An Investigation by the
Ombudsman for Children's Office

Jack's* Case: How the HSE and Tusla, the Child and Family Agency, provided for and managed the care of a child with profound disabilities

* not his real name

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Abbreviations

CFA	Child and Family Agency (Tusla)
CHI	Children's Health Ireland
CHO	Community Healthcare Organisation
NHSN	National Home-sharing and Short-breaks Network
MDT	Multi-Disciplinary Team
OCO	Ombudsman for Children's Office
HSE	Health Service Executive Disability Service
TOR	Terms of Reference
UNCRC	UN Convention on the Rights of the Child
UNCRPD	UN Convention on the Rights of Persons with Disabilities

Executive Summary

Jack

Jack is an eight-year-old boy. In the summer of 2016, when Jack was three years old, he was involved in a serious road traffic accident in another country, resulting in a brain injury and other significant life-changing injuries. Jack, who had previously met all his developmental milestones, was diagnosed with an array of physical disabilities and a profound intellectual disability that would require full assistance with all aspects of his daily care.

In April 2017 Jack's mother discharged him from hospital abroad and brought him back to Ireland, where he was immediately admitted to hospital. In January 2018 we, the Ombudsman for Children's Office (OCO), received a complaint on Jack's behalf from members of the multi-disciplinary team (MDT) in the acute paediatric hospital where Jack was now an inpatient. The team expressed concern about the delays in getting services for Jack by the relevant Health Services Executive (HSE) Disability Service so that he could leave hospital.

When Jack's mother expressed concern that she wouldn't be able to properly look after him at home, a referral was made to Tusla by a medical social worker informing them of this and seeking their help. This was followed up later by further referrals by a medical team. However, these were ultimately rejected by Tusla on the grounds that they were solely a matter for the HSE.

We undertook an investigation and visited Jack along with his mother while he was in a specialist community respite setting; the care team told us that Jack responded to his mother's voice, music and LED lighting.

Our Findings

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, the Child and Family Agency, to work individually and together to meet his needs.

During that time there were periods where Jack had no educational supports and was essentially isolated from contact with other children. He rarely saw his younger sister. Jack contracted an infection while in hospital and had to be placed in a single room. His consultant told us that following a period in the children's specialist community respite setting where he benefitted from a calmer, more consistent care arrangement, Jack was returned to the hospital. In the weeks that followed, Jack reportedly presented as distressed and was crying constantly. Both his consultant and his mother told us that since November 2019 they noticed a deterioration in Jack's health and overall well-being.

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 are 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. In addition, we found no indication that Jack's mother was made aware of these concerns, and that efforts do not seem to have been made to directly contact Jack's father in relation to his son's placement.

We have also concluded that there was a lack of adequate communication between the HSE Disability Service and the hospital following Jack's initial referral in August 2017, as well as an unsatisfactory four-month delay in the HSE response time to a complaint made by the MDT trying to get the matters resolved.

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. The HSE told us there were a further 356 children with disabilities in need of a residential placement. They were also aware of the need for increased funding for early intervention support and services for families to support children to be cared for at home.

We also believe this investigation highlights the need for Tusla to review the management of referrals they receive about children with a disability and how they engage with the HSE in providing this support.

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 co-ordination of state services. In order to address the issues that arose in Jack's case, and to ensure other children across Ireland are not similarly impacted, we have made the following recommendations to the HSE and Tusla:

Our Recommendations to the HSE

- The local HSE disability team should convene a multi-disciplinary meeting to include all services involved with Jack and his family;
- HSE Disability Services should immediately and systemically review all cases where a child remains in hospital settings beyond their medical need;
- Children with significant disabilities require a coordinated integrated approach in assessing their needs. HSE Disability Services should devise a framework for a holistic assessment of both a child and family's circumstances;
- HSE Disability Services should engage with the Department of Health to ensure services and funding are in place to support the right of children

with disabilities to grow up at home with their families;

- HSE Disability Services should conduct a national review of the current need for alternative care for children with disabilities whose parents or carers are not willing, or not able, to provide for their ongoing care;
- A new protocol should be in place to manage disagreements and complaints between the HSE Disability Services and acute hospitals.

Our Recommendations to Tusla

- Tusla should immediately issue a 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 should 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 carers present as unable or unwilling to provide for their care.

Joint Recommendations to the HSE and Tusla

- The HSE and Tusla should engage with the relevant HSE funded service provider to ensure that Jack's current host family arrangement complies with all safeguarding requirements under Children First: National Guidance and is comparable to that of children in foster care;
- The HSE and Tusla should 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;
- Tusla 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 this to maximise and guarantee inter-agency cooperation.

In response to these recommendations the CEOs of the HSE and Tusla issued a joint response to the Ombudsman for Children, fully accepting our recommendations.

Since then, Jack's care plan has been reviewed and all agencies are now working together with Jack's mother and host family to meet his needs. Jack has also been provided with a range of services, medical equipment and an individualised budget to meet any emerging needs. Tusla have assigned a liaison person to Jack's case through their family support Meitheal service. The HSE and Tusla have also 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).

Jack is now in school and has two classmates.

At a local level, both the Service Director of Tusla and HSE Chief Officer have agreed to meet quarterly due to the high volume of complex cases of interest to both agencies in the CHO.

Nationally, the HSE/Tusla joint protocol will be expanded to include acute hospital services to monitor any child with a disability in a hospital setting beyond medical need, and will act as a basis for all inter-agency work between the HSE and Tusla.

The HSE, in partnership with Tusla, will undertake a national review of the current need for alternative care for this cohort of children and produce a report by mid- 2021 outlining the requirements to ensure a comprehensive service to them and their families.

Tusla will issue guidance 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. The CEO of Tusla is also anxious that the welfare and family support dimension is maximised to benefit children such as Jack, notwithstanding the absence of protection issues.

The HSE and Tusla met with the Departments of Health and Children and Youth Affairs in February 2020 to agree the resources needed to fulfil both agencies' responsibilities. Both agencies have agreed to make every effort to resource the complex cases presenting.

Finally, an action plan is being devised to implement the shortcomings identified in the Home Sharing in Intellectual Disability: Report of the National Expert Group (2016).

Section 1: The Complaint

1.1 We received a complaint on behalf of Jack, from the MDT at the acute paediatric hospital where he was an inpatient.

1.2 A serious road traffic accident in a foreign country in 2016 left then three-year-old Jack with an array of physical disabilities and a profound intellectual disability.

1.3 Jack has epilepsy, no mobility and is thought to be completely blind (although this is not confirmed).

1.4 Jack receives nil by mouth necessitating PEG feeding and requires full assistance with all aspects of his daily care.

1.5 When Jack returned to Ireland with his mother he was admitted to hospital here, and in May 2017 was referred by the hospital MDT to the HSE Disability Services in his catchment area. The MDT provided specific reports on Jack's requirements for ongoing Occupational Therapy, Physiotherapy, Dietetics and Speech and Language Therapy. The referrers emphasised Jack's complexity of need and requested that the *HSE Disability Referrals Forum* would consider those identified needs in his long-term planning.

1.6 In October 2017, and in the absence of a response to that request for a service, the MDT made a complaint to the relevant HSE area Disability Services Manager about the length of time it was taking to receive an update on Disability Service provision and access to Disability Services for Jack.

1.7 The MDT went on to raise their concerns with the OCO in January 2018 after still not receiving a response from the HSE. Jack had since been transferred to the specialist hospital setting Monday to Friday, and spent weekends at a paediatric hospital.

1.8 In April 2018, a Senior Social Worker at the specialist hospital setting made a referral to Tusla as Jack's mother believed she would not be able to care for him properly along with his sibling at home, and wished for Jack to be placed in voluntary care in a residential centre. She expressed a wish to have him at home for several hours per week.

1.9 The Senior Social Worker also documented their concerns that if Jack was to return home his welfare might be at risk.

1.10 In the following period the OCO made several attempts to ascertain Tusla's position in respect of those child protection and welfare concerns and any broader role it had in relation to Jack's needs.

1.11 On February 1st 2020 Jack was formally placed with a *Host Family* by the HSE under the auspices of a charitable organisation.

Section 2: The Investigation

2.1 Our role is set out in the Ombudsman for Children Act, 2002. This states that we may investigate a public body, school or voluntary hospital where we believe that its administrative actions have or may have adversely affected a child. This means that we review complaints related to organisational actions or decisions to see whether they have already had or might have a negative impact on a child.

2.2 The Act sets out the focus for our investigations. We aim to determine if a child has been adversely affected by a public service's administrative actions. The Act lists seven areas whereby organisational actions might be:

i. Taken without proper authority;
ii. Taken on irrelevant grounds;
iii. The result of negligence or carelessness;
iv. Based on erroneous or incomplete information;
v. Improperly discriminatory;
vi. Based on an undesirable administrative practice; or,
vii. Otherwise contrary to fair or sound administration.

2.3 In August 2019, following preliminary examinations, we advised both the HSE and Tusla that we intended to proceed to statutory investigation with regard to the administrative actions of both agencies relating to the management of Jack's care and welfare.

2.4 As part of our investigation, we carried out a review of the case files provided by both the HSE and Tusla regarding their role and function pertaining to Jack.

We also held investigation meetings with the relevant HSE and Tusla personnel who had knowledge of Jack's case and the issues being investigated, as well as Jack's consultant paediatrician and representatives of Children's Health Ireland (CHI).

These meetings allowed us to gather further information on the HSE's complaint policies, as well as the policies and procedures both the HSE and Tusla relied on in this case, and with regard to other children with disabilities in inappropriate placements.

Section 3: Law and Policy

3.1 We review public bodies' administrative actions against relevant international standards and national law, as well as national policy and local procedures. It is not practical to list all the law, policy and procedures related to this complaint; however, we consider those referred to here as particularly relevant to a complaint concerning a child with a disability in an out of home setting.

International Standards

3.2 Ireland ratified the UN Convention on the Rights of the Child (UNCRC) on the 28th September 1992. This means that the State committed to promote, protect and fulfil the rights of all children, as outlined in the UNCRC, including children with disabilities. *Article 23 of the UNCRC* further states that '*A child with a* ***disability has the right to live a full and decent life in conditions that promote dignity, independence and an active role in the community.*** *Governments must do all they can to provide free care and assistance to children with disability'.*

3.2.1 *The Committee on the Rights of the Child's Concluding observations on the combined third and fourth periodic reports of Ireland*[1], call on the government to ensure '47(b) *"There are adequate measures for facilitating the care of children with disabilities in the home environment, where possible or appropriate,* ***in lieu of hospitalisation or institutionalization'.***

3.3 *UN Convention on the Rights of Persons with Disabilities (UNCRPD)* was adopted in 2006. Ireland signed the Convention in 2007 and it entered into force from April 19th 2018. This means that the Irish State has committed itself to promote, protect and fulfil the rights of persons with disabilities, including children, as outlined in the convention.

Domestic Law and Policy relevant to the HSE

3.4 As part of this investigation, we also looked at domestic law and policies relevant to the HSE.

3.5 The *Joint Protocol for Interagency Collaboration Between the Health Services Executive and CFA – CFA to Promote the Best Interests of Children and Families (March 2017).*

3.6 *Better Outcomes Brighter Futures: The National Policy Framework for Children and Young People 2014 – 2020* states that '*the State, as corporate parent to children in care, has a responsibility to ensure that supports are prioritised to facilitate these children and young people to reach their full potential.*

3.7 *The National Disability Strategy Implementation Plan 2013 - 2015*[2] has as its aim the promotion of an inclusive Irish society where people with disabilities can reach their full potential and participate in the everyday life of the community. Participation goal 3(c) envisages that '*People with disabilities live and are part*

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[1] CRC/C/IRL/CO/3-4, 29th January 2016

[2] http://www.justice.ie/en/JELR/NDS_ImplementationPlan_FINAL.Pdf/Files/NDS_ImplementationPlan_FINAL.Pdf

of the mainstream community' and objective 2(b) provides that the *'move from congregated settings to live in community'* be supported (at page 6).

3.8 *Progressing Disability Services for Children and Young People* is the HSE's vision to make Disability Services equitable and consistent for all[3].

3.9 The *Home Sharing in Intellectual Disability: Report of the National Expert Group (2016)* sets out that, *"A Home Sharing 'Shared Living' family is a family that provides full-time care to a person with intellectual disability similar to a fostering placement. The shared living family make their home available to a person with intellectual disability to share their home on a full-time basis as a member of their family".*

3.10 HSE Complaints Handling Policy, *"Your Service –Your Say"* provides for complainants to be responded to within 30 working days and as indicated kept updated every 20 working days after that.

Domestic Law and Policy relevant to Tusla, the Child and Family Agency

3.11 As part of this investigation, we also looked at national legislation, policies and other procedures related to foster care and children with disabilities. For example, in April 2015, the *31st Amendment of the Constitution (Children) Act 2012* inserted Article 41A into the Irish Constitution, placing an onus on state bodies to recognise and affirm the natural and imprescriptible rights of all children.

3.12 *The Child Care Act 1991* is the primary legislation-governing children's services. It sets out the CFA's statutory role regarding child protection and welfare. Section 3 of the 1991 Act 3 (1) It shall be a function of every health board to promote the welfare of children in its area who are not receiving adequate care and protection. (2) In the performance of this function, a health board shall— ***a) take such steps as it considers requisite to identify children who are not receiving adequate care and protection and co-ordinate information from all relevant sources relating to children in its area; and (c) have regard to the principle that it is generally in the best interests of a child to be brought up in his own family.***

3.13 The Child and Family Act 2013, under Section 8(8) provides that the CFA *'shall facilitate and promote enhanced inter-agency cooperation to ensure that services for children are coordinated and provide an integrated response to the needs of children and their families.'* It outlines goals of early intervention, supporting parents, and provision of quality services.

3.14 The more recent Children First Act 2015 puts elements of *Children First: National Guidance for the Protection and Welfare of Children on a statutory footing.*[4]

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[3] See http://www.hse.ie/progressingdisabilityservices/

[4] The Children First Act 2015 was enacted on 19 November 2015. (http://www.dcya.gov.ie/viewdoc.asp?fn=%2Fdocuments%2FChildren_First%2FChildrenFirstLegislation.htm).

3.15 The aforementioned revised *Children First: National Guidance for Child Protection and Welfare of Children* was published in 2017.[5] It sets out specific protocols for Social Workers in the CFA, An Garda Síochána and other front line staff dealing with suspected abuse and/or neglect. It emphasises the importance of multi-disciplinary, interagency working in the management of concerns about children's safety and welfare. Key to this is the sharing of information between agencies and disciplines in the best interests of children and the need for full co-operation to ensure better outcomes.

3.16 *Child Care Regulations (Placement of children in foster care) 1995.* These regulations set out the standards expected in the provision of foster placements.

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[5] www.dcya.gov.ie/viewdoc.asp?fn=/documents/Children_First/ChildrenFirstGuidance.htm (accessed 11/02/2020).

Section 4: Findings

4.1 The findings of our investigations relate to whether public bodies' administrative actions have adversely affected Jack.

4.2 Our findings against the HSE are as follows:

Finding 1

Jack was deemed medically ready for discharge in August 2017 but remained in inappropriate settings for over 29 months, moving between two hospitals and a specialist community respite setting, until February 2020. We find this to be wholly inappropriate and negligent, and incongruent with the principles and commitments set out in the "The National Disability Strategy Implementation Plan 2013 – 2015" and Progressing Disability Services for Children and Young People".

Finding 2

The HSE Disability Service had no coherent strategy to address Jack's needs following his referral to their service. While we acknowledge the significant efforts made by the Case Manager, the process of identifying a placement appeared ad hoc and was not guided by a clear policy framework. Furthermore, that lack of a framework around the placement of children with disabilities in alternative care meant that residential care was the first option explored for Jack. This is contrary to the principles of the UNCRPD and UNCRC. Both state that in circumstances where a child cannot be cared for by his or her parents a placement within the extended family should be considered and failing this, a placement in a non-relative family setting.

Finding 3

Following the referral to HSE Disability Services in June 2017, we found the initial communication between that service and the hospital to be poor and based on undesirable administrative practices. For example, a follow up meeting in August was not attended by the HSE, and the HSE worker that did attend a rescheduled meeting in October had limited prior involvement and no future involvement in Jack's case.

Finding 4

In October 2017, members of the hospital MDT made a complaint to the HSE Disability Services Manager regarding Jack's access to disability services and the provision of such services. Following representations by the hospital and OCO, a response from the HSE was finally made in February 2018. This delay in addressing the complaint is not in keeping with the time frames set out in "Your Service, Your Say" and is therefore an undesirable administrative practice.

In May 2017 Jack was deemed medically fit for discharge and the plan for his case was referred by the hospital MDT to HSE Disability Services in his local catchment area. The MDT told us that at that time, despite his significant medical conditions, Jack's family, possibly in conjunction with his extended family, *"could have provided for his care in the family home with appropriate supports from the HSE"*. Indeed, in May 2017 a specialised bed was set up in the family home while medical personnel provided training and guidance to his mother in regard to his personal and medical care.

A member of the MDT wrote to the HSE inviting a representative from the Disability Service to a proposed meeting of professionals to be held on August 2017. The purpose of that meeting was to *"discuss and make plans for Jack's transition back home with appropriate services in place."* In response, the HSE Disability Services said there was no one available to attend the meeting and *"unfortunately Disability Services, (in that CHO area) do not have funding to provide an immediate response, but efforts will be made to secure funding"*.

Eventually an inter-agency meeting took place in the hospital in late August 2017 and although invited, no representative from local HSE Disability Services was available to attend. A further inter-agency meeting was convened by the hospital in October 2017 which was attended by a manager from the HSE Disability Services.

According to the minutes of the meeting, the HSE representative advised of a 30-month waitlist for *"rehabilitation input"* for Jack through the Disability Services school age team. They also advised that HSE primary care services would look after Jack's initial discharge needs such as equipment and resizing his wheelchair chair as needed, if he was not in receipt of any other service by then.

Following this meeting the MDT made a complaint to the relevant area HSE Disability Services Manager about the delays in accessing disability services for Jack. In November 2017, a further discharge planning meeting took place at the hospital and although invited, HSE Disability Services did not attend, nor did they reportedly give any reason for not attending.

Later that month, Jack was transferred to the specialist hospital setting on weekdays for more specialised assessment and support. During that time Jack continued to stay in the paediatric hospital at weekends.

As the MDT got no response to their complaint, they contacted the OCO in January 2018. The OCO sought an update from the HSE to see if matters could be resolved.

In February 2018, the HSE responded to the complaint made by the hospital MDT and proposed the extension of Jack's placement for a further month in a hospital setting;

pursuit of an educational outreach support from a named Disability Service and; that the HSE Disability team would explore a temporary home support package with Jack's parents on his discharge to their care.

Jack remained in hospital for a further four months after this and the educational outreach supports did not occur.

Records from the HSE case manager from October 2018 to January 2019 showed the efforts made by them to secure a residential placement for Jack. They applied to two HSE funded Disability Services and two private providers, but none of them could provide a place for him.

In January 2019 following consultation between the HSE and the paediatric hospital, arrangements were made for Jack to return to the specialist community respite setting. This move was reported as part of an initiative to relieve pressure on the acute hospital over the busy winter period. The Case Manager went on to make a referral to a HSE funded Respite Service in April 2019.

That service responded that their waitlist for availability was 30 months long.

Jack remained between hospitals and a specialist community respite setting until February 2020. During that time there were periods where Jack had no educational supports and was essentially isolated from contact with other children. He rarely saw his younger sister. Jack subsequently contracted an infection while in hospital and had to be placed in a single room. His consultant told us that following a period in the children's specialist community respite setting where he benefitted from a calmer, more consistent care arrangement, Jack was returned to the hospital. In the weeks that followed Jack reportedly presented as distressed and was crying constantly. Both his consultant and mother told us that since November 2019 they had noticed a deterioration in Jack's health and overall well-being.

None of Jack's placements since May 2017, apart from time spent in the specialist hospital setting, were guided by his assessed needs nor were they warranted medically. In interview with the HSE Disability team it was acknowledged that there were significant delays in the process of planning and providing services for this Jack.

The HSE's Head Service of for Social Care and Disabilities informed us that it proved difficult to locate a suitable placement for Jack, partly because it was unusual to place a child so young in a full-time residential care setting. Jack's infection and the necessary hygiene precautions required to manage it meant several residential service providers were reluctant to offer him a care placement. The manager also offered that there were further *"challenges of placing child with high medical needs with children who have behavioural problems"*.

On the issue of funding, the HSE's Director of Operations told us that their office was *"only funded to do what (I) need to do in a year and the residential framework allows us to fund any placements required where there are immediate risks identified."* They continued that, *"much more investment is needed"*.

The Director further commented how, *"there is sufficient evidence to tell us what need will be in the next ten years but it is not funded"* and that it was their *"firm view that Disability Services are not funded to meet the need now or into the future"* as there is *"very little funding going into the provision of new residential placement"*.

Children with Disabilities in the CHO and Nationally

In March 2019 the senior manager in the HSE Community Healthcare Organisation (CHO) area responsible for Jack, wrote a letter to their line manager advising that at the time of Jack's initial referral in May 2017, there was a *"disability manager and limited administrative supports assigned to the service"*. However, there were no case managers in that area of over 750 service users, 128 of these are children, with 59 considered active cases. The CHO manager wrote, *"Over the past decade adequate funding has not been available or allocated to the planned needs of children in terms of residential placements". In 2017, seven children were placed as emergency placements in this CHO area; in 2018 -10 children costing €1.613 m. Projected costs in 2019 for those 2018 placements is €4.069m".*

It further advised that *"Across the CHO at that point 26 children held on Disability Supports Application Management Tool requiring a residential placement, including Jack, but no funding available." There were 'approximately 11 children as of March 29th 2019 where the families are in huge distress and children are in respite or in "high risk situations" that have potential to break down'.*

Contextualising this, the manager pointed out that HSE Disability Services had at that time (November 2019) a €12 million overspend mainly due to residential placements.

Indeed, in an interview with the HSE's Director of Operations it was reported that the DSMAT[6] had as of December 2019, identified 356 children that required residential placements. It was also noted that these numbers were likely to be an underestimation as "a lot of children aren't known to us-this is known need, but we know there is unknown need too." The Director went on to comment, *"We need to be doing more early intervention-we'd prevent a lot of this if we did" and "we are 400 clinical posts short nationally which impacts on this."*

Positively, the HSE did inform us that, in partnership with a private provider within the CHO, *"we are developing a shared care house which will open in January 2020. It will be for eight children, half time in the house half time at home".*

We also met with CHI medical staff members for their view on this issue of children waiting in hospital due to a lack of support to either return home or to a supportive service. They told us the number of delayed discharges nationally in 2017-2018 was in the region of 18/19 children. In 2019 that figure dropped to 7/8. They highlighted the need for clear, structured pathways and resources in communities to ensure children like Jack did not remain in hospital settings contra to their medical and other needs.

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[6] The Disability Supports Management Application Tool. This is a nationally agreed framework used by the HSE to assess the needs of people with disabilities requiring residential care.

Finding 5

In February 2020, the HSE Disability Services placed Jack with a host family. It is accepted by the HSE that such a placement lacks any specific regulatory framework or legal basis as highlighted in the "Report of the National Expert Group (2016)". Although it is clear that HSE staff were motivated by Jack's best interests and a desire to place him within a family setting, we find the decision to progress this placement in the absence of any legal or formal regulatory framework, and without proper authority, was based on an undesirable administrative practice.

Finding 6

In the circumstances of the plan to have Jack accommodated and cared for by a Host Family, HSE Disability Services sought and obtained consent from his mother to proceed with this arrangement. No evidence has been offered to suggest Jack's mother was advised of the serious concerns expressed in the Report of the National Expert Group Report (2016) and the fact such placements lacked a legislative or regulatory basis. It is also a concern to this Office that enquiries regarding Jack's father's position in relation to the proposed placement were limited to information gathering from his estranged wife, Jack's mother. In this context, the communication with Jack's mother and the seeking of her consent in this instance is deemed to have been based on erroneous or incomplete information.

In April 2019, the HSE Disability Service approached a service provider in the charitable sector who had experience of offering family-based respite for children and adults with intellectual disabilities and who were living primarily with their families. The process of advertising and identifying a potential host family took less than one week and a family who had previously provided respite care to children with disabilities came forward and expressed an interest in caring for Jack. A plan was put in place for Jack to be cared for by the host family from Monday to Friday with a residential respite service providing care on weekends. The family would be paid an allowance to care for Jack comparative to a foster caring allowance, and an advance payment for retention of the family's services was made.

The HSE told us that written consent was obtained by the Disability Service provider whose responsibility it was to oversee the host family placement. As Jack's parents were separated, HSE legal representatives suggested that proceeding with the placement without consultation with and consent from Jack's father might be problematic, but they were informed by Jack's mother that his father had not provided her with a forwarding address or contact number. There was no record of the HSE reaching out to extended family to try and get contact details for Jack's father or to explore whether they may have been able to contribute to Jack's care.

Jack's move to the host family was delayed as significant adaptations had to be completed to that family's home to ensure it was suited to Jack's mobility and other care needs.

In February 2020 Jack was formally placed with the host family, with access between Jack and his mother to be facilitated at the respite service on weekends.

In interview, the HSE's Director of Operations stated that this arrangement for Jack was "unique" in terms of it being considered as a long-term placement as opposed to the practice of using host families for respite breaks for children and families.

The Head of Service for Social Care and Disabilities stated, "*we have got a lot of host families; they provide amazing support and give families a break*". Regarding Jack, they stated, "*we got it really right in this case*" and "*we have an excellent plan for him*".

However, the HSE National Service Plan (2016) a *Report of the National Expert Group on Home Sharing in Intellectual Disability Services in Ireland* outlined the need for all host family placements to go through a matching panel for approval. This did not happen in Jack's case. The HSE Disability Service accepted this placement lacked any specific regulatory framework or legal basis but felt it was the best option available and preferable to Jack being placed in a residential or hospital setting. The HSE further advised that the commissioned Disability Service provider was responsible for assessing the host family and a social worker from that service would remain involved to oversee the care provided to Jack by the family. The OCO was also informed that the HSE Disability Case Manager would remain involved to co-ordinate Jack's care on an on-going basis. However, it is noted that those interviewed by this Office from the HSE said they had not had sight of, or indeed sought access to, the assessment report on the host family.

The May 2019 care plan sets out that the HSE Disability Service would undertake an annual review of Jack's care and quarterly visits to him in his placement with his host family. There is no detail as to how these reviews will be conducted.

There is no legal regulatory basis which sets out the frequency at which children in host family placements should be visited or how often these placements should be reviewed. In contrast, under the *Child Care (Placement of children in foster care) Regulations (1995)* children in foster care have their care reviewed within two months of placement, at six monthly intervals for the first two years and annually thereafter. It is evident that Jack's current placement is not covered by these regulations.

When challenged about the decision to place Jack with a host family in the absence of a regulatory framework, the Director of Operations explained that: "*Each CHO area developed a plan around the use of home sharing/host families following on from the expert group 2016. Some CHOs provide it directly through HSE and some through section 38/39 organisation.*"

They went on to state that in relation to the lack of a regulatory framework for the placement of children with a host family they were "*not comfortable with it at all*". In this context the Director advised that the matter would be raised with the Department of Children and Youth Affairs, the Department of Health, HSE and CFA during a scheduled meeting in January 2020.

Findings against Tusla, the Child and Family Agency

Finding 7

A referral was made to Tusla in April 2018 in relation to Jack and his family's circumstances. The "Intake Record" raised serious concerns about the potential risks and harm to Jack were he to be returned home. The response from Tusla was that this was a matter for the HSE. During this investigation Tusla then provided two further reasons as to why Jack's case was not accepted for initial assessment:

- ***i. These concerns did not meet their threshold for involvement***
- ***ii. Tusla did not have access to the specialised placements to meet Jack's needs.***

We believe that Tusla's decision not to undertake a comprehensive initial assessment of Jack's circumstances was unduly informed by him having a disability. We find that this was negligent and improperly discriminatory on the grounds of his disability status. Tusla have asserted that there was no deliberate attempt to discriminate against Jack or his family.

The OCO retain our position that the actions and decisions were improperly discriminatory on grounds of his disability for the reasons set out below.

Finding 8

Tusla failed to provide a consistent response about their decision making following the referral in April 2018. This confusion led to a three-month delay in other professionals putting in place a plan for Jack's care, and so we find this inconsistent communication to be based on undesirable administrative practice.

Finding 9

Tusla did not engage in any meaningful way with Jack's case when it was first brought to their attention on the back of a child protection and welfare referral in April 2018, or in follow up emails in May and June of that year. We concluded that their response served to essentially abdicate any responsibility for contributing to the consideration of Jack's need in the circumstances of the primacy of the HSE role. We find this non-adherence to the principles underpinning the Joint Protocol for Interagency Collaboration between the HSE and Tusla to have been negligent of the CFA's responsibilities in this regard.

In April 2018, a child protection and welfare referral was made by the Social Worker with the specialist hospital setting to Tusla in respect of Jack. Jack's mother appeared to be struggling with the prospect of assuming his care. She had expressed a wish for him to be placed in voluntary care of the CFA in a residential centre, and that he could continue to visit the family home regularly. In their written response Tusla said the referral had been designated as "valid" and had been sent to a Social Work Team Leader for review.

In June 2018, the Social Worker in the paediatric hospital where Jack had been placed since his return from the specialist hospital setting, wrote to Tusla seeking an update on the referral ten weeks after it had originally been made.

From the documentation provided, the social worker considered the case as '*child protection / high welfare*' which "*needs to go to patch (the area duty team) to co-ordinate response*" going on to suggest that "more questions" were needed to determine if this was a child protection issue. However, written over this and listed as a decision on that record was "*this is a HSE issue not CFA*".

In June 2018 the social worker was told that placements Tusla had access to were for children and young people "*who are at risk of harm due to family circumstances*" and that Tusla does not "*have access to the type of placement or the expertise required in managing a child with complex needs' such as Jack's*".

That correspondence stated that contact had been made by Tusla with the local HSE Disability Manager and pursuant to same; "*no child protection assessment exists that demonstrates that {Jack} needs to be taken into the care of the state*". As such, it would not be appropriate or warranted for Jack to be received into voluntary care as the "*threshold*" for same had not been met. Tusla said that there would be no further involvement as there were no child protection concerns in this case.

It is also noted therein that a key issue in the decision making here was that Jack "*is not in any harm due to the family*". As such, Tusla determined that Jack and his family's needs should be met within HSE Disability Services and they advised they were closing the case. However, in their policy document "*Thresholds for Referral to Tusla Social Work Services (2014)*" the most serious areas of concern warranting immediate Social Work attention and intervention are listed under Level Four which include situations where a:

- Parent/carer is unable to meet child's needs even with support.
- Parent/carer are unable or unwilling to continue to care for a child.
- Parent/carer are unable to care for a child.
- Child has no one to care for him or her.
- Learning/development significantly is affected by health problems.
- Child is abandoned.

We believe that Jack fell within a number of these categories above.

Tusla's Child Protection and Welfare Handbook (2011) gives the following guidance to Social Workers at the initial stage of an assessment. "*Unless the concern is resolved in the course of the referral process, an initial assessment is undertaken. This will include meeting child and meeting a child's parents, as well as contacting professionals involved in order to develop an understanding of the child and their circumstances. The purpose of the assessment is to reach a preliminary conclusion about unmet need and* *risk of harm in order to plan and provide an appropriate response. The timescale for completing an initial assessment is 20 working days".*

This did not occur.

In August 2019, the specialist community respite setting caring for Jack made a further referral to Tusla and referenced two other letters to them for similar concerns about engagement with Jack's mother. Again Tusla advised that the concerns underpinning this case did not meet the threshold of a child protection or child welfare concern. They told us that *"at this time it would also seem that professionals are not clear as to how CFA could be of assistance other than taking {Jack} into care"*. However, this time a social worker spoke to that referrer and with Jack's mother. This was the first time Tusla had spoken with Jack's mother despite the concerns set out in correspondence in April 2018, and March and June 2019 relating to Jack's welfare and requesting support from Tusla in the management of the case.

When we asked about Tusla's decision not to become involved in the case at the point of the initial referral in April 2018, the Service Director acknowledged that while there were no clear child protection issues identified in the referral, services could have been offered to Jack and his family. Namely, the *Meitheal* service, which is provided for under the *Partnership, Prevention and Family Support Service (PPFS)* provided by Tusla. It was also acknowledged that Tusla could have had a role in supporting Jack's mother and ascertaining whether, notwithstanding her difficulties, she could have been empowered to play a greater role in caring for her son. The Service Director stated that they *"did not know why this was not offered in this case"*.

Several competing reasons were put forward to us to explain the position taken regarding the referrals received in April 2018, and March and June 2019 including:

- the initial referral was too prescriptive and essentially a request for an assessment for voluntary care;
- the issue of a child left by a parent in a hospital setting did not meet the threshold for intervention;
- Tusla do not have access to the type of specialised placement or expertise Jack required and;
- the HSE ought to have engaged with Tusla pursuant to the joint protocol as opposed to making a child protection and welfare referral.

Tusla told us that there had been several meetings in the hospital that they were never invited to. In that regard the Service Director said, *"I can stand over that if we are invited to meetings, we will turn up always. We have a responsibility to be at the table if requested."*

Tusla accepts that this case could have been referred to PPFS, with the Service Director further commenting *"I don't know why that wasn't offered in this case"* in the circumstances of *"a vulnerable mother in need of support."* The Service Director went on to say that they were *"glad the OCO are looking at these types of cases, there is a policy issue here" going on to concede that "at the beginning, hands up, we could have done more checking of the information."*

In June 2019 the HSE wrote again to Tusla outlining that a plan to place Jack with a *"Host Family"* was underway advising; *"we have been informed that we should provide Tusla with formal notification regarding the placement options we are pursuing for this young boy"* and *"we would be grateful if Tusla as the statutory agency for the safety and welfare of children provide partnership in managing this challenging and unusual situation given that a suitable placement is in progress".*

In Tusla's letter to this Office in September 2019 the proposal to place Jack with a host family was referred to as an "excellent package of care identified and aimed at meeting his ongoing care needs". In interview with Tusla's Director of Operations in December 2019 the position put forward was that Jack's placement with a host family was an issue for HSE Disability Services and not Tusla.

Section 5: Recommendations

5.1 In accordance with the Ombudsman for Children Act 2002 we aim to make recommendations which are fair and constructive for all parties to the complaint. In so doing, we also have regard to the best interests of the child concerned.

5.2 We recognise the difficult task public bodies have in fulfilling their statutory role regarding children with disabilities whose parents or carers are either unable or unwilling to provide for their care in the home.

5.3 Despite those challenges it is incumbent on both the HSE and Tusla to discharge their statutory responsibilities in accordance with their relevant legislation and policy.

Section 6:
Public Bodies' Responses To The Recommendations

HSE

6.1 In response to the recommendation that the local HSE disability team should convene a multi-disciplinary meeting to include all services involved to date with Jack.

- *The local HSE Disability Services convened two inter-disciplinary meetings in July and August 2020, with a further meeting scheduled for September 2020;*
- *A formal care plan for Jack is in place and will be updated on a regular basis. All agencies are working together to address Jack's needs and those of his birth mother and host family including, as documented:*
- ***Healthcare:** Jack was recently reviewed by his medical team and will be reviewed again in September 2020;*
- ***Equipment:** Jack attended the Central Remedial Clinic (CRC) for a second fitting as he is outgrowing his chair; and his bed was replaced with a five-function bed;*
- ***Respite:** Jack availed of respite from August 2020; and is due to avail of respite again from September 2020. The intention from September 2020 is to revert to his original respite plan of every weekend, though his host family have indicated that this is not a pressing issue for them;*
- ***Legal requirements:** Tusla have confirmed that while Jack does not meet the need for child protection intervention, his situation warrants family support. In this regard, an assigned liaison person has been allocated to Jack's case (through Tusla's Meitheal service) and is assisting his birth mother and completing of consent forms and assisting Jack's mother in communicating with his medical team;*
- ***Entitlements and additional supports:** Jack's host family are being supported in accessing children's allowance, back to school allowance, Irish Wheelchair Association support, and in accessing a disabled person's parking card;*
- ***School:** While Jack attended {named special school} for the 2019/2020 school year, he has just started – initially on a reduced timetable (2.5 hours per day) and is to be increased on a staggered basis – in {named special school} for the 2020/2021 school year (with individualised transport). He has two classmates and has reportedly settled in well;*
- ***Case management:** As Jack's HSE case manager left the post in early August 2020, the Disability Services Manager will manage his case until a new case manager (i.e. a Social Worker with a background in child protection) commences with the HSE Disability Services in October 2020.*

- *Jack's host family have weekly contact with several professionals e.g., his assigned Social Worker {in the HSE funded Disability Service} and Clinical Nurse Manager (Grade 3); and his HSE Clinical Nurse Specialist for children with life limiting conditions.*
- *There is an individualised budget to meet Jack's equipment and other needs, and this will be reviewed regularly (e.g., to address any emerging needs).*
- *The Service Director for Tusla in {named area} and the HSE Chief Officer have agreed that given the high volume of complex cases of interest to both Agencies in the CHO that they will meet quarterly as the two most senior officials at this level. This will be in addition to normal service-to service engagement. This is with a view to strengthening shared working and problem solving of obstacles that might arise for case managers.*

6.2 In response to the recommendation that the HSE Disability Services should immediately and systemically review all cases where a child remains in hospital settings beyond their medical need.

- *The HSE acute hospital services will be joint signatories to version two of the reviewed 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) – hereafter referred to as the HSE/Tusla Joint Protocol (2020). This revised protocol will note that, in partnership with Tusla, the HSE Community Operations and Acute hospital services will commit to reviewing all cases where a child remains in hospital settings beyond medical need to ensure adherence to the relevant legislation, policy and guidance documents. As such, the current protocol will be expanded to include the acute hospital services. The revised protocol will be signed off in Q4 2020 and will act as a basis for all inter-agency working between the HSE and Tusla (e.g., CAMHS).*

6.3 In response to the recommendation that the HSE Disability Service devise a framework for a holistic assessment of both a child and family's circumstance.

- *The HSE and Tusla have agreed to sign off on, by the end of Q4 2020 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.*

6.4 In response to the recommendation 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 funding to support the right of children with disabilities to grow up with their families.

- *The HSE notes that the recently adopted Programme for Government commits to work towards implementing the 'Disability Capacity Review Report' (i.e. Multi-annual investment). This reflects how the HSE has 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 and the HSE is anxious to have this critical investment plan implemented forthwith;*
- *The HSE and Tusla met with both the Department of Health and the Department of Children and Youth Affairs in February 2020 to agree a Memorandum of Understating (MoU) in respect of the HSE/Tusla Joint Protocol (2017) and the resources necessary to fulfil both agencies' responsibilities. It is anticipated that this MoU will be) finalised in September 2020 and is with the relevant Departments to confirm. Both Agencies have agreed that while this is pending there will be every effort made to resource the complex cases presenting.*
- *Further to interviews in 2019, the HSE is currently leading on recruiting Children's Disability Network Managers who will manage our 91 inter-disciplinary Children's Disability Network Teams (CDNTs). These CDNTs will aim to provide a more equitable and timely service to children with complex disabilities.*

6.5 In response to the recommendation that the HSE Disability Service 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.

- *Taking this as referring to children with disabilities who are in hospital settings beyond medical need, the HSE in partnership with Tusla will 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.*
- *The HSE has provided appropriate care for children with disabilities where their parents are unable to care for their child. There have however been instances when the service provided has not reached the optimum outcome for the child as in Jack's case. Tusla has many children in its care who have both a protective requirement and a disability.*

6.6 In response to the recommendation that a new protocol should be in place to manage disagreements and complaints between the HSE Disability Services and acute services.

- *To be signed off in Q4 2020, the HSE/Tusla Joint Protocol (2020) 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).*

Tusla

6.7 In response to the recommendation that Tusla 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 will 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;*
- *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.*

6.8 In response to the recommendation that Tusla should 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 carers present as unable or unwilling to provide for their care.

- *Tusla will 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 who parents and carer's present as unable or unwilling to provide for their care. The CEO of Tusla is satisfied that the response in recommendation seven will adequately deal with this. 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.*

HSE and Tusla

6.9 In response to the recommendation that the HSE and Tusla should engage with the relevant HSE funded service provider to be assured that Jack's current host family arrangement complies with all safeguarding requirements under Children First: National Guidance and is comparable to that of children in foster care:

- *The HSE and Tusla have 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 Chief Officer of the HSE and the Service Director of Tusla will prioritise this matter to give effect to the intention of the recommendation. The CFA has made available to the HSE its expertise in respect of child safeguarding for this purpose.*
- *The Principal Social Worker confirmed that advice re. safeguarding with the host family has been provided.*

- *The CFA team also got legal advice and suggested to HSE that host family could possibly be considered as an applicant for joint guardianship after 12 months.*

6.10 In response to the recommendation that the HSE and Tusla should agree to actions to address the shortcomings identified in the current Home Sharing in Intellectual Disability: Report of the Nation Expert Group (2016) as they relate to children.

- *In respect to addressing the shortcomings identified in the current Home Sharing in Intellectual Disability: Report of the National Expert Group (2016), and while regulation in the area of Home Share is a key concern for the HSE, the identified need to introduce legislation in this area is a matter for the Government. While the HSE recognises the advantages of Home Sharing, there are strategic and operational challenges in the delivery of this model of support within an Irish context. 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.*

6.11 In response to the recommendation that Tusla 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 this to maximize and ensure inter-agency cooperation.

HSE and Tusla's Joint Response to Recommendation 11

- Informed by learning to date from the operation of the HSE/Tusla Joint Protocol (2017), and the review of cases including that of Jack, the revised HSE/Tusla Joint Protocol (2020) – that will be signed off in Q4 2020 – the agreement will ensure that there is improved inter-agency cooperation when supporting children with disabilities who may need a residential placement. This will include those children who are deemed to be inappropriately placed in hospital settings, and will be endorsed by the HSE Acute Hospital Services who will be joint signatories to this revised protocol.
- The HSE and Tusla are also committed to;
  - Providing additional CHO-based workshops regarding how to implement the revised HSE/Tusla Joint Protocol (2020) to both HSE (i.e. Acute Hospitals;
  - Disability; Mental Health; Primary Care); and Tusla managers and staff; and
  - Monitoring the implementation of this protocol in each CHO and Tusla area.

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