






## RESEARCH ARTICLE

# Stakeholder views on the barriers and facilitators of psychosocial interventions to address reduction in aggressive challenging behaviour in adults with intellectual disabilities

[version 1; peer review: 2 approved]

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## Abstract

### Background:



Success of psychosocial interventions in reducing aggressive challenging behaviour is likely to be related not only to mechanistic aspects, but also to therapeutic and system factors. The study aims to examine the facilitators and barriers that influence whether psychosocial interventions for aggressive challenging behaviour in adults with intellectual disabilities lead to positive change.


### Methods:

We conducted 42 semi-structured interviews with adults with intellectual disabilities and aggressive challenging behaviour, family/paid carers, and professionals engaged in or delivering a psychosocial intervention across the UK. Data were analysed thematically using a framework approach.

## Open Peer Review

Approval Status  

	1	2
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1. **Romina Rinaldi** , Universite de Mons, Mons, Belgium
2. **Karl Nunkoosing**, University of Portsmouth, Portsmouth, UK  
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Any reports and responses or comments on the article can be found at the end of the article.

**Results:**

Stakeholders considered therapeutic and supportive relationships and personalised care as facilitating factors of psychosocial interventions to address aggressive challenging behaviour. The operational structure of community intellectual disability services and conflicting expectations of professionals and carers were the main contextual barriers that impeded the implementation of psychosocial interventions addressing aggressive challenging behaviour in adults with intellectual disabilities.

**Conclusions:**

Findings highlight the valued components that maximise positive change in adults with intellectual disabilities who display aggressive challenging behaviour. Several operational adjustments including referral criteria, roles of professionals and workforce issues need to be addressed in services to maximise the implementation of psychosocial interventions to reduce aggressive challenging behaviour in adults with intellectual disabilities.

**Plain language summary**

The current study looked at what factors that lead to good outcomes from therapies that aim to reduce aggressive challenging behaviour in adults with learning disabilities. We also looked at the factors that may prevent positive change (*i.e.*, reduction in aggressive challenging behaviour). We interviewed 42 people including 14 adults with learning disabilities, 13 carers (6 family; 7 paid) and 13 professionals across the UK.

All stakeholders agreed that supportive relationships between the person with a learning disability and their therapist, staff consistent, personalised therapy and involvement of the person with a learning disability and their carer(s) in care planning facilitate the reduction of aggressive challenging behaviour. On the other hand, differences in expectations between professionals and carers, personal reasons (*e.g.* being the right timing for a person), and the way community learning disability services currently run may stop people from having the opportunity to take part in therapy are barriers to positive change such as reduction of aggressive challenging behaviour.

The study findings highlight the valued components that maximise the positive change in adults with intellectual disabilities who display aggressive challenging behaviour. Several operational adjustments including referral criteria, roles of professionals and workforce issues need to be addressed in services to maximise the implementation of psychosocial interventions to reduce aggressive challenging behaviour in adults with intellectual disabilities.

## Keywords

Intellectual disabilities, aggression, challenging behaviour, qualitative methods, community care, interventions

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The study findings highlight the valued components that maximise the positive change in adults with intellectual disabilities who display aggressive challenging behaviour. Several operational adjustments including referral criteria, roles of professionals and workforce issues need to be addressed in services to maximise the implementation of psychosocial interventions to reduce aggressive challenging behaviour in adults with intellectual disabilities.

## Introduction

Aggressive challenging behaviour is reported in 8% of adults with intellectual disabilities known to services (Bowring *et al.*, 2017) with rates up to 53% for verbal aggression followed by 48% for physical aggression across settings (*e.g.*, community group homes, residential settings) (O'Dwyer *et al.*, 2018). Examples of aggressive challenging behaviour might include incidents of damage to property and/or antisocial behaviour (Deb *et al.*, 2016). Aggressive challenging behaviour in adults with intellectual disabilities are often triggered by environmental factors including unexpected changes and/or demands to the person as well as other factors such as medication, mental health conditions, and level of intellectual functioning (van den Bogaard *et al.*, 2018).

Existing interventions for aggressive challenging behaviour in adults with intellectual disabilities living in the community include behavioural approaches such as Positive Behavioural Support (PBS) and/or Applied Behavioural Analysis (ABA), Cognitive Behaviour Therapy (CBT) informed anger management along with pharmacological (*e.g.*, antipsychotic medication) and alternative approaches (*e.g.*, art therapy, sensory integration) (NICE, 2015). Nonetheless, there is limited evidence for other psychosocial approaches which may be helpful to some adults with intellectual disabilities who display aggressive challenging behaviour such as Dialectical Behaviour Therapy (DBT) (Brown *et al.*, 2013) and mindfulness

(Singh *et al.*, 2013; Singh *et al.*, 2016; Singh *et al.*, 2020). Psychosocial interventions aim to meet unmet needs of adults with intellectual disabilities including housing, self-care, social and interpersonal skills, daytime activities, and housekeeping for those in family, supported or residential care homes (Gustafsson *et al.*, 2009).

Although, the evidence-base and benefits of psychosocial interventions for reducing aggressive challenging behaviour in adults with intellectual disabilities are undisputed (Browne & Smith, 2018; Vereenoghe & Langdon, 2013), it is accepted that not all adults with intellectual disabilities respond to them. In addition, there is scarce understanding of how those who receive these interventions experience them and what their expectations are. The presence of aggressive challenging behaviour impacts not only the well-being of the individual with intellectual disability who might or might not be able to communicate their needs (van den Bogaard *et al.*, 2018), but also has consequences for the surrounding environment including family members and/or paid carers who might be recipients of aggressive incidents (van den Bogaard *et al.*, 2018).

Research has explored the mechanisms that maximise engagement with psychosocial therapy for adults with intellectual disabilities. A qualitative study described the facilitators and barriers of positive therapeutic change (*i.e.*, engagement in therapy, generalisation of acquired skills) following access to mental health services (Ramsden *et al.*, 2016). Triads of six adults with mild intellectual disability who had accessed and benefited from the service, their (six) carers and three clinical psychologists working in the service agreed that a supportive network, a good therapeutic relationship, and adaptations in sessions facilitated positive therapeutic change, whereas communication and cognitive limitations as well as acceptance of the problematic behaviour impeded engagement in therapy (Ramsden *et al.*, 2016). Other studies explored the views of multiple stakeholders about PBS implementation in different settings (*i.e.*, inpatient mental health, forensic, community intellectual disability services) (Bosco *et al.*, 2019; Clark *et al.*, 2020; Karger *et al.*, 2018). Professionals, carers (family or paid) and adults with mild intellectual disabilities described PBS as a beneficial approach to get to know the needs of individuals which in turn may promote holistic care (Bosco *et al.*, 2019; Clark *et al.*, 2020; Karger *et al.*, 2018). However, professionals and care home managers emphasised that PBS plans were not only poorly implemented, but there was confusion about their purpose and use within the team (Clark *et al.*, 2020). Barriers to PBS implementation included differences in staff attitudes towards and knowledge of PBS, resistance to change, organisational issues such as understaffing, and poor motivation and engagement of staff due to PBS being perceived as time consuming (Bosco *et al.*, 2019; Clark *et al.*, 2020; Karger *et al.*, 2018). Overall, they all perceived PBS as leading to an improved collaborative and personalised approach to patient care and, therefore, were willing to adopt it in their effort to reduce restrictive practices (Bosco *et al.*, 2019; Clark *et al.*, 2020).

A recent review summarised the perceived facilitators and barriers to the use of Active Support in adults with intellectual disabilities in residential care (Flynn *et al.*, 2018). Active Support can be described as a preventative intervention that aims to maximise opportunities for adults with intellectual disabilities to be active members in the community they live in, with supervision from care home staff members. However, evidence is inconclusive in relation to its effect on minimising challenging behaviours including aggression towards people and/or property among other behaviours (Stancliffe *et al.*, 2008; Totsika *et al.*, 2008). The review findings suggested that training residential care staff, supervision, and peer support facilitated the implementation of Active Support in residential care for adults with intellectual disabilities (Flynn *et al.*, 2018). Whereas, operational issues including staff retention, lack of support and leadership followed by low levels of staff motivation and absence of knowledge on how to manage challenging behaviours impeded the implementation of Active Support uptake by staff working in residential care (Flynn *et al.*, 2018). Interestingly, a meta-analytic review suggested that following staff training, the attitude of care home staff working with adults with intellectual disabilities who display aggressive challenging behaviour changed but staff training itself was not effective in reducing aggressive challenging behaviour in adults with intellectual disabilities (Knotter *et al.*, 2018).

Overall, there is limited in depth understanding of the experience of care and the reasons that promote or impede the reduction of aggressive challenging behaviour in adults with intellectual disabilities. This qualitative study explored the experiences of triads of adults with mild/moderate intellectual disabilities with a history of aggressive challenging behaviour, their family and/or paid carers, and health and social care professionals involved in their care of previously received psychosocial interventions. The objective was to better understand what constitutes facilitators and barriers in achieving positive change defined as reduction in aggressive challenging behaviour.

## Methods

### Patient and Public Involvement

The study recruited two panels of experts by experience, one with adults with intellectual disabilities (n=4) and the other with family carers (n=5) to shape the methodology. Participants information sheets, consent forms and topic guides for each stakeholder group were developed with input from researchers and the two panels of experts by experience. The two panels guided the analytic approach and participated actively in the interpretation of qualitative findings.

### Participants

In total, 14 triads (40 participants in total) were recruited comprising of an adult with mild/moderate intellectual disability with a history of aggressive challenging behaviour who had received treatment for their behaviours, their carer (paid and/or family), and a health or social care professional involved in their care. We interviewed triads of participants

to explore in more depth and from multiple perspectives the convergence and divergence of opinions about the reduction in aggressive challenging behaviour in adults with intellectual disabilities following delivery of a psychosocial intervention. Participants were recruited via social care professionals from seven NHS community intellectual disability services across the UK (*i.e.*, England, Scotland, and Northern Ireland) covering both urban and rural areas. Social care professionals received verbal assent from adults with mild/moderate intellectual disability with a history of aggressive challenging behaviour who had received treatment for their behaviours and their carer (paid and/or family) to be contacted by a researcher to receive detailed information about the study over email, phone or videoconference due to COVID-19 lockdown restrictions. Purposive sampling aimed to achieve participant variation in age, work experience, gender, professional background, and carer roles.

Adults with intellectual disabilities were included if they: 1) had mild or moderate intellectual disability based on service records from the community team; 2) were aged 18 years or over; 3) had received a psychosocial intervention known to reduce challenging behaviour where aggression was the main feature such as verbal or physical aggression to people and/or property; 4) were able to speak English; and 5) provided consent to take part in the study. Carers were included if they: 1) were either a paid or family carer who was well informed of the person's care plan; 2) were aged over 18 years; 3) able to speak English; and 4) provided consent to take part in the study. Health and social care professionals were included if they: 1) were aged 18 years or over; 2) had been involved in the care of the person with intellectual disability; and 3) provided consent to take part in the study. Exclusion criteria for adults with intellectual disabilities included: 1) severe intellectual disability; 2) insufficient verbal ability to take part in the interview; 3) lack of mental capacity to consent. There were no further exclusion criteria for carers and health and social care professionals.

### Ethics statement

Recruitment took place between November 2020 and May 2021 which included the period of the second COVID-19 lockdown in the three UK countries (England, Scotland, and Northern Ireland). Verbal audio-recorded informed consent was obtained from all participants which was then transferred to a paper form, as due to COVID-19 lockdown restrictions, we conducted interviews remotely (*e.g.*, Zoom, Microsoft Teams, telephone calls). The study received NHS Health Research Authority approval from the East of England – Essex Research Ethics Committee (20/EE/0211).

### Procedure

Topic guides covered a broad range of topics including views about the nature of the participant's behaviour, type, and experience of support they had received, positive and negative aspects of care and intervention received (Kouroupa *et al.*, 2023). Adults with intellectual disability gave the research team permission to contact their carer (*e.g.*, family

and/or paid) and a health and social care professional involved in their care from the local community intellectual disability team (*e.g.*, psychologists, psychiatrist, nurses). Researchers were experienced users of the online communication platforms (*i.e.*, Zoom, Microsoft Teams). The mean duration of interviews was 45 minutes ranging from 18–97 minutes.

### Data coding and analysis

Interviews were audio-recorded and transcribed verbatim by an external sponsor approved agency. All identifiable information was removed. Data were analysed using the framework method for thematic analysis of interview transcripts (Braun & Clarke, 2006; Gale *et al.*, 2013; Ritchie *et al.*, 2013). The framework method enabled the open, critical, and reflexive comparison and contrast of data from each triadic group to be compared across themes (Gale *et al.*, 2013). Data from each participant group was initially analysed separately using NVivo software (version 11). Other qualitative data analysis software with similar functionalities may be used. Following review of the emerging themes and convergence of opinions from all stakeholder groups, themes are presented together. The process included: 1) data familiarisation; 2) identifying themes; 3) indexing of themes; 4) charting and summarising data; 5) interpreting and mapping data; 6) compiling this report. Three researchers (LH, AA, and AR) independently familiarised themselves with five transcripts to develop the initial coding frame for each participant group which was used to code the remaining transcripts. Codes were refined into broader categories (*e.g.*, themes) to systematically explore convergence and divergence across the entire dataset and to develop themes related to facilitators and barriers.

### Results

We interviewed 14 adults with intellectual disabilities aged 19–47 years (Mean=33 years old; SD=10). Adults with intellectual disabilities had other neurodevelopmental (*e.g.*, autism, attention deficit hyperactivity disorder) and/or mental health conditions (*e.g.*, schizophrenia, bipolar disorder, anxiety, depression, obsessive compulsive disorder). Just over half of the adults (n=8) were residing in supported living accommodation the others were residing in some form of supported living/residential accommodation. In total, 13 carers took part in interviews most of whom were female (n=11). The mean age of carers was 53 years old (SD=9; range: 41–64 years old). Finally, 13 professionals with a mean of 16 years of employment post-qualification at a community intellectual disability service participated in the study. One paid carer and one health and social care professional participated in two triads each. Details of each triad are presented in Table 1, Table 2 and Table 3.

The most common psychosocial interventions reported by all stakeholders were Positive Behaviour Support (n=7), Cognitive Behaviour Therapy (n=5) and Dialectical Behaviour

**Table 1. Socio-demographic characteristics of adults with intellectual disability.**

Characteristics	Adult with intellectual disability (n=14)
Age in years	
Mean (SD), range	33 (10), 19–47
Gender	
Male	10
Female	4
Accommodation	
Family home	6
Supported living	8
Number of additional diagnoses	
Mean (SD), range per person	2.07 (0.75), 1–3
Mental health problems ( <i>e.g.</i> , anxiety, depression, bipolar, OCD <sup>†</sup> )	13
Neurodevelopmental conditions ( <i>e.g.</i> , autism, ADHD <sup>‡</sup> )	9

<sup>†</sup>OCD: Obsessive Compulsive Disorder; <sup>‡</sup>ADHD: Attention Deficit Hyperactivity Disorder

**Table 2. Socio-demographic characteristics of carers.**

Characteristics	Carers (n=13)
Age in years	
Mean (SD), range	53 (9), 41 – 64
Gender	
Male	2
Female	11
Carer type	
Family carer	6
Paid carer	7

Therapy (n=2). Only one person had received all three psychosocial interventions.

The coding framework was organised into two main domains relating to facilitators of and barriers to positive change (*i.e.*, reduction in aggressive challenging behaviour) (see Figure 1).

**Table 3. Socio-demographic characteristics of professionals.**

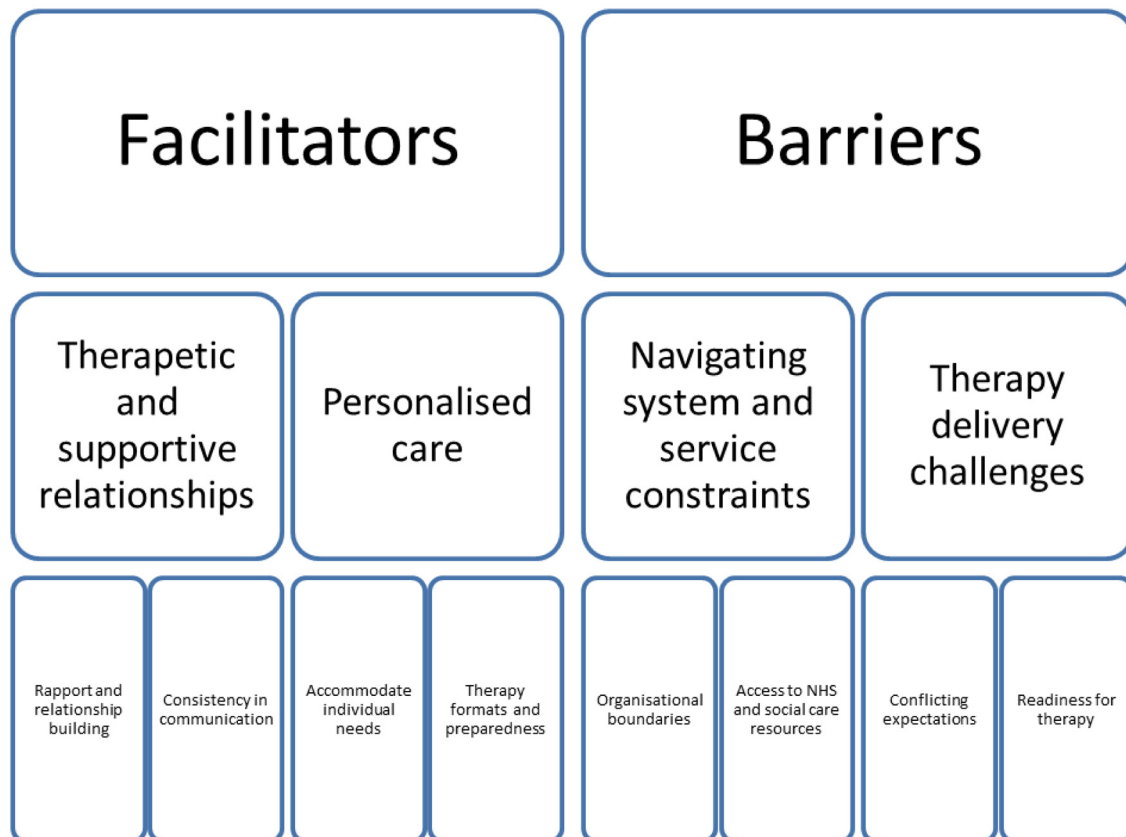
Characteristics	Professionals (n=13)
Gender	
Male	6
Female	7
Professional expertise	
Psychology	5
Psychiatry	2
Nursing	3
Social Work	3
Years of experience in intellectual disability	
Mean (SD), range	15.7 (15.0), 2–43

Facilitators of positive change following delivery of a psychosocial intervention for aggressive challenging behaviour

Therapeutic and supportive relationships and personalised care were the two main themes reported as having significant influence as to whether psychosocial interventions in adults with intellectual disabilities led to reduction in aggressive challenging behaviour (Kouroupa *et al.*, 2023). All stakeholders shared common views on the important components that lead to positive change in adults with intellectual disabilities.

**Theme 1: Therapeutic and supportive relationships**

The term therapeutic and supportive relationships refer to the therapeutic alliance of carers (*e.g.*, family and paid) and adults with intellectual disabilities with health and social care professionals and the broader supportive relationships of carers (*e.g.*, family and paid) with adults with intellectual disabilities.



**Figure 1. Summary of coding framework.**

### *Rapport and relationship building*

Developing a close and trusting relationship among all parties was important to all stakeholders. Professionals acknowledged that active listening to the person with intellectual disability and their carers (*e.g.*, paid or family) facilitated better engagement in the intervention.

“The best treatment was the rapport...it took a few times to develop...If you press the right buttons...you need to have the confidence of the patient... Listening to them is very important. Initially he would not engage much, but once he built a rapport with us, then he was keen... more motivated to attend...It is a slow process.” (700014 – Professional)

People with intellectual disabilities and family carers emphasised the importance of the therapist’s positive interpersonal skills which motivated them to attend the sessions.

“They’re funny, they’re kind. They’re enthusiastic, they’re lovely. They help me to do things that I’ve never done before.” (1100011 – Adult with intellectual disability)

Both adults with intellectual disabilities and family carers described how feeling genuinely listened to by professionals was important in developing trust and highly valued if they were to engage in an intervention.

“That she [therapist] understood what I was saying. She’d [therapist] give examples how to help and that... Willing to talk about it and not just shutting it off.” (800021 – Adult with intellectual disability)

“... they’ve all really taken onboard what the difficulties are for [1100011], and for us as well. I really genuinely feel that just being listened to has made a huge difference.” (1100012 – Family carer)

Past negative experiences such as not being able to access services, care pauses or discontinuation and/or distrust of professionals appeared to influence current contacts with professionals as reported by both carers, particularly family carers, and adults with intellectual disabilities. Therefore, setting new expectations can also be beneficial in forming new positive contact.

“...I have managed to establish a positive relationship with mum... that has been really important because it would have been really easy to disengage from the family because mum, she doesn’t trust us. It would have been very easy for her, if we hadn’t been very careful in the way we had set things up around them, to disengage.” (800024 – Professional)

“I don’t tell anybody unless I trust them [therapists]...if it’s a new member of staff, I clam up...because I’ve been hurt that many times.” (400011 – Adult with intellectual disability)

Finally, the motivation of the adult with intellectual disability was a crucial enabling factor in promoting engagement in therapy.

“[800011]’s attitude to the therapy was brilliant. He really wanted to engage with it. There was a real desire to make changes...he was sort of a dream client really...as a credit to him he was so keen to come along and change.” (800014 – Professional)

### *Consistency in communication*

Professionals focused on the role of carers (*i.e.*, family or paid) as agents for intervention delivery and success.

“Having a small predictable support staff team was really vital...they had fewer people coming and going and he built a better relationship with them...they weren’t constantly revolving; they were a stable team which is really fantastic.” (800014 – Professional)

Professionals valued working with family carers and adults with intellectual disabilities to achieve a reduction in aggressive challenging behaviour and improve quality of life. Agreed care plans informed through discussions with both family carers and the person with intellectual disability led to a collaborative approach that increased confidence in the support network of a positive outcome.

“The best training possibly that we’ve had was actually family, was informal training for his mum and his sister. So, we linked in with the family, with the health professionals, with their own internal training. So, it was quite comprehensive across the board.” (1100024 – Professional)

“She understood what I was saying. She’d give examples how to help and that...Willing to talk about it and not just shutting it off.” (800021 – Adult with intellectual disability)

In addition, professionals highlighted the value of accessing support from colleagues when dealing with complex cases as sustaining improvements and optimism.

“We’re all based in one building, we communicate any time we want about any matters, and we have regular meetings...we pass on information quickly and discuss matters, support each other, joint visits...It is a group effort, it’s not, I do one thing. We all know what each other is doing and we do seek advice from each other.” (200024 – Professional)

Similarly, paid carers acknowledged the value of professional input when working with multiple individuals with complex needs.

“...We would have struggled without the support. Sometimes it just takes a fresh set of eyes coming in to



see what we're doing, reviewing the paperwork, and trying to make suggestions of what we could potentially try and do to improve it..." (1200013 – Paid carer)

Family and paid carers focused on the importance of effective information sharing between professionals and carers to ensure a consistent approach is implemented across different contexts.

"... Everybody singing from the same hymn sheet. I have spoken to all the staff that works with [1100021] and I have made it very clear to them. You all need to be doing the same thing. It doesn't work with [1100021] if somebody is doing one thing and somebody is doing another." (1100022 – Family carer)

"They are very involved, and then even in going to the meetings and that...it won't be just, like, the same member of staff or the same team. It'll be someone else will go so they understand exactly what goes into getting the care plan up and what the person actually needs...make sure that people understand why we're doing things." (200023 – Paid carer)

One family carer highlighted the importance of anticipating problems and ensuring that contingencies are built into treatment plans to help at times of transition. Such times can be unsettling and may lead to incidents of aggressive challenging behaviour in adults with intellectual disabilities.

"I would say the psychiatrist has been the most helpful... She seems very proactive in helping him and treating him. So, she's putting in a...positive behaviour plan... She's instrumental in getting that all organised for his move...I know that I can email or phone her if I'm worried about anything." (1100012 – Family carer)

Finally, professionals recognised the vital role of family and/or paid carers in supporting intervention attendance (e.g., organising and taking them to appointments) and practicing and implementing strategies in multiple contexts to maximise therapeutic gains.

"And having [carer] there consistently was really helpful. They had a really good work relationship, and she was able to continue that work outside and remind him of the stuff that we'd discussed. He'd always leave with homework...it was something that he practiced quite a lot, so he'd done really well to engage with that process. The support staff had been vital in supporting him to access that and reminding him that it would be helpful" (800014 – Professional)

### **Theme 2: Personalised care**

Personalised care is defined as "supporting people with intellectual disabilities to build a lifestyle based on choices, preferences, shared power, rights and inclusion" (Ratti *et al.*, 2016).

### **Accommodate individual needs**

Professionals believed that focusing on the strengths and interests of the person with intellectual disabilities would facilitate engagement with the intervention.

"...my intervention has included now input from the Imam to work with him towards expressing himself, doing his prayers, but with reasonable adjustments...he would struggle with doing prayers five times a day, but he has this conflict that he's not doing that. He's very good with computers, he really engages well with computers, so the Imam...has sent him a digital Quran to work with ...the support worker who's also the same faith supports him in the prayers..." (200014 – Professional)

Adults with intellectual disabilities and family carers described the use of visual material or other aids (*i.e.*, easy read booklets, 'traffic light' system) as helpful in understanding the behavioural strategies employed by professionals which in turn maintained the individual's engagement.

"And the stickers to put on your door, I had all the stickers, red, green and amber...Red's stop and green for go...Yes, green was always good...That can help me." (200021 – Adult with intellectual disability)

Professionals reported that other factors such as humour may also improve engagement in a therapeutic conversation.

"...humour is a really good way to get [100021] engaged and positive, away from the negative... [100021]'s a big [football team] fan...he loves talking about that... that's a really good way of coaxing [100021]." (1100024 – Professional)

Finally, adults with intellectual disability and professionals reported that the choice of words play a significant role in people's engagement with services.

"Yes, I don't like when some people say loads of words that can trigger me. But she [health and social care professional] was nice" (700011 – Adult with intellectual disability)

"He did mention...Psychology. I think he said, no and then with the behaviour support plan and all that, he sort of accepted, because the word Psychology is not there." (200024 – Professional)

### **Therapy formats and preparedness**

The frequency and format of the intervention received were also seen as potential points for reasonable adjustments to maximise engagement in therapy.

"...there was a social element to the DBT...she was going along as part of a group. she enjoyed meeting new people, although it was difficult to begin with. Once she was established in the group, she enjoyed the

company. She enjoyed the social element of that there. And then they could have a chat afterwards.” (1200014 – Professional)

“Wouldn't do well in group therapy... he wouldn't be able to concentrate, and also, he probably wouldn't open us as much as he can do when it's a one to one. Other staff members have to interpret it a little bit different if you're in a group therapy you don't upset your carer when you're doing it in front of everybody, because otherwise he'd feel that you're being put down in front of people and there's all those massive impacts on them.” (800013 – Paid carer)

Family carers mentioned that it was helpful for them to be present during sessions to assist with communication and help to reassure the person.

“That's why I think it'd be handy if I'm there as well. So, if I do find that it needs to be broken down, I can break it down. Because I'm used to how my kind of language with him works, than somebody else who's mainstream doesn't.” (100032 – Family carer)

### Barriers to positive change following delivery of a psychosocial intervention for aggressive challenging behaviour

Professionals, family carers and, less commonly, adults with intellectual disabilities focused on the problematic aspects at an operational level that impeded access to psychosocial support for aggressive challenging behaviour in adults with intellectual disabilities. The two main themes reported as a barrier were navigating through the system and service constraints and therapy delivery challenges.

#### **Theme 1: Navigating system and service constraints** *Organisational boundaries*

Professionals raised the issue of eligibility criteria to access certain services (*e.g.*, Improving Access to Psychological Services; IAPT) stemming from having or not having a confirmed diagnosis of intellectual disability.

“... We came across the IAPT\* service...unfortunately because he has got a label attached to a learning disability, he was not accepted.” (700014 – Professional)

\*IAPT: Improving Access to Psychological Therapy

In addition, there were issues with mainstream mental health services not being able to adapt interventions for adults with intellectual disabilities. Professionals within IAPT services were perceived as having preconceived ideas about psychological interventions like CBT not being a suitable approach for people with intellectual disabilities who display aggressive challenging behaviour.

“Yes, resources are always short, isn't it? If he had a CBT therapist, people within IAPT, they don't think

he can do CBT...but I have done that model and I have found that he was going home, and he was maintaining the diary and he was coming back and talking about, there are alternative options.” (700014 –Professional)

Furthermore, professionals emphasised the difficulty in accessing clinic space to arrange sessions with adults with intellectual disabilities and/or carers.

“I wish we'd have had more access to facilities. I think part of the issue with the work that we did was with wanting to be consistent in terms of time and place. That can sometimes be a challenge. We don't have... access to those clinic rooms...We shared them with the social services department...Having access to...an appropriate space would have been very helpful.” (800014 – Professional)

Finally, professionals and family carers reported lack of clarity around “whose job is this” to address aggressive challenging behaviour in adults with intellectual disabilities.

“...it's just this really pervasive attitude...who's taking responsibility for it? Is it psychology? Is it nursing that was picked up by nursing who just sent it back to me... I'm a psychiatrist. It's usually not my job to provide ...” (1100014 –Professional)

“...I don't mean to sound like I'm against everybody, but I just honestly do believe so many people failed him.” (700012 – Family carer)

#### *Access to NHS and social care resources*

All stakeholders highlighted that service gaps (*i.e.*, shortage of certain professions, *e.g.*, psychologists and nurses leading to long waiting lists for psychological support) in community intellectual disability services across different areas not only limit access to appropriate psychosocial interventions to address aggressive challenging behaviour in adults with intellectual disabilities but also likely to lead to potentially adverse consequences for the person with intellectual disability.

“This social worker...the things she's promised like community transport, respite. She's promised me to find out about clubs in the area, day centres...counselling... family therapy and all that lot? We've never heard of them.” (800022 – Family carer)

“I would love to...I'm still waiting...I just need that talking therapy. When's it going to come? When it's too late? ...What do they want me to do?” (100041 –Adult with intellectual disability)

“Sadly, one of the things that I didn't think we could offer, and it would have been...more helpful would have been family therapy. We used to have a family therapy service in [Town]. But that is not available now.” (800024 – Professional)

Similar issues apply to family carers who often need access to specialist support for themselves. However, such services are either unavailable or difficult to access due to other commitments.

“...no one’s suggested anything, or offered me anything...any support for myself, mental health” (100032 – Family carer)

“I am registered with the carers where they do offer things like mindfulness and massage and things like that which is super, but they are all during the day which I can’t go to because I work.” (110022 – Family carer)

In addition, inadequate paid carer support and high staff turnover in provider services is a fundamental problem in social care. As a result, repeated training of newly appointed staff is seen as additional burden which impacts the care of those individuals already referred for intervention.

“Staffing can be an ongoing issue really...Logistics and people calling in sick and new staff arriving that don’t know the care plans. That is an ongoing challenge.” (400014 – Professional)

## **Theme 2: Therapy delivery challenges**

### *Conflicting expectations*

Professionals and family carers commented on the mismatch of what community intellectual disability services consider appropriate support to address aggressive challenging behaviour in adults with intellectual disabilities and service users’ expectations about access to support.

“... it’s not through lack of trying. I’ve just had the second referral for specialist psychology refused...he’s been consistent in saying he wants psychology input, and unfortunately, he’s not meeting the criteria for them to accept him because of his level of alcohol abuse and intoxication, they don’t believe that he’s in a place where he’s willing to buy into therapy and engage with it ... There are some system failings...there are also some rigid criteria that he failed to meet which is inflexible.” (400014 – Professional)

“They get the psychologist involved when things were really difficult...Unfortunately, it tended to be short bursts he would get...he would see a psychologist for maybe two or three months and then they would back off. Then when things got tough again, they would say oh, we will re-refer him. Then we had to go through the whole process all over again.” (100022 – Family carer)

Similarly, professionals emphasised that there are some carers who seek a ‘quick fix’ and become pessimistic when aggressive challenging behaviour persists often in the face of multiple cycles of an intervention.

“...she doesn’t consider that things have changed that much...I think her expectation is that she’s suddenly going to change completely.” (800024 – Professional)

### *Readiness for therapy*

Professionals reported that it is often the case that carers find it challenging to implement the strategies suggested in the PBS plan consistently with adults with intellectual disabilities, therefore, aggressive challenging behaviours may be maintained. Regardless of the support and/or training provided, some individuals have additional needs which affect the care that is provided if not tailored to the specific individual needs.

“Although we tried to support the family to implement some of these strategies at home this has been very hard due to her father’s learning disabilities and her mother’s mental health issues. It’s difficult for them to process this information...his parents were not able to implement any recommendations that were being made to them. There are some also language barriers.” (100024 – Professional)

“They don’t help me. [Psychiatrist] might say, do this and do that. I forgot what she even said to me.” (100041 – Adult with intellectual disability)

Professional disagreements were also mentioned as potentially contributing to tensions in care planning, but such situations may not always be destructive if there is open communication between parties.

“There are disagreements all the time... you have to disagree to agree at some points and see where things are going.” (200031 – Paid carer)

Finally, professionals and paid carers highlighted that adults with intellectual disabilities may not always be ‘ready’ to engage in therapy due to a mental health condition.

“...but at times of crisis she really struggled with actually engaging in them...if you were to prompt...she’ll just look at you, but her eyes will be really wide...she can’t even process and there is a cognitive delay from one of the previous overdoses that she had taken...” (1200013 – Paid carer)

## **Discussion**

This study illustrates the complexities of achieving positive outcomes following psychosocial interventions for aggressive challenging behaviour in adults with intellectual disabilities. Triads of stakeholders described the value of developing relationships and connecting with carers (*e.g.*, family or paid) and/or adults with intellectual disabilities. All stakeholders valued the importance of developing care plans with carers (*e.g.*, family or paid) and adults with intellectual disabilities, collaborating with other professionals, where needed, and monitoring during the implementation of care plans. Similarly, all stakeholders acknowledged the value of accommodating the needs of the person with intellectual disability in a session and making multiple adjustments to improve the experience of therapy. Nonetheless, all stakeholders identified problematic areas including access to and navigation through services and/or different views about the nature and limits of psychosocial interventions.

Our findings indicate that stakeholders across all NHS sites across the UK shared broadly similar views about the facilitators and barriers of addressing aggressive challenging behaviour in adults with intellectual disabilities. Some issues were more pertinent to people with intellectual disabilities and less so to carers or professionals and *vice versa*. Those inflection points are important gaps to be addressed but also underline the mismatch of expectations between stakeholders and services and the role of dynamic relationships among all parties involved while in psychosocial intervention to fully address the complexity of aggressive challenging behaviour. A recent study showed that the expected effect size of psychosocial interventions as reported in published clinical reports was much lower than the one expected by family carers and professionals (Hassiotis *et al.*, 2022b). There is also evidence that behavioural interventions which are often first line approach for aggressive challenging behaviour may not be useful to all individuals with intellectual disabilities (Woodcock & Blackwell, 2020).

Legislation and policy encourage professionals to collaborate with carers (*e.g.*, family, paid) to complement and enhance their role in caring for vulnerable adults (NHSE, 2015a; NHSE, 2015b) which was echoed in this study. Nonetheless, little is known about the dynamic relationship of those engaging in psychosocial interventions for aggressive challenging behaviour especially when family or paid carers are recipients of aggressive incidents. When viewed in the context of our results, this might explain why stakeholders described that the format of and preparedness to access psychosocial interventions was seen as a facilitator of positive change. Besides, this study aligns with the literature that carers value working with open-minded, sensitive, and skilled professionals to better understand aggressive challenging behaviour and developing care plans around the person's needs, interests, communication abilities and preferences (Botterill *et al.*, 2019; Cameron *et al.*, 2020; Deb *et al.*, 2022; Hassiotis *et al.*, 2022a; Surley & Dagnan, 2019; Tournier *et al.*, 2022). In line with this, adults with mild/moderate intellectual disability described that aggressive challenging behaviour reduces when they experience positive relationships (Clarke *et al.*, 2019).

Deep-rooted systemic issues in community intellectual disability services that impede the implementation of psychosocial interventions for aggressive challenging behaviour included the organisational boundaries of a service (*e.g.*, clarity of roles, referral criteria, no clinic space) and resource availability. There has been extensive literature addressing these ongoing problems in the NHS, including unclear roles within the same team, strict referral criteria to specialist services for adults with intellectual disabilities that can complicate the care pathway, high staff turnover and limited access to psychosocial therapies (Brown *et al.*, 2016; Flynn *et al.*, 2018; Hassiotis *et al.*, 2022a; Marwood *et al.*, 2018). Research indicates that simplifying these procedures enhances engagement with professionals and therapy and facilitates behavioural change (Botterill *et al.*, 2019).

There is scarce data to evaluate the implementation of psychosocial interventions for aggressive challenging behaviour in adults with intellectual disabilities to compare with this work. Pre-existing research focuses on the social care failure rather than exploring the implementation of psychosocial interventions to address aggressive challenging behaviour in adults with intellectual disabilities. Interestingly, a scoping review described that family carers were involved in the development and evaluation of care plans but not in implementation (Tournier *et al.*, 2021). The input of family carers in care plans is undisputable. A consistent approach to implementing care plans across services followed by ongoing family involvement, is equally crucial to lead to a positive change. Future research should determine whether psychosocial interventions have been implemented as intended and result in the reduction of aggressive challenging behaviour in adults with intellectual disabilities in community and/or other settings. Finally, while psychoeducation of carers to better understand the presence of aggressive challenging behaviour is important, it is equally essential for professionals to establish positive relationships with family/paid carers and/or adults with intellectual disability, where possible, and discuss with sensitivity the degree of expected and desired change of these behaviours to increase motivation and engagement with services.

### Strengths and limitations

This study examines the experiences of multiple stakeholders about the perceived facilitators and barriers of delivering psychosocial interventions to address aggressive challenging behaviour in adults with intellectual disabilities across UK services. This is particularly important as current guidelines emphasise the use of non-pharmacological interventions for the management of behaviour that challenges and reducing the inappropriate prescription of psychotropic medications in adults with intellectual disabilities (Branford *et al.*, 2018; NICE 2015). This study collected a large amount of data from participants who had received psychosocial therapies for aggressive challenging behaviour. Nonetheless, the study findings do not represent the views of adults with severe intellectual disabilities who may have a very different experience of care, because almost all suitable psychosocial interventions are provided *via* proxy. In addition, the voices of adults with mild/moderate intellectual disability remain a minority compared to carers and professionals. Collecting qualitative data from a large number of stakeholders meant that analysis of the different perspectives across the triads was also limited. Recruitment in the study began in November 2020 during the COVID-19 pandemic which might have introduced selection bias. It is likely that participants with strong views on the topic or positive relationship with professionals were keen to participate in the study. There was, also, limited representation of triads from Northern Ireland and Scotland, with only one and two triads from each country, respectively. Yet, views appear to converge across participants from all three countries and the care systems for people with intellectual disabilities are broadly organised in a similar way in the three countries. Finally, we

acknowledge that this may be a limited outcome as often the emphasis is also on improving quality of life which may lead to the eventual reduction of aggressive challenging behaviour. However, the latter is the commonest reason for referral to the community intellectual disability services and many behavioural interventions are tailored to confer immediate alleviation of the risk of injury to self and/or others and to avoid other consequences such as destruction of the environment.

## Conclusion

Adults with intellectual disabilities who display aggressive challenging behaviour face numerous challenges to accessing psychosocial therapies. There is a gap in care plans being developed with input from family and/or paid carers and adults with intellectual disabilities, and the implementation of care plans in daily practice. The present study gave an overview of multiple stakeholder's experiences of the value of therapeutic and supportive relationships and personalised care in psychosocial interventions to address aggressive challenging behaviour in adults with intellectual disabilities. It also described ongoing challenges within community intellectual disability services with negative outcomes for the implementation of psychosocial interventions. Social care funding should be at the forefront of any mental health policy briefing, and this includes establishing a good network of support to carers of adults with intellectual disabilities as well as high quality and consistent support to people with intellectual disabilities. Providing this broader input is an important and often overlooked avenue of professional support and is key to improving outcomes for those who display aggressive challenging behaviour. Nonetheless, these service improvements require shared knowledge and understanding of the need to adapt interventions for adults with intellectual disabilities among NHS staff members. Regardless of the improvements in the health and social care provision for adults with intellectual disabilities over the years, there are still serious implementation barriers that likely compromise the effectiveness of psychosocial interventions. Future research

should focus on the processes and factors that facilitate high-quality and consistent support to adults with intellectual disabilities and their carers.

## Data availability

### Underlying data

Zenodo: Stakeholder views on the barriers and facilitators of psychosocial interventions to address reduction in aggressive challenging behaviour in adults with intellectual disabilities. <https://doi.org/10.5281/zenodo.8032593> (Kouroupa *et al.*, 2023).

The project contains the following underlying data:

- Interview Transcripts.zip

### Extended data

Zenodo: Stakeholder views on the barriers and facilitators of psychosocial interventions to address reduction in aggressive challenging behaviour in adults with intellectual disabilities. <https://doi.org/10.5281/zenodo.8032593> (Kouroupa *et al.*, 2023).

The project contains the following extended data:

- Study\_Topic\_Guides.zip

Data are available under the terms of the [Creative Commons Attribution 4.0 International license \(CC-BY 4.0\)](https://creativecommons.org/licenses/by/4.0/).

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## References

- Bosco A, Paulauskaite L, Hall I, *et al.*: **Process evaluation of a randomised controlled trial of PBS-based staff training for challenging behaviour in adults with intellectual disability.** *PLoS One.* 2019; **14**(8): e0221507.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Botterill S, Cottam S, Fowke A, *et al.*: **"It put control back onto my family situation": family experiences of positive behaviour support.** *Adv Ment Health Intellect Disabil.* 2019; **13**(3-4): 91-101.  
[Publisher Full Text](#)
- Bowring DL, Totsika V, Hastings RP, *et al.*: **Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study.** *J Intellect Disabil Res.* 2017; **61**(6): 604-617.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Branford D, Gerrard D, Saleem N, *et al.*: **Stopping over-medication of people with intellectual disability, autism or both (STOMP) in England part 1-history and background of STOMP.** *Adv Ment Health Intellect Disabil.* 2018; **13**(1): 31-40.  
[Publisher Full Text](#)
- Braun V, Clarke V: **Using thematic analysis in psychology.** *Qual Res Psychol.* 2006; **3**(2): 77-101.  
[Publisher Full Text](#)
- Brown JF, Brown MZ, Dibasio P: **Treating Individuals With Intellectual Disabilities and Challenging Behaviors With Adapted Dialectical Behavior Therapy.** *J Ment Health Res Intellect Disabil.* 2013; **6**(4): 280-303.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Brown M, Chouliara Z, MacArthur J, *et al.*: **The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care.** *J Clin Nurs.* 2016; **25**(7-8): 972-982.  
[PubMed Abstract](#) | [Publisher Full Text](#)

- Browne C, Smith IC: **Psychological interventions for anger and aggression in people with intellectual disabilities in forensic services.** *Aggress Violent Behav.* 2018; **39**: 1–14.  
[Publisher Full Text](#)
- Cameron S, Swanton J, Dagnan D: **Conceptualising the therapeutic alliance: exploring the relevance of Bordin's model for adults with intellectual disabilities.** *Adv Ment Health Intellect Disabil.* 2020; **14**(5): 169–179.  
[Publisher Full Text](#)
- Clarke A, Dagnan D, Smith IC: **How service-users with intellectual disabilities understand challenging behaviour and approaches to managing it.** *J Appl Res Intellect Disabil.* 2019; **32**(5): 1203–1215.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Clark LL, Lekkai F, Murphy A, et al.: **The use of positive behaviour support plans in mental health inpatient care: A mixed methods study.** *J Psychiatr Ment Health Nurs.* 2020; **27**(2): 140–150.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Deb S, Bethea TC, Havercamp SM, et al.: **Disruptive, impulse-control, and conduct disorders.** In: *Diagnostic manual- Intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability.* 2016.
- Deb S, Limbu B, Unwin G, et al.: **Causes of and alternatives to medication for behaviours that challenge in people with intellectual disabilities: direct care providers' perspectives.** *Int J Environ Res Public Health.* 2022; **19**(16): 9988.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Flynn S, Totsika V, Hastings RP, et al.: **Effectiveness of Active Support for adults with intellectual disability in residential settings: Systematic review and meta-analysis.** *J Appl Res Intellect Disabil.* 2018; **31**(6): 983–998.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Gale NK, Heath G, Cameron E, et al.: **Using the framework method for the analysis of qualitative data in multi-disciplinary health research.** *BMC Med Res Methodol.* 2013; **13**(1): 117.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Gustafsson C, Öjehagen A, Hansson L, et al.: **Effects of psychosocial interventions for people with intellectual disabilities and mental health problems: A survey of systematic reviews.** *Res Soc Work Pract.* 2009; **19**(3): 281–290.  
[Publisher Full Text](#)
- Hassiotis A, Kouroupa A, Hamza L, et al.: **Intensive support teams for adults with intellectual disabilities displaying challenging behaviour: the IST-ID mixed-methods study.** *Health and Social Care Delivery Research.* 2022a; **10**(33): 1–106.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Hassiotis A, Melville C, Jahoda A, et al.: **Estimation of the minimal clinically important difference on the Aberrant Behaviour Checklist-Irritability (ABC-I) for people with intellectual disabilities who display aggressive challenging behaviour: A triangulated approach.** *Res Dev Disabil.* 2022b; **124**: 104202.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Karger G, Davies B, Hare DJ: **The perception of positive behavioural support: A systematic review.** *International journal of positive behavioural support.* 2018; **8**(2): 16–32.  
[Reference Source](#)
- Knotter MH, Spruit A, De Swart JJ, et al.: **Training direct care staff working with persons with intellectual disabilities and challenging behaviour: A meta-analytic review study.** *Aggress Violent Behav.* 2018; **40**: 60–72.  
[Publisher Full Text](#)
- Kouroupa A, Hassiotis A, Hamza L, et al.: **Stakeholder perspectives on intensive support teams for adults with intellectual disabilities who display behaviour that challenges in England.** *J Appl Res Intellect Disabil.* 2023; **1**–12.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Marwood H, Chinn D, Gannon K, et al.: **The experiences of high intensity therapists delivering cognitive behavioural therapy to people with intellectual disabilities.** *J Appl Res Intellect Disabil.* 2018; **31**(1): 76–86.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- National Institute for Health and Clinical Excellence [NICE]: **Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges.** NG11, 2015; Retrieved January 13, 2023.  
[Reference Source](#)
- NHS England (NHSEa): **Building the Right Support: A National Plan to Develop Community Services and Close Inpatient Facilities for People with a Learning Disability and/or Autism Who Display Behaviour that Challenges, Including Those with a Mental Health Condition.** 2015; (accessed August 2022).  
[Reference Source](#)
- NHS England (NHSEb): **Building the Right Support: Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.** 2015; (accessed August 2022).  
[Reference Source](#)
- O'Dwyer C, McCallion P, Burke É, et al.: **Prevalence and associated factors of problem behaviours among older adults with intellectual disabilities in Ireland.** *Res Dev Disabil.* 2018; **80**: 192–204.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Ramsden S, Tickle A, Dawson DL, et al.: **Perceived barriers and facilitators to positive therapeutic change for people with intellectual disabilities: Client, carer and clinical psychologist perspectives.** *J Intellect Disabil.* 2016; **20**(3): 241–262.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Ritchie J, Lewis J, Nicholls CM, et al.: **Qualitative research practice: A guide for social science students and researchers.** SAGE, 2013.  
[Reference Source](#)
- Ratti V, Hassiotis A, Crabtree J, et al.: **The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review.** *Res Dev Disabil.* 2016; **57**: 63–84.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Singh NN, Lancioni GE, Karazsia BT, et al.: **Effectiveness of caregiver training in Mindfulness-Based Positive Behavior Support (MBPBS) vs. Training-as-Usual (TAU): A randomized controlled trial.** *Front Psychol.* 2016; **7**: 1549.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Singh NN, Lancioni GE, Karazsia BT, et al.: **Mindfulness-Based Treatment of Aggression in Individuals with Mild Intellectual Disabilities: A Waiting List Control Study.** *Mindfulness.* 2013; **4**(2): 158–167.  
[Publisher Full Text](#)
- Singh NN, Lancioni GE, Medvedev ON, et al.: **Comparative Effectiveness of Caregiver Training in Mindfulness-Based Positive Behavior Support (MBPBS) and Positive Behavior Support (PBS) in a Randomized Controlled Trial.** *Mindfulness (N Y).* 2020; **11**(1): 99–111.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Stancliffe RJ, Jones E, Mansell J, et al.: **Active support: A critical review and commentary.** *J Intellect Dev Disabil.* 2008; **33**(3): 196–214.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Surley L, Dagnan D: **A review of the frequency and nature of adaptations to cognitive behavioural therapy for adults with intellectual disabilities.** *J Appl Res Intellect Disabil.* 2019; **32**(2): 219–237.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Totsika V, Toogood S, Hastings RP: **Active support: Development, evidence base, and future directions.** *Int Rev Res Ment Retard.* 2008; **35**: 205–249.  
[Publisher Full Text](#)
- Tournier T, Hendriks AHC, Jahoda A, et al.: **“Connectedness” between people with intellectual disabilities and challenging behaviour and support staff: Perceptions of psychologists and support staff.** *J Intellect Disabil.* 2022; **27**(1): 121–137.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Tournier T, Wolkorte R, Hendriks AH, et al.: **Family involvement in person-centered approaches for people with intellectual disabilities and challenging behaviors: A scoping review.** *J Ment Health Res Intellect Disabil.* 2021; **14**(4): 349–374.  
[Publisher Full Text](#)
- van den Bogaard KJ, Nijman HL, Palmstierna T, et al.: **Characteristics of aggressive behavior in people with mild to borderline intellectual disability and co-occurring psychopathology.** *J Ment Health Res Intellect Disabil.* 2018; **11**(2): 124–142.  
[Publisher Full Text](#)
- Vereenoghe L, Langdon PE: **Psychological therapies for people with intellectual disabilities: A systematic review and meta-analysis.** *Res Dev Disabil.* 2013; **34**(11): 4085–4102.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Woodcock KA, Blackwell S: **Psychological treatment strategies for challenging behaviours in neurodevelopmental disorders: what lies beyond a purely behavioural approach?** *Curr Opin Psychiatry.* 2020; **33**(2): 92–109.  
[PubMed Abstract](#) | [Publisher Full Text](#)

# Open Peer Review

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## Version 1

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### Karl Nunkoosing

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### Mark Haydon-Laurelut

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**Reviewer: Karl Nunkoosing, Principal Lecturer, Dept. of Psychology, University of Portsmouth.**

**Title: Stakeholder views on the barriers and facilitators of psychosocial interventions to address reduction in aggressive challenging behaviour in adults with intellectual disabilities**

The aggressive challenging behaviours by some persons with intellectual disabilities make life difficult for the learning disabled men and women and their carers and partners. This phenomena also occupies considerable time, effort and concerns of care and therapeutic professionals. It is good to read about a research that is inclusive of all 3 stake holders. The interviews with members of the triad which includes the person with LD and CB, their carer and professional therapist or physician is a worthy extension of the study by Ramsden *et al* (2016)<sup>1</sup>. This inclusive design stands out as a worthy example of research that merits wider application in intellectual disability research generally and in evaluation research particularly. This work is an example of 'doing research with people' rather than 'doing research on people'.

There are two types of readers for this research, psychosocial clinicians and researchers. The former will find much that constitute evidence about how to ensure that their interventions (not exclusively about aggressive challenging behaviours) lead to successful outcomes as well as practices that are barriers to enhancing the quality of life of intellectually disabled persons. However researchers are likely to have questions that require additional attention.

Whilst I understand that a report such as this cannot attend to everything, attention to the following would add to the validity and replicability of this important work:

1. More information about how and where the interviews were conducted. It appears that the participants were interviewed individually. The discussion could take up the issue about the

potential worth of interviewing the members of the triad together. Inevitably there are issues of research ethics that will influence such design decision.

2. The topics of the semi-structured interviews that were obtained from the 'expert by experience' as well as the researchers from their review of research examined in the introduction of the report.
3. Whilst the method described here is in keeping with the deductive method of Framework Thematic Analysis, this does raise issues that need attention in the discussion or limitation of the study. What were the criteria for selecting the 5 transcripts that provided the initial coding of the data? How did these 5 transcripts represent the 3 types of stake holders? I am of the view that this procedure merits further justification. When one looks for certain code in such a rich set of qualitative data, one inevitably finds what one is looking for at the risk of missing other information that may be pertinent to one's research question/s.

The interpretations of the themes are richly supported by excerpts from the interview transcripts, however when I read the excerpts from the professionals, I am intrigued to find out about their professions...

This research makes a significant contribution to knowledge about psychosocial interventions in the lives of intellectually disabled people, their carers/supporters and therapists. Its ethos of inclusivity and attention to the voices of intellectually disabled people, who are also 'experts by experience', is exemplary. Dagnan (2007)<sup>2</sup> literature review identifies psychosocial interventions as occurring at four levels. It strikes me that the discussion about 'facilitators and barriers' of such interventions, identified here, would benefit from addressing these levels. In particular it seems that some of the barriers are occurring at the social and service/organisational levels, whilst the facilitators occur at the individual or relational level.

Finally, good research evokes new research questions. Questions such as:

- What are the personal attributes of talented psychosocial therapists?
- What is the nature of the relationship between the person who experiences learning difficulties and the therapist who facilitates positive outcomes for the latter?

**Additional Review from Dr Mark Haydon-Laurelut, Senior Lecturer, Department of Psychology, University of Portsmouth**

This article explores an under researched and important area. I have a few suggestions.

A limitation to the article is the notion of 'psychosocial interventions'. The approaches described have very significant differences ranging from individual psychological therapies such as Cognitive Behaviour Therapy (CBT) to network wide behavioural assessment and planning (Positive Behaviour Support).

Please consider the rewording the following: '*Psychosocial interventions aim to meet unmet needs of adults with intellectual disabilities including housing, self-care, social and interpersonal skills, daytime activities, and housekeeping for those in family, supported or residential care homes (Gustafsson et al., 2009)*'. Therapies (for example psychological therapies such as CBT) do not routinely attempt to meet the 'housing needs' and 'housekeeping' of clients.



Additionally, discussion of for example: 'a gap in care plans being developed with input from family and/or paid carers and adults with intellectual disabilities, and the implementation of care plans in daily practice' fits clearly with some service/network approaches such as PBS and less to individual psychological therapies/psychotherapies.

Overall the very broad categorisation of psychosocial interventions works as a limitation of the research and it is suggested this could be added to the appropriate section.

The introduction notes that:

*'In addition, there is scarce understanding of how those who receive these interventions experience them and what their expectations are...'* Any studies that do exist that address this issue should be cited here.

### Methods

Further information on framework analysis would be useful as well as the advantages and disadvantages of mixed inductive and deductive analytic aspects.

### References

1. Ramsden S, Tickle A, Dawson DL, Harris S: Perceived barriers and facilitators to positive therapeutic change for people with intellectual disabilities: Client, carer and clinical psychologist perspectives. *J Intellect Disabil.* 2016; **20** (3): 241-62 [PubMed Abstract](#) | [Publisher Full Text](#)
2. Dagnan D: Psychosocial intervention for people with learning disabilities. *Advances in Mental Health and Learning Disabilities.* 2007; **1** (2): 3-7 [Publisher Full Text](#)

### Is the work clearly and accurately presented and does it cite the current literature?

Yes

### Is the study design appropriate and is the work technically sound?

Yes

### Are sufficient details of methods and analysis provided to allow replication by others?

Partly

### If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

### Are all the source data underlying the results available to ensure full reproducibility?

Yes

### Are the conclusions drawn adequately supported by the results?

Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Intellectual Disabilities and Qualitative Methodologies

**We confirm that we have read this submission and believe that we have an appropriate level**

**of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 29 August 2023

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This study explored factors affecting the success of interventions for reducing aggressive behavior in adults with intellectual disabilities. It found that strong therapeutic relationships and personalized care facilitate positive change, while differences in expectations and structural issues hinder it. To improve outcomes, operational changes like refining referral criteria and addressing workforce challenges are recommended.

The scientific literature is properly integrated and cited. However, it would be useful to better define what is meant by "psychosocial intervention" within the introduction. Indeed, this term can cover relatively broad practices and services, and insofar as the question of access and that of evidence-based practices are raised later in the discussion, it would be useful to be able to better delimit the concept and its applications.

Study design and methodological options are appropriate to the research questions. A strength of the study is the use of an inclusive research design involving panels of people with intellectual disabilities and carers in the design of the study, as well as considering the perspective of triads (people with intellectual disabilities-carer-professional).

Overall, the manuscript provides sufficient details of methods and analysis for replication. However, some missing information would appear to be relevant.

It wasn't entirely clear to me to what extent the stakeholders and/or the panel of experts by experience had been involved in analysing the data. Besides, I did not fully understand if participants were actually met once (in "triads") or did the researcher meet each stakeholder at different occasion.

Providing an overview of the interview guide would be interesting for future research.

It would be interesting to have a better idea of the relative weight of each theme and sub-theme within the analyses. In addition, the discussion mentions that certain issues were more relevant for people with intellectual disabilities than for carers or professionals, and vice versa; but the presentation of the results as they stand does not make it possible to determine in which theme or sub-themes the units of meaning linked to the discourse of people with intellectual disabilities were more or less present. This information would make it easier to understand the data.

Similarly, if relevant, it would be useful to have a perspective in relation to 'sites', as it is suggested that perspectives are consistent across these in the discussion.

**Is the work clearly and accurately presented and does it cite the current literature?**

Yes

**Is the study design appropriate and is the work technically sound?**

Yes

**Are sufficient details of methods and analysis provided to allow replication by others?**

Partly

**If applicable, is the statistical analysis and its interpretation appropriate?**

Not applicable

**Are all the source data underlying the results available to ensure full reproducibility?**

Yes

**Are the conclusions drawn adequately supported by the results?**

Yes

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** Disability studies

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

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