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Living in the Community: The Psychological Experiences of Adults with Intellectual Disabilities

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List of Abbreviations

ID	Intellectual Disability
PWID	People with Intellectual Disabilities
PWD	People with disabilities
ASD	Autism Spectrum Disorder
ICD-10	International Classification of Mental and Behavioural Disorders, 10th edition
NICE	National Institute for Health and Care Excellence
APA	American Psychiatric Association
UK	United Kingdom
UN	United Nations
BPS	British Psychological Society
TCA	Transforming Care Agenda
DoH	Department of Health
IPA	Interpretative Phenomenological Analysis
MHA	Mental Health Act
MoJ	Ministry of Justice
CD	Conditional Discharge
CASP	Critical Appraisal Skills Programme
HRA	Health Research Authority

Acknowledgements

<u>Declaration</u>

This thesis has been submitted for the Clinical Psychology Doctorate at the Universities of Warwick and Coventry. The work presented has been composed by myself and has not been submitted for any other qualification or to any other institution. This thesis is an original piece of my own work, which was undertaken with the academic and clinical supervision of Dr Anthony Colombo (Coventry University), Dr Gareth Hickman (Coventry and Warwickshire Partnership NHS Trust [CWPT]) and Dr Irram Walji (CWPT). Except for the collaborators stated, all material presented within this thesis is my own work. The systematic literature review was written for submission to 'The British Journal of Learning Disabilities', while the empirical paper was written in preparation for the 'The Journal of Intellectual Disabilities and Offending Behaviour'.

Summary

This thesis explores the experiences of adults with Intellectual Disabilities (ID), as they navigate complex community and wider social phenomena, including resettlement from secure settings and the psychological impact of marginalisation.

Chapter one is a systematic literature review of the psychological experiences of community-based marginalisation in adults with ID. A systematic search of the literature identified 12 articles that met the eligibility criteria for Thematic Synthesis. Three themes emerged from the analysis relating to a lack of belonging, feeling like a burden, and a sense of not having a meaningful future. Clinical implications include the need for therapeutic intervention to mitigate the psychological consequences of marginalisation in people with ID. Study limitations and research recommendations are also discussed.

Chapter two is an original piece of NHS-based empirical research exploring the lived transitional experiences of adults, with ID and histories of offending, who have resettled into the community from secure settings. Eight men with mild ID participated in semi-structured interviews. Three superordinate themes emerged from an Interpretative Phenomenological Analysis, highlighting transitional experiences of how participants' hopefulness about living freer community lives was undermined by experiences of loss and a sense of living with a restricted identity. Clinical implications relate to the need for specialist ID forensic provision that offers trauma-informed and compassion-focused support. Study limitations and research recommendations are considered.

Chapter three is a first-person reflective narrative piece summarising the author's experiences of conducting the research. Motivations and inspirations for the project are discussed, as is the value of reflexivity during the process of navigating and overcoming challenges; these are explored in the context of learning and personal and professional development.

Overall word count at submission: 19,319 (excluding abstracts, tables, figures, references and appendices).

Chapter One: Systematic Literature Review

Psychological experiences of community-based marginalisation in adults with Intellectual Disabilities: A systematic review and thematic synthesis

Written in preparation for The British Journal of Learning Disabilities (see Appendix A for author guidelines)

Overall chapter word count at submission (excluding tables, figures, abstract and references): 7,953

1.0 Abstract

Aims: The aim of this review was to gain a better understanding of the community-based marginalisation experiences in adults with Intellectual Disabilities (ID). **Method:** This study employed Thematic Synthesis in order to draw together findings from empirical research articles that met pre-determined eligibility criteria: studies containing samples of adults with ID, in which qualitative research designs were used to capture the experiences of marginalisation across community domains of living. **Results:** Following a methodologically rigorous systemic search of the literature, as well as a peer review and quality assessment process, a final pool of 12 studies were included in the review. Three analytical themes emerged from the Thematic Synthesis: 1) 'Lack of belonging' (feeling stigmatised and socially rejected), 2) 'Sense of burden' (feeling dehumanised and victimised), and 3) 'Living without a future' (sense of hopelessness and helplessness). **Conclusion:** These findings suggest that community-based marginalisation can have a profound impact on the psychological wellbeing of people with ID. This highlights a pressing need to address the psychological consequences of structural marginalisation, such as hopelessness and depression. Clinical and policy recommendations include services and authorities adopting proactive and trauma-informed approaches to minimise this group's sense of isolation, self-stigma, shame and powerlessness.

Key words: *intellectual disability, marginalisation, social inclusion, social exclusion, experiences, systematic review, thematic synthesis*

1.1 Introduction

1.1.1 Review subject and significance

This review aims to systematically synthesise literature concerning how adults with Intellectual Disabilities (ID) experience community-based marginalisation.

ID is a neurodevelopmental disorder representing significantly below average intellectual functioning and difficulties with adaptive behaviours (American Psychiatric Association, 2013). Presentations are classified between mild to profound.

While definitions of marginalisation vary due to differing socio-political interpretations, it is broadly defined as a multidimensional phenomenon in which processes such as stigmatisation and victimisation exclude people from mainstream society (Rodgers et al., 1995; Peace, 2001). Conversely, the World Health Organisation positions social inclusion as a quality of life dimension (Badia et al., 2013), which ecological models define as having opportunities within the domains of participation (e.g., leisure/occupation) and interpersonal relationships (Simplican et al., 2015).

Community-based physical inclusion for people with ID (PWID) was a central political aim of deinstitutionalisation (e.g., Gjermestad et al., 2017). Thereafter, the United Nations' (UN) policy on the 'Convention of the Rights of People with Disabilities' shifted towards social dimensions of inclusion (UN, 2006). In accordance with Wolfensberger's (1972) principle of 'normalisation', the UN protocol outlined how member states should protect the human rights of people with disabilities (PWD), by supporting access to social, economic and physical environments. However, policies are criticised (Goodey, 2015) because PWID remain excluded (Scior & Werner, 2016). The UN reviewed the United Kingdom's (UK) commitments and recommended more was needed to tackle discrimination (UN, 2017).

Marginalisation is a serious public health concern because it contributes to physical and mental health issues in PWID (Valtorta et al., 2016; NICE, 2016). At least 77% of PWID are lonely (e.g., Sense, 2017); they have fewer friends, rely upon family-based/professional networks (Kamstra et al., 2015) and partake in fewer group-based leisure activities (Taheri et al., 2016; Mencap, 2019). Moreover, PWID have higher unemployment rates; compared with 76% of English 16-64 year olds, only six percent of PWID are in paid work (NHS Digital, 2018). Furthermore, experiences of victimisation and workplace discrimination (Sterzing et al., 2012) are linked to interpersonal difficulties, depression and anxiety (Perren et al., 2010; Maiano et al., 2016). Coping with public perceptions of themselves as "nuisances" (Pelleboer-Gunnink et al., 2021, p. 10; Scior et al., 2020) is associated with internalised stigma in PWID (Ali et al., 2012).

1.1.2 Evaluation of previous systematic reviews

Bigby's (2012) systematic review explored how the social inclusion in PWID and 'challenging behaviour' has been researched. Ten databases were searched and 14 qualitative and quantitative papers, dated 1986-2007, were included using predetermined criteria, including samples of adults with severe ID and inclusion experiences. Articles were thematically synthesised; findings suggested this field had been overlooked, making it difficult to advance evidence-based psychosocial inclusion interventions. Researchers had primarily focused on the experiences of people with mild ID and had adopted narrow interpretations of social inclusion, emphasising social participation and overlooking other domains, including employment. Moreover, studies often lacked consideration for environmental factors that may influence inclusion.

Louw et al. (2018) conducted a systematic review exploring factors that enhance PWID's social inclusion. Three databases were searched and 24 studies dated between 2013-18 met the following eligibility criteria: PWID aged between 18-30, and mixed-methods intervention studies. Synthesised findings indicated that structured social inclusion interventions are efficacious in increasing young people's social interaction opportunities. When being

supported to develop value-driven social roles with other PWID, participants reported that their sense of self-esteem and wellbeing improved, and their social bonds felt stronger. Key themes concerned participants' sense of belonging when describing ID-specific communities as accepting, such as experiencing workplaces as open-minded.

Harrison et al.'s (2021) systematic review focused on the social networks of PWID. Twenty seven quantitative and qualitative studies, dated between 1990-2019, were identified from four databases and screened against eligibility criteria: adults with ID and/or their parents/cares self-reported social connections. Quantitative analysis revealed that PWID's networks remain small. Qualitative studies were thematically synthesised; while relationships were considered essential in the development of participants' positive self-views, findings produced themes of feeling socially "powerless" (p. 989), particularly in respect of having little control over relationships, staff-based networks or daily choice. Moreover, inclusion seemed problematic when participants experienced a negative self-identity due to criticism/stigma and/or felt "disappointed" (p. 987) about not having "ordinary" (p. 987) friendships.

1.1.3 Rationale for the current review

Research exploring community-based marginalisation has positive clinical outcomes for wellbeing (Azaiza et al., 2011) and progressive attitudes (Siperstein et al., 2009). However, to the author's knowledge, no review has directly addressed this topic and previous reviews have their limitations.

Firstly, the subject has been narrowly defined. Past reviews are limited to specific areas of inclusion (e.g., social networks) and tend to only concentrate on identifying factors which may enhance social inclusion. This review will overcome this by shifting the focus towards better understanding how social marginalisation is experienced across a range of community-based domains, including leisure, occupation and relationships.

Secondly, samples have been restricted. Previous reviews tended to emphasise the experiences of specific age groups/diagnoses and/or family/carer perspectives. Consequently, experiences from across the adult lifespan have not been successfully synthesised. As arguments are made for more nuanced conceptualisations of ID (Davey, 2008), and because marginalisation is reported regardless of ID severity/age, this review will focus on the experiences of all adults with ID.

Thirdly, past reviews favoured meta-analysis. Following increases in qualitative publications that either directly or indirectly explore marginalisation, the current review will address this by employing a rigorous analysis of qualitative articles. Findings from a review of qualitative evidence will help clinicians to improve the effectiveness of interventions that mitigate the psychological impacts of marginalisation.

1.1.4 Review question

This systematic review aims to evaluate empirical qualitative research in order to answer the following question: What are the psychological experiences/impacts of community-based marginalisation in adults with ID?

Table 1.1

Review Question SPIDER Framework

SPIDER	Main Concept
Sample	Adults with an Intellectual Disability
Phenomenon of Interest	Community-based marginalisation
Design	Interpretivist (e.g., Thematic Analysis)
Evaluation	Psychological experiences/impact
Research	Qualitative

Rigours systematic review questions are well-formulated using logical frameworks, including the SPIDER tool which manages mixed-method and qualitative research (Cooke et al., 2012). Therefore, in consultation with the supervision team and subject librarian, the SPIDER framework outlined above in Table 1.1 was used to develop the review question.

1.2 Method

Ethical approval for conducting this systematic review was obtained from Coventry University's Ethics Committee (see Appendix B).

1.2.1   Systematic literature search

Based upon a scoping search and previous reviews, four databases with relevance to the subject area, Psychology, ID and social health/science were search systematically: PsycINFO, MEDLINE, CINAHL and Web of Science.

Table 1.2

Databases Included in the Systematic Investigation

Database	Platform/host/provider
PsycINFO (Psychological Information Database)	OVID
MEDLINE (PubMED; Medical Literature Analysis and Retrieval Ovid System Online)	OVID
CINAHL (Cumulative Index to Nursing and Allied EBSCO Health Language)	EBSCOhost
Web of Science	Clarivate

As outlined in Table 1.2, although PsycINFO and MEDLINE (including PubMED) are provided by the host OVID, separate searches were run due to differing database index-terms. CINAHL was hosted by EBSCOhost and Clarivate provided Web of Science. The main searches were conducted between 22nd December 2021 and 10th January 2022. An updated search was performed on 29th January 2022.

Other sources, including grey literature, were used to identify publications. This included searching for unpublished Theses within Google Scholar, as well as research from ProQuest and the charity Mencap's website. Citation tracking was also employed; this involved browsing reference lists and using the citation index function in Google Scholar. Furthermore, email alerts were setup to

identify relevant publications that were shared and/or recommended via Research Gate.

Key search terms were organised around the SPIDER framework (Cooke et al., 2012). Key concepts, synonyms and text locations were arranged into the concept map outlined in Table 1.3 below.

Table 1.3

Key Principal Search Terms

	Main Concept	**Synonyms**	**Location**
Sample	Intellectual disability	'Learning disabilit*'	Title/Abstract/ Main Text
Phenomenon of Interest	Marginalisation	'Social inclusion' OR 'social exclusion' OR connect* OR belong* OR 'quality of life' OR discriminat*	Title/Abstract/ Main Text/
Context / domains	Community	Occupation* OR relationship* OR leisure* OR famil* OR friend* OR network* OR societ*	Abstract/Main Text
Design	Interpretivist	Interview* OR 'focus group*' OR 'thematic analy*' OR 'content analy*' OR phenomenol* OR 'narrative analy*' OR 'grounded theor*' OR 'mixed method*'	Abstract/Main Text
Evaluation	Experience	View* OR belie* OR perception* OR impact*	Title/Abstract/ Main Text
Research	Qualitative	None	Abstract/Main Text

The principal search terms used within each database were organised by sample, phenomenon of interest, context, design, evaluation and research (Cooke et al., 2012). This includes the main concept terms of 'Intellectual Disability', 'social marginalisation', 'community', 'interpretivist', 'experience' and 'qualitative'. In consultation with the librarian, synonyms of 'marginalisation', such as 'isolation' and 'alienation', were excluded based on their limited

relevance within database index-terms and because they significantly increased the number of hits.

For several reasons this review's scope and key terms are deliberately wide in respect of both context and experiences of marginalisation. Firstly, the term marginalisation is not clearly defined, as it addresses a range of complex socio-political factors that result in being excluded and disempowered from mainstream society. Secondly, this is a neglected research area, and thirdly, attempts to synthesise current literature pertaining to experiences of marginalisation in PWID is needed (Amado et al., 2013). Fourthly, Britten et al. (2002) argued that in qualitative synthesis researchers should deliberately seek to identify studies that have been conducted across a diverse range of settings/contexts, in order to achieve a desired level of abstract interpretative data analysis. Nevertheless, key terms were informed by keywords from relevant publications, a databases built-in thesaurus terms/index-searching, and in consultation with the subject librarian and supervisor.

Depending upon whether the database host had standardised indexing available, key terms were either free-text or index-terms (Butler et al., 2016). Those with standardised terms searched for key words within the full text of an article (PsycINFO, MEDLINE and CINAHL), while those without were primarily searched within titles and abstracts (Web of Science). When available additional publication filters were applied, including 'Full text' 'Qualitative Publications' and 'Research Articles' available in 'English' and published between '2010-2021'.

Table 1.4

Search Strategies

Database	Search Strategy/Boolean Equation	Results (Total = 471)
OVID (PsycINFO, MEDLINE)	Initially, the generic search algorithm was used through the vendor OVID, however, to make use of its built-in index searching function, unique search strategies were used to search either PsycINFO or MEDLINE (PubMED). Please see Appendix E for the full details of these OVID search strategies.	PsycINFO = 145 MEDLINE = 52
CINAHL	(('intellectual disabilit*' OR learning disabilit*) OR ('social marginalisation' OR 'social exclusion' OR 'quality of life' OR 'social inclusion' OR belonging* OR connectedness) AND (communit* OR family OR friends* OR 'social network*' OR occupation OR work OR 'leisure activit*') AND (qualitative[Publication Type])) AND ('limit to English[Publication Type) AND (limit to 2010-2021))	101
Web of Science	((TI=('intellectual disabilit*' OR 'learning disabilit*') AND AB=('social exclusion' OR 'social inclusion' OR choice OR opportunit* OR connection* OR belong* OR participation OR discriminat* OR 'quality of life' OR 'marginal*') AND AB=(communit* OR work OR occupation OR relationship* OR leisure OR famil* OR friend* OR 'daily living' OR network* OR societ*) AND AB=(experienc* OR view* OR belie* OR perc*) AND (Interview* OR 'focus group*') AND (qualitative[Publication Type) AND (Articles[Publication Type))	173
Configuration of Boolean search strategies: [S AND PI] AND [(D or E) AND R].		

Boolean logic and truncation were applied to search strategies; characters were replaced with operators ('*') and searched using combinations of 'AND', 'OR' and 'NOT' (Butler et al., 2016). As shown in Table 1.4, each database had its own final search equation, which was organised around the logic of the SPIDER framework (Cooke et al., 2012). These were peer-reviewed and developed in consultation with the subject librarian and supervision team.

1.2.2 Inclusion and exclusion criteria

A systematic search of the literature for qualitative studies, exploring experiences of community-based marginalisation in adults with ID, was conducted between 20th December 2021 and 31st January 2022. Publications were either included or excluded based upon predetermined eligibility criteria.

Table 1.5

Inclusion and Exclusion Criteria: Publication Type

	Criteria	Inclusion	Exclusion
Publication Type	Country	Countries that define ID by APA (2013) and ICD-10 (1992) definitions	Countries that do not recognise/define ID by APA (2013) and ICD-10 (1992) definitions
	Time	2010 - 2021	2009 and earlier
	Content	Research	Commentary
	Accessibility	Full text	Abstract only
	Language	English	Other languages
	Grey Literature	Doctoral Dissertation	Conference reports, research summaries

The current review included the following publication types (see Table 1.5). Studies which were conducted in countries/regions that define ID by APA and ICD-10 definitions were included, such as North America, UK and Western Europe. Those that did not recognise ID were excluded for operational reasons as it was unclear who the study population represented. Moreover, articles published between 2010-2021 were included to capture current literature; it was inappropriate to include an earlier period because of the time needed to implement the UN's (2006) social policy changes. For the purpose of a rigorous synthesis of original empirical evidence, research publication types were included and those that were only commentaries were excluded. Articles not in English and/or where only the abstracts were available were removed to increase reliable data extraction. Furthermore, Doctoral Theses/Dissertations were included given their robust peer-review processes.

Table 1.6

Inclusion and Exclusion Criteria: Study Characteristics

	Criteria	Inclusion	Exclusion
Sample	Population	Adults, aged 18 and above	Children, aged 17 and below
	Diagnosis	ID diagnosis in line with APA (2013) and ICD-10 (1992)	No evidence of ID
	Gender	Male/female	Transgender
PI – Phenomenon of Interest	Experiences of Community-based Marginalisation	Marginalisation/ exclusion/inclusion AND Community context domains (e.g., relationships, family, friends, staff, occupation, employment and leisure)	Inpatient settings (e.g., secure services and long-stay mental health institutions). Primary interest is to evaluate the experiences of specific psychological treatment programmes designed to enhance social inclusion
D - Design	Research Design	Designs where qualitative data can be extracted (e.g., Thematic Analysis, Interpretative Phenomenological Analysis and Grounded Theory)	Quantitative designs with statistical results only
	Data Collection	Interviews/focus groups	Structured survey questionnaires with fixed format responses
E - Evaluation	Outcome	Experiences/beliefs/ impact/views directly from PWID	Primary focus is only on the perspectives of caregivers (e.g., teachers, cares, parents, family and professionals)
R- Research Type	Epistemology	Qualitative/mixed methods	Quantitative

As outlined in Table 1.6 above, included articles also had to meet the study eligibility characteristics, which were organised around the logic of the SPIDER tool (Cooke et al., 2012).

In accordance with APA (2013) and ICD-10 (1992) definitions, articles were included if they contained samples of male or female participants aged 18 and above with diagnosed ID; studies involving children aged 17 and below and/or participants without ID were excluded. Studies with transgender participants were excluded given the additional discrimination-based issues experienced by this population (e.g., Harflett & Turner, 2016). Ethnicity and sexuality were infrequently defined in studies and could therefore not be used as inclusion/exclusion criteria.

To capture findings related to the phenomenon of interest, studies that directly explored community-based marginalisation within social contexts (e.g., relationships, occupation and leisure) were included (Rodgers et al., 1995; Peace, 2001; Simplican et al., 2015). Therefore, articles that measured exclusion within non-community contexts (e.g., hospital), or only evaluated treatment programmes/interventions, were excluded. 'Social inclusion' was included because articles frequently used the term within titles and/or abstracts, even when their results made significant reference to experiences of exclusion.

Articles where research was underpinned by qualitative epistemology were included, such as qualitative and mixed method studies using data collection methods like semi-structured interviews and/or focus groups; quantitative publications were excluded. There were no limits around qualitative designs, which included Thematic Analysis and Grounded Theory, due to the diverse techniques that are often employed to support people with intellectual and adaptive needs to voice their experiences. In line with interpretivist epistemology, articles that captured the self-reported experiences of PWID were included; studies where the only focus was the perspectives of caregivers were removed.

Table 1.7

Inclusion and Exclusion Criteria: Study Results

	Criteria	Inclusion	Exclusion
Study Results	Analysis	Themes	Numerical
	Format	Direct quotes/summaries	None
	Accessibility	Single study	None

Articles were also included based upon study results eligibility criteria (see Table 1.7). In order to extract qualitative experiences, those with analyses that produced themes and direct participant quotations, and/or author summary interpretations of their qualitative findings, were included. Numerical analyses were therefore excluded.

A peer-review inter-rater reliability process was undertaken to increase the rigour of the eligibility process (Belur et al., 2021). The author paired with another researcher who screened the final pool of papers to identify if each satisfied the publication type, study characteristics and study results inclusion criteria (see Appendices C and D). In the event of a disagreement, papers were either discussed with the supervision team, justified and included, or were excluded for not meeting eligibility criteria. Three papers were removed during this process; one was conducted in a country that did not formally recognise ID and therefore failed to satisfy sample criteria, and two insufficiently addressed the phenomenon of interest due to focusing on specific victimisation experiences (e.g., sexual assault) without explicitly referencing marginalisation.

1.2.3 Classification of studies

The process of classifying studies was recorded using the 2020 'Preferred Items for Systematic Reviews and Meta-analyses' (PRISMA) flow diagram (Page et al., 2021).

Figure 1.1

PRISMA Flow Diagram (Page et al., 2021)
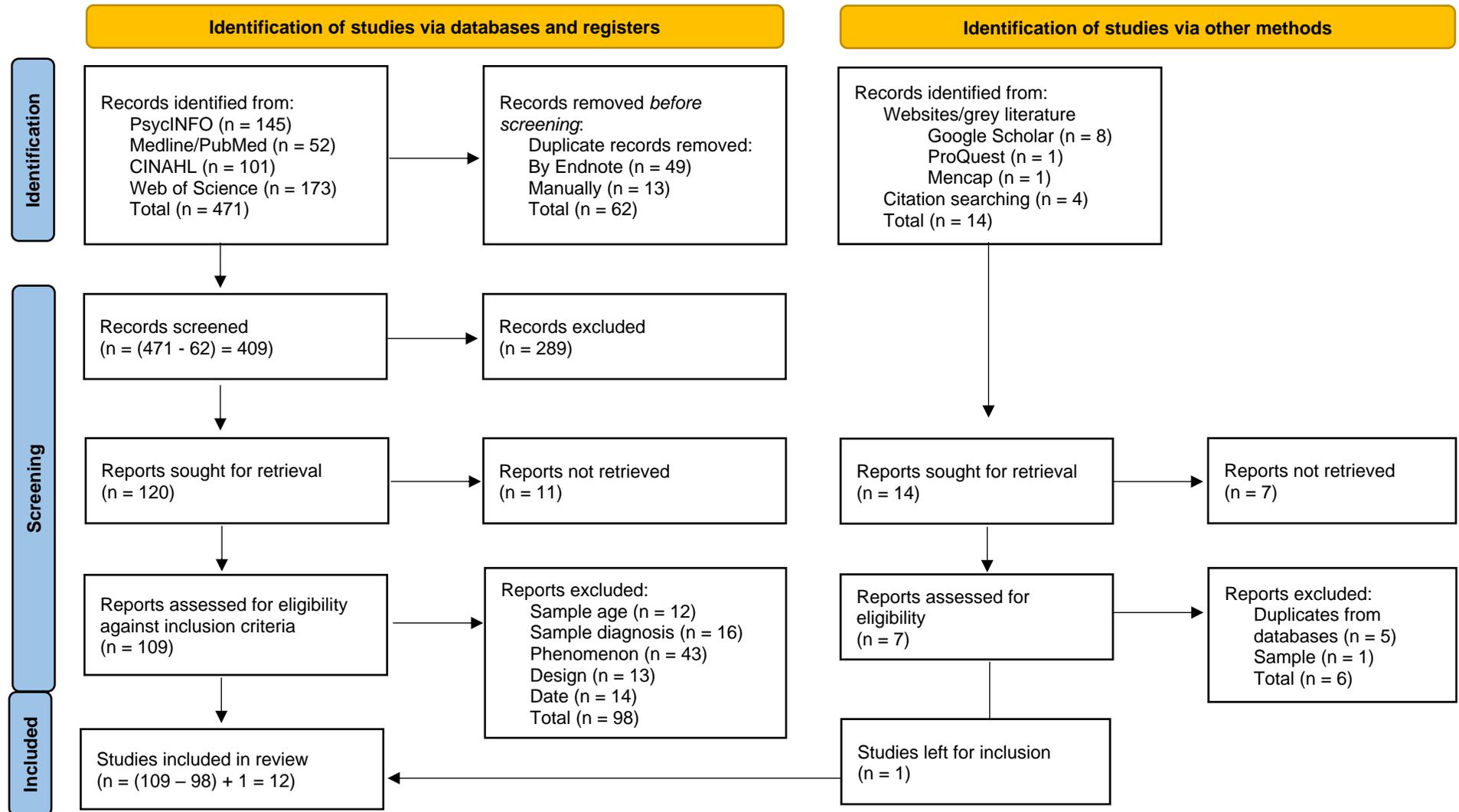
As shown in Figure 1.1 above, a total of 471 records were identified from database searches: PsycINFO (N = 145), MEDLINE (N = 52), CINAHL (N = 101) and Web of Science (N = 173). Using Endnote and manual screening a total of 62 duplicate records were detected and removed, and the titles and abstracts of the remaining 409 records were screened, of which 289 were excluded for not satisfying eligibility criteria. Of the remaining 120 reports that were sought for retrieval, 11 could not be obtained, leading to a pool of 109 reports that were assessed against inclusion criteria; 98 reports were excluded for not meeting the publication type, study characteristics and/or study results eligibility criteria.

Fourteen records were identified from citation searching and grey literature, and seven of these could not be retrieved, resulting in a pool of seven reports that were assessed for eligibility. Six of these were excluded for not satisfying eligibility criteria or for being duplicates, leaving one study left. Combined with reports from database searching, this resulted in a final pool of 12 articles that met the inclusion criteria for systematic review and quality assessment.

1.2.4 Quality assessment checks

There is no agreed upon protocol for using quality assessment in qualitative research, with some researchers arguing that it does not fit with the approach's subjective and interpretative nature (Dixon-Woods et al., 2004). Moreover, there are assessment difficulties within the area of self-reported experiences of lived phenomena, including challenges to defining the accuracy of results/interpretations. Despite this, several assessment tools have been developed and adapted by researchers (Ring et al., 2011).

This review employed the 'Critical Appraisal Skills Programme' (CASP) (CASP, 2018). This was designed as a 10-item checklist (see Appendix F) for assessing the quality of original qualitative research articles included in systematic reviews (Hannes et al., 2010). Thomas et al. (2008) suggested that when performing Thematic Synthesis any assessment tool should cover the following criteria: reporting of aims/approaches, a rationale for study methods, and evidencing

the validity of findings. The CASP is therefore an appropriate tool for the current review because its questions focus on aims, methodology, design rationale, the rigour of data analysis, the author's reflexivity, statement of findings and ethical considerations (CASP, 2018). It is considered an accessible and widely-used quality assessment tool (Verboom et al., 2016), developed to promote best practice within healthcare (CASP, 2018).

Quality assessment was calculated by scoring all 10 items/questions against a criterion of: 0 for 'not met/cannot comment', 1 for 'partially met' and 2 for 'yes, fully met' (CASP, 2018). While there is no agreed cut-off, to overcome possible reliability limitations (Ibbotson et al., 1998) an additional researcher independently rated all 12 articles against identical quality criteria (see Appendix G).

Furthermore, within SPSS, an inter-rater reliability analysis of all the papers included in the systematic review was conducted using the Kappa coefficient (Cohen, 1960).

Table 1.8

Inter-rater Reliability Coefficient (KAPPA) Scoring

Study	*K* value	Significance (*p* value)
Merrells et al., 2019	1.00	.002
Van Asselt et al., 2015	1.00	.002
Bond et al 2010	1.00	.000
Witso et al., 2020	1.00	.000
Lysaght et al., 2017	1.00	.000
Hall, 2017	1.00	.002
Carnemolla et al., 2021	1.00	.002
Ashley et al., 2019	.71	.003
Hamilton et al., 2017	1.00	.000
Sullivan et al., 2016	.62	.035
Strnadova et al., 2018	1.00	.000
Voermans et al., 2021	.72	.016

The Kappa reliability coefficient for each paper is outlined above within Table 1.8. Coefficient reliability values ranged between $K = 0.62$ and $K = 1.00$, which represents a strong pattern of inter-rater reliability (Altman, 1999). An overall

score was not computed because this does not allow for reliability variance, and because the goal is not to achieve overall reliability but to ensure the quality of each independent study satisfies criteria. In summary, each article provided evidence of their aims, rationale for methodological design, sufficient information on data analysis, and results were generally well-supported by participant quotations. Overall however, reflexivity and a breadth of ethical considerations were less evident.

1.2.5 Characteristics of the literature

A summary table of the 12 studies included for review are provided in Table 1.9 below.

Table 1.9

Study Characteristics

Author(s), (date) / country of origin	Aims and areas covered	Sample characteristics: *N,* gender, age, ethnicity, diagnosis	Design and sampling method	Data collection and data analysis	Summary of outcomes specific to the phenomenon of interest	Quality assessment (CASP) / KAPPA
Voermans et al., (2021) / Netherlands	To provide a detailed exploration of the lived experiences of adults with ID with respect to their community participation in employment and everyday lives.	*N* = 6 26-36 years / 4 males, 2 females Mild ID	Qualitative design Purposive sampling strategy	Interpretative Phenomenological Approach Semi-structured interviews	3 Themes: 1) building on my life experiences; 2) my place at work; 3) being a valuable member of society, like everyone else.	35 / *K* =.72
Carnemolla et al., (2021) / Australia	To increase understanding into the inclusion needs of adults with ID as they relate to participating in social and civic life.	*N* = 45 19-52 years (*M* = 34) / 21 males, 24 females ID	Qualitative design Purposive sampling strategy	Thematic analysis Focus groups and semi-structured interviews	3 Themes: 1) social participation; 2) respect and social inclusion; 3) employment	32 / *K* =1.00
Witso et al., (2020) / Norway	To explore the perspectives and experiences of adults with ID with regards to their everyday lives and its shortcomings.	*N* = 9 22-58 years / 3 males, 6 females	Qualitative design	Thematic analysis Focus groups	2 Themes: 1) everyday life – context, rhythm and structure; 2) social participation – belonging to a family,	34 / *K* =1.00

		Mild ID	Purposive sampling strategy		friendship, and leisure activities.	
Merrells et al., (2019) / Australia	To understand the perspectives of PWID in relation to how they experience and perceive inclusion.	$N = 6$ 18-24 years ($M = 20.5$) / 4 males, 6 females ID	Qualitative design Purposive sampling strategy	Interpretative Phenomenological Approach Semi-structured interviews	2 Themes: 1) segregated, excluded and treated like an outcast in the community; 2) challenges in experiencing, initiating and maintaining peer friendships.	38 / $K = 1.00$
Ashley et al., (2019) / Australia	To describe the qualities of the home environments of adults with ID in supported living, as well as exploring their perceptions of their occupational engagement/inclusion.	$N = 6$ 24-58 years / 3 males, 3 females ID	Mixed methods Purposive sampling strategy	Inductive thematic approach Semi-structured interviews	2 Themes: 1) social support; 2) opportunities.	35 / $K = .71$
Strnadova et al., (2018) / Australia	To explore and better understand what community belonging means to adults with ID, and what barriers to a sense of belonging exist.	$N = 24$ 20-61 years ($M = 47.09$) / 15 males, 9 females ID	Qualitative design Purposive sampling strategy	Inductive content analysis Focus groups	2 Themes: 1) meaning of belonging; 2) barriers to belonging.	34 / $K = 1.00$
Hall (2017) / United States	To better understand the community involvement	$N = 14$	Qualitative design	Phenomenological approach	4 Themes: 1) vocational endeavours;	36 / $K = 1.00$

		experiences of young adults with ID.	21-35 years	Purposive sampling strategy	Semi-structured interviews	2) leisure pursuits; 3) social inclusion; 4) support.	
			Mild to moderate ID				
Hamilton et al., (2017) / United Kingdom	To better understand the experiences of daily community-based living in adults with ID.		$N = 26$ 23-60 years / 19 males, 7 females White British ($N = 38$), Black British ($N = 1$) Mild to moderate ID	Qualitative design Purposive sampling strategy	Thematic analysis Focus groups	2 Themes: 1) independence and agency; 2) social capital and wellbeing.	34 / $K = 1.00$
Lysaght et al., (2017) / Canada	To address the question: What does social inclusion at a place of work look like for adults with ID?		$N = 74$ 21-59 years / 44 males, 30 females ID	Qualitative design Purposive sampling strategy	Grounded theory Semi-structured interviews	3 Themes: 1) social inclusion and exclusion across productivity types and contexts; 2) factors promoting inclusion in the productivity context; 3) factors that inhibit social inclusion in the productivity context.	34 / $K = 1.00$

Sullivan et al., (2016) / United Kingdom	The study aimed to further existing qualitative evidence by exploring the experiences of adults with ID and their close relationships.	*N* = 10 31-60 years / 6 males, 4 females ID	Qualitative design Purposive sampling strategy	Interpretative Phenomenological Approach Semi-structured interviews	2 Themes: 1) relationships feeling safe and being useful; 2) struggling for an ordinary life.	37 / *K* =.62
Van Asselt et al., (2015) / Australia	To explore young adults with IDs experiences of social inclusion within community spaces/locations.	*N* = 4 23-27 years / 2 males, 2 females ID	Qualitative design Purposive sampling strategy	Thematic analysis Semi-structured interviews	6 Themes: 1) self-determination; 2) naturally occurring relationships; 3) participant engagement and interactions; 4) organisational processes; 5) family; 6) community participation and social acceptance.	36 / *K* =1.00
Bond et al., (2010) / United Kingdom	To research the views of adults with ID about the realities of living independently within the community.	*N* = 9 33-56 years / 4 males, 5 females Mild ID	Qualitative design Purposive sampling strategy	Thematic analysis Semi-structured interviews	4 Themes: 1) feelings on living alone; 2) choice and control; 3) vulnerability; 4) impact of a learning disability.	34 / *K* =1.00

To confirm the accuracy of the study characteristics information, presented in Table 1.9, an additional peer review inter-rater reliability was performed. A second researcher selected two papers at random and extracted the relevant key study information in order to complete their own study characteristics table (see Appendix H). This was then compared against the author's table to explore any disagreement, and although there was none the tables were still discussed in supervision.

Each study possessed the following characteristics. All were conducted between 2010-2021 across six locations: Australia ($N = 5$), UK ($N = 3$), United States ($N = 1$), Canada ($N = 1$), Netherlands ($N = 1$) and Norway ($N = 1$). All 12 reported participant gender and recruited both males and females; there was no evidence of transgender participants, hence no studies were excluded on the basis of this eligibility criteria. In line with this review's aim to explore adult experiences, ages ranged between 18-61 years.

There are considerations regarding possible differences between publication aims. Firstly, demographics were not consistently reported, particularly ethnicity and level of ID, although all 12 employed purposive sampling to increase sample homogeneity. Secondly, although studies were conducted across a variety of countries, sharing the same ID classification meant countries/regions had similar socio-cultural levels of recognition. Thirdly, while nine studies directly aimed to explore experiences of social inclusion and/or exclusion across different community contexts/domains (e.g., relationships, occupation and leisure), three studies did so indirectly by aiming to explore the everyday experiences of PWID or interpretations of independent living. However all three produced interpretative themes pertaining to experiences of marginalisation. Furthermore, these studies interviewed participants alongside their families/carers; in line with inclusion criteria, these were retained because the primary aim and focus concerned the self-reported experiences of PWID.

Studies employed a range of qualitative methods to achieve their aims. Five studies used Interpretative Phenomenological Analysis, five used Thematic Analysis, one used Content Analysis, and one used Grounded Theory. All

authors suggested data was analysed in accordance with the principles/conventions of qualitative analysis. Furthermore, all 12 used forms of interview-based data collection methods, with eight employing semi-structured interviews, three using focus groups, and one employing both individual interviews and focus groups.

1.2.6 Analytic review strategy

Ring et al. (2011) wrote that interpretations of findings may vary due to studies using different aims and methodologies. Nevertheless, synthesis can help researchers to better understand a subject (Bearman & Dawson, 2013). Thematic Synthesis is one such primary approach (Thomas & Harden, 2008) and was used in the current systematic review. It is adapted from Thematic Analysis and draws upon its common techniques to identify and develop themes from narratives within literature (Nicholson et al., 2016). Thematic Synthesis is an appropriate method for the current review because of its strengths in informing clinical practice and policy (Campbell et al., 2003).

The three stages of Thematic Synthesis, as outlined by Thomas and Harden (2008), were followed to ensure an inductive approach was taken (Nicholson et al., 2016). Firstly, papers were re-read to increase familiarity with data, afterwhich line by line coding of an individual study was performed to develop a narrative (see Appendix I). These codes were based on an interpretation of the meaning behind the content of each sentence.

In the second stage, descriptive themes were produced from clustered codes by exploring similarities and differences between them; when needed, new codes were created to replace initial codes, although the original content was revisited to ensure these had not become too abstract and still reflected the initial study's findings (Thomas et al., 2008). This involved translating codes into concepts representing patterns of meaning, such as 'powerlessness'; these were presented as thematic maps. See Appendix I for an example.

Thirdly, in the more interpretative stage, concepts sharing common similarities were grouped into higher-order abstract analytical themes. These specifically related to the review question and transcended the original material. Initially they related to barriers and facilitators of inclusion, however this did not 'go beyond' (Thomas et al., 2008) the original study's findings (see Appendix I), hence they were reorganised to more meaningfully reflect the psychological consequences of marginalisation; this was achieved by using models of distress (e.g., Interpersonal Theory of Suicide, Van Orden et al., 2010) to become relatively more 'theory-driven' at this stage (Thomas et al., 2008). This process was repeated for all 12 studies, until a final list of analytical themes and associated subthemes (see Appendix I) were produced and represented by participant quotations and/or author summaries (Nicholson et al., 2016).

While Thematic Synthesis is protocolised, choosing what key concept data to extract and interpret from a qualitative study is challenging (Campbell et al., 2003). Moreover, it is important that the approach is transparent and acknowledges the researcher's biases when making interpretations, hence reflexivity is significant (Willig et al., 2013). Strategies were employed to achieve this, including reflective practice (e.g., journal writing), utilising regular supervision to peer review theoretical ideas and author interpretations, and validating the final themes with the project's supervisor.

1.3 Thematic Synthesis Results

Three overarching themes emerged from a synthesis of 12 articles capturing the psychological experiences/impact of marginalisation in adults with ID (see Table 1.10 below).

Table 1.10

Analytical and Descriptive Themes

Analytical theme	Descriptive subtheme
Lack of belonging	1. *Stigmatised*
	2. *Rejected*
Sense of burden	1. *Dehumanised*
	2. *Victimised*
Living without a future	1. *Hopeless*
	2. *Helpless*

Experiencing marginalisation often takes the form of being stigmatised and socially rejected, which has the psychological impact of making PWID lack any sense of belongingness; of feeling as though they are not really part of mainstream society. In turn, being socially excluded increases the risk that PWID are dehumanised and victimised by the attitudes and behaviours of others; negative interactions which encourage PWID to feel as though they are a social burden and have no value to society. Consequently, the impact of marginalisation leaves PWID harbouring a pervasive sense of hopelessness and helplessness about living without a future.

The 12 articles included in this review shared a range of experiences across each of the three main themes (see Table 1.11 below), which are represented by participant quotations and/or author interpretations.

Table 1.11

Themes Across Articles

Analytical Theme	Lack of belonging		Sense of burden		Living without a future	
Descriptive subtheme	*Stigmatised*	*Rejected*	*Dehumanised*	*Victimised*	*Hopeless*	*Helpless*
Merrells et al., 2019	X	X		X	X	X
Van Asselt et al., 2015	X		X			
Bond et al., 2010		X	X	X	X	X
Witso et al., 2020		X	X			X
Lysaght et al., 2017	X	X			X	
Hall, 2017	X	X	X	X		
Carnemolla et al., 2021	X	X		X		
Ashley et al., 2019	X	X	X		X	X
Hamilton et al., 2017	X	X	X	X	X	X
Sullivan et al., 2016		X	X	X		X
Strnadova et al., 2018	X	X	X	X	X	
Voermans et al., 2021	X	X	X	X	X	

1.3.1 'Lack of belonging'

This analytical theme summarises the findings of 12 articles that described how marginalisation left PWID feeling uprooted and detached from normal social processes, as if they did not belong. This sense of not belonging was principally experienced through their disability being the subject of social stigma and their presence in society frequently being rejected.

1.3.1.1 'Stigmatised'

A number of papers talked about how PWID experienced marginalisation as 'not belonging' because they felt stigmatised. In particular, findings suggested that stigma leads to experiencing a sense of a 'spoilt identity', in which society labelled participants as a homogenous group that had *"something wrong"* (Strnadova et al., 2018, 1098) with them. This negatively impacted participants' sense of belonging, as they appeared to self-identify as abnormal people who are socially unacceptable and underserving of respect. Van Asselt et al. (2015) reported that PWID felt ashamed for not being *"mainstream people"* (Merrells et al., 2019, 16), which appeared to precipitate a deep sense of self-stigmatisation, in which some PWID started to reject their own sense of self by describing how people with disabilities *"get on my nerves"* (Voermans et al., 2020, 246).

A common issue discussed in the articles centred on how the stigma of a 'spoilt identity' led society to view PWID as risks to themselves and others. Participants were labelled as 'incompetent', with employers and educators seemingly unconvinced about their ability to function independently, frequently asking *"what can [PWID] do?"* (Voermans et al., 2020, 244). Moreover, this stigma meant parents/caregivers subjected PWID to overly-protective care, which restricted opportunities for unsupervised communication with others (Hamilton et al., 2017). Consequently, PWID encountered difficulties being recruited to meaningful roles (Ashley et al., 2019), which left them feeling undermined. Eventually, the evidence suggests that overly-protective environments encouraged PWID to adopt a 'sick role' mentality, whereby they internalised the *"disabled identity"* (Strnadova et al., 2018, 1097) and began questioning their rights and sense of entitlement to an autonomous life.

Stigmatised as a risk to others also seems to have a significant impact on psychological wellbeing. Studies often reported that mainstream society tended to adopt prejudicial beliefs about PWID being untrustworthy because of inevitable *"behavioural issues"* (Lysaght et al., 2017, 932); over-generalised beliefs about PWID being violent/dangerous (Merrells et al., 2019) led to participants feeling like *"a public liability"* (Strnadova et al., 2018, 1098) which

overshadowed their strengths/assets. Consequently, participants reported that they often felt as though others were cautious around them, which seemed to perpetuate a sense of self-shame and reinforce self-beliefs about not deserving the same opportunities or sense of social belonging as others.

1.3.1.2 'Rejected'

The review findings seem to suggest that experiencing marginalisation through social rejection often impacted on PWID's sense of belonging. In particular, participants believed they were socially distanced from mainstream society. Participants felt *"ignored"* (Hall, 2017, 866) and indicated that *"there's a lot of resistance from [employers/services]"* (Hamilton et al., 2017, 297) to include them; some expressed frustration at others lack of motivation to adapt to their needs, and believed communities and services *"stretch [PWID] as far as they can without spending any money to give people support"* (Hamilton et al., 2017, 294). For example, there was a lack of accessible information (Merrells et al., 2019) and practical support to use public transportation or attend social/leisure activities. This seemed to lead PWID to perceive an *"us and them"* (Merrells et al., 2019, 16) divide.

The sense of social division meant PWID occupied separate spaces, both physically and interpersonally. For instance, a participant described how *"there's often a corner... that people with disabilities go [to]"* (Strnadova et al., 2018, 1097) when attending public events. Moreover, PWID reported being denied jobs and having to apply for a *"long time"* (Voermans et al., 2020, 243) before being invited to work in isolation from their colleagues. Furthermore, instead of attending mainstream leisure events (Merrells et al., 2019) most only belonged to ID-specific groups (Bond, 2010).

Participants' experiences of social distance and occupying separate spaces seemed to limit their social worlds. Physically, this meant that their social circles were restricted; PWID felt unable to access online social networks, appeared unconfident in navigating their communities (Carnemolla et al., 2021), and were denied opportunities to engage in meaningful activities (Ashley et al., 2019). Consequently, some PWID concluded that they would never have accepting

peer groups or romantic partners. As a consequence, participants described being unable to self-express (Ashley et al., 2019), with many having little sense of independence (Carnemolla et al., 2021) and feeling angry about relying upon family/staff as their source of social engagement (Witso et al., 2020). PWID appeared lonely, isolated, low in self-esteem and highly anxious about further rejection (Bond et al., 2010), which perhaps led some to self-segregate by choosing occupations where they worked alone (Lysaght et al., 2017).

1.3.2 'Sense of burden'

This analytical theme summarises the findings of 11 articles that described how PWID experienced the impact of marginalisation as feeling like an unwanted burden to society. This was associated with feeling dehumanised and victimised by their communities.

1.3.2.1 'Dehumanised'

Marginalisation was often experienced as a series of dehumanising attitudes, which led PWID to feel as though they were little more than a burden to society. In particular, participants described how others disrespected them and saw them as undesirable (Sullivan et al., 2016). There was a sense that PWID were an unwelcome group that others did not always want to be associated with, to the point where interactions with them had been incentivised, including formal caregivers who told a participant they were *"paid to like [them]"* (Strnadova et al., 2018, 1098). Furthermore, participants reported instances where they were told to *"go back to your cage [hospital]"* (Bond et al., 2010, 290), suggesting others wanted them removed from mainstream society. Consequently, PWID experienced society's actions towards them as *"resentful"* (Sullivan et al., 2016, 178), resulting in some participants' anxiety and underlying sense of being objectified, unloved and uncared for (Hall, 2017; Hamilton et al., 2017).

Participants' experiences of being unwanted seemed to lead to disempowerment. Authors discussed how PWID felt denied and silenced on basic rights by caregivers who were *"not always good at listening to [PWID's] opinions"* (Witso et al., 2020, 152). In particular, some participants did not get

lunch breaks at work (Hall, 2017) or were not consulted on where they should live and how they should be supported. Consequently, this appeared to mean that PWID experienced their lives as being *"dominated"* (Sullivan et al., 2016, 177) by the decisions of others, particularly family members who tended to *"pull you [PWID] back... when you should be independent"* (Strnadova et al., 2018, 1097).

Experiences of disempowerment meant PWID also appeared to feel the need to negotiate for independence over their lives, even at a personal cost. Despite wanting more self-reliance (Ashley et al., 2019; Hamilton et al., 2017) PWID suggested this seemed unattainable, with several participants worrying that the little autonomy they had could be *"taken away from them"* (Bond, 2010, 290). Subsequently, many desperately clung onto any semblance of power and independence, which was usually expressed in relation to going to work and/or being able to contribute something to others/society. However, some participants' anxieties meant they overcompensated and started appeasing others by forgoing employee rights and privileging their peers needs. For example, some PWID denied themselves sick days and ended up in positions where they felt they *"have to accept"* (Voermans et al,., 2020, 244) any role/job that is assigned to them. Consequently, this false sense of workplace autonomy fulfilled self-beliefs about others being more important, which perpetuated feelings of worthlessness and exclusion.

1.3.2.2 'Victimised'

A common theme arising throughout the articles reviewed was that dehumanising social attitudes seemed to legitimise victimising behaviours, which in turn encouraged PWID to harbour a deeper sense of burdensomeness about being unworthy and a social liability. In particular, findings suggested that PWID are frequently subjected to direct forms of abuse. Examples given included having objects thrown though their windows, being verbally and physically assaulted, and experiencing harassment and sexual assault (Bond, 2010; Strnadova et al., 2018; Hall, 2017). This significantly impacted PWID; they appeared to identify as vulnerable and defenceless, which in some instances restricted their confidence to leave home and use public

transportation alone. There was a sense that few places were a safe haven (Bond, 2010).

Experiences of community-based victimisation also included PWID feeling exploited. For example, participants felt that this was a longstanding issue, with many having *"grown up with bad experiences... with people taking advantage"* (Bond, 2010, 290). In particular, individuals described feeling mistreated/discriminated against in the workplace because employers commonly only offered them unpaid positions, which frustrated those who believed they *"had [just as much to offer] as a regular co-worker... who earns a full salary"* (Voermans et al., 2020, 245). Exploitation extended to their home situations too, with reports of caregivers and family members financially manipulating and stealing from PWID. Some participants appeared confused by these experiences and described a sense of never being good enough, while others seemed to normalise it as an everyday challenge. Nevertheless, exploitation appeared to undermine any semblance of confidence in others.

Feeling abused and exploited seemed to lead some PWID to live with an underlying sense of fear. While belonging to a social group was associated with *"feeling safe"* (Merrells et al., 2019, 17), experiences of rejection and abandonment meant that several participants felt unprotected. This amplified anxieties and insecurities in those that described instances of being verbally assaulted but *"there was no one to help"* (Carnemolla et al., 2021, 8). Consequently, it appeared that PWID believed community living was perilous, which made everyday situations appear challenging and exhausting, such as heightened consequential thinking and self-doubt, as well as significant difficulties trusting people they ought to have relied upon for care. This left participants feeling alienated, uncontained and socially inhibited to the point where some were *"too scared"* (Strnadova et al., 2018, 1095) to connect with their local neighbourhoods.

1.3.3 'Living without a future'

This analytical theme summarises the findings of nine articles that described how experiences of marginalisation resulted in PWID feeling both hopeless and

helpless about their social worlds, which in turn impacted on their sense of being able to live meaningful futures.

1.3.3.1 'Hopeless'

Studies pointed out that participants often experienced a pervasive sense of hopelessness in their lives. In particular, participants reported experiences of being forever *"isolated"* (Lysaght et al., 2017, 930) because of day centre closures (Hamilton et al., 2017) and/or because PWID felt their social networks would only ever be restricted to family (Merrells et al., 2019). Isolation seemed to evolve into feeling *"so lonely" (*Strnadova et al., 2018, 1095) at home and in the workplace, which appeared more pronounced when participants' family systems of support were gone. Consequently, in response to chronic isolation, PWID seemed to become despairing, which reinforced perceptions that they would be *"treated like an outcast"* (Merrells et al., 2019, 16) forever.

Study findings were also interpreted in terms of how PWID experienced hopelessness as feeling unsatisfied and unfulfilled with their lives and social positions. For instance, a lack of opportunity to gain employment, make friends or socialise, meant participants frequently saw themselves as purposeless. While volunteering and adopting caring/nurturing roles provided some self-esteem (Ashley et al., 2019; Lysaght et al., 2017), this was undermined by pre-existing feelings of burdensomeness and self-doubt. Consequently, there was an underlying sense of feeling insecure and guilty for not contributing to society, which meant PWID felt ashamed and directionless (Ashley et al., 2019; Strnadova et al., 2018).

Experiences of feeling isolated and unfulfilled/purposeless appeared to mean that some PWID were hopelessly apathetic towards their lives. For instance, internalised stigma meant that some identified as being permanently labelled and rejected, leading a few to completely abandon hopes of social connection or contribution, by *"refuse[ing] to go to work anymore"* (Strnadova et al., 2018, 1098). While some participants suggested that feeling marginalised inspired them to challenge stigma and strive for independence (Voermans et al., 2020), the vast majority insinuated that this undermined any enthusiasm; Lysaght et

al. (2017) commented on how participants' lack of meaningful role was demotivating, which Merrells et al. (2019) associated with participants tendency to accept that they were destined to live 'uninteresting lives'. While this sense of apathy left some feeling *"bored"* and *"sick"* (Ashley et al., 2019, 703), others lacked any *"reason to go to sleep or wake up"* (Ashley et al., 2019, 705).

1.3.3.2 'Helpless'

Another consequence of marginalisation was what PWID often experienced as helplessness. In particular, participants' experiences of feeling hopelessly isolated and apathetic appeared to evolve into believing they could no longer manage on their own. Some participants described not feeling able to meet the demands of community living, with one wanting to *"go into a residential home because I feel like I can't cope anymore"* (Hamilton et al., 2017, 294). Bond (2010) reported that the majority of participants were accessing mental health services, typically because participants expressed difficulties coping with trauma and depressive symptomology (Hamilton et al., 2017). Others seemed emotionally uneasy/unsettled, whereby they were *"go[ing] to bed crying"* (Bond, 2010, 288) each night, withdrawing socially, not taking care of themselves and forgetting to eat, and not being able to *"sleep that well"* (Ashley et al., 2019, 705).

Helplessness was also discussed in relation to how participants experienced heightened distress. For example, it seemed that feeling persistently victimised and unable to positively shape their own lives, as well as perceived burdensomeness, led to disillusionment with community life itself. For some, this manifested into a sense of feeling pointless and wanting to escape a life where they *"always feel left out",* by becoming "*shut down"* and contemplating *"killing [themselves]"* (Merrells et al., 209, 16).

1.4 Discussion

This systematic review aimed to answer the question: What are the psychological experiences/impacts of community-based marginalisation in adults with ID? Three analytical themes emerged from a Thematic Synthesis.

1.4.1 Marginalisation experiences in context

The review findings showed that PWID experience community marginalisation through having their disability stigmatised and their presence frequently rejected. Marginalising experiences seemed to have the psychological impact of creating a lack of belonging to mainstream society. Previous reviews of PWID have also noted the public's rejecting/stigmatising attitudes and its damaging consequences, including restricted autonomy and learning/occupational opportunities (Harrison et al., 2021; Clapton et al., 2018; Wang et al., 2021). However, previous evidence only partially captures the psychological effect of feeling a lack of belonging. Moreover, where reviews have addressed the issue, they do so indirectly through findings showing how PWID frequently understand 'belonging' only in terms of feeling part of supportive ID-specific communities (Louw et al., 2018).

This review also found that marginalisation is often evident through social interactions which dehumanise PWID and frequently result in victimisation. Marginalising behaviours leave PWID feeling like a burden to society; as worthless and unable to meaningfully contribute. Previous reviews have observed how PWID are at risk of being victimised (e.g., Harrison et al., 2021), however the notion of 'burden' is frequently understood differently. For example, while Hamilton et al. (2021) reviewed qualitative evidence of the self-reported burden in caregivers of PWID, a meta-analytic review focused on the health and socio-economic burden countries faced in caring for disabled people (Bitta et al., 2017).

The third theme to emerge from the review noted that community-based marginalisation can generate a pervasive sense of hopelessness and

helplessness amongst PWID, which may lead to feelings of 'giving up' on a society which does not offer a meaningful future. This outcome seems to reflect the findings across several reviews (e.g., Tough et al., 2017). For example, Harrison et al. (2021) found evidence of PWID's dissatisfaction with regards to their social/personal relationships. Robertson et al. (2019) also noted the impact of hopelessness resulting from marginalised experiences of ethnic minority ID groups.

1.4.2 Living with the psychological impact of marginalisation

The review's findings evidence that marginalisation can have a profound psychological impact on PWID, which in turn may influence their day-to-day lived experiences within society.

PWID who lack a sense of belonging to the social world can feel isolated from their communities (Mahar et al., 2013). As social creatures we feel the need to have social connections (Baumeister & Leary, 1995) in order to not feel isolated and abandoned, which were especially evident in PWID (Dagnan & Waring, 2004). This is reflected in their anxieties towards living with smaller social networks, which are usually limited to family and/or people with similar intellectual challenges, and concerns over the narrow range of socially fulfilling activities available, especially employment (NHS Digital, 2018; Kamstra et al., 2015; Mencap, 2019). Another significant consequence of a lack of belonging is the sense of loneliness that PWID experience (Gilmore & Cuskley, 2014; Mencap, 2019). Loneliness can significantly impact wellbeing (McVilly et al., 2006), leading to anxiety and depression which make social interactions more problematic (Merrick et al., 2006; Petroutsou & Hassiotis, 2018).

The consequences of feeling like a burden to others can lead to low self-esteem, shame and self-stigma (Paterson et al., 2011; Beck, 1967). Evidently, PWID tend to internalise society's dehumanising treatment (Ali et al., 2012), which can lead some to exhibit self-critical/self-blaming behaviours (Gilbert, 2003). Moreover, there is evidence that long-term exploitation normalises experiences of victimisation (e.g., Esdale et al., 2015), leading PWID to feel

unsafe and with little choice but to 'negotiate' their autonomy through engaging in appeasing-type behaviours, including forgoing basic rights/privileging other's needs (Voermans et al., 2020). The overall impact of living with a sense of burden is to leave PWID feeling socially unwanted, distressed and inferior (Jahoda & Markova, 2004; Szivoz-Bach, 1993).

Experiencing hopelessness and helplessness about the future leaves PWID feeling powerless within their communities; as experiencing no sense of control and 'giving up' on creating meaningful lives. Ultimately, even while living within the community, PWID often conform to the values of a 'sick role/disabled identity', appearing to see themselves as incapable of developing meaningful relationships or roles, leaving them feeling dissatisfied (e.g., Harrison et al., 2021). A perceived lack of self-determination perhaps undermines the desire for autonomy (Roy et al., 2015) and reinforces their learnt helplessness (Seligman, 1972). PWID appear ready to adopt a passive position, which deskills them, decreases their mood (Weeland et al., 2017) and increases their social inhibition and reliance upon caregivers for practical support (Callus et al., 2019).

Lacking a sense of belonging, feeling burdensome and living without a sense of future represents a set of interpersonal difficulties that may significantly increase the risk of depression and suicidal ideation (Van Order et al., 2010; O'Connor & Nock, 2014; Joiner, 2005). Evidence suggests that the risk of experiencing poor mental health and suicide desire in PWID is twice that of the general population (NICE, 2016; Hassiotis et al., 2011), including depression and interpersonal difficulties (Maiano et al., 2016; Perren et al., 2010).

1.4.3 Clinical Implications

This review's findings illustrate the juxtaposition that Durkheim (1897) noted over a century ago; that PWID's psychological difficulties could in part result from social factors, namely marginalisation. The implication is that social change is needed. Although macro-level socio-political solutions are largely beyond Clinical Psychology's remit, the review's findings can benefit

psychological policy and practice to help minimise the risk of harm resulting from marginalisation.

To mitigate the psychological impacts of isolation and loneliness, professionals should collaborate with social care to signpost/refer PWID to inclusive day centres and ID-specific educational/recreational programmes (Merrells & Bucanan, 2018). Facilitating opportunities for social participation may support the development of accepting peer groups and provide a sense of fulfilment (e.g., Bigby & Wiesel, 2019; Louw et al., 2018; Williams, 2013). Moreover, clinicians could link PWID into befriending schemes to reduce isolation, by offering protective reciprocal caring relationships from which to more confidently explore mainstream events/spaces (Ali et al., 2020; Florides, 2012).

However, ensuring PWID feel safe enough for new social engagements is important. The multi-disciplinary team (MDT) should encourage skills development that supports PWID to recognise and assert their own needs in relationships. 'Social Skills Training' is evidenced to increase self-assurance and minimise loneliness (e.g., Tilly, 2019), and online skills training may help PWID access and grow digital connections (e.g., Chadwick & Fullwood, 2018) that can support wellbeing and the development of positive social identities (Caton & Chapman, 2016). Moreover, psychologists could consult on the development of 'Structured Social Groups', which employ behavioural analysis principles to equip PWID with the functional skills needed to re-engage after extended isolation; post-attendance, PWID report an increased sense of connectedness and confidence (e.g., Wilson et al., 2017).

Additionally, to minimise this group's sense of burden and society's perception of them as incapable, the MDT could work with local employers/providers who recruit PWID (e.g., Mencap). Further to the above skills training, psychologists could collaborate with Occupational Therapists to teach PWID the functional skills needed to engage in work-based activities. Moreover, in line with the Equality Act (2010), psychologists could support employers to accommodate reasonable adjustments, by disseminating and implementing an individual's 'Positive Behavioural Support Plan'. Helping PWID to access the workplace

may reinforce to individuals and society that this group can contribute and establish purposeful roles.

MDTs should offer therapeutic approaches to minimise low self-esteem, shame and self-stigma. Psychologists may consult on systemic trauma-informed and compassion-focused approaches (e.g., Truesdale et al., 2019). These may help professionals to more effectively identify, respond to and reduce interpersonal distress and self-criticism in PWID (Clapton et al., 2018). Furthermore, Compassioned-focused Therapy is shown to help PWID overcome feelings of shame; this appears particularly helpful for promoting a sense of safeness in PWID and victimisation/trauma experiences (Cowles et al., 2018). Trauma-focused Cognitive Behavioural Therapy (CBT) is an efficacious alternative for individuals with milder ID (Byrne, 2022), particularly when social context is accounted for (Dagnan, 2008).

In line with UN policy (2006) and the Government's 'Valuing People Now' (Department of Health, 2009), clinicians should endorse 'Care Programme Approach' (NHS England, 2021) principles to mitigate perceived powerlessness. Coordinating the health and social needs of PWID in an accessible/collaborative manner, empowers individuals to express how they want to be supported (Rethink, 2020). While a greater use of advocacy initiatives may assist this (Power & Bartlett, 2019), person-centred goal plans also encourage self-determination by supporting/motivating PWID to exercise achievable control/choice. A useful measure that services could adopt to inform holistic and inclusive provision is the 'Life Star' (Good & Lamont, 2019), which encourages autonomy within psychosocial domains that individuals value (e.g., safety, meaningful activity, social networks and identity). Notably, these person-centred needs/aspirations could strengthen existing PBS plans by further increasing quality of life and feelings of normalcy in PWID (McKenzie et al., 2018; Gorvin & Brown, 2012).

While aforementioned recommendations may reduce depression and suicide, additional assessment and intervention is indicated. Despite PWID being more likely to experience psychological distress (Davies & Oliver, 2013; Dodd et al.,

2016), suicide risk is not routinely assessed for because society arguably perceives them as less capable of acting upon ideation (Wark et al., 2019; Kaminer et al., 1987). Therefore, psychologists should encourage MDTs to assess for the structural/systemic risk factors for suicidal ideation; clinicians could use the 'Clinical Outcomes in Routine Evaluation' (e.g., Barton et al., 2008) as a valid assessment to identify the impacts of social context on subjective wellbeing (Marshall et al., 2013). Thereafter, if warranted, psychologists could offer evidence-based CBT for depression (Unwin et al., 2016), with an emphasis on exploring social perpetuating factors.

Clinical Psychologists should advocate for PWID by helping to dismantle false ID stereotypes (Pelleboer-Gunnink et al., 2021; Scior et al., 2020). They can support national educational campaigns (e.g., Mencap) to raise awareness of ID and facilitate society's openness/acceptance (Louw et al., 2018). Moreover, they can re-formulate and disseminate the socio-political factors which individualise distress and amplify the psychological consequences of exclusion (Power & Bartlett, 2019; Hare-Mustin & Marecek, 1997).

1.4.4 Limitations

Given the difficulties defining the phenomenon of marginalisation, due to a plethora of socio-political factors, it is possible that extending the search terms to include 'social isolation' and 'alienation' may have identified further articles. However, through peer review and consultation with the librarian, these terms were excluded because: there were too many hits with them included, they did not consistently appear as recommended index-terms within databases, and the final terms were deemed appropriate to the subject.

While methodologically rigorous steps were taken to ensure this review focused on PWID's experiences from countries that shared the same ID classification/definition, it is possible that regional differences to social inclusion policy influenced perceived marginalisation. However, the convergence of participants' experiences across all 12 articles increases the final three themes validity.

As with qualitative synthesis, the processes of study identification and Thematic Synthesis were likely influenced by the author's interpretations. Steps were taken to reduce selection bias, including peer review assessment (Ring et al., 2011). Although articles placed more or less of an emphasis on marginalisation experiences specifically, no major study limitations were revealed and all articles passed quality assessment. Moreover, the supervision team was consulted during data analysis and the validation of final themes, in which participant quotations and/or author interpretations were used as evidence.

1.4.5 Future research

Future research could employ a Grounded Theory approach to interview PWID to capture their perceptions about how marginalisation could be reduced. This provides opportunities for participation and could lead to a co-produced model of reducing marginalisation in PWID, as well as possible implications for more targeted social inclusion policy.

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Chapter Two: Empirical Paper

Transitional experiences of men with Intellectual Disabilities, and a history of sexual/violent offending, who have resettled into the community from secure settings

Written in preparation for The Journal of Intellectual Disabilities and Offending Behaviour (see Appendix J for author guidelines)

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2.0 Abstract

Aims: The aim of this research was to gain a clearer understanding of the transitional experiences of adult men, with mild Intellectual Disabilities (ID) and histories of sexual/violent offending, as they resettle into the community from secure hospital settings. **Method:** This study employed Interpretative Phenomenological Analysis (IPA) in order to explore the experiences of eight men with mild ID aged between 28 and 60 who: following confinement to secure hospitals under the Mental Health Act for sexual/violent offences, had been living back in the community under conditions of restriction for a minimum of six months and maximum of 56 months. Two one-to-one semi-structured telephone interviews were conducted with each participant. **Results:** Following IPA analysis, three superordinate themes emerged: 1) 'A chance to "turn my story around" (hopefulness about achieving freer community lives and a renewed identity), 2) 'Feeling "torn apart" (interpreting numerous losses as abandonment), and 3) 'The cost of "trying to please others" (satisfying imposed community restrictions led to a restricted identity). **Conclusion:** These findings suggest that the transitional experience is in crisis, and highlight the need for more direct and indirect psychologically-informed compassion-focused support to address the psychosocial needs of men with ID and forensic histories, in order to help them improve self-esteem, self-efficacy and meaningful participation during the transition towards community resettlement.

Key words: *intellectual disability, forensic, offending behaviour, transition, resettlement, qualitative, IPA, experiences*

2.1 Introduction

2.1.1 Research aim and significance

This research aims to better understand what it means to experience the transition from secure care to semi-independent community living, for adult male sexual/violent offenders with Intellectual Disabilities (ID).

ID is a neurodevelopmental disorder resulting in significantly below average intellectual functioning and adaptive behaviour relative to others (American Psychiatric Association, 2013). ID is categorised between mild to profound and reduces the ability to independently understand/use complex information/skills (Department of Health [DoH], 2009).

Violence is legally defined as the actual, attempted or threatened use of physical force, including grievous bodily harm (Offences against the Person Act, 1861). Sexual misconduct includes non-consensual crimes like rape and sexual harassment, which may be aggravated by violence (Sexual Offences Act, 2003). These crimes are classified as 'indictable', meaning that they are tried as serious offences resulting in imprisonment (Crown Prosecution Service, 2021).

Diagnosed ID can be a mitigating circumstance that results in involuntary confinement in secure healthcare settings under the Mental Health Act (MHA, 2007). Secure hospitals range from high to low security and offer intensive psychiatric care (Bartlett & McGauley, 2010).

While national ID forensic-specific data is limited, a multisite study across UK secure hospitals showed that approximately 85% of patients were male and 16.2% had ID (O'Brien et al., 2010). The majority of ID inpatients have mild/borderline presentations and high rates of comorbid Personality Disorder (Taylor et al., 2013). In 2017, of 2,530 ID inpatients, 1,235 were in secure hospitals, with an average length of stay of 1,970 days (NHS Digital, 2017).

Following discharge patients typically move into semi-independent supported living (NHS Digital, 2017). However, if patients pose a public risk, Ministry of Justice (MoJ) Restriction Orders are applied, which usually involved community supervision/treatment orders (Health and Social Care Information Centre, 2016). Approximately 40% of low secure and 32% of medium secure ID patients were subject to Restriction Orders (NHS Digital, 2017), with about a 20% readmission rate due to violations of these orders (Wooster et al., 2018).

Deinstitutionalisation, the 2011 Winterbourne View scandal and the Transforming Care Agenda (TCA) gave increased impetus to closing inpatient beds and developing specialist community ID services (NHS England, 2015). However, this national plan is criticised for not meeting the distinct needs of ID offenders (Taylor et al., 2017). There are likely psychosocial challenges to successful community resettlement, including discrimination, stigmatisation, learned helplessness and anxiety (e.g., Giebers et al., 2018; Lindsay et al., 2017; Chester et al., 2017). It is hoped that this study will help Clinical Psychologists and forensic professionals to better meet the needs of PWID and forensic histories as they transition towards community living.

2.1.2 Evaluation of previous literature

Ellem (2012) interviewed 10 ex-offenders with ID to investigate their experiences of leaving prison. Thematic Analysis showed that participants experienced community resettlement as overwhelming due to reported fears of marginalisation and feeling unprepared for a release which just "happened" (p. 8) without support to consider what community living entailed. This was amplified by experiencing community services as unsupportive and difficulties "understanding and accepting" (p. 11) community restrictions. This increased a sense of loneliness, difficulties securing meaningful occupation and "resentment" (p. 11) towards supervision.

Chiu et al. (2019) conducted semi-structured interviews with 10 men with ID to explore post-prison life. Interpretative Phenomenological Analysis (IPA) revealed that participants experienced challenging releases. Expected new

beginnings involved hopes of increased community-based autonomy and relationships, but participants described actually feeling obliged to "keep out of trouble" (p. 690); they evaded opportunities for "acceptance" (p. 694) by appearing to avoid pre-prison peer groups. Moreover, because they felt unsupported by community staff/probation, who seemed hostile towards them, participants appeared to lead risk-averse lives, which avoided recall but "screwed" with their "confidence" (p. 692).

Head et al. (2018) interviewed 11 non-forensic PWID about their experiences of leaving hospital under the TCA. A Grounded Theory approach revealed that PWID can live well in the community after feeling "controlled" in hospitals that made them "depressed" and identify as "bad" (p. 68). While participants seemed to lose some "trusting" relationships with hospital staff, community living was described as an opportunity to develop new networks with staff; a sense of being viewed favourably by them facilitated a shift in their identities towards 'people' not 'patients'.

Chester et al. (2019) conducted semi-structured interviews with forensic patients ($N = 21$) detained within secure settings, as well as with their family carers ($N = 6$), to explore hospital treatment outcomes. Content Analysis revealed participants' anxiety that successful community resettlement solely meant not re-offending. This was influenced by concerns that inpatient practices had deskilled them of independent living skills and specialist community provision would be inadequate following intensive hospital support. However, some expressed hopes that participating in local communities would be protective.

Davis et al. (2015) conducted semi-structured interviews with 10 male legally-restricted ID offenders, all of whom were diverted away from hospital to community-based rehabilitation. IPA revealed themes concerning participants' "taste of freedom" and simultaneous "lack of control" (p. 148). Participants described community rehabilitation as the opportunity to "try new things" (p. 148), like establishing autonomy over their lives. Although community support sometimes seemed protective, experiences of feeling restricted were

expressed as loneliness. Moreover, some participants described actually having little control because of a lack of clarity about aspects of their community care and feeling uncertain about professionals' roles.

2.1.3 Rationale and research question

While previous research has attempted to explore the lived experiences of men with ID, as they transition towards community resettlement, there appear to be at least three limitations:

Firstly, most research has tended to focus on the transitional experiences of PWID without forensic histories, or only emphasised offenders' experiences following mainstream imprisonment. The current study will change this focus by exploring the experiences of PWID, with histories of sexual/violent misconduct, who have resettled in the community following involuntary confinement in secure healthcare settings.

Secondly, the emphasis of previous studies has been on public risk and the impacts of hospital-based treatment outcomes, with a specific focus on improving community risk assessment/management. The focus of this research will shift this emphasis towards exploring self-reported experiences of community resettlement in relation to perceived safety and the impacts of restrictions.

Thirdly, with an over-emphasis on public safety, previous research has inadequately explored expectations of community support or opportunities. To address this the current study will investigate individual experiences of community relationships, preparedness and meaningful participation.

The current study will address the following research question: What are the transitional experiences of men with mild ID, and histories of sexual/violent offending, who have resettled into the community from secure settings?

2.2 Method

2.2.1 Research design

This study employs an interpretivist epistemological position. This is underpinned by phenomenological and hermeneutic philosophical approaches, which provide accounts of lived experience in its own terms without relying upon pre-existing theory (Chan et al., 2013). It assumes that perceived meaning is more important than objective reality (Willig, 2013) and that perceptions of our lives are based upon implicit beliefs about ourselves, the world and socially constructed shared meanings (Meyers, 2008; Barker et al., 2015).

In alignment with interpretivism, the qualitative research design for the current study is Interpretative Phenomenological Analysis (IPA). IPA explores participants' experiences from their perspectives rather than describing phenomena according to predetermined categorical scientific criterion (Smith et al., 2009; Pietkiewicz & Smith, 2014). Therefore analysis begins with a detailed interpretation of a participant's idiographic beliefs/perceptions before focusing on general claims (Willig, 2013). IPA acknowledges that understanding a participant's world may not be directly or completely possible, therefore interpretative activity becomes a double hermeneutic in which researchers attempt to make sense of the participant's efforts to make sense of their own experiences (Smith et al., 2009).

IPA's significant strength is how it privileges the voices of disempowered groups (Noon, 2018); PWID are typically passive recipients without opportunities to participate (Shogren et al., 2006). As this research aimed to understand the actual experiences of community transition in PWID, IPA was an advantageous method for capturing the lived experiences of phenomenon with personal significance (Smith et al., 2009).

2.2.2 Sampling design

A non-probability sampling design, organised around the purposive sampling method, was used to establish a homogenous sample with experience of the phenomenon of interest (Barker et al., 2015). Sample homogeneity was achieved through obtaining a sample of participants that met specific criteria, which are outlined in Table 2.1 below.

Table 2.1

Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Gender	Males	Females
Age	18 and above	Children <18
Diagnosis	Mild ID (full scale IQ between 50 and 70), with a co-morbid Autism Spectrum Disorder and/or Personality Disorder diagnosis.	Uncapacious patients with moderate to profound ID (full scale IQ < 49). Non-English speaking and/or non-verbal.
Offence	Convicted for sexual misconduct (including non-consensual crimes like rape, assault and sexual harassment) and/or violent offences (including harassment, common assault and grievous bodily harm).	No evidence of sexual and/or violent offending.
Sentence	Detained within low, medium or high secure hospitals under the Mental Health Act.	Detained and discharged from non-hospital secure settings (including Her Majesty's Prison services).
Community restriction/ arrangements	Patients discharged into the community with conditions of restriction (e.g. Conditional Discharges and Community Treatment Orders).	Not in contact with the NHS or third sector health/social care community services.
Time within community	Minimum of 6 months and a maximum of 56 months.	< 6 months or > 56 months.

Men aged 18 and over were recruited because adult males are more likely to be detained to secure settings (e.g., Galappathie et al., 2017). Females were excluded because they only account for eight to nine percent of secure ID patients (e.g., Claudio et al., 2019).

Individuals with mild ID were included because the majority of detained ID patients have mild presentations (O'Brien et al., 2010) and participants required relatively strong comprehension and verbal skills for remote interviews. Moderate to profound ID was therefore excluded. Furthermore, on the basis of a gatekeeper's clinical judgement, patients with comorbid Autism Spectrum Disorder (ASD) and Personality Disorder were recruited. In the general population 46.7% of people diagnosed with ASD have comorbid ID (Postrino et al., 2016), and approximately 10% of offenders known to secure forensic services have ASD (e.g. O'Brien et al., 2010) and/or comorbid Personality Disorder (Taylor et al., 2013).

Individuals with histories of sexual/violent offending were recruited because men with ID detained to secure settings are more likely to have committed these offence types and may pose a significant risk to the public (Holland et al., 2002). Moreover, individuals living with legal restrictions were included because approximately 25-30% of ID patients were detained under forensic sections of the MHA (National Audit Office, 2015) and are therefore more likely to be subjected to MoJ restrictions, requiring a Mental Health Tribunal and/or the Secretary of State's approval for discharge (NHS Digital, 2018).

Recruiting participants who had been living in the community for a minimum of six months meant participants had time to experience the transition towards community living. This ensured that participants had the capacity to confidently recall experiences relevant to the research question (Palinkas et al., 2013).

Identification of eligible and capacious participants was supported by clinical gatekeepers from each Mental Health Trust. The full recruitment process is outlined in Appendix K, but to ensure participants met the inclusion criteria, broad offence type and ID diagnosis was confirmed by the clinical gatekeeper before informed consent was requested. Demographics (age, ethnicity, conditions/restrictions, secure setting, length of hospital stay and time in the community) were self-reported at interview.

Table 2.2

Participant Characteristics

Pseudonym	Gender	Age	Diagnosis	Ethnicity	Index Offence Type	Secure setting(s)/ length of hospital admission	Community setting(s)/ time since discharge	Community arrangements
John	Male	54	Mild ID	White British	Violence	HMP; MSU; LSU / 14 years	Supported living / 8 months	Life License
Sam	Male	28	Mild ID; ASD	White British	Sexual	MSU; LSU / 4 years	Supported living / 34 months	Community Treatment Order
Ben	Male	54	Mild ID; EUPD	White British	Violence	MSU; LSU / 6 years	Supported living / 17 months	Conditional Discharge
Carl	Male	49	Mild ID; ASD	White British	Sexual	LSU / 4.5 years	Supported living / 44 months	Conditional Discharge
Ian	Male	60	Mild ID	White British	Violence	HMP: MSU; LSU / 11 years	Supported living / 36 months	Life License
Tom	Male	28	Mild ID	White British	Violence	LSU / 2 years	Supported living / 28 months	Guardianship Order
David	Male	35	Mild ID; ASD	White British	Violence	MSU / 3 years	Residential placement / 15 months	Community Treatment Order
Jim	Male	31	Mild ID	White British	Sexual	MSU; LSU / 5 years	Supported living / 27 months	Conditional Discharge

*Medium Secure Unit (MSU); Low Secure Unit (LSU); Her Majesty's Prison Services (HMP); Emotionally Unstable Personality Disorder (EUPD)

As shown in Table 2.2 above, in line with IPA guidance (Clarke, 2010), eight male adult participants with mild ID were recruited from three NHS Mental Health Trusts. All participants had been involuntarily detained within English secure hospitals under forensic sections of the MHA, and were currently living in the community with support. Of these, the nature of their index offences were sexual (N = 3) or violent (N = 5). Participant ages ranged from 28-60 years and three had comorbid ASD. Two participants originally received fixed sentences within mainstream imprisonment before being transferred to secure hospitals under sections.47/49. While six had been detained to medium secure, and seven to low secure, five participants had resided at both as part of stepped down care. The length of hospital stay ranged from two to 14 years, and the length of time spent back in the community ranged from eight to 44 months. Community conditions of restriction included Life Licenses (N = 2), Conditional Discharges (N = 3), Guardianship Orders (N = 1) and Community Treatment Orders (N = 2).

2.2.3 Measuring instruments

A semi-structured interview guide was employed (see Appendix L) comprising of questions based on previous literature (Smith & Osborn, 2008). The guide was informed by IPA principles, being structured by topic rather than specific survey-like questions (Smith et al., 2009). General questions were broadly themed around experiences of relationships (Head et al., 2018; Davis et al., 2015), expectations of community living and preparedness (Hickman et al., 2018), safety and contact with professional services (Beadle-Brown et al., 2014; Chester et al., 2017), self-esteem/identity (Johnson, 2012), and lifestyle and community participation (Davis et al., 2015; Gilmore & Cuskley, 2014). However, as is the tradition in IPA, the participant's voice is important and so latitude was given for them to discuss whatever they deemed important.

Adaptations were made to the interview guide to help PWID to engage and communicate their experiences. Firstly, given the intellectual needs of PWID, abstract concepts could have become difficult to grasp and result in shorter interview responses (Webb, 2013). PWID require additional 'scaffolding', hence

frequent breaks were invited and concrete interview questions and prompts in the form of more direct questions (e.g. good versus bad) were used to collect 'richer' data. Rich data take many important forms in phenomenological research, including detailed descriptions (events and/or 'for examples'). Furthermore, it is important that IPA produces themes that transcend the interviews general topics (Smith et al., 2009), thus more non-leading questions than usual were included to support the lead researcher to make meaningful and accurate interpretations.

Secondly, adaptive behaviour and expressive communication needs meant it was likely that any difficulties with assertive communication could increase acquiescence (Webb, 2013). To address this issue the interviewer delivered questions non-judgementally and used the guide flexibly to offer adequate time for participants to respond. Moreover, with consent a participant's trusted support worker could be present before and after the interview; this afforded participants someone who knew them well enough to advocate on their behalves.

2.2.4 Methods of data collection

A systematic review found that IPA interviews can be used successfully with PWID (Rose et al., 2019). For example, semi-structured interviews are an advantageous qualitative design for capturing detailed lived experiences of a sensitive topic (Barker et al., 2015). Moreover, it meant the interview focus could shift towards another general topic whenever participants had wanted to express something important to their experiences that the IPA guide had not included. Furthermore, in relation to methods such as focus groups, individual interviews were helpful in minimising the risk that participants with ID provided socially desirable answers, which they may have thought more acceptable in a group interview (Willis, 2013).

To enhance participation, two audio recorded 45 minute individual semi-structured telephone interviews were conducted with all eight participants (Patton, 2002). Therapeutic skills including empathy and curiosity (Barker et al., 2015), as well as open-ended experiential questions, were used in a

conversational tone to encourage engagement (Josselon, 2013). Moreover, offering two interviews meant that questions were well paced, reducing the burden of a long interview and meaning there was sufficient time to build trust. Arguably, a participant's ability to feel safe was essential for developing the rapport needed for rigorous semi-structured interviewing (Willig, 2013).

2.2.5 Ethical considerations

This study was ethically approved and registered by Coventry University's Ethics Committee (see Appendix M), the Health Research Authority (see Appendix N), and each NHS Research/Innovation and Development (R&D) Team. PWID are classified as 'vulnerable adults' (DoH, 2009), thus the British Psychological Society's (BPS) Code of Human Ethics (BPS, 2014) was adhered to.

Every effort was made to ensure informed consent. Given this groups 'impairment of mind' capacity to consent could not be assumed; participants had to evidence to gatekeepers that they could understand and retain information relevant to the decision, weigh up this information, and communicate their decision (Mental Capacity Act, 2005). Furthermore, the Participant Information Sheet (PIS) and informed consent form were adapted in consultation with professionals working in the field and a focus group of PWID detained within secure settings (see Appendix O). In accordance with national easy-read guidance (NHS England, 2018), adaptions included enlarged text and spaced formatting, simplified language and use of photosymbols. Participants also had sufficient time to make their decision (14 days) and informed consent was only based on a full review of the PIS and selecting 'yes' to all items.

There were important correspondence considerations. Due to the COVID-19 health pandemic, efforts to reduce transmission included remote data collection methods and sharing study documentation via secure email. While there were concerns regarding fair participation, consultations with gatekeepers concluded that this was the standard information sharing method, particularly in the

context of increased COVID-19 health risks experienced by PWID (Public Health England, 2020). Gatekeepers explained that potential participants would be supervised and supported by their social care staff to communicate via their organisations trusted email addresses and computer devices.

Psychological harm was minimised in the following ways. Firstly, participants were not coerced into participating as they were told there were no consequences to refusal, and they had the right not to answer questions and/or withdraw themselves and their data up until 31st March 2022. Secondly, as agreed with each R&D team, the research only proceeded within a Trust if the relevant care team had capacity to support in the event of a distressed/concerned participant. This issue arose at one site, hence recruitment did not proceed from what was supposed to be the fourth Mental Health Trust. This minimised the risk of a distressed participant going unsupported. Thirdly, a transparent procedure for managing risk disclosures was in place, which included a duty of care to inform the appropriate agencies, although this was never needed. Fourthly, a debrief with their community support worker was provided after both interviews. This was an opportunity to talk through any issues, remind them of their rights, and to identify a named professional with whom they could contact should any issues have arisen.

Privacy is upheld by processing data in accordance with the General Data Protection Regulation (2016) and the Data Protection Act (2018). Participant data is confidential and anonymised by way of a unique participant number/pseudonym. All audio recordings were destroyed once they had been transcribed and all data is stored on a password-protected Coventry University OneDrive network. Participant consent forms and demographics are kept separately from interview responses to minimise risk in the event of a data breach. Once the doctorate is complete, Coventry University will be responsible for destroying the data five years after the study end date of September 2022.

2.2.6 Method of data analysis

Audio recordings were transcribed and analysed in line with the research aims and six stages of IPA data analysis (Smith et al., 2021). This explicitly idiographic process began with analysing the first individual case in its unique context before analysing other cases and making general claims. Appendix P contains an example of a coded transcript.

Table 2.3

The Six Stages of IPA (Smith et al., 2021)

Stage	Description
1	First encounter with the text
2	Identifying preliminary themes
3	Grouping themes into clusters
4	Tabulating themes into a summary table
5	Repeating the process with all transcripts
6	Integration of cases

In stage one (see Table 2.3) the first interview transcript was re-read and descriptive, linguistic and conceptual codes were noted in order to provide a summary narrative that was close to a participant's account. In the more interpretative second stage, emergent themes were identified which summarised key parts of the text and coding. In stage three, conceptual similarities between emergent themes were identified and clustered into subthemes with a shared meaning (see Appendix P). Stage four involved producing a summary table of an individual participant's superordinate themes; these were more structured and accompanied by quotations. During stage five the remaining transcripts were analysed using the same process. Where identified themes appeared to conflict with another participant's narrative, earlier transcripts were revisited to ensure nothing was misunderstood (Biggerstaff & Thompson, 2008). In the final stage, thematic maps (see Appendix P) were produced to aid discussions with research supervisors to identify final superordinate and subordinate themes which reflected the entire samples experiences.

The hermeneutic approach to IPA recognises the researcher's influence on the analysis through their interpretations of participants' lived experiences (Smith et al., 2009). Consequently, the researcher's reflexivity was important in exploring bias (Bell, 2010) and so the lead researcher kept a reflective log and utilised regular clinical and academic supervision. Furthermore, the validity of superordinate and subordinate themes were assessed by developing and presenting the final master-list to the research team and consenting participants. Three participants provided verbal feedback validating the themes; they reported that the superordinate themes accurately reflected their experiences of community resettlement and only asked for minor changes to the wording of those in which they felt had titles/names that were too abstract for PWID to comprehend. For example, the term 'amputation' had been proposed but participants made literal interpretations of its meaning, hence it was replaced with a direct participant quote.

2.3 Results

Three overarching themes emerged from an interpretation of the findings voiced by men with ID, and forensic histories, about their transitional experiences towards community resettlement from secure settings (see Table 2.4).

Table 2.4

Superordinate and Subordinate Themes

Superordinate theme	Subordinate theme
A chance to "turn my story around"	1. *"A chance for a freer life"*
	2. *"I'm not the same person I was"*
Feeling "torn apart"	1. *"I felt destroyed"*
	2. *"I got left on my own"*
The cost of "trying to please others"	1. *"I have to show I'm safer"*
	2. *"I feel cut-off"*

Theme one, *'a chance to "turn my story around",* reveals how participants experienced community resettlement as an opportunity for freedom and a renewed identity. Theme two, *'feeling "torn apart",* explores distressing experiences of loss and how this was made sense of. Theme three, *'the cost of "trying to please others",* voices participants' sense of how complying with community-based restrictions meant negotiating freedoms and not fully renewing their identities.

Participants shared a range of experiences across each theme, which are represented by participant quotations and outlined in Table 2.5 below.

Table 2.5

Participant Experiences within Each Theme

Superordinate Theme	A chance to "turn my story around"		Feeling "torn apart"		The cost of "trying to please others"	
Subordinate Theme	*"A chance for a freer life"*	*"I'm not the same person I was"*	*"I felt destroyed"*	*"I got left on my own"*	*"I have to show I'm safer"*	*"I feel cut-off"*
John	X	X	X		X	X
Sam	X		X	X	X	X
Ben	X	X	X	X	X	X
Carl	X	X	X	X		X
Ian	X	X	X	X	X	X
Tom	X	X	X		X	
David	X	X	X	X	X	X
Jim		X	X	X	X	X

2.3.1 A chance to "turn my story around"

This superordinate theme was interpreted from the experiences of seven participants who talked about feeling a greater sense of freedom over their daily lives, and the opportunities community living presented to enable self-change to bring out 'better' versions of themselves.

2.3.1.1 "A chance for a freer life"

This new sense of freedom was powerfully expressed by Ben who was now able to make decisions for himself about what seem the most ordinary of everyday tasks:

> *"On the unit you're locked up and have do the rules... like making drinks when they say. Here where I live now... I knew would, err, be better because I watch TV and cook when I want"*

<p style="text-align:right">(Ben, 14-16)</p>

For John and David freedom was about experiencing less surveillance over their lives:

"...when I want to have a sleep in on the morning I can now without staff checking all the time"

<div align="right">(David, 118)</div>

"It's... more private here... feels confidential"

<div align="right">(John, 94)</div>

This sense of freedom sometimes seemed initially uncomfortable:

"It's weird to walk around outside without being watched"

<div align="right">(Tom, 64)</div>

But participants also commented on how it empowered them:

"I see the old manager up the road from the hospital and he went 'where are your staff?', and I went 'I'm out by myself nowadays', and he was like 'wow'"

<div align="right">(Ian, 40-41)</div>

Participants also described experiencing freedom in terms of looking towards a better future:

"Leaving [hospital] meant I could... move on. At last things were finally going to be better"

<div align="right">(Tom, 16-17)</div>

"...I'm proper excited to, err, travel 'round and see things"

<div align="right">(Ben, 11)</div>

Often participants experienced their newly found sense of freedom as a chance for self-improvement across a range of independent living skills:

> *"I've loved learning to better cook, because in hospital most of my food was made by staff"*
>
> <div align="right">(Carl, 38-39)</div>

> *"...I clean my own flat... I do it all myself a lot nowadays"*
>
> <div align="right">(Jim, 124)</div>

Other participants felt free to explore interests that help enrich their personal lives:

> *"I've started doing my animal college course. I've wanted it for long time now, and now I can finally".*
>
> <div align="right">(David, 98-99)</div>

Being free to hope for a better future and self-improvement also seemed to be associated with experiencing a greater sense of fitting-in with mainstream society, and enhanced self-esteem:

> *"...mum says it's good [doing a college course] 'cause other people do that"*
>
> <div align="right">(David, 99-100)</div>

> *"I got a job with dogs, not paid, but cool isn't is... I'm dead proud"*
>
> <div align="right">(Ian, 98)</div>

Participants also commented that experiencing a *"freer life"* (Tom, 13) was often about feeling safe:

> *"...didn't know how I was gonna be in new places [supported living], so I needed to know I'd be alright"*
>
> <div align="right">(Sam, 75-76)</div>

To achieve this sense of safety, participants seemed prepared to accept some control over their liberty which comes with supported community-based care:

> *"Staff here... they've got my back. We... talk about my risk assessment, but now... it's also to do with how safe I actually feel"*
>
> (John, 260-261)

Also, the rules imposed upon them were often seen as helpful:

> *"I carried on with 'em rules, which is sensible 'cause I needed them"*
>
> (Tom, 16)

> *"Them rules are good, 'eh, they told me what I needed to do to be alright"*
>
> (Ben, 61)

It appears that the transition to community living is often experienced as offering a greater sense of freer living and opportunities to exercise autonomy over their lives, and to experience more privacy over what they choose to do. Freer living also means feeling able to be optimistic about the future and having the opportunity to learn and grow as a person. Participants also seemed to accept that this sense of freedom should be restrained by rules which they viewed as helpful safety nets, as least at the start of their transition towards experiencing freer lives.

2.3.1.2 *"I'm not the same person I was"*

Participants also saw the transitional experience towards community living as an opportunity to become *"better"* (David, 104) versions of themselves:

> *"Moving on I feel a bit more, umm, better in myself... I'm not perfect but I think I've changed to being a better man who people like"*
>
> (Carl, 105-106)

This sense of being a 'better' person was experienced in different ways. For Jim and John it meant:

"I get, err, treated like a normal person"

(Jim, 156)

"...trying to be nicer... to people"

(John, 300)

Participants talked about this as recognising the needs of others:

"I do me volunteering now"

(David, 102)

"I'm a helper to people, putting them before me"

(John, 301)

When talking about becoming 'better' versions of themselves, participants expressed the need to belong and be accepted within their community. Experiencing this sense of belonging was expressed as feeling important to other people:

"...I've got staff that I can talk to and they seem interested in what I actually want to talk about, like... playing games, not like hospital where only certain staff seemed bothered about me"

(Carl, 46-48)

"I reckon they [staff] actually care [about me]"

(John, 94)

Participants also expressed concern about ensuring that they felt included by their communities by belonging to the 'right' people:

"My life was with lots of not nice people... now I can make new friends"

(Ben, 123)

"...it's a chance to keep away from all that [negative peer group]"

(Ian 275)

"I... go to a cool group for people with learning disabilities, which I really like because I get to meet and talk with others"

(Carl, 54-55)

In particular, participants experienced the transition towards community living as an opportunity to become *"gooder at keeping safe" (*Jim, 228):

"I get to use my reminder cards to stay calm... on my own"

(Jim, 80)

Participants also talked about how other people's views on their level of risk mattered:

"I reckon I'm nicer 'cause they [hospital staff] told me I done the right work and they wouldn't have let me out, umm, if they thought I was really risky"

(Ian, 213-214)

Participants experienced the transition towards community living as an opportunity to not be the same person they were in hospital. This process towards becoming 'better' versions of themselves involved working towards being valued as a person, who was aware of the needs of others. Participants' goal was to establish a sense of belonging to their community, through being deserving of others' attention and care, and connecting with appropriate people. Ultimately, participants viewed their transition as a chance to prove they could get better at becoming a safer person.

2.3.2 Feeling "torn apart"

This superordinate theme was interpreted from the experiences of eight participants who spoke about losing meaningful relationships and perceived containment, and the ways in which loss facilitated feelings of loneliness.

2.3.2.1 "I felt destroyed"

A sense of feeling devastated by loss was expressed by participants who found saying goodbye to hospital-based friends *"upsetting"* (Carl, 65):

> *"...I'd been there a while and... I felt close to them [peers]. It felt hardest when I was doing the transition... I was missing them"*
>
> (David, 54-56)

For Ben and Jim this was about losing dependable social supports:

> *"It was harder because they [hospital peers/friends] were really supportive"*
>
> (Ben, 54)

> *"They [hospital staff] helped me, err, get where I am now, but mostly it was being with the guys... knowing they back me up... but that's over"*
>
> (Jim, 62-64)

Also, participants spoke of how transitioning towards community living was experienced as losing opportunities to continue these relationships:

> *"It was God awful, really harder actually... when we [a fellow inpatient] had to say bye.... Gone. I thought we'd see each other soon, but we never"*
>
> (Ian, 255-258)

Participants also described losing their connections with hospital staff:

> *"I was upset that they [staff] didn't come... I didn't get why they couldn't"*
>
> (Ben, 137)

Often, these endings appeared difficult because of their significance:

"I couldn't call staff friends, but they did feel like my friends"

(Ben, 51)

Participants also expressed loss as the physical separation from hospital:

"...it was a shock to hear them telling me to leave the unit"

(Carl, 87)

Ian seemed to experience this as losing a sense of containment:

"I felt like it [hospital] was more protected... it was never the same here [community]"

(Ian, 28)

For others, having *"got used to"* (John, 70) hospital living seemed to make transitioning towards the community harder:

"I feel like I was inside for ages. Too long"

(Ian, 7)

It appears that transitioning towards community living was often experienced as loss. This was felt in respect of finding the endings of close friendships with peers and hospital staff challenging. Loss seemed to therefore involve a realisation that community living involves permanently separating from important networks of support. Similarly, participants also experienced loss as leaving the containment of a familiar hospital setting. This seemed particularly significant for participants with longer stays who were perhaps accustomed to confined living.

2.3.2.2 *"I got left on my own"*

This sense of having been left alone was experienced as an awareness that transitioning towards community living was lonely:

"... it's lonelier than I expected"

<div align="right">(Ian, 245)</div>

Some participants experienced loneliness as abandonment:

"...[hospital staff] made it bloody terrible!... I got left here! [at supported living]"

<div align="right">(Tom, 80-83)</div>

"Dad still doesn't want to know me"

<div align="right">(David, 210)</div>

For Sam and Carl, abandonment involved acknowledging some staff's perceptions of them:

"They [hospital staff] thought I was a troublemaker anyway... maybe it's true"

<div align="right">(Sam, 283-284)</div>

"...I reckon they [hospital staff] saw me as risky"

<div align="right">(Carl, 234)</div>

Others talked about loneliness in the sense of having done to their friends what was being done to them:

"...I felt bad and, like, guilty for leaving them [friends] stuck there [hospital]"

<div align="right">(Jim, 67)</div>

"I'd went, 'I have to apologise now, but I'm leaving [hospital]'. They [friends] looked sad"

<div align="right">90</div>

Experiences of loneliness during the transition towards the community was also about being someone who *"couldn't feel safe"* (Ian, 56) alone:

"...felt like some bad things could happen"

(Tom, 167)

For Carl and Sam, perceiving loneliness as unsafeness appeared to be amplified by an unpreparedness for semi-independent living:

"...leaving [hospital] happened too fast"

(Carl, 77)

"...nobody talked about what life would turn out like"

(Sam, 113)

Some participants seemed desperate to be acknowledged and rescued from their loneliness:

"I was... really naughty... setting fire alarms off and trying to escape and hiding in the garden"

(Ian, 24-25)

"I'd play up and try and get moved"

(Sam, 13)

"I stopped listening [to staff]... I'd only do their rules when it was fair"

(Carl, 81)

Participants appeared to experience the transition as a process of becoming lonely. This sense of loneliness was about experiencing underlying insecurities that others had abandoned them. Participants also viewed the attitudes of others as important and perhaps internalised some negative self-views around

being deserving of loneliness. Ultimately, participants experienced their lonely transition towards community living as unsafeness; they questioned their own preparedness and attempted to escape/manage their situations by means of challenging behaviour.

2.3.3 The cost of "trying to please others"

This superordinate theme was interpreted from the experiences of seven participants who described a drive to satisfy imposed rules in order to evidence their reduced risk to others, and to avoid recall, which was experienced as isolating and restrictive.

2.3.3.1 "I have to show I'm safer"
Participants expressed a sense of needing to comply with community restrictions and others' expectations in order to *"prove"* (Ian, 35) their safeness:

> *"I follow the rules but I'm not sure that'll ever be enough"*
>
> (Ben, 128)

> *"I showed 'em [professionals] that I was safe and deserved it [discharge]"*
>
> (Ian, 36)

This seemed motivated by fear/anxiety:

> *"I don't want to do... wrong and end up going back to a locked unit"*
>
> (Sam, 54-55)

> *"I can't afford to go to prison...I wouldn't get... support"*
>
> (John, 120)

John and Sam conveyed how they felt controlled by professionals:

> *"I can never be left alone. It's all about check this and checking that"*
>
> (John, 112)

"Stop butting in! I need my life and privacy"

(Sam, 78)

Also, participants expressed concerns about the fragility of their newly-found freedoms:

"...professionals could make decisions all about my life again"

(Carl, 19)

Participants also commented that showing they could be safer was often about negotiating freedoms:

"I... feel like I'm tryin' to please people... so I can get things"

(Carl, 109)

"...you need to be good to go out alone"

(Ian, 36)

Ben described this as treatment compliance:

"Doing the courses... might mean they [professionals] thought I was alright to have free time"

(Ben, 14-15)

Other participants felt safeness involves compromising/sacrificing some autonomies:

"I thought about getting a job... but I can't see that never happening"

(Sam, 58-59)

"It's hard to meet people... [with] staff around you. But, err, I have to have them with the rules... so I just keep clear of people"

(David, 34)

It seems that transitioning into community living is experienced as feeling controlled by others' expectations, namely professionals, and feeling compelled to comply with community restrictions. In order to reduce the perceived risk of recall, participants saw opportunities to prove their capacity to have become safer members of the community by adhering to treatment, making compromises and relinquishing some autonomies and opportunities for connection.

2.3.3.2 "I feel cut-off"

While complying with restrictions, participants seemed to experience transitioning towards community living as feeling isolated:

"[I feel] a bit sort of left behind... makes me feel like I don't fit in"

(John, 232)

This sense of being isolated from their communities was experienced as risk. For David this was about whether he really was safe enough to lead a freer life,:

"I did [unescorted] leave alone [in hospital]... then I came here [community] and wasn't properly doing it alone. I was confused"

(David, 221-222)

Other participants talked about restricting social opportunities in order to safeguard others:

"I want to keep... the public safe"

(John, 258)

"I don't want friends now... it's risky because of the stuff I got into trouble for"

(Sam, 232)

This sense of a restricted identity seemed to be influenced by professionals' attitudes:

"Staff remember me as the guy who... [offence]... it's harder to move on"

(Ben, 131)

Isolation was also described as feeling vulnerable and unable to *"trust"* (Sam, 11) others:

"I was scared to go out. I looked over my shoulder in case"

(Ian, 64)

"People have taken advantage so sticking away keeps me better"

(Tom, 128)

Participants also expressed that experiencing the transition towards community living as isolating involves becomingly increasingly dependent upon staff:

"My staff are with me all the time. If they weren't... I'd feel unsafe"

(Ben, 95)

"I'll always carry on having staff... in case I need them"

(David, 17)

This often appeared as questioning their own ability/judgement:

"They [professionals] making sure I don't do things stupid... they check my rules properly"

(Jim, 168-169)

Whilst restrictive, this invited safeness:

"...having these community laws, umm, means I know exactly what to do to get safe"

"...it's easier if things are out of our hands"

(Sam, 72)

However, unintended consequences of a *"use it [support] or lose it"* mentality (John, 160) included feeling burdensome:

"...I'd wanna see them [nurse] more... but I don't wanna take up her time"

(Ben, 44-46)

"Professionals don't like chatting about my risk"

(Carl, 54)

Participants experienced the transition towards community living as isolating. This seemed to result from satisfying community restrictions. Participants viewed their isolation as feeling cut-off from fully renewing their identities; there was a sense of questioning their own level of risk towards/from others because of their forensic histories. Consequently, to increase safeness, isolation was experienced as becoming increasingly reliant upon services, which perhaps perpetuated feeling cut-off and burdensome.

2.4 Discussion

Three superordinate themes emerged from the transitional experiences of men, with ID and histories of sexual/violent offending, who had resettled into the community from secure settings.

2.4.1 Transitional experiences in context

Theme one found that participants experienced the transition as an opportunity to move from restricted hospital environments to more hopeful and freer community lives, where they could become safer people. This supports previous forensic and non-forensic ID studies also noting aspects of hoping to become 'better' people, by belonging to protective 'in-groups' and being treated normally (Head et al., 2018; Chiu et al., 2019; Davis et al., 2015). The current findings extend previous research (e.g., Ellem, 2012) by offering insights into why restrictions are initially appreciated for how they helpfully clarify the boundaries to unfamiliar freedom, which helps individuals explore it more confidently with a greater sense of what is acceptable and unacceptable. Perhaps this explains why some PWID have found supervision protective (Chester et al., 2019; Davis et al., 2015).

Theme two suggests the transition is experienced as the loss of meaningful friendships and hospital containment. This supports studies which found that offenders have difficulties adjusting to a life beyond confinement (Ellem, 2012). Current findings also support previous research suggesting that loss is associated with loneliness and feeling unable to cope (Hollomotz, 2021; Chester et al., 2021), perhaps because hospital-based peers and staff can become significant attachments for emotional support (Murphy, 2014; Heppell & Rose, 2021). The current findings add to this research by pointing out participants' experiences of loss/the end of relationships with hospital staff as abandonment; hypothetically, because of the inherent power staff have in these relationships (Jenkins, 1996), participants perceived the actions of staff as important (Festinger, 1954) and concluded they were deservingly rejected.

Theme three found that participants experienced the transition as needing to satisfy restrictions, which impeded their ability to lead freer lives or renew their identities. This supports earlier findings suggesting that forensic populations lead risk-averse community lives post-confinement (Chiu et al., 2019), and that PWID are motivated to comply with treatment/supervision in order to avoid recall (Chester et al., 2019). Moreover, the current finding that participants were influenced by professionals expectations supports self-concept theories, which propose others' perceptions/actions shape how PWID view themselves (e.g., Argyle, 1983).

2.4.2 Transitional experience in crisis

The evidence from the current study suggests that the transitional experience for PWID and forensic histories is in crisis. The three superordinate themes show that this population encounter a range of significant interpersonal and intrapersonal difficulties when trying to re-establish themselves in the community, of which there are three key issues.

A psychologically damaging juxtaposition seems to exist between theme one, where participants experienced a hopefulness about living freer lives and renewing their identities, and theme three where participants felt the need to satisfy imposed expectations/restrictions. Previous research has not sufficiently captured the cognitive and emotional consequences of the transition, with non-forensic ID literature suggesting optimism for change and becoming included members of society is usually actualised. However, participants felt unable to fully live freer lives and/or renew their identities. As with Labelling Theory (Becker, 1963), participants appeared to internalise restrictions/professionals' expectations as indicators of risk, which was self-fulfilled by an awareness of self-monitoring and self-limiting employment and/or relationship opportunities; this is replicated in mainstream offenders (Barnett et al., 2022). Consequently, this perpetuates their 'spoilt identities' (Goffman, 1963) as men who remain a public risk, as well as feeling hopeless and demoralised. This significantly extends previous research (e.g., Hollomotz, 2021) which looked favourably upon the notion that PWID engage in risk management during transition in order

to achieve 'prosocial' identities; paradoxically however, current findings suggest that forensic ID patients' longer-term tendency to passively comply with supervision actually impedes this identity.

The findings of theme three suggest that for a forensic ID population it appears that their transitions are experienced as institutionalisation in the community. Despite the Transforming Care Agenda's (TCA) ethos that community living is better, as well as their drive to close inpatient beds (NHS England, 2015), previous research has failed to adequately note how forensic ID patients may experience restrictive community contexts as extended confinement. This is potentially psychologically harmful; in response to high levels of supervision participants reported still feeling controlled by professionals and increasingly burdensome upon services/society (e.g., Barnett et al., 2022). Arguably, even 'least-restrictive' community models equate to deprivations of rights/liberty, and amount to a 'professional paternalism' (Graham, 2006) that perpetuates isolation, low self-efficacy and low self-esteem. This raises concerns about whether the community transition can meaningfully support the rehabilitation of PWID and offending histories.

The findings of themes two and three suggest the transitional experience may paradoxically increase risk in PWID and offending histories (e.g., Griffith & Hutchinson, 2013). Arguably, because of a pre-occupation with imposing restrictions for understandable public protection reasons, the safety needs of PWID themselves can become inadvertently overlooked; most participants in the current study described their transitional experience as feeling rushed and/or uncontained, with several engaging in behaviours of concern while feeling distressed, including disengaging from support plans and hiding from staff. This raises concerns about whether being unprepared for the transition leads to psychologically unhelpful experiences of loss, abandonment, helplessness and loneliness. Perhaps this contributes to the relatively high readmission (Wooster et al., 2018) and mental health rates in forensic ID patients (e.g., Lindsay et al., 2017).

2.4.3 Clinical implications

In an effort to improve the transitional experiences for this population, and in turn reduce risk of resettlement crisis, policy and practice changes are needed.

Firstly, to relieve the contradiction found between themes one and three, and to reduce the psychological harm of feeling hopeful but continuing to be restricted, both health and social care services should adopt a trauma-informed care approach (Purkey et al., 2018). While Clinical Psychologists may consult on this, the emphasis should be on the entire multi-disciplinary team using the principles. This means that formulations and care plans should recognise the significant impact of the transition on experiencing traumatic loss/abandonment and feeling marginalised. Moreover, policy should facilitate more person-centred and therapeutic discharge pathways (Alexander et al., 2015) in which PWID transition at a pace that feels manageable and containing. To align this with the government's 'Building the Right Support' (NHS England, 2015) initiative, this could include adequately funded 'transition windows', greater continuity (e.g., keeping the same Responsible Clinician) and longer aftercare community follow-up.

Furthermore, Clinical Psychologists and forensic professionals could subscribe to third-wave compassion and acceptance-focused approaches (Speedlin et al., 2016), which can work successfully alongside trauma-informed practice in ID forensic services (Taylor, 2021). Graham et al. (2016) demonstrated that developing a compassionate ID forensic workforce can facilitate a sense of inclusion and belonging in PWID. Importantly, the aim is to address systemic issues around experiences of stigmatisation, but when indicated individual psychological support can be offered to minimise/overcome shame and self-criticism (Gilbert, 2009).

Secondly, to avoid the community feeling like an institutional extension of secure settings, as noted in themes two and three, and to support PWID to prepare for semi-independent living, clinicians should implement national standards for person-centred pre-discharge 'exit planning'. In line with

evaluated 'leavers' groups (e.g., Hickman et al., 2018) and 'transfer' interventions (e.g., Adshead et al., 2017), aimed at addressing anxieties and preparations for moving (Madders & George, 2014), the current findings suggest that holistic multi-disciplinary programmes should offer independent living skills support and relapse prevention. Additionally, a greater emphasis could be placed on community teams assisting in integrative discharge preparations, by providing more in-reach support to secure settings (e.g., Taylor et al., 2017).

Moreover, PWID and forensic needs should be supported to access meaningful opportunities for community engagement. For instance, commissioners and local authorities could continue piloting community-based services for PWID and forensic histories, such as 'Circles UK', which support psychosocial, attachment and occupational needs (Azoulay et al., 2019). Importantly, this group should be assisted to access mainstream occupational and leisure experiences whenever possible; such approaches may strengthen opportunities for psychologically helpful experiences of belonging, pride and fulfilment.

Thirdly, as shown in theme three, there is a need to manage risk in a more measured way. Clinicians could engage in regular reflective supervision/training to increase awareness of how their attitudes and restrictive practices may impact PWID (e.g., Head et al., 2018). Moreover, because offence-specific interventions may reinforce negative self-views in ID offenders (e.g., Melvin et al., 2019), in line with the 'Good Lives Model' (Aust, 2010) formulation and treatment should also focus on positive risk-management and holistic outcomes that address broader psychosocial needs associated with semi-independent living. For instance, the group-based psychologically-informed EQUIP programme has been trialled within secure settings (Langdon et al., 2013); adapted community-based versions have facilitated resettlement by providing opportunities for experiences of a 'positive peer culture' (Devlin & Gibbs, 2010), validation and empowered social decision-making (Tearle et al., 2020).

However, the study's findings validate concerns about a TCA that promotes shorter hospital rehabilitation, in the absence of sufficiently funded (National Audit Office, 2017) or even developed community provision (Taylor, 2019). This impedes the ability to implement the above recommendations; notably, participants who felt most restricted and burdensome were discharged to areas without specialist forensic services, where there appeared to be less collaboration between health and criminal justice teams (e.g., probation). Therefore, commissioners must continue investing in a community-based multi-disciplinary workforce that is specifically trained to support the positive risk management and psychological wellbeing of ID offenders.

2.4.4 Limitations

A qualitative methodology and relatively small sample size means the findings are not generalisable to the experiences of all adult men with ID and offending histories. While the convergence across participants' lived experiences, and with earlier research, increases validity, a survey study would help to see if these findings are replicated across a wider population. Similarly, while there was a homogenous sample of White British men with mild ID, the experiences of those with more profound ID are not represented, and there is a need to look at more socio-demographic populations; the above survey could help to capture information from different cultural groups.

Further, a purposive self-selecting sample may mean that more confident individuals shared their experiences and/or this sample may reflect the views of those who were motivated to participate because of a desire to see change following particularly negative transitional experiences. Moreover, length of stay within secure services varied from two to 14 years, and time spent back in the community ranged from eight to 44 months. Hypothetically, a longer detention may have increased the likelihood of a participant feeling institutionalised, which may have made the transitional experience particularly challenging; this might not reflect the experiences of participants with relatively shorter stays under the contemporary TCA. Additionally, being back in the community for relatively longer may have impaired a participant's ability to accurately recall or

share a breadth of their lived experiences, particularly within the context of mild cognitive impairment.

2.4.5 Future research

Due to the juxtaposition found between themes one and three, an in-depth qualitative enquiry, such as IPA methodology, could be employed to interview and interpret the lived experiences of the juxtaposition between how PWID and forensic needs hope to renew their identities but ultimately feel unable to do so during community resettlement. This may encompass the exploration of a very recent impetus to consider 'extended section.17' leave as part of a model for discharging restricted ID forensic patients. Additionally, to overcome this project's shortcoming of not knowing the transitional experiences of other demographic groups, a broader survey approach looking at how transitional experiences are more generally held across different demographic/cultural groups could be employed.

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Chapter Three: Reflective Paper

Reflections on my Research Experience

Overall chapter word count (excluding references, tables and figures): 3,463

3.1 Introduction

This chapter aims to reflect on the process of conducting this research project, from conception to completion. I consider the impacts of this on both my personal development and professional status during the journey towards becoming a Clinical Psychologist. My reflections are informed by supervision conversations and areas of significance within the reflective journal I have kept over the past two and a half years. When appropriate, Johns' (1994) 'Model of Structured Reflection' is used as a frame to explore four key areas: 1) Inspiration for the topic, 2) Navigating challenges, 3) Establishing my role, and 4) Who am I now? In addition, I also draw upon therapeutic models and theories to enhance my reflection and demonstrate how the research process impacted upon me personally.

3.1.1 Reflective practice

According to the British Psychological Society (BPS), Clinical Psychologists should be competent in using reflection during research processes (BPS, 2014) to enhance their personal and professional development (Mann et al., 2009). Reflective practice may facilitate self-awareness to increase an appreciation for the impacts of diversity and socio-cultural factors that influence research (BPS, 2019). Furthermore, the BPS emphasises the need for Clinical Psychologists to position themselves as 'reflective-scientist practitioners', particularly because of their role in supporting both evidence-based practice and practice-based evidence (BPS, 2019).

Reflexivity is an important component of qualitative research, which involves an ongoing process of 'reflection in and on action', whereby a researcher explores their influence on the research process (Berger, 2015). This is therefore an essential part of conducting an Interpretative Phenomenological Analysis (IPA), particularly because of the double hermeneutic process in which the researcher attempts to make sense of the participant's efforts to make sense of their own experiences (Chan et al., 2013). Reflexivity is vital for supporting the researcher to become self-aware enough of their own position/beliefs/values in order to keep the interpretation grounded in the participants' lived experiences (Larkin

& Thompson, 2012). Therefore, throughout the research process I considered how my assumptions and biases influenced my interpretations.

Johns' (1994) 'Model of Structured Reflection' has been employed due to its evidence-base within healthcare training (Cooper & Wieckowski, 2017) and emphasis on social constructionism (Cox, 2005). The model helpfully organises the ways in which my actions were influenced by internal factors, such as intentions, attitudes and emotions, as well as external processes such as time and resources.

Figure 3.1

Johns' (1994) Model of Structured Reflection

1	**Part 1: Description** Outline of the experience.
2	**Part 2: Reflections** 'In' and 'on' action.
3	**Part 3: Influencing Factors** Consideration of internal and external factors that may have influenced my thinking and decision making.
4	**Part 4: Alternative Strategies** Thinking about how I could have managed the experience differently.
5	**Part 5: Learning** Exploring the implications for personal and professional development.

As shown in Figure 3.1 above, there are five core components to reflection. Firstly, within the 'description', I tell the story of my experience of a particular issue. In stage two, 'reflection', I explore the experience by eliciting my cognitive, emotional and behavioural responses from my journal. Then, in the third stage, 'influencing factors', I acknowledge the influence of social context on my decision-making and beliefs, such as historical and cultural factors. In the final fourth and fifth stages, 'alternative strategies' and 'learning', I consider ways I adapted to manage experiences differently, as well as the implications

for my development. Importantly, the model has been used as guide rather than a rigid frame for this reflective piece, and it is complimented by compassion-focused ideas throughout (e.g., Gilbert, 2009).

3.2 Areas of reflection

3.2.1 Inspiration for the topic

My reflective journal emphasised my drive to complete a thesis on the topic of Intellectual Disabilities (ID), and I am curious about where this came from because I recall being immediately drawn to qualitative ID research; it seemed to me there was no other option. However, I was concerned the University would be disinterested, perhaps because I tried pitching something similar during my Masters, which was rejected on the grounds of time, scope and the fact that people with ID (PWID) are all too often described as 'hard to reach' (Webb, 2013). I felt a need to prove the topics value to others, much in the same way that my interest towards understanding the transitional experiences of ID offenders has changed over time too.

Growing up in an area with relatively strong conservative values, I held a more individualistic and competitive view of society, which better fitted a medical mental health model where I tended to locate the source of distress within individuals. Unfortunately, I did not always comprehend the structural/systemic issues that shape people's lives. However, as an adolescent, studying sociology and supporting PWID highlighted issues of social diversity and injustice for me (Webb, 2013), and I began to appreciate the ways in which social exclusion and perceived power/opportunity both contributes to and reinforces peoples' beliefs about themselves.

Thereafter, working in a community ID forensic service was a rewarding and eye-opening role, where I became more familiar with the 'Power Threat Meaning Framework' (Johnstone & Boyle, 2018) in action. Ideas about power, injustice and genuine collaboration resonated with me greatly and made me question how well the needs of forensic ID patients were actually being met,

especially when anecdotally I was hearing about patients who felt excluded and silenced in the community.

Moreover, I was struck by the general lack of ID specific research, particularly the absence of qualitative investigation. I was confused and concerned by this, for it made me question how qualified psychologists were making clinical decisions with a lack of reference to what PWID think is acceptable and effective. I struggled with the belief that PWID seem to be mostly passive recipients of care without many opportunities to participate. I felt a sense of not wanting to stay quiet on the issue, hence I think I arrived on the doctorate already feeling impassioned about my research topic.

Reflecting upon my topic choice more generally, holding in mind the entire research process, I have learnt the value of feeling invested in an area; the thesis has been a long and exhausting process but having a reason to continue has given me the fuel I needed. I suspect my sense of feeling able to somewhat command the subject also relieved some anxieties. Moreover, I believe that my past clinical experience gave me a good grounding in the subject, which appeared to help me connect with participants' lived experiences. I have also learnt the importance of reflective practice in quality supervision; given my earlier experiences and beliefs it might have been easy for me to cast aside others' interpretations and consequentially bias the findings, hence I have greatly appreciated a reflective space within supervision to acknowledge my position and consider my relationship with the data.

3.2.2 Navigating challenges

Following the approval of my topic and commencement of the research, I noticed a wave of trepidation, which I first suspected was because the thesis is my most significant piece of academic research/work; it felt like a mammoth task that was suddenly 'real'. However, I realised there were several areas that felt particularly anxiety-provoking and challenging. For example, I found navigating the unfamiliar NHS ethics process and conducting my first IPA project especially hard.

3.2.2.1 Research ethics

Completing the NHS ethical review process was daunting. I noticed self-critical beliefs about *'not being good enough'* for doctoral research, as well as 'catastrophising' predictions (Westbrook et al., 2011) that *'ethics will definitely be denied'.* These fears became louder over time; completing what felt like an endlessly difficult and technically confusing process of ethics forms and documents impacted my confidence, as did significant NHS ethics delays and worries about not having made enough reasonable adjustments, such as questioning whether telephone interviews for PWID (with legal restrictions around unsupervised internet access) were adequate. I recall a sense of self-doubt while persuading local Research and Development (R&D) Teams to provide 'approval in principal', who seemed perhaps understandably cautious in the context of a global pandemic and significant NHS pressures. At the same time I was concerned that the voices of PWID were being under-prioritised.

The most significant challenge arose following ethical approval, when one Mental Health Trust withdrew due to COVID-19 staffing issues, and another contested approval on a technicality rather than a specific project issue. I felt deflated but also surprisingly energised/motivated to overcome it. I noticed my 'drive' to rectify and resubmit was stronger than ever, and at first I welcomed this until I noticed an overall decline in my physical health. Discussions with my Appraisal Tutor helped me recognise this was my 'early warning sign' for needing to be more boundaried. For instance, I realised that I had normalised working on my ethics resubmission and corresponding with R&D teams while away on a family holiday. Returning to my journal I observed my tendency to be self-critical and then overly-responsible for every part of the research process. Helpfully, I took comfort from supervision discussions highlighting that being willing to rely upon others in multisite NHS projects is a common challenge.

I decided to draw upon Compassion-focused Therapy's 'Emotional Regulation Systems' model (Gilbert, 2009). As shown in Figure 3.2 below, I decided to draw out my 'threat', 'drive' and 'soothing' systems; the size of the circle corresponded to which systems felt more dominant.

Figure 3.2

Mapping my emotional regulation systems (Gilbert, 2009)
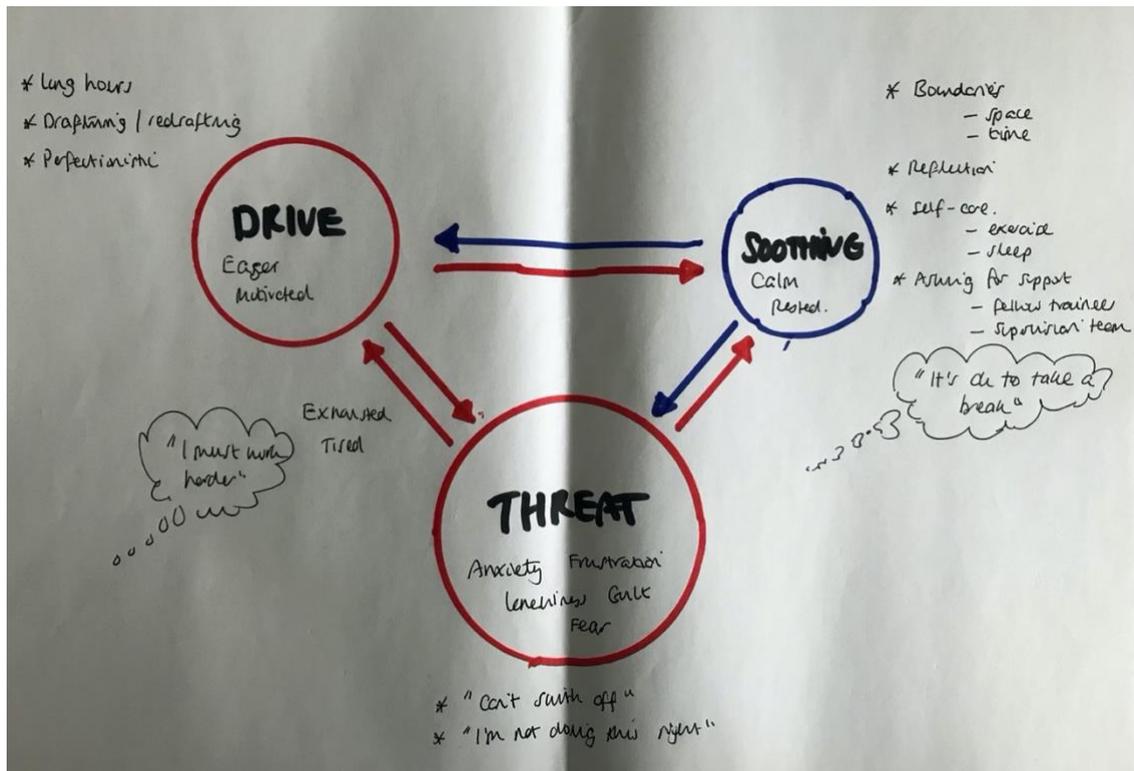
I was struck by my drawing. Instead of operating in 'pure drive' (Gilbert, 2009) and feeling value-driven, I was acting from a position of 'threat-based drive'. Perhaps I was stuck in a cycle of anxiety, over-inflated responsibility for the whole process, and thoughts like *'I must work harder'.* I noticed my sense of 'imposter syndrome' (Jones & Thompson, 2017) and need to prove myself by controlling external factors, including taking responsibility for the Mental Health Trust that withdrew because of service demands, as well as berating myself for not *'keeping up with the same pace of my fellow trainees'* who were not conducting NHS projects. Therefore, I looked to sources of self-soothing/self-care, including spending time with others and balancing time between my personal and professional life. Moreover, I drew upon Dialectical Behaviour Therapy's concepts/skills of 'willingness' and 'radical acceptance' (Linehan & Wilks, 2015), which was not easy, but I noticed myself becoming comfortable with *'letting go of the project's reigns'* and being more self-compassionate: *'Everyone goes at their own speed, it's fine. I have time'.* This helped me to celebrate little achievements in the moment.

I take away a lot professionally from this experience too. I learnt that while preparing a comprehensive ethics application is important, making good use a supervision team for support and encouragement is vital. Moreover, I appreciate the significance of building a rapport with local R&D teams and clinical collaborators; while writing this it seems trivial, but getting to know these contacts and developing a working relationship seemed to build their trust and enthusiasm for the research project, and arguably helped reach ethical approval and study registration. Perhaps these relationships tapped into my affiliative-soothing system (Gilbert, 2009).

3.2.2.2 IPA analysis: A new learning experience

Conducting IPA for the first time was a continuous learning process. Although I did question *'am I doing this right?',* I noticed that my self-doubt was met with greater self-compassion now. Nevertheless, trying to privilege individual participants' experiences, whilst doing justice to the collective experience too, was anxiety-provoking. Throughout the coding process I was determined to accurately capture the participants' voices, as I did not want to let them down, although this seemed harder whilst developing the final superordinate themes. I felt uncomfortable at the thought of my biases potentially *'shouting over'* others' experiences. At the same time, I felt pulled to include every emergent theme so *'no one was left behind'.* It became an ethical dilemma I felt incompetent to solve. Consequently, I frequently referred to Smith et al.'s (2021) IPA guidelines, which temporarily eased anxieties but increased a sense that my rigidity overshadowed any meaningful interpretative activity.

Supervision conversations about openly acknowledging my own self-beliefs as a researcher helped me understand that perhaps my concerns were influenced by my limited qualitative research experience. I wondered if I was approaching IPA too inflexibly, treating it like an objective quantitative analysis in which there are 'exact' numbers to compute and report. I was then reminded of Fisher's (2010) Model of Learning (see Figure 3.3 below), which I used when feeling incapable/'out of my depth' at the start of training.

Figure 3.3

Fisher's (2010) Model of Learning

| Unconscious Incompetence | Conscious Incompetence | Conscious Competence | Unconscious Competence |

Re-applying this model to my IPA experience was validating, because it proposes that learning involves becoming consciously aware of research skills I was still developing. I realised that I had approached IPA as if there was a definite 'answer' to my research question. This increased self-awareness helped me hold a more accepting position towards any 'conscious incompetence'. For example, my reflective journal read, *'being a psychologist is about embracing that I do not know what I do not know... yet'.* This re-enthused my creative approach to IPA, and re-analysing the first transcript felt more authentic and deeper, as if I was unburdened and more connected. This felt even stronger while discussing the themes with the participants and hearing how they felt validated. I learnt that qualitative analysis is not an exact science, which is fine when the findings resonate with the participants' experiences.

3.2.3 Establishing my role: Managing an internal conflict

While moving through the research process I considered my roles as a researcher and clinician. In particular, I reflected on what it meant to be a researcher who identifies as a practitioner. This was not something I had given a good deal of thought to before, but it became especially dominant during the interview stage where my clinical skills felt stronger than my academic competencies. Applying core therapeutic skills, such as empathy and curiosity, felt like assets which helped me to quickly develop a good rapport with each participant; I was determined to make the remote interviews feel safe and containing. I felt privileged by participants' openness to me trying to make sense of their lived experiences, and I wondered whether I enjoyed making interpretations because I was drawing upon my clinical formulation skills, which perhaps assisted me in making abstract links between ideas.

However, an area that felt unexpectedly uncomfortable was the issue of power. Thinking within the context of the 'Power Threat Meaning Framework' (Johnstone & Boyle, 2018) I had expected issues of control to arise, but not in the way it did. Within my clinical roles supporting PWID I have often worked hard to address the inherent power I have, however the power dynamic seemed different in the researcher's role. There was a sense that the hierarchy and relationship between me and the participants had been flattened and become more equal. In one way it felt refreshing to just be with a person without the added pressures of managing therapeutic agendas and strict time constraints. Conversely, I felt uncontained during the semi-structured interviews, which I think reflected having less control.

The issue of power and role became more pronounced when noticing a *"desire to rescue"* upset participants. I felt pulled to do adopt a clinical role and sit with the uncomfortable feelings, but this felt invalidating in a research context. Then, I seemed drawn towards offering advice, but again this contradicted my idea of being a researcher and it closed down some interview conversations. These interactions reminded me of Karpman's (1968) 'Drama Triangle' model.

Figure 3.4

Mapping out my interactions within Karpman's (1968) 'Drama Triangle'
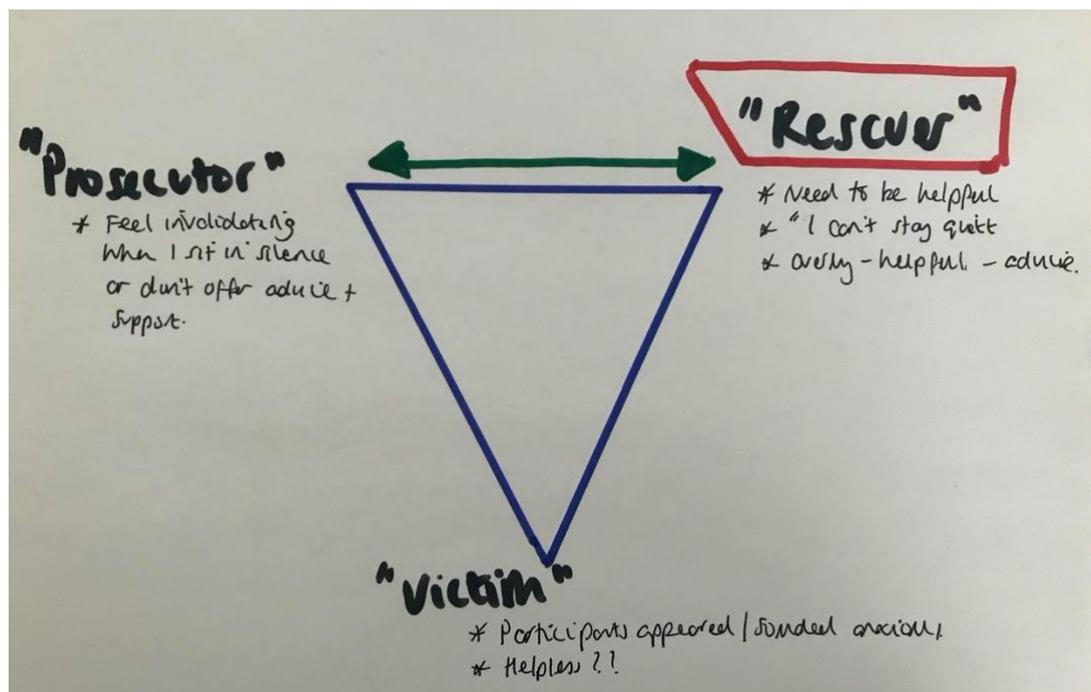
As shown in Figure 3.4 above, I reflected on sometimes feeling in 'the persecutor' position (e.g., sitting in silence and feeling invalidating), but predominantly I took the 'rescuer role' in my interactions. At first this felt ethically challenging until I realised that it was not the participants' feelings I felt conflicted with, but instead my own discomfort with holding greater uncertainty in a researcher capacity. Supervision reminded me of Mason's (2015) concept of 'safe-uncertainty', and I recognised that striving for 'safe-certainty' was blocking my engagement with participants. Moreover, drawing upon my clinical skills, I recognised how my emotional responses could be understood from a psychodynamic transference and countertransference perspective (Lemma, 2016); this helped me to be more curious towards participants' emotional experiences, which facilitated more relaxed and genuine dialogue.

I have learnt that being a researcher and a clinician can be an asset. For instance, I feel my clinical skills enhanced my reflective capacity and in-the-moment self-awareness, and made it a little easier to manage my own emotional and self-care needs in ways that did not negatively impact upon the interview process or the participants.

3.2.4 Who am I now?

This research thesis has had both personal and professional implications and, while there is no fine line that differentiates the two for me, I have discussed my most significant takeaways below.

The experience of conducting research alongside PWID has reminded me of why I will be working in community ID services after qualifying. The project has strengthened my passion and professional commitment to supporting this group. In particular, the process has highlighted to me just how marginalised and seemingly forgotten the ID forensic population is, which is why I feel so privileged to have been trusted with their narratives. The lack of bespoke clinical policy has also struck me, so going forward I will do my best to advocate for their needs when working in non-forensic ID services too, and I will seek out opportunities to get involved with meaningful co-production and maybe even some Participatory Action Research.

Moreover, some participants' arguably traumatic transitional experiences have really stayed with me. Although I already work individually with trauma on clinical placements, this process has inspired me to adopt a firmer trauma-informed care approach, especially as many of the issues raised in the interviews related to systemic failings. Therefore, I have already volunteered to support the development of a trauma-pathway on my community forensic ID placement.

Furthermore, I now feel significantly more confident in designing research, navigating ethics processes, and completing and disseminating qualitative analyses. In particular, I have come to better understand and appreciate the usefulness of qualitative methodologies, which for a long time I was inclined to view as less useful than statistical research. Unlike past university dissertation experiences, conducting this project as a more autonomous Trainee Clinical Psychologist has increased my capacity to make decisions and to consult other professionals for guidance only when appropriate/needed. Therefore, feeling more skilful as a scientist-practitioner has helped me to prepare for post-training life as a Clinical Psychologist (e.g., BPS, 2014).

In many ways I feel I have developed the most on a personal level. For the past decade I have often felt the need to prioritise academic work, mostly because I wanted to prove myself capable of getting onto clinical training. This has often meant taking full responsibility for projects and not asking for help because I feared it reflected badly on me. Therefore, perhaps during the early stages of this research process I was less likely to ask for help/support; I saw it as a failure, maybe because of some childhood experiences where an individualistic/competitive culture was impressed upon me (e.g., Dallos & Draper, 2015). However, reflecting on this research process has reminded me that I need to also prioritise self-care and respond to my own needs more compassionately. I have felt the consequences of investing everything into work but have also grown into someone who is better at managing personal-professional boundaries. In particular I feel more confident about asking my

supervision team for guidance and more comfortable with stepping back from work without feeling guilty.

Moreover, this research experience has reinforced in me the view that so much of what we understand about psychological experiences is woven into the fabric of social/interpersonal processes. It has really struck me that a running theme throughout my entire thesis is the significant and psychologically costly impacts of social-political/'macro level' issues. Some of this is in keeping with my earlier views, but in other ways this has challenged my concept of psychological support. For example, I have tentatively started asking myself whether Clinical Psychology, which can offer non-diagnostic 'micro level' support to individuals, may in the grand scheme of things unintentionally individualise distress. I have been wary of this when producing the clinical implications of my research findings, and wherever possible I have endeavoured to provide a balance of individual and systemic recommendations. In all honesty I am still grappling with this notion, but I aim to keep reflecting upon it and have already considered writing it into my next supervision contract as a point for discussion.

3.3 Conclusion

Conducting my own research and reflecting on the process has been invaluable. Throughout the research process I identified self-critical thoughts and problem-saturated stories around my abilities to undertake such a task. However, through a process of continuous learning I now recognise and appreciate the research competencies that I do hold, as well as the skills I have acquired during the doctorate, including those clinical skills that nicely complemented and/or strengthened my capacity to be a reflective-scientist practitioner. Finally, the experience has reminded me of the importance of conducting research, and I will endeavour to take this forward in my career as a qualified Clinical Psychologist.

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Appendices

Appendix A: Author Manuscript Guidelines for The British Journal of Learning Disabilities

This Journal is a member of the Committee on Publication Ethics

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript please ensure you have read the Aims & Scope.

1.2 Article Types

Your manuscript should ideally be between 6000 and 8000 words long, and double spaced.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Each paper submitted, if considered suitable by the Editor, will be refereed by at least two anonymous referees, and the Editor may recommend revision and re-submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Journal of Intellectual Disabilities requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of *Journal of Intellectual Disabilities* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'.

For guidance on conflict of interest statements, please see the ICMJE recommendations

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical

Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

2.7 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

Journal of Intellectual Disabilities requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. The editor can also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Journal of Intellectual Disabilities and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we

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If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

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3.3 Open access and author archiving

Journal of Intellectual Disabilities offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

4. Preparing your manuscript for submission

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guideline page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For

specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Reference style and language conventions

Journal of Intellectual Disabilities does not accept the abbreviations such as ID for "intellectual disability" or NDD for 'neurodevelopmental disability'. This needs to be written in full throughout the manuscript and not abbreviated.

Journal of Intellectual Disabilities adheres to the SAGE Harvard reference style. View the SAGE Harvard guidelines to ensure your manuscript conforms to this reference style.

If you use EndNote to manage references, you can download the SAGE Harvard EndNote output file.

4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Journal of Intellectual Disabilities is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/jnlid to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

The collection of ORCID IDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID ID you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID ID will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID ID is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID ID please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the *Journal of Intellectual Disabilities* editorial office as follows: ████████████████████

Appendix B: Coventry University Ethical Approval Certificate for Conducting a Systematic Review

Certificate of Ethical Approval

Applicant: Shaw Tearle

Project Title: Experiences of Community-based Social Marginalisation in
                                    Adults with Intellectual Disabilities (ID): A Systematic Review
                                    of the Qualitative Literature.

This is to certify that the above named applicant has completed the Coventry University Ethical
Approval process and their project has been confirmed and approved as Low Risk

Date of approval: 10 Jan 2022

Project Reference Number: P131053

Appendix C: Inclusion and Exclusion Criteria: Study Characteristics Table Completed by the Lead Researcher

Reference	Publication Type			Study Characteristics					
				Sample		Phenomenon of Interest	Design	Research Type	Evaluation
	2010-2021	Country	English	Aged 18+	Intellectual Disability	Community-based social marginalisation	E.g., IPA, GT, TA, focus groups, un/semi/structured interviews	Qualitative and/or mixed methods	Experiences/perceptions/beliefs about marginalisation within domains of community-based living
Merrells et al., 2019	√	Australia	√	√ Ab+M	√ Ab+M	√ Ab+M	√ Ab+M	√ M	√ Ab+M+R+D
Van Asselt et al., 2015	√	Australia	√	√ M	√ M	√ Ab+M+R+D	√ Ab+M	√ Ab+M	√ Ab+M+R+D
Bond et al., 2010	√	United Kingdom	√	√ M	√ Ab+M	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ Ab+R+D
Witso et al., 2020	√	Norway	√	√ M	√ Ab+M	√ Ab+M+R+D	√ Ab+M+D	√ Ab+M+D	√ Ab+M+R+D
Lysaght et al., 2017	√	Canada	√	√ M	√ Ab+M	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ Ab+Int+R+D
Hall, 2017	√	United States	√	√ M	√ Ab+M	√ Ab+R+D	√ Ab+M	√ M+D	√ Ab+M+R+D
Carnemolla et al., 2021	√	Australia	√	√ M	√ Ab+M	√Ab+Int+M+R+D	√ Ab+M	√ Ab+M	√ Ab+R+D
Ashley et al., 2019	√	Australia	√	√ M	√ Ab+M	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ M+R+D
Hamilton et al., 2017	√	United Kingdom	√	√ M	√ Ab+M	√ Int+R+D	√ Ab+M	√ Ab+M	√ R+D
Sullivan et al., 2016	√	United Kingdom	√	√ M	√ Ab+M	√ Ab+R	√ Ab+M+	√ Ab+M	√ Ab+R+D
Strnadova et al., 2018	√	Australia	√	√ M	√ Ab+Int	√ Ab+R+R	√ Ab+M	√ Ab+M+D	√ R+D
Voermans et al., 2021	√	Netherlands	√	√ M	√ Ab+Int	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ R+D

*Ab (Abstract); Int (Introduction); M (Method); R (Results); D (Discussion)

Appendix D: Inclusion and Exclusion Criteria: Study Characteristics Table Completed by an Independent Rater

Reference	Publication Type			Study Characteristics					
				Sample		Phenomenon of Interest	Design	Research Type	Evaluation
	2010-2021	Country	English	Aged 18+	Intellectual Disability	Community-based social marginalisation	E.g., IPA, GT, TA, focus groups, un/semi/structured interviews, written feedback	Qualitative and/or mixed methods	Experiences/perceptions/belief about everyday marginalisation within the domains of community-based living
Merrells et al., 2019	√	Australia	√	√ M	√ Ab+M+R	√ Ab+M	√ Ab+M	√ M+R	√ Ab+M+R+D
Van Asselt et al., 2015	√	Australia	√	√ M	√ M	√ Ab+M+R+D	√ Ab+M	√ Ab+M	√ Ab+M+R+D
Bond et al., 2010	√	United Kingdom	√	√ M	√ Ab+M	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ Ab+R+D
Witso et al., 2020	√	Norway	√	√ M	√ Ab+M	√ Ab+M+R+D	√ Ab+M+D	√ Ab+M+D	√ Ab+M+R+D
Lysaght et al., 2017	√	Canada	√	√ M	√ Ab+M	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ Ab+Int+R+D
Hall, 2017	√	United States	√	√ M	√ Ab+M	√ Ab+R+D	√ Ab+M	√ M+D	√ Ab+M+R+D
Carnemolla et al., 2021	√	Australia	√	√ M	√ Ab+M	√Ab+Int+M+R	√ Ab+M	√ Ab+M	√ Ab+R+D
Ashley et al., 2019	√	Australia	√	√ M	√ Ab+M	√ Ab+Int+R+D	√ Ab+M	√ Ab+M	√ M+R+D
Hamilton et al., 2017	√	United Kingdom/ England	√	√ M	√ Ab+M	√ Int+R+D	√ Ab+M	√ Ab+M	√ M+R+D
Sullivan et al., 2016	√	United Kingdom/ Scotland	√	√ M	√ Ab+M	√ Int+Ab+R	√ Ab+M+	√ Ab+M	√ Ab+R+D
Strnadova et al., 2018	√	Australia	√	√ M	√ Ab+Int	√ Ab+R+R	√ Ab+M	√ Ab+M+D	√ R+D
Voermans et al., 2021	√	The Netherlands	√	√ M	√ Ab+Int	√ Ab+R+D	√ Ab+M	√ Ab+M	√ Int+R+D

*Ab (Abstract); Int (Introduction); M (Method); R (Results); D (Discussion)

Appendix E: OVID Systematic Search Strategies (PsycINFO and MEDLINE)

APA PsycInfo <1806 to January Week 3 2022>

1   learning disabilit*.mp. or Learning Disabilities/   27621

2   intellectual disabilit*.mp.   30422

3   1 or 2 56533

4   exp Stigma/ or exp Marginalization/ or exp Discrimination/ or social marginalisation.mp. 69306

5   social exclusion/ or social acceptance/ or social disadvantage/ or social inclusion/   16640

6   "Quality of Life"/   44103

7   (belonging or connection or communit*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word] 65373

8   4 or 5 or 6 or 7   191575

9   3 and 8   2152

10   famil*.mp. or exp Family/   532718

11   exp Social Network*/ or friend.mp.   34268

12   work.mp.   545381

13   exp Friendship/   10286

14   exp Occupations/   62465

15   exp Leisure Time/ or exp Recreation/ or leisure.mp.   83497

16   exp Interpersonal Relationships/ or relationships.mp. 516402

17   10 or 11 or 12 or 13 or 14 or 15 or 16   1366517

18   9 and 17   858

19   limit 18 to (english language and yr="2010 - 2021")   509

20   (experienc* or perception* or belief* or view*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]   1534065

21   19 and 20   227

22   limit 21 to 1600 qualitative study   145

Ovid MEDLINE(R) ALL <1946 to January 20, 2022>

1   intellectual disability.mp. or Intellectual Disability/   67254

2   learning disability.mp. or Learning Disabilities/   16354

3   1 or 2 82059

4   Social Marginalization/ or social marginalisation.mp.   603

5   social exclusion.mp./   17137

6   quality of life.mp.   382154

7   (belonging or connection or communit*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]   193516

8   4 or 5 or 6 or 7   590103

9   3 and 8   2222

10   famil*.mp. or Family/   1391491

11   friend.mp. or exp Friends/ 21199

12   social network.mp. or Social Networking/   14426

13   exp Work/ or work.mp.   1209729

14   occupation.mp. or exp Occupations/   66069

15   leisure.mp. or exp Leisure Activities/   269649

16   relationships.mp.   418623

17   10 or 11 or 12 or 13 or 14 or 15 or 16   3161212

18   9 and 17   850

19   limit 18 to (english language and yr="2010 - 2021")   529

20   (experienc* or perception* or belief* or view*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]   2163399

21   19 and 20   174

22   limit 21 to "qualitative (maximizes specificity)"   52

Appendix F: Critical Skills Appraisal Programme (CASP) Qualitative Studies Scoring (2018)

Reference	Article	
Quality criteria for all studies	Rater 1	Rater 2
1) Was there a clear statement of the aims of the research?		
2) Is a qualitative methodology appropriate?		
3) Was the research design appropriate to address the aims of the research?		
4) Was the recruitment strategy appropriate to the aims of the research?		
5) Was the data collected in a way that addressed the research issue?		
6) Has the relationship between researcher and participants been adequately considered?		
7) Have ethical issues been taken into consideration?		
8) Was the data analysis sufficiently rigorous?		
9) Is there a clear statement of findings?		
10) How valuable is the research?		
Total	**XX**	**XX**

Scoring key:

2 = 'yes, fully met/present', 1 = 'partially met', 0 = No, 'not met/cannot comment'

Appendix G: Critical Skills Appraisal Programme (CASP) qualitative studies scoring (studies 1-5)

Reference	Merrells et al., 2019		Van Asselt et al., 2015		Bond et al., 2010		Witso et al., 2020		Lysaght et al., 2017	
Quality criteria for all studies	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2
1. Was there a clear statement of the aims of the research?	2	2	2	2	2	2	2	2	2	2
2. Is a qualitative methodology appropriate?	2	2	2	2	2	2	2	2	2	2
3. Was the research design appropriate to address the aims of the research?	2	2	2	2	2	2	2	2	2	2
4. Was the recruitment strategy appropriate to the aims of the research?	2	2	2	2	2	2	2	2	2	2
5. Was the data collected in a way that addressed the research issue?	2	2	2	2	2	2	2	2	2	2
6. Has the relationship between researcher and participants been adequately considered?	2	2	1	1	0	0	0	0	0	0
7. Have ethical issues been taken into consideration?	1	1	1	1	1	1	1	1	1	1
8. Was the data analysis sufficiently rigorous?	2	2	2	2	2	2	2	2	2	2
9. Is there a clear statement of findings?	2	2	2	2	2	2	2	2	2	2
10. How valuable is the research?	2	2	2	2	2	2	2	2	2	2
Total	**19**	**19**	**18**	**18**	**17**	**17**	**17**	**17**	**17**	**17**

Critical Skills Appraisal Programme (CASP) qualitative studies scoring (studies 6-12)

Reference	Hall, 2017		Carnemolla et al., 2021		Ashley et al., 2019		Hamilton et al., 2017		Sullivan et al., 2016		Strnadova et al., 2018		Voermans et al., 2021	
Quality criteria for all studies	Rater 1	Rater 2	Rater 1	Rater 2	Rate 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2	Rater 1	Rater 2
1) Was there a clear statement of the aims of the research?	2	2	2	2	2	2	2	2	2	2	2	2	1	1
2) Is a qualitative methodology appropriate?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3) Was the research design appropriate to address the aims of the research?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
4) Was the recruitment strategy appropriate to the aims of the research?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
5) Was the data collected in a way that addressed the research issue?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
6) Has the relationship between researcher and participants been adequately considered?	0	0	0	0	0	1	0	0	2	1	0	0	1	1
7) Have ethical issues been taken into consideration?	2	2	0	0	1	1	1	1	1	1	1	1	2	1
8) Was the data analysis sufficiently rigorous?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
9) Is there a clear statement of findings?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
10) How valuable is the research?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Total	**18**	**18**	**16**	**16**	**17**	**18**	**17**	**17**	**19**	**18**	**17**	**17**	**18**	**17**

Appendix H: Peer Reviewed Study Characteristics Table Completed by an Independent Rater

Author(s), (date) / country of origin	Aims and areas covered	Sample characteristics (*N,* gender, age, ethnicity, diagnosis)	Design and sampling method	Data collection and data analysis	Summary of outcomes specific to the phenomenon of interest	Quality assessment score (KAPPA)
Merrells et al., (2019) / Australia	The study aimed to understand the perspectives of PWID in relation to how they experience and perceive inclusion.	*N* = 6; 18-24 (*M* = 20.5); 4 males, 6 females; Intellectual Disabilities	Qualitative design; purposive sampling	Interpretative phenomenological approach; individual in-person interviews	2 main themes emerged: 1) *segregated, excluded and treated like an outcast in the community*: Participants described feeling left out of social groups and being treated differently in terms of employment opportunities. 2) *challenges in experiencing, imitating and maintaining peer friendships:* Participants discussed experiences of a narrowing peer/friendship and having increasingly less opportunity for face to face contact.	38 / *K* =1.00)
Van Asselt et al., (2015) / Australia	The study aimed to explore young adults, with ID, experiences of social inclusion within community spaces/locations.	*N* = 4; 23-27; 2 males, 2 females; Intellectual Disability	Qualitative design; ppurposive sampling	Thematic analysis; individual in-person interviews	5 main themes emerged: 1) *naturally occurring relationships:* Participants experienced friendships as a means for enhancing their social connections. 2) *participant engagement and interactions:* Interactions with social events vary in terms of perceived levels of real involvement. 3) *organisational process factors:* Organisational factors enhance and impede experiences of social inclusion. 4) *family:* Participant's families impacted their lived experiences, including perceived independence and level of social support. 5) *community involvement and social acceptance:* Participants experiences of community participation had implications for levels of perceived acceptance and social exclusion within their communities.	36 / *K* =1.00

Appendix I: Thematic Synthesis (Stages of Analysis)

Extract from an example coded article (stage one)

found that people are able to learn to keep themselves safer when given the right support to do so (Long & Holmes 2001).

Eight out of the nine participants interviewed talked of being subjected to abuse of some kind. Some of this was past recollections and some more recent. Bruce spoke of trusting someone who said they would be his friend and then stole from him. Celia was subjected to physical abuse and theft from her son. Robbie spoke about being sexually abused as a child and of being recently cheated financially and verbally assaulted. Kirsty was aware of how vulnerable she was when going out drinking alone and felt she was often taken advantage of sexually:

'I've grown up with bad experiences...when I was younger and all the way up, even now. With people taking advantage of me, abused and raped.' (Kirsty).

Studies such as those by Whittell & Ramcharan (2000) and Taggart et al. (2006) are pertinent to those living independently in the community. The findings of the present study support these as participants described their vulnerability and of how they had been taken advantage of and abused.

There is also a strong link between vulnerability, abuse and lack of choice and control as studies by White et al. (2003) and Calderbank (2000) have demonstrated. Calderbank (2000) suggested that community living and empowerment policies actually contribute to increasing the potential for abuse of already vulnerable people.

Health issues

This study was not designed to examine the health of the participants and there were no questions specifically asking about health in the interview schedule. However, in the course of discussing issues around support needs and coping, information regarding health was volunteered by the majority of participants. This highlights how closely linked issues around health were to living independently for the people interviewed.

A variety of health problems including asthma, diabetes, epilepsy and arthritis were experienced by participants. The main impacts of these conditions on living independently appeared to be around remembering and understanding the prescribed medication. No studies were identified directly relating to issues surrounding concordance with medication for people with learning disabilities living independently. However, given that cognitive skills such as memory and ability to tell the time are problems for many people with learning disabilities, the ability to take medication correctly has the potential to be a problem.

Several of the participants interviewed spoke of being reminded by support workers to take medication, although none of them were employing practical aids such as blister packs or alarms to remind them when to take a dose. The ability to take medication and keep healthy was directly linked by several participants to being able to remain living independently:

'If I don't take my tablets and look after myself, people will be doing stuff like putting me in a home...and it will be their decision instead of mine.' (Kirsty)

This links directly to the perceived lack of choice and control discussed by most participants. Some of them were worried about their independence 'being taken from them' if professionals thought they were not managing their health needs sufficiently. This could account for the lack of practical support being offered to participants in this study around taking medication. Similarly, a review of integrated care approaches for people with learning disabilities (Jansen et al. 2006) found there was a lack of published studies looking at the potential benefits to adopting a more integrated approach to treating the physical health needs of people with learning disabilities.

In this study, eight out of the nine participants were accessing mental health services. Again, although participants were not specifically asked about their mental health, several people volunteered information about their mental health support, in all cases this was because of a past abuse or a traumatic event. It is well documented that people with learning disabilities are more likely than the general population to have mental health problems (Priest & Gibbs 2004).

The impact of having a learning disability

Several of the participants spoke about what having a learning disability meant to them in terms of living independently in the community. Jake felt that the only difficulty having a learning disability caused him was with literacy. Kirsty related that aside from needing assistance with practical things like cooking and money management, her learning disability led her to being very trusting of others, which left her vulnerable. Robbie talked the most about the negative stigma of having a learning disability and how that had caused him to have major problems with harassment from his local community and lack of support and understanding from statutory services such as the local council and police:

'Round here they don't understand. I had one up the road...swore at me, told me to 'go back to [mental health hospital], go back to your cage'...It's really awful; I go up the street, someone's taking the mick out of me. Awful.' (Robbie).

The majority of participants socialised predominantly with other people with learning disabilities, and did not actively engage in local community activities. Social isolation such as this can lead to problems with self

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Handwritten margin notes:

Left margin:
- learnt self-segregation
- Direct Abuse
- Trust + Abuse
- Sexual Abuse
- Others take advantage
- Perceived vulnerability
- Choice?
- Capability to be independent.

Right margin:
- need to prove self able?
- Perceived choice + control
- Risk losing independence + autonomy
- Abuse, distress + trauma
- LH needs
- Dependence because of LD
- stigmatising views / Feeling they are vulnerable
- harassment (victimised)
- lack of support to be helped
- Abuse, sense of being unwanted
- Social isolation

Development of descriptive themes (stage two)

* Descriptive Themes: code organisation

Perceived Social Isolation
→ low self-esteem.
→ loneliness — page 288
→ limited social network. — page 289.
→ lack of social (ID-specific) supports.

Feeling socially threatened
→ Feeling victimised — pg 287
→ Past + present abuse — page 289
→ Harrasment — pg 289
→ stress, MH. needs + traumatic responses.
→ Perceived social vulnerability because of ID. label / identity. — pg 289

Powerlessness
→ limited confidence to engage with local community. — pg 291
→ limited choice. / Feeling controlled.
→ Feeling taken advantage. — e.g. page 290 / 291

Perceptions of others
→ Fear of losing Independence
→ ID stigma + prejudice
→ Prejudice / over-generaliced belief re. capabilities
→ Negative self-image. — page 291

Health + Independence

Development of initial analytical themes and subthemes(stage three)

Main Theme	Theme One: Psycho-social barriers to social inclusion			Theme Two: Psycho-social consequences of being a socially excluded group		
Subthemes	Social and self-stigmatisation	Vulnerable to victimisation	Social distancing	Lack of belonging	Feeling like a burden for being different	Hopelessness and helplessness
Key Issues	Over protective/controlling caregivers who fail to see the person with ID can have voice (Strnadova; Hamilton). Employers/ colleagues prejudice beliefs about ID capabilities (Carnemolla; Hall; Hamilton; Merrells; Strnadova; Ashley; Voermans). ID stigma about having something wrong/different about them (Bond; Strnadova; Voermans). Own beliefs about ID (Voermans).	Lack of welcoming shared public spaces (Carnemolla). Victimised by local community; verbal, physical, financial and sexual abuse (Bond; Hall). Feeling taken advantage of (Bond; Hall).	Lack of choice and support to participate in leisure activities (Ashley; Strnadova; Bond; Hamilton; Strnadova). Limited social outings and access to relevant age group limits peer friendships (Ashley; Van Asselt; Voermans; Bond; Merrells). Limited occupational roles, including paid roles (Hamilton; Hall; Lysaght; Merrells). Limited access to educational/learning experiences (Hamilton). Inaccessible information/signage (Carnemolla; Witso; Hall; Lysaght).	Feeling socially fearful/vulnerable (Bond; Carnemolla; Hall; Hamilton; Strnadova). Loneliness and isolation (Ashley; Bond; Hamilton; Strnadova). Feeling like an outcast (Merrells). Social networks shrink and/or become limited to PWID (Hall; Hamilton; Van Asselt).	Feeling unwanted (Hamilton; Carnemolla; Merrells; Sullivan). Low self-esteem/negative self-image (Bond). Difficulties maintaining a job/feeling insecure at work (Hall; Voermans).	Distressed/suicidal/low mood (Bond; Merrells; Ashley). Feeling purposeless and unable to meaningfully progress in occupational pursuits (Strnadova; Ashley). Perceived powerlessness/lack of daily choice (Bond; Carnemolla; Strnadova; Voermans). Greater dependence upon family and paid support (Merrells; Van Asselt).

			Lack of accessible communication platforms and opportunities to express themselves (Merrells; Ashley; Voermans).			
Narrative that connects the subthemes	Prejudice beliefs about PWID, including self-stigma, can lead to others dehumanising this group, which leads to victimisation and a situation in which PWID are forced to 'live' separately from their communities. These make it harder to achieve genuine social inclusion and acceptance.			A limited sense of social belonging can lead PWID to feel like they are a burden to others/society, which can be internalised as hopelessness and helplessness about their futures and the possibility of having any agency to change this.		
Descriptions of the meaning behind each subtheme	This subtheme describes society's, including employers and families, prejudice beliefs about what ID means for people. This may lead to experiences of stigmatisation. Consequently, having an ID becomes a very dominant part of the person's self and social identity.	This theme encapsulates how PWID are understood as being less than others, and are in a sense dehumanised, which may legitimatise particularly negative experiences, such as harassment and victimisation in their local community.	This subtheme explores how the two previous factors (subthemes) facilitate a sense of being 'othered', which forces PWID to occupy a difference social and geographical space across social and occupational community domains of living.	This theme summarises how PWID experience a sense of social disconnection from others within their local community. This is experienced internally as loneliness and isolation, as well as feeling fearful for their own safety.	This theme describes how PWID may experience being unwanted and different from the 'norm'. It speaks to a perception that they feel different from the rest of society and therefore begin to experience themselves as burdensome, worthless and insecure.	This theme speaks to PWIDs perceptions that they do not have the ability to change things and they cannot see a positive future. This presents itself as experiencing a lack of choice/freedoms, becomingly increasingly dependent upon others to manage well, and in some cases a helplessness and hopelessness that manifests as suicidal ideation.

Development of final analytical main themes and descriptive subthemes (stage three)
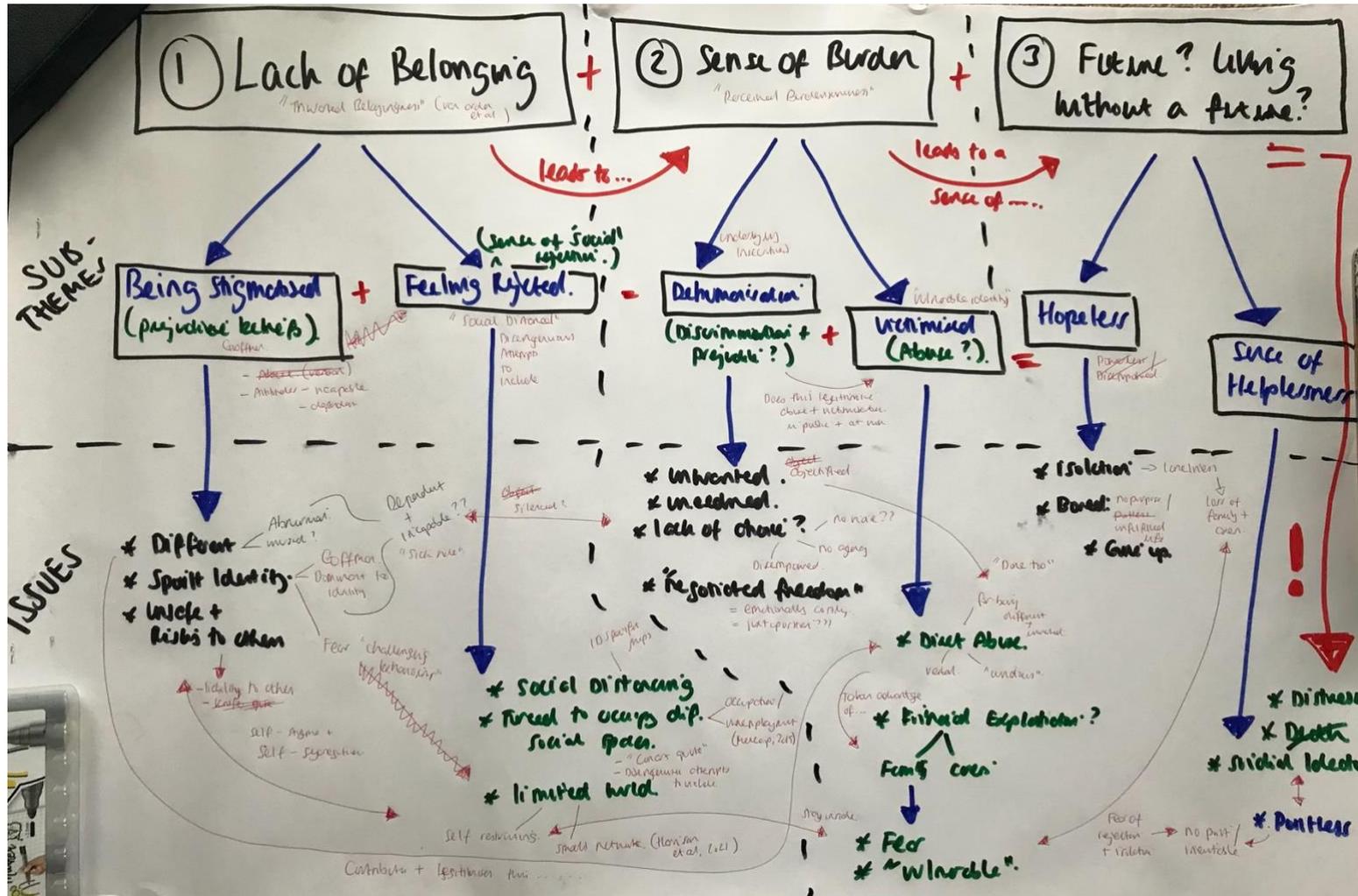
Appendix J: Author Manuscript Guidelines for The Journal of Intellectual Disabilities and Offending Behaviour

Our goal is to provide you with a professional and courteous experience at each stage of the review and publication process. There are also some responsibilities that sit with you as the author. Our expectation is that you will:

- Respond swiftly to any queries during the publication process.
- Be accountable for all aspects of your work. This includes investigating and resolving any questions about accuracy or research integrity
- Treat communications between you and the journal editor as confidential until an editorial decision has been made.
- Read about our research ethics for authorship. These state that you must:
  - Include anyone who has made a substantial and meaningful contribution to the submission (anyone else involved in the paper should be listed in the acknowledgements).
  - Exclude anyone who hasn't contributed to the paper, or who has chosen not to be associated with the research.
- If your article involves human participants, you must ensure you have considered whether or not you require ethical approval for your research, and include this information as part of your submission. Find out more about informed consent.

Research and publishing ethics

Our editors and employees work hard to ensure the content we publish is ethically sound. To help us achieve that goal, we closely follow the advice laid out in the guidelines and flowcharts on the COPE (Committee on Publication Ethics) website.
We have also developed our research and publishing ethics guidelines. If you haven't already read these, we urge you to do so – they will help you avoid the most common publishing ethics issues.

A few key points:

- Any manuscript you submit to this journal should be original. That means it should not have been published before in its current, or similar, form. Exceptions to this rule are outlined in our pre-print and conference paper policies. If any substantial element of your paper has been previously published, you need to declare this to the journal editor upon submission. Please note, the journal editor may use Crossref Similarity Check to check on the originality of submissions received. This service compares submissions against a database of 49 million works from 800 scholarly publishers.
- Your work should not have been submitted elsewhere and should not be under consideration by any other publication.

- If you have a conflict of interest, you must declare it upon submission; this allows the editor to decide how they would like to proceed. Read about conflict of interest in our research and publishing ethics guidelines.

- By submitting your work to Emerald, you are guaranteeing that the work is not in infringement of any existing copyright.

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Prior to article submission, you need to ensure you've applied for, and received, written permission to use any material in your manuscript that has been created by a third party. Please note, we are unable to publish any article that still has permissions pending. The rights we require are:

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- Print and electronic rights.

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All our journals currently offer two open access (OA) publishing paths; gold open access and green open access.

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If you've chosen to publish gold open access, this is the point you will be asked to pay the APC (article processing charge). This varies per journal and can be found on our APC price list or on the editorial system at the point of submission. Your article will be published with a Creative Commons CC BY 4.0 user licence, which outlines how readers can reuse your work.

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For UK journal article authors - if you wish to submit your work accepted by us to REF 2021, you must make a 'closed deposit' of your accepted manuscript to your respective institutional repository upon acceptance of your article. Articles accepted for publication after 1st April 2018 should be deposited as soon as possible, but no later than three months after the acceptance date. For further information and guidance, please refer to the REF 2021 website.

You can find out more about our open access routes, our APCs and waivers and read our FAQs on our open research page.

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Transparency and Openness Promotion (TOP) Guidelines

We are a signatory of the Transparency and Openness Promotion (TOP) Guidelines, a framework that supports the reproducibility of research through the adoption of transparent research practices. That means we encourage you to:

- Cite and fully reference all data, program code, and other methods in your article.

- Include persistent identifiers, such as a Digital Object Identifier (DOI), in references for datasets and program codes. Persistent identifiers ensure future access to unique published digital objects, such as a piece of text or datasets. Persistent identifiers are assigned to datasets by digital archives, such as institutional repositories and partners in the Data Preservation Alliance for the Social Sciences (Data-PASS).

- Follow appropriate international and national procedures with respect to data protection, rights to privacy and other ethical considerations, whenever you cite data. For further guidance please refer to our research and publishing ethics guidelines. For an example on how to cite datasets, please refer to the references section below.

Prepare your submission

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This is an optional service for authors who feel they need a little extra support. It does not guarantee your work will be accepted for review or publication.

Manuscript requirements

Before you submit your manuscript, it's important you read and follow the guidelines below. You will also find some useful tips in our structure your journal submission how-to guide.

Format	Article files should be provided in Microsoft Word format
	While you are welcome to submit a PDF of the document alongside the Word file, PDFs alone are not acceptable. LaTeX files can also be used but only if an accompanying PDF document is provided. Acceptable figure file types are listed further below.
Article length / word count	Articles should be between 3000 and 6000 words in length. This includes all text, for example, the structured abstract, references, all text in tables, and figures and appendices.
	Please allow 350 words for each figure or table.
Article title	A concisely worded title should be provided.
Author details	The names of all contributing authors should be added to the ScholarOne submission; please list them in the order in which you'd like them to be published. Each contributing author will need their own ScholarOne author account, from which we will extract the following details: • Author email address (institutional preferred). • Author name. We will reproduce it exactly, so any middle names and/or initials they want featured must be included. • Author affiliation. This should be where they were based when the research for the paper was conducted. In multi-authored papers, it's important that ALL authors that have made a significant contribution to the paper are listed. Those who have provided support but have not contributed to the research should be featured in an acknowledgements section. You should never include people who have not contributed to the paper or who don't want

	to be associated with the research. Read about our research ethics for authorship.
Biographies and acknowledgements	If you want to include these items, save them in a separate Microsoft Word document and upload the file with your submission. Where they are included, a brief professional biography of not more than 100 words should be supplied for each named author.
Research funding	Your article must reference all sources of external research funding in the acknowledgements section. You should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
Structured abstract	All submissions must include a structured abstract, following the format outlined below. These four sub-headings and their accompanying explanations must always be included: • Purpose • Design/methodology/approach • Findings • Originality The following three sub-headings are optional and can be included, if applicable: • Research limitations/implications • Practical implications • Social implications You can find some useful tips in our write an article abstract how-to guide. The maximum length of your abstract should be 250 words in total, including keywords and article classification (see the sections below).

Keywords	Your submission should include up to 12 appropriate and short keywords that capture the principal topics of the paper. Our Creating an SEO-friendly manuscript how to guide contains some practical guidance on choosing search-engine friendly keywords. Please note, while we will always try to use the keywords you've suggested, the in-house editorial team may replace some of them with matching terms to ensure consistency across publications and improve your article's visibility.
Article classification	During the submission process, you will be asked to select a type for your paper; the options are listed below. If you don't see an exact match, please choose the best fit: • Research Paper • Practice Paper • Book Review You will also be asked to select a category for your paper. The options for this are listed below. If you don't see an exact match, please choose the best fit: Research paper. Reports on any type of research undertaken by the author(s), including: • The construction or testing of a model or framework • Action research • Testing of data, market research or surveys • Empirical, scientific or clinical research • Papers with a practical focus Viewpoint. Covers any paper where content is dependent on the author's opinion and interpretation. This includes journalistic and magazine-style pieces. Technical paper. Describes and evaluates technical products, processes or services. Conceptual paper. Focuses on developing hypotheses and is usually discursive. Covers

	philosophical discussions and comparative studies of other authors' work and thinking. Case study. Describes actual interventions or experiences within organizations. It can be subjective and doesn't generally report on research. Also covers a description of a legal case or a hypothetical case study used as a teaching exercise. Literature review. This category should only be used if the main purpose of the paper is to annotate and/or critique the literature in a particular field. It could be a selective bibliography providing advice on information sources, or the paper may aim to cover the main contributors to the development of a topic and explore their different views. General review. Provides an overview or historical examination of some concept, technique or phenomenon. Papers are likely to be more descriptive or instructional ('how to' papers) than discursive.
Headings	Headings must be concise, with a clear indication of the required hierarchy. The preferred format is for first level headings to be in bold, and subsequent sub-headings to be in medium italics.
Notes/endnotes	Notes or endnotes should only be used if absolutely necessary. They should be identified in the text by consecutive numbers enclosed in square brackets. These numbers should then be listed, and explained, at the end of the article.
Figures	All figures (charts, diagrams, line drawings, webpages/screenshots, and photographic images) should be submitted electronically. Both colour and black and white files are accepted. There are a few other important points to note: • All figures should be supplied at the highest resolution/quality possible with numbers and text clearly legible.

	• Acceptable formats are .ai, .eps, .jpeg, .bmp, and .tif.
	• Electronic figures created in other applications should be supplied in their original formats and should also be either copied and pasted into a blank MS Word document, or submitted as a PDF file.
	• All figures should be numbered consecutively with Arabic numerals and have clear captions.
	• All photographs should be numbered as Plate 1, 2, 3, etc. and have clear captions.
Tables	Tables should be typed and submitted in a separate file to the main body of the article. The position of each table should be clearly labelled in the main body of the article with corresponding labels clearly shown in the table file. Tables should be numbered consecutively in Roman numerals (e.g. I, II, etc.). Give each table a brief title. Ensure that any superscripts or asterisks are shown next to the relevant items and have explanations displayed as footnotes to the table, figure or plate.
References	All references in your manuscript must be formatted using one of the recognised Harvard styles. You are welcome to use the Harvard style Emerald has adopted – we've provided a detailed guide below. Want to use a different Harvard style? That's fine, our typesetters will make any necessary changes to your manuscript if it is accepted. Please ensure you check all your citations for completeness, accuracy and consistency. Emerald's Harvard referencing style References to other publications in your text should be written as follows: • Single author: (Adams, 2006) • Two authors: (Adams and Brown, 2006)

	• Three or more authors: (Adams *et al.*, 2006) Please note, '*et al*' should always be written in italics.
	A few other style points. These apply to both the main body of text and your final list of references.
	• When referring to pages in a publication, use 'p.(page number)' for a single page or 'pp.(page numbers)' to indicate a page range.
	• Page numbers should always be written out in full, e.g. 175-179, not 175-9.
	• Where a colon or dash appears in the title of an article or book chapter, the letter that follows that colon or dash should always be lower case.
	• When citing a work with multiple editors, use the abbreviation 'Ed.s'.
	At the end of your paper, please supply a reference list in alphabetical order using the style guidelines below. Where a DOI is available, this should be included at the end of the reference.
For books	Surname, initials (year), *title of book*, publisher, place of publication. e.g. Harrow, R. (2005), *No Place to Hide*, Simon & Schuster, New York, NY.
For book chapters	Surname, initials (year), "chapter title", editor's surname, initials (Ed.), *title of book*, publisher, place of publication, page numbers. e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", Stankosky, M. (Ed.), *Creating the Discipline of Knowledge Management*, Elsevier, New York, NY, pp.15-20.
For journals	Surname, initials (year), "title of article", *journal name*, volume issue, page numbers. e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", *Journal of Consumer Marketing*, Vol. 22 No. 2, pp.72-80.

For published conference proceedings	Surname, initials (year of publication), "title of paper", in editor's surname, initials (Ed.), *title of published proceeding which may include place and date(s) held*, publisher, place of publication, page numbers. e.g. Wilde, S. and Cox, C. (2008), "Principal factors contributing to the competitiveness of tourism destinations at varying stages of development", in Richardson, S., Fredline, L., Patiar A., & Ternel, M. (Ed.s), *CAUTHE 2008: Where the 'bloody hell' are we?*, Griffith University, Gold Coast, Qld, pp.115-118.
For unpublished conference proceedings	Surname, initials (year), "title of paper", paper presented at [name of conference], [date of conference], [place of conference], available at: URL if freely available on the internet (accessed date). e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).
For working papers	Surname, initials (year), "title of article", working paper [number if available], institution or organization, place of organization, date. e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.
For encyclopaedia entries (with no author or editor)	*Title of encyclopaedia* (year), "title of entry", volume, edition, title of encyclopaedia, publisher, place of publication, page numbers. e.g. *Encyclopaedia Britannica* (1926), "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia

	Britannica, London and New York, NY, pp.765-771. (for authored entries, please refer to book chapter guidelines above)
For newspaper articles (authored)	Surname, initials (year), "article title", *newspaper*, date, page numbers. e.g. Smith, A. (2008), "Money for old rope", *Daily News*, 21 January, pp.1, 3-4.
For newspaper articles (non-authored)	*Newspaper* (year), "article title", date, page numbers. e.g. *Daily News* (2008), "Small change", 2 February, p.7.
For archival or other unpublished sources	Surname, initials (year), "title of document", unpublished manuscript, collection name, inventory record, name of archive, location of archive. e.g. Litman, S. (1902), "Mechanism & Technique of Commerce", unpublished manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.
For electronic sources	If available online, the full URL should be supplied at the end of the reference, as well as the date that the resource was accessed. Surname, initials (year), "title of electronic source", available at: persistent URL (accessed date month year). e.g. Weida, S. and Stolley, K. (2013), "Developing strong thesis statements", available at: https://owl.english.purdue.edu/owl/resource/588/1/ (accessed 20 June 2018) Standalone URLs, i.e. those without an author or date, should be included either inside parentheses

	within the main text, or preferably set as a note (Roman numeral within square brackets within text followed by the full URL address at the end of the paper).
For data	Surname, initials (year), *title of dataset*, name of data repository, available at: persistent URL, (accessed date month year). e.g. Campbell, A. and Kahn, R.L. (2015), *American National Election Study, 1948*, ICPSR07218-v4, Inter-university Consortium for Political and Social Research (distributor), Ann Arbor, MI, available at: https://doi.org/10.3886/ICPSR07218.v4 (accessed 20 June 2018)

Appendix K: Participant Recruitment Process

1) As a multisite study, the lead researcher identified named professionals from each NHS Mental Health Trust who acted as local gatekeepers/collaborators.

2) Gatekeepers emailed the adapted study poster to eligible participants on their caseloads. They then contacted interested potential participants to review the participant information sheet (PIS) and to assess for capacity in accordance with the Mental Capacity Act (2005). The gatekeeper had seven working days to report (by email to the lead researcher) any objections to participation or to confirm in writing their patient's capacity to provide informed consent.

3) Potential participants self-selected by either contacting the lead researcher (with support from a gatekeeper if necessary) or by consenting to gatekeepers passing on their details.

4) The lead researcher spoke by phone with potential participants to: review the PIS, remind them of their rights and present (emailed) and review the adapted informed consent form.

5) Within seven working days the lead researcher re-contacted potential participants (by phone) to provide an opportunity for questions. A support worker could be present if a participant wanted them to attend the start and end of their later telephone interviews.

6) Potential participants had 14 working days to provide written informed consent, afterwhich interview dates were arranged.

Appendix L: IPA Interview Guide

Guide

Each individual telephone interview will last approximately 45 minutes. Participants may invite a trusted support worker to attend the start and the end of each call. Participants can decline to answer any of the questions and can take breaks. Post interview, all participants will receive a full debrief.

Introductions and Pre-interview Actions:
- Explanation of the research project
- Practicalities and rights (e.g. timings, recording, breaks, refusal, withdrawal)
- Limits of confidentiality (e.g. risk/safety/criminal behaviour disclosures)
- Review and confirm informed consent to participate

Demographics:
- A. Age in years: ....
- B. Ethnicity: (please specify) ....
- C. Previous secure setting/type: ....
- D. Length of hospital stay: ....
- E. How long have you been living in the community: ....
- F. Community conditions/rules: ....

Interview Questions:
Due to the intellectual and communication needs of people with intellectual disabilities, abstract concepts may at times be difficult to grasp and so prompts in the form of more direct questions and cues (*in* italics) may be used.

1.Context Orientation Questions:
To help orientate the participant so that they are better focused on the context of the interview.
- What was it like living in a locked hospital?
  - *What were the people like in hospital?*
- What is it like living in the community?
  - *Where do you live now/what is it like?*

2.Lifestyle:
- What was your daily life like in hospital?
  - *What was your routine?*
  - *What did you like about living in hospital?*
  - *What did you not like about living in hospital?*
- What is your daily life like in the community?
  - *What do you do each day now you live in the community? (e.g. employment, volunteering, education, community participation).*
  - *What do you like about living in the community?*

- ➢ *What do you not like about living in the community again?*
- Are there things that you can do now that you could not do in hospital?
- Are there things that you could do in hospital that you cannot do now?
- Have you had to learn to do new things in the community?
  - ➢ *e.g. bills/shopping/domestic tasks.*
  - ➢ *What has this been like for you?*

3.Experiences of Contact with Professional Services:
- How do you feel about the support in hospital?
  - ➢ *What did professionals do when you were in hospital?*
- What has community support been like for you?
  - ➢ *What professionals are in your life at the moment?*
  - ➢ *What do they do now? How often do you see them now?*

4.Experiences of Relationships:
- What were relationships in hospital like for you?
  - ➢ *Who did you speak to/spend time with in hospital?*
  - ➢ *What did you do together there?*
  - ➢ *What was it like to say goodbye?*
- How do you feel about any relationships you have in the community?
  - ➢ *Who do you speak to/spend time with in the community? (e.g. family, friends, work colleagues, staff/professionals.)*
  - ➢ *What do you do together now?*
  - ➢ *How have you found getting to know people in the community?*

5.Expectations and Preparedness:
- How did you feel about one day moving into the community?
  - ➢ *What did you expect to be doing in the community?*
  - ➢ *How did you feel about those things?*
- What was it like preparing for community life again?
  - ➢ *What helped/did not help?*
  - ➢ *What was it like trying to make decisions about your life in hospital?*
- Now you live in the community, how do you feel about this?
  - ➢ *What is it like making decisions about your life in the community?*

6.Experiences of Safety:
- How safe did you feel in hospital?
  - ➢ *Who or what helped you feel safer there?*
- How safe do you feel in the community?
  - ➢ *Has this changed? How do you know it's changed?*
- What helps you to feel safer?
  - ➢ *Do you use any of the skills you learnt in hospital.*
  - ➢ *Are there things that make you feel less safe?*

7.Experiences with Identity:
- How did you think/feel about yourself in hospital?
- How did other people think/feel about you in hospital?
  - ➢ *Did you get on with everyone all the time?*
- What do you think about yourself now?

- What do other people think/feel about you now?
  - *How do you know this?*

8.Closing Questions and Thinking About the Future:
- What do you hope to do as you continue to live in the community?

Prompts to use throughout:
- Good/best?
- Bad/worst?
- Easier/harder?
- Can you think of an example?
- Can you tell me a bit more?
- How do you feel about this?

Debrief:
- Debrief form and identifying a named trusted professional whom is contactable for support
- Any questions, issues, or concerns
- Arrange time for the second interview

Appendix M: Coventry University Ethical Approval Certificate to Conduct an Empirical Research Project

Coventry University

Certificate of Ethical Approval

Applicant:	Shaw Tearle
Project Title:	Doctorate in Clinical Psychology Empirical Research Thesis : 'The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings'.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:	14 Apr 2021
Project Reference Number:	P115901

Appendix N: Health Research Authority Ethical Approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mr Shaw Tearle
Trainee Clinical Psychologist
Coventry and Warwickshire Partnership NHS Trust
Coventry University
Coventry University, School of Psychological, Social
and Behavioural Sciences
Charles Ward Building (CW123), Priory Street
CV1 5FB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

23 June 2021 revised 17 August 2021 (research sites not PICs)

Dear Mr Tearle

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	**The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings.**
IRAS project ID:	**296796**
Protocol number:	**N/a**
REC reference:	**21/WM/0124**
Sponsor	**Coventry University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **296796**. Please quote this on all correspondence.

Yours sincerely,
Amber Ecclestone

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Dr Anthony Colombo*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Coventry University Certificate of Ethical Approval]	V1.0	
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Coventry University Ethics Review Checklist]	V1.0	
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Coventry University Ethics Review Comments]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Coventry University Ethics Review Feedback]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [CWPT NHS Research and Development Team's Approval in Principle]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [HWHCT NHS Research and Development Team's Approval in Principle]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [BCHFT (Birmingham) NHS Research and Development Team's Approval in Principle]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [BCHFT (Black Country) NHS Research and Development Team's Approval in Principle]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Letter sent to gatekeepers at each NHS site]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [HWHCT NHS Gatekeeper Involvement Confirmation]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [CWPT NHS Gatekeeper Involvement Confirmation]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [BCHFT NHS Gatekeeper Involvement Confirmation]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [BCHFT NHS Gatekeeper Involvement Confirmation]		
Copies of materials calling attention of potential participants to the research [Adapted Study Poster]	V2.0	05 February 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Policy Insurance Letter]		20 April 2021
Interview schedules or topic guides for participants [Interview Schedule]	V1.0	02 February 2021
IRAS Application Form [IRAS_Form_26042021]		26 April 2021
Letter from sponsor [Coventry University Sponsor Letter]	V1.0	20 April 2021
Organisation Information Document		
Other [Standard Debrief Form]	V2.0	18 June 2021
Other [Adapted Debrief Form]	V2.0	18 June 2021
Participant consent form [Standard Consent Form]	V3.0	18 June 2021
Participant consent form [Adapted Consent Form]	V3.0	18 June 2021
Participant information sheet (PIS) [Standard PIS]	V3.0	18 June 2021
Participant information sheet (PIS) [Adapted PIS]	V3.0	18 June 2021

Referee's report or other scientific critique report [Coventry University Ethics Review Comments]		20 April 2021
Referee's report or other scientific critique report [Coventry University Ethics Review Feedback]		20 April 2021
Referee's report or other scientific critique report [Coventry University Critique of Research Protocol]		05 October 2020
Research protocol or project proposal [Empirical Research Protocol]	V2.0	05 October 2020
Response to Request for Further Information [Response to FOWC]		
Schedule of Events or SoECAT		
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		10 March 2021
Summary CV for supervisor (student research) [Supervisor CV]	V1.0	10 March 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Certificate of Employers Liability Insurance]		20 April 2021

Standard PIS

PARTICIPANT INFORMATION SHEET

You are being invited to take part in research on what it is like for men with learning disabilities, and a history of offending, who have transitioned back into the community after a period of time within a secure hospital.

Study Title: 'The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings.'

IRAS Study ID: 296796

Shaw Tearle, Trainee Clinical Psychologist at Coventry University is leading the research. This study is linked to Shaw's educational research project as part of the Doctorate in Clinical Psychology programme. Coventry University is this study's non-commercial sponsor. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

You can show this Participant Information Sheet to someone you trust. You can ask them to help you decide if you want to take part in the study.

If you choose to be in the study, please sign the Consent Form and return to Shaw at tearles@uni.coventry.ac.uk Your Support Worker can support you to sign and send the form.

If you want a support worker to be with you at the start and end of your meeting with Shaw, please ask them to sign the consent form too.

Keep this Participant Information Sheet and the Consent Form somewhere safe.

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1. What is the purpose of the study?

The purpose of the study is to learn what it is like for men with learning disabilities, and a history of offending, to live back in the community after being in a locked hospital.

2. Why have I been invited to take part?

You are being asked to take part because:

- You are a man with a learning disability.
- You have committed an offence in the past.
- You are now living in the community after spending time in a locked hospital.

3. What might be good about being in the study?

By sharing your experiences with us, you will be part of helping:

- Shaw, Coventry University and professionals to learn what you think and feel about moving back into the community after being in hospital.
- People with a learning disability, and a history of offending, talk about their experiences of living back in the community.
- To make the move back into the community better for other people.

4. Are there any risks associated with taking part?

Talking about leaving hospital and moving into the community might make some people upset. You can talk with someone you trust, such as your keyworker, should you feel upset or worried.

However, this study has been reviewed and approved through Coventry University's formal research ethics procedure, as well as the Health Research Authority and your local NHS Trust's Research and Development Team. The

study has been given a favourable opinion by the West Midlands Coventry and Warwickshire Research Ethics Committee. There are no significant risks associated with participation.

5. Do I have to take part in the study?

No. Your choice will not change the support you get from your care team, or anyone else.

Before you choose, a professional from your NHS care team (e.g. care coordinator) will speak with you about the study. They will make sure you understand the study and what will happen if you agree to take part.

If you decide to take part, please keep this Participant Information Sheet and sign the Consent Form to show that you understand your rights in relation to the research and are happy to participate.

Please note down your participant number (which is on the Consent Form) and provide this to Shaw Tearle if you seek to withdraw from the study at a later date. You are free to withdraw your information from the project data set up until the data are fully anonymised in our records.

You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. You can withdraw up until 31st March 2022. To withdraw, please contact the lead researcher: Shaw Tearle, at tearles@uni.coventry.ac.uk.

6. What will happen if I choose to take part in the study?

Shaw will talk to your NHS care team to ask them to confirm that you can take part. Your care team may check your relevant medical notes when making this decision. Before you sign the Consent Form Shaw will call you to talk through this Participant Information Sheet and the Consent Form. He will answer your questions to make sure you are satisfied.

You and Shaw will meet for two 45-minute telephone interviews. You will be able to hear and talk to Shaw from a place that is convenient to you. The total

length of your involvement will be around 3 hours, starting from when your care team first discuss the study with you.

The interview will be audio recorded on a password protected Dictaphone. It will only record the sound of your voice. Ideally you should therefore aim to have the interview in a quiet and private place.

Shaw will ask you questions about living back in the community after spending time in hospital. Shaw will ask you questions regarding how you feel about:

- Your relationships with friends, family and staff.
- How you felt about life in hospital and how you feel about community living.
- Your safety and how risk has been managed.
- Support you had in hospital and the support you have in the community.
- Activities you did in hospital and activities you do now.

Shaw will not ask about your past offending behaviour. You do not have to answer a question if you do not want to. You can stop the interviews at any time. It is your choice. A support worker you trust can be with you at the beginning and end of both telephone interviews.

At the end of the interviews Shaw will check:

- That what he has learned from you is right.
- That what you said can be used in the study.
- There is someone available to support you if you need it. This might be your support worker.

You can agree to speak with Shaw at a later date about the study's findings. You can agree to this by ticking the relevant boxes on the <u>Debrief Form</u>. Shaw will discuss this with you at the end of the interviews.

7. What happens if I report information that makes Shaw worry about safety?

If you reveal any information that suggests you or someone else is at risk, or if any criminal activity has taken place, Shaw has a duty to tell local authorities. This might include the police and your care team. This is designed to keep everyone safe.

8. Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential.

All of your data will be anonymised. This means Shaw will change your name and any of the names or places you mention. Your data will be referred to by a unique participant number rather than by name.

If you consent to being audio recorded, all recordings will be uploaded to a secure OneDrive account and deleted form the Dictaphone immediately after each interview. All digital recordings will destroyed once they have been transcribed.

Your data will only be viewed by the lead researcher/research team. All electronic data will be stored on a password-protected computer file (OneDrive, Coventry University's electronic system). Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. Coventry University will take responsibility for data destruction and all collected data will be destroyed on or before September 2027.

9. How will we use information about you?

This research project is sponsored by Coventry University who will be the Data Controller for the information you provide. This means we (Coventry University) are responsible for keeping your information safe.

We will need to use information from you for this research project. This information will include your initials, name and contact details.

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/

- at www.hra.nhs.uk/patientdataandresearch

- by asking one of the research team (details below)
- by emailing the Coventry University Data Protection Officer - enquiry.igu@coventry.ac.uk
- or by ringing us on 024 7765 8762

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10. What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

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11. Making a Complaint

If you are unhappy with any aspect of this research, please first contact the lead researcher:

- Shaw Tearle, on tearles@uni.coventry.ac.uk

If you still have concerns and wish to make a formal complaint, please write to the study's supervisor:

- Dr Anthony Colombo, on hsx412@coventry.ac.uk

Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.igu@coventry.ac.uk. For more details about how to make a complaint please visit www.ico.org.uk

Alternatively, you can contact the Coventry & Warwickshire Partnership NHS Trust Patient Advisory Liaison Service (PALS) for support: PALS.Complaints@covwarkpt.nhs.uk; 024 7653 6804. If you have a different local NHS trust, please contact NHS England: england.contactus@nhs.net; 0300 311 22 33.

Adapted PIS

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

PARTICIPANT INFORMATION SHEET

Hello, my name is Shaw Tearle. I am a Trainee Psychologist at Coventry University. This study is linked to my research project as part of the Doctorate in Clinical Psychology.

You are being asked if you want to help me learn what it is like to live back in the community after being in a secure hospital.

Before you decide, you should read this Participant Information Sheet carefully.

It will tell you why I am doing the study and what will happen if you take part.

You can show this Participant Information Sheet to someone you trust.

You can ask them to help you decide if you want to take part in the study.

If you choose to be in the study, please sign the Consent Form and return it to Shaw:

- Email: **tearles@uni.coventry.ac.uk**

If you want a support worker to be with you at the start and end of your meeting with Shaw, please ask them to sign the consent form too.

Keep this Participant Information Sheet and the Consent Form somewhere safe.

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

1. What is the study for?

Shaw wants to know what it is like for men with learning disabilities, and a history of offending, to live back in the community after being in a locked hospital.
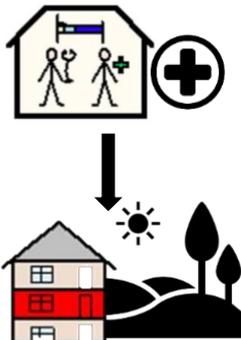
2. Why have I been invited to be in the study?

You are being asked to take part because:

- You have a learning disability.
- You have committed an offence in the past.
- You are now living in the community after spending time in a locked hospital.

3. What might be good about being in the study?

Taking part can:
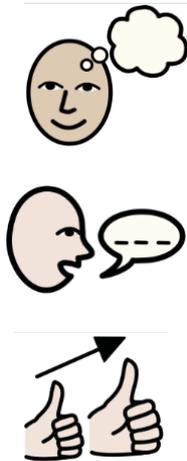
- Help people know what you think and feel about moving back into the community after being in hospital.
- Help professionals know what it is like to live in the community after leaving hospital.
- Help people with a learning disability, and a history of offending, talk about their experiences of living back in the community.
- Help make the move back into the community better for other people.

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

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4. What might not be good about being in the study?

Talking about leaving hospital and moving into the community might make some people upset.
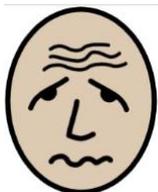
You might feel nervous about being recorded.

After the interview you might worry about what you said.

You might worry about other people reading what you said.

---

5. Is it safe to take part in the study?

Coventry University's ethics team and the West Midlands Coventry and Warwickshire Research Ethics Committee have given the study a favourable opinion. This means the study is safe.

Their job is to make certain a study is run safely and properly.

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6. Do I have to take part in the study?

No. You do not have to be in the study.

It is completely your choice.

Your choice will not change the support you get from your care team, or anyone else.

Before you choose, your care team will speak with you. They will make sure you understand the study and what will happen.

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7. What if I change my mind about taking part?
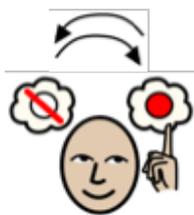
You can change your mind until your information is fully anonymised.

You can change your mind:

- Before, during or after the interviews.
- Up until 31st March 2022.

You do not have say why you changed your mind.

If you change your mind please contact Shaw by:

- Email: **tearles@uni.coventry.ac.uk**
- Or letter: **Shaw Tearle, Coventry University, CV1 5FB**

Tell Shaw your participant number. He will take what you said out of the study.

8. What will happen if I choose to take part in the study?

Shaw will talk to your NHS care team to ask them to confirm that you can take part. Your care team may check your relevant medical notes.

Before you sign the <u>Consent Form</u> Shaw will call you to talk through this form and the Consent Form. He will answer your questions to make sure you are happy.
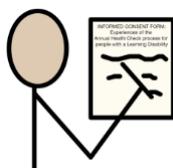
If you want to take part in the study please fill in the <u>Consent Form</u>. Please send this to Shaw: **tearles@uni.coventry.ac.uk**

Your support worker can help you to sign and send the form.

Keep these pages, the <u>Consent Form</u> and your <u>Participant Number</u> safe.

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

During the interviews you and Shaw will talk using the telephone at a time that suits you.

You will be able to hear Shaw. Shaw will be able to hear you.

There will be two interviews. This means you will talk to Shaw on two different days. The total length of your involvement will be around 3 hours.

The interviews will be audio recorded on a password protected Dictaphone. It will only record sound.
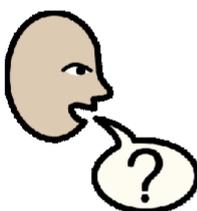
Shaw will ask you questions about living back in the community after spending time in hospital. Shaw will ask about:

- Your relationships with friends, family and staff.
- How you felt about life in hospital and how you feel about community living.
- Your safety and how risk has been managed.
- Support you had in hospital and the support you have in the community.
- Activities you did in hospital and activities you do now.
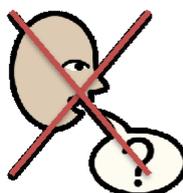
Shaw will not ask about your past offending behaviour. You do not have to answer a question if you do not want to.

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

A support/keyworker you trust can be with you at the beginning and end of both telephone calls.

At the start Shaw will check:

- You are happy to be in the interview.
- You are happy to be recorded.
- You are in a private and safe place.

Each interview will last for 45 minutes. You can take breaks. You can stop the interview at any time. It is your choice.

At the end of the interviews Shaw will check:
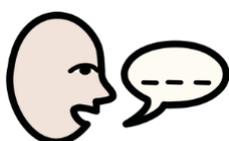
- That what he has learned from you is right.
- That what you said can be used in the study.
- There is someone available to support you if you need it. This might be your support worker.
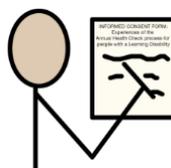
You can agree to speak with Shaw at a later date about the study's findings. You can agree to this by ticking the relevant boxes on the Debrief Form.

9.What happens if I say something that makes Shaw worry about safety?

If you reveal that you or someone else is at risk, Shaw has a duty to tell local authorities. This might include the police and your care team.

This is designed to keep everyone safe.

10. What will happen to what I say?

Your information will be used to check that the research is being done properly.

Only Shaw will hear the recordings. Shaw will write down exactly what you both said.

Shaw will briefly write about your age and learning disability. Shaw will then delete the recording.

Shaw will change your name, and the name of any people or any places you said. No one will know they are your words.

Once we have finished the study, we will keep some of your data (name and contact details) so we can check the results.

Shaw will write about the study's results in a professional magazine. No one will know it is your information.

Shaw will share what he writes at a conference.

This is a big meeting where people go to learn.
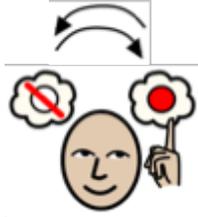
What are my choices?

You can change your mind and leave the study at any time. We will keep information that we already have about you.

You will not be able to look at or change the information we have about you.

Where can I learn more about how my information is used?

You can find out more:

- at www.hra.nhs.uk/information-about-patients/
- at www.hra.nhs.uk/patientdataandresearch

- by asking one of the research team - tearles@uni.coventry.ac.uk or hsx412@coventry.ac.uk
- by emailing the Coventry University Data Protection Officer - enquiry.igu@coventry.ac.uk
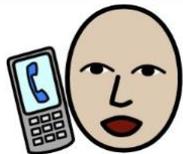
- or by ringing the research team on 024 7765 8762

11. How will my information be kept safe and private?

Shaw will keep what you say private and in a safe place. Only professionals involved in the research will see your information.

Shaw will follow the rules in the General Data Protection Regulation and the Data Protection Act.

These laws tell Shaw how to keep what you tell him private and safe.

Shaw will keep everything in a safe place. Only Shaw and the research team will have the key to the safe place.
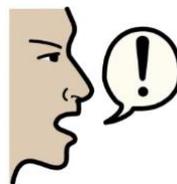
12. What if I want to complain?

If you are upset by talking to Shaw, you can tell him.

You can:

- Stop the interviews.
- Take a break in the interviews.
- Choose to speak with Shaw another day.

You can make a complaint if you are unhappy with Shaw's behaviour.

You can complain to the study's supervisor. His name is Dr Anthony Colombo.

You can email Anthony on hsx412@coventry.ac.uk

For more details about how to make a complaint please visit www.ico.org.uk.

Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.igu@coventry.ac.uk
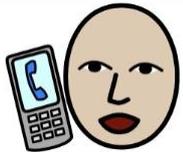
You can all the Patient Advisory Liaison Service (PALS) for support on **024 7653 6804.** If you belong to a different mental health trust you can call **0300 311 22 33**.

Standard informed consent form

<table>
<tr><td>Participant No.</td><td>**INFORMED CONSENT FORM**</td></tr>
</table>

Study Title: 'The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings'

IRAS ID: 296796

You are invited to take part in this research study for the purpose of collecting data on the experiences of men with learning disabilities, who have a history of offending, who now live within the community after being in a secure hospital.

Before you decide to take part, you must **read the accompanying Participant Information Sheet.**

The lead researcher, Shaw Tearle, will discuss this form and the Participant Information Sheet with you. Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by <u>putting your initials</u> against each of the below statements and then signing and dating the form as a participant. If a support/keyworker will be attending the start and end of your interviews, please may they also sign below.

	Statement	Initials
1	I confirm that I have read and understood the <u>Participant Information Sheet</u> (dated 5.2.2021) for the above study, and have had the opportunity to consider the information, ask questions and have had these answers satisfactorily.	
2	I understand my participation is voluntary and that I am free to withdraw my data up until 31.3.2022, without giving a reason, by contacting the lead researcher without my medical or legal rights being affected.	
3	I understand that where it is appropriate to the research, relevant sections of my medical notes may only be accessed and viewed by my medical care team. I give my care team permission to access my medical notes for this study.	
4	I have noted down my participant number (top left of this Consent Form), which may be required by the lead researcher if I wish to withdraw from the study.	
5	I understand that all the information I provide will be held securely, will be treated confidentially and will only be reviewed by professionals involved in this research.	

6	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs, and I understand it may be shared anonymously with other researchers.	
7	I understand that in the event that I disclose information that suggests either I or someone else is at risk, or if a criminal activity has taken place, the lead researcher is obliged to report it to the relevant local authorities (e.g. police and may care team).	
8	I am happy for the interviews to be audio recorded.	
9	I agree to take part in the above study.	

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Support Worker/Keyworker	**Date**	**Signature**
Lead Researcher (person taking consent)	**Date**	**Signature**
Shaw Tearle		

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

Adapted informed consent form

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

INFORMED CONSENT FORM

Participant Number: ....

Hello, my name is Shaw Tearle. I am a Trainee Psychologist at Coventry University.

You are being asked if you want to help me learn what it is like to live back in the community after being in hospital.

Before you decide, you should read the accompanying Participant Information Sheet carefully.

It will tell you why I am doing the study and what will happen if you take part.

You can show this Consent Form to someone you trust.

Shaw will talk to you about the Participant Information Sheet and this form before you consent.
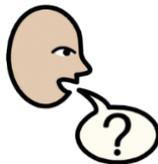
Please ask any questions before agreeing to take part.

If you are happy to be in this study, please write your initials next to all 9 statements on the next page.

If you do not want to be in this study, please do not write your initials next to each statement.

Coventry
University

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

	Statement	Initials
	1. I have read and understood the Participant Information Sheet dated 5.2.21, and have asked questions which have been answered to my satisfaction.	
	2. I understand that I do not have to participate in the study, and I can withdraw my data up until 31.3.22. It is my choice.	
	3. I give my care team permission to access my medical notes as part of the study, if necessary.	
	4. I have written down my participant number.	
	5. I understand that my data will be stored securely, will be confidential and will only viewed by professionals involved in the research.	
	6. I am happy for my anonymous data to be used for journals and conferences.	
	7. I understand that if I reveal information which suggests anyone is at risk, or criminal activity has occurred, Shaw has a duty to report it.	
	8. I am happy for the interviews to be audio recorded.	
	9. I agree to take part in the study.	

Study Title: The Transitional Experiences of Men with Intellectual Disabilities, and a History of Violent Offending, who have Resettled into the Community from Secure Settings

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If you choose to be in the study, please sign the Consent Form below.

Name: ....

Signature: ....

Date: ....

Thank you very much for agreeing to take part. Your help is really appreciated.

If your support worker will be attending the start and end of your interviews, please can they sign below.

Name: ....

Role: ....

Signature: ....

Date: ....

Researcher's Details

Name: Shaw Tearle

Signature: ....

Date: ....

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

Adapted Participant Informed Consent Form v3.0 18_06_21 IRAS ID 296796
1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

Coventry
University

Appendix P: Stages of Interpretative Phenomenological Analysis

Extract of an example coded participant transcript

Emergent Themes	Transcript	Coding
	I: Thank you again so much for providing that additional information, it's really..	Descriptive Linguistic Conceptual
Taking responsibility for mental health. Acting out of worry.	P: That's what I like because it keeps my head occupied so I don't get bored and I can't get properly depressed. And to be honest it keeps my brain busy so I don't do nothing wrong to mess up my chances here. Although I kinda, of find it harder to organise things because staff have to find things to do for us all because I haven't got a clue. Luckily they're pretty good and I can trust them to find things for me and then I get to go out with the big group of people who live here. I can sometimes go shopping on my own, oh and the garden centre, but I have to think about it umm ahead of time, sometimes, well with the staff here right.	Being busy in the community reduced boredom and depression. Is there a risk that being inactive will impact upon health/risk?
Recall hangs over them – dominating.		Scared of being recalled to hospital and being someone who does something wrong in the community.
Works hard to gain trust. Loyalty of others.		Trusts the new staff and people they live with. Relies on them. Still not someone who is fully able to be independent.
Always having to take precautions. Hard to trust self. Dependence on others.		Goes out alone. Listing to convey importance/scope of this point. Sees self as someone who has the trust of others in the community?
		Plans ahead of time. Sense of nervousness about going alone? – 'sometimes' goes alone. Trusts other judgements over self?
	I: What do you mean?	
Confusion. Lack of knowing is uncomfortable?	P: Well put it this way, look, umm because of those legal rules you asked about, you know right, I have to be careful not to sorta break them, if you get that. That could end proper badly. I have to always think about them, and	'Look' suggests importance and wanting to be understood? Is careful not to break community restrictions. Unsure of the term ('legal rules').

Actions always have consequences. Questioning own risk/safety.	my past behaviours, the bad ones yeah, which I won't mention if you don't mind, yeah? I: Of course, that's your choice. I won't ask about your past offending as part of this remember, so that's totally fine. Remember you can always say no to answering any of the questions. Do you understand that?	Breaking the rules has serious consequences. Always on mind. Managing risk is a significant part of community life, but sense that its more about consequences for self than risk to others?
Emotional discomfort. Celebrating independence. Emotional discomfort. Wanting to portray new self?	P: Oh yeah yeah, yeah. Don't worry, I'm not, just checking with you see. So, right where, what I was just telling, so right, yeah, but there are some things I can do independently alone, but I'd say a lot of it is with staff, or with the help of the staff here, help and supporting stuff. Like we made bracelets the other day which was good. I was got good at it. I wish you could see them.	Repetition could suggest nervousness and eagerness to move on. Can do some things independently now. Changed the subject to something highlighting successes? Desire to present/focus on positive community experiences.
	I: Brilliant. Have you done anything else in the community that you think is important to mention? What do you get up to?	
Vagueness.	P: Lots, like I said. Umm, so yeah.	Has done lots of important things in the community.
	I: Any experiences of work or volunteering in the community? Of working in a job?	
Confusion about future. Looking for change or purpose.	P: I've done a volunteering occupational, it's this thing right, I think that's the word, yeah, occupational therapy course and they've put	Is looking for work experiences. Supported to do this. Stammering could suggest feeling confused about employment processes. Is looking for opportunities.

		A desire to help others who have had similar experiences. Feeling confident in this area.
	me in touch with a guy who does all that, yeah.	
Wanting to be the advocate. Desire to be seen as someone who cares?	I: Can you explain some more about how you've found this? What's it like for you?	
To be a rescuer. Wishing to be rescued?	P: I think it's work with mental health people, going into these hospitals and helping the teams there. Basically, right, I got a err letter about it and it says I can help the hospital professionals with kind of to support new clients there. I can be, umm, get to be there supporting because I know about the system and stuff, don't I. I think it will be rewarding and good fun. I'm a bit excited. I think that I can tell professionals about moving into the community too, so right, so like this a bit, I mean a bit like this.	Job would be rewarding and fun. Positive about supporting others ('excited'). Sees self as an expert. Wants to be helpful member of community? Sense that his move into the community could have been better if only....
Being the expert. Comfort in the familiar.		
Enthusiasm for taking on a new role. Implicit desire to connect/belong again. Acting in ways to earn a place in society.		
	I: How do you feel about this new role for you in the community?	Wants to be honest. Feels like they need to contribute something. Emphasis on willing to be altruistic ('I'm not saying I *need* to').
Being an advocate. It can't all have been for nothing.	P: Okay. So, umm, to be honest I want to do it. I err feel like I um need to give something back after all of this time. I'm not saying I need to give it a go but I feel like I owe it after the support I've had and it wouldn't feel right to just come out here again.	Sense of needing to help others in order to feel good about self being back in the community? They owe something to someone to feel deserving of this new life?
Feeling undeserving. You must give as well as take.		Not helping means being selfish. Keenness to be a selfless person. Being selfish is not a nice position to be in for them?
Scared of being seen as selfish.	I: Can you tell me more about feeling like you owe it? What does...	Being selfish means not being a better person. Helping others avoids recall? Scared of being the person they were back in hospital? What does going backwards mean for them?

Worried about not being the person they want to be. Fear of going backwards.	P: So for example if I left and came here and didn't, right, I'd be being selfish. I: Do you know why you think that?	'I'm not being funny' conveys seriousness of point. Desire for connection/validation from others who truly get their experiences. Still feel not fully understood in the community. Lonely? Sees themselves as someone who will be accepted by those with similar experiences? 'Needs' to move forward; black and white and definitive.
It can't all have been for nothing. Wanting to connect and belong. Feeling socially isolated. Searching for acceptance. Going back isn't an option.	P: Yeah yeah I'd be not being the best person. Look, the ways I see this thing is that it helps me stop going backwards. That's the only reason I'm doing it, not being funny, it's not for the friends or nothing but it is err a chance to meet people who really get what it feels like to me. I need to move on.	Needs time to process. Harder question. Feeling overwhelmed?
Overwhelmed by past.	I: Are there things *they* need to know about your experiences?	Leaving hospital is a big step. Tapping into seeing themselves as someone who is institutionalised?
Transition is a significant process.	P: Errr, that's a big question ha. Give me time, yeah. I: No problem at all, XX. Take your time. OK?	Suggestion that residents should have shown them around supported living. Nervous about moving out of hospital.
Hospital felt familiar. Fear of change. Feeling conflicted about moving on or staying stuck.	P: Well, umm, I'd let them know that coming out of hospital is a big step, especially for me as I was in the low secure bit for a long time and it was what I knew. When I got here the staff showed me round the place and it was good but I think one of us, I mean one of the other residents, should do that because they know the background and can introduce me to the staff, right. I was quite nervous about moving out of hospital because it was sort of like, umm, well, sort of like what I was used to	Felt used to hospital. Still didn't like hospital. Hospital was somewhere familiar and relatively safe/comfortable in comparison with the community?
Unwelcome security of being in hospital.		Emphasis on 'confident'! Didn't feel confident about moving back into the community. Blames the staff in the community for not feeling confident? Difficulty accepting that they found it harder to cope with the move. Hard to trust the new staff. A carry over from difficult experiences with staff in hospital?

Feeling conflicted about emotions. Low self-esteem/self-efficacy. Others are hard to trust. Trust has to be earnt.	and I didn't know how it was going to do. Doesn't mean I'm saying I liked it there though. Maybe if one of the residents had shown me round here and told me I'd be alright would've made me feel a bit more, umm, more, umm, confident! I think staff didn't do the best job of settling me down, and to be honest it's hard to suddenly trust staff you don't know that well yet, especially like since the hospital staff were useless lots of times.	Overwhelmed and caught up in thoughts of the move could suggest a difficult transition? ('me?'). Might have been easier to listen to residents. Didn't trust/lie staff? Looking for likeminded people who will normalise and understand experiences. Are they more accepting?
Emotionally overwhelmed. Hard to trust community staff. Searching for opportunities to connect. Being understanding of others. Feeling different from others.	I: Thank you for sharing, XX. Can you tell me more about the experience of this move please? The one from hospital? P: Me? Oh yeah, umm, well I think I might have found it easier to listen and believe the other residents. I would say that I find it easier to believe them most of the time anyway. Maybe, maybe, actually maybe because they've been through similar stuff and I know we kind of understand each other that staff here just can't. No offence right. Not their fault though really.	Other residents have had similar experiences. ('Not their fault') - understanding that the new staff can never really understand their experiences. Feeling different from staff, forever?
Thankful for formal transition into the community. Feeling better understood. Timing is key.	I: What was it like for you during the move? P: I was lucky because I did transition. I did overnight stays. So I got the chance to slowly get used to this place and the staff and probably really helped me to settle down to be	Positive about the 'transition'. Good transition pace (overnight stays) because they got to know the community. Community staff had a better approach?

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	honest. I liked the umm style, right, more than just leaving and coming straight here for good – that would've been harder I think. If I can tell professionals one thing in my new job it will be that transitions are really important and shouldn't be rushed.	Happy about not having moved straight from hospital into the community.

Important that transitions shouldn't be rushed. |
	I: What do you mean? How did you experience the speed of your transition?	
Timing is key.	P: What? What you saying about?	Feeling confused.
	I: How did you feel about the speed of your move?	
	P: Ahh. Right. Sometimes mine went too slow and sometimes I went too fast ha. Fast, slow, slow and yeah yeah.	Suddenly understanding.
Repetition and increased pace – suggests the transition was significant?
Pace of transition wasn't always ideal.
Past relationships cloud new ones.
Hard to trust others.	I: What were staff like when you first moved, the new staff sorry?	
Making own decisions.
Feeling brave enough to let others close.

Social relationships can be problematic.
Socially inexperienced.

Learning to trust again. | P: Well, yeah, at first I didn't know if I could trust them or not. With my past trust is a big thing and it doesn't happen easily for me. Everyone says, like the umm hospital staff, not them actually, the urr doctors, they umm, I didn't know X (community staff worker) or any of them but I decided that I needed to try and trust them if this was going to be my new home. Hard to do though, sounds easy but | Didn't know if they could trust community staff because of the past.

Chose to trust community staff. The power to make decisions for self.
'Home' suggests feeling more permanently settled?

Hard to trust people in the community – forgotten what people can be like?
Been inside for such a long time. |

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	forget it really, because I didn't know if they were nice or decent people out this way.	
	I: Was this hard, difficult, easy?	Emphasises the difficulty with 'major huge barrier'. Had to learn to trust people again.
	P: It was a major huge barrier I had to get over. I had to learn it in a way.	
Confusion.	I: Can you say more on what you mean by these barriers? Er, things that get in the way of this?	
	P: I had to learn it, in a way.	
Hiding low self-esteem. Feeling misunderstood.	I: Can you say anymore please? Learn what exactly?	Arguably an inappropriate response the question – result of ID, poorly phrased question and/or feeling overwhelmed by the questions.
	P: Yeah.	
Letting others in again.	I: Sorry, I mean what did you have to learn to do? Did you have to do things differently?	
	P: Look, right. So. It wasn't easy, even if people said it looked easy to me as this cocky person, which is silly anyway. I realised that I couldn't hold the staff here responsible for my past, or how I was getting coping here. That's where the trust came into it. But really it was about just trying to get to know them. I can tell you one thing and that's that I trust staff here much more than I did in hospital. So can I give you an example?	'Look' suggests the point is important. Wasn't easy to move into the community. People see them as being confident when they're not. Not fully understood. Masks difficult feelings from others?
Feeling vulnerable and exposed. Feeling betrayed.		Getting to know the new staff helped them to build trust. Trusts the community staff more than hospital staff.

Anger/annoyance at broken trust.	I: Please do, yeah.	
	P: In my hospital I told staff something once, it was private, and it was the bad bits of my background. I basically told them about self-harming and why and all that, but unfortunately get this really bad, I overheard the staff talking about later than the day, and then they started asking me about if it was true. When the psychologist found out though, about the whole thing right, what they done, she went absolutely mad and reported them I think. Don't know what happened to it, but I like never heard them do it again, thankfully, phew. Shame really. Bad stuff.	Made a disclosure to staff but confidentiality was breached.
Hospital lacked privacy.		Saw psychologist as an ally, someone they could trust?
Life wasn't just their anymore.		Projection of anger?
		Unhappy, negative experience ('bad stuff').
Desire for privacy and control over own life.	I: Thanks for sharing this example, sounds like a tricky situation for you to manager. Can I ask then, did you have any privacy in hospital?	
Feels more private in the community.	P: Umm, sort of. They had to share stuff about risk, which makes sense, fine, but they were mostly private to me and us. They talked about the confidentiality stuff, bit like what you did the other day when I did the umm signing up to this. On the whole I wish I'd had more confidentiality inside.	Confidentiality was mostly upheld.
		'Mostly private' suggest this wasn't always true or what they wanted it to be.
Others are more protective. Others show more care for them.		Wanted more confidentially in hospital. Life didn't feel private? Related to trust in an way?
	I: How does this compare with your experiences back in the community?	

		More private in the community. Feels respected more by others in the community.
Collaboration is important. Appreciates transparency and honesty.	P: It's way more private here like. It feels confidential and I think I have more respect here. I feel more comfortable being properly like opened up in the community here because the staff here talk to me in private, they say come to this room and that, yeah, and really listen and don't share things unless it's about my risks.	Staff make an effort to protect privacy? Risks information is shared when needed. This seems acceptable.
Lack of choice. Felt controlled by hospital staff. Life was an open book.		
	I: How do you feel about this?	Happy with confidentiality arrangement in the community. Used to life/personal information being shared – is this normal now?
	P: I'm happy with that. In hospital I had to keep staff up to date with everything, everything, like if we wanted, OK so imagine I to umm have drinks I had to say what eaten and drinking I'd done. You'd find, well I bet you would find that harder too because it means people got to knew everything about my life! And umm I didn't get very much choice about that in the hospital.	Had to share everything in hospital. Their life wasn't just theirs in hospital? No privacy or choice about how they life was shared? Emphasised 'people knew everything about my life!'. Didn't get much choice.
Trying to embrace more choice.		
Having a valued voice. Sense of self becoming important.		
	I: What about your experiences of having or not having choice in the community?	
Freedom and opportunity.	P: Haha, wow, well I have to say I have lots more. I think. Staff are always telling me that this place is umm, well it's what they say is about being umm client led I think. Basically they. So I, which I think means they listen to what I want, which they do most of the time really.	Laughter suggest a more positive tone/experience of choice in the community? Lots more choice in the community. An understanding that community staff should and do listen more.
Restrictions on life.		

Balancing opportunities and restrictions. Feeling conflicted about possibilities. Questioning themselves.	I: So it's different out here now? P: They'd probably let me go bungey jumping haha. I: Oh wow. P: Actually, err, that's not totally true because I have a curfew. I: What that been like for you?	Expressing increased choice and capacity to do more things they want in the community. Laughter suggest a more positive tone. Has a curfew. Doesn't see themselves as someone who can actually do anything. Community living is still restricted.
Nervousness. Seeking approval of professionals.	P: Hard, sometimes. That's hard to manage sometimes, yeah, and it gets into my way of me doing things I think are important and should get done now. It feels quite complicated if I want to do something out of hours, even if it's with staff who can keep me safe, it's their job see, because I umm have to ask my probation officer you see.	Restrictions/curfews are hard. They stop from being able to do important/meaningful things. Sense that things are more complicated than they appear. Not always believed to be safe in the community.
Others judge them.	I: How have you found that? The curfew and going to probation? P: Hmm, that's usually alright like, but I get nervous because I think they think I'm doing something wrong. I: What do you mean? P: It's the look. You must get it.	Sees themselves as someone who others, such as probation, still view of risky/unsafe. Nervous about asking for permissions. Feels judged and/or mistrusted by others?

|		
Feeling like they're on trial. Feeling guilty? Still feel controlled. Others see them as unreliable and unsafe. Internalising the views of others. Mixed feelings. Looking for containment. In certainty there is safety? Feeling conflicted about beliefs. Questioning their own ability to stay safe. Questioning whether they have really changed. Fearing the worst. In certainty their safety? Am I risky? Avoiding responsibility/hiding behind the safety net. Uncertainty.	I: I'm not sure. Can you say anything more? P: Hmm...err... I: Can you describe an example? Give an example of a time, er situation? P: It feels umm, well to be honest it feel sorta awkward and reminds me of hospital. Right, so we have, had, this thing called umm section 17 leave, which I thought didn't exist here in the community. She, I mean the probation officer lady I check up with, always wants to know why I want something and it means that I can't ever be left alone. It's all about check this and checking that now, right, umm so yeah. I: How do you feel about this? P: To be honest though I guess I'd rather be on this license because I know that if I mess up I know I will be recalled. That's like certain to happen so that's quite, umm, well, I would say it's strangely reassuring haha. That's no joke, honest. It's like, umm. I don't know. But, oh and probation appointments help me to keep safer. I: In what way?	Unsure of how to communicate the experience – its nuanced? Experience is similar to hospital. 'Awkward' suggest its uncomfortable. Compares to section 17 leave. Is questioned. Repeated use of 'checking or checked' implies a sense of be monitored and/or not entirely free to make own choices. Others question their safety. Seen as someone who can never be trusted or will never be entirely safe. Preference for being on license because it would lead to recall. Sense of certainty and security from knowing what might happen – feels safer? Restrictions are reassuring. Questioning themselves and their answers ('I don't know'). Conflicted about restrictions? See themselves as reliant on others to stay 100% safe in the community? Do they lack the skills to do this themselves? Can they not keep feel confident to self-manage risk. Desire/reassurance from being held in mind – less accountable for self? Restrictions are a safer net. Imagery/metaphor implies they need this security and they might worry about reoffending/having the capacity to act in such a way that they would be recalled?

	P: So I, I, feel better safer with this license and seeing probation and the curfew to be honest. It's what we call my safety net.	Sense of being an unsafe person in the community. To themselves or others?
Wanting to be understood.	I: What do you mean by a safety net?	Difficulty explaining.
Pros and cons of community restrictions. Want versus need of restrictions.	P: This is hardest to explain. I know, I know that it's there and I know that I will be recalled. Do you get it?	
Fear of prison and going backwards.	I: Tell me more if you can please? I get this is might feel quite hard to explain in words. No rush.	Finding it hard to explain. Unsure if they are 'right' in what they think ('tell me what you think').
Questioning their own judgement. I can't cope. Am I unsafe?	P: I'm not sure how to put this. Tell me what you think, right? So, umm, it's the safety net that helps me know what might happen. So having these community law, rules or whatever, umm means I know exactly what to do to stay safe in the community, so yeah. And, and, at least if I break them I get recalled to hospital. Yes, right, so I know I said that I didn't like hospital, but recall stops me going to prison – I really can't do prison because I don't think it's good there, not the right support at all, because its bloody terrible. So the license tells me what I need to do and helps me cope anyway. Get it?	Community rules helps them to stay safe. Love – hate relationship with community restrictions. Recall to hospital and not prison. Is prison worse than hospital? Are they trying to avoid both or just prison? About keeping themselves or others safe? Wouldn't get the right support in prison. Prison experiences are bad ('blood terrible'). Feels the need to have a prescription on how to cope safely in the community. Doesn't feel confident managing alone?
Not trusting self.		
Fear of being abandoned. Abandoning some choice at the expense of certainty?		
It's only a matter of time before I go backwards.	I: Ok, so you...	
		Restrictions are instructions on keeping safe.

I will be unsafe. The community is unsafe. Avoiding responsibility.	P: They're my instructions, right, and it means, which means I have sooo many people I can call for help if I need it. I've got most numbers.	Emphasis on lots of support ('sooo many people'). Desire for support and containment in the community despite extra freedoms/choice. Wants options and to be held in mind?
	I: Right, I see, so you...	
		Expectation that they have the capacity to make a decision that warrants recall. Are they seeing themselves as unsafe or not able to cope in the community?
Abandoned in the past.	P: I basically have a backup if anything goes wrong and I feel unsafe or even if I just feel like I can't cope. I could be wrong but I think someone told me that without the license and stuff I wouldn't have backup support out here.	Needs support in order to feel like they can cope. Compliant with restrictions in order to have community support? Cost versus benefits of restrictions.
Fear of history repeating itself.		
Desperation.		'Back up' could suggest feeling like they have someone on their side?
	I: Thank you very much for sharing. I think you did you a great job of explaining, thanks. Can you say a bit more your experience of this back up?	
	P: Well I didn't have that kind of back up before. So umm, like when I got into trouble before, like years ago right, when I was younger haha, I didn't have the kind of support, yeah. I reckon I could've done with it, although knowing me I probably wouldn't have let it get given to me. Staff are more supportive.	Wasn't support in the past? ('didn't have that kind of back up before').
I am always going to be vulnerable.		Didn't feel supported enough when they got into trouble in the past. Scared that not having support inevitably leads to reoffending? What does back up mean exactly?
I need protecting.		
I will/am risky and unsafe. Internal struggle about identity.		Community staff are more supportive.
	I: Sorry to interrupt. Are you, err, talking about community staff?	
	P: Oh yeah, like the staff at home and the professionals, like XX (psychologist) here	Community professionals and staff are more supportive.

Feeling powerlessness.	with me are more supportive, umm. See what I mean? I, oh, I can't. People need to remember that someone like me is called a vulnerable person, right. I need supporting.	Conflicted about what they're saying? Professionals sometimes forget they are vulnerable. Think their needs to unseen? Convinced that being vulnerable means support is needed to manage. What does vulnerable look like? Risks of not being supported as a vulnerable person?
Anxiety.	I: Did anything help you get to the point where you felt supported enough to leave hospital, with the safety net I mean?	
Relief. Feeling excluded from the table.	P: Well, right, you see I had a parole and they decided when I'd get released. I had one in July and they passed it, but I had to wait 21 days for someone to sign the form, to say yes.	Lack of control over the process.
	I: What was the like for you? Good, bad?	
Feeling let down. Hopelessness about future. Grieving loss of future. Feeling done to.	P: Oh, umm, that wait was like really anxious, actually. I was anxious, because I didn't know what would happen, it felt, well it was completely out of my say, right. But when I got the news I was so happy.	Anxious about parole board decision. Felt uncertain. Happy about the outcome.
	I: How involved were you in this discharge, or transition process?	
Social injustice.		Was involved in conversations about doing overnight community stays.
Hopelessness. Feeling disappointed.		'You've got to understand' stresses importance.

Example participant thematic maps
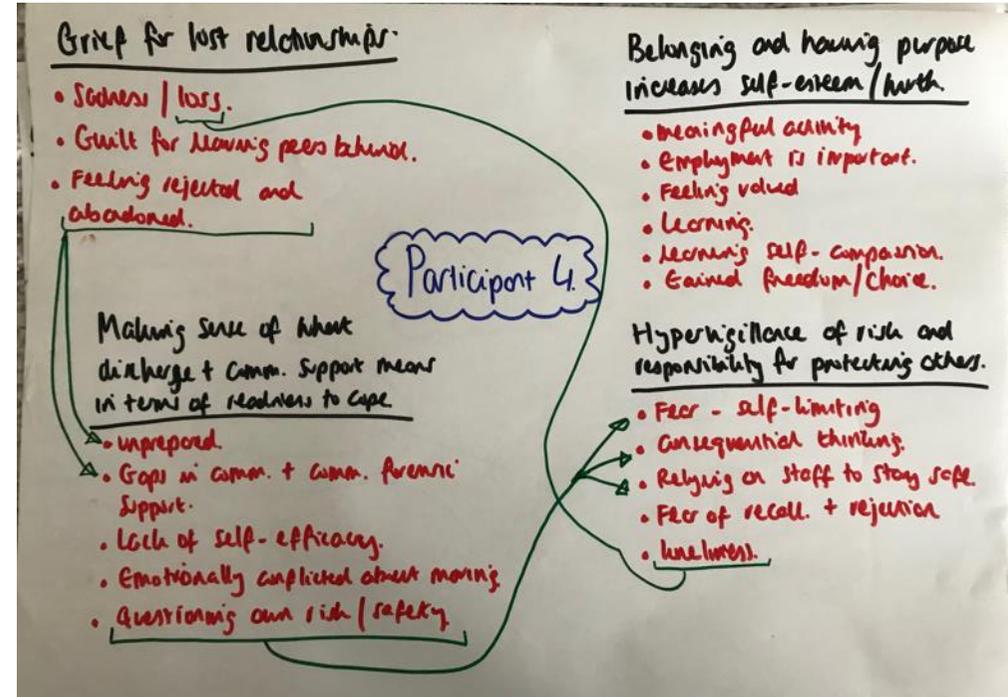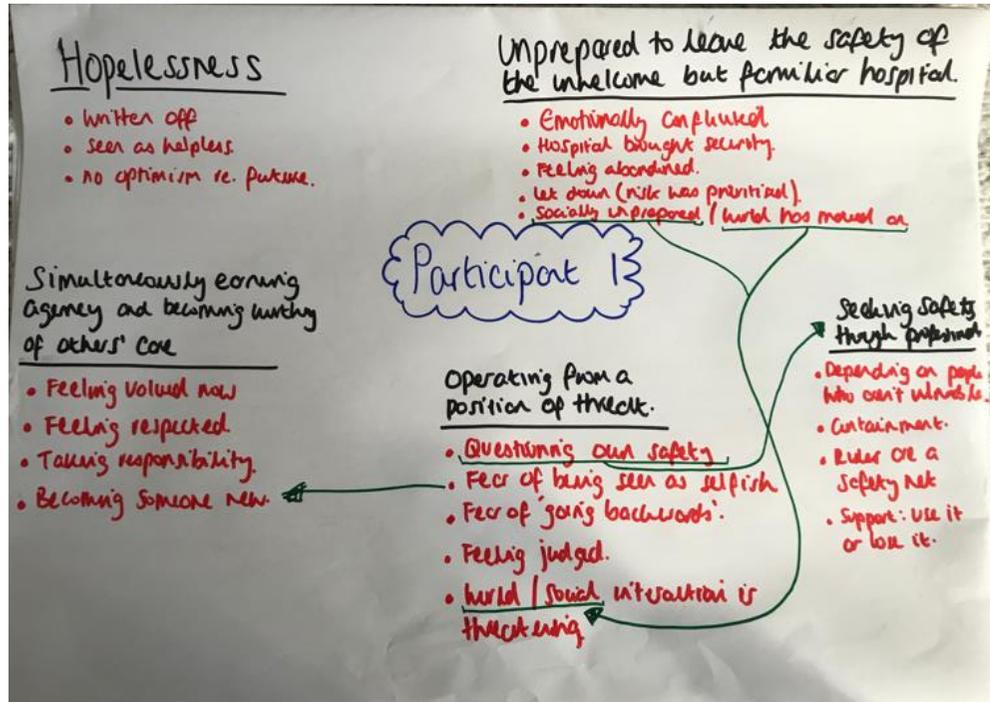
Development of superordinate themes

Theme Area One: Leaving hospital	Theme Area Two: Entering the community
Losses/negatives: - Security/containment/support (P1, P2, P5, P7) - Abandoned by staff (P1, P3, P4, P5) - Feeling unprepared to leave/risk prioritised (P1, P2, P4) - Institutionalisation effects – e.g. passivity (P2, P5, P7, P8) - Lost care/loneliness (P2, P4, P5) - Loss of peer/friendships/staff (P3, P4, P5, P8) - Emotionally conflicted about moving on (P4) - Guilt at leaving peers behind (P4) - Distressed/overwhelmed (P3, P4, P5) - Limited say over transition/kept in the dark (P2, P3, P6) - External locus of control regarding making discharge happen (P7, P8) - Shared experiences with similar others (P8)	Losses/drawbacks/negatives: - The world has moved on/marginalised (P1, P5) - Loss of certainty about own risk (P1, P2, P3, P4, P6) - Feeling judged and rejected (P1, P4, P6) - Initial loss of hope (P1) - Feeling controlled (P1, P2, P6) - Being treated unfairly (P2) - Relationships feel dangerous/keeping peers at arm's length – feeling socially vulnerable (P1, P2, P4, P5, P6) - Loneliness (P1, P4, P5, P6, P7, P8) - Loss of general safeness (P3, P4, P5, P6) - Compliance with rules limits non-social opportunities (P2, P4, P5, P7) - Fear of recall (P1, P2, P3, P4, P5, P6, P8). - Living by other people's expectations and trying to prove self (P2, P3, P5, P6) - Shame/embarrassment (P3) - Feeling like a burden (P3, P5) - Increased dependence on staff to feel safe (P1, P3, P4, P5) - Limited opportunity to express/explore risky thoughts (P4, P5, P7) - Increased consequential thinking/hypervigilance (P4, P5) - Feel responsible for other safety (P1, P4) - Unhappy about levels of community supervision (P2, P6) - Independence/choice is overwhelming (P5, P6, P7, P8)
Gains/positives: - Increased physical freedoms/choice (P3, P6) - Hopefulness (P5, P6) - Opportunity to become a safer person/to self-manage (P3, P4, P5, P6, P8) - A fresh start/different relationships (P2, P5, P7) - Reconnecting with family (P7)	Gains/positives: - Rules/professionals are a safety net or protective factor (P1, P3, P6, P8) - Supportive/trusting staff relationships (P1, P3, P5, P6, P8) - Becoming someone new (P1) - Feeling valued/respected/heard by others (P1, P4, P5, P6, P8) - Increased opportunity for taking responsibility (P1) - Meaningful activity (P3, P4) - Day-to-day choice/freedom (P3, P4, P5, P6, P7, P8) - Opportunities for learning (P3, P4, P7, P8) - Occupation (P3, P4, P7) - Sense of someone who can belong (P3, P7) - Pride/achievement (P5, P6) - Increasing self-confidence (P5) - Relative privacy (P6)

Subordinate Themes	Theme One: A chance to "turn my story around"		Theme Two: Feeling "torn apart"		Theme Three: The cost of "trying to please other people"	
Subordinate Themes	A sense of having choice and freedoms within the context of a safety net *"A chance to have a freer life" (P6)*	A chance at a renewed identity	Loss of connection and familiarity *"It's lonely, like lonelier than I was told about!" (P5)*	Underlying insecurity and uncertainty *"I felt destroyed" (P8)*	Trying to satisfy imposed rules and expectations *"My life is about waiting for people to make decisions" (P8)*	Intrapersonal impacts
	Increased freedoms and day-to-day choice (P1, P3, P4, P5, P6, P7, P8).

Opportunities for learning/achieving (P3, P4, P5, P6, P7, P8).

Rules/professionals are a safety net or protective factor (P1, P3, P6, P8).

Meaningful activity and occupation (P3, P4, P7).

Hopefulness (P5, P6). | Feeling valued/respected by others (P1, P4, P5, P6, P8).

Becoming someone knew (a person who can belong and contribute) (P1, P2, P3, P5, P7).

Opportunity to become a safer person/to self-manage (P3, P4, P5, P6, P8).

A fresh start at helpful relationships (P2, P5, P7). | Abandoned by hospital staff (P1, P3, P4, P5).

Loss of friendships and shared experiences (P3, P4, P5, P8).

Guilt at leaving peers behind (P4).

Lost security/containment (P1, P2, P5, P7). | Loneliness (P2, P4, P5).

Limited sense of agency (P2, P3, P6, P7, P8).

Distressed and emotionally conflicted about moving on (P3, P4, P5).

Initial hopelessness (P1, P2).

Loss of general safeness (P3, P4, P5, P6). | Feeling controlled, supervised and treated unfairly (P1, P2, P6).

Expecting others judge on the basis on past mistakes (P1, P4, P6).

Living by other people's expectations and trying to prove self (P2, P3, P5, P6).

Compliance with rules limits opportunities (P2, P4, P5, P7).

Complying out of fear (P1, P2, P3, P4, P5, P6, P8). | Isolation (P1, P4, P5, P6, P7, P8).

Feeling burdensome and ashamed (P3, P4, P5, P7).

Increased dependence on staff and conditions in order to feel safe (P1, P3, P4, P5).

Feeling socially vulnerable (P1, P2, P4, P5, P6).

Loss of certainty about own risk and feeling responsible for others safety (P1, P2, P3, P4, P6). |

			A lack of preparedness (P1, P2, P4).		
Description	Theme one describes participants expectations of how discharge and community reintegration was an opportunity for a renewed identity. This captures individuals hopes of gaining increased day-to-day freedoms and becoming a safer and valued member of society, as well as the 'safety net' mechanisms in which these expectations did sometimes become a reality, such as through occupation, meaningful activity, rules and supportive staff relationships.	Theme two captures participants distressing experiences of initially leaving hospital. Participants expressed a sense of feeling abandoned, disconnected and uncontained after losing meaningful relationships with friends and supportive hospital staff. This theme describes the consequences of this, such as unexpected loneliness, emotional conflict, and a sense of feeling unprepared for the community transition.		Theme three describes participants perceptions of being unable to fully renew their identities and/or form new social connections because of the social expectations of professionals and the public, as well as the need to follow imposed conditions out of fear of recall. It captures the impacts of this on participants beliefs about themselves and others, such as a disempowerment, questioning their level of risk and denying themselves opportunities for connection, as well as relying upon staff and legal conditions in order to feel safe.	