# ORIGINAL ARTICLE

# Understanding experiences of 'Gig Buddies': A befriending scheme for people with intellectual disabilities

Fiona Brand | Katrina Scior 🖻 | Alana Loewenberger

Research Department of Clinical, Educational and Health Psychology, University College London, London, UK

#### Correspondence

Fiona Brand, Central and North West London NHS Foundation Trust, London, UK. Email: fiona.brand.19@ucl.ac.uk

### Abstract

**Background:** Research into befriending for people with intellectual disabilities is limited. This study aimed to explore the impact, mechanisms of change, and limitations of a befriending scheme for adults with intellectual disabilities and/or autism.

**ARID** 

bild

WILEY

**Methods:** Participants were recruited using convenience sampling. Thirteen individuals with intellectual disabilities and/or autism were interviewed and data thematically analysed.

**Results:** Four themes were generated: 'Something fun for me'; 'A good connection'; 'Increasing independence'; and 'A life less quiet'. Befriending had direct benefits through the activities undertaken and the befriending relationships themselves being fun and reducing isolation. Befriending facilitated belonging, improved 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, supporting existing literature and revealing new information from the voices of participants with intellectual disabilities themselves.

> 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 con-

ditions. Meta-analysis suggests an overall improvement in patient-

adults with intellectual disabilities and/or autism indicates broadly posi-

tive outcomes (Brand et al., 2023). Befriending increases participation

in community-based activities, expands 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). 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,

The limited research that exists on befriending interventions for

reported outcomes, albeit with a small effect size (Siette et al., 2017).

### KEYWORDS

befriending, community participation, friendship, intellectual disabilities, social inclusion, thematic analysis

# 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 (Dean & Goodlad, 1998) is one intervention that aims to increase social inclusion, develop relationships 2005; Southby, 2019). Ali et al.'s (2021) pilot randomised controlled trial considered how befriending could impact symptoms of depression and social outcomes, showing some reduction in depression scores, though problems with recruitment and retention meant statistical analysis was limited. Fyffe and Raskin (2015) highlight that even short-term 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.

Many befriending schemes aim to foster social inclusion, defined as the interaction of interpersonal relationships and community participation (Simplican et al., 2015). However, Heslop (2005) reports that fewer than a fifth of the befriending activities identified in her study specifically increased social inclusion, with many activities homebased, or community-based but with limited interaction with others (e.g., going to the cinema). Southby (2019) also made the distinction between activities located in community settings but carried out 1-to-1 by befrienders and befriendees and activities undertaken collectively as part of, for example, a team with other people. Whilst befriending does seem to foster new interpersonal relationships between befriender and befriendee, 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.

The mechanisms of change of befriending interventions in this population are not yet understood. Research into mental health befriending suggests that empathy, safety, and spending time together (either passively or engaging in activities and talking) as well as experiencing a new type of 'healthy' relationship were seen as particularly important in eliciting change (Cassidy et al., 2019; Mitchell & Pistrang, 2011).

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 it increases social inclusion, and the effects of befriending relationships ending. Additionally, 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.

Gig Buddies is a volunteer befriending project for adults with intellectual disabilities started by the charity Stay Up Late in 2012. The aim of Gig Buddies is to enable people with intellectual disabilities to develop new friendships and skills around their interests, thereby reducing social isolation and loneliness commonly experienced by people with intellectual disabilities (Gilmore & Cuskelly, 2014). This study sought to hear the perspectives of adults with intellectual disabilities and/or autism involved with Gig Buddies, 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 to members of Gig Buddies to gather feedback on the proposed study focus and to elicit further suggestions. Eleven responses were received from adults with intellectual disabilities and/or autism, which were fed into the research questions and study design. The final research questions were:

- What are the experiences of Gig Buddies from the perspectives of participants with intellectual disability and/or autism?
- What are the mechanisms of change that contribute to these experiences?
- What are the limitations and what could be improved?

## 2 | METHOD

### 2.1 | Participants and interview procedures

Participants were recruited from Gig Buddies, a project providing befriending for adults with intellectual disabilities and/or autism across the United Kingdom and internationally. Participants were recruited using convenience sampling, offering fair access to any eligible Gig Buddies participants who wanted to take part, with study advertisements distributed through Gig Buddies' media channels. Inclusion criteria for participants were having an intellectual disability and/or autism and either having had regular monthly contact with a befriender for a minimum of 3 months or awaiting reallocation having previously had a befriender.

The Gig Buddies befriending project is open to any person with an intellectual disability and/or autism. The project aims to be inclusive, and whilst no formal diagnoses are required to join the project, staff meet with the individual (and usually a carer or family member) prior to assigning a befriender to ensure they meet the inclusion criteria. This study therefore did not record participants' specific diagnoses.

Potential participants were provided with a study information sheet and a consent form in Easy Read accessible format, and were given opportunities to ask the researcher questions about the study before providing informed consent. Participants were invited to discuss the study with carers/supporters and to have someone accompany them for the interview if this made them feel more comfortable. If they were accompanied in their interview, carers/supporters were instructed to not answer on behalf of participants, but were invited to provide clarity on questions as needed, and offer emotional and practical support.

TABLE 1 Overview of participant characteristics.

Participant ID	Approximate age	Gender	Location
P1	20s-30s	Female	Southern England
P2	20s-30s	Male	Southern England
P3	20s-30s	Male	Southern England
P4	20s-30s	Female	Southern England
P5	20s-30s	Male	Australia
P6	20s-30s	Female	Australia
P7	20s-30s	Female	Australia
P8	30s-40s	Female	Central England
P9	20s-30s	Female	Southern England
P10	20s-30s	Male	Southern England
P11	50s-60s	Male	Central England
P12	20s-30s	Male	Scotland
P13	20s-30s	Male	Scotland

Semi-structured interview schedules were developed with input from members of Gig Buddies, and were tested by their 'quality checking' team for relevance and ease of answering, leading to revision of some questions. Questions included:

- To help me get a picture, can you tell me about a 'gig' you've gone to with your buddy?
- What do you think about having a gig buddy?
  - What do you like about it?
  - What do you not like about it?
- · How has having a gig buddy changed things in your life?

Interviews, which lasted between 25 and 50 min, were conducted via video call and were audio-recorded. In total, 13 participants with intellectual disabilities and/or autism were interviewed (see Table 1).

Interviews were conducted during the Covid-19 pandemic, between July 2021 and February 2022. Periodic national or regional lockdowns had taken place from March 2020 onwards and participants faced restrictions on travel, attending events and socialising even when these were lifted. Restrictions varied by region—in England most legal limits on social contacts were lifted in July 2021, whilst at the same time New South Wales in Australia entered a new 4-month lockdown.

Ethical approval was granted by the first author's institutional ethics committee (Project ID: 19277/001).

# 2.2 | Analytic procedures

Interviews were manually transcribed and analysed by the first author. An inductive, data-driven approach to analysis was intended, taking an essentialist stance that assumed the experiences and meanings reported by the participants reflected their reality. The first author's JARID

personal perspectives and theoretical positioning were considered throughout, acknowledging that her views would impact upon design, conduct and analysis of the study (Braun & Clarke, 2021). As a white British female without intellectual disabilities or autism having never had involvement in a befriending scheme she identified both similarities and differences with interviewees. Reflecting on personal experiences and clinical work enabled some understanding of presuppositions and biases and informed attempts to minimise these by engaging in credibility checks and reflective discussions with the third author throughout the research process.

Transcripts were analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2021), with NVivo Version 12 used to complete coding and organisation of the data. Following familiarisation and initial noting, the first author systematically worked through each transcript coding data relevant to the research questions. Initial themes were generated by sorting the codes into potential themes, sub-themes and recurring codes. These were visually mapped to identify relationships and patterns in the data. Initial themes were then reviewed against the collated extracts 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). Themes were named and defined and core narrative and extracts were identified.

As a credibility check the third author independently coded 30% of the transcripts at the early stages of analysis. 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 all authors discussing, iterating and agreeing upon the final themes generated.

In the United Kingdom, the term 'learning disability' is commonly used instead of 'intellectual disability' hence some participant quotes below use this terminology.

# 3 | RESULTS

During the analysis four main themes were generated, each with several sub-themes. In order to give a sense of the relative importance of themes across interviews, themes are listed in Table 2 alongside their frequency count.

# 3.1 | Something fun for me

# 3.1.1 | It's what I want to do

For all participants, befriending was about being able to choose what activities they wanted to engage in, by making plans collaboratively with their befriender, or making a decisive choice themselves.

### TABLE 2 Overview of themes and sub-themes.

Main themes	Sub-themes	n
Something fun for me	It's what I want to do	13
	It's for me	8
	It's for fun	6
A good connection	The importance of shared interests	10
	Belonging to a group	13
Increasing independence	Safety and support	11
	Bridging new experiences and relationships	10
	Getting involved and speaking up	8
A life less quiet	Threat of isolation	13
	Someone else to do things with	13
	A friend or a professional?	11
	A welcomed intervention	13

*Note:* n = the number of participants referencing each sub-theme.

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

(BFE12)

For some, this contrasted with other areas of their lives where 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 have my own decision.

(BFE4)

I'm one of these girls that want to be outside and doing things to make me happy, not what makes my Mum and Dad [happy].

(BFE8)

## 3.1.2 | It's for me

One-to-one pairing enabled person-centred relationships between befriender and befriendee, based on mutual understanding.

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 viewed as being more flexible and personalised than attending group activities, and several participants noted that befriending enabled them to be themselves and not be judged, comparing this to other life experiences.

Some of my quirks and mannerisms to others can be a little strange... [Befriender] just accepts its part of me...

I think a big part of befriending is just accepting people for who they are—not viewing it as a joke or something to mock, or anything like that.

(BFE5)

# 3.1.3 | It's for fun

The enjoyment gained from befriending was highlighted by the majority of participants. Gig Buddies was seen as an opportunity to have fun, and to have fun together.

I think it is just fun to be out with person and just being, talking to the person you can talk to.

(BFE2)

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.

> We go to the cinema or a night out in a club or we go to exciting gigs... it's about having a lot of good time and a lot of fun.

> > (BFE13)

### 3.2 | A good connection

### 3.2.1 | The importance of shared interests

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 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.

Having shared interests was seen as a conduit to greater understanding and connection between befriender and befriendee, ensuring activities were enjoyable for both parties and distinguishing befrienders from less personalised support.

If the befriender didn't like the same stuff you like, there's no point in having them really.

(BFE12)

### 3.2.2 | Belonging to a group

Group socials, trips and events organised by the befriending scheme contributed to a sense of belonging and identity as a member of a broader intellectual disabilities community.

TABLE 3	Activities undertaken by befriending pair	s.
---------	---	----

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

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

Some noted the benefits of being around peers with disabilities, such as an increased ability to understand each other's experiences and to feel included in certain situations. However, there was also an expressed wish for more acceptance within ordinary community settings.

> Because of my learning disability and also my physical disability, I always felt like the odd one out in a situation... 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.

(BFE5)

### 3.3 | Increasing independence

# 3.3.1 | Safety and support

There was a recognition from three participants, 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

# ARID

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)

Whilst many participants took part in group leisure activities such as art classes, football clubs or social groups, some reported that group dynamics were difficult to navigate and that having a befriender facilitated access to group settings.

> 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)

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

It helps people like us to go out to places. If we go on our own, we get taken advantage of. That's why we have a [befriender], to help us stay out of that situation...

(BFE10)

Befrienders practically supported participants' access to activities by setting clear boundaries (such as where and when to meet), planning travel, and responding to concerns in the moment.

> If I go somewhere new, I also need support to help me with my travel, help be sure I've got enough money for the tickets and things and just knowing that if I get lost, I've got someone safe that will reassure me and tell me 'okay, it's okay, I'm with you'.

> > (BFE8)

Befrienders also provided reassurance and emotional support in environments that felt overstimulating or crowded, further enabling participants to access events and activities.

> If the trains get busy or if the London-ground is a bit busy and noisy, 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, to supporting ongoing relationships and managing endings. Participants spoke of the stress they felt at the ending of befriending relationships, somewhat mitigated by being found a new match quickly by the scheme coordinators.

# 6 of 11 WILEY\_JARID

When they told me I was not happy... it would have felt very stressful for me because I would need a befriender. It would have become less social.

(BFE9)

# 3.3.2 | Bridging new experiences and relationships

Several participants noted that befriending had helped them build their own confidence, having a knock-on impact on 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 Gig Buddies, I wouldn't want to talk, I'd be very shy.

> > (BFE13)

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.

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

> > (BFE3)

Befriending presented opportunities for new events and experiences that participants may not have accessed otherwise, though many did appear to be repeated, familiar activities also undertaken with family members or support workers (e.g., shopping, going out for meals).

> 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 participants held leading roles in the befriending scheme, acting as ambassadors, trustees or peer trainers.

I'm the community guy. I always get involved with any special events... That's what I do.

(BFE10)

This may, to an extent, reflect the sampling strategy, with those more engaged in the befriending scheme more likely than others to sign up for the study, so the extent to which increased leadership was an outcome of the befriending intervention was not possible to discern. However, what was clear from those who commented on their additional involvement was that they derived a sense of pride and purpose from the leadership responsibilities they took on.

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 participants 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.

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

> > (BFE11)

# 3.4 | A life less quiet

## 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 participants' 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.

> 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)

The provision of friendship or companionship was most commonly cited as the 'most important thing about befriending'. For some participants, 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.

> 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)

[Its 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.

# 3.4.2 | Someone else to do things with

Many participants needed support to take part in activities and family or professional support could not always provide this to the extent desired. Befriending was therefore seen by many as an opportunity to get out more and relieve isolation or boredom.

> 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)

### 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 participants referred to the friends or friendship generated by befriending.

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.

We sometimes give each other a hug in a nice way, in a professional way.

(BFE13)

Whilst befriending activities were based around fun, participants recognised the responsibility placed on the befriender.

Once they finished befriending... then they can have [an alcoholic] drink because they're not responsible. (BFE13)

## 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 like having someone to keep me, like, calm and relaxed.

ARID

(BFE4)

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 participants 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 and do gigs. I don't want to be on Zoom anymore...

(BFE2)

# 4 | DISCUSSION

This 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 mechanisms of change and the limitations of the scheme. Four main themes were generated, suggesting that personalised befriending interventions provide opportunities to engage in fun activities, connect with others and feel a sense of belonging to broader groups, increase individual independence and combat social isolation. Mechanisms of change identified included engaging in shared decision making, basing activities around common interests and providing practical support and companionship to promote confidence.

This first theme of this study, 'something fun for me', highlighted the value of shared decision making in the befriending relationship. Whilst empowerment in decision making for people with intellectual disabilities has long been promoted (Department of Health, 2001), there continues to be a gap between actual and desired uses of leisure time (Charnley et al., 2019), with choices often limited to 'mundane' areas (Hollomotz, 2014). In this study, the flexibility and personalisation of the one-to-one befriending pairings was appreciated, supporting findings that participants with intellectual disabilities value having something which does not have to be shared with other service users or siblings (Southby, 2019). 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. This may support findings linking engagement in enjoyable leisure activities to better psychosocial functioning (Pressman et al., 2009).

The second theme, 'a good connection', highlighted how the impact of befriending can extend beyond one-to-one befriending relationships. Belonging, defined as a feeling of being accepted or of fitting in (Scior, 2018), is often not clearly conceptualised nor the primary focus of research with people with intellectual disabilities (Fulton et al., 2021). This study's finding that befriending leads to a sense of belonging to a group has not been previously reported in befriending studies. To what extent this is specific to the Gig Buddies format and ethos of facilitating befriending (or at times after the Covid-19 pandemic) is a question for further research. The presence of a befriender was found to facilitate access to groups, both within disability-specific and ordinary community settings, supporting evidence that individual support to access community group settings increases community participation, social contacts and social satisfaction (Craig & Bigby, 2015; Stancliffe et al., 2015).

Whilst befriending for people with intellectual disabilities appears to increase community participation (Bigby & Craig, 2017; Fyffe & Raskin, 2015), some noted that activities were often conducted individually within the community (Heslop, 2005; Southby, 2019). This study found that Gig Buddies participants enjoyed a mix of home-based activities, community-based 'individual' or 1-to-1 activities (e.g., cinema trips) and community-based 'collective' activities (e.g., attending festivals), and participants alluded to both valuing support to access mainstream settings, and opportunities to be around others with intellectual disabilities. Shared interests, commonly used as a criterion to match befriending pairs (Tse et al., 2021), appear to successfully foster connections and ensure befriender and befriendee engage in activities they both find enjoyable. A further focus upon encouraging befriending pairs to engage in community-based 'collective' activities, such as jointly joining a club or social group based upon those shared interests may be one way for befriending schemes to create more continued and sustaining success for participants after interventions end.

This study's third theme, 'increasing independence', supported 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

were repeated and familiar, there were also many examples of novel events and experiences being enjoyed. Taken together with the value of decision making highlighted above, we suggest that an important element in befriending is perhaps not the novelty of the experience but the shared decision to engage in it.

Befriending relationships evolve over time, progressing from instrumental support to more equal partnerships, practically facilitated by external befriending coordinators (Bigby & Craig, 2017; Green et al., 1995; McCorkle et al., 2009). However, the endings of befriending relationships highlight power imbalances and the tensions that exist between true friendship and formal intervention. People with intellectual disabilities and/or autism often experience multiple separations and endings with caregivers, and are emotionally affected by each of these endings (Mattison & Pistrang, 2000). This study supported existing findings that the endings of befriending relationships were a source of anxiety for participants (Heslop, 2005; Mavropoulou, 2007; Mitchell & Pistrang, 2011). Whilst enhanced support from the befriending scheme coordinators and/or timely replacement of a befriender may mitigate this anxiety, financial constraints and challenges in the recruitment and retention of befrienders mean this is not always possible (Ali et al., 2021; Fyffe & Raskin, 2015; Heslop, 2005; Tse et al., 2021). The fact that befriending creates a sense of belonging and increases confidence to engage in activities in community settings provides hope that some of these gains may be sustained once the relationship ends. A structured pathway towards ending, focused upon consolidating confidence and independence, and delivered by befriending scheme coordinators rather than befrienders may be useful in facilitating ending transitions.

The fourth theme, 'a life less quiet', suggests that befriending mitigates isolation by providing companionship, echoing findings from mental health befriending studies which suggest that having someone to do things with, to listen, and to talk to, is important in bringing about change (Cassidy et al., 2019; Harris et al., 1999; McCorkle et al., 2009; Mitchell & Pistrang, 2011). With up to half of persons with intellectual disability chronically lonely and with loneliness liable to trigger or worsen mental health disorders such as depression and anxiety (Gilmore & Cuskelly, 2014), befriending, which appears to provide companionship and promote belonging, could help reduce loneliness and mental health concerns. Whilst befriending relationships sit on a spectrum from friendship to professional (Southby, 2019; Thompson et al., 2016), participants recognised that there was a degree of responsibility or obligation in the befriender role, supporting previous findings (Green et al., 1995). The question of whether befriending led to social network substitution was raised by studies that measured social network size (Hughes & Walden, 1999) or used 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.

# 4.1 | Study limitations

Using convenience sampling may have led to self-selection bias. The sample was drawn primarily from the United Kingdom, with three Australian participants, and none from other countries. The majority of participants were in their 20s-30s, with two in their 30s-40s and 50s-60s. Interviews were conducted by video call, meaning that participants had to be able to connect to the internet and navigate videoconferencing software, or have access to someone who could assist them to do so. As this study focussed upon befriendee participants, it was not possible to compare perspectives on befriending experiences between befriendees and others such as befrienders or family carers. Though some credibility checks were undertaken, further checks such as testimonial validity checks (Stiles, 1993) were not conducted due to time constraints. Additionally, 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.

# 4.2 | Implications of findings and future research

This study illustrates the benefits befriending can bring to adults with intellectual disabilities and/or autism, not only by providing companionship and opportunities to engage in enjoyable activities, but also by fostering independence, increasing belonging and scaffolding access to ordinary community events and experiences. The support for befriending relationships provided by befriending schemes (e.g., through recruitment, matching, monitoring and managing endings) appears 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 psycho-social outcomes such as wellbeing and social inclusion would be beneficial. Many questions also remain about the longitudinal effects of befriending, including the impact of relationship endings, whether outcomes of befriending are sustained and whether a minimum volunteer commitment of 1 year (common across befriending schemes) is sufficient in this population group. This study finds that befriending facilitates access to ordinary community settings, 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 could be valuable.

# 4.3 | Conclusion

This study joins two others looking at befriending in this population, benefitting from the advisory input of people with intellectual JARID

disabilities and/or autism in designing the study (Ali et al., 2021; Heslop, 2005). However, 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 and opportunity for involvement and inclusion in future research.

### ACKNOWLEDGEMENTS

The authors received no financial support for the research, authorship, and/or publication of this article.

### FUNDING INFORMATION

The authors received no financial support for the research, authorship, and/or publication of this article.

# CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

Research data are not shared.

### ORCID

Katrina Scior D https://orcid.org/0000-0002-4679-0090

### REFERENCES

- Alexandra, P., Angela, H., & Ali, A. (2018). Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 643–658. https://doi.org/10.1111/jar.12432
- Ali, A., McKenzie, E., Hassiotis, A., Priebe, S., Lloyd-Evans, B., Jones, R., Panca, M., Omar, R., Finning, S., Moore, S., Roe, C., & King, M. (2021). A pilot randomised controlled trial of befriending by volunteers in people with intellectual disability and depressive symptoms. *Journal of Intellectual Disability Research*, 65(11), 1010–1019. https://doi.org/10. 1111/jir.12886
- Bigby, C., & Craig, D. (2017). A case study of an intentional friendship between a volunteer and adult with severe intellectual disability: "My life is a lot richer!". *Journal of Intellectual and Developmental Disability*, 42(2), 180–189. https://doi.org/10.3109/13668250.2016.1219701
- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3–12. https://doi.org/10. 1111/jar.12083
- Brand, F., Scior, K., & Loewenberger, A. (2023). Psychological and social outcomes of befriending interventions for adults with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 1-13, e13168. https://doi.org/10.1111/jar.13168
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/ 1478088706qp063oa

BRAND ET AL.

- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18(3), 328–352. https://doi.org/10.1080/14780887.2020. 1769238
- Cassidy, M., Thompson, R., El-Nagib, R., Hickling, L. M., & Priebe, S. (2019). Motivations and experiences of volunteers and patients in mental health befriending: A thematic analysis. *BMC Psychiatry*, 19, 116.
- Charnley, H., Hwang, S. K., Atkinson, C., & Walton, P. (2019). 'If I were given the chance': Understanding the use of leisure time by adults with learning disabilities. *Disability & Society*, 34(4), 540–563. https://doi.org/10.1080/09687599.2018.1522244
- Coren, E., Ramsbotham, K., & Gschwandtner, M. (2018). Parent training interventions for parents with intellectual disability. *Cochrane Database of Systematic Reviews*, 7, CD007987. https://doi.org/10.1002/ 14651858.CD007987.pub3
- Craig, D., & Bigby, C. (2015). "She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disability in community groups. *Journal of Intellectual and Developmental Disability*, 40(1), 12–25.
- Dean, J., & Goodlad, R. (1998). Supporting community participation: The role and impact of befriending. Joseph Rowntree Foundation.
- Department of Health. (2001). Valuing People: A New Strategy for Learning Disability for the 21st Century.
- Emerson, E., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in northern England. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 191–197. https://doi.org/10.1111/j.1468-3148.2004.00198.x
- Fulton, L., Kinnear, D., & Jahoda, A. (2021). Belonging and reciprocity amongst people with intellectual disabilities: A systematic methodological review. *Journal of Applied Research in Intellectual Disabilities*, 34(4), 1008–1025. https://doi.org/10.1111/jar.12881
- Fyffe, C., & Raskin, L. (2015). Design and implementation of a leisure buddy program. Research and Practice in Intellectual and Developmental Disabilities, 2(1), 83–91. https://doi.org/10.1080/23297018.2015.1004224
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. https://doi.org/10. 1111/jppi.12089
- Green, F. P., Schleien, S. J., Mactavish, J., & Benepe, S. (1995). Nondisabled adults' perceptions of relationships in the early stages of arranged partnerships with peers with mental retardation. *Education & Training in Mental Retardation & Developmental Disabilities*, 30(2), 91–108. http://www.jstor.org/stable/23879060
- Hardman, M. L., & Clark, C. (2006). Promoting friendship through best buddies: A national survey of college program participants. *Mental Retardation*, 44(1), 56–63.
- Harris, T., Brown, G., & Robinson, R. (1999). Befriending as an intervention for chronic depression among women in an inner city I: Randomised controlled trial. *The British Journal of Psychiatry*, 174, 219–224. https://doi.org/10.1192/bjp.174.3.219
- Heslop, P. (2005). Good practice in befriending services for people with learning difficulties. British Journal of Learning Disabilities, 33(1), 27–33. https://doi.org/10.1111/j.1468-3156.2004.00310.x
- Hollomotz, A. (2014). Are we valuing people's choices now? Restrictions to mundane choices made by adults with learning difficulties. *The British Journal of Social Work*, 44(2), 234–251. https://doi.org/10.1093/bjsw/bcs119
- Hughes, A., & Walden, S. (1999). Befriending: A note of caution. British Journal of Learning Disabilities, 27(3), 88–92. https://doi.org/10.1111/j. 1468-3156.1999.tb00095.x
- Jameson, C. (1998). Promoting long-term relationships between individuals with mental retardation and people in their community: An agency self-evaluation. *Mental Retardation*, 36(2), 116–127.
- Lin, L.-Y., & Huang, P.-C. (2019). Quality of life and its related factors for adults with autism spectrum disorder. *Disability and Rehabilitation*, 41(8), 896–903. https://doi.org/10.1080/09638288.2017.1414887

- Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, 53(5), 463–473. https://doi.org/10.1111/j.1365-2788.2009. 01170.x
- Mattison, V., & Pistrang, N. (2000). Saying goodbye: When keyworker relationships end. Free Association Books.
- Mavropoulou, S. (2007). Developing pilot befriending schemes for people with autism spectrum disorders in a region of Greece: Lessons from practice. *Child & Adolescent Mental Health*, 12(3), 138–142. https://doi.org/10.1111/j.1475-3588.2007.00457.x
- McCorkle, B. H., Dunn, E. C., Yu Mui, W., & Gagne, C. (2009). Compeer friends: A qualitative study of a volunteer friendship programme for people with serious mental illness. *International Journal of Social Psychiatry*, 55(4), 291–305. https://doi.org/10.1177/0020764008097090
- Merrells, J., Buchanan, A., & Waters, R. (2019). "We feel left out": Experiences of social inclusion from the perspective of young adults with intellectual disability. *Journal of Intellectual & Developmental Disability*, 44(1), 13–22. https://doi.org/10.3109/13668250.2017.1310822
- Mitchell, G., & Pistrang, N. (2011). Befriending for mental health problems: Processes of helping. Psychology and Psychotherapy: Theory, Research and Practice, 84(2), 151–169. https://doi.org/10.1348/147608310X508566
- Mooney, F., Rafique, N., & Tilly, L. (2019). Getting involved in the community-what stops us? Findings from an inclusive research project. *British Journal of Learning Disabilities*, 47(4), 241–246. https://doi.org/ 10.1111/bld.12283
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, 34(3), 245–256. https://doi.org/10.1023/b:jadd.0000029547.96610.df
- Patton, M. Q. (1990). Qualitative evaluation and research methods (2nd ed.). Sage Publications.
- Płatos, M., & Wojaczek, K. (2018). Broadening the scope of peer-mediated intervention for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 48(3), 747–750. https://doi.org/ 10.1007/s10803-017-3429-1
- Pressman, S. D., Matthews, K. A., Cohen, S., Martire, L. M., Scheier, M., Baum, A., & Schulz, R. (2009). Association of enjoyable leisure activities with psychological and physical well-being. *Psychosomatic Medicine*, 71(7), 725–732. https://doi.org/10.1097/PSY.0b013e3181ad7978
- Scior, K. (2018). Keynote: Exclusion versus belonging within diverse communities International Association for the Scientific Study of intellectual and developmental disabilities (IASSID). Europe Congress.
- Siette, J., Cassidy, M., & Priebe, S. (2017). Effectiveness of befriending interventions: A systematic review and meta-analysis. *BMJ Open*, 7, e014304. https://doi.org/10.1136/bmjopen-2016-014304
- Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. Research in Developmental Disabilities, 38, 18–29. https://doi.org/ 10.1016/j.ridd.2014.10.008
- Southby, K. (2019). An exploration and proposed taxonomy of leisurebefriending for adults with learning disabilities. *British Journal of Learning Disabilities*, 47(4), 223–232. https://doi.org/10.1111/bld. 12282
- Stancliffe, R. J., Bigby, C., Balandin, S., Wilson, N. J., & Craig, D. (2015). Transition to retirement and participation in mainstream community groups using active mentoring: A feasibility and outcomes evaluation with a matched comparison group. *Journal of Intellectual Disability Research*, 59(8), 703–718. https://doi.org/10.1111/jir.12174
- Stiles, W. B. (1993). Quality control in qualitative research. Clinical Psychology Review, 13(6), 593–618. https://doi.org/10.1016/0272-7358(93)90048-Q
- Thompson, R., Valenti, E., Siette, J., & Priebe, S. (2016). To befriend or to be a friend: A systematic review of the meaning and practice of

"befriending" in mental health care. *Journal of Mental Health*, 25(1), 71–77. https://doi.org/10.3109/09638237.2015.1021901

- Tse, C. Y., McKenzie, E., Hassiotis, A., & Ali, A. (2021). A survey of befriending services for people with intellectual disabilities in the United Kingdom. *Journal of Policy and Practice in Intellectual Disabilities*, 18, 296–305. https://doi.org/10.1111/jppi.12387
- Verdonschot, M. M., de Witte, L. P., Reichrath, E., Buntinx, W. H., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303–318. https://doi.org/10.1111/j.1365-2788.2008.01144.x
- Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, 51(1), 22–32. https://doi.org/10.1352/1934-9556-51. 01.022
- Wilson, N. J., Cordier, R., Milbourn, B., Mahoney, N., Hoey, C., & Buchanan, A. (2020). Intergenerational mentoring for young adult males with intellectual disability: Intervention description and outcomes. *Journal of Intellectual & Developmental Disability*, 45(2), 99–109. https://doi.org/10.3109/13668250.2019.1582758

ARID

How to cite this article: Brand, F., Scior, K., & Loewenberger, A. (2024). Understanding experiences of 'Gig Buddies': A befriending scheme for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *37*(3), e13232. https://doi.org/10.1111/jar.13232