

Nowhere To Turn

Children with disabilities left with no support



ombudsman
do leanaí
for children

Table of Contents

1. Introduction	1
1.1 About the Ombudsman for Children	1
1.2 Rationale for this Report	1
1.3 People on the Ground	2
2. Children’s Experiences	5
3. Rights Concerns	9
3.1 The right to grow up within their family	9
3.2 The right to alternative care	12
4. What needs to change?	13

Nowhere To Turn:

Children with disabilities left with no support.

The following quote from Mr. Justice Max Barrett demonstrates the impact that this issue is having on children in Ireland. Mr. Justice Max Barrett made this comment in his determination of the High Court case about a teenage girl with a disability who had to stay in a single room in a regional hospital for close to sixty days as there was nowhere else for her to go:

“The court recalls the promise, pointed to in the Proclamation of Independence, of a republic that would cherish all the children of the nation... the court cannot but observe that Miss X [could] be forgiven if she does not feel greatly cherished by the republic at this time.”¹



¹ <https://www.casemine.com/judgement/uk/645e93bf96286752ef01fe02>

1. Introduction

1.1 About the Ombudsman for Children

The Ombudsman for Children's Office (OCO) is an independent statutory body established under the Ombudsman for Children Act 2002 (2002 Act). Under the 2002 Act, the Ombudsman for Children has two core statutory functions:

- o to promote the rights and welfare of children; and
- o to investigate complaints made by or on behalf of a child concerning the administrative actions of public bodies, which have had, or may have had, an adverse effect on the child.

The Ombudsman for Children reports directly to the Oireachtas in relation to the exercise of these statutory functions.

1.2 Rationale for this Report

In 2020 we published an investigation into a little boy called Jack who suffered traumatic life changing injuries in a car accident when he was eight years old. Following six months of intensive medical interventions, and despite having no medical requirement to be there, Jack was left in a hospital bed for over two and half years because the HSE and Tusla initially failed to work together to support his family. When the family decided they could not care for him at home, the two state agencies failed to find a suitable placement for him.

Nearly three years on, we have found positive progress has been made in Jack's case² but unfortunately there are still other children with disabilities, like Jack, who are not getting the support they need to stay at home with their families. There are also children who for many reasons cannot be cared for at home, and are in hospital or in respite centres because of the lack of the much needed alternative placements to meet their needs.

The HSE failed to implement key strategic recommendations from our Jack investigation. This failure has resulted in children with disabilities being denied the opportunity to grow up with their families due to the lack of support. Parents often reach a crisis point due to that lack of support and seek alternative care to meet the needs of their child. However, due to the lack of strategic planning by the State to source a range of such places, these children are being left in hospital beds and respite services for far too long as there is no suitable service to meet their needs.

2 [Link to Jack's Case 2023 Update](#)

In this report we share stories from children and their families, from professionals in hospitals, special schools and residential centres about the impact that this failure is having. These stories include those of parents who made the devastating decision to leave their children behind in a desperate attempt to get the services they need.

We have produced this report on behalf of all children with profound disabilities in Ireland to call on:

- 1. The HSE to immediately implement all the outstanding recommendations from Jack's case.³ Not doing so is causing harm and distress to children and families.**
- 2. The Minister for Children, Integration, Equality, Disability, Integration and Youth and the Minister of State for Disabilities to set up an independent monitoring mechanism alongside the upcoming Disability Action Plan 2024-2026 to hold the State to account for their support of these children.**

1.3 People on the Ground

What we heard from families

We are deeply concerned that since our investigation into Jack's case was first published in 2020 we continue to get complaints about the on-going failure of the State to provide adequate services to support children with disabilities to grow up at home with their families. We have received a number of complaints concerning children with complex disabilities whose parents are struggling to cope with their needs. They have requested support from the HSE, but that help and support has not been forthcoming. Parents have told us how they have had to fight for supports for their children for years on end and that they feel, quite simply, they are no longer able to manage without proper backing from the State. We have also heard from parents of children with challenging behaviour who are causing injury and harm to themselves and their siblings, and how as they grow older and physically stronger, it becomes harder to safely care for them.

Some parents have felt they have no option but to leave their children in emergency departments or respite services in an effort to get them the services they need. Parents have also told us how they're too afraid to admit how exhausted and stressed they are because whenever they have, the HSE has referred them to Tusla and questioned their fitness to parent. While other parents say they've referred themselves to Tusla, due to the impact on their other children, in the hope of triggering the support they need for the child with the complex issues.

All these parents have presented as being loving, caring and deeply committed to their child. Even when a parent comes to the difficult decision that they can no longer care for their child full time, they have remained engaged and maintained an active caring role for them.

³ [Link to Jack's Case 2023 Update](#)

What we heard from schools

We met with Principals and teachers in special schools who have described the huge emotional impact on parents who struggle to cope without adequate services. One school said there were five children, in two years, left in the school by their parents because they were desperate to get support for their son or daughter. They have described incidents where parents have not returned to collect their children from school in the hope that by doing so, their children will get the help and support they need. This often happens when the parents have repeatedly asked for help over a long period of time and either none was forthcoming from the HSE Disability Services or, the help provided was simply not enough. They have told us about the emotional toll on parents, who have shared their fears and worries with them about their children and the future. Many parents hope that they will finally feel heard by services and will be properly helped and supported to care for their child at home. These parents see themselves as facing a “Sophie’s Choice” of keeping their child at home without proper and ongoing support or sacrificing the family life of their child in order to force the State to provide that proper and ongoing support to their son or daughter. That is an intolerable position for any parent to be in. The schools are clear that these parents are not abandoning their child, but rather, they are forcing the State to fulfil their responsibility to that child.

What we heard from hospitals

We receive complaints directly from medical staff in hospitals who describe the significant negative impact of prolonged hospital stays on children beyond medical need. They told us about the impact they see on children including:

- Anxiety and heightened behaviours
- Social isolation from wider family and friends
- Exclusion from school
- Distress at returning to hospital from a day centre
- Hospital acquired infections e.g. COVID, Influenza
- Frustration and upset when a child with a life limiting condition is in a hospital environment when they do not need to be there

Inter-agency working between the HSE and Tusla remains a problem in some areas. *The Joint Protocol for Interagency Collaboration Between the Health Service Executive and Tusla – Child and Family Agency to Promote the Best Interests of Children and Families 2020* was developed to ensure both agencies worked together to meet the needs of children with disabilities, including clear lines of responsibility and funding. After our investigation, acute hospitals were also included. We understand this protocol has worked well in many cases but is not being applied consistently.

In the course of our complaints work one hospital group told us that they do not believe the HSE/Tusla protocol is working as it has *“no teeth or resources assigned to it. There is no point in an escalation structure if it is resulting in the original managers trying to manage same”*. They believe funding and internal resistance should not prevent proposed innovative solutions to meet a child’s particular needs. In the most extreme examples, they told us about three children who spent 368, 205 and 107 days respectively, in hospital when they didn’t need to be there.

What we heard from local HSE Disability Managers

Local disabilities managers told us that in some areas, the HSE does not see it as its role to provide residential care to children and that there is still conflict/no agreement between it and Tusla over which agency should fund these placements.

There remains a view that it is the remit of Tusla to provide care for children if parents are not caring for them at home. Some managers have said they would love to be able to properly plan a child’s placement but that there is no funding available unless there is a crisis, for example when a child is either left by their parents in a hospital Emergency Department or in a respite placement. One manager felt that the HSE was ‘in denial’ about the issue and the increasing number of parents who say they cannot cope and refuse to take their child home. Managers believe there are also many children’s cases that could be planned for with adequate assessment and acceptance that some children will need to be cared for by the HSE outside of the family home. These managers also told us that there is simply no strategy in place to meet this need and plan accordingly.

2. Children's experiences

Shane: 8 weeks in hospital because he had nowhere else to go

Shane is a 14-year-old boy who is non-verbal with a severe intellectual disability and ASD. He was taken to hospital by his parents, as they saw it, for his own safety. They could no longer safely manage his extremely challenging behaviour at home and were very fearful that he would seriously harm himself or someone else. Shane had no medical needs that warranted hospital care. His parents told us that this was the second time they took Shane to their local hospital because, despite the increase in respite provided by the HSE, it was simply not enough to help keep him at home with them.

Shane remained in hospital for eight weeks before the HSE Disability Services found him a long-term residential placement. Nursing management in the hospital contacted us after he was there for four weeks as they were very worried about his well-being. They struggled to care for him due to his challenging behaviour and the risks he posed to himself and to others. He assaulted staff members and was cared for in a single hospital room where they had to secure the windows in case he hurt himself. From time to time, they had to revert to the extreme option of sedating him.

This also impacted on the care of other critically ill children and their families in the hospital. Nursing management expressed their deep frustration that not enough was done by HSE disability services at an early stage to prevent Shane's behaviour escalating and that he ended up in a hospital bed, which they described as the 'wrong place, wrong time, wrong care'.

Mark: No services and no support

Mark, is a 10-year-old boy who is non-verbal with a moderate to severe intellectual disability and ASD. He also suffers from severe anxiety. Mark is fully dependent on his parents for all aspects of his care; he needs help with dressing, washing, going to the toilet and feeding. He struggles with sleeplessness and often stays awake all night. When this happens, Mark's parents also have to stay awake with him to monitor him.

As Mark grew physically, it became increasingly difficult for his parents to manage him as he was lashing out at them and home support carers more frequently. This put a huge mental strain on Mark's whole family, including his siblings. His parents told us how they couldn't give enough care and attention to their other children and how it became increasingly difficult for them to do normal things like socialising, leading to them feeling more and more isolated as a family.

The family was initially approved for twenty hours of home support per week, which they never fully received especially once it was determined that two staff were needed to care for Mark due to his behaviour. His parent told us that they only had short periods of time with this support as there was no staff available. A new agency started providing Mark's home support but this service was ended abruptly by the HSE, leaving the family

with no home support service for six months. This put a major strain on the family and was very confusing for Mark.

The HSE recommended Mark should access a children's respite service but there were no local respite services in operation due to a lack of resources.

Mark's community disability team and CAMHS Consultant Psychiatrist assessed him as being in need of a residential placement. This was initially turned down by the HSE Disability Service but after Mark's family complained to the HSE and to us, the HSE told the family that they had sourced a residential placement. However, the family are still waiting for this placement two months later and have only 6 hours support per week, and that is all on a Saturday.

Emma: Living in a respite centre for 9 months as nowhere else to go

Emma is a teenager who has a mild intellectual disability and a diagnosis of high functioning ASD. This resulted in challenges for her family over the years in accessing necessary services and supports. Over time Emma's presentation and behaviour became more difficult for her family to manage. Her parents said Emma changed from being shy and withdrawn to very anxious, distressed and at times, aggressive. They said that they struggled to manage Emma's violent outbursts which were directed at both herself and her family.

Emma was known to her local HSE disability team for several years. Her case was brought to our attention by the manager of a respite service where she was living full-time after her parents made the difficult decision that they could no longer safely care for her at home. Emma remained living there for nine months, which limited other children accessing this much needed respite service.

This manager told us that Emma returning home was the only option considered by the HSE and that they struggled to convince them to consider alternatives. The respite service also brought Emma's case to the attention of Tusla, who determined that Emma needed an out of home placement and a range of supports.

However, the HSE resisted efforts by Tusla to work together on all of Emma's needs and questioned their assessment. They also refused to consider co-funding and resourcing a placement for Emma.

We contacted the HSE and Tusla to seek clarification on their separate and joint responsibilities to her under the *Joint Protocol for Interagency Collaboration between the HSE and Tusla (2020)*. Emma's case was then escalated by both agencies who agreed they would jointly fund her residential placement and review it after three months.

Lucas: Delays in accessing support and years fighting for respite

Lucas is 14 years old and has complex behavioural needs, Autism, ADHD and a moderate intellectual disability. Lucas is at times violent towards his mum, he has severe issues with sleeping and needs to be supervised at all times to reduce the risk of harm to himself and others. Lucas's mum told us that she has very little support from extended networks or family to care for her son. She has been his full time carer since Lucas was born and has been managing by herself since Lucas's dad passed away six years ago.

Home Support:

Lucas had been receiving four hours of home support a week for a number of years from a disability support service which had made a real difference to their family, however as Lucas's behaviour was complex and sometimes violent, this support eventually broke down. After this ended Lucas's mum was left to contact the Children's Disability Network Team (CDNT) who told her to go to the support provider directly. After a number of months of delays and back and forth between social workers in the CDNT and HSE Disability Services, Lucas's mum was told she was sanctioned for further hours once a provider accepted the package. However, six months after the original support broke down this still had not progressed.

Respite:

Lucas's mum had been trying to get respite for Lucas since 2017. She was initially told by Disability Services that none was available and home support was all that Lucas could get. As Lucas's behaviour became more complex and violent over the years she repeatedly tried, with the support of her social worker, to access respite. Eventually in May 2022, while taking a parenting course with the CDNT and telling them first hand of her challenges with managing and supporting Lucas's behaviour, a referral for respite was successful, and she was told Lucas was a priority for accessing this support. However, one year later, they were still waiting for that support to be put in place.

Lucas's mum made a complaint to the HSE about the delay in accessing support for Lucas, especially as all of the professionals agreed he was a priority. The 'Your Service, Your Say' Complaints Officer upheld the complaint, but noted that they could not make recommendations on cases, or do anything about waiting times.

Lucas's mum continued to really struggle without any support, and started to suffer from carer burn out.

We asked the HSE to outline the efforts they had made to secure home care and respite for Lucas, especially as he was identified as a priority. They told us they had contacted a number of providers but that no appropriate provider had the capacity to provide Lucas's care.

A number of weeks later the HSE contacted Lucas's mum to say that a provider had agreed to create a home package and that it would begin the following week.

Lucas's mum told us what a huge relief this was for her and her son, and how they went twice to view the accommodation and meet staff. A huge amount of planning had gone into making the best of the respite and ensuring Lucas felt safe and comfortable during his stay and he was very excited.

However, less than a week before the respite was due to start, the care provider told Lucas's mum that due to an emergency admission into the service, they would have to cancel Lucas's respite. They could not tell her when it would be re-arranged. Lucas's mum told us how devastating this was for her and her son.

The OCO re-engaged HSE Disability Services and outlined the adverse impact this cancellation was having on Lucas, who had already been waiting years for support. Just over three weeks later the respite was re-arranged, which Lucas's mum told us has been '*life changing*'. She said it allowed her to '*recharge*' and helped Lucas to become more independent and confident. She told us that the respite had strengthened her and Lucas's relationship, had reduced stress levels and allowed her to care for Lucas with more patience. While she is hoping that the further respite committed to by the HSE will be arranged and followed through on, she is worried that future plans for support could once again be cancelled last minute.

3. Rights Concerns

The stories of the children we have outlined in this report highlight the significant barriers they face to the full enjoyment of their rights.

The HSE has several statutory responsibilities with respect to the provision of family supports in the home, respite care and residential placements. Article 42A.1 of the Irish Constitution recognises and affirms the natural and imprescriptible rights of all children, and the State as the body responsible for the vindication of those rights.

Ireland's ratification of both the United Nations Convention on the Rights of the Child (UNCRC) and United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) also creates further obligations for the State when designing services for children with disabilities and their families.

We note a relevant ruling in 2021 against the HSE in a High Court case concerning a child placed in hospital for a protracted period of time when she could not be accommodated safely in her family home.⁴ Despite repeated assurances – including by Taoiseach Leo Varadkar, who was Tánaiste at the time – at the time of judgement no onward placement had been sourced. Mr. Justice Max Barrett ruled that the manner in which Ms X had been accommodated was unlawful, in that the placement in hospital was not in her best interests, was detrimental to her welfare, and represented a disproportionate and unlawful interference with her constitutional and human rights. In closing his judgement, Mr. Justice Max Barrett noted that:

“The court recalls the promise, pointed to in the Proclamation of Independence, of a republic that would cherish all the children of the nation...the court cannot but observe that Miss X [could] be forgiven if she does not feel greatly cherished by the republic at this time.”

3.1 The right to grow up within their family

A child's right to grow up within their family is protected under a number of rights frameworks. But as highlighted in this report, is not realised for some children with disabilities and their families who cannot access the adequate or sufficient support for them to remain living at home.

Article 41.1 of the Irish Constitution recognises the family as the natural primary and fundamental unit group of society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law. The State, therefore, guarantees to protect the family in its constitution and authority. This is also reflected in Article 8 of the European Convention on Human Rights.⁵

⁴ High Court case of Ms Y and Miss X v. The Health and Safety Executive (HSE, 2021).

⁵ Council of Europe (2010), *European Convention on Human Rights*.

The right to family life is also recognised in many of the international human rights instruments, including the UNCRC and UNCRPD. The importance of the family in the lives of children underpins many of the provisions in the UNCRC. ⁶

Article 23(3) of the UNCRPD states that:

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

Article 23(4) obligates State Parties to ensure that a child with disabilities is not separated from his or her parents against their will or when there are no reasonable grounds in law.

As highlighted in previous OCO reports⁷, there is a broad consensus across the rights frameworks and professionals that children’s interests and rights are generally best protected within the family environment.⁸ The importance of parents and family to a child’s development and well-being has been widely accepted in research.⁹ Children have also voiced, as fundamental, the importance to their well-being of having a family and relationships with significant others.¹⁰

We know without the proper support, parents and carers can be placed under significant stress. A 2016¹¹ report on family carers’ experiences of caring for a person with an intellectual disability, documented that parents and carers of children with intellectual and developmental disabilities also experience higher levels of stress in parenting and increased risk of poor physical health. This research also highlighted that prolonged carer stress can have other significant consequences for a family and for the child with an intellectual disability, leading to an increased risk of marital problems and family dysfunction. Mothers of children with an intellectual disability are much more

6 For example, Article 7 protects the right of the child to know and be raised by their parents, Article 9 enshrines the right of a child who is separated from one or both parents to maintain regular and direct contact, and Article 18 acknowledges that parents have the primary responsibility for the upbringing and development of the child.

7 Moloney, C. et al. (2021) *Mind the Gap: Research on barrier to the realisation of rights of children with disabilities in Ireland*. p.54.

8 Kennan, D. and Keenaghan, C. (2012) *Children’s Rights and the Family: A Commentary on the Proposed Constitutional Referendum on Children’s Rights in Ireland*. p.7.

9 Munro, E. (2011) *The Munro Review of Child Protection Interim Report: The Child’s Journey*.

10 McAuley, C., Morgan, R. and Rose, W. (2010) ‘Children’s views on child well-being’ in *Child Well-Being: Understanding Children’s Lives*.

11 Attracta Lafferty et al. ‘Family carers’ experiences of caring for a person with intellectual disability’ (Dublin: University College Dublin, 2016) 29-32.

likely to experience higher levels of anxiety and depression and families of children with an intellectual disability may also experience other problems such as increased financial strain. The Cost of Disability in Ireland report in 2021, found that people with disabilities face significant extra costs that are not covered by existing programmes or social welfare payments.¹² For those with severe disabilities these costs on average ranged from €9,600 - €12,300 per year, and for those with limited disabilities from €8,700 - €10,000.

With the proper supports in place for a child with disabilities at home, they should never have to stay in inappropriate places like hospitals without medical need or residential respite centres. It is essential that the State provides the full range of resources that parents of children with disabilities need to support their care giving role. This includes supports such as intensive home care packages at a time of crisis, adequate home-help supports, regular and as needed, respite breaks, as well as practical supports such as aids and equipment. Children with disabilities also need a range of primary care services in order to maintain their mental and physical health to improve their quality of life and maximise their potential.

Respite services are critical for family carers and need to be consistently provided and adequately resourced in all parts of the country. The need for urgent investment in respite services was previously flagged by the OCO in our investigation into a young girl called Molly who was in foster care and had a disability.¹³ At that time, the OCO urged the HSE to invest in respite services. In 2020, as part of the follow up to that investigation, the Ombudsman for Children continued to challenge the slow rate of change in this essential area stating:

“There is no doubt that respite and intensive family support is essential to ensure these children grow up in a family environment and are not placed in institutions such as residential care. I believe this area demands the attention of both agencies and departments with due regard to the right of every child to grow up in a family environment. This is in accordance with article 23 of the UN Convention of the Rights of People with Disabilities which state that agencies shall ensure that children with disabilities have equal rights with respect to family life.”¹⁴

12 <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report>.

13 <https://www.oco.ie/app/uploads/2018/01/OCO-Investigation-Mollys-Case-Jan-2018.pdf>.

14 <https://www.oco.ie/app/uploads/2020/01/Molly-Two-Years-On.pdf>.

In June 2023, Family Carers Ireland called for a comprehensive national audit to evaluate the availability of respite places throughout Ireland after new Census figures revealed a marked increase in the number of people identifying as family carers. This proposal was to shine a light on both the existing needs of family carers and the many gaps in services, ultimately paving the way for an actionable plan to enhance support for this vital group.¹⁵ The latest figures from the Health Research Board also show that overnight respite is required by 1,300 children and adults.¹⁶

While the HSE National Service Plan 2019 committed €10 million to respite services, they didn't outline how much of this would go to children. Therefore, it is vital that the Government's Disability Action Plan 2024-2026 due to be published in the Autumn of 2023 should include a ring fenced figure for children's respite services.

3.2 If children cannot stay at home: The right to safe and suitable care

It is important that the State has a range of alternative placements for the short, medium and long term to meet the needs of these children who are unable to stay at home with their family. The focus should be on providing family centred care rather than residential care, but a range of options are necessary. This right is reflected in Article 23 (5) of the UNCRPD, which provides that where the immediate family is unable to care for a child with disabilities, State Parties should provide alternative care within the wider family or – failing that – seek to place children within the community in a family setting. In their General Comment No.9, the Committee on the Rights of the Child was explicit in urging State Parties to undertake deinstitutionalisation programmes, supporting children to live with their family, extended family, or in foster care. Adequate legislative measures must also be taken to facilitate the care of children with disabilities in the home environment.

Sweden has been identified as a country that has made good progress towards deinstitutionalisation.¹⁷ During the 1990s legislation made it illegal to care for children in institutions. By 2000, institutional services were eliminated. However, it was found that there was a need to have a small number of residences for short-term care arrangements.¹⁸

When a child's own family is unable to provide adequate care for the child, even with the provision of support, alternative family and community-based forms of care are more likely to meet a standard that upholds the rights of children than residential care institutions.¹⁹ Ireland must identify and plan for the needs of these children to ensure there is an adequate range of placements.

15 <https://familycarers.ie/news-press-releases/2023/june/urgent-audit-of-respite-provision-required-as-census-figures-highlight-rising-number-of-family-carers>.

16 <https://www.hrb.ie/news/press-releases/single-press-release/article/disability-services-hrb-reports-latest-figures-on-current-use-and-future-demand/>.

17 Health Service Executive, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion Annual Progress Report 2018* (Dublin, 2018).

19 Ibid.

19 Council of Europe (-) *Alternative Care* [Accessed 15.5.23].

What needs to change?

- 1. The HSE to immediately implement all of the outstanding recommendations from Jack's case. Not doing so is causing harm and distress to children and families.**
- 2. The Minister for Children, Integration, Equality, Disability, Integration and Youth and the Minister of State for Disabilities to set up an independent monitoring mechanism alongside the forthcoming Disability Action Plan 2024-2026 to hold the State to account for their support of these children.**

In our investigation into Jack's care we made a number of recommendations to the HSE to address the systemic issues we discovered as part of our investigation. The failure of the HSE to implement key systemic recommendations as summarised below is having a detrimental effect on children and families as outlined in this report. We asked the HSE to:

- o Develop a holistic assessment process to determine the needs of the child and then provide a specific support package to address the identified issues
- o Ensure there are a sufficient range of appropriate services and ring-fenced funding to support the right of children with disabilities to grow up at home with their families
- o Undertake a national review of the current need for alternative care for children with disabilities whose parents or carers are assessed as being either not willing, or not able, to provide for their ongoing care and develop a strategic plan to address same. This review must include children placed in inappropriate settings such as hospitals and respite centres.
- o The HSE and TUSLA with the Departments of Health and the Department of Children, Equality, Disability, Integration and Youth, agree actions to address the shortcomings identified in the current Home Sharing in Intellectual Disability: Report of the National Expert Group (2016) as they relate to children

We have published a 2023 update on our investigation into Jack's Case, which provides a more detailed analysis of the actions and or inactions by the HSE to these recommendations and can be accessed here (insert link).²⁰

It is essential that the HSE ensures there is an adequate governance system in place to guarantee the full implementation of these recommendations to prevent further distress to children and families.

²⁰ Link to Jack's Case (2023 Update)

Independent monitoring of the upcoming Disability Action Plan 2024-2026.

The Government has committed to providing a range of supports under the Disability Act 2005 and its provision for an assessment of need for people with disabilities, the National Carers' Strategy²¹, the First 5 Government Strategy²², particularly in the context of supporting babies and young children with disabilities and their families, and through the range of income supports provided for families caring for a child with disabilities.²³ However it is clear from the complaints we receive from families of children with disabilities that there are still major deficits in the provision of these supports and services despite these various strategic plans and commitments.

Therefore, we believe it is vital that that the Government's Disability Action Plan 2024-2026, which is due to be published in the Autumn of 2023, also has a robust, independent accountability mechanism to ensure its actions are implemented. We understand that this plan represents a key step in the expansion and reform of specialist community-based disability services including day services, respite and residential services, personal assistance and home support, as well as multidisciplinary therapy interventions for children and adults.²⁴ We also understand it was informed by the Disability Capacity Review to 2032 – A Review of Social Care Demand and Capacity Requirements to 2032 which set out the extra capacity requirements for community disability services up to 2032, based on an analysis of demographic trends and unmet need. The expectation is that it will have key priorities including actions to Increase capacity of the Children's Disability Network Teams, increased home support hours, increasing capacity for planned residential placements and expansion of respite provision.

The independent oversight monitoring mechanism that we are proposing should measure progress against the actions and timelines of the Disability Plan, flag any concerns to the relevant Ministers and publish independent reports.

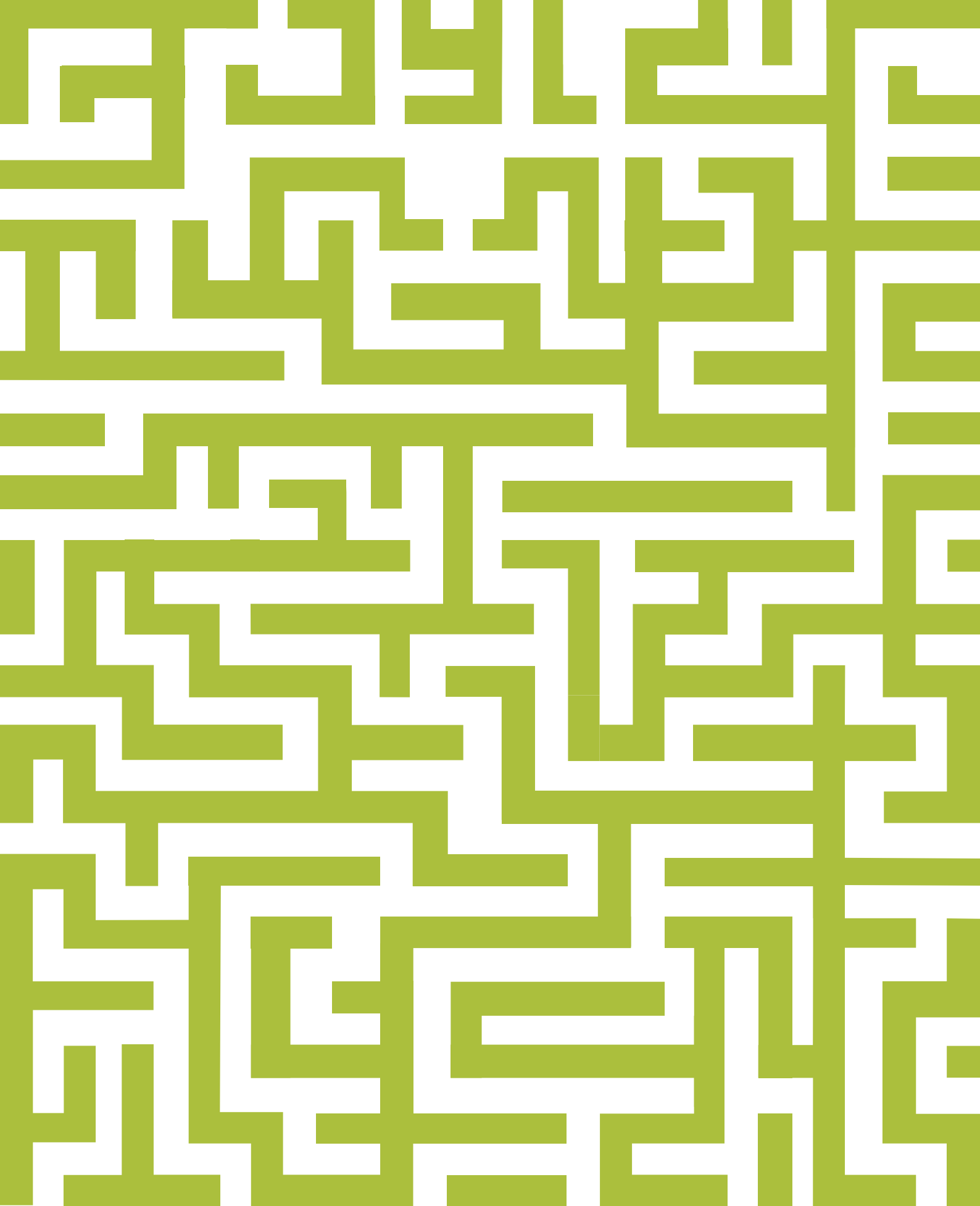
There have been simply too many plans and not enough action. These children deserve better.

21 Department of Health, *The National Carers' Strategy – Recognised, Supported, Empowered* (Brunswick Press Ltd).

22 Government of Ireland, *First 5 – A Government Strategy for Babies, Young Children and their Families 2019-2028* (Dublin, 2019).

23 For example, the Carers Benefit, the Carers Allowance and the Domiciliary Carers Allowance.

24 <https://www.oireachtas.ie/en/debates/debate/dail/2023-05-30/13/#:~:text=Fewer%20people%20received%20respite%20services,only%20a%20third%20of%20adults.>



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