Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Session 1

Our first session of Supporting Disabled Parents: Community of Practice (CoP) took place on 17th February 2026, marking the beginning of a seven-part online programme focussed on shared learning, reflective discussion and professional connection. The CoP for professionals supporting disabled parents was identified as a need arising from the HRB funded conference Supporting Disabled Parents held in Mary 2025. The programme was co-designed with disabled parents and centres the lived experience of disabled parents in each session.

The CoP facilitates non-expert conversation on a shared interest and encourages active collaboration from all attendees. We have participants from diverse backgrounds across Ireland, including, professionals supporting people with intellectual disability, professionals from Cognitive Connections , Acquired Brain Injury Ireland, The National Rehabilitation Hospital, Headway, Tusla, Starbright and the Department of Children, Disability and Equality, and Department of Justice to name a few. There were people who fill a variety of roles from social work to physiotherapy to Occupational Therapy to social care to team leaders and policy writers. One participant identified as a disabled parent, and together the wealth of experience and commitment shone through from the very start.

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The session held a short introduction so we could get to know each other and share our expectations and goals of the Community of Practice, along with outlining diverse expertise and experiences we hope will continue to flow through our reflective conversations.

This week Julie Helen gave a personal presentation on her own life experience as a mother, wife and a communications and disability specialist, who has worked in intellectual disability services for over 15 years. She combined this personal perspective with key issues and concepts such as language in disability and the ableism. Julie is a weekly columnist with the Echo in Cork and is also a guest lecturer on disability courses and Education courses in UCC. Julie has cerebral palsy and uses a wheelchair for most daily activities.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) uses person first language while identity first language is preferred in some communities. Speaking on the language of disability, Julie referred to the National Disability Authority (NDA) advice paper on Disability Language and Terminology for a list of recommendations. Julie emphasised how language really matters as it can be very emotionally difficultif a person feels they need to defend their parenting or defend where they sit in the world. The NDA gives six concrete recommendations: take a contextualised flexible approach; ask people about their preferences; avoid medicalised language; avoid stereotypes; avoid euphemisms; and avoid negative

language. For more information on language and disability please refer to the NDA guide here: NDA Advice Paper on Disability Language and Terminology - National Disability Authority.

Julie spoke about ableism and the attitudes and systems that treat people with disabilities as inferior to people that don't have disabilities. In relation to parenting the idea that a parent with a disability 'should be able to' do the things in the same way as a parent without a disability, such as washing and dressing the baby. Internalised ableism is when a disabled person themselves will believe that they are not as good as someone who can do those things.

The theme of fear around a child being removed from a parent with a disability was a thread through Julie's experience, particularly where both parents had a disability and were living independently. Julie described spending two years preparing and planning for pregnancy and motherhood, highlighting the importance and availability of both natural and external supports. Julie questioned what would have happened if a pregnancy was unplanned and she didn't have supports in place. She mentioned that she was unaware of specialist support and was fearful of seeking help in case it created a reg flag over her family.

While in hospital after the birth of her son, Julie said to the care assistant beside her that she could leave and that she would call her if she needed assistance. The care assistant said that she could not leave, and that she had been told by management to not leave Julie alone

with her newborn son. Julie emphasised that had management communicated with her previously that they would be providing extra support post birth, she would not have become so upset and fearful. Julie appreciated the need for risk management but deciphering the lack of communication made the situation more difficult than it needed to be, particularly in the context of the planning and preparation that was undertaken.

In a second issue that arose in hospital reflecting a lack of disability awareness, Julie spoke of hospital support workers moving her walking frame out of reach while cleaning the hospital room, not realising that it would inhibit her ability to get around. On a point of access, when Julie first started attending the hospital for appointments staff were not aware of accessible routes and places within the hospital.

Julie showed us that we need to remove judgment when we're supporting people and have an awareness of ableism, continue to think outside the box and recognise our own unconscious bias or unconscious ableism. When leaving the hospital, two student nurses thanked Julie for sharing her experience and allowing them to learn how to support somebody with open and honest communication.

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Discussion Themes

Fear, surveillance and communication

Part of the aim of this project is to have a space where we can have open and honest conversations about our practice so that we can learn from each other. Supporting disabled parents is an act of humanity and the piece about human rights is important. There was an emphasis on the fear that exists, or at least existed for Julie, and we reflected on how difficult it is to express that fear due to judgement. It is a common thing for disabled parents to feel fear, to feel they are under surveillance and to have challenges with communication with services throughout parenthood.

Hidden aspects of disability

We talked about the hidden part of disability, and the impact fatigue and pain can have that nobody ever sees, as well as balancing the mental load of parenting and the elements of disability. We acknowledged that there are a lot of things we don't think about.

Community perceptions of disability

Negative perceptions of disability persist in the community, and these extend to parenting. Julie gave an example of retail assistants running after her son as he left the shop,

assuming that the adult in the wheelchair beside him couldn't be his parent. The NDA 2017 survey on public attitudes to disability in Ireland considers the question of people with disabilities have children. While generally reasonably high, up to 85% of respondents were in agreement that people with disabilities should have children if they so wish, the level of support varies across type of disability, with the lowest support for mental health and intellectual disability. You can read more here [Public Attitudes to Disability in Ireland - National Disability Authority].

Supports available to disabled parents

We spoke about the supports available to families with disabled parents and Tusla has Family Support Teams throughout the country with more details in our resource section.

General resources

Convention on the Rights of Persons with Disabilities (CRPD) | Division for Inclusive Social Development (DISD)

NDA Advice Paper on Disability Language and Terminology - National Disability Authority

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Tusla resources

https://www.tusla.ie/services/family-community-support/prevention-partnership-and-family-support/

https://www.tusla.ie/services/family-community-support/family-resource-centres/

Some resources around Meitheal

https://www.youtube.com/watch?v=wp89nsR5jcE Meitheal like a Pro

https://www.youtube.com/watch?v=0RrE4u39E-c Meitheal Success Stories

https://www.youtube.com/watch?v=kF6DKMBZPzc Jennifer's Meitheal Experience

https://youtu.be/-Y-umfo7780?is=ouXrNJcjHELloeUS Charlie & Sinead's story with Meitheal.

The Changing Futures website is designed by children and young people to explain Tusla services to children and young people, but it can also be a useful, clear explanation of Tusla services and staff for grown ups!

https://changingfutures.ie/

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Media resources for further detail on Julie's Story

EP 42 - Julie - One pregnancy & Birth, Mother with Cerebral Palsy, C-section - Ireland's Birth Stories | Acast

Episode Three - Julie Helen - Hiccup | Podcast on Spotify

Julie Helen on becoming a mum: Echolive.ie

We look forward to seeing you all again on 24th February at 2.00pm

This project is supported by the Department of Children, Disability and Equality's What Works initiative, which is funded under the Department of Rural and Community Development and the Gaeltacht's Dormant Accounts Fund.