Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Part 1: Summary of Session Two and Resources

Part 2: UNCRPD, Public Sector Duty, and Disabled Parenting

Part 1

Our second session of Supporting Disabled Parents: Community of Practice took place on the 24th of February, introducing Elaine Grehan the Advocacy Service Manager for the Irish Deaf Society. Supporting the rights and access of Deaf people at local, national, and international levels for over 20 years, Elaine leads the department in its daily efforts to empower the Deaf community, informing the community of their rights and ensuring they have a strong representative in governmental consultations. Elaine was a pivotal figure in the campaign for the Irish Sign Language (ISL) Act in 2017, whose impact she discussed throughout her presentation. As a deaf parent of three hearing children, Elaine has firsthand experience of the barriers and attitudes Deaf parents face. Recognising the unique challenges faces by Deaf parents with additional disabilities — often referred to as "DeafPlus" — Elaine is committed to breaking down these barriers. Through her work with Disabled People's Organisations (DPOs), Elaine is passionate about building an inclusive society where all parents, Deaf and disabled, are respected and supported to thrive.

Elaine spoke about her experience at antenatal appointments, having to communicate with doctors through writing as no ISL interpreters were provided. Elaine mentioned that she missed out on emotional reassurance, tone and the human side of care throughout her pregnancy, sometimes leaving appointments asking herself, "have I understood what was

discussed today?". She had to endeavour to do most of her own research on pregnancy as the problem was never her deafness but access itself. Elaine also discussed how she missed out on sharing her experiences with other mothers and had to seek out another Deaf mother for connection. For the birth of her child, there was an interpreter present which allowed her to ask questions and to respond to doctors, reassuring her and allowing her to feel safe.

A key issue that Elaine highlighted was that when attending appointments with her children, doctors address her children and assume they are willing to translate. While her children are happy to translate, Elaine discussed how the onus should not fall on her children especially as the information would be very personal and should not always be discussed in front of them. There is a complete lack of privacy and no barriers to withholding this information from her children. Some people have described her children as 'brave' and Elaine finds this offensive as these barriers should not exist and that the system has failed her family. Children and teenagers should not be used as communication bridges and should not have to take on that responsibility. Exhausted by the constant fight for what should already be provided for, Elaine spoke about the extra effort in planning and emotional energy that she must exert to access basic appointments. Elaine urged that change begins when people hear lived experiences and act on it, noting that the barrier to access is attitude rather than her deafness.

Elaine described the frustration in asking for interpreters to be present at parent-teacher meetings and how one was never provided. She would have to fight to get an ISL interpreter

each time, instead of the school taking responsibility. A recurring theme brought up throughout the session was isolation from the community, in particular isolation from other parents. Elaine described how lonely she felt at her daughter's Irish dancing competitions as other parents could not communicate with her. She described a time where she brought a book to one of the competitions so that she could pretend she was feeling fine and not invisible. Elaine reiterated that other parents are not excluding her out of cruelty but instead they do not know how to include her in conversation.

Discussion Themes

The Irish Sign (ISL) Act 2017 and its impact

The Irish Sign Language (ISL) Act 2017 officially recognises ISL as a native language and the right of the ISL community to use, preserve and develop the language. It mandates that public bodies and courts provide free accredited ISL interpreters for proceedings for users that cannot hear or understand English or Irish when they are seeking access to their entitlements. Public bodies are required to do all that's reasonable to ensure that members of the Deaf community are not at a disadvantage. The Act aims to better accessibility to public services, legal proceedings and education; however, Elaine elaborated on its actual impact since 2017, noting that reportedly 52% of public bodies are not aware that they are required to provide accredited ISL interpreters.

- **3.** (1) The State recognises the right of Irish Sign Language users to use Irish Sign Language as their native language and the corresponding duty on all public bodies

to provide Irish Sign Language users with free interpretation when availing of or seeking to access statutory entitlements and services.

- (2) The community of persons using Irish Sign Language shall have the right to use, develop and preserve Irish Sign Language.

Has technology improved access?

Technology has certainly improved access as interpreters can now work remotely, saving on the need to travel and coordinate schedules. While Elaine pointed out that in-person ISL translation is better, technology has increased availability and access to ISL interpreters. A particular benefit of technology for the Deaf community is the ability to connect and communicate with others on social media. Through texting, video conversations and sharing media the Deaf community can find shared experiences and participate in discourse about Deaf culture in a supported community. Many platforms such as Facebook, TikTok and Instagram support videos in sign language allowing Deaf people to communicate directly in sign language without barriers. Elaine expressed that English cannot yet be translated into ISL and is wary of this technology developing as it may lack emotion, tone and accuracy in facial expressions. A recurring theme throughout our sessions so far is feelings of isolation and loneliness as a Deaf or disabled parent, and with the development of online social media platforms supportive communities have created space for sharing lived experiences as well as allowing for representation and advocacy. Representations of Deaf culture can be seen in films such as *CODA* (2021) and the Irish film ***A Quiet Love* (2025)**, challenging stereotypes and introducing Deaf stories to

mainstream audiences, this visibility in media creates conversation and highlights the importance of inclusion.

Elaine spoke about the education system and how critical it is for Deaf students to have access to a full and inclusive learning experience; she mentioned that schools dedicated to deaf and hard of hearing children hire teachers that cannot speak sign language. While some supports in recent years like the **Language Connect** primary school programme allows children to learn and engage with sign language, Elaine reiterated that this is currently limited to 5th and 6th class students. There are communications boards in many playgrounds in Ireland but it is important to remember that they include signs from American Sign Language rather than Irish Sign Language and American Sign Language is an entirely different language to Irish Sign Language.

IDS Everywhere is a mobile app that was developed by the **Irish Deaf Society** irishdeafsociety.ie and Centre for Deaf Studies , Trinity College Dublin, that provides commonly used phrases through learning tools, and its accessible to both children and adults for free. Elaine shared her experience of working in a role where she was working in a back office, where she felt that she was placed there so that communication would be limited with other staff and the community, she expressed that when she returned to working in the IDS, her deafness was never an issue and that communication was accessible. She explained how much of a difference it made being able to communicate with other deaf people and to her sense of belonging in the workplace.

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

A common discussion theme throughout our sessions has been the fear of surveillance as a Deaf or disabled parent, and the fear that seeking out supports may lead to a child being removed from a family. During the discussion it was brought up that currently there are no Deaf psychologists in Ireland, and that if a Deaf person wishes to speak to a Deaf psychologist they must reach out to British services, who of course speak BSL a different language, or us an interpreter, which can be experienced as difficult on very private or sensitive issues. Throughout the presentation and discussion a primary theme was highlighting that the burden lies with the professional, in education, employment and healthcare, it should not be carried by the student, employee or patient. Access is a human right, and Deaf people are rights holders, it is not the responsibility of the person seeking a service or basic communication to fight for their rights.

The **Deaf Village Ireland,** which can be found here , is a collaborative initiative bringing together all the deaf organisations in Ireland.

Guidance on writing in **Plain English** can be found here at the **National Adult Literacy Agency:** **Plain English guidelines at a glance - NALA**

The **Irish Human Rights and Equality Commission** have information on disability rights

Disability | IHREC - English

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Part 2

UNCRPD Parenting Rights & Irish Public Sector Duty Key Information

1. Overview

In our discussions over the last couple of weeks, we have spoken about rights as disabled parents so we thought it might be useful to provide some information and signposts to relevant articles of **UNCRPD** including general comments and **Public Sector Duty** in Ireland

2. UNCRPD – Key Articles on Parenting

Article 23 – Respect for Home and the Family

- Recognises the right to marry and found a family
- Protects rights in parenthood, guardianship, and adoption
- States children must not be separated from parents on the basis of disability
- Requires states to support parents in child-rearing

Key quote:

"In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents."

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

We talked about this as a key fear for disabled parents.

Article 12 – Equal Recognition Before the Law

- Confirms full legal capacity of persons with disabilities
- Requires access to supports to exercise that capacity

Key principle:

Legal capacity applies to parenting decisions and rights.

Article 19 – Independent Living

- Right to live in the community
- Requires services that support family life

Article 5 – Equality and Non-Discrimination

- Equal protection under the law
- Prohibits discrimination on the basis of disability

Article 6 – Women with Disabilities

- Recognises multiple discrimination that women with disabilities face
- Protects rights of disabled mothers which is key for parenting

An Roinn Leanaí, Míchumais agus Comhionannais
Department of Children, Disability and Equality

WHAT WORKS
SHARING KNOWLEDGE
Improving Children's Futures

ciste na gcuntas díomhaoin
the dormant accounts fund

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Communication and UNCRPD (Article 2 and Article 21)

This is one of the most powerful parts of the Convention in relation to communication and communication can impact all other rights and articles.

"Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia… as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication…"

This explicitly includes:

- AAC (Augmentative & Alternative Communication)
- Easy Read / plain language
- Assistive technology
- Human support (e.g. someone reading or explaining)

Article 2 also treats sign language as a full and recognised language and public services must provide sign language interpretation

Article 9 – Accessibility

"States Parties shall take appropriate measures to ensure… access… to information and communications…"

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Communication is mentioned here but not as strongly as Article 21. Article 9 deals more with physical access supports.

It does mention that

- Information must be provided in accessible formats
- It states that those formats must be not just available but usable to those who need them.

Examples of formats include

- Easy Read documents
- Audio versions
- Visual supports
- Screen-reader compatible formats

UNCRPD puts an obligation on states to:

Accept alternative communication:

“Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication…”

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Provide accessible information:

"Providing information intended for the general public… in accessible formats and technologies appropriate to different kinds of disabilities…"

Do it without delay or extra cost:

"…in a timely manner and without additional cost."

Article 12 – Legal Capacity (communication link)

This is often overlooked. States must provide support to exercise legal capacity

That includes:

- Communication support
- Time to process information
- Alternative ways to express decisions

Article 13 – Access to Justice

"States Parties shall ensure effective access to justice… including through the provision of procedural and age-appropriate accommodations…"

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

In practice:

- Courts must allow:
    - AAC
    - Intermediaries
    - Simplified communication

Easy to Read / Plain Language

- Simplified text
- Visual supports
- Step-by-step explanations

Audio & Human Support

- Someone reading information aloud
- Explaining in accessible ways

Visual & Tactile Formats

- Braille
- Large print
- Symbols
- Visual schedules

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Under the UNCRPD, states must

1. Recognise communication methods

- Not insist on "standard" communication

2. Provide information in accessible formats

- Without a person having to fight for it
- Not penalise a person for needing support

4. Ensure participation

- You must be able to:
    - Understand
    - Express views
    - Be involved in decisions

Difficulty in communicating is often seen as a lack of capacity which is often incorrect and can lead to difficulty for disabled parents.

This is especially important in:

- Child protection
- Social work assessments

- Court processes

If you can't access information or express yourself, you:

- Can't participate properly
- May be judged unfairly
- May appear "non-engaging"

This all feeds into the fear we have discussed previously and the challenges in engaging with services.

Communication barriers can lead to:

- Misinterpretation of parenting ability
- Incorrect capacity assessments

Article 12 Health

Equal access to healthcare, including reproductive health- this is particularly relevant to pregnancy and fertility support.

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

General Comments on UNCRPD by the UN themselves (Interpretation of Rights)

What are General Comments?

General Comments are authoritative interpretations issued by the UN Committee on the Rights of Persons with Disabilities.

They:

- Clarify how rights should work in practice
- Address real-world issues
- Guide governments and courts

You can read more about General Comments here: General comments | OHCHR

General Comment No. 1 – Legal Capacity

Key quotes:

"Legal capacity and mental capacity are distinct concepts... deficits in mental capacity must not be used as justification for denying legal capacity."

"The denial of legal capacity has... been used to justify... the removal of children from parents with disabilities."

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

General comment 1 is important for Ireland, particularly in terms of Assisted Decision Making legislation, and is well worth a read.

General Comment No. 5 – Independent Living

Parenting relates strongly to independent living for disabled people and the family is an important element of our culture and legislation.

Key quotes:

"Children have the right to grow up in a family environment."

"States parties must provide support to families... to prevent abandonment, neglect or segregation."

Key meaning:

- Families must be supported to stay together
- Institutionalisation is not acceptable

We know that there are still too many disabled people living in congregated settings or nursing homes and this is a significant barrier to family life.

See this report on younger people's experiences of living in nursing homes: Ombudsman.ie - Wasted Lives

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

General Comment No. 6 – Equality

Key quotes:

"Discrimination can be... systemic and structural..."

"Women with disabilities are often considered unfit to be mothers..."

Key meaning:

- Bias against disabled parents is recognised
- States must actively address discrimination

The fact that the general comments acknowledge that women and girls experience even more barriers than men and that steps must be taken to avoid this is important in the context of disabled parenting as it puts a challenge to professionals in supporting roles to understand and work with the reality disabled parents face.

General Comment No. 7 – Participation

Key quote:

"Persons with disabilities... must be closely consulted and actively involved in decision-making processes..."

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

Key meaning:

- Parents must be involved in decisions affecting their children

Public Sector Duty in Ireland

Public Sector Duty is set out in the Irish Human Rights and Equality Commission Act 2014.

It requires public bodies to:

- Eliminate discrimination
- Promote equality
- Protect human rights

Public Sector Duty | IHREC - English

What Public Bodies Must Do under public sector duty

1. Assess

- Identify risks to equality and human rights in their activities

Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 2

2. Address

- Take action to remove barriers and provide supports to disabled people

3. Report

- Document actions in annual reports and other public facing documents

These notes are intended as a launchpad for further consideration in the area and we will come back to talking about rights again and again.

If you have any questions or queries feel free to contact Julie at julie.helen@ul.ie

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

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