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## Improving the initial assessment process in the oxford health learning disability service

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### Abstract

An investigation of service users' experiences of the South Learning Disability (LD) team in 2019 revealed dissatisfaction with the initial assessment process. The present study aimed to improve the initial assessment process in the LD Service by introducing new resources developed collaboratively with service users. 20 clinicians, 10 service users and 4 carers completed questionnaires on their experience of the initial assessment and the new resources. Using thematic analysis, main themes emerged relating to staff's experiences of the initial assessment pre-pilot: 'Is this really necessary? a lot of work for little reward', 'Not very LD-friendly', 'Value in a thorough assessment' and 'A need for a streamlined, inclusive approach'. Themes relating to staff's experiences of using the developed resources were found: 'Making it LD-friendly', 'Time saving' and 'One size does not fit all'. Quantitative data showed new resources reduced service users' anxiety and improved their understanding of the assessment.

**Keywords:** Learning disability, accessibility, initial assessment, communication aids

### 1. Introduction

Individuals with a learning disability (LD) and/or autism display a preference for predictability (Brigid Flannery & Horner, 1994; Goris *et al.*, 2020) <sup>[4-5]</sup> and intolerance of uncertainty (Sáez-Suanes *et al.*, 2020; Uljarević *et al.*, 2018) <sup>[8, 10]</sup>. Literature highlights the role intolerance of uncertainty has on anxiety symptoms within the LD population (Reid *et al.*, 2011). Additionally, communication difficulties are prevalent in individuals with LD and lead to barriers when expressing their needs to healthcare professionals (Smith *et al.*, 2020). Although literature is scarce, it is hypothesised that anxiety in LD may relate to the tendency to perceive novel situations as threatening; heightened responses to sensory stimuli and communication difficulties may further increase the likelihood of individuals with LD to perceive new environments as unpredictable and threatening, increasing anxiety (Sáez-Suanes *et al.*, 2020; Uljarević *et al.*, 2018) <sup>[8, 10]</sup>. Therefore, services should ensure their processes are as predictable as possible to reduce anxiety and distress. To ensure predictability of the assessment process and reduce uncertainty for the service user, National Institute for Health and Care Excellence (NICE) guidelines for assessment and interventions with individuals with LD recommend providing information to the individual prior to the assessment. This should include the rationale for, and nature of, the meeting, and awareness that certain sensitive questions may be asked (NICE, 2016) <sup>[6]</sup>.

### 1.1 Project background and aims

In 2019, the Patient Experience Lead of Oxford Health LD Service investigated service users' experience of the care they received from the South LD team. A focus group was held with service users from the patient experience group. Feedback highlighted that service users felt the initial assessment process could be improved, reporting the following: service users wanted more understanding and clarity of consent and confidentiality, especially that they have the option to decline to answer personal questions. The initial assessment was felt to be overwhelming as there are many topics covered, and service users did not like carers answering on their behalf. Service users reported it would be helpful to have access to an easy read version of the assessment questions prior to the appointment, so they are prepared on what questions to expect. To help with the vast number of topics to cover, a key ring communication aid was suggested to orient service users to what questions are being asked

in each part of the appointment. This project aimed to understand the initial assessment experience from a staff and service user experience, then implement new resources into the initial assessment process over a four-month period (Dec 2022 - Mar 2023) and evaluate how they impact the initial assessment process from both service user and staff perspective.

## 2. Method

### 2.1 Participants

34 participants (20 clinicians, 10 service users and 4 carers) took part in the study using purposive sampling (see below). Participants included individuals with a LD who completed an initial assessment with the LD team between December 2022 to March 2023. Where service users were unable to provide a response due to a communication impairment, carers were asked to complete a questionnaire assessing their experience of the assessment. Participants were LD service staff, across the North, City and South Oxfordshire teams, who completed an initial assessment between Dec 2022 to Mar 2023.

### 2.2 Design

This study used thematic analysis; a qualitative method which involves identifying, analysing, and reporting themes in data. Questionnaires with a mixture of open-ended and closed questions were developed, based upon the 2019 review of the initial assessment and the author's research aims.

### 2.3 Ethical Considerations

All data was anonymised to prevent identification of individuals. Project approval was granted by the Service Governance Committee.

### 2.4 Procedure

Resources were developed collaboratively with the Patient Experience group. The resources were: an easy-read version of the Initial Assessment questions, to be sent out to service users prior to their appointment; and a Keyring Aid, a communication aid using simplified language and images to orient service users to different topics discussed in the Initial Assessment. Over a four-month period, resources were distributed in all initial assessments within the Oxford Health LD service. Prior to the initial assessment, all referred service users were sent the easy-read Initial Assessment Questions. All staff conducting initial assessments were provided with a Keyring Aid. Following the initial assessment, if consented, service users (or carers if service users were unable to provide a response) were provided with questionnaires asking for feedback on the resources and the initial assessment process. Upon completion of the trial period (March 2023), staff who led initial assessments were emailed a post-implementation questionnaire to reflect on their experience of the initial assessment using the new resources.

## 3. Results

Closed questions were analysed using descriptive statistics. Thematic analysis was conducted on all open-ended questions, as outlined by Braun & Clarke, (2006) <sup>[1]</sup>.

### 3.1 Themes

#### Staff's perspectives of the Initial Assessment (prior to implementation of the resources)

##### 1. Is this really necessary? A lot of work for little reward Relevance of the process

Staff questioned the necessity of the process; particularly around how useful it is to collect the information at that point in time: "It is overly lengthy and unnecessary; much of it should be completed by clinicians upon allocation rather than prior to considering whether the person will even be picked up by the team" (S17). Staff reflected on the usefulness of the information: "we collect a lot of info which doesn't get used" (S14); "Sometimes we focus on getting a lot of general information and lose sight of the referral need" (S6).

#### Uncomfortable questions

Staff wrote about their discomfort at asking sensitive questions: "I am asking a person to reveal an awful lot to me without being able to give them a certain indication of the benefit this will bring to them" (S17). This led to staff feeling self-conscious when describing the process to service users and carers: "Sometimes embarrassing explaining the process of what we do" (S1).

#### Time is of the essence

A concern for staff appeared to be the time taken to complete the process: "it can be a long process and to be doing this on top of your clinical work you can easily lose a whole day to work that isn't related to your caseload". (S18). This extended to the concern of the time taken for service users: "if support workers are involved & they have limited time funded time to give support - I'm not sure this is best for client that their support is used for this particular assessment?" (S15). Often staff find themselves rushing through the assessment to complete the topics, which may lead to incomplete information gathering: "I often find myself having to rush through the second half of the IA and the risk assessment more" (S3).

#### 2. Not very LD-friendly

##### Service users' feelings

Staff reflected on the initial assessment experience from the perspective of service users: "it can be quite invasive and overwhelming for the patient" (S13). Staff wrote about noticing service users becoming confused and anxious during the appointment: "Sensitive questions can cause service users to look concerned or confused" (S11).

##### Service users' disengagement

Staff identified that often service users would not be included in the appointment: "sometimes the carer does not involve the patient as much as they would like as the process takes too long and is not person centred" (S13). Staff queried the accessibility of the appointment: "I don't think it is LD friendly at the moment." (S14). The non-person-centred approach can lead to service users disengaging: "Service users can become disengaged with a long appointment." (S11)

#### 3. Value in a thorough assessment

Despite the drawbacks mentioned above, staff did comment on the benefits of having a thorough assessment in planning the best approach: "carers are really appreciative of a thorough assessment and consideration of who can help with what." (S16). Staff commented on how the process often led to the discovery of additional needs: "useful to check medications and medical diagnoses against our records (if we have them), and establishing unmentioned

health needs that service users/family/carers may not have picked up on” (S5).

**4. Need for a streamlined, inclusive process**

**An efficient way of working:** Ideas of how to streamline the assessment were highlighted with a greater focus on the primary need: “Complete more initial assessments by profession, e.g., SLT completing dysphagia/communication referrals as a primary need, still collecting the other data as secondary needs, but focusing less on this.” (S5). Staff wrote about how to condense the appointment: “more general information completed in advance by family/ carers” (S6).

**Enabling a person-centred approach**

Staff were keen to implement a process more accessible for service users: “I think for it to have a more accessible format to involve the SU would be great, as is being trialled.” (S4).

**Staff’s perspective of the Initial Assessment (post implementation of the resources)**

**1. Making it LD-friendly**

**Greater inclusion and engagement:** Staff wrote about the impact of the resources in engaging and including the service user, particularly the keyring aid: “It was a great way to make client feel more involved.” (S1). It was noted that it was useful to engage service users even with communication impairments: “(they) did not have the communication skills to follow but enjoyed looking at the pictures and said “angry, sad” etc” (S4). Staff reflected on the visual aspect of the keyring aid: “I think the keyring aid is a great way to engage the service user. As it is visual, the service user can look at the images and point/comment on them” (S11).

**Greater understanding and preparedness**

Staff commented on how the resources, particularly the easy-read information sheet, aided service users understanding of the appointment: “easy read sheet was helpful in helping the service users and carers to be more prepared and know what to expect for the appointment.” (S9). Staff also reflected on the use of asking the questions in the style of the questions on the easy-read information sheet: “I think the accessible sheet was useful to have as I used it to ask the questions in a more accessible way.” (S12). Staff wrote that the keyring aid seemed to enable

greater understanding for service users: “I found it helpful to orientate the client through themes of questions” (S2).

**2. Timesaving**

**Staff wrote about the easy-read information sheet reducing the appointment time:** “I found it reduces the time it takes me to do the assessment (because I just ask your simply worded questions and elaborate where needed rather than trying to ask around topics myself)” (S5). Staff reflected on the impact of the resources in improving efficiency: “I found it most useful to give the client the paper version whilst I typed answers straight onto the RiO form on my laptop” (S6).

**3. One size does not fit all**

**Barriers to using the resources**

Despite positive feedback, staff reflected on the differences in service users’ responses to the resources: “for another they did not engage with it, it did not feel appropriate for them based on their ability level” (S9).

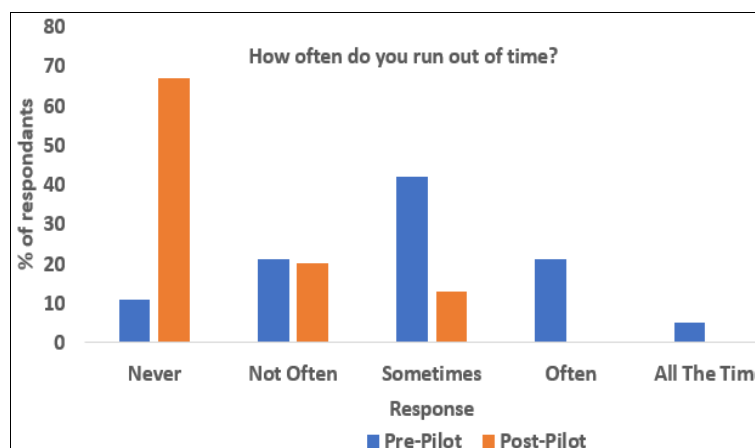
**Suggestions for improving the resources**

Staff requested the resources to include more questions specific to risk and to relationships/sex: “more general topics to be included, e.g. relationships (as well as sex) add in more questions about risk” (S6).

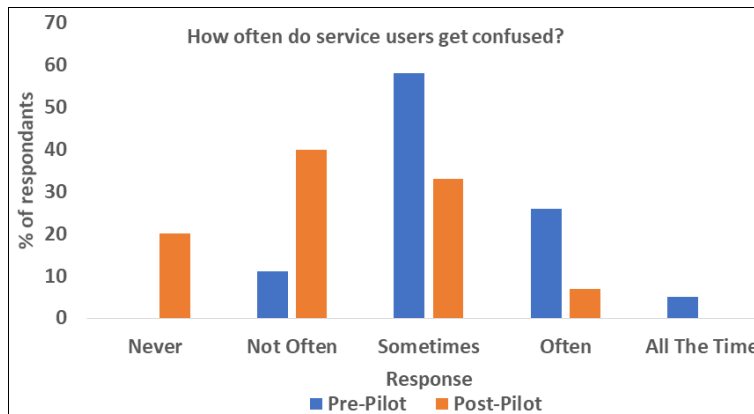
**3.2 Descriptive Statistic**

**Figures 1a, b, c, d and e: Staff pre-pilot questionnaire vs post-pilot questionnaire data**

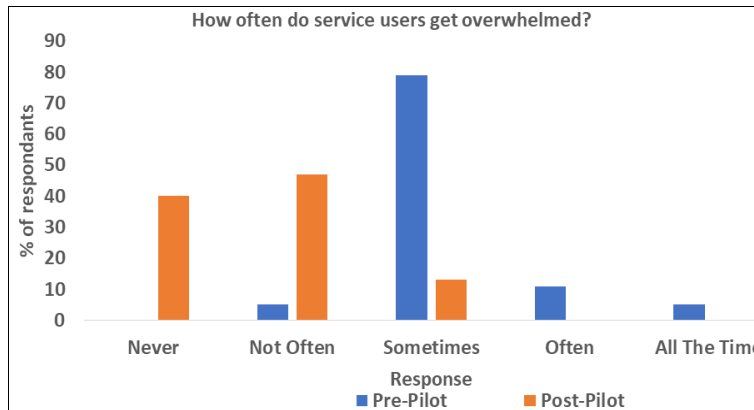
Figure 1a shows that overall staff were less likely to run out of time in post-pilot assessments than pre-pilot assessments. Figures 1b and 1c show that staff were less likely to notice service users becoming confused and overwhelmed in assessments with the resources, compared to assessments without resources. Figures 1d and 1e show that staff were less likely to notice service users being anxious in post-pilot assessments. As different service users were present in each initial assessment, individual differences of service users, such as temperament, will contribute to the outcomes. However, the data shows an overall trend that service users in assessments with resources were less likely to be anxious, confused or overwhelmed, and staff were less likely to run out of time, compared to assessments without resources. This supports the qualitative feedback that the resources improved the LD-friendliness and efficiency of the assessment.



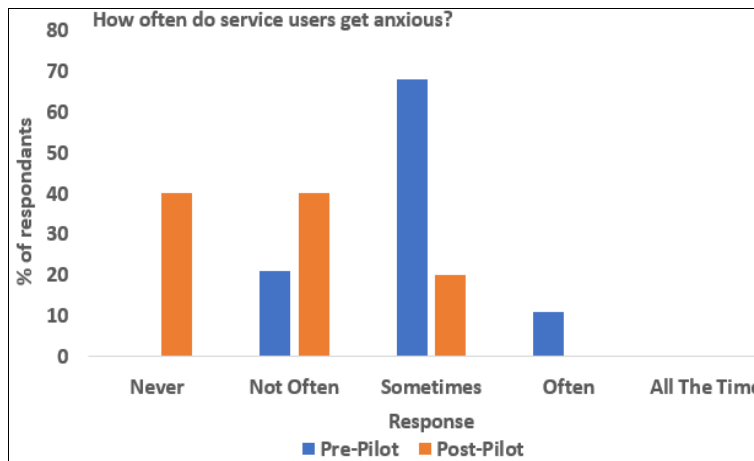
(a)



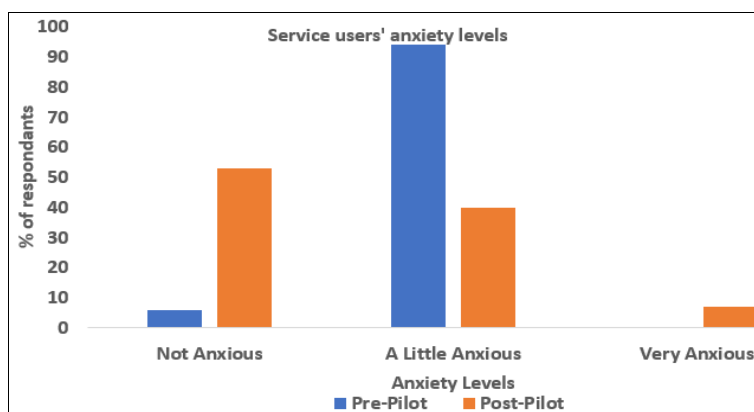
(b)



(c)



(d)



(e)

**Fig 1:** a, b, c, d and e: Staff pre-pilot questionnaire vs post-pilot questionnaire data

### 3.3 Complementary Information from Service Users and Carers

Due to limited feedback received from service users, qualitative data was added as complementary information rather than separately thematically analysed. Both service users and carers reflected on the impact of the keyring aid in engaging the service user: “Liked pointing at pictures and commenting on them, it was good” (C4); “I like looking at the pictures” (SU2). Service users wrote about how the keyring aid helped them understand topics in the appointment: “Reminds me of what you were saying and what the questions meant.” (SU1); “Helped me understand

the questions” (SU2). Carers appreciated the easy-read information sheet in preparing them for the appointment: “It was helpful to read through ahead of meeting to know what information was needed. We could then talk to (service user) about the meeting and let them know what questions were going to be asked.” (C2). Service users all reported they did not wish to change the resources in any way. One carer suggested how to improve the practicality of the keyring aid: “Maybe on a stand that could be easier to use.” (C2).

Overall, service users reported a good experience of the initial assessment (Tables 1 and 2 below).

**Table 1:** Service user feedback (N=10)

	Keyring Aid		Information Sheet	
	Yes (%)	No (%)	Yes (%)	No (%)
Easy to use?	70	30	90	10
Was it helpful?	70	30	100	0
Would you like to change it?	0	100	0	100

**Table 2:** Carer feedback (N=4)

	Keyring Aid		Information Sheet	
	Yes (%)	No (%)	Yes (%)	No (%)
Easy for service user to use?	75	25	75	25
Helped service user to feel more prepared?	N/A	N/A	100	0
Helped service user to understand the questions?	75	25	N/A	N/A
Helped service user to feel less anxious?	50	50	75	25

### 3.4 Researcher Bias

The author acknowledges that the thematic analysis process is subjective and therefore there is potential bias. The author attempted to prevent these biases by developing the service-user questionnaire with a patient experience group member, additionally deciding appropriate questions and sharing data with both supervisors to discuss codes and themes.

### 4. Discussion

The aim of this project was to evaluate the implementation of new resources in the initial assessment process of Oxford community LD services across a four-month period and assess how they impact the initial assessment from both staff, service user and carer perspectives. To evaluate their impact, a staff survey was used to understand staff’s perspective of the initial assessment process prior to the new resources being trialled. Main themes that emerged from this were: ‘Is this really necessary? A lot of work for little reward’, ‘Not very LD-friendly’, ‘Seeing value in a thorough assessment’ and ‘Need for a streamlined, inclusive process’. The 2019 review of the initial assessment process reported service users found the appointment overwhelming due to the vast number of topics and did not like carers answering on their behalf. They reported wanting more understanding and clarity, particularly around answering sensitive questions, an easy read version of questions prior to the appointment and a key ring aid to use in the session. Whilst there were some barriers to using the new resources and suggestions for improvement, such as adding risk assessment questions, using the recommended resources appeared to help service users understand the purpose of the assessment and reduced feelings of being overwhelmed.

#### 4.1 Limitations

A major limitation of this study was low representation of feedback from service users. Only 10 service users and 4

carer questionnaires were collected, a low representation of service users who carried out initial assessments within the trial period. Additionally, pre-pilot and post-pilot assessments involved different service users; therefore, when comparing pre-pilot versus post-pilot data it is difficult to establish a causal effect between the resources and improved outcome.

### 5. Conclusion

Understanding staff and service users’ views of the initial assessment, particularly around the need to ensure a person-centred approach and increase the efficiency of the process, are valuable in considering ways to conduct the initial assessment across all Oxford LD teams. The evaluation of the new resources justifies the consistent use of these resources in assessments, as overall they address the staff and service users concerns of the initial assessment process. Findings can be shared with other LD services to demonstrate the use of resources in improving accessibility and efficiency of initial assessments, meeting NICE guidelines, and improving the experience of the process from both a service user and clinician perspective. Considering the minor barriers in using the resources and suggestions on how to improve them enables the maximum benefits of these resources.

### 6. Recommendations

Based on the findings, recommendations were developed and disseminated to the LD community teams:

1. Add in more sensitive questions covering risk assessment and sex/relationships.
2. Provide an instruction sheet for clinicians on how best to use the resources whilst bearing in mind the person-centred approach and how to adapt for each individual.
3. Encourage clinicians to use the easy-read information sheet in the session (Asking the more accessibly

worded questions, providing a paper copy to the service user/carer to read through, writing straight into RiO template form to save time).

4. To increase efficiency of the appointment, consider asking carers/service users to complete more general information in advance of the appointment.
5. Consider the need to increase the accessibility and inclusivity of the process by involving the service user as much as possible, being aware of the fatigue and confusion the appointment can cause, asking questions in the most accessible way (Using the resources where possible to aid with this).
6. Honorary Assistant Psychologists to monitor any future changes in the RiO core assessment template and update the resources accordingly (perhaps reviewing on a 6 month basis).

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