



# Jack's Case: One Year On

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March 2022



ombudsman  
do leanaí  
for children

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Jack suffered brain damage and other significant life changing injuries in a road traffic accident. He needs 24/7 care in all aspects of his life. Jack is now nine years old.

Jack 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 he was placed with a host family

Now Jack is

- ✓ at school,
- ✓ has his own accessible bathroom,
- ✓ can sit-up,
- ✓ can communicate better
- ✓ and is getting respite.



In November 2020 the Ombudsman for Children's Office published its report on the investigation into the care of Jack\*, a nine-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.

In January 2018 the OCO was alerted to Jack's case after being contacted by the hospital multi-disciplinary team. They were concerned about how long it was taking for a package of supports to be put in place for Jack by the HSE so that he could be discharged from hospital. Despite being cleared by his doctors to be discharged from hospital in 2017, Jack remained living between different medical settings for two and a half years.

During this time a referral was made to Tusla, the Child and Family Agency, by a medical social worker as Jack's mother expressed concern that she would not be able to properly look after him at home. This referral was rejected by Tusla along with follow up referrals by a medical team, on the grounds that there were no child protection concerns and that Jack's case was a matter solely for the HSE.

In February 2020, the HSE under the auspices of a disability service run by a charitable organisation, placed Jack in the care of a host family.

We investigated Jack's case and found that the administrative actions of both the HSE and Tusla had a negative impact on his life. After Jack was deemed medically ready for discharge from hospital in August 2017, he remained living between two hospitals and a specialist community respite setting for two and half years due to the failure of the HSE Disability Services and Tusla to work individually and together to meet his needs.

The OCO believes that if the HSE and Tusla had worked together at an early stage Jack may have had the opportunity, with adequate support, to grow up with his family. Even if it was not possible for him to return home, he could have been moved sooner to a more homely environment and even gone to school. We were also concerned that Jack's eventual placement with a host family by the HSE Disability Services was made without any legal or formal regulatory framework or proper authority.

We found that Tusla should have completed an initial assessment on Jack and his family when they were informed by the medical social worker and medical team about their concerns and the potential risks and harm to him. They refused on the basis that these were issues for the HSE Disability Services, and that Jack did not meet their threshold for care. It is our view that this decision was unduly informed by Jack having a disability.

Finally, this investigation 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 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 provided a detailed action plan and commitments at the time. This report outlines how life is for Jack now, and what progress has been made on implementing the recommendations.

## 2021 Update on Jack

Jack is thriving since we last met him.

During our investigation in 2018 Jack had no educational supports and was essentially isolated from contact with other children. He remained lying prone for long hours in different hospital settings. Both his consultant and his mother told us that since November 2019 they noticed a deterioration in Jack's health and overall well-being and were gravely concerned about him.

In December 2021 we met with Jack in his host family's home. Jack has now been living with his host family for in excess of 18 months and is clearly benefiting from being placed in a family environment where he is afforded consistent, high quality care which fully meets his needs. He has his own decorated bedroom with en-suite bathroom which is fully wheelchair accessible and he has lots of toys that suit his needs. The professionals working with Jack report a significant improvement in his health which coincided with his move to the host family placement.

Jack had previously been unable to sit upright but he is now sitting upright for up to 5 to 6 hours at a time. Although Jack is non-verbal, he is much more able to communicate his preferences through facial expressions, movement and vocalisations. His host family carer told us that she regularly plays music to Jack and Jack can make her aware what songs he enjoys and which ones he dislikes. Jack can also communicate if he is in discomfort, such as if he has been too long sitting in an upright position or if he is experiencing pain.






Jack is now attending school 5 days per week and has his own class mates. He recently made his First Holy Communion and his host family showed us photos and told us that he received cards from relatives, friends and even neighbours in the community, who have gotten to know Jack.






His respite care facility was closed for a period in 2020 due to the pandemic but it has since resumed respite every second weekend and the host family feel this level of support is sufficient for them. Jack's host family have an allocated social worker through the local non-statutory disability service provider and her remit is to oversee and support home sharing placements for children and adults with intellectual disabilities. Jack's mother also has support from Tusla to help facilitate and sustain contact.

Jack's host family carers intend to apply for legal guardianship of Jack with the support of Tusla and the HSE. Jack's mother is reported to be fully supportive of Jack's placement with his host family and in agreement that it is Jack's best interests for them to be granted guardianship. Jack's mother can see Jack when he attends respite as the respite centre is close to her home and she keeps in contact with Jack.

# Update on Recommendations and Commitments

As a result of our investigation, both the HSE and Tusla made a number of significant and ambitious commitments. Below we have outlined the main recommendations made in Jack’s case, the commitments made by the HSE and Tusla, and what has happened since. We recognise that these commitments were made before the pandemic which demanded an immediate and urgent response by both agencies in the past two years.

Recommendations	
<p><b>1. Plan for Jack</b></p> <p>All relevant stakeholders remain involved in Jack’s care. Jack is thriving living with his host family.</p>	
<p><b>2. Review all cases of children in hospital settings beyond medical need</b></p> <p>HSE now closely track and actively seek resolution to the small cohort of children who remain in hospital beyond medical need but still a small number of children without medical need remain in hospital for an unacceptably long length of time.</p>	
<p><b>3. Framework for holistic assessment of a child and family’s circumstances</b></p> <p>The HSE says the guidance framework is still going through the approval process. Concern remains over the significant delay in implementation.</p>	
<p><b>4. Ring-fenced funding to support the right of children with disabilities to grow up at home with their families</b></p> <p>A multi-annual budget is urgently needed for this cohort of children but in the interim, an adequate package of funding including a value for money analysis should be put in place.</p>	
<p><b>5. National review of the need for alternative care for children with disabilities.</b></p> <p>The HSE says a national review has not been finalised and no report has been produced. However, the HSE told us that there are 529 children with disabilities with active applications for services such as support hours, respite services and residential care.</p>	

Recommendations	
<p><b>6. A new protocol needed to manage disagreements and complaints between the HSE disability services and acute hospitals. In particular for cases of delayed discharges.</b></p> <p>The HSE says acute hospitals have been actively involved in managing all cases where there are children in acute hospitals beyond medical need alongside the HSE and Tusla.</p>	
<p><b>7. Guidance needed for all social work areas so that child protection and welfare referrals about children with disabilities are assessed and managed the same as all other referrals.</b></p> <p>The integrated governance structure for the escalation of any issues is now operational. Guidance issued and communicated to all social work areas and Tusla staff.</p>	
<p><b>8. Review of the initial assessment process to ensure children with disabilities whose parents and carer's are unable or unwilling to provide for their care, are not discriminated against.</b></p> <p>A key priority for Tusla is to ensure a consistent approach to children that are not subject of harm, but have high needs relating to care and support services.</p>	
<p><b>9. Jack's current host family arrangement should comply with all safeguarding requirements under Children First: National Guidance</b></p> <p>There are no concerns regarding the host family placement. HSE say it is compliant with the requirements under Children First: National Guidance and is comparable to that of children in foster care. However home sharing remains unregulated.</p>	
<p><b>10. Address the shortcomings identified in current Home Sharing arrangements</b></p> <p>The OCO remains deeply concerned that while the care of children in foster care is subject to legal regulations and inspection by HIQA, home sharing remains unregulated.</p>	

# Recommendations to the HSE Disability Service

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## OCO Recommendation 1:

***Without delay, the local HSE disability team should convene a multi-disciplinary meeting to include all services involved to date with Jack, and his family. They must agree a plan to meet his needs which upholds his rights and is in his best interest. This plan should be regularly reviewed and the HSE should ensure that an adequate ring-fenced budget is set aside to meet Jack's needs annually based on his most up to date plan.***

In response to this recommendation the HSE told us that the local HSE Disability Services convened two inter-disciplinary meetings, a formal care plan for Jack was in place and all agencies were working together to address Jack's needs and those of his birth mother and host family. Tusla allocated a liaison person to Jack's mother through their family support Meitheal service and there was an individualised budget to meet Jack's equipment and other needs.

## Update 2021

The HSE told us that all relevant stakeholders remain involved in Jack's care, with regular multi-agency meetings taking place. They told us that services continuing to support Jack include:

- The local Children's Network Disability Team (CDNT) from whom Jack receives Physiotherapy and Occupational Therapy supports on an ongoing basis.
- The local Public Health Nursing service who continue to provide support around continence and other related issues.
- The disability service provider with charitable status who provide respite on alternate weekends.
- The children's service who also provide respite for 15 nights per year.
- Special School with transport provided by the Department Of Education.
- His Paediatric Consultant and a Clinical Nurse Specialist 3 in a Children's Health Ireland hospital (whose care he is under).
- A children with life limiting condition organisation.
- The HSE noted that Jack is reported to be thriving living with his host family and no concerns have been noted.

## OCO Recommendation 2:

***HSE disability services should immediately systemically 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 and Tusla informed us that the HSE acute hospital services would be added as a joint signatory to version two of the 'HSE/Tusla Joint Protocol for Interagency Collaboration between the HSE and Tusla – Child and Family Agency to Promote the Best Interests of Children and Families' (2017).

They told us that this revised protocol would note that, in partnership with the Child and Family Agency, the HSE Community Operations and Acute hospital services will commit to reviewing all cases where a child remains a hospital setting beyond medical need to ensure adherence to the relevant legislation, policy and guidance documents. As such, both agencies committed that the protocol would be expanded to include the acute hospital services.

### Update 2021

The HSE provided us with a copy of the revised HSE/Tusla joint protocol which was finalised in April 2021 which now includes the Acute Hospitals sector.

HSE told us that they now closely track and actively seek resolution to the small cohort of children who remain in hospital beyond medical need. The HSE provided us with a copy of their most recent audit, dated 1st October 21 at which time, there were 10 children in the hospitals throughout the country beyond medical need.

It was evident from the audit that many cases are being resolved quickly with the cooperation of all agencies through putting support packages in place to enable children to return home where possible. It is also notable that if a full-time return home is not possible perhaps due to difficulties in securing the supports required for this to happen, efforts were being made to ensure children spent as much time as possible at home. Children's Health Ireland told us that while communication between the agencies have improved since the report was published there is still some children inappropriately remaining in an acute hospital setting due to a lack suitable services.

The HSE informed us that while they, with Tusla, have worked proactively to meet the needs of children in acute hospitals beyond medical need, it has proved challenging at times to source appropriate supports for them (e.g., highly specialised and bespoke residential care placements or qualified paediatric nurses to facilitate home care packages). This is due to the complexity of some of these children's presentations and the non-availability of appropriate service provider staff.

For example, from their audit, one child was identified as having been in hospital for a period of 10 months, and a second for a period of 13 months beyond medical need.

While we very much welcome the revised Joint Protocol and are reassured that its implementation is a priority for both agencies, it is of significant concern that there are a small number of children remaining in hospital in the absence of medical need



for unacceptably long periods of time. This places more import on the following recommendations.

### OCO Recommendation 3:

***By the very nature of their presentation children with significant disabilities require a coordinated integrated approach in assessing their needs. In this regard this Office recommends HSE disability services devise a framework for a holistic assessment of both a child and 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 and Tusla 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. This will include their family circumstances. This will also include a determination of the viability of a return to home, or to shared caring arrangements with their family or extended family. The intention is that such assessments will inform the provision of specialised bespoke care and support packages to address the identified needs of the child.

### Update

The 'HSE/Tusla Jack Report Working Group' has drafted a document entitled 'Guidance and Framework for Service Delivery to Children with a Disability in Hospital Beyond Medical Need'. A copy of which was provided to the OCO. The HSE have told us that the guidance framework is currently going through the approval process within the HSE and Tusla following stakeholder engagement. It is anticipated that the guidance framework will be finalised by the end of Quarter 1, 2022.

While we acknowledge the unprecedented pressures faced by public services over the past two years, we are concerned about the significant delay in implementing this recommendation.

### OCO Recommendation 4:

***We recommend 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 in 2020 that they engaged with the Department of Health over a long period of time to ensure that services, including children's services, are improved to meet existing and emerging needs, and how this needs to be funded accordingly. The HSE and Tusla had met with both the Department of Health and the Department of Children and Youth Affairs in February 2020 to agree a Memorandum of Understanding

(MOU) in respect of the HSE/Tusla Joint Protocol (2017) and the resources necessary to fulfil both agencies' responsibilities. The HSE was also leading on recruiting Children's Disability Network Managers who will manage their 91 interdisciplinary Children's Disability Network Teams (CDNTs).

## Update 2021

The HSE report that since the publication of the Jack investigation they have progressed efforts to provide a sufficient range of services and funding to support the right of children with disabilities to grow up at home with their families:

- In accordance with 'Progressing Disability Services for Children and Young People', the HSE has now established inter-disciplinary CDNTs throughout the country that aim to provide a more equitable and timely service to children with complex disabilities. This was supported by a significant investment of €9.5m to cover CDNT posts and €7m for Children's Disability Network Manager posts.
- While filling posts is a challenge, the HSE told us that they were recruiting 100 CDNT posts in 2021, along with a further 85 posts to maintain existing on-site services in special schools.
- In September 2021 the HSE received funding for an information system that will support CDNTs to deliver family-centred practice and outcomes-focused interventions.
- In 2020 the HSE / Tusla signed off on a Memorandum of Understanding (MOU 2020), in relation to funding of placements for children with complex disabilities identified at the time. Under this agreement the funding of existing placements for children with complex disabilities is to be shared on a 50:50 basis between the HSE and Tusla. The HSE told us that funding of newly identified cases is subject to available resources.
- As of 31<sup>st</sup> December 2021, there were a total of 187 cases which come under the Joint Protocol between the HSE and Tusla and are subject to the MOU. Currently the HSE either partially or fully funds 100 out of the 187 cases.
- Of the 100 cases already paid for by the HSE, only 75 of these are either fully or partially funded (€17.5m 2022 cost as per the HSE/Tusla Joint Protocol, funding gap of €1.7m). The remaining 25 cases were also funded either fully or partially by the HSE (all 2021 new cost, circa €4m unfunded cost in 2022) however the HSE had not received any funding allocation in respect of these cases.
- 87 cases are not currently being paid for by the HSE, these have an estimated cost of €16.6m for 2022. Of note in some of these cases the estimated funding required is uncertain and reflects possible future need.
- Due to children gradually ageing out of Tusla care and the HSE cost share increasing to 100%, the estimated shortfall in funding pertaining to the 187 cases increases year on year (€22.3m in 2022; €24.7m in 2023; €26.6m in 2024). The HSE advise that €7.6m of 2022 funding is yet to be allocated and it is anticipated that this will offset some of the shortfall.

- The HSE told us that there are a number of factors which contribute to the MOU not being fully implemented with regard to funding of services, these include;
  - a difficulty identifying legacy cases where Tusla were fully funding cases which under new MOU should be partially/fully funded by the HSE;
  - a shortfall in funding provided through the estimates process;
  - and emergency cases which incur significant funding which has not been included in the estimates process. The HSE have advised that there have been significantly more emergency cases than anticipated whereby families can no longer care for their child, this can have very significant funding implications.
- The HSE told us that despite significant increase in funding of children's disability services in recent years, funding continues to be provided on a year to year basis which impacts on the ability of services to plan for anticipated needs. The HSE advised us that along with Tusla they are working on a detailed investment plan covering a 3 year period.
- Tusla told us that the implementation of the MOU remains a challenge given the resource pressure on both agencies.

The OCO urges that a multi annual budget is put in place for this cohort of children but in the interim, an adequate package of funding including a value for money analysis is put in place. This work should also inform the recommendation below in relation to alternative care.

### **OCO Recommendation 5:**

***We recommend 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.***

Taking this as referring to children with disabilities who are in hospital settings beyond medical need, the HSE in partnership with Tusla agreed to undertake a national review of the current need for alternative care for this cohort of children and produce a report by the end of Q2 2021 outlining the requirements to ensure a comprehensive service to these children and their families.

## Update 2021

The HSE told us that, informed by the learning of the needs of children with complex disability who were, and currently are, in acute hospitals beyond medical need, a HSE/ Tusla 'Jack Report Working Group' are working on a national review of the current need for alternative care for this cohort of children.

The HSE told us that as of yet, this national review has not been finalised and no report has been produced. The HSE told us that the group has been considering a continuum of supports that would promote children remaining within a family setting; to include, family support, shared care, substitute family care and foster care.

The HSE advised that the focus of this review is not on the development of residential services for children as this is not in the children's best interests. However, where all other options have been considered and are not viable, the HSE and Tusla will together seek to set up bespoke residential arrangements for particular children. The HSE have acknowledged that despite both agencies working together it can be challenging to put such arrangements in place due to a shortage of suitably trained staff. They also told us about the prohibitive costs of private companies providing such residential care.

The OCO sought information from the HSE regarding the numbers of children currently awaiting support services including residential care. The HSE informed us that there are 529 children listed on their DSMAT (Disability Services Management Tool) system as having active applications for services.

Of the 529 children, 80 (15%) are listed as having applications for residential care and 449 (85%) are listed as having applications for other support services such as respite and/or support hours. The HSE clarified that these numbers reflect requests from parents or guardians for support. In the case of children listed as having applications for residential care other supports may be offered and may avert the need for residential care. At the time of our investigation there were 356 children listed on the DSMAT system as having an application for support services. Therefore, this represents a significant increase of 48%. The HSE said this increase most likely related to the phased introduction of the DSMAT system across regions and therefore may be reflective of improved data collection rather than increased demand.

Tusla told us that they make every effort to ensure that children in their care are placed in family settings and in this regard they have ran specific recruitment campaigns for foster carers for children with disabilities.

The OCO notes that the HSE and Tusla had committed to completing the alternative care review by Q2 2021. However this important action remains outstanding. The OCO is very concerned about the failure of the HSE and Tusla to prioritise this due to the profound impact on children, most particularly in circumstances where there has been a significant increase in the numbers of children with unmet support needs.

The OCO has repeatedly advised of the right for every child to grow up with their families and no child should miss out on that right due to a lack of services. We also believe that if that is not possible, then an alternative family based setting should be explored.

The OCO notes however that there are 80 children identified as requiring residential care. This is a significant number and we understand that difficulties in securing appropriate residential care placements is a contributory factor to children remaining in hospital settings beyond medical need. In such circumstances, if all other family based settings are exhausted and following a comprehensive assessment, residential care is deemed to be in their best interest, then the OCO is of the view that residential care should be considered as part of the alternative care review.

### **OCO Recommendation 6:**

***The HSE complaints procedure is specifically related to service users. In this 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 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.***

We were informed that the HSE/Tusla Joint Protocol (2021) will provide a clear pathway as to how disagreements and complaints between different HSE services will be managed. This will detail courses of actions in relation to delayed discharges of children from medical settings (see Recommendation #2).

### **Update 2021**

Acute Hospitals are now included in the HSE/Tusla Joint Protocol (2021). The HSE informed us that acute hospitals have been actively involved in managing all cases where there are children in acute hospitals beyond medical need alongside the HSE and Tusla. This has included, where necessary, escalating cases to National Office for resolution (as set out in Joint Protocol).

The HSE also informed us that the National Acute Hospital's Office has a representative on the National HSE/Tusla (Joint Protocol) Oversight Group and noted that the Joint Protocol has been actively used to resolve some cases of children in acute hospitals beyond medical need.

## OCO Recommendations to Tusla

### OCO Recommendations 7:

***The CFA should immediately issue guidance to all social work areas that child protection and welfare referrals about children with disabilities must be assessed and managed the same as all other referrals and in accordance with national policies and procedures.***

Tusla told us they would issue guidance without delay to all Tusla areas that child protection and welfare referrals in respect of children with disabilities must be assessed and managed the same way as all other referrals and in accordance with national policies and procedures. They also told us that, of equal importance arising out of this case, the CEO of Tusla is anxious that the welfare and family support dimension is maximised to the benefit of children such as Jack notwithstanding the absence of protection issues. This will continue to be emphasised in management guidance to staff.

### Update

Tusla informed us that a Joint Working Group between Tusla and the HSE, co-chaired by the National Director for Operations and Integration and the HSE Operational Lead for Disability Services has enabled them to advance the integrated governance structure for the escalation of operational issues in accordance with the 2021 Joint Protocol. The integrated governance structure for the escalation of any issues was completed in April 2021 and is now operational.

Workshops have been delivered to staff across Tusla to clearly outline the roles and responsibilities of staff in Tusla and the HSE, in line with the Revised Protocol. As part of these workshops, it has been communicated to all social work areas, that child protection and welfare referrals, about children with disabilities, must be assessed and managed the same as all other referrals and in accordance with national policies and procedures.

## OCO Recommendation 8:

***The CFA should review the implementation of initial assessment process under the Signs of Safety Practice Model to ensure it does not discriminate against children with disabilities whose parents and carer's present as unable or unwilling to provide for their care.***

Tusla told us they would review the implementation of the initial assessment process under the Signs of Safety Practice Model to ensure it does not discriminate against children with disabilities whose parents and carer's present as unable or unwilling to provide for their care. It is important for all observers to note that Signs of Safety as a practice model does not discriminate against children with disabilities. Every effort will be made to ensure that no policy of Tusla excludes children who have a disability.

### Update 2021

Tusla advised us that the Signs of Safety framework, a revised business process was introduced in July 2020 and is now complete. Surveys have been conducted with parents and staff to seek their feedback and to evaluate the implementation of Signs of Safety as a national approach to practice.

Tusla informed us that a key priority for the agency in 2021 has been ensuring a consistent approach to practice across all response pathways, including a focus on service delivery for children who have not been intentionally harmed, or, abused by their parents but who have high needs relating to care and support services.

In 2022 Tusla will be piloting a new approach to service delivery for children with high needs who are at low risk of harm. This will be piloted in five areas initially. Referencing the shortage of qualified social workers nationally, Tusla told us that this service delivery approach will be multi-disciplinary. Tusla told us that this will not replace the requirement for supports from other state agencies but it is hoped that it will ensure a more timely response to child welfare referrals for this group of children. The OCO welcomes this initiative.



## OCO Recommendations to HSE and the CFA

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### OCO Recommendation 9:

***The HSE and the CFA should engage with the relevant HSE funded service provider to be assured that Jack's current host family arrangement complies with all safeguarding requirements Children First: National Guidance and is comparable to that of children in foster care.***

The HSE and Tusla told us that they agreed to arrange an assessment of whether Jack's current host family arrangement complies with all safeguarding requirements (as per Children First: National Guidance for the Protection and Welfare of Children 2017). The Principal Social Worker confirmed that they provided advice on safeguarding to the host family. They also got legal advice and suggested to the HSE that the host family could possibly be considered as an applicant for joint guardianship after 12 months.

### Update 2021

Both agencies informed us that local HSE Disability Service and the Tusla social work department continue to work together to meet Jack's and his host family's needs. The HSE state that the assigned Social Worker, with the Disability Service has confirmed there are no concerns regarding the host family placement, it is compliant with the requirements under Children First: National Guidance and is comparable to that of children in foster care.

Tusla have advised that the local social work team are committed to assisting the host family and Jack's mother with regard to the host family's application for legal guardianship of Jack. While the host family are committed to caring for Jack on a long-term basis they wanted assurances from the HSE that an alternative placement would be made available to Jack in the event of them being unable to care for him in the future. We understand that the HSE has now committed to providing a suitable alternative placement in the event that his host parents become unwell or are unable to continue to support him in their home.

Tusla told us that a social work team leader is allocated to Jack. She has attended all professionals meetings in relation to Jack's care. Tusla have advised us that Jack will continue to have an allocated social worker going forward. Tusla are supporting Jack's host family carers with applying for guardianship and the legal process involved. They have also ensured that Jack's mother has legal advice in relation to this. Tusla have committed to coordinating Jack's contact with his family going forward.



## OCO Recommendation 10:

***The HSE and the CFA should, in conjunction with the Department of Health and Department of Children and Youth Affairs, agree actions to address the shortcomings identified in current Home Sharing in Intellectual Disability: Report of the National Expert Group (2016) as they relate to children.***

The HSE told us that regulation in the area of Home Share is a key concern for them, but the identified need to introduce legislation in this area is a matter for the Government. The report provides a blueprint for resolving these issues and an implementation plan to progress the work of the National Expert Group on Home Sharing is being devised. In this context, each CHO Area was allocated funding in order to introduce/strengthen the Home Sharing model in their local area and to establish contract arrangements with Service Providers and Host Families.

### Update 2021

#### **Profile of home sharing arrangements for children and adults with disabilities.**

The HSE informed us that they undertook a National Home Sharing Assurance Review in September 2021 after the publication of the Jack report. They found that there was 351 people with disabilities in home sharing arrangements nationally.

However, the HSE initially could not tell us how many of these 351 were children or whether they related to full-time, part-time or respite care arrangements. When pursued the HSE were able to establish that Jack was one of 3 children placed in home sharing on a full-time basis. They also told us that some Tusla foster carers would become home sharing carers under the remit of the HSE or funded section 38/39 Disability Service Providers when the children in their care reach adulthood. However, the HSE did not know how many young people with disabilities were subject to these arrangements as this data is not being gathered at a national level. However they were aware of at least nine such arrangements with one further one planned.

#### **Safeguarding of children and adults in home sharing arrangements**

The HSE informed us again that regulation in the area of Home Sharing is a key concern for them and there was an identified need to introduce legislation in this sector. They advised that this was a matter for the Government but they have had no engagement to date with the Department of Health to progress this issue.

We contacted the Department who pointed to a number of policy developments in relation to safeguarding of vulnerable adults which have been implemented in recent years. While it states that it was committed to considering if any additional legislative provisions were required to underpin this form of service delivery, as part of its wider consideration of the appropriate legislative framework for disability services, no action has occurred.

Therefore, home sharing arrangements for adults and children with disability, remains unregulated despite the known risks outlined in the National Expert Group in 2016.

The HSE told us that implementation plan to progress the work of the National Expert Group on Home Sharing will be devised but there is no timeline for this. Recently, in response to queries from the OCO, they told us in February 2022 that they had just appointed a National Lead for Home Sharing.

The OCO remains deeply concerned that while the care of children in foster care is subject to legal regulations and inspection by HIQA, home sharing remains unregulated. While the OCO is in full support of young people remaining with their foster families into adulthood where possible, we are of the view that regulation of home sharing is crucial to ensure that these vulnerable young people are protected into adulthood. We state this against the background of two published interim reports from the Farrelly Commission into the abuse of ‘Grace’<sup>1</sup> and others in a former foster home in the South East, which has been the subject of abuse allegations.

We are also concerned about the apparent reliance on private providers for residential care and respite care for these children. This has been recognised as a serious issue for children in State care by Tusla and therefore, we fail to understand why it has not been given a similar priority by the HSE for children with disabilities.<sup>2</sup>

Children, including children with disabilities, have a right to grow up within a family environment and if it is not possible for them to remain within their family of origin the state is obliged under the UN Convention of the Rights of the Child and UN Convention on the Rights of Persons with Disabilities to seek alternative care within a family setting. Jack has benefited greatly by being placed in the care of a host family and it is concerning that the HSE has not taken significant steps to advance home sharing as a viable, safe and regulated care option for other children and young adults in similar circumstances.

## **OCO Recommendation 11:**

***The CFA and the HSE should ensure local areas are competent and equipped to implement the Joint Protocol and that there is a structured process for the monitoring and reporting of the implementation of the Joint Protocol to maximize and ensure inter-agency cooperation. Consideration should be given to the inclusion of the acute hospital sector in these meetings.***

## **Update 2021**

To ensure that local areas are competent and equipped to implement the HSE/Tusla Joint Protocol (2021) the HSE and Tusla have jointly provided follow-up area based workshops with a focus on implementing the Joint Protocol for both HSE and Tusla managers and staff. Senior HSE and Tusla managers have jointly presented their Joint Protocol implementation plans at these workshops.

<sup>1</sup> <https://www.gov.ie/en/publication/856fd-farrelly-commission-of-investigation-substantive-interim-reports/>

<sup>2</sup> <https://www.irishtimes.com/news/social-affairs/tusla-to-draw-up-plan-to-reduce-dependence-on-private-residential-care-1.4772408>

The HSE and Tusla have both appointed Joint Protocol National Leads for their respective agencies with responsibility for the implementation of the Protocol. In Q4 2021 a CHO/ Tusla Area-specific audit of compliance with the MOU and the Joint Protocol was undertaken jointly by both agencies and the findings presented to the Leadership Teams of both the HSE and Tusla.

## Conclusion

Jack's case is a stark example of the transformation that can occur when a child with a disability is placed in the right environment with adequate supports and care. Jack is now sitting up, is part of a community, attends school and is physically in much better health.

We believe that every child should have the right to grow up with their families and no child should lose that opportunity due to a lack of resources, services and/ or coordination of state services. We warmly welcome the efforts made by everyone to ensure Jack is reaching his potential.

However, we also believe that this case has highlighted the very significant gaps at policy, funding and operational level to support the right of children with disabilities to grow up with their families. There is a lack of data and insight into their needs. This in turn means there is a lack of strategic planning with associated funding to ensure there is sufficient services and supports. We are particularly concerned about the lack of urgency at government level to address the recommendations from the National Expert Group on Home sharing.

We would urge the government to assume a stronger leadership role in ensuring there is adequate planning and funding to meet the needs of these vulnerable children.

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