



INCLUSION IRELAND

National Association for People with an Intellectual Disability

**Pre-Budget
Submission 2019**
**Department of Children and
Youth Affairs**

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About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.

Public Sector Duty

In the most recent strategy statement, the Department of Children and Youth Affairs notes its obligations under Section 42 of the Irish Human Rights and Equality Commission Act, 2014.

Inclusion Ireland would encourage the Department to ensure that all decisions made for Budget 2019 are in line with this duty by being proactive in promoting equality; ensuring human rights are realised and eliminating discrimination.

As part of taking steps to fulfil its public sector duty, the Department of Children and Youth Affairs should ensure that agencies under its remit are also compliant with the duty. Action should be taken by the Department to ensure that children with disabilities are not excluded from Tusla.

About this Submission

Inclusion Ireland held consultations in Cork, Tullamore & Sligo as well as an on-line survey with respondents from all 4 provinces of Ireland. People with a disability, their family members and people who work in disability all took time to complete the survey.

Inclusion Ireland is moving towards complete accessibility of its work and this document contains an easy to read summary at the start.

Easy to read summary



An Roinn Leanai
agus Gnóthaí Óige
Department of Children
and Youth Affairs

The Department of Children and Youth Affairs is a very important government department.

The Department looks after children, young people and families in Ireland.

This submission is asking the Department to look at 5 things for the Budget in 2019.



What is the Budget?

The Budget is the Government plan of how money will be spent for the coming year.

Inclusion Ireland is asking the Department to look at 5 areas



1. Supporting parents with an intellectual disability

We are asking the Department to put in place supports for parents with intellectual disabilities

2. Tusla and children with disabilities

We are asking the Department to support Tusla (the child and family support agency) to look after children with disabilities

3. Supports in early years' settings

We are asking for the Department to support young children with disabilities in pre-school

4. Personal budgets

We are asking the department to take steps to allow children with disabilities to have a personal budget

5. Advocacy

We are asking for the Department to put a plan in place so children can have an advocate



Introduction

In the Programme for Partnership Government, there is a commitment to:

- Develop a National Parenting Support Plan with a range of practical and supportive measures for all parents
- Target investment at early intervention to improve outcomes for children
- Further develop early childhood care and education programmes
- Eliminate any persisting discrimination on the nine grounds,
- Equality of opportunity,
- Support persons with disabilities in maximising their potential,
- Remove barriers which impact on access to services, education, work or healthcare,

Inclusion Ireland believes that people with disabilities should live self-determined lives and Budget 2019 provides an opportunity to create a more equal & just society and to develop pathways into a life in the community for children and adults with a disability.

Inclusion Ireland has identified 5 areas of reform for Budget 2019 that fall within the remit of the Department of Children and Youth Affairs

Budget 2019

1. Supporting parents with an intellectual disability
2. Tusla and children with disabilities
3. Supports in early years' settings
4. Personal budgets
5. Advocacy

1. Support parents with an intellectual disability

Article 23 of the United Nations Convention on the Rights of Persons with Disabilities commits States Parties to eliminating discrimination against persons with disabilities in matters relating to family and parenthood. It affirms the right of persons with disabilities to found a family and to access supports to do so. It asserts that in no case should a child be separated from parents on the basis of the disability of either the child or parent.

However, evidence from the Child Care Law Reporting Project would suggest that, in practice, these rights are not upheld for either parents with a disability or their children.

According to the Child Care Law Reporting Project¹ the most common reason for seeking a care order for a child is parental disability (15% of cases). In a further report, Coulter notes: "Cognitive disability on the part of the parents was identified by all the reporters as a recurring issue, raising questions about the training of social workers to identify levels of cognitive disability and tailor supports accordingly". The report continues that "reporters formed the impression from the hearing that more engagement with the family could have averted the proceedings, or allowed for an application for a supervision order instead of a care order."²

Research by the National Disability Authority³ found that parents with an intellectual disability are more likely than other parents to have their children taken into care, and up to 48% of children of parents with intellectual disability were likely to be in care. However, a consistent finding of research indicates that "Maternal IQ is not systematically correlated with parenting competence". Much evidence demonstrates that parents with an intellectual disability can adequately care for their children given the appropriate support⁴.

¹ Coulter, C., Final Report, Child Care Law Reporting Project, 2015

² Coulter, C., An examination of lengthy, contested and complex child protection cases in the District Court, 2018.

³ NDA (2010) Research on intellectual disability and crisis pregnancy, parenting and sexual health for caregivers, health professionals and service providers. Dublin: NDA

⁴ Willems, D. L., De Vries, J.-N., Isarin, J. & Reinders, J. S. (2007) Parenting by persons with intellectual disability: an explorative study in the Netherlands. *Journal of Intellectual Disability Research*, 51, 537– 544;

As it stands, parents with an intellectual disability may lose their children into the care system because of a lack of individualised, tailored supports.

Inclusion Ireland asks for Budget 2019, related to supporting parents with a disability are:

1. As part of its commitment to develop a National Parenting Support Plan, the Department should commission research on the supports that are available to parents with an intellectual disability and what supports are required. This research should also examine how the child protection system may be more accessible to parents with intellectual disabilities.
2. Fund Tusla to devise or commission parenting programs that are accessible to parents with intellectual disabilities, including the use of easy to read materials.

2. Tusla and children with disabilities

When it was established in 2014, Tusla took over many of the HSE's functions, aiming to take a new approach to child protection and family support which was "responsive, inclusive and outward looking".⁵

The decision was made at the time to exclude children's disability services from the remit of Tusla. This has resulted in many children with disabilities being unable to access child and family services. It has led to a situation where Tusla, its staff and its agencies, particularly the 106 Family Resource Centres throughout the country, are not adequately resourced and trained to support children with a disability and their families.

Inclusion Ireland has come across a number of situations where Tusla has refused to get involved where there are clear concerns for children with a disability. These include the restraint and seclusion of children in schools and refusing to work with a disabled child in a family whilst being prepared to support a child without a disability in the same family.

Booth, T & Booth, W. (1993) Parenting with learning difficulties: lessons for practitioners. *British Journal of Social Work*, 23: 459-480.. McConnell, D., Mayes, R. & Llewellyn, G. (2008a) 'Women with Intellectual Disability at Risk of Adverse Pregnancy and Birth Outcomes.' *Journal of Intellectual Disability Research*, 52, 6, pp 529-535.

⁵ Tusla Newsletter, January 2014 http://www.tusla.ie/uploads/content/News_Newsletter_Jan_2014.pdf

The Ombudsman for Children has expressed concern over the treatment of children with disabilities. One recent report, into the case of 'Molly' highlights that the decision to exclude children with disabilities from Tusla's remit is leading to poorer outcomes for children with a disability.

Both UNICEF and the UN Economic & Social Council have highlighted the need for child protection systems and services to be non-discriminatory. The UN Convention on the Rights of the Child and other United Nations Conventions which Ireland has ratified together with the Irish Constitution, national law, legal precedent and the European Convention on Human Rights create clear obligations for the Irish state to protect all children from harm equally.

By excluding children with disabilities from its remit, Tusla has not only reneged on its promise to take an inclusive approach but, in the view of Inclusion Ireland, has directly discriminated against children with disabilities, leaving them without an effective agency which ensures their support, welfare and protection.

What people said in our consultation about Tusla and children with disabilities

"A child with a disability is a child, pure discrimination."

"Tusla do not have a budget to do what they are doing. If children with disability were included it would look like abuse issues."

"Tusla don't have the expertise in additional needs"

"We should be able to access the support of Tusla. We self-reported 5 years ago when our son was violent with the family. We felt his siblings were at risk. No follow up"

"Tusla should support children with disabilities. This needs to change. Every child deserves equal opportunities in life"

"Voluntary services (family support groups) are setting up their own services but it is a double edged sword. You always feel you have a begging bowl. In a decent world there would be people trained to work with my child."

Inclusion Ireland asks for Budget 2019, related to supporting parents with a disability are:

1. Review the decision to exclude children from the remit of Tusla. The review should examine what restructuring needs to take place to ensure an inclusive child and family agency and what funding is required to do this.

3. Supports in early childhood care and education

The Access and Inclusion Model (AIM), the programme to support young children with a disability to access the Early Childhood Care and Education (ECCE) scheme, has been shown to be a huge success. Children are supported to access the ECCE through generic supports, or for a child who has complex needs through individualised supports such as a support worker. However, these supports are only available to a child attending the ECCE scheme.

The ECCE scheme is for 15 hours per week and for a total of 38 weeks in each of two years. For the rest of their early year's engagement, the child will have no supports in place. This means a parent has to pay for support for the child or their ability to engage in education is severely restricted.

The National Council for Special Education are implementing a pilot project on the provision of therapeutic inputs in early year's settings and schools. 75 pre-school settings will benefit from this program which involves delivery on site of occupational and speech therapy.⁶ This is particularly welcome as early intervention has been shown to be highly effective for children with a disability, especially when delivered in preschool settings.

⁶ <http://ncse.ie/wp-content/uploads/2018/05/In-school-therapy-service-launch-statement-for-upload.pdf>

What people said in our consultation about early childhood care and education:

"As an early year's educator who operates summer camps over the summer months, it would be great if children with additional needs could access supports to allow them to participate in summer camps like their peers without parents having to pay for summer camp as well as an SNA/tutor to support their child"

Inclusion Ireland asks for Budget 2019, related to early childhood care and education are:

1. Extend the AIM supports to children who attend early year's settings in addition to ECCE. At present a child may receive a targeted support for ECCE but would not have this support in the rest of their day at the early years' service.
2. Provision must be made in Budget 2019 to roll out the pilot therapy project in early years' settings into all early years' settings.

4. Personal budgets

Personal budgets are seen as one tool to enable choice and control for persons with disabilities in their lives. In October 2016, The Minister for Disabilities established a Task Force to make recommendations on a personalised budgets model which will give persons with disabilities more control in accessing Department of Health funded personal social services.

Pilot or 'demonstration' projects are expected to be established later this year. However, the decision to exclude children from these pilot studies is hugely disappointing.

The pilots will assess how personalised budgets work in a practical sense. Conducting these projects without the inclusion of children will mean that no data will be collected on how the programme might work with younger people in Ireland, potentially preventing under 18s from accessing personalised budgets for years to come.

Though the initial roll out of personal budgets focuses on services funded by the HSE, there is a need for a whole of government approach to

personal budgets so that people can use a personal budget to meet needs that are not covered by HSE-funded health and social care services.

The Department of Children and Youth Affairs, as well as other key government departments, should develop a unit to co-ordinate its department's personal budget responsibilities.

What people said in our consultation about personal budgets for children:

Individual budgets - my family say would be good for me to live a better life. I would like to go places without my family"

"Personalised budgets for children to offset lack of services and supports and help realise potential".

Inclusion Ireland asks for Budget 2019 related to personal budgets are:

1. Set up a unit to coordinate personal budgets within the Department of Children and Youth Affairs

5. Advocacy

Advocacy is an essential tool for the support of children and families where there is a disability. In Ireland, the provision of advocacy is fragmented and without cohesion. Ireland's only statutory advocacy service is the National Advocacy Service (NAS) that provides a representative advocacy service to adults with disabilities but there is no national, statutory advocacy service for children.

'A Programme for a Partnership Government' makes a commitment to establish an independent patient advocacy service. Despite consulting the public on this in 2017, no service has been established to date.

The National Disability Inclusion Strategy 2017-2021 commits to examining the need to establish statutory, national advocacy services for children and adults with mental health difficulties but makes no mention of children with other disabilities.

The lack of an advocacy service for children emerged as a key issue in Inclusion Ireland consultations.

What people said in our consultation about advocacy services for children:

"My son has a disability. To be an advocate is difficult for a family member. My son has had numerous surgeries he required. Only I persisted he would not have got it."

"I am a parent of 2 children with Autistic Spectrum Disorder. We cannot access an advocate as they are under 18. Parents need help speaking up as we are broken with constant fighting and battling".

"Advocacy for families is essentially non-existent. This is essential for younger people with disabilities"

"Parents are worn out trying to be advocates for their children/young adults and sometimes they are too tired from day to day chores that they are not able to advocate for their disabled son/daughter.

"Prior to my son being 18 there was no advocacy service for him at all."

"As I am just under 16 the NAS, national advocacy service, say they don't have the capacity to take cases on for my age group".

Inclusion Ireland asks for Budget 2019, related to advocacy are:

1. An independent National Advocacy Authority (NAA) should be established with the involvement of key government departments including the Department of Children and Youth Affairs and the Department of Employment Affairs and Social Protection.
2. The NAA should develop a national advocacy strategy for persons with a disability, including children.

6. Conclusion

The Department of Children and Youth Affairs is a key player in the promotion of equality and social inclusion for children and families where there is a disability. However, there are clear areas in which the

Department can improve on its support, including the provision of supports to parents with intellectual disabilities as well as children.

Better Outcomes, Brighter Futures' the national policy framework for children and young people recognises that:

“All forms of...discrimination are unacceptable and must be challenged in schools, youth organisations, communities, at work or online, and the State has a duty to ensure its laws, policies and practices do not discriminate⁷”.

Yet, there are many aspects of current practice that result in discriminatory outcomes for families where there is a disability, including the exclusion of children with disabilities from the remit of Tusla, exclusion of children from the proposed model of personal budgets and the lack of an independent, statutory advocacy service for children.

Although supports for children and families with disabilities fall under varying areas of departmental responsibility, the Department of Children and Youth Affairs has the opportunity to demonstrate leadership in ensuring that Budget 2019 take steps to ensure equality for children with disabilities and families.

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⁷ DCYA. Better outcomes, brighter futures. National policy framework for children and young people, 2014-2020. p.79.