Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 4

Our fourth session of Supporting Disabled Parents: Community of Practice took place on the 21st of April, which introduced Zarah Doyle who serves as the Head of National Supports in AsIAm. Zarah leads the National Supports Team in providing services and programs to support Autistic individuals and their families. Her work includes AAC programmes, Child and Family, Adult Support and Wellbeing. Zarah presented her experience parenting at intersections of Disability and Care, having received a late autism and ADHD diagnosis while also being the primary caregiver of three children one of whom is an Autistic adult and has an intellectual disability. Zarah spoke about the hidden realities of family life, the unnoticed effort it takes to support her family, and designing flexible supports for real life.

Hidden Realities

Zarah discussed the mental load of busy minds, constant processing, risk assessment, sensory overload and emotions, having to stay one step ahead anticipating how daily routines will play out. Much of the effort it takes to support her family goes unnoticed as stability can be mistaken for capability, systems are designed for what is measurable and

visible and when support is given it is often only at a point of crisis. Zarah described the personal cost and mental load of thinking behind every routine, highlighting that this effort does not appear on case files and as the system isn't aware of this mental load, support is not flexible in its approach.

Disabled parents can be reduced to simple tales within the system as they are not designed to identify and support complexities. Narratives of a parent who is a hero/failing, or is strong/overwhelmed flatten the reality of the invisible effort that disabled parents put in. Facing expectation as a parent, while also advocating for their children where prerequisite skills are not always taught, the real challenge isn't parenting it is navigating the system.

Hidden Mental Load

- Heightened sensory intensity
- Deep emotion
- Executive functioning
- Managing own regulation
- Shut down if overwhelmed
- Emotionally in tune

- Justice orientated
- Not occasional – constant

When disability is a family reality

Differentiating how families with disability can have multiple family members with different support needs, Zarah explained that 'family centered' must include the whole family, as there may be not one child, one diagnosis, one advocate. There is pressure across the family, and there are parents who provide support while also needing support themselves.

Designing support for real lives

For support to be meaningful, there needs to be flexibility, trust, predictability and a shared understanding.

Flexibility

- Timelines
- Communication and creating context (transcript app, explanatory story)
- Create time and space to do things differently

Trust

- Saying what is meant

- Reduce overthinking
- Sidetracks

Predictability

- Will there be music playing in the waiting room?
- What will need to be brought?
- How long will the appointment be?

Shared understanding

- Collaborative relationships between parents and professionals

What disabled parents want systems to understand is that:

- Capacity is contextual
- Coping has a cost
- Asking for help and repeated disclosure takes energy
- Stability doesn't mean ease

Then support is:

- More timely

- More humane
- Better informed

Key takeaways:

- Parents are already adapting
- Disabled parenting is Normal not exceptional
- There is pressure building before a crisis
- Disabled parents cannot just try harder
- Design with and not around disabled parents

Public Sector Duty

We looked at this previously, but Public Sector Duty was raised again in this discussion, with the following points made:

- Underutilized in some ways
- Burden should lie with the provider/professional not on the disabled parent
- We need an attitudinal shift
- Asking questions
    - Do you need any help?
    - How can we make this more comfortable?

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Universal Design

We touched on Universal Design in this discussion, for example in the need for predictability of systems and environments. We will return to a more detailed discussion of Universal Design, and considerations about how we can implement it, in our final session on 23rd June.

Discussion themes

This weeks discussion also brought up 'autism friendly shopping hours' where music is turned down and brightness is reduced, however Zarah reflected on how this is sometimes carried out at impractical hours taking into consideration school and work times. Disabled parenting is still stigmatized and as mentioned in previous sessions, fear around asking for help exists. Disabled parents are aware that they may be negatively evaluated when seeking support and there continues to be a fear that a child may be removed from the home if parents cannot meet their needs. The discussion reminded participants of power dynamics between parents and professionals, suggesting that sometimes humanity gets lost in practice.

Isolation as a parent was brought up emphasizing the importance of connection and validation. It was said that finding 'pockets of positivity' can be difficult, especially around puberty age as parents are struggling.

As I Am Resource Library [As I Am | Ireland's Autism Charity | Resource Library]

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Communication

We discussed also in this session communication and how some people communicate differently, are non-speaking or minimally speaking. Regardless of how someone communicates, they still have a right to make decisions and be involved in decision making about their own life. This Ted Talk by Jo Watson reflects on the communication and decision-making processes of a man who is non-speaking. Jo Watson Supporting Decision Making .

Language & Disability | Disability Terminology | The National Disability Authority - National Disability Authority.

Irish Film and Documentary

The group reflected on the short documentary Grace. **Grace** aired on Monday 15th December 2025. This short film is written and directed by Anna Rogers. It centers around Grace who has Down Syndrome and the decisions around her, including her relationships and sexuality. The film can be accessed on RTE Player [Grace - RTE Player].

An Irish documentary, **Somebody to Love,** produced by Wildfire Films in 2014, explores sexuality and parenting and the limitations – social and legal - that disabled people can encounter. Note that since this documentary was made the law has changed in Ireland; however the personal stories of disabled persons still ring true. The documentary is available on Vimeo Watch Somebody To Love Online | Vimeo On Demand on Vimeo.

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The feature length film, Sanctuary, with the cast from the Blue Teapot Theatre Company, Galway, is also a recommended watch!



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