Exploring the need for a

Representative Advocacy Service for Children with Intellectual Disabilities in Ireland

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August 2024

Research commissioned by Inclusion Ireland

Inclusion Ireland
The National Association for People with an Intellectual Disability.

Ollscoil na Gaillimhe
University of Galway

An tIonad Dlí & Beartais Míchumais
Centre for Disability Law & Policy

Foreword

We were pleased to commission this independent piece of research conducted by the Centre for Disability Law and Policy at the University of Galway. I would like to thank the team at CDLP for their work with us and for the particular focus on ensuring that children and young people were in the driving seat in the design of the research. Our plan is to use this research as a conversation starter with the state and to continue to push for better for children and their families.

Inclusion Ireland is a national advocacy organisation for people with an intellectual disability. Part of our work involves listening and responding to children and their families when they call us to look for information and support. It has become increasingly clear in the last number of years the enormous pressure that children and families are under in accessing what should be some fundamental and basic rights; the right to a high-quality education in your local school, the right to access health and social care supports in a timely manner, the right to live an ordinary family life with the meaningful support from the state to do so. We find in our work that children are often labelled as "complex" when it is in fact the systems they are forced to navigate which are unreasonably complex. The vision of "integrated care" where the child is at the centre and all organisations and services (mental health, disability services, hospitals, education, primary care)work harmoniously to support them and their family seems a distant dream to many. It is a daily occurrence that we hear of one parent giving up work just so they can be the primary advocate in navigating this world- applying to 30 schools, fighting to get access to appropriate basic supports like assistive technologies or adaptations to their home. This further compounds the economic disadvantages that many children with intellectual disabilities also face. In all of these conversations, we must remember the children and families who might never call us. We must recognise that there are children with disabilities living in direct provision, children who speak multiple languages when most services are provided through English, children from the Traveller community who face discrimination on multiple levels. Where are their voices?

We know that representative advocacy alone cannot fix these deep systemic issues, but we also know it could be a good start alongside other urgent measures. We have seen the effect that the National Advocacy Service has had on the lives of disabled adults who access it. We want the same for children. We know that loneliness and isolation and the sense of "battling alone" has a profound effect on the child and their family. A state funded, independent advocacy service could at least begin to shine a light where it needs to be shone and may even prevent crisis situations in families occurring. To show children and their families they are not alone, to walk the path alongside them as they navigate complexity and to have hope of some justice in accessing what should be the right of every child in this state; to live an ordinary decent life as part of a loving, supported family.

Derval McDonagh
Chief Executive
Inclusion Ireland

Acknowledgements

This research was supported and assisted by a number of people and the authors would like to sincerely thank them all.

To begin we must acknowledge that the project was supported by a dedicated and passionate youth advisory group. We would like to thank Francis Carr, Jessica Howard, Caoimhe McMahon, Roisin Walsh, Tierney Burke, Leah Connolly and Veronica Frawley for their time, expertise and guidance in conducting this research. Our recruitment documents, research questions and the project overall is much better for having worked with you. We would also like to thank Judith, Dave, Caroline, Katie and Patrick who supported the youth advisors to participate in our online meetings.

A particular word of thanks for the research participants – children, parents and representatives of key informants - for sharing their experiences and their time. You shared important insights into the lives of children with intellectual disabilities and their families in Ireland. We are grateful as well to those who shared our materials or supported us in our recruitment of participants.

The team would also like to acknowledge the assistance of Ciara Gill and colleagues in the Ombudsman for Children's office in securing a venue for our children's focus group. Our sincere thanks to Joanna Forde at the Centre for Disability Law and Policy for her support in organising focus groups at the Institute for Lifecourse and Society and overall administrative support to the project.

Finally, this project was commissioned by Inclusion Ireland. Their funding and guidance allowed the team to conduct research into the need for representative advocacy services for children with intellectual disabilities in Ireland. The research team would like to thank Emer O'Shea, Petria Malone, Derval McDonagh and all the team at Inclusion Ireland for their assistance.

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Executive Summary

Background

Children and young people with intellectual disabilities often require advocacy support when the state doesn't provide the supports and services they need. While there are existing services that work with certain groups of children or with certain groups of people with disabilities, there is no representative advocacy service which serves all children with intellectual disabilities in Ireland. Inclusion Ireland asked researchers at the Centre for Disability Law and Policy in the University of Galway to explore if children with intellectual disabilities need a representative advocacy service. For this research, representative advocacy means the appointment of a professional advocate who works to empower children to speak up for themselves. The advocate makes sure that children have their views heard in the decisions affecting them and supports them to have their rights respected and to bring about positive change in their lives.

Research Approach

There were two parts to the research. For the first part, the researchers looked at representative advocacy services for children with intellectual disabilities in other countries to learn if similar services would work here in Ireland. For the second part of the study, the researchers spoke to children with intellectual disabilities, to parents of children with intellectual disabilities, and to key informants working in fields related to children or disability. In focus groups and one-on-one interviews we discussed if an advocacy service was needed and what an advocacy service should do.

Learning from Other Countries

This research focuses on three jurisdictions where some form of independent representative advocacy is provided or funded by the State to disabled children: England and Wales, Canada, and Australia. These were chosen as they all include at least some legal recognition and government funding for representative advocacy for disabled children. None of these examples is a perfect model for representative advocacy but they all offer lessons about the structure, governance, funding and provision of representative advocacy services to disabled children.

Key Findings from our Research

There are gaps in supports that could potentially be filled by a representative advocacy service for children with intellectual disabilities. Parents talked about wanting support at important times in their child's life, such as in their early years, around the time of diagnosis or during illness, and during times of transition like starting or changing school or moving to adult services. Parents described how they relied on other parents for information, support and connections. Children and families would benefit from an advocate's help with setting up appointments and from support during meetings.

Not everyone agreed that a new service was needed - some participants argued that adequate resourcing and provision of existing services, therapies, education and other disability-specific supports was needed rather than a new advocacy service.

A new representative advocacy service should be able to support children with intellectual disabilities across all areas they need support with. Parents said the areas that most often needed support were education, health, housing and social welfare.

Parents and key informants want advocates to have the authority and independence to secure children's individual rights. This would mean knowledge of all the different systems the child is engaged with and the authority to bring about change for the better.

Parents were concerned that children with the most complex support needs would not be heard in a representative advocacy service that was designed for children in general. A deep knowledge about how intellectual disability is experienced by children was seen as essential, especially for advocates who would be dealing with health services.

People had differing attitudes to children's rights. Some parents didn't like how existing services excluded or talked over their children. Other parents thought that trying to include children in the advocacy process would be wasteful and that a representative advocacy service for families would be more helpful. Key informants noted the difficulties in representing the child's will and preference when the parent is usually the final decision-maker.

Everyone agreed that any future children's representative advocacy service must have enough funding and resources to do its job well.

Recommendations

This research has shown that there is a clear gap in supports for children with intellectual disabilities in Ireland that representative advocacy could fill. A representative advocacy service could help children with intellectual disabilities to have their human rights respected. However, agreement on the need for and form of such a service was difficult to achieve. With this in mind, we make the following general recommendations for any future representative advocacy service for children and young people with intellectual disabilities:

- Any law establishing an advocacy service must include the right of each child to receive a representative advocate where needed to ensure the protection of their human rights.
- Respect for the will and preferences of disabled children must inform all aspects of advocacy.
- It must have authority, be independently funded and adequately resourced.
- It must be designed with accessibility for children with intellectual disabilities at its core.

Conclusion and Future Directions

Further research is needed before any conclusions can be made as to which model of representative advocacy provision would best meet the needs of children with intellectual disabilities in Ireland. Any future service should be easy to access and should not have complicated application forms or procedures. A representative advocacy service should be part of a broader provision of accurate and accessible information, advice, advocacy and support.

Introduction

Children with disabilities and their families, particularly children with intellectual disabilities and multiple or complex disabilities, regularly have to advocate to receive the basic supports and services they require. A number of representative advocacy services operate in Ireland however, there is no dedicated service which supports children with intellectual disabilities or indeed disabled children generally. Existing advocacy services cater for specific population groups – such as children in care (EPIC) – or only cater for adults with disabilities (NAS). As a result, most children with disabilities – including children with intellectual disabilities – will not have access to advocacy supports. In the meantime, organisations representing the interests of children with intellectual disabilities throughout the country are overwhelmed with requests for advocacy, information and support. This research aimed to explore the need for a representative advocacy service for children with intellectual disabilities and their families in Ireland and outline what form such a service should take. The research was commissioned by Inclusion Ireland and conducted by researchers at the Centre for Disability Law and Policy, University of Galway. This report documents the findings of that research including the findings of empirical research with children with intellectual disabilities, their families and key informants in the field.

Report Structure

The report has five main sections. Section 1 outlines the background and current context of advocacy in Ireland. This includes exploring the concept of representative advocacy as discussed in this research and the applicable international human rights law. Section 2 outlines the right to children's advocacy in international human rights law, while Section 3 presents the current situation in Ireland. Section 4 of the report explores how advocacy is provided in three jurisdictions – England and Wales, Canada and Australia. Section 5 presents the empirical findings from our research with children and young people with intellectual disabilities, their families and key informants in the field. Section 6 presents our conclusions and initial recommendations.

Research Methodology

A desk based literature review of both academic and grey literature and national and international law and policy was conducted to explore the impact of representative advocacy on the lives of children with intellectual disabilities and best practice in the field. Three distinct jurisdictions - England and Wales, Canada, and Australia - were chosen for a focused literature review to document the forms of representative independent advocacy for disabled children and young people which are provided or funded by the State. The criteria for inclusion in the review were that there should be legislative recognition of representative advocacy for disabled children as well as government funding of some arrangement for representative advocacy services to disabled children, either through voluntary, community or other grassroots level. The review explored the structure, governance, funding and provision of representative advocacy services to disabled children in each jurisdiction.

Ethical approval was sought from the University of Galway Research Ethics Committee to collect data from children with intellectual disabilities, their parents and key stakeholders in the field. In keeping with the ethos of the UN Convention on the Rights of Persons with Disabilities, the researchers took a self-identification approach to data collection. Therefore, evidence of a child's intellectual disability diagnosis was not required in order for children or their parents or guardians to participate in the research.

In line with a disability human rights research methodology the project had an advisory group of 7 young people with intellectual disabilities, aged between 18 and 25 years. The advisory group held three online meetings over the course of the research and provided advice and critical insights into the recruitment of participants, and accessible data collection techniques. The group also supported the analysis of the findings.

Data collection in this research was primarily completed online. Two focus groups with parents of children with intellectual disabilities were held in May 2024. They were attended by 12 parents of children with intellectual disabilities, aged between 4 and 17 years, from across Ireland. The research initially planned to conduct two focus groups with children with intellectual disabilities: one with children aged between 9 and 12 years of age and one with children aged between 13 and 17 years of age. Unfortunately, the research team was not in a position to recruit sufficient children with intellectual disabilities to conduct these focus groups. Instead, individual interviews were conducted with two children with intellectual disabilities, aged 15 and 17. While the findings from these interviews are included in this report, the research team acknowledges the very small sample size and that this is a limitation of the research. The team also failed to recruit children who were non-speaking or who communicate differently in the research. While the experiences of this group was discussed in the both the parents focus groups and the key informant interviews, this is no substitute for the children's own perspectives. This is recognised as another limitation of the project and an area for further research.

Finally, the team conducted semi-structured interviews with 10 stakeholders across government departments, State bodies and civil society organisations. They included organisations representing or with expertise in relation to advocacy, children's rights, disability and family representative organisations.

Background and Context

Representative Advocacy

Children and young people with disabilities, particularly those with intellectual and/or multiple disabilities, often require advocacy when the supports and services they need are not being provided by the state.[1] Parents and families of children with disabilities are compelled to engage in advocacy efforts to ensure their children receive appropriate services, especially in the realms of health services and education.[2] These advocacy efforts have historically played a significant role in securing compulsory education for children with intellectual disabilities.[3] However, existing research shows that parents and families may not always want or be able to perform an advocacy role and disabled children and young people may require formal services to assist them.[4] Representative advocacy can be seen as a component in ensuring the well-being of children and young people in service delivery systems and in providing insights that children and young people have into the systems and processes impacting their lives.[5]

For the purpose of this research, representative advocacy for children and young people is understood as the appointment of a professional advocate that works to empower children to speak up for themselves, ensures they have their views heard in the decisions affecting their lives, and supports them to have their rights respected and to bring about positive change in their lives.[6] It involves professional, trained experts in advocacy dealing with specific issues and working with an individual until that issue reaches conclusion. Representative advocacy should be independent and based on a human rights based framework to ensure that the child's voice is heard and their rights respected.[7] Independent representative advocacy services should be provided by non-governmental advocates who operate outside disability services, although providers may include children's charities or disability advocacy organisations.

Certain forms of children's advocacy do not fall within this definition of representative advocacy. Under the Child Care (Amendment) Act 2022 children have a right to a Guardian ad Litem (GaL) in childcare proceedings in court. A GaL may be appointed by the court to act as an independent voice for the child and to represent their best interests in any legal proceedings affecting them. For the

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[1] Christian Ryan and Elizabeth Quinlan, 'Whoever Shouts the Loudest: Listening to Parents of Children with Disabilities' (2018) 31 Journal of Applied Research in Intellectual Disabilities 203.

[2] Meghan Burke and Samantha Goldman, 'Documenting the experiences of special education advocates' (2016) 51(1) The Journal of Special Education 3.

[3] Meghan Burke et al., 'Examining the relation between empowerment and civic engagement among parents of individuals with intellectual and developmental disabilities' (2021) 34(6) Journal of Applied Research in Intellectual Disabilities 1569.

[4] Samantha Goldman, 'Special education advocacy for families of students with intellectual and developmental disabilities: Current trends and future directions' in Robert M. Hodapp and Deborah J. Fidler (eds.), International Review of Research in Developmental Disabilities (Elsevier Academic Press, 2020).

[5] Daniella Bendo, 'Roles, Responsibilities, and Rights: An Organisational Analysis of Provincial and Territorial Child and Youth Advocate Offices in Canada' (2021) 29(4) International Journal of Children's Rights 806.

[6] Department of Health, National Standards for the Provision of Children's Advocacy Services (England; 2002); EPIC – Empowering People in Care, 'Amplifying Voices: Enshrining the Right to Independent Advocacy for Children in Care and Care-Experienced Young People in Legislation' (Dublin, 2023).

[7] Jane Dalrymple, 'Constructions of Child and Youth Advocacy: Emerging Issues in Advocacy Practice' (2005) 19(1) Children & Society 3; Michele Cascardi, Cathy Brown, Svetlana Shpiegel and Ariel Alvarez 'Where have we been and where are we going? A conceptual framework for child advocacy.' (2015) 5(1) Sage Open.

purpose of this research, we do not consider GaLs to be representative advocates due to their limited and specific role. We also exclude legal advocacy (representation in legal proceedings by a legal professional) from our understanding of representative advocacy in this research, as representative advocacy is broader than simply access to the legal system. Self-advocacy, parent or family advocacy and the ad hoc advocacy efforts of Disabled Persons Organisations (DPOs) and other organisations for people with disabilities are also excluded.

A right to advocacy in international human rights law

The UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD) provide essential frameworks for the rights of children and persons with disabilities. While neither convention contains an explicit right to advocacy, reading the provisions of each Convention in tandem with the general principles implies that such a right exists. The CRC emphasizes a child's right to dignity, respect, and the right to express their views and have them given due weight in all matters affecting them.[8] These are reinforced for children with disabilities, including children with intellectual disabilities, in the CRPD. Article 7(3) CRPD mirrors the provisions of the CRC by guaranteeing disabled children the right to have their views respected on an equal basis with others. It further places an onus on States to ensure that disabled children have access to disability- and age-appropriate assistance to realise that right.[9] To achieve this States must put measures in place to ensure disabled children, including those with high support needs, can access support to express their views. This includes ensuring they have access to and be facilitated to use any mode of communication.[10] The CRC Committee has previously recognised the importance of a child having the option to participate in decision making with the support of a representative. This can be support from a parent, a legal representative or another person such as a social worker or an advocate.[11] Therefore arguably, representative advocacy is one form of disability and age appropriate assistance that should be available to children with disabilities to participate in decision-making.

Representative advocacy in Ireland

The current landscape of representative advocacy for children with intellectual disabilities in Ireland is sparse. No comprehensive representative advocacy service exists to serve all children with intellectual disabilities at present. In this section, we outline previous legislation which would have provided a qualified right for disabled children to access a state-funded representative advocacy service. We then address the existing patchwork system of advocacy provision which has emerged since Ireland's failure to implement the Personal Advocacy Service originally set out in the Citizens Information Act 2007. Advocacy was first placed on the legislative agenda in Ireland with the establishment of Comhairle (now renamed the Citizens Information Board (CIB)) in 2000.[12]

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[8] Jeffrey Goldhagen, et al., 'Thirtieth Anniversary of the UN Convention on the Rights of the Child: Advancing a child rights-based approach to child health and well-being' (2020) 4(1) BMJ Paediatrics Open.

[9] UN Convention on the Rights of Persons with Disabilities, Article 7(3).

[10] Committee on the Rights of the Child and Committee on the Rights of Persons with Disabilities, Joint Statement: The Rights of Children with Disabilities (March 2022).

[11] Committee on the Rights of the Child, 'General Comment No. 12 (2009) The Right of the Child to Be Heard' UN Doc. No. CRC/C/GC/12; Committee on the Rights of the Child, 'General Comment No. 9 (2006) The Rights of Children with Disabilities' UN Doc. No CRC/C/GC/9.

Comhairle was established under the remit of the then Department of Family and Social Affairs, as a statutory agency with responsibility for providing advice, information and advocacy to the public.[13] Until the establishment of the National Advocacy Service (NAS) in 2011, the main focus of the CIB's work was the provision of information through resourcing and supporting independent Citizens Information Centres nationwide rather than specifically promoting advocacy, particularly for people with disabilities.

However, some steps were taken regarding the establishment of an advocacy service. As part of its legislative mandate to provide advocacy, CIB commissioned a number of reports to discuss how advocacy for people with disabilities could best be legislated for and regulated in the Irish context.[14] The CIB also undertook a pilot scheme in 2008 whereby Advocacy Resource Officers were assigned to particular services to deal with advocacy issues arising and "to develop, support and train Citizens Information Service staff in the principles and practice of providing advocacy as part of an overall service".[15] An external evaluation of this pilot found that the scheme "provides a worthwhile and effective means of building capacity for quality advocacy work among Citizens Information Service information providers."[16] This role appears to have evolved into what are now referred to as Advocacy Support Workers, employed by Citizens Information Services, whose role includes providing representative advocacy to meet individual customer needs and particularly those of persons with disabilities.[17]

The Personal Advocacy Service established in the Citizens Information Act 2007 was designed to be Ireland's statutory advocacy service, to which the Act set out a legislative entitlement for people with disabilities in certain circumstances. Qualification for a personal advocate from this service was to be based on need. To qualify for an advocate the applicant would have to show that they cannot access services by reason of a disability and that there is a substantial risk of harm to the applicant if they do not receive the relevant service.[18] Both adults and children with disabilities were to be eligible to apply, but in the case of children, it must be proved that the parent is not capable of assisting the child in obtaining their entitlements; or that the parent is themselves a disabled person who would qualify in their own right for advocacy, before a child will be deemed to have a legislative entitlement to this service.[19] This limitation was most likely inserted into the legislation to take account of the primacy of the parental role as enshrined in the Constitution.[20] However, the Irish Constitution was subsequently amended to explicitly recognise the rights of children and ensure that parental rights no longer presented a barrier to State intervention in order to uphold the best interests of the child where required. As a result, any new legislation detailing a right to advocacy for disabled children in Ireland would not face the same restrictions and could arguably be more expansive.

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[12] Comhairle was renamed the Citizens Information Board by the Citizens Information Act 2007, section 3(1). It was established in 2000 to replace the National Social Service Board (National Social Service Board Act 1984).

[13] Comhairle Act 2000, s7(1)(a).

[14] See for example, Comhairle, The Jigsaw of Advocacy (Dublin, 2003).

[15] Citizens Information Board, Speaking Up for Advocacy – Issue 10 (2008).

[16] ibid.

[17] See Citizens Information Service, 'Jobs – Advocacy Support Worker, North Leinster CIS' (September 2024) <https://www.citizensinformationboard.ie/downloads/jobs/17092024_ASW_Candidate_Pack.pdf> (accessed 30 September 2024).

[18] Comhairle Act 2000, s7A(2) as inserted by Citizens Information Act 2007, s5.

[19] ibid.

[20] Article 41.1.1° and Article 42.1 Bunreacht na hÉireann, 1937.

Unfortunately, the provisions relating to the Personal Advocacy Service in the 2007 Act were never commenced. Instead, government, through the Citizens Information Board, funded a pilot programme of community and voluntary advocacy services for people with disabilities from 2005-2010, prior to the establishment of the National Advocacy Service (NAS) in 2011. The structure of NAS differs in some respects from how the Personal Advocacy Service was envisaged, and advocates working in NAS do not have the benefit of the legislative powers set out in the 2007 Act. Further, while the Personal Advocacy Service would have provided a legal entitlement to advocacy for both disabled children and adults, NAS only works with disabled people over the age of 18.

As a result, there is no representative advocacy service operating in Ireland that is dedicated to representing disabled children. A small number of representative advocacy services have been established to support specific population groups. Children with intellectual disabilities may, in certain circumstances, also be in a position to access these services if they are part of those populations. For example, children and young people in care or with care experience may access representative advocacy supports from EPIC - Empowering People in Care. EPIC operates a nationwide, one-to-one service and represents children and young people in care, aftercare or with care experience up to 26 years of age. Children and young people may request an advocate directly or a parent, guardian or professional can request one on their behalf. Independent Mental Health Advocates, operated by Youth Advocate Programmes Ireland, provide services for children receiving treatment in all HSE adolescent in-patient units in Ireland.[21] They also support adolescents in some private facilities and those receiving community supports in certain regions.

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[21] Youth Advocate Programmes Ireland, 'Independent Mental Health Advocacy' <https://yapireland.ie/what-we-do-yap-ireland/our-services-yap-ireland/independent-mental-health-advocacy/> (accessed 30 September 2024).

Representative Advocacy in Other Jurisdictions

In order to understand how a representative advocacy service for children with intellectual disabilities could potentially be developed in Ireland, it is important to consider the different models of representative advocacy services for disabled children in use in other jurisdictions. Different jurisdictions use different definitions and types of children's advocacy, many of which overlap in their focus, purpose, or methods. In jurisdictions where the right to advocacy is on a statutory footing, there may be a legal duty to provide independent representative advocacy but that right may be restricted to certain groups, such as children and young people in care, children with defined needs, or to children who have a substantial difficulty in being involved in the advocacy process.[22] There is often no common process for the delivery of advocacy to these populations, with arrangements often devolved to local authorities, outsourced to independent agencies, or organised through a patchwork of voluntary groups.

In this research, we have chosen to focus on three distinct jurisdictions where some forms of representative independent advocacy are provided or funded by the State to disabled children: England and Wales, Canada, and Australia. These jurisdictions have been selected as they all include at least some legislative recognition of representative advocacy for disabled children, combined with government funding or commissioning of community and voluntary organisations which provide representative advocacy services to disabled children at the grassroots level. None of these jurisdictions represents a perfect model for representative advocacy which could be replicated in the Irish context, but lessons can be learned from all of them in terms of the structure, governance, funding and provision of representative advocacy services to disabled children.

England and Wales

In England and Wales, there is no universal entitlement to advocacy for children and young people who may need it. Instead, the right to advocacy is linked to the child's circumstances causing them to be classified as a looked-after child, a child in need, or a care-leaver.[23] A child in need is defined as one who is unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired, without the provision of services; or a child who is disabled.[24] Qualifying children and young people[25] wishing to make a representation have a statutory entitlement to independent advocacy. Statutory guidance provides a wide definition of representations.[26] Guidance for advocates working with children with special educational needs and disabilities includes support with implementing Education, Health and Care

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[22] As example of this is England and Wales. For more information see, Children's Commissioner, The State of Children and Young People's Advocacy Services in England (London, 2023). <https://assets.childrenscommissioner.gov.uk/wpuploads/2023/12/Audit-FINAL.pdf> accessed 30 September 2024.

[23] Children's Commissioner, The State of Children and Young People's Advocacy Services in England (London, 2023).

[24] Department for Education (England & Wales). 'Effective Advocacy for Looked-After Children, Children in Need and Care Leavers: Statutory guidance for local authorities'. (London, September 2023)

[25] This includes children up to the age of 18, except for those classified as care-leavers who have a right to access advocacy up to the age of 25.

[26] Department for Education and Skills (England & Wales), Getting the Best from Complaints: Social Care Complaints and Representations for Children, Young People and Others (2006). <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/273895/getting_the_best_from_complaints.pdf> accessed 30 September 2024.

Plans, support during the transition to adulthood – including support and advice to manage personal budgets – and support during complaints, mediation and disagreement resolution processes.[27] Research by the Children's Commissioner in 2023 estimated that the total number of children entitled to advocacy services stood at 942,564, with more than half of those (472,938) classified as children with special educational needs or disabilities.[28]

Children's advocacy services were first developed in the 1980s and 1990s by local authorities in response to exposures of abuse in children's residential homes and foster care.[29] These arrangements were formalised by the Adoption and Children Act 2002[30] which amended the section 26A of the Children Act 1989 to place a duty on local authorities to make provisions for advocacy services for children or young people intending to make a complaint under Children Act procedures. The Advocacy Services and Representations Procedure (Children) (Amendment) Regulations 2004 set out the various requirements for advocacy provision. Current benchmarks for advocacy provision in England are established in the recently updated National Standards for the Provision of Children's Advocacy Service[31] and its accompanying guidance document Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989.[32] Welsh services follow the National Independent Advocacy Standards and Outcomes Framework for Children and Young People in Wales 2015. These are further supported by the Special Educational Needs and Disability Code of Practice.[33]

Both England[34] and Wales[35] have created the position of Children's Commissioner to promote and protect children's rights in accordance with the CRC. The position is broadly equivalent to the position of Children's Ombudsman in other jurisdictions. The Children's Commissioner's statutory powers include investigatory powers to ensure 'the availability and effectiveness of advocacy services for children.'[36] The Children's Commissioner for England cannot deal with individual cases but can conduct investigations which affect the wider population, while the Welsh Commissioner may investigate an individual's claim.

The management and delivery of children's advocacy services are the remit of local authorities. The Director of Children's Services in each of the 152 English and 22 Welsh local authorities is responsible for children's advocacy in their area. Local authorities may use a mix of commissioned or

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[27] Department for Education and the Department of Health (England), Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities (2015). <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf> accessed 30 September 2024.

[28] The report notes that the total figure may be an overestimation due to poor record-keeping by some local authorities. 22% of local authorities were unable to provide detailed data. Children's Commissioner, The State of Children and Young People's Advocacy Services in England (London, 2023) 21.

[29] The Care Leaver's Association, 'Uncovering the past abuse of children in care' (2014) <https://www.careleavers.com/history> (accessed 30 September 2024).

[30] Adoption and Children Act 2002, s119 (England and Wales).

[31] Department of Health (England), National Standards for the Provision of Children's Advocacy Services (London, 2002).

[32] Department for Education and Skills (England), Providing Effective Advocacy Services for Children and Young People: Making a Complaint under the Children Act 1989. (London, 2004).

[33] Department for Education and Department of Health (England), Special educational needs and disability code of practice (2015).

[34] The position of Children's Commissioner for England was created under the Children Act 2004.

[35] The position of Children's Commissioner for Wales was created under the Children's Commissioner for Wales Act 2001.

[36] Children Act 2004, s2(3)(g) (England).

in-house advocacy services as they deem appropriate, resulting in wide regional variations in how advocacy supports are managed and delivered. The most common arrangement is for local authorities to outsource advocacy provision to a voluntary organisation. For example, Coram Voice is an independent advocacy provider that primarily works with children in care as commissioned by local authorities. Using special grant funding, Coram delivers additional advocacy services to children and young people with a disability up to the age of 25 in London, Manchester and the North-West of England. In Lancashire, Advocacy Focus is an independent organisation providing a wide range of advocacy services, including general children's advocacy, services for children and young people with an intellectual disability, and mental health advocacy. They accept referrals from the local authority, health professionals, self-referrals and referrals from family.[37]

Children with disabilities may access advocacy in a number of ways. In secure settings, the Ministry of Justice contracts independent advocates through Barnardo's, a large children's charity. Local authorities and service providers are responsible for employing visiting advocates to facilitate access to advocacy for children in residential settings like children's homes or mental health units. Some children detained in mental health units are eligible to have access to an Independent Mental Health Advocate (IMHA).[38] IMHAs are independent advocates, meaning they do not work for health or social services or the local authority. Referrals to an IMHA can be made by the child, their nearest relative, a clinician or approved mental health professional. Individuals must be informed of the IMHA service as soon as they become a qualifying patient in a medical organisation and be reminded about the service regularly. The role of the IMHA is to ensure the individual has access to information, to attend meetings with them and to support them to speak up or have their opinions and feelings heard. Additionally, children over the age of 16 that lack capacity to make important decisions about their health and welfare may access an Independent Mental Capacity Advocate (IMCA) as a safeguard. The role of IMCA was established under the Mental Capacity Act 2005.[39] Their duties include gathering information about the person's wishes, beliefs, feelings and values, communicating with healthcare staff and other people in the person's life, representing the person in meetings, and challenging decisions that they judge not to be in the person's best interest, extending to court action if necessary.[40]

On average, local authorities employed one advocate for every 3,053 children eligible for advocacy services; however, ratios in individual authorities ranged from one advocate per 58 eligible children to one advocate for every 26,639 eligible children.[41] Section 26A(5) of the Children Act 1989 requires local authorities to publicise information about their arrangements for the provision of advocacy services, their procedures for considering representations, and their processes for receiving complaints about their advocacy services. Despite this, many children do not receive a referral to an

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[37] See: Coram Voice, Annual Report 2023. (March 2023) <https://coramvoice.org.uk/wp-content/uploads/2024/06/Coram-Voice-Annual-Report-2023.pdf> (accessed 30 September 2024); Advocacy Focus, Advocacy Services in Lancashire (2024) <https://advocacyfocus.org.uk/adult-advocacy-services-in-lancashire>.

[38] In England, children have a right to an IMHA if they are a voluntary patient under consideration for ECT or other procedures included in S58 of the Act, if they are subject to detention or treatment under Section 2 or 3 of the Act or subject to a Community Treatment Order. In Wales, children have a right to an IMHA if they are an informal patient, have been sectioned, or are subject to a CTO.

[39] Mental Capacity Act 2005, s35 (England and Wales).

[40] Mental Capacity Act 2005, s36 (England and Wales).

[41] The Children's Commissioner, The State of Children and Young People's Advocacy Services in England (London, 2023) 6.

advocate, and when they do, many referrals do not result in children getting direct support from an advocate.[42] 18 local authorities reported making no referrals at all to children's advocacy services in the period 2022-2023, despite their statutory obligation to ensure access to advocacy for eligible children and young people.[43] There were also variations in referral rates for different groups of children, with estimated figures suggesting that homeless children received the most referrals (50%) and children with special educational needs and disabilities receiving the lowest rate of referrals, at just 2-3%.[44] These figures demonstrate that providing a statutory right to children's advocacy does not result in access to advocacy, particularly for children with disabilities.

Canada

Canada is a federal State with the power to make laws split between the national or federal government and across each of the ten provinces and three territories. As a result, the right to access an advocate or the provision of advocacy services varies across the country. Almost all of the provinces or territories across Canada have an independent office, appointed by the legislature, to uphold the rights and interests of children and young people.[45] Known as either the Child and Youth Advocate, Representative, or Commissioner, many have systemic advocacy, public education or engagement and investigations within their remit. A number of provinces or territories also empower the office holder to act on behalf of a child or young person to resolve an ongoing issue. In some instances, these powers are limited to children in care or children at risk of abuse, neglect or exploitation. However, others can advocate on behalf of a child in receipt of a broad range of government services including disability services.

The Representative for Children and Youth (RCY) British Columbia has one of the broadest mandates across the provinces and territories. The Representative can support children and young people up to the age of 19 years old and 'included adults', who are defined as people under 27 years of age in receipt of community living support or who as a child received a 'reviewable service'. Their functions are to support, assist, inform and advise children, young people, included adults and their families in respect of designated services which include disability services, mental health services, and services for young people as they transition to adulthood. This role includes, but is not limited to, providing information and advice about how to effectively access designated services and how to become effective self-advocates, and advocating on behalf of the individual receiving or eligible to receive a service.[46] In practice, the majority of queries will be dealt with by an 'Intake Advocate' who can provide information, referral and coaching or advice on navigating the issue.[47] This support for self-advocacy may be ongoing until an issue reaches an acceptable resolution. However, some cases require an advocate to be more involved and, in that instance, an RCY Advocate will take over. The RCY Advocate will work to ensure 'the young person's rights, views and/or best interests' are understood and central to the process. This can range from attending meetings with or on behalf of the individual, facilitating discussions around services and key decisions, and helping a child or young

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[42] The Children's Commissioner, 2023, p.7.

[43] ibid, p.22.

[44] ibid, p.24.

[45] Canadian Council of Child and Youth Advocates, 'About the Canadian Council of Child and Youth Advocates' <https://www.cccya.ca/> (accessed 30 September 2024).

[46] Representative for Children and Youth Act, s6 (British Columbia, Canada).

[47] Representative for Children and Youth, Annual Report 2022/23 and Service Plan 2023/24 to 2025/26 (September 2023) <https://rcybc.ca/wp-content/uploads/2023/09/RCY-ARSP-2023-web.pdf> (accessed 30 September 2024).

person ‘speak up’ for their rights.[48]

The Manitoba Advocate for Children and Youth (MACY) has a responsibility to support, assist, inform, and advise children, young adults, and their families in relation to designated services.[49] In this instance young adults are those aged over 18 years and under 21 years and designated services include disability, mental health, education, child welfare and addiction services. Children and young adults in receipt of designated services have a right to communicate with the advocate,[50] however, requests for advocacy can also be submitted by their families or anyone involved in the life of the child.[51] The Advocate for Children and Youth Act 2016 allows the Advocate to give priority to those who do not have others to ‘advocate for their rights, interests and viewpoints.’[52] The Advocacy team will work with the child or young person, listen to their concerns, ensure their voices are amplified, and work closely with them to seek the most appropriate resolution to the issue.[53] Following an intake process the case may undergo basic advocacy where the issue is resolved with information on the options available and how to navigate systems.[54] However, for complex cases a file will be opened and a plan agreed with the individual on how best to approach seeking a resolution. The 2016 Act provides that an advocate must be provided access, at a reasonable and safe time, to a designated service to carry out their duties[55] and may require any public body or person to provide information necessary to enable them to carry out their responsibilities.[56]

The Nunavut Representative for Children and Youth conducts individual case advocacy on behalf of children and young people who have a complaint about a service provided by a government body or who cannot access a service. Young people with a broad range of disabilities or impairments may avail of their support until they reach the age of 22. The Representative’s duties under section 3 of the Representative for Children and Youth Act include children and young peoples’ views are heard on matters which affect them, that they have access to services and their concerns in relation to services are given ‘appropriate attention’, and facilitating communication between children, young people and their families and service providers.[57] Upon receipt of a complaint an Intake Specialist determines if the issue is within the Representative’s mandate.[58] Issues which are within the mandate are assigned to a Child Advocate who will talk to the child or young person and their family to establish the facts and provide basic or comprehensive advocacy support. Basic advocacy support can include support to communicate with service providers, making referrals and self-advocacy

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[48] Representative for Children and Youth, Annual Report 2021/22 and Service Plan 2022/23 to 2024/25 (September 2022) <https://rcybc.ca/wp-content/uploads/2022/10/RCY-AR-2021-22_FINAL.pdf> (accessed 30 September 2024).

[49] Manitoba Advocate for Children and Youth, ‘Advocacy Services’ <https://manitobaadvocate.ca/what-we-do/advocacy-services/> (accessed 30 September 2024).

[50] Advocate for Children and Youth Act 2016, s33(1) (Manitoba, Canada).

[51] Manitoba Advocate for Children and Youth, Annual Report & Service Plan 2022-23 (October 2023) <https://manitobaadvocate.ca/wp-content/uploads/2023/11/MACY-Annual-Report-2023-ENG.pdf> (accessed 30 September 2024).

[52] Advocate for Children and Youth Act 2016, s11(2) (Manitoba, Canada).

[53] Manitoba Advocate for Children and Youth, Annual Report & Service Plan 2022-23 (October 2023) <https://manitobaadvocate.ca/wp-content/uploads/2023/11/MACY-Annual-Report-2023-ENG.pdf> (accessed 30 September 2024).

[54] Manitoba Advocate for Children and Youth, Annual Report 2021-22 (October 2022) <https://manitobaadvocate.ca/wp-content/uploads/2023/06/MACY-Annual_Report_InsideEN_2022-FIN_screen-1.pdf> (accessed 30 September 2024).

[55] Advocate for Children and Youth Act 2016, s15 (Manitoba, Canada).

[56] Advocate for Children and Youth Act 2016, s17 (Manitoba, Canada).

[57] Representative for Children and Youth Act 2015, s3 (Nunavut, Canada).

[58] Nunavut Representative for Children and Youth, ‘Individual Advocacy’ <https://rcynu.ca/our-work/what-we-do/individual-advocacy?_ga=2.168614434.26364492.1695746805-1917614065.1695746805> (accessed 30 September 2024).

coaching. More complex cases may require the advocate to attend or arrange case conferences, meetings with the family and the service provider or for the advocate to develop innovative solutions to the issue. In the event that the issue falls outside of the scope of the office information is provided on alternative sources of support or information. The Intake Specialist will follow up to ensure the support or information is received. The New Brunswick Child, Youth and Seniors' Advocate provides a similar level of advocacy, ranging from basic to systemic, as outlined above. However, their mandate includes representing the rights, interests and viewpoints of children (aged under 16), young people (aged 16-19), adults under protection (people with physical or mental disabilities aged 19 – 65) and older people (aged over 65).

The Northern Territories is the only jurisdiction in Canada without an Advocate for Children and Youth or equivalent position. Disabled people, regardless of their age or the nature of their disability or impairment, can access information, referral and advocacy support through the North-West Territories Disabilities Council.[59] The Council receives funding from a range of sources including the Government of the Northwest Territories, the Government of Canada (federal government) and a number of community partners. Their Information Referral & Support service provides information about existing services, supports individuals to link with services including writing applications or letters and may attend meetings or appeals related to disability issues as a neutral third party or advocate if required.[60]

Civil society organisations in other provinces have also responded to the need for support to access information and advocacy services. In Nunavut, the Nunavummi Disabilities Makinnasuaqtiit Society (NDMS) provides advocacy services to disabled people including children with disabilities.[61] The NDMS is a cross-disability organization and their advocacy supports range from support for self-advocacy to informal and formal advocacy support for individuals.

The Ministry of Social Services in Saskatchewan contracted Inclusion Saskatchewan to provide an advocacy service for individuals with intellectual disabilities and their families.[62] Individuals do not require a formal diagnosis to access the service and it may also be accessed by autistic people, or people with fetal alcohol spectrum disorder (FASD) or attention-deficit/hyperactivity disorder (ADHD). The service can provide support in relation to a wide range of issues including education, health, social services, justice, and personal finances. The 'Inclusion Consultant' may support the individual and their family by researching issues, providing information attending meetings and providing assistance to navigate appeals processes. The support offered will be tailored to the individual's needs. Similar individual and family support services are provided by Inclusion Nova Scotia[63] and Inclusion British Columbia.[64] However, it is not clear how these programs are funded.

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[59] North West Territories Disabilities Council, 'Information Referral & Support' <https://www.nwtdc.net/information-referral-and-support> (accessed 30 September 2024).

[60] North West Territories Disabilities Council, Information, Referral and Support Brochure (2022) <https://www.nwtdc.net/s/IRS-Brochure-2022.pdf> (accessed 30 September 2024).

[61] Nunavummi Disabilities Makinnasuaqtiit Society, 'NDMS Services' <https://nuability.ca/services/> (accessed 30 September 2024).

[62] Inclusion Saskatchewan, 'Support & Advocacy' <https://www.inclusionsk.com/support> (accessed 30 September 2024).

[63] Inclusion Nova Scotia, 'Individual and Family Support' <https://www.inclusionns.ca/individual-family-support> (accessed 30 September 2024).

[64] Inclusion BC, 'Individual and Family Advocacy' <https://inclusionbc.org/what-we-do/individual-family-advocacy/> (accessed 30 September 2024).

Australia

As Australia is a federal jurisdiction, the provision of disability advocacy is organised through both Federal and State levels of government. In federal legislation, there is no statutory right for disabled children to have an advocate; instead, the law provides that the government may fund disability advocacy, including for children. This funding covers all types of advocacy including individual or representative advocacy. However, most of the federally funded disability advocacy organisations focus on systemic advocacy to change government policies, support systems and legal entitlements. At the federal level, advocacy is defined in the Disability Services and Inclusion Act 2023, which sets out that

> "advocacy supports or services means supports or services:
> (a) to assist a person with disability to exercise choice or control in matters that affect the person, including the provision of legal services; or
> (b) to assist a person with disability to understand and advocate for their rights and to uphold and enforce their rights, including the provision of legal services; or
> (c) to influence community attitudes, government policy or laws in relation to the rights and freedoms of people with disability."[65]

The first two categories of advocacy in this definition relate to the kind of representative advocacy for children with disabilities which is the focus of this research. The 2023 Act also sets out statutory criteria which all funded services, including advocacy services, must adhere to. This ensures that funded services, including advocacy services, are providing a service in line with the guiding principles of the Act, in a manner that is fiscally responsible and accountable, with robust complaints and reporting processes.

The National Disability Advocacy Framework 2023-2025 is a shared policy commitment to disability advocacy between the Australian federal, state and territory governments to ensure there is access to advocacy services for all people with disability nation-wide.[66] This Framework specifies that disability advocacy in general "enables people with disability to participate in the decision-making processes that safeguard and advance their human rights"; whereas it describes individual advocacy as a "one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer, to prevent or address instances of unfair treatment or abuse".[67] It also recognises that disability advocacy should be directed by the will, preferences and rights of the person with disability and commits Federal, State and Territory governments to "collecting, using, and reporting nationally consistent and evidence based data for administration and planning of disability advocacy and improvement of services systems."[68]

The Federal Department of Social Services in Australia funds the National Disability Advocacy Program (NDAP) to provide people with disability access to effective advocacy support. The program provides support for people with disability who are facing complex challenges in situations where people feel unable to act, speak or write about a difficult situation on their own, or do not have the

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[65] Disability Services and Inclusion Act 2023, s8 (Australia)

[66] Department of Social Services, National Disability Advocacy Framework 2023-2025 (June 2023) <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/national-disability-advocacy-framework-2023-2025-0> (accessed 30 September 2024).

[67] ibid, p.3.

[68] ibid, p.5-6.

support required to resolve an issue. The Department also runs the Disability Advocacy Support Helpline to provide phone-based disability advocacy support throughout Australia which can connect people to advocacy support in their local area. Its website also lists the organisations which receive federal funding under this programme in each of the states and territories.[70]

In addition to these initiatives, the Department funds the Disability Advocacy Network of Australia (DANA), a national representative body for independent disability advocacy organisations throughout Australia.[71] DANA has developed a 'Future of Advocacy' project, drawing on the expertise of its member organisations, to inform funding and policy decisions for the Federal Government from 2025 onwards, after the current National Disability Advocacy Framework ends.[72] This project calls for additional funding, consistent frameworks to measure advocacy outcomes and levels of unmet need, and increased opportunities to collaborate on systemic issues, to be priorities within the next iteration of the National Disability Advocacy Framework.[73] This project does not include any targets which are specific to disabled children or children with intellectual disabilities in particular.

A project to develop a national Standard for Advocacy in Ageing and Disability has been co-led by DANA and the Older Persons Advocacy Network (OPAN).[74] The Standard was completed in 2024, and the Joint Accreditation System of Australia and New Zealand has been contracted by DANA and OPAN to develop a scheme that can be used to assess the compliance of advocacy services with the Standard.[75] Currently services funded by NDAP are audited using a scheme which certifies their compliance to the National Standard for Disability Services (NSDS). The new scheme being developed will be specific to advocacy services able to be applied to any funded advocacy service in the aged care and disability sectors across Australia. The scheme development project is due to finish in early May 2025, with the goal of implementation by July 2025.[76] No information is available on the extent to which this new Advocacy Standard or the proposed scheme, include outcomes specifically tailored to disabled children or children with intellectual disabilities in particular.

All of these legal principles, frameworks, standards and guidelines for advocacy at the Federal level are directed at people with disability in general – and do not distinguish between providing advocacy to disabled adults or disabled children. There appears to be no legislation at the federal level in

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[69] Department of Social Services, 'National Disability Advocacy Program (NDAP)' (June 2024) <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap> (accessed 30 September 2024).

[70] Department of Social Services, 'List of agencies funded under the National Disability Advocacy Program (NDAP)' (June 2024) <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-advocacy-program-ndap-operational-guidelines/list-of-agencies-funded-under-the-national-disability-advocacy-program-ndap> (accessed 30 September 2024).

[71] Disability Advocacy Network Australia, 'What We Do' <https://www.dana.org.au/about/what-we-do/> (accessed 30 September 2024).

[72] Disability Advocacy Network Australia, 'Future of Advocacy Project' (August 2024) <https://www.dana.org.au/future-of-advocacy-project-latest-update/> (accessed 30 September 2024).

[73] Disability Advocacy Network Australia, 'Future of Advocacy Project: What We Know' <https://www.dana.org.au/current-work/future-of-advocacy-project/what-we-know/> (accessed 30 September 2024).

[74] Disability Advocacy Network Australia, 'The Advocacy Standards Project' <https://www.dana.org.au/current-work/the-advocacy-standards-project/> (accessed 30 September 2024).

[75] Standards Australia, Standard AS 5391:2024, Advocacy in Ageing and Disability (June 2024) <https://store.standards.org.au/product/as-5391-2024> (accessed 30 September 2024).

[76] Disability Advocacy Network Australia, 'The Advocacy Standards Project' <https://www.dana.org.au/current-work/the-advocacy-standards-project/> (accessed 30 September 2024).

Australia which provides for a federal organisation offering advocacy to children in general including disabled children. There are however various Children's Commissioners (similar to the role of the Office of the Ombudsman for Children in Ireland) in each of the Australian States or Territories, but none of those examined within this project had a legal obligation to provide individual representative advocacy to disabled children – rather they have a focus on advocating for children in general, particularly at the systemic level, or responding to individual complaints regarding the violation of children's rights.

At the level of individual States and Territories in Australia, different legislation and policies exist in each jurisdiction which give those governments the power to provide or to fund disability advocacy including advocacy for disabled children. The only clear example of legislation recognising the right of a disabled child to an advocate is in Queensland. In Queensland, the Office of Public Guardian provides Child Advocates to all children and young people in the child protection system (disabled and non-disabled children), including those in the care of the state.[77] These Child Advocates are all legal practitioners, and their role seems similar to that provided by a guardian ad litem in Ireland.[78]

In Victoria, the Office of Public Advocate has a statutory function to "undertake advocacy for persons with disability on an individual or systemic basis."[79] The Office is also responsible for adult guardianship and substitute decision-making, which makes up the bulk of its annual work-load.[80] The definition of 'persons with disability' in this law does not refer to adults or children, and as a result it may be interpreted to include both.[81] In the Office's annual reports it does not provide a breakdown of its statistics on the number of individual advocacy cases it undertakes each year by age-range,[82] so it is difficult to confirm how many (if any) disabled children receive individual advocacy from this Office. It is also important to note that access to individual advocacy from this statutory body is not recognised as an individual right or entitlement of a disabled child; instead, it is within the functions of the Office to provide this service, and the Office determines who meets its eligibility criteria for individual advocacy and in what order of priority they will receive an advocate as these issues are not addressed in the legislation. However, the legislation does specify that all services provided by the Office of the Public Advocate, including individual advocacy, must the adhere to the guiding principles of this law, which include a principle that the "will and preferences of a person with a disability should direct, as far as practicable, decisions made for that person."[83]

Since the National Disability Advocacy Program in Australia primarily funds advocacy organisations that operate at the national level, these organisations are more likely to focus on systemic advocacy than individual advocacy. As a result, most individual advocacy for disabled people, including

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[77] Office of Public Guardian (Queensland), 'Child Advocate' <https://www.publicguardian.qld.gov.au/i-am-a-child-or-young-person/who-can-help-you/child-legal-advocacy> (accessed 30 September 2024).

[78] Child Protection Act 1999, s108C (Queensland, Australia).

[79] Guardianship and Administration Act 2019, s15(c) (Victoria, Australia).

[80] See for example, Office of the Public Advocate (Victoria), Annual Report 2022-2023 (October 2023) p. 33 <https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opa-annual-reports/648-opa-annual-report-2022-2023> (accessed 30 September 2024).

[81] Guardianship and Administration Act 2019, s3(1) (Victoria, Australia).

[82] See for example, Office of the Public Advocate (Victoria), Annual Report 2022-2023 (October 2023) p. 17 <https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opa-annual-reports/648-opa-annual-report-2022-2023> (accessed 30 September 2024).

[83] Guardianship and Administration Act 2019, s8(1)(b) (Victoria, Australia).

disabled children is funded by State/Territory Governments, rather than the Federal Governments. These State/Territory advocacy organisations sometimes focus on a specific sub-group of disabled people, such as indigenous disabled people, ethnic minorities, or children, for example Sydney's Indigenous Disability Advocacy Service,[84] Action on Disability in Ethnic Communities[85] in Victoria and the Association for Children with Disabilities,[86] also in Victoria. Within some of the organisations which are explicitly focused on disabled children and their families, very little information is available online about the eligibility criteria for any individual advocacy services they might provide.

One interesting example of individual representative advocacy for disabled children is provided by the Youth Disability Advocacy Service (YDAS).[87] This organisation is located within the Youth Affairs Council of Victoria. This group works with children and young people with disabilities, including intellectual disabilities, aged 12-25. It allocates a professional advocate to each child or young person to support them to realise their human rights.[88] YDAS can accept advocacy referrals from parents of disabled children but will generally only provide individual advocacy where the disabled child or young person has given their permission.[89] Importantly, YDAS supports disabled children who are both diagnosed and undiagnosed – recognising that access to diagnosis is a privilege which not all disabled children and families have access to. Unfortunately, in April 2024, YDAS closed its waiting list for advocacy services.[90] This is further evidence of the underfunding of disability advocacy in general, as identified by DANA in its Future of Advocacy project,[91] and in particular, of the need for more sustainable advocacy funding for disabled children specifically.

Overall, the provision of individual representative advocacy to children with intellectual disabilities throughout Australia is a patchwork of services with different funding streams and priorities, which can make it difficult for children and their families to understand who to contact when they need advocacy support. There are no clear individual legislative entitlements for children with intellectual disabilities to a representative advocate on all issues impacting their human rights. Disabled children appear to fall through the gaps in statutory advocacy services designed for disabled people in general (such as the Office(s) for Public Advocate at State/Territory levels) and the Children and Youth Commissioners across the different States and Territories do not appear to have a consistent individual advocacy function which would be inclusive of disabled children. Some individual advocacy services within particular States do provide interesting models of practice such as YDAS in Victoria, and the existence of a national database of individual advocacy organisations as well as a

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[84] Sydney Region Advocacy Corporation, 'Indigenous Disability Advocacy Service (New South Wales)' <https://www.srac.ngo/idas> (accessed 30 September 2024).

[85] Action on Disability in Ethnic Communities, 'Disability Advocacy Support Program' <https://adec.org.au/advocacy-support/> (accessed 30 September 2024).

[86] Association for Children with Disability, 'Advocacy' <https://www.acd.org.au/advocacy/> (accessed 30 September 2024).

[87] Youth Disability Advocacy Service, 'About YDAS' <https://www.yacvic.org.au/ydas/about/about-ydas/> (accessed 30 September 2024).

[88] Youth Disability Advocacy Service, 'Get advocacy support' <https://www.yacvic.org.au/ydas/advocacy/get-advocacy-support> (accessed 30 September 2024).

[89] ibid.

[90] ibid.

[91] Disability Advocacy Network Australia, 'Future of Advocacy Project: What We Know' <https://www.dana.org.au/current-work/future-of-advocacy-project/what-we-know/> (accessed 30 September 2024).

national helpline for disability advocacy and support are also potentially useful considerations for future developments in the Irish context.

In conclusion, this comparative research on representative advocacy services for disabled children in England and Wales, Canada and Australia, contains some important lessons for the potential establishment of any representative advocacy service for children with intellectual disabilities in Ireland. One key finding is that recognition of a duty on State bodies to provide advocacy is not sufficient to ensure representative advocacy for this community – and an individual right to representative advocacy for disabled children could be a key component of redressing this power imbalance. Another key issue is the fragmented nature of delivery of representative advocacy services. There are potential strengths to a commissioning model for advocacy services which can enable local or regional services to be more responsive to groups with specific needs – e.g. disabled children from indigenous communities or ethnic minorities – and ensure that different impairment groups, including children with intellectual disabilities have access to services which fully understand and respect their access needs. However, care is needed to ensure that this does not result in exclusion of children from more isolated rural areas in terms of their access to representative advocacy. Furthermore, if the primary providers of representative advocacy for disabled children are community and voluntary organisations, this cannot occur in a manner which enables the State to abdicate its responsibility for ensuring equitable access to these services for all disabled children who need them.

Findings from the Empirical Research

The purpose of this study was to explore the need for a representative advocacy service for children and young people with intellectual disabilities in Ireland and to draw out what form a children's advocacy service could take. As this is an under-researched area and as there is no dedicated service which provides representative advocacy for children with intellectual disabilities, it was decided to directly engage with three groups whose experiences could help establish whether there is a need for such a service; children with intellectual disabilities; parents of children with intellectual disabilities; and key informants working in fields related to children or disability. Ethical approval was sought from the University of Galway Research Ethics Committee. In keeping with the ethos of the CRPD, the researchers took a self-identification approach and evidence of intellectual disability diagnosis was not required in order to participate in the research. All interviews were held between March and June 2024.

The research team planned to hold in-person focus groups with children with intellectual disabilities in Dublin and in Galway. Despite positive responses from children's groups and parents, recruitment proved difficult. In the end, two children with intellectual disabilities participated in a one-to-one interview, one in-person and the other through an online video call. They chose their own pseudonyms. 'Isabel' is 17 years old and lives with her family in a rural setting. 'Mark' is 15 and lives with his mother in the city. Neither had any previous experience of formal advocacy services. The interview was structured around 3 accessible activities: a social story about a child accessing advocacy services and 2 word-matching games about the attribute of a good advocate and what an advocacy service would be like.

Two focus groups were held with parents and guardians of children with intellectual disabilities. Up to 12 parents expressed an interest in attending each session, with 9 ultimately attending the first session and 3 attending the second. While we did not collect detailed demographic information about the children or their parents, discussions showed that along with intellectual disability, there was a range of other lived experiences including physical disability, communication impairment, autism and experience of foster care. Key informant interviews were held online with 10 representatives from a selection of children's or disability organisations, state agencies and voluntary groups. In some cases, 2 representatives joined the call. Two members of the research team conducted each of these interviews. Discussions centred on 3 main topics: the need for a representative advocacy service for children with intellectual disabilities; the scope of a new service; and its responsibility, powers and governance. Findings from these discussions are explored below.

Existing frameworks and establishing the need for representative advocacy

In the absence of a dedicated representative children's advocacy service for children with disabilities, participants were asked about their experiences of children's advocacy within existing frameworks. These discussions shed light on how advocacy was conceptualised, its purpose and functions, and whether there was a need for a new dedicated service. There was general agreement among professionals that a new advocacy service for children with intellectual disabilities would be beneficial, with some clearly demarcating between services which offer support, those which offer information, and those providing advocacy. For parents, these strands were interconnected and undifferentiated. All agreed that accurate and up to date information was difficult to access and rarely proactively forthcoming, with parents relying on other parents for information and connections. Peer support groups were the most common form of information and advocacy support parents had accessed.

> *I'm not aware of any [] advocacy and maybe I've been looking, am I looking in the wrong places for help that I wasn't aware of?... this is the case for people that there just isn't anywhere to turn or anything. What we've learned really to date is from each other and from other parents or somebody will share something that's really useful. And then we pass that on and start building connections yourself. But it's, it's very difficult. - Parent 12*

Despite the focus group including parents who were active advocates for their children and their community, they had little direct experience of or contact with formal advocacy supports. One parent spoke about receiving patient advocacy services in one of the children's hospitals and how the advocate was able to push for certain needs of the child, allowing the parent to focus on their child. The other parents in the group were unaware that this service existed. The sole parent whose child could access a dedicated representative advocacy service due to her foster care experience reported that she was not aware of the relevant service and as far as she knew, the child had never been offered access to an advocate.

Overall, lack of access to information was a recurring theme, with some parents noting that comprehensive information about available services and supports would in some cases have prevented a subsequent need for advocacy.

> *Even from the very start, would this advocacy, would it be that I, I have my 6 month old child and I really don't know what to do, what services? I don't know what or how I start early intervention. That's a very important piece. If I had known that I could've had access to a Jack and Jill nurse for the first three years of [child]'s life, that would have been a game changer for me. But no one gave me that information. - Parent 11*

Parents noted the particular importance of advocacy and information supports in the early years of the child's life, around the time of diagnosis, during times of transition especially in relation to securing school places and moving to adult services, and more generally in finding accurate and comprehensive sources of information. The emotional impact of having to search for information and request support was mentioned frequently, and the frustration of discovering that services were available if the parent had known about them and requested them.

> *It's kind of sad when we talk about something like this and thinking of, yeah, if I had someone at the very early stage, you know, holding my hand how life would have been that little bit easier for me at times. - Parent 11*

Parents agreed that there is a gap in supports but whether this gap could be filled by an advocacy service was less clear, with some parents arguing that adequate resourcing and provision of existing services, therapies, education and other disability-specific supports would reduce the need for access to advocacy services. Other parents stated that there would always be a need for advocacy as some parents may experience burnout, may be isolated, or may be less equipped than others to secure supports for their children, particularly if their children need specialised supports.

> *There's a huge group that that misses out on a lot of representation in disabilities as those that are severe and profoundly intellectually disabled, and the only voice they'll ever have is their parent's or whoever's caring for them. - Parent 11*

Scope of the new service and what it should offer

The role of the advocate

There was broad agreement on what the role and duties of the children's representative advocate should be. The ability and authority to provide advocacy support across the range of children's services was considered to be core to the function of a new advocacy service. The provision of information and support around applications for services was also seen as integral, as well as offering support at meetings if needed, particularly in relation to education. Although having no official representative powers, some informal parent advocacy groups had volunteers who accompanied parents to meetings to support the parent in making their case or to provide practical support like notetaking, transport, or simply moral support. These actions featured in the parents' portrait of a children's advocate.

> *[…] here's things that you're going to come up against, like [home adaptation] grants, but nobody can see why you're applying for them. Somebody to come in and maybe sit down with your local council and be like, look, she needs this for XY and Z. She's not just looking for it for the craic. Sometimes you get this letter back saying deny, denied, but they don't get the whole situation. So, somebody that could arrange that meeting for you … target the right people and then, yeah, obviously you'll attend. – Parent 1*

Many parents expressed a role for advocates at key moments in the child's life, such as at birth and/or the time of diagnosis, around developmental checks when additional conditions or disabilities might be diagnosed, and during periods of transition, with school placements and the transfer to adult services being a consistent concern. One parent described the experience of attending medical appointments alone with her child, the difficulty of speaking up to advocate for her child in the face of discriminatory treatment, and the support that an advocate could potentially offer the child and family.

> *She basically said sure he might never talk anyway. And I was so shocked. I felt really intimidated at being on my own. And I just went, oh, OK. And stupidly I accepted her to say that. But if I had someone that I could say 'Can you come with me? Can you sit in here? Can you actually put this lady back in her box and say he has rights to hear and he has right to this device?' He has rights to have this. - Parent 6*

Parents noted the similarity between a children's advocate and the role a social worker should have in securing services, supports and therapies for a child in need. In doing so they noted the shortage of social workers across the disability sector. A key difference between social workers and advocates in their view was that an advocate should be independent of the agencies they are seeking to secure supports from, making them less likely to accept a lack of resources as a reason for denial of services.

> *And is that what's the foundation of the advocacy service? I think you really need because you could go into, like [Parent 10] said, you could nearly be a social worker in the in the whole side of it, you know and we don't have social workers within the disability sector. And you know, so that's really, really hard. There's very, you know, it's they're not really on the, they're not that many on the ground anymore, you know, supporting us. So, it is really hard, but that piece is missing as well. So. – Parent 11*

Others proposed that along with expert knowledge of the disability landscape, in order to fully understand what was needed by children with disabilities and their families, advocates would need to have lived experience, although whether that meant lived experience of disability or of being a parent to a child with a disability was unclear.

> *They would have to have a very holistic approach to it all, knowing that, you know, it's as we say, it's not one-size-fits-all. I definitely see there has to be someone with a good lived experience within that organisation as well as people that have that high level of information all about the rights and the entitlements, the laws and policies definitely and then hand in hand support. - Parent 11*

Universal vs. specialised service for children with intellectual disabilities

There were divided opinions as to whether a new children's representative advocacy service should serve all children, children and young people with disabilities, or children and young people with intellectual disabilities. Parents expressed concern that children with the highest levels of need or the most complex support needs would not receive the representative advocacy service that they require if the service was developed with a remit to provide advocacy services to children in general. Examples of inaccessible services, rushed processes, absent supports and discriminatory treatment were given, showing the requirement for the service to have a deep understanding of accessibility for children and young people with intellectual disabilities.

> *I mean, there's just no understanding of what it actually and like. I feel like if there was some kind of independent advocacy service, then somebody might be able to turn around to a CDNT and say, do you know that this is what it's like if a person has an intellectual disability, they're not trying to be bold like we had one person tell us to put her on the naughty step. I was like, are you, are you joking me right now? - Parent 8*

Children's experiences in current services, including clinical settings, showed how existing facilities are not set up with children with intellectual disabilities in mind. Inclusive and accessible practices that could inform a new service were also described, including staff practices and environmental design that demonstrate understanding and acceptance of the needs of children and young people with intellectual disability. Specific examples included the design of consultation rooms, private waiting rooms or process design that excluded the need to wait, flexibility of staff to come and meet the child where they are – on a corridor, in the car park , at home – and non-judgemental approaches to children who cannot regulate their behaviour. An accessible service should have considerations like these baked into their design, management and delivery.

> *I just feel like if there was a service I was in specifically for intellectual disability. They might have a better understanding of how to keep the child and family safe from a practical perspective.- Parent 8*

This need for deep knowledge about how intellectual disability is experienced by children was named as essential for an advocate who would be dealing with health services. The 'snowball effect' of one problem or condition leading to further physical, emotional or behavioural problems was described by one parent, and how this kind of complexity is reflexively medicalised by professionals in the health service rather than examined holistically to determine the root cause of the problem. Experience and knowledge of this type of complexity would be needed for an advocate to be able to argue for services to take the time to resolve issues rather than dismiss or force unwanted interventions on the child.

> *If we had somebody who was kind of understood intellectual disabilities and was able to say, OK, well, what is she trying to communicate with us instead of just treating her as, you know, one medical problem. If they looked at her in a holistic manner and saw that she was a person trying to communicate something. A huge problem for people with intellectual disabilities is dying from preventable diseases such as constipation because people are like, oh, that person's aggressive, let's restrain them instead of asking why is this person behaving in this way? - Parent 8*

Parents and professionals expressed a fear that the concerns of children with intellectual disabilities might get lost in a broad-reaching service for all children – or all disabled children and young people – as well as a concern that a service with a remit solely for children with intellectual disabilities would not have the breadth of knowledge needed to operate across all sectors relating to children's needs and well-being. Prospective advocates would require expertise in law and policy, especially in the area of education and health, but would also need to share a rights-based outlook on intellectual disability that would enable them to anticipate and facilitate the particular needs of an individual child in the advocacy process. This would extend to understanding how to facilitate communication. A key informant with experience of children's representative advocacy noted that regardless of their disability status, children and young people can struggle to express their support needs, and that advocacy with children and young people with disabilities required a different approach, specifically requiring more time.

> *Not every young person is able to actually put words to or describe to us what it is that they would like our support around. So, our advocacy in this sector tends to take a little bit more time. - Key Informant 2*

Children's rights-focused service

While the need for an agency that would protect and secure individual children's rights was generally accepted, opinions on how focused that service would be on the child herself were somewhat divided, particularly between parents and professionals. One parent spoke about how important it would be for the advocate to have knowledge of how to include the child in the process, listening to them, speaking directly to them, and recognising the child as a rightsholder. She recounted meetings where she attended with her teenaged child, only to have the professional exclude him from the conversation and speak in negative terms about him.

> *Even the services you're in, they're speaking to you in front of the child who is listening. He's 13. He can repeat word for word. I've come out of things where he said, do they think I'm stupid? I think there's absolutely no community support for intellectual disability whatsoever. – Parent 4*

Both of the child interviewees spoke about how important it would be for the advocate to engage directly with them even when parents were present and that the advocate should have the kind of personality that would allow them to talk comfortably together from the outset.

> *A friendly person. Yeah. In in a kind way in a kind way. And if they're lovely. I could trust that. Honest, definitely. Honest and honest, yeah. Because somebody who, I don't know, but maybe, to be a good person, be a good person. And friendly. Yeah. And nice. Nice. Yeah. - Mark*

> *Friendly, kind, lovely, easy to talk to. Explain things to me. And listen to my voice, and what I hear in my head. - Isabel*

Many parents took a very different view, claiming that it would be wasteful of a service to attempt to include the child directly in the advocacy process. Many of these parents had children who did not communicate using formal spoken language, sign language or assistive devices. Some suggested that their child would not understand the process or have the capacity to make decisions. These parents saw the focus on a children's representative advocacy service as unnecessary or unwanted, believing that family advocacy would be a more helpful model. The reasons for this varied widely. Some parents favoured a holistic approach to the child in which the family environment – including the presence of siblings or parents with disability - necessitated an approach to advocacy that was very involved with improving the circumstances of the child by supporting the whole family. Services such as the Family Resource Centres were mentioned as an existing structure that took a whole-family approach to disability support.

> *They need to help parents who, I suppose what the focus is, maybe their child doesn't have a voice because they're unable to have that voice or they're non-speaking or they don't have the intellectual capacity to advocate themselves. - Parent 10*

Professionals raised the challenge of providing representative advocacy services in a way that balanced the rights of the child with those of the parent. One informant noted how well informed children and young people can be regarding their rights, partly due to education programmes in school but also related to the sharing of information on social media. This knowledge sometimes creates conflict between the child and parent around decision-making, with issues like children's objections to parents' restrictions on choices around education featuring in some of their recent advocacy work. How children's advocates would navigate inter-family disagreements was highlighted as an area of potential difficulty.

> *Just one last thought is that it's definitely a more challenging space to equip advocates to interact with parents where they [the parents] have decision making rights. Yet, you're supporting advocacy for the child. It is a much more complicated space to operate in. – Key Informant 8*

> *How it balances, you know, the rights of the parents, the rights of the child, I think would definitely be a meaty issue for them to work through, absolutely. – Key Informant 9*

> *I think a real challenge for us, particularly as our community evolves and we often have*

> *young people now who are very informed about autism who really understand their experience, maybe more than ever before, particularly with the rise of like, TikTok and so much information up and so on. Now that you can mediate between a scenario whereby the advocacy wishes of the parents acting on behalf of the child may be quite different, and indeed at times may be less informed or less compliant to the UNCRPD to what the preferences of the young person would be. – Key Informant 9*

Consideration around consistency and trust were raised by parents and professionals alike. From a parent's perspective, their experiences of fractured disability supports would mean a new service would have to focus from the start on building trust with families. Consistent access to a familiar team of advocates knowledgeable about the child's circumstances and needs, children and their families would be needed to build a relationship of trust with the advocate appointed to represent them.

> *I think there will be a lot of work needed up front to give people confidence that that kind of it wasn't just another kind of bureaucratic elements and that isn't particularly empowered or particularly representative. – Key Informant 8*

This view was shared by professionals, particularly in relation to services for autistic children and young people and the need for disability services generally to 'rebuild faith in the system'.

> *That challenge of that continual support and which is important to most individuals, but particularly important to autistic individuals, from a predictability point of view as well, in order to make it meaningful. – Key Informant 10*

Location and accessibility

One of the child interviewees suggested that the advocacy service should be based at an office where children could choose to go if they didn't feel comfortable having someone in their home. She saw the importance of home visits for people who needed them, but also the importance of a neutral space.

> *I don't like to talk to people on my own. Strangers. I'm afraid if I'm alone or if they come to my address. I would close my house and do not talk to them. I go by car, to Dublin or Cork. – Isabel*

All participants agreed that any advocacy service should be accessible on a regional basis and that advocates should be mobile and able to visit children in their homes. This was seen to be a basic requirement not just in terms of accessibility, but for building the relationship of trust and understanding between the advocate and the child. A parent compared this in-home accessibility to a situation in which she arranged for a disability services manager to come and visit her son in order to witness first-hand his needs and wishes around supports. Without this in-person witnessing of the level of supports needed, the services manager would not have understood the relationship between the parent, her son and his carer or his need for additional supports.

Other accessibility concerns relating to processes and staff have already been detailed in the preceding paragraphs, with parents giving examples of the good and bad practices they and their children have previously encountered. Parents described the need for 'joined-up thinking' – an appreciation of the complexity of supports and services required by some children, understanding of the ways in which intellectual disability interacts with autism or other disabilities and health conditions, and the additional barriers that children with intellectual disabilities can face when trying to access services, assessment, diagnosis and/or treatment for other conditions.

> *There needs to be joined up thinking like I can get. It'll be fantastic to get an advocate for ID but if that person doesn't understand autism and the autism doesn't understand the ID and nobody else understands the medical issues like diabetes... So… they overlap. That's where the issue is. It needs to be. You can't have the ID people not understanding autism. It has to go together... It's the joined up thinking there has to be you can't have separate silos right. It has to be joined up. – Parent 8*

Other informants – parents and professionals – expand this point to argue for an intersectional approach to advocacy, naming additional circumstances in the life of a child with an intellectual disability – such as homelessness, care status, refugee or asylum status and more - which may cause them to require extra support in order to access services.

Responsibility, powers and governance of the new service

There was no consensus on how the right to advocacy for children and young people should be established in legislation. Equally, opinion was divided or absent on the format of State structures that would be required to oversee, manage and deliver a new service. Both parents and professionals saw the establishment of authority and powers of compellability as core to the functioning of a new children's advocacy service. Representatives from organisations already active in the advocacy landscape viewed this authority as essential if children's advocates were to be able to successfully secure children's rights in schools or healthcare settings. This was evidenced by the resistance they met to their own recommendations for change in similar areas.

> *The weakness is that our findings or recommendations aren't, we don't have powers of compellability under the legislation. So, we can't force them to do what we agreed - Key Informant 3*

Parents were in agreement, pointing to their own experiences of having meetings with providers and either being denied services for their children or coming to agreements but never receiving the promised follow-up supports. Parents understood the difficulties they had experienced in securing services and supports for their child as part of a wider public service crisis that had no end in sight. In the context of waiting lists and staff shortages, parents expressed doubts as to whether an advocacy service could be equipped to function as it should and would instead end up as another expensive, failed project.

> *Whoever would be in this role, they need to have teeth, you know? I mean, it can't be just another administrator walking around the houses, knocking on doors and being very politely told 'Oh, no'. You know, we've all experienced as parents. So, I would be quite concerned that we're going to see another NGO pop up that doesn't have a read on what the parents really need. That'll be my main concern with this, just more funds being sucked up into NGOs. – Parent 5*

The independence of the new service was closely linked by some respondents to its ability to effectively deliver its services. Parents were very clear that such a service would have to be entirely separate from bodies tasked with the delivery of public services to children, such as the HSE or the Department of Education. Some saw the potential for responsibility for representative advocacy to be placed with an independent organisation already involved in systemic advocacy, effectively piggybacking on to the processes, networks and knowledge already in that organisation's possession.

> *Who should be responsible for it? Yeah, I don't think a whole team needs to be opened… It needs to be people who know [about intellectual disability], combined with people with teeth and people who will listen. I'm not the biggest fan of [organisation name], but they have a lot of that. They have the money, they have the profile, they have the connections. – Parent 2*

Other parents believed a fresh start and a discrete organisational identity would be more beneficial to establishing the new service as an independent body, suggesting that such an approach would not exclude the service from learning from and utilising existing groups' networks and frameworks.

> *I do think though it could do it a separate new identity as well because it might draw some more attention to it. Because of what has been happening and not been happening like why this had to be set up. I don't think a new group will be a bad idea. And not starting from scratch, linking in like this, into frameworks there from other groups. – Parent 1*

Advocacy practitioners were more guarded about where a new advocacy service should be located. One informant prioritised the alignment of values between the new service and the body within which it might be placed, stating that without careful attendance to matters such as values, codes and governance, the new service could end up 'captured' by the agenda of other organisations, losing its independence and effectiveness.

> *Independence has got to be guarded carefully. So, where it's positioned in terms of its funding and its governance and oversight is critical to that, but also the advocacy practise oversight, the value, the code of practise and I suppose everything has to be filtered back through values and you know that's where it goes wrong and that needs to be right from the get-go. And if it's not, advocacy can end up in a very dodgy place and it can end up being a puppet on a string for different organisations who need jobs done. – Key Informant 8*

General Recommendations

Overall, this research has demonstrated that there is a clear gap in the provision of representative advocacy to children with intellectual disabilities in Ireland. Many participants in this research identified that **there is potential for a representative advocacy service for children with intellectual disabilities** to realise the human rights of this community. However, consensus on the actual need for such a service, as well as its precise structure, governance and operation was more difficult to achieve.

With these caveats in mind, there are some general recommendations we can make derived from knowledge of existing systems in other jurisdictions as well as the feedback from research participants. Further exploration of these points is required before the any genuine effort is made to develop a representative advocacy service for children with disabilities in Ireland. It is vital that any future research or efforts to develop a representative advocacy service actively involves children with intellectual disabilities.

Individual right to advocacy vs statutory duty to provide advocacy

Experience in other jurisdictions has demonstrated that a duty on state bodies to provide advocacy provides less protection than a recognition of the individual right of each child to access representative advocacy when needed to realise their human rights. This can also be seen in the Irish context, where the provision of advocacy is recognised as one of the functions of the Citizens Information Board, but no corresponding legislative right to representative advocacy for children in general, or disabled children in particular, exists. Therefore to maximise effectiveness of any future potential representative advocacy service, we recommend that it be established as part of a suite of robust and substantive individual legal rights protections for disabled children, including the right of each child to receive a representative advocacy where needed to ensure the protection of their human rights.

Will and preference approach to representative advocacy for disabled children

In keeping with a human rights based approach under the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, respect for the will and preferences of disabled children must be at the core of any future representative advocacy service. For children with particularly complex support needs and those who use unique forms of communication, those who know them well, especially their family members, will be crucial in supporting representative advocates to understand the will and preferences of the child. All representative advocacy must centre on the child’s will and preferences, and should not allow vested interests of service providers or others to take precedence. Other jurisdictions have also emphasised an advocate' s role in supporting the child to develop self-advocacy skills or their confidence to express their views, will and preferences.

Provision of advocacy by statutory bodies or community and voluntary organisations

Under a human rights framework, recognising the individual right of the child to access advocacy and designating a state body with responsibility for ensuring this right is fulfilled would be the simplest way to develop a children’s representative advocacy service. However, some participants in this research expressed a desire for grassroots organisations to be involved in delivering representative advocacy services as these groups would have the most relevant local knowledge and expertise on how to navigate the relevant systems. Examples from other jurisdictions demonstrate that a commissioning model where the State outsources the management and delivery of advocacy services for children can be challenging and that problems exist in ensuring funding and sustainability of independent advocacy organisations. Further research on the possibilities for ensuring state responsibility and joined up thinking in the delivery of representative advocacy services is required before any more detailed recommendations can be made in this respect.

Independence and authority of representative advocacy service

All participants in this research and the evidence from other jurisdictions demonstrates the central importance of ensuring both independence and authority of any future representative advocacy service for children with intellectual disabilities in Ireland. The role of funding and resources in ensuring independence is critical for any future representative advocacy service. The development of trust with children with intellectual disabilities and their families is also vital to ensure the success of any future representative advocacy service – and many participants emphasised the need for any new service to assert its authority and be well-respected by both grassroots and government bodies in order to achieve the desired change for individuals as well as at a systemic level.

Universal service for all children or tailored service for children with intellectual disabilities

There was no clear consensus among participants in this research about whether any new representative advocacy service should be universally available to all children who need it or tailored specifically for children with intellectual disabilities. However, a distinct view emerged from this research that any new representative advocacy service, if designed for children in general, must be designed with children with intellectual disabilities at its core, to ensure it would be accessible in practice for this community. Some participants suggested a 'hub and spokes' type of model where a general representative advocacy service for all children could be established but the provision of individual advocacy to a specific child would be done by an advocate or team that matched that child's specific needs and potential intersectional identities or issues faced (for example, for children with intellectual disabilities from the Traveller community or those living in direct provision, among others).

Conclusion and Future Directions

Further research is needed before any conclusions can be reached on the precise model of representative advocacy provision that would best meet the needs of all children, taking into account the complexities of a potential commissioning model and the lessons learned from other jurisdictions in this respect. Regardless of the model ultimately selected for future delivery of a representative advocacy service, research participants, especially parents of children with intellectual disabilities, emphasised that the service should be easy to access, without complex eligibility criteria or bureaucratic barriers for children who need a representative advocate in order to ensure the service could be truly effective in practice.

As outlined above, a view emerged from research participants that **a representative advocacy service could only truly be effective if it was provided as part of a continuum of accurate and accessible information, advice, advocacy and support** to realise the human rights of children with intellectual disabilities. This means that the establishment of a representative advocacy service as a stand-alone effort to secure disabled children's rights, in the absence of a radical overhaul of existing State and voluntary structures to support disabled children and their families, would not achieve its desired goal of empowering children with intellectual disabilities and supporting the realisation of their fundamental rights, including their rights to education, and right participate fully in the communities to which they belong.

This research also demonstrated the complexity and challenges of engaging with children and young people with intellectual disabilities directly to ascertain their views on the creation of any new representative advocacy service. While the insight of the young adults with intellectual disabilities in our Advisory Group were vital, we **struggled to recruit children under 18 with intellectual disabilities themselves for focus groups** where they could share their views. Any future development of a representative advocacy service for this group in Ireland would need to take into account the time required to build relationships of trust with children and young adults with intellectual disabilities and to ensure their meaningful participation in the design, development and delivery of this service.

Bibliography

Legislation

Adoption and Children Act 2002 (England and Wales).

Advocate for Children and Youth Act 2016 (Manitoba, Canada)

Child Protection Act 1999 (Queensland, Australia)

Children Act 2004 (England)

Children's Commissioner for Wales Act 2001 (Wales)

Citizens Information Act 2007 (Ireland)

Comhairle Act 2000 (Ireland)

Disability Services and Inclusion Act 2023 (Australia)

Guardianship and Administration Act 2019 (Victoria, Australia)

Mental Capacity Act 2005 (England and Wales)

Representative for Children and Youth Act (British Columbia, Canada)

Representative for Children and Youth Act 2015 (Nunavut, Canada)

UN Documents & Official Reports

Committee on the Rights of the Child and Committee on the Rights of Persons with Disabilities, Joint Statement: The Rights of Children with Disabilities (March 2022).

Committee on the Rights of the Child, 'General Comment No. 12 (2009) The Right of the Child to Be Heard' UN Doc. No. CRC/C/GC/12.

Committee on the Rights of the Child, 'General Comment No. 9 (2006) The Rights of Children with Disabilities' UN Doc. No CRC/C/GC/9.

Department for Education (England & Wales). 'Effective Advocacy for Looked-After Children, Children in Need and Care Leavers: Statutory guidance for local authorities' (London, September 2023).

Department for Education and Skills (England), Providing Effective Advocacy Services for Children and Young People: Making a Complaint under the Children Act 1989 (London, 2004).

Department of Health (England), National Standards for the Provision of Children's Advocacy Services (England; 2002).

Department of Social Services (Australia), National Disability Advocacy Framework 2023-2025 (June 2023) <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/national-disability-advocacy-framework-2023-2025-0>.

Standards Australia, Standard AS 5391:2024, Advocacy in Ageing and Disability (June 2024) <https://store.standards.org.au/product/as-5391-2024>.

Chapters, Journal Articles and Reports

Arstein-Kerslake, A, Maker, Y, Flynn, E, Ward, O, Bell, R, Degener, T, 'Introducing a Human Rights-based Disability Research Methodology', Human Rights Law Review, (2020) 20(3) 412–432, <https://doi.org/10.1093/hrlr/ngaa021>.

Bendo D, ‘Roles, Responsibilities, and Rights: An Organisational Analysis of Provincial and Territorial Child and Youth Advocate Offices in Canada’ (2021) 29(4) International Journal of Children’s Rights 806.

Burke M and Goldman S, ‘Documenting the experiences of special education advocates’ (2016) 51(1) The Journal of Special Education 3.

Burke M, Rossetti Z, Aleman-Tovar J, and Rios K, (2021). ‘Examining the relation between empowerment and civic engagement among parents of individuals with intellectual and developmental disabilities’ (2021) 34(6) Journal of Applied Research in Intellectual Disabilities 1569.

Cascardi M, Brown C, Shpiegel S, and Alvarez A, ‘Where have we been and where are we going? A conceptual framework for child advocacy.’ (2015) 5(1) Sage Open.

Children’s Commissioner, The State of Children and Young People’s Advocacy Services in England (London, 2023).

Citizens Information Board, Speaking Up for Advocacy – Issue 10 (2008).

Comhairle, The Jigsaw of Advocacy (Dublin, 2003).

Coram Voice, Annual Report 2023. (March 2023) <https://coramvoice.org.uk/wp-content/uploads/2024/06/Coram-Voice-Annual-Report-2023.pdf>.

Dalrymple J, ‘Constructions of Child and Youth Advocacy: Emerging Issues in Advocacy Practice’ (2005) 19(1) Children & Society 3.

EPIC – Empowering People in Care, ‘Amplifying Voices: Enshrining the Right to Independent Advocacy for Children in Care and Care-Experienced Young People in Legislation’ (Dublin, 2023).

Goldhagen, J, Clarke A, Dixon P, Guerreiro, A. I. F, Lansdown G, and Vaghri Z, ‘Thirtieth Anniversary of the UN Convention on the Rights of the Child: Advancing a child rights-based approach to child health and well-being’ (2020) 4(1) BMJ Paediatrics Open.

Goldman S, ‘Special education advocacy for families of students with intellectual and developmental disabilities: Current trends and future directions’ in Robert M. Hodapp and Deborah J. Fidler (eds.), International Review of Research in Developmental Disabilities (Elsevier Academic Press, 2020).

Manitoba Advocate for Children and Youth, Annual Report & Service Plan 2022-23 (October 2023) <https://manitobaadvocate.ca/wp-content/uploads/2023/11/MACY-Annual-Report-2023-ENG.pdf>.

Manitoba Advocate for Children and Youth, Annual Report 2021-22 (October 2022) <https://manitobaadvocate.ca/wp-content/uploads/2023/06/MACY-Annual_Report_InsideEN_2022-FIN_screen-1.pdf>.

Office of the Public Advocate (Victoria), Annual Report 2022-2023 (October 2023) p. 33 <https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opa-annual-reports/648-opa-annual-report-2022-2023>.

Representative for Children and Youth, Annual Report 2021/22 and Service Plan 2022/23 to 2024/25

(September 2022) <https://rcybc.ca/wp-content/uploads/2022/10/RCY-AR-2021-22_FINAL.pdf>.

Representative for Children and Youth, Annual Report 2022/23 and Service Plan 2023/24 to 2025/26 (September 2023) <https://rcybc.ca/wp-content/uploads/2023/09/RCY-ARSP-2023-web.pdf>.

Ryan C and Quinlan E, 'Whoever Shouts the Loudest: Listening to Parents of Children with Disabilities' (2018) 31 Journal of Applied Research in Intellectual Disabilities 203.

Web Pages

Action on Disability in Ethnic Communities, 'Disability Advocacy Support Program' <https://adec.org.au/advocacy-support>.

Association for Children with Disability, 'Advocacy' <https://www.acd.org.au/advocacy/>.

Canadian Council of Child and Youth Advocates, 'About the Canadian Council of Child and Youth Advocates' <https://www.cccya.ca>.

Disability Advocacy Network Australia, 'What We Do' <https://www.dana.org.au/about/what-we-do>.

Inclusion BC, 'Individual and Family Advocacy' <https://inclusionbc.org/what-we-do/individual-family-advocacy>.

Inclusion Nova Scotia, 'Individual and Family Support' <https://www.inclusionns.ca/individual-family-support>.

Inclusion Saskatchewan, 'Support & Advocacy' <https://www.inclusionsk.com/support>.

Manitoba Advocate for Children and Youth, 'Advocacy Services' <https://manitobaadvocate.ca/what-we-do/advocacy-services>.

North West Territories Disabilities Council, 'Information Referral & Support' <https://www.nwtdc.net/information-referral-and-support>.

North West Territories Disabilities Council, Information, Referral and Support Brochure (2022) <https://www.nwtdc.net/s/IRS-Brochure-2022.pdf>.

Nunavummi Disabilities Makinnasuaqtiit Society, 'NDMS Services' <https://nuability.ca/services/>.

Nunavut Representative for Children and Youth, 'Individual Advocacy' <https://rcynu.ca/our-work/what-we-do/individual-advocacy?_ga=2.168614434.26364492.1695746805-1917614065.1695746805>.

Office of Public Guardian (Queensland), 'Child Advocate' <https://www.publicguardian.qld.gov.au/i-am-a-child-or-young-person/who-can-help-you/child-legal-advocacy>.

Sydney Region Advocacy Corporation, 'Indigenous Disability Advocacy Service (New South Wales)' <https://www.srac.ngo/idas>.

The Care Leaver's Association, 'Uncovering the past abuse of children in care' (2014) <https://www.careleavers.com/history>.

Youth Advocate Programmes Ireland, 'Independent Mental Health Advocacy' <https://yapireland.ie/what-we-do-yap-ireland/our-services-yap-ireland/independent-mental-health-advocacy/>.

Youth Disability Advocacy Service, 'Get advocacy support' <https://www.yacvic.org.au/ydas/advocacy/get-advocacy-support>.

Published by Inclusion Ireland, © 2024

Inclusion Ireland

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with an Intellectual Disability.

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