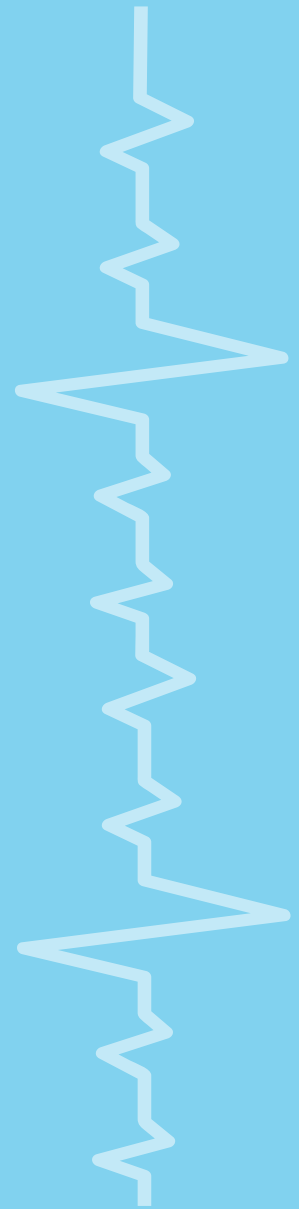


Headphones, Odd Shoes & A Second Chance at Life

An Exploration of the Experience
of Children in Care & Care-leavers
with Disabilities

March 2023



empowering people in care



Coimisiún na hÉireann
um Chearta an Duine
agus Comhionannas
Irish Human Rights and
Equality Commission

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under the Irish Human
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D E B O R A H
E R W I N



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About EPIC, Empowering People in Care

EPIC, Empowering People in Care (EPIC), is a national organisation that works with and for children and young people who are currently living in state care or who have experience of living in care. This includes those in residential care, special care, and foster care, as well as children accommodated by the State under Section 5 of the Child Care Act, 1991 and those sentenced or remanded by the courts in Oberstown Children's Detention Campus. EPIC also works with young people preparing to leave care, in aftercare services, and with young adults with care experience up to the age of 26 years.

EPIC is the only independent organisation providing a direct 1:1 advocacy service to children and young people in the care of the State or in aftercare services in Ireland. EPIC also conducts research and policy work and runs a youth participation and engagement programme.

Researcher's Acknowledgements

I would like to express my sincere thanks to the children and young people who participated in this research for their time, honesty, and the insight they brought to this study, it was an honour to work with you. Thanks also to the young people who were part of the Youth Research Advisory Group, their sound advice was invaluable and I'm very grateful for their dedication to the task. Thanks to all the EPIC Advocates who supported the children and young people's participation in the study throughout, and thanks to the staff at EPIC for their encouragement at each stage of the research, particularly John Murphy who has been steadfast presence from the outset.

About the Researcher

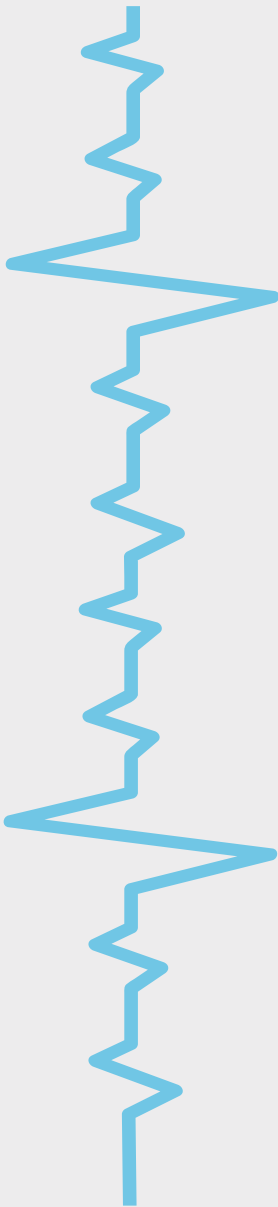
Deborah Erwin is a professionally qualified youth work practitioner with over 22 years' experience of youth and community work and youth service management. Working independently since 2015, Deborah has built a successful consultancy portfolio including programme design and development, strategic review, and facilitation as well as building on her skills as a Researcher. Previous clients include the East Belfast Community Development Agency, Centre for Children's Rights at Queen's University Belfast, Community Youth Work at Ulster University, National Youth Council of Ireland, and RAND Europe.

E: debs@deboraherwin.org

M: +44 (0)7971 081245

W: www.deboraherwin.org

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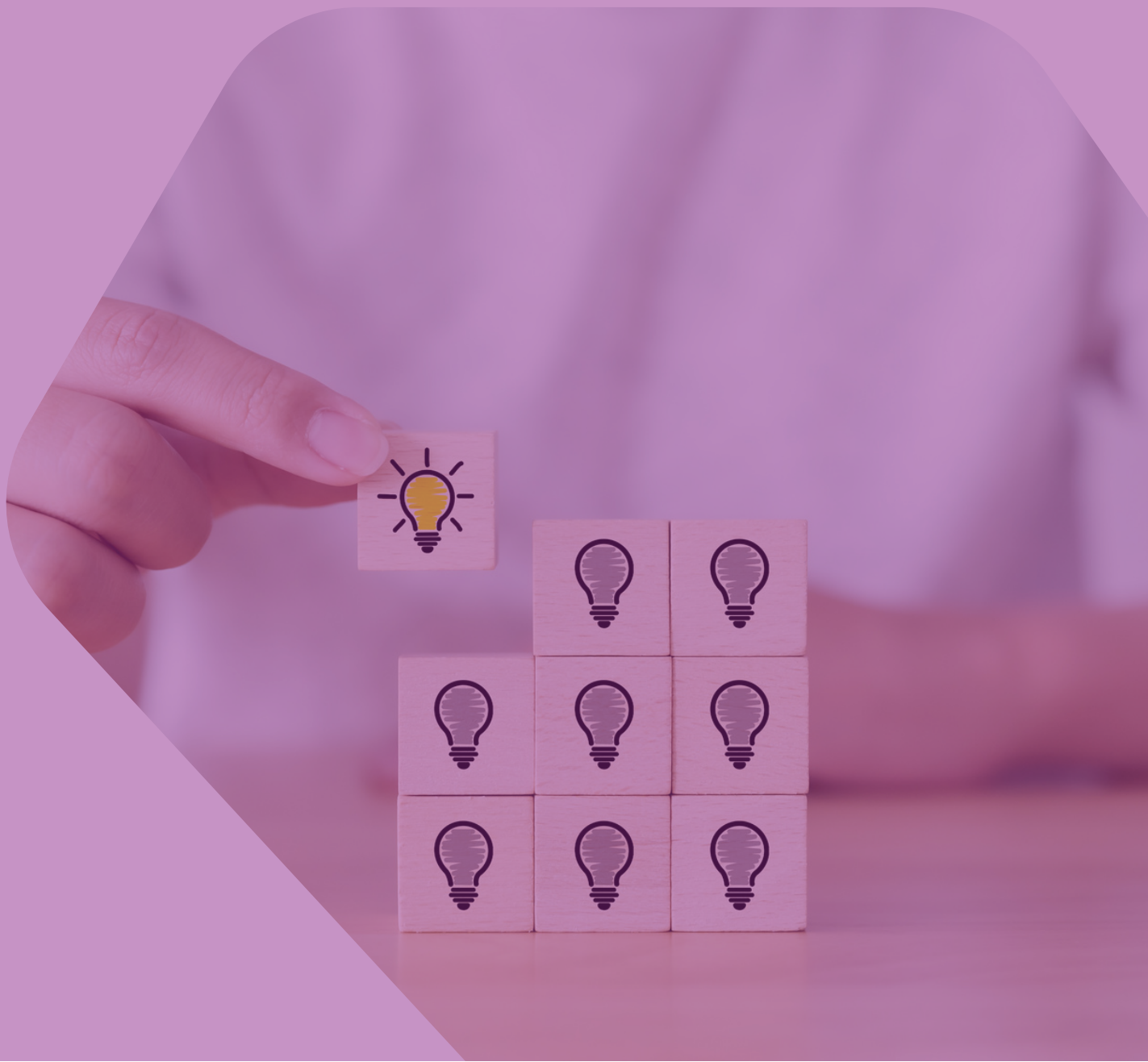


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01

Executive Summary



Overview

In November 2021, EPIC commissioned Deborah Erwin to conduct an exploratory study of the lived experience of children in the care system, and young people after care with disabilities.

The study has four aims and is centred on the following questions:

- To develop an understanding of the experiences of children and young people with disabilities while they are in care, in aftercare services or who have experience of the care system up to the age of 26.
- To enable these children and young people to directly participate in awareness raising, in line with their rights under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the UN Convention on the Rights of the Child (UNCRC).
- To generate evidence to support policy makers and practitioners to progress implementation of the UNCRPD amongst children and young people in the care system and in aftercare services.
- To explore the level of knowledge amongst care-experienced children and young people on the UNCRPD.

EPIC invited the participation of children and young people with disabilities who are, or have been in care, with whom they work. The study was structured to ensure appropriate levels of support and accountability, and to allow the meaningful participation of the children and young people. Eight children and young people participated in the research: six in online focus group discussions over three sessions, and two in an online or telephone interview. The research participants are representative of a range of care experience, including foster care, residential care, and aftercare services, and a range of disabilities are represented, including physical disability, intellectual disability, or learning difficulty. At the start of the research, six of the participants were aged 18 or over, and two participants were under 18. Half of the study participants are female, and half are male. The participants live in different parts of the country, including Tipperary, Dublin, Cork, and Wexford. A qualitative methodology was applied to the research questions, and the focus groups and interviews explored areas of positive practice, challenges, or gaps experienced by the participants.

Key Findings

Supportive individuals made the most impact on participant's care experience. When invited to share an example of a positive experience they'd had as a child in care with a disability, much of the response from participants centred on human interactions. Support and influence from a variety of key people was identified, including carers, professionals from within and beyond the care system, and peers. Most of the participants were able to identify particular people who made a tangible difference in their care experience whether through provision of practical supports, health supports, legal supports, or emotional support. One young person described being in care as having given them "a second chance at life" which demonstrates just how life-changing care can be for children and young people.

Negative experiences in care came from stigma, insufficient awareness, and obstacles accessing appropriate accommodation. Reflecting on challenges experienced, participants spoke about wrong assumptions being made about their disability, a lack of awareness of 'invisible' disabilities, struggles with change or communication, and a lack of recognition among care professionals of the distinctive nature of certain disabilities. They spoke of the intricacies of finding acceptance among peers, complicated dynamics with family members, and a sense of missing out on conventional teenage social experiences. Difficulties in securing appropriate accommodation, and accessibility issues in foster homes, residential care, and social housing also featured prominently. The intersectionality between being their care experience and their disability is clear throughout many of the challenges and difficulties described.

There were significant challenges in identifying supports & services in a timely and effective manner. Securing appropriate supports was a big hurdle for several participants – with one describing it as "a never-ending challenge". Participants shared their experience of struggling to identify and access services, and encountering slow responses, delays, cancellations, rejections, or accessibility issues, which are indicative of a range of 'systems let-downs'.



Several gaps in provision emerged, including a lack of coordination between agencies, insufficient awareness of available supports for children and young people with disabilities within the care system, and limited capacity to respond to ongoing support or accessibility needs. Most of the participants described positive experiences of Social Workers and other professionals, underlining the importance of a strong rapport between child and professional. Unfortunately, there were a range of negative interactions which had a detrimental impact on their care experience, including poor communication, disregard for disability needs, and a sense that their views were not being sought or considered in decision-making.

There was limited awareness among participants of their rights under the UNCRPD, in theory and practice. There was a general awareness of human rights, including disability rights, and the participants had a good conceptual understanding of how children in care should be treated fairly. However, most struggled to identify specific sets of rights that might relate to them. Several felt awareness of rights is important and felt strongly about their right to have a say in their care. The UNCRPD resonated well with the participants, particularly in relation to respect for their inherent dignity, being viewed in terms of their capacities, and their right to information. When asked if their individual care experience matches with how their rights are stated in the UNCRPD, fairness was a common theme in the responses, specifically regarding employment and equal opportunities, with several negative examples given of rejection due to what was seen as unfavourable perceptions of disability in wider society, or a lack of accessibility and adaptation at a structural level. Accessibility presented as an ongoing challenge in everyday practicalities and care placement.

Ideas and Messages for Change. When considering how the care system might be improved for other children and young people with disabilities, three areas for change emerged from the responses:

1. **Interactions with professionals:** Suggestions included active listening, better preparation of children and young people for change, ensuring their input in decision-making, follow-up on commitments that have been made, ongoing access to formal support networks, and the need for a softer approach to managing behaviour, including greater use of reflective practice.
2. **Structural issues in the care system:** Examples were given of the need to improve Aftercare Services efficacy to link young people with disabilities to wider supports and services, ensuring smoother transitions from children's disability services to adult services.
3. **Improved capacity for disability services:** Participants highlighted the need for increased awareness amongst policymakers of children and young people with disabilities in the care system, the need to ensure better access to information for professionals and foster carers on disabilities (including lesser understood conditions such as Foetal Alcohol Spectrum Disorder), a desire for improved responsiveness to specific disability needs, and the necessity of reducing waiting times for services and barriers to accessibility.

Conclusions and Recommendations

This study provides a valuable snapshot of the participants' lived experience as children and young people with disabilities in care, aftercare and beyond. There are many positives in what they have to say about their time in care or in aftercare services, as well as a range of different practical challenges, both socially and in terms of accessing supports and services. What becomes clear from the research is that it is the obstacles to inclusion and participation that shape the experience of disability and that marginalise these children and young people.

It is important to acknowledge how care and disability intersect in these children and young people's lives, and the issues this creates as they navigate everyday life and the wider care system. One of the participant's talked about the importance of responding to children and young people in care with disabilities, saying that "they're different to other people and they have to be listened to for what their needs are". Considering the challenges that the children and young people describe, it may feel to them that they are the ones 'putting in the hard yards'. Yet they are the ones living with disabilities, in care or in aftercare services, and facing a range of different issues that arise from these dual identities.



Responsibility ultimately lies with the Government and the appropriate statutory agencies to fulfil their obligations under the UN Conventions on the Rights of the Child, and on the Rights of People with Disabilities, respectively.

The findings from this research provide a strong case for the responsible authorities to consider the following recommendations:

- **Disaggregate data related to children and young people in care and aftercare services by disability** to create an evidence-based understanding of their needs and appropriate policy and practice responses.
- **Develop flexibility in systems to enable an intersectional approach to care and disability.** This includes the opportunity to ensure supports stay in place for young people turning eighteen and transitioning to aftercare and adult services, especially where a particular disability presents a distinct set of ongoing challenges. It also applies to accessibility issues to ensure all social services – including care placements – can be accessed by all children and young people regardless of their disability.
- **Increase the level and availability of information about disabilities across the care system.** A practical example of this which was suggested by one of the participants in the study was to ensure there is a Disability Officer in each Tusla Region to provide support to Social Workers on how to respond to different disability needs. Another practical measure might be to ensure all social work graduates joining Tusla have opportunities to undertake modules informed by care-experienced children and young people with disabilities to build their capacity. Foster carers and residential care workers also need access to ongoing dedicated training and information on the care of a child or young person with a disability, and enhanced understanding of where to access relevant services and supports.
- **Apply a rights-based approach to care** to ensure the voice of the child or young person is facilitated and heard in decision-making, particularly in relation to care planning, care reviews and transitions into or out of care and aftercare, especially regarding their access to disability supports and services.
- **Provide additional resources** to ensure all children and young people with disabilities in care and aftercare have timely and effective access to quality supports and services.

Next Steps

On foot of the recommendations of this report, EPIC proposes the following actions be considered by the relevant bodies responsible for care-experienced children and young people with disabilities.

Recommendation	Action	Relevant Bodies
Disaggregate data related to children and young people in care and aftercare services by disability	The strengthening of ethical data collection and monitoring should be considered by both the HSE and Tusla in the context of a review of the Joint Protocol for Interagency Collaboration Between the Health Service Executive and Tusla, the Child and Family Agency, to Promote the Best Interests of Children and Families, with the objective of developing a coherent evidence base to inform policy delivery and service provision for children in care with disabilities. This would include bringing together administrative data from agencies working with children in care and with people with disabilities respectively.	Tusla, HSE, HIQA
Develop greater flexibility in systems to enable an intersectional approach to care and disability	The Child Care Act, 1991 should be examined and reformed in the context of where a young person in care with a disability is transitioning to adulthood and responsibility for aspects of their care are transferring from Tusla to the HSE. In this situation, the relevant bodies should have a formal, joint responsibility for planning and provision of services.	DCEDIY

Recommendation	Action	Relevant Bodies
Increase the level and availability of information about disabilities across the care system	Statutory agencies with responsibility for care and disability should establish a specific role for children in care with disabilities. These functions should report periodically on the situation of children in care with disabilities to identify best practice, as well as gaps or systemic obstacles in their care. Those appointed should work consistently with their counterpart in the other body to ensure a 'continuum of care' approach is adopted to ensure the best interests of children or young people with disabilities are upheld throughout their care journeys and in the transition to adulthood.	Tusla, HSE
	An examination of opportunities to incorporate the principles of universal design in health and child and family services should be undertaken with a view to increasing accessibility. Access Officers (appointed under the Disability Act 2005 s.26) could be further trained to assess feasibility at local level as a first step, potentially with guidance from the National Disability Authority's Centre of Excellence in Universal Design.	Tusla, HSE
	Specialised lead Social Workers should be appointed at regional level to advise and support social work teams on how best to support children in care with additional needs, and their carer.	Tusla
	To promote the role of social work in healthcare and its intersection with child protection, the role of Chief Social Worker in the Department of Health should be established.	DoH
	All social work graduates joining Tusla should have opportunities to engage with modules that are informed by care-experienced children and young people with disabilities to assist in building their capacity and knowledge of the distinct issues affecting this cohort.	Tusla, DFHERIS
	Foster carers and residential care workers should have ongoing access to dedicated training and information on the care of a child or young person with a disability and an enhanced understanding of where to go to access relevant services and supports.	Tusla
Apply a rights-informed approach to care	DCEDIY is currently undertaking a review of the Child Care Act, 1991, with a view to amending the legislation this year. It is critical that the Department establishes the right to independent advocacy in the upcoming Child Care (Amendment) Bill to enable care-experienced children and young people with disabilities to access independent advocacy services.	DCEDIY
Ensure adequate resourcing	In the context of a future review and evaluation of the implementation and operation of Joint Protocol for Interagency Collaboration between Tusla and the HSE, that oversight and monitoring of delivery of care to children with disabilities be included as a performance indicator.	Tusla, HSE



02

Introduction



In early 2021, EPIC Ireland held an interactive webinar on Disability and the Care System^[1] which highlighted several issues arising from children and young people's day-to-day experiences of care and disability. Children and young people involved with EPIC, including members of its Youth Council, were keen to gather further evidence on the lived experience of children in care or young people in aftercare services with disabilities and asked EPIC to establish a project as the basis for further advocacy on these issues. Consequently, EPIC secured funding from the Irish Human Rights and Equality Commission (IHREC) for this research initiative.

In November 2021, Deborah Erwin, an independent Researcher with a background in youth work, was contracted to conduct this exploratory study. Following an application to Tusla's Independent Research Ethics Committee, ethical approval was granted. The study has four aims and is centred on the following questions:

Aims for the Research

- To develop an understanding of the experiences of children and young people with disabilities while they are in care or aftercare services, or who have experience of the care system up to the age of 26.
- To enable these children and young people to directly participate in awareness raising, in line with their rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCRC).
- To generate evidence to support policy makers and practitioners to progress implementation of the UNCRPD amongst children and young people in aftercare services..
- To explore the level of knowledge amongst care-experienced children and young people on the UNCRPD.

Research Questions

1. What are the experiences of children and young people with disabilities while they are in care or in aftercare services?
 - a. What do they identify as areas of positive practice and experience?
 - b. What do they identify as the challenges and gaps in provision of their care experience?
2. What do the research participants understand as their rights under the UNCRPD and does their care experience match with how these rights are stated in the UNCRPD?

Although this is a small-scale study conducted with a limited number of children and young people with disabilities, it offered a vital opportunity to gather evidence through a rights-informed lens directly from the participants.. The report includes an outline of the research methodology a literature review, findings and recommendations.



[1] <https://www.youtube.com/watch?v=ZUgk4Kz4p04>



03

Methodology



The purpose of this study was to understand the experiences of children and young people with disabilities while in care or in aftercare services, and to look at how policy and practice can change for the better. Given that this is an under-researched area, direct engagement with children and young people was central to the task to learn about their views as care-experienced children and young people with disabilities and their understanding of their rights under the UNCRPD. A qualitative methodology was applied to the research questions drawing on a phenomenological approach that seeks to understand the lived experience of children and young people in care or in aftercare services with disabilities as they navigate their everyday realities. The children and young people that participated in the research are engaged in EPIC's services and programmes and had ongoing support from a designated EPIC Advocate throughout the project.

Research Design

The research design for this exploratory study comprised three stages – desk research and research preparation, focus groups and discussion, and analysis and reporting.

Desk Research and Research Preparation

In the initial preparatory stage, desk-based research focused on reviewing relevant policies and legislation in Ireland, international human rights standards, and research relevant to the situation of children in care with disabilities. This information was summarised in a literature review (pg. 14-22).

Project Structures

The study was structured to ensure appropriate levels of support and accountability and the meaningful participation of the children and young people:

A Steering Group provided oversight for the project through monitoring progress, addressing any obstacles in implementation, giving ethics support, and advising on dissemination of key findings and learning. The Steering Group consisted of the Ethics Focal Point on EPIC's Board, EPIC Management and research staff, and an EPIC Youth Council Member.^[2]

A Youth Research Advisory Group (YRAG) made up of two young people from EPIC (including the EPIC Youth Council Member from the Steering Group who acted as an interface between the groups) provided advice on the research design, delivery, and data interpretation. This is reflective of a co-inquiry model where the participant's lens as care-experienced children and young people with disabilities is incorporated into the study's design and the data collection processes.

The Researcher played the lead role in conducting the project through desk research, supporting the involvement of the YRAG, facilitating the focus group discussions, performing data analysis and interpretation, and reporting.

EPIC Advocacy Officers linked with each of the children and young people involved and gave additional support to the YRAG & Focus Group Participants, which will continue beyond the formal conclusion of the study. They also provided advice to the Researcher on appropriate disability supports for each child and young person to enable maximum participation in the project.

Ethical Approval

A key component of research preparation was the process to obtain ethical approval from Tusla's Independent Research Ethics Committee (REC) which included a review of the project's methodology, structures, participant recruitment, safeguarding, consent, data protection, and risk management procedures. As part of the ethical approval application, the Researcher prepared consent and assent forms, information leaflets aimed at three groups – children and young people, Social Workers and EPIC Advocates, and parents/guardians, in addition to an information session plan and a focus group discussion guide.

[2] The EPIC Youth Council is a group of young people with care experience aged 18-26 years who advise EPIC on issues and themes of concern to children and young people in care, and work on campaigns and projects to improve the care system.



Focus Groups and Discussions

After ethical approval, the field work phase began in September 2022. Two information sessions were held for EPIC Youth participants and their Advocates, outlining the research project and the roles of the Youth Research Advisory Group and focus group participants. The Researcher explained key parameters such as the consent process, risks and benefits, right to withdrawal, privacy, data, safeguarding, confidentiality, and complaints. Two young people participated in the YRAG, supporting data review and interpretation, providing feedback, and contributing to dissemination planning. Eight children participants took part in two online focus group discussions exploring positive practices, challenges, gaps, and the rights of care-experienced children and young people with disabilities. Follow-up sessions were held to check and clarify the data. The discussions were designed to be accessible and interactive, using PowerPoint, visual images, videos, and Mentimeter. Discussion materials were made available in advance for those with hearing impairments or learning difficulties. Rest breaks were held to ease physical discomfort, and Advocates provided support throughout the sessions.

Profile of the Research Participants

The children and young people involved in the study are representative of a range of care experience including foster care and residential care, as well as those are or have previously in receipt of aftercare services. A range of disabilities are also represented among the participants, including physical disability, intellectual disability or learning difficulty, and some of these may be described as invisible disabilities. At the start of the research, six of the participants were aged 18 or over and two participants were aged under 18. Half of the study participants are female, and half are male. The children and young people live in different parts of the country including Tipperary, Dublin, Cork, and Wexford.

Analysis

The Researcher made transcripts of all the focus group discussions and interviews before creating a thematic analysis of the data using both deductive and inductive approaches. Initially, the data was organised deductively into categories aligned with the questions and activities used for the focus group discussions. The next layer of analysis took an inductive approach by identifying themes as they emerged from the data. These two processes enabled the Researcher to distinguish patterns of meaning and key areas of learning. The YRAG's input on the interpretation of data was helpful and their advice and insight were invaluable in keeping the research grounded in the experience of care-experienced children and young people with disabilities.



04

Literature Review



As this study is grounded in a rights-based approach, the clear starting point for a review of relevant literature on care-experienced children and young people with disabilities are the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. These are the treaties which place legal obligations on ratifying states to protect and promote the rights of children including children with disabilities.

United Nations Convention on the Rights of the Child (UNCRC)^[3]

Ireland ratified the UNCRC in 1992 and it is the most ratified human rights treaty at international level, with all UN member states except one (the United States) having done so. According to Article 4, ratification creates the expectation that states “undertake all appropriate legislative, administrative and other measures” to implement children’s rights. The Convention comprises 54 articles on all aspects of the lives of children that pertain to a range of civil, political, economic, social, and cultural rights. These rights are considered universal, inalienable, indivisible, and interdependent. Any person under the age of 18 is viewed as a child according to the UNCRC and in particular, it creates recognition of the child “as a full human being with integrity and personality and the ability to participate freely in society” (Lundy 2007:928).

There are four general principles expressed in the Convention: non-discrimination, the best interests of the child as a primary consideration, the child’s right to survival and development, and respecting the views of the child.^[4] The principle of non-discrimination is important in the context of this research because it relates to equality of opportunity for all children, regardless of their level of ability. The principle of the right to survival and development means that ratifying states are required to enable fulfilment of these rights through the necessary resources and access (Moloney et al 2021).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)^[5]

The UNCRPD was adopted by the United Nations General Assembly in 2006 and its purpose, as set out in Article 1, is to:

“Promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.

The concept of dignity is central to the UNCRPD because it regards people with disabilities as subjects with rights and with agency rather than as objects of treatment and protection. This reflects a move away from a medical model of disability. The UNCRPD describes disability in the Preamble as,

“An evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others”.

Article 1 of the UNCRPD further states that,

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

This means that the UNCRPD not only promotes the recognition of persons with disabilities, but it also allows for broader designations of disability and the combating of discrimination.^[6] Consequently, the UNCRPD offers a shift towards a human rights model that – like the UNCRC – encompasses civil, political,

[3] <https://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

[4] <https://www.unicef.org/armenia/en/stories/four-principles-convention-rights-child>

[5] <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

[6] Lindqvist, G. (2010). The UN Convention on the Rights of Persons with Disabilities: An Instrument to Enhance Inclusive Development. *International Journal of Disability, Community & Rehabilitation*.



economic, social, and cultural rights, in addition to upholding non-discrimination from a legal perspective (Moloney et al 2021).

Several of the eight guiding principles^[7] found in the UNCRPD overlap with principles and key concepts in the UNCRC, such as respect for inherent dignity, non-discrimination, equality of opportunity, and full and effective participation and inclusion in society. There is also explicit reference to children with disabilities in relation to “*respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities*”.

Like the UNCRC, the UNCRPD includes an Optional Protocol whereby individuals can make complaints on the basis of rights violations to the UN Committee on the Rights of Persons with Disabilities. However, unlike the UNCRC, Ireland has not yet accepted the UNCRPD Optional Protocol, which as noted in the OCO’s Mind the Gap report (Moloney et al 2021), means that this avenue for redress is not available to people with disabilities in the State.

Finally, it is important to note the intended interplay between UNCRC and UNCRPD as a way of supporting their meaningful implementation. For example, in General Comment No. 5 of the UNCRC, states are encouraged to ratify the UNCRC in full, including its optional protocols, and other international human rights instruments. As Moloney et al (2021) point out, this indicates the need for synergy in complying with international human rights standards. The UNCRPD itself underscores the intersectional relationship between the UNCRC and UNCRPD in Article 7, where the requirement of states is to “*take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children*”. Furthermore, in Article 4 of the UNCRPD there is an onus on ratifying states to consult with people with disabilities – including children with disabilities – in legislative and policy-making activities on issues that affect their lives, which links with Article 12 of the UNCRC which provides for the right of children to express their views in matters affecting them, and have their views given due weight.

Barriers to the realisation of the rights of children with disabilities in Ireland

In the first instance, it is important to acknowledge that this has been a challenging literature review given the lack of an evidence base pertaining to the lives of care experienced children and young people with disabilities in Ireland and other jurisdictions.

Key to this review is the OCO’s Mind the Gap report (Moloney et al 2021) which conducted desk-based research to provide a comprehensive overview of the barriers to the realisation of the rights of children with disabilities in Ireland, as well as proposing a range of measures to address these. The report recognises the cross-cutting nature of rights affecting a range of areas in the lives of children and young people with disabilities, such as education, health, housing, and welfare. It also provides insight into Ireland’s legislative and policy infrastructure for upholding the rights of children with disabilities. Although the document does not focus specifically on care-experienced children and young people with disabilities, it includes a section on alternative care with respect to the right to family life (common to both the UNCRC and the UNCRPD) as well as protecting inclusion in the community for people with disabilities (UNCRPD.) Several other sections also touch on relevant issues for children with disabilities in care.

Three main points highlighted in the Mind the Gap report are:

1. Children with disabilities are overlooked in legislation and policies relating to children.
2. Children with disabilities are not effectively included in consultations and research in relation to legislation and policies that affect them.
3. Children with disabilities are broadly invisible in data resulting in an insufficient evidence base to understand the impact of legislation and policies (Moloney et al 2021).

[7] <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html>



The Child Care Act 1991^[8] was signed into law prior to the existence of the UNCRPD and it is currently under review.^[9] Its focus is the provision of care and protection of children, and it garnered criticism in the Mind the Gap report because it does not make explicit provision for children with disabilities. The report also makes clear that while there are a range of laws and policies addressing the rights set out in the UNCRC and the UNCRPD, there are several gaps in Ireland’s provision of protections for children with disabilities, and a lack of evidence on how some of these protections are delivered in policy and practice. The legislative context which applies to disabled children and young people in care is broadly the same as for other children and young people in care, yet there are indications that the system is not working for disabled children and young people in care in the same way as their peers who do not have additional needs.

An example of this can be found concerning care placements and the right to family life enshrined in the UNCRPD. Article 23 states,

“Where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting”.

However, the Mind the Gap research cites work by the Child Care Law Reporting Project^[10] which shows that children who are intellectually disabled are disproportionately more likely to be taken into residential care than foster care:

“More than 90% of children in care are in foster family placements. When the data is disaggregated to take account of children with an intellectual disability, only 50% of children with an intellectual disability are placed in a foster care setting” (2021:62).

Historically, there was a high reliance on institutional care in Ireland, and Gilligan (2019) writes of the move towards family placement. This reflects a shift in understanding of the right to family life and its application to children with disabilities which brought ‘permanency planning’ to the fore (Baker 2011). In addition, research demonstrated that outcomes are better when children and young people, including children and young people with disabilities, are brought up in a family environment (Baker 2011, Dowling et al 2012), as *“stability in living arrangements promotes children’s emotional development”* (Baker 2011:3).

According to the UNCRPD, the onus is on the State to provide the necessary supports to facilitate family and community-based care placements as stated in Article 23:

“States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families”.

In the Irish context, Moloney et al (2021) point to a variety of reasons why there may be a tendency for children with disabilities to be placed in residential care settings, including complexity of needs, placement breakdowns, or lack of experience of children with disabilities among foster carers and a lack of adequate supports.

In 2011, the HSE launched a new strategy Time to Move on from Congregated Settings – A Strategy for Community Inclusion^[11] in which the first recommendation was for the *“closure of congregated settings and transition of residents to community settings”* (HSE 2011:14). A further recommendation is the provision of *“purpose-built community housing funded by the HSE... for any children under 18 years old moving from congregated settings”* (ibid.:17), which may be pertinent to the circumstances of young people with disabilities who are moving towards transitioning from care arrangements.

[8] <https://www.irishstatutebook.ie/eli/1991/act/17/enacted/en/html>

[9] The review process has been slowed by the COVID-19 pandemic: https://www.gov.ie/en/publication/97d109-review-of-the-child-care-act-1991/?utm_source=pocket_mylist

[10] <https://www.childlawproject.ie/>

[11] <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/timetomoveon.html>



Such transitions align with Article 19 of the UNCRPD which sets out,

“The equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.

In its report critiquing the implementation of the HSE’s strategy, Inclusion Ireland cites a lack of leadership and meaningful coordination from the government and statutory bodies that deal with health, social care, equality, and human rights as one of the main barriers to effective deinstitutionalisation (Inclusion Ireland 2018a).

In relation to children in care with disabilities, Moloney et al (2021) emphasise the structural factors at play, such as the fact that children’s disability services fall under the responsibility of the Health Service Executive (HSE) and not Tusla – the Child and Family Agency. Referring to a report by Inclusion Ireland, they note,

“It has led to a situation where Tusla’s staff and Tusla funded agencies, including the Family Resource Centres nationally, are not adequately mandated, resourced and trained to support children with a disability and their families when a child welfare or protection concern arises” (Moloney et al 2021:61).

In 2017, the Joint Protocol for Interagency Collaboration Between the Health Service Executive and Tusla – Child and Family Agency to Promote the Best Interests of Children and Families^[12] was signed to address the issues arising from a lack of effective ways of working between the agencies, to bring clarity regarding roles and responsibilities, and to establish areas of joint responsibility, in the hope of enhancing interagency collaboration as a means of promoting the best interests of children and families. Consequently, several policy actions were implemented, such as the establishment of the Children and Young People Services Committees, the Child and Family Support Networks, and development of a national practice model from Tusla, Meitheal. This model is intended to drive a needs-based approach to supporting children and families and sets out:

“To ensure that the needs and strengths of children and their families are effectively identified and understood and responded to in a timely way so that children and families get the help and support needed to improve children’s outcomes and realise their rights” (Tusla 2013:1).

Moloney et al (2021) cite two separate cases investigated by the Ombudsman for Children’s Office concerning individual children with disabilities in care which illustrate the problems of insufficient supports for such children and poor interagency working between Tusla and HSE. In one, ‘Grace’, a young woman with intellectual disabilities, was repeatedly abused by her foster carers and “despite repeated allegations of abuse, the HSE failed to act to ensure Grace’s safety” (Inclusion Ireland 2018:20). In the other case, ‘Molly’, a teenager with Down’s Syndrome and autism, was receiving an insufficient level of supports and services to meet the extent of her needs and despite having grown up with the same foster family, her foster carer was told Molly would have to go into a residential care facility. The OCO found that:

“Neither agency saw Molly as a child in care and also a child with a disability. Instead Tusla recognised her protection and welfare needs but made no distinction with regard to her disability requirements. The HSE recognised her disability needs but made no distinction with regard [to] her protection and welfare vulnerabilities as a child in care” (OCO 2018:2).

Since these investigations and the signing of the Joint Protocol between the HSE and Tusla, there is evidence of improvements to services and supports which have benefited children with disabilities in care. However, there are still issues around how children with disabilities are identified as requiring support (Moloney et al 2021) which is suggestive of their wider invisibility at the policy level which inhibits adequate support in practice.

[12] <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/hsetusla-joint-working-protocol.pdf>



Similarly, there have been observed improvements regarding interagency cooperation, however there are also indications on the ground that the Joint Protocol *“is having limited impact and there is little evidence to date on the effectiveness of the inter-agency structures established in terms of supporting children with disabilities and their families”* (ibid.: 61-62). For example, Inclusion Ireland has observed instances where some children with intellectual disabilities have been referred back to the HSE by Tusla without further consideration or action, and its submission to the then DCYA expresses concern about children with disabilities who may be overlooked because they fall between two stools (Inclusion Ireland, 2018).

The specific cases described above have had serious impacts for the children in question, as well as pointing to the failure of the State to follow through on its responsibilities and to adequately protect children and young people with disabilities in its care. A literature review relating to care-experienced children and young people with disabilities by a team from Queen’s University Belfast (Dowling et al 2012) raises concerns about adequate child protection because of higher incidences of abuse among children with disabilities.

Such data is particularly troubling given some of the prevalence statistics in the literature. For example, findings from the Child Care Law Reporting Project outline that one in four children in the care system in Ireland have special needs, whether psychological, physical, or educational or a combination of these (Moloney et al 2021). A similar proportion is cited in a study delivered by EPIC, Empowering People in Care, which researched the needs and circumstances of children and young people aged 17-18 years who were receiving aftercare support in North Dublin, and which found that 25% of the cohort under review had a diagnosed learning disability (Daly 2012). EPIC’s Annual Advocacy Service Report for 2019-20 shows that one in eight advocacy cases were with children and young people with a diagnosed additional need or disability (EPIC 2020). Bearing these statistics in mind, it is clear there is a need to highlight the specific circumstances of care-experienced children and young people with disabilities to make them more visible in data and research.

Furthermore, it is important to note that official data in Ireland from Tusla and the Health Information and Quality Authority (HIQA) on the numbers of children and young people in care is not disaggregated by disability (Moloney et al 2021) and so it is difficult to respond appropriately. Indeed, Moloney et al regard the lack of data disaggregation as a significant obstacle to upholding the rights of children with disabilities more broadly:

“The lack of up to date, disaggregated data emerged as a key barrier to the realisation of rights for children with disabilities. In many contexts, without up-to-date data, it is difficult to make an evidence-based argument for reform, or to understand the exact impact of specific laws, policies and programmes on children with disabilities. Even where data does exist, it is often fragmented, and definitions of disability vary across different data sources, making it difficult to generate a comprehensive and holistic account of the experiences of children with disabilities” (2021:124).

Challenges facing children and young people with disabilities in care

In the foreword to the *Mind the Gap* report on barriers to the realisation of the rights of children with disabilities in Ireland, the Ombudsman for Children, Dr Niall Muldoon, notes the ‘uphill battles’ faced by children with disabilities and their families in general with regard to housing, education, transport, aids, mental health care as well as assessment of need. EPIC’s Annual Advocacy Service Report for 2019-20 also notes that their advocacy work with children and young people with disabilities tends *“to involve complex issues and require longer time to resolve”* (2020:16). This report, along with a small number of other studies on care-experienced children and young people, serves to highlight several challenges that affect this cohort concerning specific areas of policy and practice including participation, supports and services, care placement, and planning for leaving care.



Participation

Opportunities for children and young people with care experience to have their say is an area where several barriers are identified in the literature.. In terms of the foundations for participation, Article 42a of the Irish Constitution translates the UNCRC's Article 12 (children's right to express their views) into law. In 2010, the Office of the Minister for Children and Youth Affairs (OMCYA) initiated a consultative process with 211 children and young people in the care of the State, in detention, and in residential services for children with a disability. These discussions explored the issues that matter to the children and young people, how they would like to be heard, and mechanisms for them to express their views. The following year, the then Department for Children and Youth Affairs (DCYA) published a report of the consultation's findings, *Listen to our Voices!*, which makes several significant recommendations on future structures through which children and young people can express their views effectively. The report notes how the consultations indicated that children and young people are rarely asked for their view or feedback and recommended that,

“The existing structures designed to ensure the voice of the child is heard are reviewed and that a culture of participation is developed in which young people are consulted on the key decisions that affect their lives on an ongoing basis” (DCYA 2010:2).

Consequently, a range of initiatives took place to ensure greater focus on the voices of children in Ireland, including those with disabilities, and those in the care system. For example, listening to and involving children and young people is one of the transformational goals set out in *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020* (DCYA 2014). This is further strengthened by the *National Strategy on Children and Young People's Participation in Decision-making 2015-20* (DCYA 2015) which provides a national policy framework rooted in a rights-based approach. One of its four priority objectives is that “children and young people will have a voice in decisions that affect their health and well-being, including on the health and social services delivered to them” (2015:12) and it makes specific mention of ‘vulnerable’ children and a measure to set up reference panels of children in care to ensure that they “are listened to, asked the right questions and better protected with actions that emphasise the importance of staff training and support” (ibid.:14). One of the features of the Strategy is its adoption of the Lundy Model of Participation (Lundy 2007) which places emphasis on adults enabling the right of children to be heard and emphasises the following four elements:

SPACE: Children must be given safe, inclusive opportunities to form and express their view

VOICE: Children must be facilitated to express their view

AUDIENCE: The view must be listened to.

INFLUENCE: The view must be acted upon, as appropriate (2007:933).

In 2018, several authors conducted an analysis of HIQA Inspections regarding performance against children's participation rights for children in care (Brady et al 2018). This found evidence of good practice, but some discrepancies in practice between different settings, namely residential care and foster care. Consequently, Tusla published its *Child and Youth Participation Strategy 2019-23* which has the express aim that “every time a decision is taken that directly affects a child or young person, their views are taken into consideration” (Tusla 2019:33). This strategy is complemented by Tusla's National Charters for Children and Young People^[13] which were developed in consultation with children and young people using the Lundy Model of Participation.

While these initiatives and policies create a credible foundation for participatory practice, some authors in various contexts note examples where care-experienced children and young people with disabilities are not sufficiently included in consultation. In their search of studies on the involvement of children and young people with learning disabilities, Roberts et al (2018) struggled to obtain qualitative research that takes account of children and young people's voices in a way that would reveal what the children and young people view as important for themselves. Dowling et al (2012) also comment on the absence of the views of disabled care-leavers in research.

[13] <https://www.tusla.ie/services/family-community-support/prevention-partnership-and-family-support-programme/participation/childrens-charter/>



This results in a dearth of literature that draws on children and young people's voices directly, and policy makers are missing out on their perspectives as persons with disabilities to shape policy and legislation, indeed the report by Moloney et al notes:

"Several instances whereby children with disabilities have not had any documented opportunities to participate in the development of legislation, policy and programmes which affect their lives" (2021:8).

An Irish study of care-leavers' experiences of aftercare planning (Glynn and Mayock 2018), while not specific to care-leavers with disabilities, provides some insight on barriers to participation in aftercare planning such as a lack of trust, prior negative experiences, and housing insecurity. The researchers also found that *"participants who were less engaged in the planning process reported lower levels of satisfaction and were more likely to limit or even avoid participation"* (ibid.:13).

Moloney et al (2021) make the point that care-experienced children and young people with disabilities are not a homogenous group and will have different needs. This means that they require various kinds of support to participate meaningfully in consultations, so there are implications for the training of professionals as well as researchers.

Roberts et al (2018) write about their study with young care-leavers with learning disabilities in England and about healthcare in terms of the transition from paediatric to adult services. Based on their review of literature in the English and Swedish contexts, they draw attention to the fact that children and young people, particularly care-leavers can be a valuable *"source of knowledge for policy and practice"* (2018:54) and provide examples of research showing how the views of children and young people with learning disabilities may contrast significantly from those of professionals or their carers. This underscores the potential to strengthen the evidence base through including the *"unique insight"* of disabled children and young people (Moloney et al 2021:10) and Roberts et al emphasise that *"decision-makers need contextual information and evidence on the ways in which policy interventions play out on the ground"* (2018:62).

It is therefore encouraging that in January 2022, the Minister for Children, Equality, Disability, Integration and Youth, Roderic O'Gorman, T.D announced a new research initiative^[14] which will gather longitudinal data to study the lives of children in care, young people leaving care, and adults who were in care as children. Although at the time of writing there is no specific mention of care experienced children and young people with disabilities in the information about the project, it will generate valuable evidence about care and aftercare that is rooted in children and young people's lived experiences and which can be applied to future policy and practice.

Supports and Services

As the OCO investigation into Molly's Case (OCO 2018) highlighted, adequate supports for foster carers are a key issue in relation to children and young people with disabilities. Baker reports serious levels of dissatisfaction among adoptive parents, birth families and foster carers in comparison with adoptive parents, birth families and foster carers of children without additional needs (2011). This dissatisfaction particularly pertains to issues with Social Workers – their responsiveness, reliability to follow through on promises made, and whether they understand the child. The report also notes a study which records that *"a higher proportion of disabled children either had no Social Worker or a Social Worker who rarely visited them"* (2011:9).

Dowling et al 2012 underline the importance of supports and services, including family support, that is both practical and emotional, warning that,

"Insufficient family support combined with (and contributing to) parental stress related to caring for disabled children who have multiple and/or complex needs contributes to families reaching a decision to seek an out-of-home placement for their child" (2012:7-12).

[14] <https://www.gov.ie/en/press-release/d7c8d-minister-ogorman-launches-largest-ever-examination-of-the-lives-of-children-in-care-and-adults-who-were-in-care-as-children/>



Despite various policy efforts – including assessments of need, the National Carers’ Strategy, the First 5 Government Strategy, and income supports – the research indicates that not all family carers get the services they need (ibid.; Inclusion Ireland 2018b). With respite services, provision can be geographically patchy in Ireland – over half of the respondents in one study indicated they were unable to access crisis respite care (Moloney et al 2021).

Care Placement

A range of care placement challenges are described in the literature for children and young people with disabilities. Baker (2011) in her examination of permanence, refers to a general lack of placements for children with disabilities and recruitment issues, and notes how this can have a knock-on effect on securing placement stability, particularly to get a good match between the foster carer and child, and to ensure the placement is suitable for that child or young person’s needs. The concern about a lack of placement options in the Irish context, particularly for those with complex needs is reiterated by the Children’s Rights Alliance (2022). Baker (2011) suggests that one of the factors in placement breakdown for children with disabilities is a higher prevalence of emotional or behavioural issues.

Baker’s scan of literature (ibid.) also considers issues with contact for children with disabilities, for example that birth parents with a disabled child may treat them as if they are younger because of a perception that they are developmentally delayed and consequently emphasises the need to ascertain the child or young person’s perspective of contact:

“Therefore, it is important for workers to understand the impact of various contacts and take account of the children’s views. Workers may need additional support and resources to do this and to ensure that contact is of a high quality” (2011:9).

Baker’s review of permanence and placement stability in the UK care system is helpful in explaining that permanence for children in care is about achieving a situation where *“they do not move around the care system, achieve stability of placement, and have a family they can rely on and where they feel included”* (ibid.:4). She also points to guidance from the Department of Education in London on care planning which views permanence in terms of three key components: emotional permanence which is about attachment, physical permanence which is about stability and legal permanence which comes from the carer’s parental responsibility (ibid.). For children with disabilities, this kind of stability may be achieved through a variety of options including staying with or returning to the birth parent while also ensuring family support is in place, long-term relative foster care, long-term foster care, adoption, or residential placement (ibid.).

Leaving Care

Leaving care is a key time of transition – generally, research evidence shows that care experienced children and young people face poorer outcomes in comparison with their non-care experienced peers across various markers in educational attainment, health, housing, and employment (Baker 2011, Ellis & Johnston 2022). The circumstances of young people leaving care are recognised in *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020* which outlines a commitment to enabling effective transitions within the national outcome of achieving ‘economic security and opportunity’ for children and young people. This commitment is focused on giving young people leaving care adequate preparation and support *“to negotiate the system and transition to stable independent living, further education, training or employment”* (DCYA 2014:94). The Aftercare service is a key mechanism that advances this commitment and where a young person has a care history, Tusla holds a statutory duty to ascertain their ‘need for assistance’ through development of an aftercare plan which determines aftercare supports based on the needs assessment (Tusla 2017).

The lack of research data is a repeated issue regarding young people leaving care with disabilities, and this comes to the fore in some of the literature reviewed here (Dowling et al 2012, Roberts et al 2018) even though the statistics are from Northern Ireland, they indicate young people with disabilities are over-represented among care-leavers (Dowling et al 2012).



An overriding theme in the literature for young people leaving care with disabilities is unsatisfactory transitions. Issues include inadequate planning and preparation, difficulties accessing appropriate housing or accommodation, a lack of employment options, and difficulties accessing supports or moving from children's to adult services (Baker 2011, Daly 2012, Roberts et al 2018). Referring to healthcare for young people with learning disabilities, Roberts et al (2018) observed,

“They experience gaps in relation to smooth transitions in mental health, general practice and dental services and to areas, which are widely acknowledged as the determinants of health, including housing and finance” (2018:56).

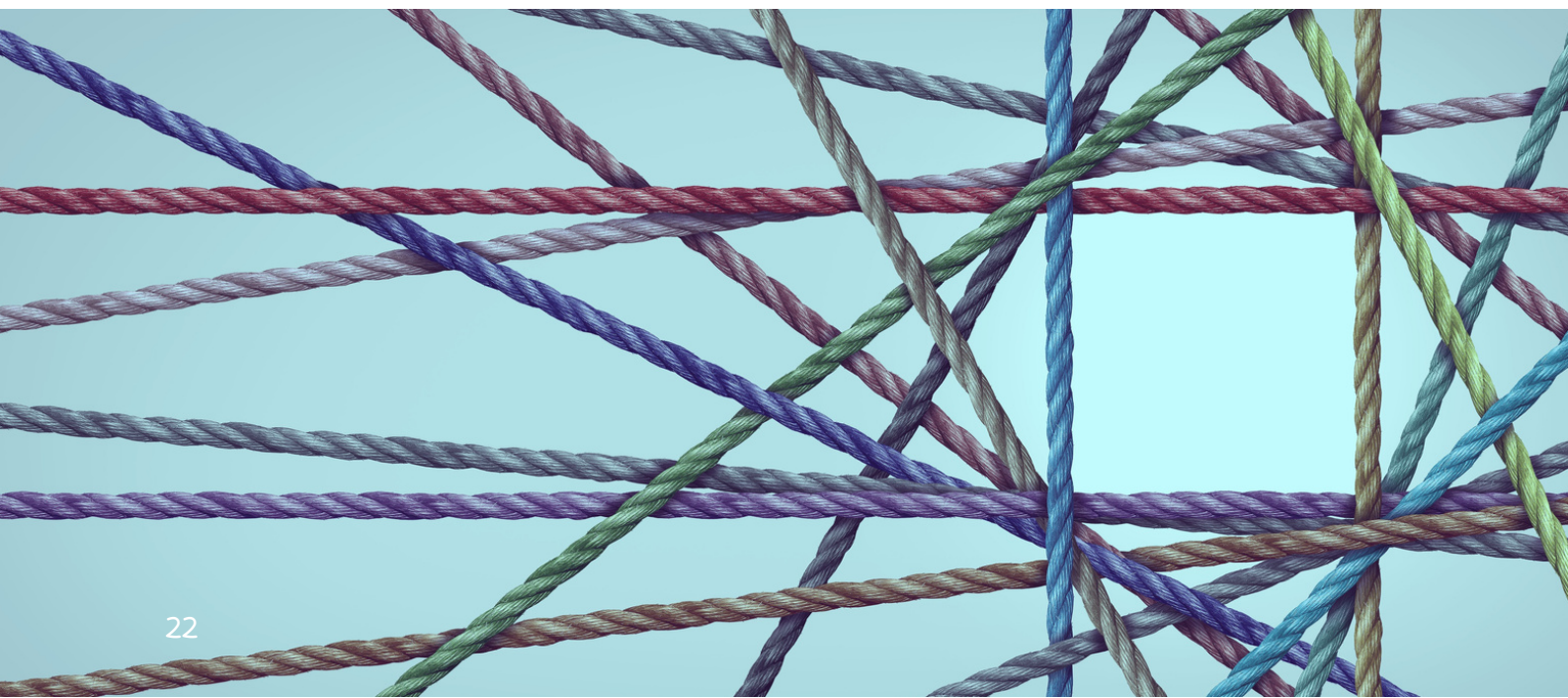
Associated with such difficulties, some authors point to threshold-related challenges for care leavers with disabilities where the young people do not meet the eligibility criteria to access supports or services, and this can apply in areas such as accommodation (Baker 2011) or health (Roberts et al 2018). In the latter case Roberts et al cite an example of a medical practitioner stating,

“We have this very difficult situation at the moment whereby you'll be a young adult, you'll be through school, it'll be very well recognised you have learning needs [but]... if you have an IQ above seventy, you don't meet the criteria for getting a service... And if you don't meet their criteria, where do you get your support from?” (ibid.:55).

In the Irish context, Daly (2012) shares findings from Aftercare Workers identifying the lack of a clear referral procedure for disabled care-leavers to transition to adult disability services which meant that young people could face long waiting lists, as well as difficulties establishing who holds responsibility for the young person's care and who pays for services. Daly (2012) further underlines the serious nature of these issues especially for young people with moderate to severe disabilities and in need of long-term supports, and Baker advocates for a person-centred approach where *“transition planning should have as its main focus the fulfilment of disabled young people's aspirations” (2011:12).*

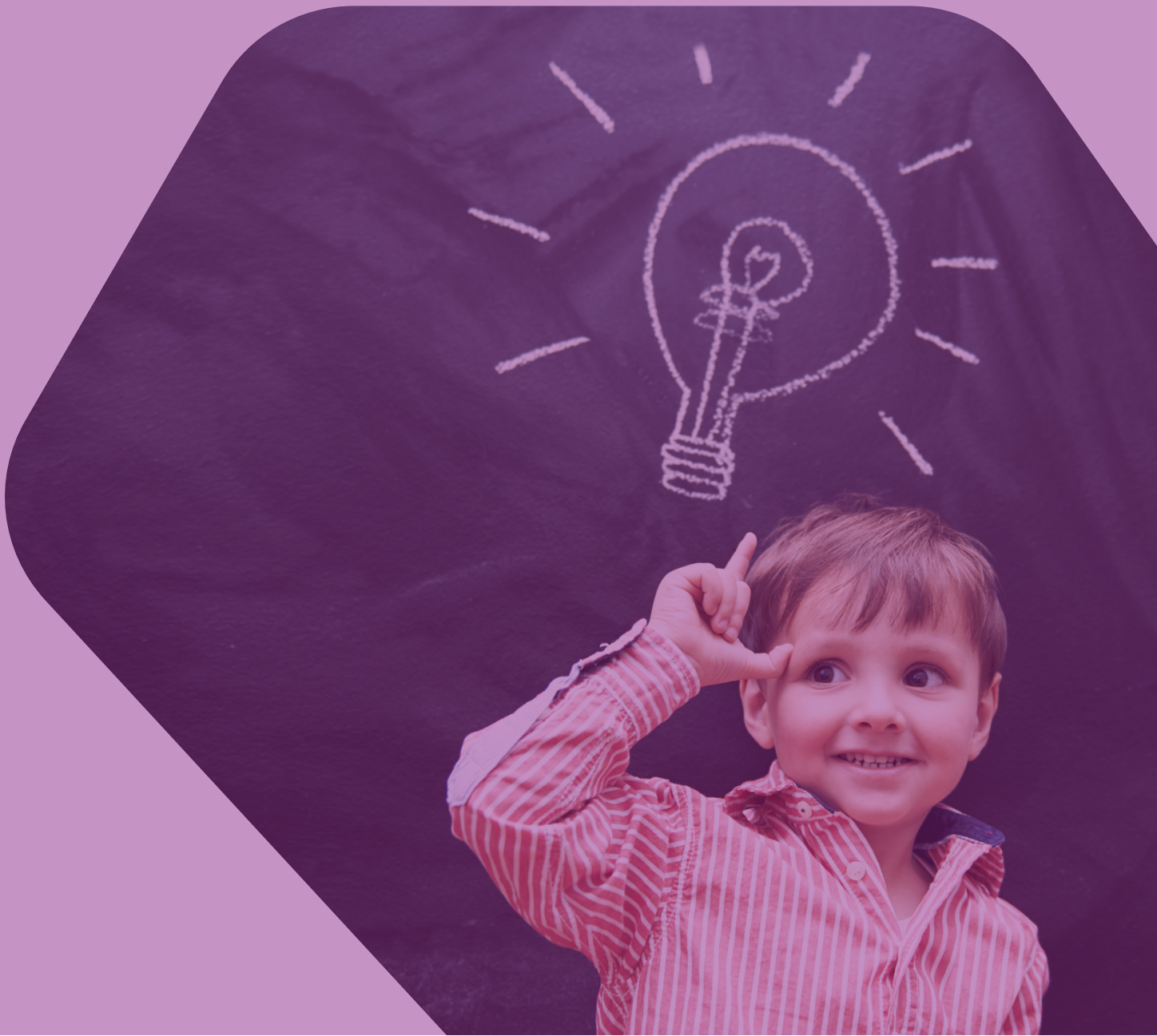
The lack of recognition of the challenges that are specific to the lives of young people with disabilities leaving care is of concern to Moloney et al (2021) who point out that the emphasis on working towards independence and autonomy overlooks the struggles of young people with disabilities transitioning to adulthood with limited supports available through the Assisted Decision-Making (Capacity) Act 2015 which does not apply to those under 18.

Finally, the prevalence of mental health difficulties among care-leavers are raised by Dowling et al (2012) and Daly (2012.) However, they also note that it is difficult to ascertain clear causality in terms of whether this arises from pre-existing emotional issues or whether it's due to the transition from care to independence itself given the associated challenges such as unemployment, or housing instability. Dowling et al (2012) stress the knowledge gap in relation to the emotional and mental health needs of care-leavers with disabilities.



05

Findings & Analysis



If you were to write a book about your care experience as a child or young person with a disability, what would you name it?

Partly as a warm-up activity and partly as a general way into the conversation on their experiences of care or aftercare services, the research participants were invited to consider how they would title a book about their lives. Seven of the participants suggested titles including two who put forward two options each. Their answers are listed below in no particular order (Fig. 1), and while it was a light-hearted activity, the children and young people's ideas were revealing and insightful about their care experience, and how they see themselves and understand their lives.



Fig. 1 Book titles suggested by research participants

Some of the titles are self-explanatory, while others are better appreciated with some elaboration. For example, one of the young men thought of two titles, 'Headphones' and 'Odd Shoes':

"For the 'Headphones', I would say kind of you're in your own reality, you're not really paying attention to the world, and you're just getting on with your day-to-day life as best you can. And 'Odd Shoes' because not all of us fit in the same category or the same box, some people like to be odd and have their own personalities".

Another young man decided his book title would be, 'Undeclared Through the System' and this was reflective of what he saw as the many challenges in the care system, including personal experiences such as difficult interactions with Social Workers, or his observations of the vulnerability of children and young people as they navigate their care experience:

"And even different social workers would ask me the same questions and I'm like, 'I answered this question already'. It's just like a merry-go-round to be honest. It's - for a child that is 18 and they have to fend for themselves, it's not right, so, for a young person there's so many challenges. But what I've noticed since I've been in EPIC, we've so many courageous young people and it's kind of like 'yeah I am in care, but I'm undefeated, the system didn't defeat me'".

A young woman in aftercare services initially suggested 'Don't Diss My Ability' for her book title, creating a play on the word 'disability' because she felt that professionals did not see her in terms of her abilities and overlooked what she offered:





"I feel like growing up as a young person in care with a disability, they never focused on my ability, they were always – people such as social workers and stuff were always focusing on the negatives about me and if you're negative towards someone, you get a negative response back. I suppose the message is to look at the bright side of each person, look at everyone's strengths because I don't believe that that was done for me. So, it's kind of a powerful statement for a book cover – don't diss my ability, like don't disrespect all the things I'm good at because I was good at lots of things and I never – no one really saw that, they only saw what I was doing wrong."

She described her second title, 'I'm In Care So Please Care' as *"kind of a shout out to a lot of professionals that work with people in care – you need to look at the needs rather than just at the title of being in care"*.

The different book title suggestions reflect a diversity of experience, as well as the children and young people's creativity, and the exercise shows what can get lost if everyone is treated the same. Many of the titles convey the participant's perception of feeling different and unique through a particular set of life circumstances, and there is also a degree of pushback against labelling and judgement. Some of the titles hint at the isolation and vulnerability that can be felt by children in care, but there is also grit, courage and strength expressed in some of the ideas, and it's possible to say that the titles provide a way of stating, 'I'm here'. While some of the participants might feel like they are engaging with a system bigger than themselves, the titles indicate that the children and young people who responded to this question see themselves as having capacity and agency despite experiencing adversity. They want to assert their capacity and agency, that they want to be heard and to be recognised for who they are.

What are the experiences of children and young people with disabilities while they are in care or in aftercare services?

Positive experiences of care/aftercare services as a child or young person with a disability

Across the focus group discussions and interviews, the participants were invited to share an example of a positive experience they'd had as a child or young person in care with a disability. In two of the focus group discussions the participants responded initially via an interactive Mentimeter poll before getting into the conversation – the written responses they submitted include the following statements:

"I learnt to be independent by the staff members in the residential care."

"Growing up in care was like a second chance at life."

"I got to visit the Newstalk radio station I also saw Cork's 96FM & Cork's RedFM. I also went to multiple summer camps."

"Having two families is different but you get used to it. I have had loads of meets with my mam and dad, but my favourite is when I meet my mam. I'd say, because though, she doesn't feel like my mam, I sometimes like meeting up with her even though it is awkward."

The other participants cited the following positive experiences in their verbal responses to this question:

- Access to early intervention and supports.
- Relatives providing foster care.
- Support from a Guardian ad Litem and an EPIC Advocate.
- Meeting new people and having a shared bond with those who understood the care experience.
- Getting involved with EPIC, accessing its support, and seeing its work on behalf of care-experienced children and young people in general.

As the conversations in the wider focus group discussions and interviews unfolded, other positive experiences became apparent including things like feeling part of the foster family or going to an all-



disability primary school which the child or young person concerned valued for *“having everybody there with a disability, it was really good, and I had a lot of friends, and you never felt like you were different”*. Two research participants were each able to name a particular Social Worker who had made a significant impact on their lives at key points during their time in care. One of them described her experience of the Social Worker who worked with her for just over two years in her teens following a very rocky period, as *“probably one of the most best experiences I’ve had in care,”* because of his consistent support and his honesty. The other participant remembered a Social Worker who had worked with her as a younger child fondly saying, *“she was so, so nice and if I ever got a chance to, I’d love to meet her again because she’d be so surprised to see me now”*. Another young person noted that his Aftercare Worker had been very helpful at the point when he was trying to access supports to go to college, and although this didn’t work out, he commented on how she had tried her best for him.

It is striking to note that across the responses from all eight participants, many of their positive experiences centre on human interactions and the support of a variety of key people from foster carers, relative foster carers and peers, to professionals including Social Workers, GALs, Aftercare Workers, residential care workers, EPIC Advocates, teachers and health professionals. The influence of these people is clearly significant as far as practical supports, health supports, legal supports, guidance, and emotional supports are concerned. One participant said of his grandparents who have provided him with foster care *“if it wasn’t for them... god knows where I’d be”*. Another participant, who benefited from early intervention, paid tribute to her foster carer who had developed awareness of her specific disability and worked hard to get a multi-disciplinary team in place. This meant that she had access at an early stage to expertise from a range of professionals including physiotherapy, paediatrics, psychology, and speech and language therapy, and she reflected that, *“the fact that I got so many supports early on, I think that’s kind of helped me become the person I am today, being very outspoken and stuff.”* Another young man felt that if it hadn’t been for the support of his GAL and his EPIC Advocate, *“I think it would be a lot harder ... I would just be another file put down at the very bottom and forgotten about.”*

Many of the comments also reflected the importance of key social experiences, whether attending summer camps or getting involved in youth advocacy. A group participant spoke about how much she valued meeting new people during her time in care said this was because of the shared bond, observing that:



“Being in care is hard enough but then having a disability on top of that you tend to feel extra alone, and you feel like nobody else is going through this situation, nobody understands you, so to find somebody that may be in a similar situation to you is really important”.

One participant who named their involvement in EPIC as a positive experience described it as an “eye-opener” not only because of the support he received from the organisation, but also through seeing what its staff do with and for other children and young people. A committed Youth Council member currently, he intends to maintain his links with the organisation for the rest of his life. He shared that,



“They’ve been just an amazing organisation for me to be involved in because I’m very outspoken as you can see, so I wanted to join an organisation that wants to make change and EPIC has been a great organisation for that because that’s the centre of the work and you can see that from a day-to-day basis, it’s constantly trying to put the young person in care at the centre of the work, and it’s been an amazing organisation to be a part of”.

There is of course a need for some nuance here as reflected in one of the statements above about family contact and how it can be tricky for children and young people to navigate having both a birth family and a foster family. Some of the positive experiences of being a child in care with a disability may have come with complicated feelings attached. This was the case for one of the younger participants who shared that seeing her natural mother is a positive experience, but that there are times when she likes having two families, and times when she doesn’t. She has been with her foster family since she was a small baby and feels her foster parents are like her own parents, and there are times when her



biological parents don't feel like her own parents *"because they wouldn't know me as well as people here [in her foster family] who would do more stuff than my own parents would do, so it's ok having two families."*

One participant described their care experience as having given them *"a second chance at life"* which demonstrates just how life-changing being in care can be for children and young people at a tough yet formative time of their lives.

Challenges in the care experience as a child or young person with a disability

The next part of the focus groups and interviews asked the children and young people to give an example of a challenge they have faced as a child in care or young care-leaver with a disability. Again, some of the focus group participants provided brief written responses using the Mentimeter tool followed by further discussion, while others responded verbally. The Mentimeter responses included the following:

"I didn't see my father for 3 years while in care".

"Trying to explain something to someone ... and they don't understand what you mean, and trying to make friends".

"Changing schools & going to a special school when I could have gone to a mainstream school. Finding it hard when certain staff members move on. Finding it hard to understand how it is inappropriate to have their phone numbers".

"When your needs aren't met you kinda feel like you've done all the work for nothing you want to do so much but then they kinda shut you down".

Meanwhile the verbal responses to the question about challenges can be summarised as follows:

- Feeling disrespected and not getting taken seriously, particularly in relation to accessing and navigating health supports and interventions.
- Repeated questioning from Social Workers about aspects of care planning.
- Dealing with symptoms associated with a specific disability and feeling misunderstood by Social Workers due to their lack awareness of the condition.
- Navigating serious decisions regarding healthcare related to a disability and dealing with delays in accessing that healthcare.
- Accessibility challenges in residential care and foster homes.

As can be seen from the above, the challenges identified by the children and young people in response to the specific question, and in the wider conversations that evolved, are wide-ranging and often specific to each child or young person's personal circumstances. Broadly, the challenges can be grouped into three areas:

i) Challenges related to the child or young person's disability

In one of the focus groups where the disabilities represented included a learning difficulty, intellectual disability and autism, the children and young people shared frustration regarding what they saw as wrong assumptions being made about their disabilities, particularly in relation to their education. All three had received special needs schooling when they had wanted to go to a mainstream school. One young man looked back on his experience at this time saying,



"Growing up, obviously people in my family knew that I was different, I don't know how to interpret it - 'different' in a way. And I had a lot of pent-up anger, and I didn't know what was going on, and then I was put into a special needs school that I didn't need to go to, I just needed extra support".



Another young man described how he initially started at his school with just one hour a day and was given 'Social Stories' as an educational practice but felt it was diminishing of his abilities. The others had similar experiences, with one young woman commenting, *"you feel like, it's like they might treat you as if you were 'handicapped', I don't mean to say that, but you feel like that."* One of the other young women in the study had a very positive experience of her all-disability primary school with regards to the social aspects, but felt that educationally it didn't present enough of a challenge:



"Because I was above the level of education being taught, so I was basically just sitting there learning things that I already knew of, and it was just boring really. It wasn't much of an education if you already knew everything that you were being taught".

Some of the children and young people also observed a general lack of awareness or understanding of 'invisible' disabilities, and where there was some awareness, they felt it was limited to conditions such as autism. One young man related his experience, *"when I say to people like, 'oh I have a learning difficulty', and they're either kind of taken aback by it or they're like, 'oh really? I didn't notice' or 'you don't look like you have one'"*.

Regarding further education, one young woman described an experience of feeling unwelcome at a college because she wasn't aware she was meant to disclose a disability and she found some of the questions from staff unhelpful and even *"a bit like bullying"*. She recalled, *"the teacher just kind of said to me about how come I'm a bit slow and they said, 'oh we didn't know you had a disability' and blah blah. I just said I'd leave"*, however she is a lot happier at the college she now attends and finds it a more supportive and understanding environment.

It is important to remember that dealing with change can be more challenging for children and young people with learning difficulties or neurodivergence. This was evident among those who spoke of not fully understanding decisions that were being made about their care or disability, or how they found it difficult when there were staffing changes or struggled to understand professional boundaries and the limitations of relationships with care staff.

Similarly, communication can be difficult for some children and young people with learning difficulties or an intellectual disability. As illustrated by the comment submitted via Mentimeter cited above (pg. 27), one young man admitted to struggling to communicate effectively, particularly in instances where he needed to contact formal agencies or make enquiries about supports or services.

The research indicates a lack of recognition of the distinctive nature of certain disabilities, and how they lead to specific sets of needs which must be attended to in a timely manner. For example, one of the participants with a physical disability described a significant challenge in her life at the time when she was due to get a hip replacement to resolve chronic pain from a dislocated hip due to spina bifida. Unfortunately, following delays in getting the surgery, she developed cellulitis in her hip twice, and because of the infection, she was no longer eligible for the hip replacement. At this point she was faced with an incredibly difficult decision – either keep the hip and live with chronic pain, or have the hip removed and be pain-free but unable to walk again. Another young man expressed his frustration with a lack of implementation of commitments made about various supports as he navigated some health challenges related to his disability, and gave an example regarding an important hospital appointment with a consultant during the previous summer:



"My health at the time had been decreasing so the Tusla people promised there'd be a car coming to collect me. Because I was under the age of 18, someone had to go with me, so they would have brought someone. The taxi came, there was no one in the car and Tusla had cancelled the appointment because, they didn't even tell me, at the very last second, like the day before, they said, 'yeah we can't find anybody so' they cancelled the thing... they didn't communicate with [the taxi driver]... they don't follow up on their promises, they don't follow up on their decisions or plans".



In another case, one of the research participants who has Foetal Alcohol Spectrum Disorder (FASD) and is currently in aftercare services, talked about going through a particularly rough patch as a teenager because of how the condition was affecting her communication abilities, behaviour, learning and movement. She related that there were Social Workers who accused her of using her disability as an excuse for her behaviour – “they used to tell me to try harder and they used to tell me that I was getting worse and stuff when actually, my condition can actually get worse as you get older”. This indicates a lack of understanding of the condition itself, and the young person felt it hampered her development because her last psychological assessment had been conducted when she was 13 years old, but she consequently had to fight to get mental health supports in place in her mid-teens. Furthermore, her school failed to implement any of the practical educational supports that had been outlined by the psychologist following the assessment due to a lack of staffing and resources. Indeed, the principal at this school had once told the young person that he didn’t believe in FASD as a condition. This reflects a lack of wider awareness in society of such conditions.

One of the research participants with a physical disability expressed her thoughts on what she viewed as common misconceptions in wider society about what it means to have a disability. This has a knock-on effect in terms of how people with disabilities must work hard to get recognition for their needs, and is especially pertinent to young people with disabilities transitioning from care and seeking support to live independently:



“There’s this stigma with the world that people with disabilities are living at home with mummy and daddy, get their food handed to them, they don’t have to lift a finger, they don’t have to do anything, they don’t have to worry about money or rent or electricity or anything like that. Yeah, ok, for some people that is the truth but for others it’s – it couldn’t be further from the truth”.

ii) Challenges of navigating interpersonal relationships, and relationships with biological family

There were several comments across the focus groups, and in one of the interviews, about the intricacies of navigating both interpersonal and biological family relationships. Some of the children and young people talked about the challenge of making friends or finding acceptance among peers because of their disability or care experience. For example, one young person with FASD related that when she tried to explain her condition to a friend, they asked her if she was an alcoholic, which the research participant found insensitive and a misconception of the disorder. She finds it difficult that many young people in her peer group get involved in alcohol or substance abuse when FASD has had such a profound impact on her own life and shared that “I get called boring a lot because you’re not out partying all the time, so I don’t really have many friends at all”.

One of the aspects of making friends that was challenging for a couple of the children and young people with learning difficulties/intellectual disability was that they had experiences where they got picked on or bullied and one young woman talked about how “if you’re vulnerable you could maybe... you’re more a target to things” and a young man agreed saying how he “took everything seriously – I couldn’t tell if someone was taking the piss or something”.

For a few of the participants, there was a sense of missing out as teenagers in care, one of them reflected, “I wanted to have normal interaction... I wanted to be able to go in and out of the house and chill around like what normal teenagers do, but I didn’t have that chance”. Another young person described the hurt he experiences when peers don’t invite him on nights out. He mentioned an evening where he went to a peer’s 18th birthday celebration without having been directly invited, but went to get out of his comfort zone, only to find himself getting passed over as some of his peers headed on to friends’ house and he got left behind because he needed the bartender to put up the ramp for his wheelchair:





"I've been talked down to, I've been treated differently, and it's not nice, it's very annoying – treated differently by my peers and they go to each other's houses, they go out, they do all these things, they go to the pub, they go disco-ing, they do this, and they do that, they don't ask me. I always hear people's stories after... I know that I'm not into this party thing but it's not being asked... not being asked to stuff is the biggest killer... it's energy sapping, it's very depressing. You have to go yourself... Look, that's my experience but I had to go myself. And I wasn't asked, that was the sad fact".

This kind of experience is reflective of the isolation that has occurred for some of the research participants in different ways. One of the young people who has an intellectual disability and has transitioned out of care and aftercare, talked about how she lives on her own. Currently her mother is ill in hospital, and she has an aunt, but the aunt is not someone who is overly supportive. As she is lacking an informal support network, she is finding it difficult to access formal support systems for her mother, as well as herself, aside from her EPIC Advocate.

Some of the research participants had experiences where their biological parents sometimes treat them as younger than they are and give the impression they still see them as young children in how they talk to them. A young man aged 23 spoke of how his mother *"still thinks or refers to us as children, I don't think she realises, well she realises that we're adults now, but she'll still think like, that you're a child basically"*. The words of a young woman, aged 12, indicates that her birth mother perhaps does not fully grasp that she is growing up, and there seems to be some tension between sensing she is not fully known by her biological mother, and asserting herself and her own identity:



"A lot of the time, like last Christmas, like mammy, she bought me like – I'm not being rude – but she'd buy me 6-year-old stuff and I'm like older even though she doesn't really... even though she's trying to be nice, she just has to know that I'm older now".

As illustrated by one of the Mentimeter statements (pg. 27) regarding a participant not seeing her father for three years while in care, there can be complicated dynamics with family members. She elaborated on what happened when she initially went into residential care as a teenager. Although she was settling in well, *"it was just my father didn't want to visit me, I don't know if maybe he felt like ashamed that I was put into care or maybe he would have wanted my life to be a bit different"*. Another participant mentioned having difficult access meetings with her natural mother and siblings where she felt uncomfortable.

iii) Challenges with care placement accommodation and housing

A recurring challenge for some of the research participants currently in aftercare services, or having aged out of aftercare support, was the difficulty in getting accommodation, with long waiting lists for housing as well as prohibitive rental costs.

One young woman with a physical disability also spoke about her time in care when she was younger, and where she encountered accessibility issues in some foster homes and in residential care:



"Fortunately for me at that time I was able to walk – I was able to go up and down the stairs, but it was very difficult for me to constantly have to go up and down stairs with chronic pain and a dislocated hip. So, I think that's something that really needs to be taken into consideration when a young person is in care with a disability too, that they need to be placed in a suitable environment where they're not going out of their way to just live there and putting themselves in potential danger of hurting themselves".

Now as an adult and dependent on her wheelchair to get around, she has secured housing through an Approved Housing Body but has also come up against various accessibility hurdles. Initially she was placed in an apartment on the third floor, but the lift would often break down and when this happened, she wouldn't be able to go anywhere, including work or to the shops for groceries. There were instances when the lift was out of order for 24-48 hours, during which time she was effectively confined to her apartment, and staff at the complex went to the shops for her.



This situation also created concerns about what would happen in an emergency such as a fire, and the housing provider informed her that in such an event she should remain in the apartment and wait for the fire service but had no advice on what she should do if the fire is in her apartment. Through engagement by EPIC's advocacy service, she was able to get moved to a ground floor apartment which resolved the situation. However, issues like this create not only safety issues, but also inhibit independence.

Reflecting on these challenges, it is vital to note that advocacy and self-advocacy have been particularly important in the face of these obstacles. For some of the participants, foster parents have made a key difference in seeking out and securing different supports or services. For others, it's been the representation and intervention by their Guardian ad Litem and/or EPIC Advocates that has ensured their voices have been heard and their needs met. Some of the participants noted that their experiences have taught them to speak up for themselves to address problems. One participant reflecting on her battles with accessibility issues noted that *"I feel like there's always obstacles in the way but it's about speaking out and you know, getting it changed"*. Another young woman talked about applying the learning from her foster parents' efforts on her behalf, and the experience of not feeling heard, to intentionally work on her communication skills: *"there was really a long period of time where I wasn't listened to, so ever since then I've really learned how to speak up for myself in a very positive way"*. Similarly, one participant shared how he had been paying attention to his own personal development to work on his capacity to articulate his needs clearly, respectfully, and constructively, and how he has seen this pay off in his most recent Child in Care Review meeting.

Some of the research participants have also become motivated in their concern for others to support advocacy efforts for other children in care and/or with disabilities. It is clear from the participants' stories that they often felt they had to persevere despite various difficulties and barriers, and that they have demonstrated resilience. One of the young women observed how this emerges because of the 'in care' and disability labels:



"Growing up in care – you have a bit more resilience because people do talk bad about you for being in care anyway, and then they talk bad about you having a disability, you're just kind of unphased anymore, it's just another thing".

However, her words also conveyed a measure of resignation that dealing with other people's judgement is *"just another thing"* to contend with in the experience of care and disability.

Supports & Services

In seeking to unpack the participants' positive and less positive experiences of care as children and young people with disabilities, particularly in terms of identifying positive practices and gaps in provision that they feel need to be addressed, the focus groups and interviews explored some questions around their experience of service provision.

Supports & Services: What's Working

When invited to think about which supports or services work well and what it is that makes them effective, the research participants referred to several different organisations and professionals. A couple of children and young people named their Guardian ad Litem as a key source of support in relation to helping them to have their needs met, or helping to ensure family contact happens, and there were many positive comments across the discussions about EPIC's Advocacy Service in terms of quality, effectiveness, and encouragement.

There were some positive school or college experiences among the participants, where they identified teaching and non-teaching staff who were helpful, understanding of their needs, and supportive of their education and aspirations. For example, a young man mentioned a school disability nurse who had spoken up for him when he was trying to access further education opportunities. A young woman felt that her school was understanding of her disability and talked about how her teachers provided reassurance, especially in the transition to secondary school:





"[The school is] very good, and I don't really know if they know I'm in care, but they know I have a disability... with the teachers, in my first year of secondary school, I could feel butterflies in my stomach, I was that nervous. But then, I feel like the teachers, even though they kind of weren't saying it, or not kind of showing it, they kind of made you feel not as nervous because like you knew, you'd be spending 6 years at secondary school, so you'd have to get used to it and they kind of let you know that you don't have to be so afraid".

One of the other young men in the focus groups has been to a few different colleges and was getting the most out of his current college experience:



"There's people there that that want to help, I'm not saying like the rest of them [previous college experiences] didn't want to help, I'm saying like, it seems more familiar, like um there's one or two people that are a bit like, it's just relatable in a way. And yeah, I just like the atmosphere as well".

His comments reflect the value not only of a generally supportive environment, but also the value of the time that staff take to support young people's learning on a one-to-one basis:



"The majority of them in my college are very patient with you, like if you don't understand something or if you can't work something out or spelling even, they'd be like, 'right, let me help you' and just help you figure it out".

Supports & Services: Getting Support in Place

The conversations with the participants revealed that aside from their comments on the quality of services or supports they had received, the difficulty in getting support in place in the first instance was a big hurdle, with one participant saying,



"The fight to get supports is like a never-ending challenge, just the fight to get it, it's just - I feel so bad for [name of foster carer] having to explain everything for months on end to get supports for me, for my brother and sister, it's like, it's just crazy, we were just never taken seriously at all".

Indeed, the challenge of navigating disability and care services seemed to be a recurring theme among the research participants as they tried to figure out where to go, who to ask, what to ask for, and to understand how things work and what is possible. A 19-year-old young woman commented,



"We don't know what supports are out there. I never did. No one ever told me even about EPIC, I had to do this research on my own... all the other organisations that I worked with were - I never found them out through Tusla, which is their job, to get you in touch with the people that are there to help you and they never really did that".

Often this issue is compounded by the disabilities the children and young people live with, for example, the insufficient availability of information on conditions like FASD and consequently little recognition or validation of this diagnosis among professionals and service providers. This has contributed to a poor understanding of how it can affect children and young people and their memory and communication – essential for accessing supports and navigating the care system – and the ongoing, often lifelong, challenges they face. A couple of the participants feared judgement on appearances, because their disability is intellectual rather than physical, with one reflecting, "sometimes you can only be noticed if you say you're not able to walk".

The participants description of their struggles to access services, and experiences of slow response, delays, cancellations, or rejections are indicative of various 'systems let-downs'. In one of the focus groups, it emerged that a research participant who first entered care around age 12 and who received an aftercare allowance upon turning 18, had been not allocated an Aftercare Worker until he was almost 23.



During his transition to adulthood, he had not been made aware of his entitlements such as aftercare planning, which may have helped him access accommodation or disability supports. Another young person applied three times for assistive technology supports which had been recommended by her school and was rejected each time. The third application was submitted with a letter of support from her EPIC Advocate and social work department but was refused based on a writing assessment which showed the young person was able to write the required number of words within the specified time limit. However, this did not take into consideration other factors, such as how her writing hand tires quickly, and her writing deteriorates when writing for a longer period. She was disappointed given all the efforts that had been made, and said she felt like it was for nothing.

Another young woman attempted to obtain counselling, but the initial service she was offered was not wheelchair accessible, and so she had to wait even longer for support. One of the focus group participants tried to arrange transport from college via their aftercare service, but it was 5 months before it was put in place. She also shared that she had learned from experience to put all her interactions with professionals into writing, and her comments indicate a certain amount of cynicism about engaging with formal services:



"Unfortunately, one thing I've learned from growing up in care with a disability, is never ring a Social Worker or any service ever, ever, ever. You write them emails or a letter because if you ask for something, they'll try to say you didn't ask for it and for somebody with a memory condition like me is questioning herself and then they're like, completely like, turn their back on me, 'oh you should have done that' when I know I did do that. So, you have to send emails and letters because, they'll actually try to gaslight and say that, like put it back on you when really, it's their job and it should go back on them".

Some of the participants stories suggest that an area of systemic failure is a reliance on a crisis-led mode of working. For example, one of the young people relayed a turbulent period in her mid-teens when she reached a very low point and was desperate for *therapeutic intervention*. *It took seven weeks to get counselling arranged, which from her point of view "when you're 15, seven weeks feels like two years, so that was really challenging"*. Her perception was that it takes a crisis before an intervention can be put in place:



"After a certain age, they see you doing well and they don't really want to link in with you anymore, they kind of only want to work with you if there's a crisis or something has happened, so they let things get too bad before stepping in... I've noticed they only want to step in if it's an absolute crisis, if shit's hitting the fan".

This participant also felt that her experience of crisis interventions, including with CAMHS, were inadequate *"you're in there for about 20 minutes, they calm you down and they send you off without... the HSE linking in with other services that can help you, like, educationally or with mental health"*. She highlighted that having a disability may mean that children and young people are more likely to struggle with mental health issues which can make the situation harder.

What becomes clear in the stories shared by the research participants is that there is a very real impact on children and young people because of the energies they and their carers expend in their efforts to access supports or services. The sense of fatigue was apparent in some of their comments, such as one young woman saying, *"there's the likes of me and others that are really out here trying to get the supports that we need to really succeed"*. Another young person, a wheelchair user, was keen to progress his education and go to college and despite the best efforts of his Aftercare Worker, was unable to get the funding in place to provide a Care Assistant. He found that there was a lack of consistency across different colleges and what they could offer, and the process became more bewildering. He questioned, *"why give me the opportunity to go to college if you're not going to fund it?"* In the end he stopped *pursuing a college education which has inhibited his independence and ultimately, he felt that "in a way we were losing before we even started"*. Another young woman agreed with these sentiments observing that children and young people in care or in aftercare services can sometimes feel like they have been set up to fail.



During his transition to adulthood, he had not been made aware of his entitlements such as aftercare planning, which may have helped him access accommodation or disability supports. Another young person applied three times for assistive technology supports which had been recommended by her school and was rejected each time. The third application was submitted with a letter of support from her EPIC Advocate and social work department but was refused based on a writing assessment which showed the young person was able to write the required number of words within the specified time limit. However, this did not take into consideration other factors, such as how her writing hand tires quickly, and her writing deteriorates when writing for a longer period. She was disappointed given all the efforts that had been made, and said she felt like it was for nothing.

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Another young woman agreed with these sentiments observing that children and young people in care or in aftercare services can sometimes feel like they have been set up to fail.

Many of the discussions indicated that the participants experience anxiety, isolation, vulnerability, disappointment, and are sometimes treated with a lack of dignity and respect. A young man shared how he was “*freaking out*” about what would happen when he no longer had access to aftercare support beyond the age of 23. Another young man talked about his sense of anger because his needs were not being met, and he recognised this as an issue common to others with disabilities saying, “*we’re angry that we’re not getting our needs, we’re angry we’re not being heard and listened to*”. In another focus group, a young woman talked about feeling like “*you have to stand on your own two feet*”. This seemed to be particularly true for those in aftercare services or beyond – one young person who is currently receiving aftercare support felt like she had less people fighting for her and was conscious that she could no longer burden her foster carer. She also expressed a sense of invisibility as she tried to navigate her way through disability services: “*you don’t know how to access supports and what’s maybe out there – like I never felt seen or heard or accounted for*”.

A couple of research participants also acknowledged the mental health impacts of navigating both care and disability at a time in their lives when there are multiple transitions, which are made harder when they feel they are not being taken seriously:



“What people have to realise, as a disabled person, it’s very hard getting into teenage life, there will be depression and there will thoughts of suicide and all of this and you have to fight through it”.

Supports & Services: Gaps in Provision

In exploring the children and young people’s experiences of accessing various supports and services it is possible to identify what they see as several key gaps in provision. Firstly, it seems that there is a lack of system coordination whereby services are not working or linking well together, including within Tusla and aftercare services, the HSE, and the Child and Adolescent Mental Health Service (CAMHS). Some of the research participants had experienced inconsistencies in service provision and seldom found all parts of services functioning effectively or holistically. This speaks to some of the implementation issues raised in the literature review regarding the Joint Protocol between the HSE and Tusla. For example, a young woman related her experience:



“My Aftercare Worker told me literally not to continue with my education because my college was too far, she didn’t want to contact the disability service about that, the disability service doesn’t really show interest in working with me when I was promised that they would after I turned 18, and they’d bring me home from college, but half of them don’t even know that I even have a disability so I don’t even – I brought it up to one of them and they didn’t even know”.

One participant thought that Tusla itself as an organisation lacked awareness of available supports or services for children and young people like him and that more capacity needs to be built into the system:



“I know of some supports, but there’s also supports that I don’t know of... organisations like Tusla should be able to tell you those supports but they don’t seem to know the supports themselves... I think they should have a sister organisation that – if they don’t know the supports, maybe the other organisation might help them”.

He also expressed concern about the high level of referrals and requests for services received by EPIC and felt this indicated a need for more capacity to respond to the needs of children in care and particularly to advocate for children and young people in care with disabilities. One of the other participants went so far as to describe the HSE as a ‘cobweb service’ because she felt she was getting little response:





"The HSE may as well be a cobweb service because every time I try to contact them, they literally answer and say 'what do you want'. I'm trying to get supports for myself and no one is listening. I haven't gotten any counselling since after I turned 18, no psychology assessments... I haven't had any review meetings since I've been in aftercare, I haven't even finished my aftercare plan and I'm in aftercare two years".

A couple of participants mentioned resourcing for services, calling for more funding for continuous supports, particularly for those in aftercare who have ongoing support needs related to their disabilities and there was a perception that less supports are available for young adults. One pointed to a gap in how schools are resourced to support children in care with disabilities and the need for more joined-up working that recognises the dual challenges of care experience and disability. Her view was shaped by a difficult period when she stopped attending school because of a combination of difficulties – experiencing stigma as a child in care, behavioural issues and learning needs arising from her disability and the school's failure to put adequate supports in place.

From a practical perspective, accessibility challenges were a recurring theme for some of the research participants with physical disabilities. One of the participants said that she does not see herself as different to other people because of her disability, but that it's the obstacles in life that make her feel different. She underlined the need for a more proactive approach to ensuring that buildings where services are located are fully accessible for people with disabilities so that they can get the supports they require to which they are entitled.

Supports & Services: Interactions with Social Workers & other professionals

As previously highlighted, the research shows the positive difference made by many professionals in the lives of the participants and how some key relationships created a bedrock of support for them in their care journey. Most of the research participants had positive experiences of Social Workers or other key workers at different points of their time in care, or while in receipt of aftercare. Key features of those relationships included rapport, the worker's knowledge of the child or young person, their constancy and reliability in the child or young person's life, how they were enjoyable to be around, and how they made the child or young person feel safe. One of the participants remembered how her favourite Social Worker was a fun person who played games with her and her sister and described how – when the Social Worker was leaving – she gave the young person a Lego set because she knew the girl liked Lego. Another participant who was full of praise about a specific Social Worker said that "[he] never lied to me, he was very present, he was ongoing, he was there for when I was 16 up until I was 18 and he never made promises to me that he couldn't keep".

This feedback underlines the importance of a rapport between a child or young person in care and their Social Worker or Aftercare Worker. The word 'rapport' indicates that this relationship is less superficial than some other professional relationships and is characterised by a respect for dignity. One of the participants reflected on her positive experiences of Social Workers and said that what made them good was that "they made you feel safe and like they actually listened to you, and they actually took you for who you were". Highlighting the distinct sets of challenges present in the lives of children and young people with disabilities she added "and that's especially for disability children 'cos like they're different to other people and they have to be listened for what their needs are". Comments from the other participants also suggest that it takes time to build trust, the worker needs to have empathy and compassion, they need to show consistency over time, and they need to follow through on the commitments they make.

Unfortunately, the research also revealed negative interactions with Social Workers and other professionals which had a detrimental impact on the children and young people's care experience. One of the under-eighteen participants mentioned above (aged 12 and in care since she was a baby) estimated she'd had over 10 Social Workers during her time in care, a few of whom had not been around for long, and she was very clear that "if you're told you have a Social Worker, you [the Social Worker] can't just stay with us for one day and then go".



There were other examples where research participants felt their Social Workers were not listening or communicating well. One of the participants described a situation when he wasn't happy at his school and was afraid to speak up because *"I knew I wasn't going to be listened to"*. Another participant talked about not feeling heard in many of her interactions with Social Workers, or with her current Aftercare Worker, and felt that set a negative tone for her care experience as well as making her feel unsupported: *"I don't think many of us feel very heard and I think that that's a huge thing, if you don't feel heard, you're not going to have a very positive experience or approach"*. A young woman with an intellectual disability talked about a variety of experiences of navigating some key transitions, and described not fully understanding what was going on or how the care system worked in relation to significant issues, such as court orders or accommodation options.

Stories emerged from the participants where they felt their disability and/or specific needs relating to that disability were disregarded, especially in cases where their condition was not properly understood. One young man had the impression that at times, Social Workers were unsure of how to engage with him because of his disability:



"I thought Social Workers were kind of – not all of them, but they were kind of apprehensive with me... I feel like because I had a disability, they kind of not talk about everything, they didn't know which way to approach certain things because I had a disability".

Other comments from the research participants revealed occasions where the child or young person was made to feel that the Social Worker's job was more important than the child or young person's circumstances, or that they didn't matter and their needs weren't a priority. This was particularly prevalent when they felt that professionals didn't do what they said they would. Decision-making was cited as an area where children and young people did not always feel that their voice was facilitated, and some felt that their perspectives were disregarded. For example, a young woman related how she had to force an argument to have her concerns about a particular respite facility heard:



"They tried to send me somewhere where I knew I wouldn't be safe because I knew somebody that was living there, I just knew I wouldn't be safe there. Like it's actually against their rules not to send you somewhere where you know the person and I had to tell her that, I had to tell her, like her job basically is to keep me safe, and she was trying to put me in an unsafe situation. And then she told me that I shouldn't be speaking to her like that and stuff like this when really it was just me trying to do what was best for me because she didn't have my best interests really".

While annual Child in Care Review meetings were understood as a key opportunity to have a say, they were also considered difficult by a few of the participants, with one explaining how she stopped attending. This was partly because her disability made it difficult for her to participate in a focused way for an hour and to communicate effectively, and she was worried about coming across as rude, and partly because she felt so negatively about the meetings. She attended her last care review when she was turning 18 but felt like she wasn't listened to.

There were a few signs from the discussions that the participants sometimes found it hard to understand the roles of different professionals and who does what, particularly when there can be a range of professionals coming in and out of their lives. Some of the participants found changes in staff unsettling and it also meant they didn't get to know their workers particularly well or build trust. Endings were difficult for several participants. One of the young women who had a strong relationship with her Social Worker as a younger child shared her sadness when the worker was moving on, while not fully grasping what it meant, *"even though I knew she was leaving, I didn't know that I wouldn't really be keeping in touch with her"*. One of the young men who has Autistic Spectrum Disorder struggled to understand professional boundaries and why he wasn't allowed to continue contact with residential care workers if they left the job, or why his Social Worker was involved when he was acting out at school, rather than staff from his residential care home.



What do the research participants understand as their rights under the UNCRPD and does their care experience match with how these rights are stated in the UNCRPD?

The second part of the focus group discussions and one-to-one interviews concentrated on the participants general awareness of disability rights as expressed in the UNCRPD and how these are upheld in their experience of care or aftercare. Initially the Researcher explored the children and young people's knowledge of any laws or standards they felt would relate to them as children in care, or care experienced young people with a disability, and their awareness of the types of organisations or groups of people they perceive to have responsibility for ensuring they are looked after and treated well. Focus group participants were shown an online video about the UNCRPD made by a disability rights organisation from Australia^[15] followed by a brief presentation providing an overview of the UNCRPD.

In the one-to-one interviews, this information was shared verbally without the video. Following the video and/or presentation, the Researcher facilitated a discussion with participants which focused on four key principles within the UNCRPD which also overlap with UNCRC principles:

- Respect for dignity (also described as respecting people for who they are)
- Non-discrimination
- Equality of opportunity
- Participation & inclusion in society

The children and young people were invited to consider the extent to which they believed they'd had real-life experiences of these principles in action during their time in care and after care.

Awareness of disability rights

There was a general awareness of human rights among most of the participants who seemed to have acquired this knowledge largely in informal ways, but most struggled to identify specific sets of rights or standards that might relate to them as children in care or care-experienced young people with disabilities. When prompted, only one of the participants had heard of the UNCRPD but was unaware of what it sets out. A couple of the participants mentioned the Disability Act and there was greater awareness of the UNCRC and the concept of children's rights among half of the participants. Some of the research participants were able to express a general awareness of broad rights, such as the right to education, right to shelter, right to safety where you live or the right to have a say.

One of the participants was clear that they hold rights *"the same as an able-bodied person... I wouldn't consider there just to be a simple section for disabled people"*. Another admitted to knowing that disability rights exist but not the details of what those rights are or *"how they relate to me as a young person in care or aftercare with a disability, none are set out, I don't even know do any apply over my disability"*.

In reflecting on their knowledge of their rights and hearing more about the UNCRPD and how it relates to their lives, some of the participants indicated that they had not previously been made aware of this kind of information with some expressing a desire to have their rights more explicitly communicated to them. Responding to the video on the UNCRPD, one of the participants commented,



"I like how it was made and all the information is quite easy to see and stuff and they gave everyone a chance to say what they have rights to, I really like that video, but it's not something that's ever spoke about at all. I think there needs to be more videos like that that are more accessible, 'cos there's videos on everything but they're just not accessible".

In the same focus group session, another participant shared their view that children in care or care experienced young people should be more aware of rights as a means of engaging with policymaking, but felt that people with disabilities get side-lined by government in this area:





"I feel like I should know more and as a person with a disability I should know about the UNCRC, I know policy's boring, but I feel like, me as a person, I need to know some of it, maybe not all of it. And I feel like it's not, it's not brought into practice with the government as much as it should be. I feel like people with disabilities are pushed to one side in terms of government and rights and stuff because... they don't see the person, they see the disability, they look past the person's ability".

Both participants took the view that agencies may be afraid of people knowing their rights because people will expect those rights to be protected and those organisations will be held to greater scrutiny to uphold them.



"No one really wants to go out of their way and tell people with disabilities what they need to like do or the rights that they have because if you tell somebody their rights then they have to uphold to those rights, I think that's what people are afraid of. Once people know rights then people expect those rights".

When asked to identify organisations or groups of people meant to ensure children in care or care experienced young people are looked after and treated well, the research participants were able to name a range of bodies including Tusla, the HSE, and the government, as well as schools, county disability services, children's services, early intervention services and aftercare services.. They identified relevant groups of professionals such as Social Workers, Guardians ad Litem, foster carers and GPs. Several independent organisations working with children and young people in care or with disabilities were also named, including EPIC, the Irish Wheelchair Association, the Central Remedial Clinic and Barnardos.

A couple of the focus group participants with learning difficulties or intellectual disability struggled with some of the terminology around human rights, but further discussion demonstrated how they were able to make a connection between the concept of rights and ensuring information is kept confidential, or that professionals are held accountable for treating people well. Among all the research participants, there was plenty of evidence of a strong conceptual understanding of how children in care should be treated well and fairly and according to their specific needs.

For many of the participants, one of the areas where there was substantial strength of conviction was the right to have a say. Several picked up on the way in which the Australian UNCRPD video featured people whose speech was affected by their disability and were using different methods of communicating such as sign language or assistive technologies – one participant pointed out how the film showed *"they still had the right to talk and have a voice"*. She went on to assert that *"I have the right to speak up for myself and I have the right to say what needs to be said"*. Another participant located the right to have a say in the context of decision-making around care placements and care planning saying,



"A person who's able to make a decision, they should ask them, 'how do you feel?' or not to be just putting something into place and maybe they're not comfortable with it or something".

Some were very aware of how they can use their voice to help others, and this was a motivation for not just their personal advocacy but also becoming an advocate on behalf of others. For example, one participant commented that *"if I have a chance to make it better even for somebody else that doesn't feel that they have a voice and are going through similar things that I am, I'm more than happy to speak out"*. Based on his encounters with other children and young people with disabilities, he was similarly motivated to help bring about change:



"If I have to be an advocate for EPIC in the future for different children with disabilities or they don't even have to have disabilities actually... I just want everybody to feel the freedom that I feel, the freedom of speech and it's sad that, the fact that I've heard stories and they haven't been respected and it angers me".



More broadly, one of the participants welcomed learning more about the UNCRPD and its purpose because of how it underlines that people with disabilities have a right “to live a full life” and to be viewed in terms of their capacity. He continued, “I think what really opened my eyes about it was the ‘we have the right to do stuff’ – like we’re capable of doing it, I think that’s what perked my ears up a bit”. This provides an indication of the resonance of the UNCRPD for children and young people with disabilities, particularly in relation to the promotion of respect for their inherent dignity. The same participant felt that the UNCRPD brings into focus how people “should be able to access certain things or have extra supports if they are in need of it and they should have advice”.

Another participant felt very strongly about the need for the right to information to be upheld in relation to knowing how to find and ask for disability supports, access to information and resources on disabilities, and having children’s and disability rights explained in a way that is appropriate. This participant felt the right to information should be supported in real terms by assisting children and young people to understand decisions about their care, as well as in providing greater transparency about those decisions. Regarding the issue of transparency, she shared that,



“A lot of things weren’t said to me because they were afraid it was going to affect me but what it really did was it made me feel like secrets were being kept around me and instead of not telling me things, they should have told me things in a way that was suitable for me, rather than not saying it all because that’s your right as a person - to know what’s going on in your life”.

This participant reflected on situations during her time in care where she felt she was made to engage in access visits with her birth mother and with siblings when she didn’t feel safe and was uncomfortable about some of the people who were present. At the time, she wasn’t aware that she had the option to have a say about who would be there or to say no to a visit because she felt afraid of a particular relative. She also described aspects of respite care which at the time were normalised, but afterwards she realised they were problematic:



“Certain things happened in my respite care that shouldn’t have happened, and I thought they were normal things that happened – for example falling asleep on the stairs, I thought that was normal, sure – when my foster parents found out they were shocked. Like I thought all of these things were normal because none of them were explained to me. It goes back to the UNCRPD, the Disability Act, none of these things were explained to you as a young person in care”.

UNCRPD principles in practice

There was a mix of positive and negative reflections on key principles underpinning the UNCRPD, the positives included respect for dignity, equal opportunities, non-discrimination and participation and inclusion in society. The concept of dignity or ‘respect for who you are’ was particularly resonant for some. One participant who had faced significant difficulties in getting disability supports in place in relation to their care was adamant that “it costs nothing to be respectful”. Pointing to previous care reviews where he felt he had been talked over by the professionals in the room, he shared how he had worked hard to find ways to communicate his needs effectively and assertively. Emphasising that “I don’t want to get people’s respect through intimidation, I want people to listen.” It was evident that he had clarity on how people should be treated and listened to as a basic courtesy, regardless of their age or ability. Conscious of other children and young people with disabilities who had faced similar struggles, he was appalled by what he saw as disrespect and a lack of acceptance of people with disabilities:



“The people that have disrespected people that I know with different disabilities that I described earlier, it’s just disgusting really, people need to count themselves lucky with the bodies they have... and for different reasons people just need to accept from now on that there’s people with disabilities in the community and not to look down on them, not to look at them as if they’re just an object”.



By contrast, another one of the participants was quick to say that his experience of foster care was one where he was treated equally, and in the same focus group session another participant agreed, sharing that her time in foster care had been more positive than when she had been in residential care. This was partly because her foster family was “just like a family”. Unfortunately, the foster care experience of another of the participants had been less positive because they described being treated like the ‘Cinderella’ in the family:



“I thought of myself as the ‘Cinderella’ of the house, I was always expected to stay in and clean, I was only allowed to go out for so long, whereas there was boys living there, and like, this was my foster family’s actual children, they weren’t foster children, so they were basically allowed to do whatever they wanted, so I was treated completely different to them”.

As noted, one of the research participants had a limited and limiting experience of aftercare because supports were only put in place shortly before his 23rd birthday. He seemed reluctant to be critical but shared how he felt he hadn’t seen much of his Aftercare Worker and would have liked more contact, particularly given some housing issues which remained an ongoing challenge at the time of this research. He felt strongly about housing as an issue for young people leaving care and aftercare, and while very aware of the challenges presented by the housing crisis for many people in Ireland, he also felt that the potential impact of homelessness is especially serious for young people in this situation who have disabilities:



“I wouldn’t say we’re kind of fair on housing in a way. I know there’s a housing crisis at the moment... I feel like, especially a person – like everyone deserves a home, but I feel like, if someone with a disability is left homeless, I think they’re at a very vulnerable position”.

Fairness was a common theme across the focus groups and interviews and was seen as highly relevant in terms of employment and equal opportunities by several research participants. Three of the participants spoke of having been turned away with clichéd responses from prospective employers following job enquiries such as “oh you’re not the right fit” or “oh we’re not taking any people at this time” or “oh we’re overstaffed now”. There was recognition from one young person that it might be difficult to prove that discrimination is taking place because an employer might be in a genuine situation where they’re not recruiting, but as someone who is still in full-time education, he is already anticipating significant rejection in this area as he looks to the future. The story told by one of the other participants of spending two years applying for jobs after leaving school was illustrative of two key challenges in seeking employment – the dilemma of whether to disclose their disability and the struggle to get constructive feedback that they could apply to their job search following a rejection. In the case of the former where she didn’t disclose her disability she described how,



“I would either get to the place and I can’t get in or I’d get to the place, I’d meet the person I’m meant to be doing the interview with, and they look like they’ve seen a ghost, ‘cos they’re like, ‘oh!’”.

Then consequently when she did disclose her disability, she would be invited for interview and perform well only to be told afterwards,



“Oh, we’ve found someone more suitable for the job’ and anytime I asked for feedback they’d always say, ‘your interview was brilliant, you seem like a lovely person, we just found somebody more suitable’. So of course, you found somebody more suitable because you found somebody who wasn’t in a wheelchair”.

This conversation revealed two areas where she felt change is needed to improve what young people with disabilities transitioning from care perceive as their employment prospects going forward. One is about attitudinal change in relation to perceptions around disability because she felt that those interviewing her were not seeing her or her abilities but only her wheelchair.



She also pointed out what she saw in wider society as a false set of assumptions about the kinds of jobs people with disabilities want to do:



"...that we all just want to be in an office and answering phones and on the computer – you'll never see me doing that. That is not for me, I'm a people person, I love interacting with people, I love kids, you know, I want to be out there meeting people, talking to them, I don't want to be stuck behind a computer screen and a phone talking to people. So, there needs to be more equal opportunity jobs for everybody in every area, not just in the area that society expects us to be in".

The second area is at the structural level, to improve the availability of jobs accessible to people with disabilities. This participant felt there should be more proactive employer recruitment, support, and advice for people with disabilities that takes each person's interests, qualifications, skills, and abilities as the starting point. In a focus group, a young man with a learning difficulty agreed that young people with disabilities should be able to access employment opportunities in a way that can be adapted to their needs:



"If you're qualified for and you have experience in something, but if you find something a bit more difficult, they should be more adaptable to it – basically what I'm saying is people should be able to find the job that suits their needs".

The issue of accessibility was one that was seen as presenting ongoing challenges within a disability rights framework in relation to the UNCRPD principles of non-discrimination and inclusion. One of the young people who is reliant on a wheelchair to get around talked about facing barriers with everyday practicalities such as accessing buildings or using public transport. For example, although she regularly encountered bus drivers who are very accommodating, she has had experiences where some have not let her access the designated wheelchair spot on the bus because another passenger was there with a buggy. There were even instances where despite her remonstrations, some drivers refused further engagement and drove off. On other occasions, she found some drivers force her to comply with the rule of wheelchairs facing backwards on the bus even though this gives her motion sickness. While she is willing to comply with the rules, it's the imposition of rules that she finds difficulty with noting that *"I shouldn't have to be humiliated into doing something I'm not comfortable doing... I don't think anyone should be forced to do something that they're not comfortable doing"* which reflects a concern for being treated with dignity.

She also highlighted how the principles of non-discrimination and inclusion need to apply to the accessibility of specific components of care such as accommodation, and wider aspects of the care experience such as available activities in residential care:



"I think accessibility is number one key, if a person can't get around where they're living safely and they feel comfortable, they shouldn't be placed there. There is no logic of placing somebody in a house that's in a wheelchair and either can't walk at all or has very minimal ability to walk and they're expected to go up the stairs. ...if there is a back garden – they need to be able to access that. ...if they're in care, obviously the people that are looking after them, they need to take into consideration the activities, make sure that everything is inclusive for everyone".

Many of the research participants were very aware of how their voice matters, a key element of fostering the meaningful participation and inclusion in society of people with disabilities as per the UNCRPD. For example, one young man articulated how he feels it is important that people with disabilities get to express their views:





"We have a voice for a reason, it's to stand out and give your opinion, it might not be the right opinion but at least you have your voice to say regardless of whether it's through a computer or if it's through a voice box or whatever, nobody should be shut down".

For another, it was particularly important that they use their voice constructively as a means of enabling children and young people with disabilities to be heard on an equal footing and to act out of an awareness of their own dignity. His comments also display a recognition of the work that is still needed in society to welcome the voices of children and young people with disabilities:



"Of course my voice matters and you know, those of us with disabilities, they've pushed us down and quietened us for so long, now it's time to show that - if you want to push down my voice then I'm going to rise above you for sure and if you want my opinion you're going to have to ask to meet at my half of the table".

Several of the group described themselves as outspoken, whether naturally so, or having learned to be because of different challenges they had faced in their care experience. One young woman recognised this characteristic as a means of bringing about positive change for herself and others:



"I'm lucky that I've had a very outspoken personality trait, so it's something that I do use as a very powerful tool, I think voices are more powerful than people think, and I think that if people took the time to listen to others, we'd have a very understanding world".

Ideas and messages for change

The last part of each of the focus group sessions and interviews explored the participants' ideas around how the care experience might be improved for other children and young people with disabilities using the lens of their own experiences. These yielded a range of actions they felt would make a difference at the micro and macro levels. The participants were also asked to consider what they would want to say to those they perceive to have influence within the care system. This activity encouraged the participants to craft a key message in one or two sentences encapsulating their thinking about the change they would like to see. Some provided a written statement via an online Mentimeter poll, while others responded verbally.


Beyond the remit of health and social care services, one young man responded to the last question by naming housing, employment, and education as three wider areas where he felt the specific needs of care-experienced young people with disabilities should be recognised and taken into account: "*Housing accommodation, and the right to a job that suits the person with a disability, and same with education*".

The participants responses across the discussions and interviews can be grouped into three areas for change:

1. Interactions with professionals


As noted, the relationships between children and young people in care and professionals are pivotal to the care journey and beyond. Genuine listening is an especially vital component of these relationships as indicated by several research participants, including one of the youngest who said that social workers need to actively demonstrate they are listening to children: "*you can't just listen to them, you have to write it down. You can't just listen to them and not listen to them*". Via the Mentimeter poll, she underlined the importance of honouring what children and young people with disabilities have to say because of their distinct needs:






"These kids they are different to other people, and they need to be heard because they have a right for something to say. You guys need to listen because everyone has a say especially a kid like [me] and all the other kids in care - with a disability or without".

A call to ensure children and young people's input into decision-making was another key message which goes together with listening to them: *"make sure young people have a voice for deciding their plan for care and aftercare"*. This is a practice that not only acknowledges children and young people's agency but is also integral to a rights-based approach. Elaborating on this statement, the participant, who has an intellectual disability, emphasised the importance of preparing children and young people for things like changes in their care arrangements. This links with previous points about the right to information and transparency in decision making, and is particularly important at key moments of transitions:



"Maybe just prepare people... in my experience, I felt I wasn't prepared... they were saying, oh I'd be moved different places as well, like foster care, but then they called it supported lodgings and I'd never heard of that... maybe just like prepare people like if there's something going to happen or explain it, like why's it going to happen".


When one of the participants considered their experiences to date, they felt that they would like more direct, face-to-face engagement to discuss decisions that are being taken, or when an action is promised but not implemented. This emphasises the importance of professionals following through on the commitments they make to children and young people:



"Say if you had something that happened to you and they said they'd do it, but then they never really did it and they treated you, 'oh I done that person or finished that project' when they never did. And then for them to come and meet you and talk about the issue, they've to come to you personally instead of doing it overline and they say they'd do it but never did, and they talk about the issue. You [the professional] put it to yourself to do it".

Another participant suggested that EPIC considers how it can expand its advocacy services to provide a level of support for care-experienced young people beyond the age of 26. He felt that people may still need support after this point, and it might be helpful to have someone to call on with questions or queries. This suggests some young people may benefit from having ongoing access to formal support networks for care-experienced people.

Finally, one of the participants called for social workers to adopt a softer approach to managing behaviours, or situations where a child or young person is acting out, and to make greater use of reflective practice. She considered it important to acknowledge different transitions or changes in the young person's life where *"maybe they're after working with a new counsellor or psychologist that they're not getting along with, maybe they're being bullied at school over their disability"*. The young woman pointed out that emotional regulation can be challenging for some children and young people in care, even when they don't have a disability:




"I think having a softer approach is a huge thing 'cos often when you're in care, even if you don't have a disability, it can be quite hard to manage your emotions because you don't really know who to trust and stuff. I think that's a huge thing that needs to be looked at".




2. Structural issues in the care system

Several points were raised by the research participants that relate to areas where they would like to see change at a structural and systemic level. For example, one participant was critical of aftercare as a service, and thought that it was not fulfilling its purpose, particularly for young people with disabilities. They questioned the efficacy of how it is meant to link young people with different services and supports as their own experience had not been positive in this regard.^[16] They felt there is a contradiction in the approach of promoting care leaver independence as a voluntary service, while simultaneously failing to facilitate effective signposting to other relevant supports. In their view, this means that people with disabilities can get left high and dry:



"How are people – aftercare is about promoting independence and stuff - but how is people supposed to be independent when they've relied on particular services when they were in care, and then can't access those same supports in aftercare?"


Moreover, they explained that in relation to their own disability, FASD, that they have difficulties with memory and processing challenges, so they don't always remember to initiate contact with their Aftercare Worker and can struggle to articulate their needs:



"They told me that when I was turning 18, 'you have to work with us, if you don't ring us, we're not really going to ring you, you have to tell us what you want to do'. Which sounds good – 'oh they're going to be there if you need them' – but then I don't always know what to ask for because I don't always know what type of questions to ask, my brain doesn't allow me to do that. I sound like someone who's very outspoken, but my brain doesn't allow me to say the things I want to say or in the right way or to gather the questions in my brain... I'd worry for people that don't have that ability to speak up for themselves – how are they going to get the supports?"

Having reaped the benefits of early intervention when they were younger, they felt as an adult turning 20, it was harder to access the kinds of supports which they believed would help their progress with their studies and into working life. In addition, their view was that their Aftercare Worker had not been highly effective to date. They shared their opinion on the need to ensure professionals work closely with young people in aftercare services with disabilities to help connect them to relevant supports, particularly as they leave care.

Deciding on his message for those with influence on the care system, one participant was very blunt in his assessment of what he saw as a lack of follow-through and implementation of supports and services:



"What I would say to a Taoiseach or Head of Tusla is, 'I'm disappointed in you, you have this big idea that you're all for helping people out, you're all for respecting everybody and making sure they get their place but when it comes down to it not only do you do it last-minute, but you couldn't be arsed'".

[16] According to the Statement of Purpose in Tusla's National Aftercare Policy for Alternative Care, "Tusla is committed to promoting and achieving the best outcomes for young people in care in keeping with the role of the "good parent". Tusla is committed to maintaining support to care leavers through the delivery of programmes which enable young people to adequately prepare for leaving care and in ensuring consistency of support to these young people/young adults in aftercare from 18 years and up to 21 years of age."



3. Improved capacity in relation to disability

One of the participants started off her ideas for a message about services calling for greater awareness and recognition amongst policymakers that there are children and young people with disabilities in care:



"I think that they need to be more aware that we are here in the first place 'cos I never really felt represented in their policies or anything... And I think that they just need to be more aware of different disabilities".

In addition, she expressed a strong desire for there to be more awareness and resources in relation to her condition, FASD, particularly because it is more prevalent than many people think, and Ireland has one of the highest rates in the world^[17]. She was keen for professionals and foster carers to have more access to information generally about disabilities, and to get training in the specific disability that the person they are caring for has, so that they can better understand how it affects their behaviours and to prevent discrimination.

Another participant agreed that there needs to be better responsiveness to specific disability needs. There was also a comment about effective prioritisation to address waiting lists for services..

For one of the participants with a physical disability, accessibility was a key issue to be addressed across the care system, and her message focused on ensuring care placements are accessible:



"I just think they need to have more insight and a bit more common sense in thinking of everybody in the situation – you cannot open a residential home and just automatically assume 'we're not going to get anybody in here with a disability'".

In interview, she had also talked about the need for architectural designers to show a better understanding of accessibility issues, ensuring there are ramps, disabled toilets and other measures put in place consistently. She called for a more empathetic approach to factoring accessibility into design, recommending online campaigns such 'A Day in the Life of a Wheelchair User' to enable greater awareness of the challenges people like her face every day: "sit in a chair while you are planning these places for people to live, and see how far you go in being able to live, because they won't get very far".

Lastly, another participant, also a wheelchair user, reiterated the need for greater understanding of what it is like to navigate everyday life in a wheelchair:



"Until you've sat in a chair for 24 hours in, in a manual chair...there's transport, there's getting taxis, there is going places, it's very hard until you have a car and you have the privilege of going wherever you want. I would say unless you're in my situation, don't speak... Isn't it funny, there's the Head of Tusla and the head of the ministers... and none of them are in wheelchairs?".

[17] <https://endpae.ie/new-research-study-on-fasd-in-ireland/>



05

Conclusion & Recommendations



While this study has been exploratory in nature and modest in scale, the data that has emerged from the research participants' experiences and stories has been rich, revealing, insightful, often raw, and peppered with ideas about how services can improve. Children in care or young care-leavers with disabilities can often be labelled as 'vulnerable' or 'marginalised' and this may sometimes be true, but such terms do not tell the whole story of their lives. This project therefore provides a valuable snapshot of their lived experience as children and young people with disabilities in care, in aftercare services, and beyond. There are vital lessons not just for those actively working in the care system or disability sector, but also for society more widely, especially on how we can address the barriers that inhibit inclusion and participation. The research has given the participants a platform to share how they experience the world around them, a chance to say, 'I'm here, I matter, I want to be heard.' They have asserted themselves as rights-holders able to participate in decisions about their care experience, rather than as subjects of decisions making; these are stories that are worth listening to, not just because of the children and young people's inherent dignity and worth, but also to ensure the rights of children in care with disabilities are considered and upheld in policy and practice.

There are many positives in what the research participants have to say about their time in the care system and in aftercare services. Over and over, what stands out is how there are key people who play a significant role in care-experienced children and young people's lives – carers, social workers, educators, and many others. As a result of being in care, many of these children and young people have had a second chance at life, finding their way into different support systems whether formal or informal – schools, foster families, residential care homes or youth organisations. These have offered spaces of safety and security where their needs are met. Places where they can grow with a measure of stability, places that offer belonging where they can be more fully themselves, where they can learn and discover their skillsets and develop their aspirations for the future.

However, the research also shows the range and extent of the challenges the participants have faced. From practicalities like accessibility problems in care placements, to social challenges as they navigate childhood, adolescence, and different sets of often complex relationships, to dealing with issues that arise from their disability. Obstacles persist as they seek to access supports and services, navigate the care system, disability services and education options, engage with different professionals, and contend with structural inequality and system failings.

Consequently, a lot of the participants responses in this study often conveyed a deep sense of anger, of feeling disrespected and unheard, of injustice, and anxiety about how they will find their way, or weariness of having to keep chipping away at the obstacles in their path. Indeed, a striking phrase from the data is when a young person with a physical disability who uses a wheelchair and who has been in both residential and foster care said, *"I don't see myself as any different, but there is a lot of obstacles in life that make me feel different"*. This is resonant with the UNCRPD's view of disability, that it:

"...results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others" (Preamble to the UNCRPD).

Understood in this light, it is the obstacles to inclusion and participation that shape the experience of disability and that marginalise these children and young people. As noted in the findings, the young person quoted above had described their struggles to gain employment – these challenges were not about their abilities or disabilities. Rather they arose because of the barriers imposed externally in societal attitudes or ignorance, and by a lack of adaptations in the physical environment. It is perhaps possible to say something similar about how care identity can be treated similarly, with the limiting perceptions that can be associated with the label of being 'in care'.

Among the research participants it emerged that rights awareness is quite low, especially with respect to disability rights, the existence of the UNCRPD and how it relates to their lives. However, the study enabled the participants to engage with some of the key principles from the UNCRPD and these ideas resonated with them strongly. It is important to acknowledge how care and disability intersect in the participants lives, and the challenges this creates as they navigate everyday life and the wider care system.



One of the participants expressed it beautifully when she talked about the importance of responding to children and young people in care with disabilities saying that *“they’re different to other people and they have to be listened to for what their needs are”*. The challenges these children and young people face can have far-reaching impacts, at times contributing to a sense of vulnerability, yet at the same time the children and young people’s unique individuality, agency, and capacity to direct their lives should be respected and nurtured as they grow.

Through the research, it became evident that the circumstances the participants find themselves in often require that they engage in extra work to navigate these various issues, whether it is preparing applications for assistive technology, or contacting different colleges to find out what disability supports are available or engaging with different agencies and local authorities to figure out housing availability. Indeed, one of the participants described dealing with some of the challenges he faced such as engaging with professionals in the care system or dealing with rejection by peers as ‘energy-sapping’:

“Like I can’t even finish this because I’ll tell you why, I had a big speech for this one but I’m just letting you know it’s energy-sapping, going to meetings, talking to these people. They’ve never set foot in a [wheel]chair in their life, they don’t live my life”.

A few of the participants talked about working intentionally on their own personal development to enhance their communication skills. This was so that they could engage effectively with professionals and services when they felt that they weren’t being listened to, and to develop their resilience so that they could withstand negative judgement from others. While this is highly commendable and shows great maturity, some might associate this with the concept of ‘emotional labour’ that is defined as *“unpaid, often invisible work that a person is compelled to do by others to keep them happy”*.^[18]

Considering the challenges that the participants described in this research – their difficulties navigating the care system, their struggles to access supports or services, the lack of coordination between services and agencies and other systems issues – it may feel to them that they are the ones ‘putting in the hard yards’. Yet they are the ones living with disabilities, in care or in aftercare services, and facing a range of different issues that arise from their care experience. They are not the professionals in the room, and responsibility ultimately lies with the Government and relevant statutory agencies to fulfil their duties and deliver on their responsibilities as the Corporate Parent. This aligns with some of the points raised in the study by Ellis and Johnston (2022) which highlights how structural barriers external to the children and young people’s individual capacities are a key factor in the struggles they face to succeed. Indeed, there were a few instances when the conversations with the participants indicated an internalised sense that they need to work harder or be stronger or tougher in the face of different challenges. Perhaps there needs to be more proactive efforts at a systemic level to ensure supports are available and accessible to children and young people in care or in aftercare services with disabilities to enable them to thrive in supportive environments. A couple of the participants were also cognisant of the pressures faced by staff working for agencies like Tusla, including caseload pressures:

“Getting things done before things hit rock bottom would be a great start. I understand – I really do understand the immense pressure that people that work with Tusla and services like that are under, like there’s huge gaps for them too, but when they’re dealing with people with individual needs, especially when you’re working with disability and when you’re working with many other services, like there’s certain things that do need to be prioritised in that sense. And having so many people working with someone at the one time can be quite challenging – you don’t really know what to really ask for, I wasn’t really listened to. Listening is a great thing. My rights were never explained to me, the list of supports were never given for me or my foster carer”.

[18] Resnick, A. (2021) What is Emotional Labor? [online] Available from: <https://www.verywellmind.com/what-is-emotional-labor-5193184> [Accessed 21st December 2022].



Despite everything, the conversations with the research participants were expressive of their dignity and presence, as well as their desire to grow, to be independent, and to help others by sharing their experience. Based on what they have said, it is possible to say that they don't want to be defined by their disability. There are times when they need additional support and people they can trust to call upon with a query, to help them navigate challenges, or to access systems of support. The data also indicates that they want to succeed, they want to be as independent as possible, they want to be listened to, they want to have a meaningful say in decisions, they want to be supported appropriately and adequately, they want their disability to be understood, they want action on commitments made, and they want to be treated with respect for their dignity in a way that celebrates their uniqueness. As one of the research participants summed it up, *“with people with disabilities, I feel like they should be more independent and be able to look after themselves, but if they need support, it should be there for them”*.

Clearly there are many lessons in this study to take away for the care system as a whole. There are obviously general best practices at the individual level for supporting children and young people in care or in aftercare services with disabilities well – and none of this is new or radical – but things like taking time to listen to children and young people, focusing on building rapport, communicating clearly and so on. Children and young people want to be seen not just as a ‘case’ but as a human being with hopes, dreams and aspirations.

This study was solely focused on the children and young people's experiences and did not examine the perspectives of those working in different social services, whether as practitioners or at a management level. However, based on the stories told by the participants of their experience, it is possible to identify some issues at the structural level that may benefit from attention. These include areas like coordination and effective interagency working,, expanding capacity, and provision of effective support for social workers and other professionals so that they are equipped with relevant knowledge about disabilities, and better supported to give the kind of care children and young people deserve, for example through adequate supervision and reflective practice.

Consequently, it may be useful to consider the potential for key improvements and adaptations that create space for wider change at structural level. Some of the following questions may be helpful in supporting the ongoing work spearheaded by others, including Tusla, the HSE, and the Irish Association of Social Workers, in this regard:

- What would adequate training and reflective practice for professionals look like, how can caseload pressures be addressed, what initiatives would encourage more consistency in the workers allocated to children and young people?
- What initiatives might improve transitions from care to aftercare so that these are smoother experiences for young people with disabilities, and an enabler for their ongoing development rather than a time of anxiety and stress?
- What might a strategy to ensure continuous supports rather than a crisis intervention mode look like to ensure that disability supports are available to those who need it? How might this benefit children and young people and service delivery?
- What initiatives will help prevent children and young people falling between Tusla and the HSE?



Recommendations

Finally, the findings from this research provide a strong case for the responsible authorities to consider the following recommendations:

Disaggregate data related to children and young people in care and aftercare services by disability to create an evidence-based understanding of their needs and appropriate policy responses.

Develop flexibility in systems to enable an intersectional approach to care and disability.

This includes the opportunity to ensure supports stay in place for young people turning eighteen and transitioning to aftercare and adult services, especially where a particular disability presents a distinct set of ongoing challenges. It also applies to accessibility issues to ensure all social services – including care placements – can be accessed by all children and young people regardless of their disability.

Increase the level and availability of information about disabilities across the care system.

A practical example of this which was suggested by one of the participants in the study was to ensure there is a Disability Officer in each Tusla Region to provide support to social workers on how to respond to different disability needs. Another practical measure might be to ensure all social work graduates joining Tusla have opportunities to engage with modules that are informed by care-experienced children and young people with disabilities to build their capacity. Foster carers and residential care workers also need to have access to ongoing dedicated training and information on the care of a child or young person with a disability, and enhanced understanding of where to go to access relevant services/supports.

Apply a rights-based approach to care to ensure the voice of the child or young person is facilitated and heard in decision-making, particularly in relation to care planning, care reviews and transitions into or out of care and aftercare, especially in regard to access to disability supports and services.

Provide additional resources to ensure all children and young people with disabilities in care and aftercare have timely and effective access to quality supports and services.



next chapter

THE FUTURE
IS BRILLIANT

Move Forward

06

Next Steps

by EPIC, Empowering People in Care



On foot of the recommendations of this report, EPIC, Empowering People in Care, proposes the following actions be considered by the relevant bodies responsible for care-experienced children and young people with disabilities.

Disaggregation of data related to children and young people in care and aftercare by disability.

While no two experiences of care will ever be the same, it is important that data is available to, identify, and resolve any systematic obstacles or discriminations affecting children in care and care-experienced young people with disabilities.

The Tusla Performance and Activity Reporting Site and associated Data Catalogue are important sources of rich data for stakeholders including government, representatives of state agencies, academia and civil society. However, there is no specific and centralised monitoring data about children in care with disabilities. This represents a major gap in relation to the ability of duty bearers to respond appropriately and in an informed fashion to the needs of these children and young people. Additionally, there is no publicly available statistical monitoring of accessibility to health services for children in care with disabilities.

Action 1: The strengthening of ethical data collection and monitoring should be considered by both the HSE and Tusla in the context of a review of the Joint Protocol for Interagency Collaboration Between the Health Service Executive and Tusla – Child and Family Agency to Promote the Best Interests of Children and Families, with the objective of developing a coherent evidence base to inform policy delivery and service provision for children in care with disabilities. This would include bringing together administrative data from agencies working with children in care and with people with disabilities respectively.. (Tusla, HSE, HIQA)

Greater flexibility in systems that enables an intersectional approach to care and disability. Some participants within the study noted that the period before turning eighteen and upon leaving care was a time of great anxiety and uncertainty. Furthermore, some experienced disjuncture in their care as a result of the move from the care of Tusla to adult disability services. Young people reported feeling “in limbo” without clarity on what they could expect in terms of aftercare supports and services, and it appeared that responsibility for such was falling between the HSE and Tusla. This indicates that the collaborations outlined the Joint Protocol are not working as they should in some areas, and that this is significantly impacting on the wellbeing of some young people with disabilities, who are not experiencing a safe and dignified transition from care.

Additionally, the care journey of a child or young person should be consistently treated as a continuum, whereby the transition to adulthood is planned well in advance of the young person turning eighteen. This would allow for greater forward planning by the respective agencies and reduce the uncertainty experienced by the young person.

Action 2: The Child Care Act, 1991 should be examined and reformed in the context of where a young person in care with a disability is transitioning to adulthood and responsibility for aspects of their care are transferring from Tusla to the HSE. In this situation, the relevant bodies should have a formal, joint responsibility for planning and provision of services. (DCEDIY, HSE, Tusla)

Make more information about disabilities available across care services. The level of oversight and level of consultation regarding the access of services is not clear regarding the general case management of care arrangements for children in care with disabilities within Tusla. As noted by the OCO, the HSE does not have disability managers to undertake case management roles (OCO 2018:2).

To ensure that effective case management and oversight between the agencies is established and maintained, specialised officers within staff must be identified and trained with links to cooperate with other agencies equivalent officers.

Action 3.1: Statutory agencies with responsibility for care and disability should establish a specific role for children in care with disabilities. These functions should report periodically on the situation of children in care with disabilities to identify best practice, as well as gaps or systemic obstacles to their care.



Those appointed should work consistently with their counterpart in the other body to ensure a 'continuum of care' approach is adopted to ensure the best interests of children or young people with disabilities are upheld throughout their care journeys and transition to adulthood. (Tusla, HSE)

Action 3.2: An examination of opportunities to incorporate the principles of universal design in health and child and family services should be undertaken with a view to increasing accessibility. Access Officers (appointed under the Disability Act 2005 s.26) could be further trained to assess feasibility at local level as a first step, potentially with guidance from the National Disability Authority's Centre of Excellence in Universal Design. (Tusla, HSE)

Action 3.3: Specialised lead social workers should be appointed at regional level to advise and support social work teams on how best to support children in care with additional needs, and their carers. (Tusla)

Action 3.4: To promote the role of social work in healthcare and its intersection with child protection, the role of Chief Social Worker in the Department of Health should be established. (DoH)

Action 3.5: All social work graduates joining Tusla should have opportunities to engage with modules that are informed by care-experienced children and young people with disabilities to assist in building their capacity and knowledge of the distinct issues affecting this cohort. (Tusla, DFHERIS)

Action: 3.6: Foster carers and residential care workers should have access to ongoing, dedicated training and information on the care of a child or young person with a disability and an enhanced understanding of where to go to access relevant services/supports. (Tusla)

Apply a rights-informed approach to care. Consistent evaluation and re-evaluation of rights-informed approaches to care encourages greater openness and transparency around decision-making with care planning, care reviews and transitions into or out of care and aftercare services and facilitates greater accountability that is consistent with optional protocols included in the UNCRPD and the UNCRC, particularly Articles 29 and 13 respectively, which deal with a child with disabilities right to be heard in matters that affect them.

However, the right for a child in care to be heard in matters related to their care outside of legal proceedings has yet to be fully enshrined in legislation. This is despite the same right being enshrined in Article 42A of Bunreacht na hÉireann, as a result of a referendum held by the State in November 2012. Independent advocacy is recognised internationally as a means of upholding and vindicating a child's right to be heard in matters that affect them via Article 12 of the UNCRC, and in the United Kingdom, it is enshrined in legislation via the Children Act 1989. The right to independent advocacy for certain adults with disabilities was also established by the Citizens Information Act 2007.

Action 4: DCEDIY is currently undertaking a review of the Child Care Act, 1991, with a view to amending the legislation this year. It is critical that the Department establishes the right to independent advocacy in the upcoming Child Care (Amendment) Bill to enable care-experienced children and young people with disabilities to access independent advocacy services. (DCEDIY)

Ensure adequate resourcing to provide adequate disability supports for children in care and young people with care experience or in aftercare services ensuring every child and young person has access to an allocated key worker, disability supports at their educational or training institution.

In 2018, the Ombudsman for Children (OCO) published a report into the findings of the 'Molly Case', a teenager with Down's Syndrome and autism, who was receiving an insufficient level of supports and services to meet the extent of her needs (OCO 2018:2). This study worryingly noted that "a higher proportion of disabled children either had no social worker or a social worker who rarely visited them". Reviewing the case one year on, the OCO stated 'definite progress' had been made for Molly but remained concerned about the 'working relationship between Tusla and the HSE' and that the implementation of the Joint Protocol for Interagency Collaboration has 'progressed but there is still a long way to go'. The OCO further stated that not enough had been done by Tusla and the HSE since Molly's Case has been brought to their attention.



For example, there was obstacles regarding joint planning identified due to the failure to agree a common understanding of the children with a moderate or severe disability. These are critical obstacles in oversight that have a direct impact on resource planning and therefore, on the care of a child with disabilities.

The Joint Protocol for Interagency Collaboration between Tusla and the HSE appears to have difficulties in implementation when looked at through the lens of care for moderate or severe disability in foster care by the OCO in 2019.

To date, no full review has been conducted for children of all disability categories (mild, moderate, severe) in all care settings (foster care, residential care and special care). In order to ensure that all children with a disability that are in the care of the state reach their full physical, cognitive, educational and emotional potential, enhanced oversight and appropriate resourcing is necessary, and must be evaluated on a continuous basis.

Action 5: In the context of a future review and evaluation of the implementation and operation of Joint Protocol for Interagency Collaboration between Tusla and the HSE, oversight and monitoring of delivery of care to children with disabilities should be included as a performance indicator. (Tusla, HSE)



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Glossary

CAMHS	Child and Adolescent Mental Health Service
DCYA	Department of Children & Youth Affairs
DCEDIY	Department of Children, Equality, Disability, Integration & Youth
FASD	Foetal Alcohol Spectrum Disorder
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHREC	Irish Human Rights and Equality Commission
OCO	Ombudsman for Children's Office
OMCYA	Office of the Minister for Children and Youth Affairs
REC	Research Ethics Committee
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
YRAG	Youth Research Advisory Group



empowering people in care

7 Red Cow Lane, Smithfield, Dublin 7
Co Reg no: 381973
Reg Charity no: 15742.
Chairperson: Barry O'Sullivan

www.epiconline.ie
info@epiconline.ie
01 8727661

 @epicireland
 @epicempoweringpeopleincare
 @epicireland
 EPIC - Empowering People in Care
 thecareexperience.libsyn.com