



Jack's Case: 2023 Update

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ombudsman
do leanaí
for children

Jack's Case: 2023 Update

In 2016, Jack suffered brain damage and other significant life changing injuries in a road traffic accident and needs 24/7 care in all aspects of his life. Jack, who is now 11 years old, spent two and half years in hospital when he should have been discharged. The HSE and Tusla could not work together to find a placement for him. In 2020 Jack was placed with a host family.

Now Jack is

- ✓ Thriving with his host family
- ✓ He is an integral part of the local community where he lives
- ✓ Going to special school, which fully meets his educational needs
- ✓ Attending respite every second weekend
- ✓ Goes to social events like family weddings



Jack's host family intend to care for him for as long as they can, but know there may come a time when his needs are too great for them. The HSE has assured them that a residential placement will be sourced for Jack if this happens, close to his host family.

Jack's mother is also very happy with the care Jack is receiving and she continues to have access with him on special occasions

In November 2020 the Ombudsman for Children's Office published its investigation into the care of Jack*¹, an eight-year-old boy, who was first referred to the HSE Disability Services when he was 4 years old.

Jack suffered brain damage and other significant life changing injuries in a road traffic accident abroad in 2016, resulting in him requiring 24/7 care in all aspects of his life. Following the accident Jack's mother returned to Ireland with him where he was admitted to hospital immediately. Despite being cleared by his doctors to be discharged from hospital, Jack remained living between different medical settings for two and a half years.

We investigated Jack's case and found that this was due to the failure of the HSE Disability Services and Tusla, the Child and Family Agency, to work individually and collectively to meet his needs. We highlighted systemic failures by the HSE to provide adequate support and services to children like Jack, with disabilities, who were living in inappropriate settings. They told us they were aware of the need for increased funding for early intervention support and services for families to support children to be cared for at home. They also recognised that some children may need residential care.

In order to address the issues that arose in Jack's case, and to ensure other children across Ireland are not similarly impacted, we made a number of recommendations to the HSE and Tusla. They accepted our findings and recommendations, and provided a detailed action plan and commitments at the time. In March 2022 we published *Jack's Case: One Year On* which reported on how well Jack was progressing since we

¹ Jack is a pseudonym.

completed our investigation and how the HSE were progressing the development of services for other children with disabilities in line with our recommendations.

Jack's Case: 2023 Update is our second follow up report into his case and we have found that Tusla has implemented all of our recommendations. However, the HSE has failed to fully implement five out of our six recommendations, and these continue to have a devastating impact on children and families today.

We are publishing this statement alongside our **Nowhere to Turn**² report, where we share some of the complaints we have received from other parents of children with disabilities since our investigation into Jack's case to show how Ireland, in 2023, treats some of its most vulnerable children.

2 [Nowhere to Turn link here](#)

Recommendations not fully implemented by the HSE

OCO Recommendation 1:

The HSE should review all cases where a child remains in hospital settings beyond medical need to ensure adherence to the relevant legislation, policy and guidance documents and provide this office with that information

The HSE told us that in the Autumn of 2022 they brought together key stakeholders to bring a coordinated focus on challenges for service provision for children with mental health, disabilities and/or complex needs. At that time, they intended to develop and implement a plan to improve access to care for these children. They told us about challenges in terms of funding, finding / contracting private providers and how difficult it is to find accommodation during a housing crisis. They also said that a severe shortage of staff was impacting the provision of disability services for children and that they were actively working on workforce planning, recruitment and retention.

Update 2023

The HSE still does not have a comprehensive plan to address the issue of children staying in hospital beyond medical need. As of October 2022 there were 39 children in that situation, with 35 in Children's Health Ireland at Temple Street, Crumlin and Tallaght hospitals beyond medical need and four other children in regional hospitals.

The HSE have now committed to undertake a national audit of all children delayed in hospital the week commencing the 11th September 2023 to assess the number of children whose discharge is delayed, reason for same and duration of the delay and remedial actions needed. They agreed to submit this report to the OCO. They have also agreed to adapt their current internal tracking system to allow easy identification of children in hospital and the period of their delay to allow active monitoring nationally of trends.

The HSE told us there is weekly engagement with the CHI hospitals in Dublin to consider children with Disability or Mental Health diagnoses and their ongoing placement, recognising these are dedicated children's hospitals. However, the HSE now intends to reinforce with all Hospital Group CEOs and Chief Officers the importance of children, whose transfer of care has been substantially delayed being escalated to the most senior levels for action and review.

OCO Recommendation 2:

Children with significant disabilities require a coordinated integrated approach in assessing their needs. We recommended the HSE Disability Services devise a framework for a holistic assessment of both a child, and their family's, circumstances. This should facilitate a determination in the first instance, of the viability of a return to, or shared caring arrangements with their family or extended family. Those assessments must then be followed by specialised bespoke care and support packages to address the identified issues.

The HSE told us that by the end of Q4 2020, they would have a new framework for a holistic assessment of children who are deemed to have been inappropriately placed or remain in hospital settings.

Update 2023

This assessment framework is still not in place. The HSE told us there is a draft Assessment Framework, “Guidance and Framework for the Case Management of Children with Complex Needs in Hospital Beyond Medical Need” in a final consultation stage with all stakeholders and is due to be completed by the end of October 2023.

OCO Recommendation 3:

We recommended that the HSE Disability Services nationally engage with the Department of Health to agree strategic actions to 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.

The HSE told us there is a significant shortfall in funding to provide support services and alternative services for children with disabilities. The information from the HSE reflects funding for alternative places for children i.e. residential care. The current National Disability Tusla database lists 272 cases in total. Only 105 of these cases are currently fully, or partially, funded by the HSE to the cost of approximately €29m. The other 167 cases represent a potential future cost of approximately €40.5m for 2024.

In addition to those children, the HSE state that, as of October 2022, there were 448 applications for non-residential service and 75 for residential services. No information about funding or costs were provided for these children's respite, home care or other support packages.

Update 2023

The HSE told us that the Disability Action Plan, to be published in September 2023 by the Department of Children, Equality, Disability, Integration and Youth, will set out a substantial scale of investment to meet the needs of disabled people, including the needs of children. It will include the potential for planned development of services

including residential services, centre-based respite, alternative respite options such as home-sharing, as well as the implementation of the actions included in the Roadmap for Service Improvement.

The HSE also told us that these include several immediate actions that will benefit children and their families including a tender for alternative care options, greater supports for children attending special school, improved access to Children's Disability Network Team Services and improved implementation of the National Access Policy.

The HSE told us that the biggest challenge over the coming years is the availability of vital staff members, particularly in agencies being funded to provide these services under Section 39 of the Health Act 2004. The HSE hope that the HSE Resourcing Strategy, developed in 2022, will help increase the workforce supply with enhanced training places but this will take time and resources will be prioritised for children's services with the greatest need.

OCO Recommendation 4:

We recommended that the HSE Disability Services 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. The outcome of this analysis should inform a strategic plan to address same.

A draft report by the HSE called 'Supporting Children with Complex Needs at Risk of Social Admission' was shared with the OCO in August 2022 that included useful recommendations and analysis, but lacked any specific targets or timeframes. More recently the HSE told us the report is still being discussed and had not yet been agreed on with key stakeholders.

The HSE has always maintained, through its engagement with the OCO, that residential care is provided for children only in the most exceptional of circumstances and that, as such, their focus in completing this review would be on services to prevent children coming into residential care. The OCO fully agrees that alternative care and in particular residential care, should be a last resort. However, it is clear that there is now a small, but significant cohort of children with disabilities who can only get the supports they need within residential care. It is incumbent on the HSE to consider how best to meet and plan for this need and we remain concerned that there is still an over reliance on the private sector to do this.

Update 2023

The HSE has not completed this review of need and there is no strategic plan in place to address these issues. The HSE told us that they anticipate this review will be completed by the end of 2023 and will consider what services, alternative to a residential placement, may be required to maintain such children within their family home. It includes:

- a review of the academic literature relating to the definition of disability
- risk factors for Emergency Department presentation and/or hospital admission and stay beyond medical need
- a review of related data from front-line services relating to such children and what alternative service elements might maintain such children in their family home
- makes service-related recommendations that will promote same.

They further advise that once this review is concluded and agreed with relevant stakeholders, it will provide a direction for social admissions.

We note this review still fails to address the issue of the range of placement options if a child cannot remain at home. We remain extremely concerned that children are still spending significant periods of time in hospital beyond medical need and that the HSE has continued to place children in alternative care settings in the absence of any clear evidence based strategy.

The HSE also told us that they continue to develop respite services and is committed to using the available budgets for the provision of both centre-based and alternative respite services. However, we note that parents continue to contact us about the lack of adequate or indeed any respite services in their area and the impact this is having on their children and their family.

OCO Recommendation 5:

The HSE complaints procedure is specifically related to service users. In Jack's case a complaint was being made by professionals in one part of the HSE (acute hospitals) in relation to another part of the HSE (disability services). A new protocol should be put in place to manage disagreements and complaints between the HSE disability services and acute hospitals. Specifically, this should reference courses of action in relation to delayed discharges of children from medical settings.

There is a new HSE/Tusla Joint Protocol which includes a clear pathway as to how disagreements and complaints between different HSE services are managed including delayed discharges of children from medical settings.

Update 2023

The HSE advised us in August 2023 that a review is being undertaken in relation to the functioning of the Joint Protocol which will seek to address the issues raised in relation to its effectiveness. In the interim, they told us that Community Operations (Disability, Mental Health and Primary Care) continue to support local decision makers in relation to difficult cases, including early decision making in approving expenditure, engagement with Providers, cross-care group problem solving and supporting service responses. The HSE did acknowledge that this needs to be broadened out in some cases where acute hospital services are involved.

The HSE state that there are clear escalation pathways to resolve onward placement issues. However, we found the protocol has been implemented in some areas but not in others. Where it has been implemented it has worked very well but this has not been consistent and children have remained in inappropriate placements for long periods of time.

OCO Recommendation 6:

We recommended that the HSE should, in conjunction with the Department 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.

The HSE told us that while regulation in the area of Home Share is a key concern for them, the decision to legislate is one for Government. The HSE and the Department of Health told us that a multi-stakeholder implementation group for the Home Sharing in Intellectual Disability: Report of the National Expert Group (2016) is being devised. It is concerning to us that it is only being devised seven years later.

According to the HSE, there are currently 180 children availing of these placements. For most children these placements offer respite / short-breaks, however there are a small number of children who, like Jack, are placed in full-time home sharing placements.

There are also a significant number of young adults who have either transferred from the foster care system to home sharing programmes or are due to transfer in the coming year. The potential benefits of these placements for children with disabilities, and indeed their families, cannot be overstated. The opportunity to live in a family based setting is the next best alternative when a child can't be taken care of by their own family.

Equally, the OCO fully recognises and supports children with disabilities remaining with their foster families into adulthood if this is assessed to be in their best interests.

Update 2023

The National Disabilities Office told us it now has a fully established Working Group from June 2023 to progress this as a priority, including the development of a proposal for inclusion in the 2024 National Service Plan. The proposal provides for additional resources of €5.17m to grow, expand, and strengthen Home Sharing Services and set up 325 new placements (65 new Shared Living and 260 new Short break). It also includes the recruitment of additional social workers and coordinators to ensure the necessary oversight of the current and new development. Increasing capacity in this sector will provide an alternative option for respite and costly residential placements, and would support individuals to benefit from a family environment and community setting.

We remain concerned about the prolonged delay in implementing this recommendation. It is even more distressing in light of the ongoing inquiry into the abuse of 'Grace' a disabled girl who remained in her foster placement into adulthood without any formal oversight of the arrangement.

Conclusion

We believe that Jack's care since being placed with his host family in 2020 should be the rule, and not the exception, for how children with disabilities are cared for by the State. Jack continues to go from strength to strength as part of his host family. He is going to a school that fully meets his educational needs, is attending respite every second weekend and he still has regular, positive contact with his mother and sibling. We are also reassured that if there ever comes a time when Jack's needs may become too great for his host family to manage, a plan will be put in place for Jack to stay close to them.

Jack's case has become a real example of what can be achieved when the HSE and Tusla fully cooperate with each other and work in tandem on a child's care plan. However, we remain concerned that this is still not the case for all children with disabilities across the country. The OCO has continued to receive complaints from parents of children who have desperately tried to access the adequate supports and services they need. The recommendations following the Jack investigation were far reaching and intended to support every child's right to grow up within their families at home. However, nearly three years later, we are extremely concerned that there are recommendations still to be implemented and we urge the HSE to do so to avoid further distress to children with disabilities and their families.

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