Understanding experiences of a befriending scheme for people with intellectual disabilities

Fiona Brand

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Thesis declaration form

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

Signature: [redacted]

Name: Fiona Brand

Date: 1st July 2022

Overview

This thesis sought to advance understanding of befriending interventions for people with intellectual disabilities. It is presented in three parts.

Part 1 is a literature review, detailing a systematic search of the existing literature on befriending for people with intellectual disabilities. Eleven studies were identified and evaluated using narrative synthesis. Psychological and social outcomes for befriendees, befrienders and carers were reported.

Part 2 is an empirical paper reporting a qualitative study of the experiences of those involved with a befriending scheme for people with intellectual disabilities and/or autism. Through semi-structured interviews with befriending recipients, volunteers and family carers it considers the experiences, ‘active ingredients’ and limitations of the scheme.

Part 3 is a critical appraisal of the research process undertaken for the empirical paper in Part 2, including discussion of methodological issues and personal reflections on the research process.

Impact statement

This thesis, which focuses upon experiences of befriending schemes for adults with intellectual disabilities informs both academic research and clinical practice. The first part comprises a literature review, collating the findings of existing studies into befriending for people with intellectual disabilities and/or autism. This review reports a broad range of positive psychological and social outcomes of befriending for befriendees, befrienders and carers. However, it also highlights the paucity of existing research in this area, with only eleven studies of varying quality published over the past twenty-five years. Its findings about the outcomes of befriending interventions inform clinical practice in suggesting the use of standardised, validated measures across befriending services in order to enhance service evaluation and inform discussions around the impact of befriending over different time periods. Additionally, the review's results inform future directions in academic research, namely a need for further understanding the effectiveness of befriending and the mechanisms of change driving that, the extent to which befriending leads to community participation or social inclusion, and the longitudinal effects of the intervention, particularly for those who experience unexpected endings of befriending relationships. The review also highlights the limited evidence to date of co-produced studies between researchers and people with intellectual disabilities, impacting upon methodological design considerations for future academic studies.

The second part of the thesis is a qualitative study directly into the experiences of people involved in a befriending scheme for adults with intellectual disabilities and/or autism. Among its key findings are that befriending is valued as an intervention, due to its impact upon fostering independence, providing companionship to mitigate social isolation and providing a sense of group belonging. Findings that emphasise the importance of shared decision making, the value of group interactions between befriending scheme participants and the effectiveness of practical and emotional support in scaffolding and growing independence can all be applied to the clinical practice of befriending schemes, informing befriender training, service organisation and prioritisation of activities. Additionally, the study may provide additional information for service commissioners and directors about the active ingredients and the potential benefits of befriending. Academically, the qualitative study supports and extends existing evidence around befriending and raises questions for future directions in research. Suggestions expand upon those prompted by the literature review and include understanding more about what works with relationship endings, whether effects of befriending are sustained following this, and whether the minimum volunteer commitment of one year (common across befriending schemes) is sufficient in this population group. Additionally, the study findings around befriending leading to a sense of belonging to a group, and its success in facilitating access to ordinary community settings suggests that future research comparing one-to-one befriending with models where multiple befriending pairs access community settings together could be beneficial. Methodologically, it could impact academic practice by illustrating and reflecting upon different approaches to inclusive research with people with intellectual disabilities in this area.

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Part 1: Literature Review

The psychological and social outcomes of befriending interventions for adults with intellectual disabilities: A systematic review and narrative synthesis

Abstract

Aims: This review aimed to understand the key characteristics and psychological and social outcomes of befriending interventions for adults with intellectual disabilities.

Method: A review of studies focused upon befriending interventions for adults with intellectual disabilities was conducted. Systematic searches of electronic databases (PsycINFO, MedLine and Web of Science) identified eleven studies for inclusion in the review.

Results: A narrative synthesis of the studies' findings, along with a critical appraisal of the quality of each individual study was completed. Community participation, changes to social networks and impact on mood were the most frequently reported outcomes for befriendees, whilst knowledge and experiences and opportunities to give back were most reported for befrienders.

Conclusions: The review highlighted that the existing research in this field is somewhat limited in scope though methodologically diverse. Future research should focus upon strengthening the evidence on effectiveness and impact of befriending interventions, (including on a longitudinal basis), understanding the mechanisms of change that lead to this, and eliciting the views of people with intellectual disabilities on their experiences.

1. Introduction

Friendship is an important element of human life. It provides companionship and emotional support and facilitates community integration and development of social networks. Making and maintaining friendships promotes individual wellbeing, offers opportunities to share pleasure and enjoyment and provides a sense of valuing others and feeling valued by others (Peel et al., 2009). Friendships impact quality of life for people with intellectual disabilities, directly influencing the domains of emotional wellbeing, interpersonal relations and social inclusion (Schalock et al., 2002).

However, individuals with intellectual disabilities face barriers to social inclusion and often find it hard to make and maintain friendships (Abbott & McConkey, 2006; Merrells et al., 2019). Social networks are frequently reported as small and made up primarily of family members, paid carers and other people with intellectual disabilities (Duggan & Linehan, 2013; Emerson & McVilly, 2004; Verdonschot et al., 2009). Prevalence of loneliness is higher compared with the general population (Alexandra et al., 2018; Gilmore & Cuskelly, 2014) and barriers such as not having anyone to go out with, being unsure about what there is to do, and lacking confidence impact upon making new friends and participating in the community (Abbott & McConkey, 2006; Mayer & Anderson, 2014).

In the UK, the government has long sought to enable people with intellectual disabilities to develop friendships and engage in a variety of community activities (Department of Health, 2001). A huge array of initiatives have been implemented, to varying effect (Bigby et al., 2018; Duggan & Linehan, 2013; Howarth et al., 2016). One particular intervention that aims to improve quality of life and wellbeing and enhance social support is “befriending”, which seeks to develop a one-to-one, friend-like relationship, organised and supported by an external organisation (Balaam, 2015). Befriending has been implemented internationally, across a range of populations considered to be vulnerable to social isolation including individuals with physical health or mobility problems (Rantanen et al., 2015; White et al., 2012), socially isolated older adults (Mountain et al., 2014), carers for people with dementia (Charlesworth et al., 2008), people with mental health problems (McCorkle et al., 2009; Priebe et al., 2020) and people with intellectual disabilities (Southby, 2019; Tse et al., 2021).

Despite its popularity, the evidence base for befriending is limited. One meta-analysis of befriending across various populations (including one study of people with intellectual disabilities), found a small positive effect for combined primary outcomes, but no significant benefit on single outcomes including quality of life, loneliness or depression (Siette et al., 2017). Another considered the impact of befriending on emotional wellbeing, reportedly using depression symptoms as the primary outcome of interest because this was the most reported outcome across studies, though they acknowledged it may not be the most appropriate measure for befriending interventions. Looking across populations including pregnant women, carers and those with physical or mental health problems, the review found a modest positive effect upon depressive symptoms but none upon perceived social support (Mead et al., 2010). There is comparatively more research evidence for befriending amongst mental healthcare populations, though the practice varies widely with regard to implementation of personal boundaries, expected relationship duration or the extent to which it is viewed as a professional relationship or a friendship (Thompson et al., 2016). One study found that both befriendees and volunteers valued the relationships formed through befriending, with befriendees particularly benefitting from participating in the local community and learning new skills (Mitchell & Pistrang, 2011). A recent randomised controlled trial found that befriending significantly increased the number of social contacts in patients with schizophrenia, including at six-month follow up (Priebe et al., 2020). Other studies have explored the characteristics, motivations or experiences of mental health befriending volunteers (Cassidy et al., 2019; Klug et al., 2018; Toner et al., 2018), suggesting that volunteers are motivated by ‘getting’, by enhancing their personal growth, and ‘giving’, by supporting others and contributing to society.

Reviews focusing upon inclusion for people with intellectual disabilities have considered broader health and social care interventions such as person-centred planning or skill-based sessions (Howarth et al., 2016), ‘natural supports’ such as existing family and social networks (Duggan & Linehan, 2013) or participation in sport (Zhao et al., 2021). The outcomes of befriending interventions for people with intellectual disabilities and whether these foster friendships or promote social inclusion have not been specifically reviewed. Strategic decisions around commissioning of services, service management and best practice for befriending schemes could all be influenced by having a greater understanding of the existing research on befriending for people with intellectual disabilities.

1.2. Research questions

This review aimed to address the following questions:

- What are the key characteristics of befriending interventions for adults with intellectual disabilities?
- What are the psychological and social outcomes of befriending interventions for adults with intellectual disabilities?
- What future research directions are required to advance the evidence base?

2. Method

2.1. Search strategy

The search strategy and study selection process are illustrated in Figure 1. This literature review was conducted following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). Systematic searches were conducted in October 2021 using the PsycINFO, MEDLINE and Web of Science databases. Initial search terms were generated to describe the population with intellectual disabilities and the befriending intervention. These were refined through scoping searches within the selected databases, reviewing published search strategies from previous reviews of befriending in other populations, and consulting with a subject specific librarian. A decision was made to utilise multiple diverse search terms for ‘befriending’ in order to retrieve all relevant articles (due to an expectation of there being nuanced differences between befriending and other similar interventions). An additional search term was added to remove articles which referenced children or adolescents but not adults (as the focus of this review was upon adults with intellectual disabilities).

Search terms were used to retrieve references relating to 1) intellectual disabilities, 2) befriending and 3) adults. These search terms were combined using an “AND” Boolean operator. Where possible, the search was also limited to peer-reviewed journals. See Table 1 for a full list of the search terms used in each database.

From these database searches, 4746 references were retrieved and exported to EndNote X9. References were de-duplicated using a systematic approach (Bramer et al., 2016) leaving 3025 articles to be screened. The titles and abstracts of these references were screened for eligibility and 2977 were excluded. The reference lists of the remaining studies were manually searched and a further three studies were identified for full text screening.

Table 1

Summary of search terms

Category	Type of term	Terms used
Intellectual disabilities and/or autism	Subject headings	PsycInfo: Learning disabilities/ or autism spectrum disorders/ Medline: learning disabilities/ or intellectual disability/ autism spectrum disorder/ or asperger syndrome/ or autistic disorder/ Web of Science: No subject headings
	Search terms	intellectual* disab* or developmental* disab* or learning disab* or intellectual development disorder or IDD or mental* retard* or mental* handicap* or intellectual* impair* or autis* or asperger*
Befriending	Subject headings	PsycInfo: Friendship/ Medline: Friends/ Web of Science: No subject headings
	Search terms	befriend* or buddy or buddies or friend* or companion* or lay helper or compeer or peer support* or peer relation* or mentor* or unpaid care* or informal care* or voluntary care* or natural* contact* or natural* support* or supported sociali?ation or peer assistance or community support or nonprofessional volunteer or nonprofessional worker* or citizen participation or civic participation or community participation or social networks or social network
Adults	Search terms	NOT ((adolescen* or school or child*) not adult*)

2.2. Study selection

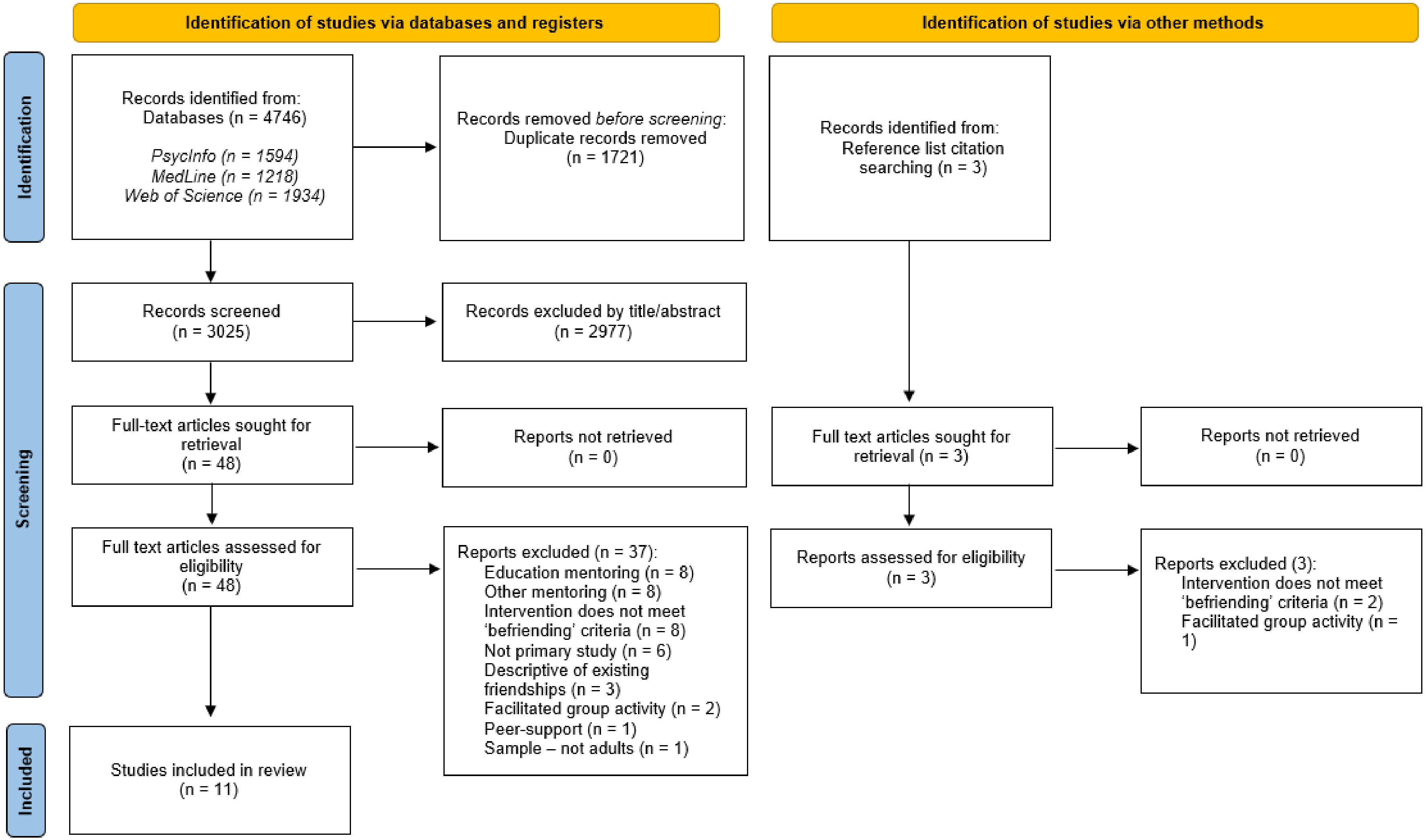
The search strategy detailed above (and displayed in Figure 1) yielded a total of 51 references. The full texts for these references were retrieved and screened against the following eligibility criteria. For the purpose of this review, befriending was defined as a one-to-one ‘friend-like’, emotionally supportive relationship, with a commitment over time, organised and supported by an external organisation and where one party was deemed likely to benefit. We distinguished this from mentoring (which typically had more focus upon pre-determined goals, training or teaching, and was often related to particular transitions e.g. school, university, workplace), peer-support (where someone with intellectual disabilities supports another person with intellectual disabilities) or friendship (a more private, spontaneous relationship where the relevant parties would otherwise have met).

The inclusion criteria were: (a) studies reporting findings on adults described as having intellectual disabilities and/or autism; (b) studies focused upon befriending interventions as defined above; (c) primary studies with any type of design, including quantitative, qualitative or mixed methods; (d) studies published before October 2021 when the search was conducted. Exclusion criteria were: (a) studies not relating to the target population (e.g. dementia, post-stroke aphasia, acquired brain injury); (b) studies not relating to befriending as defined, e.g. group interventions, peer-support, mentoring or one-off support; (c) studies focusing upon friendship with a paid worker or family member rather than a volunteer; (d) secondary studies such as systematic reviews or meta-analyses; (e) discussion papers or meeting abstracts.

Studies were screened by two members of the research team. There was a high level of agreement as to the studies for inclusion (94%). Where there was disagreement around the eligibility of studies this was typically due to difficulties deciding whether a study intervention counted as ‘befriending’ or not. For example, a study by Pottie & Sumarah (2004) outlines a community living arrangement that leads to friendships between people with and without intellectual disabilities. However, the friendship element is not specifically managed or supported by an external agency. Following a discussion about the applicability of eligibility criteria in the studies under question, agreement was reached between the reviewers as to which studies would be included.

Figure 1

Search strategy and study selection process



2.3. Data extraction and analysis

A data extraction form was developed based upon the research questions, and data from each of the included studies was extracted. Narrative synthesis (Popay et al., 2006) was used to analyse the identified papers. This included tabulating outcomes, comparing differences and quality appraising each of the studies. The major findings were grouped into categories which were refined over the course of the synthesis through ongoing comparison and discussion.

3. Results

The search strategy and study selection resulted in the inclusion of 11 studies (see Table 2 for a descriptive overview). The studies were published between 1995 and 2021, and were conducted in the United Kingdom (UK), the United States of America (USA), Australia and Greece.

The respective focuses of the studies were broad ranging, with two studies detailing the features of particular befriending relationships through a case study design, two using surveys to evaluate existing schemes, two describing the development of new schemes, and two focusing upon the experiences and challenges of befriending services. Additionally, there was one pilot randomised controlled trial looking at befriending and depressive symptoms, one quasi-experimental study looking at the impact upon social network size and one examining the changing perceptions of participants as befriending relationships evolve.

Sample sizes ranged from two participants to several thousand participants per study, dependent upon the design. Data were most commonly collected through semi-structured interviewing, with seven studies employing this method. Three studies used surveys with a mix of multiple choice, Likert scale and open-ended response options. In two studies particular quantitative outcome measures were used, for example to assess depression symptoms and social network size. To analyse the data, six of the studies utilised qualitative analysis approaches, two presented only descriptive quantitative data and three employed mixed methods of analysis.

Table 2

Descriptive overview of studies reviewed

Author (year)	Study design	Study focus	Location and Sample	Data collection methods	Data analysis methods
Ali et al. (2021)	Pilot randomised controlled trial (RCT)	To assess the feasibility and acceptability of a future larger RCT of one-to-one befriending for people with intellectual disabilities and depressive symptoms	UK; 6 befriendees, 10 befrienders	Quantitative outcome measures (inc. Glasgow Depression Scale for People with Learning Disability (GDS-LD)), semi-structured interviews	Mixed - Linear regression, descriptive statistics and thematic analysis
Bigby and Craig (2017)	Case study	To detail the qualities of friendship between a person with intellectual disabilities and a person without intellectual disabilities, and the factors supporting its development and sustainment	Australia; 1 befriendee, 1 befriender	Semi-structured interviews, participant observation	Grounded theory
Fyffe and Raskin (2015)	Qualitative	To describe the program design of a 'Leisure Buddy' program, issues arising in its implementation and initial outcomes	Australia; 18 befriending matches	Semi-structured interviews with coordinator, program documentation review	Not outlined explicitly - qualitative synthesis into themes
Green et al. (1995)	Qualitative	To examine the changing perceptions of befrienders in the early stages of an 'arranged partnership'	USA; 19 befrienders	Semi-structured interviews	Not outlined explicitly - qualitative synthesis into themes
Hardman and Clark (2006)	Survey	To describe the characteristics of and perspectives on a befriending program	USA; 1145 befriendees, 1222 befrienders	Cross-sectional survey (multiple choice/Likert scale responses)	Descriptive statistics (frequencies and percentages)

Author (year)	Study design	Study focus	Location and Sample	Data collection methods	Data analysis methods
Heslop (2005)	Qualitative	To explore the key issues befriending services face, factors that contribute to good practice and to make recommendations for good practice	UK; 34 befriendees, 42 befrienders, 46 parent carers, 15 befriending scheme workers	Semi-structured interviews	Not outlined explicitly - qualitative synthesis into themes
Hughes and Walden (1999)	Quasi-experimental	To explore whether the social lives of service users improved when a befriending intervention was introduced	UK; 4 befriendees, 10 befrienders	Semi-structured interviews to collect information on social network size, frequency of visits, participation in activities	Mixed - Descriptive statistics (frequencies and percentages) and narrative extracts
Jameson (1998)	Survey	To evaluate an existing program and examine factors fostering stable relationships	USA; 25 befrienders	Cross-sectional survey (Likert scale responses)	Descriptive statistics (frequencies and percentages)
Mavropoulou (2007)	Qualitative	To describe the development of two pilot befriending schemes for people with autism spectrum disorder (ASD)	Greece; schemes recruited 35 people with ASD and 82 volunteers	Unspecified	Narrative descriptions (some descriptive statistics not analysed)
Southby (2019)	Case study	To explore the complexity of befriending as an opportunity for adults with learning disabilities to access mainstream leisure	UK; 4 befriendees 4 befrienders 3 staff members, 3 family members, 1 employer	Semi-structured interviews, participant observation	Thematic analysis
Tse et al. (2021)	Survey	To explore characteristics and challenges for befriending services and volunteer motivations and experiences	UK; 8 befriending service coordinators 58 befrienders	Cross-sectional survey (checklist, Likert scale and open-ended questions)	Mixed - Descriptive statistics, logistic regression and thematic analysis

3.1. Critical appraisal of the studies

In line with Popay et al.'s (2006) guidance around assessing the robustness of a narrative synthesis, a standard quality assessment tool, the QualSyst tool (Kmet et al., 2004) was used to critically appraise the papers.

QualSyst provides a systematic, reproducible, and quantitative means of assessing research quality across a broad range of study designs. It sets out separate criteria for assessing qualitative and quantitative methods (see Table 3 for an overview of checklist items). In this review, six papers were appraised using the qualitative checklist, two were appraised using the quantitative checklist, and three mixed-methods studies were appraised using both checklists.

Table 3

Qualsyst criteria, by Qualitative and Quantitative checklists

Item number	Criterion
	Qualitative checklist
1	Question/objective sufficiently described?
2	Study design evident and appropriate?
3	Context for the study clear?
4	Connection to a theoretical framework/wider body of knowledge?
5	Sampling strategy described, relevant and justified?
6	Data collection methods clearly described and systematic?
7	Data analysis clearly described, complete and systematic?
8	Use of verification procedure(s) to establish credibility?
9	Conclusions supported by the results?
10	Reflexivity of the account?
	Quantitative checklist
1	Question/objective sufficiently described?
2	Study design evident and appropriate?
3	Method of subject selection described and appropriate?
4	Subject characteristics sufficiently described?
5	Random allocation to treatment group described (if possible)?
6	Blinding of investigators reported (if possible)?
7	Blinding of subjects reported (if possible)?
8	Outcome/exposure measures well defined and robust to bias? Means of assessment reported?
9	Sample size appropriate?
10	Analysis described and appropriate?
11	Some estimate of variance reported for main results/outcomes?
12	Controlled for confounding?

Item number	Criterion
13	Results reported in sufficient detail
14	Results support conclusions?

Studies were rated against the relevant checklist(s), scoring either Yes (2), Partial (1), No (0) or N/A for each item, dependent upon the extent to which they fulfilled the criterion. To increase rating reliability, a second reviewer independently scored five of the studies. Both reviewers assigned the same scores to four of the five studies reviewed but disagreed on the assignment of ‘Yes’ versus ‘Partial’ on some items in the fifth study. Where there was disagreement on the ratings given, the reviewers discussed any discrepancies and came to a mutual agreement on the scoring. The first reviewer then completed the rating of the remaining studies independently. For each study a final summary score was calculated by summing the total score across relevant items and dividing by the total possible score. These summary scores were used as an overall indicator of the relative quality of the studies.

An overview of the quality appraisal ratings is shown in Table 4. For the nine studies employing qualitative approaches, the range of summary scores was 0.2 to 0.95, with an average score of 0.75. These studies scored highest against the ‘question/objective description’, ‘clarity of study context’ and ‘connection to theoretical framework or wider body of knowledge’ criteria (items 1, 3 and 4). Performance against the ‘use of verification procedures’ criterion (item 8) was more mixed, with five studies fully satisfying the criterion requirements, and 4 studies not achieving them at all. Reflexivity of account was particularly weak across the qualitative studies, with only four studies scoring partial fulfilment of the criteria. Whilst these studies mentioned the potential sources of the methods used on the data obtained, they did not explicitly assess the likely impact of the authors’ own personal characteristics.

Of the five studies using quantitative measures, summary scores ranged from 0.6 to 1.0, with an average of 0.82. The quantitative studies had higher scores against the ‘method of subject selection or information sources description’ criterion (item 3), as the sampling strategies for surveys and experimental designs were clearly outlined. The studies scored lowest on average for the ‘controlled for confounding’ criterion (item 12), with the two studies (Ali et al., 2021, Hughes & Walden, 1999) deemed to have incompletely controlled for confounding factors.

The broad range of scores was indicative of the variety in papers selected. Whilst Kmet et al. (2004) do not specify particular cut-off thresholds, the reviewers met to discuss whether to include the two studies with lower quality ratings (Hughes & Walden, 1999 and Mavropoulou, 2007). As one of the aims of this review was to comprehensively review the existing research and its limitations, it was agreed that the two studies would be included, but that explanations of the study limitations would be considered alongside the synthesis. In the presentation of reported outcomes below we reference the quality rating scores of the papers discussed, in order to give an indication of the validity/reliability of the data for each main finding.

Table 4

Quality appraisals of included studies by study design

	Qualitative QualSyst scores										Summary score
Study	1	2	3	4	5	6	7	8	9	10	
Ali et al, 2021	2	2	2	2	2	2	2	2	2	1	0.95
Bigby & Craig, 2017	2	2	2	2	1	2	2	2	2	1	0.90
Fyffe & Raskin, 2015	2	2	2	2	2	2	2	2	2	1	0.95
Green et al., 1995	2	2	2	2	1	2	1	0	2	0	0.70
Heslop, 2005	2	2	2	2	2	2	1	2	2	0	0.85
Hughes & Walden, 1999	1	1	1	1	1	1	1	0	1	0	0.40
Mavropoulou, 2007	2	0	1	1	0	0	0	0	0	0	0.20
Southby, 2019	2	2	2	2	2	2	2	2	2	0	0.90
Tse et al, 2021	2	2	2	2	2	2	1	2	2	1	0.90

	Quantitative QualSyst scores														Summary score
Study	1	2	3	4	5	6	7	8	9	10	11	12	13	14	
Ali et al, 2021	2	2	2	2	2	2	0	2	2	2	2	1	2	2	0.89
Hardman & Clark, 2006	2	2	2	2	-	-	-	2	-	1	-	-	1	1	0.81
Hughes & Walden, 1999	1	1	2	2	-	-	-	1	0	1	-	1	2	1	0.60
Jameson, 1998	2	2	2	1	-	-	-	1	-	1	-	-	2	2	0.81
Tse et al, 2021	2	2	2	2	-	-	-	2	-	2	2	-	2	2	1.00

Note: 2 = yes, 1 = partial, 0 = no, - = Not applicable

3.2. Key characteristics of befriending interventions

Below we draw out the key features of the interventions detailed in the eleven studies, including definitions of the befriending construct, recruitment methods, matching criteria and the aims and parameters of the activities undertaken.

3.2.1. Befriending as a construct

Across the studies there was not one clearly agreed definition of befriending, though four of the eleven papers use Dean & Goodlad's (1998, p. 2) definition of befriending as 'a relationship between two or more individuals which is initiated, supported and monitored by an agency that has defined one or more parties as likely to benefit. Ideally, the relationship is non-judgmental, mutual and purposeful, and there is a commitment over time.' The intervention offered, which fitted the definition of befriending used within this review's search strategy, is also called an 'intentional friendship' (Bigby & Craig, 2017), an 'arranged partnership' (Green et al., 1995), a 'leisure buddy program' (Fyffe & Raskin, 2015), and a 'Best Buddies' program (Hardman & Clark, 2006; Jameson, 1998).

Where the studies do not explicitly use the term 'befriending', the key features of the construct remain the intentionality of the friendship, the provision of external support in its set up and maintenance, and the focus on an individual, rather than group-based, intervention.

3.2.2. Recruitment methods

Recruitment methods for befrienders and befriendees appeared similar across the studies, though three did not detail the recruitment methods used by the befriending schemes studied (Heslop, 2005; Southby, 2019; Tse et al., 2021). Public advertising appeared the most common recruitment method, mentioned by six of the eleven studies. Given the 25-year range of publishing dates, some new recruitment channels did emerge in the later studies, with the inclusion of websites and social media alongside more established channels such as newspapers and brochures. For those studies where college students acted as befrienders (Green et al., 1995; Hardman & Clark, 2006; Jameson, 1998;

Mavropoulou, 2007) recruitment was on-campus through classes, adverts and student organisations. Befriendees were typically recruited from existing disabilities charities or waiting lists, intellectual disabilities services and through word of mouth.

3.2.3. Matching criteria

The techniques and criteria used to match participants varied but included several of the same elements, with shared interests, age, gender, and location reported most often (see Table 5 for an overview). All six of the studies that reported matching criteria mentioned shared interests, with Tse et al. (2021) reporting this as the most common criterion from their survey. However, Fyffe and Raskin (2015) noted that successful matches were sometimes formed contrary to the specific preferences that participants believed would be important (e.g. age, gender, interests). It is of note that Heslop's (2005) paper setting out best practice recommendations for befriending schemes did not present specific guidance on matching criteria, potentially implying that an idiosyncratic approach is required.

Table 5

Befriending pairs matching criteria

Study	Interests	Age	Gender	Location	Availability	Personality	Other
Ali et al., 2021	Y	-	-	-	Y	-	-
Bigby & Craig, 2017	-	-	-	-	-	-	Criteria not stated
Fyffe & Raskin, 2015	Y	Y	Y	Y	-	-	-
Green et al., 1995	Y	Y	Y	Y	-	-	Severity of disability, volunteer experience
Hardman & Clark, 2006	Y	-	-	-	-	Y	-
Heslop, 2005	-	-	-	-	-	-	Criteria not stated
Hughes & Walden, 1999	-	-	-	-	-	-	Criteria not stated
Jameson, 1998	Y	Y	Y		Y	Y	-
Mavropoulou, 2007	-	-	-	-	-	-	Criteria not stated
Southby, 2019	-	-	-	-	-	-	Criteria not stated
Tse et al., 2021	Y	Y	Y	Y	-	-	-

3.2.4. Aims, parameters and activities undertaken

Comparing the befriending interventions across the eleven studies, the basic parameters (such as frequency of contact and activities undertaken) were similar (see Table 6). Four of the studies set an expectation of contact once a week (Ali et al., 2021; Green et al., 1995; Hardman & Clark, 2006; Mavropoulou, 2007) and two also set specific expectations around at least half of the activity sessions being spent in the community (Ali et al., 2021) and the recreation activities being community-based and of mutual interest (Green et al., 1995). Nine studies report the types of befriending activities undertaken, showing a combination of home-based activities and community-based activities. There is significant commonality across the studies with activities such as visiting cafes/restaurants, walking and going to the movies appearing most frequently as examples.

Differences existed in the extent to which the intervention aimed to enhance social inclusion or community integration. Four of the studies outline interventions that explicitly aim to increase community integration (Ali et al., 2021; Fyffe & Raskin, 2015; Heslop, 2005; Jameson, 1998). For example, in Fyffe and Raskin's (2015, p. 84) study, the befrienders are seen as acting as a "bridge to the resources and opportunities in the wider community". However, others focused more upon forming friendships with others (Hardman & Clark, 2006; Hughes & Walden, 1999).

To an extent these differences may be explained by the different approaches towards and understandings of the over-arching construct of social inclusion. Simplican et al.'s (2015) ecological model defines it as an interaction between community participation and interpersonal relationships, where both are necessary for full social inclusivity. However, despite its place at the heart of many social policies and the extent to which it is cited in academic research, social inclusion is often not clearly defined, and multiple understandings of the construct exist (Bigby, 2012), including within the eleven studies reviewed in this paper.

Table 6

Aims, basic parameters and activities undertaken across studies

Study	Stated aims of befriending activities	Expected frequency, duration, or type of activity	Example activities undertaken
Ali et al., 2021	To enhance social and emotional support and community participation	Once a week, for an hour; >50% of activities to be community based	Visits to cafes/ restaurants, going for walks, having a conversation at home.
Bigby & Craig, 2017	n/a	n/a	Swimming, choir, coffee club, church friendship circle.
Fyffe & Raskin, 2015	To experience a more inclusive lifestyle through developing a social relationship	No specific requirements – expectations of flexibility in arrangements	Going to movies, visiting antiques shops, going to restaurants
Green et al., 1995	n/a	Once a week; community based activities, of mutual interest, engaged in as equals	Going out to eat, tour of a cathedral, window shopping, bowling, playing pool, basketball.
Hardman & Clark, 2006	To enhance the lives of people with intellectual disabilities through one-to-one friendships	Contact once a week; 2 or 3 one-to-one activities per month	Friendship activities: Phone calls, eating out, going to movies, watching movies at home, sports events, eating at home, sports or outdoor recreation. Teaching activities: social skills, transportation, job skills, personal finance.
Heslop, 2005	To reduce social isolation and increase community participation; to provide a range of different activities and support for accessing local leisure facilities	n/a	Home-based activities including having a meal, watching a video. Going out to the movies, to the gym, going bowling.
Hughes & Walden, 1999	To form friendships and to practise skills in developing relationships	n/a	n/a
Jameson, 1998	To get more involved in the community while sharing mutually satisfying activities	n/a	Eating together (out or at home), phone conversations, going to the movies, shopping, taking walks, going to concerts/theatre, physical recreation.
Mavropoulou, 2007	To improve the quality of life of people with Autism Spectrum Disorders	Once a week	n/a
Southby, 2019	n/a – Note that an inclusion criterion for the study was taking part in mainstream activities, not segregated or private setting activities	n/a	Visiting cafes, visiting restaurants, shopping, tourist attractions, theatre, music performances, museums, bowling, golf
Tse et al., 2021	n/a – Varied across services	n/a	Visiting cafes/restaurants, visiting parks/outdoor spaces, spending time indoors, art/creative activities, museum/ galleries, farm/zoo, cinema

3.3. Reported psychological and social outcomes of befriending

The key findings relating to the psychological and social outcomes of befriending for people with intellectual disabilities and their befrienders were collated from the eleven studies, compared, and grouped into different outcome categories. Where studies mentioned multiple outcomes in their findings they were coded into multiple categories.

Table 7 gives an overview of the outcome categories and illustrates which studies reported each outcome. Across the eleven studies, five key outcomes for befriendees were reported, with “community participation” (reported in six studies) and “changing social networks” (reported in five studies) most commonly occurring. Changes to “mood” and “confidence/independence” were each reported in four studies, and “new experiences” were reported in three. For befrienders, three key outcomes were reported, with “knowledge and experiences” reported in five studies, “giving back” in four studies, and “expanded social communities” in three studies. Additionally, broader outcomes for carers and family were reported in two studies.

Table 7

Overview of reported outcomes of befriending interventions

Study	Befriendee outcomes					Befriender outcomes			Other
	Community participation	Changing social networks	New experiences	Mood	Confidence & independence	Knowledge & experiences	Giving back	Expanded social communities	Broader impact
Ali et al, 2021	Y	-	-	Y	-	-	-	-	-
Bigby & Craig, 2017	Y	Y	Y	-	-	-	-	Y	-
Fyffe & Raskin, 2015	Y	Y	-	-	Y	-	-	Y	Y
Green et al, 1995	-	-	-	-	-	Y	Y	-	-
Hardman & Clark, 2006	Y	Y	-	-	Y	Y	-	-	-
Heslop, 2005	Y	-	-	Y	Y	-	-	-	-
Hughes & Walden, 1999	-	Y	-	-	-	-	-	-	-
Jameson, 1998	-	-	-	-	-	-	Y	-	-
Mavropoulou, 2007	-	-	-	Y	-	Y	-	-	-
Southby, 2019	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tse et al., 2021	-	-	Y	-	-	Y	Y	-	-

3.3.1. Outcomes for befriendees

Community participation (social outcome)

Six studies noted specific outcomes around community participation. The quality ratings of the studies ranged from 0.85 to 0.95, with an average of 0.91. Two reported that befriendees benefitted from increased participation in community-based activities (Bigby & Craig, 2017, and Fyffe & Raskin, 2015) as a result of their partnership. However, Southby (2019) pointed to a distinction between activities done as part of a collective group in mainstream settings, (e.g. with a team or club), and activities performed individually between a befriending pair in a community setting, (e.g. going bowling or to the cinema). He argued that whilst befriending may increase the number of activities carried out in community settings, the sense of inclusion may be lesser than in more 'segregated' intellectual disability specific settings. Similarly, Heslop (2005) reported that fewer than a fifth of the activities identified in her study specifically increased social inclusion.

Two of the studies attempted to measure befriendees' perceptions of community participation. Hardman and Clark (2006) found that 46% of befriendees agreed that they felt more comfortable participating in the community following the befriending intervention. Though this is not a majority, the authors point to the fact that 74% of the befriendees already had friends without disabilities prior to the intervention, and thus may already have had prior opportunities for community participation (implying that they already felt quite comfortable in the community). The study had a quality appraisal score of 0.81, though for this data point the proportion of befriendees selecting 'neutral' or 'disagree' is not presented, so the authors' interpretation is hard to confirm. Ali et al.'s (2021) pilot RCT showed some shift in the means for social participation outcome measures for both control and intervention groups. The study has a high quality appraisal rating (0.89 on the quantitative QualSyst measure), however, due to the small sample size these shifts in mean were presented as descriptive statistics and were not statistically analysed. The study does report that 63% of the befriending sessions undertaken were outside of the home, indicating that the community-based expectation set for activities in this study was being met.

Taken together, the findings suggest that befriending does lead to increased presence within the community, though the degree of 'true' social inclusivity may be more uncertain.

Changing social networks (social outcome)

Five studies reported changes to a befriendee's social network as an outcome of the befriending intervention. The quality ratings of these studies range from 0.6 to 0.95 (average 0.86). Three of the studies report positive changes, relating to forming new friendships and increasing and diversifying social networks. For example, both case study vignettes included in Fyffe & Raskin's (2015) study illustrate forming new friendships as a key outcome of befriending, and each of the befriendees in Southby's (2019) study described their befriender as a friend, valuing having one-to-one, less hierarchical and more flexible relationships. In Hardman & Clark's (2006) study, 26% of the befriendees surveyed said it was the first time they had had a friend without disabilities, suggesting that the befriending scheme had facilitated access to a new 'type' of friend for these participants.

However, two of the studies reported more mixed results. Hughes & Walden's (1999) intervention study found changes in network composition, with three of the four participants appearing to substitute existing network members for befriending volunteers over the course of the study and follow up. This study used descriptive quantitative measures of social network size, though it rated relatively poorly against the QualSyst criteria (scoring 0.6) with limitations noted with study design, sample size and analytic methods in particular. Bigby & Craig's (2017) study, which had a significantly stronger QualSyst score of 0.9, did identify having a new friend as an outcome, but also noted some substitution within the befriendee's close network, with the befriendee's mother visiting less often once the befriender was involved.

Overall, the findings tentatively suggest that befriending does add new members to a befriendee's social network, but that this might be at the cost of existing members.

New experiences (social outcome)

Opportunity for befriendees to engage in new experiences was an outcome reported in three of the papers (all with QualSyst scores of 0.9). Bigby and Craig's (2017) case study reported that the befriending intervention enabled the befriendee to try out new activities and join groups she may not otherwise have been able to (for example starting to attend a choir or playing bingo). Southby's (2019) study found that activities undertaken offered an opportunity to do new things, including educational or cultural activities. However, he noted that when meet ups between befriending pairs were not planned in advance the activities undertaken were often repeated. "Casual" leisure activities that the befriendee particularly enjoyed or that they also undertook with support workers (e.g. going to a cafe/restaurant) seemed to be most commonly repeated, leading to concerns that the unique dynamics of a befriending relationship were not being fully taken advantage of. Tse et al. (2021) also noted that some volunteers reported certain frequently repeated activities (in the context of this becoming tedious for the volunteers). As shown in Table 6 above, the range of activities undertaken across the studies is broad, though it also shows significant repetition of certain activities. Overall, the findings suggest that whilst befriending offers opportunities for new experiences, engaging in more familiar and known experiences is the common result.

Mood (psychological outcome)

Four of the studies reported an impact of befriending upon the mood of the befriendee. The quality of these studies was extremely varied and scores ranged from 0.2 to 0.9 (with an average of 0.71). Ali et al.'s (2021) pilot RCT found that depression scores were four points lower after 6 months in the intervention group compared with the control group (equivalent to a moderate effect size). However, the pilot only recruited and matched six pairs in its intervention arm and the result was not statistically significant. Southby's (2019) qualitative case study findings were that befriending activities supported individual wellbeing and promoted happiness. Two studies reported the potential and actual negative effects on mood when the befriending relationship ended: Heslop (2005) recognised a need for services to focus on the befriendees' emotional wellbeing, reporting that 12 of the 14 befriendees interviewed who had experience with a previous befriender felt "sad, disappointed, angry and upset" about the pairing coming to an end. In Mavropoulou's (2007) study, the parents of befriendees noted breaks and endings as sources of anxiety and disappointment (though we note that the quality of this study was only rated as 0.2, with particular deficits against the methods and analysis criteria). Taken as a whole, the studies tentatively suggest both benefits and risks to mood.

Confidence and independence (psychological outcome)

Four of the studies reported outcomes relating to confidence for people with intellectual disabilities, reporting increased confidence and independence as a result of the interventions. The quality appraisal rating for these studies ranged from 0.81 to 0.95 (with an average of 0.88). Southby (2019) reported that befriending helped promote individual independence (away from family and services) and improved befriendees' confidence and communication skills. Fyffe and Raskin (2017) suggested that even shorter matches can increase confidence to build networks and have new experiences, and in Hardman and Clark's (2006) study, 44% of the befriendees surveyed felt more comfortable speaking up for themselves. However, Heslop (2005) noted that whilst many of the befriending schemes aimed to increase self-esteem and independence, empowerment of befriendees was sometimes limited (e.g. with limited influence upon frequency of contact or activity choice). Considered together the findings suggest that befriending can contribute to increasing confidence and independence for people with intellectual disabilities.

3.3.2. Outcomes for befrienders

Knowledge and experiences (psychosocial outcome)

Five studies reported that befriending enabled befrienders to gain new knowledge and experiences, including developing different perceptions of people with intellectual disabilities (Green et al., 1995). Eight out of ten of those surveyed by Hardman & Clark (2006) reported having a more positive attitude about, and understanding of people with intellectual disabilities. The befriending relationship was also reported to offer new and different perspectives on matters (Tse et al., 2021) and opportunities to gain specific experiences to support future academic endeavours or employment (Southby, 2019, Tse et al., 2021, Mavropoulou, 2007). The studies had quality appraisal scores ranging from 0.2 to 0.9 (with an average score of 0.7).

Giving back (psychosocial outcome)

'Giving back' was reported as a key outcome of befriending by four of the studies, with quality appraisal ratings of 0.7 to 0.9 (averaging 0.83). This involved offering both practical help and emotional support (Tse et al., 2021). Green et al. (1995) identified that befriending relationships involved befrienders taking on elder sibling roles that offered the opportunity for altruism and giving something back, but also involved a sense of obligation. Southby (2019) also noted that whilst befriending offered the opportunity to 'give back' there was the ongoing challenge of negotiating a balance between friendship and a professional/service relationship. Jameson (1998) looked at the reciprocity of befriending relationships and found that whilst befrienders 'gave' more in terms of concrete acts, 70% of respondents thought the level of reciprocity was equal in their befriending relationships. Overall, the findings suggest that befrienders value the opportunity to give back through befriending, but that negotiating the actualities of each relationship can present challenges.

Expanded social communities (social outcome)

Three of the studies reported that befriending interventions enabled befrienders to expand their own social networks or communities. The quality appraisal scores ranged from 0.9 to 0.95, with an average of 0.92. One of Fyffe and Raskin's (2015) case vignettes highlights how the befriender has made a new friend for whom she feels "genuine respect and affection", whilst Bigby and Craig (2017) and Southby (2019) note that befrienders participate in new community groups and get a chance to 'do new things'.

3.3.3. Outcomes for carers

Two papers reported specific outcomes that extended beyond the befriender and the befriendee. These papers had QualSyst scores of 0.9 and 0.95, with an average of 0.93.

Fyffe and Raskin (2015) recognised that the process of befriending provided respite for family carers, though noted that this was typically “shorter and less predictable than traditional respite breaks”. Southby (2019) also considered the impact for family carers, reporting that existing family relationships have the potential to be disrupted by the befriendee becoming more empowered. Southby also considered the impact of befriending interventions upon residential service providers, noting that the presence of a befriender in the befriendee’s social network led to somewhat reduced pressure to find stimulating activities for residents.

4. Discussion

The aim of this review was to synthesise the literature on the characteristics and outcomes of befriending interventions for people with intellectual disabilities. The review identified eleven studies for inclusion, with various study designs and focuses.

4.1. Key findings

The befriending interventions reviewed shared certain key features typical of the befriending construct, even where the term ‘befriending’ was not explicitly used. Schemes employed similar recruitment and matching methods for their befriending pairs and aimed to foster friendships and to increase community participation. Definitions of, and approaches to fostering social inclusion differed between the studies. Few interventions had strict parameters around frequency or duration of contact, though some did specify that activities should be community based. Activities undertaken by befriending pairs were broad ranging, including home and community-based activities, with casual leisure activities such as going to cafes, going for walks or going to the cinema most popular.

The eleven studies reported a range of outcomes for befriendees, befrienders and carers. For befriendees, the most frequently reported outcomes were that befriending leads to increased participation in the community and adds new friends to a befriendee’s social network (reported in six and five studies respectively), suggesting that the primary aims of the befriending services are often being achieved. However, the degree of true social inclusion fostered by the activities undertaken, and the potential substitutive effects of new befriending friends upon existing social networks temper the positivity of these findings somewhat. Similarly, whilst befriending can positively impact a befriendee's mood, it also presents a risk of negatively impacting emotional wellbeing, particularly where there is a lack of empowerment or where the ending of a befriending relationship is not adequately managed (reported in four studies). Befriending appears to lead to increases in confidence and independence for befriendees (reported in four studies), which may contribute to the mixed findings on new experiences (reported in two studies), with befriendees feeling more confident contributing to decision making and voicing their preferences for doing familiar, repeated activities rather than always striving for novel experiences. These findings on befriendee outcomes support existing research in mental health populations which suggest befriending promotes community participation (Mitchell & Pistrang, 2011) and increases a befriendee's number of social contacts (Priebe et al., 2020).

For befrienders, whilst certain challenges such as negotiating the friendship/professional relationship balance are mentioned, individual outcomes seem more universally positive overall. Findings indicated befrienders gained knowledge and experiences, felt a sense of giving back and expanded their social communities through taking part in befriending (reported in five, four and three studies respectively). This echoes the experiences reported by studies looking at volunteer experiences of mental health befriending (Cassidy et al., 2019; Toner et al., 2018) and may highlight the power dynamic between befriendee ('deemed likely to benefit' from befriending) and befriender who acts as a volunteer, therefore having more control over the experience and the way the relationship is enacted. Two studies also noted that befriending has a broader impact upon carers, providing respite for family carers and reducing the pressure on other services to organise activities.

4.2. Limitations of the evidence base

Despite the popularity of befriending schemes, and their potential role in promoting friendship and social inclusion for people with intellectual disabilities, this systematic review (with its intentionally broad search terms) only identified 11 studies. Like other reviews of befriending in other populations (Siette et al., 2017) and of other interventions promoting social participation for people with intellectual disabilities (Howarth et al., 2016), this review suggests that befriending does have positive outcomes but that a stronger evidence base is required to inform policy and practice. On an individual basis, the majority of the studies identified appeared of relatively high quality, with the qualitative and quantitative studies scoring averages of 0.75 and 0.82 respectively. However, the methodological diversity of the studies and the fact that the majority were qualitative and exploratory in nature makes it difficult to draw firm generalisable conclusions from the data available. The studies utilising quantitative approaches were limited with regard to data analysis due to small sample sizes, for example in the most recent study, a pilot RCT by Ali et al. (2021). One other key limitation of the evidence base is the limited input of people with intellectual disabilities into study design and conduct. In their RCT protocol, Ali et al. (2020) reported consulting with befriending scheme participants with and without intellectual disabilities during the planning stage of the study, and plans to engage a ‘public and patient involvement’ group to advise on materials, attend study management meetings, and contribute to data collection and dissemination. Heslop (2005) also acknowledges the contribution of an advisory group to her study, though the extent of their involvement is not explicated. None of the other studies identified in this review mention any input from people with intellectual disabilities. Lack of direct input from people with intellectual disabilities into the research questions, study designs or collection and analysis stages, leads to a lack of representation and an imbalance of power in the conduct of research.

4.3. Limitations of the current review

This review had a number of limitations. Firstly, whilst a second reviewer screened articles to be included at full text stage and blindly rated a third of the studies using the quality appraisal tool, the rest of the review was conducted by an individual researcher, increasing the risk of bias in the synthesis and interpretation of results. Secondly, though no English language filter was applied on the databases searched, only search terms in English were used, which may have impacted upon the comprehensiveness of the review. Thirdly, the review may be limited by the exclusion of grey literature in a field which may include important practice-based research not published within academic journals. Additionally, the scope of this review was designed to be broad in order to understand the existing evidence base. However, this did lead to a particularly diverse set of studies being included, increasing the difficulty of the synthesis and potentially also the risk of bias in the synthesis of the findings.

4.4. Implications for future research and practice

It is of note that, of the eleven included studies (published over a 27-year period), three were high-quality studies published within the preceding three years. It is hoped that this indicates a renewed interest in understanding befriending in this population and that this necessary research continues to be conducted. This review highlights the limited body of evidence pertaining to the effectiveness and impact of befriending interventions for people with intellectual disabilities. Following on from the pilot RCT conducted by Ali et al. (2021), future research could look to evaluate befriending using broader eligibility criteria and focusing upon a broader range of outcomes. In practice, there has been a shift within befriending services in the UK over the past 15 years from limited data collection to consistent outcome collection and evaluation (Tse et al., 2021). Extending this by use of standardised, validated measures across befriending services could create opportunity for robust longitudinal studies of outcome data. This review further indicates a need for clarity around social network substitution, the extent to which community participation means ‘true’ social inclusion, and the longitudinal effects of befriending, including for those befriendees who have experienced the endings of befriending relationships. There is also a need for further exploratory analysis of the mechanisms of change and optimal methods of delivery of befriending in this population, and for more research that hears the voices of people with intellectual disabilities directly, both as participants and as contributors to research design and conduct. In including these voices directly, research could consider what adults with intellectual disabilities themselves prioritise in terms of the desired outcomes of any befriending intervention and how this links with understandings of social inclusion.

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Part 2: Empirical Paper

Understanding experiences of a befriending scheme for people with intellectual disabilities

Abstract

Aims: Research into the impact of befriending for people with intellectual disabilities is limited, despite it being fairly well-established practice in the UK. This study aimed to better understand the experiences of individuals involved in a befriending scheme for adults with intellectual disabilities and/or autism, broadly exploring the impact, active ingredients, and any limitations of the scheme.

Methods: Participants were recruited from a befriending scheme using convenience sampling. Thirteen individuals with intellectual disabilities and/or autism, one befriender and two family carers were interviewed about their experiences of the befriending scheme.

Results: Four main themes were generated using thematic analysis: ‘Something fun for me’, ‘Feeling part of something bigger’, ‘Increasing independence’ and ‘A life less quiet’. The themes revealed that befriending had direct benefits through the activities undertaken and the befriending relationships themselves being fun and reducing isolation. Befriending also facilitated a sense of belonging and access to mainstream activities, and fostered independence by providing safety and support. The importance of shared interests and external support for the relationship was highlighted.

Conclusions: Positive outcomes of befriending were found, along with some of the active ingredients that appeared to contribute to these, supporting existing literature and revealing new information from the voices of participants with intellectual disabilities themselves.

1. Introduction

Adults with intellectual disabilities are vulnerable to social and community exclusion (Merrells et al., 2019; Mooney et al., 2019), have social networks often made up solely of family members, paid carers and others with intellectual disabilities (Emerson & McVilly, 2004; Lippold & Burns, 2009; Verdonschot et al., 2009), and report high levels of loneliness (Alexandra et al., 2018; Gilmore & Cuskelly, 2014). In individuals with autistic spectrum conditions, prevalence of friendships and peer relationships, and participation in social and recreational activities are low (Orsmond et al., 2004), and adults with autism report more loneliness than neuro-typical adults (Lin & Huang, 2019).

Befriending, a voluntary, purposeful relationship which is initiated, supported and monitored by an agency that has deemed one or more parties as likely to benefit (Dean & Goodlad, 1998) is one intervention that aims to increase social inclusion, develop relationships and enhance community participation. Befriending interventions have been researched across multiple populations including older adults, adults with mental health problems, carers and people with physical health conditions (Siette et al., 2017).

The limited research that exists on befriending interventions for adults with intellectual disabilities and/or autism indicates broadly positive outcomes. Studies suggest that befriending increases befriendees' participation in community-based activities, expands their social networks and provides opportunities to engage in new experiences (Ali et al., 2021; Bigby & Craig, 2017; Fyffe & Raskin, 2015; Hardman & Clark, 2006; Heslop, 2005; Southby, 2019). However, the extent to which community participation leads to social inclusion is questioned by some. As conceptualised by Simplican et al.'s ecological model (2015), social inclusion combines both interpersonal relationships and community participation domains, and one without the another cannot equate to comprehensive social inclusion. Heslop (2005) reports that fewer than a fifth of the befriending activities identified in her study specifically increased social inclusion and Southby (2019), who distinguishes between collective and individual activities, argues that engaging in individual activities in mainstream community settings may create less sense of social inclusion than collective activities in ‘segregated’ settings. He also questions the novelty of the activities undertaken, noting that casual leisure activities that are short-lived and require limited training or preparation to engage in, such as visiting cafes or going to the cinema, seemed to be most commonly repeated, whilst more serious leisure activities that require more specialised skill, knowledge and shared interest were less common (Southby, 2019). Hughes and Walden (1999) and Bigby and Craig (2017) point towards social networks changing through substitution, with the befriender taking the place of a previous network member rather than simply adding to the overall network size.

Research also indicates that befriending can have a positive impact on befriendees’ mood, promoting wellbeing and happiness, and increasing confidence and individual independence (Ali et al., 2021; Fyffe & Raskin, 2015; Hardman & Clark, 2006; Heslop, 2005; Southby, 2019). Ali et al.’s (2021) pilot randomised controlled trial considered how befriending could impact symptoms of depression and social outcomes for people with intellectual disabilities. The pilot showed some reduction in depression scores, though problems with recruitment and retention meant statistical analysis was limited. Fyffe and Raskin (2015) highlight that even short matches can increase a befriendee’s confidence and build communication skills. However, the potential for emotional harm is highlighted by Mavropoulou (2007) and Heslop (2005), who report the endings of befriending relationships often being a time of anxiety and sadness for befriendees. Southby (2019) also notes that existing family relationships can potentially be disrupted by a befriendee’s empowerment through befriending.

For befrienders, reported outcomes of befriending include gaining new knowledge and experience, an opportunity to give back by offering practical help and emotional support, and expanding their own social communities (Bigby & Craig, 2017; Fyffe & Raskin, 2015; Green et al., 1995; Hardman & Clark, 2006; Jameson, 1998; Mavropoulou, 2007; Southby, 2019; Tse et al., 2021). The befriender role was found by Green et al. (1995) to resemble the role of an elder sibling, combining altruism and obligation. Similarly, Southby (2019) describes a unique beneficial relationship that can sit anywhere along a spectrum from friend to professional. Southby (2019) also reports that befriending can relieve the pressure felt by residential care providers to find stimulating activities for residents, and Fyffe and Raskin (2015) note that it provides short respite breaks for family carers.

To date, there has been limited consideration of the active ingredients or processes contributing to the outcomes of befriending interventions for adults with intellectual disabilities and/or autism. Research with other populations has elicited befriendees' views on their experiences and likely mechanisms of change. A qualitative study of mental health befriending by Mitchell and Pistrang (2011) found that empathy, a sense of safety, and opportunity to talk things through and get a different perspective were key to the intervention. The befriending relationship was described as being similar to that with a friend, with some reference to the ending of the relationship being a source of anxiety and uncertainty. Getting out and doing things together, as well as experiencing a new type of 'healthy' relationship were seen as particularly important in eliciting change. In another study of mental health befriending, Cassidy et al. (2019) found that both passively being there in the company of a befriender, and doing things together helped improve mood and outlook on life. The relationship was identified as falling along a spectrum from friendship to a more professional role, as it also was in a systematic review of mental health befriending (Thompson et al., 2016).

The existing evidence base for befriending for adults with intellectual disabilities and/or autism provides some indication of the outcomes of befriending but raises questions around social network substitution, the extent to which community participation equates to social inclusion, and the effects of befriending relationships coming to an end. Additionally, though befriending is a commonly used initiative, there is limited understanding of the experiences and perspectives of people with intellectual disabilities and/or autism themselves. Whilst some studies have directly surveyed, interviewed or observed people with intellectual disabilities and/or autism (Ali et al., 2021; Bigby & Craig, 2017; Hardman & Clark, 2006; Heslop, 2005; Southby, 2019), the majority have collected data from volunteer befrienders, family carers, professional carers or scheme coordinators (Fyffe & Raskin, 2015; Green et al., 1995; Hughes & Walden, 1999; Jameson, 1998; Mavropoulou, 2007; Tse et al., 2021). Even fewer have engaged in co-produced research in this area, with Ali et al. (2021) and Heslop (2005) the sole studies reporting the involvement of people with intellectual disabilities in the design or conduct of their research processes.

This study sought to hear the perspectives of adults with intellectual disabilities and/or autism, ensuring that the research topics were ones that felt important to them and that the research design accounted for their support needs. Due to resource constraints, a fully collaborative or people-led approach was not possible, so an advisory approach to inclusive research was taken (Bigby et al., 2014). At early stages of the study design, a survey was sent out to members of the befriending scheme that had agreed to participate in this study, to gather feedback on the proposed study focus and to elicit further suggestions. Eight written responses and three verbal responses were received from participants with intellectual disabilities and/or autism, which were fed into the research questions and study design.

The final research questions used to guide exploration were:

- What are the experiences of a befriending scheme for adults with intellectual disabilities, from the perspectives of befriendees, befrienders, families and carers?
- What are the 'active ingredients' that contribute to these experiences?
- What are the limitations of a befriending scheme for adults with intellectual disabilities and what could be improved?

2. Method

To explore the experiences of individuals involved in a befriending scheme for adults with intellectual disabilities, a qualitative research design was used. Qualitative methods are appropriate where questions are exploratory, allowing the opportunity to go deeper into issues of interest and understand individual views (Barker et al., 2016).

2.1. Researcher perspective

In qualitative research it is good practice to outline one’s own perspective as the researcher, specifying theoretical orientations and personal anticipations (Elliott et al., 1999). When conducting reflexive thematic analysis it is important for researcher to own their perspectives, personal and social standpoints and positioning (Braun & Clarke, 2021). During the research design stage, I conducted a bracketing interview with a trainee clinical psychologist colleague, with the aim of drawing awareness to my presuppositions about the study topic (Tufford & Newman, 2012). An excerpt from this interview is included in Appendix A and further reflections are included in Section 1.3 of Part 3 of this thesis. My interest in the area of study arose as a result of my personal experiences. Though I had not been directly involved with befriending schemes, I was familiar with the concept as a family member had been a volunteer befriender for an older adult with mental health problems for several years. Through personal relationships with people with intellectual disabilities I had witnessed their experiences of social exclusion and challenges arising in connecting with others and maintaining friendships. Professionally, prior to starting the study I had undertaken limited direct clinical work with people with intellectual disabilities or autistic spectrum conditions.

Given these experiences, I went into the study with an expectation of finding befriending for adults with intellectual disabilities to be a positive intervention, though I was interested in understanding the contributing factors driving this. I was excited to hear the voices of participants directly, and yet somewhat nervous about my own ability to support them to participate fully and to best interpret the data, given that I do not personally know what it is like to live with intellectual disabilities or autism. I tried to mitigate this nervousness by inviting input from people with intellectual disabilities and/or autism at the beginning of the project (in an advisory capacity), and by reflecting on this in supervision throughout data collection and analysis stages.

It is likely that a combination of the above factors may have introduced some additional bias towards positive outcomes of befriending and influenced the collection and analysis of the data. Throughout the study I attempted to bear these presuppositions in mind, to consider ways in which they may have created bias, and to work to actively counteract this where possible (for example ensuring the sample included some befriendees who had experienced the ending of relationships and engaging in credibility checks and reflective discussions with a second researcher during the analysis phase).

2.2. Participants

Thirteen befriendees, two family carers and one befriender were interviewed for this study. The initial study design involved recruiting participants from just one of the befriending scheme locations, and interviewing equal numbers of befriendees and other participants. In this scenario, presenting detailed demographic data would not have been appropriate as it could have led to the identification of interviewees, and as such limited demographic information was collected. However, as initial recruitment was slower than expected the study was opened up to interested participants from other locations, enabling some characteristics to be included in order to situate the sample (see Table 1).

Due to the small numbers of participants other than befriendees, in order to preserve confidentiality for this report, all participants shall be identified by their study identification number. BFE1-BFE13 are befriendee participants with intellectual disabilities and/or autism, and OP1-OP3 are other participants, either befrienders or family carers.

Table 1

Overview of participant characteristics

Participant ID	Participant type	Approximate age	Gender	Location
BFE1	Befriendee	20s-30s	Female	Southern England
BFE2	Befriendee	20s-30s	Male	Southern England
BFE3	Befriendee	20s-30s	Male	Southern England
BFE4	Befriendee	20s-30s	Female	Southern England
BFE5	Befriendee	20s-30s	Male	Australia
BFE6	Befriendee	20s-30s	Female	Australia
BFE7	Befriendee	20s-30s	Female	Australia
BFE8	Befriendee	30s-40s	Female	Central England
BFE9	Befriendee	20s-30s	Female	Southern England
BFE10	Befriendee	20s-30s	Male	Southern England
BFE11	Befriendee	50s-60s	Male	Central England
BFE12	Befriendee	20s-30s	Male	Scotland
BFE13	Befriendee	20s-30s	Male	Scotland
OP1	Volunteer Befriender	n/a	Male	England
OP2	Family carer	n/a	Female	Australia
OP3	Family carer	n/a	Female	England

2.3. Ethics

Ethical approval was granted by the University College London Research and Ethics Committee (Project ID 19277/001). See Appendix B for a copy of the ethical approval letter.

2.4. Participant selection

For this study we partnered with a befriending scheme set up in the South of England which operates in multiple UK and international locations, both directly and via partner charities. The scheme focused its provision upon adults with intellectual disabilities and/or autism, recognising that the conditions are often co-occurring and that people with either are vulnerable to many of the same exclusionary factors. The scheme matched adults with intellectual disabilities and/or autism with a volunteer befriender based upon several criteria, including shared interests. It aimed to enable people with intellectual disabilities and/or autism to enjoy cultural activities, make friends (with people who were not paid to be there), take a lead on how they spend their lives and be actively involved in mainstream community life.

Differing sampling strategies were utilised to recruit befriendee participants (adults with intellectual disabilities and/or autism) and other participants (family members, professional carers, friends or befrienders) for the study. Befriendees were recruited using convenience sampling. Advertisements for the study were distributed by the befriending scheme co-ordinators by email and social media. Potential befriendee participants were invited to contact the researcher directly to express interest. Other participants were not recruited directly but were nominated by befriendees at the end of their interviews and subsequently contacted by the researcher to gauge their interest in participating.

Minimum inclusion criteria for befriendee participants were having an intellectual disability and/or autism and having either regular monthly contact with a befriender for a minimum of three months or awaiting reallocation having previously had a regular befriender. For other participants, the inclusion criterion was befriendee consent to contact.

2.5. Recruitment procedure

Once potential participants had expressed interest, the researcher contacted them to screen against the inclusion criteria, provide a study information sheet and answer any questions. If they were willing to proceed, an interview was scheduled and participants were sent a consent form. Both information sheet and consent form were provided in Easy Read accessible format, having been piloted with people with intellectual disabilities working at the befriending scheme (see Appendices C-F). Due to the Covid-19 pandemic, all interviews were conducted remotely, using telephone or Zoom video conferencing software. Interviews lasted between 25 and 50 minutes. Each interview was audio-recorded using an external voice recorder and manually transcribed by the researcher prior to analysis. Each participant received a £10 gift voucher or charity donation in return for their time.

2.6. Data collection

The study research questions were co-developed with input from eleven adults with learning disabilities and/or autism taking part in the befriending scheme. They responded to a request for ideas either by completing a paper survey, an online survey or participating in a brief video call with the researcher. Some initial questions were proposed by the researchers and tested with respondents for relevance. Respondents contributed additional questions and raised particular areas they were interested in the research covering (see Appendix G for examples of the written responses received).

Using this input, the initial research questions were finalised and expanded upon to develop semi-structured interview schedules for each set of participants. The interview schedules were reviewed by a 'quality checking' team with intellectual disabilities and/or autism at the befriending scheme who provided feedback on whether the questions felt relevant and whether any were difficult to answer. The interview schedules were designed to elicit reflections on experiences of the scheme and its impact on the participant. There were also questions regarding active ingredients, the differences between befriending and other activities, and potential improvements or limitations of the scheme (see Appendix H for interview schedules). Though keen to elicit themes which may provide insight beyond this particular befriending scheme, we chose to make explicit reference to the befriending scheme multiple times, in line with guidance for successful interviewing with people with intellectual disabilities (Hollomotz, 2018), which suggests that questions should be concrete and relevant to individuals' experiences. Additionally, the decision was made to ask about the 'importance' of various elements rather than explicitly asking about the 'impact'. This choice was made following consultation with the 'quality checking' team who fed back that discussing 'impact' felt difficult conceptually.

2.7. Data analysis

Interview transcripts were analysed using reflexive thematic analysis with the aim of generating themes – patterns of shared meaning unified by a central concept or idea – which captured the key features of the participants' accounts (Braun & Clarke, 2006, 2021). The research was conducted taking an essentialist stance, assuming that the experiences and meanings reported by the participants reflected their reality. At the level of individual transcripts, coding of data was mostly semantic rather than latent, involving more description than interpretation. This fitted with the relatively concrete use of language by interviewees with intellectual disabilities and guarded against overinterpreting or misinterpreting meanings at times when miscommunication or misunderstandings occurred. An inductive, data-driven approach to analysis was intended, whilst acknowledging that the existing theoretical pre-conceptions and understanding of the researcher may have contributed to the grouping and generation of themes (see 2.1. Researcher Perspective above). NVivo Version 12 was used to complete coding and organisation of the data.

The researcher first familiarised herself with the data by transcribing each interview and re-reading through the transcripts, making notes on ideas for initial codes and ideas. The second stage involved complete coding, systematically working through each transcript to code data relevant to the research questions. For this study, an inductive, data-driven approach was taken, so all transcripts were individually coded before grouping of codes was considered. At stage three, initial themes were generated by looking across the different transcripts and sorting the codes into potential themes, sub-themes and recurring codes. These were roughly mapped out to give a visual idea of the relationships and patterns the researcher was identifying in the data. Stage four involved reviewing the themes against the collated data at an extract level and across the entire dataset. Several iterations of coding, reordering and regrouping occurred until the themes and subthemes were judged to reflect the key meanings in the data and to demonstrate both internal homogeneity and external heterogeneity (Patton, 1990). The final stages involved naming and defining the themes and sub-themes and identifying the core narrative and extracts needed to summarise it in this report. As the coding and analysis was primarily conducted by the researcher, the requirement for credibility checks was considered. At the early stages of the analysis process, a second researcher independently coded 30% of the transcripts. The intention was to facilitate discussion of which data were considered relevant for inclusion rather than to establish inter-rater reliability or an exact consensus of coding. It also informed discussions that were held at a later stage of analysis when codes had been grouped and patterns identified, with both researchers discussing, iterating and agreeing upon the final themes generated.

3. Results

During the analysis four main themes were generated, each with several sub-themes (see Table 2). These themes each reference distinct aspects of the befriending experience – ‘Something fun for me’, ‘Feeling part of something bigger’, ‘Increasing independence’ and ‘A life less quiet’. In order to give a sense of the relative importance of themes across interviews, frequency counts have been included in Table 2.

Table 2

Overview of themes and sub-themes

Main themes	Sub-themes	n	(n)
Something fun for me	It's what I want to do	16	13
	It's for me	11	8
	It's for fun	8	6
	The importance of shared interests	13	10
Feeling part of something bigger	Belonging to a group	16	13
	Accessing ordinary community settings	9	6
Increasing independence	Safety and support	14	11
	Bridging new experiences and relationships	13	10
	Getting involved and speaking up	9	8
A life less quiet	Threat of isolation	15	13
	Someone else to do things with	16	13
	A friend or a professional?	13	11
	A welcomed intervention	16	13

Note: n = the number of participants referencing each sub-theme. (n) = number of participants with intellectual disabilities and/or autism referencing each sub-theme.

3.1. Something fun for me

Participants reported a number of important features of befriending relating to having something fun for themselves. Key aspects were befriendees being able to have something personalised to them, and to able to choose what activities they wanted to engage in. The importance of having shared interests so that both befriender and befriendee could have fun together was also emphasised.

3.1.1. It's what I want to do

For many, befriending was about going out and doing activities they genuinely wanted to do, and had actively chosen to do, either through making plans collaboratively with their befriender, or by being able to make a decisive choice themselves.

> *She comes up with ideas as well, but most of the time it's about what I want to do. (BFE12)*

> *It's really fun, you know, try new things, try to learn, and making new choices about where you go and what you do. (BFE6)*

For some, this contrasted with other areas of their lives, particularly with their families, where their sense was that decisions were often made by others.

> *My family tend to make decisions… and I don't have much of a say but with friends and my befriender I can, sort of, have my own decision. (BFE4)*

> *Sometimes it was a decision between both of us... But 99% of the time it was, he used to go 'What you want to do today?' and I used to pick… Basically like only one other person I can pick with is [friend's name]. Anyone else, it's 'Oh well, you've got to do it.' (OP3)*

3.1.2. It's for me

Participants commented on the person-centred nature of the befriending relationship, with the one-to-one pairing seen as enabling a deeper relationship between befriender and befriendee.

> *They get to know each other in a more intimate setting, it's just the two of them and it's more one-on-one time… you can sort of foster and build that relationship a bit further. (OP2)*

> *Just because then they get to know you a bit better and they can bond with you a bit better. (BFE12)*

Attending events and activities with a befriender was also viewed as being more flexible and personalised than attending group activities. One befriendee contrasted his experiences of having to stay at football practice to the very end with his experiences with his befriender:

> *I said to [Befriender] 'I'm ready to pack it in, I want to go back home' and then he said, 'OK, let's go', because if I'd been there for like over the 2-hour mark, I get, like, that's it, two hours is the maximum for me. (BFE10)*

Several befriendees noted that befriending provided them with an opportunity to be themselves and not be judged, comparing this to other experiences in their lives.

> *Some of my quirks and mannerisms to others can be a little strange and some people view it as a joke, that's fine. With [Befriender] he just accepts it's part of me... And I think a big active ingredient of befriending is just accepting people for who they are, what goes on there. No viewing it as a joke or something to mock, or anything like that... (BFE5)*

> *It just means I can go out and just be like myself. (BFE2)*

3.1.3. It's for fun

Both befriendees and befrienders emphasised the pleasure and enjoyment gained from befriending. It was seen as an opportunity to have fun, and to have fun together.

> *It's great fun. I enjoy having my befriender. (BFE11)*

> *Having a laugh, having a great time. And that's the part of it is going out, going clubbing, having a laugh. And I love it. (BFE13)*

> *It's just, it's fun, which is one of the main reasons I did it. I did it because I thought it was a brilliant charity but, you know, most things in life work better if they're fun. (OP1)*

In contrast to interventions focused upon developing certain skills, finding a job, or exercising, befriending offers an opportunity for fun and play that some adults with intellectual disabilities find hard to access. Having permission to do something just for the sake of fun was illustrated by one particular anecdote from a befriending pair, about trying (unsuccessfully) to cook chips on a barbecue:

> *BFE2's befriender: Even if they're really silly ideas, as long as they're not dangerous, we go along with them and we give it a try, don't we?*

> *BFE2: Yeah (laugh). Chips on the barbecue. We thought 'don't be ridiculous' (laugh)… But we'll do jacket potatoes next time!*

3.1.4. The importance of shared interests

Having shared interests was seen as a conduit to greater understanding and connection between befriender and befriendee.

> *They match you up with somebody who you're like… if the befriender didn't like the same stuff you like, there's no point in having them really. (BFE12)*

> *Having a [befriender] with mirroring interests means that they, um, understand you more often than those that don't. (BFE4)*

> *Even if you just found the one thing that you both like that is often enough to bring you two together. (BFE5)*

Other participants noted the importance of shared interests in order that the activities undertaken together were pleasurable for both parties. They emphasised the role of common interests in distinguishing the befriender role from less personalised support.

> *I think that shared, shared interest or just kind of getting on with each other well, in the sense of, it's really not a taxi service to get from one place to another. A befriending service really ought to make it feel like [befriendee] has got another friend who is there for her. (OP3)*

> *I think it's finding common ground… it should be a natural, enjoyable thing for both of us as much as possible. (OP1)*

3.2. Feeling part of something bigger

Befriendees, befrienders and family carers alike noted that befriending can create opportunities to feel part of something, reaching beyond the individual interactions between befriending pairs and promoting a sense of belonging to a broader group. Additionally, befriending was reported to facilitate access to other group settings, both in disability specific and ordinary community settings.

3.2.1. Belonging to a group

In addition to the one-to-one pairings between befriender and befriendee, many befriending pairs would attend group socials, trips and events organised by the befriending scheme, contributing to a sense of belonging and identity as a member of a broader 'befriending scheme group'.

> *I think [the befriending scheme] is a great thing because everyone joins in, and kind of like, joins the fun of it, you know? (BFE6)*

> *It doesn't have to just be you and your befriender, it could be a group of us, it could be other befrienders… I like being in a group together. (BFE13)*

Befrienders and family carers noted benefits of being part of a broader befriending community, creating opportunities for befriendees and befrienders alike to meet others they related to and to share responsibility.

> *I really enjoy the wider social events so I can relax more, I can meet other people… It's just safety in numbers. I think if those numbers are similar people to himself and myself, then you're less on duty, if you like. (OP1)*

> *She certainly needs to see others with disabilities who are living life well and being reassured that her life is not terrible just because she has a disability… Being involved in a community where people are active and able to do things and enjoy it is really important. (OP3)*

The Covid-19 pandemic made it difficult for individual pairs to meet up in person, both due to Government restrictions, and to the different health vulnerabilities of befriendees, befrienders and their households.

> *With a lot of people with disabilities, the coronavirus like had a lot of impact on our lives... it just felt like everyone was so far away, including [befriender]. (BFE8)*

In response, the befriending scheme set up regular online events to connect befriendees, befrienders and coordinators virtually. This seemed to result in a strong sense of belonging amongst those who attended, but left some who had limited access to online communications feeling lonely and left out of the group events.

> *[It] has been brilliant, especially with all the online events they've been doing... People from as far as actually away down South, Wales, and that, I speak to now through the other [befriending scheme] projects. Me and them have got to know each other quite well. (BFE12)*

> *But it's been really upsetting and angry just to know, 'Oh I'm missing out' on a [befriending scheme] event or a Zoom. (BFE8)*

Beyond befriending, many befriendees took part in group leisure activities in other settings. Many participated in clubs or classes based around particular interests such as drama, art, football or music, as well as attending more general social groups, often those set up specifically for people with disabilities. However, some interviewees reported that group dynamics can be difficult to navigate. The presence of a befriender appears to facilitate access to group or social settings which befriendees may otherwise find it hard to access.

> *Groups she definitely finds difficult to manage... Therefore, if she doesn't get enough support things tend to go wrong. (OP3)*

> *When I've got support to interact with other people, that helps me a lot more, so I would find it a bit hard if I sort of went to a gig or something and they're all complete strangers and I was by myself. (BFE4)*

3.2.2. Accessing ordinary community settings

One of the befriending scheme's aims was to increase befriendees' involvement in ordinary community settings. The range of activities undertaken by befriending pairs covered a broad range of home-based and community-based activities (see Table 3). With the exception of some disability-specific activities (such as parties or socials run by the scheme or specific nightclub events for people with disabilities), the majority of activities were undertaken in ordinary community settings, either individually between befriender and befriendee, or along with others from the befriending scheme. None of the befriendees mentioned collectively taking part in any community teams, clubs or groups along with their befriender.

Table 3

Activities undertaken by befriending pairs

Home-based activities	Community-based activities
Eating meals	Attending befriendee's public performances
Video gaming	Cinema trips
Video calling each other	Crazy golf
Visiting each other's homes	Cultural festivals, music festivals
	Football matches
	Night clubs (for both disability specific and mainstream nights)
	Drinking in pubs/bars
	Karaoke
	Meals out in cafes/ restaurants
	Music gigs
	Parties and socials run by befriending scheme
	Picnics
	Quiz nights
	Shopping
	Silent disco
	Theatre shows/ musicals
	Tourist attractions (including zoo, circus, local sights)
	Visiting garden centres

There was a recognition, from both befrienders and befriendees, that people with intellectual disabilities and/or autism may require more support to access certain community settings and that befriending was one way of providing this.

> *For someone like you, if you go clubbing, you know, you just go out. Someone that has like learning disability… they need extra support to go out, or encouragement because it's a bit more difficult for them because they're a bit more, I would say, vulnerable in society. (BFE13)*

> *You know, you go to a normal club, you don't see hardly any disabled people… And it's just a joy to see these people enjoying themselves when,*

> *you know, they're kind of excluded from doing so a lot of the time, so that's been a big bonus… (OP1)*

Some participants noted the benefits of being around peers with disabilities, such as an increased ability to understand each other's experiences and to feel included and comfortable in certain situations. However, there was also an expressed wish for more acceptance within ordinary community settings, and a sense from one befriender that activities with befriending scheme members could be one way of challenging others' perspectives and going further in terms of social integration.

> *Because of my learning disability and also my physical disability, I always felt like the odd one out in a situation… but in [befriending scheme] you're surrounded by people who go through similar experiences so you can relate to them, you don't feel weird or uncomfortable. (BFE5)*

> *I suppose it fosters more understanding and maybe a sense of relatability… But at the same time, I do think that also there needs to be basic understanding and empathy even in mainstream settings as well. (OP2)*

> *More actual integration would be the next step I think... just invading your local nightclub or nasty Saturday night disco down the road and just, you know, scaring the local 'beer monsters' on the pull with a load of people that they're not expecting to see there and seeing how that pans out. (BFE14)*

3.3. Increasing independence

Participants noted that the befriending relationship provides safety and support to the befriendee, both in practical and emotional terms. The external support for the pairing from the befriending organisation was reported to be important at all stages of the befriending relationship life cycle. The provision of this support appears to foster befriendee independence, enabling access to new relationships and experiences, and encouraging leadership and self-advocacy.

3.3.1. Safety and support

The presence of a befriender appeared to make befriendees feel safer in settings where they might have felt threatened or at risk.

> *Sometimes, it's scary when you meet, that some total stranger, you know, you don't, don't know... I feel more safe with her, she's really nice. (BFE6)*

> *[Having a befriender] helps people like us to go out to places, if we go on our own, then umm, we get taken advantage of. That's why we have a [befriender], to help us stay out of that situation... People can make me want to join a gang with them and use me as a scape goat. (BFE10)*

Befrienders appeared to practically support their befriendees' access to activities by setting clear boundaries (such as where and when to meet), planning and organising event attendance in advance to account for any additional needs of their befriendee, and monitoring the reactions of others interacting with their befriendee.

> *If we go to big events like festivals, I try to set guidelines, you know, 'make sure you're in eyesight or make sure you're with someone if you're away from me'. (OP1)*

> *I do feel safe when I go out with them… you meet your befriender at a meeting place. It's great. You're within that contact with your volunteer all the time so if you're lost we organise where to meet… it gives me that security. (BFE13)*

Befrienders were also noted to provide reassurance and emotional support in environments that felt overstimulating or crowded, further enabling befriendees to access events and activities.

> *I have someone that can reassure me if the trains get busy or if the London ground is a bit busy and noisy, that I can just hold someone's hand or just talk to them and take my mind off of all the busy people and everything… (BFE8)*

External support from the scheme coordinators appeared important at all stages, from setting up matches (which took time and sometimes multiple attempts), to supporting ongoing relationships and managing endings. Befriendees spoke of the stress they felt at the ending of befriending relationships, somewhat mitigated by being found a new match quickly by the befriending scheme coordinators.

> *Between the time when the application process started and then when getting a [befriender], I think it was quite a while… I suppose it wasn't distressing, but I suppose more in the sense of disappointing. (OP2)*
>
> *There also has to be quite a clear setup of what is expected and for that to continue to be managed… continuing to kind of make things clear and be able to communicate what is the purpose and how it works. (OP3)*
>
> *When they told me I was not happy, but I got a new one straight away… it would have felt very stressful for me because I would need a befriender. It would have become less social [but having a new one straight away helped]. (BFE9)*

3.3.2. Bridging new experiences and relationships

Several befriendees noted that befriending had helped them build their own confidence, which then had a knock-on impact on their engagement in other relationships and activities.

> *Since I've joined [scheme] it's built up like confidence. Now I'm doing a college course and I'm able to talk more in a group… If it wasn't for [befriending scheme], I wouldn't want to talk, I'd be very shy. (BFE13)*

> *It's sort of inspired me and given me the confidence I should say to reach out to new people outside of that [befriending scheme] bubble. (BFE5)*

> *Somehow it not just being an individual one-on-one but actually helping her to access other stuff I think is a really useful part of befriending. (OP3)*

Some who felt socially anxious appreciated having a befriender to support them in social situations and saw having a befriender as an opportunity to develop themselves.

> *I think I'd say I'm like more confident… If I didn't have someone, I would probably be a bit more nervous… and unsure of what to do. (BFE4)*

> *When as socially awkward as I am, you need, you need to take advantage of whatever opportunity there is to, er, better that. (BFE3)*

Having a befriender presented opportunities to attend new events and have experiences that befriendees may not have had knowledge of, or access to, otherwise, though we note that many of the activities did appear to be repeated, familiar activities that could also be undertaken with family members or support workers (e.g. shopping, going out for meals).

> *They've done things I didn't even know were possible… they went to some disco thing at the aquarium. I didn't even know that was a thing, and I probably wouldn't have come across that. (OP2)*

> *You can open yourself up to new experiences, find something you didn't think much of initially, and realise "Oh, this is really cool, I like this". (BFE5)*

3.3.3. Getting involved and speaking up

Many of those interviewed also held leading roles in the befriending scheme, acting as ambassadors, trustees or peer trainers. We note that this may, to an extent, be a reflection of the sampling strategy, with those more engaged in the befriending scheme more likely than others to sign up for the study. It was also not possible from the comments to discern whether this was as a result of the befriending intervention itself. However, what was clear from those who commented on their additional involvement was that they derived a sense of pride and purpose from the additional leadership responsibilities they took on.

> *[On being an ambassador] It helps us decide what we're planning to do in the next month or coming up… I'm the community guy. I always get involved with any special events... That's what I do. (BFE10)*

> *I'm also a trustee for the charity as well. I attend all of the trustees' meetings which is a very important job for me, discussing all the stuff we have to discuss. (BFE2)*

Several befriendees commented on the key messages they were helping to disseminate, and their role in holding others to account on behalf of other people with intellectual disabilities.

> *I'm also an ambassador as I mentioned. Basically, to spread the word about no bedtimes [a befriending scheme campaign]. (BFE12)*

> *We're doing a campaign… because we should be at the top of the health waiting lists because we've got learning disabilities. (BFE11)*

After each interview with a befriendee the researcher asked if they would like to nominate their befriender, a family member or a professional carer to take part in the study. It was of note that befriendees rarely nominated a family member, carer or befriender as their first choice, opting instead to suggest other friends of theirs with intellectual disabilities or autism involved in the befriending scheme or simply choosing not to nominate anyone at all.

3.4. A life less quiet

The potential for, and actuality of, social isolation was acknowledged across many participants, particularly in the context of the pandemic. Befriending appeared to reduce or mitigate isolation by providing companionship, someone to talk to and an additional person to do activities with. Views varied amongst participants as to where befriending sat on the spectrum of friendship to professional relationship, but it was positively regarded and welcomed as an intervention by befriendees, befrienders and family carers.

3.4.1. Threat of social isolation

Across many of those interviewed there was a sense of being socially isolated, which had become more pronounced during the Covid-19 pandemic. Having intellectual disabilities or autism appeared to contribute to this isolation, affecting befriendees' sense of not being accepted by others without disabilities, and being exacerbated by external factors such as being moved from one residential care setting to another.

> *I felt, even before lockdown I just kept feeling like I was on my own. There is no-one who's got disability like me. Where do I go? (BFE8)*

> *I was a very solitary individual if that makes sense… I felt like the only place I could be me was on my own. (BFE5)*

The provision of friendship or companionship was most commonly cited as the ‘most important thing about befriending,’ being referenced by five of the fifteen interviewees questioned.

> *The most important thing for me is basically you've got somebody you can meet and talk to… Somebody you can go to if you've got any problems as well. They are more than just somebody who takes you out. (BFE12)*

> *I can't really remember what I thought going into it… but I suppose that back then I would have been more reliant on as much social contact as I could get… I needed the, just contact, needed the contact even more. (BFE3)*

For some befriendees, their befriender was seen as a confidant to turn to with problems, matters that were upsetting them, or issues they felt unable to share with family members or carers.

> *When I want to talk to my family, sometimes they listen and sometimes they won't… With my befriender and my friends, I'm able to say more things and they're quite happy to listen. (BFE4)*

> *[It’s someone] that's not a carer or a manager... I can discuss it and talk about it, and just get him to sit with me and support me really. (BFE2)*

> *She help me with the different times, when I'm feeling sad or angry. (BFE6)*

> *It helped me grow a friend, helped me grow trust with someone and just knowing that if I'm feeling sad or low, I can talk about things that might be bothering me. (BFE8)*

3.4.2. Someone else to do things with

The reality for some of the befriendees interviewed was that they often needed support to take part in activities in the community. However, there was a recognition that family or professional support could not always fulfil this role to the extent desired.

> *It gives her a chance to sort of go out and do different things… obviously we can't be there all the time. (OP2)*

Befriending was seen as a way to relieve isolation or boredom, offering opportunities to get out more.

> *I think [befriending] is the best thing in my life, I think it's a really fun thing for me to do when I'm feeling alone, or like, nothing, nothing to do at home. (BFE6)*

> *It helps me get out more and not be stuck in the building. (BFE10)*

> *It's just, um, less quiet for me, in a good way. (BFE3)*

For family carers, the befriendee having an additional person to go and engage in leisure activities with meant there was less pressure on them, and a sense that they could be more selective in the activities they did engage in with the befriendee.

> *It does take the pressure off me sometimes, in that respect. (OP2)*

> *If she goes and does that with someone else, I can spend time helping her learn how to cook or go and do things that are going to help her do*

> *something more in the future. So that's where I tend to put my focus. So it's quite useful that she's got someone to go with to do activities with and have fun with. (OP3)*

3.4.3. A friend or a professional?

The befriending relationships explored in this study were incredibly diverse, with each befriending pair falling at different points along a friend to professional spectrum. Many of the befriendees referred to the friends or friendship generated by befriending.

> *[The most important thing about befriending] is just friendship. It's, uh, invaluable to us all, even if we don't realise it at times. (BFE3)*

> *It's simply just having a mate, you know, someone you can talk to, someone you can hang out with, it's just having a mate really. (BFE5)*

> *I've sort of got another friend and I can actually like do things with her when she's not busy. (BFE4)*

Some appeared to view their befriender towards the more professional end of the spectrum, though distinct from other support provision. From a family carer's perspective, there was a sense that whilst befriending provided active support, it was distinct from a more genuine friendship.

> *We sometimes give each other a hug in a nice way, in a professional way... (BFE13)*

> *I say 'true friendships'… the contemporaries and sort of someone 'like her' if I can put it like that… Whereas older people or people who are actively trying to support her is something that she really enjoys and benefits from… but then that's not really quite a friendship in the same way. (OP3)*

Whilst befriending activities were based around fun, one befriendee saw the distinction between being able to drink or not drink alcohol as a signal of the responsibility their befriender held when out with them.

> *Once they finished befriending… if they choose to meet up with someone then, then they can have a drink because they're not responsible. (BFE13)*

This responsibility appeared to also be felt by the befriender, as illustrated by an example of needing to leave a concert minutes before a much-anticipated act took to the stage.

> *We had to go, (laugh) which was annoying, but you know... If they're not enjoying it, or if they are distressed, then that's the priority. So yeah, it can be frustrating, but that's, you know, part of the job so… (OP1)*

3.4.4. A welcomed intervention

Every participant interviewed viewed the befriending scheme as a 'good thing' overall, with it being praised effusively by many participants. Many attributed their judgement of the scheme to it having a personal impact on their mood.

> *[Having a befriender makes me] Happy and jolly. Make me happy, make me laugh. (BFE1)*

> *I feel more calmer and happier… I like having someone like someone like to keep me like calm and relaxed. (BFE4)*

> *Makes me more independent... Makes me happy, um, when I have a [befriender]. (BFE11)*

For others, befriending was viewed positively because it had provided opportunity to take part in pleasurable experiences that could then be talked about and shared with others.

> *You get to do some really cool events and go to some really cool places. And you get a story out of those events, so you can tell people where you've been, what you've done, who you got to meet. (BFE5)*

The set-up of the befriending scheme was generally viewed very positively and, when asked about the limitations of the befriending scheme, several participants responded that 'nothing could make it better'. The message that came across repeatedly was that befriendees wanted to be doing more activities (both familiar and new) and to be meeting up more, either with their befrienders or with the broader social group provided by the befriending scheme. The ongoing Covid-19 pandemic and the associated changes to befriending appeared to be one additional element in this.

> *More meeting up with people [would make the scheme better]. (BFE11)*

> *I just want to get out… I just want to do gigs. I don't want to be on Zoom anymore... for life on Zoom, you're in a box and you think, 'what are you doing in a box?' We're not [befriendees] in a box, we're [befriendees] OUT... (BFE2)*

4. Discussion

4.1. Overview of findings

The present study used a qualitative approach to better understand the experiences of individuals involved in a befriending scheme for adults with intellectual disabilities and/or autism, considering the impact, the active ingredients, and the limitations of the scheme. Four main themes were generated from the data, each with several subthemes.

The first theme, ‘something fun for me’ revealed the way that befriendees appreciated having something that was personalised to them, that they made the choice to engage in, and that was about doing what they wanted and having fun together, engaging in activities of shared interest. The second theme, ‘feeling part of something bigger,’ highlighted how the impact of befriending can extend beyond the one-to-one interactions between befriender and befriendee, promoting a sense of belonging and providing support to access other group activities, both in intellectual disability specific settings and in ordinary community settings. The third theme, ‘increasing independence’, explained how befriending fosters independence by providing a sense of safety, along with practical, emotional and external support, resulting in befriendees being able to access new relationships and take part in new experiences. Additionally, many befriendees show independence by getting involved with leadership roles in the befriending scheme and speaking up for other people with intellectual disabilities. The fourth theme, ‘a life less quiet’, referenced how befriending mitigates isolation, providing companionship in the form of someone additional to talk to and do things with. Views varied on where a befriender sat on the spectrum of ‘friend to professional’, but the sense was that, regardless, befriending was appreciated and more of it was desired.

4.2. Comparison with the literature

The present study’s findings support and build upon previous findings from the literature on befriending for people with intellectual disabilities and autism. As outlined in detail in Part 1 of this thesis, existing research suggests that befriending for people with intellectual disabilities increases community participation, changes social networks, offers opportunities for new experiences, impacts mood and increases independence and confidence. It raises questions about whether community participation facilitates social inclusion, whether social networks grow or are substituted for others, and what the long-term effects are of befriending interventions. Below we compare the results of this study to the existing literature, both within befriending for intellectual disabilities specifically, and in related areas with other populations or interventions.

Whilst empowerment in decision making for people with intellectual disabilities has long been promoted (Department of Health, 2001), research shows a continued gap between actual and desired uses of leisure time in people with intellectual disabilities (Charnley et al., 2019). This could indicate that power to make decisions continues not to be shared, or that choices are limited to more ‘mundane’ areas (Hollomotz, 2014). This study found that the opportunity for shared decision making in befriending relationships, and the resultant focus upon doing activities befriendees enjoyed and had actively chosen to partake in, was vitally important. Whilst other studies had highlighted the common use of shared interests as a criterion to match befriending pairs (Tse et al., 2021), this study suggests the reason this is important is due to shared interests fostering a better connection and ensuring befriender and befriendee engage in activities they both find enjoyable. Befriendees with intellectual disabilities have previously been found to value having something just for them which does not have to be shared with other service users or siblings (Southby, 2019). This study similarly found that the flexibility and personalisation of their one-to-one pairing was particularly appreciated by befriendees. Additionally, for adults for whom interventions are often focused upon teaching specific skills, for example social or relationship skills (Płatos & Wojaczek, 2018; Ward et al., 2013), workplace skills (Wilson et al., 2020), or parenting skills (Coren et al., 2018), the provision of a personalised intervention that facilitates fun and entertainment simply for fun’s sake appeared to be particularly valued by participants. This may support findings linking engagement in enjoyable leisure activities to better psychosocial functioning (Pressman et al., 2009).

A sense of belonging, defined as a feeling of being accepted or of fitting in (Scior, 2018), has been considered in research with people with intellectual disabilities, though clear conceptualisations of it are lacking and it is often not the primary focus of the research (Fulton et al., 2021). This study finds that befriending leads to a sense of belonging to a group, a finding not previously reported in existing studies of befriending for people with intellectual disabilities and/or autism. The extent to which this effect is found within other befriending schemes (or at other times after the Covid-19 pandemic) will require further research. The presence of a befriender was also found to facilitate access to groups, both within disability-specific and ordinary community settings. This supports existing findings that individual support to access community group settings increases community participation, social contacts and social satisfaction (Stancliffe et al., 2015) and that access to expertise, specifically the feedback, support and modelling of a person accompanying the person with intellectual disabilities can impact community participation (Craig & Bigby, 2015). Whilst befriending for people with intellectual disabilities appears to increase community participation (Bigby & Craig, 2017; Fyffe & Raskin, 2015), there were questions raised as to whether this constituted ‘true’ social inclusion (Heslop, 2005; Southby, 2019). This study, which found a mix of home-based, community-based ‘individual’ activities (where unlikely to have much interaction with others, e.g. cinema trips) and community-based ‘collective’ activities (e.g. attending festivals or performing at music gigs), was not able to draw any firmer conclusions on this question. Mention was made of a desire for more social integration by one befriender, and befriendees alluded to both enjoying the support to access mainstream settings, and the opportunity to be around others with intellectual disabilities.

This study supported the existing findings that befriending fosters independence by providing safety and support (Cassidy et al., 2019; McCorkle et al., 2009; Mitchell & Pistrang, 2011) and helping bridge new relationships and experiences (Fyffe & Raskin, 2015; Southby, 2019). Some studies questioned whether repeating familiar ‘casual’ activities risked befriendees missing out on novel leisure and social experiences (Southby, 2019) or led to lower befriender satisfaction with the relationship (Tse et al., 2021). This study found that whilst many activities undertaken did appear to be repeated and familiar, there were also many examples of novel events and experiences being enjoyed. Taken together with the importance of decision making highlighted above, we suggest that the important element is perhaps not the novelty of the experience but the shared decision to engage in it.

Befriending relationships, like others, change over time and go through different stages of evolution (Bigby & Craig, 2017; Green et al., 1995). McCorkle et al.’s (2009) study of befriending for people with mental health problems suggested that relationships progressed from a ‘taxicab phase’ (focused on instrumental support such as driving befriendees to places) to a more equal partnership only over a number of years, facilitated by support from co-ordinators around setting limits and having direct conversations. Similarly, Bigby and Craig (2017) reported that consolidation of the friendship studied took

3.5 years of committed resources. Whilst time and familiarity appear to shift a befriending relationship further towards the ‘friend’ rather than the ‘professional’ end of the spectrum, endings can highlight the tensions that exist between true friendship and formal intervention. People with intellectual disabilities and/or autism often experience multiple separations and losses of caregivers over time and are emotionally affected by each of these endings (Mattison & Pistrang, 2000). The majority of befriending relationship endings discussed with the interviewees in this study appeared to be initiated by befrienders rather than befriendees. Regardless of the reason for the ending (often cited as having other commitments, or moving away), the power imbalances between the pair become uncomfortably evident at a point where one decides to discontinue the ‘friendship’ that has been formed. In today’s digitally connected world friendships do not automatically cease due to increased geographic distance, and few have an end date of contact set and enforced by an external agency.

This study indicated that containment and support was important for befrienders and befriendees alike. It also supported existing findings that the endings of befriending relationships were a source of anxiety (Heslop, 2005; Mavropoulou, 2007; Mitchell & Pistrang, 2011). The suggestion that swift replacement of a befriender may mitigate this anxiety suggests a need for a befriending scheme to be equipped to support relationships (promoting retention), recruit on an ongoing basis (to ensure a sufficient pool of volunteers), and closely supervise befrienders such that there is sufficient notice of impending endings. Studies consulting befriending scheme workers highlight financial constraints as a major, continuing issue (Heslop, 2005), with half of services surveyed in 2020 reporting financial challenges, particularly for charity-run schemes reliant on fundraising as the major source of funding (Tse et al., 2021). Additionally, studies report challenges recruiting and retaining befrienders (Ali et al., 2021; Fyffe & Raskin, 2015; Tse et al., 2021). This study did not consult befriending scheme coordinators so does not comment on the potential financial or recruitment challenges, though high turnover of befriending scheme staff was mentioned by one participant.

The importance of a befriender as ‘someone else to do things with’ echoed findings from befriending in mental health populations which suggest that ‘getting out’ and ‘doing stuff’ is key to bringing about change (Cassidy et al., 2019; Mitchell & Pistrang, 2011). Similarly, having someone to listen and to whom a befriendee could speak about personal issues supported existing literature (Harris et al., 1999; McCorkle et al., 2009), though the extent to which the role extended to ‘giving advice’ (Cassidy et al., 2019) was not explicated by the present study. In line with previous findings (Southby, 2019; Thompson et al., 2016), this study found that befriending relationships sit on a spectrum from friendship to a more professional role, with both befrienders and befriendees recognising that there was a degree of responsibility or obligation in the befriender role (Green et al., 1995). The question of whether befriending led to social network substitution was raised by studies using explicit measures to measure social network size (Hughes & Walden, 1999) or a single-case study design (Bigby & Craig, 2017). Whilst the present study was not set up methodologically to be directly comparable, we found no evidence that befriending led to replacement of another social network member by the befriender. Rather, the findings suggest that, in the context of barriers to social inclusion and dependence upon family carers or others to support with participation, befriending caters to an unfulfilled requirement for additional interaction and contact. The suggestion from family carers participating in this study was that befriending positively impacted befriendees’ social networks by providing an additional person for them to have fun with and allowing carers themselves to prioritise activities they viewed as valuable for the befriendee.

4.3. Study limitations

This study had several limitations. Firstly, using convenience sampling as the method of recruitment may have impacted the representativeness of the sample, with befriendees with positive befriending experiences they wanted to share potentially more likely to self-refer to the study. Including those who had experienced the end of befriending relationships and were in-between befrienders may not have fully mitigated this self-selection bias.

Secondly, there were challenges in recruiting other participants such as befrienders or family carers, partly because befriendees did not often nominate them, and partly as many of them did not respond or dropped out during the recruitment process. As such there was limited opportunity to compare perspectives on the befriending experience or relationship between befriendees and other participants. Thirdly, demographic details such as age or ethnicity were not routinely collected for interviewees, meaning the sample was not fully situated, and that potentially relevant information was not available to contribute to the analysis or critical appraisal of the researcher's interpretations. Fourthly, though some credibility checks were undertaken, further checks such as testimonial validity checks (Stiles, 1993) were not conducted due to time constraints. Finally, due to the impact of the Covid-19 pandemic, participants were being asked to reflect on a relationship that had recently undergone significant disruption. This may have led to idealisation of pre-pandemic befriending experiences, an increased sense of reliance on or value for the relationship which may not have existed previously, or simply less accurate recall of perceptions or experiences.

4.4. Implications of findings and further research

This study illustrates the benefits befriending can bring to adults with intellectual disabilities and/or autism, not only by providing much needed 'fun' and opportunities to do enjoyable activities, but also through broader effects of becoming more independent, feeling part of something and accessing group activities and ordinary community events and experiences. The set up and scaffolding of befriending relationships by befriending schemes (e.g. through recruitment, matching, monitoring and managing endings) is an essential part of the intervention and requires ongoing financial support from commissioners.

In terms of future research, there remains limited empirical evidence around the effectiveness of befriending and as such, controlled trials measuring impact on wellbeing or social inclusion would be beneficial. Questions also remain around the longitudinal effects of befriending. This study supported existing findings that endings are a source of anxiety. However, there is a need for further longitudinal research looking at the effects of relationship endings or having multiple befrienders over time versus having a more long-term relationship. Understanding more about what works with endings, whether effects of befriending are sustained, and whether the minimum volunteer commitment of one year (common across befriending schemes) is sufficient in this population group are key areas for future research.

This study finds that befriending facilitates access to ordinary community activities, but also finds that value is placed upon being around others with disabilities. Future research into understanding the interaction of these elements and whether one-to-one befriending has the same impact as going out with multiple befriending pairs in mainstream settings would be beneficial. In this study we have included people with intellectual disabilities and/or autism who were participating in the befriending scheme. There is an even greater paucity of existing research into befriending for adults with autism when compared to the limited literature for adults with intellectual disabilities, and as such further research in this population is advised.

This study joins two other studies focusing upon befriending for people with intellectual disabilities and/or autism that sought to include people with intellectual disabilities in the design or conduct of the study (Ali et al., 2021; Heslop, 2005). This study utilised an advisory approach, calling on experts-by-experience to help prioritise, design and advise on the research process. There is a need for more coproduced and inclusive research in this area. Moving towards more of a ‘collaborative group’ approach, defined as ‘partnerships or collaborations in which people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued’ (Bigby et al., 2014, p. 8) would appear to fit well with befriending interventions in this population. Indeed, this study, which benefitted from very engaged and motivated advisors from within the befriending scheme, and which generated subthemes around having something ‘for me’ and ‘getting involved and speaking up’ mirrors the appetite for and opportunity for involvement and inclusion in future research.

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Part 3: Critical Appraisal

Introduction

A critical appraisal comprises the final part of this thesis, offering reflections on the empirical study outlined in Part 2 which sought to understand the experiences of those involved with a befriending scheme for adults with intellectual disabilities. Overall, I found the experience of completing the study incredibly rewarding and feel I have learned a great deal both professionally and personally. My aim here is to critically appraise the research process by expanding in more detail upon certain methodological issues introduced in the empirical study and by providing my personal reflections on these methodological issues and the research process as a whole.

1. Methodological issues

1.1. Sampling

The first issue identified with the sampling strategy is that use of convenience sampling may have led to self-selection bias, meaning that the sample could have been skewed towards those with more positive experiences of the scheme or those more used to talking about it with others or promoting the scheme. Whilst efforts were made to ensure the sample included some befriendees who were between befrienders (awaiting reallocation), or who had experience with multiple befrienders over the time of their involvement in the scheme, self-selection biases may still have been operating. Expanding recruitment efforts towards ‘ex-befriendees’ who were no longer engaged with the scheme may have mitigated this further. Alternatively, changes to study design and inclusion criteria, such as removing the criteria around length of relationship (at least three months prior to recruitment) and then conducting interviews at two time points, regardless of whether the befriendee was still engaged with the scheme, would have proved valuable in establishing a more longitudinal view of the relationships and potentially understanding more about unsuccessful relationships or less positive experiences.

The second issue identified with the sampling was that the methods used to identify and recruit other participants such as family carers, befrienders or professional carers resulted in far fewer interviews with this group than anticipated. Having a proportionately higher number of the interviews with people with intellectual disabilities and/or autism was positive in that it allowed opportunity to hear from more befriendee participants with intellectual disabilities themselves. However, it did mean that opportunities to compare perspectives on befriending experiences between befriendees and other participants were limited. For example, differing views on whether a befriender is viewed as a friend or a professional, or whether befriending is viewed as a positive or disruptive intervention by professional carers were not able to be explored.

In reflecting on the reasons for the different balance of interviews achieved, I firstly noted that when other participants were nominated by befriendees they were less likely to agree to take part in the study, and more likely to drop out before completing an interview if they had. Potentially they felt less invested in or connected to the befriending scheme or felt they did not know enough about it to offer an opinion, or perhaps their personal circumstances meant they had less time for research interviews and/or less interest in the incentive payment offered to compensate for their time undertaking an interview. One family carer who did participate emphasised several times that it was not always clear to her exactly which friend or group the befriendee was talking about, and that she therefore could not speak confidently about befriending in some areas, supporting the idea that carers may not have felt qualified to speak about befriending themselves. Secondly, when invited to nominate a family member, carer or befriender for further interview, many befriendees either did not identify anyone they would propose I spoke to, or instead suggested interviewing other friends of theirs with intellectual disabilities and/or autism involved in the befriending scheme. This highlighted an assumption I held, that I had not identified whilst considering the study design, either in my discussions with the befriending scheme participants or coordinators or in my personal reflections in my research diary – that adults with intellectual disabilities would be familiar with and supportive of others in their networks speaking, if not on their behalf, then at least in support or explanation of their experiences. In retrospect, this feels very presumptive and, as shown by the befriendees' choices here, many would prefer solely to engage directly themselves or to privilege the voices of others with disabilities over those without disabilities who might be perceived to be speaking 'for them'.

Future studies of this nature should carefully consider the aims of their research and the mix of participants they would need to recruit. If a more diverse sample is required, potentially inviting expressions of interest directly from carers or befrienders could increase the potential participant pool, though we note this would not address our finding that often adults with intellectual disabilities did not feel it was necessary to have anyone supplementing their own stories. An alternative approach could be to recruit befriending pairs and conduct both individual and group interviews, as has been employed in mental health befriending research (Mitchell & Pistrang, 2011). Whilst the possibility of focus groups was briefly considered in this study in order to capture perspectives from multiple befriendees at once, challenges in conducting focus groups with people with intellectual disabilities were highlighted (Kaehne & O'Connell, 2010) and more individual approaches to data collection were pursued.

1.2. Data collection

One of the major factors which impacted upon data collection was the Covid-19 pandemic. It instantaneously altered the practice of befriending, limiting face to face contact, restricting access to community activities, ruling out group gatherings. For this study, a key question became whether and when the pandemic (or more latterly the most recent 'wave' of the pandemic) would pass, enabling a return to more 'normal' ways of life, and subsequently more established befriending practices. The uncertainty around this led to some delays in finalising the study design, and decisions to delay conducting data collection in the hope that befriending could resume as before, and interviewees could comment on it as a current experience. In retrospect, we understand that there is now a 'new normal' in general ways of life and that this may mean some permanent changes for befriending interventions too (for example engaging in more informal, virtual contacts). Delaying the study may have led to data collection being conducted during a period when participants were significantly more socially isolated than previously, and therefore more reliant upon or appreciative of their befriending experiences. It may also have impacted upon recall of memories or perspectives on events and experiences that occurred prior to the pandemic.

The pandemic also impacted the data collection as it led to all interviews being conducted on Zoom or by telephone. This changed the dynamics of the interview process, with technological issues such as poor internet connection, or interruptions from others in the background often disrupting the flow of the interview. Visibility of body language and non-verbal cues, as well as pre-interview informal interactions were all restricted by use of a remote rather than an in person interview format. This impacted upon building rapport, comfort and trust with some participants interviewed, which may have influenced the answers given or the degree of depth explored. Being able to incorporate some in person interviews would, I believe, have led to more detail in some areas of enquiry.

Additionally, data collection was conducted solely by myself, meaning a reliance upon my ability to ask questions clearly, rephrase and clarify as required, and follow up appropriately. It was my first experience of clinical working or qualitative research within this population so I was keen to ensure my interview style was appropriately supportive and effective. To review and reflect upon this, early in the data collection phase I listened back to the first interviews conducted and shared transcripts with my supervisor in order to gain feedback. Together we agreed that I might be at risk of adhering too rigidly to the interview schedule and missing out on valuable elaboration. We considered adjustments to my interview technique, including asking more follow on questions not included on the schedule in response to particular points of interest and being transparent and open if I did not understand a participant's response, asking for further clarity or explanation.

Though the interview schedules were piloted with a group of befriending scheme participants with intellectual disabilities and/or autism, this was conducted by scheme coordinators who then provided feedback from the group. In future, I would want to ensure that I, as the interviewer, attended that piloting session directly, for several reasons. Firstly, it would have given me practice utilising the schedules with the population in question. Secondly, it would have enabled me to understand more fully the questions which continued to prove difficult to understand for befriendees, and the best ways of explaining these, providing extra clarification or alternative wording as necessary. As it was, I think it took me several interviews to consistently match my interview style and level of questioning with the communication and comprehension abilities of the interviewees (which varied widely).

1.3. Analysis

Overall, the decision to utilise reflexive thematic analysis was one I continue to support, as it offered a systematic, flexible approach (Braun & Clarke, 2006) that allowed for variations in level of detail from interviewees. Whilst content analysis, which emphasises the frequency of occurrence of information (Krippendorff, 2018), was considered, the richness of the data lent itself more appropriately to thematic analysis. The epistemological stance was primarily an essentialist one, and I made a conscious decision to focus upon semantic rather than latent codes and emphasise description over interpretation in the initial stages of analysis. This was driven by a combination of: my limited research experience with people with intellectual disabilities; an acknowledgement of myself as someone who does not identify as having an intellectual disability or autism; the lack of collaborative involvement from people with intellectual disabilities in the analysis process; and my own subsequent nervousness about misinterpreting or overinterpreting non-verbal or indirect information.

Reflecting back, and with the increased experience and confidence that comes with now having completed a thematic analysis of this data, taking a more critical or constructionist stance might have lent an additional layer of insight or understanding to the research findings. However, this would require addressing one of the limitations of this study which was the omission to systematically collect demographic information such as gender, age, ethnicity or social class, all of which would have helped situate the sample. The initial decision to not collect this data was driven by an abundance of caution around the anonymisation of participants and a desire for them not to be personally identifiable (in the context of there being a relatively small potential sample of befriendees with intellectual disabilities and/or autism within this befriending scheme). However, I now recognise that collecting this information would have strengthened the quality of this study and that there are ways in which collecting it could have been managed appropriately, accounting for identifiability and anonymisation.

A further consideration when looking back on the analysis process is the extent to which my preconceptions going into the study were accounted for. As detailed in the Methods section of Part 2 of this thesis, I understood that my personal experiences of relationships with people with intellectual disability, along with my indirect exposure to a befriending intervention for an older adult with mental health problems influenced the expectations I held when starting this study. These expectations were broadly that befriending in an intellectual disability population was likely to have positive benefits for all parties involved. The findings of the literature review conducted (detailed in Part 1 of this thesis) only served to reinforce this.

Throughout the data collection stage I attempted to elicit both positive and negative feedback upon the scheme, reminding participants of my neutral position as a researcher outwith the befriending scheme and including specific questions in the interview schedules about concerns, limitations, and ‘bad things’ about the scheme. This approach elicited a broad range of data on participants’ experiences, including positive and negative perspectives. Once the data had been transcribed, initial coding of the transcripts was carried out. At this stage a second researcher independently coded the first five transcripts as a credibility check to enable discussions about potential biases. This exercise found our coding of information to be highly consistent, with the exception of me omitting to code four instances of positive outcomes (pertaining to having fun and permission to make silly decisions). In supervision we reflected that I appeared to be maintaining a balanced view of the outcomes and discussed ways to continue doing that by sticking closely to the data with my coding for the remaining transcripts. A further discussion was conducted once codes had been initially grouped, articulating emerging findings and proposing initial themes and the likely relationships between them, again lending some confidence that I was not overly privileging positive outcomes. However, despite all of these measures and attempts, I must assume that my perspectives and expectations will have influenced the conduct of this study in some ways. It is not possible for qualitative research to be conducted solely to ‘give voice’ to participants without some selection, editing and deployment of evidence by the researcher (Fine, 2002), and in thematic analysis themes are actively generated by the researcher rather than passively emerging from the data (Braun & Clarke, 2006). I hope that by outlining my presuppositions, experiences and attitudes in both the empirical paper and this critical appraisal I have in some way owned my own perspective (Elliott et al., 1999) and given readers extra information with which to interpret and understand this study.

1.4. Inclusive research

From the inception of this project, it felt important to me to hear the voices of those with intellectual disabilities and to consult and include them in the research process. I was distinctly aware of my own position as someone without intellectual disabilities or autism, and my lack of experience working with this population.

I had been interested by the different approaches towards inclusive research set out by Bigby et al. (2014), outlining how people with intellectual disabilities could be included in advisory, leading and controlling, or collaborative group capacities. I was also inspired by some wonderful co-produced projects such as Charnley et al.’s (2019) paper on understanding the use of leisure time by adults with intellectual disabilities and the work by Building Bridges Research Group on what stops people with intellectual disabilities getting involved in their communities (Mooney et al., 2019).

A strength of the current study (outlined in Part 2 of this thesis) is its collaboration with participants with intellectual disabilities in deciding the study focus and design, and use of an advisory group to review and pilot materials such as information sheets, consent forms and interview schedules. However, due to resource limitations and the practical realities of the research project being conducted as part of the Clinical Psychology Doctorate (e.g. having inconsistent, part-time days to complete it around clinical placements and not having access to extensive funding or other researchers) a more inclusive approach was not possible. Moving forwards, I think it is important that, where resources allow, there is more input and leadership from people with intellectual disabilities themselves in the research that concerns them. There are challenges and considerations to be accounted for no matter which approach to inclusive research is taken, but I believe it should be a core principle that research is done ‘with’ rather than done ‘to’.

Whilst the current time constraints have limited the opportunity to conduct testimonial validity checks thus far, I hope to feedback the findings of the study to participants and scheme coordinators and gather their views as an additional form of credibility check.

2. Personal reflections on the study process

As noted above, my initial reflections were focused upon the positive expectations and biases towards befriending I may have held coming into the project. However, over the course of the research process my personal perspectives and challenges evolved. During the course of conducting the interviews and analysis I felt a great degree of pressure to get things right in order to adequately ‘give voice’ to the people I was meeting. In the process of analysis and write up I felt like I held so much information and so many opinions from many different people but was struggling to consolidate and express them. I reflected upon whether this was, to an extent, mirroring the experiences of some of the befriendees I was interviewing, who I sensed had more to say that they actually did. For me, the process of picking up a pen and paper and drawing out the emerging findings helped me to ‘unblock’ some of the pressure and move forwards with analysing and making meaning from the data. This also caused me to reflect upon the use of interviews as the route to data collection and whether incorporating other, potentially more creative, forms of discussion and discourse could have better supported some of the befriendees to participate fully.

The study itself raised a lot of emotive content, touching upon core human experiences such as isolation, belonging, acceptance, attachment and loss, and highlighting the additional challenges faced by those with intellectual disability and/or autism in these domains. I was incredibly moved by the experiences of the befriendees I spoke to, noting their strength through adversity and exclusion, and the importance of the befriending relationship to many of them. At times I found myself having quite strong emotional reactions to the study content and process, particularly as I was conducting it during a global pandemic at a time of isolation and loss for so many of us, and this sometimes made it hard to engage with and progress with. I had not previously considered the difficulties faced when studying concepts you strongly personally identify with, and which may be influencing your own engagement with the process and content. My learning here was around the value of supervision as a means to reflect, problem-solve and be contained.

Generally, I would describe my perspective as a researcher in this area as having evolved. I have a much better informed and nuanced opinion on befriending for people with intellectual disabilities but continue to hold my perspective that it is a positive intervention overall. In comparison to the nervousness I felt at the start of the study around my ability to support befriendees to participate fully and to interpret the data, I have more confidence in my role as a researcher and in the findings that I have generated from this study. I have great respect for all the participants who contributed to this study as interviewees or as advisors, and am motivated to conduct more inclusive research in my professional role moving forwards.

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Appendix A: Excerpts of Bracketing Interview

Interviewer: And do you have any initial thoughts on what you might find?

Researcher: I guess that I've spent quite a while, kind of, getting to know the charity and speaking to the directors, planning the project a bit and, you know, then I've looked through some of the literature and that has, I guess, because it's "literature" it's been evaluating something in some way and it sort of shows that schemes are generally effective… So I think I've got this preconception that the experience of being in a befriending scheme of this type will be positive for the most part. And then I think I've probably got like a slight, kind of, expectation that it will be positive in these particular ways, because that is what the charity values are and what they're aiming for and what they're promoting and things, but whether that's actually the experiences of the participants or not is a question to be found out…

Interviewer: Yeah, yeah… and like – sorry, go ahead.

Researcher: No, I was just going to say that it's one of those areas where there's not lots of research that's from the voices of the people with learning disabilities themselves and so hopefully that could be one of the really like good different parts about this project…

Interviewer: Yeah. But it sounds like because of that also there's very much this unknown like you say your preconceptions are maybe based at least partly on the research so far that's much more evaluative and saying 'yes, these are helpful', but, as you say you don't know what those individuals are going to experience… So what brought you to the topic initially?

Researcher: So, when it was presented as a potential project, there was something that was like 'Oh yes, that sounds so so interesting to me', and you know, I think that partly because the charity itself sounds really interesting. You know, it's based around music and you know I'm musical myself and I kind of really get the value of that for people, and I think that that was one element. I liked the fact that it was qualitative and I, kind of you know, I think I align slightly more with qualitative research, even though I haven't done it in a psychologically kind of informed way for many years. But I like that kind of getting people's stories and things… And, and then sort of the fact that it's working with people with learning disabilities. It's sort of an area that haven't worked in before clinically. I have a family member who has moderate learning disabilities and so I have had personal experiences with that in a sort of, you know, in a different way… I think I was a bit intrigued to like work with people, and you know kind of get to spend a bit more time with some people with learning disabilities as well as part of the project. And, yeah, I think those are the main things that attracted me to it…

Appendix B: Ethical Approval Letter

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

22nd April 2021

Dr Alana Loewenberger
Clinical, Educational and Health Psychology Dept,
UCL

Cc: Fiona Brand

Dear Dr Loewenberger

Notification of Ethics Approval with Provisos
Project ID/Title: 19277/001: Understanding experiences of a befriending scheme for people with intellectual disabilities

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **30th September 2022**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: https://www.ucl.ac.uk/srs/file/579
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Lynn Ang
Joint Chair, UCL Research Ethics Committee

Appendix C: Participant Information Sheet for Befriendees

Information about our research

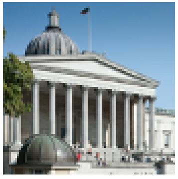
Version 2

You can ask someone you know to help you read this sheet.

We are the research team:

Alana

Fiona



We are doing research with University College London and Gig Buddies.

Research means finding out about things.

We are doing research to find out about projects like Gig Buddies for people with learning disabilities and autism.

We would like you to take part in this research.

This sheet will give you information about the research and what we will ask you to do if you want to take part.

You can talk about it with other people like your family and friends if you want.

Why we are doing this research:

Gig Buddies matches someone with a learning disability or autism with a volunteer. There are other projects that do this around the UK.

Studies have found out some of the benefits and some of the challenges of these projects.

However, we do not know very much about what is important for people and what is helpful about these projects.

The research will help us understand more about projects like Gig Buddies.

We are asking you to take part

We are asking you to take part because you are involved with Gig Buddies, a charity that works with people with learning disabilities and autism.

About the research

If you agree to take part we would set up a meeting with you.

You and one of the research team would meet up online for an interview.

An interview is having a talk with a researcher.

We would ask you some questions like what you think about Gig Buddies and what is important.

We would record your answers and write some notes so we can remember what you say.

Choosing to take part in research

You can choose if you want to take part in the research.
It's up to you.

You can say no.

If you say no to the research, you won't be treated any differently.

If you say yes to the research, we will ask you to sign a consent form.

This consent form says that you agree to take part in the research.

Changing your decision

You can stop taking part in the research up until 4 weeks after your interview.

You don't have to tell us why.

You can tell us to destroy any information that we have about you up until 4 weeks after your interview.

What we do with your answers

Your answers will be confidential. That means we don't share it with anyone.

Only the research team will see your answers.

Where we keep your answers

We will keep your answers in a locked place on a computer.

The computer will use passwords to keep your answers safe.

Your name will not be on the answers.

When we have finished the research, we let you know what the research found out.

We will not use your name in our report.

Good things about taking part

What you say may help to make projects like Gig Buddies better.

What we find through the research might help other people with learning disabilities.

We are giving people who take part in an interview a £10 gift voucher to spend on whatever they want.

Things that might be difficult

Some questions might be difficult to answer.

We will make sure that there is someone to talk to about anything you found difficult.

You can stop taking part in the research at any point.

Further information and contact details

If you have any questions or would like any more information about the research you can talk to the research team.

You can contact Fiona Brand
Email: [redacted]
Phone:

Appendix D: Consent Form for Befriendees

Consent Form

Version 1

Please tick the box if your answer is 'Yes'.

1. Have you read the information sheet or has it been read to you? ☐

2. Do you understand what the project is about? ☐

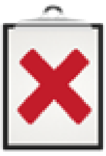
3. Do you understand the good things about taking part? ☐

4. Do you understand what might be difficult about taking part? ☐

5. Have you asked all the questions you want? ☐

6. Were your questions answered in a way you understand? ☐

7. Do you understand that your answers will be recorded? ☐



8. Do you understand that it is OK to stop the interview at any time? ☐

9. Do you understand that you can stop taking part in the research up until 4 weeks after the interview? ☐

10. Have you had time to think about if you want to take part? ☐

11. Are you happy to take part? ☐

✓ **If you want to take part, please sign below:**

Name:______________________________________

Signature: _____________________________________

Date:_______________________________________

✗ **If you don't want to take part, you don't have to sign.**

Appendix E: Information Sheet for Family, Carers and Befrienders

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL
AND HEALTH PSYCHOLOGY

INFORMATION SHEET for Family, Carers and Befrienders

UCL Research Ethics Committee Approval ID Number: 19277/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Understanding experiences of a befriending scheme4 for people with learning disabilities

Department: Clinical Education and Health Psychology
Researcher details: Fiona Brand (fiona.brand.19@ucl.ac.uk),
Principal Researcher details: Dr Alana Loewenberger (alana.loewenberger.09@ucl.ac.uk)

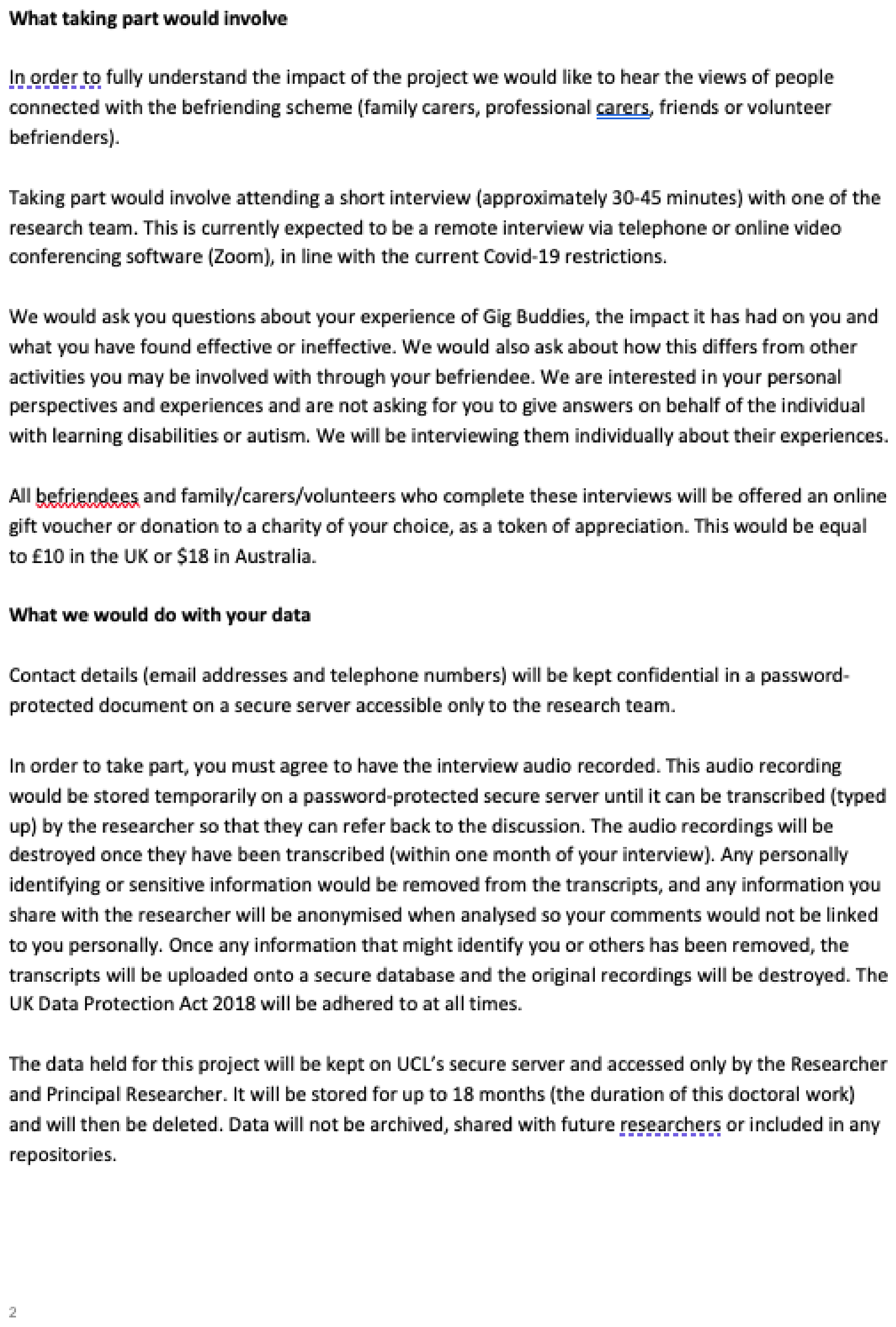
You are being invited to take part in a research project. Before you decide it is important for you to understand why the research us being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

About our research

We are a research team from University College London (UCL) doing some research in collaboration with Gig Buddies. The project seeks to understand experiences of involvement in befriending schemes, where someone with a learning disability or autism is matched with a volunteer in a befriender/ befriendee relationship. Whilst there is limited existing research into the challenges and benefits of such schemes, there is relatively little known about the impact they can have for the people with learning disabilities and for their broader networks.

As the identified relative, carer or befriender of someone involved with the Gig Buddies project you have been nominated by them as a potential source of further information.

We are requesting your involvement in this study. Your participation is entirely voluntary.



What taking part would involve

In order to fully understand the impact of the project we would like to hear the views of people connected with the befriending scheme (family carers, professional carers, friends or volunteer befrienders).

Taking part would involve attending a short interview (approximately 30-45 minutes) with one of the research team. This is currently expected to be a remote interview via telephone or online video conferencing software (Zoom), in line with the current Covid-19 restrictions.

We would ask you questions about your experience of Gig Buddies, the impact it has had on you and what you have found effective or ineffective. We would also ask about how this differs from other activities you may be involved with through your befriendee. We are interested in your personal perspectives and experiences and are not asking for you to give answers on behalf of the individual with learning disabilities or autism. We will be interviewing them individually about their experiences.

All befriendees and family/carers/volunteers who complete these interviews will be offered an online gift voucher or donation to a charity of your choice, as a token of appreciation. This would be equal to £10 in the UK or $18 in Australia.

What we would do with your data

Contact details (email addresses and telephone numbers) will be kept confidential in a password-protected document on a secure server accessible only to the research team.

In order to take part, you must agree to have the interview audio recorded. This audio recording would be stored temporarily on a password-protected secure server until it can be transcribed (typed up) by the researcher so that they can refer back to the discussion. The audio recordings will be destroyed once they have been transcribed (within one month of your interview). Any personally identifying or sensitive information would be removed from the transcripts, and any information you share with the researcher will be anonymised when analysed so your comments would not be linked to you personally. Once any information that might identify you or others has been removed, the transcripts will be uploaded onto a secure database and the original recordings will be destroyed. The UK Data Protection Act 2018 will be adhered to at all times.

The data held for this project will be kept on UCL's secure server and accessed only by the Researcher and Principal Researcher. It will be stored for up to 18 months (the duration of this doctoral work) and will then be deleted. Data will not be archived, shared with future researchers or included in any repositories.

What will happen to the results of the research study

The research findings will be written into academic reports, presentations and reports which might be published, within the UK or internationally. It will not be possible to identify any of the individuals who take part in the study from the reports, as all the information will be anonymised, with information from many individuals grouped together.

LOCAL DATA PROTECTION PRIVACY NOTICE

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice for participants in health and care research studies.

The categories of personal data used will be the name of the organisation through which the person participates in this research, participant name and contact details. The lawful basis that will be used to process this personal data is 'Public task' for personal data. The lawful basis used to process special category personal data will be for research purposes.

The data will be processed so long as it is required for the research project (up to 18 months). If we are able to anonymise or pseudonymise the personal data provided we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how personal data is being processed, or if you would like to contact us about your and/or the rights of the participants you are supporting, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Complaints

If you have any concerns or complaints about the way the research is being managed you can contact Fiona Brand in the first instance at fiona.brand.19@ucl.ac.uk. If you wish to escalate your complaint you should email the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk

Choosing to take part in the research

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way.

If you do decide to take part, you are still free to withdraw up to 4 weeks after taking part in the interview and without giving a reason. Please note, your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you wish to withdraw from the study, please contact the research team. We will keep the information about you that we have already obtained but it will not be used in the study. To safeguard your rights, we will use the minimum personally identifiable information possible.

- If you would be happy to take part in an interview you will need to complete our online Consent Form (via Qualtrics). This involves ticking some boxes online to signal your consent to take part and providing your contact details so the research team can get in touch.
- If you do not wish to be contacted you do not need to complete the Consent Form.

Further information and contact details

If you have any questions or would like any more information about the research you can talk to the research team.

Please contact Fiona Brand (Clinical Psychology doctoral student at UCL)

Email: fiona.brand.19@ucl.ac.uk
Phone: +44 7724 831 491

Thank you for reading this information sheet and for considering taking part in this research study.

Appendix F: Consent Form for Family, Carers and Befrienders

**RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL
AND HEALTH PSYCHOLOGY**

CONSENT FORM for Family, Carers and Befrienders

Understanding experiences of a befriending scheme for people with learning disabilities

Department:	Clinical Education and Health Psychology
Researcher details:	Fiona Brand (fiona.brand.19@ucl.ac.uk),
Principal Researcher details:	Dr Alana Loewenberger (alana.loewenberger.09@ucl.ac.uk)
Data Protection Officer details:	data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee. Project ID number: 19277/001

Thank you for taking the time to read the study information sheet and considering taking part in this research. Before you agree to take part, we want to ensure that you understand the study and what taking part in an interview involves so the person organising the research must explain the project to you before you agree to take part.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

	Tick box
I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me by taking part. I have also had the opportunity to ask questions which have been answered to my satisfaction.	
I understand that in order to take part in the study I must agree to the interview being audio-recorded. This recording will be password-protected and kept on a secure server until it is transcribed by the researcher (within one month of the interview). It will then be destroyed.	
I understand that any personally identifiable or sensitive information will be removed from the transcriptions. Transcriptions and contact details will be password-protected and stored on a secure server accessible only to the research team. This data will be stored for up to 18 months and then deleted.	
I understand that all personal information will remain confidential and that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	
I understand how my information will be processed and have read and agree to the 'Local Data Protection Privacy Notice' detailed in the Information Sheet.	
I understand that my personal information (name, contact details and responses to interview questions) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing personal data and 'research purposes' will be the legal basis for processing special category personal data.	
I understand that I can contact the data protection team at UCL (data-protection@ucl.ac.uk) if I have any concerns about how personal data is being processed.	
I understand that if I have any complaints about the way the research is managed I can contact Fiona Brand (fiona.brand.19@ucl.ac.uk), or escalate to the Chair of the UCL Research Ethics Committee (ethics@ucl.ac.uk).	
I understand that taking part is entirely voluntary and that I can decide at any time that I no longer wish to take part in the interview.	

I understand that I can withdraw my data from the study up until 4 weeks after taking part in the interview. Information already obtained would be kept but not used in the study.	
I understand that I can choose not to answer a question or to withdraw from the interview or from the study without having to give a reason.	
I consent to participate in the study and agree to be contacted by the research team to take part in an interview.	

Signed: ________________________ Date: ______________

Name: ____

Phone number: ____

Email address: ____

Preferred method of contact (please tick): Telephone ☐ Email ☐

The name of the gig buddy who I know is: ______________________

Thank you for taking the time to complete this form.

Appendix G: Excerpts of member input to research questions

Survey ID	What do you think we should be talking about? What would you like us to know or find out?	We might also talk to family members or support staff about Gig Buddies. What do you think we should ask them?
1	The friendships is important to me. I enjoy the social events. Would like some more quieter social events. Possibly activities or classes (such as painting/ crafting things) go out to shows and to see films	
2	Different gigs that gig buddies could go to. More opportunity's to go to other live gigs like Glastonbury with gig buddies. Job opportunities for people with learning disabilities. Different ways of some gig buddies getting the opportunity to get their ideas out there to the wider audience if they would like to. Opportunities for buddys and gig buddy's to go to gigs and meet their idols.	What gigs have you enjoyed? Have you enjoyed being a gig buddy? Are you enjoying gig buddys? Are there any gigs you'd like gig buddies to be involved in?
3	How it started up Talk to LGBTQ people with learning difficulties about what they do How to get more buddies/ volunteers How to match people together	How the group started up
4	If we could go out for day trips like for instance to a zoo or better still for a picnic.	"How long they have been a gig buddy for? Why do they want to be a gig buddy "
5	I like GB because I feel I have a special friend who takes out to do things I enjoy	Anything you would want to.
6	It is different from other things I do as I have someone to do the things with and go places with. It's about having a friend, companion and getting out to socialise. The only thing is they haven't matched me up with the right person. I'm bubbley, love having a laugh. The buddy I have is quiet and not compatible but I'm grateful to have a gig buddy. I think they should do a trial first with matching up people. Not assume or guess somebody will be a good match. Also think it should be a weekly meeting up and not once a month. Someone like me whose stuck indoors and has no friends, no help or local support.	
7	Gig Buddies is for autistic people too, so don't leave us out!	

Appendix H: Interview Schedules

Interview schedule for people with Intellectual Disabilities

Confirm that consent has been provided to be interviewed and recorded.
Confirm that recorder is switched on.

Orientation to topic

We're here to talk about projects like Gig Buddies where someone with a learning disability gets paired up with a volunteer. All the answers you give will be kept safe by me and the research team and will not be shared with anyone else.

- Do you have a gig buddy at the moment?
- What do you do with your gig buddy?
- To help me get a picture, can you tell me about a gig you've gone to with your buddy?

Impact of participating in a befriending scheme

What do you think about having a gig buddy? Is it a good thing or a bad thing? Why do you say that?
Possible prompts:

- *Is having a gig buddy important in your life? [Why do you say that?]*
- *What do you like about it?*
- *What do you not like about it?*

Has having a gig buddy changed things in your life? In what way?
Possible prompts:

- *Do you do anything differently?*
- *Do you speak to different people?*
- *Do you feel any differently?*

Mechanisms of change/ 'active ingredients'

What is important for you about having a gig buddy?
Possible prompts:

- *Relationships – Is your relationship with [befriender] different to other people?*
- *Decision making – Is there a difference in who gets to make the choices?*
- *Shared interests – Are you interested in the same things as your gig buddy?*
- *Community – Does having a gig buddy connect you with different communities?*
- *Virtual vs. in person – Does it feel different if you meet up in person or online?*

What is **most** important for you about having a gig buddy? *Summarise answers above/offer choice.*

Differences between befriending and other activities

What other activities do you do in your spare time?
Possible prompts:

- *Clubs, sports, going out, seeing people?*
- *Are you involved with any other projects where you are paired with a volunteer?*

How is Gig Buddies different to these?

Potential improvements

What would make Gig Buddies better?
Is there anything else you'd like to be doing with your gig buddy?

Conclusion

Is there anything else you'd like to tell me or think I should know?

Interview schedule for other participants (carers/family/befrienders)

Confirm that consent has been provided to be interviewed and recorded.
Confirm that recorder is switched on. Confirm confidentiality.

Orientation to topic

Our research is looking at befriending schemes, like Gig Buddies, where someone with a learning disability gets paired up with a volunteer. We're interested in your perspective on the impact & effectiveness of these schemes.

- Can you tell me about your relationship to the Gig Buddies befriending scheme?
- How long has it been for? Has it changed over time?
- What kind of involvement/connection do you have currently?
- Have you ever had involvement with any other befriending schemes? *(If so, what?)*

Impact of involvement in a befriending scheme

What impact has involvement with a befriending scheme had on you personally?
Possible prompts:

- *Has it meant you spend your time differently?*
- *Are there particular benefits or challenges it presents for you?*
- *Have there been any changes in your relationships?*
- *Have you noticed any direct/ indirect effects on [befriendee]?*

Would you say engaging with a befriending scheme has a positive or negative effect on your life?

- *In what ways?*

Did you have any expectations or concerns about engaging with the befriending scheme beforehand?

- *What were these? How do you think/feel about those now?*

Mechanisms of change/ 'active ingredients'

What do you think is important for a befriending scheme?
What is **most** important for you in a 'successful' befriending scheme?

Differences between befriending and other activities

From your perspective, what are the differences between befriending (such as Gig Buddies) and other activities that [befriendee] is involved in? What are the similarities?

[For befrienders specifically]:

- Did you consider or have experience of other forms of volunteering, engaging in leisure activities or befriending with people with learning disabilities?
- How does befriending compare to these other options?

Potential limitations/improvements

Is there anything else you think a befriending scheme should be providing or considering?
What would make the befriending scheme better?

Conclusion

Is there anything else you'd like to tell me or think I should know?

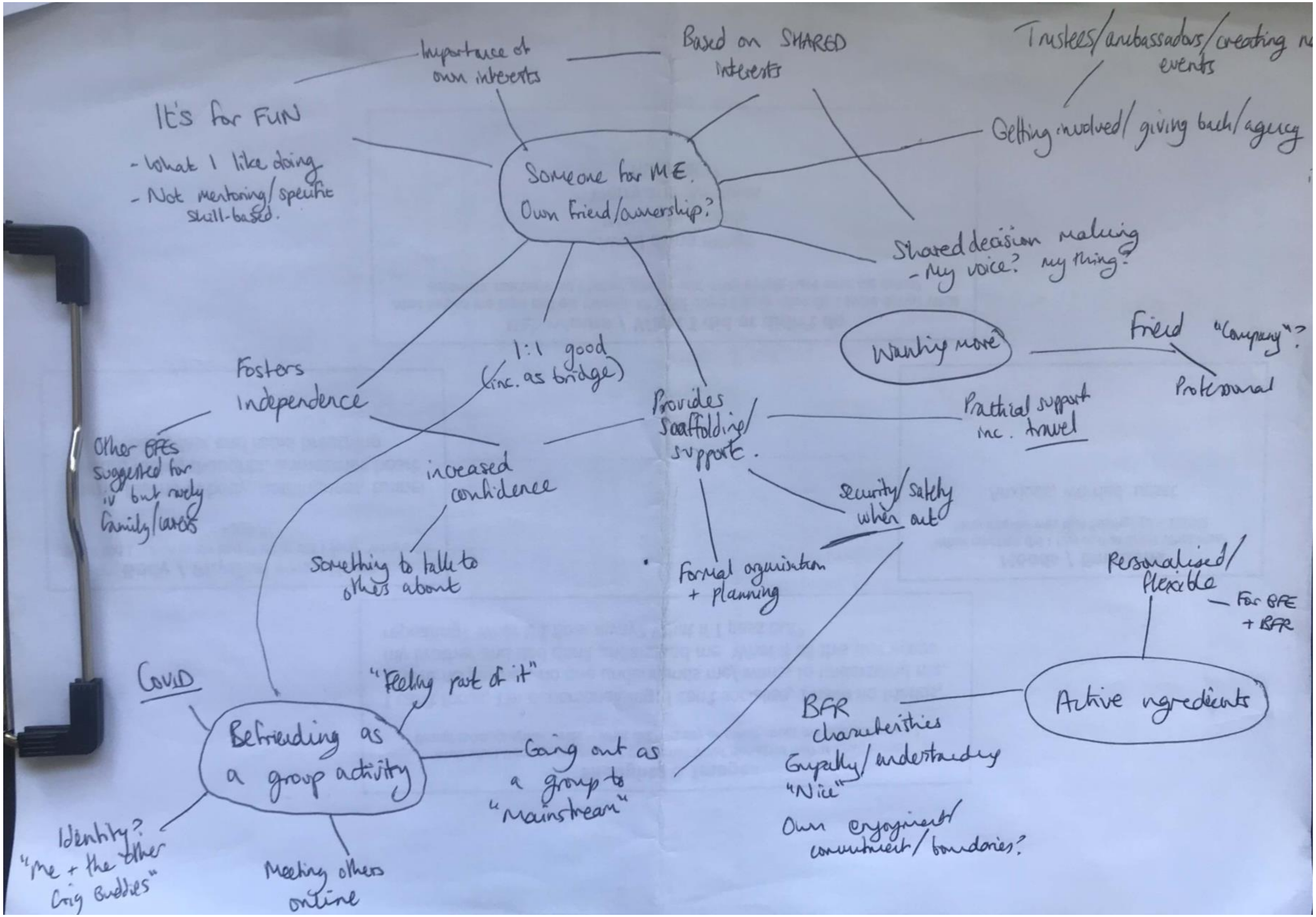
Appendix I: Example of transcript coding

[P5]: I think it's a great thing, you know. I'll be really honest I really struggled with social situations and coming out of my shell a lot. I kind of retreated into myself and Gig Buddies was a great way for me to just be myself and live a little to be honest.	Can be myself; BFing increases confidence or independence; BFR supports with social anxiety or awkwardness;
[R]: Mmhmm. Yeah, okay, interesting so that, that sort of recognising that there was some situations that you found, that you were finding quite difficult. And, what do you think it is about gig buddies that's helped with that and helped you feel a bit more comfortable?	
[P5]: Well, because of, because of my learning disability and also my physical disability, I always felt like the old one out in a situation, like I was the one that sort of stood out a little bit in the wrong way. But in Gig Buddies you're surrounded by people who go through similar experiences so you can relate to them, you don't feel weird or uncomfortable or anything like that.	Felt like odd one out; can relate to other befriendees
[R]: Mmmm. OK, OK. Yeah, and so would you say that having [Befriender] as you Gig buddy is important in your life?	
[P5]: Absolutely it's always helpful to have someone you can. not only just hang out with but also just talk with as well.	BFR provides company; BFR someone to talk to
[R]: And sort of, I guess thinking about being able to hang out with [Befriender]. What do you find different about hanging out with him versus other people?	
[P5]: Well, I think, there is no judgement with [Befriender], when when my learning disability makes me do something others would consider strange, [Befriender]'s just like 'yeah, that's cool', and they don't seem to mind it, which I find very refreshing actually.	BFR is non-judgemental and accepting
[R]: So that sort of lack of judgement that he, that he brings... And would you say that's different from relationships with other people?	
[P5]: In some situations, yeah, it's nice to have that lack of judgement.	
[R]: Yeah yeah okay great. And so that's sort of, some of the things you like about having a gig buddy. Are there any things you don't like about it?	
[P5]: Not really, actually. It's been a really good experience.	BFing a good thing
[R]: Good to hear that. Umm. And, would you say that having a gig buddy has changed things in your life?	

[P5]: It has, it's made me more open and outgoing and sort of, it's living a bit more because I know that if I can do it in these kinds of situations, with Gig Buddies, with [Befriender], I can do it in other places as well, and it's sort of brought me out of my shell a little bit.	BFing experiences knock on to other situations BFing increases confidence
[R]: OK, great so being more open and kind of being brought out of your shell. Can you sort of tell me a little bit about what life was like before you came to Gig Buddies?	
[P5]: Um, I was a very solitary individual of that makes sense. I liked to do a lot of things by myself cause that was where I felt I wasn't getting judged for doing things differently from others, and I felt like it was the only place I could be me was on my own. Well with Gig Buddies I realised, you know, you can just be yourself around everyone, and these, both the staff, and the participants, oh and the volunteers for that matter are very welcoming, very understanding, very open, there's no judgement there, it's really nice.	Previously was solitary as felt different to others; BFR positive characteristics; BFing staff nice; talk to other BFEs
[R]: Mmmm OK, yeah, that, that's really good to hear. And so, sort of again, having like no judgement but having it from various different people, the different people you kind of meet there. [Yeah] And it's interesting what you say there, that you know maybe before you were keeping to yourself, you know a bit more and feeling that you had to be on your own to be your real self [yeah] for a bit...	
[P5]: Almost like I had to hide stuff there a lot.	
[R]: Mmm. OK. Who did you talk to before before gig buddies came along? Who were the sort of key key relationships and people in your life?	
[P5]: Well, no romantic relationships, I was single, still am. Just some friends from the [organisation] which is another organisation I'm a big part of. I've spent a lot of years of my life with them, so I got quite close with them over the years. And, I still keep in touch with people, and before Gig Buddies came along they were my primary source of things and, Gig Buddies has sort of inspired me and given- given- given- me the confidence I should say to reach out to new people outside of that, Gig Buddies bubble and potentially develop some relationships with them.	Other leisure interests; specific interest involvement; BFing leads to expanding social groups BFing knock on to other situations
[R]: Great okay. So sort it's been Gig Buddies itself, but then actually expanding your community beyond the [organisation], beyond Gig Buddies, even sort of further.	
[P5]: Yeah	
[R]: Great, great stuff and so I guess it does seem like it sort of	

changed how many people you are speaking to? It's kind of expanded that?	
[P5]: Yeah, it has.	BFR someone to talk to
[R]: Mmm. And then, and I guess, does it change the sort of things that you talk to about, talk, talk to people about?	
[P5]: Yeah, it has, yeah, it does actually because with Gig Buddies, you get to do some really cool events and go to some really cool places. And you get a story out of those events, so you can tell people, where you've been, what you've done, who you got to meet, those kind of things.	Going out with BFR, doing things; BFing provides experiences to talk to others about
[R]: Do you feel as though they are kind of, there's a difference in who you confide in or I don't know about, whether [Befriender] is someone that you feel like you confide in a different way?	
[P5]: I do, I do confide in him, I feel like I can be comfortable with him to be very open and honest with him so, there are a lot of things in my personal life that I talk with him about.	BFR someone to talk to; BFR nonjudgemental accepting
[R]: Mmmhmm. OK. Great, and so I guess then thinking about sort of some of the active ingredients of having a gig buddy... What's the sort of most important things? Umm. It sounds as though you've kind of said that the relationship with [Befriender] is a bit different to with other people, but could you describe that a bit more for me?	
[P5]: Yeah, of course, so umm. I, with [Befriender], as I said, no judgement, some of my quirks and mannerisms to others can be a little strange and some people view it as a joke, that's fine. With [Befriender] he just he just accepts it's part of me. It's something he does and there's no judgement there so. And I think a big active ingredient of Gig Buddies is just accepting people for who they are, what goes on there. No viewing it as a joke or something to mock, or anything like that...	Feeling mocked by others in the past; BFR accepting; BF scheme accepting
[R]: And being with the Gig Buddies 'crew', I guess kind of sort of more broadly with [Befriender], and sort of more generally - Has it how you feel or how you act when you're out in different places in, in different gig venues, in different areas?	
[P5]: It has actu-, it has, yeah. As I said, I used to be almost ashamed of what I had, I felt like I had to hide it but now I'm at peace with it in a lot of ways. I just sort of have it out, and if people are turned off by it, that's their problem, I don't feel I should have to change who I am for someone else.	Become more accepting of own disability Can be myself

Appendix J: Early thematic map


Importance of own interests
Based on SHARED interests
Trustees/ambassadors/creating n
events
It's for FUN
- What I like doing
- Not mentoring/specific skill-based.
Someone for ME.
Own friend/ownership?
Getting involved/giving back/agency
Shared decision making
- My voice? my thing?
Wanting more
Friend
"Company"?
Professional
1:1 good
(inc. as bridge)
Fosters independence
Provides scaffolding/support.
Practical support inc. travel
Other BFEs suggested for it but rarely family/carers
increased confidence
Security/safety when out
Something to talk to others about
Formal organisation + planning
Personalised/flexible
- For BFE + BFR
COVID
"Feeling part of it"
Befriending as a group activity
Going out as a group to "Mainstream"
Active ingredients
BFR characteristics
Empathy/understanding
"Nice"
Own enjoyment/commitment/boundaries?
Identity?
"me + the other Gig Buddies"
Meeting others online

Appendix K: Early code categorisations

Impact/ effects/ outcomes?

Effects for me

- BFing makes me calmer and relaxed
- BFing makes me happy
- BFing has changed my mental state
- BFing may have improved social skills - query

Effects for others

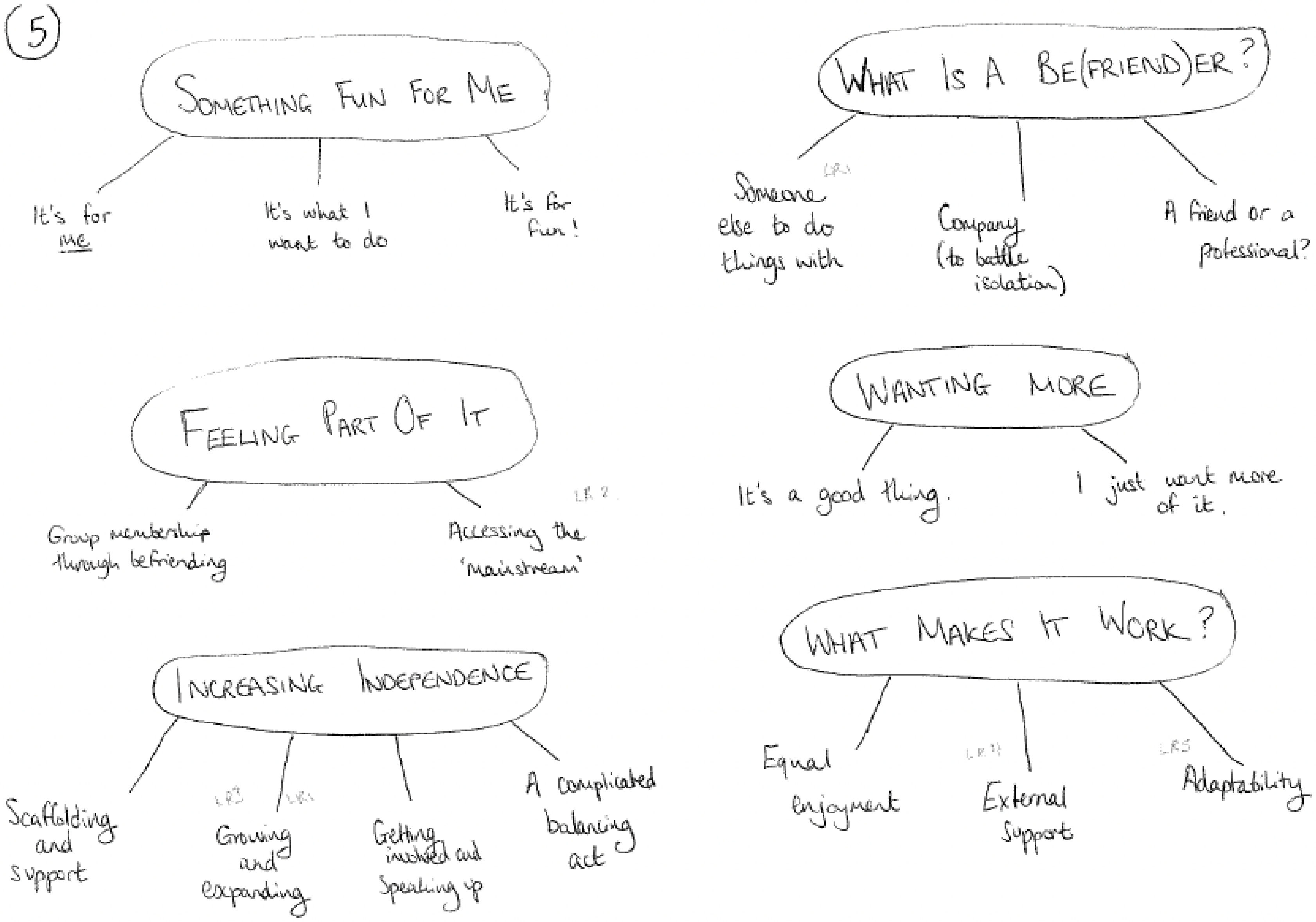
- BFE has support from others outside of BFing
- Hard to separate effect of BFing vs other activities or support
- BFR BFE meet each others families
- BFing means family or carers can be more selective in activities they do
- BFing mean family can do other things themselves
- BFing takes the pressure off family or carers to do everything

Active ingredients/ what is important?

- Trust between all parties (BFE, BFR, family) is important
- Most important thing - count and keep
- BFR experience with or understanding of disability important
- Staying in touch regularly is important
- Location is important
- Location is important\Location impacts how often meet up
- It's important to get on with your BFR
- Trust between all parties (BFE, BFR, family) is important
- Importance of BFR being nice
- BFing scheme staff nice
- BFing scheme staff passionate and enthusiastic
- Empathy and understanding most important

Inclusion of people with intellectual disability	
	BFing link to broader LD community
	Good to be around others with disabilities
	Inclusion, empathy and understanding in mainstream community settings important
	Inclusivity and accessibility important
	Motivated by annoyance at how people with disabilities treated at gigs
	Disability specific activities foster understanding and relatability
	Disabled people excluded or not present in 'normal' clubs
	Mainstream vs LD specific activities
What is a friend?	
	Permission to make bad decisions
	BFR interest and enjoyment also important
	BFing = friendship
	BFing = friendship\BF matching leads to friendship
	BFing falls in between family and professional support
	BFE doesn't understand relationships as well, and may not distinguish BFR from other rels
	BFE expectations of BFing relationship can be unrealistic
	BFR doesn't count as a friend
	Dependent on BFR availability
	Being a BFR a responsibility. Can be frustrating. Part of the job.
	BFR not allowed to drink alcohol when BFing
	Importance of external support for BFing friendship
	Keep BFR and other friends separate
	Staying in contact via messaging apps
	Tension between peer friendships being difficult but BFing or similar not being friendship in same wy
	BFR seen as mature senior figure
	Experience of BFR being late or unreliable
	Volunteer expenses a consideration
	Friends and family better than BFR

Appendix L: Later thematic map


5
SOMETHING FUN FOR ME
It's for me
It's what I want to do
It's for fun!
WHAT IS A BE(FRIEND)ER?
LR1
Someone else to do things with
Company (to battle isolation)
A friend or a professional?
FEELING PART OF IT
LR2
Group membership through befriending
Accessing the 'mainstream'
WANTING MORE
It's a good thing.
I just want more of it.
INCREASING INDEPENDENCE
LR3
LR1
Scaffolding and support
Growing and expanding
Getting involved and Speaking up
A complicated balancing act
WHAT MAKES IT WORK?
LR4
LR5
Equal enjoyment
External Support
Adaptability