



Provided by the author(s) and University of Galway in accordance with publisher policies. Please cite the published version when available.

Title	Re(al) Productive Justice: Parenting toolkit
Author(s)	Flynn, Eilionóir; Dagg, Jenny; Ní Fhlatharta, Maria; Burns, Emma Q.; Sperrin, Áine
Publication Date	2023
Publication Information	Flynn, Eilionóir, Dagg, Jenny, Ní Fhlatharta, Maria, Burns, Emma Q., & Sperrin, Áine. (2023). Re(al) Productive Justice: Parenting toolkit. Galway: University of Galway. https://doi.org/10.13025/m5a2-g942
Publisher	University of Galway
Link to publisher's version	https://doi.org/10.13025/m5a2-g942
Item record	http://hdl.handle.net/10379/17695
DOI	http://dx.doi.org/10.13025/m5a2-g942

Downloaded 2024-04-19T18:39:15Z

Some rights reserved. For more information, please see the item record link above.



Re(al) 
Productive
Justice

GENDER AND DISABILITY

Parenting toolkit



OLLSCOIL NA GAILLIMHÉ
UNIVERSITY OF GALWAY

CENTRE *for* DISABILITY
LAW & POLICY

W
wellcome

Table of Contents

Parenting.....	1
About this toolkit	3
Top Tips.....	5
1. Accessible service provision.....	5
1.1. Accommodating disability access needs.....	5
2. Support.....	6
2.1. Making appointments.....	6
2.2. Attendance of a support person at appointments	6
2.3. Referring to peer support	7
2.4. Respect and reflect	7
3. Case study: Máire	7
4. Planning for parenting	8
4.1. Information	8
4.2. Parenting techniques	9
4.3. Making referrals.....	10
4.4. Equipment.....	10
5. Starting life as a parent.....	12
5.1. Infant feeding.....	12
5.2. The Public Health Nurse.....	12
5.3. Developmental check-ups	13
6. Disability specific parenting support	14
6.1. Social capital	14
6.2. Formal support.....	14
6.3. Formal intervention	15
6.4. Transition into education.....	15
7. Resources	16
7.1. Resources for accessible information and communication.....	16
7.2. Resources for advocacy and peer support	17

Parenting

For many disabled people, becoming a parent is an arduous journey primarily due to the inaccessibility of the social environment and society's prejudicial assumptions about the capacity or capability of a disabled person to parent their child. Disabled parents remain an invisible parenting cohort in Ireland. Disabled people are often adept at advocating for the removal of barriers they face on a daily basis or seeking support when barriers are insurmountable. When it comes to being a parent however, these daily barriers and new ones can be felt more acutely. Parenting brings unexpected challenges as care needs change with the growing and developing child. Disabled people are aware of both the abilities and limitations that their impairments impose, along with the responsibilities they bear to care for their child, similar to all parents. Despite this, they harbour innate fear that as parents, their expert witness of their abilities and limitations go unheard and that any attempt to seek support is viewed as a failure in their capacity or capability, requiring intervention or even threat of separation from their child. For this reason, many disabled parents are fearful of support, of feeling invisible within the supportive realm, and of support being accessible to them. This toolkit presents some measures that professionals who support disabled parents can take to make their parenting journey a more accessible one.

About this toolkit

The Re(al) Productive Justice project is about disabled people and reproductive justice. Reproductive justice is about the choice to have a child, the choice not to have a child, and being properly supported in those decisions. Disabled people should be able to make decisions about having children, to make choices about not having children, and to be properly supported in those choices. However, many barriers exist which prevent disabled people from having the same choices as everyone else. Disabled people have a right to access medical, social work and legal services related to making decisions - and having their decisions respected - around fertility and contraception. Services should be designed and delivered so that they meet the needs of everyone who needs to access them.

Who is this toolkit for?

The Parenting Toolkit is for health, social care and legal professionals who support disabled parents as part of their daily professional practice.

What kinds of disability does it cover?

Our understanding of disability follows the ethos of the UN Convention of the Rights of Persons with Disabilities to include “those who have longer term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation of society on an equal basis with others” (UN, 2006). We consider this statement an open-ended inclusive approach to the question of ‘who counts’ as disabled.

The toolkit is designed to be relevant to a wide range of disabilities, including, but not limited to people with chronic or long-term illnesses, people with a physical, sensory, and/or intellectual disability, people with experience of mental health services (including those who identify as survivors of psychiatry), the d/Deaf community, autistic and neurodivergent people, and those who do not identify with any label or diagnosis but who have experienced discrimination because they are viewed by others as disabled.

What topics are covered in this toolkit?

This toolkit focuses on disabled parents and provides useful information for practitioners to support disabled people who are planning for parenthood and life as a disabled parent. The toolkit uses quotes from our Oral Histories and Key Informants experiences to set the context for each issue. Case studies allow you to reflect on your own practice. A non-exhaustive list of Dos and Don'ts will guide you through each issue. Finally, a list of resources that might be useful in your practice is included.

Who made this toolkit?

The toolkit was developed by researchers at the Centre for Disability Law and Policy, University of Galway, as part of the Re(al) Productive Justice: Gender and Disability project. We benefited from collaboration with health, social care and legal professionals and with our stakeholder and ambassador group which includes a range of disabled people and health, social care and legal professionals.

Where can I go to find out more?

This toolkit is one of a series produced by the Re(al) Productive Justice team. The full list of topics covered includes Parenting, Pregnancy and Childbirth, Fertility and Contraception, and Abortion, as well as two short guides, the Communication Guide for Health and Social Care Professionals and the Know Your Rights guide aimed at disabled people and people who experience discrimination in accessing services because of their physical or communication access needs.

For more information you can visit our dedicated Re(al) Productive Justice project website: <https://www.universityofgalway.ie/centre-disability-law-policy/research/projects/current/real>.

To find out more about the research conducted on the reproductive experiences of disabled people in Ireland, you can read our oral histories which have been archived at the Digital Repository Ireland: <https://doi.org/10.7486/DRI.ws85q6171>.

We are also publishing a book on the findings of our research, which will be available in 2023.

If you have questions not answered by this toolkit, please email realproductivejustice@nuigalway.ie.

Top Tips

1. Accessible service provision

1.1. Accommodating disability access needs

If your service supports disabled parents, you have a legal obligation to make your service accessible to disabled people. Be aware that every disabled person has different access needs, and something that works for one person may not work for another person (even if they have the same disability). While an individual's access needs can fluctuate, this does not mean that they do not really need the access they have stated. For example, depending on the individual's condition, they may walk unaided or using crutches on some days but use a wheelchair on other days. If they ask for wheelchair access, but arrive without a wheelchair to a certain appointment, this does not mean they will never need wheelchair access in the future so it should continue to be provided unless the person says they no longer need it. Even if you find someone's access request unusual or have never received that kind of request from someone with that disability before, do not question whether they 'really need' what they have asked for, but work as best you can to provide that or check with them if there is an alternative solution that will work. There are many ways in which your services can be more accessible for disabled parents.

Do:

- Make it standard practice to ask about access needs in advance of the person's visit.
- Be able to advise on the access features of your service and ensure they are available if required.
- Engage translation or interpretation services where necessary.
- Share your learning from delivering services in an accessible manner with your colleagues.
- Seek feedback about how the person experienced the service and make improvements.

Don't:

- Get frustrated if information needs to be repeated or reframed.



"And there were some practical, some physical things like I will need a ramp because of the buggy because of the dog because we're longer, we're wider, I will need an accessible bathroom because I've to fit a buggy and a dog in at the same time. I live in Dublin so buses, trains I will ask for assistance for the ramp. Again, it's all safety, I can't just nip on and off like I used to and I do sometimes get the – you don't need it, or here we'll just lift the buggy on, and I say, 'No thank you', you know, just because I'm not a wheelchair user doesn't mean I'm not allowed use a ramp or that kind of stuff so, but I'll do what I need to. Accessibility definitely with a buggy to get places..."

- Nadine, blind parent

2. Support

2.1. Making appointments

When the person is making appointments for parenting support, and discloses a disability, the provider should explain what supports are available for disabled people during appointments and this information should also be added to the provider's website so that disabled people will know in advance before booking an appointment what they can expect. Take this example of website accessibility information:

"At this practice, we have step free access to all consultation and waiting rooms for our patients. We can arrange sign language interpretation for patients who need it but we generally need 48 hours' notice in order to book an interpreter. We welcome people with assistance dogs. People can make appointments by telephone or using our online booking form."

It is important to have a number of different ways for people to make appointments.

- Email or text options provide access for disabled people who cannot make appointments by phone, including Deaf people.
- On appointment forms, or as part of the general response when people enquire about appointments, it can be helpful to ask, 'do you have any specific access needs we can help with'?
- Many people do not identify as disabled but will answer a question about access needs.

2.2. Attendance of a support person at appointments

Some disabled parents may wish to bring a support person with them to appointments. The supporter may be needed to facilitate effective communication between the person and the practitioner, to support the person to process the information received at the appointment afterwards, or to provide emotional support. The support person may be a friend or family member, or a paid supporter such as a personal assistant or key worker. Attendance of supporters at appointments should be facilitated by health professionals. Even during public health emergencies, such as the COVID19 pandemic, HSE guidelines maintained that disabled people should be permitted to have support people accompany them to health appointments (including in pregnancy).

However, it is vital that practitioners always speak directly to the disabled person about their appointment, not to their supporter. If a practitioner has concerns about supporters exerting pressure or undue influence on the disabled person when making decisions related to their parenting, they should try to communicate with the disabled person alone to ascertain if the person is providing informed consent. The boundaries of the support role should be discussed at the first appointment. A supporter may be assisting the disabled person to understand information provided, but does not have any legal authority to provide consent on the person's behalf (unless the person is a ward of court and the supporter is the Committee of the ward). While supporters or interpreters may assist with communication, it is the professional's responsibility to ensure that jargon-free, easy to understand information is provided, and the clinician must satisfy themselves that the person is giving free and informed consent to any treatment or intervention and not rely solely on the supporter to ascertain that consent is provided.

If a Deaf person needs a sign language interpreter, it is the responsibility of the relevant service to arrange interpretation. The Irish Deaf Society provides details of how to book an in-person interpreter (<https://www.irishdeafsociety.ie/interpreters/booking-an-interpreter>) while Sign Language Interpreting Service (SLIS), the national Sign Language Interpreting Service for Ireland,

provides information for booking a remote/online interpreter (<https://slis.ie/iris>). It is essential that where a person has asked for sign language interpretation that it is provided at every subsequent appointment. Deaf parents should not have to rely on family members to interpret for them, as this can violate their privacy, and healthcare staff with basic ISL skills are no replacement for a professional, qualified, ISL interpreter. Services should be aware that Deaf people from Northern Ireland may need British Sign Language interpretation, and Deaf people from other countries also may not have sufficient ISL – so it is essential that the service finds out exactly what type of interpreter the person needs so that this can be arranged in advance.

2.3. Referring to peer support

Like all challenges in life, turning towards our peers who have similar experiences provides solace that we are not alone, while also imparting knowledge of what can be different. Peer support for disabled people ensures informal sharing of experiences, knowledge of supportive pathways and increases social capital.

2.4. Respect and reflect

It is important to incorporate a practice of reflection on the way in which you provide your service of support. This can include, for instance, a short weekly activity of responding to the question of – what went well, what did not go well, and what could I change for the next time? Reflection is also required on the way in which you respected a person’s wishes within your service. Did you, for instance, respect a person’s wishes and support them in that wish even though you may have thought it was a bad idea? The Deaf community may wish to retain their cultural specificity rather than opt for cochlear implants for their children. A parent may not wish for their child to attend an autism unit as a result of their own experience of a segregated education setting. Additionally, it is important to be open to the many ways that parents can connect with their children that is beyond an abled-bodied perception of parenting. Remaining open to learning new practices, new knowledge and new forms of connection is of the utmost importance when supporting disabled parents in fulfilling their parental rights and duties towards their children.

3. Case study: Máire

Máire’s third child is two years old and she is concerned about her daughter’s language development. She makes an appointment with an appropriate professional to address her concerns. With public health restrictions only one parent is allowed to accompany the child. Máire requires a support person to attend the appointment and so her request is denied in the interest of maintaining public health. Instead, Máire’s husband attends the appointment without her.

What went wrong here?

- Despite public health restrictions, disabled people have a right to a support person and for that request to be accommodated.
- Máire is excluded from the health care of her child.

4. Planning for parenting

4.1. Information

Becoming a first-time parent can be daunting with many unknown junctures in the road ahead as a child develops. While there is much care, support and guidance provided during pregnancy, often neglected are the practicalities or everyday issues that may arise when a person becomes a parent. To prepare in advance, many parents seek information online, from healthcare providers, or turn to parenting forums (mumsnet.ie or rollercoaster.ie). While there are multiple parenting forums that provide experience, tips and peer support to parents, along with an increase in parenting support information from healthcare providers (such as this HSE site: <https://www2.hse.ie/wellbeing/child-health/my-pregnancy-and-my-child-books.html>), this type of general information is often not disability specific nor accessible.

Disabled parents seek information that is relevant to their experience of parenting with a specific disability, e.g., parenting with a mental health diagnosis or parenting with an intellectual disability. Health and social care professionals should ask disabled parents what types of resources they wish to access and they should be in a position to provide disabled parents with specific information, forums, organisations and resources relating to parenting with general impairments. Many such groups are hosted as closed groups within Facebook; however, it is important that a national peer support network is publicly available. The UK has an equivalent group called the Disabled Parents Network (<http://disabledparentsnetwork.org.uk>) which, while not relevant in some areas such as social or financial supports, may still allow parents to connect with disabled parents with similar lived experiences. It is important to ensure that general and specific resources are collated and that they are in accessible formats for disabled parents, i.e., plain English or easy-to-read formats, screen reader compatible, braille, or ISL interpretation.

Do:

- Ask a disabled parent what type of information on parenting they wish to access.
- Ask a disabled parent what format they would like this information.
- Provide disabled parents with recommended peer support groups.
- Refer the person to an DPO, organisation, agency, or professional that can support the person further if requested.
- Do collate the information that has been helpful and share it with colleagues or practitioners in a similar field.

Don't:

- Assume universal parenting guides or resources apply to disabled parents.



“...when I first discovered I was having a baby, I naively thought that there would be a whole range of supports that people with disabilities, or couples with disabilities could avail of. So, I started, as we all do, started googling and searching, and discovered very quickly there was absolutely nothing. When you put in disabled parenting into the search engine, you just came back with, if you are the parent of a child with a disability – it had nothing in relation to parenting with a disability in Ireland. So, I then started looking, I found some things in the UK, and also in America and just different research from that perspective.”

- Elaine, physically disabled parent



“...I felt that more support should have been given. For example, CODA, there's no CODA in Cork which is quite disappointing because I always look to other parents in the same situation maybe with the same age children that they could share their experiences and what problems arose and how you would look through that and work with your children. But at the moment, you only have the CODA in Dublin, it's a very strong CODA (children of deaf adults) group, but in Cork we don't have that. And I know that years ago there was a CODA group, years ago in Cork and it was well organised. But now, no, there's nothing in Cork.”

- Orla, deaf/blind parent

4.2. Parenting techniques

It is important to remember that there are many ways to complete parenting tasks and all techniques are individual, i.e., there is no one way of doing something. In a child's early years, some disabled parents will need to adapt traditional parenting techniques and they will have questions and concerns about how they can successfully complete tasks in adaptive or alternative ways. In providing information and advice health professionals should remain non-judgemental. Adaptive or alternative parenting techniques are common among disabled parents as they adapt to their new circumstances. The disabled parent can be supported to access, for example, a physiotherapist or occupational therapist so that the parent can gain practice and confidence in their specific parenting techniques, or to peer support groups that can advise on what worked and did not work for parents with similar disabilities. In addition, such techniques may need to be adapted further as the child develops, i.e., how you change a young baby will change as they develop to wriggle, crawl and walk and so it is important that the person has a resource or network that can be accessed over time.



“...why don't I get the physio department to work with you and we can do some one to one around, okay, your physical wellness, but also, we can look at ways of maybe looking at techniques that can help you. ... So, we went to... he referred us to the physio department, and we met with a physiotherapist. And she was fantastic. She said... both myself and Seán met with her, and she said, look, I hold my hands up, I've never dealt with this situation before. But... I think I was about three or four months pregnant at this stage. And she said, let's work together, and let's come up with solutions so that by the time you're ready to have the baby, you'll be able to manage. You mightn't be able to manage a hundred per cent, but you'll have techniques.”

- Elaine, physically disabled parent

It is vital to consider that if you would not ask a non-disabled parent how they would do something, i.e., how would you stop your child running into traffic, then it is similarly not suitable to ask a disabled parent. For instance, many parents with mobility impairments report being asked how they will protect their child once he or she begins to walk, while parents with intellectual disabilities report being asked how they will cope with particular behaviours or questions as their child develops. While it is important to ensure that a child is safe and protected it is also important to balance the needs of the parent. Framing questions in a way that does not generate fear, shame, or disrespect for the parent is crucial. Instead, it is important to remain non-judgemental about the person's parenting skills and fully explore any questions or concerns the parent may have, including referring the parent to other specialists if desired for further consultation to enhance their skills.

4.3. Making referrals

In referring the parent for other forms of care, treatment or support, it can be helpful to pass on information about the person's access needs to other practitioners so that the parent does not face further barriers to their care. Check with the person how they would like their access needs communicated when information is passed on to another person/practitioner/service - they may not want the full details of their medical history disclosed and it may not be appropriate to do so.

4.4. Equipment

Disabled parents seek adjustable child friendly equipment, e.g., cot, sling, buggy or car seat. While brands directed at parents do not market themselves as disability specific, many have adjustable features that are useful for specific disabilities. It is important that information on accessible equipment be gathered for future disabled parents and for knowledge sharing within care settings and practices. Additionally, health and social care providers should have resources for disabled parents that include, for example, a list of professionals who specialise in assisting disabled parents with developing alternative techniques, brands that provide adjustable child friendly equipment, or specific brands that have been recommended by parents with similar disabilities (see UK example: equipment for parents with disabilities). They should also be able to advise disabled parents on the process of seeking support including financial support to purchase such equipment. In communicating such information to a disabled parent, accessibility of the information is paramount, e.g., provided in plain English, easy-to-read, screen-reader compatible, braille, or ISL interpretation.

Health and social care professionals should be familiar with publicly accessible baby changing stations within their locality and universally designed playgrounds in their regions and be in a position to provide this information to disabled parents. This information is held by local government.



"I did speak to an occupational therapist because obviously equipment just doesn't exist for disabled parents and I think I said that anyway when we were chatting that time, but I do remember the OT being really nice, lovely, lovely person and really what we did was we had a chat about my ideas and what I might do because she couldn't think of any equipment. She researched it and she couldn't find anything."

- Anne-Marie, physically disabled parent

Online communities of disabled parents can be helpful for practical tips and equipment hacks. See the Resources section at the end of this toolkit for a list of some disabled parent-led organisations and services.



Watch a short video where Grace talks about accessing and adapting equipment that suits her parenting needs. (<https://www.universityofgalway.ie/centre-disability-law-policy/research/projects/current/real/Toolkits/Parenting/Grace/Equipment>).

Do:

- Provide non-judgemental care.
- Ask a disabled parent what support they require to develop alternative parenting techniques that are specific to their disability.
- Support a disabled parent to access adaptable equipment.
- Provide disabled parents with a list of recommended brands that cater for various impairments. (see Resource section for links).
- Provide the person with a list of peer support groups in which they could gain further support and confidence.
- Arrange for your service to be audited for accessibility.
- Consider the supportive and solution driven way in which your questions can be framed.
- Share your resource list with fellow practitioners and regularly update with suitable resources and continue to share with fellow practitioners.

Don't:

- Ask a disabled parent - "how will you manage?" in reference to parenting techniques.
- Don't assume nor insist that a disabled parent needs to have support within the home in order to adequately care for their child.

5. Starting life as a parent

5.1. Infant feeding

How a disabled parent chooses to feed their child should be respected. Professionals should not assume that disabled parents will opt for one feeding method over another and they should provide information on all the available choices in an accessible manner. Run through a checklist to see if there is anything in particular that they need support with – e.g., an alternative holding technique for latching and breastfeeding the child, or support to make and sterilise bottles. If, for instance, bottle-making machines are accepted for non-disabled parents then equally they should be for disabled parents. Suitable referrals to an occupational therapist, lactation consultant, or breastfeeding support group can be made to ensure further feeding support. In suggesting a referral to another person/professional/provider you will need to ensure that the service is accessible for the disabled parent as referred to in *Accessible service provision*, and if appropriate, communicate the access needs of the parent to the service.

5.2. The Public Health Nurse

For many new parents the public health nurse (PHN) is the main contact point and connection once parent and child are home. It is crucial that the PHN supports the disabled parent in a non-judgemental manner. It is not appropriate for the PHN to question the way in which the disabled parent has arranged their home to suit their needs; instead, they should approach the home from the perspective of the disabled parent and their specific access needs. For example, a blind parent will arrange their home in a way that is accessible for them, including childcare equipment. Their adaptations may appear unconventional to a non-disabled person but they are suitable and well-considered by the disabled parent. It is not appropriate to assume that because the parent has a disability that the child will too, nor is it appropriate to suggest a specific disability as negative, for example, expressing concern that because the parent is deaf that the child is also deaf, or suggesting that because the deaf parent uses sign language with the child that this is developmentally detrimental for the child.



“A public health nurse came but I was ignored. Maybe because I'm a man.”

- Yomi, physically disabled parent

It is important to acknowledge that many new or first time non-disabled parents struggle with daily childcare tasks, face sheer exhaustion, and persevere rather than seek support. This is similarly the case with disabled parents. However, disabled parents face an additional barrier: they are fearful of requesting support as they are often subjected to higher standards than their non-disabled peers and fear that negative perceptions of their disability will overshadow their legitimate request for support. It is crucial that requests for support from disabled parents are received and responded to in a non-judgemental way, with accessible communication and referrals made to address the request as early as possible.

In homes where there are two parents and both have specific disabilities it is crucial that both parents are given support, not just the parent that gave birth to the child. The PHN can address any concerns or requests for support that the second parent may have. For example, they may need one-to-one practice with holding and nappy-changing techniques or support to discover alternative ways in which they can play and physically engage with their child.



“I was put under phenomenal pressure by the Public Health Nurse. She actually said to me, at seven and a half months pregnant, she rang me one day and she said to me - what things are sorted? And I said, well, I’m doing this and I’m doing that. And she said, well look, we need to get these things in place, we need to have things in place, otherwise this is going to become a child protection issue. And Séán came home from work and he found me in the sitting room in floods of tears, in floods.”

- Elaine, physically disabled parent

5.3. Developmental check-ups

When a parent is making an appointment for a developmental check-up for their child and discloses a disability, the PHN should refer to the points made in the section on “accessible service provision” and “making appointments” to ensure that the process and appointment is accessible for the parent. Developmental check-ups for children of disabled parents should be conducted in a non-judgemental way. Many disabled parents have non-conventional ways of communicating and connecting with their child. This does not automatically mean that their way of communicating or connecting with their child is creating a deficit developmentally. It is important to address any concerns or requests for support that the disabled parent may have, and being creative in providing a referral to an organisation/service/professional for support, if required.

Do:

- Remain curious about the alternative ways in which a disabled parent may require support.
- Provide creative solutions to requests for support. Just because you have not made a referral for this type of support previously does not mean that it is not possible.
- Provide reflective feedback with fellow practitioners about what worked well and did not work well to enable collective learning.

Don't:

- Hold a disabled parent to a higher standard than a non-disabled parent as a result of their disability.
- Assume that because a parent has a disability that the child will also have this specific disability.
- Assume that the parent will view the diagnosis of their child having a disability as negative.
- Assume that there is only one way for a parent to connect or communicate with a child.

6. Disability specific parenting support

6.1. Social capital

There is no doubt that parenting is a full-time job. The ability to cope with the demands of parenting is reliant on a combination of family status, family network, kinship relations, and wider social network. A disabled parent may be isolated and excluded from a variety of networks from which to access support due to factors like socioeconomic circumstances or accessibility. Assessing for weak links within a disabled parent's support network is often a first step in addressing their concerns and strengthening their skills. This aligns with a parenting support strategy (see: https://www.tusla.ie/uploads/content/Tusla_Investing_in_Families_Parenting_Support_Strategy.pdf) in providing 'top up' support for parents. Where possible, practitioners should connect disabled parents to peer support groups, DPOs, or local community support organisations such as Family Resource Centres (<https://www.tusla.ie/services/family-community-support/family-resource-centres>) as these can often provide opportunities to share parenting experiences and build knowledge and confidence. If you are providing referral information, it is important that this information is given in an accessible format and that access needs are communicated in advance, if required.

6.2. Formal support

Tusla, the Child and Family Agency, provide numerous tailored formal supports for parents through their Family Resource Centres and social workers. Examples include Respite, Home Help, or Meitheal. When formal interventions take place for a family with a disabled parent, it is important that dialogue is maintained to ensure that specific needs are addressed as changes take place over time. For example, while respite may have been welcome at a certain time and for a certain length of time, this may change as the child grows or as the disabled parent's access needs change. Professionals conducting formal interventions should ensure that the way they communicate with the disabled person is accessible. The disabled person should be asked for their favoured communication methods and all practitioners involved should respect that preference.

A parenting capacity assessment is another tool used by practitioners to identify gaps in parenting skills and ideally to fill that potential in a positive way with targeted parenting support. These assessments take place in formal clinical settings or within parenting residential units. Disabled parents who have experienced these assessments in both environments report that rather than being used to implement support, they are ultimately used against them to legitimise the temporary or long-term separation of the disabled parent and their child. Although some disabled parents have been recommended to enter residential care units where they can gain consistent support in developing their parenting skills and undergo parenting capacity assessments, often these are experienced as coercive. The parent may often be fearful that lack of compliance will result in the separation of parent and child. In recommending that a parent should be admitted to a residential parenting unit, all other forms of in-home family support should be exhausted. The accessibility needs of the disabled parent must be considered, for instance:

- Is the environment suitable for someone with a sensory disability or a mental health diagnosis, and have details of access needs been transmitted from one service to another?
- Have all the consequences of complying to such a request been suitably communicated to the disabled parent?
- Are you satisfied that they have given informed consent?
- If a parenting capacity assessment is to take place, how has this been tailored for the specific disabilities of the parent, and what effective supports have been implemented?

- If the parent is to move from a residential parenting unit back to their home environment are in-home supports activated prior to transfer to ensure continuity of care?



“...an aspect of assessments are how people interact with their children and so on, it’s not just kind of a questionnaire, it’s also an observation of their... But I think that’s problematic, not just for people with disabilities, for everybody. I mean people are... if they feel they are being watched, it’s not exactly a way of having a spontaneous relationship with the child, and especially if the child is not normally with you and you have an access visit which is being observed by other people. And maybe the child is cranky that day or whatever. And far too much hinges on things like that.”

Kirsty, legal professional

6.3. Formal intervention

If a formal intervention such as the separation of a child from their parent is being initiated, it is crucial that the constitutional rights of families are considered. Is the disabled parent being held to a higher standard of care because of their disability? It is important to ascertain if the parent’s needs around caring for their child have been addressed and that all avenues of possible support have been exhausted prior to separation to ensure that the action is justified. Part of your role is to ensure that the parent has legal support and representation, such as the Legal Aid Board (<https://www.legalaidboard.ie/en>) and an independent advocate, for example, the National Advocacy Service (<https://advocacy.ie>). As recent research has indicated, children of disabled parents are more likely to be subject to Voluntary Care Agreements than the children of non-disabled parents. Professionals need to be clear about the Voluntary Care Agreement process and the consequences of agreeing to this option. Parents should be informed that they can remove the child from the voluntary care situation and put in contact with the supports that are available to help them through the process. All information around this process should be accessible for the parent, with adequate time given to raise questions or concerns prior to informed consent.



“They do the assessment, but they do the wrong assessment, and that’s the problem. They would do a parental capacity assessment, but the parental capacity assessment is based on what a fully, healthy or fully abled, a fully abled person can parent a child. So, they’re not, it’s like comparing apples with oranges...”

- Kiera, Social Worker

6.4. Transition into education

It is necessary to ask disabled parents with children transitioning into the education system what supports might help them to assist their child’s full participation in school life. This could include information in specific formats such as ISL interpretation, support to access online or digital devices, or support with conducting homework tasks. Access needs may change over time and should be assessed regularly as the child moves through the education system. When planning school or educational events, accessibility must be taken into consideration in advance. Parents should be asked whether they have access needs that would facilitate their attendance. When planning extracurricular activities, it is imperative to consider the accessibility of the environment in which these activities will be held. Consider whether the environment will be as accessible for a disabled parent to volunteer or chaperone in as it is for nondisabled parents. Accessibility considerations should be included in all communications with parents and in all events at which parents are invited to participate. Accessibility measures should be audited regularly as access needs change or as new parents join and parents of older children move on.

7. Resources

7.1. Resources for accessible information and communication

Some measures to make information accessible are simple to achieve. Others require specialist knowledge or equipment. The information below provides links to special services as well as to resources that will help equip you to create your own accessible documentation.

ISL interpreting

- The Irish Deaf Society can teach you how to book an Irish Sign Language interpreter: <https://www.irishdeafociety.ie/interpreters/booking-an-interpreter>.
- The Irish Remote Interpreting Service (IRIS) provides a booking service for remote sign language interpreters: <https://slis.ie/iris>.

Braille

- The National Council for the Blind Ireland (NCBI) has a commercial Braille production service which can reproduce materials in a range of accessible formats including audio, Braille and large print: <https://www.ncbi.ie/supporting-you/everyday-living/library>.

Screen-reader accessibility

Learn how to make information available in electronic formats that are accessible to blind and visually impaired people and others who use screen-reader technology. Word documents work best. If you offer information for download on your website, it is recommended that both Word and pdf versions of files are made available.

- Microsoft has an explainer on how to make Word documents accessible: <https://support.microsoft.com/en-us/office/make-your-word-documents-accessible-to-people-with-disabilities-d9bf3683-87ac-47ea-b91a-78dcacb3c66d>.
- For pdfs, Adobe has support for how to create and modify tagged pdfs: <https://accessible-pdf.info/basics/acrobat/create-and-modify-pdf-tags-in-acrobat>.

Plain English

The National Adult Literacy Agency (NALA) has resources for making information about your service available in a jargon-free format like Plain English.

- Visit the NALA guidelines for writing in Plain English: <https://www.nala.ie/publications/writing-and-design-tips>.
- Allow them to do the work for you through NALA's commercial service for converting existing documents into Plain English: <https://www.nala.ie/plain-english/editing-training-services>.

Easy-to-Read English

People with an intellectual disability or people with limited literacy can be supported by making information available in Easy to Read formats.

- Inclusion Ireland has created guidelines for creating Easy to Read documents which can support you to convert your own documents into a more accessible format. Inclusion Ireland also offers commercial service to convert documents into Easy to Read: <https://inclusionireland.ie/wp-content/uploads/2020/10/makeiteasyguide2011.pdf>.

Social Stories

A Social Story is a step by step guide that provides a walkthrough of your service. It can be in written, audio, illustrated or video format.

- AsIAM has a video explainer of how to create a social story on their website. Social Stories were developed for use by autistic people but can assist anyone who requires detailed information about a service: <https://asiam.ie/create-social-story-business-organisation>.

For a good example of clear communication, visit the Irish Family Planning Association video on early abortion care: <https://www.youtube.com/watch?v=XrQarH3ktDs%20>.

7.2. Resources for advocacy and peer support

Offer to refer the disabled person to an independent advocacy organisation or peer support group if there are any concerns about the disabled person's rights not being respected, if they seem isolated or if they might benefit from speaking with others who have similar experiences.

Independent advocacy

Practitioners supporting pregnant disabled people in any capacity should also be able to support individuals to make a complaint if they wish to do so – the advocacy options below are additional supports for people who wish to access independent support for this process.

- The National Advocacy Service offers free, independent advocacy to support disabled people in vulnerable situations including those isolated from their communities with few natural supports: <https://advocacy.ie>.
- The Patient Advocacy Service assists individuals to make complaints about experiences in acute public hospitals, which includes maternity hospitals. Telephone: 0818293003; web: <https://www.patientadvocacy.ie>.

Disabled People's Organisations

Organisations run and controlled by disabled people (known as Disabled People's Organisations (DPOs) and different from disability service providers) can often identify possible peer support networks for disabled people. These include:

- [Disabled Women Ireland](https://www.disabledwomenireland.org) aims to be a national voice for the needs and rights of self-identified women and non-binary/genderqueer/gender non-conforming people with disabilities and a national force to improve the lives and life chances of people with disabilities: <https://www.disabledwomenireland.org>.
- Disability Power Ireland is a grassroots, cross-impairment DPO whose mission is to enhance the visibility and inclusion of the disabled community by focusing on the arts and culture as powerful vehicles for changing public perception about what it means to be disabled: <http://disabilitypride.ie>.
- Independent Living Movement Ireland aims to ensure that disabled people achieve independent living, choice and control over their lives and full participation in society as equal citizens: <https://ilmi.ie>.
- Irish Deaf Society seeks to achieve and promote the equality and rights of Deaf people in Ireland: <https://www.irishdeafociety.ie>.
- Neuropride Ireland aims to create a community where neurodivergent (ND) people can connect, share their ideas and experiences, and be proud of who they are: <https://www.neuropride.ie>.
- National Platform of Self Advocates is a DPO run by people with intellectual disabilities for people with intellectual disabilities which aims to be the nationally recognised voice on policy and issues affecting the lives of people with intellectual disabilities: <http://thenationalplatform.ie>.

Supports for parenting

Individual disabled people with lived experience of parenting can be found sharing tips and resources on social media, particularly on TikTok and Instagram. As with any pregnant person, if a practitioner is concerned about trauma and abuse then appropriate referrals for support should be made.

- The Disabled Parenting Community Project has compiled some 'How To' videos for disabled parents: <https://disabledparenting.com/welcome-to-the-disabled-parenting-project-community/how-to-videos>.
- One of Through the Looking Glass's aims is to pioneer adaptive resources for disabled parents and produce resources like this pdf with examples of accessible or adaptive baby care products: <https://lookingglass.org/wp-content/uploads/Baby-care-products-chart-TLG-9-2016-1.pdf>.
- The Disability, Pregnancy & Parenthood community offers practical information and peer support for disabled parents: <https://www.dppi.org.uk/find-information>.
- The Research Institute for Disabled Consumers is a UK charity led by disabled people that provides independent research to create accessible and inclusive products and services. They produce consumer guides on different adaptations from a disabled reviewer's perspective that can help with accessibility at work or at home: <http://www.ricability.org.uk/features-reviews/guides/home-adaptations>.
- Designability is another UK-based organisation that creates products with and for disabled people, including this project to develop a pushchair for wheelchair users: <https://designability.org.uk/projects/projects-2022/developing-a-wheelchair-baby-carrier-which-will-enable-parents-to-transport-their-baby>.
- The Norah Fry Institute has a range of online resources to support parents with intellectual disabilities through pregnancy and parenting: <http://www.bristol.ac.uk/sps/wtpn/forparents>.

Supports for trauma or abuse

As with any pregnant person, if a practitioner is concerned about trauma and abuse then appropriate referrals for support should be made.

- The HSE maintains a list of current supports for people experiencing domestic violence and abuse. <https://www2.hse.ie/wellbeing/mental-health/domestic-violence-and-abuse.html>. However, it is important for practitioners to check before making a referral whether that service will be accessible to your patient. It is possible to check the accessibility of a specific service without disclosing personal or identifying information about a particular disabled person.
- AIMS, the Association for the Improvement of Maternity Services, offers a number of supports to pregnant people and parents, including a birth trauma peer support group, (<http://aimsireland.ie/birth-healing>), a pregnancy and birth support Facebook group (<https://www.facebook.com/groups/pregnancyandbirthireland>), as well as support to patients who want to access their records related to pregnancy and birth or make a complaint.

Please be aware that many of the organisations listed in this section are run entirely by unpaid volunteers and may take time to respond to requests for individual support.



Centre for Disability Law and Policy
The Institute for Lifecourse and Society
Upper Newcastle Road
University of Galway
Ireland
T. +353 86 4181673



realproductivejustice@nuigalway.ie



[@CDLPJustice](https://twitter.com/CDLPJustice)



Or visit the [Re\(al\) Productive Justice website](https://www.cdlpjustice.ie)



OLLSCOIL NA GAILLIMHE
UNIVERSITY OF GALWAY

CENTRE *for* DISABILITY
LAW & POLICY

W
welcome