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ORIGINAL ARTICLE OPEN ACCESS

Using a Capability Approach to Explore How People With Intellectual Disabilities Can Lead Flourishing Lives

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ABSTRACT

Background: People with intellectual disabilities remain disadvantaged in many aspects of everyday life. Capability approach is an underused approach in social care research and has at its core the importance of having capabilities or opportunities to do what we value. We use this approach to explore how people with intellectual disabilities can be supported to lead flourishing lives.

Methods: Interviews and focus groups were conducted with 50 people with intellectual disabilities and 28 family carers. Data were analysed using an adapted template approach and conceptual analysis.

Results: Our analysis led to the identification of one overarching theme; 'Doing what you love and growing' and sub-themes; 'Choice, opportunity and empowerment', 'Being out in the world' and 'Lowered expectations and static lives'.

Conclusion: People with intellectual disabilities can lead capability-deprived lives. Methodological and practice innovation is needed to better understand what people value and ensure they have capability sets that enable flourishing lives.

1 | Introduction

People with intellectual disabilities are among the most economically and socially marginalised groups in England (Cluley, Fyson, and Pilnick 2020) experiencing inequalities in health and life expectancy, relationships and employment (Bernal, Wiese, and Todd 2022; Giri et al. 2022; Bates et al. 2021). This is in part due to austerity-related cuts which affected Western economies after the 2008 Global Banking Crisis, underlining inherent contradictions within a neoliberal system in which individuality is prized (Malli et al. 2018). In the UK, this led to social care cuts and a tightening of eligibility criteria disproportionately impacting disabled people. While disabled people are responsible for organising their own support, albeit in an unequal, ableist society (Cluley, Fyson, and Pilnick 2020), the lives of people with intellectual disabilities are scrutinised through

a care lens which erases non-care-related areas (van Holstein et al. 2023). This focus generates risk averse support (Nind and Strnadova 2020) and the restriction of choice to the largely mundane (Hollomotz 2014). Here we draw on Sen's capability approach (CA), an alternative way of working in this area (Johnson and Walmsley 2010), to explore whether this approach can shed insights into how people with intellectual disabilities can be better supported to lead flourishing lives.

CA has been influential in developing understandings of individual wellbeing to reduce social injustices (Sen 2009; Nussbaum 2007). It is described as 'an intellectual discipline that gives a central role to the evaluation of a person's achievements and freedoms in terms of their actual ability to do different things a person has reason to value doing or being' (Sen 2009, 16). The key underpinning principle that

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everyone is worthy of respect is particularly salient in relation to a group who have been consistently dehumanised (Goodley and Runswick-Cole 2016).

Core CA concepts are *the means* (resources people can draw on); *functionings* (what people are and do); *conversion factors* (personal, social and environmental factors that enable the transformation of resources into functionings); and *capabilities* (opportunities to do things people value) (Sen 2009). The distinction between capabilities (what is possible) and functionings (what is achieved) is key to CA. This focus on opportunities, relevant to all of us, offers an alternative consideration of the lives of people with intellectual disabilities by removing the ‘care lens’. This is important as uneven evidence remains for the longstanding social care intervention ‘person-centred support’ (Ratti et al. 2016; Jackman-Galvin and Partridge 2022). Much is spoken about people with intellectual disabilities within the social care sector with little apparent change.

While CA recognises that people are not equally placed to realise capabilities due to structural inequalities such as ethnicity, gender, sexuality and disability, the approach has been criticised for involving an assumption of self-interested individuals and over emphasis on the importance of agency, which not everyone wants to, or can, assume (Reader 2007). Agency is arguably a shifting concept, which can be operationalised by staff and family members (Magito-McLaughlin, Spinosa, and Marsalis 2002). Indeed, interactions play a crucial role in the development of aspirations (Benoot et al. 2022). For Sen (2004, 76), discussions are vitally important to ‘practice the arts of aspiration’ and reconciling ‘the demands of the moment against the disciplines of patience’. The argument CA that has not sufficiently addressed power and oppression (Dean 2009) is countered by the distinction between individualistic and ‘relational political’ interpretations with the latter highlighting the importance of relationships, bringing issues of power to the forefront (Deneulin and McGregor 2010).

Despite its strong social justice underpinnings, CA is relatively little used in social care research (Gupta, Featherstone, and White 2016; Tanner, Ward, and Ray 2018; Kjellberg and Jansson 2020; Benoot et al. 2022). Charnley et al. (2019) apply CA to make sense of their findings around the use of leisure time by people with intellectual disabilities. Participants were constrained in what they could access leading to loneliness, boredom and anxiety. People were ‘capability poor’ (Burchardt 2004), experiencing a poverty of opportunity (Roberts and Atherton 2011). Benoot et al. (2022), exploring the capability to aspire among people with intellectual disabilities living in a care home, found interactions with significant others and pocket money were conversion factors although both could work against the development of aspiration sets. Significant others who recognised what people valued and discussed this with them were key.

CA provides concepts and a framework rather than theory to explain social inequalities (Robeyns 2006). This raises methodological questions around how to operationalise CA in relation to identifying what people *may* achieve rather than what they do (Babic, Graf, and Germes Castro 2010; Egdell and

McQuaid 2016; Yap and Yu 2016). Sen raised concerns that the oppressive circumstances in which disabled people live may lead to a lowering of expectations which makes focusing on functionings rather than capabilities problematic (Saith 2001), especially in relation to people who may lack capacity to make decisions (Robeyns 2016).

2 | Methods

The wider Flourishing Lives project had two phases. First, focus groups and interviews with adults with intellectual disabilities and family members explored what participants felt a good life was for themselves or their family member. Second, a learning community of support workers, people with intellectual disabilities, family carers and academics explored via online workshops how people could be better supported to lead flourishing lives. In this paper, we focus on phase one findings, the qualitative fieldwork.

The research team included people with intellectual disabilities and family carers, and the academic lead has considerable personal experience of learning disabilities and working with people with learning disabilities. Relevant training was incorporated into the study design and accommodations, such as team and individual online meetings, were introduced to ensure people could share their views. Draft versions of accessible research documentation were discussed, and lay members contributed to interview and focus group schedules, recruitment, developing and disseminating project outputs. A pilot interview was conducted with a person with intellectual disabilities and questions lightly tweaked following discussion with the team.

2.1 | Recruitment and Consent

Purposive, random and snowballing methods were used, including contact with service providers, self-advocacy and family groups via email, social media, provider websites and existing research team networks. Inclusion criteria were people with intellectual disabilities aged 18 and over, living in England and able to give informed consent to take part, and family members of adults with learning disabilities. While we tried to generate ethnic diversity, the sample was White British. This limitation was an outcome of a lack of relationships with ethnic minority communities and a reliance on provider supported recruitment. This remains an ongoing challenge and leaves our wider evidence base weakened by an absence in collective knowledge resources (Spaul et al. 2020; Fricker 2007).

The sample included 50 adults with intellectual disabilities and 28 family carers. Participants with intellectual disabilities lived in supported living homes, with their family, in residential care and a small number were in part-time, paid employment. Two participants were married, one with a child and another was about to move in with his long-term girlfriend.

A preparatory online meeting was held with participants to talk through the project, deal with technical issues and answer

questions. Participants were supported by family members or support workers in some instances to join the call or to help go through project information.

2.2 | The Interviews and Focus Groups

Fieldwork took place between October 2020 and May 2021 and moved online due to the COVID-19 pandemic. Twenty interviews were conducted with 13 people with intellectual disabilities and 14 family carers. Three interviews included participants with intellectual disabilities and a family carer, one with two family carers, and two family carers were interviewed as a couple. Interviews lasted between 37 and 70 min.

Thirteen focus groups were held with 37 people with intellectual disabilities and 14 family carers. Two focus groups included participants with intellectual disabilities and family carers. Focus groups were smaller than anticipated (n3-7) due to COVID-19-related staffing difficulties and lasted between 55 and 132 min.

A support worker was present in two interviews and two focus groups to help participants fully engage.

The session focused on what made people happy, and what helped them to do things they value. A prompt set of components of good care was identified through an initial literature review to help participants think more about their lives and the lives of people they support. This included leisure activities, being safe, money and relationships, overlapping considerably with Nussbaum's (2000) list of fundamental capabilities.

Recordings were transcribed in full, checked and anonymised by members of the research team.

Ethics approval was granted by the Health, Psychology and Social Care Ethics and Governance Committee, Manchester Metropolitan University. Consent was recorded at the start of each interview and focus group.

3 | Data Analysis

A template was created for each transcript drawing on a CA-based common question framework developed by Hollywood et al. (2012). Templates included sections for data relating to *resources* (the resources participants were able to draw upon or described in relation to their relative), *empowerment* (the extent to which participants were empowered to make informed choices), *internal conversion factors* (individual characteristics such as educational qualifications, skills, experience and confidence) and *external conversion factors* (structural factors including social environment and labour market). We added a category *endurance* to capture issues around lowered expectations. Data that sat outside this framework were coded as 'other'. Sara Ryan completed the templates with the support of a research associate.

A conceptual analysis was conducted across the templates, which involved generating mind maps (Ziebland and

McPherson 2006), reading and re-reading the data, generating themes, identifying patterns and thinking about the data in a less linear way. This allowed linkages to be made and questions asked of the developing analytical groupings. The 'other' category was revisited to ensure that relevant extracts had not been missed.

4 | Findings

Our analysis led to the identification of one overarching theme; 'Doing what you love and growing' and three sub-themes; 'Choice, opportunity and empowerment', 'Being out in the world' and 'Lowered expectations and static lives'. There were unresolved contradictions and questions in our analysis, which we raise in this section and return to in the discussion.

5 | Doing What You Love and Growing

Opportunities participants described valuing included being outside, gaming, spending time with family, friends and pets, working or volunteering, helping others and looking at family photos. A small group of mothers and a sister were able to build programmes of activities that aimed to help their relative 'grow'. They described fighting the system to achieve this, and some acknowledged that they could do this because of their knowledge of law, social care, contacts and/or professions. They were able to negotiate barriers and develop alternative support encouraging their relatives to pursue sports, drama, music, travel, film, game design and writing. In effect, they counteracted the oppressive circumstances their relatives may be subjected to with resources and conversion factors. Joan's son, for example, lived with his older parents and a live in carer and played in a band following his love of music. She described how,

Monday to Friday he's busy from 9.30 'til 5.30 or later, depending on the day, every single day with short breaks for meals, medication, toileting. That suits him very well. When he's not got something, he gets much more symptomatic. He gets more anxious. (Interview 1)

It was not clear whether busy schedules were evidence of flourishing lives or an indication that filling time was important to ward off distress. We suggest that these instances may provide a glimpse into the grimness of day-to-day life without meaningful activities and hint at anxieties participants had about their future lives more generally. Scheduling weekly activities was welcomed by several participants with intellectual disabilities who suggested that these were a comfort. Matt, who lived in his own flat with daily support workers and his mother nearby to help, said 'You need a reason every day to keep going...If I'm not kept busy, that's when I start to panic because I have no idea what I'm going to do' (FG12).

The resource rich group operated relatively autonomously, having achieved a direct budget that enabled the employment of support staff and funded preferred activities. Family member

participants could form part of the support package if their relative needed 2:1 care and undertook the work of managing staff, and overseeing the delivery of activities. They had access to wider support and could supplement 'gaps' in the budget. Sian's son lived in supported living, attending college part time and working in a school kitchen 1 day a week.

So, Charlie has a fantastic life but it's what's going around it that makes it happen. He feels he's totally in control of his life but he's not because we work really hard. Myself, the PAs, the house, to make sure that it all runs smoothly for him. (FG3)

There was acknowledgement within this group that parents were growing older and would not always be able to fulfil this role, leading to further layers of preparatory labour. Mary described her careful administrative task of preparing information files for Will's father and brother to guide them. Will lived in supported living, and Mary said she worried about his future and was 'very disillusioned about what care can do' (Interview 11).

Some participants with intellectual disabilities also rejected what providers offered them or aspired to a better life although they were not able to draw on the same resources or conversion factors. Jim, for example, said he developed his 'own ways of doing things' after 'doing battle' with his local provider and losing. He felt there was an expectation by social workers that he would fit in with their system.

Parents with fewer resources who described struggling appeared more accepting of existing services. They had little freedom to plan activities that their relatives would enjoy and viewed support as having potential to give them back some time and autonomy. Jane, whose son lived with her said, 'We do live in a deprived area, even though it's a holiday town, it is low budgets, you know, low income [...]... And nobody cares that we're on a low income and that worries me' (FG14).

5.1 | Choice, Confidence and Empowerment

While capabilities refer to opportunities, the concept of choice dominates the social care landscape and can be subjected to normative leanings and confusion around what 'choice' means, and what methods should be used to support it (Harris 2003). Some parents emphasised how they tried to ensure that their child was supported to make choices. As Jane said, 'Even if he changes his mind. I do it with everything: with clothing, with holidays, with food, with any decision. I try and include him in everything' (FG14). We noted that other participants had ideas about the activities their adult child 'should' pursue, which seemed to reflect their own beliefs about what a 'full life' should include. Jolene, whose son lives with his parents, described how she was determined 'particularly as a boy, that he should have a sport' (Interview 14), which leads us to question whose aspirations are these? (Benoot et al. 2022).

Self-confidence, a key individual conversion factor, affected every aspect of participants' lives in terms of making their own decisions, becoming more independent, getting a job and

accessing activities. Several participants told us they, or their relatives, relished opportunities to try new activities, such as travelling independently. Doing something new, feeling it had gone well, and the sense that something had shifted within as a result, helped people feel more confident. Joe's sister Maria described the importance of work to her brother.

I thought, 'This is him blossoming'. He had a part-time job where he was delivering leaflets, with support... to give him that kind of confidence of 'I can do this'. And he was going door-to-door, getting out in the community, being confident in where he is going. (Interview 5)

For Addy, moving into supported living helped with his confidence.

Since leaving home, I've done so much. I've managed through joining the chorus, through competitions they've had, I've travelled to [city in the US], against my mother's wishes. I've grown in confidence. Confidence, I think, means a great deal. (FG 9)

Relationships with support staff were highlighted as critical for building confidence. Support workers modelled how participants could be more assertive and make their own choices. In effect, people were empowered to achieve capabilities. Matt (FG12) described how his support workers gave him more self-belief, which he felt was the first step, 'But it's just taking that small step of "Okay, I've got that far, now I can take that next step"'. Seb, who lived in supported living with full time support, said,

I think it's forming a relationship with the staff and also probably get hired in a job, that helped me a lot. That I was going to people and they were in the same position as me. So I was like 'it's okay for you to speak up, it's okay for you to say no, you can do that if you want'. That boosted my confidence. (FG 1)

Further blocks were identified around the perceived overprotectiveness of family members, which could lead to the withering of aspirations (Benoot et al. 2022). Several participants said that they had no opportunity to build life skills such as cooking, cleaning, money management, which contributed to a lack of confidence. Pam, who lived on her own after a period in a care home and Steve, who has lived alone without support for 30 years, said,

Pam: I think it hurts having to own up that I'm having these problems.

Steven: You're not on your own, because there are a lot of people with intellectual disabilities Pam, including me, but I've kind of fight back and tell my mum to do one, right. Some parents are very over-protective, won't let you join anything. (FG9)

Loss of confidence was also attributed to bullying in social and health care settings, missing out on educational opportunities and when activities stopped due to setbacks. One participant had a seizure rowing and found it difficult to return to the activity, while COVID-19 was cited as leading to a loss of confidence such as travelling on public transport.

The importance of what parents described as guiding choices in some areas, particularly relating to health and self-care, was also discussed. Family members explained that this meant ‘persuading’ the person to do something they might not choose to do which was beneficial for their health. ‘It’s their choice’ was a response often provided to family members when they queried why relatives stayed in bed or were allowed to eat junk food. Prompting relatives to do more than ‘sit around in his pants playing on the computer’ was considered appropriate when supporting the person to make the ‘right’ choices. Ralph’s son moved into supported living just before he turned 50.

He often needs encouraging to do something that he enjoys doing...If you say to him ‘Would you like to go for a walk?’ ‘No!’. Well, if they call that the freedom of choice and take that first answer as ‘no’, you know, it’s not good for him and he does enjoy going for a walk. So, I think that there has to be a certain sort of guided choices really. (Interview 19)

Guiding choices included encouragement to think about the future despite some reluctance by people with intellectual disabilities. Mary, again referring to her own ageing, said,

I think Will is very much in the here and now. So, it’s very hard to make decisions for the future because his is about, ‘What are we doing today? What am I eating today?’ It’s not... he doesn’t think about... he doesn’t have imagination. He doesn’t think about, “I want to do this,” particularly. [...] I feel it’s just led by me and as I get older, maybe I won’t be making the right choice for him...as my world shuts down more...I feel like someone should be helping him. (Interview 11)

Younger participants, like 19-year-old Les said he needed more time to think about the future. He worried he might not fit into an environment perceived to be tailored to people with severe intellectual disabilities. Other younger participants said they did not want to think about moving until they were in their 30s. Some had glimpsed what a future in supported living might look like and felt it was not for them. It was apparent participants needed support to feel empowered and confident enough to make decisions about their future. Kane who was in his late 20s, and lived with his parents, said,

I need to find out with my parents...or my brother, to think about how to be safe side and to look forward (and) work with me by supporting me with my own house...They can help me by supporting that. (FG1)

Some family participants described frustration about the lack of thought about the future, and lack of information about what could be possible. Joe’s sister, Maria described a sense of aimlessness; ‘We’re just going to carry on doing the same thing day-in day-out...I feel like that’s really important for him to actually have some thoughts for the future...Like what’s going to happen next?’ (Interview 5).

5.2 | Relationships, Being ‘Out in the World’ and Belonging

Confidence and empowerment are closely aligned to feelings of belonging, and participants challenged ideas they passively received support, demonstrating how they give back to others by being loving, offering kindness, help and support. Jen, who lives with her partner, described how,

I just love being there for people. The amount of people I’ve cheered up on Zoom, haven’t I Rob? I’ve cheered people up when they’ve been down, and they’ve picked me up when I’ve been down. We’ve all been there for each other. (FG4)

This reciprocity generates feelings of belonging, and the importance of relational agency, of fluency in using and giving support is crucial to developing independence (Nind, Coverdale, and Croydon 2021). Participants described how they contributed, albeit sometimes reluctantly, to household work. Others had a sense of giving back to the wider community through paid or voluntary work. Jim acted as a representative for people with intellectual disabilities and was involved in charity fundraising. Those who excelled at sports (our sample included a national and international medallist) offered coaching or acted as ambassadors for inclusive sport. The sense of connectedness to others through this work reinforced to participants that their lives had value. Day centres, charities and other organisations for people with intellectual disabilities had a role in supporting participants to be sociable, build and maintain relationships.

Weekly events and activities provided social opportunities. While some parents viewed friendships made through these activities as superficial, participants with intellectual disabilities regarded their friends as offering emotional support and opportunities to be themselves.

I don’t think he really aspires to anything (else). That sounds very dull, doesn’t it? [Laughs] But, you know, as long as he’s well looked after I think he would be happy and I think he would like to continue going to the meeting place and meeting other people there and doing as much as he’s able to do. (Ralph, Interview 19)

Intimate relationships were highlighted by some participants as important to their wellbeing. Life partners were an important part of an imagined future, which was acknowledged by family members. One participant spoke about the importance

of having a sex life and actively sought out support from a 'sex coach'. Some parents said they hoped that their adult children would have 'some(one) to cuddle' while others worried about potential interactions, afraid their relative might get in to trouble for saying 'inappropriate' things. It was not clear if parents wanted to encourage better communication or close potential relationships.

Some participants described living at home with few opportunities to meet people their own age. They socialised with their parents' friends or were mostly in the company of carers. Mary described how her son has 'a selection of friends with Down's syndrome, ten friends that we, as a group (of parents), made a group for them to meet up'. She said that her 29-year-old son needed young men in his life and yet his carers, albeit 'absolute superstars' were in their late 60s and early 70s (Interview 11).

Parents attributed the absence of relationships to a lack of social skills and understanding of social rules. Resources were again an important factor in social events, and some participants were unable to pay for supported social activities.

Several participants took great pleasure at simply being 'out in the world'. It gave them a sense that they were free and living life. For Maria, her brother 'wants to see more of the world and go places... he wants like sand and warm weather and big open spaces', and Cath whose son lived at home with her, described how,

He just likes being with people and he does like being out...He's got his freedom pass and he'll just go all the way to the other side of London on the bus. He just likes being out and about and travelling around and talking to people (FG3).

There was a sadness detectable in the data. Participants with intellectual disabilities were presented as travelling outward 'into the world' and spending short periods there without feeling they fitted in. Les said, 'I want to be out in the world. I don't know where I fit in...I have a foot in two worlds' (Interview 14). Colin lived in his own flat without social care support:

I pretty much keep myself to myself. I've extremely very few friends. I'm not even sure I could do a handful in digits, you know...It's just that's the way I am... A normal day to me is the solitude. I feel like I'm an oddball and I've got not much chance of having any sort of relationship. (Interview 4)

The awareness of not fitting in appeared to be particularly acute at critical junctures in life, particularly those perceived to be effortlessly navigated by non-disabled people such as getting a job, getting married, having children. Several participants talked about things that seemed off limits to themselves or family members. Stella, whose son lived in supported living said he realised in his mid-twenties that there were some life experiences he did not think he would attain,

And he said, 'I would like a wife, I would like children. I would like to be able to drive a car and ride a motorbike...

How likely do you think is that to happen?' And I found it an incredibly hard moment. (Interview 17)

We note that from the language used, there was a strong implication in several accounts that not to be 'out' was to feel confined and shut away from the world. Some participants worried relatives living in residential care, particularly those with profound intellectual disabilities would not be supported to stay connected to the world, 'One aspiration I've got...is that I want him to stay connected with the world. I worry that if he isn't supported to meet his family (and) his friends (and), go out and do things, that he would become isolated. So that's my aspiration for him; to be happy and connected to the world' (Sian, FG3).

5.3 | Lowered Expectations and Static Lives

The final sub-theme offers a salutary reminder of what underpinned this research; that many people with intellectual disabilities lead limited lives in the UK. While people are often reliant on social care staff or family members to do things they value, our analysis demonstrated a reluctance by caregivers to fully explore and act on what was important to people. Social care support was perceived to be system orientated and people's preferences, or family suggestions were overridden by rules, practices or lack of resources. Georgie described how her daughter, who is in her 40s and lives in a residential home, is not able to do things she wants to do because she is dependent on staff availability (FG11), while Cath returned to the point about resources:

We all need to feel that we've got enough money and the resources that we need to be able to live the lives that we want to live... They have no freedom of choice if they literally have £20 to live on a week, have they? (FG 3).

Sen's concerns around the downgrading of opportunities for disabled people were realised as a culture of acceptance of supporting people to do the minimum was apparent. Participants described routines largely focused on the basics of food, shelter and safety with little curiosity about supporting someone to thrive.

He's got a lot to give, and he wasn't really being thought about. It was more, 'How can we get through shifts? What can we do to sort of fill the time up until it's time for him to go to bed and have his bath and clean him?' That's not good enough for my brother. (Maria, Interview 5)

'Filling time' is a stark opposite to flourishing and, for people with intellectual disabilities, this approach to support can be experienced across weeks, months and years.

6 | Discussion

We set out to explore if CA could shed new insights into the lives of people with learning disabilities, an area which has remained resolutely resistant to change. Despite challenges around operationalising CA, our research design, drawing on the work of

Hollywood et al. (2012), enabled us to better understand how interactions between people, and material, social, economic and political factors, mediated by interrelated conditions of austerity and social care culture, influence the opportunities people with intellectual disabilities have to do the things they value. It is vitally important that social care staff and family members recognise what people value doing to ensure they have opportunities to live flourishing lives.

Barriers to conversion factors, such as social care cuts, can be worsened by a lack of encouragement, support and aspiration reinforcing Sen's concerns around lowered expectations. We found a systemic acceptance that people can lead capability deprived lives with inequalities around access to opportunities (Nind, Coverdale, and Croydon 2021). We also identified a sense of loneliness, anxiety and underlying sadness, which could, in part, relate to the ongoing impact of COVID measures. Some people wanted relationships or work that fulfilled them, for their lives to have opportunities, which enabled them to feel they contributed to society and gave them a sense of achievement. This seemed challenging even with, or sometimes despite, family support.

The differential access some families had to material and personal resources to create what appeared to be capability rich lives was very apparent. Internal conversion factors here involved determination and a preparedness to fight, and the often gendered, everyday labour of maintaining aspirational programmes. It has been argued that caring for a loved one is perceived as a capability (Horrell, Stephens, and Breheny 2015); however, we found resource poor parents who were trying to balance their needs with those of their adult children.

We were unable to make definite conclusions about whether the aspiration rich programmes described were articulations of capabilities or functionings. It was not clear how much autonomy people with intellectual disabilities had in the choice of these activities, or whose aspirations they met (Kendall and Cameron 2014; Benoot et al. 2022). It was not clear whether these programmes constituted attempts to create flourishing lives by families operationalising the agency of their relatives or attempts to stave off feelings of uncertainty or anxiety. The presumed need for protection over living a full life may further obstruct the risk-taking necessary to lead flourishing lives (Nind and Strnadova 2020).

Within the current social care landscape, including a precarious and poorly paid workforce, the labour undertaken by parent carers can be critical. Indeed, Macpherson et al. (2023) use the term debilitating instead of disabling to capture how changes in support can generate suffering, frustration, exhaustion and disillusionment. However, family carers will eventually grow too old to continue with this labour and guidance (Ryan et al. 2024).

There were other anomalies within the analysis, for example, around friendships and activities that participants with intellectual disabilities described as important and family members were dismissive of. We wonder if there may be a reluctance or inability to fully explore what people with intellectual disabilities really want to do and enjoy which is reflected in existing research. Family carers may feel compelled to conform to a

normative model of caring in terms of 'meaningful activities', overriding the wishes, desires and aspirations of their relatives. Related to this was the 'gentle persuasion' by family members which has been explored in relation to parents of autistic children; Robeyns (2016 p389) was unable to decide whether parental interventions to stop activities like stimming reflected well informed attempts, or well-intended and badly informed attempts to improve flourishing, or simply prejudice.

Participants described the importance of learning new skills and developing confidence with the help of support workers, and this role is key to realising the potential of people with intellectual disabilities (Nind, Coverdale, and Croydon 2021; Macpherson et al. 2023). It is clear that we need to establish more effective ways of appraising the opportunities people would like, and how these are put in place that move beyond considerations of choice. As Hollywood et al. (2012) highlight, it can be hard to assess what young people value if they have not had the opportunity to think about and articulate this. In effect, being aspirational is a freedom in its own right (Benoot et al. 2022) and we suggest supporting people to articulate what it is they value needs further methodological innovation. A limitation to our project is a research design in which we asked people, or family members, what was important to them. While the use of the component list prompts helped generate discussion, it was difficult to move beyond what participants did to more abstract questions around capabilities and freedoms.

7 | Conclusion

Our research demonstrates that the lives of people with intellectual disabilities are often shaped through the eyes and assumptions of others, rather than an understanding of what is important to them. Using CA allowed us to identify nuances within this, including resource rich parents who create full lives for their children while leaving unanswered questions about the extent to which these lives feature capabilities or functionings. We conclude that this is in part symptomatic of the problem. People with intellectual disabilities may be asked what it is they value but are not empowered or supported to fully explore what 'flourishing' means to them.

This lack of opacity needs closer attention in social care provision and research. Focusing on what people do allows lowered expectations to remain the norm and may even be considered good. We argue radical change in what support is funded should include consideration of the development of opportunities for people to undertake meaningful activities and be fully out in the world. A necessary step is to develop methodological innovation to understand what people with intellectual disabilities value and what it might take to achieve this.

Author Contributions

Sara Ryan made substantial contributions to conception and design, analysis and interpretation of data. Rosaleen O'Brien made substantial contributions to analysis and interpretation of data. Sara Ryan and Rosaleen O'Brien have been involved in drafting the manuscript and revising it critically for important intellectual content, given final approval of the version to be published, and agreed to be accountable for

all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Ethics Statement

Ethics approval was granted by the Health, Psychology and Social Care Ethics and Governance Committee, Manchester Metropolitan University.

Consent

Consent was recorded at the start of each interview and focus group.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data are available on request to the first author.

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