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The Lived Experience of People With Intellectual Disability in Community Settings: A Comparison of Self-Reports and Staff Reports

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ABSTRACT

Background: There is a need for more qualitative research focusing on the lived experiences of people with an intellectual disability and a better understanding of how these experiences align with other voices in their lives, such as family and support staff.

Methods: In this qualitative study, we asked people with an intellectual disability ($N = 87$) and their support workers ($N = 120$) similar questions about factors contributing positively and negatively to the lives of those with an intellectual disability. We conducted a thematic analysis combining data across respondents, while also identifying areas of similarities and divergence between self-reports and staff reports. The setting was community-supported living schemes and group homes in the UK.

Findings: Qualitative themes, representing key positive and negative factors in the lives of people with an intellectual disability, were (1) Positive impact of social relationships on well-being, (2) positive impact of participation and roles on self-determination and well-being and (3) negative impacts of difficulties affecting day-to-day life. These three themes are all linked to a broader sense of identity, purpose and self-determination. These were broadly consistent across self-reports and staff reports, although there were some points of divergence, particularly in Theme 3.

Conclusions: These findings reveal areas that are key to maximising the quality of life of people with an intellectual disability and suggest that self-reports and proxy reports can sometimes offer unique perspectives. Our findings can be used to ensure that the priorities of people with an intellectual disability are considered in their care.

1 | Introduction

Many individuals with an intellectual disability receive a degree of support in daily living, and community-based supported living and group homes are common in the United Kingdom and other countries. To ensure that people with an intellectual disability accessing this support achieve the best possible quality of life, we need to understand and prioritise the factors that are most important to them.

Previous research has addressed this question via a number of different approaches, qualitative and quantitative methods, self-report and observation methods, but similar themes tend to emerge. Schalock et al. (2011) proposed an influential model that describes three factors contributing to the quality of life of people with an intellectual disability: independence (personal development and self-determination), social participation (interpersonal relations, social inclusion and rights) and well-being (physical, mental and material). These authors emphasise that quality of life is a

multidimensional concept, shaped by individuals themselves, their immediate surroundings and the broader society in which they live.

Similar themes were identified in a systematic review of qualitative studies asking people with an intellectual disability about their everyday lives: participation in everyday life (skills, social, community), individualisation and attitudes, and agency and choice (Gjermestad et al. 2017). This review concluded that despite great progress in the equality and integration of people with an intellectual disability into society post-deinstitutionalisation, some people still experienced clear violations of human rights when it came to choice and self-determination.

Recent research has suggested that loneliness and mental health are growing concerns among people with an intellectual disability. Mencap (2022) surveyed the people they support and reported high levels of loneliness and almost a third of individuals struggling with mental health. Similarly, although moving from group homes (4–6 other individuals, 24-h support) to supported living (1–4 people, with drop-in support) can lead to a greater sense of autonomy, it can also increase loneliness (Bigby, Bould, and Beadle-Brown 2017). However, research has also found that life satisfaction amongst people with an intellectual disability is similar to that in the general population (Lucas-Carrasco and Salvador-Carulla 2012; McGillivray et al. 2009).

The review by Gjermestad et al. (2017) highlighted the need for more research focusing on the lived experiences of people with an intellectual disability. Objective (observation) measures of quality of life can be informative, but there is often a low correlation between these and self-report (subjective) measures (Verdugo et al. 2005). Furthermore, past research has too often relied on proxy reports from parents and professionals (Beail and Williams 2014; Mansell and Beadle-Brown 2012). Although proxy reports may be unavoidable in some situations (Emerson, Felce, and Stancliffe 2013), they are not consistent with the principles of self-determination and individualisation, and can also be unreliable (Cummins 2002; Havercamp et al. 2022; Santoro, Donelan, and Constantine 2022). Reliance only on proxy reports can also lead to misidentification of mental health conditions (Todorov and Kirchner 2000).

However, this does not mean that speaking to those closest to individuals with an intellectual disability cannot provide useful insights. Service providers and their staff play a key role in the opportunities and outcomes of the people they support, as do family members (Araten-Bergman and Shpigelman 2021; Bradshaw et al. 2004; Giesbers et al. 2019; Kozma, Mansell, and Beadle-Brown 2009; Mansell and Beadle-Brown 2012). Therefore, it is important to understand their own priorities when it comes to enhancing the life satisfaction of the people they support and the extent to which the two perspectives align.

Interestingly, previous research comparing self-reports and proxy reports (staff and family) on quantitative quality-of-life measures has found that self-reports tend to be slightly more positive (Claes et al. 2012; Schmidt et al. 2010). Besides this, comparison of quantitative measures has yielded mixed results in terms of agreement, with some finding generally good agreement (Balboni et al. 2013; Golubović and Škrbić 2013; McVilly, Burton-Smith, and Davidson 2000; Schmidt et al. 2010;

Simões and Santos 2016) and others finding poor agreement (Janssen, Schuengel, and Stolk 2005; Zimmermann and Endermann 2008). Generally, the agreement is higher for objective quality-of-life measures, such as 'income' and 'daily activities', than for social, emotional or psychological well-being (Claes et al. 2012; Umb-Carlsson and Sonnander 2006; White-Koning et al. 2005). A recent mixed-methods review found that people with Down syndrome and proxy raters tended to agree on the impacts of social inclusion on quality of life, but disagree on their degree of independence and self-determination (Ijezie et al. 2023). Agreement is also dependent on how well the person with an intellectual disability is known to the proxy (Schwartz and Rabinovitz 2003; Simões and Santos 2016).

More research comparing self-reports and proxy reports has been identified as a key research need (Santoro, Donelan, and Constantine 2022). Previous research has often focused on quantitative measures of life satisfaction, well-being and quality of life. These are useful for profiling across a range of pre-defined domains, but could potentially miss individual, person-specific factors by constraining respondents to set items. Qualitative research can provide insights into these unique perspectives and explanations for self and proxy discrepancies (e.g., Scott and Havercamp 2018; van Heumen and Schippers 2016). Therefore, the purpose of this study was to fulfil this research gap by conducting a large qualitative study about the lived experiences of people with an intellectual disability, which compared self-reports and proxy reports.

In this study, we asked 90 people with an intellectual disability and their support workers similar questions about factors contributing positively and negatively to the life of the individual with an intellectual disability and compared their responses. We present the results as a thematic analysis across both participant groups, but identify points of association and divergence. We were particularly interested in whether staff and the people they support would differ in their perspectives on self-determination and well-being, given previous research suggesting that this remains a key research priority (Gjermestad et al. 2017) and potential area of misalignment between self-reporting and proxy reporting. The participants in our study were accessing supported living and group home schemes run by Innovate Trust, a charity that spearheaded the move from institutions into group homes in the community in 1975. This model has been replicated across the United Kingdom and other countries, and continues to evolve.

2 | Methods

2.1 | Participants

Ninety individuals with an intellectual disability (mean age 46 years, SD = 14.4, range 22–82 years) were recruited via Innovate Trust, a supported living provider in South Wales. Three of these individuals were unable to participate due to difficulties understanding the tasks and questions, leading to a final sample of 87. All individuals supported by the charity were invited to participate, with the exclusion of individuals with a high degree of complex needs, who were unable to provide informed consent. Individuals lived in group homes or individual 'core and cluster' flats, and had a range of support

needs—from a few hours a day to 24/7 support. The participants also took part in a study exploring outcomes of smart speaker devices for people with an intellectual disability (Smith et al. 2023), which was why the number of participants was larger than is often the case for qualitative research. The large number of participants allowed us to capture the breadth of experiences, and there was no time limit on interviews. The duration of interviews and quantity of data were variable across participants, and the saturation point took longer to reach than it might have done for interviews with participants without an intellectual disability. The large quantity of data also allowed us to assess patterns within the staff–individual dyads.

An additional 120 support staff (age range: 16–67 years, without an intellectual disability) also participated.

2.2 | Procedures

All procedures were approved by the Cardiff University, School of Psychology Ethics Committee [EC.18.03.13.5263].

2.3 | Consent Procedure

We had a thorough consent procedure in line with the Mental Capacity Act 2005. The Mental Capacity Act is designed to protect individuals' rights to make their own decisions. The principles include (1) start by thinking I can make a decision and (2) do all you can to help me make a decision. We therefore provided information in a simple format (e.g., simple wording and pictures) with guidance from the charity. A public research partner with an intellectual disability provided feedback on the consent and information sheet before we started the study. We had separate consent boxes for each step of the study to decrease memory demands. We also made clear to individuals that not taking part would have no impact on their care, as we wanted to ensure that individuals felt no pressure to participate. Participants had to repeat the main elements of the information sheet back to the researcher to demonstrate that they understood what the study involved.

The staff working at the charity (support staff and management level) knew the participants well and only arranged for the interviewer to visit individuals who they deemed to have the capacity to consent. If staff were unsure, then the interviewer went for a visit just to meet with the individual over a friendly chat. If the interviewer had any doubt that the individual had the capacity to consent, they did not attempt to recruit them in to the study. This only happened in one instance and the researcher ensured that this was dealt with in a sensitive manner.

2.4 | Qualitative Interview Approach

A structured set of open-ended questions (Supplementary Materials S1) was used to elicit qualitative responses regarding good and bad aspects of participants' lives, including difficulties that individuals may be experiencing or new things that they may be trying. The interviews with the participants with an intellectual disability were carried out in person. Participants chose a location where they felt comfortable; this was typically at home and in a room where they felt comfortable and had privacy. One individual felt at ease in a more public setting and therefore requested to meet with the interviewer at their familiar local café. The time of the interview was always chosen based on the preference of the participant.

All participants were asked if they would like to have their support staff present during the interview and those with communication difficulties usually opted to have them present. If an individual appeared to struggle with comprehension of a question, the interviewer would rephrase or ask the support staff if they felt that there was a better way to phrase the question. Staff from the charity also gave practical advice before the interview for each participant. For example, if a participant had hearing difficulties, the staff member made the interviewer aware of this so that they were able to sit nearby, facing the individual, and speak loudly. Staff also advised when it was helpful for the interviewer to speak slowly for an individual. If a participant was autistic, the interviewer was made aware of this and given advice on their preferred communication style (e.g., increased space or avoiding eye contact).

Interviews typically lasted between 5 and 20 min; however, there was no time limit. The interviewer made sure not to rush participants, with the intention to give individuals time and space to think and respond.

On a few occasions, a participants' reduced communication was due to factors other than their communication ability; for example, if they were having 'a bad day'. In these instances, the interviewer would ask the participant if they would prefer they came back another day, and usually the interviews would then take place as planned the next time.

The support workers provided written responses, as they were not always available for interviews during the researcher's visit and were often supporting other individuals in the house. The research officer at the charity first suggested which staff member worked most closely with the participant at the time of testing. The researcher then asked the staff member if they felt they knew the participant well enough to be able to fill in the survey about them. There were 12 instances where we asked two support staff to fill in the form together—this occurred when there had been a recent transition in key workers or more frequent staff turnover in the house.

2.5 | Researcher Reflexivity

As an outsider to the organisation, participants may have been less inclined to report difficulties to the interviewer. To mitigate this, the interviewer aimed to build rapport with participants before the interview, encouraging openness and honesty. The interviewer was female, which could have influenced the extent to which she could relate to the experiences of male participants. The power dynamics inherent in the researcher–participant relationship were continually reflected upon. The researcher made efforts to minimise these dynamics by adopting a participatory approach, ensuring participant assent and discussion with support staff.

Additionally, the research team all identify as middle class and white, which may influence their worldview and interpretation of participants' experiences. This social and cultural background could affect the research process, from the framing of research questions to data interpretation. Additionally, the research team's belief in the empowerment and inclusion of disabled people may have influenced the focus of the study and the interpretation of findings. Although this belief aligns with ethical research practices, it is important to acknowledge its potential impact on the research.

The interviewer had several years of experience working with individuals with intellectual disabilities and had completed a PhD with a similar population. The researcher's extensive professional background in psychology and intellectual disabilities, particularly Down Syndrome, provided a solid foundation for understanding the participants' experiences. However, this expertise may also introduce preconceptions and a bias towards interpreting data through a specific theoretical lens, potentially overlooking alternative perspectives or the unique experiences of some participants.

The researcher approached the data from the perspective of someone without an intellectual disability, which may have influenced the thematic analysis. Ideally, a co-researcher with an intellectual disability would have contributed to the thematic analysis to provide a unique perspective. However, this was not feasible within the constraints of the study. Reflexive practices during data analysis included engaging in regular discussion with colleagues on theme development. This collaborative approach helped to identify and challenge any potential biases in the thematic analysis.

The study's constraints, including time and resource limitations, were acknowledged as factors that shaped the research design and implementation. Reflexive consideration of these constraints helped to contextualise the findings and highlight areas for future research improvement.

2.6 | Qualitative Data Analysis

An inductive thematic analysis was carried out using the Braun and Clarke (2006) approach. Themes were not limited to the data collection questions. The researcher familiarised themselves with the transcribed data via multiple re-readings of transcripts, with notes made and reassessed. NVivo qualitative data analysis software was then used at the initiation of the coding phase. Nvivo was used to help organise a large amount of qualitative data and keep track of various codes. The researcher explored potential themes, with multiple codes contributing to a given theme. During this stage, thematic maps were created to provide a visual overview of themes and the relationships among them. The themes and thematic maps were discussed with colleagues to determine whether the patterns and overall narrative resonated with others and whether interpretations were judged as meaningful and credible. The researcher referred back to the original codes and data sources repeatedly to ensure that the themes accurately captured patterns across the data set. Each theme was given a label that clearly captured the contents and meaning of the theme. Finally, representative transcript extracts were selected to give examples for each theme.

3 | Results

Three themes were constructed and are shown in Table 1. The first two themes—positive impact of social relationships and positive impact of participation and roles on self-determination—represented factors that contributed positively to overall well-being. In contrast, the third theme—negative impacts of difficulties affecting day-to-day life—presented challenges to well-being. In the sections below, quotes from individuals with an intellectual disability are in standard type, whereas staff quotes are in italics. Generally, the same topics were mentioned by people with an intellectual disability and staff across all themes. However, when assessing each individual–staff couplet separately, there were some specific discrepancies. These were mostly concentrated within Theme 3 (difficulties affecting day-to-day life). There were also some differences in discussions of relationships between housemates. These are described in more detail below.

3.1 | Theme 1: Positive Impact of Social Relationships on Well-Being

Relationships with housemates were often mentioned in relation to well-being, in both positive and negative contexts. Family, friends and romantic relationships were all mentioned in a positive context.

TABLE 1 | Summary of themes and subthemes.

Theme 1: Positive impact of social relationships on well-being	Theme 2: Positive impact of participation and roles on self-determination and well-being	Theme 3: Negative impacts of difficulties affecting day-to-day life
- Impact of positive/negative relationship with housemates on well-being.	- Value of regular leisure activities.	- Mental health (e.g., anxiety).
- Value of family (seeing them/ keeping in touch).	- Learning and developing skills.	- Daily personal care and physical difficulties.
- Value of friendships.	- Desire to work and volunteer.	- Memory difficulties and need for prompts.
- Value of romantic relationships.		

3.1.1 | Relationship With Housemates

Participants with an intellectual disability lived in a variety of different housing situations, with many residing in shared group homes with housemates who were chosen by the local authority and often matched based on factors such as maximising the efficiency of support needs, rather than broader compatibility. Other housing configurations were core and cluster buildings, where participants lived in individual flats with a shared communal area. Who they live with is therefore one area of their lives where individuals with an intellectual disability are still lacking choice and agency.

Despite this, individuals generally got on well with their housemates. They reported spending time together outside the house and sometimes referred to their housemates as friends: 'went for breakfast with co-tenant. Getting along really well with tenants'; 'spent time with friend/co-tenant'; '*co-tenants have been getting along, no issues. Co-tenant and service user have done activities together, e.g., shopping, going to the park*'; '*all housemates get along. All ladies have the same interests and consider themselves as friends. They have recently talked about a weekend away together*'. Thus, housemates were often considered to be friends, suggesting that positive relationships could develop despite a lack of control over who they lived with.

However, where individuals did not get on well with housemates, it caused upset, frustration and low mood: 'one tenant can be argumentative, it's upsetting. Staff sort it'; 'not been the best week, not really getting on with housemates. Winding each other up'; '*co-tenant has followed them around repeating things over and over to them. Making them feel really anxious*'. Noise was also an issue: 'Getting on with housemate, but not sleeping well because housemate is noisy at night (shouts out)'; '*housemate shouting and shouting makes service user sad and cry*'.

There were a number of instances where staff discussed negative experiences and emotions when these were not mentioned by the person with an intellectual disability. For example, one individual's self-report was worded positively: 'skittles and bowling on a Tuesday, I love it. Been at work, seen a couple of friends there, but had the day off yesterday' and said they were 'getting along with housemates' and said 'nothing bad…just sometimes arguments'. In contrast, the staff reported several negative incidents that were not mentioned in the self-report. For example. '*(their) mood has been a bit up and down and has tried to start arguments with staff but soon calmed down after a while. Usually service user is polite and helpful when in a good mood*'.

In another individual–staff dyad, the support staff reported that '*they were shouted at this week by housemates and was called names, later that person apologised and they made up*'. However, the individual themselves said 'nothing bad' (happened this week) and 'no arguments'.

In another dyad, the individual and staff were well aligned apart from the fact that the staff mentioned the person they support was upset one day: '[their] *housemate [was] shouting and shouting makes service user sad and cry*' and '*Somebody in day centre upset service user this week. finds the rain and thunder and*

lightning scary', whereas the participant with an intellectual disability did not mention the incident saying: 'I'm happy all day' and things have 'been good' and instead talked about the numerous positive things that had happened in their week. Both the individual and staff said that they had a good memory, and therefore, it would be surprising if the individual had forgotten the incident.

There were sometimes discrepancies in the other direction, with individuals reporting difficulties with housemates where their support staff did not. For example, one individual said they 'don't like it when there's too much talking. Take refuge in my room'. Their support staff did not report any difficulties. This was a participant with very good adaptive skills, and the difficulties that they discussed were not related to daily living support needs, but rather how they felt.

3.1.2 | Family and Friends Beyond the Household

The importance of social connection and socialising beyond the household was consistently emphasised by people with an intellectual disability. Spending time with family and friends was often cited as a good aspect of individuals' weeks, for example, 'Watching football on the TV with a friend was good'; 'Went out with friend to the pub for lunch, I go pub lunch twice a week'; 'Getting on well with a lot of friends'. Spending time with family was also valued: 'Going to pub and going to café and seeing mum were good things'; 'looking forward to seeing older sister and baby'; staff also noted that '*(they) enjoyed spending time with parents*'. Participants also reported using varied means of keeping in touch with friends and family, for example, over the phone: 'chatting to family on the phone' and 'calling sister and son, love speaking to family'.

3.1.3 | Romantic Relationships

Being in a romantic relationship was mentioned by 11 of the individuals with an intellectual disability during the qualitative interviews. They were always mentioned as good aspects of individuals' weeks: 'been on date Friday with fiancé'; 'Spending time with boyfriend once a week'; and '*They brought their girlfriend over, they are over the moon*'.

Staff sometimes described taking on a supportive role in maintaining the relationships and mentoring individuals regarding the appropriate pace. For example, one individual was keen to get married quickly to their fiancé and spoke about how support staff had encouraged them to take their time. The individual talked about how he had appreciated this guidance. The support staff was there during this conversation. In another instance, an individual opened up about their anxiety about the potential initiation of intimacy in their romantic relationship and said that their support staff had been very helpful as someone to talk to about this, and again helped them to understand that they could move at a slow pace.

Most of the participants with an intellectual disability were not in romantic relationships, and some individuals spontaneously

mentioned a desire to be in a romantic relationship when asked about experiences of loneliness. It may be relevant to keep in mind that all of the individuals in this study were living in group homes. Individuals with intellectual disability in relationships that become very serious may be more likely to move to a different living situation with their romantic partner and, therefore, our sample may be less likely to include individuals in serious long-term relationships.

3.2 | Theme 2: Positive Impact of Participation and Roles on Self-Determination and Well-Being

Keeping busy through leisure and recreational activities, attending classes to learn new skills and also helping out/having a role, either voluntarily or in employment, were all mentioned positively by both participants with an intellectual disability and support staff. Overall, we also found that people with an intellectual disability discussed their jobs/roles as the good components of their lives more often than staff did, with staff focussing more on activities and relationships. In general, the participants in this study did not like doing things that were not their own choice or being told what to do, for example, 'I find it annoying if people tell me to get up at a particular time' and 'I get annoyed with staff telling me what to do'.

3.2.1 | Activities and Learning and Developing Skills

Many of the activities that people participate in are organised by the supported living provider and take place with other supported individuals with an intellectual disability: 'Skittles and bowling on a Tuesday, I love it'; 'Good things were cooking and swimming'; '(I) like gardening. Enjoy music. Participation groups at the hub'; and *'they enjoy their activities like pop art and going to XXX for gardening'*.

Participants reported enjoyment from attending classes to learn new skills, which tended to be run by the supported living providers: 'Go to XXX. projects for people with an intellectual disability. Gardening twice a week. Tuesday I do reading and writing class and Wednesday I do computer class. I enjoy them all'; 'Enjoyed lots of classes, been going to new ones to try. Art class, music class'. Some of the younger individuals also attended college, and this was always referred to as a positive aspect of their lives. One of the individuals who initially seemed somewhat anxious became very relaxed and enthusiastic when the interviewer asked if they would like to show their college project (this was a project on a topic that the individual was passionate about).

3.2.2 | Working and Volunteering

Many people with an intellectual disability expressed a desire to have a job and liked to work or have a role; '(I like) being busy, working'; 'I liked being in charge of money/reception at pop art'; 'We were helping out in the kitchen, serving and cleaning'; and '*(they) just asked to do "Take Charge", hoping for a job*' ('Take Charge' is a project run by Innovate Trust to help unemployed individuals with an intellectual disability gain skills, confidence and move towards volunteer roles).

There were a number of instances where people with an intellectual discussed helping out in ways where it was clear that it was central to their self-identify, for example: '(I'm) good at helping' and 'Helping out, always do'.

Interestingly, although the participants with an intellectual disability often talked about helping other people, their staff more often mentioned the help that the individuals needed, for example, prompting to do chores. In one dyad, both the individual and the staff member reported that spending time with a friend had been a positive experience that week, but in the self-report, the participant said: 'helping neighbour with [their] garden. Showing him how to do things', whereas the staff report included only '*spending time with friends*' without the mention of helping. Interestingly, the participant also went on to talk about self-challenge: 'I'd like new gardening tools to see what I'm capable of'.

In most instances, the participants with an intellectual disability were not in paid employment, but having opportunities to help or volunteer allowed them to feel busy in the absence of employment and provided a sense of purpose and self-competence: 'doing dishes for the staff', 'want to go to day centre to play piano for people', 'working in oxfam (voluntarily) has been good' and '(I) have been helping (support worker) to get clothes off the line'. Opportunities to actively participate as part of the organisation's recruitment procedures or board membership were also mentioned: '*the service user was able to be included in job interviews and ask their own questions*'. 'On the board at (charity name) tonight (I) enjoy it' and as part of their role they were 'being invited to MGM meeting' and said 'I'm purchasing new clothes to attend'. Although individuals were overwhelmingly positive about attending activities and classes run by the charity specifically for people with an intellectual disability, it was also noted by one of the more able individuals that 'At [sports team] I am now playing in the league, since the beginning of last month. Means I'm playing with people who don't all have intellectual disability so it's more competitive'. This again highlights a desire for self-challenge as well as being able to interact more with the wider community, which the individual said they liked.

3.3 | Theme 3: Negative Impacts of Difficulties Affecting Day-to -Day Life

Mental health problems (e.g., anxiety), challenges related to daily personal care and physical impairments and difficulties remembering things were all factors reported in response to what had been bad that week or whether they had any difficulties. It was in the discussion of difficulties that we observed the greatest discrepancies between self-reports and staff reports.

3.3.1 | Mental Health Problems

Anxiety was the most commonly mentioned mental health problem faced. '(I) dislike staff moving around, causes anxiety'; '(difficulty) controlling my anxiety and my anger'. Staff mentioned anxiety affecting self-determination: '*has difficulty doing most things for themselves as he/she gets really anxious about*

things'. Cognitive difficulties such as poor memory were also a source of anxiety: *'has very poor memory, this is on a daily basis. Sometimes gets very anxious because can't remember'*.

3.3.2 | Daily Personal Care and Physical Difficulties

Difficulties regarding mobility were reported in the context of self-determination and independence: 'Walking can be difficult at the moment, wobbly leg'; 'walking, bad hip. Putting socks on. lifting/physical'; *'he asks for support to fasten shoes/trainers'*; and *'(difficulty) walking long distances, though this has been improving since joining the gym'*. Difficulties or lack of independence regarding personal care were more likely to be mentioned by staff: *'showering - not keen at all'* and *'personal hygiene declining'*. However, there was sometimes consistency between staff and self-reports in discussing personal care difficulties, for example, in one dyad, the individual said: 'bit more help needed lately with things like showering and food prep. Sometimes forget things' and the support staff correspondingly said: *'has been getting confused recently, e.g., forgetting how to turn shower on, although could do that before'*.

3.3.3 | Memory Difficulties and Related Challenges

Memory difficulties were a common challenge in daily life, particularly around tasks and planning: 'hard to remember to do things around the house and my plans for the day'; 'miss appointments because I forget'; 'have to check my diary a lot, very forgetful'; 'hard to remember where I put keys'; and *'(difficulty) remembering to clean their teeth'*. Individuals were more likely to remember things of interest to themselves compared to tasks such as chores: 'I remember the things I like, but forgetful with other things'. As noted above, memory difficulties were often a source of anxiety. These memory difficulties had negative influences on work and college, for example, an individual who reported 'forgetting how to find something on the computer (at college)...a particular piece of work I couldn't remember how to find'.

Overall, memory difficulties were mentioned more frequently by staff than the people they support. For example, one individual reported that nothing bad had happened that week and that 'nothing is tricky' and 'I have a great memory'. For this same individual, their long-term support worker reported various challenges: *'has been verbally aggressive towards staff due to taking food when they shouldn't or being asked to do something'*. The staff also reported: *'thinks it's their birthday tomorrow but it's a month away. Needs a countdown to help understand how many days'*.

Another individual responded 'everything's been fine' and 'nothing difficult at all' in contrast to their support worker, who noted *'in public this week he/she had a confrontation with someone on their walk home from work'* and *'Has recently lost [item], and now is paranoid about losing replacement[item]. He/she can be forgetful and puts things away and goes into aggressive mood when they cannot find something immediately'*.

For one individual who was very positive reporting 'nothing is bad', 'no arguments at all', 'Nothing is tricky' and that they

'remember things', the corresponding staff-report noted *'sometimes because the service user is very chatty and loud their co-tenants can isolate them'* and *'anxiety has been very high lately but this usually happens in the run up to Christmas, lots of verbal prompts needed recently'*. In another instance, an individual claimed that it was a 'good week' with no difficulties and that 'I have a good memory', whereas their support staff reported *'he/she has been given extra support/staff hours'* due to *'mental health deterioration'* and that they have had difficulties with *'sleeping, cooking, personal day to day life'*.

4 | Discussion

This large study provided qualitative insights into the lived experience of individuals with an intellectual disability residing in supported housing in the community. We focused on the factors that contribute positively and negatively to their lives, particularly relating to self-determination and well-being, and compared self-perceptions versus staff perceptions.

4.1 | Summary of Findings

Three key qualitative themes were as follows: (1) positive impact of social relationships on well-being, (2) positive impact of participation and roles on self-determination and well-being and (3) negative impacts of difficulties affecting day-to-day life. Overall, individuals with an intellectual disability were positive about their self-determination and well-being, but we also identified areas that service providers and practitioners could target in the future. The themes in the staff reports were generally consistent with the reports of the people they support. However, staff tended to comment on challenges and difficulties more often than the people with an intellectual disability did themselves, which is consistent with the expected staff focus, given that their role is to support such difficulties. The opposite pattern prevailed for the importance of roles and helping out as positive experiences for individuals with intellectual disability; these were mentioned much more often by the individuals themselves than by staff. There is an interesting parallel here; all parties, staff included, are attending to their own roles and sense of purpose.

4.2 | Positive Impact of Social Relationships on Well-Being

The theme of valuing personal relationships with friends, family and partners was common in qualitative interviews, across both individuals with an intellectual disability and their support staff, consistent with previous research (Friedman and Rizzolo 2018; Gjermestad et al. 2017; Schalock et al. 2011). We found that housemates were often viewed as companions, but also sometimes as a source of frustration. The UK government guidelines for best practice in supported living (GOV.UK. 2020) state that living space for daily activities needs to be appropriate for the number of housemates. Standards such as these are important, but our findings also suggest that it is essential that housemates get along well enough to enjoy these shared spaces.

Research by the National Development Team for Inclusion (2022) reported that compatibility between residents is often ignored in residential care and supported living schemes. Sometimes, individuals are placed together for logistical or financial reasons, rather than compatibility. Given recent findings from Mencap (2022) regarding high levels of loneliness among individuals with an intellectual disability, ensuring that housemates are compatible as companions could potentially alleviate feelings of loneliness for some.

We found that romantic relationships were highly valued, consistent with previous research (Bates, Terry, and Popple 2017; Scott et al. 2014). Loneliness was not a qualitative theme in this study, but it was sometimes mentioned in relation to wanting a romantic partner. Only 11 of the participants reported being in a romantic relationship. Staff sometimes described taking on a supportive role in maintaining the relationships and mentoring individuals regarding the appropriate pace. However, more opportunities to develop romantic relationships are clearly needed and previous research suggests that supporting organisations and staff can play a key role in this (Giesbers et al. 2019). Since our data have been collected, the service provider has gained funding from the local authority to support social events to help develop relationships, so we hope that such initiatives can be replicated elsewhere.

4.3 | Positive Impact of Participation and Roles on Self-Determination and Well-Being

This theme captured two main elements: (1) the importance of participation in leisure activities and (2) the importance of roles and contributions to society and daily life. Both of these elements reflect the development of new skills and experiences. Participants with an intellectual disability reported many opportunities to participate in activities and socialise. In line with the Equality Act, the UK Government states that reasonable adjustments should be made to support individuals to access activities and our research provides further evidence of how much this is valued, something that was also highlighted in a recent review (Gjermestad et al. 2017).

Many of the participants in the study wanted to have a job so they could contribute to society and have a 'normal life', but most participants were not in paid employment. This reflects generally low levels of employment in this population (around 5%; NHS Digital 2021). Cummins (2020) suggests that the two main ways in which people gain a sense of purpose in life are by having an active role in a family group or via outside employment. People with an intellectual disability who have paid jobs report significantly higher quality of life (Kober and Eggleton 2005; Simões and Santos 2017). We found that in the absence of employment, participants sought other activities to support their sense of purpose, such as volunteering and skill development. However, more opportunities for paid employment, and thus a greater degree of social inclusion and financial independence, are clearly needed. Previous research highlights that businesses often perceive barriers to employing people with an intellectual disability (Kocman, Fischer, and Weber 2018). Supplying information, changing organisational strategies and legal changes are all important to help overcome these. The

finding that people with an intellectual disability were more likely than staff to mention helping others and having a job/role (in response to being asked what has been good this week) indicates that the importance of roles in positive self-perceptions may be sometimes overlooked. Self-determination can be increased by using 'self-management' strategies that promote independence (Sandjojo et al. 2019), which could include prompts for daily tasks that stress competence and purpose, for example, 'you're good at doing this, can you help me'.

Employment was also mentioned in relation to day centres; people with an intellectual disability enjoyed going to a day centre if they had a job/role there, but did not tend to enjoy going without a job/role. Attending a day centre was not a choice for the participants, but was part of a support model overseen by the local council. Going forward, it seems appropriate that more choice is given over attendance at day centres. If day centres are to be used, our research highlights the value of jobs/roles within them.

4.4 | Social Relatedness and Sense of Identity

Across the first two themes, social relatedness appears to be key, with activities and roles contributing to the development of these social connections. These connections help us to understand who we are and where we fit in society. This is ultimately our sense of identity. Previous research has shown that having a positive sense of identity is strongly linked to positive well-being in the general population (Haslam et al. 2009).

4.5 | Competence, Autonomy and Sense of Identity

In addition to the social component is the sense of purpose and competence across these first two themes, which is strongly linked with identity. Social relationships provide individuals with a role, for example, someone's friend, someone's partner and someone's son/daughter. Individuals have a purpose in that relationship and a sense of value if that relationship is positive. Activities and work can also provide individuals with a role as well as group membership. Group memberships can give individuals a sense of value and identity (Kyprianides, Easterbrook, and Brown 2019).

Friendships, activities and work are chosen by the individuals themselves (self-determined) and these were mentioned as positive aspects of individuals' lives in this study. The only relationships or roles mentioned in a negative context were those that were not chosen by the individuals themselves, for example, co-tenants and day centre attendance. There are more limitations for individuals with intellectual disabilities regarding both social relationships and roles, for example, limitations in job opportunities, difficulties making friends and limits on activity options for some individuals due to their need for support. Individuals in this study were not always able to meet people in a context where they are alone/independent. These factors may have influenced the relationships that individuals

in this study developed (e.g., the close friendships with co-tenants reported by some individuals) and their associated roles and sense of purpose and identity.

Individuals' roles and the groups that they are part of also provide a sense of belonging. We found a desire for inclusion and 'normalcy' (e.g., jobs, helping out, relationships and marriage). We know that this population also experiences stigma and exclusion. In this context, it is therefore unsurprising that positive social connections, social activities and roles appear to play a crucial role in the well-being of the individuals in this study. Overall, our results were highly consistent with self-determination theory (Deci and Ryan 2012), which positions competence, autonomy and relatedness as fundamental needs essential for a fulfilled life.

4.6 | Negative Impacts of Difficulties Affecting Day-to-Day Life

Memory difficulties were a key threat to self-determination and independence, and could also impact mental health, particularly anxiety. Prompts and reminders for everyday tasks were sometimes needed; for example, remembering to take medication or remembering plans for the day. In a recent study, we found that smart speakers could be a useful assistive tool for people with an intellectual disability to provide reminders and prompts, and that these types of virtual assistants were preferred to prompts and reminders from support staff because they did not challenge self-determination (Smith et al. 2023).

There was a clear difference between self-reports and staff reports of memory difficulties. Individuals with an intellectual disability often mentioned having a good memory, whereas staff tended to discuss the prompts that were needed (consistent with the staff's role in providing this support). The same tendency for people with an intellectual disability to report fewer difficulties in general was found when analysing individual–staff dyads, including low mood or negative experiences. This pattern was less common among individuals with fewer complex needs, who tended to report more difficulties.

4.7 | Mental Health

Participants in our study mentioned a number of different factors that could affect mental health. In particular, situations in the household that were not within the individuals' control were a source of anxiety, such as changes in staff and relationships with other housemates. Given our finding across the first two themes regarding the importance of social connection, it is perhaps unsurprising that changes in staff and co-tenants had a negative impact on mental health and associated well-being. The staff–individual relationship is a unique one, as individuals would sometimes refer to staff as their friends and often do activities with staff that may typically be done with friends, for example, shopping and cinema trips. However, the relationship is a professional one for staff. In the context of high staff turnover, individuals with intellectual disability may regularly feel a loss of social connection when staff leave. There is a

lack of choice (self-determination) in the ending of these social connections and in the introduction of a new close social contact (the new support staff).

The same is true with regard to co-tenants. The lack of control and autonomy may heighten feelings of frustration and anxiety when co-tenant relationships are negative. This is exacerbated by funding models where individuals with low support needs are often placed in group homes with individuals with high support needs to optimise the efficiency of support worker time, rather than matching tenants on broader compatibility. Research has shown lower levels of loneliness for people with intellectual disability living with co-tenants they chose themselves and for individuals living with family (Alexandra, Angela, and Ali 2018).

Noise was reported as a key issue and contributor to anxiety, and sometimes, participants said that there was nowhere to go in the house where the noise did not bother them (i.e., even going to their bedrooms was not sufficient). This comes back to the importance of compatibility within group homes and the impact that this can have on well-being.

4.8 | Physical Difficulties and Day-To-Day Care

Although personal care was a source of difficulty for some individuals with an intellectual disability, this tended to be reported by staff rather than the individuals themselves. Declining abilities around personal care tended to be due to memory difficulties, such as forgetting to clean teeth or shower. Although a number of participants mentioned physical impairments (e.g., difficulty walking), memory challenges were mentioned more often in relation to anxiety. Interventions to support memory such as automated prompts could be helpful to increase independence and reduce anxiety (Smith et al. 2023).

All the above challenges, for example, anxiety, memory, physical and day-to-day care difficulties, may also negatively impact the ability to build positive social connections and to get out and be part of groups (e.g., activities and jobs). This may lead to fewer opportunities for participation and less sense of purpose. These difficulties are experienced in the context of already being part of a vulnerable population. For example, employment discrimination and increased difficulty making friends are reported for individuals with intellectual disability (Alexandra, Angela, and Ali 2018; Kocman and Weber 2018).

4.9 | Self-Report Versus Staff Report

Our findings indicate that self-perceptions and staff perceptions are not always concordant and may particularly differ on what factors are prioritised for independence. Staff were sometimes more focussed on support needs for personal care or daily living, whereas participants with an intellectual disability focused more on freedom of choice. For example, an individual might need a high level of support, but if they receive this in a way that focuses on maximising their autonomy and choice, they might have a higher sense of self-determination than an

individual with lower support needs who has less choice. Similar patterns of results have been found in previous studies using quantitative measures (e.g., Janssen, Schuengel, and Stolk 2005).

Across a number of areas, self-reports were more positive than staff reports. This finding is consistent with much of the quantitative literature (Balboni et al. 2013; Claes et al. 2012; Janssen, Schuengel, and Stolk 2005; Schmidt et al. 2010; Simões and Santos 2016). A number of different explanations for this difference have been suggested, including that people with an intellectual disability have a more optimistic and positive outlook (Hartley and MacLean 2006) and that they may compare themselves to other people with an intellectual disability, whereas staff may use other comparisons (Stancliffe, 1999) or that there is a desire to avoid the stigma of perceived vulnerabilities (Finlay and Lyons 2000; Jahoda et al. 2010). Self-preservation may have been a tool or defence mechanism for individuals with intellectual disability in this study to provide a positive sense of identity.

4.10 | What Can Staff Reports Tell Us?

Proxy responding is commonly used in the intellectual disability field, even though previous research has sometimes found low concordance between self-report and staff report (e.g., Janssen, Schuengel, and Stolk 2005; Perry and Felce 2002; Zimmermann and Endermann 2008). It is likely that the degree of concordance is dependent on how well the proxy-rater knows the individual. For example, Simões and Santos (2017) found good agreement when the proxy-reporter had known the person for at least 2 years (family or long-term staff members). In the current study, we did not always know how long staff members knew the people whom they supported or how well they knew them; however, we know that the staff turnover in the supported living sector is generally high (Skills for Care, 2021). However, we did make every effort to ensure that staff members with the best possible knowledge of the individuals completed the questionnaire, and in some cases, we asked two staff members to complete it together, as using more than one responder will increase reliability (e.g., Claes et al. 2012).

It is always appropriate to ask people with an intellectual disability themselves about their experiences wherever possible and not rely on proxy reports. The discrepancies in the self-reports versus staff reports in our data highlight how important this is. However, our findings indicate that it may be helpful to speak to staff, in addition to individuals themselves, if we want to know more about support needs relating to daily living skills, as some people with an intellectual disability may not report all the difficulties that they experience. It is also important to be aware that staff are not always aware of internal perceptions of well-being. Therefore, proxy reports in the area of well-being and self-determination should be interpreted with caution, and we should keep in mind that feelings of agency can be very different from practical support needs. However, consistent with previous perspectives (Claes et al. 2012; Schalock et al. 2002; Simões and Santos 2016; Stancliffe, 1999), our findings suggest that both sources of information can often be helpful.

4.11 | Interview Reflections

A large number of people took part in the study, more than is often typical of qualitative research, because the participants were taking part in a parallel study on smart technology. We were therefore able to gain a large and diverse set of experiences across a range of ages and people living in different settings (e.g., group homes, core and cluster). The large quantity of data also enabled us to look for patterns within the staff–individual dyads. The interviewer did not get the impression that saturation level had been reached excessively during the interview process by having such a large sample size, but rather, that the diverse range of voices permitted a range of different perspectives. For example, a relatively small minority of individuals discussed their experiences being in relationships and these experiences would have been missed had the sample size been smaller. There was no time limit on the interviews, so although we had a large number of participants, each was given the time to talk for as long as they were willing to.

The large number of participants also allowed us to interview participants across a wide age range (22–82 years). We did not ask participants specific questions about how their age interacted with their well-being and daily life factors and if this had changed over the course of their life span. Living situations may have changed significantly for certain individuals over time. For example, some older participants may have originally lived within hospital-based institutions before moving to community-based settings in the 1970s and 1980s. Future research could examine potential differences in perspectives between older and younger participants.

4.12 | Limitations

Participants in this study were all supported by the same service provider (Innovate Trust). Innovate Trust has a strong track record in supporting individuals to live full and rich lives, and has won awards for their supported living schemes. Therefore, it is possible that our findings would not generalise to all other individuals with an intellectual disability accessing other services or living with family. However, participants were located in different geographic areas, with different local authorities, agendas and economic environments.

A key limitation of our interview approach was that participants with an intellectual disability were given the option of having a member of staff from Innovate Trust (support worker or member of the participation team) present during the interview; this choice was selected by around half of the participants. Although this was supportive for many individuals and facilitated their communication with the interviewer, it could have also led to them feeling inhibited, particularly around discussing any negative aspects of their support arrangements. However, having a staff member present was always the choice of the participant, and the interviewer ensured that the individual with an intellectual disability seemed comfortable and provided answers in their own words.

Data from staff members were collected via written responses rather than interviews due to time constraints on staff time. We would have preferred to have interviews with staff, as this could

have led to richer data; the interviewer could have prompted staff to expand on or clarify their responses. We therefore acknowledge this as a limitation. However, we were aware that staff were very busy, often supporting more than one individual in a household, and it was therefore not feasible to ask them to take time out of the role to sit with the researcher without the individual/s they support present. In the future, it would be interesting to cross-compare responses during interviews or potentially even carry out joint interviews between staff and the people they support.

5 | Summary and Conclusions

This study highlights that positive social relationships and participation in varied activities were key positive aspects in the lives of people with an intellectual disability. Individuals also enjoyed having a sense of contribution or role, highlighting the importance of supporting volunteering and employment.

Various challenges were faced by participants in this study, specifically mental health, physical impairments, personal care, and memory difficulties. These negatively impacted the self-determination and well-being of some participants. These areas can be targeted in order to increase self-determination and well-being in the future, possibly via new assistive technologies.

Our findings also highlight that researchers and practitioners should not rely on proxy (e.g., staff) reports (where possible) when assessing well-being and feelings of self-determination of adults with an intellectual disability, because these do not always align well with individuals' own perceptions. However, staff reports may be useful to supplement self-reports when assessing daily living support needs to ensure that individuals receive appropriate levels of support.

Author Contributions

Liz Smith: conceptualisation, methodology, interviews, thematic analysis and writing–original draft, reviewing and editing. **Petroc Sumner:** conceptualisation, methodology, thematic refinement and writing– reviewing and editing. **Georgie Powell:** conceptualisation, methodology, thematic refinement and writing–reviewing and editing.

Ethics Statement

All procedures were approved by the Cardiff University, School of Psychology Ethics Committee [EC.18.03.13.5263].

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data will not be available because it is qualitative interview data and is difficult to anonymise completely.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.