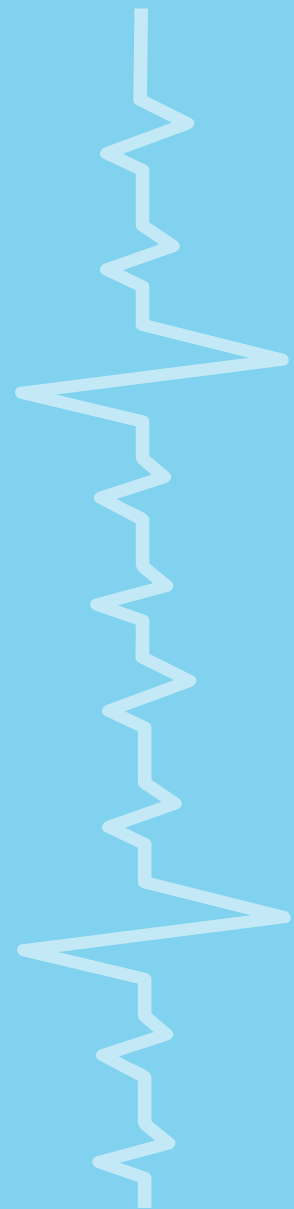


# Headphones, Odd Shoes & A Second Chance at Life

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

Executive Summary

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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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.

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## 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
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





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





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