'Above and Beyond': The Perceptions of Mothers of Children with Autism about 'Good Practice' by Professionals and Services

Catherine E. Stanford[a], Vaso Totsika[bc], Richard P. Hastings[ac]

University of Warwick, CEDAR,

[a]CEDAR, Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick, Coventry, CV4 8UW

Email: catherine.stanford@warwick.ac.uk (corresponding author)

r.hastings@warwick.ac.uk

[b]University College London, Wing B, Maple House, Tottenham Court Road, London, W1T 7NF

Email: v.totsika@ucl.ac.uk

[c]Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, School of Clinical Sciences at Monash Health, Monash University, Melbourne, VIC, Australia

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Abstract and Keywords

The aim of the present study was to investigate positive experiences with professionals and services, from the perspective of mothers of children with autism. Parents' negative experiences with services are well documented, but the experiences of 'good practice' have been less well researched. Seventeen mothers of children with autism aged between 5 and 10 years old were interviewed regarding their experiences of accessing services for their child, and in particular their experiences of good practice. Using inductive thematic analysis, three core themes were identified. These related to mothers valuing aspects of professionals' engagement, manner, and interactions with mothers; elements of professional and services provision (such as knowledge, community building, and hands-on skill development); and the ways services delivered their provision (e.g., through personalisation and adaptation, and ease of access). The findings of this study illustrate that these are clearly aspects of good practice valued by mothers of children with autism, which could be generalised to other neurodevelopmental conditions. Future research should consider establishing directional links between good practice concepts, for example using grounded theory.

Key Words: autism spectrum disorders; good practice; best practice; maternal experiences; service use; thematic analysis

Introduction

Parents of children with autism spectrum disorders (ASD) often report low satisfaction and frustration with a variety of services for their children (Corcoran et al., 2015). A particular focus within the literature has been on the stress parents' experience during their child's diagnosis (Crane et al., 2016; Osborne & Reed, 2008; Skilos & Kerns, 2007). The diagnostic process is often described by parents as being highly distressing, with parents experiencing initial shock, guilt, and concerns for their child's future, as well as broader family impacts, such as negative behaviours that create a non-optimal family environment for the children, including siblings (Mitchell & Holdt, 2014; Corcoran et al., 2015; Smith-Young et al., 2020). Parents' stress is exacerbated during the diagnosis period by factors associated with professionals and services, for example, working with multiple professionals, less

parental collaboration, and concerns about prolonged waiting times (Moh & Magiati, 2012; Reed et al., 2016). Often, the outcome of a diagnostic evaluation leaves parents dissatisfied as well (Chamak et al. (2011). Feelings of stress and service dissatisfaction extends beyond the initial diagnosis period, as parents get more involved with health care and education services (Jabery et al., 2012; Corcoran et al., 2015; Brookman-Frazee et al., 2012; Schieve et al., 2007; Starr & Foy, 2012; Kendall & Taylor, 2016).

Studies have identified several factors associated with parental dissatisfaction across different stages of service contact. Waiting times is a key factor associated with parental dissatisfaction across services, including both the time taken to receive a diagnosis, and time spent on waiting lists to access services (Crane et al., 2016; Renty & Roeyers, 2006; Brookman-Frazee et al., 2012). Parents also report dissatisfaction due to the level of information they are provided about the support they can access, including information about autism, or financial support (such as disability living allowance in the UK; Mansell & Morris, 2004; Renty & Roeyers, 2006). Concerns have been raised by parents feeling unable to access professionals and services, due to excessive service costs and confusing entry criteria, as well as more general feelings that some services do not effectively support families' needs (Dillenburger et al., 2010; Keenan et al., 2010; Osborne & Reed, 2008; Renty & Roeyers, 2005; Smith-Young, 2020). Parents also report frustration regarding service access, for example, concerns their child will be unable to access early intervention in a timely manner, and parents even describe relocating to access appropriate support (Smith-Young et al., 2020; Corcoran et al., 2015). Parents describe frustration with professionals' behaviour, the complexity of professionals' language, their perceived tendency to make quick judgements about children, inability to adapt to children's needs, and failure to include parents' views and voices (Braiden et al., 2010; Dillenburger et al., 2010; Keenan et al., 2010; Osborne & Reed, 2008; Renty & Roeyers, 2006; Smith-Young, 2020).

A smaller number of studies have identified some of parents' positive experiences with professionals and services. In a survey of 109 parents in England, Mansell and Morris (2004) identified that parents valued specific agencies, including mainstream and special schools, as useful sources of support. Parents have reported valuing effective, enduring, and sensitive relationships with professionals in interviews with 16 families in Canada (Woodgate et al., 2008). In interviews with 11 Northern Irish mothers' Braiden et al. (2010) identified positive parental experiences during the diagnostic process.

Parents, for example, described discussions with professionals about their child as comprehensive, that communication had been done in an open and transparent manner, and that their views had been sought and included. Similarly, Rabba et al. (2019) identified in their focus groups and interviews (with 13 parents in Australia), the value parents placed in discussing their child's diagnosis with an empathic and open professional. The importance of structure for parents was also echoed in Abbott et al.'s (2019) study where, in their evaluation of feedback sessions in North East England, parents valued having a structured opportunity to discuss their child's diagnosis, and to ask questions. The importance of communication and collaboration has emerged from large-scale survey studies across different countries (Belgium, Canada, and the UK), where parents identify that clear sharing of information between professionals and parents, continuity of care, knowledge and experience positively affect parents' satisfaction with services including diagnostic services (Crane et al., 2016; Renty & Roeyers, 2006; Starr & Foy, 2012). Although research findings do exist, as the preceding brief review illustrates, the majority of research describing positive experiences of parents did not seek to identify, explicitly, the nature of 'good practice' as reported by families of children with autism. Parents' perceptions of good practice have been explored in families of children with broader complex health needs. Carter et al. (2007) developed through appreciative interviews and workshops with 69 stakeholders (including mothers, fathers, a child, psychologists, teachers, and speech and language therapists) 'best practice statements' for working with families of children with complex needs. These statements included references to shared decision-making, close working relationships, clear communication, and parental choice (Carter et al., 2007, p. 527).

To ensure excellent service provision, professionals in health care and education are expected to follow best practice guidelines that have been informed by empirical evidence. Such guidelines are designed to encourage professionals to engage in actions that are known to enhance performance, are efficient, evidence based, and allow for consistently high quality (Kang et al., 2005; Perleth et al., 2001). The American Academy of Paediatrics Committee on Children with Disabilities (2001), for example, issued nine recommendations for paediatricians regarding the developmental screening of infants and children with developmental delays. These included rapid referral of families to appropriate early intervention, close relationships with other community based teams, and being accessible to families. Similarly, seven principles of best practice were identified in Australia for youth health care including: collaboration, evaluation, and professional development opportunities (Kang et

al., 2005). More specifically related to autism, in healthcare the National Institute of Health Care Excellence (NICE) and Social Care Institute for Excellence (SCIE) in the UK put forward a number of recommendations for best practice, including inter-disciplinary team collaboration, a core level of professional knowledge, and the expectation of personalised, consistent care across settings (Kendall et al., 2013). Similarly, in education, best practice provision for children with autism spectrum disorders is highlighted as tailoring interventions to stakeholders, ongoing parent-teacher collaboration, and specialist knowledge training (Guldberg, et al., 2011).

However, there is some debate as to whether guidelines and recommendations truly lead to the delivery of good practice by agencies, and whether this professional view of 'best practice' is reflected in parental opinions of what they value to be 'good practice'. Triano et al. (2008) proposes that guidelines do not effectively alter professionals' behaviour, and guidance is often driven by economics as opposed to being focused around individual and other stakeholders' needs. Therefore, whilst the notion of best practice must still be considered integral to the efficient and effective operation of services, there is a growing acknowledgement that professionals and services must be sensitive to what parents consider 'good practice' to be. Research must expand to consider how good practice "resonates at the bedside" when individuals and families are accessing services, and how practice can be "consistently delighting" families and other stakeholders (Mosadeghrad, 2013, p. 215; Novak et al., 2008, p. 45).

In the present study, our main aim was to investigate what parents of children with autism consider to be 'good practice'; the aspects of professional or service support that they value. Mothers of children with autism were interviewed, and specifically encouraged to consider and report any examples of what they would consider to be 'good' practice they may have encountered when accessing professionals or services.

Method

Participants

A total of 17 mothers were included in this research. The mothers' children were mainly male (82%) with a mean age of 7.12 years (S.D. 2.03, range 5 to 10 years). Mothers of all children reported that their child had received an autism diagnosis from a relevant healthcare professional. The mean age of diagnosis for children was 4.24 years (ranging from 1 to 8 years). Additional diagnoses included sensory problems (2 children), developmental coordination disorder (DCD; 1), global developmental delay (1), hypermobility (1), hypertonia (1), and selective mutism (1). All participants were assigned a pseudonym. Mothers were recruited via social media advertisements and diagnoses were provided via parent report (more information in procedure). Information about mothers and their children is reported in Table 1.

Interview Schedule

A bespoke interview schedule was designed to explore parents' experience of professionals and services. In the first part of the interview, mothers were asked open-ended questions regarding "events and milestones that occurred during [their child's] early years" and then further prompted, "which services did you use during your child's early years?" In the following part of the interview, mothers were asked to describe which services, professionals, individuals, or processes they engaged with that they would describe as "most helpful", "very good", or "supportive", and what services they might recommend to other parents. If mothers reported a particularly negative experience, they were prompted to consider any improvements that might have benefited either themselves or families in the future, so that this part of the interview was explicitly focused on good practice. The interview was designed to build rapport, and encourage honesty, thus promoting the quality of the research (Braun & Clarke, 2006). This rapport building also allowed mothers to reflect on their experiences of services, before being asked more explicitly about good practice.

Procedure

Ethical approval for the research was obtained from the University of [BLINDED]. Initially, 25 parents (all mothers) responded to an online advertisement for the study distributed via social media channels. Parents were invited to participate in an interview to discuss their experiences of accessing support services, particularly in relation to any good experiences they had with services. They were provided with a link to an information webpage, which both briefly outlined the purpose and details of the interview, and provided a full participant information sheet as an attached document. Following this, another link was provided to a webpage where parents could read and sign a consent form, before completing a contact form. Although the advertisements were directed towards parents and caregivers of children with autism, only mothers responded.

Mothers were contacted by the first author to check inclusion criteria for the research, and to schedule the best format and time for the interview to be conducted. To fully meet inclusion criteria, participating individuals were required to live in England, and have a child aged between 5 and 10 years old with a formal diagnosis of autism (as reported by the parent). Of the 25 mothers, two did not provide any contact information, one mother was excluded as their child was not in the age range for this study, one mother withdrew from the study prior to completing an interview, and three mothers were not were not contactable after submitting their consent forms and contact information. Eighteen interviews were conducted. One mother had confirmed her child's diagnosis of autism over the telephone, before clarifying during the interview that their child had a diagnosis of pathological demand avoidance (PDA) and so her interview was excluded from the subsequent analysis. All mothers opted to complete their interview over the telephone, although all were offered the option for a face-to-face interview. The mean interview length was 64.45 minutes, ranging between 26.46 minutes and 163.54 minutes long. All interviews were audio-recorded.

Data Analysis

Interviews were transcribed verbatim, with identifiable information removed from transcripts. These transcripts were then analysed by realist, inductive thematic analysis (Braun & Clarke, 2006). This method was selected as it led the analysis to be data driven, meaning parents' views directly contributed to code generation, as opposed to being interpreted through an existing theoretical lens. All interviews were conducted, and then re-read post transcription, by the first author to ensure complete familiarisation with the content, and interesting points were noted. The qualitative analysis was undertaken using NVivo software (version 12).

Initial codes were primarily generated from information provided in the good practice part of the interview, although some content in the first part was reviewed and included when directly related to positive experiences mothers had with professionals or services. Initial codes were generated by reading transcripts line by line, and generating codes as each new concept was identified (ensuring the ability to create from these codes robust descriptions). These initial codes were then grouped and re-organised into sub-themes and over-arching themes. An initial coding framework was created by the first author based upon initial familiarisation with the data, and this was continuously reviewed by all authors. Overarching themes and sub-themes were iteratively reviewed, by the second and third authors, both in two formal meetings and continuous email and telephone communication over a period of five months, to ensure the validity and distinctiveness of themes, underpinning the credibility of the analysis. Disagreements regarding codes were dealt with by going back to the raw data and reviewing the codes in the broader context of the interview transcript, to ensure the contextual validation of codes. This process was repeated for identifying the relationships between sub-themes (see Figure 1). To ensure the dependability of our analysis, revisions and amendments to iterations of the coding schemes and N-Vivo files created were documented. To increase credibility, a researcher independent of this study was consulted to review the first thematic map created (Nowell et al., 2017). The analysis was finalised when the research team reached consensus on the themes and sub-themes as well as their proposed associations.

As the first author primarily led the development of codes for the themes and sub-themes during the analysis, it must be acknowledged that their experiences and background (in prior family research, and in school settings) may have influenced the codes generated, although the researcher reflected

on her own potential biases and was aware of the importance of confronting biases throughout this process. The process of continuous discussion between the three authors on the codes and themes minimised any potential drift due to individual researchers' biases. The aim of the thematic analysis was to identify the themes and sub-themes of good practice across all interviewees and across the whole body of the interview. Therefore, the analysis of each transcript was not triangulated with individual participants. Rather than understanding individuals' lived experiences of good practice, our aim was to explore emerging themes of good practice across participants as a whole. All mothers' quotes are reported using their assigned pseudonyms.

Results

Summary of Good Practice

The themes and sub-themes from this analysis are presented in Figure 1, as well as the potential associations between themes. Themes are displayed as three rectangular boxes feeding into the overall "good practice" concept. Sub-themes are presented as individual items within these boxes. Each sub-theme represents an individual element of good practice. Associations between sub-themes, across differing themes, are presented as dotted lines in Figure 1.

[INSERT FIGURE 1]

Themes

Each of the three themes and further sub-themes describing good practice will be discussed in the following sections.

Valued engagement: professionals' interaction.

In this theme, mothers' accounts focused on the manner with which professionals engaged with them and their children during face-to-face interactions. This theme is comprised of seven sub-themes.

Rapport with children highlights that mothers valued professionals who were able to build up a relationship with their child. This includes examples during a singular experience with a professional: *"and she* [neurological development professional] *spoke to [child], she acknowledged [child] and sat*

him down and gave him an activity to do" (Phoebe). This sub-theme also includes comments concerning long-term rapport and relationship building: "*I think they* [Child and Adolescent Mental Health Services, CAMHS] *took the time to build up a relationship with [child's name]"* (Olivia).

Good practice was also reported by mothers as professionals' **emotional understanding and experiences**, where professionals engage with mothers showing understanding and empathy: *"you feel like you are talking to someone* [paediatrician] *who is understanding, the manner that they interact with you. You can be talking about something upsetting, and just helpful when they say don't worry"* (Emily). Mothers also noted that professionals with personal experiences of autism or disabilities had heighted emotional understanding: *"I think what was nice about her* [speech and language therapist] *as well she had been through similar things like I sometimes find if you're talking to somebody that has got experiences that you can relate to as well it just opens it up a little bit, that helps as well sometimes"* (Diane).

Good practice was also reported by mothers to be seen in professionals who go **above and beyond** in their role requirements to support families: *"I even ended up phoning her* [child development coordinator] *a few times because […] I didn't know who the point of contact was and I phoned her and she actually said he's gone past that age […] but she spent hours on the phone with me anyway, just out of kindness"* (Megan).

Mothers reported professionals' **personable manner** to be related to good practice. This sub-theme primarily described professionals who were friendly, relatable and approachable: *"It's quite unsettling when you don't know anybody and you're kind of there to get support and she's* [centre staff member] *just been there from the start, super friendly and really nice and welcoming"* (Stephanie).

Considerate practice by professionals was also highly valued by mothers: *"it was really good to have somebody* [speech and language therapist] *tell you in advance that they want to see you at the school […] she could have turned up and then said can I have a minute to speak to you and it wouldn't have been productive"* (Phoebe). Mothers commented that they appreciated professionals' informing them of what to expect when engaging with a service or process, as well as professionals taking measures to ensure mothers' and children felt comfortable: "*they* [university] *took photos of the room so [child] could see the room before he got there, they explained what was going to happen […] instead of*

saying twenty minutes because at that stage [child] wouldn't understand so instead of saying twenty minutes they'd say three episodes of 'Thomas the Tank Engine" (Chloe).

Mothers also commented on **open, honest, clear communication** as being related to good practice. This is when professionals communicated with mothers in a clear and transparent manner :*"she was so professional that she approached me saying I don't think some of these issues are spot on. She had no problems communicating with me regarding that at all […] she actually said to me "if I'm wrong I'm wrong, but I'd rather say than not say"* (Chloe). Mothers also, felt listened to by professionals in turn: "*she* [learning mentor] *has been amazing, a lot of the stuff she has listened to us, and taken on board some of the things we would recommend for child"* (Phoebe).

Mothers also reported good practice to be professionals **providing affirmation** for their concerns about their child, confirming that mothers were engaging in helpful strategies or practices to support their children: "*empowering, you know she was the one who told me we were doing a really good job and you know […] sort of acknowledgement that we were doing the right thing*" (Megan).

Appreciated provision.

Mothers highlighted several types or dimensions of provisions that they felt reflected good practice, at both professional and service level. Appreciated provision included six sub-themes.

Knowledge, at both the service and professional staff level, was commented on by mothers. Mothers commented that good practice was related to professionals' who were highly skilled and knowledgeable: *"yeah she was an excellent, experienced* [Special Educational Needs Coordinator; SENCO]. *She knew exactly what she was talking about*" (Rebecca). Mothers also identified good practice as related to the knowledge of services that provided information: "[Special Educational Needs and Disabilities Information Advice and Support Service; SENDIAS] *and* [Independent Provider of Special Education Advice; IPSEA] *are brilliant for information"* (Wendy). Practical knowledge was also mentioned by mothers as relating to good practice: *"the* [charity] *kept telling me "you've got to apply for* [Disability Living Allowance; DLA] *for him […] I didn't understand why you needed DLA, because without DLA you couldn't access some of the other short break and other provisions*" (Phoebe).

Mothers also reported good practice as involving **hands-on working and skill development.** This includes skills children were taught via practical work: *"so the Portage* [home visit education service] *[…] it was very good because it was trying to teach her like social skills like in an easy fun way"* (Alice). Hands-on working and skill development was also related to skills mothers learned directly: "*the best strategy that I have always found is to move their attention onto something else […] that was learnt from Portage"* (Stephanie).

Mothers also valued when services **provided resources:** *"*[Charity] *they have given us a grant to get all new bedding and also for an iPad"* (Alice).

Mothers felt that good practice was reflected by professionals or services **moving things forward.** Some comments related to diagnosis: "*and then of course doing the* [Autism Diagnostic Observation Schedule; ADOS) *with* [university] *as well that helped myself with the diagnosis and that helped them with actually going through the process* [with a paediatrician]" (Bethany). Other comments, however, focused more generally on professionals or services moving things forward: *"if it wasn't for the SENCO and his keyworker at the pre-school we wouldn't have got where we are now"* (Leah).

Provision leading to **community building** was also mentioned by mothers in relation to good practice. This refers to services that provide families with a peer network. One way a service may do this is through its primary provision purpose: *"they've always been* [children's centres] *really good for meeting other parents and getting out when you've got a new-born"* (Diane). This might also be because of a secondary outcome: *"so it was really helpful to be there* [community autism talks] *with other parents, grandparents, or carers who have children on the spectrum can be really helpful"* (Emily).

Mothers also noted that good practice related to provision that led to **meaningful outcomes for mothers and children.** These were outcomes that mothers could see had resulted from the provision they had received. Meaningful outcomes were related to children's own development: *"everything that she* [speech and language therapist] *was speaking of worked quicker, he started calling me "Mummy" or using single words"* (Sally). Meaningful outcomes were also related to impacts on the mother themselves: *"because they're* [charitable services] *helpful as well, the service that they provide ensure that family life is a bit easier and more… makes family life easier and more manageable"* (Alice).

Good delivery of services.

The third element of good practice relates to the way services are organised and operate to deliver support. This theme includes four sub-themes.

Mothers reported good practice to reflect services that were **consistent and dependable.** Mothers, for example, being able to see the same professionals and access the same services was a constant source of support: *"I've seen the same paediatrician since [child] was diagnosed at four [...] and I believe that has helped immensely"* (Chloe). Similarly, services were valued for being dependable when accessed: *"they just were. They were always available to talk"* (Leah).

Ease of access was also identified by mothers as a dimension of good practice. One factor encompassed in this is speech: *"but as soon as we had concerns [...] they* [heath visitors] *jumped* (Bethany). Affordability was also commented on: *"the prices are affordable to go on these* [training courses] (Diane). The universality of provision was also noted in relation to ease of access: *"so even if you didn't qualify for any service you could still go along every day to the children's centre".*

Mothers also identified **personalised and adaptable** service delivery to be related to good practice. Personalisation may take place through home visits, and the working practice of professionals: *"well just because of how they* [Portage] *helped both the children and me. It was about us"* (Stephanie). Similarly, adaptable provision was mentioned in relation to tailoring services to suit each child: *"and then things went horribly wrong at school [...] and she was unsure of even going to CAMHS, and CAMHS were "that's ok mum can come in too [...] so they have been very adaptable to [child's] needs and how she is feeling"* (Olivia).

Finally, mothers commented on **early and timely intervention** for their children as reflecting good practice. This sub-theme included comments from mothers regarding how they felt they and their child had benefitted from early intervention: *"whereas with me I was able to catch it early so all these courses and things I went on helped* [Communication and Interaction Support Service; CIASS]" (Erica). Mothers also mentioned how they may have benefited from earlier, timelier intervention: *"I think looking back now it would have been nice for people to have picked up the ASD and then the referrals and maybe have been given some information and leaflets on that, that would have been quite nice"* (Olivia).

Associations between sub-themes

Although thematic analysis cannot substantiate connections between themes, there was evidence from transcripts that certain sub-themes tended to be more frequently mentioned together by mothers. Where mothers discussed more than one element (sub-theme) of good practice in relation to a professional or service, these were collated and then analysed to examine whether specific codes appeared to cluster together.

Many mothers commented on professionals or services that demonstrated **hands-on working and skill development** and **personalised and adaptable service delivery**. Emily, for example, discussed concrete examples of Portage working with her child, *"that was his first introduction to [Picture Exchange Communication System; PECS]"*, but also how Portage was "*very personal […] very personalised to him and interactive, working with him and showing me what to do with him"*. **Hands-on working and skill development** was also mentioned alongside comments that services were **consistent and dependable**. Phoebe, for example, discussed a learning mentor having *"worked with [her child] using interactions with play dough to start using other cutlery"* but also remarked, *"she has been that constant for him no matter what grade or part of school he is in"*.

Mothers also linked both **knowledge** and acting **above and beyond** in relation to individual professionals or services. Stephanie, for example, notes that a professional *"seemed to have all the answers"* but also went above and beyond their role saying *"if you want me to come out and help you go through it* [EHCP information] *I will. She was willing to come out and fill out forms with me and read through it all".* Finally, both **knowledge** and **emotional understanding and experience** were commented on by mothers in relation to individual professionals. Wendy, for example, indicated that her child's play group was valuable because *"they really were a wealth of information"* but also identified *"I think you just get emotional support, you get the information"*.

Discussion

The aim of the present study was to explore perceptions of good practice as identified by mothers of children with autism, formed from their experiences accessing various professionals and services for their children. Findings from interviews with mothers of children with autism identified good practice

relating to the way professionals *engage* with mothers and children, including building rapport, being considerate in how they implemented practice, and demonstrating emotional understanding. Mothers also identified good practice to be related to what professionals and services are able to *provide,* be that the service's primary intention (such as hands-on skill development) or a secondary outcome (such as community building). Finally, mothers noted good practice in relation to what, how, or when services *deliver,* for example personalised provision, which is consistent and dependable, and embodies early and timely intervention.

The findings corroborate previous evidence on good practice identified in other studies. Previous literature, for example, stressing the importance of empathic, sensitive, caring professionals who communicate clearly and openly, maps onto several sub-themes identified in the **valued professional engagement: professionals' interaction** theme, such as **personable manner, open, honest, clear communication** and **emotional understanding and experience.**

Previous findings, including the importance of services being accessible and flexible, also relate to the sub-themes of **consistent and dependable, ease of access,** and **personalised and adaptable** (Carter et al., 2007; Keenan et al., 2010; Rabba et al., 2019; Renty & Roeyers, 2006; Woodgate et al., 2008). Specific sub-themes, such as **personalised and adaptable** services appear to be the antithesis of factors related to parent dissatisfaction, for example failure to adapt provision to support children in education (Kendall & Taylor, 2016). However, certain sub-themes such as professionals going **above and beyond** what is expected of them exemplify factors only relevant to good practice. In other words, not all factors that describe good practice are the opposite of factors relating to poor practice.

Similarly, previous findings on the importance of autism-specific guidance on liaising with external agencies (Mansell & Morris, 2004; Renty & Roeyers, 2006) relate to the current study's sub-theme of **knowledge.** Parents' preference for reduced waiting times, and dissatisfaction with services where they experience delays (Osborne & Reed, 2008; Renty & Roeyers, 2006) link to the sub-theme of good practice being **early and timely intervention.** The themes from the current qualitative study also broadly map onto published professional recommendations/guidance: the need for timely intervention, a high level of professional and specialist knowledge, and personalised tailored intervention (Gulberg et al., 2011; Kang et al., 2005; Kendall et al., 2013). A further aspect of best

practice recommendations is the idea of collaboration between services, parents, and professionals (Kang et al., 2005). While this did not emerge as a stand-alone theme of group practice as identified by parents, elements of this recommendation are encapsulated in part in the sub-themes of **consistent and dependable** services and **open, honest, clear communication** between professionals and parents.

The over-arching theme **valued engagement: professionals' interaction** echoes the emerging notion, especially in healthcare, that increased focus should be given to how professionals may best engage with parents, and consideration given to how parents in turn feel about these interactions (Mosadeghrad, 2013; Novak et al., 2008). Acting with a personable manner, and using open, honest, clear communication are elements that some professionals might consider as obvious or standard. However, these qualities were highlighted by mothers as those that actually set apart the "good" professionals they encountered.

 The present study has a number of limitations that should be considered when interpreting these findings. First, due to the study aims, individual interviews were not discussed with participants. Although mothers' voices directly contributed to the themes developed through their interviews, and other steps were taken to ensure researcher biases did not influence the interpretation of codes, future research could explore the development of good practice themes collaboratively with parents during analysis. Another limitation was that all diagnoses were reported by mothers and most children were reported to have attended or to be attending a mainstream school setting. Thus, the findings may not generalise to families whose children might attend special schools. Although some links can be drawn across themes, there was not enough evidence via thematic analysis to substantiate any relationships or directional links between good practice concepts. For example, knowledge and emotional understanding and experience may well occur frequently together, but the current findings cannot be used to examine whether emotional understanding makes a mother more likely to notice or appreciate the knowledge of a professional. Therefore, future research could consider using grounded theory to establish the relationship these good practice themes may have to each other. Finally, mothers often required prompting by the interviewer to discuss good practice experiences in further detail. In future, researchers should consider adopting different interview structures, or using different methodology (e.g. focus groups) when asking parents of children with autism to consider what good

practice means to them. The current study was also retrospective, prompting some mothers to think back to consider good practice over 10 years of their child's life. Although this type of approach was necessary to create broad and encompassing themes, driven by parents' long-term experiences, future research might focus on the experiences parents of children with autism have during, or immediately following accessing services.

Implications

Even with the limitations in mind, the findings have relevance and potential implications for professionals and services. Aspects of good practice, such as **personable manner** and **considerate practice,** are elements that could potentially be easily incorporated in professionals' and agencies' everyday work, with no need to consider expensive re-structuring of provision. The identified theme **valued engagement: professionals' interaction** also emphasises a previously less discussed element of good practice, which was of clear importance to mothers in this study, and so could be considered in future research and by professionals and services. Mothers valued practice that led to meaningful outcomes, which may suggest that good or best practice might demonstrate improvement and progress in a way that is tangible and recognised by parents (Kang et al., 2005; Perleeth et al., 2001)

Perhaps the most striking finding was that these mothers of children with autism did not appear to raise specific good practice factors related to their child's autism specific needs. While, of course, specialist knowledge of autism is expected and would be identified as skilled provision, elements of good practice identified by these mothers could be relevant to parents of children with a variety of diagnoses. If findings from the current research were to be replicated, professionals and services could easily consider adapting their provision to engage and display good practice to a variety of parents (e.g. those with children with a range of neurodevelopmental conditions) who access their provision.

Acknowledgements and Conflicts of Interest

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Table 1
Demographic information for mothers and their children

Participant	Child Gender	Child Age (Year)	Region	Diagnosis Age (Year)	Diagnoses
Tanya	Male	8	South East	3	ASD
Megan	Male	6	North West	1	ASD, global developmental delay, hypermobility, hypertonia, sensory issues
Alice	Female	10	South East	3	ASD
Phoebe	Male	7	Midlands	5	ASD
Sally	Male	5	Midlands	4	ASD
Erica	Male	5	Midlands	3	ASD
Bethany	Female	5	South East	4	ASD and DCD
Rebecca	Male	6	South West	6	ASD
Wendy	Male	10	South East	8	ASD
Olivia	Female	10	x	8	ASD
Chloe	Male	9	Midlands	4	ASD
Lola	Male	10	Midlands	4	ASD
Leah	Male	5	x	3	ASD
Stephanie	Male	8	South East	3	ASD, selective mutism, sensory issues
Diane	Male	6	Midlands	5	ASD
Rhiannon	Male	6	South East	6	ASD
Emily	Male	5	South East	2	ASD

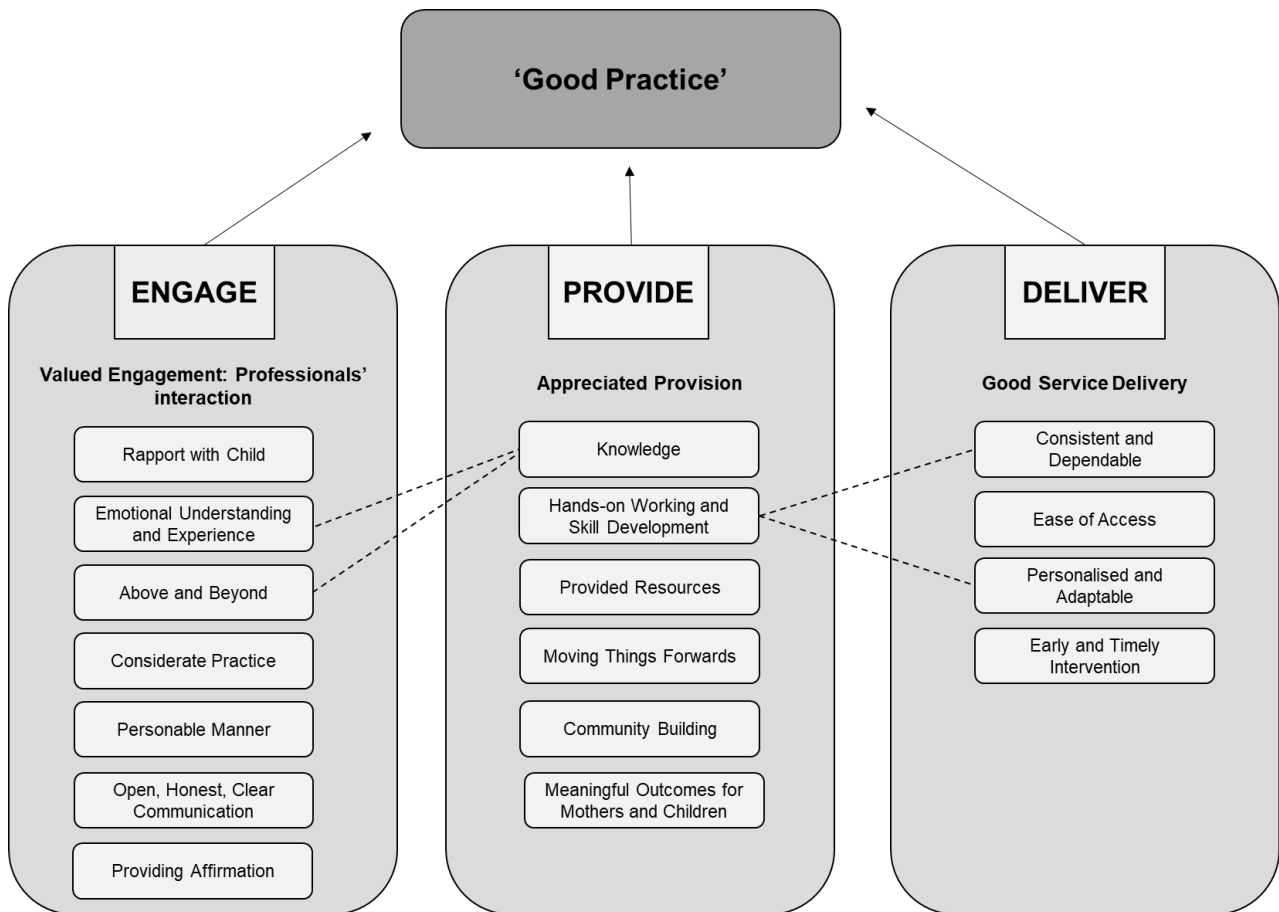*Note. x signifying location not disclosed during the interview*

Figure 1. Summary model of good practice as reported by mothers