The views of people with intellectual disabilities and their families and carers on shared decision-making and staff's viewpoints on deprescribing medication for people with intellectual disabilities

Amy Calderbank
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Supervised by:
Dr Jennie Day
Dr Andrea Flood

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Contents

Word Count

Section	Words
Introductory Chapter	1105
Systematic Review	11199
Empirical Chapter	10403
Appendices	2279
Total	**24986**

Introductory Chapter: Thesis Overview

It is currently estimated that there are approximately 1.5 million people living with a learning disability within the United Kingdom (UK), which is 2.16% of adults in the UK (Mencap, no date). There are numerous definitions of learning disability, however within the UK the most common definitions used are the World Health Organisation (WHO) definition, the Government's White Paper Valuing People: A New Strategy for the Learning Disability for the 21st Century (2001) definition, and the National Institute of Health and Care Excellence (NICE) definition. These definitions are as follows:

- *"A condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor and social abilities"* (WHO, 1992). The WHO also classify learning disabilities in terms of severity, ranging from mild to profound.
- A learning disability is "*a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development.*" (Department of Health, 2001).
- *"a learning disability is generally defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood"* (NICE, 2015).

The term 'learning disabilities' is widely used and accepted across the UK, and within the National Health Service (NHS), for example 'community learning disability team' (CLDT). However, 'intellectual disabilities' is becoming the term which is accepted internationally and within research (NICE, 2015) and so for this thesis this terminology will be used.

Within the UK, CLDTs are multidisciplinary teams often consisting of nurses, psychiatrists, psychologists, speech and language therapists, physiotherapists and occupational therapists with the aim to deliver high-quality healthcare (Slevin et al, 2008). The role of a clinical psychologist within a CLDT is diverse, with an aim to promote valued, inclusive lives for individuals with an intellectual disability (British Psychological Society, 2011). Clinical psychologists play an important role in increasing collaboration, communication, and understanding amongst the multidisciplinary team (Carr et al, 2016), whilst also identifying and assessing mental health challenges and delivering psychological therapy (British Psychological Society, 2016).

This thesis comprises of two papers: a systematic literature review and an empirical research paper, both of which are briefly described below. Both papers have been prepared for submission to the Journal of Intellectual Disabilities (Appendix 1). A systematic literature review was conducted exploring individuals with an intellectual disability and their families' experiences of shared decision-making (SDM), which for the purpose of this review was defined as a collaborative decision (NICE, 2015b), between an individual with an intellectual disability and/or their family member and another party. Systematic reviews have previously explored SDM experiences of patients accessing cancer treatments (Kashaf and McGill, 2015), patients accessing musculoskeletal physiotherapy (Grenfell and Soundy, 2022), and of patients with symptomatic severe aortic stenosis (van Beek-Peeters et al, 2020). However, to the researcher’s knowledge no systematic review has been completed exploring experiences of SDM within an intellectual disabilities population.

A comprehensive systematic search was completed which identified seventeen qualitative papers. Thematic synthesis revealed five analytical themes: 1) The

Influence of Interpersonal Factors and Relations, 2) Knowledge, Information and Communication, 3) Paternalism and Protection, 4) Reflection and Impact on the Self, 5) Power, Control and Choice.

This review demonstrated the complexity of SDM within the intellectual disability population, with varied factors for consideration. Through this review, some papers referred to difficulties faced in healthcare decisions (Goldsmith et al, 2012; Horner-Johnson et al, 2022; McCarthy 2010; Redley et al, 2013; Sheehan et al, 2019; Walmsley et al, 2016; Whitehead et al, 2016), particularly related to medication use. Sheehan et al (2019) highlighted the importance of SDM for the use of psychotropic medications for individuals with an intellectual disability. Findings revealed that individuals with an intellectual disability were highly compliant with medication, based largely on holding an unquestioning view of medication as being important and beliefs that the psychiatrist holds the power. Some individuals were unaware of their right to be involved in the decision-making process, whilst families and carers also described their lack of involvement in decisions.

It is well documented that the use of psychotropic medications is high amongst individuals with an intellectual disability, often in the absence of diagnosed mental health conditions (Costello et al, 2022). The ‘stopping over medication of people with a learning disability, autism or both’ (STOMP) initiative was introduced in 2016 following concerns of the unnecessary use of psychotropic drugs, placing people at risk of developing physical health conditions and even causing premature death (Mehta & Glover, 2015). However, it is unclear to what extent STOMP has impacted the rates of prescribing and deprescribing (Branford et al, 2019).

A recent online questionnaire was sent to UK psychiatrists working in the field of intellectual disabilities, asking for their opinions on the challenges faced by psychiatrists to implement STOMP, and asked for them to share any positive experiences from the implementation process (Deb et al, 2023). Thirty-nine percent of psychiatrists returned the questionnaire, and results demonstrated that in areas which had support for STOMP implementation psychiatrists reported better multi-agency working, increased awareness of STOMP amongst stakeholders, satisfaction in the process with successful antipsychotic rationalisation, and improved quality of life facilitated by reduced medication adverse events (Deb et al, 2023). Areas which were lacking support for STOMP implementation reported feeling dissatisfied and little success in medication rationalisation (Deb et al, 2023).

Despite the introduction of STOMP, the over-medication of individuals with an intellectual disability continues to be seen across CLDTs (Javaid et al, 2020). The empirical paper therefore explored factors which are influential in the deprescribing of psychotropic medications amongst CLDTs. A Q-Methodology study was conducted with NHS professionals based in CLDTs across the Northwest of the UK. Findings from the Q-Sort revealed three factors: *"Willingness to Deprescribe and Trying Alternative Interventions", "Perceptions of Risk and Behaviours that Challenge",* and *"Professional Opinions, Rational Clinical Judgement and Safe Ethical Practice".* Findings from this empirical study demonstrate how complex deprescribing decisions are in practice, with multiple factors to be considered. Implications for practice following this study include the need for training in deprescribing guidelines and STOMP awareness, and enlightening multidisciplinary teams of their role to implement STOMP guidelines. Future research is recommended for a Q-Sort to be completed with individuals with an intellectual disability and their families to gain their views of factors which they feel are

influential in the deprescribing process to ensure a holistic view can be gained of the current situation.

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Chapter 1: Systematic Review

A systematic review of individuals with an intellectual disability and their families' experiences of shared decision-making

Amy Calderbank

Prepared in accordance with guidelines from the Journal of Intellectual Disabilities

Abstract

Shared decision making (SDM) has become increasingly prevalent over recent years, which has sparked a change in thinking within intellectual disability services towards decision-making (Bigby et al, 2022). This review focused on the experiences of people with an intellectual disability and families in SDM. A systematic search identified 17 qualitative studies from APA Psychinfo, APA Psycharticles, PubMed, CINAHL Plus and Medline databases. A thematic synthesis identified five themes: 1) The Influence of Interpersonal Factors and Relations, 2) Knowledge, Information and Communication, 3) Paternalism and Protection, 4) Reflection and Impact on the Self, and 5) Power, Control and Choice. It is recommended that a future systematic review is conducted to collate professionals' experiences of SDM within the field of intellectual disabilities to gain a wider view. Future research into strategies and practical tools to aid SDM within the field of intellectual disabilities would also be helpful.

Keywords: Collaboration, Experiences, Intellectual Disability, Review, Shared Decision-Making

Introduction

SDM has become increasingly present over recent decades (Bomhof-Roordink et al, 2019; Frosch et al, 1999; Härter et al, 2017; Stiggelbout et al, 2012), however how articles define SDM differs conceptually. For example, Makoul et al (2006) conducted a systematic review to determine the range of conceptual definitions, identifying 161 definitions, with 31 different concepts. In over 50% of the definitions, concepts relating to “patient values/preferences” and “options” appeared. Researchers proposed that the essential elements for SDM include defining/explaining the problem, presenting options, discussing the pros/cons, considering patient values/preferences, discussing patient ability/self-efficacy, doctor knowledge/recommendations, checking understanding, making or explicitly deferring decision and arranging a follow up.

Bomhof-Roordink et al’s (2019) systematic review searched seven databases with an aim to provide an overview of SDM models within healthcare settings across various patient populations. This review demonstrated that ‘describing treatment options’ was the most prominent component across models. In over 50% of the included articles (40), making the decision, patient preferences, tailoring information, deliberation, creating choice awareness and learning about the patient were all important components used within models.

SDM ensures individuals have a good understanding of the benefits, harms, and possible outcomes of different options available. SDM allows patient preferences to be incorporated into consultations – improving knowledge, transparency, communication, and leaves patients feeling informed regarding their treatment, reflected in NICE guidelines (Hoffmann et al, 2014; NICE, no date; Shay et al, 2015).

The United Nations' Convention on the Rights of Disabled Persons (United Nations, 2006) recognises that individuals with an intellectual disability should be recognised by law as equal to others (Article 12), and that those with disabilities have the right to the highest attainable standards of health (Article 25). This convention challenges paternalistic views previously held towards individuals with an intellectual disability (Frosch et al, 1999; Sheehan et al, 2019), and has generated a change in thinking towards decision-making processes within CLDTs (Bigby et al, 2022).

In practice, research has shown that SDM within intellectual disability populations can be complex, hindered by negative attitudes from healthcare professionals regarding individuals' capabilities (Stiggelbout et al, 2015). Individuals may struggle to weigh up options and hold long-term consequences in mind, and their severity of intellectual disability can complicate decision-making (Noorlandt et al, 2020).

To the best of our knowledge, there is no existing review focusing on individuals with an intellectual disability and their families' experiences of SDM. The current review therefore aims to increase understanding, focusing on the research question: What are the experiences of individuals with an intellectual disability and their family members regarding shared decision-making?

A review protocol was devised by the research team, however the review was not registered online. There were no competing interests of the review authors.

Method

Eligibility Criteria

Table 1 shows the inclusion and exclusion criteria for this systematic review.

Table 1. Eligibility Criteria

Inclusion criteria	Exclusion criteria
Peer-reviewed journal	Grey literature
Individuals (with intellectual disabilities, 18+) and/or their families' experiences of SDM	Studies which only commented on staff experiences, or if within the results section it was not clear which data was obtained from service users and/or families. Studies were excluded if participants were children.
Qualitative methodology	Quantitative methodology
The paper was available in English	The paper could not be obtained in English

Search Strategy

Five electronic databases (APA Psychinfo, APA Psycharticles, PubMed, CINAHL Plus and Medline) were searched using search engines OVID and EBSCO. The search terms included the following: ("mental* handicap*" or "intellectual* impair*" or "mental* retard*" or "learning disabilit*" or "developmental disabilit*" or "developmental disorder*" or "intellectual disabilit*" or "intellectual developmental disorder*" or "down* syndrome" or "Trisomy 21" or "learning diff*") AND ("Shared decision*" or "Shared decisionmaking" or "Shared decision-making" or "Patient decision*" or "Patient decisionmaking" or "Patient decision-making" or "SDM" or "Sharing decision" or "decision support*" or "shared N4 decision"). The search terms were cross checked by another member of the research team (JD). Comprehensive searches were initially conducted in October 2022, and updated in May 2023. The updated search revealed one additional paper which was added to the final articles for synthesis.

Data Extraction

Study characteristics pertinent to this review were then extracted into a Microsoft Excel document. These are summarised in table 2. For studies that included data from both staff and service users or families, the data relating to service users and/or families experiences was extracted and included. Where extraction of the service users and/or family's data was not possible (for example, if it was not possible to differentiate between data obtained from staff) then this was excluded. Themes described in results sections that were not generated at least in part by service user and/or family experiences were not extracted.

Assessment of Study Quality

To ensure reliability and validity of the studies, a quality appraisal was completed using the CASP Qualitative Studies Checklist (Critical Appraisal Skills Programme, 2018; Appendix 3). This checklist consists of ten questions which enables the researcher to evaluate elements of the study including the validity of the results, reporting of the results, and how the results can help locally (CASP UK, 2018). Each of the final papers were quality assessed by the lead author (AC) who assigned a numerical score to each of the articles. Each question was numerically scored depending on whether the criteria had been met entirely (1), whether criteria was partially met (0.5), or not met at all (0; Butler et al, 2016) with a maximum possible score of 10. An external researcher (HG) independently appraised the final articles. High quality papers were those with a score of 9-10, moderate quality papers had a score of 7.5 – 8.5 and low-quality papers were those which obtained scores less than 7.5 (Butler et al, 2016). Scores were consistent between the reviewers, which suggested a level of trustworthiness for the review.

Data Synthesis

A qualitative synthesis was felt to be best aligned to the nature of the explorative questioning and collecting patient experiences. Thematic synthesis has been shown to be an effective methodology for analysing patient experiences (Atmojo et al, 2020; Doyle et al, 2013; Harden et al, 2004), and considering many of the included articles had used thematic analysis, thematic synthesis was felt most appropriate for this review. Thematic analysis has developed over time and is considered a "family of methods" as opposed to a singular method with one defined way of practising (Braun & Clarke, 2023).

For this thematic synthesis, studies were analysed and coded 'line-by-line', and these initial codes were developed into 'descriptive themes', which were generated into 'analytical themes' (Thomas & Harden, 2008). The lead researcher (AC) independently line-by-line coded each of the articles, forming descriptive themes with sub-themes. A second researcher (AF) then provided feedback which contributed to re-coding themes. Three rounds of coding took place before both researchers felt satisfied. Themes and sub-themes were named using language from the articles wherever possible.

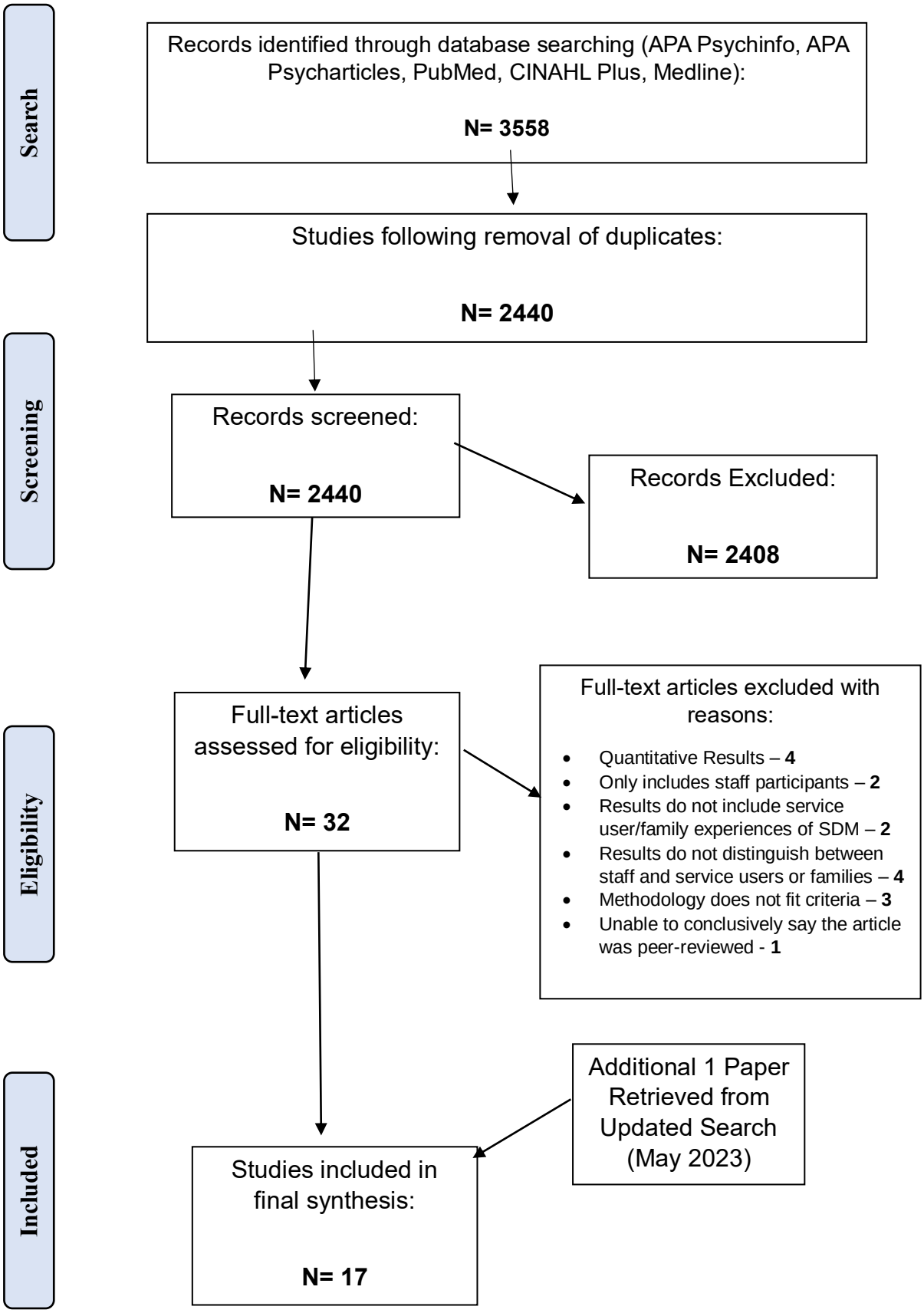
Both these researchers have experience in working in intellectual disability services and reflected that they actively advocate for SDM, and service user involvement where possible, however are also constrained at times by service policies and legal contexts such as the mental capacity act. It is therefore important to acknowledge reflexivity, and the potential for bias whilst developing and interpreting themes (Galdas, 2017).

Results

Study Selection

The lead author (AC) searched the five listed databases using the inclusion and exclusion criteria; the initial searches yielded 3558 results. Records were exported from the databases into a free web-tool (Rayyan). Duplicates were identified and removed using the Rayyan software. Records were first screened by their titles, and then abstracts. 10% of the articles were verified by two external researchers (EP and HG) who screened papers by their titles and abstracts, following the inclusion and exclusion criteria. Articles selected for inclusion were approved by all three researchers, showing consistency between the reviewers. Following the initial screening process, 32 papers were exported into the Microsoft Excel spreadsheet. Where suitability was unclear from screening the title and abstracts, the author referred to the full-text paper. Upon reading the full-text articles, a further 16 of the papers were excluded for a variety of reasons as evidenced in Figure 1. One additional study was added to the final articles with the re-run of searches completed in May 2023.

Figure 1. PRISMA Diagram



Study Characteristics

All the studies were published between 2000 and 2023, indicating that research SDM within intellectual disability populations has become of interest in recent times. The studies were carried out in: United Kingdom (6), Australia (3), New Zealand (2), The Netherlands (2), United States of America (1), Norway (1), Catalonia (1), and Israel (1).

Four of the papers identified experiences from family members only, five papers collected data from those with an intellectual disability only, one paper collected experiences from families and individuals with an intellectual disability, one paper collected experiences from families and staff, three papers collected data from individuals with an intellectual disability and staff, two of the papers collected data from individuals with an intellectual disability, family and paid staff, and one paper collected data from individuals with an intellectual disability and those with mental health difficulties (whose data was disregarded if they did not have an intellectual disability also). Staff data from any of these studies was disregarded in this review.

Most of the articles included had primary aims referring to SDM and/or the process of making choices. Three of the articles did not refer to SDM within their titles or primary aims, however referred to SDM within the results and therefore appropriate for the review (Goldsmith et al, 2012; Sommerstad et al, 2021; Whitehead et al, 2016). Nine papers focused on decisions relating to healthcare (Goldsmith et al, 2012; Horner-Johnson et al, 2022; McCarthy, 2010; Redley et al, 2013; Sheehan et al, 2019; Sommerstad et al, 2021; Wagemans et al, 2013; Walmsley et al, 2016; Whitehead et al, 2016), three focused on choices in day-to-day decisions in living accommodation (Espiner & Hartnett, 2012; Noorlandt et al, 2023; Pallisera et al, 2021), and five focused on general experiences of SDM (Bigby et al, 2019; Bigby et al, 2021; Bigby

et al, 2022; Webb et al, 2020; Werner & Chabany, 2016). Table 2 below summarises the study characteristics.

Table 2. Characteristics of included studies.

No.	Author, year of publication and title	Research Aims	Participants	Sampling Approach	Setting	Methodology	Analysis	Themes				
								1	2	3	4	5
1	Bigby et al (2021) *"I used to call him a non-decision-maker - I never do that anymore": parental reflections about training to support decision-making of their adult offspring with intellectual disabilities*	To fill the gap in evidence about building the capacity of decision supporters.	18 Parents of individuals with ID	Purposive Sampling	Australia	Semi-structured interviews and mentoring discussions	Line-by-line coding using grounded theory techniques	X		X	X	X
2	Horner-Johnson et al (2022) *"It Would Have Been Nice to Have a Choice": Barriers to Contraceptive Decision-making among Women with Disabilities.*	To conduct an initial exploration of the experiences of women with disabilities in finding, understanding, and using contraceptive information.	17 in total study (4 specifically ID whose data were used for this review)	Volunteer Sample	USA	Focus Groups – Interviews	Content Analysis		X		X	X
3	Sommerstad et al (2021) *Experiences of ward atmosphere in inpatients with intellectual disability and mental illness: clinical implications for mental health nursing*	To enhance the understanding of ward atmosphere for inpatients with co-occurring ID and mental illness, by exploring patients' experiences from a specialised mental health inpatient unit.	10 Adults - ID and MH	Purposive Sampling	Norway	Semi-structured Interviews	Content Analysis			X	X	X
4	Sheehan et al (2019) *Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a*	To explore experiences of psychotropic medication use among people with intellectual disability (ID) and their carers, with a focus on how medication decisions are made.	14 adults with ID, 12 family carers and 12 paid carers	Purposive Sampling	UK	Semi-structured Interviews	Thematic Analysis	X	X	X	X	X

	multistakeholder qualitative study in the UK											
5	Werner & Chabany (2016) *Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents.*	Examined the perceptions of persons with ID, persons with MH, and parents regarding guardianship and SDM.	33 individuals (ID, MH, Parents of people with ID and Parents of people with MH)	Convenience Sampling	Israel	Focus Groups – Interviews	Content Analysis			X	X	X
6	Wagemans et al (2013) *End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives*	To clarify the process of end-of-life decision-making for people with intellectual disabilities from the perspective of patient representatives	16 patient representatives after the deaths of 10 people with ID	Purposive Sampling	Netherlands	Interviews	Grounded Theory	X	X	X		X
7	Webb et al (2020) *Service users' experiences and views of support for decision-making.*	To inform how the new support principle should be implemented in practice.	41 people with MH problems and/or ID (only ID ppts used)	Purposive Sampling	UK	Semi-structured Interviews	Thematic Analysis	X	X	X	X	X
8	Redley et al (2013) *'The involvement of parents in healthcare decisions where adult children are at risk of lacking decision-making capacity: a qualitative study of treatment decisions in epilepsy*	To consider the role of parent-proxies in the management of epilepsy in adult children with ID who are at risk of lacking capacity to make decisions about their health care	21 mothers	Convenience Sampling	UK	Semi-structured Interviews	Analytic Induction				X	X
9	Espiner & Hartnett (2012) *'I felt I was in control of the meeting':*	To examine the perspectives of adults with an intellectual disability, their family, caregivers and/or advocates and key	10 Individuals with ID (5M, 5F), 10 family / caregivers / and/or	Purposive Sampling	New Zealand	Semi-structured Interviews	Content Analysis	X	X		X	X

	facilitating planning with adults with an intellectual disability	staff on a newly introduced approach to the facilitation of personal plans.	advocates, third group was key staff members										
10	Pallisera et al (2021) *'Being in control: Choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff.*	To study the role of people with intellectual disability in taking decisions regarding the support provided under the supported living model.	13 people with intellectual disability, and 6 support professionals	Purposive Sampling	Catalonia	Semi-structured Interviews	Thematic Content Analysis	X			X	X
11	McCarthy (2010) *'Exercising choice and control - women with learning disabilities and contraception*	To ask women with learning disabilities about the experience of being prescribed contraception.	23 women with learning disabilities	Volunteer Sampling	UK	Semi-structured Interviews	Multistage Narrative Analysis	X	X			X
12	Whitehead et al (2016) *'Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers.*	To explore how people with intellectual disabilities (ID) and their support workers experience and practice autonomy in relation to the management of diabetes.	People living with an ID and type 1 (N = 8) or type 2 (N = 6) diabetes and their support workers (N = 17)	Convenience Sampling	New Zealand	Semi-structured Interviews	Thematic Analysis			X		
13	Bigby et al (2022) *Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences.*	To understand more about the difficulties parents of adults with intellectual disabilities experienced in providing decision support and their strategies for resolving them.	23 parents of adults with ID	Purposive Sampling	Australia	Semi-structured Interviews	Thematic Analysis	X	X	X	X	X
14	Bigby et al (2019) *Providing support for decision making to adults with intellectual*	To understand the experiences of family members and disability support workers in providing support to adults	11 family members, and 12 workers in disability support	Volunteer Sample	Australia	Individual or Focus Group Interviews	Thematic Analysis	X	X	X	X	X

	disability: Perspectives of family members and workers in disability support services	with intellectual disability in Victoria, Australia	services.									
15	Walmsley et al (2016) *The experiences of women with learning disabilities on contraception choice*	This research set out to root the reproductive experiences of women with learning disabilities within the context of wider debates on human rights, reproductive justice and supported decision-making.	19 women with learning disabilities	Volunteer and Snowballing Sampling	UK	Interviews	Unsure	X	X			X
16	Goldsmith et al (2012) *Informed consent for blood tests in people with a learning disability*	To explore the information needs of people with mild-to-moderate learning disabilities with respect to consent for blood tests and to identify ways of facilitating informed consent.	14 participants with a ID	Purposive Sampling	UK	Observations and Interviews	Thematic Analysis	X	X		X	
17	Noorlandt et al (2023) *Degree of autonomy in making independent choices by frail older people with intellectual disabilities in a care home: A descriptive ethnographic study*	To gain more insight into autonomy of older people with intellectual disabilities in a residential care facility in making choices.	6 Participants with ID	Purposive Sampling	The Netherlands	Observations and Interviews	Ethnographic Approach, analysed using the 'constant comparative method'			X		X

Note: ID = Intellectual Disability, MH = Mental Health. Themes: 1)The Influence of Interpersonal Factors and Relations, 2) Knowledge, Information and Communication, 3) Paternalism and Protection, 4) Reflection and Impact on the Self, 5) Power, Control and Choice.

Quality Assessment

The results of the quality assessments yielded scores ranging from 8– 10. These scores can be seen in table 3. The quality of the papers therefore used in this review ranged from moderate quality to high quality (Butler et al, 2016). Fourteen of the papers were rated as high quality, meeting most of the CASP criteria and therefore enabling rich interpretations of the data, and three of the papers were deemed to be moderate quality.

All papers included a statement of aims, methodology, and design of the study. One of the common methodological problems within the papers included in the review was the lack of acknowledgement and reflection on the relationship between the researcher and participants. This was the lowest scoring area for the articles, with only five out of the seventeen papers making some form of reference to this and therefore failing to acknowledge any potential researcher bias.

Table 3. CASP Ratings for Included Papers: Quality Assessment Table

Authors	Aims	Methodology	Design	Recruitment	Data Collection	Researcher Bias	Ethics	Data Analysis	Findings	Valuable	Score /10
Bigby et al (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Horner-Johnson et al (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Sommerstad et al (2021)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	9.5
Sheehan et al (2019)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	9.5
Werner & Chabany (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Wagemans et al (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Webb et al (2020)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	9.5
Redley et al (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Unsure	8
Espiner & Hartnett (2012)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
Pallisera et al (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
McCarthy (2010)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes	8.5

Whitehead et al (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Bigby et al (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Bigby et al (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Walmsley et al (2016)	Yes	Yes	Yes	Yes	Yes	Unsure	Unsure	Yes	Yes	Yes	9
Goldsmith et al (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Noorlandt et al (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10

Note: Questions in full (CASP, 2018), see Appendix 3.

Summary of Findings

Five themes emerged from the data: 1) The Influence of Interpersonal Factors and Relations, 2) Knowledge, Information and Communication, 3) Paternalism and Protection, 4) Reflection and Impact on the Self, 5) Power, Control and Choice.

Table 4. A table showing the themes and subthemes

	Theme	*Subtheme*
1	**The Influence of Interpersonal Factors and Relations**	• **Importance of Knowing the Individual** (1, 4, 6, 7, 14) • **Personal Qualities and Attributes** (1, 4, 7, 10, 12, 13, 14, 16) • **Advantages of Support Networks** (1, 7, 9, 11, 14, 16) • **Supportive Collaboration** (4, 6, 15)
2	**Knowledge, Information and Communication**	• **Reasonable Adjustments and Adaptations** (2, 4, 6, 9, 11, 13, 16) • **Feeling Informed and Consenting to Decisions** (2, 4, 11, 15, 16) • **Limited Awareness and Insight** (11, 13, 16) • **Limited Opportunities for SDM** (7, 13, 14)
3	**Paternalism and Protection**	• **Negative Assumptions and Judgements** (1, 3, 4, 5, 14) • **Limiting Decisions Based on Consequences** (5, 13, 14) • **Managing Risk and Safeguarding** (4, 5, 6, 7, 13, 14, 17) • **Family Influencing Decisions** (1, 5, 13, 14) • **Advocating on Behalf of Others** (4, 6, 13)
4	**Reflection and Impact on the Self**	• **Confidence** (1, 7, 9) • **Self-efficacy and Autonomy** (5, 7, 9, 10, 13, 16) • **Self-Advocating** (1, 9, 16) • **Experiences of Feeling Heard** (2, 3, 4, 8, 9, 10) • **A Lack of Involvement Causes Negative Emotions** (3, 4, 5, 7, 8, 14) • **Self-Reflection and Changed Perspectives** (1, 14)
5	**Power, Control and Choice**	• **Invited Participation** (2, 4, 7, 8, 9, 13) • **Forced into Decisions** (15) • **Professionals Hold the Power** (3, 4, 6, 7, 10, 11, 17) • **Varying Levels of Choice in Decisions** (1, 3, 4, 7, 9, 10, 13, 17) • **Navigating Limits and Boundaries** (5, 6, 14) • **Giving Control to Others** (3, 4, 5, 7)

Note: The numbers in brackets correspond to articles found in Table 2.

Theme 1:The Influence of Interpersonal Factors and Relations

The first theme highlighted interpersonal factors and relational interactions between individuals with an intellectual disability and family participants in SDM. This theme highlighted some of the personal qualities individuals participating in SDM utilise and demonstrate, whilst also highlighting the importance of the relationship between service users and their family members.

Importance of Knowing the Individual. Participants acknowledged that knowing an individual well was an important factor when supporting decision-making (Bigby et al, 2019; Sheehan et al, 2019; Webb et al, 2020), with one family member explaining "to work with the person you're helping to make the decision you need to have as much information about that person as possible and what their needs are" (Bigby et al, 2019). Knowing the individual was described as understanding an individual's needs and their cognitive capacity, life experiences, strengths and weaknesses and communication preferences (Bigby et al, 2019).

Families expressed an intuitive "sense of knowing" the needs of their loved ones, and acknowledged the ease to which they exerted influence at times due to feeling they understood and knew the individual well (Bigby et al, 2021; Sheehan et al, 2019). Families reflected how this could place their loved ones in vulnerable positions as individuals may be susceptible to their suggestions, "I've realised how many decisions I was constantly making …out of every person on the planet, he loves me the most. And therefore, he's acutely vulnerable to suggestions that I make and my view of him, and my attitude towards everything that he might do or might be. Therefore, it's very

difficult to separate my intention from his" (Bigby et al, 2021). Some families reported that if they had not visited their loved ones often, they felt this gave them a less prominent position within the decision-making process (Wagemans et al, 2013).

Personal Qualities and Attributes. Families spoke of actively listening and hearing preferences (Bigby et al, 2021; Webb et al, 2020). Families shared the importance of being alert to preferences and actively listening to the views their loved ones were expressing (Bigby et al, 2019; Bigby et al, 2021; Bigby et al, 2022).

Families supported their loved ones to be more assertive regarding their preferences, encouraging individuals to speak for themselves and express their own needs (Bigby et al, 2022). Some individuals expressed their concerns regarding not being assertive enough, "sometimes I am afraid to ask for help in case they're busy, or I want to save time, or I don't want to cause a fuss" (Webb et al, 2020). Individuals who had attempted to be assertive were sometimes not successful in gaining the outcomes they desired, "I just get ignored, I feel like I'm getting ignored… when I say something about medication it's basically 'you just have to take the medication'" (Sheehan et al, 2019). Individuals expressed finding it hard to be listened to, and a need to "insist" (Pallisera et al, 2021). Despite individuals with an intellectual disability expressing their concerns regarding being assertive and not listened to, one parent described her approach as being assertive "If I think the doctor's wrong, I tell 'em, just like that". Other family members within the same study shared that they sometimes felt assertiveness was necessary to express the needs of their loved ones (Sheehan et al, 2019).

Time, effort and patience were other personal qualities highlighted to be important for SDM (Bigby et al, 2019; Bigby et al, 2021). Participants expressed that it can be easy

to take the easier route and not explore options with individuals with an intellectual disability, highlighting the day-to-day effort family members experience in ensuring their loved one's preferences are heard and that options are presented appropriately (Bigby et al, 2021).

Trust between the decision makers was another interpersonal attribute which appeared to be important in the decision-making process (Bigby et al, 2022; Goldsmith et al, 2012; Sheehan et al, 2019; Whitehead et al, 2016). Family members spoke about attempting to build trust for their loved ones in their own judgements (Bigby et al, 2022). Papers highlighted the prominent levels of trust both families and individuals with an intellectual disability had in healthcare staff (Goldsmith et al, 2012; Whitehead et al, 2016), which can lead to “passive compliance”, due to high levels of trust in the doctor (Sheehan et al, 2019).

Advantages of Support Networks. Many of the papers spoke of a shared process, which involved a support network to navigate through the decision-making process (Bigby et al, 2019; Bigby et al, 2021; Espiner & Hartnett, 2012; Goldsmith et al, 2012; McCarthy, 2010; Webb et al, 2020). McCarthy (2010) highlighted that having a support network involved in the decision-making process can present both advantages and disadvantages, noting the former to include feeling comfortable, safe, and having someone who could act as an intermediary between themselves and the doctor. Other papers noted support networks offer the opportunity for individuals with an intellectual disability to seek advice from a range of people (Bigby et al, 2019; Bigby et al, 2021; Goldsmith et al, 2012; Webb et al, 2020), and helps form the “recognition of inter-dependence” (Webb et al, 2020). Disadvantages were rarely named, apart from

Espiner and Hartnett (2012) who highlighted the difficulty in achieving attendance from wider support networks and the potential to overlook involving significant allies.

Supportive Collaboration. Families spoke about their experiences collaborating with professionals to reach joint decisions (Sheehan et al, 2019; Wagemans et al, 2013), describing professionals as supportive, and that it was reassuring to hear similar views to their own from the doctor (Sheehan et al, 2019). Individuals with an intellectual disability shared their experiences of receiving advice from professionals during healthcare appointments which contributed to their decision-making (Walmsley et al, 2016), with individuals describing "joint decisions" being made with doctors (Sheehan et al, 2019).

Theme 2: Knowledge, Information and Communication

This theme focuses on individual and family experiences of feeling knowledgeable throughout the decision-making process and their experiences of communication channels.

Reasonable Adjustments and Adaptations. Regarding receiving accessible information, many participants expressed they had not received any adapted information (Goldsmith et al, 2012; Horner-Johnson et al, 2022; McCarthy, 2010), despite participants expressing they would have liked to have been provided with accessible information (McCarthy, 2010,). Some participants shared they had received accessible information "I like the pictures 'cos I do not read. I like the colours and the

big pictures" (Espiner & Hartnett, 2012), although this participant's experience appeared to be in the minority.

Many individuals shared that they had difficulties in understanding professionals, particularly during healthcare appointments (Goldsmith et al, 2012; Horner-Johnson et al, 2022; McCarthy, 2010; Sheehan et al, 2019). Individuals referred to doctors using "long words" and "jargon" (Goldsmith et al, 2012; Horner-Johnson et al, 2022), with some individuals sharing "I don't bother asking if it's going to be a verbal answer because I am not going to understand it anyway", "doctor language is like in one ear and out the other" (Horner-Johnson et al, 2022). This experience was shared by some family carers expressing "I can't go on the internet… I'm not very good in reading and writing, I don't understand everything, so that's why I don't bother" (Sheehan et al, 2019).

Some adaptations and adjustments were described, including providing additional time during decision-making consultations (Bigby et al, 2022; Sheehan et al, 2019; Wagemans et al, 2013). Families shared their experiences of providing their loved ones with additional time to process and explore preferences (Bigby et al, 2022), and equally appreciated when they had experienced being given "time to talk" (Sheehan et al, 2019).

Feeling Informed and Consenting to Decisions. Experiences were mixed around participants feeling informed. During healthcare appointments, individuals often reported lacking in understanding and not feeling well informed regarding decisions being made surrounding their health with examples including medication decisions, decisions surrounding contraception, and having blood tests (Goldsmith et al, 2012;

McCarthy, 2010; Sheehan et al, 2019; Walmsley et al, 2016). Individuals reported not understanding why a particular decision had been made or why they required a particular procedure (Goldsmith et al, 2012; McCarthy, 2010; Walmsley et al, 2016), and the information provided regarding procedures prior to gaining consent varied from none to detailed descriptions (Goldsmith et al, 2012). Some participants shared experiences of not being informed about potential side effects of medications, "I wasn't told that there was like a lot of women coming forward having problems with it. I found out after I was already taking it and I was like, I was really kind of upset that they didn't tell me" (Horner-Johnson et al, 2022). Individuals who experienced feeling uninformed felt disempowered (Sheehan et al, 2019), further perpetuating and minimising the role of individuals with an intellectual disability in decision-making.

In contrast to these experiences, some individuals appeared well informed, although these experiences were in the minority, for example with only two out of nineteen feeling informed in Walmsley et al (2016)'s study. The small number of participants feeling informed was consistent across all papers included in this review. Women who were well informed reported being able to talk through options with their doctor. Goldsmith et al (2012) also highlighted some examples of individuals feeling informed, with healthcare professionals explaining procedures to individuals and talking through their decision-making process.

Limited Awareness and Insight. Families showed concerns that their loved ones lacked awareness and insight which could hinder their experiences of SDM, by limiting possibilities and options (Bigby et al, 2022). In some cases, professionals attempted to establish an individual's level of awareness and insight (Goldsmith et al, 2012).

Parents expressed concerns that an individual with intellectual disabilities' lack of insight could impact experiences (Bigby et al, 2022). A lack of awareness was also discovered regarding the rights of individuals with disabilities, particularly their legal right to accessible information under the Disability Discrimination Act which individuals nor their advocates appeared to be aware of (McCarthy, 2010).

Limited Opportunities for SDM. Families reported that their adult children often had limited experience of SDM (Bigby et al, 2019; Bigby et al, 2022). Parents expressed that their children had limited life experiences which impacted on their experience of SDM, limiting their knowledge and preferences (Bigby et al, 2022), which could result in lacking confidence to make decisions for themselves (Bigby et al, 2019). Webb et al (2020) highlighted how the care of people with intellectual disabilities has changed over time, with increasing opportunities for participation in SDM, "those options weren't there for people with an intellectual disability, the way they are now".

Theme 3: Paternalism and Protection

This theme consists of families' experiences within SDM processes. Families often expressed traditional views of care and decision-making which were paternalistic, feeling a need to protect but this could be experienced as marginalising for people with intellectual disabilities (Ward, 2011).

Negative Assumptions and Judgements. Families described how they judged loved ones to be unable to participate in SDM processes (Bigby et al, 2021; Werner &

Chabany, 2016). Families shared experiences of questions being addressed to them only and professionals not checking whether families had consulted with their children before making decisions, as captured in this quote from a parent “Did you speak to the participant about this? Do they agree? It’s nowhere. So they’re perpetuating the old system, which is that parents act for children, and that doesn’t matter how old the children are…Sometimes planners don’t even talk to him. They just talk to me.” (Bigby et al, 2021).

Some families described individual’s capacities to be involved in decision-making as a static trait, and that they are incapable of making decisions, “they cannot make decisions by themselves; they do not have the skills” (Werner & Chabany, 2016). Some families shared their concerns regarding SDM processes, and showed resistance in replacing guardianship with SDM as they viewed their adult children to be incapable and needing guardians as the central decision-makers (Werner & Chabany, 2016).

Some families explained a shift in their assumptions and judgements and reflected that they had changed the way they described their loved one's abilities. For example; “it has actually changed some of my language, the way I speak about it…I always used to call Caleb a non-decision-maker and I’ll never ever, ever in my life call him that again because very few people are non-decision-makers to be honest” (Sheehan et al, 2019). Subsequently this led to the confidence to challenge others “I’ve actually got confidence now to correct them… I actually do that now. Even people who have these kids [and say], “My person’s non-verbal” and I go, “Do they make any noises?” They go, “Yeah.” “Well, why do you call them non-verbal? Those noises mean something” (Bigby et al, 2021; Sheehan et al, 2019).

Individuals with an intellectual disability spoke about the importance of others not making assumptions, and pre-empting what they may say, “you made time, you didn’t just guess what I was going to say” (Sommerstad et al, 2021), with families also acknowledging the ease they could make assumptions, expressing “I’m able to listen more and hear what he’s actually saying, and not what I think he’s saying” (Bigby et al, 2021).

Families shared their experiences of preferences and decisions being unrealistic and therefore judging these as unachievable (Bigby et al, 2019; Bigby et al, 2022). Families expressed their concerns that loved ones could not fully understand expectations and outcomes of certain decisions, and there was a need to apply “a layer of realism” (Bigby et al, 2019).

Limiting Decisions Based on Consequences. Families spoke about their experiences of considering the consequences of decisions and how this then impacts the amount of choice they allowed their children. If decisions were viewed to have fewer consequences, being “simple and trivial decisions” (Werner & Chabany, 2016), then individuals were provided with choice “there’s some decisions without consequence and I’ll let him do it. So, making a decision on a meal, it’s up to him totally” (Bigby et al, 2022).

However, parents found it difficult to allow individuals to make decisions for themselves if they felt the consequences of such decisions had not been understood or if there would be injurious health impacts (Bigby et al, 2019; Bigby et al, 2022). One technique some parents shared was to allow individuals to experience making decisions despite potential negative consequences (Bigby et al, 2022).

Managing Risk and Safeguarding. Families shared their experiences of needing to safeguard during decision-making processes (Bigby et al, 2019; Bigby et al, 2022; Wagemans et al, 2013; Webb et al, 2020; Werner & Chabany, 2016). Parents perceived risk in numerous areas including decisions which may impact health or wellbeing, accepting necessary support, attending areas which may increase anxiety, and going out alone (Bigby et al, 2022).

Some parents spoke about fearing making decisions due to the potential consequences, particularly about medication and side effects and wanting to minimise risks where possible (Sheehan et al, 2019). Families expressed wanting to avoid harm for loved ones and found the responsibility of making healthcare decisions on behalf of loved ones difficult, with strong desires to prevent harm and maintain quality of life (Wagemans et al, 2013).

Families shared their concerns regarding individuals with an intellectual disability having the ability to make decisions, feeling it was wrong to teach their adult children skills in an area in which they are unable to use their own judgement as this may place them at additional risk (Werner & Chabany, 2016). Some parents expressed concerns about their adult child making decisions about finances (Werner & Chabany, 2016), and on occasions parents saw a need to override decisions made by their adult children to manage risk (Bigby et al, 2019).

Individuals with an intellectual disability provided few viewpoints on their experiences of managing risk in decisions, although one participant stated, “I think it’s important for people with an intellectual disability to have their own choices in life but be supported and be given the option, but obviously they do be to keep them safe too” (Webb et al, 2020). One woman shared her experience of wanting to take her dolls into the

community with her, although staff disagreed due to worrying the resident will be laughed at, she expressed "'Because why are the dolls not allowed to go everywhere? They're afraid we'll forget [them]. Well who forgets his children? No one. (laughs) And yes they are afraid they laugh at me. Well, I said that doesn't interest me at all, I don't care. It's my life. And I have to be able to do what I want" (Noorlandt et al, 2023).

Family Influencing Decisions. Parents shared their beliefs that within decision-making there are often right and wrong choices to be made (Bigby et al, 2021; Bigby et al, 2022; Werner & Chabany, 2016). Parents spoke about having their own vision for their loved ones (Bigby et al, 2019), and wanting to direct them towards making decisions which were in line with their opinions (Werner & Chabany, 2016). Parents held the view that it was their role to ensure their adult children did not make "poor" or "wrong" decisions, and to guide decisions to the "right" or "appropriate" outcome where possible (Bigby et al, 2022). Some parents did reflect that to minimise their influence they could try and reduce their investment in reaching decisions they deem as "right" and be more confident in individual judgement (Bigby et al, 2022).

One of the methods in which parents were seen to be influencing the outcomes of decisions was to restrict the information given during the decision-making process. Families shared their experiences of exerting influence by creating limits on options presented. Examples of this could be seen in quotes, "I'm going to have a look at lots of other things and then I'll come to you with the ones that I think are the best and you're going to choose" (Bigby et al, 2022) and "it's not just simply saying to a person such as my daughter what would you like to do, it's a matter of curating the options which are appropriate … including providing options which fit" (Bigby et al, 2019).

Another method used by parents was the careful use of communication to influence

outcomes. Parents shared their experiences of being “a great salesperson” or having to “do some manipulation” (Bigby et al, 2022) to determine outcomes of decisions. Parents shared how they would often highlight certain positives and negatives of options to persuade individual’s choices, reinforcing and emphasising options in line with their views (Bigby et al, 2019; Bigby et al, 2021). Examples of this were parents “sowing the seeds about the direction she wanted her daughter’s life to go in” and “we did provide [the information] in such a way that we knew what decision she would make” (Bigby et al, 2019). Parents shared their experiences of guiding individuals, “we should consult with them but we should also push them a bit. If we think differently, then we pull them in our direction and show them that our way is better” (Werner & Chabany, 2016).

Families also spoke about choosing support workers who hold similar views to maintain consistency with their overarching vision for their adult children, influencing outcomes through controlling and managing staff teams (Bigby et al, 2019).

Advocating on Behalf of Others. Families shared their experiences of feeling a requirement to advocate for others rights (Bigby et al, 2022; Sheehan et al, 2019), taking a “more direct approach” on behalf of their children when communicating with professionals to ensure their views were heard (Sheehan et al, 2019). Parents shared experiences in which they felt a need to override their children’s preferences on occasion, otherwise feeling that their wellbeing would be jeopardised (Bigby et al, 2022), “if I was not behind [son] and asking for him, demanding for him … he would be in a worse place now, mentally… If he didn’t have me he would definitely be worse off in all sorts” (Sheehan et al, 2019). One family member shared their experience of advocating on behalf of their sibling who was non-verbal during a serious health

decision. She shared reflecting on what her sister would have wanted and trying to advocate for decisions in line with these preferences, “thought it, ... it’s what [name of patient] would not have wanted, this resuscitation. It would then be OK for a while and then she’d have to go through it all again” (Wagemans et al, 2013).

Theme 4: Reflection and Impact on the Self

This theme considers how the experience of participating in SDM can impact an individual’s sense of self, influencing emotional responses and providing a space for self-reflection. The positive impacts SDM experiences can have on an individual’s confidence, independence, and ability to advocate for themselves are highlighted, whilst some of the difficult aspects of SDM such as feeling unheard are described.

Confidence. Individuals' confidence could be seen to be variable dependent on the decision being made, for example “money wise I am not confident about…, but in terms of shopping and getting food for myself…I am actually happy enough to do that myself” (Webb et al, 2020). Another individual expressed that if they felt more self-confident this would have changed their experience of decision-making, allowing them to express aspirations as opposed to remaining silent (Espiner & Hartnett, 2012). Levels of confidence were impacted by individuals' experiences of participating in SDM which built confidence for future participation (Bigby et al, 2021; Webb et al, 2020). Parents noticed changes in confidence within their children (Bigby et al, 2021), and individuals with an intellectual disability expressing “I feel very confident that like if I have made my own decision and people accept it and then I would have felt I would have achieved something that hadn’t really been achieved before, and that I wouldn’t

have not needed anybody else to go through while making that decision" (Webb et al, 2020).

Self-efficacy and Autonomy. Levels of independence differed amongst individuals throughout the articles. Families expressed that they work towards creating independence (Bigby et al, 2022; Werner & Chabany, 2016), and individuals with an intellectual disability often wanted to portray their ability to be independent (Pallisera et al, 2021; Werner & Chabany, 2016), occasionally dismissing those "less able" (Goldsmith et al, 2012). Individuals expressed the importance of free will and being their "own person" (Webb et al, 2020). Individuals valued their autonomy throughout the decision-making process, with feelings of freedom creating a sense of wellbeing (Pallisera et al, 2021). Independence and self-determination were noted as being a process of growth (Espiner & Hartnett, 2012), with some individuals fearing independence despite expressing it also being important to them (Werner & Chabany, 2016). Some families did not feel it was appropriate to give their loved ones full independence regarding decision-making, particularly if decisions were complex (Werner & Chabany, 2016).

Self-Advocating. Individuals with an intellectual disability experienced the opportunity to self-advocate in decisions (Espiner & Hartnett, 2012; Goldsmith et al, 2012), expressing their own opinions and hopes for outcomes, "I made the plan up… it was what I want to do" (Espiner & Hartnett, 2012). Individuals spoke about not wanting to be viewed as 'children', "they want their support worker to go with them all the time. I'm not like that, I just go on my own. I am not a baby, I'm an adult" and "yes, not like

children… you're just like anybody else then" (Goldsmith et al, 2012), advocating for how they wanted to be treated and thought of by professionals. One mother shared how professionals had shared with her "well, your son's becoming a real little advocate for himself" (Bigby et al, 2021), through encouragement in decision-making processes, increasing in confidence to assert his own needs.

Experiences of Feeling Heard. Both individuals with an intellectual disability and their family members shared their experiences of feeling heard and listened to (Espiner & Hartnett, 2012; Horner-Johnson et al, 2022; Pallisera et al, 2021; Redley et al, 2013; Sommerstad et al, 2021). Individuals shared "I have felt listened to" (Espiner & Hartnett, 2012), and shared their experiences of outcomes which had happened as a result of them making requests, in regard to staffing "we get the support we've asked for" (Pallisera et al, 2021), to healthcare decisions "I brought my issues up with my primary care physician and she was really helpful" (Horner-Johnson et al, 2022), and in activities "when I say that there is something I want to do, it usually happens" (Sommerstad et al, 2021).

Families shared their encounters with professionals listening to their views and making them feel heard in decisions, with some professionals seeming to depend on families to provide information (Redley et al, 2013). Parents shared their memories of SDM resulting in joy for their loved ones, "the confidence and pleasure from being listened to" (Espiner & Hartnett, 2012).

Positive experiences of 'feeling heard and listened to' were not universal however across the studies. Some individuals and families reported feeling unheard and misunderstood (Espiner & Hartnett, 2012; Redley et al, 2013; Sheehan et al, 2019).

Individuals reported feeling as though they had been ignored “I just get ignored, I feel like I’m getting ignored … when I say something about [medication], it’s basically you just have to take the medication” … and not “heard out properly” (Sheehan et al, 2019).

Some individuals reported how this then can lead them to not contributing in discussions, “I just don’t say nothing ‘cos I feel like I’m not heard out” (Sheehan et al, 2019), and others shared how this can lead to frustration and them feeling like a “pest ringing all the time as they put you onto someone else when you ring the office…why do we have lifestyle plans…why do you bother…they are just a waste of time…they are rubbish” (Espiner & Hartnett, 2012). Whilst Redley et al (2013) expressed “it is our contention that were a mother (a parent-proxy) to volunteer her views on a change of treatment, or be asked her views on a proposed change of treatment, only to have those views side-lined or dismissed she may well feel that she was being ignored and that the interests of her son or daughter were being threatened.”

A Lack of Involvement Causes Negative Emotions. Individuals reported to experience a range of negative emotions associated with the SDM process, including frustration (Bigby et al, 2019; Webb et al, 2020), anger (Sommerstad et al, 2021; Webb et al, 2020; Werner & Chabany, 2016), sadness (Sommerstad et al, 2021), stress (Sheehan et al, 2019; Webb et al, 2020), and anxiety (Webb et al, 2020). Individuals with an intellectual disability expressed their anger, frustration and stress regarding not being involved in decisions, and decisions being made without their consultation – “I should have been asked” (Webb et al, 2020). Some also expressed their anger about the outcomes of certain decisions, being restrictive and expressed a greater desire for independence (Werner & Chabany, 2016).

Family members experienced feeling “undermined” by professionals putting their “two cents worth” in (Bigby et al, 2019), decisions being made behind their backs (Sheehan et al, 2019), and reported professionals being “rude”, “patronising” and “unavailable”. They described treatments being started without consulting them which sometimes led to serious adverse effects of the health of their loved ones (Redley et al, 2013). Some families shared that a “dramatic bust up” or a “battle” with professionals was considered necessary at times to reset and include the participation of family carers in decision-making processes (Sheehan et al, 2019).

Self-Reflection and Changed Perspectives. Through families' experiences of SDM, they expressed some changed perspectives and paused for self-reflection. Some families reflected on the power they held in decision-making, in that most decisions had been made by them and how they had missed opportunities to include their adult children with intellectual disabilities (Bigby et al, 2021). Parents expressed their concerns at the level of influence they held, and reflected on how they may have done things differently in the past (Bigby et al, 2021). Parents shared a change in attitude from viewing individuals as incapable of making decisions, to a movement of treating individuals as equal, with respect and dignity, “these are human beings and deserve as much respect and dignity as anybody” (Bigby et al, 2019).

Theme 5: Power, Control and Choice.

This theme encapsulates subthemes which demonstrate power and control within SDM. Subthemes cover the level of invited participation families and individuals experience in decision-making, experiences of forced decisions, levels of choice

individuals are provided with, families experiences of navigating boundaries, and individuals opting to give control to others during decisions.

Invited Participation. Six of the articles referred to involvement and inclusion in decisions (Bigby et al, 2022; Espiner & Hartnett, 2012; Horner-Johnson et al, 2022; Redley et al, 2013; Sheehan et al, 2019; Webb et al, 2020).

Individuals with an intellectual disability shared a want to be involved in decisions, “tell me what’s going on!” (Sheehan et al, 2019), and when they were not invited to be an active participant this led to negative emotions, viewing decisions as “just happening”, reinforcing a sense of powerlessness (Sheehan et al, 2019). People shared experiences of professionals not inviting families into the decision-making process (Horner-Johnson et al, 2022). In the minority were those who felt they had been invited and felt as though they had control in decisions, “I felt I was in control of the meeting – it was my meeting” (Espiner & Hartnett, 2012).

Families shared their experiences of making decisions knowingly without inviting participation from their adult children, “I plan his whole universe without telling him … I’ve planned another week off in October to take him away for a couple of days. But I won’t tell him until a couple of days beforehand. Or otherwise, he just gets so hyped that by the time you come to get out the door, there can be tears and all sorts of difficult behaviours” (Bigby et al, 2022). Families were seen to do this in the best interest of others, thinking about the impact on their wellbeing. Some parents shared their experiences of not being invited to participate in decisions (Redley et al, 2013), demonstrated in this quote, “It’s always a bad experience when you’re not involved…

I wasn't in control of anything really, and there was no-one out there I could turn to", and parents reported decisions made without their knowledge (Sheehan et al, 2019).

Forced into Decisions. Some individuals shared their experiences of feeling pressured and forced into decisions, particularly regarding healthcare decisions. Walmsley et al (2016) reported experiences of women who felt "forced and coerced" into having contraceptive implants, "They forced me to have an implant when I was in the care home. They said if I don't have the implant they'd throw me out. I'll never forget that". Another woman shared a similar experience about starting a contraceptive pill, "'Had to, didn't I? I had no choice. They were giving it to me every day." These experiences were found in other articles, with other women sharing their experiences of being pressured to initiate contraceptive use, one woman explained her doctor had said "You need to try this, you need to be on this, because otherwise you're going to be multiplying like crazy. And so I wasn't too happy, and now I'm like, I want more children and they're not popping out as quickly as I wished they would." These articles highlight experiences in which individuals have not felt heard and felt pressured and forced into decisions with minimal collaboration.

Professionals Hold the Power. Both families and individuals with an intellectual disability shared their experiences of professionals holding the power and making final decisions. Individuals shared that their pathways had been determined by the choices of professionals (Pallisera et al, 2021). They shared experiences about healthcare decisions (Sheehan et al, 2019; Sommerstad et al, 2021; Wagemans et al, 2013; Webb et al, 2020), such as "The doctor decides the most. I decide a little"

(Sommerstad et al, 2021), “the doctor might have been clearer ... I was never told that it’s the doctor who is actually responsible” (Wagemans et al, 2013), and family referred to psychiatrists as “the expert” with the “ultimate power” (Sheehan et al, 2019). Women shared their experiences of seeking support for contraception advice. McCarthy (2010) identified very few women who voiced they had made their own decision to start contraception, rather this was usually made by their GP, parents or care staff. Some articles discussed other areas in which individuals felt professionals hold the power, such as decisions regarding living arrangements, who people could have to stay overnight, and education and finances (Webb et al, 2020, Pallisera et al, 2021). On occasion individuals shared their experiences of having professionals overrule their decisions, for example regarding food choices staff consider unhealthy (Noorlandt et al, 2023).

Varying Levels of Choice in Decisions. Six articles commented on the levels of choice individuals with intellectual disabilities get during decision-making, with individuals with an intellectual disability reflecting on both positive and negative experiences of choice in decisions (Espiner & Hartnett, 2012; Noorlandt et al, 2023; Pallisera et al, 2021; Sheehan et al, 2019; Sommerstad et al, 2021; Webb et al, 2020). Some individuals shared positive experiences of being presented with genuine choice and options and their preferences being listened to (Espiner & Hartnett, 2012; Noorlandt et al, 2023; Sommerstad et al, 2021; Webb et al, 2020). However, some also shared experiences in which they had little choice in decisions, “I have to take my medication, I ain’t got no choice… It’s the doctor’s orders to keep on the medication … there’s not a lot you can do about it” (Sheehan et al, 2019). One participant noted that they felt the level of choice related to an individual’s level of independence, “I don't know about other

residents, but when I walk in here at four o'clock, [in the morning] they don't say anything about it. But if someone else who needs more guidance wants to do the same, they say that's not possible. Interviewer: And why do you think that is? Participant: Because I may be more independent than they are" (Noorlandt et al, 2023).

Some parents acknowledged and expressed they “worry about it sometimes that maybe I’m not giving her the choice” (Bigby et al, 2022). Other families spoke about their experiences of attempting to expand horizons and enable choice making (Bigby et al, 2021; Bigby et al, 2022). One parent shared their experience, “she’ll come up, show me a recipe that’s in a magazine and say, “I want to do that.” And rather than saying “Well, we’ll do it tomorrow. Because we’ve got to buy the ingredients and it takes two hours to cook, like doing all the planning associated with implementing that decision. Now I’m more prone to say, “Well, who do you want to do it with or where do you want to do it?” Sort of bringing [her] into it and let her make choices” (Bigby et al, 2021). Similarly, a parent shared, “…what I’ve done always is just get the list and you’ve got to select and rank order…this time I thought…I’ll print this out and show it to Sally, discuss it with Sally and give her an opportunity to actually select stuff” (Bigby et al, 2022)

Navigating Limits and Boundaries. Regarding family members experiences in SDM processes, some of them referred to needing to navigate boundaries throughout the process. Some shared they are unclear as to the relevant legislation regarding boundaries and limitations relating to them as ‘patient representatives’ in decision-making (Wagemans et al, 2013), however showed some reflection and awareness to

there being boundaries during decisions. However, this was not found in all articles. Other families did not raise issues regarding boundaries in decisions, “suggesting that family members saw their role in support as having few if any boundaries” (Bigby et al, 2019). One family expressed “We are guardians of everything from the toenail to the purchase of I don’t know what... For his body, his property—everything that is connected to the same person” (Werner and Chabany, 2016).

Giving Control to Others. Four articles reported that individuals were often happy to give others control in decision-making (Sheehan et al, 2019; Sommerstad et al, 2021; Webb et al, 2020; Werner & Chabany, 2016). Some shared they were happy for others to make decisions due to their trusting relationships with staff, “‘I don’t care about who makes decisions here. I trust the staff and know them well. They listen to me” (Sommerstad et al, 2021), whilst others were happy for others to take control due to viewing them as the experts, “Doctors should make the decisions about medicine … they have more experience … [I prefer to] leave it to the doctor” (Sheehan et al, 2019). Two articles included experiences of individuals being happy for others to make decisions due to a lack of confidence and even fear in participating in decisions (Werner & Chabany, 2016, Webb et al, 2020). Some individuals reported fearing independence, having a preference in giving control to others to make decisions for the benefit of feeling secure and safe (Werner & Chabany, 2016). The type of decisions could also have an impact on whether individuals gave control to others, with individuals particularly lacking confidence in decisions regarding finances (Webb et al, 2020).

Discussion

This is the first known systematic review of SDM experiences within the intellectual disability population, and therefore the review had a broad research aim to report on patient and family experiences of SDM. This review consisted of 17 articles, the majority of which were published in 2019 or later. Five analytical themes were synthesised collecting experiences of SDM from the perspectives of individuals with an intellectual disability and their families. Participants experiences highlighted both the positives and challenges of SDM within five analytical themes: 1) The Influence of Interpersonal Factors and Relations, 2) Knowledge, Information and Communication, 3) Paternalism and Protection, 4) Reflection and Impact on the Self, and 5) Power, Control and Choice. Each of these themes had several subthemes as listed previously.

The findings from this review have highlighted some positive examples of SDM being completed in practice, involving both individuals with an intellectual disability and their families in decision-making. To successfully implement SDM, this review has highlighted the importance of an understanding support network, building trust, and knowing the individual. Professionals need to be willing and open to collaboration and decision supporters need to demonstrate personal qualities and attributes to facilitate decision-making, including active listening, patience, motivation and effort.

This review also included examples of SDM not being successful and has highlighted areas for improvement. Individuals and families experienced feeling negative emotions when not included in decisions, lacking information and feeling uninformed throughout decisions, and feeling powerless and unheard. Despite some shifts in thought, some paternalistic views were captured in some of the articles with parents and professionals feeling a need to protect individuals with an intellectual disability through decision-making. A variety of methods were used to do this such as restricting

information, managing risk in decisions, and judging individuals' ability to participate and therefore acting on their behalf.

Strengths and Limitations

A strength of this review is that this is the first systematic review to synthesise individuals with an intellectual disability and their families' experiences of SDM processes. It therefore offers something new to the intellectual disability field, and as SDM is becoming increasingly prevalent within the intellectual disability population this feels an important and timely review which can contribute to understanding individual and family experiences and improve practice.

A further strength of the review is themes were created using line-by-line coding, and so the researcher re-coded the results sections of all seventeen articles to create new themes and sub-themes. These codes were then reviewed by the research team to improve validity. Themes were created using participant quotes wherever possible, as opposed to solely relying on previous researchers interpretations and once themes were developed these were checked with the original article themes to ensure that the synthesised findings were grounded in the context in which they had been constructed, preserving context and meaning (Thomas & Harden, 2008). Themes were reviewed by a second researcher to reduce bias of interpretation of results.

It is acknowledged that this review contained a variety of settings, both in terms of country but also local settings (e.g., healthcare systems, living accommodation). Whilst this allows rich heterogeneity to the findings, there may be differences in how countries define and manage intellectual disabilities, which could make some of the findings less applicable to the UK.

Within the selection of articles, only 10% of titles and abstracts were checked by a second reviewer, and therefore this is acknowledged as a limitation. This review only included peer-reviewed journal articles and did not include any grey literature. It is possible there are further experiences of individuals with an intellectual disability and/or their families in SDM processes which have not been captured within the seventeen studies, which may be within grey literature. Only studies available in English were used for this review. It is also possible there may be relevant articles which are not published in English which could have valuable contributions and wider perspectives on the topic.

The quality of papers contained within this review was overall very good, ranging from moderate to high (Butler et al, 2016). Many papers however failed to score points for the CASP checklist question "*Has the relationship between researcher and participants been adequately considered?".* Reflexivity refers to a certain level of consciousness and awareness a researcher has of their position within the research (Dodgson, 2019), which is important in acknowledging as failing to do so can impact the interpretation of results and therefore the results published, impacting the overall utility (Galdas, 2017).

Some of the papers refer to participants being selected by gatekeepers and/or the researchers solely and it is important to consider how recruitment strategies, may influence results gained. The majority of articles used semi-structured interviews, and it is important to consider how these interview schedules were developed, and to what extent the researcher's pre-conceptions and prior experiences of the topic area could have impacted wording of such questions and equally the choice of questions asked (Galdas, 2017).

Implications for Future Research and Practice

Overall, SDM has been becoming increasingly valued within the field of intellectual disabilities, and across clinical practice with clinicians being urged to facilitate SDM (Joosten et al, 2008; Shay & Lafata, 2015). Recommendations for future researchers publishing qualitative research within the field of intellectual disabilities would be to consider their relationship with participants in order to ensure bias is minimised and acknowledged and reflected upon where possible.

To gain a more rounded view of SDM in practice it would be important to consider the views of professionals when participating in SDM, both health care professionals (e.g., doctors, nurses), but also care support staff (e.g., in shared living accommodation, day centres). It would be helpful for a future review to gather staff experiences of SDM across a range of settings to see similarities and differences between their perceptions and those of individuals with an intellectual disability and their families.

The research papers relating to reproductive choice (Horner-Johnson et al, 2022; McCarthy, 2010; Walmsley et al, 2016) contain some concerning findings in relation to informed consent for starting contraception, and reporting feeling pressured and forced into decisions. It would be beneficial for future research to understand further decision-making processes occurring during these appointments, from the professionals and carers points of view. Targeted research within this area could hopefully improve future practice so that people feel effectively empowered to meaningfully participate in decisions about reproductive choice.

In addition to this, some research has been published investigating practical methods and tools to enhance SDM within the intellectual disability population and it would

therefore be useful for a systematic review to be completed of such practical methods and tools to gain a holistic understanding of best practice in facilitating SDM.

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Chapter Two: Empirical Paper

Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population

Amy Calderbank

Prepared in accordance with guidelines from the Journal of Intellectual Disabilities

Abstract

Approximately 35,000 individuals with an intellectual disability are prescribed psychotropic medications in the absence of a mental health diagnosis within the United Kingdom (UK; NHS, 2022). This study aimed to investigate factors which are influential in the deprescribing of psychotropic medications within an intellectual disability population. Q-Methodology was used to elucidate factors relevant in the deprescribing process. Thirty-two NHS professionals working across community learning disability teams (CLDTs) in the Northwest of England undertook a 53 statement Q-Sort task. PQMethod was used to analyse the data, revealing three factors accounting for 49% of the variance in the data. The factors were interpreted under the following headings: Willingness to Deprescribe and Trying Alternative Interventions, Perceptions of Risk and Behaviours that Challenge, and Professional Opinions, Rational Clinical Judgement and Safe Ethical Practice. This study highlights the need for training to raise awareness around deprescribing guidelines, risk management, and staff's awareness of their role in medication reviews.

Keywords: Decision-Making, Deprescribing, Intellectual Disabilities, Medication, Q-Methodology

Introduction

It is estimated that 35,000 adults with intellectual disabilities in the UK are administered psychotropic medication daily in the absence of a diagnosed mental health condition (NHS, 2022). Whilst prevalence rates of conditions such as depression, schizophrenia and bipolar disorder are higher in this population than in the general population (Buckles et al, 2013; Cooper et al, 2015), not all individuals with an intellectual disability who are prescribed pharmalogical interventions, typically offered to people with mental health conditions, have been formally assessed as meeting diagnostic criteria. Data collected from General Practitioner (GP) practice systems revealed that between 2021 – 2022, the percentage of patients with an intellectual disability who had been prescribed psychotropic medications was significantly higher than in patients without an intellectual disability (antipsychotics 14.5% compared to 0.9%, antidepressants 21.2% compared to 10.7%, benzodiazepines 7.1% compared to 1.8%; National Health Service Digital, 2022).

The NHS website highlights some of the potential side effects from psychotropic medications such as weight gain, feeling tired or ‘drugged up’, and physical health problems (British National Formulary, 2023). Psychotropic medications can cause cardiovascular side effects (Marano et al, 2011), thyroid functioning abnormalities (Khalil & Richa, 2011), and in some cases death (Gøtzsche, Young & Crace, 2015). These side effects are concerning, as recent figures suggest 71.8% of individuals with an intellectual disability attend their annual health check (NHS Digital, 2022), and it is recommended individuals should have physical examinations, blood tests and an ECG prior to commencing some psychotropic medications (Mind, 2021).

Stopping the Over-Medication of People with a Learning Disability and Autistic People (STOMP)

STOMP is a national project which started in 2016 (NHS, 2022) involving a variety of organisations (NHS England, Royal Colleges of Nursing, Psychiatry and GPs, the Royal Pharmaceutical Society, and the British Psychological Society). The aim of the project is to help stop the overmedicating of individuals with a learning disability, autism and/or both to improve their quality of life. STOMP outlined three key aims including the encouragement for individuals with a learning disability to have regular medication check-ups, to ensure families and support staff are included in decisions regarding medication, and to inform individuals about other interventions/therapies so they are less likely to need as much medication, if any (NHS, 2022).

Prescribing trends have highlighted some encouraging data (NHS Digital, 2022). Since the introduction of STOMP, rates of anti-psychotic prescribing have decreased, with some psychiatrists being reluctant to prescribe this kind of medication (Deb et al, 2020). However, there has been a rise in the number of antidepressants being prescribed, and the use of anti-epileptic medications being used off licence (medication being prescribed for use in a different way than stated in its licence; Gerrard & Rhodes, 2022).

Some local evaluation programmes have attempted to monitor the implementation of STOMP guidelines within their trust (Branford et al, 2019). In the Northeast of England, a GP pilot STOMP clinic program was rolled out in 2017; a collaboration between a Positive Behaviour Support (PBS) team and a prescribing pharmacist. The outcomes from the clinic demonstrated that involvement from a PBS team had a positive impact in implementing deprescribing regimens, with 90% of individuals who stopped medications being able to remain drug free when maintaining the additional PBS

(Gerrard et al, 2019). In the Northwest of England, a collaborative programme revealed consultants require additional support regarding capacity issues, the need for joint working between CLDTs and GP practices, and the necessity to involve wider social networks (Branford et al, 2019).

Clinical psychologists have a crucial role in promoting psychological interventions as alternatives to medication to facilitate and support the aims of STOMP (Morris et al, 2018). These alternatives may include facilitating team formulations, joint multidisciplinary working, assessing and formulating risk, delivering psychological therapies, and assisting with the implementation of PBS (British Psychological Society, 2011; British Psychological Society, 2016; Morris et al, 2018).

Why Prescribe?

A common reason for initiating psychotropic medications for individuals with intellectual disabilities is challenging behaviour which is an off-label use of licensed medication (NICE, 2019).

Molyneux et al (1998) revealed that the likelihood of being prescribed psychotropic medications within an intellectual disability population included the presence of challenging behaviour, having a recorded mental health condition, being under review of a consultant psychiatrist, and lastly being resettled from a long hospital stay. Similarly a study by García-Domínguez et al (2022) demonstrated that the greatest rates of prescribing psychotropic medications were for individuals displaying stereotyped behaviour, oppositional and/or aggressive behaviour, and “destructive disorders”. Antipsychotics were the most common form of psychotropic medication

being prescribed and influencing factors for prescribing included the presence of a mental health condition, behavioural problems, older age, and living in residential facilities.

Wastell, Skirrow, and Hare (2013) completed research with NHS staff asking, “what factors are influential in the clinical decision-making process to start psychotropic medication?” Q-methodology revealed a four-factor solution under the following headings “high-quality safe ethical practice, risk is a rationale for reactive prescribing, pragmatic management, and contextual issues”. Individuals prescribed psychotropic medications for challenging behaviour may remain on medication for long periods of time due to favourable drug response, infrequent medication reviews, a lack of confidence in healthcare staff to make changes to medication, and a lack of availability or appropriateness of alternative treatments (Sheehan & Hassiotis, 2017).

The Wider System

Coordination is needed amongst the wider system surrounding the individual with an intellectual disability to ensure safe and appropriate use of psychotropic medications and follow-up procedures (Song et al., 2020). Lalor and Poulson (2013) derived two key themes from their study with non-medically trained care staff regarding their views on the prescribing of psychotropic medications. Staff reported feeling powerless in decisions; witnessing the effects of medication and having concerns regarding patient’s quality of life. Staff also reported medication being used inappropriately, in replacement of other psychotherapeutic ways of working and this led to frustration and feelings of powerlessness. Staff also raised concerns regarding the lack of training surrounding psychotropic medications.

Interviews with families of individuals with an intellectual disability have highlighted the importance of ensuring medications are being prescribed for the good of the individual with an intellectual disability as opposed to the needs of the family (Edwards et al, 2017). Some studies have found families often feel they have little influence over medication decisions (Branford et al, 2019; Sheehan et al, 2018), despite international guidelines stating to “allow the person and/or their family or carers to influence the decisions that are made and included in the treatment plan” (Deb et al, 2009).

Surveys with family carers of individuals with an intellectual disability have revealed that there is a divide with some families feeling involved in decisions, and others feeling marginalised and perceiving limited influence on decision-making. Complex emotions are evoked in families regarding psychotropic medication decisions, and families reported mixed outcomes in effectiveness of medication (Sheehan et al, 2018).

Clinical psychologists are part of the wider system surrounding individuals with an intellectual disability and are trained to work both at an individual and system level, synthesising information and working proactively to achieve good outcomes (British Psychological Society, 2011). Clinical psychologists play a role in assessing and determining an individual's ability to make decisions and to facilitate choice in day-to-day decisions and should lead on the promotion of decision-making within the mental capacity act (British Psychological Society, 2011).

If change is to occur to improve prescribing in line with evidence, a systems approach must be considered (Bamidele & Hall, 2013), with a movement towards decision-making being more inclusive of family members, with individualised decisions for people with intellectual disabilities and to ensure new policies do not result in powerlessness and exclusion (Edwards et al, 2017).

Rationale and Study Aims

Despite the implementation of STOMP, data suggests that the overmedicating of individuals with an intellectual disability remains an issue. For this reason, the primary aim of this research was:

- To understand factors which are important in the clinical decision-making process when deciding to stop and/or reduce the use of psychotropic medications within a community intellectual disability population.

Method

Overview of the method

Q-Methodology (Q) combines both qualitative and quantitative methods in order to identify individuals who share common viewpoints (Valenta & Wigger, 1997). Q uses a ranking procedure which asks participants to assign each item to a position in a 'forced' distribution grid, dependant on the extent to which they agree or disagree with a statement (Watts & Stenner, 2005). A strength of Q is therefore that it is representative of real-life decisions in which people consider a variety of issues and weigh these up against one another, meaning Q as a methodology provides an in-depth and realistic perspective, hence it was felt most appropriate for this research project.

Q-Methodology

Epistemology. Q-Methodology (Q) is a social constructionist method which is not based on a particular psychological model, but assumes perceptions are constructed

from social interactions and experiences. Q originated in the work of Stephenson (1936) who developed a formal methodology, deriving initially from the quantitative analysis known as factor analysis. Q was initially developed for the study of human subjectivity including phenomena such as opinions, attitudes, beliefs, and values. The difference between the two methods is that Factor Analysis factors by item (i.e., each individual item on a scale) but Q factors by person (i.e., the way each person ranks all the items or statements).

Q does not impose meanings a priori, instead it asks participants to rank-order statements depending on what feels valuable and important to them, therefore placing significance and meaning on individuals' views and opinions (Watts & Stenner, 2005). Participant's final rankings are analysed using 'inverted' factor analysis techniques, which means each participants q-sort rankings are treated collectively as an individual variable, as opposed to each singular item as with a traditional factor analysis (Churruca et al, 2021). Similarities and patterns are then identified, and factors may emerge depending on how participants have sorted the data.

Stages in Q. Q has seven key stages as follows (Damio, 2016):

1. Identifying the topic – Researchers first select their topic for exploration, which ideally should be a complex and socially contested topic, which can generate a multitude of opinions and views, in which we can expect to find variation and "hear many voices" (Stainton, 1995).
2. Developing the Q-set – Developing the Q-set involves collecting a set of statements from a variety of resources e.g., interviews, published literature, grey literature etc., ideally until saturation is reached. This process may be referred to as 'sampling the concourse', collecting all the possible statements

which may be made about the topic in question (Damio, 2016). A Q-grid is designed for participants to place the statements onto. The Q-grid must be symmetrical and designed to have the fewest rows at the furthermost ends (Herrington & Coogan, 2011).

3. Piloting the Q-set – The agreed Q-set and Q-grid should be piloted to gain a sense of how the Q-sort is received and whether any modifications need to be made before the administration phase.
4. Selecting participants – Q uses purposive sampling, and participants are recruited who are “theoretically relevant to the problem under consideration” (Exel & Graaf, 2005). Q participant sample sizes often range between 12 and 40 participants, which is deemed sufficient for Q (Cairns, 2012; McKeown & Thomas, 2013; Webler et al, 2009).
5. Q-sorting – Participants are provided with a clear question and asked to rank-order statements depending how much they agree or disagree with each statement in relation to the question. This process is typically completed using a grid, a forced quasi-normal distribution (Damio, 2016). Researchers note participants comments throughout and may ask for opinions on statements after the sorting is complete.
6. Quantitative analyses – Each of the completed Q-sorts are used as variables in the analysis process. The analysis identifies factors through correlating each of the Q-sorts with one another, identifying similarities in configuration (Churruca et al, 2021). Each person is assigned a score which indicates the percentage loading on each factor.
7. Qualitative interpretations of the factors – This final stage involves qualitatively analysing how the factors have been sorted, applying narratives and

interpretations to the data, and assessing which participants have loaded onto each of the factors (Churruca et al, 2021).

Q in Intellectual Disabilities Research. Q has been used to involve people with intellectual disabilities in evaluating person-centred planning (Combes, Hardy & Buchan, 2004), and to understand factors which influence women with intellectual disabilities in decisions on accessing cervical and breast cancer screening (Sykes et al, 2022). Research with professionals and families of those with an intellectual disability has included studies exploring beliefs about the sexuality of individuals with an intellectual disability (Brown & Pirtle, 2008), beliefs about why individuals self-harm (Dick et al, 2011), to understand clinical psychologists attitudes towards the biology and 'new genetics' of intellectual disabilities (Hare et al, 2016), and, as previously mentioned, to gather viewpoints regarding factors influencing the use of psychotropic medication (Wastell, Skirrow & Hare, 2013). The last of these examples is pertinent to the current study, exploring staffs' viewpoints of factors influential in clinical decision-making around prescribing of psychotropic medications.

Ethics

Prior to the start of the study, approval was granted by the Doctorate in Clinical Psychology Research Review Committee, University of Liverpool on 25/10/21 (Appendix 5). Ethical approval was sought from the UK Health Departments Research Ethics Service for the study protocol and other relevant participant documentation. Ethical approval was granted by the West Midlands – Coventry and Warwickshire Research Ethics Committee on 28/07/2022 (Appendix 4), as this was the next

scheduled committee which took place via video conference. Service managers and principal clinical psychologists were contacted from each of the identified NHS trusts to seek their support for the project. Once ethical approval was obtained, HRA approval was sought (Appendix 7), and the research and development (R&D) departments for each of the three participating trusts were contacted and provided with a copy of the ethical approval, alongside all participant documentation. Once a R&D team had given approval, recruitment could then commence within that trust. Altogether, there were three NHS trusts and twelve CLDTs contacted for participation. This research was sponsored by the University of Liverpool (Appendix 6).

Consent

Participants were provided with an information sheet detailing all aspects of the study and given the opportunity to ask the researcher any questions they had regarding the study. Separate information sheets were created for those participating in stage one of the research, the semi-structured interviews (Appendix 8 and Appendix 9), and those participating in stage two of the research, the Q-sort (Appendix 14). The information sheets outlined details of the study, the voluntary nature of the study, and participants right to withdraw. Those who chose to participate were asked to sign a consent form. Separate consent forms were designed for those participating in the interview stage (Appendix 10 and Appendix 11) and those participating in the Q-sort (Appendix 15). Confidentiality was always assured. All participants were assigned a unique personal code to ensure anonymity and minimise the risk of participants being identified.

Stage 1 Interviews: Recruitment

Purposive sampling was used to recruit participants. Healthcare staff were invited to participate in the interviews by the lead researcher face-to-face at CLDTs meetings to advertise the research and advertising emails were sent to each of the CLDTs administrators, who forwarded the email to all team members asking for volunteers for the project. Potential participants were provided with the information sheet, and participants volunteered to partake in the research. In order to recruit families and/or individuals with an intellectual disability partaking in the interviews, healthcare staff were asked to make initial contact with potential participants and to provide individuals with the information sheets. If they expressed an interest to participate in the study, healthcare staff asked for consent to share their contact details with the lead researcher (AC) to enable them to make contact to discuss further. The lead researcher would then contact the family to discuss the research and arrange an initial meeting to provide further details of the study and answer any questions.

Stage 1 Interviews: Participants

The inclusion criteria for individuals being able to participate within the interview stage was that participants must be aged 18+, and have an intellectual disability and be either currently prescribed psychotropic medication and/or have been prescribed psychotropic medication in the past (for at least one year), OR a person who cares for or has cared for somebody who matches above criteria, OR an NHS healthcare professional who currently works in a CLDT. Participants had to be fluent and literate in English and have the capacity to consent to and participate in an interview for up to 30 minutes. Individuals who lacked the ability to consent to participate in the research were excluded, along with individuals who did not speak English fluently. Research

also excluded individuals living in inpatient settings and staff working in inpatient services, as the focus of the study was community-based participants. Details of the participants can be viewed in Table 1.

Table 1. Participant Characteristics for Stage One - Interviews

Interview	Professional Specialism	Gender	Length of time working in intellectual disability services
1	Specialist Physiotherapist	F	5 years 6 months
2	Specialist Nurse and Non-Medical Prescriber	M	8 years
3	Senior Nurse Practitioner	M	17 years

Stage 1 Interviews: Materials

The materials required for conducting the interviews were as follows:

- Information sheets
- Consent forms
- Semi-structured interview guide (option of easy-read document)
- Portable Dictaphone
- Debrief forms

Stage 1 Initial Semi-Structured Interviews: Venue

All participants were interviewed in the location of their choice. All three staff members were interviewed within their work bases – CLDTs.

Stage 1 Interviews: Guide

A semi-structured interview guide was developed by the research team which included questions on an individual's medication journey and how prescribing was initiated, the length of time medication was prescribed for, the risks and benefits of the medication, and the medication reviewing process. An interview schedule was made for families, carers and healthcare staff (Appendix 12), and an easy-read version was created for individuals with an intellectual disability (Appendix 13). The inspiration for the interview guide came from previous published research, grey literature and two of the researchers' personal experiences of working in intellectual disability services (AC and AF). Using a semi-structured interview permitted the direction of each interview to be led by the interviewee, which allowed for a variety of responses to be collated. These were used to form relevant Q-sort statements.

Stage 1 Interviews: Procedure

Participants were provided with an information sheet and a consent form at the start of each interview and were given the opportunity to ask questions. Participants were informed the interview would be semi-structured with a guide, however they would be able to share any views they felt important to the topic. Participants were informed they were free to withdraw at any point during the interview and they could choose not to answer any questions they did not feel comfortable to answer.

Each interview took between 15 and 30 minutes. Interviews were recorded using a Dictaphone loaned from the University of Liverpool. The recordings were then transcribed in full before being analysed to form part of the Q-sort statements. One of

the researchers transcribed one of the interviews, and a university approved transcribing company transcribed the other two interviews.

Stage 2 Q-Sort: Selecting Data from Transcripts

This process was completed by the author, a Trainee Clinical Psychologist with a background of working in intellectual disability services (AC) and a supervisor who is a Senior Lecturer in Public Health and a pharmacist specialising in mental health, who was experienced in Q research (JD). The interview transcripts were read and re-read in order for the research team to feel immersed in the text. The research team then highlighted key quotes from the transcripts to extract relevant statements to the research question. These statements were then placed within an excel document. This process produced a total of 86 statements. The 86 statements were then categorised, which led to the creation of 22 categories. Some of these categories included behaviours that challenge, risk to self/others, medication is inevitable, alternative interventions and power.

Stage 2 Q-Sort: Additional Statements

Alongside the statements collected within the interviews completed in stage one, statements were also created using grey literature and published literature within the field of intellectual disabilities and mental health (including published research articles, the Mencap and Challenging Behaviour Foundation website, and mental health forums to capture service user voices). This process resulted in 52 additional statements being added to the Q-sort which were added to the statements created from the interviews in stage one. In total there were 138 initial statements.

Stage 2 Q-Sort: Developing the Final Statements

For authenticity, the language used by interviewees was kept wherever possible. A small number of participant statements were re-worded to ensure clarity. All three researchers independently read all statements (138), removing duplicates and statements which were not considered relevant in answering the Q-sort question. The researchers then came together to review the relevance of the remaining statements. During these discussions, the use of language within some of the statements was considered. Researchers debated whether to make the use of language directional (e.g., ***reduces*** the chances of deprescribing) or whether to keep statements neutral (e.g., ***influences*** deprescribing). A mixture of directional and neutral statements formed the final Q-Sort.

The researchers agreed on a final set of 58 Q-sort statements. These statements were then emailed to the original participants from stage one for their feedback. Participants provided comments regarding the wording of some of the statements which resulted in some further amendments.

Stage 2 Q-Sort: Pilot Study

Once the statements were finalised, one of the researchers who has a background in working in intellectual disability services piloted the study on themselves (AC). This raised a question as to whether too many of the statements were non-directional. The statements were also piloted with two trainee clinical psychologists (GH and RW). Their feedback included advice to change some of the wording within statements, a suggestion that some of the statements had overlapping content and could be reduced

into singular statements, and that some of the statements were considered too complicated.

Following the pilot, the three researchers met for a final time to review the Q-Sort as a whole and to implement the feedback. The final Q-Sort was reduced to 53 statements (Appendix 17). Once the statements were finalised, they were printed onto individual cards using large font. Placement cards were also created ranging from strongly agree to strongly disagree, and strength of agreement/disagreement cards (ranging from -5 strongly disagree to +5 strongly agree) which provided a structure for participants to sort statements on the Q-sort matrix.

Stage 2 Q-Sort: Recruitment

The author attended multidisciplinary CLDT meetings, and provided a research presentation to explain the process of completing a Q-sort. Emails were also sent to CLDTs to advertise the research and request volunteers. After this, the author visited the CLDTs to recruit staff participants.

Stage 2 Q-Sort: Participants

The inclusion criteria for participating in stage two of the research was that individuals were NHS employees working in a CLDT. Participants could be from any relevant professional background including nurses, psychologists and doctors. Participants had to be fluent and literate in English.

In total, staff based in twelve CLDTs were invited to partake in the Q-Sort, and the final participants came from five of these teams across the Northwest of England. In total 32 participants took part in stage two. Participants worked in a variety of professional

specialisms (Table 2) and had varied experience of working in intellectual disability services (from 11 weeks – 42 years, mean = 8 years 7.5 months). Two participants were prescribers. Participants ages ranged from 21 – 62 years. Participants identified as White British (25), British Asian (3), Mixed Other (2), White Irish (1), and Pakistani (1).

Table 2. Participant Characteristics for Stage Two – Q-Sort

Professional Specialism	Gender
Speech and Language Therapist	Female
Learning Disability Nurse and Clinical Lead	Male
Specialist Physiotherapist	Male
Assistant Psychologist	Male
Advanced Nurse Practitioner	Female
Occupational Therapist	Female
Speech and Language Therapist	Female
Learning Disability Nurse	Female
Assistant Psychologist	Male
Learning Disability Nurse	Female
Learning Disability Nurse	Female
Learning Disability Nurse	Female
Associate Practitioner - Intensive Support Team	Female
Associate Practitioner	Female
Senior Nurse Practitioner	Male
Speech and Language Therapy Student	Female
Speech and Language Therapy Student	Female
Speciality Doctor	Male
Speech and Language Therapist	Female
Specialist Physiotherapist	Male
Learning Disability Nurse (Intensive Support Team)	Female
Community Learning Disability Nurse	Male
Assistant Psychologist (Intensive Support Team)	Female
Assistant Psychologist (Intensive Support Team)	Female
Community Learning Disability Nurse	Female
Speech and Language Therapist	Female
Nurse Associate	Female
Community Learning Disability Nurse	Female
Assistant Psychologist	Female
Clinical Psychologist	Female
Learning Disability Nurse Student	Female
Clinical Psychologist	Female

Stage 2 Q-Sort: Materials

The materials required for conducting the Q-sort included the following:

- Information sheets
- Consent forms
- Demographic information sheet
- Question Card “to what extent do you think the following factor is important when making the decision to reduce or stop an individual’s medication?”
- Cards containing Q-sort statements

- Q-sort layout sheet (-5 most disagree to +5 most agree)
- Debrief forms

Stage 2 Q-Sort: Venue

Participants were seen at their place of work at a time convenient for them. Participants completed the study in a private office.

Stage 2 Q-Sort: Procedure

Participants were provided with the information sheet and the researcher explained the study details. Participants were offered the opportunity to ask any questions. It was emphasised that participation within the research was voluntary, and participants could withdraw at any time without providing a reason. If participants agreed to partake in the study, they were provided with two consent forms, one for the researcher to retain and one for them to keep.

The researcher read aloud the question, “to what extent do you think the following factor is important when making the decision to reduce or stop an individual’s medication?” and provided participants with a written copy of this. Participants were then asked to read through the 53 statements and create three initial piles, those they agreed with, those they disagreed with, and those they felt neutrally towards. Participants were advised they could change their mind at any point in time and could move statements as they wished.

Once the statements had been sorted, the researcher re-introduced the concept of the Q-sort grid which ranged from -5 (most disagree) to +5 (most agree). The number of

cards which participants could place under each heading was explained, and a written reminder was provided along with a visual grid (Appendix 18).

Participants were encouraged to view each statement in relation to the others. Participants sorted the statements which they agreed with onto the distribution, starting by selecting the two statements they agreed with most (+5), then the next three they agreed with most (+4) and so on. Once participants had completed this, they then replicated this process for the pile of 'disagree' statements. Finally, participants then sorted the statements which they had initially felt neutral towards into the remaining spaces on their distribution. Comments offered during the task were recorded verbatim by the researcher. Participants took between 20 minutes – 55 minutes to complete the Q-Sort.

Once participants had completed the Q-sort, they were then asked how they had found the process. The researcher also collected some demographic information (Appendix 19). To conclude, the researcher provided participants with a debrief sheet (Appendix 16) and participants had the opportunity to ask any remaining questions.

Stage 2 Q-Sort: Factor Analysis of Q-Sort

Data analysis was completed using PQMethod – 2.35 with PQROT 2.0 which is a software program specifically created for Q-Methodology by Schmlock (2014). The online PQMethod Manual was used to assist with the data analysis (Schmlock, 2014).

Initially, factors were extracted using a centroid factor analysis (QCENT in PQMethod program). Brown's (1980) method was used for the centroid factor analysis and in line with this, seven centroids were initially extracted as recommended in the PQManual. In Q there are no firm rules on how many factors should be extracted for the final

analysis, although there are several considerations which should be accounted for when choosing the final factors for analysis (Herrington & Coogan, 2011).

One of these considerations is to choose factors based on interpretation of the Eigenvalues. Following analyses, three factors were significant in terms of the Kaiser-Guttman criterion (Stenner & Watts, 2012), with Eigenvalues greater than one, which is taken as the cut off for significance (13.22, 1.70 and 1.02). Another consideration for the analysis of factors was to consider how many factors had significant loadings, using the automatic flagging feature in PQMethod. Adhering to Humphrey's rule, a minimum of two Q-sorts should have significant factor loadings on an extracted factor (Stenner & Watts, 2012). All three of the extracted factors with Eigenvalues greater than one had more than two significant factor loadings.

Using these criteria, these three factors were selected for rotation using the varimax method (QVARIMAX option in PQMethod software). Once this was completed, the final Q analysis of the rotated factors was performed in the software and a file output was produced with the results which outlined the statement placements in each exemplar factor. The exemplar factors were then interpreted by examining the placement of statements with particular consideration of placement of statements at the poles (-5, -4, -3 and +3, +4 and +5).

Results

Factor Loadings

Following the recommendation that "a few factor extractions" are carried out before the final choosing of factors (Damio, 2018), numerous factor extractions were completed and three factors were included in the final data set as the researcher felt

this explained a high level of the study variance in the fewest number of factors, as recommended by Watts (2009).

Three factors were identified in relation to the research aim which was "to understand factors which are important in the clinical decision-making process when deciding to stop and/or reduce the use of psychotropic medications within a community learning disability population". These are as follows: (1) "*Willingness to Deprescribe and Trying Alternative Interventions", (2) "Perceptions of Risk and Behaviours that Challenge",* and (3) *"Professional Opinions, Rational Clinical Judgement and Safe Ethical Practice".* These three factors accounted for 49% of the variance. Child (1970) stated that "a factor loading in the factor analysis is worth considering for interpretation when it represents about 10% or more of the variance", and so all three factors were taken to the next stage for further analysis (see table 3).

Automatic flagging was used for this study which is based on two principles (Zabala & Held, 2018). The first is that the loading is significantly high, for this study the significant factor loading at the 0.01 level is 0.35 (2.58(1÷√53) = 0.35[1] (Damio, 2018). The second principle is that the square loading for a factor is higher than the sum of the square loadings for all other factors – meaning that the loading is much larger than the loadings of the same Q-sort for other factors (Zabala & Held, 2018). Following these principles, five participants did not significantly load onto any factor, and the remaining 27 significantly loaded onto one factor with no confounding Q-sorts (Zabala & Pascual, 2016). Only one participant loaded negatively onto one factor (participant 27 on factor 2), which means this participant demonstrated the polar opposite viewpoint represented by the factor, rejecting this perspective (McKeown & Thomas,

[1] "The researcher then has to calculate a significant factor loading manually using this formulation of 2.58(1/√No of items) for a 0.01 significance" (Damio, 2018).

1988). Significant factor loadings can be seen in table 3, and demographic information for each of the participants who significantly loaded onto the factors can be seen in table 4.

Table 3. Factor matrix after varimax rotation of all participants' loadings on each factor.

Participants	Factor 1	Factor 2	Factor 3
1	0.33	0.70*	0.19
2	0.73*	0.18	0.16
3	0.62*	0.12	0.36
4	0.57*	0.41	0.24
5	0.15	0.49*	0.34
6	0.34	0.51	0.46
7	0.46	0.28	0.43
8	0.61*	0.43	0.11
9	0.56*	0.20	0.24
10	0.51*	0.26	0.35
11	0.57*	0.20	0.17
12	0.53*	0.14	0.45
13	0.41	0.38	0.40
14	0.09	0.22	0.50*
15	0.68*	0.29	0.35
16	0.18	0.41*	0.30
17	0.33	0.15	0.39*
18	0.08	0.67*	0.24
19	0.20	0.49	0.63*
20	0.61*	0.09	0.38
21	0.61*	0.30	0.24
22	0.08	0.68*	0.10
23	0.58*	0.25	0.16
24	0.49	0.28	0.47
25	0.31	0.21	0.54*
26	0.65*	0.17	0.48
27	0.48*	-0.08	0.35
28	0.48	0.18	0.48
29	0.60*	0.54	0.07
30	0.85*	0.22	0.08
31	0.42*	0.17	0.29
32	0.34	0.58*	0.08
% variance	24	13	12

*Significant loading determined by Humphrey's rule

Table 4. Demographic information for participants who significantly loaded onto factors.

Demographics	***Factor 1 (17)***	***Factor 2 (6)***	***Factor 3 (4)***
Gender	Male (6) Female (11)	Male (2) Female (4)	Male (0) Female (4)
Age	22 – 62 years	22 – 47 years	21 – 57 years
Ethnicity	White British (13) White Irish (1) British Pakistani (2) Mixed (1)	White British (5) Mixed Other (1)	White British (3) British Pakistani (1)
Years Qualified	3 years - 37 years Includes 3 Non-Qualified Roles	3 years 6 months – 16 years Includes 1 Non-Qualified Role	6 years – 16 years Includes 1 Non-Qualified Role
Professional Specialisms	Nursing Speech and Language Therapy Psychology Physiotherapy	Nursing Speech and Language Therapy Psychiatry Psychology	Nursing Speech and Language Therapy
Time spent working in learning disability services	6 months - 39 years	8 months – 21 years	11 weeks – 35 years
Prescribers	No (16) Yes (1)	No (5) Yes (1)	No (4) Yes (0)
% of sample	53%	19%	13%

Factor arrays were constructed for each of the factors which are an exemplar viewpoint for a participant significantly loading onto that factor. These were prepared using the statements which had the weighted average for the individual Q-sorts that

loaded significantly within that factor (Watts & Stenner, 2012). These can be found in Appendix 20. These factor arrays reflect an example Q-sort for a participant loading significantly within this factor (Brown, 2004). With the creation of these arrays, distinguishing statements could be analysed which are statements which participants loading on that individual factor have placed in a significantly different position to participants who load on another factor, making it distinguishable for that particular factor (Herrington & Coogan, 2011). Distinguishing statements can help emphasise differences between the factors and aid interpretation, and these are significant at $P < .01$. Key verbatim quotes from participants can also be found in Appendix 21 for each of the three factors.

Factor Descriptions

The following factor descriptions are based upon the interpretation of statement rankings, the factor arrays, qualitative information gathered during the process, and demographic information (Table 2).

Factor One – Willingness to Deprescribe and Trying Alternative Interventions. Seventeen participants significantly loaded onto this factor, accounting for 24% of the variance. There was a mixture of males (6) and females (11) who varied in age (22 – 62 years), with a range of ethnicities, professions and length of time working in intellectual disability services. Table 5a and 5b show the most important pole statements for factor one.

Table 5a: Factor 1 Strongly positively endorsed statements

Strongly Agree

+4	+5
Judgement has to be independent of what commissioners think – it is important that clinicians have an independent view based on clinical need.	The best amount of medication for someone with LD to be on is none in terms of antipsychotics, if that's not possible we should be working as close as we can to that goal.
You should always consider deprescribing, as service users may have side effects that aren't recognised or that they are unable to communicate.	It's easier to reduce or stop medication if a positive behaviour support plan is in place.
Psychological interventions are more appropriate for people with LD than medication– they are better long term.	

Table 5b: Factor 1 Strongly negatively endorsed statements

Strongly Disagree

-5	-4
Challenging behaviour is a chronic condition which will require medication	If the person with LD doesn't engage with psychological therapy, then medication is the only answer
Medication is the only option when behaviour becomes unmanageable	STOMP guidelines have had no impact on deprescribing
	It is important to deprescribe medication to remove people from the caseload

Overall, this group's answers aligned with the ethos of STOMP guidance, as seen in table 5a and 5b. This group strongly disagreed that challenging behaviour is a chronic condition and communicated a willingness to try alternative interventions to medication such as positive behaviour support plans, and psychological interventions (table 5b).

Participants also showed a strong disagreement for “medication is the only option when behaviour becomes unmanageable”.

Alongside showing a willingness to try alternative interventions, participants disagreed that “if things are working it is best not to change things” (-3), and one participant loading on this factor voiced how this could be a “good opportunity to make change”. This was significantly distinctive for this factor, compared with factor two (0) and factor three (+1).

They acknowledged the impact staff can have on affecting change, agreeing that “the level of risk can cause hesitancy to deprescribe medications” (+3) and that a “staff team’s motivation to attempt other interventions can impact the ability to deprescribe medications” (+3) which some voiced they found “incredibly annoying”.

Of note, this factor differed significantly in that participants felt “there is more of a positive risk-taking culture that is being pushed forward which encourages deprescribing” (+3), compared with factor two (-1) and factor three (0). Distinguishing statements for factor one can be found in table 6.

Table 6. Significant distinguishing statements for factor one with positions.

No. Of Statement	Factors		
	One	Two	Three
26. The best amount of medication for someone with LD to be on is none in terms of antipsychotics…	+5	-2	0
50. Psychological interventions are more appropriate for people with LD than medication– they are better…	+4	0	0
25. There is more of a positive risk-taking culture that is being pushed forward which encourages…	+3	-1	0
30. Deprescribing will allow better understanding of the underlying cause of a behaviour.	+2	-1	-1

34. If medication is prescribed for challenging behaviour which is occurring frequently, then depr…	+1	+5	-2
7. Medications can stop individuals learning new ways to cope.	+1	-1	-1
23. If a service user asks for their medication to be stopped, then it should be stopped.	+1	-1	-2
15. Staff and families may under report the side effects due to wanting to maintain medication presc…	0	+1	+2
22. It is important to keep families and care teams on side as they are the ones administering the medicate…	0	+2	+2
43. If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.	-1	+2	-3
48. Sometimes it is not possible to stop medication as it is required as a PRN.	-2	0	+1
18. Staff are afraid they will be blamed if they deprescribe medication, and something goes wrong.	-2	+1	+2
19. If things are working, it is best not to change things.	-3	0	+1
32. Challenging behaviour is a chronic condition which will require medication.	-5	-5	-4

*Note: *Significance at P<.01*

Factor Two – Perceptions of Risk and Behaviours that Challenge. Six participants significantly loaded onto this factor, accounting for 13% of the variance. Participants included both males (2) and females (4), with an age range of 22 – 47 years, and with a range of ethnicities, professions and experience working in intellectual disability services. Tables 7a and 7b show the important pole statements for factor two.

Table 7a: Factor 2 Strongly positively endorsed statements

	Strongly Agree
+4	+5
The level of risk can cause hesitancy to deprescribe medications.	If medication is prescribed for challenging behaviour which is occurring frequently, then deprescribing is less likely.

The staff team's motivation to attempt other interventions can impact the ability to deprescribe medications.	If medication is prescribed for challenging behaviour which is viewed as having a severe impact, then deprescribing is less likely.
If the service user presents as a risk to themselves, it is harder to reduce medications.	

Table 7b: Factor 2 Strongly negatively endorsed statements

Strongly Disagree

-5	-4
Challenging behaviour is a chronic condition which will require medication.	If the person with LD doesn't engage with psychological therapy, then medication is the only answer.
The service user is usually the final decision maker on medication changes.	If there is prior self-harm, the dose should not be reduced.
	Service users prefer to be without medication because that is their true self.

This group expressed opinions which indicated risk-aversion (see tables 7a and 7b). Participants strongly agreed that if medication had been prescribed for challenging behaviour which was either severe or frequent then deprescribing would be less likely. Participants disagreed with the statement "there is more of a positive risk-taking culture that is being pushed forward which encourages deprescribing" (-1), and some participants vocalised they feel it is more of a "managing risk culture", which reflects "how over-worked, under-paid we are and the lack of resources". Another participant expressed "maybe there is in other areas of mental health, but not in the learning disability world".

Participants strongly disagreed that "service users prefer to be without medication because that is their true self" (-4). One participant loading on this factor explained

that they were unsure some service users would have this “level of cognition or insight”, and that being on medication may be “all they have ever known”.

Participants strongly disagreed that “the service user is usually the final decision maker on medication changes”. Participants vocalised they feel service users are often “disempowered” and feel as though they need to agree rather than expressing a desire to change. Participants rated “the psychiatrist is usually the final decision maker on medication changes” as +2.

“GPs are happy to be involved in managing deprescribing” was a distinguishable statement for this factor, with participants rating this as -2, compared with 0 for factors one and three. Participants vocalised “God no” and “I wish” regarding this statement and went on to share difficulties experienced when attempting to collaborate with GPs. Distinguishing statements for factor two can be found in table 8.

Table 8. Significant distinguishing statements for factor two with positions.

No. Of Statement	Factors		
	One	Two	Three
33. If medication is prescribed for challenging behaviour which is viewed as having a severe imp…	0	+5	0
34. If medication is prescribed for challenging behaviour which is occurring frequently, then dep…	+1	+5	-2
36. An individual’s medication won’t be reduced if the placement is considered to be at risk.	-2	+3	-1
42. If a family member has been physically assaulted, it is unlikely the medication will be deprescribed.	-1	+2	-1
43. If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.	-1	+2	-3
1. It is important to have somebody external (e.g., a carer or support worker) who can monitor and report…	+3	+1	+5
10. General Practitioner’s (GP) are happy to be involved in managing deprescribing.	0	-2	0

21. The service user is usually the final decision maker on medication changes.	-3	-5	-3

*Note: *Significance at P<.01*

Factor Three – Professional Opinions, Rational Clinical Judgement and Safe Ethical Practice. Four participants loaded significantly onto this factor, which was the smallest number of significant loadings, accounting for 12% of the variance. Participants were all female and ranged in age (21 – 57 years). Participants also had varied experience of working in intellectual disability services (11 weeks – 35 years), although none were psychologists or psychiatrists. Tables 9a and 9b show the important pole statements for factor 3.

Table 9a: Factor 3 Strongly positively endorsed statements

Strongly Agree

+4	+5
Families and carers often have strong views, stronger than their knowledge base may warrant	Judgement has to be independent of what commissioners think – it is important that clinicians have an independent view based on clinical need
You should always consider deprescribing, as service users may have side effects that aren't recognised or that they are unable to communicate	It is important to have somebody external who can monitor and report withdrawal effects
If the medication is not working, it is usually deprescribed	

Table 9b: Factor 3 Strongly negatively endorsed statements

Strongly Disagree

-5	-4
It is important to deprescribe medication to remove people from the caseload	Withdrawal effects put prescribers off deprescribing
Medication is the only answer when behaviour becomes unmanageable	STOMP guidelines have had no impact on deprescribing
	Challenging behaviour is a chronic condition which will require medication.

Participants within this factor appeared to agree with statements which demonstrated rational clinical judgment. Participants aligned with statements which portrayed healthcare staff to be making decisions which are in line with guidance and may be perceived as the "correct" decisions. For example, "if the medication is not working, it is usually deprescribed" (+4), which is significantly different from how participants sorted this statement in factors one and two, who both placed this statement at zero. In other factors, participants spoke about how they wished this was the case, however this is not what occurs in real world practice, whereas participants within factor three have rated this as +4.

Similarly, participants strongly agreed with "If invasive monitoring (e.g., blood tests) are required with a particular medication, but this can't be facilitated, then that medication can't be prescribed" (+3), compared with participants in factors one and two who rated this as -2. This was significantly distinctive for this factor and may indicate that the people loading on this factor feel that adhering to prescribing guidelines and demonstrating safe ethical practice are important.

Participants in this factor appeared to hold some negative opinions towards family involvement, ranking "families and carers often have strong views, stronger than their

knowledge base may warrant" +4, which was significantly distinctive from factor one (0) and factor two (+1). This, alongside disagreeing with "if the family stop administering the medication of their own accord, the prescriber may be more likely to deprescribe." (-3) contribute to the impression that family's views are not as valued as professional opinions, and healthcare staff will make their own judgments regardless of others' influences. Distinguishing statements for factor three can be found in table 10.

Table 10. Significant distinguishing statements for factor three with positions.

No. Of Statement	Factors		
	One	Two	Three
4. Families and carers often have strong views, stronger than their knowledge base may warrant.	0	+1	+4
17. If the medication is not working, it is usually deprescribed.	0	0	+4
13. If invasive monitoring (e.g., blood tests) are required with a particular medication, but this can't…	-2	-2	+3
6. Having a diagnosed mental health condition affects prescribing decisions.	+2	0	-1
34. If medication is prescribed for challenging behaviour which is occurring frequently, then…	+1	+5	-2
43. If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.	-1	+2	-3
2. If the family stop administering the medication of their own accord, the prescriber may be more likely…	-2	0	-3
12. Withdrawal effects put prescribers off deprescribing	-1	-1	-4
41. It is important to deprescribe medication to remove people from the caseload.	-4	-3	-5

*Note: *Significance at P<.01*

Consensus Statements

There were seven statements which were in consensus amongst all three factors, meaning that these statements were non-significant at the P > .05 value and so

therefore do not distinguish between ANY pair of factors. These statements can be seen in table 11.

Table 11. Consensus statements across all three factors with positions.

No. Of Statement	Factors		
	One	Two	Three
8. Service users thinking they no longer need medication could be a sign of their illness.	-1	-2	-2
9. There are clear guidelines that explain how to discontinue or reduce medications that facility…	+1	0	0
11. STOMP guidelines have had no impact on deprescribing.	-4	-3	-4
20. The psychiatrist is usually the final decision maker on medication changes.	+2	+2	+1
24. The staff team's motivation to attempt other interventions can impact the ability to deprescribe medications.	+3	+4	+3
29. Service users prefer the doctor to make the decisions about medication.	0	0	+1
31. If it is not clear why a medication was started, it will always be deprescribed.	-3	-2	-1

*Note: *Non-Significant at P<.05*

Discussion

Summary of Findings

This study has identified viewpoints from NHS healthcare staff who work in CLDTs regarding their perspectives on factors which are influential in the deprescribing process of psychotropic medications within an intellectual disability population. The findings demonstrate differences in the way staff consider deprescribing. Researchers have reflected on their positionality and ensured repeated reflection throughout the interpretation of results to minimise any biases (Brown & Rhoades, 2017).

Factor one (*Willingness to Deprescribe and Trying Alternative Interventions*) was endorsed by over half of the participants. Participants loading on this factor expressed opinions which were in line with STOMP guidance, which acknowledges psychotropic medications can cause problems if people take too high a dose, take them for too long, or they are prescribed for an unindicated condition (NHS England, no date). Participants endorsing this factor emphasised a willingness to try alternative interventions, such as implementing PBS plans and psychological interventions which are becoming increasingly popular within CLDTs (Challenging Behaviour Foundation, no date; Gore et al, 2013; Witwer et al, 2022). This is in line with national policy documents which emphasise the need for alternatives to medication (British Psychological Society, 2004; Department of Health, 2007; NICE, 2015).

Factor two (*Perceptions of Risk and Behaviours that Challenge)* participants appeared more risk-averse, strongly agreeing that the level of risk can cause hesitancy to deprescribe, and that if challenging behaviour was present and severe or frequent in nature deprescribing would be less likely. Research in other fields have demonstrated hesitancy to deprescribe can be for numerous reasons including a fear of being seen to be withdrawing care from a patient or making things worse, and due to limited guidance on how to deprescribe safely (Ailabouni et al, 2016; Peat et al, 2022; Sawan et al, 2020). Both the prescribing and deprescribing of psychotropic medications can place individuals at risk of adverse events and poor quality care (Flood, 2018). Some prescribers are reluctant to deprescribe if medications have been prescribed over long time periods making it difficult to judge the impacts and risks of deprescribing (Sheehan & Hassiotis, 2017).

In broader terms, a reluctance to deprescribe may also relate to ‘therapeutic disdain’ which has been felt amongst individuals with intellectual disabilities for numerous

years. This was first described in an article named 'the un-offered chair' which discusses how professionals judge individuals with an intellectual disability to be unable to engage in alternatives to medication, such as psychotherapy (Bender, 1993). There has been a change in attitudes amongst health professionals valuing psychotherapy and alternatives to medication, which was demonstrated in the Royal College of Psychiatrists (2004) survey of psychiatrists and psychologists. This study found 83% of respondents reported a moderate or high demand for psychotherapy for individuals with an intellectual disability. However, it is possible that there are remnants of this disdain still present amongst some health professionals which could influence attitudes to deprescribing.

Participants within factor two expressed their frustrations at the lack of involvement from GPs. Research published by Kouladjan et al (2016) shared pharmacists airing their frustrations with GPs disregarding their recommendations for deprescribing, and GPs expressed their views that deprescribing of certain medications should be undertaken by specialists. Decisions can be influenced by staff attitudes towards off-label prescribing, levels of confidence, and knowledge (De Kuijper, 2017; Jones et al, 2015).

Factor three (*Professional Opinions, Rational Clinical Judgement and Safe Ethical Practice)* participants appeared to have a positive view of adherence to clinical guidelines, and valued professional judgement. Participants agreed with statements that favoured safe ethical practice, and seemed convinced that these guidelines are adhered to in practice (e.g., medications are usually deprescribed if not working, and if invasive monitoring is unable to be facilitated then medications cannot be prescribed). NICE guidelines recommend that through titration of antipsychotics professionals should monitor any side effects, weight, blood pressure, glucose levels,

and overall physical health, with individuals attending health checks annually (NICE, 2014). In reality, previous research has revealed that adherence to antipsychotic monitoring guidelines are notoriously low nationally (Deb et al, 2020; Javaid et al, 2020), with national projects highlighting the low uptake of monitoring and measures to improve metabolic abnormalities within the intellectual disability population (Thomson et al, 2016). Individuals may refuse to comply with physical health monitoring procedures and there are no published guidelines to indicate to professionals what they should do in these instances (Ali et al, 2020; Murphy et al, 2015). Murphy et al (2015) highlighted four ways in which professionals may encourage engagement in physical health monitoring: continual encouragement, compliance therapy, contingency management and control and restraint.

Clinical Implications

Findings from this study are initially reassuring, with the majority of participants loading significantly on factor one which expressed opinions in line with STOMP guidance. The current findings do however also raise a number of areas for consideration. Firstly, many of the participants highlighted their knowledge gaps in reference to guidance on deprescribing psychotropic medications. Participants often expressed they were unaware of guidance but “hoped there would be clear guidance out there”. These findings indicate a need for training on guidelines within CLDTs, to raise awareness and build staff confidence for their participation in medication reviews. Close auditing and monitoring of training, and also deprescribing processes would ensure increased knowledge and quality amongst decision-making within teams.

STOMP guidance emphasises how healthcare professionals should be working together to implement the recommendations, which include actively exploring

alternatives to medication, ensuring accurate record keeping about a person's health and wellbeing, and following relevant NICE guidance which is applicable to all members within a CLDT (NHS England, no date). Findings from this study have evidenced some willingness from staff teams to implement alternatives to medication, and clinical psychologists have a significant and important role to play in implementing alternatives, including improving access to psychological therapies (Morris et al, 2018).

It was noted many staff verbalised they were not routinely involved in medication reviews and/or did not see their role within this and felt this was the psychiatrist's role. The NICE guidelines for prescribing psychotropic medications within intellectual disability populations recommend conducting a “full multidisciplinary review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping)” [NG11] (NICE, 2015). The researcher gained a sense these guidelines are not widely known throughout services, and it appeared multidisciplinary reviews were not necessarily being held across teams, with allocated staff expressing they had not been invited or attended medication reviews. One of the hypothesised reasons for these multidisciplinary reviews not being completed may be due to the underfunding, lack of resources, and low staffing levels leading teams unable to facilitate these discussions.

Between the factors, inconsistent approaches to risk management were highlighted, with some professionals being more risk-averse than others. Differences amongst professionals in assessing risk could be due to numerous factors which should be discussed and considered within teams and how these impact risk assessment and management plans. Clinical psychologists have a role to play in the assessment and management of risk which may occur for individuals with an intellectual disability when

medication is changed (Morris et al, 2018), and could facilitate these discussions amongst teams to ensure consistency in approach.

Limitations

The main limitation of the study was that no participants with intellectual disabilities and/or their family members were recruited for the stage one interviews, which would have contributed to the formation of statements. Researchers had initially aimed to interview three individuals with an intellectual disability and/or their family members regarding their experiences of being prescribed psychotropic medications, or their experience of supporting their loved one through their medication journey. Ethics committees had agreed for this, however only if initial contact was made with the potential participants via gatekeepers (allocated healthcare workers within the NHS CLDTs). Unfortunately, no healthcare staff identified or contacted service users asking for voluntary participation for the interviews, and due to time constraints, the researcher was required to move onto recruitment for stage two.

It is hypothesised that the difficulties in recruitment may have been in part due to the stress and pressures NHS staff are currently under, and staff may have found it difficult to find the time to take on these additional requests from the research team, alongside the time constraints. The research team were therefore conscious to not lose the voice of individuals with an intellectual disability and their families, and so one of the researchers read through disability forums to identify service users voices to form statements, however this is acknowledged as a limitation of the research and some opinions of this population group may have been omitted from the statements as a result of this.

As the selection of statements is heavily influenced by the research team, some researchers have reported researcher bias as a potential problem in Q (Zabala et al 2018). To make sure researcher bias was minimised wherever possible, the statement selection process was systematic and transparent. All three researchers were involved in the process, two of whom have backgrounds working in CLDTs (AC and AF) and the other researcher has a background in mental health pharmacy (including intellectual disabilities; JD). Statements were reviewed by participants from the interviews for their comments and feedback which was actioned, and a pilot trial was also completed with two trainee clinical psychologists.

This study used a purposive sampling method and therefore there is a possibility that those who volunteered to participate in the study did so due to them having an invested interest in STOMP and/or deprescribing. Those who did not volunteer to participate may have had varied viewpoints which may not have been captured within the study. It is acknowledged that as only two prescribers participated, the voices from the prescribing community are limited, despite them having the most crucial role within deprescribing.

A general limitation of Q is that the methodology is unlikely to uncover all possible viewpoints within the population. The study findings may therefore not be generalisable to wider populations, although this is not an aim of Q, rather Q-studies focus on uncovering authentic opinion clusters (Barbosa et al, 1998; Valenta & Wigger, 1997). It is also important to reflect whether participants provided socially desirable answers, and whether the factors are truly representative of opinions held in real life.

There were no distinguishing participant characteristics for any of the factors. Participants from a variety of professions loaded onto each of the factors (although no

psychiatrists or psychologists on factor 3), and participants varied in age, ethnicity and time spent working in intellectual disability services. There may however have been participant characteristics which researchers did not collate which may have been influential in their Q-sort decision-making. For example, past experiences of service users being deprescribed medications, personal experience of psychotropic medications, and involvement in risk management.

Medication Journey

One of the initial inspirations for this study was Wastell et al's (2013) Q research which investigated factors influencing the prescribing of psychotropic medications for challenging behaviour within an intellectual disability population. Similarities can be seen between Wastell et al's factor 1) "High-quality safe ethical practice" and our factor 3) Professional Opinions, Rational Clinical Judgement and Safe Ethical Practice, and also between researchers factor 2) "Risk is a rationale for reactive prescribing" and our factor 2) Perceptions of Risk and Behaviours that Challenge. Together, Wastell et al's (2013) and the present research demonstrate factors which are consistent and present along an individual's medication journey, and are contributing to and influencing medication decisions (e.g., risk, behaviours that challenge, practice guidelines, clinical judgement).

Future Research

Overall, this study has demonstrated how complex the decision-making process is for practitioners considering deprescribing medications within CLDTs. Although this study did not aim to assess professionals knowledge of deprescribing guidelines, some of

the comments made by staff highlighted gaps in knowledge of guidelines and also their role within medication reviews. Research could therefore examine staff's knowledge of the evidence base and guidelines for deprescribing, and could also explore whether and if so what role staff from different professional backgrounds feel they have in implementing STOMP guidance.

This study has highlighted many factors which contribute to deprescribing decisions, particularly contextual factors which are at play – including influences from family, risk, and physical health. As previously mentioned, clinical psychologists have a role to play in the implementation of STOMP guidelines (Morris et al, 2018), but also within the application of the recommendations following this study including assisting in training of staff within CLDTs, increasing knowledge and awareness of risk assessment and formulation, and being present and involved in medication reviews in adherence with NICE guidelines. It must be acknowledged that there was a limited number of prescribers who participated within the research, and so future research may wish to replicate specifically with prescribers, with the possibility of including pharmacists and General Practitioners. . It would also be good to replicate this study in other areas of intellectual disability services (e.g., forensic, inpatient) to further identify factors contributing to deprescribing decisions. Future Q-sort studies could also explore the views of individuals with an intellectual disability and their families to gain their perspectives of what factors influence the deprescribing of psychotropic medications.

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Appendices

Appendix 1

Manuscript Submission Guidelines: Journal of Intellectual Disabilities
Essential information is provided here. Please see author guidelines for full details: https://journals.sagepub.com/author-instructions/jld

Article Types
Your manuscript should ideally be between 6000 and 8000 words long, and double spaced. Please also supply an abstract of 100-150 words, and up to five keywords, arranged in alphabetical order.

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.

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.

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 - https://uk.sagepub.com/en-gb/eur/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.

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.

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.

Appendix 2

Section and Topic	Item #	Checklist Item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title page, page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract, Page 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Introduction, Page 2-3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Introduction, Page 2
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Method, Page 4
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Method, Page 4
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Method, Page 4
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Results, Page 7
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Method, Page 5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Method, Page 5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Results, Page 9-13
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Results, Page15-17
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Results, Pages 7-8
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A

Section and Topic	Item #	Checklist Item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Results, Page 7
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Method, Page 6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Results, Page 15-17
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Results, Page 15-17
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Results, Page 7-8
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Results, Page 8
Study characteristics	17	Cite each included study and present its characteristics.	Results, Page 9-14
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Results, Page 15-17
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Results, Page 11-13
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Results, Page 18-40
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Results, Page 18-40
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Discussion, Page 41-42

Section and Topic	Item #	Checklist Item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	Discussion, Page 42-44
	23c	Discuss any limitations of the review processes used.	Discussion, Page 42-44
	23d	Discuss implications of the results for practice, policy, and future research.	Discussion, Page 44-45
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Introduction, Page 3
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Introduction, Page 3
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	Introduction, Page 3
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix 3

CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

CASP
Critical Appraisal Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

CASP
Critical Appraisal Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal Skills Programme

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:	

Appendix 4

NHS
Health Research Authority
West Midlands - Coventry & Warwickshire Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

28 July 2022

Miss Amy Calderbank
14 Balmoral Avenue
LEYLAND
PR25 4HX

Dear Miss Calderbank

Study title:	**Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population**
REC reference:	**22/WM/0136**
Protocol number:	**UoL001684**
IRAS project ID:	**309255**

Thank you for your response which was received on 22 July 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair and a named member of the Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the

Appendix 5

UNIVERSITY OF LIVERPOOL

D.Clin.Psychology Programme
Division of Clinical Psychology
Whelan Building, Quadrangle
Brownlow Hill
LIVERPOOL
L69 3GB

Tel: 0151 794 5530/5534/5877
Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

Amy Calderbank
Clinical Psychology Trainee
Doctorate in Clinical Psychology Programme
University of Liverpool
L69 3GB

25 October 2021

RE: Factors Influencing the De-prescribing of Psychotropic Medication within a Community Learning Disability Population
Trainee: *Amy Calderbank*
Supervisors: Jennie Day and Andrea Flood

Dear Amy,

Thank you for the submission of your amended proposal to the Chair of the D.Clin.Psychol. Research Review Committee.

I can now confirm that your amended proposal and budget meet the requirements of the committee and have been approved by the Committee Chair.

Please take this Chairs Action decision as ***final*** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Alys Griffiths
Vice Chair D.Clin.Psychol. Research Review Committee

Appendix 6

Dr J Day
Institute of Population Health
University of Liverpool,
Waterhouse Building, Block B,
Brownlow Street,
Liverpool,
L69 3GF

Miss Karen Wilding
Senior Clinical Research Governance Manager

Clinical Directorate
4th Floor Thompson Yates Building
Faculty of Health and Life Sciences
University of Liverpool
Liverpool L69 3GB

Tel: 07717 863747
Email: sponsor@liverpool.ac.uk

02 March 2022

Sponsor Ref: UoL001684

Re: Sponsorship Approval

Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population

Dear Dr Day,

After consideration at the LHP SPARK Non-Interventional Sponsorship Sub-Committee on 23 February 2022 I am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the UK Policy Framework for Health and Social Care Research for the above study.

The following documents have been received by the Clinical Research Governance Team, in their capacity as Sponsor office;

Document title	Version	Date
Protocol	1	10 Jan 2022
Participant Consent Form	1	10 Jan 2022
Participant Consent Form Q-sort	1	10 Jan 2022
Debriefing sheet	1	22 Nov 2021
Participant Information Sheet Interview Stage 1	1	10 Jan 2022
Participant Information Sheet Q-sort Stage 2	1	10 Jan 2022

Please note this letter does NOT allow you to commence any study activity. This includes (but is not limited to) recruitment of participants, collection of human material samples, analysis of existing human material samples, collection of data or analysis of existing data

Appendix 7

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Amy Calderbank
14 Balmoral Avenue
LEYLAND
PR25 4HX

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

01 August 2022

Dear Miss Calderbank

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

Study title:	**Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population**
IRAS project ID:	**309255**
Protocol number:	**UoL001684**
REC reference:	**22/WM/0136**
Sponsor	

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.

Appendix 8

Study Title: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population (Stage 1)

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thank you for reading this.

1. What is the purpose of the study?

STOMP (stopping over medication of people with a learning disability, autism, or both with psychotropic medicines) is a national project which started in 2016. The aim of the project is to help stop the overmedicating of individuals with a learning disability, autism and/or both in order to improve their quality of life. It is estimated that 35,000 adults with learning disabilities are taking psychotropic medication daily in the absence of a diagnosed mental health condition (NHS, 2021).

Current data collected from GP practice systems regarding prescribing in patients with a learning disability reveals that within the time frame 2019 to 2020, the percentage of patients with a learning disability who had been prescribed antipsychotics was significantly higher than in patients without a learning disability (15.2% compared to 0.9%), rates of prescribed benzodiazepines was also significantly higher (7.2% compared to 2.1%), and the rates of prescribed antidepressants was also significantly higher (11.6% compared to 4.4%) in patients with a learning disability compared to those patients without a learning disability (NHS Digital, 2021).

Therefore, the aim of this project is to gain an understanding of the factors which are important in the clinical decision-making process when deciding to **stop and/or reduce** the use of psychotropic medication within a community learning disability population.

2. Why have I been invited to take part?

You are being invited to participate in this research, in either stage 1 or stage 2. You are being asked to participate in stage 1 of the research: the interview stage.

We are inviting you to take part because we would like to hear about your experiences of being prescribed psychotropic medications [OR] your experiences supporting an individual who has been prescribed psychotropic medications (including families, paid carers, and NHS staff). We are aiming to interview approximately 6 people.

3. Do I have to take part?

No. You do not have to take part if you do not want to. Please read this information sheet before you decide. Participation is entirely voluntary, and you are free to withdraw your

participation, without explanation. You will not be at a disadvantage if you decide not to take part.

4. What will happen if I take part?

You will be asked to participate in a semi-structured interview regarding your experiences with psychotropic medications. The interview will have some structured questions to answer which will ask about your experiences of being prescribed psychotropic medication, attending medication reviews with the psychiatrist/GP, and the deprescribing and/or reduction of such medications [OR] your experiences of supporting somebody who has been prescribed psychotropic medications. As this is a semi-structured interview however, the interview will mostly be guided by you and the areas you wish to discuss.

The interview will take place with the researcher Amy Calderbank, Trainee Clinical Psychologist. The interview will be a one-off interview, with an approximate duration of 30 minutes.

The interview will be audio recorded and will be transcribed externally by a university approved transcriber. At this stage, your data will be made anonymous which means that your name and other personal identifying information will be removed.

At the end of the study, participants will be provided with a debrief form which will contain contact details for the research team should they wish to ask any questions in the future.

5. How will my data be used?

All data will be processed and stored in accordance with GDPR regulations. The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator / Supervisor acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Jennie Day – j.day@liverpool.ac.uk. Further information on how your data will be used can be found in the table below.

How will my data be collected?	Recordings of interviews will be audio transcribed by a university approved transcriber.
How will my data be stored?	Recordings of interviews will be password protected and stored securely until they have been transcribed, following which they will be destroyed. Transcriptions and all other study data will be anonymised and stored in password protected folders in line with the University's research data management policy.
How long will my data be stored for?	Following completion of the study, the primary supervisor will be the assigned the data custodian and the data will be stored for a minimum of 5 years.

What measures are in place to protect the security and confidentiality of my data?	Your electronic data will be stored on a secure university network, and files will be password protected. Any paper copies of data will be stored in a secure filing cabinet. The researcher and the supervisory team are bound by confidentiality. This means that they will not discuss your data with anyone else and only the research team will have access to the data, which will also be anonymised. **Please note that confidentiality will only be breached if we feel that something you discuss indicates a risk of harm to yourself or others. In these cases, we have a duty to protect you/others and to keep you/others safe which may involve discussing information with relevant services. Wherever possible, we will inform you of this, and support you.**
Will my data be anonymised?	Once transcribed all identifying information will be de-personalised through the creation of a unique participant codes. To further ensure protection of confidentiality, any quotes used for the Q-sort will be chosen carefully and de-personalised.
How will my data be used?	Audio recordings from the interview will be transcribed and de-personalised by an approved transcriber. Anonymous transcriptions will then be analysed by the researcher to find any key statements which could be used for the Q-sort (which will be administered to health professionals). These statements will then be combined with other key statements from literature, websites, and videos. The statements will form a Q-sort for health professionals to complete. The researcher may contact you (with consent) to review the final set of statements, and for you to provide your feedback on the Q-sort before administering to NHS staff. Some of the statements gathered from the interviews may be used within the final written report as example statements; these will be made anonymous. The data will be commented on and written into a report which will be submitted as part of the researcher's (Amy) thesis for their Doctorate in Clinical Psychology. It is anticipated that the research will be submitted for publication in an academic journal. Information about the study including the anonymised results may also be presented at a conference or professional practice event.
Who will have access to my data?	Amy Calderbank (researcher), and the supervisory team (Dr Jennie Day and Dr Andrea Flood).
How is the project monitored and audited?	The research team will have regular meetings to ensure the project is monitored accordingly and running to the agreed time scale. As the research is being completed as part of a Doctorate in Clinical Psychology thesis, there is a time scale that needs to be adhered to. Amy (student researcher) will be responsible for keeping the supervising team up to date regarding the research's progress. Any

	written work will be checked by project supervisors, Jennie and Andrea, who both have experience supervising research projects.
Will my data be archived for use in other research projects in the future?	No.
How will my data be destroyed?	Paper copies of data will be shredded and disposed of in confidential waste bins. Electronic copies of data will be deleted from computer systems.

6. Are there any risks in taking part?
The nature of the research is discussing a longstanding issue regarding the overmedicating of individuals with a learning disability, and therefore there is the potential this topic may cause upset. Please be assured you can always abstain from answering any questions which may feel too uncomfortable and can withdraw from the study at any point.

In situations where emotional distress does occur, the researcher will ask if you would like to pause the interview and allow you time to consider if you wish to continue or not. The researcher carrying out the interviews is a Trainee Clinical Psychologist, experienced in working with sensitive issues and so will be able to provide immediate support and contact details of any relevant support services, if needed.

7. Are there any benefits in taking part?
It is hoped this research will provide valuable information, in line with STOMP (stopping over medication of people with a learning disability, autism, or both with psychotropic medicines) which can help improve our understanding about the factors which contribute to the deprescribing and/or reduction in psychotropic medications being administered.

8. What will happen to the results of the study?
The results of the study will be typed into a report which will be submitted to the University of Liverpool as part of the researchers (Amy) thesis for their Doctorate in Clinical Psychology program. Amy Calderbank (student researcher) is being supervised by Dr Jennie Day and Dr Andrea Flood. The sponsor for the study is the University of Liverpool.

We are aiming to publish the findings as a journal article which will be read by other professionals from both research and clinical backgrounds. It is also hoped the findings will provide valuable insight into the factors which contribute to deprescribing and/or reducing an individual's psychotropic medication, which will be useful for the STOMP initiative. Results may therefore be shared at future conferences and practitioner seminars to make others aware of the findings.

All information appearing in any reports or presentations will be entirely anonymous, meaning no one will be able to identify anyone that took part. You will have access to all reports, and a summary of the results can be provided if this were something you would like. You will have access to both Amy and Jennie's email addresses should you wish to request a copy of the findings.

9. What will happen if I want to stop taking part?

You can withdraw your participation from the study at any time without explanation. After participating, you can also withdraw up to two weeks post participation. However, it will not be possible to withdraw data after two weeks in accordance with the lawful basis of 'public task'. If you would like to withdraw from the study, you can contact the researcher whose details are listed below.

10. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Amy Calderbank at A.Calderbank@liverpool.ac.uk or Dr Jennie Day j.day@liverpool.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

11. Who can I contact if I have further questions?

Researcher:

Amy Calderbank (Trainee Clinical Psychologist)
A.Calderbank@liverpool.ac.uk
The University of Liverpool
The Whelan Building
Brownlow Hill
Liverpool L69 3GB

Supervisors:

Dr Jennie Day (Primary Supervisor): j.day@liverpool.ac.uk
Dr Andrea Flood (Secondary Supervisor): amflood@liverpool.ac.uk

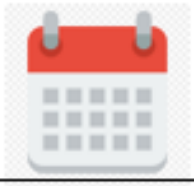
Sponsor:

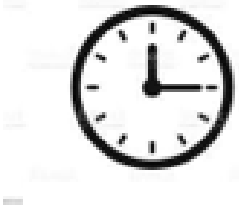
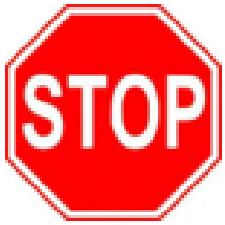
Karen Wilding,
University of Liverpool
Clinical Directorate
4th Floor Thompson Yates Building
Liverpool
L69 3GB
01517948739
sponsor@liv.ac.uk

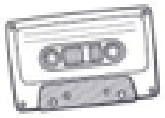
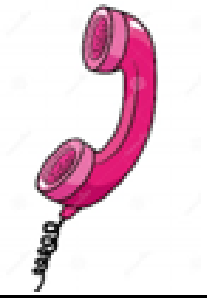
Thank you

Appendix 9

Study Title: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population (Stage 1)

What is this research project about?	
UNIVERSITY OF LIVERPOOL	My name is Amy. I am doing some research at the University of Liverpool.
	My research project is about medicines which people take for their mental health.
	These medicines can cause problems when people take them for too long, or too high a dose.
	Sometimes they can cause side effects like putting on weight, feeling tired, or physical health problems.
	In the United Kingdom there are approximately 35,000 people with a learning disability taking these medicines, when they do not have the health conditions the medicines are for.

What do I need to do?	
	I would like to ask you questions about your medication.
	The interview will take approximately 30 minutes.
	The interview will ask you questions about: - The type of medication you take - What the medication is for - What you think about the length of time you have taken the medicine for - What you think the good things are about the medication, and what you think the bad things are about the medication
	You can skip any questions you don't want to answer, and you can stop at any time.

	The interview will be audio recorded on a Dictaphone.
	A third party will listen to your recorded interview so they can transcribe the interview (write down word for word what we talk about).
	At the end of the study, you will be given a 'debrief sheet'. This will have contact details for the research team, and you can contact them if you have any questions.
	Some of the statements gathered during our interview will be used in research with NHS staff. Amy might contact you to review these statements in the future, if you agree this would be OK.
Do I have to take part?	
	You do not have to take part in this research. It is your choice. You can change your mind at any time by letting Amy know you do not want to do the interview anymore.

	If you do not want us to use your data you have **up to two weeks** to let the research team know that you do not want them to use your data. It will not be possible to withdraw after two weeks in accordance with the lawful basis of 'public task'.
Will I get anything for taking part?	
	Yes. You will receive a £15 voucher for your participation.
Are there any risks in taking part?	
	Sometimes people may become upset when talking about their mental health and medication.
	You can skip any questions you do not want to answer and can stop the interview at any point. If you do become upset, Amy will be able to support you and can contact any relevant people / services to support you if needed.

Is taking part in the research private?	
	What we talk about will be kept private, in a safe place, and will be anonymous. This means the information won't have your name on, so nobody will know the data is yours!
Storing the data	
	Your information will be kept safe and secure. Only members of the research team will have access to your data.
Monitoring the project	
	The research team will have regular meetings to make sure the project is going to be completed on time. Any written work will be checked by Jennie and Andrea (Amy's supervisors). They both have experience supervising students!

How will the information be used?	
	Amy will write a report about the research for the University of Liverpool. The results will also be published in a journal article. You can have a copy of the results if this is something you would like. You will have access to both Amy and Jennie's email addresses and can email them to ask for a copy of the findings.
What if I am unhappy with the research?	
	If you feel unhappy with the research, or there is a problem please let Amy or Jennie know. A.calderbank@liverpool.ac.uk (Amy) j.day@liverpool.ac.uk (Jennie)
UNIVERSITY OF LIVERPOOL	If you would like more information about how your data is used, or would like to speak to the sponsor for this research you can contact: The University of Liverpool Karen Wilding sponsor@liv.ac.uk 01517948739
Thank you	

Appendix 10

Participant Consent Form

Version number & date: V2, 06/07/2022
Research ethics approval number: 309255
Title of the research project: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population
Name of researcher(s): Amy Calderbank, Dr Jennie Day, and Dr Andrea Flood

Please initial box

1. I confirm that I have read and have understood the information sheet dated V2 06/07/22 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves participating in an interview regarding your experiences of being prescribed psychotropic medications [OR] your experiences of supporting an individual who has been prescribed psychotropic medications. The interview is likely to last up to 30 minutes. ☐
3. I understand and agree that my participation will be audio-recorded, and I am aware of and consent to your use of these recordings for the following purposes: recordings will be transcribed by a university approved transcriber (third party), and statements will be extracted from the recording, to be used to form a Q-Sort which will be administered to NHS professionals. ☐
4. I understand all information appearing in any reports will be anonymous and de-personalised. This means that in order to protect my anonymity all names (including my own) will be changed as well as any other identifying information, such as any details of any places or dates. ☐
5. I agree that my information can be quoted in research outputs such as journal articles, presentations and the researcher's doctoral thesis. However it will not be possible to identify me as all quotes will be anonymised, given different names, and any identifying information will be changed. ☐
6. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
7. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time up to a period of 2 weeks after participation. I understand that following 2 weeks after participation I will no longer be able to request access to or withdrawal of the information I provide in accordance with the lawful basis of 'public task'. ☐

8. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my fully anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
9. I understand that the confidentiality of the information I provide will be safeguarded and won't be released without my consent unless required by law. I understand that if I discuss information which raises considerations over the safety of myself or the public, the researcher may be legally required to discuss my information to the relevant services or authorities. ☐
10. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool. ☐
11. I understand that copies of my interview transcript will be retained for a minimum of 5 years and stored and destroyed in line with the University's research data management policy. ☐
12. I agree to take part in the above study. ☐
13. After my involvement in the interviews, I consent for Amy to contact me via telephone / email to review the final Q-Sort set of statements. ☐

Participant name	Date	Signature
Name of person taking consent	Date	Signature

Principal Investigator
[Dr Jennie Day]
[jday@liverpool.ac.uk]

Student Investigator
[Amy Calderbank]
[A.Calderbank@liverpool.ac.uk]

Original signed copy – Held with research team
Second signed copy – Handed to participant

Appendix 11

V1 IRAS: 309255

Participant Consent Form

Version number & date: V1 19/11/2021
Research ethics approval number: 309255
Title of the research project: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population
Name of researcher(s): Amy Calderbank, Dr Jennie Day, and Dr Andrea Flood

	I have received the information sheet. I understand that I will be doing an interview about my medication.	
	I understand that the interview will be recorded. The recording will be transcribed, which means somebody will write down what I have said.	
	I understand that my information will be anonymous. This means my name won't be on the information.	
	I understand I can stop at any point. I understand I don't have to do the interview if I don't want to.	

	I understand the information will be stored in a secure, safe place.	
	I agree to take part in the research.	

My Name:

_____

Date:

_____

Name of researcher completing form with participant:

_____

Principal Investigator
[Dr Jennie Day]
[jday@liverpool.ac.uk]

Student Investigator
[Amy Calderbank]
[A.Calderbank@liverpool.ac.uk]

Appendix 12

Interview Guide (semi-structured)

I am interested in medications that are called psychotropic medications, which are prescribed for mental health conditions such as depression. Psychotropic medications affect how the brain works. There are four main categories of psychotropic medications which includes antidepressants, antipsychotics, sleeping pills and minor tranquillisers, and lithium and other mood stabilizers.

I will be asking questions related to a specific service user or family member that you support. In the first section I will ask questions about the start of the individuals medication journey, when the medication was first prescribed. The second section asks questions about the length of time the medication was prescribed for, and in the third section I will ask you about your perceptions of the risks and benefits of the medication. Finally, I will ask about the medication reviewing process, and how medication changes are made.

If you do not understand any of the questions, please ask for clarification, and if would like to skip any questions please let me know.

The start of the medication journey:

What type of medication is the person taking? (e.g., name of medication, is it an antidepressant, antipsychotic etc.)

Why were these medications prescribed? / What was the medication prescribed for? (e.g., mental health diagnosis, challenging behaviour…).

Who prescribed the medication?

What were you told about the medication? (Prompts: benefits, side effects, length of time prescribed for…)

How were you involved in the decision to prescribe the medication?

Were any other interventions offered prior to medication? (e.g., input from nursing, PBS plans, psychological therapy…).

Time:

How long has the individual you support been prescribed the medication for? (Approximate days / months)

Were you provided with information regarding how long the medication would be prescribed for?

How appropriate was the length of time the medication was prescribed for?

How do you feel about the length of time the medication has been prescribed for?

Who else talked to you about the length of time to take the medication for?

What reason did they give for prescribing the medication for this length of time?

Risks and Benefits:

What risks or side effects of the medication where you told about?

What benefits of the medication where you told about?

How did the medication help?

How was the medication unhelpful?

Review Process:

What did the medication review process look like for the individual you support (e.g., MDTs, meetings with the psychiatrist etc)?

Who was involved in the medication reviews?

How did the person prescribed the medication give their viewpoint/experience of the medication?

How were their viewpoints listened to/taken on board?

How were the benefits of the medication discussed?

How were the side effects discussed?

How were the dose changes discussed and considered?

How was stopping the medication discussed?

What are the plans for supporting the person in stopping medication? / Why do you think the individual you support was able to stop taking their medication? (Prompts: what factors do you think facilitated the reduction / stopping of the medication?)

What factors do you think are important when reducing a person's medication?

Why would someone decide to stay on their medication?

What other factors may be influential as to whether somebody is taken off their medication / medication is reduced (e.g., health concerns, side effects…).

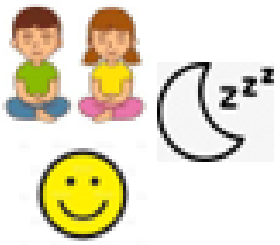
Is there anything else you would like to say about medication use which we have not covered…

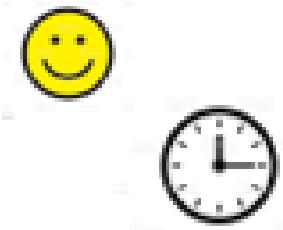
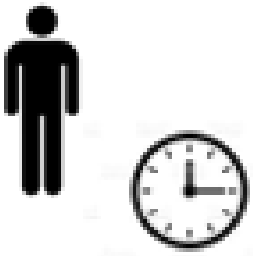
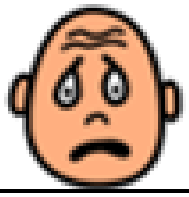
Appendix 13

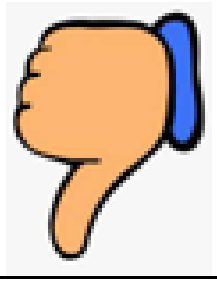
Interview Structure (semi-structured)

This interview will ask you some questions about your medication. If you do not understand any of the questions, please let me know and I can try and help. If you would like to miss out any questions, please let me know.

The interview has different sections. The first section is about you and the type of medication you take, the second section is about the length of time you have been taking the medication for, the third section will ask about the risks and benefits of the medication and the final section will ask questions about the review process.

You and Your Medication	
	What do you call your medication? (Pills, tablets, medicine...) - ***note to interviewer to use this terminology***
	Do you know why you were given your medication? (Prompts: what is your medication for? why do you take the medication? Mental health diagnosis? – feeling sad / angry? Behaviours which challenge?)
	Do you know what the medication is supposed to help with? (Prompts: is the medication to change your mood? Is the medication to make you sleep?)
	Where you offered any other help before taking the medication? (Prompts: Have you had any nursing input? Psychology input? Therapy? Do you have any behaviour support plans?

Time	
	Do you know how long you have been taking the medication for? (Days, months, years…)
	Do you feel happy with this amount of time? (Prompts: do you think you should have taken the medication for a shorter time? / For a longer time?)
	Why do you think this was (or wasn't) a good amount of time to take the medication?
	Did anybody else talk about whether this was a good length of time to take the medication for? (If yes) Who? What did they say?
Risks and Benefits	
	Do you have any worries about taking your medication?
	Do you know if there are any risks / side effects of your medication? (Prompts: do you feel sleepy taking the medication? Does it make you feel dizzy? Do you get a dry mouth? etc…)

	Do you feel the medication is helpful? / Do you feel the medication is good? (If yes) In what ways do you feel the medication is helpful? (Prompts: does the medication make you feel happier? Calmer? Does the medication help you sleep?
	Do you feel the medication is not helpful? / Do you feel the medication does not work? (If yes) In what ways do you feel the medication is not helpful? (Prompts: does the medication make you feel sad? angry? Does the medication make you too sleepy?
Reviewing Your Medication	
	Do you have meetings to talk about your medication?
	Who goes to the meetings to talk about your medication? (e.g., mum, dad, nursing, psychiatrist, psychologist, staff..).
	Do you think you will ever stop taking the medication? (If yes) when do you think you might be able to stop taking the medication? OR: Why do you think you were able to stop taking the medication?
	Who do you think is involved in deciding whether you should stop taking the medication?

Appendix 14

Study Title: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population (Stage 2)

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thank you for reading this.

1. What is the purpose of the study?

STOMP (stopping over medication of people with a learning disability, autism, or both with psychotropic medicines) is a national project which started in 2016. The aim of the project is to help stop the overmedicating of individuals with a learning disability, autism and/or both in order to improve their quality of life. It is estimated that 35,000 adults with learning disabilities are taking psychotropic medication daily in the absence of a diagnosed mental health condition (NHS, 2021).

Current data collected from GP practice systems regarding prescribing in patients with a learning disability reveals that within the time frame 2019 to 2020, the percentage of patients with a learning disability who had been prescribed antipsychotics was significantly higher than in patients without a learning disability (15.2% compared to 0.9%), rates of prescribed benzodiazepines was also significantly higher (7.2% compared to 2.1%), and the rates of prescribed antidepressants was also significantly higher (11.6% compared to 4.4%) in patients with a learning disability compared to those patients without a learning disability (NHS Digital, 2021).

Therefore, the aim of this project is to gain an understanding of the factors which are important in the clinical decision-making process when deciding to **stop and/or reduce** the use of psychotropic medication within a community learning disability population.

2. Why have I been invited to take part?

You are being invited to participate in this research, in either stage 1 or stage 2. You are being asked to participate in stage 2 of the research: the Q-sort stage.

We are inviting you to take part because we would like to gather viewpoints from a variety of healthcare professionals (psychiatrists, psychologists, nurses, healthcare support staff etc.) regarding factors they feel are important when deprescribing and/or reducing psychotropic medications. We are asking you to participate in this research because you may have been involved in discussions around medication changes for people with a learning disability. We are aiming to invite approximately 30 staff members to participate.

3. Do I have to take part?

No. You do not have to take part if you do not want to. Please read this information sheet before you decide. Participation is entirely voluntary, and you are free to withdraw your participation, without explanation. You will not be at a disadvantage if you decide not to take part.

4. What will happen if I take part?

You will be asked to participate in a Q-sort. A Q-sort is a systematic approach to investigating a variety of viewpoints regarding a particular subject matter. For this research, you will be asked to rank-order statements to answer, "When thinking about making decisions to stop or reduce medication for people with a learning disability, how much do you agree or disagree with the following statements?" There are no right or wrong answers when completing the Q-sort activity, only individual opinions.

You will complete the Q-sort independently. The length of time taken to complete the Q-sort will differ greatly between participants, however it is thought to take between 15 – 60 minutes.

The researcher may note down any verbal communication you have with the researcher during the process regarding your thoughts on how you find completing the Q-sort. For example, "this is really difficult", "I am struggling to weigh up these two quotes against each other". These verbal comments may then be used in the final written report for the research, either for the student researcher's thesis and/or within a research journal article. It will not however be possible to identify you from these quotes, as any quotes collected will be anonymised.

The data gathered from the Q-sort (how you arrange the statements) will be made anonymous which means that your name and other identifying information will be removed.

At the end of the study, participants will be provided with a debrief form which will contain contact details for the research team should they wish to ask any questions in the future.

5. How will my data be used?

All data will be processed and stored in accordance with GDPR regulations. The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator / Supervisor acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Jennie Day – j.day@liverpool.ac.uk. Further information on how your data will be used can be found in the table below.

How will my data be collected?	Data will be recorded by the researcher (Amy) during the Q-sort. This will involve how you arrange the Q-sort, and also possible key

	statements you express about your thoughts and opinions when arranging the Q-sort.
How will my data be stored?	All study data will be anonymised and stored in password protected folders in line with the University's research data management policy.
How long will my data be stored for?	Following completion of the study, the primary supervisor will be the assigned the data custodian and the data will be stored for a minimum of 5 years.
What measures are in place to protect the security and confidentiality of my data?	Your electronic data will be stored on a secure university network, and files will be password protected. Any paper copies of data will be stored in a secure filing cabinet. The researcher and the supervisory team are bound by confidentiality. This means that they will not discuss your data with anyone else and only the research team will have access to the data, which will also be anonymised. **Please note that confidentiality will only be breached if we feel that something you discuss indicates a risk of harm to yourself or others. In these cases, we have a duty to protect you/others and to keep you/others safe which may involve discussing information with relevant services. Wherever possible, we will inform you of this, and support you.**
Will my data be anonymised?	Your data will be made anonymous as you will be assigned a unique ID, and so you will not be identifiable from the data collected within the Q-sort.
How will my data be used?	The data gathered from the Q-sort regarding how you choose to arrange the statements will be analysed using a computer software program named 'PQMethod'. Some of your thoughts and opinions you express during the exercise may also be recorded and used in the final written report; these will be made anonymous. The data will be commented on and written into a report which will be submitted as part of the researcher's (Amy) thesis for their Doctorate in Clinical Psychology. It is anticipated that the research will be submitted for publication in an academic journal. Information about the study including the anonymised results may also be presented at a conference or professional practice event.
Who will have access to my data?	Amy Calderbank (researcher), and the supervisory team (Dr Jennie Day and Dr Andrea Flood).
How is the project monitored and audited?	The research team will have regular meetings to ensure the project is monitored accordingly and running to the agreed time scale. As the research is being completed as part of a Doctorate in Clinical Psychology thesis, there is a time scale that needs to be adhered to. Amy (student researcher) will be responsible for keeping the supervising team up to date regarding the research's progress. Any written work will be checked by project supervisors, Jennie and Andrea, who both have experience supervising research projects.
Will my data be archived for use in other research projects in the future?	No.

How will my data be destroyed?	Paper copies of data will be shredded and disposed of in confidential waste bins. Electronic copies of data will be deleted from computer systems.

6. Are there any risks in taking part?
There are no known risks to you participating in this research. The nature of the research is highlighting a longstanding issue regarding the overmedicating of individuals with a learning disability, and therefore there is the potential this topic may cause upset. If a situation does arise in which you become distressed through participating in the Q-sort, the researcher will allow you time to consider whether you wish to continue participating in the research or not. The researcher carrying out the interviews is a Trainee Clinical Psychologist, experienced in working with sensitive issues and so will be able to provide immediate support and contact details of any relevant support services, if needed.

7. Are there any benefits in taking part?
It is hoped this research will provide valuable information, in line with STOMP (stopping over medication of people with a learning disability, autism, or both with psychotropic medicines) which can help improve our understanding about the factors which contribute to the deprescribing and/or reduction in psychotropic medications being administered.

9. What will happen to the results of the study?
The results of the study will be typed into a report which will be submitted to the University of Liverpool as part of the researchers (Amy) thesis for their Doctorate in Clinical Psychology program. Amy Calderbank (student researcher) is being supervised by Dr Jennie Day and Dr Andrea Flood. The sponsor for the study is the University of Liverpool.

We are aiming to publish the findings as a journal article which will be read by other professionals from both research and clinical backgrounds. It is also hoped the findings will provide valuable insight into the factors which contribute to deprescribing and/or reducing an individual's psychotropic medication, which will be useful for the STOMP initiative. Results may therefore be shared at future conferences and practitioner seminars to make others aware of the findings.

All information appearing in any reports or presentations will be entirely anonymous, meaning no one will be able to identify anyone that took part. You will have access to all reports, and a summary of the results can be provided if this were something you would like. You will have access to both Amy and Jennie's email addresses should you wish to request a copy of the findings.

10. What will happen if I want to stop taking part?
You can withdraw your participation from the study at any time without explanation. After participating, you can also withdraw up to two weeks post participation. However, it will not be possible to withdraw data after two weeks in accordance with the lawful basis of 'public task'. If you would like to withdraw from the study, you can contact the researcher whose details are listed below.

11. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Amy Calderbank at A.Calderbank@liverpool.ac.uk or Dr Jennie Day j.day@liverpool.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

12. Who can I contact if I have further questions?

Researcher:
Amy Calderbank (Trainee Clinical Psychologist)
A.Calderbank@liverpool.ac.uk
The University of Liverpool
The Whelan Building
Brownlow Hill
Liverpool L69 3GB

Supervisors:
Dr Jennie Day (Primary Supervisor): j.day@liverpool.ac.uk
Dr Andrea Flood (Secondary Supervisor): amflood@liverpool.ac.uk

Sponsor:
Karen Wilding,
University of Liverpool
Clinical Directorate
4th Floor Thompson Yates Building
Liverpool
L69 3GB
01517948739
sponsor@liv.ac.uk

Thank you

Appendix 15

Participant Consent Form

Version number & date: V2 08/07/2022
Research ethics approval number: 309255
Title of the research project: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population
Name of researcher(s): Amy Calderbank, Dr Jennie Day, and Dr Andrea Flood

Please initial box

1. I confirm that I have read and have understood the information sheet dated V2 06/07/22 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves participating in a Q-sort, which may take up to one hour in duration. ☐
3. I understand that that during the Q-sort with the researcher written notes may be taken. ☐
4. I understand all information appearing in any reports will be anonymous and de-personalised. This means that in order to protect my anonymity all names (including my own) will be changed as well as any other identifying information, such as any details of any places or dates. ☐
5. I agree that my information can be quoted in research outputs such as journal articles, presentations and the researcher's doctoral thesis. However it will not be possible to identify me as all quotes will be anonymised, given different names, and any identifying information will be changed. ☐
6. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
7. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time up to a period of 2 weeks after participation. I understand that following 2 weeks after participation I will no longer be able to request access to or withdrawal of the information I provide in accordance with the lawful basis of 'public task' ☐
8. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my fully anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
9. I understand that confidentiality and anonymity will be maintained, and it will not be possible to identify me in any publications. ☐

10. I understand that the confidentiality of the information I provide will be safeguarded and won't be released without my consent unless required by law. I understand that if I discuss information which raises considerations over the safety of myself or the public, the researcher may be legally required to discuss my information to the relevant services or authorities. ☐
11. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool. ☐
12. I understand that a copy of my Q-sort will be retained for a minimum of 5 years and stored and destroyed in line with the University's research data management policy. ☐
13. I agree to take part in the above study. ☐

Participant name	Date	Signature
Name of person taking consent	Date	Signature

Principal Investigator
[Dr Jennie Day]
[jday@liverpool.ac.uk]

Student Investigator
[Amy Calderbank]
[A.Calderbank@liverpool.ac.uk]

Original signed copy – Held with research team
Second signed copy – Handed to participant

Appendix 16

V1 22.11.21 Project ID: 309255

Debrief Sheet

Title of project: Factors Influencing the Deprescribing of Psychotropic Medication within a Community Learning Disability Population

Name of Researcher: Amy Calderbank (A.Calderbank@liverpool.ac.uk)

Thank you for taking part in this study. We are extremely grateful for your valuable contribution.

The purpose of the study was to gain an understanding of the factors which are important in the clinical decision-making process when deciding to **stop and/or reduce** the use of psychotropic medication within a community learning disability population. The research consisted of two stages. Stage 1 was completed with individuals with a learning disability and/or their families and carers regarding their experiences of being prescribed psychotropic medications, as well as health professionals viewpoints on this topic. The second stage of the research involved administering a Q-Sort to NHS professionals asking, "When thinking about making decisions to stop or reduce medication for people with a learning disability, how much do you agree or disagree with the following statements?" Some of the statements used within stage 2 were formed from data gathered in stage 1.

Data collected will now be stored securely in line with the university's research data management policy. If you wish to withdraw your data from this study, you have up to 2 weeks as after this time it may not be possible due to your data being made anonymous and analysed.

For further information regarding medication use in the LD population please visit:

STOMP – NHS England:
https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

The Challenging Behaviour Foundation:
https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/

NICE Guidelines for initiating and reviewing psychotropic medications in a LD population:
https://www.nice.org.uk/sharedlearning/adhering-to-the-nice-guidance-for-initiating-and-reviewing-antipsychotic-medications-in-people-with-a-learning-disability-for-the-prevention-and-intervention-of-challenging-behaviours

Thank you again for taking part in this piece of research. If there is anything you would like to discuss in relation to this study, please contact the researchers.

Amy Calderbank
Trainee Clinical Psychologist

Dr Jennie Day
jday@liverpool.ac.uk

Amy Calderbank
A.Calderbank@liverpool.ac.uk

Appendix 17

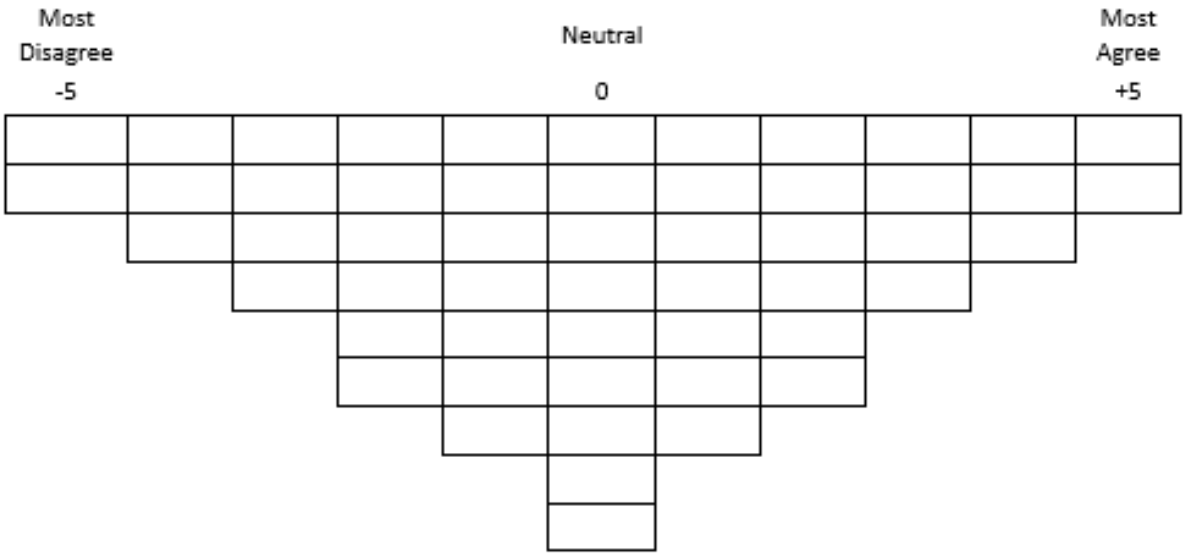
List of Q-sort statements

1. It is important to have somebody external (e.g., a carer or support worker) who can monitor and report withdrawal effects.
2. If the family stop administering the medication of their own accord, the prescriber may be more likely to deprescribe.
3. When deciding whether to stop or deprescribe, it can be difficult to discern whether family or carers have their own agenda.
4. Families and carers often have strong views, stronger than their knowledge base may warrant.
5. The patient may interpret the proposal to deprescribe as a message that no treatment is needed.
6. Having a diagnosed mental health condition affects prescribing decisions.
7. Medications can stop individuals learning new ways to cope.
8. Service users thinking they no longer need medication could be a sign of their illness.
9. There are clear guidelines that explain how to discontinue or reduce medications that facilitate deprescribing decisions.
10. General Practitioner's (GP) are happy to be involved in managing deprescribing.
11. STOMP guidelines have had no impact on deprescribing.
12. Withdrawal effects put prescribers off deprescribing.
13. If invasive monitoring (e.g., blood tests) are required with a particular medication, but this can't be facilitated, then that medication can't be prescribed.
14. If service users report side effects, it is more likely that medication will be reduced.
15. Staff and families may under report the side effects due to wanting to maintain medication prescribing.
16. You should always consider deprescribing, as service users may have side effects that aren't recognised or that they are unable to communicate.
17. If the medication is not working, it is usually deprescribed.
18. Staff are afraid they will be blamed if they deprescribe medication, and something goes wrong.
19. If things are working, it is best not to change things.
20. The psychiatrist is usually the final decision maker on medication changes.
21. The service user is usually the final decision maker on medication changes.
22. It is important to keep families and care teams on side as they are the ones administering the medication to the service user.
23. If a service user asks for their medication to be stopped, then it should be stopped.
24. The staff team's motivation to attempt other interventions can impact the ability to deprescribe medications.
25. There is more of a positive risk-taking culture that is being pushed forward which encourages deprescribing.

26. The best amount of medication for someone with LD to be on is none in terms of antipsychotics, if that's not possible we should be working as close as we can to that goal.
27. Service users prefer to be without medication because that is their true self.
28. Service users want medications to be stopped so they are more in control of their lives.
29. Service users prefer the doctor to make the decisions about medication.
30. Deprescribing will allow better understanding of the underlying cause of a behaviour.
31. If it is not clear why a medication was started, it will always be deprescribed.
32. Challenging behaviour is a chronic condition which will require medication.
33. If medication is prescribed for challenging behaviour which is viewed as having a severe impact, then deprescribing is less likely.
34. If medication is prescribed for challenging behaviour which is occurring frequently, then deprescribing is less likely.
35. Some individuals need to remain on medication in order to be able to access health services.
36. An individual's medication won't be reduced if the placement is considered to be at risk.
37. Deprescribing is less likely when the psychiatrist (or non-medical prescriber) is a locum.
38. Non-medical prescribers are more likely to deprescribe medications than a psychiatrist.
39. Deprescribing is more likely if the prescriber knows the person well.
40. Judgement has to be independent of what commissioners think – it is important that clinicians have an independent view based on clinical need.
41. It is important to deprescribe medication to remove people from the caseload.
42. If a family member has been physically assaulted, it is unlikely the medication will be deprescribed.
43. If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.
44. If the service user presents as a risk to themselves, it is harder to reduce medications.
45. If there is prior self-harm, the dose should not be reduced.
46. The level of risk can cause hesitancy to deprescribe medications.
47. We don't know what some of these medications do for the aging population, so it is important to deprescribe.
48. Sometimes it is not possible to stop medication as it is required as a PRN.
49. Medication is the only option when behaviour becomes unmanageable.
50. Psychological interventions are more appropriate for people with LD than medication– they are better long term.
51. It's easier to reduce or stop medication if a positive behaviour support plan is in place.
52. If the person with LD doesn't engage with psychological therapy, then medication is the only answer.
53. Some people need to be on medication to enable them to engage with psychological therapy.

Appendix 18

Participant:



Notes:

Appendix 19

Demographic Participant Sheet

Participant Number	
Age	
Sex	
Ethnic Group	
Professional Specialism	
Years Qualified	
Time working in LD services (months/years)	
Are you a prescriber?	

Appendix 20

Factor 1 Array

Most Disagree					Neutral					Most Agree
-5					0					5
Challenging behaviour is a chronic condition which will require medication.	If the person with LD doesn't engage with psychological therapy, then medication is the only answer.	If things are working, it is best not to change things.	Staff are afraid they will be blamed if they deprescribe medication, and something goes wrong.	Service users thinking they no longer need medication could be a sign of their illness.	Staff and families may under report the side effects due to wanting to maintain medication prescribing.	If medication is prescribed for challenging behaviour which is occurring frequently, then deprescribing is less likely.	The level of risk can cause hesitancy to deprescribe medications.	It is important to have somebody external (e.g., a carer or support worker) who can monitor and report withdrawal effects.	Judgement has to be independent of what commissioners think – it is important that clinicians have an independent view based on clinical need.	The best amount of medication for someone with LD to be on is none in terms of antipsychotics, if that's not possible we should be working as close as we can to that goal.
Medication is the only option when behaviour becomes unmanageable.	STOMP guidelines have had no impact on deprescribing.	If there is prior self harm, the dose should not be reduced.	Non-medical prescribers are more likely to deprescribe medications than a psychiatrist.	Service users prefer to be without medication because that is their true self.	It is important to keep families and care teams on side as they are the ones administering the medication to the service user.	There are clear guidelines that explain how to discontinue or reduce medications that facilitate deprescribing decisions.	If service users report side effects, it is more likely that medication will be reduced.	Deprescribing is more likely if the prescriber knows the person well.	You should always consider deprescribing, as service users may have side effects that aren't recognised or that they are unable to communicate.	It's easier to reduce or stop medication if a positive behaviour support plan is in place.
	It is important to deprescribe medication to remove people from the caseload.	If it is not clear why a medication was started, it will always be deprescribed.	Sometimes it is not possible to stop medication as it is required as a PRN.	If a family member has been physically assaulted, it is unlikely the medication will be deprescribed.	Service users prefer the doctor to make the decisions about medication.	If the service user presents as a risk to themselves, it is harder to reduce medications.	Having a diagnosed mental health condition affects prescribing decisions.	The staff team's motivation to attempt other interventions can impact the ability to deprescribe medications.	Psychological interventions are more appropriate for people with LD than medication– they are better long term.	
		The service user is usually the final decision maker on medication changes.	An individual's medication won't be reduced if the placement is considered to be at risk.	Some individuals need to remain on medication in order to be able to access health services.	Families and carers often have strong views, stronger than their knowledge base may warrant.	Medications can stop individuals learning new ways to cope.	We don't know what some of these medications do for the aging population, so it is important to deprescribe.	There is more of a positive risk-taking culture that is being pushed forward which encourages deprescribing.		
			If the family stop administering the medication of their own accord, the prescriber may be more likely to deprescribe.	If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.	Service users want medications to be stopped so they are more in control of their lives.	Deprescribing is less likely when the psychiatrist (or non-medical prescriber) is a locum.	Deprescribing will allow better understanding of the underlying cause of a behaviour.			
			Withdrawal effects put prescribers off deprescribing.	The patient may interpret the proposal to deprescribe as a message that no treatment is needed.	General Practitioner's (GP) are happy to be involved in managing deprescribing.	If a service user asks for their medication to be stopped, then it should be stopped.	The psychiatrist is usually the final decision maker on medication changes.			
				If the medication is not working, it is usually deprescribed.	If invasive monitoring (e.g., blood tests) are required with a particular medication, but this can't be facilitated, then that medication can't be prescribed.	Some people need to be on medication to enable them to engage with psychological therapy.				
					When deciding whether to stop or deprescribe, it can be difficult to discern whether family or carers have their own agenda.					
					If medication is prescribed for challenging behaviour which is viewed as having a severe impact, then deprescribing is less likely.					

Factor 2 Array

Most Disagree					Neutral					Most Agree
-5					0					5
Challenging behaviour is a chronic condition which will require medication.	If the person with LD doesn't engage with psychological therapy, then medication is the only answer.	Medication is the only option when behaviour becomes unmanageable.	General Practitioner's (GP) are happy to be involved in managing deprescribing.	Medications can stop individuals learning new ways to cope.	Sometimes it is not possible to stop medication as it is required as a PRN.	Staff and families may under report the side effects due to wanting to maintain medication prescribing.	It is important to keep families and care teams on side as they are the ones administering the medication to the service user.	An individual's medication won't be reduced if the placement is considered to be at risk.	The level of risk can cause hesitancy to deprescribe medications.	If medication is prescribed for challenging behaviour which is occurring frequently, then deprescribing is less likely.
The service user is usually the final decision maker on medication changes.	If there is prior self harm, the dose should not be reduced.	It is important to deprescribe medication to remove people from the caseload.	Service users thinking they no longer need medication could be a sign of their illness.	If a service user asks for their medication to be stopped, then it should be stopped.	Having a diagnosed mental health condition affects prescribing decisions.	It is important to have somebody external (e.g., a carer or support worker) who can monitor and report withdrawal effects.	Some people need to be on medication to enable them to engage with psychological therapy.	It's easier to reduce or stop medication if a positive behaviour support plan is in place.	The staff team's motivation to attempt other interventions can impact the ability to deprescribe medications.	If medication is prescribed for challenging behaviour which is viewed as having a severe impact, then deprescribing is less likely.
	Service users prefer to be without medication because that is their true self.	STOMP guidelines have had no impact on deprescribing.	If invasive monitoring (e.g., blood tests) are required with a particular medication, but this can't be facilitated, then that medication can't be prescribed.	Withdrawal effects put prescribers off deprescribing.	If things are working, it is best not to change things	Deprescribing is less likely when the psychiatrist (or non-medical prescriber) is a locum.	If a family member has been physically assaulted, it is unlikely the medication will be deprescribed.	You should always consider deprescribing, as service users may have side effects that aren't recognised or that they are unable to communicate.	If the service user presents as a risk to themselves, it is harder to reduce medications.	
		Non-medical prescribers are more likely to deprescribe medications than a psychiatrist.	If it is not clear why a medication was started, it will always be deprescribed.	When deciding whether to stop or deprescribe, it can be difficult to discern whether family or carers have their own agenda.	There are clear guidelines that explain how to discontinue or reduce medications that facilitate deprescribing decisions	Some individuals need to remain on medication in order to be able to access health services.	If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.	Judgement has to be independent of what commissioners think - it is important that clinicians have an independent view based on clinical need.		
			The best amount of medication for someone with LD to be on is none in terms of antipsychotics, if that's not possible we should be working as close as we can to that goal.	There is more of a positive risk-taking culture that is being pushed forward which encourages deprescribing.	We don't know what some of these medications do for the aging population, so it is important to deprescribe.	Families and carers often have strong views, stronger than their knowledge base may warrant.	Deprescribing is more likely if the prescriber knows the person well.			
			Service users want medications to be stopped so they are more in control of their lives.	The patient may interpret the proposal to deprescribe as a message that no treatment is needed.	If the family stop administering the medication of their own accord, the prescriber may be more likely to deprescribe.	If service users report side effects, it is more likely that medication will be reduced.	The psychiatrist is usually the final decision maker on medication changes.			
				Deprescribing will allow better understanding of the underlying cause of a behaviour.	Psychological interventions are more appropriate for people with LD than medication- they are better long term.	Staff are afraid they will be blamed if they deprescribe medication, and something goes wrong.				
					Service users prefer the doctor to make the decisions about medication.					
					If the medication is not working, it is usually deprescribed					

Factor 3 Array

Most Disagree					Neutral					Most Agree
-5					0					5
It is important to deprescribe medication to remove people from the caseload.	Withdrawal effects put prescribers off deprescribing.	If the person with LD doesn't engage with psychological therapy, then medication is the only answer.	Service users thinking they no longer need medication could be a sign of their illness.	If it is not clear why a medication was started, it will always be deprescribed.	Some individuals need to remain on medication in order to be able to access health services.	Sometimes it is not possible to stop medication as it is required as a PRN.	med if they deprescribe medication	The level of risk can cause hesitancy to deprescribe medications	Families and carers often have strong views, stronger than their knowledge base may warrant.	Judgement has to be independent of what commissioners think - it is important that clinicians have an independent view based on clinical need.
Medication is the only option when behaviour becomes unmanageable.	STOMP guidelines have had no impact on deprescribing.	If the family stop administering the medication of their own accord, the prescriber may be more likely to deprescribe.	Non-medical prescribers are more likely to deprescribe medications than a psychiatrist.	Medications can stop individuals learning new ways to cope.	There are clear guidelines that explain how to discontinue or reduce medications that facilitate deprescribing decisions.	The patient may interpret the proposal to deprescribe as a message that no treatment is needed.	If service users report side effects, it is more likely that medication will be reduced.	If invasive monitoring (e.g., blood tests) are required with a particular medication, but this can't be facilitated, then that medication can't be prescribed.	You should always consider deprescribing, as service users may have side effects that aren't recognised or that they are unable to communicate.	It is important to have somebody external (e.g., a carer or support worker) who can monitor and report withdrawal effects.
	Challenging behaviour is a chronic condition which will require medication.	The service user is usually the final decision maker on medication changes.	Service users prefer to be without medication because that is their true self.	If a family member has been physically assaulted, it is unlikely the medication will be deprescribed.	Some people need to be on medication to enable them to engage with psychological therapy.	Service users prefer the doctor to make the decisions about medication.	It is important to keep families and care teams on side as they are the ones administering the medication to the service user.	The staff team's motivation to attempt other interventions can impact the ability to deprescribe medications.	If the medication is not working, it is usually deprescribed.	
		If a staff member has been physically assaulted, it is unlikely the medication will be deprescribed.	If a service user asks for their medication to be stopped, then it should be stopped.	Having a diagnosed mental health condition affects prescribing decisions.	There is more of a positive risk-taking culture that is being pushed forward which encourages deprescribing.	When deciding whether to stop or deprescribe, it can be difficult to discern whether family or carers have their own agenda.	We don't know what some of these medications do for the aging population, so it is important to deprescribe.	It's easier to reduce or stop medication if a positive behaviour support plan is in place.		
			If medication is prescribed for challenging behaviour which is occurring frequently, then deprescribing is less likely.	An individual's medication won't be reduced if the placement is considered to be at risk.	Service users want medications to be stopped so they are more in control of their lives.	Deprescribing is more likely if the prescriber knows the person well.	If the service user presents as a risk to themselves, it is harder to reduce medications.			
			If there is prior self harm, the dose should not be reduced.	Deprescribing will allow better understanding of the underlying cause of a behaviour.	General Practitioner's (GP) are happy to be involved in managing deprescribing.	The psychiatrist is usually the final decision maker on medication changes.	Staff and families may under report the side effects due to wanting to maintain medication prescribing.			
				Deprescribing is less likely when the psychiatrist (or non-medical prescriber) is a locum.	The best amount of medication for someone with LD to be on is none in terms of antipsychotics, if that's not possible we should be working as close as we can to that goal.	If things are working, it is best not to change things.				
					Psychological interventions are more appropriate for people with LD than medication- they are better long term.					
					33.If medication is prescribed for challenging behaviour which is viewed as having a severe impact, then deprescribing is less likely.					

Appendix 21

Participant Quotes By Statement

4 – “I have experience of this being true, however some families have done so much researching and their knowledge is infinitely better than mine”

4 – “Difficult one to say, they might have an agenda but we don’t know it”

4 – “they have knowledge of the person, but they don’t have clinical knowledge and that is important in making these decisions”

4 – “We aren’t the ones administering the meds and they’re the ones facing the difficulties, we can come away from the difficulties”

7 – “Can become overreliance on medication, e.g., if experienced therapy and use medication to block out they don’t learn ways to process or cope with trauma”

9 – “I would hope there is yes so I will agree, but I am not a prescriber”

9 –“ I would like to think there are so I am going to say agree but I am not actually sure, I know that is not always the case but I would hope so…”

9 – “I am not sure about the guidance, but surely it is clear guidance with the introduction of the whole STOMP agenda – so I think I need to keep that one in agree”

9 – “Because not a prescriber some I am not sure, what we hear from doctors or prescribers – we do advocate for PBS and STOMP – medication is last resort”

10 - “I wish”

10 – “Absolutely not, my god no” I

11 - “I am unsure about the STOMP one – I assume it would have had an impact but I am not sure”

11 – “Would like to think it could make some effect but not as much as hoped”

11 – “I do think STOMP has had a huge impact for the best”

13 – “I agree with the statement, but not sure whether that happens in practice – questionable”

13 – “Don’t think that is always the case, think that it does get prescribed, not that its cant because it is -but don’t think it should be”

15 – “may over report if they want it stopped, may under report if they aren’t aware what side effects to be looking for”

17 – “No I don’t think that does happen, hmmm usually? Thinks sometimes it’s actually added to instead”

17 – “Well I think it should be but in practice it probably isn’t”

18 – “I feel objectively made more harm – resulting in hospital taking people off medication, increased aggression, told nationally meant to be doing… but it can cause harm”

19 – “Window of opportunity, optimum – introduce something they may be more tolerant to – activities, increasing skills. But I do disagree, good opportunity to introduce new things if things are working.”

19 – “Going to disagree, could be a plato, people may have been on medications for years that aren’t having an effect”

20 – “Doctor making final decision – yes I think there name would be final to sign off, but hopefully talking to the MDT”

21 – “They should be but I don’t think they are usually no”

21 – “I am not sure, I am presuming it is an MDT approach, might have some kind of input but I am not sure…”

23 – “Service user feels disempowered, feel like they need to agree to keep going with it rather than express they would like a change.”

24 – “Defo true and incredibly annoying”

24 – “agree totally, it shouldn’t but it does”

25 – “Maybe in other areas of mental health, not sure in LD world”

25 – “Over worked, under paid lack of resources….”

27 – “Many service users might not have insight or cognition to know, but may be all they’ve ever known – would they consider to be their true selves without medication if that’s all they have ever known”

27 – “God I hate that… should we facilitate people's true self If that is kicking punching hurting themselves and others?”

31 – “If we don’t know why medication started – I don’t think it always is, I don’t think everybody questions things do they”

35 – “lack of healthcare settings which are set up to be able to support people with a LD, so they have to remain to fit in to the services, if better funding and resources with integrated LD health services then perhaps people wouldn’t need to remain on medication to access services…”

37 – “Possibly as they don’t have to keep working with service users/families, can come and make decisions”

38 – “ooh difficult, I wouldn’t like to think so, but I think potentially – nurses are more holistic…”

42 – “I don’t think we take that as serious as we should”

43 – “It depends on the nature of why they were assaulted in the first place, could be a valid reason why they were…”

46 – “I feel it shouldn’t, but I know in practice it does. Also depends on what the risk is, is it to self or others? ….”