Intellectual disabilities[1] and Trauma-Informed Care

Churchill Fellowship Report by Dr Beverley Samways

Photo by Rémi Walle on Unsplash

Trustee of The Mercers' Charitable Foundation

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[1] 'Intellectual Disabilities' is the term for 'learning disabilities' in the USA. As 'learning disabilities' means something different in the USA, I have stuck with the term 'intellectual disabilities' to avoid confusion.

Contents

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Intellectual disabilities[2] and Trauma-Informed Care

"…the difficulty with this whole trauma informed piece is what we're really trying to change is the interactions between people. It's difficult to measure... but it really matters" (Dr John Keesler).

Executive Summary

The purpose of the Fellowship was to discover the most effective trauma-informed approaches for care services supporting children and young people with severe intellectual disabilities, particularly those who self-injure or present as distressed. I am a self-injury specialist, and the founder of Unique Connections, which exists to improve the lives of people with intellectual disabilities who self-injure. We are invested into shifting the focus in the care sector towards trauma-informed and relationally-informed practice.

People with intellectual disabilities are four or five times more likely to experience trauma than the general population. Some studies suggest that those supporting people with intellectual disabilities - Direct Support Professionals - may have higher rates of trauma, both from external experiences, and from experiencing trauma in their work. All this is sometimes occurring within organisations which are systemically traumatised. Thus, in some contexts, there may be traumatised individuals being cared for by traumatised staff within traumatised organisations.

Trauma-informed care (TIC) is an organisational approach that recognises the impact of trauma on a person, as well as the way in which trauma can affect groups and communities (OHID, 2022). TIC helps organisations understand the centrality of safe practices and how these can be translated into individualised care that helps a person to be and *feel* safer. It embeds core principles into practice and culture, including trust, empowerment, collaboration, choice, cultural consideration and safety (OHID, 2022). TIC was first piloted in the USA, and is much more established practice, with some states stipulating that care-giving organisations cannot operate unless they have embedded TIC organisationally.

Through the Churchill Fellowship, I spent five weeks travelling the East Coast of the USA, visiting a range of specialists: trauma institutes; TIC and intellectual disability researchers; service providers; and other related experts.

This report presents overviews of three TIC organisational change institutes, and the START programme; together, these provide a comprehensive picture as to how TIC is embedded into care-giving organisations. Following this, I present the learnings from visiting various organisations who were implementing TIC in practice in various forms, and the insights I gained from them.

The report concludes by applying these learnings into the UK context, and making some recommendations. It considers the cultural differences between the USA and UK, and the current state of children's social care in the UK, including its strengths. It makes three core recommendations:

1. A tailored TIC-inspired model for change should be created specifically for the care sector supporting children with intellectual disabilities in the UK.
2. The TIC-inspired model should be dual-focused:

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    - the first focus should be on one individual in crisis, as a way of evidencing impact and outworking practical applications with DSPs.
    - The second focus should be on strategically embedding TIC-informed principles into the organisation’s systems and processes.
3. The model should reflect and uphold the UK priorities for building children’s social care on the principles of love and belonging.

1. Introduction

1.1 Purpose of the Fellowship:

> To discover the most effective trauma-informed approaches for care services[1] supporting children and young people with severe intellectual disabilities, particularly those who self-injure or present as distressed

This report begins by outlining the presenting problem which inspired my Churchill Fellowship. Section one talks through the impact of trauma on people with intellectual disabilities and the individuals and organisations supporting them. It outlines how Trauma-Informed Care (TIC) seeks to address this. It also considers the current state of the sector in the UK, which sheds light on both the necessity and challenges of introducing TIC in a meaningful and tailored way.

Simone Davis, director from the Signal Centers' Adult Services, shows me around the center, and talks me through their principles of care.

Photo credit: Signal Centers

In Sections two-five, I present the learnings from the opportunity afforded me to meet with numerous individuals and organisations with expertise in TIC and intellectual disabilities. I conclude by considering how we might apply this to the UK context, and I make recommendations for next steps.

1.2. Personal Background:

I am the founder of the consultancy Unique Connections, which exists to improve the lives of children and adults with intellectual disabilities who self-injure. We work with specialist schools and care organisations to find tailored relational, trauma-informed and emotionally literate ways forward with people presenting with entrenched self-injury and related concerns. As an organisation, we seek to influence policy and practice more broadly, shifting the focus towards trauma-informed and relationally-informed practice.

UNIQUE CONNECTIONS

Dr Beverley Samways pictured in conversation at Signal Centers, Chattanooga.

Photo credit: Signal Centers, Chattanooga

I have 22 years of professional and research experience with young people with severe intellectual disabilities, sensory loss and autism. My ESRC-funded PhD explored the emotional lives of three teenagers with severe intellectual disabilities who self-injured.

1.3 What is Trauma?

Understanding trauma helps explain why trauma-informed care is necessary.

Trauma is not an event, but how a person experiences an event or events – specifically event(s) that an individual experiences as harmful or life-threatening.

Experiences that induce stress, anxiety or fear are an ordinary part of a human life. Fear triggers the amygdala to dominate the brain’s responses, relegating high level problem-solving capacity in favour of rapid, intuitive and physical responses that equip the body for a fight, flight, freeze or flop response. Fear responses recruit the whole of a person: physiologically, mentally and emotionally. Typically, these fear-inducing events are recoverable – with the person being able over time (whether minutes or days) to ‘recover’ and revert to feeling safe-enough in the world again.

However, repeated or routine fear-inducing experiences, or an extreme fear-inducing experience, can cause the brain to reset (Perry, 2006) so that the person functions in a perpetual fight, flight, freeze state.

This is what it means to be 'traumatised'. It is not primarily or exclusively an 'emotional' state – but a neurological, biological, psychological and social state (OHID, 2022) affecting how a person experiences and interacts with themselves and the world around them. In essence, **a traumatised person no longer feels safe in the world nor in their own body and mind**.

Photo by Patrick Fore on Unsplash

Critically, because a traumatised state is adaptive not biologically or genetically wired, there is potential for recovery; but it requires both environmental and interpersonal interventions. Recovery is unlikely to occur spontaneously, i.e. time does not necessarily heal trauma.

1.4 Trauma and Intellectual Disabilities

People with intellectual disabilities are four or five times more likely to experience trauma than the general population (Beail et al., 2021). Influencing factors include a heightened risk of experiencing abuse, experiencing losses through multiple transitions between services, stigma-related experiences, and being more likely to leave the family home as a child. Attachment, a key resilience factor, is often slower and much more likely to be disrupted (Fletcher et al., 2016).

People with intellectual disabilities can find it more difficult to process a traumatic event, due to lower resilience factors. For example, lower understanding or less spoken communication can make it more difficult to process stressful events; some individuals will have less peer support, and there are increased risks for developing associated mental health difficulties. In addition, young people with autism are likely to have a more enduring stress response to a stressful or traumatic event (Keesler, 2020).

To compound this, if a person has intellectual disabilities or autism, their response to trauma is more likely to be overlooked or ascribed to a person's disability or condition (diagnostic overshadow).

Case illustration

A young person Unique Connections worked with had a preoccupation with having something in his mouth, and would often cram his mouth full. This was ascribed to sensory needs, which may have been a factor. His history of neglect prior to coming into care, and a more recent experience of visiting a family member with a mouth injury were not initially considered as possible contributing factors.

People with intellectual disabilities are more likely to experience a traumatic event, less likely to be able to process it, and more likely to have the impact of the event overlooked or pathologised.

1.5 The care sector: history and current UK context

Some children and adults with intellectual disabilities are cared for in respite, residential schools, children's homes and care homes. The government reports that children with mild, severe or profound intellectual disabilities represent 9.2% of looked-after children (around 8,000). The care sector has weathered a great deal in the last few years, and has been impacted at three levels: organisationally, direct-care, and the shadow of history.

1.5.1 Organisations

I had the privilege of meeting Larry Shallenberger from Sarah Reed care organisation in Pennsylvania. In our conversation recorded on YouTube here, he articulates the journey of the last few years for the care sector. He describes how care-giving organisations have navigated the Covid-19 pandemic, reckoned with the implications of the social justice movement, and been impacted by global insecurities and the cost of living crises; these back-to-back events have led many organisations to become traumatised.

Individuals become traumatised when their fear-inducing experiences overwhelm their internal resources to respond. In parallel, many organisations have found the dual pressures of the internal work of supporting traumatised individuals (which they may or may not recognise that they do), and the external strains and pressures of the events of the last few years have overwhelmed their resources. They have adapted to systemically operate and organise around fight, flight and freeze mechanisms. This can present in a multiplicity of ways, but might include: chaotic or irrational decision-making and processes; communication systems collapsing; defended or blaming narratives emerging; strained relationships between departments and external stakeholders; and a sense of overwhelm and exhaustion that leads to disengagement or large-scale resignations.

Organisations supporting people who are traumatised can experience a 'parallel process' and begin to present with the signs of trauma as an organisation.

1.5.2 Direct Care Professionals (DSPs)

Prior to the pandemic, Keesler (2019) reported in his study of Adverse Childhood Experiences (ACEs) with Direct Support Professionals (DSP)[1]'s that, on average, DSPs scored twice the rate of ACEs than the general population. In the same year, it was found that 35% of DSPs had witnessed a traumatising event in work (Strand, et al, 2004). Thus, care staff (DSPs) are more likely to have had a potentially-traumatising event as a child, and more likely to experience trauma in their job.

Photo by kevin turcios on Unsplash

Post-Covid-19 there was a 'great resignation': multiple-experienced and seasoned professionals who simply quit their jobs or took early retirement. This has impacted the care sector profoundly: a great deal of resilient, experienced and seasoned staff are no longer in the sector. Those left in the sector have weathered a potentially collectively-traumatising event.

Those who have since joined the sector, are significantly less experienced and knowledgeable, and are often being hastily trained and inducted to make up the shortfall. We already had a workforce with higher rates of trauma than average, this is likely to have only increased post-pandemic. Thus, there are signs that Direct Support Professionals may have higher rates of trauma, both from external experiences, and from experiencing trauma in their work.

1.5.3. The history of caring for people with intellectual disabilities

To compound the difficulties, our services for people with intellectual disabilities and autism stand in the shadow of a long history of institutionalising people with disabilities. Whilst the institutions themselves are now closed in the UK, the shadow of this history continues to loom large in the sector. Control and containment are still apparently in the DNA of how we care for people with intellectual disabilities and, when under extreme stress, the sector reverts to type (a parallel process of how we as individuals often revert to control and authoritarian strategies when overwhelmed by stress).

This is exemplified in the daily incarceration of around 2,000 people with intellectual disabilities in mental health units on any given day in the UK. The legacy of our sector creates well-worn tracks that are easily reverted to in times of high stress.

The sector all too often responds to traumatised people with intellectual disabilities through containment and control. At Unique Connections, we witness this keenly in the differentiated way that people with intellectual disabilities who hurt themselves are talked about, understood and treated in comparison to those without intellectual disabilities (Samways et al., 2022).

In short, there is a growing sense that TIC is necessary for the care sector, particularly for services providing 52-week care to those with intellectual disabilities.

1.5.4. The sector in summary:

The sector providing services for people with intellectual disabilities in the UK has to reckon with its current reality:

- It provides services for people with much higher rates of trauma than the general population
- within a historical context of containment and control that it is still trying to shake off.
- The current direct support staff providing care are broadly less experienced and resilient and are more likely to be traumatised themselves.
- All this is sometimes occurring within organisations which are systemically traumatised.

Thus, in some instances we have traumatised individuals being cared for by traumatised staff within traumatised organisations, in the shadow of a traumatic history.

As we face this difficult reality – we have to hold on to the key truth about trauma:

it's recoverable.

Case illustration

'I come to work every day feeling hopeful, determined to be positive, but as soon as I get through the door I can't think straight. All the systems are broken and the communication lines are down. It's completely overwhelming. I don't think I can take it anymore.'

DSP working in a trauma-organised social care setting.

1.6. What is Trauma-Informed Care (TIC)?

Trauma-informed care is an organisational approach that recognises the impact of trauma on a person, as well as the way in which trauma can affect groups and communities (OHID, 2022).

Trauma-informed care helps organisations understand the centrality of safe practices and how these can be translated into individualised care that helps a person to be and *feel* safer. TIC embeds core principles into practice and culture, including trust, empowerment, collaboration, choice, cultural consideration and safety (OHID, 2022).

It seeks to equip teams and systems to 'see beyond an individual's presenting behaviours' (OHID, 2022) and diagnosis and ask 'what has happened to this person?' and 'what does this person need?' – rather than 'what is wrong with them?' TIC also helps organisations identify how to avoid re-traumatising practices, and supports them to create environments and cultures that set a context for supporting individuals to move towards healing from traumatisation.

Trauma-informed principles and practice are rapidly being introduced into the education sector in the UK, primarily through the work of Trauma Informed Schools; this is beginning to find traction in SEN schools, but is much slower. Similarly, there are some efforts being expended to introduce TIC into the care sector, particularly the mental health sector (Restraint Reduction Network, 2023; National Trauma Transformation Programme, 2023), but there are barriers to implementation in the care sector, particularly in the sector supporting those with intellectual disabilities; this is making progress slow and difficult.

There are particular complexities to implementing TIC in services supporting people with severe intellectual disabilities and autism. Many of those receiving support have little or no spoken communication, so cannot easily communicate what has happened to them or how they feel about it. In addition, it is accepted best practice to support with behavioural rather than therapeutic responses to distressed presentations. So there is very little space for the hard work of TIC in these services, despite it being sorely needed at every level.

A full discussion of the why, how and what of TIC in services supporting people with intellectual disabilities with Dr John Keesler is available here.

> 'We've bought in TIC on a few occasions and it's great – until the questions are asked about how we apply this with non-speaking young people, then there's a lack of answers'.
> *(Principal of an SEN school)*
>
> 'We've tried different TIC trainers every year for five years, we can't find anyone who can help us do this with our young people'.
>
> *(Responsible Individual for children's homes for young people with IDD-MH)*

2. Overview of the trip

The Fellowship allowed me to visit a range of specialists: trauma institutes; TIC and intellectual disability researchers; service providers; and other related experts. The wide range of conversations I was able to engage in helped me to both crystalise the difficulties in implementing TIC in the sector, and learn about a variety of ways forward.

The trip in numbers:

- 13 States
- 3000 miles within the US
- 7 Service providers
- 5 Universities
- 5 Trauma institutes / specialist trauma providers

I was able to visit a wide range of services and institutes and engage with people with a range of expertise. A full list of people and organisations visited can be found in the appendix. For instance, I visited community care providers in Indiana, Buffalo and Chattanooga, spent three days in the specialist hospital Kennedy Krieger, meeting with a host of medical professionals, and met with a number of trauma institutes. Each place I visited or person I spent time with contributed some of their thinking and experience to better-understanding the narrative, needs, what is currently working – and not – in the US, and how we might translate this into the UK.

There are some key figures which this report does not directly reference – but I am grateful for the ways in which they gave me their time, connected me with others I benefitted from meeting, and influenced my thinking more widely. In particular, my gratitude is extended to Becca Brendal MD of Harvard Medical School Center for Bioethics; William Sullivan MD of Kennedy Institute of Ethics at Georgetown University; Dave Buck of Chattanooga Autism Centre; John Campo and team at Kennedy Krieger, and particularly Dr Louis Hagopian, Marcos Grados, Dr Marian Ofonedu and Dan Hoover. [3]

Left: Rebecca Brendal MD, Harvard; right: William Sullivan MD, Kennedy Institute of Ethics.

This report does not attempt to describe or distil each organisation's or individual's particular contribution to the sector (hyperlinks are embedded for further inquiry into each organisation / expert). Rather, I will report in relation to the mission and purpose of the trip, answering the question: *how can we embed TIC into care services supporting children and young people with severe intellectual disabilities in the UK?*

The topics of conversation were broadly similar from one space or individual to another:

- That there were higher rates of trauma within the population diagnosed with Intellectual and Developmental Disabilities (IDD)[4] than in the general population.
- This is harder to identify and more likely to lead to 'diagnostic overshadow' (ascribing a person's trauma-presentation to their known diagnosis).
- That if trauma is recognised in someone with IDD, it is not clear what can be done to help.
- There is significant insecurity in the workforce, and high staff turnover.
- That there are higher levels of traumatisation in the workforce, which may be a product of having weathered Covid-19, that the direct care staff are typically recruited from

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[3] Unless otherwise stated, all photos are my own.

[4] IDD is the US equivalent term for severe learning disabilities and profound and multiple learning disabilities.

marginalised demographics more susceptible to traumatic events, and/or a product of the work itself.

3. Programmes which help organisations embed TIC

I connected with three trauma institutes and the START programme, all of which have programmes and experience that have helped care-giving organisations supporting people with IDD embed TIC. I have summarised these programmes below, as together they provide excellent frameworks for what TIC is, and how it is implemented within an organisation.

3.1 The Institute of Trauma and Trauma-informed Care (University at Buffalo School of Social Work).

ITTIC have written their TIC organisational change programme and manual and have implemented it with dozens of organisations, including those supporting people with IDD. They typically contract with an organisation for one to three years for trauma-informed organisational change.

Logo credit: Institute on Trauma and Trauma-Informed Care

3.1.1. The programme

Their programme is anchored in the **Five Guiding Values/ Principles** of TIC (Harris and Fallot, 2001) integrated with considerations of diversity, equity, inclusion, and accessibility. The five values/principles are:

1. Safety
2. Trustworthiness
3. Choice
4. Collaboration
5. Empowerment

It presents **10 Key Development Areas** – in which change is broken down into **Three Stages: Pre-implementation, Implementation and Sustainability.**

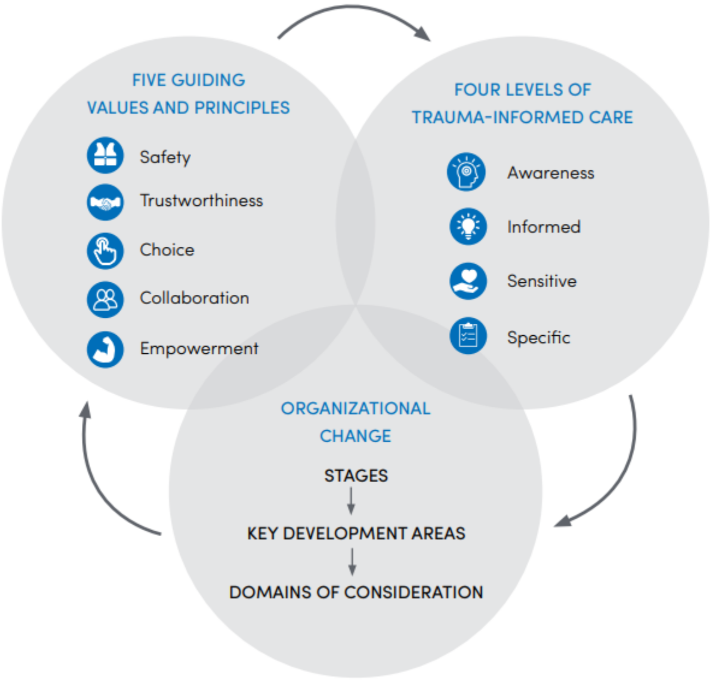
1. **Leading and Communicating:** establishing leadership buy-in, investment and consistent message from leadership & a committee/team to lead the change process.
2. **Building a Trauma-Informed Workplace:** ensuring HR practices including hiring and induction are trauma-informed and trauma-sensitive.
3. **Training the Workforce:** building a realistic and sustainable plan for ongoing trauma-informed education and training at all levels.
4. **Addressing the Impact of the Work:** increasing workforce awareness of how to prevent/manage secondary traumatic stress, vicarious trauma, and compassion fatigue. Implementing systems to support vicarious resilience and post-traumatic growth.
5. **Establishing a Safe Environment:** ensuring that the physical space, environment, atmosphere and culture are trauma-informed and trauma-sensitive.
6. **Screening for Trauma:** deciding whether to screen for trauma and/or adversity, what tools and follow up is needed.

7. **Treating Trauma:** having on-site trauma-specific treatment or accessible referral places.
8. **Collaborating with others:** creating mechanisms with partner organisations to collaboratively ensure trauma-informed networks, communities and systems.
9. **Reviewing Policies and Procedures:** confirming that all policies and procedures are written and conducted in a trauma-informed and trauma-sensitive manner.
10. **Evaluating and Monitoring Progress:** establishing mechanisms for evaluating and monitoring trauma-informed organisational change and its impact on the organisation and its outcomes.

These Key Development Areas incorporate the guidance provided by the **10 Domains of Consideration from SAMHSA (2014):**

1. Governance and Leadership
2. Policy
3. Physical Environment
4. Engagement and Involvement
5. Cross-Sector Collaboration
6. Screening, Assessment, Treatment Services
7. Training and Workforce Development
8. Progress Monitoring and Quality Assurance
9. Financing
10. Evaluation

The model can be pictured thus:



Picture credit: ITTIC

In practice, they support the organisation to implement the model through a range of training, coaching and consultancy practices. Contract workplans are tailored to the specific needs of the organisation. For instance, they may contract to an organisation for 10 hours a month: two for teaching, two hours consultation, two hours observing practice and two hours of flex. They feel TIC implementation is as much about being present and modelling the principles, as formal training.

Photo credit: Prof Susan Green.

My thanks to Prof Susan Green and Dr Sam Koury (pictured above) for their time, openness and encouragement during my visit to ITTIC.

3.2. Traumatic Stress Institute Model

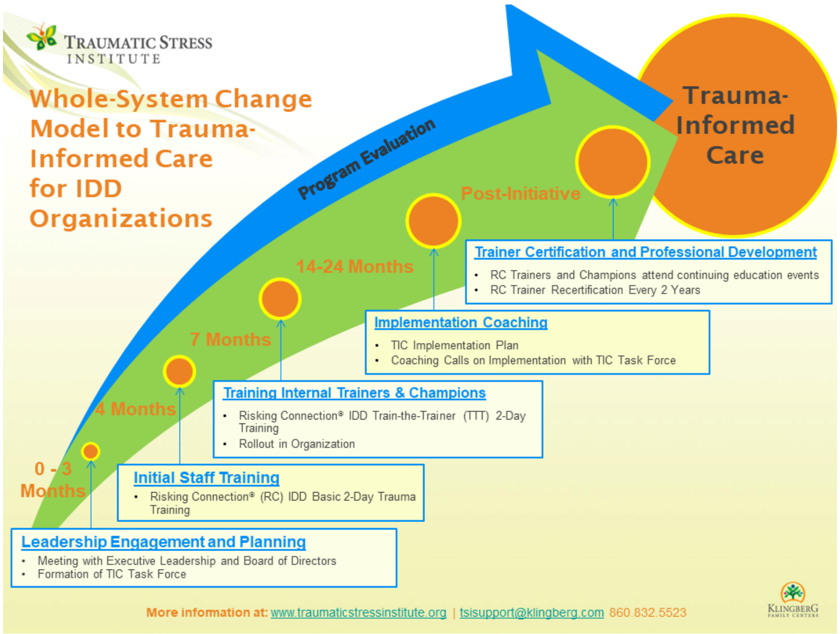
TRAUMATIC STRESS INSTITUTE

Logo credit: TSI website

The Traumatic Stress Institute (TSI) offers a whole-systems change model to TIC over 18-24 months; it seeks to transform every section of the organisation. In 2019, they developed an adapted programme for IDD organisations and systems.[1]

TSI works both with individual organisations and multiple organisations at one time using a learning collaboration method for dissemination of innovation. Organisations are placed in a learning collaborative of between three and five organisations. This gives them a community to both encourage and hold each other accountable. A high level of commitment from senior leadership, a whole-system engagement with core training and bespoke plans for rolling out TIC implementation are required.

It starts with leadership training, which facilitates the creation of a tailored plan for implementing TIC principles organisationally. Throughout the process, evaluation is key to see where and how change is being effective, to leverage the strengths of the organisation and to inform adaptations.



Picture credit: TSI website

They provide their trauma training: Risking Connection, a two-day training, specifically adapted for IDD organizations, offered to 100% of the workforce. This training provides a common language and a framework for understanding that relationships are the primary agent of change – so it asks organisations to consider how they are promoting connections both interpersonally and community-wide. It acknowledges that caring for traumatised people poses risks to staff, including vicarious trauma and compassion fatigue. Risking Connections is also delivered as a train the trainer model, so that organisations can continue to embed and renew this training.

Risking connections – revised for IDD is taught over two days, providing staff with:

- A philosophy and lens for understanding the impact of adversity and trauma
- Common language and a trauma framework or map to understand the impact of trauma on people's behaviour.
- Background about the groundbreaking ACE study
- Knowledge about the power of relationships as the agent of change for people that have suffered trauma.
- Awareness about compassion fatigue and what organisations and individuals can do to address it.
- Information about the importance of self-awareness and noticing one's reactions to individual people served.

My gratitude for Dr Steve Brown for his time in talking through both TSI's model, but also some of the intricacies and complexities of helping organisations implement it.

3.3. Sanctuary Model.

The Sanctuary Model is arguably the best-established tool for embedding trauma-informed care systems-wide into an organisation, offering a 'blueprint for clinical and organisational change, which… promotes safety and recovery from adversity through the active creation of a trauma-responsive community' (ANDRUS, 2023). It was established collaboratively at ANDRUS more than twenty years ago, in work led by Sandra Bloom. It has more than 200 certified organisations worldwide (including a handful in the UK).

The model requires a three-year commitment from an organisation to recalibrate its culture, processes, philosophy and systems to align with TIC and the Sanctuary Model. It is the longest and most comprehensive model to implement, and its claims are similarly comprehensive – improved outcomes for clients, improved staff retention and satisfaction, and decreased violence. (TSI and ITTIC typically focus on reducing re-traumatisation).

3.3.1. The programme

Sanctuary Model implementation is grounded in four pillars:

3.3.1.1. Pillar One: Underpinning theoretical philosophies

- Understanding the effect of trauma, and that many behaviours are adaptive responses to a loss of safety.

- Parallel Process – that organisations operate in parallel ways to humans, mirroring the same responses and defenses when under threat or experiencing a loss of safety.

- A philosophy for creating safe environments through embedding the **Seven Commitments**

3.3.1.2. Pillar two: SELF – Safety, Emotion, Loss, Future.

Trauma-informed shared language and problem-solving strategies, represented by the **SELF** framework. The SELF framework offers a shared language to multi-disciplinary teams, and a mechanism for planning, conversing and decision-making in complex organisations.

SELF is a non-linear framework. Situations or problems can be started from any of the four factors, to prompt discussion and find solutions for ways forward. Often it helps to start with future and work back from there, considering concerns and potential interventions related to safety, emotions and loss.

(Source: The Sanctuary Institute, 2011).

3.3.1.3. Pillar three: The seven Sanctuary commitments

These offer a particular way of practicing as an organisation.

1. Commitment to nonviolence – safety skills are built and modeled by the organisation
2. Commitment to emotional intelligence – learning and modeling emotional-regulation and management
3. Commitment to Inquiry and Social Learning
4. Commitment to Democracy – self-control, self-discipline and healthy authority

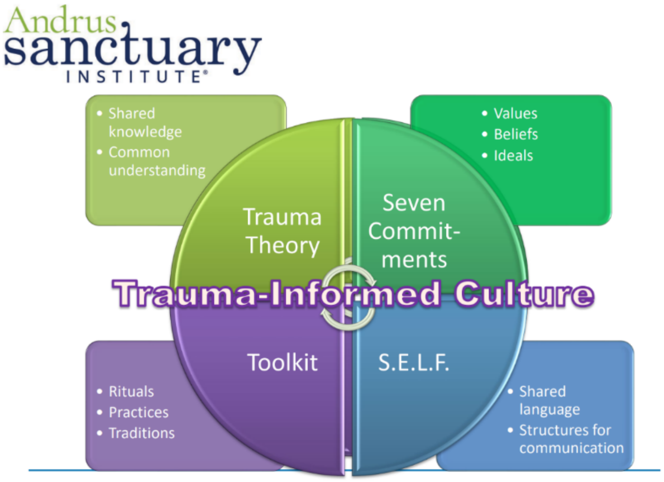
5. Commitment to open communication – learning boundaries, overcoming barriers, reduction of defensive practices.
6. Commitment to Social Responsibility – healthy attachments and social skills
7. Commitment to Growth and Change – restoring hope, meaning and purpose (ANDRUS, 2023)

3.3.1.4. Pillar four: The Tool Kit

Sanctuary also provides a range of tools that an organisation can embed into their daily practice. These are operational tools which reflect and embed the commitments. For instance, red flag reviews are held in response to critical incidents, and can be called by any member of the community, including clients.

Community meetings are held between all members of the community once a day (clients, staff, leaders, etc.), during which each person is asked: 'what are you feeling? What goal do you have for today? Who can you ask for help?' These questions, asked quite quickly in a way that discourages deep introversion, help a team increase their awareness of each other's feelings, learn to focus on the future and increase interdependency.

Sanctuary seeks to support each organisation intentionally and systematically embed TIC, not just into practice, but into their policies, systems, philosophy, vision, culture and interpersonal relationships.



Source: Inquiry Calls Presentation provided by The Sanctuary Institute, 2024

3.3.1.5. Implementation:

The organisation is assigned a faculty member to assist them, who, in addition to delivering training and train-the-trainer, offers 15 days and 15 phone calls for additional consultancy.

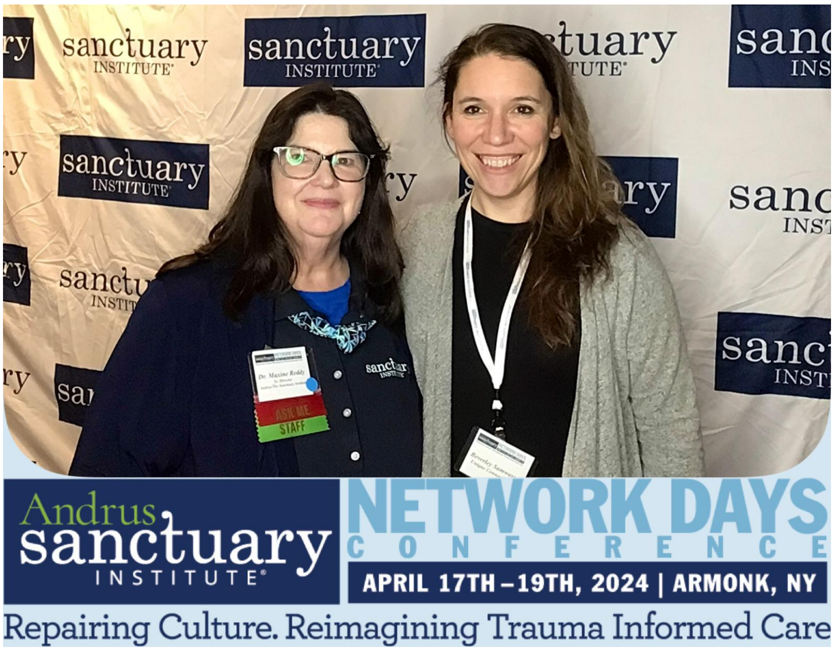
Year One - engaging: intensive training and consultation, and establishment of core team to lead the change. It includes on-site needs assessment, involving interviews with leadership, staff and clients, identifying strengths and target areas for intervention. A small team will attend Sanctuary's five-day training, to learn the model and how to begin implementing it. They will form the organisation's Sanctuary Steering Committee. In addition, a larger core team will be established, whose role it is to apply the understanding to practice and policy.

Year Two - embedding: using a set of standards for embedding a trauma-responsive culture and expanding the available tools. This includes adapting policies and practices to align with Sanctuary;

operationalizing the seven Sanctuary Commitments, with more focus on evaluating practice and culture.

Year Three - evaluating: self-evaluation and formal external evaluation for accreditation against the Sanctuary Implementation Standards.

Full details of the theory backing the model, and implementation are available here: https://journals-sagepub-com.bris.idm.oclc.org/doi/10.1606/1044-3894.4287



My gratitude to Maxine Reddy (pictured above) for meeting with me, providing me with key information and looking out for me during the Network Days Conference.
(Source: Sanctuary Network Days)

3.4. START: Systemic, Therapeutic, Assessment, Resources and Treatment

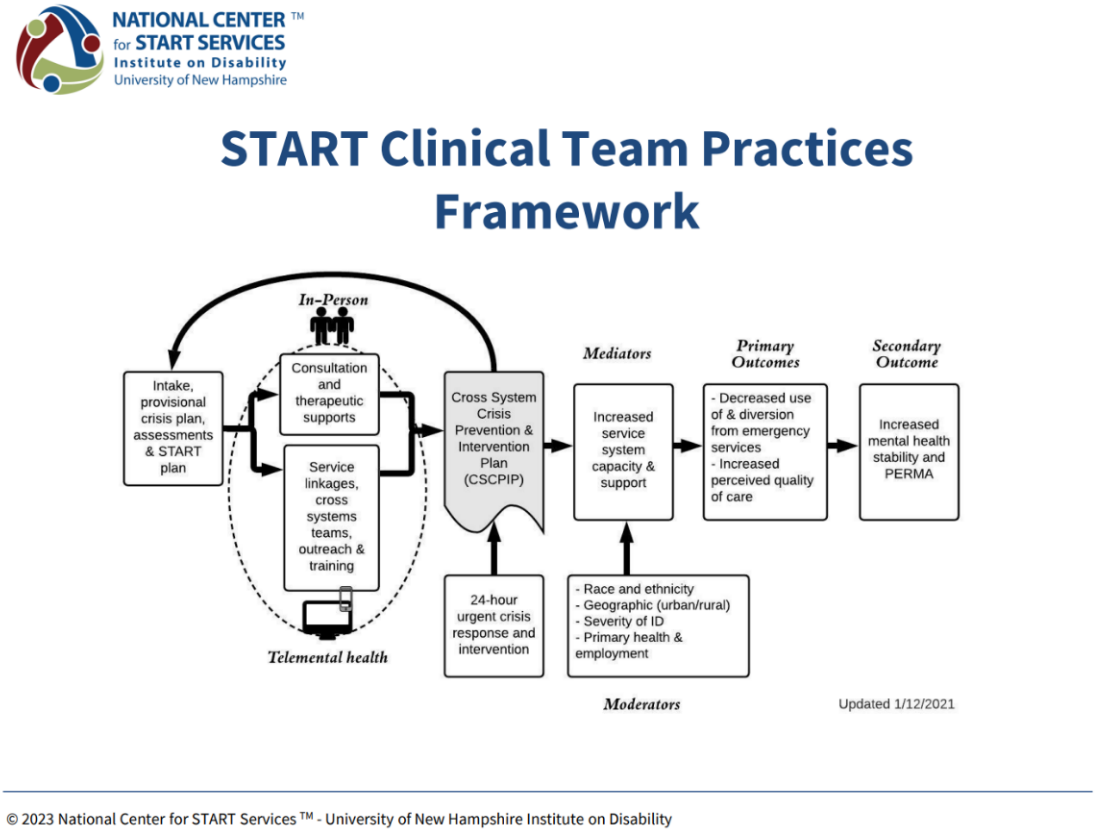
START is not a TIC organisational change model, but has some cross over and particular relevance to this enquiry. Their mission is to improve the lives of people with intellectual and developmental disabilities (IDD) and mental health needs (IDD-MH) and their systems of support, through program implementation, research, evaluation, training and professional development. It is an evidence-based, community crisis prevention and intervention service model for individuals aged six and older with IDD-MH.

START was developed by Dr Joni Beasley and Dr Robert Sovner in Massachusetts in 1988. In 2010, Dr Beasley founded the Center for Start Services, which is now directed by Dr Karen Wiegle. START offers regional services in 11 states, with a total of 32 states having START partnerships in some capacity. Their most recent impact report notes that, in 2023, they responded to 2780 crisis calls, with 81% of individuals remaining in community (as oppose to hospitalisation). They served 3579 people with IDD-MH, with 72% having a reduction in mental health symptoms.

3.4.1. START programme

People with IDD-MH are referred into the START Program, often when they are in crisis – they might be at risk of being admitted into hospital or experiencing a mental health crisis. Other referrals come prior to known stressors or difficult events, such as before a key transition. Intervention, whilst tailored to each client, typically follows this pattern:

- Extensive evaluation. Initial open conversation with stakeholders, followed by planned assessments and evaluations to gather clear data and inform what intervention is needed. They adopt a strengths-based (rather than deficit-based) model and establish the person's interests and skills, what brings them joy or helps them regulate. The individual is engaged through this process. They start with an assumption of trauma as baseline for the individual (but not necessarily the system).
- START produces a cross-systems provisional crisis plan, which is shared widely. This is short enough to comprehend and digest quickly.
- A full medical / biological review is undertaken. A psychiatrist does a medicine review and clarifies diagnosis. (They find that some people have a plethora of diagnoses that can be consolidated under one umbrella.) They also check that pain is not a source of the crisis, and review the person's overall health and diet.
- They consult with the relevant multi-disciplinary (MD) professionals. New Hampshire (NH) START has a large MD team (including psychologists, psychiatrists, neurologists, OTs, etc.) that they can refer 12 adults and 12 children to annually for a comprehensive review.
- A comprehensive evaluation of the services and systems of care around the individual is conducted, with a focus on building capacity (see section 4.2.1).
- The necessary work with the individual is established, focusing on building executive functioning and emotional regulation.
- Linkage work is established to build capacity into the individual's wider systems of support (see 4.2.3).
- In the first 40-50 days of engagement with the individual and system, a full cross-systems crisis plan is agreed and disseminated.
- START usually stays engaged with the individual and the system for between 14-18 months. Once the individual and the system is stable, they can be discharged, but referral back in for support remains open to them.



NATIONAL CENTER ™ for START SERVICES
Institute on Disability
University of New Hampshire

START Clinical Team Practices Framework

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Source: National Centre for START services, University of New Hampshire

3.4.2.2. Resource centres

Some of the START programmes also run resource centres; (I met with the resource centre team in New Hampshire).

People on the START program can come to the resource centre for four to five days if it's a planned visit, and 30 days if it's a crisis admission. The days are very well structured, with planned activities from 8am – 8pm, many of them designed to build resilience: DBT skills, positive psychology activities and toolkits for coping.

The START centres employ the PERMA model for embedding positive psychology across the services. PERMA = positive, engagement, relationships, meaning and achievement. They apply these five principles every day: e.g. Monday starts with a positive comment, Friday they discuss achievement, etc. This is a way to embed positive psychology into the day-to-day culture. (This is reminiscent of the check-ins that Sanctuary use).

3.4.2.1. Building capacity: training and support to teams around the individual

START have some core training programmes designed for direct support professionals (DSPs) and for care coordinators or equivalent. For DSPs, they run six sessions across six weeks, covering:

- Positive psychology principles, including strengths-based approaches (strength-spotting); family & person-centred practice; cultural & linguistic competency; trauma-Informed care; biopsychosocial, wellness-based approaches.
- An overview of IDD and ASD, including the BioPsychoSocial vulnerabilities of IDD (executive functioning, communication, sensory needs).
- Identifying signs of MH; overview of common diagnoses – anxiety, depression, and trauma; exploring the connections between vulnerability of IDD and MH

- Trauma and emotional regulation.
- Positive identity development; trauma-informed care in action; promoting wellness through PERMA+ (a model for embedding positive psychology across services).
- Emotion recognition and regulation (including how staff will recognise and manage their own emotions), and universal experiences of overload; relaxation and stress reduction; creative expression.

To care coordinators they offer similar content, but with a focus on leadership, working with families, including the individual in decisions, leadership and advocacy, race, class and justice, and systemic engagement.

3.4.2.3. Linkage work

START spends a lot of resource on linkage, and encourage their partnering organisations to do the same. The New Hampshire resource centre described gathering a database of 1,000 linkages – establishing connections with every service and community group which might touch on the lives of people with IDD-MH: dental surgeries, health care clinics, GPs, emergency services, community group, faith groups, etc. They use these linkages to access help for the individuals they support, but also to stay connected where they are needed.

This has meant on occasions that a person with IDD-MH has presented at A&E or the police station, and START has immediately been contacted. They have built trust with the services, which means they are sometimes first to know about admission to mental health services, and can start a conversation about discharge from the first day of admission, with the offer of a step-down service if required. This builds rigour into the system.

3.4.2.4.Additional support structures

START run the National Online Training Series (NOTS), a monthly online presentation of an anonymised case study from one of the START services, followed by live Q&A highlighting a particular concern, such as polypharmacy or sensory overload, etc.

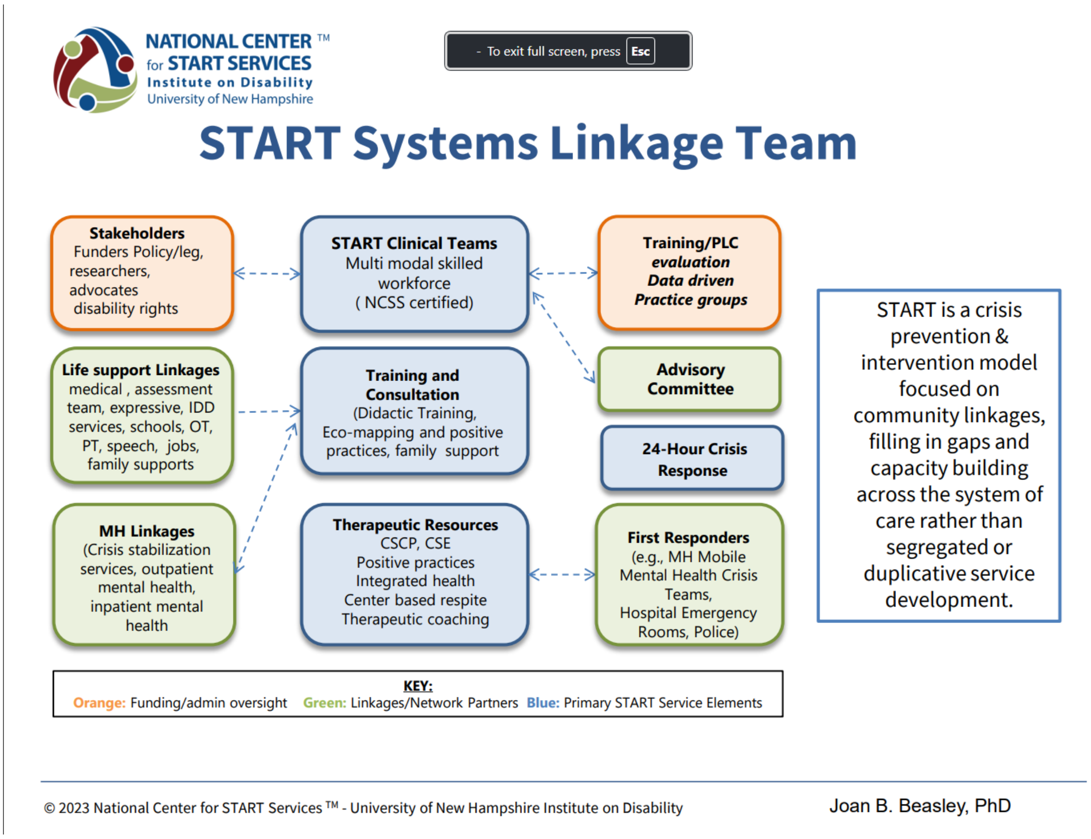
They have an annual conference where they upskill key team members from across START nationally.

START has a lot of its training as asynchronistic resources, which they offer to teams they're working with. They understand training as a way of understanding the immediate system - so they're not averse to going in and training initially, to build understanding, but they would want to follow up with reflective practice to see whether it's bedding in. They would also do pre and post-evaluation of knowledge assessment and post-satisfaction training and evaluation.

3.4.2.5. Data capture

Key to START's success is that it is an evidence-informed service. The National Center for START Services holds a national database which serves as a repository for all programs nationwide, capturing pre-evaluation, mid-evaluation, post-evaluation and more. Whilst some of this can be gleaned through surveys, etc., the initial evaluative work for a new programme is always in-person, so that they can rigorously evaluate the strengths and capacity needs of the service.

They stressed the need to evidence efficacy, and tend to focus on making an economic argument for their services, rather than the moral argument. Thus, data provides an evidence-base for treatment, but is also fed back into their programmes - evidence-informed treatment – so that the data informs the review and improvement of their programmes. Most particularly, research is conducted to improve care and includes the perspectives and experiences of self-advocates and families.



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START Systems Linkage Team

Stakeholders
Funders Policy/leg, researchers, advocates disability rights

START Clinical Teams
Multi modal skilled workforce
(NCSS certified)

Training/PLC
evaluation
Data driven
Practice groups

Life support Linkages
medical , assessment team, expressive, IDD services, schools, OT, PT, speech, jobs, family supports

Training and Consultation
(Didactic Training, Eco-mapping and positive practices, family support

Advisory Committee

24-Hour Crisis Response

MH Linkages
(Crisis stabilization services, outpatient mental health, inpatient mental health

Therapeutic Resources
CSCP, CSE
Positive practices
Integrated health
Center based respite
Therapeutic coaching

First Responders
(e.g., MH Mobile Mental Health Crisis Teams, Hospital Emergency Rooms, Police)

START is a crisis prevention & intervention model focused on community linkages, filling in gaps and capacity building across the system of care rather than segregated or duplicative service development.

KEY:
Orange: Funding/admin oversight Green: Linkages/Network Partners Blue: Primary START Service Elements

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Joan B. Beasley, PhD

Source: National Centre for START services, University of New Hampshire

Photo source: Left – my own; Right – Dave Buck.

My thanks to Dr Joni Beasley (pictured left) for hosting my visit, and connecting me with so many key people in the US. My gratitude also goes to Bob Scholz and Karen Weigle for the time they gave me and the insights they shared (Karen pictured right with Dave Buck from Chattanooga Autism Center).

4. TIC in action.

The above organisations all do consultancy or intervention work with care-giving organisations. However, it was important to also connect with organisations who were directly providing services to people with ID. Attending the Sanctuary conference allowed me to connect with a number of leaders from care-giving organisations and hear about their process of embedding TIC organisational change. I was also able to visit a complex service provider in New York state, Stone Belt in Bloomington, and Thrive Orange County in Indiana, which have or are implementing TIC. In addition, I visited Orange Grove Centre and Signal Centres in Chattanooga. Whilst these organisations were not formally implementing TIC, I share below the insights they shared that felt like pieces of the puzzle.

4.1. Specialist service provider in New York state

I had the privilege of visiting a service provider that offered a wide array of complex provisions, including an intensive treatment programmes for young people with IDD-MH, homes for adults with IDD, and individualised residential alternative homes for life.

The organisation were Sanctuary-certified for several years, but then a change of senior management led to a change of ethos and de-certification. Wanting to re-certify as trauma-informed, they approached the Traumatic Stress Institute, and found that their IDD-specific TIC organisational change model was a good fit. They have aimed for 100% of their employees trauma-trained (from admin, to finance, to direct support, to CEO), but are probably achieving around 75%.

I had the privilege of meeting with the CEO, who talked me through their journey, highlighting the culture change TIC implementation had achieved – that they were a kinder, more compassionate and more open organisation at every level. Her articulation of the impact of TIC was inspiring and hopeful. I asked how this was translating at DSP level, and she encouraged me to ask during my visit to their Residential Treatment Facility for teenagers with interpersonal, emotional, psychiatric, social, family or educational issues, and adjoining Intensive Treatment Unit for those with IDD-MH.

I was given a tour with the operations manager and had the chance to ask a house manager about TIC implementation. He replied that the team understood that the children had experienced adversity, which was contributing to their behaviour. This is a key understanding, and they clearly offer a person-centred, compassionate provision.

However, further questions led to a discussion of occasional prone restraints (being held in a lying-down position) with the young people. It was difficult for me to reconcile TIC as an organisationally-embedded philosophy with the continued sanctioning of prone restraints, which are known to be high-risk and traumatising.

This exchange typified the struggle to meaningfully translate TIC at the DSP level of practice, which was an ongoing discussion with every care organisation I engaged with. Some (but not all) of the TIC institutes also recognised this difficulty.

4.2. Thrive Orange County

Brandy Terrell chairs Thrive Orange County, a program at Southern Indiana Community Health Care (SICHC), which seeks to build TIC into the whole community and workforce settings. I was able to spend the day with her and John Keesler. She described a lot of the practicalities around implementing TIC into the Orange County community, which showed signs of trauma across multiple sectors.

Brandy Terrell and Dr John Keesler.

Trauma-Informed Care (TIC) initiatives began when SICHC's CEO Nancy Radcliff and her sister Romona Osborne were introduced to ACEs research while attending a conference. Together with Dr. Yoder, their chief medical officer, they identified high rates of Adverse Childhood Experiences (ACEs) among their obstetric patients This discovery, coupled with similar findings in the 7-12th grade population, led to the creation of Thrive Orange County.

They began with a community-wide awareness campaign and a strategic planning event. This resulted in a strong community desire to develop a youth mentoring program to address the high prevalence of ACEs. Around the same time, they became aware of the high rate of births to young parents (including 19-year-olds). This work became an important component of their coalition's efforts, in partnership with Indiana University School of Public Health.

Brandy stressed the need to 'address **the most pressing need for the organisation**, rather than have our own strategic plan and try to impose it'. For Orange County, they used agreement around the need to address births to young parents as a platform to inform and educate the community about the impact of ACEs and trauma, and begin to build TIC systems and ethos systemically.

She explained that to take a rigid TIC agenda into an organisation and try to implement it is, ironically, not trauma-informed. Instead, working out **the most urgent change needed and how to measure it evidences impact and trustworthiness.** Addressing community priorities established trustworthiness. This helps the community / organisation see a modelling of operating from safety, collaboration, empowerment, trustworthiness and choice in the relationship.

She described her focus on building meaningful relationships with people at all levels of influence. Winning the ears and hearts of the people tilts systems. '**We try to help people with their need, not push our agenda. Being helpful is the best way to build trust; changing organisational or community structures requires a significant amount of trust.** We don't bring a strategic plan for the year – instead we let our strategic plan look like whatever the community says it's going to look like in real time. This builds trust and relationships, and we become known for addressing the immediate needs of the community. These are pieces of the puzzle, and they move the community and quality of life.'

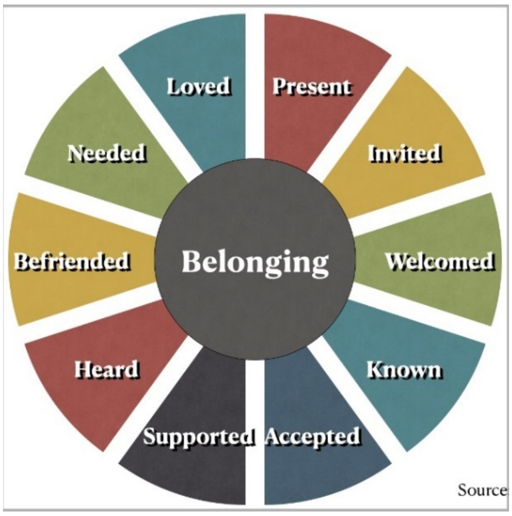
This approach is helpful when considering organisations who are intrinsically traumatised. One of the weaknesses of the TIC models is that they often will not start organisational change work without assurances that the organisation has a level of stability and resilient-enough systems to commit to the process. This rules out organisations – or communities – who are trauma-organised. And indeed, such organisations would not realistically be able to engage with TIC organisational change. However, Brandy's work was with a community that showed some signs of being organised around trauma. Her practical, solutions-based, relational approach with the community has been very impactful, and provides some keys to working with traumatised organisations.

4.3. Stone Belt Arc Inc

Stone Belt offer wide-ranging services for people with IDD and MH-IDD. I was able to visit their therapy centre, Milestone, and their centre for adults, Stone Belt, with Dr John Keesler. Stone Belt have been working with Dr Keesler to integrate TIC into their practice. They are doing this without the wide-ranging, strategic TIC packages, and more gently and carefully as an internal project, informed by research.

Milestones clinic is a therapy centre for people with ID. I spent my time there with Stephanie, one of the therapists – and TIC leaders, and met with the MD team in the afternoon. At StoneBelt, Employment Fundamentals day program for adults with IDD and MH-IDD, I spent the day with Rev Dr Sarah McKenney, the spiritual support coordinator co-TIC leader. We stayed in the recreation room, so that various people who use the service came and joined us as we spoke. This, in itself, felt like a good application of TIC practice.

One of the key principles underpinning their ethos and practice is the notion of belonging.



Source: Carter and Biggs, 2021.

Stone Belt is trying to establish belonging at the practical, social and existential level.

They consider each individual as a whole, relational, spiritual being, and they look for ways to unlock and respect that.

They look to rediscover and reacquaint themselves with the reality that those they serve are fully human, inherently spiritual and made for fullness of life.

They implement the belonging wheel in two ways: supporting their clients to experience belonging in their community. They recognise that those they support aren't and shouldn't get those needs met through paid staff members and other people with I/DD that they see every day. So they work to ensure that those spiritual health needs are being met in their community with real and mutual friendships. Secondly, they strive to ensure staff are experiencing belonging professionally: the more people are known (professionally), supported and heard (within TIC principles), they will feel more respected and a critical and needed member of the organisation.

Implementing TIC concepts has been carefully adapted to the practical needs of the organisation, balancing the need for information and training, with the capacity of the team and systems. For example, one therapist presents one TIC concept a month at team meeting. They take 15 minutes to do this, and present it on one piece of A4 paper. They illustrate with stories. The team then takes 15 minutes to discuss, reflect and develop practical ways to implement this. This pared-down approach has been found to be better received and more impactful than attempting to release DSPs for long training sessions.

They have found that any system-impacting TIC intervention needs to be very simple. In addition, it can't be costly, it can't be time-consuming, and it can't be notional or cerebral. Instead, it needs to be grounded in practice and improving the lives of those the DSP's serve. They have carefully chosen language that can be shared across the organisation – language that feels grounded and 'real' in terms of TIC and the individuals the organisation supports.

On the therapeutic level, they consider simple ways to flatten power hierarchies, such as talking individuals through their care plan, and supporting them to speak up when a DSP doesn't follow it; they also consider the trust-erosion that occurs in individuals who have worked with multiple professionals and services through their lifetime.

Stone Belt's approach to implementing TIC felt like a starkly different approach to the relatively intellectual and philosophical language of some of the TIC institutes, (for example, committing to democratisation or inquiry). Stone Belt's carefully-paced and grounded approach was more connected to the moment-by-moment interactional change that TIC attempts to build. It was more pedestrian and less grand-narrative than the TIC institutes' models, but left me with some key practical solutions for how we might make meaningful impact at the DSP level.

Reflection: I have reflected on my sense that Stone Belt's approach to TIC-implementation felt 'pedestrian' (usually a pejorative comment) – and how maybe this is a critical key for implementation in the IDD sector. How can we go at walking pace, side-by-side with those we serve (rather than cruising above it in a way that allows us to detach from the real-world problems of implementation)?

4.4. Signal Centers

Simone Davis leads the adult day service at Signal Centers, Chattanooga; this is a community-based program serving 60 individuals with IDD and their families. We spent some time together, hosted by Dave Buck from Chattanooga Autism Centre.

The team from Signal Centers (Source: Signal Centers)

Simone described how navigating the pandemic made the team aware of the significant losses that those they serve had experienced – and might continue to experience – and the need for them to find therapeutic ways to support them with this. (Loss is a known source of trauma for people with IDD.)

She described how she equips her team to do this work in practical and candid ways.

- She frames the work as relational and emotional from interview stage onwards. She explains to her staff: *'you're going to build relationships, you're going to make friends, and then difficult things are going to happen, some of the friends that you make here will die, some of them will stop coming to the service, some will lose people along the way. So this is emotional work, and loss and grief and death is all connected with it'.* By stating this as one of the functions of the work, she sets the expectations of the staff team.
- She refocuses the team on their 'why' at every opportunity, collectively and individually. *('you're not here for the money; you're not here for the prestige; you're not here because it's easy work; so why are you here? Give me your 'why'?')* She finds that when presented with the question 'why are you doing this job?', most team members ground themselves in the relationships they are building with the participants. This keeps the focus of the work on relationship-building, and resets the team's motivation.
- She carefully contains and structures the sharing of difficult news. One: she usually hears it first, so takes time to process it and regulate herself. Two: she tells the team and gives them time to receive and process the news. Three: they share it together with the center friends at the start of the day, so they can spend the day letting the questions and conversations surface naturally. Four: they let caregivers and family members know that they have shared this news.

These four simple tools build resilience against vicarious trauma in the staff, and actively seek ways of supporting those with IDD to potentially prevent difficult experiences becoming traumatic, and build therapeutic support into their ordinary care which makes space for recovery from trauma. A full interview with Simone, in which she describes her approach and ethos can be found here.

4.5. Orange Grove Centre, Chattanooga

Rick Rader at Orange Grove described a high-level commitment to community engagement. This was also a considerable focus at Signal Centers. These organisations actively engaged with local schools, universities, community spaces and local celebrities as an ongoing strategy. This was motivated by a number of factors:

- they want as many people as possible to know what they do through active experience
- this equips society – one person at a time - to understand how to support people with IDD
- it is an investment into futures donors
- it is an investment into future employees.

They believed that a week's work experience from a high school student, or a two-week medical placement, or an hour-long tour with an influential person was an investment in changing future services for people with disabilities. For instance, a medic placement would return to their specialism better-skilled for how to engage and treat a non-speaking individual.

They have high levels of volunteers, internships, and they have a lot of placements. They acknowledged that this requires high amounts of organisational time and resource in the short term with low amounts of immediate reward, but they understand this as an investment in societal understanding as a whole, as well as future employees, future allies, future donors.

This magnanimous sector-wide, long-term lens struck me as in contrast to often-times siloed specialist provisions. There is a pattern in the UK that the more 'specialist' a service is, the further it removes itself from the general population, often on the assumption that there will be little understanding of what they do. But this is becoming a self-fulfilling prophesy.

Discussions with the multi-disciplinary team at Orange Grove Source: Orange Grove

Additionally, the legacy of some out-of-county provisions, warns us that isolated services are at higher risk of closed cultures and organisational abuse. This community engagement piece – echoing the linkage work of START – builds an additional layer of resilience around organisations.

Lastly, Rick Radar (Orange Grove) discussed how we do a disservice to the job when we downplay the challenge of it. We need to communicate that this work is difficult in order to attract innovators and problem-solvers. Better pay and benefits will not attract people into the job – it's the work itself that attracts people. The opportunity to do extraordinary work with extraordinary people and learn about humanity in a very different way – work which is fundamentally relational.

4.6 What I learnt from organisations implementing TIC

In practice, TIC was not straightforward for services supporting people with IDD. This was reflected in many conversations with care providers attending the Sanctuary Network Days conference. TIC organisational change can have huge impacts on big-picture vision, ethos and culture, and these are hugely important.

But the difficulty in translating this all the way down to the interactional level between a DSP and a person with IDD is very difficult. Sometimes the big picture success can obscure what is happening interpersonally, or decrease curiosity about this. Finding meaningful ways of engaging at the 'grassroots' level – like Stone Belt, Thrive and Signal demonstrate – is unlikely to look or sound exciting, but it has the potential to make meaningful change. This does not negate the 'big picture' work – both are necessary.

Lastly, I was reminded again and again, that data-gathering and data-sharing is a key element of TIC. This is not a data-mining exercise, but a commitment to open communication and information exchange. In TIC models, evidence is captured at all levels, and then rapidly fed back to those from whom it was captured – so that questionnaires and interviews are experienced as genuinely collaborative and consultative. This helps build trustworthiness and collaboration.

5. Difficulties with implementing TIC in the IDD sector: regression and engagement

5.1 Regression

The Sanctuary Model recognises the multiple stressors operating at different organisational levels (as illustrated above), and how this can cause an organisation to manifest PTSD symptoms in a parallel process to how an individual might, until it has organised itself around trauma, rather than healing.

One common organisational manifestation of this was stressed by both Dr John Keesler and Dr Steve Brown (TSI). They warned how, as organisational stress increases, organisations tend to regress to the mean – they will increase control, and reduce collaboration, trust-building and choice, because this helps *them* feel safe. As TIC work begins, there is often an ongoing pull back to the mechanisms of hierarchical control in overly-stressed organisations. Thus for any TIC intervention, margin needs to be built into implementation time and stages, in acknowledgement that TIC will take a hit when pressure and stress increases.

5.2 Engaging DSPs in TIC

Steve Brown from TSI discussed that it had been difficult to engage organisations from the IDD sector in TIC organisational change work. There was generally less interest and impetus for the work. This is reflected in the small number of IDD organisations that have implemented TIC in the UK and USA.

Most of the TIC models require at least once full day of training with everyone – some require more than this, followed by ongoing reflection and adaptability. Sanctuary comments: ‘In residential settings…the need for constant supervision of the children can create challenges for release of team, training time, and opportunities for direct care workers to participate’. (ANDRUS, 2023).

Getting a group of DSPs in a room for the day can be logistically challenging. But some of the organisations I talked to were achieving this, only to find that DSPs appeared to struggle to listen, engage and reflect on the training – and that the principles were not being adopted or implemented. This resonates with our own experience at Unique Connections. On reflection, I have come to understand that the difficulty with engaging DSPs is not a problem with DSPs – but a problem with what we are asking of them.

> I remember my own mornings as a DSP – often high-paced, with multiple interactions, juggling the medical, physical, nutritional, interpersonal and relational needs of several young people with IDD-MH. I would be primarily focused on the here-and-now-ness of the young person in front of me – how were they physically, emotionally, relationally right now, and how can my immediate interaction with them be most helpful?

DSP’s work is present-focused, grounded, visceral, interpersonal and practical. It is the stuff of the amygdala and vagal nerve and empathy and intuition – it is work that requires a person to react and respond and rely on their instincts. This is the work we need DSPs to do and, in the best-case scenario, people wired for this sort of work seek it out and it brings them life.

Due to the constraints of making space for DSPs to attend training, we find at Unique Connections we are often asked to train teams straight after they have delivered several hours of direct care, and many of them will go back to it at the end of our session. Some even nip off at lunch to check on those individuals who are on their mind.

TIC training asks DSPs to switch mindsets out of their dominant operating system. Many of the models are philosophically rooted, and ask for a reflective or curious state of mind – which requires a highly regulated state and access to the problem-solving centre of the brain. Some aspects of TIC are notional or even philosophical. This is not the sort of thinking DSP work lends itself to. When we ask them to shift focus to notional, organisational concerns, we are being unreasonable. In short, I am not sure of the reasonableness of asking a care staff member to spend two hours supporting with personal care and mealtimes, and the subsequent two hours reflecting on how best to commit to TIC values and commitments.

At this point, my mind turns back to Brandy’s focus: what is the perceived need of the community? And to the START programme – introducing organisational change and influence around the needs of an individual in crisis. DSPs are fundamentally preoccupied with the needs of those they serve – and they should be, this is the job we ask them to do.

A meaningful way forward with DSPs might be to ensure we engage with them at the point of their greatest perceived need – most likely the person who is causing them greatest concern. And use this work to introduce tailored support, as well as cultural and organisational work, that slowly tilts the organisation and the culture into a TIC space.

6. Applying this into the UK context – what might be possible?

6.1. The current context

1. We know that people with IDD have a high chance of presenting as traumatised.

2. We know that DSPs have higher-than-average rates of Adverse Childhood Experiences(ACEs), implying that levels of trauma are likely to be higher than in the general population.

3. We know that the impact of the pandemic and the ensuing years, plus the difficulty of the work, increases the chance that care-giving organisations are traumatised.

4. There is evidence that the sector is at breaking point.

In the UK, we have a great deal of trauma in the sector, which is eroding safety, resilience and connectedness at every level.

And yet… the needs of the sector point to Trauma-Informed Care as needed.

6.2. Key cultural differences between the USA and UK

In the USA, the above situation is being addressed through TIC organisational change with some evidence that it is impactful across the three levels – organisationally, with DSPs and with those with IDD. However, organisations tend to be much larger, with much greater administrative and leadership capacity, and greater economies of scale. In addition, the culture in America leans towards therapeutic interventions – with personal therapy and therapeutic interventions being far more ordinary. This means that there is prior-context for some of the language that we find in some of the TIC packages. The UK context has a number of key differences:

> There are different assumptions and expectations in the USA about how organisations are run. By illustration, I was talking with a USA colleague recently about a care organisation's struggles to engage with us on a quite low-level initial conversation about potential TIC organisational change. He asked me: 'what did they do last time they did organisational change?' I explained I had never known a UK care provider engage in formal organisational change.

1. UK organisations tend to have less administrative and organisational capacity, with a culture more suspicious of therapeutic approaches and language.

2. Anecdotally, through my interactions with LAs, organisations and commissioners, it seems social care – particularly children's social care – is in crisis. This poses a serious problem for the TIC organisational change model.

All of the TIC institutes (except START) will not work with an organisation unless there is enough basic resilience and stability to maintain a two-to-three year commitment to TIC organisational change. There needs to be enough leadership and organisational capacity to engage, and enough resources to commit to an organisational change process. This is not common in the UK.

3. It seems that some of the goals of TIC are too low for what is needed in the UK, e.g. reducing or eliminating re-traumatisation of those that the organisation cares for. Whilst laudable, it does not feel like it goes far enough. Do we want to stop re-traumatising those in social care? Or do we want to create healing environments?

4. It's not clear if the established TIC models are always impacting the interactional level between DSP and the individuals they care for; we should not compromise on this, as meaningful change for each individual must include change at the interactional level.

It does not feel like the TIC organisational change models can just be imported from the USA and expected to function or bring the meaningful change we need in the UK. Instead, we need to use some of the ethos and principles of TIC organisational change, and translate it to UK policy and practice.

6.3 Key strengths of the UK context

Despite the social care crisis, we have some advantages in the UK.

Firstly, our smaller organisations don't lend themselves to TIC organisational change, but they do lend themselves to individualised and person-centred care. They lend themselves to making changes at the interactional level.

Secondly, we have some key concepts at the heart of children's social care which use language we don't find in TIC, but which is critically important. The recent government consultation paper, **'Children's Social Care: Stable homes built on Love'** (2023) is illustrative.

This paper echoes the long-established Key Principles from the Guide to the Children's Home Regulations, which state: **'Children in residential child care should be loved, happy, healthy, safe from harm and able to develop, thrive and fulfil their potential'** (2015: 6).

Picture source: Arleen wiese on Unsplash

The UK social care context would struggle with some of the notional and therapeutic language of the TIC models. However, it has been trying to legislatively embed the principles of love and belonging in the sector for the last decade. This is a huge opportunity to explore what this might mean to practically embed love into organisations within a TIC-inspired model for restoring resilience.

This points to the development of a tailored TIC-inspired, love-and-belonging-focused package of organisational support and change aimed at social care services for children and young people with intellectual disabilities. Such a model would need to:

- be specifically written for organisations who are caring for those with intellectual disabilities, and cognisant of the complexities of supporting non-speaking individuals.
- be written for the UK context – ideally in collaboration with those in the sector, so that it is mindful of practical constraints, as well as what can be culturally tolerated.
- find shared language that fits the UK sector and makes sense to DSPs.
- have as its focus the support and coaching of DSPs, leaning into their practically-grounded work, rather than being philosophically-grounded, to respect and uphold the work that they are employed to do.
- be written in collaboration with people with neurodiversity.
- be piloted with several organisations working in a collective.

There are key learnings from START's approach, which builds organisational, systemic and individual capacity around one individual in crisis. However, the vision for organisational change that the TIC models hold and deliver is also critical for long-term change in organisations. We should be seeking to build care organisations that are resilient enough to weather future crises, whatever they look like.

Lastly, I think one of the biggest UK problems with implementing TIC might be our biggest opportunity. What if a UK-tailored TIC-inspired model was grounded in the work of DSPs - the person-to-person, moment-by-moment interactions between caring adults and children being cared for? This is envisioned as a dual-level intervention that seeks to coach and build capacity into a team around one individual in crisis, whilst simultaneously working on embedding TIC values into the organisation and culture.

As we hold in one hand the evidence about the trauma presentations inherent in the social care system in the UK, we must hold in the other hand the truth that trauma is recoverable. People and organisations become traumatised because they are adapting to their current context and their experiences. Intentionally and deliberately rebuilding the structures and systems of safety invites an organisation to adapt again – and recover.

6.4. How could this be achieved?

- There is interest from some USA connections in partnering to help create something like this, namely from ITTIC, TSI, START and John Keesler.
- There is an awareness that the sector is struggling and that wholesale change is required.
- There is a growing interest in TIC, and some great education-focused initiatives.
- Unique Connections is invested in this work.

7.Conclusion

This Churchill Fellowship has offered an opportunity to thoroughly examine TIC organisational change in the USA. The USA presents a context in which TIC and the ideas around it are more culturally assimilated, and in which the sector is starting from an assumption that this sort of work is necessary.

This has enabled me to reflect on the context of the social care sector which supports children and young people with intellectual disabilities. I am persuaded that trauma is a significant aspect of the work – as trauma presentations are higher than average for every person involved, from those living in social care services, to the direct care staff, to the organisations, and maybe even the sector as a whole.

TIC seems like an obvious intervention. However, it needs culturally adapting to the context of the UK. It also is not fit for purpose for those organisations that are organised around trauma in an entrenched way.

This strategic work needs to partner with the persistent, quiet focus of the role of love and belonging in the UK children's social care legislation and guidance. This creates a space to go beyond simply creating safe spaces that do not traumatise, and move towards the creation of safe places, where love and connection are sought, and belonging is deliberately built-in. We must hold onto a certain hope that we can establish safety, love and belonging as the foundations for care services supporting children with intellectual disabilities, and move forward determinedly together to rebuild a resilient sector, that faces up to and offers healing to trauma at every level we find it. For we can certainly do it together.

Summary of recommendations

A dual-focused TIC-inspired model for change should be created specifically for the care sector supporting children with intellectual disabilities in the UK.

Focus One: applying TIC-inspired principles with one individual in crisis, as a way of evidencing impact and outworking practical applications with DSPs.

Focus Two: strategically embedding TIC-informed principles into the organisation's systems and processes.

Crucially, these TIC-informed principles should reflect the UK priorities for building children's social care on the principles of love and belonging.

Further reading

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Appendices: List of contacts and organisations

Dates, Location & Key Host	Project	Key contact	Overview	Related resources
27th – 30th March Chattanooga, Tennessee Hosted by Dr Dave Buck	Adult Day Center Signal Centers	Simone Davis	Community support for adults with IDD	Vlog with Simone
	Orange Grove Centre	Rick Rader MD	Wide ranging services for children and adults with IDD.	Instagram post with Rick Rader:
	Bridges ABA clinic	Dr Dave Buck	Part of Chattanooga Autism Center. Focused, 1:1 ABA training for children aged 2-8.	
31st March – 3rd April Hosted by Dr John Keesler University of Indiana, Bloomington, Indiana	Stephanie Milestones @ ID and MH clinic	Dr John Keelser, trauma and ID researcher at Indiana University (IU)	Mental health support and counselling for people with ID	YouTube Conversation with Dr John Keesler
	Rev Dr Sarah McKenney Stone Belt,		ID advocacy and support	YouTube Conversation with Sarah McKenney
	Dr Brandy Terrell, Southern Indiana Community Health Care		Community-wide TIC project.	
	Prof. Greg Lewis, professor of 'intelligent systems', as part of the extended research into polyvagal theory	Connected through Dr Stephen Porges		Summary of conversation with Prof Greg Lewis
3rd – 5th April Buffalo	Institute of Trauma and Traumatic-informed Care, University at Buffalo (UB)	Prof Sue Green & Dr Sam Koury	Trauma Institute which consults to around 15 organisations, with a manual developed in collaboration with Sandra Bloom.	
9th April – 11th April New Hampshire Hosted by Dr Joni Beasley	The New Hampshire START team at the University of New Hampshire	Dr Joni Beasley, researcher professor and founder of START	START's mission is to improve the lives of people with intellectual and developmental disabilities (IDD) and mental health needs (IDD-MH) and their systems of support, through program implementation, research, evaluation, training and professional development.	
		Bob Scholz, director of programme development		
		Valarie Tetreault, START Program Director		

12th April, Boston	Center for Bioethics, Harvard Medical School	Rebecca Brendal, MD,	Dr. Brendel's clinical practice has focused on patients with complex psychosocial problems, including trauma, dementia, mental illness, homelessness, substance abuse, decisional incapacity, lack of community support, and poverty.
	Traumatic Stress Institute (TSI)	Steve Brown	TSI offers a whole-systems change model to TIC over 18-24 months; it seeks to transform every section of the organisation. In 2019, they developed an adapted programme for IDD organisations and systems. [1]
15th – 19th April IBM centre for learning, Yonkers	The Sanctuary Institute (meeting on 15th; Network Days conference 16th-19th).	Maxine Reddy, Senior Director	The Sanctuary Model offers a 'blueprint for clinical and organisational change, which… promotes safety and recovery from adversity through the active creation of a trauma-responsive community' (ANDRUS, 2023).
22nd – 24th April Kennedy Krieger Institute, Baltimore Hosted by John Campo, Vice President of Psychiatric Services and Luke Kalb, director of the Informatics Program at the Center for Autism and Related Disorders	Neurobehavioural Unit	Dr Hagopian and team Director of NBU	Dr Hagopian and the NBU have been leaders in research around self-injurious behaviour. It was an immense privilege to meet Dr Hagopian and his team, and visit the NBU.
	Center for Child and Family Traumatic Stress	Dan Hoover, Clinical child and adolescent psychologist	Dan Hoover and the Center for Child and Family Traumatic Stress have begun closer collaboration with the NBU, in recognition of the trauma-presentations of many of the children in the NBU. This was very encouraging for me.
	Maryland Center for Developmental Disabilities	Marian Ofonedu Director of Training,	Marian Ofonedu has done so key research in suicide and IDD, which I was interested in. She also shared some key insights around organisational change.
	Katherine McCalla	Assistant clinical director for the Center for Autism and Related Disorders	
	Adolescent Psychiatric Ward	Marcos Grados, Assistant professor of psychiatry and behavioral sciences	Marcos Grados graciously toured me around the adolescent psychiatric ward. We discussed some key cases of complex presentations from young people with MH-IDD.
25th April Washington DC	William Sullivan MD, Kennedy Institute for Ethics, Georgetown University, Washington.		Dr. William F. Sullivan's clinical and academic work integrates ethics and primary health care of people with intellectual and developmental disabilities (IDD). We had some fascinating discussions about development of international standards for the primary care of people with IDD.