Chambers, Claire Megan (2020) *The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity: and Clinical Research Portfolio.* D Clin Psy thesis.

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

AND

Clinical Research Portfolio

Claire Megan Chambers, BSc (Hons) Psychology, MSc Applied Psychology (Mental Health and Psychological Therapies)

Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

February 2020

Acknowledgements

Firstly, I would like to say a huge thank you to Professor Andrew Jahoda for his guidance and support through the whole research process during what had been a challenging time. Your patience and encouragement were greatly appreciated. I'd like to thank Dr Karen Stevenson and her colleagues for their support with the recruitment process, without this I think I would still be recruiting.

Thank you to all the support providers who took the time to meet with me and for supporting individuals to take part in the study. Thank you to all the participants who kindly gave up their time to share their experiences even though these experiences had been difficult for them. I really enjoyed hearing your stories and I hope through sharing these experiences, it contributes to changes enabling you to live the lives you want and deserve.

Thank you to all my classmates, it was an honour to meet you all and to have such a caring and supportive cohort. A special thanks to my friends for the support during difficult times, listening to the rants and giving me continuous encouragement.

To my family, my mum, dad, siblings and their partners, nieces and nephews, thank you for your continued support and grounding, without which I would have struggled to complete this course. A special thanks to my mum for all her motivation, encouragement and necessary proof reading.

Contents

Chapter 1: Systematic Review

Adults with mild intellectual disabilities views of the barriers and facilitators to feeling socially included. A meta-synthesis

Chapter 2: Major Research Project

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

Appendices

Chapter 1: Systematic Review

Adults with mild intellectual disabilities' views of the barriers and facilitators to feeling socially included. A meta-synthesis

Word Count: 8908 (with quotes and references)

Prepared in accordance with authors' guidelines from the Journal of Applied Research in Intellectual Disability (see appendix 1, p70)

Abstract

Background: Social inclusion has been shown to be important in reducing isolation, improving mental health and self-esteem. However, people with intellectual disabilities can often face challenges to making social inclusion become a reality. This review aimed to identify the barriers and facilitators to social inclusion through synthesising the experiences and perspectives of adults with intellectual disabilities.

Method: A systematic search was conducted on CINAHL, PsychINFO, Medline and SOCINDEX and identified eight relevant articles. Walsh and Downe's Quality Appraisal Framework (2006) was used to assess the quality of these papers. Meta-ethnography was used to synthesise the findings.

Results: Superordinate themes related to barriers included: 1) The attitudes of others: Treat me the same 2) Lack of understanding, accommodation and opportunities in employment; 3) Challenges of socialising and building a social network: Practical barriers and individual skills. The following superordinate themes related to facilitators: 1) Welcoming attitudes of others; 2) Community Presence; 3) Support to develop social and independent skills.

Conclusions: This review highlights the importance of ensuring that residential and employment services pay serious attention to creating social opportunities for those they support.

Key words: social inclusion; adults; intellectual disabilities; barriers; facilitators

Introduction

Social inclusion has been an important area of research for people with intellectual disabilities, with the recognition that they should be afforded the same civil rights and opportunities as people without disabilities (Thompson et al., 2009). Inclusion has also been a focus for policies In Scotland (Scottish Executive, 2013) and England (Department of Health, 2001). The research literature has tended to focus on measuring social inclusion by ascertaining the number of community activities people with intellectual disabilities are involved in or by asking family or support workers for their perspectives (e.g. Crisp, 1996; Hunter & Perry, 2006). Given the focused policies and drive towards an inclusive society, it is essential that we explore the views of people with intellectual disabilities to assess whether these practices go far enough to realise this goal, or identify what changes need to occur. This review encompasses the current literature exploring the barriers and facilitators to social inclusion from the perspective of people with intellectual disabilities.

Overmars-Marx, Thomese, Verdonschot and Meininger (2014) state that the "concepts of inclusion mostly pertain to the experience of valued and expected social roles, being recognised as a competent individual and trusted to perform in social roles in the community and, finally belonging to a social network" (p.266). Despite changes in policy and a drive to promote choice and a sense of agency (Scottish Executive, 2013), many people with intellectual disabilities face barriers to social inclusion. They continue to experience stigma in relation to their disability which impacts upon their self-esteem and undermines the development of a sense of community (Cummins & Lau, 2003). Schwartz and Robinovitz (2001) highlighted that acceptance of people with intellectual disabilities by their neighbours was often hindered through their attitudes and preconceived judgements. Hall (2005) states that the feeling of social exclusion can be maintained by the experience of taunts or physical abuse by others, being ignored or through avoidance of community activities due to fear of these occurring, based on prior negative experiences. This fear of difference or of experiencing stigma associated with the label of intellectual disability impacts on the individual's self-concept and their social relationships, ultimately creating a barrier to social inclusion (Anderson & Bigby 2015; Beart, Hardy

& Buchanan 2005). Hall (2009) concluded that people with intellectual disabilities wished to be accepted but faced discrimination from people in the community who were unable to see past their disability and see them as an individual. This discrediting label can therefore have an impact on their identity. However, it is important to note research has shown that positive identities can be formed through undertaking the valued role of becoming an advocate for others (Anderson & Bigby, 2015). Anderson & Bigby (2015) found that a number of positive identities were reported by their participants including being a self-advocate, an expert, being business like and an independent person. Assuming these roles had enabled them to build confidence to speak out about their preferences and choices. They also felt that their skills were valued and had increased their independence by, for example, being more confident to travel independently (Anderson & Bigby, 2015).

In her review, Hall (2009) highlighted that people with intellectual disabilities felt more included within their work environment if they believed they were valued and their employers had reasonable expectations of them. These employees desired increased responsibility and autonomy. The reviewed studies suggested that if the employees had a supportive relationship with their manager, this provided them with assistance in maintaining their employment and gave them opportunities for inclusion. Positive roles such as being an employee, volunteering or even being a supportive neighbour, can help people with intellectual disabilities gain social capital and counteract discriminatory views that contribute to social marginalisation (Cobigo, Ouellette-Kuntz, Lysaght & Martin, 2012).

Hall (2009) found that participants preferred staff to be supportive rather than take on a caring role, helping them to develop skills and fostering social connections. A lack of knowledge as well as limited functional and adaptive skills were identified by Overmars-Marx et al. (2014) as barriers to social inclusion. Overmars-Marx et al. (2014) emphasised the impact of social skills deficits on individuals' abilities to form meaningful connections with people in their communities. They proposed that neighbours may need to adapt to people with intellectual disabilities and their presence in the neighbourhood, suggesting greater presence in the neighbourhood as well as a change in neighbours' attitudes would facilitate inclusion. Overmars-

Marx et al. (2014) also pointed to the role of professionals in promoting understanding and helping people to build social connections. They suggested professionals could facilitate the development of social skills through creating informal groups or networks of people with intellectual disabilities.

Hall (2009) identified that social inclusion can be hindered by the location of their residence. Some people with intellectual disabilities may live in places with limited transport links. This can make it difficult for them to attend social events as many have no other means of transport except asking support workers or family, thus reducing their independence.

Research has shown that people with intellectual disabilities are at increased risk of loneliness due to deficient social networks and poor social integration (McVilly, Stancliffe, Parmenter & Burton-Smith 2006). Forrester-Jones et al. (2006) found that people with intellectual disabilities had impoverished social networks with the majority made up of family members, support staff or professionals. Verdonschot, de Witte, Reichrath, Buntinx and Curfs (2009) stated that if people with intellectual disabilities did have wider friendship networks, they were rarely able to see these other friends. due to difficulties with transport or lack of staff to facilitate seeing them. Not only do friendships provide a source of social interaction, they can also provide access to resources for example transport to events (Hall, 2009). Social inclusion is not only important for preventing loneliness but also for increasing a sense of acceptance and connection (Strnadova, Johnson & Walmsley, 2018).

Lippold and Burns (2009) propose that people with intellectual disabilities and people with physical disabilities may experience social exclusion in different ways, suggesting that intellectual disability is seen as a more discrediting label than a physical disability. Thus, through including both groups within their analysis, some richness of experience may not have been captured in previous literature reviews about social inclusion by Overmars-Marx et al. (2014) and Hall (2009). No meta-synthesis review of qualitative studies has been conducted on the barriers and facilitators to social inclusion from the perspective of people with intellectual disabilities. Understanding people with intellectual disabilities and their views is vital in order to inform and shape policies and services, ensuring support is delivered in a way that is appropriate and sensitive to their needs. This systematic review will identify and synthesise themes from qualitative studies exploring the experiences and perceptions of people with intellectual disabilities' in relation to the barriers and facilitators to social inclusion.

Due to the broad definition of social inclusion and the limited research on this topic with people who have intellectual disabilities, this review will consider social inclusion in its broadest terms. This includes looking at social inclusion in different areas of community life, including employment and neighbourhood networks, both emphasised as key areas of social inclusion by Schalock, Keith, Verdugo and Gomez (2005). This review will explore the key barriers and facilitators to social inclusion identified in published qualitative studies, exploring the experiences and perceptions of adults with intellectual disabilities.

Method

Search strategy

A search strategy was created by reviewing the topic area and identifying common terms used within intellectual disability research. In addition, advice was sought from the University of Glasgow librarian in relation to the search strategy and databases to be used. Searches were conducted on electronic databases to search for articles within peer reviewed journals published in the English language. The databases searched included Medline, PsychINFO, CINAHL and Soc Index. Where possible, search terms were mapped to individual database index terms or subject headings, as well as using free text terms, to ensure all relevant articles were captured.

The following search terms were used:
Learning disabilities OR Intellectual Developmental Disorder OR Developmental Disabilities OR “learning disab* OR “intellectual disab*” OR “mental* retard*” OR Intellectual Developmental Disorder (Attitudes Toward) OR Mentally Disabled Persons OR Mental Retardation X linked OR Learning Disability OR “mental* impair*”

AND

Social isolation OR social integration OR social participation OR social inclusion OR social acceptance OR community participation OR community involvement

AND

Facilitat* OR barrier* OR challenge*OR enable* OR help* OR prevent* OR assist*

Boolean terms of AND and OR were used to combine the search categories. In addition, a number of peer reviewed journals were searched individually for any further relevant articles not captured via the search strategy. These journals included: The British Journal of Learning Disabilities; the Journal of Intellectual and Developmental Disability; the Journal of Applied Research in Intellectual Disability and the Journal of Intellectual Disabilities. Scopus was also used to identify any further articles. All articles identified by searches were reviewed for their relevance in accordance to the inclusion and exclusion criteria. The last database search was conducted on 9th February 2019.

Inclusion and exclusion criteria

The following inclusion criteria were set:

- Articles exploring the barriers and facilitators to social inclusion as perceived by adults with intellectual disabilities
- Only qualitative studies
- Participants aged 18 or over
- Articles published in a peer-reviewed journal.
- Articles published in English language
- Articles published since 2000, as by this date most of the long stay hospitals in the UK were closed and there was a commitment, internationally to support community residential options.
- Articles published in Western countries with social care and delivery systems similar to that of the UK, allowing for comparison.

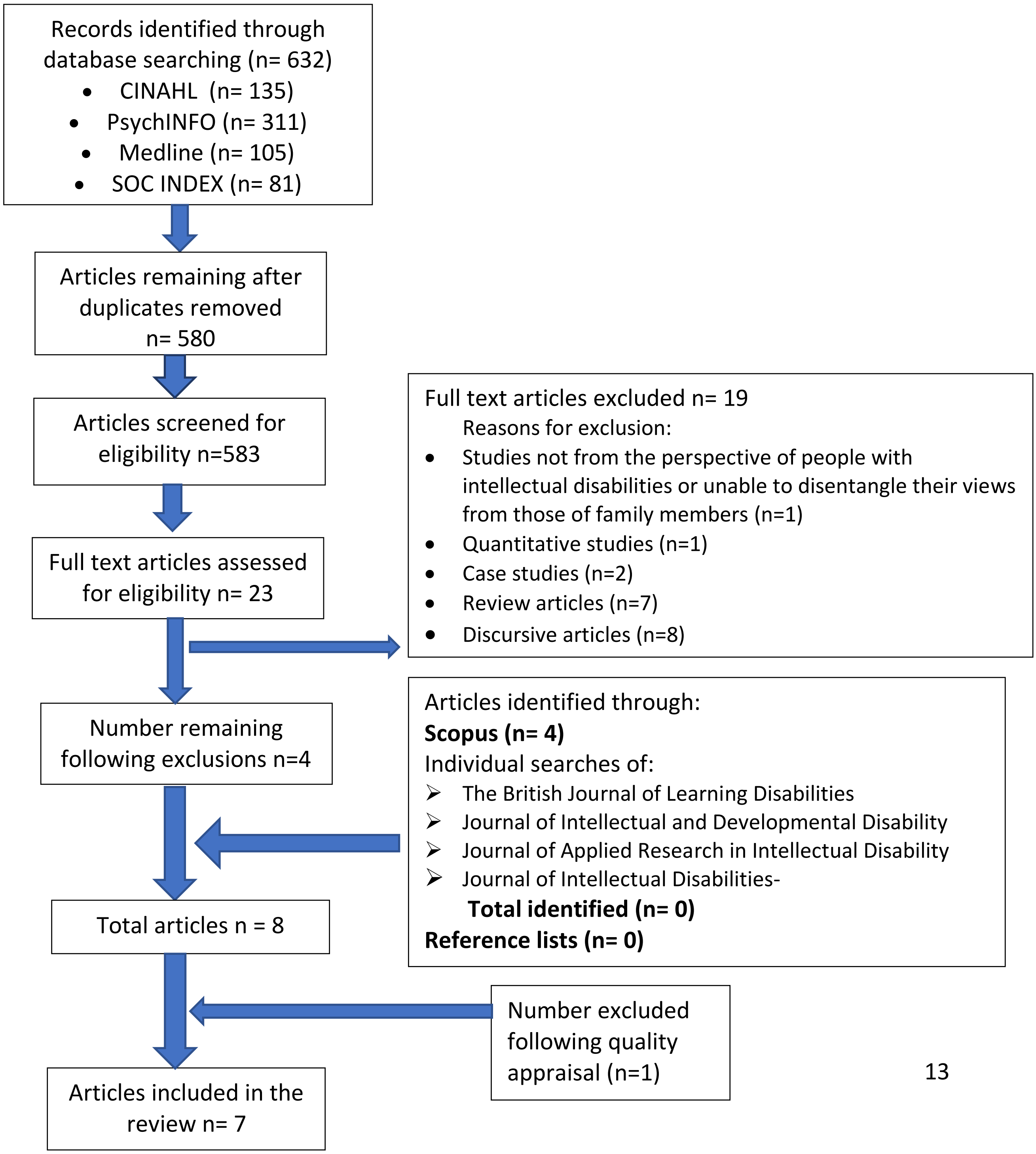
The following exclusion criteria were set:

- Case studies
- Review articles
- Mixed method studies where it was not possible to separate the quantitative and qualitative results
- Studies using proxy report by staff, family or professionals as the focus of the review was on exploring the views of people with intellectual disabilities themselves.

Procedure

The review process followed PRISMA guidance. During each database search, the titles of the articles were first reviewed for relevance. If the titles were considered to be relevant, then the abstracts were reviewed. If the abstracts were not available, or did not provide enough information to determine relevance, then full text was sought and compared to the review question. Following review of abstracts and consideration of relevance, the full text papers were read. Scopus was used to identify any further relevant articles and a number of relevant journals were hand searched (see Figure 1 for journal names) Eight papers were identified as relevant to be included in the review. The reference lists of these articles were then reviewed. No further articles were identified. An overview of the search process is provided in Figure 1.

Figure 1: Overview of systematic search process and article selection



Data extraction

Information was extracted from the reviewed studies shown in Table 1. This provides a summary of the characteristics of each study including the authors, year and country of publication, aims of the study, participant demographics, data collection method, method of analysis and the themes.

Table 1: Key Characteristics and Themes Generated by the Included Studies

Study **Country**	**Study aim**	**Data collection method**	**Method of Analysis**	**Sample**	**Themes**
Abbott & McConkey (2006) UK	Gain insight into how people with intellectual disabilities perceive the barriers to their social inclusion and the ways these barriers could be lessened or removed	Focus groups	Latent content analysis	68 people aged between 21 and 82 years	**Social inclusion:** ➢ talking to people ➢ Being accepted ➢ Using community facilities ➢ Opportunities **Barriers to social inclusion** ➢ Personal abilities and skills ➢ The community ➢ Staff and management ➢ The home/scheme **Overcoming the barriers** ➢ Personal abilities and skills ➢ The community ➢ Staff and management ➢ The home/scheme
Welsby & Horsefall (2011) Australia	To understand the process of social inclusion from the perspective of people with intellectual disabilities	Semi-structured interviews discussion using arts-based activities Field notes, photograph and transcripts	Thematic analysis	5 women aged 28 to 52 years	➢ The women's experiences of inclusion/exclusion ➢ Working to live ➢ Practices of exclusion at work ➢ Consuming as a practice of inclusion ➢ Anger: an excluded emotion ➢ Maintaining social relationships
Hall (2017) USA	To describe the community involvement of young adults with intellectual disability and identify factors that assist or limit their involvement	Semi-structured interviews	Phenomenological Approach	14 people with Intellectual Disabilities aged between 21-35 years	**Vocational endeavours** ➢ Employment ➢ Day programmes ➢ Volunteer ➢ Leadership **Leisure pursuits** ➢ Recreation ➢ Social groups ➢ Church ➢ Community events **Social inclusion** ➢ Social connections ➢ Acceptance **Supports** ➢ Job coach ➢ Transportation
Merrells, Buchanan & Waters (2017)	To explore how participants experience social inclusion based	Semi-structured interviews	Phenomenological Approach Thematic Analysis	10 participants aged 18-24 years living in	➢ Segregated, excluded and "treated like an outcast" in my community

Australia	on their lived experience and perspectives.			the community or with family	➢ Challenges in experiencing, initiating and maintaining peer relationships
van Alphen, Dijker, van den Borne & Curfs (2017) Netherlands	To examine the kinds of interactions people with intellectual disabilities have with neighbours, and the types of relationships they want with neighbours	Semi-structured interviews	Content Analysis	39 (22 women, 17 men) aged between 15 and 75 years old	**Neighbouring** ➢ Superficial neighbouring ➢ Involved neighbouring ➢ The significance of neighbours for feeling at home **Facilitating factors and barriers to neighbour interactions** ➢ The organisation of care frames context and opportunities ➢ Formalising relationships ➢ Apprehension towards interactions with others
Wilson, Jacques, Johnson & Brotherton (2017) Australia	To explore and understand people with an intellectual disability's experience of inclusion in a structured social group.	Semi-structured interviews	Descriptive Analysis	10 adults (7 men, 3 women) aged between 19 and 48 years	**Supported engagement fosters wellbeing** ➢ Socialisation improves health and wellbeing ➢ Social engagement expands circle of friends **Developing social belonging and connectedness** ➢ A diverse support system helps connect socially ➢ Psychosocial connection develops a sense of belonging
Byhin & Kacker (2018) Sweden	To describe how young adults with mild to moderate intellectual disability experience and perceive attitudes, treatment and participation in the application process for daily activity/ sheltered employment	Semi-structured interviews supported with pictograms	Content analysis	14 participants aged between 21-23 years old	**Attitude and treatment:** ➢ Perceptions of bad treatment and attitude ➢ Attitudes and approach **Participation** ➢ their own impact on participation ➢ opportunities for participation **Transition from school to employment** ➢ Applications for daily activity ➢ starting employment **Psychosocial work environment** ➢ Supportive factors ➢ Hindering factors ➢ Opportunities **Future** ➢ Development opportunities Fears and concerns
Overmars-Marx, Thomese & Meninger (2019) Netherlands	Gain a better understanding of the perspective of people with learning disabilities on neighbourhood social inclusion	Semi-structured interviews with use of photo voice	Content analysis	18 participants aged 30-65 years	➢ Attractiveness of the neighbourhood ➢ Social contacts in the neighbourhood ➢ activities in the neighbourhood ➢ Independence ➢ Public familiarity

Quality Appraisal

The Walsh and Downe (2006) quality appraisal tool was used in this review. Walsh and Downe (2006) completed a robust literature review of quality appraisal tools available at the time of review, collating the characteristics of the checklists and the frequency in which they were used across the studies. The authors then synthesised these characteristics and developed a tool with 12 criteria and suggested prompts within each, creating a more comprehensive appraisal tool informed by the literature (see Appendix 2, p79). These included, that the study provides a clear rationale, provides a context of the literature, appropriate method and data collection, appropriate analytic approach, has a clear audit trail, data in support of interpretation, evidences researcher reflexivity, is sensitive to ethics and finally has relevance and transferability. The authors proposed that if a study meets over 50% of the prompts in the tool for that specific essential criteria (shown in Appendix 2, p79), they are considered to have met that essential criteria.

A second researcher, independent of the study team, rated a sample of the studies (4) selected for review. There was 92% agreement between both raters' quality ratings using this tool. Discrepancies were explored and discussed, until consensus was reached for all ratings.

Method of Synthesis

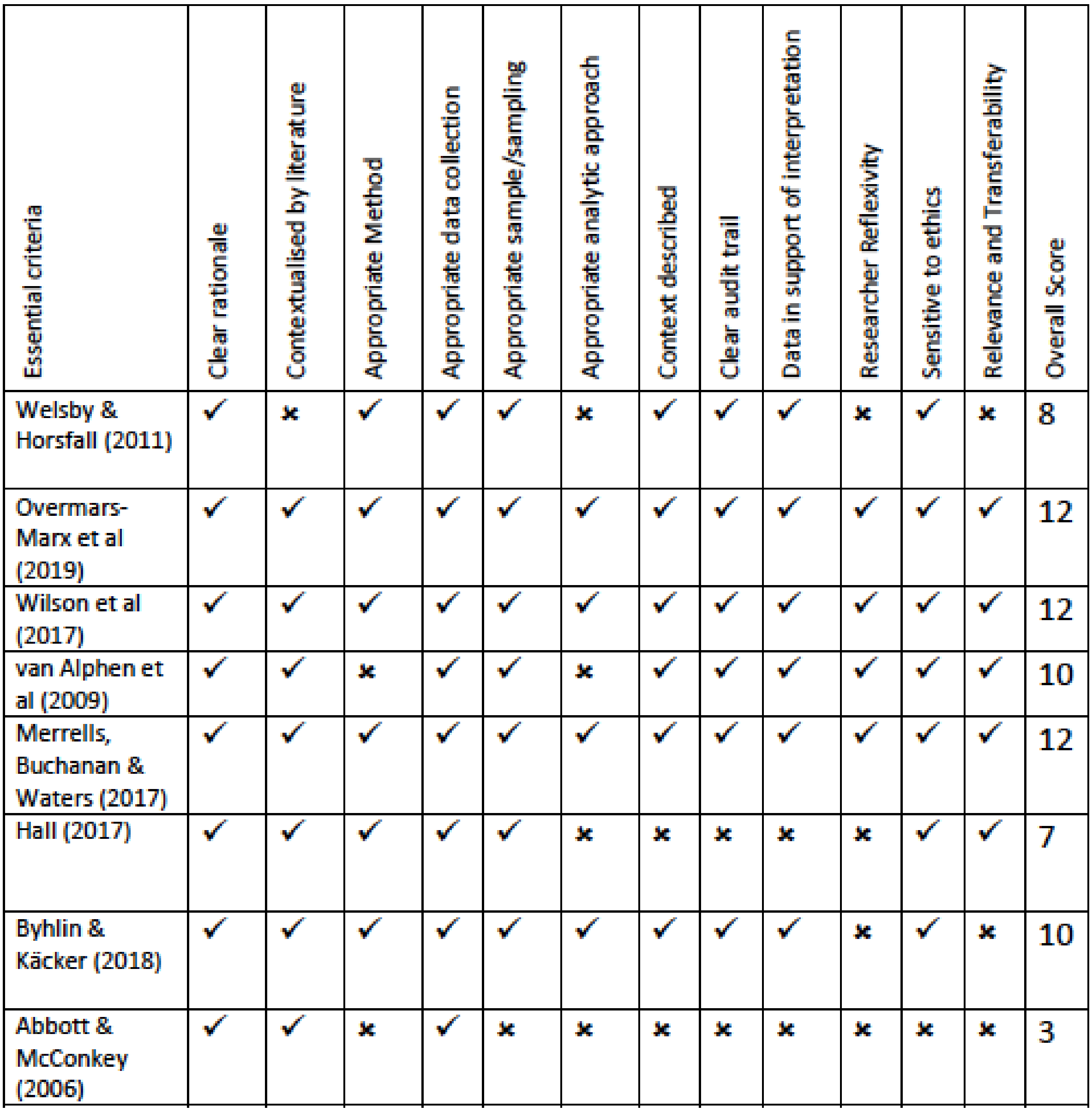
Meta-ethnography is the process by which researchers select, analyse and interpret research studies to synthesise the findings and develop a new understanding or conclusions about a specific topic. It is an interpretative approach, seeking to combine findings and establish a more in-depth interpretation or third order concept. Although the approach seeks to develop a new understanding of the topic it also aims to maintain the integrity of the findings of the original articles. This is the approach used within this review. Noblit and Hare (1988) proposed a seven-stage framework for conducting a meta-ethnography (see Appendix 3, 83), i) defining the research question, ii) systematically reviewing the information according to the pre-defined inclusion and exclusion criteria, iii) selecting the studies to be included, iv) reading and comparing the studies, and, identifying similarities and differences in content, v) identifying themes, vi) compiling a table of themes, illustrated with quotations, vii) Creating a table of new, third order themes from the existing study findings.

Results

Quality Appraisal

The identified articles were reviewed using Walsh and Downe's quality appraisal tool. The final ratings are displayed in Table 2, indicating the quality ratings for each paper.

Table 2: Quality Appraisal of Articles



Essential criteria	Clear rationale	Contextualised by literature	Appropriate Method	Appropriate data collection	Appropriate sample/sampling	Appropriate analytic approach	Context described	Clear audit trail	Data in support of interpretation	Researcher Reflexivity	Sensitive to ethics	Relevance and Transferability	Overall Score
Welsby & Horsfall (2011)	✓	✗	✓	✓	✓	✗	✓	✓	✓	✗	✓	✗	8
Overmars-Marx et al (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
Wilson et al (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
van Alphen et al (2009)	✓	✓	✗	✓	✓	✗	✓	✓	✓	✓	✓	✓	10
Merrells, Buchanan & Waters (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
Hall (2017)	✓	✓	✓	✓	✓	✗	✗	✗	✗	✗	✓	✓	7
Byhlin & Käcker (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✗	10
Abbott & McConkey (2006)	✓	✓	✗	✓	✗	✗	✗	✗	✗	✗	✗	✗	3

The Abbott and McConkey (2006) study was rated as poor in quality, lacking the evidence to meet the listed quality criteria. The study was not clear on the rationale for analysis, process of analysis, how decisions were made, lack of discussion in relation to researcher reflexivity, and no discussion about ethical approval. Walsh and Downe (2006) suggest that studies considered to be of poor quality, which may be the result of oversight or strict journal word limits, should not be included within the synthesis. This study was therefore excluded on that basis. Seven studies were deemed appropriate for synthesis following quality appraisal.

Meta-Synthesis

The themes displayed by the authors of the eight included studies are captured in Table 1. Seven new third order themes highlighting the barriers to social inclusion were identified through the process of meta-ethnography these are presented in Table 3 and presented in diagrammatic form in appendix 4, p84. These will be discussed in turn.

Table 3: The third order themes identified through synthesis

Barriers	Facilitators
Attitudes of others: treat me the same • "I want to be treated normally": Desire for equality and acceptance **Lack of understanding, accommodation and opportunities in Employment** • Seeing beyond the disability: desire for participation and involvement • employment practices result in limit opportunities **Challenges of socialising and building a social network** • Location of residence and resultant reliance on staff • No social spaces • Restrictive support service practices • Lack of knowledge, confidence or social skills	**Welcoming attitudes of others** • Making the effort to talk **Community presence** • Being known/community familiarity • Opportunity to engage in community events **Support to develop social and independent skills** • Practicing skills in a safe environment

Barriers to social inclusion

Attitudes of others

1. “I want to be treated normally”: Desire for equality and acceptance

This theme refers to the negative attitudes and assumptions members of the public are thought to hold about people with intellectual disabilities. This theme emerged in five of the studies included in this review (Byhlin & Kacker, 2018; Hall, 2017; Merrells, Buchanan & Waters, 2017; van Alphen et al., 2009; Welsby & Horsfall, 2011).

Van Alphen et al.’s (2009) study highlighted the negative attitudes people had about their disability and in particular, their perceptions of the constraints this would have on their ability to function, potentially seen as not able to contribute to a community. Similar to those without disabilities, people with disabilities just wish to be treated equally and accepted into the community. However, they can often feel judged by non-disabled people who focus on their disabilities rather than their strengths or what they can contribute to the community. A participant in van Alpen et al.’s (2009) study describes her experience of this:

> *Well every person with a disability, you have to give them a chance. I think (…) They should not be put in a corner. Every person is unique, and that is often, very often forgotten…When those neighbours started a petition, that was not very nice, but there was a counter petition…things were nice again (van Alphen et al. (2009), p751).*

It is important to note that the participant in van Alphen’s study (2009) also felt supported by some members of her community as a result of the counter petition. Some participants in the reviewed studies such as in Welsby and Horsfall (2011), identified feeling supported in their community and their employment. Thus, these negative attitudes were not thought to be held by all members of the public.

What was apparent across the studies was that some participants did not feel welcome within their communities. For example, some participants reported being spoken to in a patronising manner. They talked about the desire to be treated with the same respect as others without disabilities. A participant from Byhlin and Kacker's (2018) study said:

> *Some people talk as if we were toddlers/…/ we are adults (Byhlin & Kacker, 2018, p175).*
>
> *Often when you tell someone you have an intellectual disability their attitude changes…you only tell them if you have to. Normally they start shouting at you and speaking really…really…slowly…Depending on what you need and how I'm feeling. I tell them there is no need to shout! I am not deaf. I only have an intellectual disability…well it's true. There's no need to shout and talk to us like we're children, we're not stupid. (Welsby & Horsfall (2011), p804).*

It may be that dependent on participants' mood, some days engaging with members of the community is considered to be too much of an effort due to fears of being made to feel inferior, ignored or rejected. Therefore, the attitudes of community members may act as a barrier to social inclusion.

The reviewed studies illustrated how participants wanted to be treated equally to others in society, particularly in how people spoke to them, how they are treated by employers and in having fair access to transport.

> *I'm like any worker anywhere, it's just that I have an intellectual disability (Byhlin & Kacker (2018), p176)*

In Hall's study (2017), participants discussed their frustration that people do not make more of an effort to understand them, especially if they find it difficult to communicate. They described feeling that they were being ignored and that their views were not worthy of other people's attention or interest. Participants appeared to want other people to strike a balance between displaying interest in them and communicating in a way that is respectful and non-patronising. Some participants thought that others viewed people with intellectual disabilities not only as different but as inferior.

> *That branding, people's reactions about what they think. You shouldn't discriminate/…/just having a diagnosis doesn't mean you're inferior to everything (Byhlin & Kacker (2018), p176).*

This participant in Byhlin and Kacker's (2018) study appears to suggest others view an intellectual disability as a discrediting label. The use of the word 'everything', suggests an awareness that they may struggle with some aspects of daily living, but the quote emphasises their frustration that people focus on incapacities rather than their strengths. This may have presented challenges to their self-concept and desire to be seen as someone capable and accepted.

The reviewed studies also highlighted that participants managed this sense of difference and rejection in different ways. One participant described how instead of becoming upset that her neighbour actively avoided speaking to her, she chose to see the humour in it. She talked about how she enjoyed taunting him by going out when he was in the middle of doing something, knowing this would result in him retreating into his home (Welsby & Horsfall, 2011). This suggests that participants had different ways of managing these experiences.

Lack of understanding, accommodation and opportunities in employment

2. Seeing beyond the disability: desire for participation and involvement in employment

This theme was apparent across five of the reviewed studies (Byhlin & Kacker, 2018; Hall, 2017; Merrells, Buchanan & Waters, 2017; van Alphen et al., 2009; Welsby & Horsfall, 2011). Participants in the reviewed studies discussed the challenges of securing and maintaining employment, partly due to a lack of understanding and patience around their disability resulting in difficulties engaging with their manager/employer or other colleagues:

> "*in retrospect it was fun while it lasted. It just didn't seem to last very long. Either I was getting laid off or I didn't get along with my boss" (Hall, 2017, p863).*

Participants in Welsby and Horsfall's study (2011) highlighted the challenges maintaining employment, citing expectations from their managers and colleagues as creating difficulties. They reported that either their disability was acknowledged, and they were seen as being unable to achieve certain tasks or their disability was disregarded when they did not meet expectations about productivity.

Welsby & Horsfall (2011) also highlighted the resulting impact this can have on people with intellectual disabilities and their ability to lead independent lives. It can inhibit the finances available to socialise transport to socialise.

Participants talked about limited opportunities within their work role, with no scope for development and promotion, and difficulties obtaining additional hours of work (Welsby & Horsfall, 2011). Some participants also mentioned being left out of staff meetings and believed their suggestions were not valued (Byhlin & Kacker, 2018). There appeared to be a strong sense of injustice at not having the same opportunities as other employees and, as previously discussed, therefore being made to feel different:

> *I want to participate/…/so that I know what's being said. I'm not allowed to join them (P12, Byhlin & Kacker, 2018, p177)*

However, this was not true for all participants within the reviewed studies. Welsby and Horsfall (2011) found that some of their participants found team meetings challenging because they had difficulty processing the information quickly enough to follow what was being discussed. Others did not wish to attend staff meetings. Thus, not being part of staff meetings was viewed as a barrier to acceptance in the work place for some participants but not to all in the reviewed studies.

3. Employment practices resulting in limited opportunities

Three of the reviewed studies (Byhlin & Kacker 2018; Hall, 2017; Welsby & Horsfall 2011) identified barriers within employment which led to a lack of social opportunities for those with intellectual disabilities. Hall (2017) endorsed the lack of opportunity to build social relationships within the work setting (Hall, 2017). One reason discussed, was their limited working hours. This resulted in them not being entitled to breaks and subsequently informal opportunities to talk with colleagues and make social connections. This highlights that important structural issues need to be given consideration, to enable barriers to inclusion in the workplace to be overcome. However, it is important to highlight that this was not the case for all participants. A small number of participants highlighted that they attended work get-togethers and did have the opportunity to talk to colleagues at breaks (Hall, 2017).

Challenges to socialising and building a social network

4. Location of residence and resultant reliance on staff

Four of the reviewed studies reported that where participants lived could be a barrier to social inclusion (Hall, 2017; Merrells, Buchanan & Waters, 2017; Overmars-Marx et al., 2019; van Alphen et al., 2009). They reported that where they live, depending on how rural, can have limited social opportunities. Some had groups that were available for them to attend but for others a lack of social events or challenges in relation to available public transport meant that some participants felt lonely. They described a lack of transport in the evenings, relying on family or staff to take them to events or the need to book transport in advance, limiting opportunity for spontaneous socialising. This makes it difficult for people with intellectual disabilities to develop independence and an added challenge to forming and maintaining relationships.

5. No social spaces

One reviewed study (van Alphen et al., 2009) identified that it was challenging for participants to invite people to their home. This was because there were no social spaces to entertain visitors, and they had to take visitors to their bedroom (van Alphen et al., 2009). This highlights how an inappropriate placement can act as a barrier to social inclusion. Suitable and appropriate housing is assigned based on a number of factors but it’s important that if we are encouraging social inclusion we ensure that these system factors do not hinder this goal.

6. Restrictive support practices

Two studies noted that restrictive practices of those supporting people with intellectual disabilities can act as a barrier to social inclusion by preventing them from independently forming social relationships or travelling independently (van Alphen et al., 2009; Welsby & Horsfall, 2011). This appeared to be as a result of fears for individuals’ safety but prevented them from leading the lives they wanted.

Welsby and Horsfall’s (2011) study explored the views of women with an intellectual disability and their experiences of social inclusion as people who have experienced exclusionary practices. The study involved an art-based approach as well as follow up semi-structured interviews. These women seemed to develop a bond through sharing their challenging experiences of work and being supported. However, a rule had been formed by staff about sharing mobile numbers. The participants stated that this rule had been put in place as a precaution for their personal safety and perhaps to reduce the risk of exploitation. It is not clear the circumstances around why these rules may have been instigated in the first place but in the context of this study, it acted as a barrier for these women to build upon and strengthen the bond they had formed through taking part in the research project. It was also preventing them from enhancing their social network.

The van Alphen et al. study (2009) identified how sometimes people with intellectual disabilities’ ability to integrate into the community can sometimes be restricted by the safety practices of their support organisation. These practices sometimes meant that they had to rely on others to transport them to work and they were unable to travel independently. This also had the effect of reducing their opportunities to interact with non-disabled people in their local community.

> *I'm not allowed to do anything yet. I've been here so many years, I'm not allowed to do anything. Back then at —, I was allowed to ride my push bike to the farm on my own, but Ruud says here I can't. So, I take the bus. [The traffic is] too busy.* (van Alphen et al., 2009, p752).

7. Lack of knowledge, confidence or social skills

Five of the reviewed studies highlighted the challenges participants had engaging in the community (Byhlin & Kacker, 2018; Overmars-Marx et al. 2018, van Alphen et al., 2009; Welsby & Horsfall, 2011; Wilson et al., 2017). The studies reported that individuals with intellectual disabilities had difficulties finding out about the opportunities for social contact that were available in their local communities and knowing how to access them. Many expressed feelings of anxiety or felt they lacked the skills to source the necessary information. Some felt that support staff played an important role in conveying information to them about possible activities and events.

A number of participants within the reviewed studies also discussed a lack of confidence or skills in how to initiate conversations with members of the community. Resulting on a reliance on their support workers to introduce them to new people. This lack of autonomy may hinder the natural formation of relationships or encourage an expectation of the support worker or family members to be present to facilitate interactions.

Some participants in the reviewed studies also reported that a lack of independent travel skills may also act as a barrier to social inclusion as it may prevent them from attending an event or activity especially if staff are not available to provide transport.

Facilitators to social inclusion

Welcoming Attitudes of Others

1. Making the effort to talk

Five of the reviewed studies talked about the salience participants attached to being greeted by people in their communities, this included neighbours, work colleagues, people in the shops (Byhlin & Kacker, 2018; Hall 2017, Merrells, Buchanan & Waters, 2017; Overmars-Marx et al. 2019, van Alphen et al., 2009). They discussed how it was important that these people made an effort to speak to them.

> *That you really try/…/if you are tired/…/or if you wake up on the wrong side and still try (P7,* Byhlin & Kacker, 2018, p175)

Participants of the reviewed studies commented that they felt part of the community when others asked them how they were and greeted them. This appeared to provide them with a sense that people cared how they were doing and were genuinely interested in them as illustrated below:

> *They are nice and always ask how I'm doing/…/they always show that they care* (P6, Byhlin & Kacker, 2018, p177).

An important factor to facilitating the feeling of inclusion within the workplace seemed to be a welcoming attitude to them being employed (Hall, 2017; Merrells et al., 2017; Welsby & Horsfall, 2011). This appeared to include a supportive manager who they could go to if they were struggling to meet the demands of their role and feeling respected by having their views acknowledged, for example in team meetings. This provided them with a sense of autonomy and control over their lives as well as feeling like a valued member of the team. This highlights the importance of inclusion in the workplace, making people feel part of something bigger than them, creating a sense of belonging within a group.

It appeared to be important to participants in the reviewed studies that people in the community took an interest and made an effort to speak to them, especially since many of them reported that they found it difficult to initiate conversations with new people.

Community Presence

2. Being known/community familiarity

Five of the reviewed studies talked about how the participants felt included through taking part in activities such as volunteer work, work placements and taking on social roles in the community (Byhlin & Kacker, 2018; Hall, 2017; Merrells, Buchanan & Waters, 2017; Overmars-Marx et al., 2019; Weslby & Horsfall, 2011). One participant discussed how he felt a valued member within his church community as he had an important role using the projector and teaching others how to do this (Overmars-Marx et al., 2019). Another participant talked about becoming a referee for the local football team and baby-sitting for neighbours (Overmars-Marx et al., 2019). These roles appeared to engender a sense of acceptance and belonging in their community and neighbourhood. Participants also felt pride about making contributions to their community. In addition, these roles helped to foster broader social contacts in the community.

These work placements, volunteer roles and social roles not only brought people with intellectual disabilities contact with the community, it also enhanced community familiarity, enabling members of the community to get to know them. Therefore, it’s important that people with intellectual disabilities are given the opportunity to take on these roles as highlighted in Byhlin and Kacker (2017) as otherwise many can feel disconnected from their community and lonely. Overmars-Marx et al. (2019) highlighted the importance of having family connections in their local community and living in a community for a long time. This meant that people with intellectual disabilities were familiar to others in their community and helped them to feel more accepted. Overmars-Marx et al. (2019) referred to this as “public familiarity”. They suggested that it is easier for people with intellectual disabilities to integrate into their community and be accepted by its members if they have existing social ties. Being close to family, not only allowed greater contact with them reducing loneliness, it also meant that they had access to natural supports who could facilitate travel and socialising. This was identified as a barrier to attending social events or forming connections. Overmars-Marx et al. (2019) therefore highlight the need for careful consideration when sourcing and placing individuals with intellectual disabilities.

However, it is important to note that not all participants wished to have close relationships with other people in their neighbourhood:

> *If there is a communal activity we have contact and when we meet we say hi. We don’t visit each other, but I don’t feel the need to (Overmars-Marx et al., 2019, p87)*

It seems that for some people with intellectual disabilities it’s important that support is provided for them to initiate interactions with neighbours and wider people in the community but also that they can decide what level of interaction they feel comfortable with. Therefore Overmars-Marx et al. (2019) highlight the differing needs of people with intellectual disabilities and that this should be considered at an individual level, providing support where they wish to foster more meaningful connections with others.

3. Opportunity to engage in community events

This theme emphasises the importance of being included in a community. Participants in three of the studies valued events such as neighbourhood barbeques and fun fairs (Hall, 2017; Overmars-Marx et al., 2019; van Alphen et al., 2009).

> *‘There’s a pancake feed–it’s definitely the highlight–a parade, cookout, garage sales. . .a volleyball tournament. . .and then a street dance at the end’ (Hall, 2017, p865)*

They felt these events brought them into contact with people who lived nearby and helped to build longer lasting relationships. Many participants across the studies wanted someone to accompany them to events, to help facilitate interactions.

Support to develop social and independent skills

4. Opportunity to practice skills in a safe environment

This theme encompassed a number of factors and was apparent in five of the reviewed studies (Hall, 2017; Overmars-Marx et al., 2019; van Alphen et al., 2009; Welsby & Horsfall, 2011; Wilson et al., 2017). Participants in the reviewed studies talked about having the opportunity to develop independent living skills through shopping, using public transport and reducing their reliance on staff to take them out. Hall's (2017) study talked about the use of a job coach to teach the participants skills to use public transportation, with the goal that they could travel to work and social events independently and not be held back by staffing concerns. This may have helped participants to feel more in control of their lives, not dependent on others to assist them in achieving goals.

Two studies (Merrells, Buchanan & Waters, 2017; Wilson et al., 2017) described how being involved in social groups with other people with intellectual disabilities, assisted participants to develop skills in a safe environment. They felt these experiences helped to build their confidence in connecting with others.

> *'get to go to Luna Park [fun fair]. . . so they're things I just don't have the confidence to do by myself, I wouldn't be able to'* (Wilson et al., 2017, p853)

Participants who took part in social groups with other people with intellectual disabilities described how they went on to socialise with other members outside of the group, developing these relationships. One participant went on to say how being part of the group helped him to show his personality:

> *[the social group] brings out some of my personality…I'm very caring…so [the paid group leader] knows that I help, and I actually enjoy that cos I get to help my other team (Wilson et al., 2017, p855)*

Discussion

These findings highlight the importance people with intellectual disabilities attach to feeling accepted within their communities. Those in employment felt that work not only provided an opportunity to earn money but also provided an opportunity for them to become known in their community (Strnadova, Johnson & Walmsley, 2018). However, participants in the employment studies often felt they were not treated the same as other colleagues, resulting in them feeling undervalued and excluded from decision making in their workplace. This emphasis on difference and a sense of inferiority has been a source of common concern in studies (Amado, Stancliffe, McCarron & McCallion 2013; Strnadova et al., 2018).

A further finding from this review in relation to support services, was that service providers can create barriers to inclusion due to efforts to manage risk. Paradoxically, when trying to protect people from negative judgements and discrimination, services can sometimes inadvertently reduce their opportunities for social inclusion (Amado et al., 2013). The review also showed that support workers can also place emphasis on practical caring tasks and lose sight of their role to facilitate personal choice and social opportunities. It is important that support organisations balance their need to keep individuals safe with ensuring they are not depriving people of their civil rights.

In addition, the reviewed studies discussed how a lack of confidence and social skills were perceived barriers to individuals participating in community events. This could lead to a dependence upon support staff to facilitate social opportunities. Abbott and McConkey (2006) have also noted that some people with intellectual disabilities seem to lack the motivation to initiate conversations with people they meet. Thus, a lack of confidence may, in part, be due to past experience of negative interactions, which make some individuals reluctant to engage in conversations due to fear of rejection.

More positively, this review highlighted how structured social groups that include other disabled members can act as a platform for building individuals' social skills and confidence, as they are perceived to be safe and accepting environments. In Wilson et al.'s (2017) study, participants reportedly valued the skills learnt, enabling them to apply these skills in interactions with non-disabled members of the community, and helping to reduce their sense of isolation. Therefore, supportive opportunities to develop social skills may make an important contribution to reducing social isolation and developing a supportive social network.

A key finding in this review was that people with intellectual disabilities greatly appreciated when other people, like neighbours, showed understanding and patience when interacting with them. Overmars-Marx et al. (2014) similarly emphasised the role neighbours have in adapting to people with intellectual disabilities skills. These findings highlight the need for work at a broader community level, to change public attitudes and promote greater understanding and acceptance of people with intellectual disabilities. Amado et al. (2013) highlighted how professionals and staff play a key role in providing information to neighbours to facilitate connections between them and people with intellectual disabilities, helping to bridge the social divide.

The importance of community presence or community familiarity in facilitating social inclusion was highlighted within this review. This may be achieved by either having family in the community or having lived there a long time. Having this presence can enhance a sense of connection and provide social capital. The current review also discussed the importance of having valued social roles, which people were more likely to have if they were longstanding members of the community. Overmars-Marx et al. (2014) described how these roles can help to promote positive perceptions of people with intellectual disabilities as people who contribute to their communities, rather than a focus on their deficits. Playing a purposeful role in one's community leads to a feeling of being part of the collective and increases a sense of belonging (Strnadova et al., 2018). This can also be achieved through people with intellectual disabilities being offered more employment opportunities in the community to highlight the valuable contributions they can make to communities and society.

A lack of transport was a common barrier to taking part in social activity. People with intellectual disabilities in the reviewed studies were often reliant on family or support staff to provide transport. A reliance on others meant people often missed out on opportunities due to issues like poor staffing levels or illness. Transport difficulties has been a longstanding concern (Abbot & McConkey, 2006; Beart, Hawkins, Kroese, Smithson & Tolosa, 2001) and highlights the value of independent travel training in helping individuals to have choice and control in their lives and the ability to arrange more spontaneous activities. Using public transport also increases community presence.

Finally, it is important to note that some participants in the reviewed studies were happy with their current level of social activity and did not wish to have more social contacts at work or in their neighbourhood. It has been suggested that people may be avoiding social situations because they wish to avoid discrimination (Hall, 2009), or may just be as a result of personal preference (Amado et al., 2013). Policy documents such as The Keys to Life (Scottish Executive, 2013), emphasise the need to ensure people receive support in a way that promotes choice and provides a sense of agency. However, each individual’s needs and preferences should be considered in relation to social inclusion.

Limitations

A number of measures were put in place to ensure the analysis was carried out in a robust and transparent manner. These included a second independent rater conducting a quality appraisal review of the articles. In addition, the theme formation and interpretation were discussed with a second researcher to ensure the integrity of the data was not lost in the synthesis. A reflective diary was also used throughout the process of analysis to capture key decisions that were made.

The studies included in this review explored the views of adults. However, a broad age range of participants was included in the studies, living in different circumstances. Moreover, the studies focussed on home or work life. Hence, the different views expressed in the studies might have reflected particular individual characteristics, life stages, life circumstances or the different aspect of their lives they were being asked about. Interestingly, however, common themes did appear to emerge from across the different studies and were consistent with the wider literature in this field.

This is an evolving area of research, with the life circumstances of individuals with intellectual disabilities changing as a consequence of new legislation and policies and practices. Hence, it is important to continue to chart whether there is movement in the direction of social inclusion.

Implications for services and policy makers

The review findings indicate that social inclusion is greater than mere presence in the community. It involves forming meaningful connections with a variety of people including family, support workers, friends and acquaintances, who all play a differing role in the individual’s life and meet various practical, emotional and social needs. From the reviewed studies, concerning the experiences of people with intellectual disabilities, it would appear that society is far from realising the goal of “true” social inclusion.

One of the most important barriers highlighted within the review was the prejudice and discrimination they continue to face from employers, colleagues and members of their communities. More education and awareness training are required for the general public, alongside targeted work with employers and support workers, to highlight what they can do to support individuals with intellectual disabilities to form meaningful connections in their workplaces and neighbourhoods. There are also practical implications, in terms of the priority given to supporting people’s social aspirations and the funding available to provide access to opportunities. This may require support organisations to recognise the need to focus on a person with intellectual disabilities emotional and physical wellbeing rather than just their practical needs. However, this would also require recognition from policy makers about the value of doing so and to make the necessary funding available. Considering the impact loneliness and a lack of inclusion can have on mental wellbeing, the risk of failing to meet people’s emotional and social needs may mean that they will require greater support from services in the long-term.

Investment in the development of people’s independent travel and social skills may also help to increase their community presence and options to participate in social activities. Some skills-based training could be implemented, enabling the development of these skills. This would result in their increased independence, a sense of agency and thus improving their quality of life.

Future research

These review findings highlight how service practices can act as a barrier to social inclusion. Future research should examine how services balance their efforts to ensure the safety of service users with responding to the rights and choices of people with intellectual disabilities. A particular focus on how decisions are made about supporting people’s social opportunities and what factors are considered, may help inform policies and practices.

Conclusion

The current review draws attention to people with intellectual disabilities’ continued desire to be accepted by their neighbours and work colleagues. However, the participants in the studies also demonstrated considerable insight into some of the main barriers and facilitators to achieving greater social inclusion. Perhaps it is time to act on their advice.

References

Abbott, S. & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. Journal of Intellectual Disabilities, 10 (3), 275-287.

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, *51*(5), 360–375. https://doi.org/10.1352/1934-9556-51.5.360

Anderson, S., & Bigby, C. (2015). Self advocacy as a means to positive identities for people with intellectual disability: we just help them, be them really. *Journal of Applied Research in Intellectual Disabilities, 30* (1), 109-120.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, *18*(1), 47–56. https://doi.org/10.1111/j.1468-3148.2004.00218.x

Beart S., Hawkins D., Kroese B. S., Smithson P. & Tolosa. I. (2001) Barriers to accessing leisure opportunities for people with learning disabilities. British Journal of Learning Disabilities 29, 133–8.

Byhlin, S. & Käcker, P. (2018). ‘I Want to Participate!’ Young Adults with Mild to Moderate Intellectual Disabilities: How to Increase Participation and Improve Attitudes. Scandinavian Journal of Disability Research, 20(1), pp. 172–181. DOI: https://doi.org/10.16993/sjdr.58

Cobigo, V., Ouelette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action, 2(2), 75-84.* DOI10.5463/SRA.v1i1.10

Crisp, R. (1996) Community integration, self-esteem, and vocational identity among persons with disabilities. Australian Psychologist, 31, 133–137.

Cummins, R. A., & Lau, A. L. D. (2003). Community Integration or Community Exposure? A Review and Discussion in Relation to People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, *16*(2), 145–157. https://doi.org/10.1046/j.1468-3148.2003.00157.x

Department of Health (2001) Valuing people: A new strategy for learning disability for the 21st century. London: Her Majesty's Stationary Office.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., … Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, *19*(4), 285– 295. https://doi.org/10.1111/j.1468-3148.2006.00263.x

Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health and Place*, *11*(2), 107–115. https://doi.org/10.1016/j.healthplace.2004.10.007

Hall, S. A. (2009). The social inclusion of people with disabilities: A qualitative meta-analysis. *Journal of Ethnographic & Qualitative Research*, 3, 162-173.

Hall, S.A. (2017). Community Involvement of young adults with intellectual disabilities. Their experiences and perspectives on inclusion. Journal of Applied Research in Intellectual Disabilities, 30 (5), 859-871.

Hill, R. A., & Dunbar, R. I. M. (2003). Social network size in humans. Human Nature, 14(1), 53–72. doi:10.1007/s12110-003-1016-y

Hunter, S. & Perry, R.W. (2006) Social inclusion and choice for adults with learning disabilities: Some lessons from reprovisioning, Practice, 18:3, 207-219, DOI: 10.1080/09503150600904169

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

McVilly, K., Stancliffe, R., Parmenter, R., & Burton-Smith, R. (2006). 'I get by with a little help from my friends': Adults with intellectual disability discuss loneliness. Journal of Applied Research in Intellectual Disability, 19, 191–203. doi:10.1111/j.1468-3148.2005.00261.x

Merrells, J., Buchanan, A. & Waters, R. (2017). "We feel left out": Experiences of social inclusion from the perspective of young adults with intellectual disability, Journal of Intellectual & Developmental Disability, DOI: 10.3109/13668250.2017.1310822

Noblit, G. W., & Hare, D. R. (1988) Meta-ethnography: Synthesising qualitative studies. Newury Park, CA: Sage Publications.

Overmars-Marx, T., Thomése, F., Verdonschot, M., & Meininger, H. (2014). Advancing social inclusion in the neighbourhood for people with an intellectual disability: An exploration of the literature. *Disability and Society*, *29*(2), 255–274. https://doi.org/10.1080/09687599.2013.800469

Overmars-Marx, T., Thomese, F. & Meininger, H. (2019). Neighbourhood social inclusion from the perspective of people with intellectual disabilities: Relevant themes identified with the use of photovoice. Journal of Applied Research in Intellectual Disability, 32, 82-93.

Scottish Executive (2000) The same as you? A review of services for people with learning disabilities. Edinburgh: Scottish Executive.

Schwartz, C., and S. Rabinovitz. 2001. "Residential Facilities in the Community for People with Intellectual Disabilities: How neighbours' Perspectives Are Affected by the Interaction of Facility and Neighbour Variables." Journal of Applied Research in Intellectual Disabilities 14: 100–109.

Schalock, R. L., Keith, K., Verdugo, M. A., & Gómez, L. E. (2010). Chapter 2: Quality of life model development and use in the field of intellectual disability. In Kober, R. (ed.) *Enhancing the Quality of Life of People with Intellectual Disabilities: From Theory to Practice (pp.17-32)*. Netherlands: Springer. https://doi.org/10.1007/978-90-481-9650-0

Scior, K., Kett, M., Hastings, R., Werner, S., Hamid, A., Belton, C., … Patel, M. (2015). *Intellectual Disabilities: Raising Awareness and Combating Stigma- a Global Review*. (September). https://doi.org/10.13140/RG.2.1.4021.5528

Scottish Government (2013) The Keys to Life- Improving Quality of Life for People with Learning Disabilities. Edinburgh: Scottish Government.

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

Strnadová, I., Johnson, K., & Walmsley, J. (2018). "… but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities? *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1091–1102. https://doi.org/10.1111/jar.12469

Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., … Yeager, M. H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, *47*(2), 135–146. https://doi.org/10.1352/1934-9556-47.2.135

Van Alphen, L.M., Dijker, A.J.M., van den Borne, H.H.W. & Curfs, L.M.(2009). The significance of neighbours: views and experiences of people with intellectual disability on neighbouring. Journal of intellectual Disability Research, 53 (8), 745-757.

Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Impact of environmental factors on community participation of persons with an intellectual disability: A systematic review. *Journal of Intellectual Disability Research*, *53*(1), 54–64. https://doi.org/10.1111/j.1365-2788.2008.01128.x

Walsh, D. & Downe, S. (2006) Appraising the quality of qualitative research. Midwifery 22: 108-119.

Welsby, J. & Horsfall, S, D. (2011). Everyday practices of exclusion/inclusion: Women who have an intellectual disability speaking for themselves? Disability & Society, 26 (7), 795-807.

Wilson, N.J., Jacques, H., Johnson, A. & Brotherton, M.L. (2017). From social exclusion to supported inclusion: Adults with intellectual disability discuss their lived experiences of a structured social group. Journal of Applied Research, 30, 847-858.

Chapter 2: Major Research Project

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

Word count: 9310 (including quotes and references)

Prepared in accordance with authors' guidelines from the Journal of Applied Research in Intellectual Disability (see appendix 1, p70)

Plain English Summary

TITLE: The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

BACKGROUND: Research has highlighted that people with intellectual disabilities value support (Bigby, Bould & Beadle-Brown, 2017) but they can also experience dissatisfaction with how it is delivered (Giesbers, Hendriks, Jahoda, Hastings & Embregts, 2019). Giesbers et al. (2019) also reported some mixed feelings about telling people in their communities they were supported, suggesting a fear of negative judgement. Further research is required to explore how these experiences of receiving support may impact upon how people with intellectual disabilities view themselves.

AIM: This study aimed to explore people with intellectual disabilities' perceptions about their support and explore in more depth, whether this had an impact on how they view themselves.

METHOD: Ten adults aged between 24 and 36 years old with a mild or moderate intellectual disability, living within their own tenancy or clustered housing and in receipt of support were recruited. Participants were recruited from a number of support organisations across the West of Scotland. Semi-structured interviews were carried out, the interviews were recorded and written word for word. Interviews lasted between 32 and 60 minutes. The data were analysed using an approach which explores the lived experiences of those taking part.

RESULTS: Analysis identified two overarching themes: 1) support feels like a need and a comfort; 2) Acceptance of support is influenced by the sensitivity of its delivery. Personal histories were found to impact on individual's ability to trust others and form meaningful connections. Participants (in the study) were also found to fear disclosing to others that they were supported. This was due to fear of being negatively judged, as they had experienced in the past. They would therefore introduce support workers as friends rather than support staff to avoid these judgements.

CONCLUSIONS: How support is delivered to individuals with intellectual disabilities can impact upon how they see themselves. Important factors within this are the sense of control they have over their support and whether they feel respected and valued. Services should consider the aspects of support valued and what changes can be made to promote positive identities. This study highlighted the need for people with intellectual disabilities to be involved in choosing their support staff to determine if they can form a meaningful connection. They should also be involved in their support planning to ensure it meets both their needs and expectations. Finally, careful consideration should be given to where individuals are placed in the community to ensure they have opportunity to connect with others and be close to their established support networks.

REFERENCES

Giesbers, S.A.H., Hendriks, L., Jahoda, A., Hastings, R.P. & Embregts, P.J.C.M. (2019) Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32, 446-456.*

Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *42*(4), 309–319. https://doi.org/10.3109/13668250.2016.1253051

Word count: 500 (with references)

Abstract

Introduction

Research has highlighted that people with intellectual disabilities value their support but also report areas of dissatisfaction in how it is delivered. Previous research has also been conducted on the stigma associated with having an intellectual disability, but little research has emerged on the impact being supported has on their sense of identity.

Method

Ten adults aged between 24 and 36 years with a mild or moderate intellectual disability, living within their own tenancy or supported accommodation and in receipt of paid support were recruited. Semi structured interviews were carried out and data were analysed using Interpretative Phenomenological Analysis.

Results

Analysis identified two overarching themes: 1) support feels like a need and a comfort; 2) Acceptance of support is influenced by the sensitivity of its delivery. Personal histories were found to impact on individual’s ability to trust others and form meaningful connections.

Conclusions

The way support is delivered to individuals can affect the sense of control they have over their lives and feelings of being respected and valued, ultimately impacting on their self-identity. Services should consider the aspects of support valued and what changes can be made to promote positive identities.

Keywords: intellectual disability, support, identity, Interpretative Phenomenological Analysis, experiences

Introduction

Current UK policies including The Keys to Life (Scottish Government, 2013) and Valuing People Now (Department of Health, 2009), highlight the importance of people with intellectual disabilities playing an active role in determining the support they need. These policies employ person centred principles. Person centred principles focus on helping people with intellectual disabilities feel more included in society, have more control over life decisions and be supported to achieve their aspirations (Thompson et al., 2009). The approach also aims to focus less on deficiencies and more on bridging the gap between peoples' competencies and what is required to function in society, through the introduction of support (Thompson et al., 2009).

People with intellectual disabilities live within residential environments such as independent tenancies with outreach support (dispersed housing) or cluster housing settings (Scottish Government, 2013). Cluster housing often consists of a number of small houses situated on the same site within a location in the wider community (Mansell & Beadle Brown, 2009). These individuals may still receive support, but a number of support workers may cover the site. In both housing environments people with intellectual disabilities may receive different levels of support from paid support workers. Considering the UK's focused policies (Scottish Government 2013, Department of Health, 2009) towards improving the quality of life of people with intellectual disabilities, it is important to explore their views in relation to the support they receive.

A number of researchers have investigated the views of people with intellectual disabilities' in regard to the support they receive and their relationships with support staff (Bigby, Bould & Beadle-Brown, 2017; Clarkson, Murphy, Caldwell & Dawson, 2009; Dodevska & Vassos, 2013; Giesbers et al., 2019; Hatton, Wigham & Craig, 2009). These studies indicated that people with intellectual disabilities greatly valued support workers' interpersonal skills such as being a good listener, kind, honest,

respectful as well as their sensitivity in how they delivered the support (Clarkson et al., 2009; Dodevska & Vassos, 2013; Hatton et al, 2009).
Hatton et al. (2009) and Dodevska and Vassos (2013) interviewed both people with intellectual disabilities as well as accommodation managers. Both studies found that accommodation managers appeared to value specific knowledge and skills such as awareness of person centred principles or being a team player, in contrast to service users who valued support workers' interpersonal skills. Thus, Hatton et al. (2009) and Dodevska and Vassos (2013) highlight that services may have different priorities and preferences to those of people with intellectual disabilities. This emphasises the need to include people with intellectual disabilities in decisions about their support.

Clarkson et al. (2009) found that participants valued their support workers' ability to build rapport and their willingness to help. They felt valued by their support workers and part of that sense of being valued, was for support workers to recognise their abilities and provide support only when it was needed (Clarkson et al., 2009). Participants in Clarkson et al. (2009) and Bigby et al.'s (2017) studies reported that individuals with intellectual disabilities value the sense of security and reassurance that support provided. However, both studies also highlighted that participants had an awareness that some staff were not interested in spending time with them, were unwilling to help and failed to listen to them.

Service users in Clarkson et al.'s (2009) study highlighted that building trust in their support workers took time for people with intellectual disabilities. Giesbers et al.'s (2019) study reported similar findings and suggested that participants' personal histories affected their ability to form close relationships with not only their support workers but also people in the wider community. Giesbers et al. (2009) suggested that the personal histories of individuals with intellectual disabilities influenced the kind of support they valued. Many participants reported that not being consulted about changes to their support and a high turnover of staff made it difficult to form close relationships and resulted in many feeling a sense of rejection or abandonment (Giesbers et al., 2019). This again emphasises the importance of people with intellectual disabilities having an active role in decision making about their support.

Giesbers et al. (2019) found that within their sample, participants had an awareness of negative societal attitudes towards those with intellectual disabilities who receive support. Some individuals with intellectual disability reported prejudice and rejection when people in the community found out about where they lived. These public attitudes contributed to participants' ambivalent attitudes about receiving support. Participants of the study highlighted their feeling of difference and a reluctance to express to others where they live for fear of negative judgements, discussing an "us" and "them" distinction. According to Mead (1934), a key factor in the development of the self-concept is that of becoming an object to oneself, reflecting upon how as individuals we are treated by significant others. Cooley (1956) also refers to this as the "looking glass" self, where a person becomes aware of themselves in the evaluative responses of others around them. Therefore, an awareness of stigmatisation towards oneself is likely to threaten a person's sense of adequacy and perhaps also their wellbeing (Jahoda & Markova, 2004). Dagnan and Waring (2004) found that core negative beliefs about the self were positively associated with the experience of feeling different and suggested this as a process of internalising the experienced stigma.

In Giesbers et al.'s (2019) study, one participant seemed to emphasise that being in receipt of support services highlights a key difference and an undesirable identity as a person with a disability in need of support. Goffman (1963) referred to this as a "spoiled identity". Giesbers et al.'s (2019) study highlighted how participants struggled accepting that label of disability which suggested a difference and made them vulnerable to negative judgements and rejection from others. As a result of this difficulty accepting a label of disability, participants therefore struggled to accept their need for support, despite having an awareness of the need for it.

What the research suggests is that support is valued by some, however others struggle with accepting that they need support within certain areas to function in society (Giesbers et al., 2019). In addition, a number of studies highlighted that the way support is delivered i.e. the sensitivity in which it is delivered, impacts upon their sense of satisfaction with it (Bigby et al., 2017; Clarkson et al., 2009; Dodevska & Vassos, 2013; Giesbers et al., 2019). Previous research has suggested that being in receipt of support may impact upon identity (Giesbers et al., 2019). Therefore, this study aims to explore people with intellectual disabilities' perceptions about their support and explore in more depth, whether this has an impact on their identity.

Interpretative Phenomenological Analysis (IPA) is a qualitative approach which can be used to explore a participant's lived experience and how they make sense of this in relation to their place within the world (Smith, 2004). IPA is an idiographic and hermeneutic approach and therefore aims to gather an in-depth account of the participant's experiences. The information gathered is the researcher's attempt to make sense of the participant views, making IPA a double hermeneutic approach. IPA has been successfully used to explore the identity of people with intellectual disabilities in previous research (Groves, Rayner & Muncer, 2017; Wilkinson, Theodore & Raczka, 2015) and thus, the most appropriate approach for this current study.

Method

Participants

Participants were eligible to take part if they had a diagnosed mild to moderate intellectual disability and were either living independently within their own tenancy or within shared accommodation and in receipt of support services. They had to be within the age range of 18 to 40 years to ensure all those taking part are at a similar life stage. In addition, English was required as a first language and participants were required to have sufficient verbal skills to be able to recall and discuss a recent experience. To be included they also needed to be able to provide informed consent. Participants were only excluded from taking part if they had any additional difficulties which prevented them from engaging in the interview process.

A purposive sample of ten participants with mild to moderate intellectual disabilities, in receipt of support services across a local government area in the West of Scotland agreed to take part in the study. The diagnosis of mild or moderate intellectual disability and other inclusion criteria were confirmed by their support organisations. This sample size was in keeping with Smith, Flowers and Larkin’s (2009) recommendations.

The participants’ ages ranged from 24 to 36 years old, with a mean age of 30.4 years and included 5 men and 5 women. All participants received regular one to one support. Some participants who lived in shared accommodation also had the option of access to additional support 24 hrs a day. Staff were either based in the participant’s home or in an adjacent building, as part of a core or cluster model of housing. The number of hours of support received, ranged from 2 hours of support per week to up to 12 hours per day, depending on their identified need. Characteristics of the participants are listed in Table 1. Pseudonyms are provided to protect anonymity.

TABLE 1: Characteristics of the participants

Variable	**Michael**	**Sarah**	**Ian**	**David**	**Gillian**	**Linda**	**Paul**	**Alison**	**Harry**	**Kirsty**
Gender	Male	Female	Male	Male	Female	Female	Male	Female	Male	Female
Age (years)	26	26	35	36	30	31	36	31	24	29
Living situation	Own tenancy	Shared accom*	Own tenancy	Own tenancy	Own tenancy	Own tenancy	Supported accom*	Own tenancy	Supported accom*	Supported accom*
No of support hours	10 hours a week	24 hour support available plus dedicated support time	12 hours a day	2 hours per week	30 hours a week	10 hours a day	2 hours per day and staff available 24hours	12 hours a day	Staff available 24 hours a day plus dedicated support time	Staff available 24/7 plus dedicated support time
Level of intellectual disability	Mild	Mild	Moderate	Mild	Mild	Moderate	Mild	Mild	Moderate	Moderate
Employment/ work placement	**VWP	No	No	No	**VWP	No	No	No	No	**VWP
Family support * **	Limited	Limited	Limited	Limited	No	No	No	Limited	No	No

**Supported accommodation*

** *Voluntary work placement*

*** Limited family support means just seeing family in a social capacity approximately once a week.

Semi-Structured interview

Semi-structured interviews were used in keeping with the IPA method. An interview schedule was created identifying key topic areas. A review of relevant literature looking at people with intellectual disabilities' views of support as well as key research in the area of stigma and identity informed the interview questions (BIgby et al., 2017; Clarkson et al., 2009; Dagnan & Waring, 2004; Dodevska & Vassos, 2013; Giesbers et al., 2009; Jahoda & Markova, 2004; Jahoda, Wilson, Stalker & Cairney, 2010). Topic areas included a) gathering information about the type of support they receive; b) exploring their experience of receiving support and the way it is delivered; c) what support they think they need and how this compares with what's provided; d) exploring the relationships they have with the staff supporting them e) how support is viewed in the community. An iterative approach was used. Specific questions about identity were not asked in the interviews because the researcher did not wish to unduly influence the participants' accounts. Instead, the aim was to explore the subject of identity as an aspect of the participants' experiences. The first few participants' interviews were reviewed and discussed with the research team to determine how the approach to interviewing was working and led to minor changes to improve the structure and flow of the interview. These involved changes to the way questions were asked to make them more understandable as well as changes to the order of questions to stimulate a more natural discussion of experiences. All interviews were included within the analysis. The interview schedule can be viewed in appendix 9, p113.

Procedure

Upon meeting the participant, the researcher went through the information sheet both verbally and with the use of pictures to ensure the participant understood the purpose of the study, what it involved, the positive and negative aspects of taking part as well as their right to withdraw at any time. This was in accordance with the procedure for gaining informed consent recommended by Arscott, Dagnan and Stenfort Kroese (1998). The information sheet and consent form can be viewed in appendices 7 and 8, p102 and p110.

Nine of the participant interviews took place in their homes and one participant interview took place in a private room within the support organisation offices. Two participants wished their support workers to be present at their interviews. The support workers were asked to treat the information shared in the interview as confidential and not to be discussed with other members of the team without the participant's consent.

Interviews were conducted by the primary researcher and lasted from between 32 mins to 1 hour, with a mean duration of 41 mins. Although there was a proposed structure to the interview, it was a discursive approach which allowed them to raise additional topics that could be explored in their interview.

The interviews were audiotaped with the participant’s informed consent and transcribed verbatim. Pseudonyms were used, and all identifiable information removed to ensure anonymity for the participants.

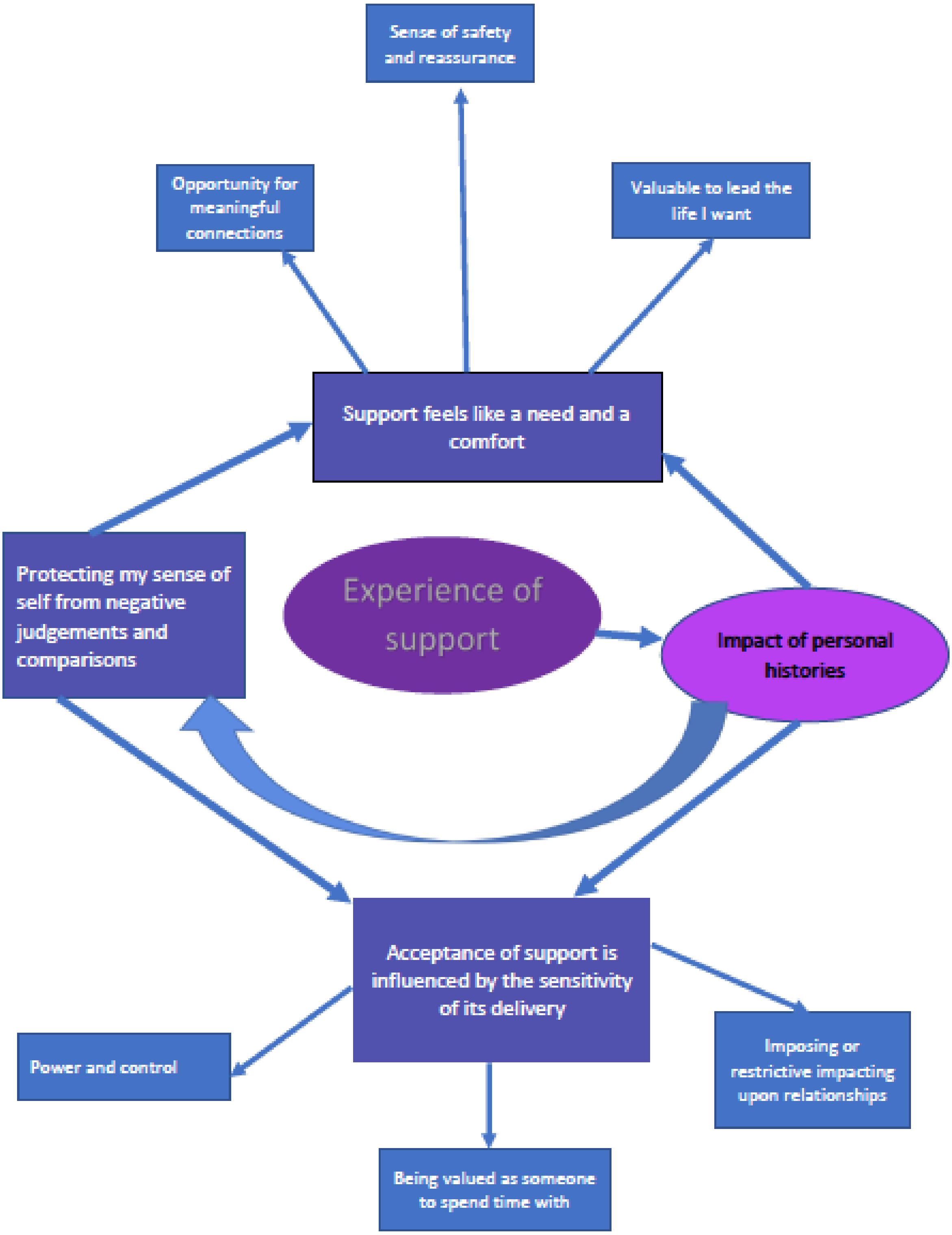
Data Analysis

Analysis was conducted using Interpretative Phenomenological Analysis (IPA). IPA allows an in-depth exploration of the participant’s experience, including how they see themselves and their place within the world. The analysis followed the procedure as suggested by Smith, Flowers and Larkin (2009). Recordings were transcribed by the researcher to allow for full immersion in the data. Transcriptions were then read on a number of occasions and key information highlighted. Key aspects of how the participant described their experience were explored, including evidence of any strong emotive comments, interesting use of language or contradictions in what was being said. The main themes were identified, and summaries of each of the participants’ narratives were also completed, to ensure the analysis remained linked to the participants’ individual experience and perspectives. Connecting themes were combined and a descriptive label applied to the overarching themes which were developed. Two transcripts were reviewed with the research team in supervision, to audit the analysis process and decision making. Following this, the analysis was then completed for all the participants. The initial stage of the analysis involved producing a diagram of the subordinate and superordinate themes, to illustrate the broader patterns across participants. The diagram was developed with the input of the research team and is shown in Figure 2. A reflective diary was also kept, monitoring the process of decision making when determining themes.

Ethical Considerations

Ethical approval was obtained from the College of Medical, Veterinary and life Sciences, University of Glasgow Ethics Committee (Appendix 6, p101).

Figure 1: Diagram of identified themes



Results

Through this research two superordinate themes emerged 1) Support feels like a need and a comfort, and 2) Acceptance of support is influenced by the sensitivity of its delivery. Within each superordinate theme, subordinate themes were identified. Within 1) Support feels like a need and a comfort, the subordinate themes identified included: sense of safety and reassurance; opportunity for meaningful connections and finally valuable to lead the life I want.

The subordinate themes that fell within 2) Acceptance of support is influenced by the sensitivity of its delivery included: Power and control; Imposing and restrictive impacting upon relationships and finally being valued as someone to spend time with. In addition, intertwined within these identified themes were the influences of the impact of personal histories as well as a need to protect their sense of self from negative comparisons or judgements that threaten this. The superordinate and subordinate themes are presented pictorially in Figure 2.

1: Support feels like a need and a comfort

Sense of safety and reassurance

For eight of the participants, there was a clear recognition that having support helped them feel safe and reassured. Having this support enabled them to live alone, go into town and provided them with the support they needed to live daily life. This could be understood in the context of the participants’ past histories which included experiences of being abused, exploited or ridiculed by other people. Many of the participants also discussed how the presence of workers enabled them to manage their responses to others as they felt safe.

> *I need that support to go out… so I can go out places… I wouldn't go out anywhere… I would be too anxious to go out myself… (with support workers there) I won't be alone then. (Linda)*

> *I can phone, there's this button you can phone for someone on call, it's like you press the button, it can go to manager's phone and they can be down here straight away… so if my family does come to that door, I can call that button and the manager can come down straight away. it feels that, if anybody comes to that door in the middle of the night I can press it and then it'll be ok. Then I know somebody's coming. (Gillian)*

> *Sometimes I hear shouting (from neighbours) … I phone staff and they come and make it better. (Harry)*

Valuable to live the life I want

All of the participants described the tasks support workers help them with; including shopping, housework, administering medication, bills, budgeting and taking them to appointments. However, eight participants emphasised the importance being supported had, enabling them to live the lives they wanted and how vital this support was for their functioning.

> *They do cooking, clothes on, showering, teeth and face, at night they put my jammies on. That I can't do myself. I cannot do it myself. They clean my house, I'm supported to do it, I'm working off a cleaning rota… It's a bit strange when I'm here myself between the (support) hours by myself. If I could I would get all the support they could give me, but I know they can't, they are on a budget…if I had more then I would go out more and I'd visit family more. I don't get to see my family as often as I'd like. (Ian)*

> *(They support) just everyday life in general. They help me get out and about. If I didn't have staff, I'd be stuck in the house…I do have family, but they work and they…there's young kids in the family...I've had support since I was sixteen because I was obviously, I wanted to get out and do some things and my mum and sister were working and my step dad wasn't there at that point.*

> *So, I had day services coming in…and I'd go out with day services… (so they) obviously support me to do things day to day and not just sitting about the house. (Alison)*

Both Ian and Alison had physical disabilities in addition to having an intellectual disability. Receiving support was vital not only for their practical needs but also their general wellbeing. They valued having the company of their support workers and the ability to access their community.

One participant highlighted the important role staff play in providing much needed stability and structure in his life, as Michael describes:

> *I often think about what I'd be doing if they weren't because I'd just be drinking all the time, you know. If they didn't… A help. I hate it but I love it at the same time… if I need money, for daft things that I want, like if I want to buy something stupid I couldn't do it, that's a good thing for me. Because I would just buy, buy, buy constantly… if they weren't there everywhere would be a tip, the house would be upside down and my routine would be all over the place. So when they are there everything's fine. (Michael)*

One participant described the presence of support as helping to build his confidence and talked about working towards becoming more independent. He highlighted the role support workers played in helping him pay his bills, do food shopping and cook; skills he was now learning after the death of his mother. In several instances, participants felt that support staff had taken on the role family members had previously played in promoting their independence.

> *I feel a lot confident now. Em my confidence got back up..em…by them helping me so it is…I'm not as, I can um… do things that I couldnae used to do before like cook, do cooking like, I used to cook years ago but em I didn't bother with cooking anymore but now I'm building cooking back up again. (David)*

Therefore, most participants highlighted how support was vital for them to live the lives they wanted to, as not only did it provide them with practical support, but opportunities to develop independent skills, provided structure and support and also access to their communities and activities. These were identified as key in living the lives they wanted to live.

Opportunity for Meaningful Connections

Nine of the participants highlighted the value of forming meaningful relationships with support workers, with some commenting that this lasted even after the worker had left the support organisation.

> *Yeah I still keep in contact with her. I've had a lot of support workers come and go over the years. My original team, Hugh, I like him, I still keep in contact with him. Yeah I got on really well with a guy, he left for another job so he did, he showed up at my Papa's funeral on his day off. (Michael)*

> *It's good because you get to ken them and everything. When they leave they keep in touch with you (Gillian)*

In addition, participants highlighted the importance of the relationships they have with staff and how they value staff, often seeing them more as friends than workers:

> *I like to do that… Going out for my lunch and going shopping with them… because I'm going out with all the staff in here and I get to spend time with them… like all the staff that are in here… its good getting support… it's (good) getting out, emm chatting emm and being pals with my support workers. (Kirsty)*

> *I'm quite close to a lot of my staff like Nigel I've known him for the last 8 years I've been getting support. They are more like friends than support workers… if there is anything worrying me I always go to them… (they) give us a bit of company, give us a laugh so they do. And they have all got like individual interests, but a lot of my interests are the same as theirs. Nigel for example is*

> *fishing, David likes playing Xbox, Stephen has the same taste in music, like the Killers so different interests but the same really… I'm hoping this new guy is a good match. (Michael)*

> *when I go out shopping I go out for my lunch on a Tuesday so me and my staff have lunch and we just talk about things and how our week's been and that, its just about that… to see what they were up to at the weekend and they ask how you have been and all that sort of stuff. It's really nice when somebody says that to you… It makes you feel good. (Sarah)*

These participants highlight the value they place on the relationships they have with support workers and how key this in making them feel good about themselves. As evident in their quotations, participants viewed their support workers as friends and sought reciprocal interactions from them, identifying this as a good aspect of being supported. In addition, Michael emphasises the importance of matching support workers to ensure they are people with whom individuals can form meaningful relationships. These relationships are what participants particularly valued.

Participants also felt that having these longer-term relationships with their support workers provided an opportunity to broaden their social networks. For instance, a number of participants talked about workers supporting them to attend an organised group known as 'Dates n Mates'. This group provides opportunities for people with intellectual disabilities to develop both friendships and romantic relationships.

> *Uh I met them through bowling, I went to an activities group because my support worker said to me that why don't you go to get involved in activities just to kinda get me out of the house as well. That's when I started meeting new people. (David)*

In the comment above, David highlights the important role his support workers have in suggesting activities and encouraging participants to build a social network. This was key in David's circumstances as he received very few support hours and it was important that he sought meaningful connections with people other than his support workers to avoid feeling lonely.

Protecting my sense of self from negative judgements and comparisons

Although many of the participants described the value of being supported, some also felt that needing and receiving support created a sense of being different to others. Five participants discussed this challenge of how people with intellectual disabilities are at times seen by others and the impact of this on them. One participant commented that he would often introduce his worker as a friend or family member, rather than saying they supported him. He talked about being relieved when others could not tell he was being accompanied by support workers rather than friends. He went on to describe the negative attitudes of a friend when he disclosed that he received support, with the friend thinking he was perhaps ‘crazy’ or someone to be wary of. He suggested that this was due to his friend’s ignorance about why some people require support. He went on to explain that his friend’s view changed once he got to know him better. It seemed that some participants felt unsafe about revealing their need for support, fearing they would face negative judgements from others in the community.

Thus, the participants clearly recognised that support played a vital role in helping them realise their aspirations, however, equally there was a level of ambivalence about being supported and about others knowing that they received support. This ambivalence was reflected in contradictory statements, such as saying that they did not need support but then going on to list a number of activities and skills they required support workers to help them with.
This can be understood in the comments some participants made in relation to how people in the community perceive people with disabilities who need support. For instance, Michael stated:

> *Sometimes they think you are a bit doolally in the head… what do you need support for, what have you done? You know, that kinda thing. There’s a guy I*

> *work with doing my home jobs, I told him, then at first he didn't kinda get it but then he got to know me and he has realised that there's nothing really wrong, that I get support. So, I do. I think it depends if the disability is visible. Em, I know there's a few people up here, people were making fun of. Like people with Down Syndrome, you can see that and if they are getting support. The likes of myself they just think aw he's out with friends or family. (Michael)*

This comment highlights an awareness of negative judgements being made about people who require support and a perception that they need to be wary of them. Michael describes witnessing others being ridiculed and appears to manage this stigmatised identity by making a downward comparison to someone with a visible disability who may be less able to disguise their need for support. He therefore suggests that he managed to protect himself from this by creating the guise that support workers were his friends or family members.

Linda also talks about how people who are supported are viewed in the community:

> *cause some people (pause) take the mickey out of folk when they need supported or they are disabled or something and obviously that's not fair on them (Linda)*

She emphasises how unfair it is that people with disabilities have to endure being ridiculed for having a disability and appears to suggest that having a disability is a devalued identity within society.

2. Acceptance of support is influenced by the sensitivity of its delivery

Power and control

Four participants reflected on how support is delivered and the impact this can have on how they feel about being supported. For example, Gillian expressed unhappiness about the delivery of her support. She felt staff were bossy and patronising and had a tendency to treat her as though she was a child. Thus, while she appreciated the support she received, she felt that her staff's approach did not fit with her perception of being an adult and the control she wanted to have over the tasks of everyday life.

> *Sometimes aye they are too pushy like telling me what to do and everything and I just want to do it all myself, but I know they're here to help me, but they don't need to shout at me every minute. Sometimes I'm angry. Sometimes I need to flip, but no need to shout at me they're not my mum or dad. They are just support workers. (Gillian)*

Kirsty also highlighted this stating:

> *I just didn't like the staff in there…sometimes they were being cheeky sometimes…it made me feel upset…Emm…(saying) you need to go to your bed on time. They would tell me what to do sometimes. (Kirsty)*

Gillian's and Kirsty's views provide insight into the participants' sensitivity about how their support is delivered and the importance of being given a sense of choice and control in their lives.

Imposing or restrictive impacting upon relationships

Five participants highlighted dissatisfaction with perceived restrictions or feeling that support was imposing or intrusive at times. Participants described the experience of being supported as being watched suggesting they were infantilized by their support workers at times.

> They don't need to be over my shoulder a lot and I can do things myself like meeting up with my pal and I don't need them at the back beside me to watch every move I make. (Gillian)

> I've noticed on a few occasions this year as well, they seem to watch me as a hawk for some strange reason which is absolutely and totally unnecessary…and I had to say one day to the persons what the hell are yous

> watching me like a hawk for? I don't think its fair or very advisable that way. (Paul)

Paul and Gillian's comments illustrate the importance of how support is delivered and the effect this can have on how they feel about support.

One participant highlighted that she was not allowed to have people to stay overnight with her. This was due to past experiences of being exploited. She needed the approval of her social worker and support workers before arranging for someone to stay, as she explained:

> *It just feels like my life is getting controlled. You canne have people staying when you want…that's just not fair… That's cause I was letting a lot of people in my house and taking advantage of me and taking my money off me and hanging about with the wrong people so they put me in (accommodation)… keep an eye on me. They are just looking out for us. So, nothing happens to us…so that they can keep an eye on me…all the time…I get fed up looking at them. (Sarah)*

Sarah's comments point to her dissatisfaction about the restrictions placed upon her. However, she appears to hold conflicting views as she also recognises that the workers are acting with good intentions and want to prevent her from being exploited. Thus, in the end, it is difficult for her to resolve the tension between the impact of the workers' actions on her sense of self as someone capable of making her own decisions about her life, and her recognition that she needs support to stay safe.

Another participant discussed the challenges of developing romantic relationships when being supported. She reported her partner's dissatisfaction about workers accompanying her to all their activities, but she felt she had little ability to make changes to this arrangement.

> *I was going with somebody named Liam, he didn't like my staff being with me, he wanted just me and him but I can't help that. Staff have to come with me.*

> *Liam is raging he doesnae want support like. He wants me and him to do things but and don't want staff to come along. (Gillian)*

This again appears to highlight the importance of how support s delivered and how participants need to feel that they have some sense of agency over their lives. It seems that what feels like control or monitoring may be the support organisation's way of ensuring they are safe from exploitation from others given their past experiences however these individuals appear to experience this as controlling and patronising.

Being valued as someone to spend time with

Five participants described the importance of support workers giving them their full attention and being willing to participate in activities with them. One participant talked about her dislike of workers being on their mobile phones when they went out for coffee together. This had made her feel that the workers did not care about her or see her as a valuable person to spend time with. Another participant described an incident where a support worker refused to engage in a joint activity, preferring to watch from the side-lines. This made the participant feel that the worker failed to recognise him as a person or enjoyable to be around. As Gillian and Michael explained:

> *Sometimes when we're getting a coffee they keep checking their phone every minute that (makes me think) they don't want to talk to me and they just wanna check their phone. It's someone called Anna, she's on her phone constantly in work, you're not supposed to go on Facebook at your work and she does it. And she doesn't help with my housework either, she just sits there all day with her phone...she doesn't want to be in work, she's just on her phone every minute…I want them to put their phones away and have a conversation with me. (Gillian)*

> *I felt like he wasn't a carer as such because he didn't care, he was just there for something to do and it was at his own leisure what he done. Because I would say to him "aw can we go go-karting" and he just stood at the side*

> *watching. He wasn't really making the effort though… he was just sitting in the side lines, keeping an eye on me. (Michael)*

Another participant highlighted his annoyance that support workers did not let him know when they would be late for his specified meal support times and appears to feel let down by this.

> Sometimes they don't bother to turn around to say they are going to be late and all that for your tea supports. Sometimes I think to myself, well if they are going to be late then I'm going out. I'm not waiting any longer than I already have. (Paul)

For Paul he seemed to feel very let down by this as he was working with his support workers to learn how to cook his own meals. Paul seemed to feel that support workers did not value spending time with him or failed to prioritise his needs over others at times.

Participants illustrated the need to feel like valuable people to spend time with and this appeared to be influenced by support workers coming being present and taking an interest as well as doing activities with them, experiencing shared enjoyment. Again, this highlights the importance of these relationships being reciprocal as this is what appeared to influence how valued these individuals felt.

Impact of personal histories

Seven participants described having difficulty forming close bonds with support workers. They reported that they often needed time to build these relationships. And highlighted the importance of workers being reliable and consistent as these were identified as key factors in building that sense of trust. The participants who identified this as a challenge talked about having a history of being abused, neglected or exploited by others and having difficulty trusting the intentions of others.
For example, Paul discussed being physically abused by his family and described the impact this had on his ability to form relationships with other people.

> *Most of my life I’ve been subject to violence and uh I’ve been through all that most of my life... Ever since I was born she (his mother) would uh, all because I was out enjoying myself with college friends and that she pushed me down the stairs outside the house and that.... It happened to me quite a lot... I was eventually removed from that environment… Looking back on them anyway it should have been done long before anyway (removal from his mother’s home) …there’s very few folk I can trust after what happened to me when I was younger…if I know them very well for a long time then I do tend to trust them… (Paul)*

Due to these experiences this was why Paul found it so challenging when staff were late to support him at tea time. For Paul this this seemed to reinforce his view that others can’t be trusted or depended on. He also discussed how he has little patience for new workers, preferring those who have known him a long time.

Linda also described finding it difficult being supported which seemed to be influenced by her experiences of being made fun of for being anxious when she was at school. She reported to still experience anxiety, and this seemed to influence the amount of time she could tolerate her support workers being in her home, reporting that she often sent them home early as she needed to be alone, feeling overwhelmed.

> *They support me twelve, twelve til half eight. It’s usually six o’clock when I send them away… because I want more alone time… I was so anxious about going out... I used to think people don’t like me because of my anxiety…I don’t know, I don’t know why I felt like that. I just did… They used to make a fool of me at school (Linda)*

These are just two illustrations of the impact participants’ past histories have had on their ability to form relationships with their support workers and how they experience the support they receive.

Participants’ past histories not only affected how they experienced support and the relationships they had with support workers, but they also impacted upon their acceptance of the identity of someone in need of support. These negative experiences of being ridiculed as described affected their ability to let others know they were being supported. They perhaps feared the identified difference of needing support would lead to a recurrence of negative judgement and rejection. Thus, by introducing them as friends or avoiding disclosing that they receive support, they protected themselves from this negative experience.

Discussion

A key finding in the current study was that similar to previous studies, participants held nuanced views about their support (Giesbers et al., 2019; Bigby et al., 2017; Clarkson et al., 2009). The findings showed that participants valued the support they received but also held strong views about having agency and a position within society.

Consistent with Giesbers et al. (2019), this study highlighted the importance of considering the personal histories of people with intellectual disabilities, in reaching an understanding of how their background experience helped to influence their perspectives about the support they receive. Some participants described how previous experiences of being abused or exploited impacted upon their ability to trust others. High turnover of staff also meant that some participants struggled to form close bonds with their support workers. More positively, some participants described how receiving support provided reassurance and helped them to feel safe (Bigby et al., 2017; Clarkson et al., 2009). They also felt that support workers provided them with confidence to live fuller lives, such as obtaining work placements. A number of participants reported that support workers filled gaps in their limited support networks, providing a person to have coffee with, go fishing or go-karting with. Yet, many participants highlighted a dissatisfaction with the way in which their support was delivered, indicating that they wished to have more control over the people who supported them and the nature of their support. They wanted to feel valued and listened to.

An important finding from this study was that participants particularly valued the company and social support from their workers, and the opportunity to form a meaningful relationship with someone. Van Asselt-Govert et al. (2014) and Forrester-Jones et al. (2006) both highlighted that people with intellectual disabilities often have poor social networks with professionals and support staff playing a significant role. Hence, the value support workers place on their relationships with the individuals they support may have a significant impact on their wellbeing. A sense of self is derived from the evaluative behaviours of others (Cooley, 1956), which means that a good relationship is likely to contribute to a positive view of self.

However, research has found that staff do not often see their role as promoting meaningful relationships between themselves and those they support. Rather they believe that they should be encouraging individuals’ friendships with others (Pockney, 2006). In contrast, the participants in this study wanted support staff to see them as a valuable person to spend time with. Participants were aware when staff were not interested in spending time with them and this was a key area of dissatisfaction. This made them feel that their support workers were not caring. Sullivan, Bowden, McKenzie and Quayle (2016) also found that people with intellectual disabilities wanted to be valued and to have their views respected in their relationships with support workers and professionals.

The current study highlighted the ambivalence participants had about their need for support. Many participants recognised their need for support with certain aspects of their lives but contradicted this by later stating they did not need support. Giesbers et al. (2019) also identified ambivalence in relation to individuals’ stated wish for support. This was sometimes linked to a reluctance to tell others about their support needs and where they lived for fear of being negatively judged or stigmatised. It seems that for some participants, their need for support challenged their views of their own competence and, as a result, their sense of self. This fits with Goffman’s (1963) views of a “spoiled identity”, meaning that to be seen to need support would highlight a difference or “spoiled identity” in comparison with others and subject them to negative judgements and possibly rejection. This view is likely to have also been influenced by past experiences of negative judgements in relation to their disability. This fear of being seen as different or incompetent may have led some of the participants to try to disguise the fact that they were being supported, introducing support workers as friends rather than staff.

The classic longitudinal study by Edgerton (1967, 1993), who charted the journeys of a cohort of individuals with intellectual disabilities when they left a long stay institution in California in the 1970’s also highlighted the sense of agency people with intellectual disabilities desired in their lives. In addition, he highlighted the conflict they had between their wish for agency and their recognition that they needed support. They also wished to be accepted and to be respected in the same way as others in society but, once again, it could be difficult to reconcile this aspiration with their need for support. Similarly, in the current study, a number of participants appeared to feel that their need of support threatened their sense of self as a competent individual. However, this was not the same for all participants, with some valuing the support they received which enabled them to do activities they hadn’t felt confident to do before.

Limitations

This study has provided insight into people with intellectual disabilities’ experiences of support. It shows the complex challenge people have managing an awareness or recognition that they need support with the wish to highlight their competencies. There were however some limitations to this study. The participants were recruited through a small number of service providers from the West of Scotland. The findings may therefore reflect the views of people with intellectual disabilities in particular support services. The experiences of people receiving different types of support may be quite different.

A further limitation is that two participants (Linda and Alison) requested that their support workers remain present during their interviews. This may have affected their ability to express open and honest views about their support, as they may have been reluctant to express negative views with their workers present. However, this did not appear to inhibit Alison’s expressions of dissatisfaction about her support.

It was not possible to check the findings with the participants of the study. This is an important part of the analysis process and should be included in future studies.

Clinical Implications and conclusions

This study highlights how people with intellectual disabilities highly value support which is delivered in a way that makes them feel like they have agency over their lives and makes them feel respected and valued. It identifies the importance people with intellectual disabilities place on their relationships with support workers. They want to be with workers who want to spend time with them, and not people who are just paid to spend time with them. This begs the question about how service providers can meet these aspirations. One step is to include individuals with intellectual disabilities in the recruitment of their own support workers, to help ensure the person applying might be someone with whom they could build a meaningful connection. However, careful consideration also needs to be given to how support can be delivered sensitively, and to help them form meaningful connections in the communities where they live.

In addition, at a policy and organisation level, careful consideration should be given to where individuals are placed in the community, keeping in mind the proximity to family, friends and opportunities for work and socialisation. This would reduce the need for reliance on support staff and increase individuals with intellectual disabilities' confidence and self-esteem and as a result help them to build a more positive sense of self.

Finally, Bigby and Beadle-Brown (2018) highlighted that support organisations should give careful consideration to those they employ as support staff, ensuring they have attributes, values and commitment that fit with the role. This study appears to suggest that at times individuals with intellectual disabilities have experienced being supported by individuals who do not seem to have been suitable to the role. However, at a broader funding and policy level, there also has to be the resource to allow support workers to have the time to provide social and emotional support. This would provide opportunity for support workers to understand the person's history and to support them to lead meaningful lives in their communities. This practice would not only improve physical and mental wellbeing, increasing their quality of life but also contribute to the formation of a positive sense of self.

References

Arscott, K., Dagnan, D. & Stenfert Kroese, B. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.

Bigby, C., & Beadle-Brown, J. (2018). Improving Quality of Life Outcomes in Supported Accommodation for People with Intellectual Disability: What Makes a Difference? *Journal of Applied Research in Intellectual Disabilities*, *31*(2), e182–e200. https://doi.org/10.1111/jar.12291

Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *42*(4), 309–319. https://doi.org/10.3109/13668250.2016.1253051

Clarkson, R., Murphy, G.H., Coldwell, J.B. & Dawson, D.L. (2009). What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual Disability*, 34, 283-289.

Cooley C. A. (1956) Human Nature and the Social Order. (Original York published 1902) Free Press, New York. Craig

Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy*, *11*(4), 247–254. https://doi.org/10.1002/cpp.413

Department of Health. (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities*. https://doi.org/10531

Dodevska, G. A., & Vassos, M. V. (2013). What qualities are valued in residential direct care workers from the perspective of people with an intellectual disability and managers of accommodation services? *Journal of Intellectual Disability Research*, *57*(7), 601–615. https://doi.org/10.1111/j.1365-2788.2012.01565.x

Edgerton, R.B. (1967, 1993). *The cloak of competence*. England. University of California Press.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A, Bechem, J. et al. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long stay hospital. *Journal of Applied Research in Intellectual Disabilities*, 19, 285-295.

Goffman, E. (1963; 1990). *Stigma: notes on the management of spoiled identity*. England; Penguin.

Groves, E., Rayner, K. & Muncer, S. (2017). It's good, they're like me, the same but different: An interpretative phenomenological analysis of the identification of women with down's syndrome. *Journal of Applied Research & intellectual Disabilities,* 1-9.

Hatton, C., Wigham, S., & Craig, J. (2009). Developing measures of job performance for support staff in housing services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 22, 54–64. https://doi.org/10.1111/j.1468-3148.2008.00439.x

Giesbers, S.A.H., Hendriks, L., Jahoda, A., Hastings, R.P. & Embregts, P.J.C.M. (2019) Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32, 446-456.*

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Dsiability Research, 48,* 719-729.

Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with Stigma and the Self-Perceptions of People with Mild Intellectual Disabilities. *Journal of Social Issues*, *66*(3), 521–534. https://doi.org/10.1111/j.1540-4560.2010.01660.x

Mansell, J., & Beadle-Brown, J. (2009). Dispersed or clustered housing for adults with intellectual disability: A systematic review. *Journal of Intellectual and Developmental Disability*, *34*(4), 313–323. https://doi.org/10.3109/13668250903310701

Mead, G. H. (1934). Mind, self and society. Chicago: University of Chicago Press.

Pockney, R. (2006). Friendship or facilitation: People with learning disabilities and their paid carers. *Sociological Research Online*, 11 (3), 1-9. https://doi.org/10.5153/sro.1382

Scottish Government. (2013). *The keys to life: Improving quality of life for people with learning disabilities*. Retrieved from http://www.gov.scot/Publications/2013/06/1123/11%5Cnhttp://185.123.98.6/~keystoli/wp-content/uploads/2015/06/The-Keys-to-Life-Implementation-Framework-and-Priorities.pdf

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in Psychology, 1, 39-54.*

Smith, J.A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. SAGE, London.

Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2016). The Close Relationships of People with Intellectual Disabilities: A Qualitative Study. *Journal of Applied Research in Intellectual Disabilities*, *29*(2), 172–184. https://doi.org/10.1111/jar.12168

Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., … Yeager, M. H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, *47*(2), 135–146. https://doi.org/10.1352/1934-9556-47.2.135

Van Asselt-Goverts, A.E., Embregts, P. J.C.M., Hendriks, A.H.C. & Frielink, N. (2014). Experiences of support staff expanding and strengthening social networks of people with mild intellectual disabilities. *Journal of Community & Applied Social Psychology,* 24, 111-124.

Wilkinson, V.J., Theodore, K. & Raczka, R. (2015). As normal as possible: Sexual identity in people with intellectual disabilities transitioning to adulthood. *Sexuality & Disability, 33*, 93-105.

Appendix 1: Journal of Applied Research in Intellectual Disabilities

JARID

Author Guidelines

Crosscheck

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit **http://authorservices.wiley.com/bauthor/** for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be pubished if such research has been conducted in full accordance with ethical principles, including the **World Medical Association Declaration of Helsinki** and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.
All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.
Ethics of investigation: Papers not in agreement with the guidelines of the **Helsinki Declaration as revised in 2013** will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at **www.consort-statement.org**. A CONSORT checklist should also be included in the submission material (**www.consort-statement.org**).
The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: **www.clinicaltrials.org**, **www.isrctn.org**. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.
The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

Source of Funding: Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

2.5 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

2.6 Copyright Assignment

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:
CTA Terms and Conditions
http://authorservices.wiley.com/bauthor/faqs_copyright.asp

3. ONLINEOPEN

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):
Creative Commons Attribution License OAA
Creative Commons Attribution Non-Commercial License OAA
Creative Commons Attribution Non-Commercial -NoDerivs License OAA
To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services **http://authorservices.wiley.com/bauthor/faqs_copyright.asp** and visit **http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html**.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal’s compliant self-archiving policy please visit: **http://www.wiley.com/go/funderstatement**.

5. **SUBMISSION OF MANUSCRIPTS** Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to **http:// mc.manuscriptcentral.com/jarid**. If this is the first time you have used the system you will be asked to register by clicking on ‘create

an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:
1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.
Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.
By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at **https://authorservices.wiley.com/statements/data-protection-policy.html**.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length. Words in

Tables, Table captions/legends, Figures and Figure captions/legends are excluded in the limit.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at **http://authorservices.wiley.com/bauthor/english_language.asp**. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.
-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.
Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

APA - American Psychological Association
References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.
A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the **APA FAQ**. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

Journal article
Example of reference with 2 to 7 authors
Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483
Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain, 126*(4), 841-865. doi: 10.1093/brain/awg076
Example of reference with more than 7 authors
Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sec differences in developmental reading disability: New findings from 4 epidomiological studies. *Journal of the American Medical Association, 291*(16), 2007-2012. doi 10.1001/jama.291.16.2007

Book Edition
Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.
Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Preparation of Electronic Figures for Publication Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).
Further information can be obtained at Wiley-Blackwell's guidelines for figures:
http://authorservices.wiley.com/bauthor/illustration.asp.
Check your electronic artwork before submitting it:
http://authorservices.wiley.com/bauthor/eachecklist.asp.

Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: Colour figures may be published online free of charge; however, the journal charges for publishing figures in colour in print. If the author supplies colour figures at Early View publication, they will be invited to complete a colour charge agreement in RightsLink for Author Services. The author will have the option of paying immediately with a credit or debit card, or they can request an invoice. If the author chooses not to purchase color printing, the figures will be converted to black and white for the print issue of the journal.

Cover Image Submissions This journal accepts artwork submissions for Cover Images. This is an optional service you can use to help increase article exposure and showcase your research. For more information, including artwork guidelines, pricing, and submission details, please visit the **Journal Cover Image** page.

7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.
Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:
www.adobe.com/products/acrobat/readstep2.html
This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.

As changes to proofs are costly, we ask that you only correct typesetting errors. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the Publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

7.2 Early View (Publication Prior to Print)

The *Journal of Applied Research in Intellectual Disabilities* is covered by Wiley-Blackwell's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have a volume, issue or page number, so Early View articles cannot be cited in the traditional way. They are therefore given a DOI (digital object identifier) which allows the article to be cited and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

7.3 Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit **http://authorservices.wiley.com/bauthor/** for more details on online production tracking and for a wealth of resources include FAQs and tips on article preparation, submission and more.

For more substantial information on the services provided for authors, please see Wiley-Blackwell's Author Services.

7.4 Author Material Archive Policy

Please note that unless specifically requested, Wiley-Blackwell will dispose of all hardcopy or electronic material submitted two issues after publication. If you require the return of any material submitted, please inform the editorial office or Production Editor as soon as possible.

7.5 Offprints and Extra Copies

Free access to the final PDF offprint of the article will be available via Author Services only. Additional paper offprints may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields: http://sheridan.com/wiley/eoc

If you have queries about offprints please email **erica.garrett@sheridan.com**

7.6 Video Abstracts

Bring your research to life by creating a video abstract for your article! Wiley partners with Research Square to offer a service of professionally produced video abstracts. Learn more about video abstracts at **www.wileyauthors.com/videoabstracts** and purchase one for your article at **https://www.researchsquare.com/wiley/** or through your Author Services Dashboard. If you have any questions, please direct them to **videoabstracts@wiley.com**.

Appendix 2: Walsh & Downe (2006) Quality Appraisal Tool

Table 5: Summary criteria for appraising qualitative research studies

STAGES	ESSENTIAL CRITERIA	SPECIFIC PROMPTS
SCOPE AND PURPOSE	Clear statement of, and rationale for, research question/aims/purposes	• Clarity of focus • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated
	Study thoroughly contextualised by existing literature	• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
DESIGN	Method/design apparent, and consistent with research intent	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate
	Data collection strategy apparent and appropriate	• Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?
SAMPLING STRATEGY	Sample and sampling method	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given

		• Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained
ANALYSIS	Analytic approach appropriate	• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/ conceptual frameworks evolved. • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved I stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion rationale if it was not
INTERPRETATION	Context described and taken account of in interpretation	• Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena
	Clear audit trail given	• Sufficient discussion of research processes such that others can follow 'decision trail'

	Data used to support interpretation	• Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions
REFLEXIVITY	Researcher reflexivity demonstrated	• Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher’s influence on stages of research process • Evidence of self-awareness/ insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with
ETHICAL DIMENSIONS	Demonstration of sensitivity to ethical concerns	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
RELEVANCE AND TRANSFERABILITY	Relevance and transferability evident	• Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined

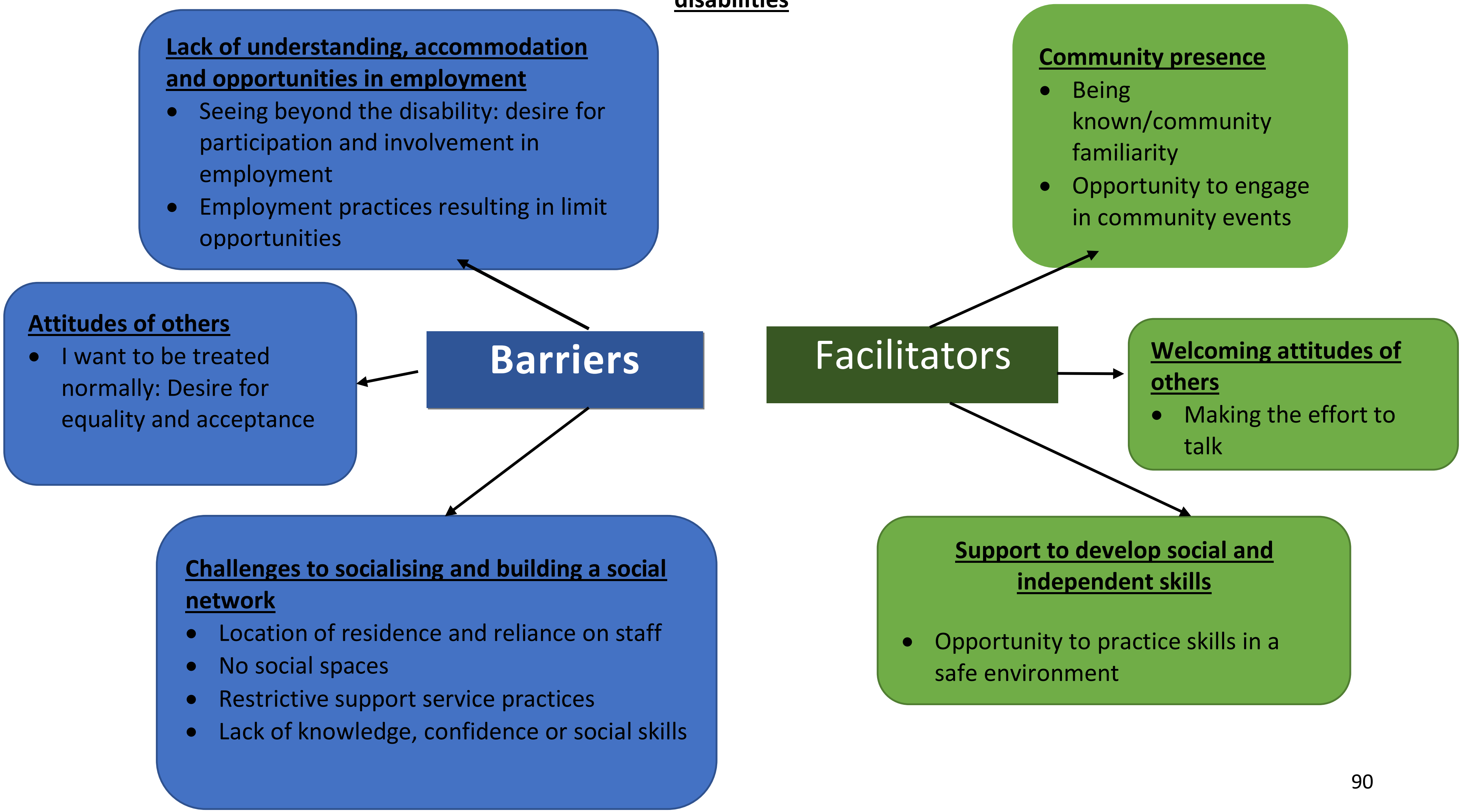
	• Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and ‘makes sense’ • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved

Appendix 3: Noblit & Hare's (1988) seven stages of meta-ethnography

Noblit and Hare seven stages

1) Defining the research question
2) Systematically reviewing the information – deciding on the inclusion criteria, locating relevant articles and quality assessment
3) reading the studies, identifying initial themes, then secondary themes, becoming familiar with the content
4) Determining how the studies are related to each other – compiling a list of themes into relevant categories.
5) Translating studies into one another – compare the first study with the second and the combined synthesis with the third etc.
6) Synthesising translations – combining the synthesis to develop a new understanding of the material
7) Expressing the synthesis – Presentation of findings/ publication

Appendix 4: Synthesised themes of the barriers and facilitators from qualitative studies of people with intellectual disabilities



Barriers

Lack of understanding, accommodation and opportunities in employment

- Seeing beyond the disability: desire for participation and involvement in employment
- Employment practices resulting in limit opportunities

Attitudes of others

- I want to be treated normally: Desire for equality and acceptance

Challenges to socialising and building a social network

- Location of residence and reliance on staff
- No social spaces
- Restrictive support service practices
- Lack of knowledge, confidence or social skills

Facilitators

Community presence

- Being known/community familiarity
- Opportunity to engage in community events

Welcoming attitudes of others

- Making the effort to talk

Support to develop social and independent skills

- Opportunity to practice skills in a safe environment

Appendix 5: Proposal

Major Research Project Proposal

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

Claire Chambers

Version 2

Word Count **3316**

Abstract

Background: People with intellectual disabilities may require or be viewed to benefit from daily functional support. However, being provided with such support may bring challenges for those with intellectual disabilities. Those receiving this level of support may find their sense of identity is impacted upon. Limited research exists into the perceptions of provided support for those with intellectual disabilities. Further research is needed to better understand people with intellectual disabilities' experiences of being supported and if this impacts upon their identity.

Aims: The aim of this study is to investigate how people with intellectual disabilities experience and perceive the support they receive and how this impacts upon their identity.

Methods: Between six and ten adults aged between 18 and 40 years, with a mild or moderate intellectual disability and who live in their own tenancy or shared accommodation will be recruited from care organisations across the West of Scotland. Each participant will take part in a semi-structured interview exploring their views about the support they receive. This will include discussion about how their support influences how they are viewed by other people in society. The data will be analysed using Interpretative Phenomenological Analysis.

Applications: The findings of the study may inform support provision and the importance of tailoring support to the individual.

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

Identity is an important aspect of human development. Formed through social interactions and resulting in internalised values and views, it can determine the social role a person holds and how they relate to others (Dorozenko, Roberts & Bishop, 2015). In order to develop a positive identity, a person must feel accepted by others (Goffman, 1963). However, those who have experienced societal stigma, such as people with intellectual disabilities (Goffman, 1963) may take on acting roles (social roles) to hide the deeply discrediting attribute that could be rejected by society.

Historically people with intellectual disabilities (ID) were seen as deviants or eternal children by society and were not warranted the same human rights (Dorozenko et al., 2015). In more recent times an emphasis has been placed on people with ID being provided with greater self-determination and increased social integration, important factors in building positive identities. There has also been a strive to promote quality of life and empowerment through the process of person centred planning (PCP). This approach aims to individualise and create services that address personal preference, interest and future aspirations (Thompson et al., 2009). Additionally, people with ID as a result of their impairments, may often require support with daily living activities and social integration (Thompson et al., 2009). The need for this support could be perceived as a visible stigma (Goffman,1963). For example, often those in receipt of support can be seen being supported by others in society or live in environments dedicated to those with disability, therefore highlighting difference. In addition, a person’s knowledge of needing support and how this makes them different from the “normal” group can be subject to negative self-evaluation and possibly rejection. This can be considered an invisible stigma. Goffman (1963) would suggest that people with ID would therefore play social roles to mask their “spoiled identity”.

Research on stigma and its impact on how people with ID see themselves has been mixed. Jahoda and Markova (2004) found that people did not reject the identity of an intellectual disability but rather they rejected the societal view of disability as incapability, therefore protecting their self-esteem. In addition, Cunningham and Glenn (2004) found that people with ID were aware of their disability status, however only a small number found this stigmatising identity to be distressing. Cooney, Jahoda, Gumley and Knott (2006) had similar findings that self-esteem and future aspirations were not affected by perceived stigma. However, Abraham, Gregory and Wolf (2002) and Paterson, McKenzie and Lindsay (2012) found that the more stigmatising the experiences were, the lower the self-esteem.

Research has highlighted some factors that can prevent stigma affecting identity including, group identification and social support by being part of an advocacy group (Anderson & Bigby, 2017). Paterson, McKenzie and Lindsay (2012) found that improving social integration or increasing social support can also help protect against reduced self-esteem, impacted upon by perceived stigma. However, many people with ID have poor social supports. Support staff or professionals may make up the majority of relationships for people with ID and are therefore fundamentally not reciprocal (Forrester-Jones et al., 2006). Yet support staff can play a vital role in supporting individuals with intellectual disabilities to promote social integration and build social networks which can enhance self-esteem, buffer against mental health problems and improve quality of life (McConkey & Collins, 2010).

The value people with ID place upon received support has been highlighted within research (Giesbers et al., 2019; Clarkson, Murphy, Caldwell & Dawson, 2009). This included support staff responding to both their practical and emotional needs and this being delivered in a way that was deemed sensitive and empowering. In particular, people highlighted how much they valued the close friendships they formed with staff, who responded by being nurturing and trustworthy. Research has however highlighted that due to austerity, support services are being reduced, resulting in support providers putting an emphasis on meeting practical needs over and above social needs and wellbeing (Hamilton et al., 2017). This change in practice and disregard for needs other than the practical, may have an impact on the identities of people with ID and their views of belonging within society.

Research has also highlighted some dissatisfaction people with ID have with their support, particularly the manner in which their support was provided. Examples given were of staff at times appearing disinterested in supporting them or favoring other individuals using the service (Clarkson et al., 2009; Stenfert Kroese, Rose, Heer & O’Brien, 2013; Giesbers et al., 2019). A study in the Netherlands that explored people with intellectual disabilities’ experience of residential support, found that three of the six participants were ambivalent about the support they received (Giesbers et al., 2019). This negative evaluation of their support appeared to have a significant emotional impact on their sense of self.

To date, there has been limited research exploring the impact support can have on the identities of those with ID. What the research suggests is that support is valued by some, however others struggled with accepting that they need support within certain areas to function in society. Previous research has suggested that being in receipt of support may impact upon identity but results of studies have been mixed in regard to awareness and experiences of stigma. Few qualitative studies have been completed with people with ID about their experience of residential support, this study will be concerned with their own lived experiences rather than of those who support them. This study will also investigate how receiving support has an impact on their identity in relation to having an intellectual disability. This research could therefore help to inform more sensitive service delivery and practice, supporting the positive identities of those with intellectual disabilities.

Aim

The current study is an exploratory study aiming to understand the experiences of people with intellectual disabilities of being supported and how this impacts upon their identity.

Design

Interpretative Phenomenological Analysis (IPA) is a qualitative approach which can be used to explore a participant’s lived experience and how they make sense of this in relation to their place within the world (Smith, 2004). IPA is an idiographic and hermeneutic approach and therefore aims to gather an in-depth account of the participant’s experiences. The information gathered is the researchers attempt to make sense of the participant views, making IPA a double hermeneutic approach.

IPA has been successfully used to explore the identity of people with ID in previous research (Wilkinson, Theodore & Raczka, 2015; Groves, Rayner & Muncer, 2017).

Plan of investigation

Participants

Inclusion criteria

Adults with a diagnosed intellectual disability, living independently within their own tenancy or living in shared accommodation and in receipt of a support services.

They must be able to provide informed consent to take part in the research.

Have sufficient verbal skills to be able to recall and discuss a recent experience.

They must have English as a first language.

They must be between the ages of 18-40 years, to ensure all those taking part are at a similar life stage.

Exclusion criteria

Anyone with additional difficulties that would prevent them from engaging in the interview.

Sample

Participants will be recruited from October 2018 – March 2019 from Care providers across the West of Scotland (the areas of Glasgow and Ayrshire & Arran). Connections will be made with care providers and they will be asked to identify participants who meet the above inclusion criteria and would be willing to take part in the research.

Recruitment

The researcher will approach care providers explaining the purpose of the research. If they agree to take part, the researcher will provide information about the specific inclusion and exclusion criteria. The care staff will then be asked to identify those who meet criteria and to provide them with an information sheet with the details of the purpose of the study and the researcher’s contact details. Potential participants will be made aware that participation in the research is voluntary. In addition, they will be asked to inform the potential participant that they can take the information away and take time to consider if they wish to take part. The information sheet includes a consent slip for the participant’s details to be passed to the researcher. Participants can use the stamped self-addressed envelope provided to send the consent slip to the researcher, indicating they wish to take part.

Research Procedures

The primary researchers, having had no previous contact with the participants, will provide opportunity for potential participants to ask questions and discuss concerns prior to giving consent. The information sheet and consent form (see Appendix 1) will be reviewed with the participant, questions will be asked to ensure understanding and to check for evidence of acquiescence and capacity to consent. The researcher will ensure that the participant understands the purpose of the research, what the research involves, the positive and negative aspects of taking part and their right to withdraw at any time. This is in accordance with Arscott, Dagnan and Stenfort Kroese (1998) who recommended standards of practice for gaining informed consent from people with ID.

Every opportunity will be made to ensure the participant fully understands by adapting language to suit individual need. The research will be conducted within a quiet room within the care organisation responsible for their support package.

Demographic Information

Demographic information will be gathered via a questionnaire, asking participants to provide information about their age, setting they live in and amount of support they receive.

Semi-Structured Interview

Consistent with an IPA approach, semi structured interviews will be used. Interviews will last no longer than one hour however, breaks will be offered and participants will be monitored for evidence of fatigue. The interview with the first participant will be used to test the topic guide, ensuring participants feel comfortable discussing their support experiences with the researcher. This interview will be conducted with the view of including it within the analysis and discussion. The interview will begin by discussing day to day activity, what activities they enjoy and the support they receive, to help them feel comfortable with the interview process. The schedule will then move into more sensitive topics for example satisfaction with support and what they believe others think about them receiving support. Although there is a proposed structure to the interview, it is an idiographic process and will be guided by what the participant brings to the interview. This will lead to a more in depth understanding of their experience.

Data Analysis

Interpretative Phenomenological Analysis will be used to allow in depth exploration of the participant's experience, including how they see themselves and their place within the world. Analysis will follow the procedure as suggested by Smith, Flowers and Larkin (2009). Transcriptions will be read on a number of occasions and key information highlighted. Key themes will then be identified along with quotations to be compiled into a master table of themes to be used to aid discussion. The first transcript will be reviewed within supervision to audit initial themes that emerge. A reflective diary will be kept monitoring the process of identification of themes. In addition, themes and the process of their development will be discussed during supervision.

Justification of sample size

Smith, Flowers and Larkin (2009) recommend a sample size of between four and ten for a Doctorate degree, with greater emphasis on an in-depth analysis, requiring a smaller sample size to meet the aims of IPA research. A minimum of six participants will be recruited for this study, with a maximum of ten participants to ensure in depth analysis is achievable.

Settings and Equipment

The research will take place within the care organisation's offices.

Audio recording equipment will be required, and consent sought from participants. A laptop will be obtained from the University of Glasgow, encrypted to the university's standards.

Health and Safety Issues

Researcher safety issues

Interviews will take place in the care organisation’s offices, day placements or NHS facilities during the hours of 9am to 5pm. If interviews take place within day placements the researcher will ensure support staff are close by to call upon if assistance is needed. The researcher will work in line with the facility’s own health and safety policies and procedures. In addition, the researcher will use observational skills as well as direct questioning to determine if the participant is happy to continue with the interview process and terminate the interview if they are asked to do so, ensuring their own safety in the process.

Participant safety issues

There is potential for participants to become distressed or frustrated when responding to questions about support experiences. This will be discussed with participants when obtaining consent to participate in the study as well as a reminder that they can withdraw at any point up until submission. Participants will be able to call upon someone they are familiar with if they become distressed by the content. The research team has carried out a number of IPA studies with people with intellectual disabilities, covering a range of sensitive topics. They have largely found that participants have been positive about discussing topics as experts of their lives and experience.

Ethical Issues

- Ethical approval will be sought from the University of Glasgow Research Ethics Committee.

- The researcher will communicate the processes of the research at a level understandable to the participant, ensuring to ask for feedback to check their capacity to consent. Participants will be informed of their right to withdraw. Data will be anonymised by the removal of identifying details and stored on a password protected, encrypted laptop in accordance with the University of Glasgow data protection policy and procedures.
- Participants' will be monitored for any signs of distress during the interview. If risk issues arise, the researcher will report this information to the participant's care team, to ensure continued support.
- Individuals will be informed of confidentiality in accordance with University of Glasgow policy and procedure.

Financial Issues

Stationary cost for the materials including printing costs for participant information sheets, consent forms and debriefing sheets may be incurred. In addition, the cost of stamped self-addressed envelopes will be required. The costs are highlighted in Appendix 3.

Timetable

Time Scale	**Research Component**
21st May 2018	Final Proposal Submission
July-August 2018	Application to University of Glasgow Research and Ethics Committee
August – September 2018	Meet with care organisations to discuss involvement, information to staff and information sheet about the research to be passed on to potential participants.
September – February 2019	Recruitment and Data Collection
February- March 2019	Data consolidation and Analysis
May 2019	Draft Thesis Submission
July 2019	Final Thesis Submission

Practical Applications

This study will contribute to existing theory and research by investigating people with ID experiences' of being in receipt of support and how this impacts upon their self-identity. This study will allow an in depth understanding of their experiences, what they value about support and changes we can put in place to ensure that services do not inadvertently contribute to the stigmatising experiences of people with intellectual disabilities.

References

Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community and Applied Psychology, 12,* 430-443.

Anderson, S., & Bigby, C. (2015). Self advocacy as a means to positive identities for people with intellectual disability: we just help them, be them really. *Journal of Applied Research in Intellectual Disabilities, 30* (1), 109-120.

Arscott, K., Dagnan, D. & Stenfert Kroese, B. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.

Clarkson, R., Murphy, G.H., Coldwell, J.B. & Dawson, D.L. (2009). What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual Disability*, 34, 283-289.

Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: Perceived stigma, social comparison and future aspirations. *Journal of intellectual Disability Research, 50,* 432-444.

Cunningham, C., & Glenn, S. (2004). Self awareness in young adults with Down Syndrome: 1. Awareness of Down Syndrome and disability. *International Journal of Disability, Development and Education, 51,* 335-361.

Dorozenko, K.P., Roberts, L.D.& Bishop, B.J. (2015). Imposed identities and limited opportunities: Advocacy agency staff perspectives on the construction of their clients with intellectual disabilities. *Journal of Intellectual Disabilities, 19* (3), 282-299.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A, Bechem, J. et al. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long stay hospital. *Journal of Applied Research in Intellectual Disabilities*, 19, 285-295.

Goffman, E. (1963; 1990). *Stigma: notes on the management of spoiled identity*. England; Penguin.

Groves, E., Rayner, K. & Muncer, S. (2017). It's good, they're like me, the same but different: An interpretative phenomenological analysis of the identification of women with down's syndrome. *Journal of Applied Research & intellectual Disabilities,* 1-9.

Hamilton, L.G., Mesa, S., Hayward, E., Price, R., & Bright, G. (2017). There's a lot of places I'd like to go and things I'd like to do': The daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom. *Disability & Society, 32:3, 287-301.*

Giesbers, S.A.H., Hendriks, L., Jahoda, A., Hastings, R.P. & Embregts, P.J.C.M. (2019) Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32, 446-456.*

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Dsiability Research, 48,* 719-729.

McConkey, R. & Collins, S. (2010). Using personal goal setting to promote the social inclusion of people with intellectual disability living in supported accommodation. *Journal of Intellectual Disability Research,* 54, 135-143.

Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparisons and self esteem in adults with an intellectual disability*. Journal of Applied Research in Intellectual Disability, 25,* 166-176.

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in Psychology, 1, 39-54.*
Smith, J.A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. SAGE, London.

Stenfert Kroese, B., Rose, J., Heer, K. & O'Brien, a. (2013). Mental health services for adults with intellectual disabilities – what do service users and staff think of them? *Journal of Applied Research & Intellectual Disabilities,* 26, 3-13.

Wikinson, V.J., Theodore, K. & Raczka, R. (2015). As normal as possible: Sexual identity in people with intellectual disabilities transitioning to adulthood. *Sexuality & Disability, 33*, 93-105.

Appendix 6: Ethical Approval Letter

University of Glasgow

Institute of Health
& Wellbeing

Athena SWAN
Gold Award
ECU GENDER CHARTER

TMM / PR

22 October 2018

Claire Chambers

Dear Claire,

Major Research Project Proposal

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

The above project has been reviewed by your University Research Supervisor and by a member of staff not involved in your project, and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely,

T M McMillan
Professor of Clinical Neuropsychology
Research Director

Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences
University of Glasgow
Mental Health and Wellbeing
Admin Building, Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW G12 0XH
Direct line: +44(0) 141 211 0354 Fax: +44(0) 141 211 0356
Email: thomas.mcmillan@glasgow.ac.uk
Tw: @DClinPsyGlasgow

The University of Glasgow, charity number SC004401

THE QUEEN'S
ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION
2013

Appendix 7: Participant Information Sheet

Participant Information Sheet

University of Glasgow

A research study about how you experience the support you receive and if this has any impact on how you see yourself.

Please read this information sheet

You can ask someone to read it with you

You can talk with family, friends or staff about the research study

Photo

My name is Claire

I am studying at University of Glasgow

What is this study about?

I am doing a research study about how you view the support you get

I want to find out about what people think about their support
What they say to other people about being supported

I hope this research will help services learn how to support people in a way that makes them develop a positive view of themselves.

18-40

Why do you want me to take part?

I am asking you to take part because you are an adult aged 18-40 years who lives on their own or in supported housing and receives support

My research study starts in July 2018 and finishes in July 2019

Do I have to take part?

You can say yes if you want to take part

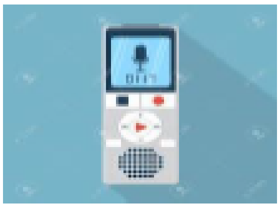
You can say no if you do not want to take part.

Your answer will not change the service or support that you get

What will happen?
I will meet you at your support service offices or your home

We will meet for about 1 hour.

I will ask you to fill in a consent form to say you are happy to take part.



The meeting will be recorded with a voice recorder

What if I change my mind and do not want to take part during the study?

You can ask me to stop at any time
If you change your mind this will not affect the support or services you get

Will anything bad happen to me if I take part?

You have to give up 1 hour of your time

It is unlikely that anything bad will happen to you as a result of taking part

Are there any good things about taking part?

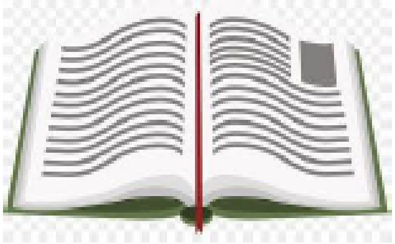
People who have taken part in other studies have found it interesting

Will other people find out about what I say?

Anything you say is private
The only time I may have to talk to someone else about you is if I am very worried about you or someone else

The information you give me will be kept safe on a computer

A report will be written about the study
Your name will not be used in this report



What will happen to what I say?
I will write a report about what you and other people have said
Other people will be able to read the report. A copy will be kept at the university library

How can I take part?
You can fill in the reply slip

You can contact me on the telephone

You can contact me on my email address

You can tell staff or family and they can contact me.

I will arrange to meet with you to talk about talking part.

If you have questions about the study
You can contact me
Claire Chambers
Trainee Clinical Psychologist
Mental Health & Wellbeing,
Gartnavel Royal Hospital
1055 Great Western Road,
Glasgow,
G12 0XH

Tel: 0141 xxxxxxxx
Email:

You can also ask my supervisor questions
Professor Andrew Jahoda

Consultant Clinical Psychologist

Mental Health & Wellbeing,

Gartnavel Royal Hospital

1055 Great Western Road,

Glasgow,

G12 0XH

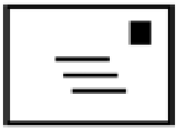
Tel: 0141 xxxxxxxx

Email:

Experience of support study Reply slip

If you would like to take part in the Experience of support study, please fill in your details

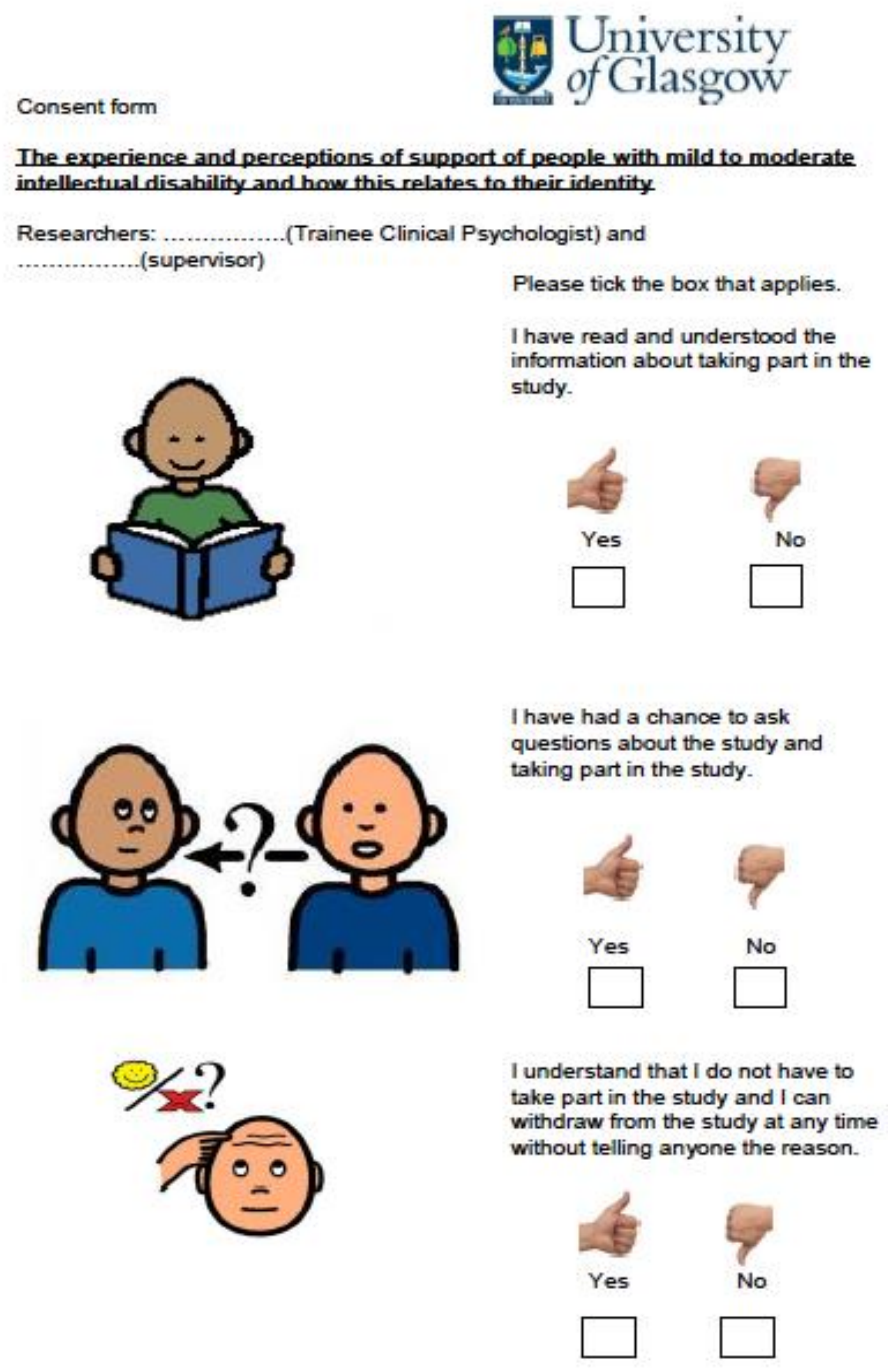
Name ____
Address ____
____
Telephone number ____________________________________
Support Provider _____________________________________



You can post it to me in the stamped addressed envelope
You can give it to me or a staff member

Claire Chambers
Trainee Clinical Psychologist
Mental Health & Wellbeing, Gartnavel Royal Hospital
1055 Great Western Road, Glasgow, G12 0XH
Tel: 0141 xxxxxxxx Email:

Appendix 8: Participant Consent Form



Consent form

The experience and perceptions of support of people with mild to moderate intellectual disability and how this relates to their identity

Researchers: ……………..(Trainee Clinical Psychologist) and ……………..(supervisor)

Please tick the box that applies.

I have read and understood the information about taking part in the study.

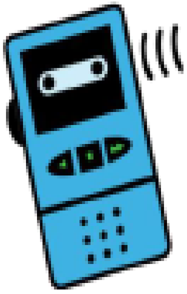
Yes ☐ No ☐

I have had a chance to ask questions about the study and taking part in the study.

Yes ☐ No ☐

I understand that I do not have to take part in the study and I can withdraw from the study at any time without telling anyone the reason.

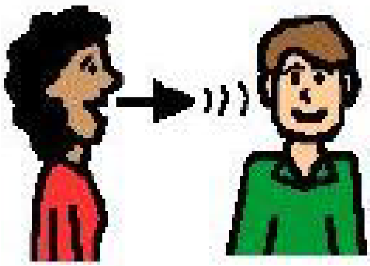
Yes ☐ No ☐



I am aware that the interview will be recorded by the researcher, Claire Chambers and will only be used for this current study.

👍 Yes ☐

👎 No ☐



I am aware that the researcher, ... may publish direct quotations of what I have said during the interview, but this will not include information about who I am. Others will not be able to identify me from the information published.

👍 Yes ☐

👎 No ☐

I agree to take part in this study.

👍 Yes ☐

👎 No ☐

Name of participant ____________________ Signature__________________________

Date __________________

Name of researcher_____________________ Signature ___________________________

Date _________________

Appendix 9: Topic guide for interviews

1. Where do you live at the moment?

2. Tell me a bit about what it's like living there?
   Prompts: What are the best bits about it?
   What are the things you don't like about it?
   Who do you live with?

3. Who are the staff who give you support?
   What do the staff do?

4. What kind of ways are xx (names of support staff) helpful to you?

5. What kind of ways are staff unhelpful?

6. How do you feel about getting support from staff?

7. What do you tell other people if they ask where you live?

   If relevant - Prompts : What do they say?

8. What does it feel like if you go out with someone who is supporting you?

9. What do other people think when they see someone being helped by a support worker?

10. If you could change the support you get in any way, how would you change it?

Appendix 10: Sample of Analysed Transcript

Descriptive/exploratory comments	Transcript	Emergent themes
Support staff make decisions	Participant: Well I think the boys check the fridge but don't tell me, ken I just get what I need. As long as I don't buy junk food they are quite happy. You know like microwave meals and all that.	Power and control
	Researcher: so they try to encourage you not to do those things. Em how does it feel to have support staff whenever you are out shopping?	
Initial hate, felt different Threat to sense of self Changed over time recognition of value of company Staff as replacement for lost friendship	Participant: Right back at the beginning I absolutely detested it, I hated it! Because it made me feel different from everybody, but I've got to that point in my life where I enjoy, I like having the company you know. I like seeing the boys. My best friend he moved down south recently.	Difference/ fear of negative judgement Opportunity for a meaningful connection
	Researcher: Uh huh.	
Lonely, loss of friendship Support as company Importance of similar interests Different staff compliment different interests	Participant: So, I don't see him that often, once or twice every four or five months. Staying overnight sometimes. So, when the boys come in you know like I said, they're like pals, give us a bit of company, give us a laugh so they do. And they have all got like individual interests, but a lot of my interests are the same as theirs. (name of support worker) for example is fishing, (name of other support worker) likes playing Xbox, (another support worker) has the same taste in music, like the Killers so different interests but the same really.	Meaningful connections, good company Good match to aid meaningful connection
Worry of what new staff will be like	Researcher: Yeah. So, you feel it's quite a good match then?	

	Participant: Yeah. I'm hoping this new guy (name) is a good match.	
Importance of the right match, a friendship with support staff	Researcher: Yeah you hope he is.	Having agency over your support
	Participant: He'll be getting the boot if he's not (laughs)	
Personal preferences listened to	Researcher: so, are all your support staff male then?	And this being respected
Support suggested change – led by challenges in staff or genuine concern about rigidity?	Participant: yeah. I did have a female member of staff, but she left about 2 years ago so she did, and I got on fine with her as well. Originally, I had asked for all males when I first started but then they felt it was time for me to get a wee change. She stayed not far from where I am, 10 or 15mins.	
Support staff as fluid/changing	Researcher: so, you got on quite well with her.	Challenges of consistency of staff and impact on relationship
Abandoned by previous support workers	participant: Yeah, I still keep in contact with her. I've had a lot of support workers come and go over the years. My original team, (names support worker) I like him, I still keep in contact with him, but the rest of the team and the team leaders just sort of buggered off really.	Loss of relationships
	Researcher: So, there's a few that you have kept in contact with and built that relationship.	cared about, valued as a person
Touched that old support worker came – that he cared	Participant: Yeah, I got on really well with a guy, he left for another job so he did, he showed up at my Papa's funeral on his day off. The first words I said to him was "what are you doing at a funeral on your day off?" (laughs)	
	Researcher: (laughs)	
	Participant: I didn't think he was going to show up at my house.	

Important to maintain the pretence that they are family or friends.	researcher: So, what's it like whenever em you are in the shop and you are dealing with the people at the tills but you are with your support worker as well? What's that like?	Disguising the need for support Protecting the self
	Participant: I find it fine, I think a lot of the time they think I'm either with my pal or my dad you know. Because Darren and Stevie, well Darren has just turned 50 and Stevie is in his 50s, Jonny he looks about the same age as me he's 36. It's good, he's a dead baby face you know.	
Fear of negative judgments, being seen to be supported Easier to see as friends, to let others see as friends	Researcher: But you were concerned whenever you first started being supported?	Negative views of others
	Participant: It was just folk seeing you out and about and thinking aw here's his support worker but now I know that folk can't tell. You know if somebody says who's that young guy I just say my pal. So, I do.	
	Researcher: Yeah. Why do you think you say that?	
Rationalisation – but they are friends	Participant: They are more pals than anything else.	
Some people ok to tell Caution disclosing need for support	Researcher: Sorry say that again?	Caution in disclosing the need for support
	Participant: They are more pals than support. I told (girlfriend) pretty much right away when we first met that I had support workers, so I did. And I have one of them out with me every day and what I'm doing. So, I told her, you didn't say anything did you? I found it easy enough to tell her.	
	Researcher: What's the qualities that you wouldn't want in a support worker?	Importance of meaningful connections with staff

Important to care Not interested in spending time with you	participant: Stuck up. Too far up their own backsides. I had one like that a while back and I got him shifted to a different team, I put that many complaints in.	Genuine effort shows you care
Joining in shows you care	Researcher: What was that like then?	Seen as someone enjoyable to spend time with
	participant: I felt like he wasn't a carer as such because he didn't care, he was just there for something to do and it was at his own leisure what he done. Because I would say to him "aw can we go go- karting" and he just stood at the side watching. He wasn't really making the effort though.	The right kind of support worker
No interest or time for him	Researcher: So, it's a really different experience then because you're not really doing with.	
	Participant: Aye he was just sitting in the side lines, keeping an eye on me. He used to be in the police before that, so he was. I think that sort of impacted on his personality, so it did.	
	Participant: It was just hi and bye, that sort of thing.	
Protecting sense of self, don't really need support, could escape from it but it is helpful	Researcher: That sounds hard. Em, so why do you think you receive support then?	Provides safety and is valuable to lead the life I want
Ambivalence about the need for support, don't really need but keeps him safe and functioning Provides reassurance and comfort	Participant: I was being a dafty when I was eighteen, so I was. You know I went off the rails a lot and ended up in the mental health hospital detained so I was. I didn't let that stop me, I escaped so I did. They used to call me Houdini (laughs), one minute I'm there, the next I'm gone. Eh and they said I would get back into the community if I accepted support. So, I did and then over the years it developed, its uh no need for support but I get uh,	

	if they weren’t there everywhere would be a tip, the house would be upside down and my routine would be all over the place. So, when they are there everything’s fine.	