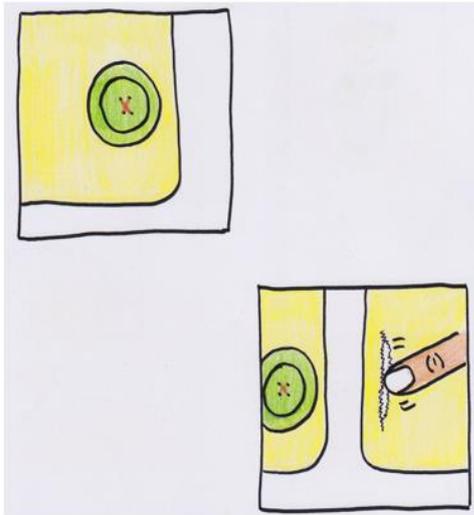
Joey remembered another rhyme; 'pinch the lowest popper on one side that you can find, now do the same on the other side so they are side by side...



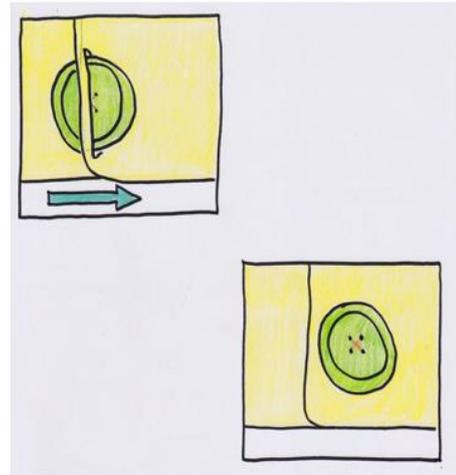
...Now squeeze them both together so that the bump goes in the hole, and now that they are fastened, you have reached your goal'. Joey was happy with this coat but still had one more to try on.



Like the other two, he put his left arm through the left sleeve, pulled the coat around his back and put his right arm through the right sleeve. Joey like the big buttons, and remembered a rhyme he learned for fastening them



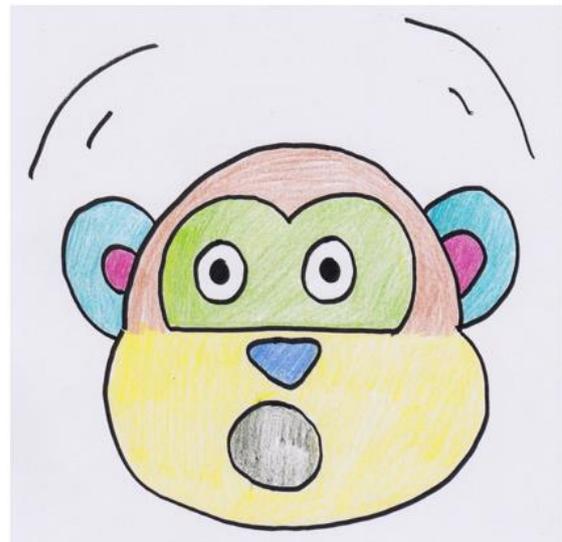
'find the bottom button and hold the edge nice and firm, now find the bottom button hole and wiggle your thumb through like a worm...



...Push the button into the hole and use your thumb to guide it through, then pull it out the other side, that's all there is to do'



After trying all three coats on Joey had to decide which one he liked best. "I like them all so much; I think I'll take all three!" So, Joey went home with three new coats and a smile on his face.

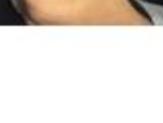
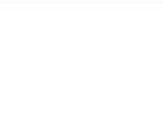
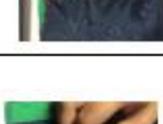


"Oh no! I forgot Alice's gift!!" cried Joey when he got home. But that's a story for another time.

The End.

### 11.10. Observation schedules: zips, buttons, poppers and shoelaces

Zips:

1		Can find zip on IPG/material and say 'zip'	VI* VE*
2		Holds zip parts in fist	VI* VE*
3		Holds top part of the material	VI* VE*
4		Holds top of the zip with appropriate strength*	VI* VE*
5		Pinches zip slider with appropriate strength*	VI* VE*
6		Pulls slider down 100%	VI* VE*
7		Removes the tail from the slider so zip is fully open	VI* VE*
8		Finds the unfastened slider if it has moved from the base of the zip	VI* VE*
9		Holds the slider in a fist	VI* VE*
10		Pinches the slider with appropriate strength*	VI* VE*
11		Wiggles the slider down to the base of the zip	VI* VE*
12		Pulls the slider down 100% in a sweeping motion	VI* VE*
13		Can find the tail of the zip	VI* VE*
14		Holds the material and the tail in a fist	VI* VE*
15		Pinches the material next to the tail with appropriate strength*	VI* VE*
16		Combines pinching the tail and pinching the slider with appropriate strength*	VI* VE*
17		Can place the tail alongside the slider	VI* VE*
18		Can place the tail at the top of the slider	VI* VE*

VI = verbal instruction; VE = verbal encouragement – **circle** as appropriate

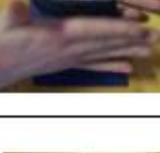
19		Can insert the tail 50% into the slider	VI* VE*
20		Can insert the tail 100% into the slider	VI* VE*
21		Can hold the inserted tail in a fist	VI* VE*
22		Can pinch the inserted tail with appropriate strength*	VI* VE*
23		Can find the tag on the slider	VI* VE*
24		Can hold the tag in a fist	VI* VE*
25		Can pinch the tag with appropriate strength*	VI* VE*
26		Can wiggle the slider upwards	VI* VE*
27		Can pull the slider up 50%	VI* VE*
28		Can pull the slider up 100%	VI* VE*

## Buttons:

11		Can hold the unfastened button in a fist	VI* VE*
10		Can find the unfastened button	VI* VE*
9		Pushes the button through the hole 100%	VI* VE*
8		Pushes the button through the hole 75%	VI* VE*
7		Pushes the button through the hole 50%	VI* VE*
6		Pushes the button through the hole 25%	VI* VE*
4		Pinches the button hole with appropriate strength*	VI* VE*
3		Pinches the button while fastened	VI* VE*
2		Holds the button parts in a fist	VI* VE*
1		Can find the button on the IPG/material and say 'button'	VI* VE*
22		Pushes the button through 100%	VI* VE*
21		Pushes the button through 75%	VI* VE*
20		Pushes the button through 50%	VI* VE*
19		Pushes the button through 25%	VI* VE*
18		Uses pincer grasp to match the button and the hole	VI* VE*
17		Uses palms of the hands to match the button and hole vertically	VI* VE*
16		Uses palm of the hand to rest the button hole on top of the button horizontally	VI* VE*
15		Holds both the button and the button hole	VI* VE*
14		Can find the stitching around the button hole and pinch with appropriate strength*	VI* VE*
13		Can hold the material including the button hole in a fist	VI* VE*
12		Can pinch the unfastened button with appropriate strength*	VI* VE*

Poppers:

1		Can find popper on IPG/material and can say 'popper'	VI* VE*
2		Holds popper parts in a fist	VI* VE*
3		Can pinch the popper parts using appropriate strength*	VI* VE*
4		Can pull pieces apart to unfasten	VI* VE*
5		Sweeps hand across the material to scan for pieces	VI* VE*
6		Sweeps hand across the material and finds one piece	VI* VE*
7		Holds found piece in one hand and uses the other hand to scan for the other	VI* VE*
8		Finds corresponding piece with other hand	VI* VE*
9		Holds both unfastened pieces in a fist	VI* VE*

10		Pinches both unfastened pieces with appropriate strength*	VI* VE*
11		Uses palm of hand to rest one piece on top of the other horizontally	VI* VE*
12		Uses palms of the hand to match pieces vertically	VI* VE*
13		Uses pincer grasp to match pieces vertically placing popper in the hole	VI* VE*
14		Uses appropriate strength to push the pieces together to fasten	VI* VE*

1		Can find laces on I/P/G/material and say 'laces'	VI* VE*
2		Holds aglet(s) in fist	VI* VE*
3		Pinches aglet(s) with appropriate strength*	VI* VE*
4		Pulls aglet(s) to unfasten the bow	VI* VE*
5		Uses index finger and thumb to unfasten the knot	VI* VE*
6		Holds unfastened laces in fists	VI* VE*
7		Pinches unfastened laces	VI* VE*
8		Can cross hands over using appropriate strength*	VI* VE*
9		Can swap the laces over the hands	VI* VE*
10		Keeps right hand still bringing right lace over the left using appropriate strength*	VI* VE*
11		Can push the right lace through the gap 50%	VI* VE*
12		Can push the right lace through the gap 100%	VI* VE*
13		Moves right hand to grasp right lace on the other side	VI* VE*
14		Holds lace in fists	VI* VE*
15		Pinches laces with appropriate strength*	VI* VE*
16		Pulls laces apart to form a loose knot	VI* VE*
17		Pulls laces apart to form a tight knot	VI* VE*
18		Uses both hands to make 1 loop (bunny ear)	VI* VE*
19		Pinches with one hand to make 1 loop (bunny ear) using appropriate strength*	VI* VE*
20		Holds 1 <sup>st</sup> loop and uses pinch to make 2 <sup>nd</sup> loop – keeping first loop in tact	VI* VE*

Laces:

<p>21</p> 	<p>Pinches loops with appropriate strength to keep loops in tact</p>	<p>VI* VE*</p>
<p>22</p> 	<p>Can swap the loops over the hands, keeping the loops intact</p>	<p>VI* VE*</p>
<p>23</p> 	<p>Keeps left hand still and the left loop intact brings right loop forward</p>	<p>VI* VE*</p>
<p>24</p> 	<p>Pushes right loop under left loop 50% keeping both loops intact</p>	<p>VI* VE*</p>
<p>25</p> 	<p>Pushes right loop under left loop 100% keeping both loops intact</p>	<p>VI* VE*</p>
<p>26</p> 	<p>Pulls loops apart to form a knot keeping one loop intact</p>	<p>VI* VE*</p>
<p>27</p> 	<p>Pulls loops apart to form a knot keeping both loops intact</p>	<p>VI* VE*</p>