**Accessible Summary**

●Pharmacists are an important source of support for people with learning disabilities, healthcare professionals and carers

●Pharmacists can support carers and healthcare professionals to manage medicines in line with STOMP principles

●Healthcare staff and carers were interviewed to see how they felt about working with a pharmacist and how this helped them to look after people with learning disabilities

●Healthcare professionals and carers felt that the pharmacist was very helpful and listened to them

**Abstract**

**Background**

The issues surrounding the prescribing and monitoring of medications for people with learning disabilities and behaviours deemed to be challenging, and are complex in their management for patients, healthcare professionals and carers. The aim of the study was to explore the impact of the Pharmacist Independent Prescriber (PIP) on a medication clinic for people with learning disabilities and challenging behaviours from the perspectives of healthcare professionals and carers in a UK mental health Trust setting.

**Methods**

Qualitative methods were used to provide an understanding of the participants’ interactions with the pharmacist in the context of the medication clinic. Individual, semi-structured interviews were carried out with staff and carers, audio recorded and transcribed verbatim. A thematic analysis was carried out to identify themes which illuminated the participants’ experiences. Recruitment took place December 2017 – August 2018.

**Results**

9 participants took part (6 staff and 3 full-time carers). Eight themes were constructed from the data; five from staff and three from the carer cohort:being open to innovation and change in collaborative practice, challenging traditional norms in collaborative approaches to person-centred care, proactive empowerment via maximisation of expertise and resources, supporting and empowering informed decision making, encouraging collaborative debate around medication, establishing authentic and interactive dialogue, gaining trust of the PIP’s role in the management of patients and feeling empowered to challenge ambiguity and inconsistency in prescribing practice.

**Conclusion**

The PIP is a valued asset, with high levels of interaction between all staff, carers, and an integral aspect of services provided.

**Operational definitions**

PIP Pharmacist Independent Prescriber

MDT Multi-disciplinary team

NHS National Health Service

NICE National Institute for Health and Care Excellence (UK)

STOMP Stopping over-medication for people with a learning disability, autism or both

**Introduction**

This study took place within a UK National Health Service (NHS) mental health Trust, where the role of a pharmacist within the learning disability and autism specialist service has historically focused on the provision of supply, advice and medicines management within in-patient (ward based) settings. The implementation of the national transformation of care agenda for people with learning disabilities has led to service provision focused on providing effective care in community settings as opposed to an ongoing reliance on inpatient wards.

Inpatient ward teams within this specific Trust have acknowledged the longstanding role of the pharmacist and have largely been supportive in their implementation of medicines optimisation processes, with a specific focus on the safe handling and administration of medications. Emphasis has been placed on the effectiveness of educational interventions around medical prescribing in the context of the interprofessional and multi-disciplinary teams (MDTs). This pharmacy role had not previously been extended to the community services within the geographical locality of the Trust.

Recent policies published by NHS England (2015) such as “Building the Right Support”, have presented operational approaches, are implementable at a national level. These focused on the development of community teams for people living with a learning disability and/or autism with behaviour deemed to be challenging, including people living with mental health conditions, which impact on daily living (NHS England, 2015). Aligned with this was a published framework approach to the core principles of care, including quality of life improvement and access to the correct support (National Institute for Health and Clinical Excellence, 2015). In 2017, supplementary policy documents supporting implementation of this framework model identified optimal team structures for potential integration in healthcare praxis, commensurate with NHS agency and structure (NHS England, 2017). Similar to other multi-agency and multi-professional settings which provide opportunities for collaborative care and interprofessional working across a range of medical, healthcare and ancillary care staff, the role of the pharmacist remained unmentioned in any of these newly released policy guidelines.

People living with learning disabilities, autism or both have a demonstrably higher chance of polypharmacy characterising their medical history, which can be directly attributed to several issues:

1. The rates of serious mental illness are equal to, or potentially higher, than the national average (Smiley, 2005).
2. Physical healthcare issues are known to be higher in people with a learning disability, which contributes directly to their consequently reduced life expectancies (Emerson E, 2012).
3. Inequality in healthcare provision is demonstrably preventable via appropriate access to individualised and appropriate access to healthcare intervention and management.

For example, it is estimated that the prevalence rate of epilepsy, in people formally diagnosed with a learning disability, was 26% often necessitating the prescription of multiple anti-epileptic medications (McGrother C, 2006). Such factors mean the consequent risk of polypharmacy is greater in the learning disability population. This indicates potential to utilise the skills of a specialised clinical pharmacist in the context of medicines optimisation and management.

**Medicines Optimisation**

The misuse use of psychotropic medications in the management of behaviour perceived to be challenging, in those without mental illness was highlighted as a cause for ongoing concern in 2012 (Department of Health, 2012). Subsequently, research in 2016 provided inferential statistics to suggest that each day in England, alone, 30,000-35,000 people with a learning disability and/or autism are prescribed psychotropic medications in relation to their challenging behaviour (Public Health England, 2015). A consequence of both, was the launch of the STOMP (Stopping over-medication for people with a learning disability, autism or both) campaign, which advocated challenging inappropriate medication use in patient care ( Branford, Webster,et al, 2018). This liminal shift in approaches to the management of people with learning disabilities, was further supported by the publication of guidance documentation in direct relation to the use of prescribed antipsychotics (National Institute for Health and Clinical Excellence, 2015). Emphasis was placed upon the potential of non-pharmacological approaches rather than continued reliance on medications, of which there is a limited evidence base (National Institute for Health and Care Excellence, 2017; National Institute for Health and Clinical Excellence, 2015).

To address the current challenges faced in community care provision and an increasing awareness of the need for judicious medicines optimisation, a designated role within pharmacy practice, a Pharmacist Independent Prescriber (PIP) was appointed in this Trust. The initial aim of changing practice with this new appointment, ironically was to deliver the historical in-patient service model. The role evolved in response to the need for specific support with medications optimisation. It was here that the PIP’s role developed to encompass caseload management and the utilisation of non-medical prescribing skills, which is line with the aims and objectives of the transforming care and STOMP agendas.

 In the Trust, the change to the PIP’s role was a direct response to the need to minimise waiting times for referral to specialist care, to better balance caseload numbers for learning disability consultant psychiatrists and served to utilise and incorporate the skills of a clinical pharmacist within the context of a unique clinic model.

The medication clinic was then established as a potential alternative to the long established lone working psychiatry model to enable access to medication as a clinical intervention.

The medication clinic model centres predominantly around an MDT and with an educational focus. The collaboration of medical and healthcare disciplines such as psychiatry, nursing, occupational health, speech and language therapists, physiotherapists and pharmacy, in conjunction with the person living with learning disability and their family / carer is illustrative of multiple perspectives on individual needs. This enables consideration of different treatment options which incorporate medication and non-pharmacological alternatives where appropriate. Combining the staff and carer perspectives, together with an educational component in their individualised care pathways, patients, their families and carers are then consequently in a stronger position to make informed choices about care, facilitated by the PIP.

The potential value of the medication clinic to the Trust is better communication amongst the MDT and with carers and patients, but prior to this study there was only anecdotal opinion. The aim of this study was to evaluate the role of the PIP from the perspectives of both staff working within the community service and carers who had engaged with the PIP as part of their caring responsibilities.

**Methods**

To understand the perspectives of both participant groups, a qualitative approach was adopted to illuminate all participants’ experiences (Charmaz, 2006). Qualitative methods allow exploration, rich description and understanding of phenomena under investigation (Sofaer, 1999). An interpretivist approach was used for the study which is congruent with qualitative methods. This approach means that there is an assertion that individuals possess their own subjective meaning making of situations and interactions, and that each participant’s narrative is an equally individualised interpretation, based on social and cultural norms (Creswell, 2009). This helped to understand the role of the PIP within long established hierarchies of medicine and healthcare encounters (Foronda, MacWilliams, & McArthur, 2016) from which the different perspectives of individual participants can be understood. Thematic analysis was selected as the most appropriate qualitative framework in which to approach the data collected. Thematic Analysis is a an established qualitative analytic method used to identify and code ideas, words, phrases and concepts into themes which facilitate the distinguishing, evaluation and conveying of patterns found in the collected data (Braun & Clarke, 2006), and can be used across a diverse range of theoretical frameworks. Different approaches to thematic analysis, generally all follow a set of steps (see Table 1) which are not linear, since data is often read many times, compared with other data and with analysis moving back and forth between the steps until no new codes emerge, making it possible to identify a core group of themes. This inductive process is referred to as a ‘constant comparative’ approach (Corbin & Strauss, 2008). The thematic framework used for this study was informed by Braun and Clarke’s method (Braun & Clarke, 2006) and guidance proffered by Robson (Robson, 2011).

The main advantage of thematic analysis is that it enables the researcher to make ongoing associations with the commonality or frequency of emergent themes and then examine them within the context of the whole study. Thematic analysis also allows researchers to pick up nuanced or hidden themes that may impact on the issues generated by the participants, which is important to be able to clarify meanings of specific accounts and outcomes discussed in each interview. Since the process is a repetitive one, active comparison of the data collected both individually and collectively can be positioned relatively and where appropriate, used to guide future participant interviews, where the topic guide was able to be specifically modified in accordance with the need to identify and frame new knowledge. Since data in this study also had to be collected at different times, the issue of temporality was negated by having a systematic approach, which allowed the individual and collective analysis of data.

A summary of the thematic analytic approach taken for this study is as follows (see Table 1):

*Insert Table 1 here*

Staff participants were recruited by two designated clinical Trust members. Staff who worked with the PIP were approached with detailed written information about both the study. Interested participants were then invited to contact the Chief Investigator, who answered any questions and confirmed that participation was voluntary and confidential. Individual interviews were carried in a private meeting room at the hospital. Written consent was obtained, the interviews were audio-recorded, facilitated by the use of a topic guide, and averaged between 45-60 minutes. All interviews were anonymised and transcribed verbatim.

People with caring responsibilities were purposively sampled and recruited to the study by nominated clinical staff. Carers were approached either in person and/or by telephone, followed up with written information. Additionally, the local carers’ centre, who ran support groups for carers of people with learning disabilities assisted with the recruitment implementing specific inclusion and exclusion criteria for carers (see Table 2). All potential participants received a study information pack containing a letter of invitation, a participant information sheet, a participant consent form, a participant contact form and a pre-paid, addressed reply envelope.

*Insert Table 2 here*

Three carers were recruited to the study, with one interview taking place in a carers’ home, and the other two were carried out over the telephone in accordance with the participants’ individual needs and preferences. The face to face interview lasted 45 minutes and the two telephone interviews lasted 30 minutes. All interviews were assisted by a topic guide (see Table 3, audio recorded and transcribed verbatim. Data was collected December 2017 – August 2018.

*Insert Table 3 here*

Data was collected by the Chief Investigator, with independent data analysis executed with another researcher (XX). Both independently reviewed the data transcriptions, with a mutual consensus on the final themes being agreed between the two researchers.

This study received formal institutional ethical approval from both Northumberland Tyne and Wear NHS Foundation Trust and the University of Sunderland.

**Results**

Nine participants recruited to the study with six members of staff (4 nurses, 1 psychologist, and 1 psychiatrist). The six staff members (5 female, 1 male) recruited to the study were all permanent employees of the Trust in the community learning disabilities setting. Three people with caring responsibilities for persons with learning disabilities and behaviour deemed to be challenging (3 female) were also recruited.

 To protect confidentiality, each participant was assigned an anonymised code, so any in-vivo quotes could not potentially identify an individual participant. To further assure anonymity, any in-vivo quotes from staff did not refer to specific clinical disciplines.

There were five core themes identified in the staff cohort, and three core themes in the carer cohort (see Table 4).

*Insert Table 4 here*

**Staff**

1. ***Being open to innovation and change in collaborative practice***

The PIP contributed to the multidisciplinary approach providing support to the other team members. The PIP worked with each practitioner and observed their clinics to gain deeper knowledge and a broader perspective. The PIP acknowledged the various viewpoints, both from the clinical team and a person-centred approach when recommending what was felt to be the most appropriate course of action for the individual whose case was under review:

*The psychiatrist would usually focus on the medication, and then we could look at the social side and other things like speech and language and psychology, so we would be able to suggest other things rather than just medication. When the PIP arrived, my manager asked me to speak to him about the medication clinic. It had been suggested that he came and offered support around the community and see what kind of things he could provide support with. I said ‘Great, come and have a look, come and see and do some observations at the clinic and see what you could suggest… (Participant A)*

*What we’ve also looked at is understanding the change in the role for pharmacy and what support they might need. I do a lot about internal teaching and training for staff. So you might get your traditional supervision in terms of the role of a pharmacist, but in the context of the community team, here are a lot more situations that a pharmacist will be exposed to which they would have not experienced previously. Supervision is offered in terms of what somebody needs if they are going to do this community role, instead of prescribing from a distance to facing a family or a person, what issues this might raise and how they might manage these, especially the emotional understanding and issues that may arise (Participant C)*

*If you have a pharmacist on the ground, it helps psychiatrists and physicians a lot in the sense you have someone to discuss medication with. I am able to meet him and say ‘I have this patient who is on this medication and I’m thinking of doing this – what do you think as a pharmacist?’ It’s a true MDT approach; you can’t do it all alone (Participant F)*

1. ***Challenging traditional norms in collaborative approaches to person-centred care***

The role of the PIP challenged the norm that the psychiatrist makes a decision regarding a patient’s medication, and the pharmacist prescribes this. The PIP was seen as a professional who created a non-challenging, open space for a two-way conversation with the psychiatrist to ensure that the most appropriate course of action regarding medications, be it initiating, changing, increasing, lowering or ceasing medication, was in the best interests of the patient and often involved discussions with carers. All staff interviewed were supportive of the principles of the STOMP agenda and saw the PIP as a resource in which to discuss medication issues in line with STOMP, but acknowledged this had developed over time. It was evident that staff interviewed all had a collective ethos of working together to provide patient care, not against each other.

*I think this is where we have struggled a little bit, getting psychiatry on board with the idea of a pharmacist being in clinics….I think they had been previously, but you are aware of the STOMP agenda. The traditional role of a psychiatrist is to prescribe the medication, so if somebody comes in, like a pharmacist with a special skill set and sort of challenges the diagnosis that the psychiatrist has made, along with his treatment plan based on his professional assessment, then I can see there would potentially be a conflict (Participant A)*

*We try to make sure staff don't perceive people in isolation, because then you don’t get the rest of the system information. I’ve had psychiatrists say to me, ‘people (patients and carers) are coming to see me, there is a pressure to act’ and the traditional pressure to act is to medicate, so how do you manage some of these pressures and demands and not get drawn into that? It’s very difficult.*

*It was a lot about building up trust with the psychiatrist and the role of the pharmacist, actually this is what he is here for and this is what he can help you with. It became a really good working relationship and I think the psychiatrist felt supported by the pharmacist and he brought him in if there was a question about the medication during the appointment*

1. ***Proactive empowerment via maximisation of expertise and resources***

The PIP works together with the whole team to ensure that everyone has all of the information about the individual. This ensures that appointments are an effective use of time and that the patients do not need to repeat the same information to each health professional.

*With the medication clinic, the patients and carers would only be coming in for a 30 minute appointment with the psychiatrist for a review, and that is where the role for us (the MDT) is massive. We need to be doing the background work and make sure they (psychiatrists) are getting the bigger picture (Participant B)*

*It is a team approach and what I need from the PIP is support for my work, and I support his. Not like a bargain, but the patients and carers need to see that it’s a joint approach and it comes as a package and that we are promoting the same thing, despite our different professions. Quite often I have in-depth knowledge of a care team or family members and I can pass this information on to the PIP ahead of the review, so he is aware of any strong feelings or situations and we can work out a joint approach (Participant E)*

1. ***Supporting and empowering informed decision making***

The PIP and the MDT work with the individual and their carers to ensure that the best decisions for the individual are made. The PIP work with individuals to ensure that they have all of the information they need and can question any decisions made about their medication if required. They also work with carers to make sure that the MDT have a detailed picture of the individual.

*We need to be looking far more people making decisions about their medication as well, and questioning things like side effects. We have quite an acquiescent population, who, if the doctor says do something, you do it. I can see a role for pharmacists around education for people around ‘actually, there are some decisions to make in this. Medication has its role but you need to think about these things when your making some of these decisions yourself, or when you are taking some of these and be more assertive towards their choices around medication (Participant C)*

*There’s no way you are going to make any headway without carers on board, and with most of the patients we see,, collateral information from the carers is very, very vital. They know the patient much more than we do. We involve carers in the management of our patients, carers’ in learning disability and psychiatry is extremely important*

1. ***Encouraging collaborative debate around medication***

The PIP works together with care providers to ensure that they understand why decisions around an individual’s medication have been made. They work together to ensure that the most appropriate medication is given to provide the best quality of life for the individual.

*The more we educate, the more it should be a debate. It should be a discussion around ‘this is an option, these are the side effects, but actually we feel this might benefit you. Let us decide how we are going to monitor that and see if it works, rather than here’s your script, go on and take it (Participant D)*

*We have staff in residential care settings who are not on board with positive behavioural support or STOMP. Having medicated patients is easy, less pressure, less staff and we try to educate and explain that if there is no rationale for the medication, then we need to challenge it. We need to weigh up the risks and benefits because some staff may not work with the person if they are not on medication, but if they are suffering from side effects then their quality of life is compromised and you need to give staff an argument they can’t argue with in a sense (Participant E)*

*STOMP is about overmedicating, it’s not about don’t medicate. The PIP has been instrumental in educating people that STOMP does not mean stop. People tend to interpret STOMP as don’t medicate and I have had issues with care providers about this. With these patients, you need to be very wary about attributing everything to mental health problems whereby you overmedicate a patient. At the same time, you want to make sure you don’t fall into a bit of diagnostic overshadowing where you attribute everything with a patient to their behaviours. It is especially difficult when some patients can’t communicate. (Participant C)*

**Carers**

The three participants recruited were all female and defined themselves as full-time carers of adults with learning disabilities and behaviours deemed to be challenging in domestic settings, i.e. performing caring responsibilities in a home environment.

All three carer participants reported positive interactions with the pharmacist, there were no negative or challenging situations reported. All three carers had experienced issues with medications, which necessitated contact with the PIP as part of the person’s ongoing care within the LD service.

Three core themes were identified:

1. **Establishing authentic and interactive dialogue**

At the heart of effective communication, participants felt that there were fundamental differences in the accessibility of practitioner led knowledge, which were dependent upon the capacity of professionals to establish an authentic and interactive dialogue, which could then be used to support them. This is particularly well evidenced in the following quote,

*I find it easier to communicate with the pharmacist because when there was a psychiatrist, I*

*was never very comfortable with my daughter seeing a psychiatrist, to be honest, because*

*who’s to say that there’s anything when she’s brain damaged [as opposed to having a*

*diagnosed mental health condition]? I don’t know. Never made sense to me, but I went*

*along with it because there was no other option. I find it easier to speak with the pharmacist*

 *about the medication, because he’ll listen to my point of view as well, rather than a doctor*

*just saying, “She’s got to have this.” Well, I could never understand when she [relative of*

*carer] was referred to a psychiatrist in the first place, to be honest. But you go along with it*

*because, to be quite honest, you don’t have much choice. (Participant H)*

1. **Gaining trust of the PIP’s role in the management of patients**

The respect for pharmacist’s knowledge of pharmacology was evident throughout the interviews. It was apparent that patients trusted the knowledge of systemic health issues that patients lived with and how best they might be addressed with the appropriate medication. The following quote is indicative of this and also supports the notion that pharmacists are an invaluable and integral part of prescribing practice.

*I think the pharmacist knows more about the medications, to be honest, than some doctors do.*

*I think doctors just know- they have a list of medications and say, “Oh, we’ll try that,”*

*whereas the pharmacist knows what the medication is for, what it should be doing, that sort*

*of thing. And I’m not convinced doctors always do. Especially not GPs. I mean, they’ve tried*

*some drugs with my daughter and the side effects she’s had with that drug are not a known*

 *side effect. They’ll say, “Well, that’s not a known side effect,” and I’ll say, “But it was a side*

*effect for her.” And the pharmacist accepts that the effects of drugs are not always the same*

*on her as they might be on other people. Because they do say with brain damage, a drug can*

*have an opposite effect to what it’s supposed to have. Which I’ve seen happen a couple of*

*times with my daughter. One time, when she was screaming, the GP prescribed a drug and,*

*within three days, she was just screaming the roof off the house. It had to be that drug and*

*GP said, “Oh, it’s not a known side effect,” and I said, “Well, I’m going to stop it,” and I*

 *stopped it and the screaming subsided. (Participant I)*

1. **Feeling empowered to challenge ambiguity and inconsistency in prescribing practice in relation to the STOMP agenda**

Many participants interviewed felt that there was a degree of ambiguity and inconsistency in prescribing practice and there is often the existence of co-morbidity that warrant entirely separate acknowledgement and recognition. The following quote gives an insight into one participant’s experience of long term prescribing in learning disabilities,

*She’s been on it (risperidone) for absolutely years. And apparently, which I couldn’t*

*understand, I was told, if she was to present with those symptoms now, they would never have*

*prescribed risperidone for her. They would have tried an antidepressant, which I can’t*

*understand, but apparently that’s the way they’re going these days. Yes. And I said, “Well, I*

*wouldn’t be happy with that because how do I know if she’s depressed? How do you know if*

*she’s depressed? I don’t know so you don’t know.” Brain damage is a condition. It’s not a*

*mental illness,it’s completely different. So, an antidepressant would be- but what was it about*

 *the risperidone that- in terms of why it was prescribed? It’s an antipsychotic. (Participant H)*

**Discussion**

From all participants’ perspectives, the PIP was both a valued resource and an integral part of the decision-making about the management of the person with learning disabilities and behaviour deemed to be challenging.

Despite the different roles the staff participants had in the multi-disciplinary team, all were positive about the role, contribution and expertise of the PIP, which appeared to increase confidence in decision-making in patient care

From carers’ perspectives, it was apparent they felt comfortable speaking with the PIP about straightforward issues e.g. medication and dosages, but also raising subjective issues, e.g. behaviour changes based on the carers’ intuition or observations, and feeling these concerns were taken seriously and acted upon. Carers also reported trust and confidence in the advice and recommendations of the PIP. Medication issues which underpin the STOMP initiative e.g. medications being prescribed for conditions outside the indicated use were reported and the proactive role of the PIP in acknowledging, understanding and proactively addressing these issues was evident. In one case, the person’s medication was decreased, but a negative change in behaviour resulted in the medication being reinstated, but going through the process was deemed as a positive intervention despite the outcome not being the optimal choice.

Expectations of roles and responsibilities of PIPs vary, however many assumptions about potential implications to practice are rooted in longstanding historical interprofessional conflicts which may break down capacity for communication between professional groups (Hindi, Schafheutle, & Jacobs, 2019). Greatest concerns surround the ongoing need for optimal communication and effective interprofessional working in the context of patient centred care, as opposed to the consultant led services which has largely characterised historical practice. Other clinical debate include the potential for GPs to be freed from the relentless prescribing practice of their own daily clinics, in order to focus on dealing with more complex medical cases, empowering pharmacists to develop and extend their professional and clinical roles (Maskrey, Johnson, Cormack, Ryan, & Macdonald, 2018) .

Recruitment to this study was not straightforward, especially with psychiatrists and carer participants. The recruitment of carers proved more challenging than originally anticipated, and the study was extended by six months to allow more time to recruit increased numbers. Feedback from staff recruiting to the study showed that although many carers were supportive of the study, and indeed involving the carer voice in research, the complexity of their lives and caring responsibilities imposed time constraints which made participation prohibitive whether by interview or survey. The research team were cognisant of the time demands, and individual situations, so only one follow up approach was made after the initial contact, so as not to appear coercive, in line with the ethical approval obtained for the study.

The traditional medical model asserts that consultants have the power to decide the best course of patient treatment; the PIP role challenges this assertion and offers a change of culture in the context of first line patient consultation, assessment, diagnosis and management. There is an acknowledged reticence and reluctance to changes in clinical practice. This may affect relationships and processes, which could potentially impact on positional power within a traditional medical environment, where there is an established historical organisational hierarchy. The psychiatrist recruited to this study was positive about the role of the PIP but it is fully acknowledged that this may not be the case with all or any other psychiatrists. Further attempts to recruit more psychiatrists to the study in order to gain a wider variety of perspectives from practice were unsuccessful.

It is notable that currently, only 6% of psychiatrists in the UK workforce specialise in learning disabilities, which is relatively low compared with the other six psychiatric specialties available at the point of elective psychiatric training e.g. 15% in old age psychiatry (Centre for Workforce Intelligence, 2014). The role of the PIP within the MDT has potential to support the limited resources of the psychiatrist and bring a wealth of discipline specific knowledge and skills to the medication review clinic, which has the potential to contribute to the wider medicines optimisation agenda, consequently the improvement of patient safety, quality of life for patients and to directly support carers involved in advocating and supporting people living with these conditions in practice every day.

**Conclusion**

Traditional medical models have historically determined an organisational hierarchy which have shaped prescribing practice. Contemporary approaches and changes in legislation and policy surrounding care of people with learning disabilities have rightly justified new patient centric approaches to first line patient assessment, diagnosis and management. MDT approaches to patient care are now characterised by the diversity of healthcare professionals caring for people with learning disabilities and their families and carers. This study highlights the importance of authentic, interactive dialogue between these healthcare professionals and carers, which is deemed to be important in understanding the often complex care needs of this group of patients from both perspectives. A national shortage in psychiatrists opting to specialise in the field of learning disabilities warrants immediate strategic address, both in relation to optimising uptake of this as an area of professional expertise and due recognition for their contribution to clinical professional practice. This also has ramifications for the need to advocate for greater interest and awareness raising in Learning Disabilities at all stages of Undergraduate and Postgraduate education, whether during initial education or longer term, as an integral part of Continuing Professional Development.

The strengths of this study are that it provides an in-depth account of an MDT and carers’ experiences of the PIP working in a community learning disabilities service focusing on the medication issues in patients with learning disabilities and behaviours deemed to be challenging. Concurrently, the study captured the experiences of three carers who provided additional insight into the role of the PIP and the perspectives of the impact on the persons they care for as a means of triangulating the evidence captured surrounding often very vulnerable members of society. This study took place in one community service and was related to the role of one PIP so the organisation of care in other Trusts may not be the same. Owing to the reported complex responsibilities of the carers and the time constraints on them, only three participants were recruited to the study, so it is acknowledged that the view of the carers is not indicative or representative of those of the entire population of carers for people with learning disabilities and challenging behaviours. It is also noted that only one psychiatrist chose to take part in the study, again this clinicians’ perspectives are not necessarily that of the wider population of learning disability psychiatrists

All carers recruited to the study undertook their caring responsibilities in a domestic home environment, and cared only for one person. We did not recruit any carers working in a residential home or respite care environment, where they may be caring for more than one person simultaneously. This is a common environment in which caring responsibilities take place, and we acknowledge that the experiences of carers in a domestic and one to one setting may not reflect the experiences of carers working in other environments who have contact with the PIP. Emphasis from the extant literature is focused not on residential care home settings but on settings where the prime emphasis of having a PIP appears to be freeing up more GP time in order to increase their ‘value’ in their everyday working practice.

This also has important implications for the future training of the pharmacy workforce across the UK. There is potential for pharmacists to extend and develop their practice within the field of learning disabilities, which is a dynamic and evolving area of clinical practice as a result of initiatives such as the STOMP agenda and the acknowledged inequalities in the care of people with learning disabilities. As such, pharmacists with specific responsibility for prescribing within a learning disability clinical context must be able to think autonomously and professionally, to discern the need for considered decision making processes. As annotated in the international literature base, individual educational learning outcomes can be passed on for formal recognition, so whilst this study has incorporated an overview of how a PIP has utilised the role to drive change in practice, this needs to be developed in other learning disability settings to more fully determine the need for change beyond current practice (Haines, 2019).

The role of the PIP in the care of persons with learning disabilities and behaviour deemed to be challenging is an innovative position which has potential to continue to make a positive difference to the quality of life in this cohort of patients, and provide reassurance and support for people who care for them in both healthcare and domestic contexts of care.

The challenges of managing a complex group of patients whose methods of communication to assert their needs are not straightforward. The importance of understanding how communication is conveyed and the meaning and actions behind this is important in the context of medication management. This means ensuring that the voice of the carer, who is often the ‘voice’ of the person being cared for, is considered within medication management, especially when the person is cared for in a domestic home environment is represented in the care pathway. The carers’ role in speaking on behalf of the people they care for can be reinforced and supported through the expertise of the PIP. Additionally, the PIP is able to educate others, both professional and non-professional to understand the side effects of medications and their impact on the person, and reinforce understanding of the principles of the STOMP initiative medications through reviewing, understanding the social contexts of the patient and carer and highlight the significance of the role of medication in the management of these patients, whether the medication is stopped, increased or remains the same. It is evident that that the role of the carer for people with learning disabilities and behaviour deemed to be challenging is demanding and time consuming, and their lives are often complex and not their own. In a research context, voice of the carer is important to not only understand the needs of the people they care for, but also more fully understand the complexity of their lives and how they can be further supported in order to ensure their caring responsibilities are carried out without detriment to their own health and well-being. Future consideration should be taken into how this group can be reached in terms of recruitment to carry out research with this often under-represented and hard to reach cohort.

Additionally, we recommend that the role of the PIP within the field of learning disabilities is embedded into undergraduate and postgraduate pharmacy curricula to illuminate the contribution that pharmacists can bring into traditional medically dominated models of care, to extend the scope of the pharmacist role in future practice. The authors welcome both clinical and pedagogic debate in the subject.

**Data Statement**

Research data are not shared owing to the need to protect participant confidentiality and anonymity.

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