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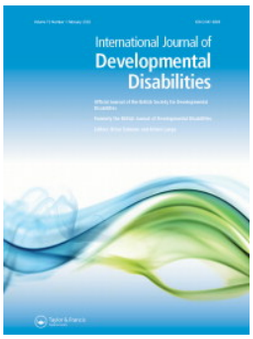

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The views and lived experiences of individuals with intellectual and developmental disabilities who live in secure services: a meta-ethnography

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ABSTRACT

Objectives: In the United Kingdom, numerous scandals of abuse in in-patient services for individuals with intellectual and/or developmental disabilities (IDD) have prompted major policy reforms in service delivery, including a move towards reducing long-stay hospital beds and increasing community living. Despite widespread critiques and concerns about their effectiveness, secure settings continue to be commissioned for individuals with complex forensic or mental health needs, often due to limitations in community provision. To avoid repeating past failures, changes to the current service models are warranted. An initial step is understanding first-hand perspectives to inform more effective and supportive care. This meta-ethnography aimed to synthesise the literature relating to the lived experiences of people with IDD living in secure services.

Methods: Using Noblit and Hare's meta-ethnographic model, a systematic search of the literature was conducted on Embase, PsychInfo, and Ovid Medline. To evaluate the methodological quality of studies, the Critical Appraisal Skills Programme framework was used.

Results: Eleven studies were included. Four primary themes were formulated: sense of self; where is my power?; navigating social relationships; and necessary evil. Of these, subthemes were formed to explore shared and contrasting views on belonging and identity, powerlessness, and meaningful social contact.

Conclusions: The findings reveal shared narratives from people with IDD that highlight areas for improvement in in-patient care services. While insights can guide service redesign, the methodological quality of several studies was low, underscoring the need for more rigorous research. Clinical and research implications are discussed.

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Intellectual disabilities; secure services; service users views; meta ethnography; developmental disabilities; participant views

Introduction

In the United Kingdom (UK), there have been numerous inquiries documenting the abuse endured by individuals with intellectual and/or developmental disabilities (IDD) in long-stay secure and/or in-patient hospitals. In 1967 the abuse endured at the Ely hospital in Cardiff was reported in the national press, it included excessive use of sedatives to control behaviour, exploitation and lack of care, and physical violence including rough handling, threatening, as well as bullying behaviours (Butler and Drakeford 2003). Inquiries were raised to assess how individuals with learning disabilities were treated in National Health Service (NHS) hospitals. This led to the establishment of the Hospital Advisory Service, to regularly report on the conditions of long-stay institutions (National Health Service 1969). Subsequently the 'Better Services for the Mentally Handicapped' white paper presented recommendations for care, including the closure of long-stay institutions (Boardman 1971). Despite these measures the abuse of individuals with learning disabilities in hospital settings has reoccurred. Recommendations drawn from resultant inquires have echoed that of the Ely Hospital investigation, including seeking patient' perspectives (e.g. British Broadcasting Corporation 2012; Buckinghamshire County Council 1998; Commission for Healthcare Audit and Inspection 2006; Department of Health 2012).

The occurrence of scandals, the rise of the normalisation principle, and evolving ideologies were key drivers of deinstitutionalisation (Mansell et al. 2007). A significant influence on these ideological shifts was Goffman's (1961) theory of total institutions. Goffman combined psychological and sociological perspectives to criticise the medical model of IDD,

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reframing it as a socially constructed phenomenon rather than an intrinsic pathology. His theory highlighted the impact of institutional environments on individual identity and behaviour, contributing to a broader understanding of IDD and the harms of institutionalisation (Hamlin and Oakes 2008).

Although care models have evolved since the 1960s, Goffman's work remains foundational and is frequently cited. His concepts can still be applied, though cautiously, to modern IDD secure services. Goffman's key argument was that institutions inherently exert control over multiple aspects of daily life, such as sleeping and eating routines. This often leads to the erosion of pre-institutional identities and the imposition of new identities shaped by institutional norms, which often differ from broader societal values (Bruce 2021; Goffman 1961). Notably, identity disturbances have been linked to mental health difficulties, including depression and anxiety (Klimstra and Denissen 2017; Potterton et al. 2022), as well as to feelings of alienation and social maladjustment (Sokol and Eisenheim 2016). Given these associations with psychological well-being, the continued relevance of Goffman's theory and subsequent research support the importance of minimising institutional practices and promoting a more socially integrated care model.

After a widespread abuse of people with IDD was uncovered at Winterbourne View (British Broadcasting Corporation 2012; Department of Health 2012). Transforming Care, a program focussed on people with IDD to help them live in the community with the right local support, reducing hospital admissions, and closing inpatient beds, was developed as an initiative to review hospital placements and facilitate transfers to community settings (Department of Health 2012, 2015). However, in 2019 a further documentary highlighted abuse at Whorlton Hall (British Broadcasting Corporation 2019), despite the continued focus in social policy to close long-stay hospitals and reduce admission to secure settings (Department of Health 2001, 2015). It is to be noted that though the reported scandals provide evidence of institutional failings, the data is drawn from investigative journalism and inquiries, rather than systematic research. Consequently, they do not provide generalisable evidence of the broader systemic conditions experienced by people with IDD. Furthermore, little to no systematic evaluation of whether and how recommendations were implemented across services has been presented, and the available evidence lacks comprehensive longitudinal tracking of outcomes for individuals post-scandal, i.e. in terms of quality of life, limiting the understanding of the sustainability of the changes that have been implemented.

Various factors may contribute to the repetitive nature of the scandals witnessed in institutional care, including issues with implementing active support (Bigby et al. 2020), poor staff culture (Fox et al. 2024), and funding difficulties (Brown, James, and Hatton 2017). Specifically, a difficulty to provide appropriate accommodation for some individuals with IDD in the community has been raised as a notable factor (Bevan et al. 2018).

The struggle to appropriately fund and provide community housing for some individuals with IDD in the UK has led to a need for the continuation of secure services even though this is contrary to the values expressed by society and service providers (Department of Health 2015). Secure services provide higher levels of security for individuals who may pose risk to themselves or others, or with treatment needs that may be difficult to manage in the community (Urheim and VandenBos 2006). These institutions restrict the choice and freedom of those detained to reduce risk (Adams et al. 2018), although there is an important moral imperative to close them, due to limitations in funding for appropriate community services there is currently a need for this sort of care. To address the need for this care for individuals with IDD whilst also considering the long history of scandals and abuse in institutional care, the planning, development, and delivery of secure services needs to draw on patient and public involvement, increasing opportunities for those with lived experience to inform treatment planning and delivery (Livingston et al. 2013).

There is recognition in the NHS that the experiences of patients and the public within care settings should be sought as they offer unique insights into what is successful and/or in need of development, informing service improvement (NHS England 2015). The Department of Health, England released the 'White Paper, Valuing People', urging the exploration of the consumers and stakeholders' views, noted as essential for the implementation of initiatives (Department of Health 2001). Patient and public involvement in research has been associated with various benefits, such as improvements in care coordination, improved clinical outcomes, and greater service accessibility (Crawford et al. 2002).

Historically, the exclusion of individuals with IDD from research was due to the adoption of a model solely focused on impairment, which in turn marginalised and ignored the voices of individuals with IDD (Montgomery et al. 2022). Furthermore, Sigelman's early work on acquiescence argued that people with learning disabilities were inclined to agree with contradictory questions, a

claim that shaped ethics and research practice for many years to justify their exclusion from research (Sigelman et al. 1981). However, Rapley and Antaki later demonstrated that such patterns were largely produced by the structure of interviews and the interactional demands placed on participants, rather than an inherent characteristic of people with learning disabilities (Rapley and Antaki 1996). This critique dismantled a longstanding rationale for their exclusion and further highlights how methodological assumptions contributed to the marginalisation of their voices. These findings have encouraged NHS ethics committees to turn aside from protectionism and instead recognise the importance and empowerment gained from their participation in research (Gilbert 2004).

This change in perspective provided momentum for research exploring the views of people with IDD of the support they receive in community services (O'Brien and Rose 2010; Robinson et al. 2016). Over the years, this research has highlighted participants desire for greater choice and control, as well as a need for professionals to re-examine and adapt their relationships. These studies have predominantly focused on the experiences of service users in community settings, with only a few studies exploring lived experiences in secure settings (Fish and Morgan 2021; McDonald 2012; Traver-Edo et al. 2021). A review exploring the experiences of inpatient mental health services urged for more research on the topic, particularly in secure settings (Lake et al. 2014).

Aims

This present study aimed to conduct a meta-ethnography to explore the views and lived experiences of people with IDD who live in secure services.

Methods

A meta-ethnography was conducted for the current study to synthesises the data on the views and lived experiences of individuals with IDD in secure services. This meta-ethnography has been registered on Prospero.

Outline

This meta-ethnography followed the step-by-step method provided by Noblit and Hare (1988) and adapted by Sattar et al. (2021). A systematic search of the literature was conducted to answer the primary question of the review: 'What are the experiences and views of people with IDD who live in secure services?'

Search strategy

A systematic search of the literature was first conducted on 19 July 2024, repeated on 2 December 2024, and repeated grey literature search on 2 January 2026. Three electronic databases were used, Embase, Ovid Medline, and PsychInfo. Grey literature was also searched on Google scholar, along with reference checking. The search terms used related to the construct areas identified (Table 1).

Systematic search

The inclusion criteria included qualitative studies exploring the views, experiences, and/or accounts of secure settings by adults who are or were in a secure service for people with IDD. Secure services were defined as inpatient settings that provided support for adults with IDD, under private or public healthcare, including long-stay hospitals and forensic services. A diagnosis or a borderline diagnosis was used to categorise IDD. Services were limited to adult services only. Studies were required to have quotes from participants regarding their experiences of the service and/or facets of the service, such as the activities provided or their relationships with staff. Studies were included only if they were peer-reviewed studies that explored the broader lived experiences of adults with IDD residing in secure

Table 1. Search terms for systematic search.

Key constructs					Limits
Secure settings Inpatient setting* OR Inpatient service* OR Secure setting* OR Secure service* OR Secure hospital*	'AND'	Intellectual/developmental disorders Intellectual disab* OR Learning disab* OR Retard* OR Development* disab* OR Autis* OR ASD OR Autism spectrum disorder* OR Development* disorder* OR Mental impairment OR Mental handicap	'AND'	Experiences Experience* OR Thought* OR View* OR Report* OR Perception* OR Account*	English language Human studies

services and provided sufficient first-order participant quotations to enable meta-ethnographic translation. Consequently, papers that focused exclusively on discrete, procedural, or behavioural phenomena were not included. These topic-specific studies, while clinically and ethically important, typically centre on acute incidents or narrowly defined behaviours rather than the wider relational, social, and environmental context of daily life in secure care. By contrast, studies examining social or therapeutic activities were included because these activities are embedded within the broader lived experience of secure settings and illuminate themes such as relationships, identity, autonomy, and engagement. Where experiences of restraint, self-injury, or sexual behaviour emerged naturally within the context of broader accounts, these narratives were incorporated into the analysis. Excluding studies that focus solely on single behaviours or procedures ensured that the synthesis maintained conceptual breadth and methodological consistency, enabling the development of higher-order constructs representative of everyday life in secure IDD services.

Search results

The database search yielded 378 records, including 16 grey literature records. This resulted in 259 records after the elimination of duplicates. Title and abstracts of studies were screened against the inclusion and exclusion criteria. Common exclusion for studies at this stage included study design not meeting the inclusion criteria. Twenty-three articles were screened against the inclusion criteria, of these, 13 met the criteria (Figure 1).

Extraction of studies characteristics

Data extraction was completed by the first author. Data relating to participant demographics, analytic tools, as well as researchers' position was extracted from relevant full text articles for the purpose of the analysis. Eleven studies were included in the meta-ethnography. The individual views and experiences of secure settings was documented for at least 159 participants, as the retrospective case-series study by Beckman, Nelson, and Labode (2022) did not clarify how many participants were included in their study.

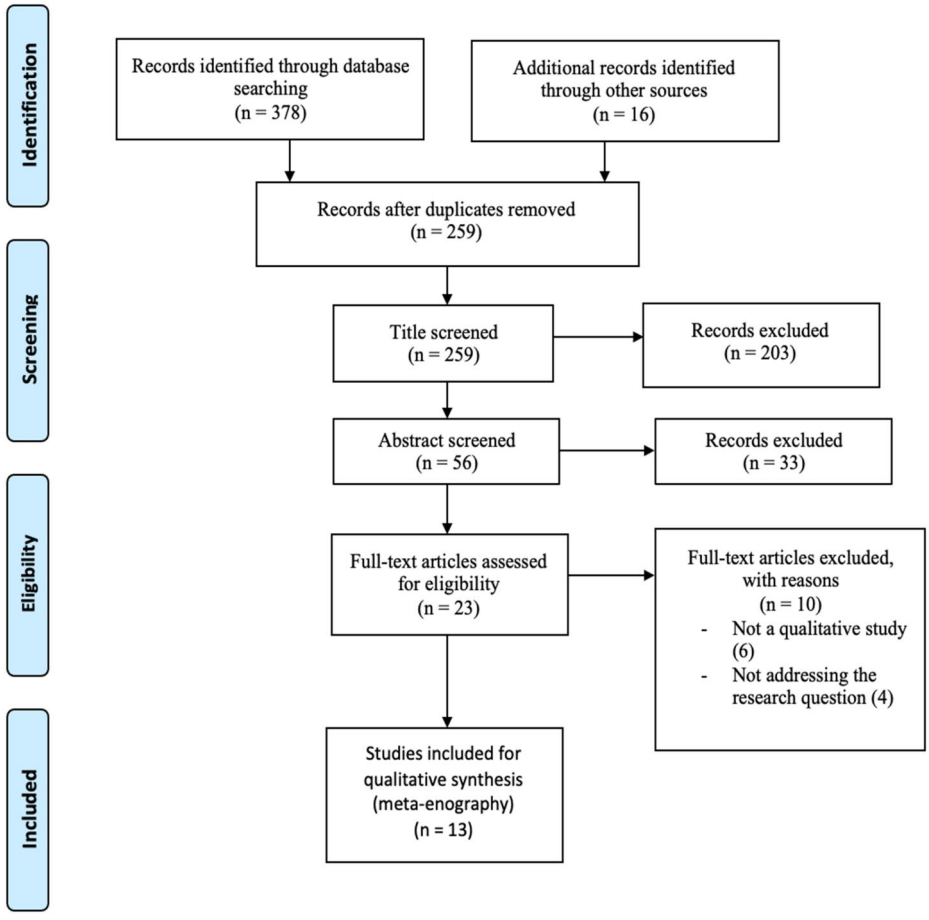

Figure 1. Prisma flowchart detailing the systematic search for articles to be included in the meta-ethnography.

Table 2. Theme synthesis, third-order construct.

Primary theme	Subtheme/concepts	Studies contributing to the theme
Sense of self	Where do I belong? Identity and depersonalisation Personal growth	(Beckman, Nelson, and Labode 2022; Chinn et al. 2011; Fish 2016; Heppell and Rose 2021; Hudson et al. 2018; Neimeijer et al. 2021; Parkes et al. 2015; Williams, Thrift, and Rose 2018; Wood et al. 2008)
Where is my power?	Seeking autonomy Lack of control	(Beckman, Nelson, and Labode 2022; Chinn et al. 2011; Fish 2016; Heppell and Rose 2021; Neimeijer et al. 2021; Murphy, Estien, and Clare 1996; Murphy and Mullens 2017; Williams, Thrift, and Rose 2018; Wood et al. 2008)
Navigating social relations	How staff shape experiences Living with other residents What about my friends and family?	(Beckman, Nelson, and Labode 2022; Chinn et al. 2011; Clarkson et al. 2009; Fish 2016; Heppell and Rose 2021; Hudson et al. 2018; Murphy, Estien, and Clare 1996; Murphy and Mullens 2017; Neimeijer et al. 2021; Williams, Thrift, and Rose 2018; Wood et al. 2008)
Necessary evil	Unpleasant yet needed	(Murphy, Estien, and Clare 1996; Murphy and Mullens 2017; Neimeijer et al. 2021; Williams, Thrift, and Rose 2018; Wood et al. 2008)

Participants were from a range of secure settings, including medium-low secure forensic units and psychiatric units. For some studies, levels of intellectual functioning were determined using the Wechsler Adult Intelligence Scale (WAIS), one study utilised the ICD-10, however most studies provided poor reporting on the measure used to determine diagnosis of IDD or assessing level of intellectual functioning. All participants were described as falling within the borderline to moderate range of intellectual functioning.

Participant ages ranged approximately between 17 and 61, though some studies did not specify participant ages. The majority of the studies (11) were conducted in the United Kingdom (UK), one study in the Netherlands, and another from the United States of America (USA). Only six studies detailed the ethnicity of participants. Of these studies, most participants were White British, others were from a range of ethnic backgrounds including Asian British, Black British, and White Irish. Majority of participants identified as male (71.1%).

Quality appraisal

The Critical Appraisal Skills Programme (CASP) checklist is a 10-item checklist, which was used in the present study to measure the quality and validity of included studies and assess for risk of bias (CASP 2024). The quality rating of papers was checked against inter-rater reliability for 20% of papers. The inter-rater reliability value between the author and an independent researcher was 0.75 (Cohen's Kappa, Sim and Wright 2005), suggesting strong inter-rater reliability. There was a mixed level of risk of bias most of the studies partly met most of the CASP checklist criteria, with one study meeting the criteria in full.

Data extraction

The extraction of raw data involved extracting first-order (quotes from participants) and second-order data (the authors' interpretations of participant quotes). The data was extracted as verbatim, to ensure important data was not lost and that the terminology used was preserved (Noblit and Hare 1988; Sattar et al. 2021).

Results

Four primary themes were developed, each with subthemes/concepts. Table 2 displays the themes: (1) Sense of self; (2) Where is my power?; (3) Navigating social relations; and (4) Necessary evil.

Theme 1: sense of self

The first primary theme presented narratives on perceptions of self within secure settings and how this was shaped. Reoccurring concepts were contrasting narratives on the experience of belonging, identity and depersonalisation, as well as skillset development and personal growth.

Where do I belong?

Many participants reflected on their sense of belonging since admission to a secure service. Participants reflected that transition to a service often does not lead to experiencing their new environment as 'home', as services are often seen as solely a place to live in. Participants interviewed by Williams, Thrift, and Rose (2018) carefully defined the concept of 'home', indirectly depicting how distantly they view secure services from their perception of home, 'it's a home when you comfortable, and you happy cos you have your own personal stuff…'. The quote also alludes to the use of personalisation in the person's immediate environment to foster familiarity and contribute to developing an emotional attachment, evoking a sense of belonging.

People admitted to in-patient services far from their home and their community, reported experiencing a reduced sense of belonging:

> At home there they speak in my language, and it's easier to speak in my language but I haven't spoken my language for a long time now… I used to speak Bengali loads of times when I was in London but I don't do that now because nobody speaks it here (Chinn et al. 2011).

The picture painted by this quote is an experience of a slow but yet noticeable stripping of cultural identity contrasted by a longing for it. For some, their loss of cultural identity and belonging may be perceived as a permanent change, due to long-stay placement or difficulties with gaining leave. This could contribute to possible long-term effects such as an enduring lack of belonging, often associated with behavioural difficulties as well as physical and mental health problems (Allen et al. 2021).

However, some reports highlighted that being part of a group or engaging in a meaningful activity presented the opportunity to experience belonging (Hudson et al. 2018; Neimeijer et al. 2021). Participants identified being part of their therapeutic 'group' as a place where they found support and sociability (Neimeijer et al. 2021). Community football fostered companionship and togetherness amongst the group and with staff members, 'I enjoy the footie, I enjoy meeting the patients, having a laugh and a joke' (Hudson et al. 2018). Participation in a valued activity appears key in developing integration and inclusion, fostering belonging to a team and a purpose. Interestingly, activities that could foster belonging are not required to be elaborate nor expensive in nature, as highlighted by Beckman, Nelson, and Labode (2022). The authors recognised that group celebrations of birthdays and holidays, mimicked family gatherings, which evoked belonging even when far from home (Beckman, Nelson, and Labode 2022). It may also be that this highlighted a sense of 'mattering', the experience of feeling significant and valued by others (Flett 2022).

Identity and depersonalisation

Participants reflected on aspects they missed about their life in the community and that these were forcefully taken away from them despite being important parts of who they were, 'I used to go into Derby town centre with my mum's old school friend. But I miss all that since I'm here (hospital)' (Williams, Thrift, and Rose 2018). The quote from the participant indicated a loss of a cherished routine which contributed to their sense of identity. Similarly, Fish's (2016) ethnographic work highlights how women in secure settings experienced their identities as constrained and regulated through institutional norms. Participants described being positioned as 'vulnerable' or 'risky', labels that shaped how their behaviour, relationships, and even sexuality were interpreted by staff. Identity emerged as something negotiated within restrictive environments, where people struggled to retain a coherent sense of self beyond the institutional frame.

Narratives on depersonalisation painted a perceived lack of recognition for individual characteristics and an uncomfortable experience of homogeneity (Chinn et al. 2011; Williams, Thrift, and Rose 2018). The organisation of schedules and routines on a group basis left participants reporting little chance for personal autonomy (Chinn et al. 2011) and exercising individual preferences, such as adding personal touches to their routine. 'I want to have my own place, have my own support, be my own person… have my own place again' (Williams, Thrift, and Rose 2018); the emphasis on 'own person' in this quote strongly highlights a yearning for their individualisation and a recognition of an identity shaped by the institution. Interestingly, the difficult balance between providing group activities to foster belonging and wanting to be addressed and recognised as individuals was noted by participants.

The paper by Hudson et al. (2018), illustrated this balance through community football. The authors highlighted that engagement in community football helped participants to develop a new identity they were proud of, a sporting identity shared with others, which helped improve their self-esteem and experience belonging, 'I am a totally different person when I play football than when I am in here' (Hudson et al. 2018). They noted that the characteristics of secure settings would undoubtedly impact peoples' sense of self, but alternative identities can be encouraged through meaningful group activities.

Personal growth

Some participants reported on developing skills whilst in secure services, which contributed to their sense of self. Narratives on personal growth ranged from experiencing greater ability to manage mood and behaviour (Heppell and Rose 2021; Wood et al. 2008), to everyday successes, such as preparing meals or receiving certificates after completing therapeutic courses (Neimeijer et al. 2021). Furthermore, the time spent engaging in meaningful activities helped people develop a sense of purpose, independence skills and kept them busy (Beckman, Nelson, and Labode 2022; Hudson et al. 2018), 'I just work work work because it gives me something to do, it keeps me active' (Chinn et al. 2011).

Participants seemed to value the interpersonal developments they made. It provided them a goal to look forward to and improved their skillset. This is important when considering long-term goals, such as discharge back in the community, and ensuring people are supported to manage some of the demands of community living.

Theme 2: where is my power?

The second primary theme highlighted participants' desires for autonomy, greater control over decision making, and their perceived lack of opportunities to be independent. Notably, it was highlighted that gaining a greater sense of autonomy was closely related to developing a stronger sense of identity.

Seeking autonomy

Often, many participants reported having transitioned from living at home with parents to an in-patient unit, with little to no experience of living independently or with staff support in the community. In the study by Heppell and Rose (2021), a participant (aged 27) commented on being in secure services for 11 years and reflected on his worries of going on unescorted leave.

> Interviewer: do you mean you're a little worried about going out by yourself?
>
> Participant: yeah. Because I haven't been had unescorted for … I've never had unescorted for rest of my life. (Heppell and Rose 2021)

Despite the noted worries, he shared his desire to live in the community and have independence, which he did not experience in the in-patient unit. This may suggest that the restrictions placed in secure services may delay or impede successful discharge to community settings.

Many participants described themselves as capable of independence and wanting to be seen as independent '… I like my own space. I like to be independent' (Williams, Thrift, and Rose 2018) but reflected that they may never experience independence due to organisational restrictions. One person expressed 'you don't get freedom … I wish I could leave here' 'I don't want to be in hospital. Because you ain't got your freedom, like, when you're out there you've got your freedom' (Williams, Thrift, and Rose 2018). This perhaps describes a captive experience, where the community is the desired treasure representing freedom and autonomy, whereas services represent restrictions that may be or are interpreted as punitive. Restrictions were perceived as punishments, and participants reflected those left them feeling on edge, 'seclusion for negative behaviour or comments being over the top and makes me careful about what I can say' (Murphy and Mullens 2017). This paints a metaphorical picture of 'a muzzle' over their mouth, where service users have to hold back from expressing themselves.

An interesting notion raised was that autonomy in secure services may be unattainable as greater freedom is solely afforded because of rule adherence, irrespective of agreement with the rules, and when the rules are broken the freedom is taken away. Participants commented on receiving 'rewards for good behaviour', such as leave to hospital grounds or family visits (Beckman, Nelson, and Labode 2022). Fish (2016) similarly documents how women's autonomy was tightly regulated through formal rules and informal ward cultures. Decisions about contact with family, friendships on the ward, and intimate relationships were often framed as matters of risk management rather than personal agency.

Participants felt that a balance needs to be struck. Staff need to recognise when they should be given the chance to practice autonomy, 'I don't like that (when sociotherapists are strict). That way you will never become independent', whilst also providing a containing and secure environment to keep them safe (Neimeijer et al. 2021).

Lack of control

Frustration was noticeable in narratives regarding organisational restrictions, leading to a lack of control and powerlessness. People reported a lack of control over their life as they had little say on their care and their transitions to secure settings, '… that's going to be scary because you don't know where you're going to live. Because they can put you anywhere can't they?' (Williams, Thrift, and Rose 2018). A real sense of fear is noticed in this narrative, the perception of powerlessness makes the experience of the future daunting.

During transition to secure settings, participants felt that they were left in the dark and had no say in decisions made, 'we don't have a choice about being here. How would anybody feel about someone coming into your home and telling you what to do' (Parkes et al. 2015). This speaks to a forceful experience in a new environment with restrictions on their autonomy and freedom, and people becoming passive receivers of care. Restrictions were particularly experienced as anxiety inducing when rules constantly

changed, such as access to the kitchen (Murphy and Mullens 2017).

The perceived lack of control ranged from everyday decisions to decisions about care. Participants' attested to not having control over their daily diet, managing their money and possessions, nor feeling that their opinions are regarded in multidisciplinary team (MDT) meetings: 'no one's been listening to my opinion at the moment. As far as I'm concerned, it's been going out of one ear and the other' (Chinn et al. 2011). A muted voice is depicted, in this quote, stripped of autonomy and control, a form of epistemic injustice (Fricker 2007). A frustration is gathered from these quotes, perhaps participants experience restrictions as a form of provocation, further aggravating their experience in services or it is the result of being wronged in their capacity as a knower and lack of professional humility shown to them. This is key to recognise as it may attest to how people experience their needs are being met and their desire to shape *how* they are met. Agency is asserted in small ways, through the controlled choices over the immediate environment, such as engagement in activities or decor (Chinn et al. 2011).

Theme 3: navigating social relations

The third primary theme highlighted how participants navigated social relations in secure settings and raised questions of how their social needs were met. Reoccurring subthemes included participants experiences in relating with staff, the contrasting benefits and difficulties of relating with other residents, and their views on their external social relationships.

How staff shape experiences

Accounts of both negative and positive experiences with staff members were reported. An important factor that helped to shape a positive experience was feeling 'seen' as more than just a patient, 'they treat you like a human being. They don't treat you like a patient. They talk to you like a human being […] And other placements I been to, its we're staff, you're patient' (Heppell and Rose 2021). Participants expressed that if staff were to get to know them as a person, rather than a patient, staff members would be better equipped to interpret and understand their symptoms and the function of behaviour correctly (Neimeijer et al. 2021). Staff should take initiative for contact, show interest and be patient, and most importantly not judge (Neimeijer et al. 2021). Staff members were spoken of warmly when people felt understood, 'if you look at it positively, you have more people around you, more people that understand you a bit better' (Hudson et al. 2018). Various accounts of valued attributes in staff members were shared, such as humour and helpfulness. It was clear relationships with staff members held meaning and made a positive impact in their life; the expression of being valued highlighting a sense of mattering to others (Flett 2022).

A question around boundaries may be raised relating to relationships with staff. A few participants described viewing staff as friends 'he's my closest friend, my best friend, special friend, more than a friend' (Murphy, Estien, and Clare 1996) or in a parental role, 'he [staff member] is not just like a friend to me, he is like a father to me. Because he has been there for me. And honest truth, I look at him like my father' (Clarkson et al. 2009).

Participants equated the rapport they had with staff to be indicative of the quality of care they would receive, with those who reported poor rapport with staff, reporting negative experiences of care. Those who described feeling misunderstood – 'the cocky ones and that, the ones that don't understand you', not listened to – 'well I had a pain once and they said I was putting it on … they called me a hypochondriac', and mistrusting of staff members – 'I wouldn't tell them … cos I know they wouldn't keep everything confidential', spoke of how such negative interactions were associated with greater distress and difficulties managing emotions and behaviours (Chinn et al. 2011; Clarkson et al. 2009). There were reports of being demeaned by staff, treated unfairly, intimidated, and called names, such as 'idiot' and 'nutcase'. Participants described feeling treated 'worse than a dog', (Chinn et al. 2011). This demonstrates how unsympathetic and threatening experiences with staff members can be setting conditions for behaviours that may later be described as challenging, which may, in turn, adversely influence sense of self and internalised stigma for the person with IDD.

Living with other residents

There were reports on both the positive and negative experiences of living and engaging with other residents. However, there were fewer reports on positive experiences

One participant commented on the meaningful aspect of being in a group and the shared trust gained, 'It is positive that we are one group and that we trust each other' (Neimeijer et al. 2021). 'One group' presents the view of uniformity and shared

experience between people and where there is trust, they might rely on each other for social needs. In Hudson et al. (2018) paper, participants mentioned that football as a regular activity led to friendships and they spoke fondly of others, 'I enjoy footie, I enjoy meeting the patients, having a laugh and a joke' (Hudson et al. 2018).

The majority of participants reported disliking their experience of living with others. They highlighted difficulties with being grouped with people with different needs, different ages, and different personalities, which often led to arguments and fall outs (Williams, Thrift, and Rose 2018). Furthermore, managing the differences in need and complexity was described as tiring and anxiety inducing, as they became hypervigilant of potential dangers from other residents' (Neimeijer et al. 2021). Participants expressed a need to 'get away', 'I'd rather have my family any day than these [patients]' (Williams, Thrift, and Rose 2018), suggesting a discomfort with living and interacting with others not of their choosing and a sense of feeling 'trapped'. People were placed in a service, sometimes indefinitely, with individuals they may be unlikely to develop a rapport with.

The behaviour of others infringes upon the autonomy experienced, for example, restriction in movements at certain times are introduced for all due to difficulties with managing the behaviour of some residents (Neimeijer et al. 2021). This could also mean meaningful and cherished activities being taken away, 'I was disappointed in all of us patients for blowing roller-skating. Some people were horseplaying' (Beckman, Nelson, and Labode 2022). Fish (2016) similarly documents how women's autonomy was tightly regulated through formal rules and informal ward cultures. Decisions about contact with family, friendships on the ward, and intimate relationships were often framed as matters of risk management rather than personal agency.

For many, navigating social relationships may be difficult due to their diagnosis and symptoms, however there are also aspects of living in secure settings that seem to worsen their ability to navigate the social milieu effectively.

What about my friends and family?

A reduced proximity to family and friends is noted as a result of admission to secure settings, negatively impacting on contact and existing relationships. Participants shared their concerns on how the distance would negatively impact their contact with their family, 'I said I don't want to go there because it is far from home' (Parkes et al. 2015). Their concerns indicate they may feel that their contact with their community is not being considered during the transition/admission process despite their desire to maintain a connection with their home community, with a hope to one day return home.

Contrarily, some people do not want to live close to home. In Heppell and Rose's (2021) study, participants described desiring to be far from home due to their hometown and family being associated with negative memories and a fear that due to their offending histories, they may be targeted, 'because of what I do in the past, I might end up … you know. People might know me or might do me in or something' (Heppell and Rose 2021).

Theme 4: necessary evil

The final primary theme referred to views of secure settings being necessary yet undesirable.

Unpleasant yet needed

Though many participants wished they did not live in an in-patient unit, some acknowledged the necessity of these settings. They recognised that the hospital environment may be unpleasant, yet needed for their development, 'it isn't the ideal place to live but on the other hand, I've got the help I've always wanted' (Williams, Thrift, and Rose 2018), 'although there are strict rules, I feel less anxious here' (Murphy and Mullens 2017). Participants who felt their behaviour was 'out of their control', welcomed the assistance provided by services, even though it equated to an admission (Murphy, Estien, and Clare 1996). Participants recognised that the hospital environment may help to meet their needs, such as helping them understand their difficulties, but highlighted the frustrations of needing to be exposed to an unpleasant environment to have their needs met and develop the necessary skills to live independently (Neimeijer et al. 2021). Further conflicts related to their experience of treatment, such as viewing admission as 'punishment', but regarding some treatment as helpful 'sessions about drugs, alcohol, anger management; they've all helped' (Wood et al. 2008).

Discussion

The aim of this review was to synthesise the lived experiences of individuals with IDD living in secure services. The findings suggest a range of experiences

across people with IDD in secure settings, with recurring narratives which share the difficulties of belonging, the stripping of identity and culture, an unfailing sense of powerlessness, and the recognition of the unpleasant yet needed nature of secure services. Navigating social relationships was often challenging for people, with contrasting reports on their experiences with staff, including considerations of relational boundaries, difficulties with living with other residents, and a lack of contact with their home community. These narratives are reflected in the language used in many of the papers where many everyday events are reframed as clinical activities and relationships are often seen as instrumental.

The results of the review reported various narratives describing difficulties with experiencing a sense of belonging within secure services (Chinn et al. 2011; Williams, Thrift, and Rose 2018). This raises questions regarding the possible consequences that a lack of belonging may cause, especially for those with long-term stays in services. Belonging fosters safety and support, and it is found to be a key component for managing distress and behavioural difficulties (Allen et al. 2021). A persistent lack of belonging is associated with increased behavioural, mental, and physical health risks and difficulties (Allen et al. 2021). A possible way to mitigate this is through participation in community activities. In a recent study, individuals with intellectual disabilities defined belonging as spending time with friends and family, taking part in community activities, and having opportunities to connect with people (Kaley et al. 2021). Interestingly, the narratives shared also highlighted the possible experience of a sense of mattering amongst participants. Though, in the literature 'mattering' is a relatively neglected core component of the concept of 'self', it is an important protective factor crucial for well-being, of which absence can be deleterious (Flett 2022). The notable reports from participants hinting towards a sense of mattering, suggest that this psychological construct can be fostered in secure settings, providing residents with higher self-esteem. The findings from this review provide evidence for the current inspection regime by the Care Quality Commission (CQC; Care Quality Commission 2015) the CQC is England's independent regulator for health and adult social care, responsible for ensuring services like hospitals, provide safe, effective, compassionate, high-quality care. A core element of CQC inspections is the promotion of regulated activity in secure settings, including seeking and acting upon patient feedback on the experience of these activities (Care Quality Commission 2015).

Queries around identity, including depersonalisation, were identified in the review, as participants alluded to feeling like less of their own person whilst in secure settings. They described the need for 'ownness', such as a recognition of their individual needs, personal characteristics, and personalisation of their environment (Neimeijer et al. 2021; Williams, Thrift, and Rose 2018). The geographical distance of the service from their home community also contributed to depersonalisation and was experienced as a stripping of their religious and cultural identity (Chinn et al. 2011). Interestingly, the loss of identity may be met with the development of a new identity, which may often not be positive. Previous literature found that people recognised a change in how they thought of themselves within hospital (as a 'bad' person) compared to after discharge (Head et al. 2018). It notes that admission to a secure service may cause an experience of a new 'undesirable' self.

Though difficulties with belonging and identity were noted, there were many narratives reporting on the development of skills, purpose, and personal growth as a result of living in a secure service (Chinn et al. 2011; Hudson et al. 2018; Neimeijer et al. 2021). Upskilling supported individuals social development and encouraged interactions with others, further nurturing a stable sense of self.

Where is my power?

Lack of autonomy and independence were raised throughout patient narratives. Despite people describing themselves as capable of independence and wanting greater independence. The lack of control experienced over decision making, the many organisational restrictions, and their opinions not being considered, resulted in autonomy being perceived as an impossible achievement (Heppell and Rose 2021; Murphy and Mullens 2017; Neimeijer et al. 2021; Parkes et al. 2015; Williams, Thrift, and Rose 2018; Wood et al. 2008). Their powerless and voiceless experience painted an anxiety-inducing picture of being trapped in service, without a way out. However, opportunities to exercise some control, such as decorating their room, were spoken of positively, demonstrating ways in which autonomy can be encouraged. The impact of a lack of power and autonomy is variously highlighted in research. Powerlessness is known to threaten one's identity (Aujoulat, Luminet, and Deccache 2007) and was viewed as a constant

component in the journey through in-patient settings (Boudioni et al. 2015).

Navigating social relations

Participants indicated that a positive relationship with staff members improved their overall experience of care and views of the service (Chinn et al. 2011). This is in line with the literature, which denotes interactions with attentive and caring staff as a primary driver of good patient experience (Adams et al. 2024), with staff recognising that building a trusting relationship as supporting their ability to meet people's needs (D'Sa, Fletcher, and Field 2024). 'Mutual protection' and wanting to be seen as a 'person' were notable narratives shared by participants. Interestingly, they place their sense of safety with staff, trusting staff to create a comfortable and safe environment (Head et al. 2018). In cases where this does not occur, people are left to fend for themselves, and left feeling unprotected. The relational dynamics echoed in Fish's (2016) work similarly highlight the importance of staff–patient relationships in shaping everyday experiences of containment and care. The need to be 'seen as a person' was also echoed in a recent review (Havana et al. 2023), suggesting a desire by people with IDD for their individuality and voices to be recognised and considered, thus promoting epistemic justice. Narratives on negative experiences with staff were defined as greatly distressing and unpleasant, with participants describing staff as untrustworthy, unfriendly and unsympathetic (Clarkson et al. 2009).

Notably, positive relationship with staff seem to blur boundary lines for some, who regarded staff as 'friends' or in a parental role (Beckman, Nelson, and Labode 2022; Murphy, Estien, and Clare 1996). Though there are gaps in the literature exploring non-sexual boundary crossing between professionals and those in their care, a recent study highlighted a possible consequences such as stress, burnout, and increased risk for staff, as well as forming a slippery slope for future boundary violations (Lampe et al. 2023). As such, it would suggest that attention needs to be placed on the maintenance of boundaries when developing rapport with service users, for instance providing training for greater professionalisation of the care staff role.

Living with residents of different ages, personalities, and needs was experienced as difficult, with many people wanting to 'get away' due to a discomfort and a lack of safety resulting from violent behaviours from other residents (Beckman, Nelson, and Labode 2022; Chinn et al. 2011; Williams, Thrift, and Rose 2018). This recurring narrative seems to suggest that people with IDD want professionals to recognise that they too have to learn to cope with the behaviours they find challenging from other residents (Murphy and Mullens 2017). This may exasperate people and their capacity to regulate in a challenging environment, bringing an even greater strain on staff and the service to meet sometime conflicting support needs (Emerson et al. 2021). A possible practical suggestion to tackle this would be to develop smaller services, to reduce conflict and provide more personalised care. However, themes related to shared meaningful activities counteracted this, as it fostered purpose and friendship amongst the group (Hudson et al. 2018). This is in line with reports in the wider literature, where shared engagement in activities fostered real connections (Tournier et al. 2023).

Lastly, participants shared contrasting narratives concerning contact with friends and family, with some wishing their service was closer to home and others wanting to be as far as possible from home (Chinn et al. 2011; Heppell and Rose 2021; Parkes et al. 2015). For those experiencing distance from their family, it begs the question of where would they get their social contact and support from. It appears that for many, their relationship with staff is their sole social contact, which if it were to be negative it would be unfulfilling and not meeting their needs. There is a sense that people with IDD living in secure services are forced into solitude and unfulfilling relationships for the rest of their lives. It is found in the literature that adults with disabilities are at greater risk to experience loneliness and remain lonely over time, which is of concern due to the detrimental impacts of loneliness on physical and mental health (Emerson et al. 2023). It would suggest a need for services to intervene and tackle loneliness in services, such as by increasing access to joint activities and meaningful relationships.

Necessary evil

Many participants spoke on the conflict between the hospital being undesirable, yet in some cases their best alternative (Murphy, Estien, and Clare 1996; Murphy and Mullens 2017; Neimeijer et al. 2021; Williams, Thrift, and Rose 2018; Wood et al. 2008). This speaks to a desire for services to find ways to improve the desirability of the service, whilst still maintaining boundaries and restrictions. Living in a secure hospital environment needs to move away

from the many negative aspects of the living environment that would not be tolerated in community settings. Patients often describe frustrations that hospitals are not conducive to recovery and present too many barriers to access to the community (Glasby et al. 2024), as such, warranting a change to current systems and processes.

Evaluating the review: strengths and limitations

A primary limitation of the review is the small number of studies synthesised. Though there is not a recommended minimum number of studies for a meta-synthesis (Finlayson and Dixon 2008), a suitable number of studies is dependent on the research question and can vary substantially. The methodological quality of many of the included studies was rated as moderate to low quality. For almost all studies, the epistemological positioning of the authors was either not clarified or mentioned, possibly augmenting undetected influences and biases. There was a lack of detail regarding recruitment strategy, as well as design methods and analyses, and it was often difficult to extract information the individual differences participants, such as ethnic background. There were limited reports on the experience of views of women as well as limited ethnic diversity in samples. A greater number of diverse views may present an increased understanding of the cultural competencies of services. It is noted by the authors the extensive body of work undertaken by Fish and colleagues on the experiences of women with learning disabilities in secure settings (e.g. Fish 2016, 2018; Fish and Morgan 2021). This research has foregrounded issues such as restraint, seclusion, sexuality, relationships, and gendered vulnerability, offering rich insights into aspects of secure care that remain underexplored. Although not all of this work met the inclusion criteria for the present synthesis, it provides an essential contextual foundation and highlights the need for further research that attends to gendered and intersectional experiences within secure IDD services.

Due to the small number of studies found, all studies that met the inclusion criteria were included irrespective of quality rating. Given the inclusion of low-quality studies, the present results should be interpreted with caution.

Implications

Further research of higher-quality and with robust methodology are required. This is of importance due to the long-term implications the findings may have on individual's lives. It is important to note that the majority of the studies were conducted in the UK. As such, these findings may best be generalised to services in the UK, rather than globally. The current context for service delivery in the UK is a significant change from in-patient settings to community services, though it is still recognised as important to ensure that in-patient services provide a beneficial treatment model. To achieve this, service providers should continue to explore and adapt service provision according to the views of those with lived experiences, recognising the need for these services despite their undesirability, whilst continually seeking to improve them. Perhaps, a greater emphasis on a clear pathway from secure setting to community living, with the inclusion of rehabilitation facilities to support skill development and greater autonomy, preferably in close proximity, would support the voices and desires of people with IDD who need or have to draw on such services (NICE Guideline NG53 2016).

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Data availability statement

The data used in the production of this paper were obtained from existing papers that are all in the public domain and they have been cited and referenced in the paper.

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