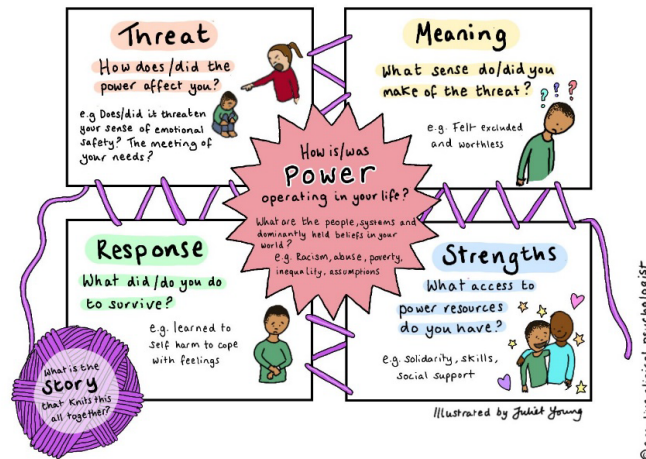# Using the Power Threat Meaning Framework to make sense of experiences parenting a child diagnosed with a learning disability: An exploration of fit and utility.

Background – What did we know already?

-   Research suggests that parents of children diagnosed with a learning disability (LD) experience higher levels of distress and are sometimes viewed by professionals as problematic or 'lacking resilience'.
-   However, less attention has been paid to the distress parents experience as a result of the barriers they face from wider society and the way services are organised.
-   The Power Threat Meaning Framework (PTMF) is a way of helping people create more self-compassionate ways of understanding their experiences of distress (or suffering).
-   It was introduced as an alternative to psychiatric diagnoses and attempts to move away from asking "what is wrong with you?", to "What has happened to you?"
-   The Framework has been useful for different groups of people, but had not previously been explored with parents of children diagnosed with an LD.

Aims – What were the aims of this research?

Project 1.

-   We wanted to know how parents found developing a PTMF narrative. What was helpful/unhelpful? What needed adjusting in terms of using the Framework? How might the Framework be used to support other parents?

Project 2.

-   We wanted to know if the PTMF could be used to help understand any distressing experiences parents of children diagnosed with a LD.

Method – What did we do?

- Seven parents completed three to four interviews to explore and co-develop a non-blaming understanding of their parenting experiences.
- We used the information from the interviews to identify the similarities and differences in parents' experiences.

Results – What did we find?

Project 1.

Three main themes were generated:

1. Altered worldview

- Parents reported creating a PTMF narrative supported them to move towards less self-blaming understanding of their experiences, and supported them to recognise their strengths and the operations of power around them.
- These new understandings were described as empowering and providing practical tools parents believed would support them in managing threats moving forward.

2. Reflections on the PTMF as an approach

2.1. Accessibility of the PTMF

- Parents said the PTMF captured the gravity of the challenges they had experienced as parents, but that some of the language used to explain the PTMF was hard to understand and therefore made it difficult to fully comprehend all the different parts of the PTMF.
- Parents also advised they liked the flexibility of the PTMF and the examples given to explain different threat responses as this helped them identify their own threat responses.
- Parents shared some helpful suggestions in how to make the PTMF more accessible, including more examples of completed narratives in different formats (e.g., illustrations) and supporting parents to develop narratives in groups as this could offer peer support.

2.2. Narrative development as a relational approach

Parents reported it was important to have someone else with them whilst they developed their narrative because the other person could support them to:

i. Apply the theory of the PTMF into practice,

ii. Feel validated in their experiences by having someone witness and affirm what had happened to them, and

iii. Overcome practical barriers to independent narrative development, like parents having limited time and multiple competing priorities in their day-to-day lives.

3. The applicability of the PTMF to parents and ID services

3.1. Utility of the PTMF

- Parents believed the PTMF would be helpful for parents and professionals to develop less blaming understandings of parents' experiences and could help create more collaborative ways of working between parents and professionals.
- Parents emphasised that the timing of introducing the PTMF would need to be carefully considered due to the potential for difficult feelings to be raised during narrative development.

- The need for multiple sessions to develop a narrative was also emphasised, so parents had plenty of time to discuss their individual and shared family experiences.
- Parents advised it would be helpful to review their narrative periodically as family circumstances change over time and it would be an ongoing process to make meaning of the emotions they experienced.

3.2. Not a silver bullet
- Parents shared scepticism around the feasibility of professionals and services adopting a more PTMF-informed approach.
- Parents advised that in order for meaningful change to occur for their families those in power (e.g., managers and bureaucrats) would need to be willing to make strategic and policy changes and work collaboratively with parents and carers.

Project 2.

Parents' experiences aligned with the five domains outlined in the Power Threat Meaning Framework.

1. Power- What has happened to you?

The PTMF suggests that *power* is pervasive in everybody's' lives, and when operating negatively, it can cause suffering. Parents outlined different challenges they had in their (and their child's) lives.

Table 1. *How power operates in participants' (parents) lives*

Form of Power	Examples from participants' experiences
Interpersonal Power: *power* operating through relationships that might promote/deny support, protection, validation or love.	*Witnessing their child being abused/humiliated/discriminated; lack of support from family, friends and other parents; barriers to emotional connection and communication with child; challenges protecting other children from marginalisation/distress; criticism from professionals*
Economic and Material Power: ability to access essential resources necessary for fulfilling needs.	*Restricted and/or absent funding/opportunities for children with an ID and parents; lack of consistent and coordinated support from services; changes to eligibility criteria; financial difficulties; lack of time due to work and caring demands.*
Legal Power: Use of the law to support or inhibit rights and can be used to enforce unfair/harmful policies	*Parents no longer have legal responsibility for child once they are over 18; information not shared with parents; Mental Capacity Act prevents parents making decisions for child; professionals use legal power to control services provided.*
Embodied Power: physical/bodily attributes that are valued by societies e.g. physical health, cognitive ability	*Parental illness; menopause; parental exhaustion*
Embodied Power available to child: physical/bodily attributes of the child	*Physical health problems e.g., heart condition, epilepsy; changes in hormones; cognitive abilities; how the child communicates.*

Social and Cultural Capital: access to valued resources such as education, knowledge and connections that makes life easier	*Services are opaque and difficult to navigate; information is not given to help navigate systems; parents views are discredited by professionals; parents views regarded as less valid than professionals; parents experience barriers to accessing knowledge about child's needs/condition; lack of connection with parents to gain knowledge.*
Ideological Power: control of meaning, language and agendas	*Tragedy discourse; deficit and devalued view of child, parent and life; individualistic discourses; parental responsibility; parents expected to cope; parents expected to prioritise child at all times; parent defined as incompetent, neglectful, mad, overinvolved, demanding; difficulties of child are overlooked-normalisation discourses*

2. Threats – how have these affected parents?

As a consequence of challenging experiences (or negative operations of power) people can experience threats to parents' own needs, and the needs of their child.

- Parents experienced challenges to their ability to protect and nurture their children (e.g., being unable to stop others from discriminating against them).
- Parents experienced difficulties maintaining supportive relationships.
- Parents experienced threats to their experience of belonging and connection to wider society/and the community.
- Parents experienced threats to their ability to access appropriate education, social support for their child and financial security as a family.
- Parents experienced threats their identity where being a parent of a child diagnosed with a LD is perceived as 'lesser' by sections of wider society.

3. Meaning – what sense parents make of their experiences?

This highlighted how parents made sense of what has happened to them and the threats they experienced that would often change depending on the situation they were talking about. Commonly parents made sense of their experiences in the following ways:

Table 2. *Examples of Meanings constructed by parents*

Powerless	Emotionally Overwhelmed
Silenced	Trapped
Responsible	Betrayed
Injustice	Misunderstood
Excluded	Marginalised
Shamed and defective: Not a good enough parent	

4. Threat Responses – what parents do to survive?

Threat responses are the understandable strategies that parents used to protect themselves from adversity and threats they have experienced. These threat responses helped parents to achieve certain outcomes such as maintaining a sense of control; getting support for their child (and them); seeking attachment/connection; regulating overwhelming feelings.

Table 3. *Examples of threat responses parents used to survive.*

Function	Examples of Threat Responses
Maintaining a sense of control; protection against powerlessness	Advocating/fighting for their child's rights/needs, access to services and others with disabilities; seeking/gaining knowledge of systems/legal frameworks; focusing on practical actions; focusing on the positives; following up with/maintaining pressure on services
Getting support for them and their child	Advocating/fighting to access services; emphasising child's needs; building alliances with professionals; "playing the game" and acting so professionals don't see parents as threatening; accessing privately funded resources/opportunities; finding and supporting children to access opportunities.
Protecting self and family from rejection, harm and scrutiny	Mistrust of professionals/services; building alliances with professions; avoiding meetings with professionals; avoiding paperwork; disconnect from loved ones; emotional disconnection; humour; withdraw child from school/environment; withdraw from others; advocating/fighting; self-blame/criticism; self-silencing; accepting insufficient support; suppressing emotions; normalising/minimising the impact on their lives; resisting deficit discourses and embracing positive discourses; cautiousness.
Seeking attachment	Connecting with parents that 'have been through it'; join parent carer groups; honestly sharing experience with professionals; under-sharing personal experiences to protect others.
Preservation of identity	Resist being positioned as devalued; noticing the systems legal responsibility; engaging in social action; maintaining own interests.
Communicating need for support	Expressing worry and concern; expressing anger; rumination; sadness; hypervigilance; visual disturbances; fear; fast heart rate; physically collapsing
Regulate overwhelming feelings	Prioritising family care; stopping hobbies; disconnecting from emotions (e.g., 'coldness'); distraction-exercise; disconnecting from loved ones; develop a 'thick skin'; minimising impact on family life; walking out of professional meetings; thinking about the short term; building shared responsibility for child with partner/family; intellectualising; developing a daily structure; clear out paperwork; controlling diet; accept support from professionals; access private therapy; talk honestly to professionals; 'Letting the stress out' (e.g., shouting/'ranting')

5. Strengths – what parents do to survive?

Despite the experiences parents had they overwhelming discussed what has helped them along the way.

- Parents valued and gained support from people who had been through similar experiences.
- Parents felt that the lived experience of supporting their child help challenge and change their previously held assumptions about disability; resulting in being able to notice the joy

they brought to their lives and the personal growth including being more determined and compassionate towards others.
- Others found value in being able to maintain their interests and engagement in activities that they enjoyed.

Moving forward – What can be done next?

- More research is needed with diverse groups of parents of children diagnosed with a LD to understand more about the utility of the PTMF for these people.
- We have made suggestions for how future research can do this. For example, it might be helpful to use more creative ways to support parents to develop their narratives.
- We have made suggestions for how services can effectively introduce the PTMF into LD services and use it with parents. For example, by not forcing parents to engage in a PTMF approach, offering multiple sessions to develop a narrative, and offering parent peer support spaces to create narratives if parents are not comfortable doing this with a professional.
- We have identified the common experiences parents have had and written a story (or a provisional pattern) that we hope will be helpful for parents who wish to begin developing their own understanding of their experiences (see Appendix A).
- We are preparing our research for publication in a peer reviewed journal.

If you have any questions about what we found or would like to be sent a copy of the research once it is published, please contact the research team via email:

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A provisional pattern about parenting a child with intellectual disabilities in an ableist society.

The text below represents an initial outline of a provisional pattern for parents of disabled children. We have attempted to bring the different elements of the Framework together into one meta-narrative we hope will be a useful starting point for some parents to reflect on their own experiences.

Parenting is widely recognised as a rewarding though often challenging experience that brings many competing demands to parents' identities, relationships and other spheres of their lives. Having a child with an ID diagnosis presents parents with many additional threats: From the moment the possibility of diagnosis is considered, professionals and others in a parent's network can become focussed on 'abnormalities' in a child's development, with parents themselves experiencing concern that their child is not fitting in with expected norms. The reactions of others in a parent's network can result in feelings of marginalisation; that both their child and their family are 'othered', experienced as people to be pitied or patronised, and/or as nuisances to be accommodated. Further threats to alienation and identity can occur when parents must sacrifice work or careers due to needing to provide care or opportunities for their child in the context of inadequate support or educational/occupational opportunities. The diagnosis of ID enables scrutiny from professionals and others with regards to their child's abilities and behaviour, and the parent's competency, with many parents experiencing blame and criticism.

The child's embodied difficulties with intellectual and social skills are compounded by lack of access to inclusive spaces and appropriate support. Discrepancies from social norms become more apparent as the child approaches adolescence as the demands of educational systems and the complexity of interactions with peers increase. Threats faced by the child are threats to the parent, who can feel powerless to prevent bullying and discrimination by other children, parents, professionals, teachers and members of the community. Caught between competing sets of societal expectations (often reinforced through services), parents can feel trapped between feeling the need to protect their child from exclusionary/oppressive environments, and the responsibility to support integration and/or independence. This creates a context in which parents readily experience themselves as bad or inadequate parents, and as powerless to protect the needs of their child; meanings that can be reinforced when unable to access appropriate levels of support. Changes in legal status as children reach adulthood can further disempower parents as they can no longer make decisions about their child's support needs without capacity assessments, which can serve as another barrier to accessing appropriate support. However, parents again become trapped by competing expectations which simultaneously position parents as responsible for facilitating their child's independence by reducing their involvement, whilst also expecting them to plug substantial gaps within support packages.

Recognition that services are underfunded and professionals are overstretched can result in meanings such as rage/injustice, feeling abandoned/responsible, and experiencing oneself as ungrateful. Parents can come to experience themselves as failures/bad parents when they inevitably struggle to live up to ideals in the context of inadequate support; meanings that can be reinforced through experiences of criticism, dismissal, silencing or invalidation from services.

Parents commonly respond with a variety of threat responses such as advocating for their child, hypervigilance to potential criticism or exclusion (to them, child or other members of their family), researching options, making links with other parents, seeking referrals for assessments and other strategies to try and get their family's needs met. However, parents might encounter further threats of alienation and blame when these threat responses result in them being regarded as ungrateful or troublesome. In a context where professionals are forced to gatekeep access to educational, welfare,

and support resources, parents frequently experience burdens of having to emphasise difficulties, speaking to a narrative of problems being with the child and the family not being able to cope, in order for support to be given. The threats of emotional overwhelm associated with not being able to provide their child with a safe environment in which they are accepted, valued and enabled to thrive is significant, and when parents are not able to get the support they need for their child they might respond to protect against emotional overwhelm by shutting off, alienating themselves from others, acquiescing to professionals or utilising various distraction strategies. Parents may risk being viewed as uninterested or not providing enough support in such instances.

For many parents, having a child with intellectual disabilities enables greater awareness of the impact of inequity and ableism, and supports greater empathy with those who are marginalised and disempowered by welfare and social policies. Parents experience love and joy in their relationships with their children and can take pride in their child's values and achievements in ways that resist societal standards of educational or economic 'success'. Parents find solidarity with other parents of disabled children, which can support them in resisting social expectations and managing with the emotional threats that come with ongoing advocacy for their child.