

# The development of a trauma informed care framework for residential services for adults with an intellectual disability: Implications for policy and practice.

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#### ORIGINAL ARTICLE

## The development of a trauma informed care framework for residential services for adults with an intellectual disability: Implications for policy and practice

Paddy McNally<sup>1</sup> | Laurence Taggart<sup>1</sup> | Mark Shevlin<sup>2</sup>

<sup>1</sup>Ulster University, Institute of Nursing and Health Science, Newtownabbey, United Kingdom, UK
<sup>2</sup>Ulster University, School of Psychology, Coleraine, UK

#### Correspondence

Paddy McNally, Ulster University, Institute of Nursing and Health Science, Shore Road, Newtownabbey, BT37 0QB, UK. Email: mcnally-p8@ulster.ac.uk

#### Abstract

Trauma informed care has become an evidenced based approach for inpatient and residential services for people in the general population who are likely to have been impacted by trauma. Given the increased vulnerability to psychological trauma for adults with an intellectual disability, it should follow that residential services for adults with an intellectual disability would also benefit from a trauma informed care approach. Two focus groups and individual interviews with seven adults with an intellectual disability and six workshops with seven service providers were conducted to co-produce a trauma informed care framework for residential services that was evidence-based and guided by established models (MRC, Developing and evaluating complex interventions, London: MRC & NIHR, 2019; Wight et al., Journal of Epidemiology and Community Health, 70, 520-525, 2016). The framework was developed into four chapters: 'Setting the context'; 'Organisational change'; 'Workforce development'; and 'Trauma focussed services'. A logic model outlining the mechanisms of change was refined over the course of the co-production workshops. This is the first study to develop and co-produce a trauma informed care framework for residential and supported living accommodation for adults with an intellectual disability. The framework has implications for local policy and practice in its current cultural context. Future development is required to operationalise and test the framework and to explore its adaptability to international contexts.

#### K E Y W O R D S

co-production, intellectual disability, policy, practice, residential, trauma informed care

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Abbreviations: 6SQuID, six steps in quality intervention design; DoH, department of health; EMDR, eye movement desensitisation and reprocessing; MRC, medical research council; NICE, national institute for health and care excellence; PRISMA-ScR, preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews; SAMHSA, substance abuse and mental health services administration; TF CBT, trauma focussed cognitive behaviour therapy; WHO, world health organisation.

### INTRODUCTION

There is a developing movement for the consideration of the impact of trauma on the mental health, physical health, and social outcomes for people in the general population (Felitti & Anda, 2009; Hughes et al., 2017; Kessler et al., 2010; Larkin et al., 2014; Mongan et al., 2017; Shevlin et al., 2015). It is now widely acknowledged that most people in the general population will have some experience of trauma. For example, Kilpatrick et al. (2013) in their large American study found that 89% of their participants experienced at least one significant traumatic event in their lifetime. Prevalence rates of traumatic experiences and childhood abuse for the general population have been reported as significant for at least one in six adults (Bellis et al., 2015).

In the United States, trauma is described by the Substance Abuse and Mental Health Services Administration as

> An **event**, a series of events or set of circumstances that is **experienced** by the individual as physically or emotionally harmful or life threatening, and that has lasting adverse **effects** on the individual's functioning and mental, physical, social, emotional, or spiritual well-being. (Substance Abuse and Mental Health Administration (SAMHSA), 2014, p.7)

Circumstances are often in the context of close relationships that are difficult to escape from (Reed et al., 2016) and it should be noted that often close relationships for people with an intellectual disability include relationships with paid carers. The effects of ongoing and repeated traumatic experiences have been recognised in the ICD-11 as complex post-traumatic stress disorder (The World Health Organisation, 2018).

There is also increasing evidence that people with an intellectual disability are more vulnerable to traumatic experiences than those without an intellectual disability due to difficulties such as reduced expressive language skills, credibility of reporting, understanding that they have been violated. over-dependence on others. etc. (McGlivery, 2018) and systemic risks, such as sudden changes to living arrangements, multiple placements, bullying and losing the right to parent (British Psychological Society, 2017). More so, people with an intellectual disability have a higher frequency of exposure to trauma and abuse than others in the general population (Dion et al., 2018; Nixon et al., 2017; Spencer et al., 2005). That being said, it is also likely that not all trauma experiences of people with an intellectual disability are reported (Sullivan & Knutson, 2000). It is recognised that some trauma experiences may be different to others in the

general population and can be related to the disability itself, a reduced sense of agency and a feeling of being different (Hughes et al., 2019; McNally et al., 2021; Schepens et al., 2019).

National Institute for Health and Care Excellence guidelines on post-traumatic stress disorder in the UK (National Institute for Health and Care Excellence (NICE), 2018a) have recommended several evidencebased treatments and interventions for individuals who have been impacted by trauma, such as Eye Movement Desensitisation and Reprocessing (EMDR), Trauma Focussed Cognitive Behaviour Therapy (TF CBT), and psychotherapeutic input targeted at the general population. There is also an increasing evidence base to support effective outcomes with these approaches adapted for people with an intellectual disability, such as EMDR (Barrowcliff & Evans, 2015; Karatzias et al., 2019; Mevissen et al., 2011), TF CBT (Carrigan & Allez, 2017; Kroese et al., 2016) and general psychotherapeutic approaches (Nunez-Polo et al., 2016; O'Malley et al., 2019). Additionally, there is growing evidence of positive outcomes for organisations in services such as children's services and mental health services that adopt a trauma informed care approach (Bryson et al., 2017; Muskett, 2014) and a call for a similar service provision for people with an intellectual disability (McNally et al., 2021; Truesdale et al., 2019; Willott et al., 2019), which can incorporate the individual therapeutic approaches described above into a broader systems approach.

Keesler (2014) describes trauma informed care as a systems-focussed model for service delivery, which is a fast-growing model of service delivery in the field of trauma for the general population. The principles of trauma informed care have **safety**, **trustworthiness**, **choice**, **collaboration and empowerment** at their core (Fallot & Harris, 2001). These principles map on to other approaches in the delivery of intellectual disability services, such as person-centred care (NICE, 2018b), positive behaviour support (NICE, 2015), and valuing people (Department of Health (DOH), 2009; DOH, 2001), however trauma informed care applies the principles with a trauma lens.

SAMHSA (2014) outlines the 4Rs assumptions of trauma informed care for services as:

- Realisation—having an understanding of the widespread impact of trauma.
- Recognition—being able to recognise the signs and symptoms of trauma.
- Response—being able to respond to reduce the impact of trauma; and
- Resist retraumatisation—through organisational change.

A trauma informed care approach is increasingly being employed in mainstream children's services, mental health, and forensic services. As a result of this trauma informed care approach there are clear outcomes of reduction in restrictive practices, staff turnover, staff sickness, and improved staff wellbeing (Hales et al., 2019).

McNally et al. (2021) highlighted that current service provision focusing on behavioural approaches may not be the most appropriate approach for some adults with an intellectual disability whose behaviour presentation is mediated by trauma responses, and the approach taken could potentially be retraumatising for them. Additionally, Kildahl et al. (2020) purports that environments can become retraumatising by being reactive and restrictive rather than using appropriate supports that are proactive and supportive. Retraumatisation can occur by limiting people's opportunities for self-determination (Schepens et al., 2019) and can be underpinned by a power and trust dynamic in relationships where caregivers are in control (O'Malley et al., 2019), which is often concurrent with service models that focus on behavioural approaches. It is also important to recognise that it may be difficult to assess the impact of trauma for some adults with an intellectual disability (Kildahl et al., 2020), however providing trauma informed care is not predicated on the identification of trauma among clients or providers (Muskett, 2014).

In an international systematic review of community and inpatient care services for people with an intellectual disability, Colins and Murphy (2022) highlighted that there are risks of experiencing trauma in these settings which could be mitigated against by,

- **education** around what constitutes abuse and by promoting a sense of agency.
- ensuring good staff training and support.
- creating regular clinical supervision and reflective space for staff.
- creating an organisational culture that promotes good working conditions and collaboration across the service.

While there is increasing evidence for employing the individual therapeutic approaches to trauma for people with an intellectual disability as described above, trauma informed care has yet to be fully implemented and evaluated across the globe. Given the increased vulnerability and the relational aspects of trauma experiences, it makes sense that this should be in place for services supporting people with an intellectual disability. The development of a trauma informed care approach for residential services for adults with an intellectual disability as described in this paper followed the guidance from an international review of the literature on the implementation of trauma informed care by Bunting et al. (2019) incorporating the structure proposed by Hanson and Lang (2016) outlining the broad domains of commonality across all settings: **'organisational change'**; **'workforce development'**; and **'trauma focussed services'**. This structure was developed by considering the key messages from international frameworks implemented across children's services, health settings, educational settings, and residential settings for juvenile justice. In the development of the framework for adults with an intellectual disability it was also necessary to **'set the context'** for the need for implementation.

This is the first study to describe the process of coproducing a trauma informed care framework for residential services for adults with an intellectual disability. Having a recognised framework for implementing trauma informed care, that has the potential for international application, will help guide intellectual disability services to what the evidence-base requires for them to be more effective organisations, with trauma responsive systems and cultures.

### AIM AND OBJECTIVES

The aim of this study was to co-produce the development of a trauma informed care framework that is deliverable by staff working within residential services for adults with an intellectual disability, with key stakeholders who include people with an intellectual disability, service managers, practitioners, direct-care staff and carers.

To meet this aim there were three objectives of this study. Firstly, to explore the experience of the application of the principles aligned with trauma informed care with adults with intellectual disability living in residential settings using focus groups and individual interviews. Secondly, to co-produce the structure, content and resources of the trauma informed care framework through key stakeholder discussion and feedback, with the resultant framework to be presented in chapters reflective of the Hanson and Lang (2016) structure. And thirdly, to present and refine a logic model with key stakeholders to ensure that the trauma informed care framework can be deliverable by staff working within residential services for adults with an intellectual disability.

### METHODS

# Foundational frameworks that informed the study

This paper is the third published paper as part of a larger study to develop a trauma informed care framework Stage 1: Review of the wider literature to define and understand the problem and its causes - Scoping review 2021 Stage 2: Exploration of staff knowledge of trauma for adults with an intellectual disability - Mixed methods study 2022

Stage 3: Coproduction of trauma informed care framework with key stakeholders

Stage 4: Presentation and refinement of Logic model with key stakeholders Stage 5: Operationalise, test and refine the trauma informed care framework on a small scale Stage 6: Full testing of the framework using methods such as, cluster randomised controlled feasability study

FIGURE 1 6SQuID model for the development of a trauma informed care framework.

(McNally et al., 2021, 2022) for staff working in residential accommodation for adults with an intellectual disability, based on the Hanson and Lang (2016) structure as described above. The study follows the Medical Research Council's Guidance for Developing Complex Interventions in health and social care settings (MRC, 2019) which describes the components required for development and implementation of complex interventions applying systems change theory to real world contexts (O'Cathain et al., 2019). This study follows the initial development stage outlined in the guidance, drawing on the theoretical base, involving stakeholders in coproduction, and further increasing the likelihood of uptake with the use of a logic model for implementation change. The 6SQuID model (Wight et al., 2016) of developing a complex intervention as outlined in the 'Six steps in quality intervention development' paper was used to add a structured and robust scientific approach to the development of the framework, within the MRC guidance. The six steps have been tailored to the current study (see Figure 1).

## Stage 1: A systematic scoping review (Stage 1 of the 6SQuiD model)

A systematic scoping review was recently published by the authors (McNally et al., 2021) of what is known in the literature about psychological trauma for adults with an intellectual disability, using the Arksey and O'Malley (2005) framework and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR: Tricco et al., 2018) for conducting scoping studies. This review of the trauma literature identified and summarised the key themes emerging from the data from 41 international English language peerreviewed papers across the timeframe of 2000–2020, including papers from the US, Canada, UK, Australia, Asia and Europe. The review highlighted vulnerabilities of adults with an intellectual disability to trauma, how trauma symptoms manifest, and the lack of access to appropriate interventions offered. The authors concluded that a trauma informed care framework was an appropriate approach to consider for people with an intellectual disability.

## Stage 2: A qualitative study (Stage 2 of the 6SQuiD model)

A mixed methods study was further recently published by the authors to assess what was understood about trauma and trauma informed care for adults with an intellectual disability (McNally et al., 2022), using semistructured interviews across three distinct staff groups working in residential services for adults with an intellectual disability. This involved direct care staff, managers and specialist practitioners across Northern Ireland. The interview schedule followed the format of SAMHSA's (2014) 4Rs assumptions of trauma informed care and the data gathered from the interviews were analysed using a framework analysis, developed by Ritchie and Spencer (1994). This study demonstrated that staff had a general understanding that trauma had an impact on many of the people they worked with, but they had a limited understanding of how to assess and intervene to best support their needs. Clear barriers to the organisational approach to trauma informed care were described such as a lack of resources, high staff turnover and competing

agendas within organisations. Similar findings were echoed in other international studies (Rich et al., 2020; Truesdale et al., 2019; Yatchmenoff et al., 2017).

# Stage 3: Co-production of the framework (Stage 3 of the 6SQuiD model)

This third paper addresses Stages 3 and 4 of the 6SQuiD model in describing how the authors developed and coproduced a framework for the implementation of trauma informed care for residential services which was developed from an evidence-base (McNally et al., 2021, 2022) and in collaboration with adults with an intellectual disability and other key stakeholders.

Co-production recognises and employs the expertise of various stakeholders, going beyond developing interventions **'***for'* to developing interventions **'***with'* relevant stakeholders including service users and providers (Slay & Stevens, 2013), and it increases the likelihood of the framework being implemented within the organisational context (Voorberg et al., 2014). For this study, the key stakeholders in the co-production workshops also worked towards the development and refinement of a logic model to summarise the mechanisms of change required for the framework to be implemented. The approach used also reflects an approach consistent with trauma informed care as well as the broader philosophy of disability services.

## Stage 4: Refining the logic model (Stage 4 of the 6SQuiD model)

Logic modelling has become a recognised process to: define a problem; understand the mechanism underlying the changes required to solve the problem; and identify the processes required to produce an outcome for the individual, staff and organisation (Knowlton & Philips, 2013). Implementing complex change in social systems can be challenging and logic models are often used to map the causal processes through which interventions produce outcomes (Mills et al., 2019). There are several recent exemplars within the intellectual disability field where researchers and clinicians are using a logic model approach to address certain problems in complex systems such as challenging behaviour and Positive Behaviour Support (Scott et al., 2018) and obesity (Taggart et al., 2021).

### Design

This study involves a two-stage process. Firstly, focus groups and individual interviews were held with adults

with intellectual disability from one large voluntary organisation to establish their experiences of the principles of trauma informed care. And secondly, a series of coproduction workshops were held with key stakeholders (managers, practitioners, etc.), to develop and verify the content of the chapters of the framework, which was also guided by the experiences of adults with an intellectual disability. It is anticipated that these key stakeholders could also support the delivery of the framework once it was developed.

## Focus groups and individual interviews with adults with an intellectual disability

While the ideal for participatory research with adults with an intellectual disability would be led by people with an intellectual disability holding power and control throughout the process, the reality often falls short (Dorozenko et al., 2016). It was considered imperative however to meaningfully include the views and experiences of adults with an intellectual disability in the coproduction of the trauma informed care framework, as outlined in the Department of Health Co-production Guide (DoH, 2018). Inclusion of adults with an intellectual disability in the co-production of the framework was also important as it is reflective of the core principles of trauma informed care. For this study, in line with the principles of participation outlined in 'Nothing about us without us' (Charlton, 2000), it was deemed important that focus groups and individual interviews with adults with an intellectual disability were completed first, so that their voices fed into the co-production of the framework with other stakeholders.

Adults living in residential accommodation in the participating voluntary organisation for this part of the research were informed of the study by their organisation's independent advocate sharing and discussing an accessible participant information sheet. They were then invited to participate in the focus groups. Seven participants (five men, two women) with an intellectual disability verbally consented to participate. Participants had lived in residential accommodation for a period of time ranging from 8 years to 26 years, with an average of 18 years.

Two focus groups were arranged with the adults with intellectual disability, to be facilitated by the first author and an independent advocate from the voluntary organisation. Due to COVID-19 restrictions, contact with the participants were made using a remote platform and following the first focus group, participants requested that they move to individual interview for the second session as they struggled with the group format for discussion on

	TAB	<b>ELE 1</b> Key questions for the focus group/ $1-1$ interviews.
	1	Where you live, what helps when someone is sad/ angry or worried?
	2	Where you live, what makes you feel safe?
	3	Where you live, what are the experiences for making choices?
	4	Where you live, what are the experiences of working together?
	5	Where you live, what are the experiences of trust?
	6	Where you live, what are the experiences of empowerment?

a remote platform. One further session was arranged to provide feedback to the adults with intellectual disabilities on the themes produced and to check their validity with the participants (August—September 2021). The focus group and interviews explored the participants' experiences of the five core elements of trauma informed care: safety; choice; collaboration; trustworthiness; and empowerment (Fallot & Harris, 2001).

Participants were then asked to discuss what they liked about how residential services currently operate in relation to the core elements; what they would like to see more of; and what they would change (see Table 1).

#### Data analysis

The focus groups and the interviews were recorded, with permission, and transcribed verbatim and the transcripts were subjected to a theoretical thematic analysis (Braun & Clarke, 2013, p.175) using Braun and Clarke's (2006) framework: (1) familiarisation of the data by reading and re-reading; (2) two researchers independently applying codes to relevant data guided by the trauma informed care literature; (3) searching for the main themes within the theoretical framework; (4) review of the themes with all authors; (5) agreeing on the message conveyed within each theme; (6) and writing up the narrative around each theme. Further rigour was added by checking the validity of the themes with participants.

### Co-production workshops with key stakeholders

Participation was invited from a purposeful sample of key stakeholders: practitioners (psychologists and behaviour practitioners) (n = 4); residential and senior managers (n = 4); and direct care staff (n = 4) from three statutory organisations and the two voluntary organisations across Northern Ireland. Family members were also invited to

participate, however with no uptake. Participant information sheets were shared via each local collaborator and written consent was gained for participation in, and recording of, the workshops. With the significant impact of COVID-19 on residential services at the time of the study, it was anticipated that there would be an impact on attendance at the workshops (see limitations section). Due to COVID-19 pressures, it was extremely difficult to recruit direct care staff for this part of the study and in total, four practitioners and three managers participated in the six co-production workshops.

A series of six, 2 hour, co-production workshops took place monthly over six months (October 2021–March 2022) with managers and practitioners from these organisations across Northern Ireland, facilitated by the first author. The evidence base established from the scoping review in Stage 1 of the 6SQUID model (McNally et al., 2021), the findings from the semi-structured interviews with staff (McNally et al., 2022) in Stage 2 and the themes established from the focus groups and individual interviews with adults with an intellectual disability, were shared with the key stakeholders and referred to throughout the process.

#### Data analysis

Due to COVID-19 restrictions, the workshops were conducted using an online platform, audio recorded and transcribed verbatim. The data collected from each workshop were anonymised, summarised and the main content for each chapter from each workshop were shared at the following workshops for corroboration of their validity with the key stakeholders. The framework chapters developed from each of the workshops were continually refined and utilised to shape the trauma informed care framework (See Figure 2) and the logic model (See Figure 3).

### Ethics

The project received ethical approval from the Office for Research Ethics Committee Northern Ireland (ORECNI—IRAS no: 277539).

#### Findings

The findings from the focus groups and interviews with adults with an intellectual disability were presented in the initial co-production workshop and referred to over the six workshops, to be held in mind when developing

6

7

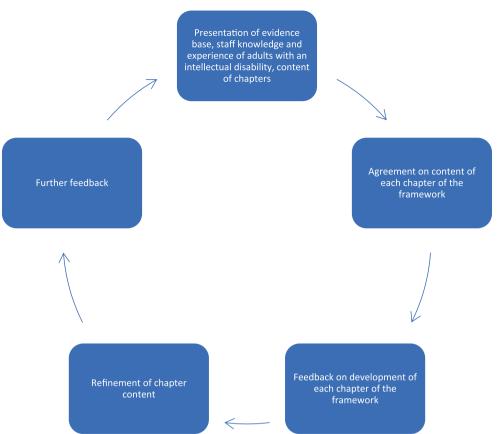


FIGURE 2 Refinement process of co-production workshops.

the content of the trauma informed care framework. The information gathered in the workshops was subsequently organised into chapters that reflected four major areas of organisational change for the implementation of trauma informed care.

# Focus groups and individual interviews with adults with intellectual disability

The description of the themes identified from the focus groups and individual interviews with adults with an intellectual disability were shared with the participants in the co-production workshops. The adults with intellectual disability were able to highlight the times when they experienced general care practices that aligned with the principles of trauma informed care but also times when they did not.

#### Theme 1: Managing emotions

The adults with intellectual disability reported on what they found helpful when they were upset. They described those **relationships they had with others** were important to help them soothe their distress, '*Staff offer a listening ear*', '*I like to see my mum*' and '*It would help if you could get counselling*'. Participants also described **keeping active** also helps, '*I get out for walks*', '*keeping busy helps*'.

The adults with intellectual disability also reported on what caused upset for them. They described that **loss of relationships** as a source of upset, '*I miss them when they go'*, '*My mum passed away'*. Additionally, they described feeling **restricted due to COVID-19** as a source of upset, '*I'm not able to do things'*, '*I can't see my family because of COVID'*.

### Theme 2: Safety

The adults with intellectual disability stated that they experienced a sense of safety when **staff were familiar with them and their needs**, '*Staff don't have to look up your support needs*' and knowing that **staff are available**, '*It's good to know that staff are there if I need them*'. They also felt safe if the **environment was safe**, '*They make sure there are no trip hazards*'.

#### Logic model for the implementation of the trauma informed care framework

CONTEXT (using the CICI framework (Pfadenhauer et al., 2017):

- Geography: Service providers in Northern Ireland providing residential and supported living accommodation for adults with an intellectual disability
- Epidemiology: Higher prevalence of trauma for adults with an intellectual disability. Presentation of trauma as depression, anxiety and behavioural manifestation
   Socio-cultural: Dominance of behavioural models of intervention and overuse of medication. Need to follow NICE Guidelines for trauma interventions (2018)
- Socio-economic: Financial costs and benefits to the implementation of a trauma informed care framework. Ethical and moral implications for ineffective treatments for trauma (medications, behavioural approaches)
- Political: Human rights approach (UN 2006). Person centred care. Lack of accessibility for adults with an intellectual disability to trauma interventions offered within the general population
- Legal: Rules and regulations have to be established to protect adults with an intellectual disability. Use of evidence-based safe interventions (NICE Guidelines 2018)

• Ethical: Ensuring the application of the principles of trauma informed care that will guide decision making within organisations.

INPUTS / RESOURCES	MECHANISMS OF CHANGE	OUTCOMES		
<ul> <li>Leadership buy-in through training and commitment to integrate trauma informed care within existing ethos /</li> </ul>	<ul> <li>Training staff at all levels and in all roles about trauma for adults with an intellectual disability</li> <li>Training of specialist staff to implement evidence-based interventions for residents</li> <li>Ensuring that training is an ongoing process of modelling practice</li> <li>Organisational policies and procedure reviewed with consideration given to the principles of trauma informed care</li> <li>Creating pathways for residents to access specialist trauma interventions are indicated</li> <li>Building in staff support structures through changes in organisation policies and procedures.</li> <li>Promotion of physically and relationally of safe environments</li> <li>Integration of trauma informed care into existing approaches and models of care, such as PBS, Person Centred Care, Physical intervention training</li> </ul>	SHORT TERM OUTCOMES (approx. 1yr)	MEDIUM TERM OUTCOMES (approx. 3-5yr)	IMPACT / SYSTEMS OUTCOMES (tipping point) (10yrs plus)
<ul> <li>frameworks of care</li> <li>Prioritising strategic goals for trauma within your organisation</li> <li>Building organisational readiness - ability to invest time and resources, while acknowledging barriers</li> <li>Funding for additional costs for organisational change</li> <li>Funding for specialist training in evidence-based interventions for specialist practitioners, such as EMDR, TF-CET, DBT.</li> </ul>		Residents - Reduction in trauma triggering events - Reduced distress - Reduced linity - Reduced injury - Red	Residents Improved quality of life Residents feel safe in their own home, with improved relational and environmental safesy Reduced traumatic stress symptoms Improved access to pecialist services and trauma interventions Increased understanding of abuse and their rights	Residents           - Continued Improvement of quality of life           - Residential placements that are resident needs led           - Increased life expectancy for residents           - Pathways for involvement in the organization
Direct care staff/ Managers/ Specialist practitioners time     Selection of TIC evidence-based models such the     Sanctuary model, Attachment, Regulation and     Competency, Sollinul models.     Trauma informed care champions / Trauma Informed     Care task force     OUTPUTS / ACTIVITIES		Staff     Increased avareness of trauma, vulnerabilities     to trauma, and recognition of the impact of     trauma for adults with an intellectual disability     Change in staff practice     Broader understanding of challenging     behaviours/ distress behaviours and mental     health.     Reduced distress     Reduced injury	Staff Better working conditions Increased job satisfaction Reduced burnout/ compassion fatigue More skilled staff working with residents who have complex trauma histories Increase in staff acceptance of trauma informed care Staff more reflective of the emotional/ relational aspects of their work.	Staff - Continued improved working conditions - Continued job satisfaction - Staff being trauma aware and trauma responsive - Valued and included as part of the organization
Trauma training to all staff     Ongoing staff support both from within organisational structures and specialist practitioners     Promotion of self-care for staff     Creating reflective space for staff		Organizations - Routine screen/ enquiry regarding trauma history for residents as common practice - Awareness and responsiveness to staff experience of trauma - Reduced behaviours that challenge services	relational aspects of their work Organizations Trauma informed care embedded in existing frameworks of care Reduced sick leave Reduced staff turnover	Organizations - Services that are trauma responsive - Reduced requirement for hospital admissions - Reduced placement breakdown
<ul> <li>Creating releases space for staff</li> <li>Screening assessments for staff within organisations</li> <li>Evidence-based interventions delivered when appropriate to residents who are impacted by trauma</li> <li>Trauma informed policies implemented</li> <li>Collaboration with key stakeholders including: residents, staff, specialist practitioners, management and family members</li> <li>Setting outcome measures for purpose of monitoring and review</li> </ul>		Availability of trauma expertise for adults with a     Competing service demands     Challenges to staff recruitment     COVID     Competing sexpectations of service provision from     Rubed demands for residential placements     Direct are plor role is not currently attractive to     High turnover of support staff     Lack of ecognition of trauma as an issue within     Lack of ecognetion of trauma as an issue within	m organisational perspective and family perspective the work force organisations	

**FIGURE 3** Logic model for the implementation of the trauma informed care framework.

The adults with intellectual disability were clear that they can feel unsafe from **actions of co-tenants**, '*If they're shouting or banging doors*, *I feel a bit nervous*'. They also described worrying about **losing their home and social network**, '*If you leave, you can't visit*'.

#### Theme 3: Choice

The adults with intellectual disability described positive experiences of making choices. Many described being able to **choose their own activity**, '*I get to decide where I go for walks*', '*I can go for a coffee whenever I want*'. They also described a **move towards independence**, 'Staff help me set my goals and to develop new skills for independence' and being involved in **choice about their home**, 'we make choices in weekly meetings'.

Participants also described limits to their ability to make choices. They described restrictions due to COVID-19, 'I like to get away but can't because of COVID' and that **staff are not always being available to provide support**, 'I'd like to do more, but it depends on staff availability'.

#### Theme 4: Collaboration

The adults with intellectual disability reported on collaboration at different levels. They stated that they could get **help from staff to make decisions** about their lives '*Staff helped me pick paint for my bedroom*', that they wanted to **work with trusting staff**, '*I speak to staff I trust in my core team*', they appreciated when they were **asked their opinion** before decisions were made, '*Staff asked my opinion about others visiting my house during COVID times*', and some were involved in **decision making at an organisational level**, '*I sit on the advisory board*'.

The adults with intellectual disability stated that they did not appreciate having to **negotiate their needs with co-tenants' needs**, 'I don't need staff to sleep over and others do. I don't like staff sleeping over'. They also wanted to be more involved in **choosing staff** who support them, 'when staff leave, I don't know when they're going to be replaced. I'm not aware of the process' and they reported that they are **not always informed** of what is happening in their homes, 'Staff try to let me know in advance if something is happening, but I don't always hear them due to hearing problems'.

#### Theme 5: Trustworthiness

The adults with intellectual disability described a sense of trust when they were **informed about things that affected them**, 'things are talked about in meetings' and when they are **informed in advance**, 'a staff member left, and we were told in advance'. They described that they reported feeling less trustful when they **aren't informed of changes** happening in their home, 'memos get sent out so that staff know', 'we keep our ear to the ground', particularly if it involved **not being aware of staff changes**, 'We do not like it if staff are away for a long time: are they coming back?'.

#### Theme 6: Empowerment

The adults with intellectual disability reported that they felt empowered when they were able to make choices **and set their own goals for independence**, '*I can change my daily routine as I please*'. However, they reported that they felt disempowered by **restrictions that were outside of their control**, '*Some decisions are made for my own good, like COVID restrictions. We don't like them, but we go with them*'.

#### **Co-production workshops**

The overarching structure and chapters of the trauma informed care framework was influenced by the Hanson and Lang (2016) structure of:

- · Setting the context
- Organisational change
- · Workforce development, and
- Trauma-focussed services.

## Development of chapter 1 of the framework: Setting the context

While several of the key stakeholders were not completely familiar with the evidence base for the impact of trauma for adults with an intellectual disability, they were able to acknowledge the evidence presented from the scoping review (McNally et al., 2021) corresponded to their experiences. Both managers and practitioners agreed it was important to highlight 'how people with an intellectual disability are much more likely to experience trauma, for all sorts of reasons' (Manager) and provide examples of specific experiences for adults with an intellectual disability. Additionally, given the context of trauma informed care for residential environments, it was agreed among the managers and practitioners that it was also important to look at both trauma risk factors and protective factors for care settings: 'Part of recognising trauma is recognising where it has stemmed from and for the majority of service users it is from the very environment that they have been forced to live in' (Practitioner).

In the initial co-production workshop, some of the practitioners proposed to include a description of how complex trauma impacted on the developing brain and an agreement was reached between the practitioners and the managers to include a brief overview of Bruce Perry's neurosequential model (Perry, 2002) in this chapter.

The managers and practitioners agreed early in the co-production process that the content of this first chapter should also include a description of psychological trauma, its impact and potential for the development of resilience for adults with an intellectual disability. In addition, they agreed on the necessity of an overview of the evidence-base for interventions for adults with an intellectual disability and a description of trauma informed care to help inform all staff who demonstrated limited understanding in the earlier mixed methods study (McNally et al., 2022).

Both the managers and practitioners concurred that this chapter required brevity and clarity of communication for all levels of staff to access, and that it is 'clear and [it's] accessible for the staff that work with our clients as well' (Manager). It was also considered relevant to the understanding of the circumstances that the adults with intellectual disability and residential staff were currently facing, to make 'sense to what people are dealing with at the moment' (Practitioner).

## Development of chapter 2 of the framework: Organisational change

With both practitioners and managers recognising the need for leadership buy-in and '... a need for compassionate leadership at the highest levels in organisations' (Practitioner), the development of this second chapter again reflected the combination of the evidence-base and participants' experience as described in the findings from the focus groups and interviews with adults with an intellectual disability. Managers described a need for a cultural shift towards trauma informed care that 'becomes embedded in people's language' (Manager) and the development of policies and procedures that reflect consideration of trauma, and practitioners concurred.

From managers and practitioners shared views on how the principles of trauma informed care would be put into practice within the organisation structure, this chapter of the framework considered the mechanisms of how staff and resident views are incorporated to promote their involvement. Managers and practitioners strongly concurred that the physical and relational environment were key to promoting a sense of safety, stating that '*relationships are key—they are everything*' (*Manager*), which is also reflective of the safety theme expressed by the adults with an intellectual disability in the focus groups. While considering what an organisation can do in response to trauma, practitioners and managers described that there was also a need to explore what the organisation can do to promote resilience for staff and residents. Managers in particular were able to give a number of examples of their everyday practice to include in the framework as guides to good organisational practice.

At this point in the development of the framework, one of the practitioners suggested that internet links and pictures should be included throughout the framework, 'links on the internet to the various bits and pieces and video representations and pictures' (Practitioner). It was reported by some other participants that inclusion of internet links to other sources of information would be over-inclusive, and a consensus was reached to include pictures and diagrams to aid readability. Managers and practitioners also debated the inclusion of supporting quotes from adults with an intellectual disability, taken from the transcripts of the focus groups and interviews. While some practitioners were unsure of the need to include these quotes, one manager in particular achieved agreement from all participants by highlighting the importance of ensuring the voices of adults with an intellectual disability were promoted throughout the framework, in keeping with the principles of trauma informed care.

### Development of chapter 3 of the framework: Workforce development

Managers and practitioners were most engaged in this chapter of the framework as it resonated with their current day-to-day experiences. Managers' experiences, in particular, were clearly aligned with the evidence-base when it came to considering the chapter on workforce development. Managers acknowledged that training was very important for staff in understanding trauma and its presentation for people with an intellectual disability, which was supported by practitioners' views, and they concurred with the literature describing that training was an ongoing process, 'the training is one thing for sure but it's then implementing that training into practice' (Manager). The acknowledgement of training needs was also reflective of staff need as identified from the mixed methods paper by McNally et al. (2022). Additionally, the need for ongoing staff support was deemed vital, equally by managers and practitioners, both in relation to how staff are valued, 'Staff don't always feel valued and maybe they aren't as well paid by other people—doing the most difficult job' (Practitioner), and how staff manage the day-to-day challenges of the job, 'they are talking, debriefing, making each other a tea or coffee—they are the ones that are still there' (Manager). Managers were able to give good examples from their own practice, such as handovers, team meetings, debrief, support from each other, and recognition of achievements, to include as a guide for the implementation of this aspect of the framework.

There was agreement from both practitioners and managers that staff care and self-care are an important part of the implementation of trauma informed care, however, all participants acknowledged that this aspect of the proposed framework is more difficult to achieve with current service pressures.

## Development of chapter 4 of the framework: Trauma-focussed services

In the development of this chapter, practitioners described an understanding for the potential to develop 'therapeutic and healing relationships' (Practitioner) in everyday relationships between staff and adults with an intellectual disability by adopting a trauma informed care approach within an organisation. However, managers initially described their understanding that therapeutic responsibility belonged to the practitioners, '[Residential] staff don't have the skills to work with trauma' (Manager). Following the presentation of the evidence-base for this chapter and the presentation of Golding's Pyramid of Need (Golding & Hughes, 2012), practitioners and managers were in agreement that psychological intervention is not always necessary or requires specialist individual therapies.

Where psychological intervention was deemed necessary there was an agreement between the managers and practitioners that there remains a need to train appropriate practitioners in evidence-based therapeutic approaches, as currently managers encountered that *'there is an access problem'* (*Manager*) to psychological therapies. The challenges to accessing psychological therapies was also highlighted by adults with an intellectual disability in the focus groups and interviews. There is also an agreement between practitioners and managers that there are challenges to assessment of the occurrence and impact of trauma, as often '- you aren't going to know everyone's trauma background' (*Practitioner*) however 'It's in the process of initial assessment that we get to know about the person' (*Manager*).

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In this chapter both managers and practitioners concurred with their views that adults with an intellectual disability should also have access to training regarding their emotions and how to cope if feeling emotionally overwhelmed, '*How to label things—what these feelings mean*' (*Practitioner*) as part of the trauma informed care approach.

### Participant experience and final refinement in the development of the framework

In general, all participants reported that they found their involvement in the development of the framework useful, and some managers and practitioners stated that they felt reassured that they were '...already doing some of this, but it's nice to add a framework for what all needs to happen' (Practitioner). In the final review of the framework, managers and practitioners agreed that it would be helpful to the reader to include key learning points for each of the defined chapters and an infographic that facilitates a quick visual representation of where they are at in their organisational journey to providing trauma informed care.

### Logic model

Prior to the co-production workshops, the first author developed an initial theoretical logic model established from the trauma informed care evidence-base. This was discussed and further refined with the practitioners and managers in the co-production workshops considering real world application, exploring the change mechanisms required for implementing trauma informed care for residential services for adults with an intellectual disability. The logic model was presented in each workshop, following discussion of the framework content, for all participants to consider and refine the model based on what would work in the current context. Moore and Evans (2017, p.132) suggested that particular attention to 'context and the ecological fit of programmes with the systems whose functioning they attempt to change' is required to maximise change potential. Considering the realist perspective of implementing complex interventions, such as the framework, Pfadenhauer et al. (2017) developed the 'Context and Implementation of Complex Programmes (CICI) framework' comprising of three dimensions to examine the context and system:

• **Context** consists of geographical, epidemiological, socio-cultural, socio-economic, ethical, legal, political;

- **Implementation** consists of implementation theory, process, strategies, agents and outcomes;
- **Setting** refers to the specific organisation in which the program is put into practice.

Inclusion of activities in the CICI also evolved during the co-production refinement with managers and practitioners.

#### DISCUSSION

This is the first study to develop and co-produce a trauma informed care framework for residential facilities for adults with an intellectual disability. It describes the process of co-production of the framework with the adults with intellectual disability and other key stakeholders and of identifying the mechanisms of change within the logic model that are required for the implementation of the framework. The study was guided by the Medical Research Council Guidance on developing complex interventions (MRC, 2019).

The study utilised a robust methodology using the 6SQuID model to help structure and develop the trauma informed care framework (Wight et al., 2016). Earlier in the process, the authors completed stage 1 of the 6SQuID model, publishing a scoping review of the international trauma literature for adults with an intellectual disability in order to define the problem and understand the causes (McNally et al., 2021). The authors then further completed stage 2 of the 6SQuID model publishing an explorative study of staffs' knowledge of trauma for adults with an intellectual disability in order to identify the causal or contextual factors that are malleable and have the greatest scope for change (McNally et al., 2022). This current paper reports on stage 3 of the 6SQuID model, the coproduction process with the adults with an intellectual disability and other key stakeholders in order to identify how to bring about change and how to deliver the change mechanisms. Co-production in the development of the framework, and co-production of the refinement of the logic model, were important to obtain a realistic perspective on what will work in clinical practice within the local context for residential facilities, to educate key stakeholders on the current evidence base, and to promote ownership and uptake of implementation (Wight el., 2016).

The development of such clinical frameworks have often excluded participation from adults with an intellectual disability due to their complexity and given the cognitive impairments/restrictions in communication of many of the prospective participants (Prusaczyk et al., 2017). However, it was considered imperative within this project to meaningfully include the adults' views in the co-production of the framework as outlined by the Department of Health Co-production guide (DoH, 2018). Inclusion of the views of adults with an intellectual disability in the co-production of the framework is also important as it is reflective of the core principles of collaboration and empowerment in trauma informed care (Fallot & Harris, 2001). Rather than present the adults with the detail of the final framework, their involvement was achieved by exploring the experiences of the principles of trauma informed care and their voices leading on the development of the framework.

The framework was developed using the internationally recognised Hanson and Lang's (2016) structure, derived from their critical review of existing trauma informed care frameworks in well-established child welfare services, such as, Harris and Fallot (2001): National Child Traumatic Stress Network (2007); SAMHSA (2011). The co-production of the framework specifically for inteldisability services/residential facilities lectual was deemed important as the prevalence of experiencing potentially traumatising events is reported significantly higher for adults with an intellectual disability across the globe (Dion et al., 2018; Nixon et al., 2017; Spencer et al., 2005; Wigham & Emerson, 2015). Furthermore, the recent scoping review of the international literature by McNally et al. (2021) highlighted differences in experiences of trauma, signs and symptoms of trauma, and assessment of trauma for adults with an intellectual disability. With these differences in mind, and considering the local context, it was necessary to include an initial chapter in the framework relating to the experiences of adults with an intellectual disability and to the context for trauma informed care for residential services for adults with an intellectual disability in Northern Ireland, in addition to Hanson and Lang's (2016) chapters of organisational change, workforce development, and traumafocussed services.

The initial context chapter developed for the framework includes a broad overview of trauma and trauma informed care, using definitions from SAMHSA (2014), the principles outlined by Fallot and Harris (2001) and reviews the evidence and literature reviews for population groups such as child welfare (Bryson et al., 2017; Bunting et al., 2019) and adult mental health (Muskett, 2014), where trauma informed care is increasingly being implemented worldwide. More specifically, the context chapter describes the evidence base for the impact of trauma for adults with an intellectual disability derived by the scoping review (McNally et al., 2021) and highlights vulnerability factors associated with having an intellectual disability (McGlivery, 2018), setting out some of the protective factors for adults with an intellectual disability, particularly for those living in residential settings (Colins & Murphy, 2022). Additionally, the context chapter considers the UK instances of institutional abuse for adults with an intellectual disability (Muckamore Abbey Hospital Review—Department of Health, 2020; Winterbourne View Report—Department of Health, 2012; Worthing—BBC news, 2021) and the impact of the long history of conflict-related violence in Northern Ireland (O'Neill et al., 2014) with its potential impact on adults with an intellectual disability (Berger et al., 2015).

The chapter on organisational change focussed on what was required from an organisational perspective to implement trauma informed care in residential settings for adults with an intellectual disability. Whilst examples of what needs to occur from an organisational perspective were drawn from the intellectual disability context, the core elements were similar to those reported in other frameworks employed internationally, such as those described in the review by Bunting et al. (2018) ensuring leadership buy-in; development of trauma informed policies and procedures; and ensuring collaboration within the organisation, including service user involvement.

Similarly, the chapter on workforce development reflected Bunting et al.'s (2018) overview of the need for staff training and inclusion of trauma informed practices that promote staff safety and emotional wellbeing. Considering the final chapter of trauma-focussed services, it should be stated that while some of the therapeutic residential and supported living aspects of service delivery would be specific to adults with an intellectual disability, there is an opportunity for trauma-focussed services offered to the general population to have reasonable adjustments to include provision for adults with an intellectual disability.

Despite their increased vulnerability to traumatic experiences, people with an intellectual disability are comparatively less accounted for in trauma policy (Morris, 2021) and, while development of specialist trauma services and trauma informed care features in the UK's National Health Service (NHS) (2019) mental health plan, it does not describe service provision or adaptation for those with an intellectual disability. This paper goes some way to addressing this discrepancy. The development of the framework has significant implications for policy and practice within the UK and has been endorsed by the Northern Ireland Mental Health Champion and the regional branch of the British Psychological Society for its relevance to residential service provision for adults with an intellectual disability. Although the framework has been developed in the Northern Ireland context, the main body of the framework draws from the

international literature and therefore it has international implications, as it can easily be adapted to other countries with some consideration to their particular cultural context.

Existing frameworks for service delivery, such as Positive Behaviour Support, are currently dominant for residential services for adults with an intellectual disability. Positive Behaviour Support is considered a best practice support for adults with an intellectual disability who have complex and challenging behaviours (British Psychological Society, 2018). Taking part in the coproduction process allowed participants to see how trauma informed care could exist within these frameworks, dispelling staff misconceptions that it was a replacement framework (McNally et al., 2022). This was evidenced by participants expressing that they felt they were already engaging in some of the necessary elements for trauma informed care in their current practice and acknowledgement of the need for an additional trauma lens. One of the key findings from McNally et al.'s (2022) exploration of staff knowledge of trauma informed care was that staff universally viewed training on trauma as crucial to the implementation of trauma informed care. From this study, participants have developed an understanding of all the elements required for the implementation of trauma informed care, of which training is a small part.

There are some current operational challenges to implementing the trauma informed care framework. The production and refinement of the logic model reflects that a trauma informed care framework is viewed as an idealised position to be attained over time and that organisations are not ready to fully implement what is required. This challenge is further compounded by pressures to service delivery due to the impact of the COVID-19 pandemic (Hughes et al., 2023). However, the logic model sets achievable targets for organisations for the short, medium to long-term. Implementing a trauma informed care framework within an organisation bears positive outcomes for the organisation in staff retention and reduced staff turnover (Sanders, 2009); healthier working environments and increased work satisfaction for staff (Hales et al., 2019); positive changes to staff knowledge and attitudes (Purtle, 2020); and reduction in restrictive practices, such as seclusion and restraint, for service users (Hale & Wendler, 2020; Wale et al., 2011) which is in line with the Care Quality Commission (2020) review 'Out of sight—Who cares?'. Conversely, lack of implementation of trauma informed care within an organisation sees a number of negative outcomes, such as distressed adults with an intellectual disability displaying anxiety, depression and behaviours that challenge, inappropriate use of medication that can have numerous side-effects and is unethical and immoral, a

greater likelihood of staff burnout and greater costs for service organisations (Keesler, 2020).

There are some limitations to this study, in that it was conducted during the COVID-19 pandemic and it was difficult to get full representation from all key stakeholders in residential services and resulting in a small number of participants. While having the voice of individuals with an intellectual disability was imperative to the study, having only voices from one organisation limits the findings to the experience within that organisation's culture, ethos and practice. There was also evidence of a lack of staff knowledge of trauma and trauma informed care demonstrated in the McNally et al. (2022) paper, which limits the level of true co-production and co-creation of the framework. Although there is opportunity for international application, in its current format the framework has been localised to the Northern Ireland context.

### CONCLUSION

This paper describes the development of a co-produced trauma informed care framework that is deliverable by staff working within residential services for adults with an intellectual disability and that has potential benefits for organisations, staff and service users alike.

A robust methodological approach using the 6SQuID model has been taken to shape the framework from the international evidence base to co-produce a framework that can realistically be applied in context. It has the potential for international application with adaptation to each country's cultural context for similar residential provision. Future development of this study would involve the operationalisation of the elements of the framework so that they can be implemented and tested for their impact for organisations, staff, and adults with an intellectual disability, as outlined in stages 5 and 6 of the 6SQuID model.

The full trauma informed care framework can be viewed at: https://www.ulster.ac.uk/\_\_data/assets/pdf\_\_file/0004/1446412/A-framework-for-the-implementation-of-Trauma-Informed-Care-in-residential-and-supported-living-services-for-adults-with-a-learning-disability.pdf

### CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### ETHICS STATEMENT

The project received ethical approval from the Office for Research Ethics Committee Northern Ireland (ORECNI— IRAS no: 277539).

#### ORCID

Paddy McNally https://orcid.org/0000-0003-4440-3541 Laurence Taggart https://orcid.org/0000-0002-0954-2127

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