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ORIGINAL ARTICLE



Supporting adults with intellectual disabilities to be more involved in decisions about their mental health medications: A co-produced mixed methods study

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ABSTRACT

Background: People with intellectual disabilities are more likely to take mental health (psychotropic) medications than other people. Despite long-standing concern about this, there has been little focus on how people with intellectual disabilities can be supported to be more involved in decisions about their medications.

Method: This co-produced study included interviews ($N = 40$) and an online survey ($N = 134$) with people with intellectual disabilities, family members, paid carers and prescribers.

Results: It was most commonly medical professionals who made decisions about medications, despite most participants stating that it was the people who take the medications who should make decisions. Very few people with intellectual disabilities had been given written information in an accessible format.

Conclusion: Prescribers, family members and paid carers should adopt relational approaches to decision making and use accessible resources to support the involvement of people with intellectual disabilities in decisions about their mental health medications.

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Co-production; psychotropic medications; mental health; learning disabilities; decision making

The focus of this article is on how people with intellectual disabilities can be better supported to be more involved in decisions about their psychotropic medications. Psychotropic medications are a group of medications that include antipsychotics, antidepressants, hypnotics, sedatives, anxiolytics (anti-anxiety medications); antiepileptics, and psychostimulants (Song et al., 2020). In global North contexts, these medications are usually prescribed to affect people's cognition, mood, and behaviour; however, adults with intellectual disabilities are much more likely to be prescribed psychotropic medications than the general population (Song et al., 2023). The current study was founded on principles of inclusion, and in this spirit, when carrying out the study, we used the more accessible term "mental health medications"; but here, as we draw on literature and policy context, we use both "mental health" and "psychotropic" medications.

The international research evidence shows that people with intellectual disabilities are more likely to be diagnosed with mental health conditions than other

people; however, the number of people with intellectual disabilities who are treated with psychotropic medication far exceeds the number of people who have been formally diagnosed with mental illness (Sheehan et al., 2018; Song et al., 2023). Furthermore, people with intellectual disabilities are frequently prescribed psychotropic medications in the absence of a mental health diagnosis and without appropriate clinical justification (Folch et al., 2019). One reason for this is the use of psychotropic medications to manage behaviours that challenge, despite a lack of evidence to support this practice (Sheehan et al., 2017). In these instances, psychotropic medications are being used as a form of behavioural control or chemical restraint, raising concerns around rights and quality of care. These international trends are repeated in England, where between 22% and 40% of people with intellectual disabilities are prescribed multiple psychoactive medications (NHS England, 2023). Reducing or withdrawing long-standing antipsychotic medication among people with intellectual disabilities is possible

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(Ahmed et al., 2000), and has been the focus of health policy internationally, such as the NHS England “stopping over-medication of people with a learning disability, autism or both” (STOMP) programme (Branford et al., 2019).

People with intellectual disabilities have been historically disempowered as health management decision-makers, with medical practitioners often making decisions for them (Castro et al., 2016; Elwyn et al., 2012; Sullivan et al., 2021). Evidence suggests that people with intellectual disabilities are insufficiently informed of important information about their medications or included in discussions about their medications, and therefore lack influence to shape decisions (Sheehan et al., 2019). This is compounded by people with intellectual disabilities not always being able to read labels on their medication, struggling to remember verbal information given to them, and health professionals often talking to carers rather than the patient (Fish et al., 2017). An intellectual disability is not a reason to exclude someone from decisions about their health care. The English Mental Capacity Act (2005) states that everyone should be assumed to have capacity to make decisions unless proven otherwise, and supported to make their own decisions wherever possible. In support of this, there is an increasing emphasis on the importance of supported decision making. Supported decision making has been defined as a process by which a third party (such as a carer) helps someone to make a legally enforceable decision for themselves (Devi, 2013; Kohn & Blumenthal, 2014). According to the UK’s NHS (2024), supported decision making may involve providing all the relevant information, information being explained or presented in a way that is easy to understand, and using different methods of communication.

Despite this legal and theoretical context, research has shown that people with intellectual disabilities are not always supported to make their own decisions (Davidson et al., 2018), with research focusing on how to empower people with intellectual disabilities to be more involved in decisions around mental health medications still largely absent from policy and practice debates. To enable and facilitate people with intellectual disabilities to become involved in decision making, we need greater insight into people’s understanding and experience of taking these medications. Cavanagh et al. (2024) identified only 10 articles that included data from people with intellectual disabilities, and of those, the focus was usually on using quantitative methodologies and/or on the discontinuation of psychotropic medications for behaviours that challenge, rather than looking more broadly at the range of contexts in

which psychotropic medications might be over-prescribed in the first instance, and how people with intellectual disabilities could be supported to play a greater role in this decision making. Thus, our research questions were:

- (1) What do adults with intellectual disabilities, their family members and paid carers know about mental health medications?
- (2) How are adults with intellectual disabilities supported to make decisions about their mental health medications?
- (3) How can people with intellectual disabilities be supported to be more active and confident partners in decision making around their mental health needs?

Method

Design

The overarching aim of the project was to develop a toolkit of resources to support people with intellectual disabilities to be more involved in decisions about their mental health medications. It was a co-produced research project with a cross-sectional mixed methods design. Co-production (Martin, 2010; McMullin & Needham, 2018) is an inclusive research approach whereby boundaries between researchers and other project partners are blurred. The approach is underpinned by an asset-based model, where people who usually only participate in research are understood to have something to offer in the process of knowledge production (Boyle et al., 2013). In co-produced research with people with intellectual disabilities, all members of a research team are able to exert some control over its process and outcomes (Walmsley & Johnson, 2003).

The co-production element of the research was key, involving collaboration with four self-advocacy groups (charities whose purpose is to bring people with intellectual disabilities together to support advocating for themselves). The research focus and design were developed with people with intellectual disabilities and their allies through a series of online meetings. The research team included seven paid co-researchers with intellectual disabilities. Co-researchers took part in all aspects of the research, including: discussions about the focus of the literature review; design of interview schedules and survey questions; conducting interviews alongside a university-based researcher; data analysis and dissemination, including presenting at inter/national conferences. We rejected a unidirectional model of research training, which sees university researchers transferring their knowledge to co-researchers. Instead, we took an

asset-based approach to recognising that many of the co-researchers brought experience of working in research. We worked together to identify areas of strength and development needs across the whole project team and together developed a shared understanding of research methods, analysis and, crucially, of research ethics to ensure all members of the team understood their collective responsibility to deliver ethical and high-quality research.

The mixed methods design included qualitative and quantitative approaches to collecting data. Qualitative data were collected using semi-structured interviews with four groups: people with intellectual disabilities; family members; paid carers; and prescribers. Following a literature review (Cavanagh et al., 2024), interview questions were developed by the whole research team through a series of online workshops. These were shared with the project's advisory group (made up of two experts by experience, two prescribers, one paid carer and one family carer), with their feedback incorporated into the interview schedules.

Quantitative data were collected using an online survey, the "Three Key Questions" survey. Participants were people with intellectual disabilities; family members; paid carers; and prescribers. Feedback from project planning meetings was that potential participants were time pressured and may not engage with a long survey. Consequently, the research team developed the Three Key Questions survey, based on the principle that the focus would be on a small number of key issues identified through the qualitative phase of the study and the survey could be completed with minimal time commitment. Potential survey questions were developed during the initial stages of qualitative analysis, and these were discussed during co-analysis workshops (see below for details); the selection and wording of questions were developed to maximise relevance and accessibility. These discussions were facilitated through an activity we called "Is this a good question?" whereby potential survey questions paired with happy, sad or neutral face emojis were circulated around the group, and workshop attendees could add comments or tick the emoji that represented their thoughts on the potential question. A pragmatic approach was then taken to choose questions that would achieve the projects objectives and were considered to be appropriate and accessible by the project's collaborators.

The survey, thus, complemented the interview data by offering a different mode of participation in the research and providing an opportunity to reach more participants. We acknowledge limitations in the reach of an online survey for people who may experience digital exclusion (Caton et al., 2024), so we designed the

survey with the purpose of removing some barriers to participation. Questions were presented to respondents as video clips of five of the co-researchers with intellectual disabilities asking the questions, with audio versions of possible response options. Where appropriate, participants were given the option to choose multiple responses relevant to their own experiences. The three key questions were adapted to encourage each participant group to reflect on their experiences, but all focused on three areas: (1) information people give or are given about mental health medications, (2) alternatives to medications, and (3) decision making about medications.

Participant recruitment

For people with intellectual disabilities, family members, and paid carers, recruitment was facilitated through multiple methods, including through the four collaborating self-advocacy organisations, wider networks of intellectual disability and family organisations, and via social media. Prescribers were recruited into the study through research team professional networks, special interest groups, social media, and through the sponsor UK NHS Trust¹ organisation. According to the funding remit, all participants lived or worked in the North of England.

Procedure

Our initial plan was that all the interviews would be conducted by a pair of researchers – a university-based researcher and a co-researcher with intellectual disabilities. However, logistical challenges with co-ordinating busy diaries resulted in just over half the interviews being conducted by a researcher pair. The interview schedule was co-produced by the whole team to ensure it was accessible to all the interviewers and as a result used PhotosymbolsTM to support the text and different colour pages to indicate shifts in topics. Interviews took place between November 2023 and May 2024. An initial meeting took place with participants prior to each interview to discuss the project, give participants the opportunity to meet the interviewers prior to the interview and to answer any questions. We also adopted this approach due to a challenge early on in the participant recruitment phase of the project whereby we were contacted by "imposter participants" who asked to take part in the research, possibly due to financial gain (Chandler & Paolacci, 2017). Interviews were undertaken online and lasted between 30 min and 1 h. Before the interview, consent was audio-recorded. Short breaks were offered during interviews when needed, and at the

end of the interview, participants were reminded where they can go for support, if needed. The online survey data were collected from April to June 2024.

Ethics

The project received ethics approval from the Faculty of Health and Education at Manchester Metropolitan University (ID 50717) and for the involvement of UK NHS staff (the prescribers), from the Health Research Authority (IRAS Project ID: 323964). Research ethics approval for the involvement of the prescribers was more complex and time-consuming, therefore their involvement followed the involvement of the other three groups. This meant that interviews with prescribers were the last to be carried out and survey circulation to prescribers also happened after circulation to other networks; so while there appears to be a 1-month crossover of interview and survey data collection, this was not the case for any specific group. Interview participants received a shopping voucher to thank them for their participation. The interview questions explored sensitive issues around mental health with the potential to cause emotional distress. The university interviewers were experienced researchers, who were sensitive to the participants' situations and where necessary signposted to relevant support services.

Ethical consideration was also given to the involvement of the co-researchers with intellectual disabilities to ensure that the research was conducted in an ethically sound way. As part of the process of research training and skills development, we talked as a team about the risks of engaging in emotionally demanding research and how we could best support participants and research team members. We ensured that co-researchers were supported by the university-based researchers before, during and after the interviews. We held an interview skills workshop, had conversations about the easy-read version of the review of literature, ensured that all materials were accessible, and held an informal debrief after each interview. As well as being paid for their involvement in the project, co-researchers were also invited to an end-of-project celebration event and awarded certificates of achievement to recognise the development of research skills.

Analysis

Interviews were audio-recorded and transcribed verbatim. We developed our own novel approach to co-producing analysis based on Gale's (2013) framework analysis, with accessibility adaptations to ensure genuine co-produced analysis. This novel approach involved

initially re-visiting each interview and condensing it into a short summary. This was primarily carried out by the university researcher, with co-researchers being asked to contribute their impression of the overall experience of the participant. Using an online graphic design tool (Canva), these summaries were then converted into 10 composite illustrated storyboards. The storyboards presented interview data in an accessible and manageable format to share and analyse with co-researchers and collaborating self-advocacy organisations. Our inclusive approach to framework analysis then followed a three-step process.

Step 1: Analysis workshops and code generation

Analysis workshops were held at each of the four collaborating self-advocacy organisations; jointly facilitated by university researchers and co-researchers with intellectual disabilities. Approximately 40 additional people with intellectual disabilities took part in this step, with each workshop being attended by 8–12 people who regularly attend each self-advocacy organisation. In small groups, workshop participants discussed the storyboards and completed worksheets asking: (i) what was important to them about the story; (ii) what worked well for the person with intellectual disabilities in the story; (iii) what stopped things from going well in the story; and (iv) what was important for the future for the person with intellectual disabilities in the story. The lead author coded the worksheets using an inductive approach, alongside deductive coding based on the study's research questions.

Step 2: Additional codes from coding of a sample of transcripts

While Step 1 included data from all the interviews and provided a useful co-produced grounding to the development of the final coding framework, it was based on summaries. To ensure robust framework development, it was also important to add coding from some of the full transcripts. Additionally, it was important to include the wider research team in code generation to ensure we captured a multidisciplinary perspective. Therefore, we coded a sample of five transcripts (two transcripts from people with intellectual disabilities, one from each of the other groups of participants) across the university research team (which included practitioners). This was done both deductively to answer our research questions and inductively to explore additional areas of interest and to avoid forcing the data into pre-determined categories. Codes from this step were combined with codes from Step 1 to finalise the coding framework.

Step 3: Applying the framework

The remainder of the transcripts were then coded using the final framework following Gale's (2013) more traditional approach to framework analysis.

This article focuses on the deductive coding that answers the research questions, combined with the survey data from survey questions 1 and 3.

Results

Participant characteristics

Interviews

Twenty adults with intellectual disabilities participated in interviews. All participants were able to provide informed consent and communicate their views directly to the research team. Participants had the comprehension and communication skills required to engage in a semi-structured interview, either remotely or in person, and did not require proxy interview responses. Participants ranged in age from under 25 years to 65 years, and 60% were women. Most participants identified as White British, with one participant identifying as British Chinese and one as British Asian. Participants represented a range of support needs and living situations, including people living independently with minimal or intermittent support, people living with family members, people living in supported accommodation, and people receiving more intensive forms of support. Seven family members were also interviewed. Five were women and were parents of adults with intellectual disabilities. The relatives they supported represented a range of support needs, including adults living in the family home and people receiving specialist inpatient support. In addition, eight prescribers and five paid carers took part in interviews. Prescribers included medical, nursing and pharmacy prescribers working in primary and community care settings. All paid carers were women and provided support to adults with intellectual disabilities in community settings.

Survey

The survey included responses from a total of 134 people: 32 people with intellectual disabilities, 48 family members, 16 paid carers and 38 prescribers. Participants with intellectual disabilities were not asked about their intellectual disability, but as recruitment was largely through collaborating self-advocacy organisations, it is likely that respondents were those with mild intellectual disabilities. In terms of medication use, 62% of people with intellectual disabilities were taking mental health medication; 14% had taken it in the past and 24% had never taken it. In terms of age distribution, people with intellectual

disabilities' ages ranged from 17 to 66 years (8% were under 25; 56% were aged 25–39; 28% were aged 40–59; and 8% were 60 or older). Paid carers were all aged 25–59 years old, family carers ages ranged from under 25 to over 60 years and prescribers were aged between 25 and 60 years. People with intellectual disabilities were 43% men, 57% women; paid carers were 13% men, 87% women; family carers were 11% men, 89% women and prescribers were 33% men, 63% women (3% preferred not to say). Where relevant, survey respondents were asked about their specific roles. Paid carers were mostly team leaders within adult social care provision, with other roles including support workers and advocates. Family carers were mostly parents, with some siblings and other relatives. Prescribers included general practitioners (GPs), psychiatrists, nurses, specialty doctors, and pharmacists.

Three themes that addressed the research questions: “knowledge,” “information” and “support to make decisions,” are presented below. As the Three Key Questions survey was developed with the aim of focussing on a small number of key issues identified through the interview phase of the study, the survey findings largely match onto the interview themes and are presented alongside interview findings below. Pseudonyms have been used when presenting quotes from participants to protect anonymity.

Knowledge

Within this theme we present interview data from people with intellectual disabilities, family members, and paid carers. People with intellectual disabilities who were interviewed were mostly knowledgeable about the names of their medications and day-to-day medication regimens. Most spoke about experiencing side effects and knew it was the medications causing them to feel dizzy or sleepy. Participant Stephen said, “But, at 8:00 in the morning, I take medication ... and then, I take the same medication at 17:00 in the afternoon. That's 5:00. And then, 10:00 at night, I take another dose of medication.” And Carol remarked,

They make me really drowsy during the day. It's like my head is still asleep and I've got to focus, get on a bus, or do what I've got to do, leave my flat, I don't really feel like doing it because I want to go back to bed.

While some of the people with intellectual disabilities interviewed knew why they were taking the medication, many did not. Participant Alice said, “I take bipolar medication ... Mirtazapine and quetiapine I don't know if that's to do with my mental health ... I just want to know what it does, what actually is this medication, because I haven't a clue.”

Similarly, the family members of people with intellectual disabilities who were interviewed had a general understanding of what medication their relative was on and usually what the dose was, but there were some who were not sure what the medication was for. Families were divided and sometimes conflicted in their knowledge of whether medication helped their relative or not:

I think it just ... I'm not sure exactly the medical term, but I think it just calms her down. It stops her being so anxious. (Bernard, Dad)

As soon as he started, it made a difference straight away, and I could see a difference in him. He was a lot happier, enjoying life, going to activities, going with his pals without lashing out. (Fatima, sibling)

Some of the interviewed family members were guided by the medical teams whom they trusted to make the right decisions:

It is worrying because I don't always know myself what the medications are for and I trust the doctors really to give him the right medication. (Susan, Mum)

Family members were often knowledgeable about medications for a new issue, but once medications have become established, fewer questions were asked:

After a while, I thought, "Right, okay. He's in a routine. He's a lot happier. Let's take it away." And, as soon as we took it away, he reverted back to his old self again. And I thought, My goodness, this medication is helping. So he's been on it now many, many years. (Fatima, sibling)

In interviews, the paid carers were knowledgeable about the mental health medications of the people they supported. Some supported up to five people with their medications and described being responsible for ordering, administering, and monitoring the taking of the medications and monitoring for side effects:

I work for five people, five ladies. Each one has a different diagnosed mental health ... or illness, whatever it's called. So, I've seen, you know, a fairly wide range of mental health medication, from sertraline, quetiapine, diazepam, clozapine ... and [name] is on lithium, as well. (Clare, Paid Carer)

Information

The second theme was around information that participants identified as being useful and appropriate to help people with intellectual disabilities be more involved in decision making around their mental health medications.

People with intellectual disabilities

In total, 25 people with intellectual disabilities responded to the survey question about what information they had been given about their mental health medications. People could tick multiple options. People most commonly reported they had been given printed information that was NOT easy to understand (40%), followed by talking to the doctor and that being easy to understand (28%), being given printed information that was easy to understand (like easy read or pictures) (24%), talking to the doctor that was *not* easy to understand (28%), and talking to a family member and that being easy to understand (24%).

Despite interview findings that most people knew a lot about their medications and daily medication regimes, this was not universal, and some participants with intellectual disabilities stated they required more information about their medication, including very basic information such as the name of the medication, its purpose, and side effects: "I'd like to know what I'm taking and why" (Chloe). For those participants who had been given written information, many reported struggling to understand it if it had not been given in an accessible format. Very few people with intellectual disabilities who were interviewed had been given written information in an accessible format. For those who had been, they reported that it had been useful: "If it wasn't in Easy Read, I wouldn't have understood, but in Easy Read, it's easy" (John).

Family members

Thirty-seven family members responded to the question about what information they had had to help them support their relative with their medications. They most commonly said that they talked to a doctor, and it was easy to understand (35%), that they had been given written information that was NOT easy to understand (30%), or that they had been given links to generic online information (27%). In interviews, some family members said they wanted more information to help them understand their relative's medication and that it was often difficult to know where to find accessible information. One parent said their son was sent some booklets to read and fill out about managing their mental health, but these were meaningless as their son could not read: "It's like the mental health team, they send them a booklet with big writing on. It's great if they can read and write, but our kids can't read and write" (Ann, Mum).

Paid carers

Eight paid carers responded to the survey question about information; 38% said that they had had

information in accessible formats; 38% used links to generic online information; and 38% said they had spoken to the doctor, but it was not easy to understand.

Prescribers

Thirty prescribers answered the survey question about what information they give to people with intellectual disabilities. Prescribers said they: talked to the patient (100%); talked to the patient's family member (97%); talked to the patient's paid carer (93%); gave information in accessible formats (e.g., easy read, pictures, plain English) (83%); provided links to online information accessible for people with learning disabilities (37%); and provided information that is not in easy read (27%). In interviews, some prescribers said they used easy read and accessible materials to aid understanding, adapting or breaking down information or writing down key points. However, some prescribers were not confident that they were doing all they could to support people. Some prescribers said that they need to know more about where to locate appropriate resources and that they relied on verbal discussion:

I don't have very much in the way of written or visual information that I can share with patients. There may well be lots out there, but I don't know where to find it. So that would be really helpful to have some leaflets and some sort of visual information to share with my patients to help understanding. Not just for the patients, but for their carers as well. (Wendy, Clinical Pharmacist)

Support to make decisions

Survey respondents were asked who they think should, and who actually does make decisions about mental health medications for people with intellectual disabilities; their responses are combined here with interview data.

People with intellectual disabilities

In total, 27 people with intellectual disabilities answered the survey question about who made the decisions about the medications they were taking. People most commonly said a doctor or nurse (74%), followed by themselves (56%), family (30%), or their carer or support worker (7%). In interviews, some people indicated they had not been involved in decisions; reasons given for this included the authority of the health professional being seen as absolute, fear of rehospitalisation, being too unwell to be involved, not being listened to, not being given the opportunity to ask questions, and telephone appointments making communication difficult:

They just made a decision to put me on them ... It was just the doctors' decisions and that's it. I feel like I didn't have a choice because they're authority. A bit intimidated actually, to be honest ... He's a bit of an old school doctor, put it that way. He's not very understanding. He just tends to say you're doing all right, aren't you, trying to convince me to stay on them. (Carol)

But I just have to take it because they told me to. (Chloe)

Sometimes I'm like, what if I don't take my meds, I might get sectioned again. (Li)

I do get interrupted quite a lot, and I don't always get the chance to answer questions. (Stephen)

When people had been better supported, they spoke about the roles of paid carers and family members in offering support with reading information to make decisions about their medications. Other participants said that the way the health professional interacted with them was a factor in whether their perspective was included in decisions: "I think I was asked by the GP more than I was by the psychiatrist because the GP was more personable, more kind" (Lynne).

Family members

In total, 39 family members answered the survey question about who should make the decisions about the medications their relative was taking, and who actually made the decisions. In contrast to people with intellectual disabilities, family members most commonly said that their relative with intellectual disabilities should make the decisions (33%), followed by themselves (the family member) (28%), a doctor or nurse (18%), or paid carers (13%). In terms of who *actually* made the decisions, family members most often said it was a doctor or nurse (59%) followed by themselves (41%), the person with intellectual disabilities (33%) or the paid carer (10%). In interviews, when family members were asked about how the decision to start medication was made, they rarely spoke about the person with intellectual disabilities being involved in the decision-making process. Family members either referred to themselves making the decisions or about shared decision making between the family and the doctor, nurse or pharmacist. Most family members referred to the need for a combined knowledge from themselves and medical professionals to best support their relatives' mental health. While doctors, nurses and pharmacists were seen by family members as experts, they emphasised that they were the ones who ultimately knew their relative best and therefore their views also needed to be listened to and respected:

So, it's to help educate the parent as well, talk to the parent because the parent is the best person who lives with them, who knows. And they're the ones who can tell you what's right and wrong. And they can educate the professional as well because there might be something there that you can pick up off the parent. (Eloise, Mum)

Paid carers

In total, nine paid carers answered the survey question about who should make the decisions about the medications the person they support was taking; the most common response was the person with intellectual disabilities (56%). In terms of who actually makes the decisions, paid carers most commonly said it was a doctor or nurse (89%), followed by the person with intellectual disabilities (44%). The interview data showed limited evidence that paid carers were involved in actively supporting people to make decisions. Most of the paid carers described their role within mental health-related appointments or meetings as supporting the person to communicate and conveying important information to the health professionals. As such, there was an implication that this was more to support the health professional rather than the person with intellectual disabilities:

You want the person to be the one that talks about herself. But, in Cleo's case, for instance ... they don't go straight to the point. They go round lots of things, and then you start hearing stories that don't make sense. And then, that's when you need to intervene and then redirect the appointment to what the problem is. (Maria, Paid Carer)

Outside of appointments or meetings, paid carers referred to spending time supporting the person with intellectual disabilities in understanding or gaining more information:

Well, she can read so it's lucky, but it would be probably an easy read. And she'd always come to us and ask if she needed any information as well if we needed to explain it more. (Amy, Paid Carer)

Prescribers

In total, 30 prescribers answered the question about who should make the decisions about the medications the person they support was taking, and who actually made the decisions. Prescribers most commonly said it was the patient with intellectual disabilities who should make the decisions (80%), followed by the doctor or nurse (60%), or a family member of the patient (60%), then a paid carer (20%). In terms of who actually makes the decisions, prescribers most commonly said it

was a doctor or nurse (67%), followed by the patient with intellectual disabilities (47%), a family member (47%), or a paid carer (27%). As the following quotes illustrate, how prescribers supported people with decision making largely centred on supporting them to understand information and adapting information:

I think the biggest part of it is trying to involve the patient and make sure that they understand and that you can agree on how things are going to improve and get better. (William, GP)

And really trying to keep things very simple around what we're trying to achieve with medication and using ... pitching information at a level that you hope somebody can understand and then asking them, is that something that you understand? Or if not, you can explain it and rephrase it in a different way. (Aamir, Clinical Pharmacist)

How and where reviews or meetings took place was viewed as important and could have an impact on how comfortable and confident the person felt in making decisions, with efforts made to conduct meetings in a manner that suited the individual:

I'll either do face-to-face or home visit depending on what the individual wants, really. I used to be really anti-telemedicine, but some people have actually said they prefer telemedicine, so they prefer being on a screen and less distraction and all of that. So it's really dependent on what the individual wants in terms of the mode of how we deliver the consultation. (Cheryl, Intellectual Disability Nurse)

How people were supported to make decisions about their mental health medication was dependent on the prescriber's judgement of the person's capacity to be involved in the decision making. However, it was sometimes the case that prescribers tried to involve people with intellectual disabilities in discussions about their mental health medication even if they thought they lacked capacity:

So even though the person may lack capacity and doesn't know the names of the medications that they take, I would always try and support that with the easy read leaflet in trying to say, this is something that I can maybe come out and see you and talk through the medication that you're on and help you to understand as much as you're able to understand. But also listening to that person, if that person is also saying, maybe they're saying they're feeling tired or they've got side effects, so it's taking that person's views into consideration, even though they lack capacity and it's a best interest decision. (Michael, Community Intellectual Disability Nurse)

Some prescribers identified a challenge with communications with paid carers due to a lack of

consistency in who accompanied the person to the meeting. This could be problematic as opinions could differ across the paid carers who attended:

The other thing that I find difficult sometimes is dealing with people's carers, carers keep changing ... if they live in a care setting, and their learning disability is more serious, then sometimes it's difficult to deal with carers because they're always changing. They all have different views on things. (Wendy, Clinical Pharmacist)

There was also a sense that prescribers could be doing things better, such as by providing more written accessible information or taking part in some extra training: ... maybe I could make more use of written information; that's probably a little criticism of myself (Aamir, Clinical Pharmacist):

I'll be honest, I've not gone and looked for additional training in looking after patients with learning disability. And I'm thinking that I should, but I feel like, I always try with every patient, when I'm not sure what to do, to do the best that I can and read around things, so have learnt that way. But I'm not quite sure if it's enough when it comes to helping people with learning disabilities to manage mental health and to make prescribing decisions. (Sarah, GP)

Discussion

A key factor to facilitate better involvement in decision making around mental health medications is the foundational knowledge that people with intellectual disabilities and the people who support them have about mental health medications. In answering our research question around what people with intellectual disabilities, family members and paid carers know about mental health medications, our data has shown that people with intellectual disabilities were mostly knowledgeable about their day-to-day medication regimes and side effects. However, many people with intellectual disabilities and those that support them did not know *why* they were taking the medication and whether it was helpful. As has been shown by previous research (Chinn, 2020), in the current study, very few people with intellectual disabilities told us that they had been given written information about their medications in an accessible format, which could be considered a poorly grounded foundation for supporting people with decision making. In contrast, 83% of the prescribers who completed the survey reported providing accessible information. The discrepancies between prescriber reports and experiences of people with intellectual disabilities suggest a gap in perceptions of accessibility and/or that accessible resources are often not truly tailored to the needs of the

person, such as sending booklets to patients who cannot read.

Our second research question focussed more specifically on how the people with intellectual disabilities in our study were supported to make decisions about their mental health medications. Our findings illustrate a contrast between the consensus that people with intellectual disabilities should be the primary decision-makers and the reality where the prescriber's authority retains the most influence. Some interviewees did not feel supported to be involved in the decisions, and some of the prescribers and paid carers felt underconfident in doing enough to involve people in decision making, suggesting current practices where carers become the primary partners in consultations. Where participants reported good examples of involvement, they tended to link to positive relational experiences that recognise that decision making is cultivated through stable and trust-based relationships.

Our final research question involved using our data to consider how people with intellectual disabilities can be more involved in decision making. As stated in the introduction, in England, the legal framework is in place to provide an expectation that people with intellectual disabilities should be supported to make decisions around mental health medications. Our data suggest that the reality is that supported decision making is rarely happening. The data presented here illustrates that some family members, and both health and social care professionals wanted to support people in decision making but many had concerns about whether they were meeting their obligations in this.

It is important to consider why supported decision making doesn't always work in the way it should. Although specifically focussed on steps towards deprescribing, Adams et al. (2025) found that prescribers identified lack of support, resources and education, and poor communication as barriers to better confidence around deprescribing. Furthermore, Francis et al. (2024) identified three categories of barriers to supported decision making: organisational barriers (resources, culture, risk management), process barriers (lack of knowledge, time) and relationship barriers (fear and distrust from both "service users" and clinicians). In the present study, organisational barriers were prominent in the lack of accessible resources and a clinical culture where medical authority is seen as powerful; process barriers were evident in the self-reported under-confidence of prescribers and paid carers who felt they lacked the necessary training to include people with intellectual disabilities; and finally, relationship barriers were found to be central, with people with intellectual disabilities saying they felt

intimidated or interrupted, and the reported paid carer staff turnover preventing consistent support.

While the availability of accessible and more appropriate information such as that generated from our project is relatively easy to address, other barriers that have been identified are more systemic and therefore difficult for individuals to address. There are complex personal and environmental factors such as relationships between people with intellectual disabilities, supporters, and prescribers, a perception of unequal power between health-care providers and people with intellectual disabilities (Sheehan et al., 2019), and mental health issues potentially impacting on the ability to make decisions (Shogren et al., 2017). Supported decision making can only happen if good support is in place to allow confidence and experience in making decisions to grow. In a context where prescribers are under time pressures and social care staff are underconfident and lacking in training, the implementation of supported decision making is unlikely to achieve its intended outcome. Our findings do not challenge the principle of supported decision making as reflected in UK policy, rather we suggest that the relational and resource conditions needed are often absent.

We consider what needs to change to create an environment where people with intellectual disabilities can be more involved in decision making. While the Mental Capacity Act has been subjected to critique for reproducing autonomy as self-sufficient, rational, unemotional and masculine (Series, 2015), feminist theorists argue instead for a relational understanding of autonomy that recognises we are all in nested dependencies with one another (Kittay, 2011). Drawing on relational autonomy, Ho (2008) argues that in health service settings, patients do not see themselves as independent units, rather they discuss their health and treatment with those closest to them. In this context, then, it becomes important to recognise relational identity and the importance of the involvement of those closest to the patient in decision making. When people with intellectual disabilities are offered choice in care systems, their “autonomous agency” is often reduced to being asked to choose from a “therapeutic menu” of pre-determined and/or limited choices (Ho, 2008, p. 132).

Ghosh et al. (2025) similarly presented “collective collaboration” as a potential solution to mitigate problems related to medication use in people with intellectual disabilities. Their work highlights the need for decisions to be supported through collaborations that we view as complementary to Ho’s (2008) vision of relational autonomy. In the current study, we propose a complementary approach whereby we extend ideas of supported decision making to consider “relational decision making.” Our data emphasised how relationships have been key when

participants identified being involved in decisions. People spoke about ways they were supported, and these included paid carers and family members who offered support with reading information to make decisions about their medications. The friendly and approachable manner of doctors, nurses or pharmacists was also a factor in whether people with intellectual disabilities felt that their perspective was included in decisions. This illustrates that we need a strong support network around all decisions. Through the co-production process, participants identified the need for practical resources to support discussions about mental health medications. This led to the development of a toolkit comprising easy-read questions and answers booklets, a glossary of terms, a compilation of people’s stories and “Conversation Cards,” which are a conversation-prompt resource designed to support discussions between people with intellectual disabilities, family members and professionals about medication use and review (MedMentalHealth, n.d). Importantly, use of this resource would support relational and ongoing conversations around people’s mental health medications.

Limitations

Several methodological considerations should be taken into account when interpreting the findings reported. Firstly, the people with intellectual disabilities who took part in interviews were all able to provide informed consent, and those who took part in the survey were digitally skilled enough to do so. Consequently, the experiences of people with more profound disabilities and those with different ways to communicate were not represented.

Secondly, it was noticeable that people with intellectual disabilities, paid carers, and family members who took part in the study commonly reported concerns and may have had more critical perspectives. Our participant recruitment relied on research team professional networks and self-advocacy collaborating organisations. It is important to consider our findings alongside a suggestion that people who were interested in participating might have done so due to having concerns about their own or someone they support’s experiences with mental health medications. Conversely, the prescribers who took part were mostly those engaged in initiatives aimed at reducing over-medication and/or those wanting to improve their practice.

Conclusion

Our study has demonstrated that supported decision making around mental health medications for people

with intellectual disabilities is uncommon, despite broad agreement among people with intellectual disabilities, family members, paid carers and prescribers that it should be central. Barriers include accessing easy-to-understand information, confidence and training among supporters, and systemic support within health and social care, and power imbalances within clinical relationships. Paying attention to relational approaches and increasing availability of accessible resources may help create the conditions needed to ensure people are more involved in decisions about the medications they take. We propose a relational decision-making approach recognising involvement as an ongoing process built through good communication over time. Our project developed a suite of resources including “conversation cards” to support more inclusive conversations around mental health medications.

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Author contributions

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