# Molly Two Years On

Have Tusla and the HSE delivered on commitments to children with a disability in the care of the State?

January 2020





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# **Summary**

In 2018 the Ombudsman for Children's Office published Molly's case, a report detailing a complaint we received about a child with a disability who is in foster care. We are returning to this case for the second year in a row to track the progress made by the HSE and Tusla on commitments made in response to the 2018 report.

Molly is 16 years old now and was born with Down Syndrome and severe autism. She was abandoned by her biological parents at birth. She has grown up with her foster family after being placed there soon after she was born. Molly is dependent on her foster carers in all areas of her care, including feeding, toileting, bathing, and dressing.

Molly's foster carer made a complaint to us about the level of supports and services being provided by Tusla and the HSE to meet Molly's needs and support her placement. We found that there was a lack of co-ordination between the two agencies which meant that services and supports provided by both organisations were insufficient.

Neither agency saw Molly as a child in care and also a child with a disability. Instead Tusla recognised her protection and welfare needs, but made no distinction with regard to her disability requirements. The HSE recognised her disability needs but made no distinction with regard her protection and welfare vulnerabilities as a child in care.

We also found that this is a problem facing many children with disabilities in care. We were told by Tusla that in 2015 there were 472 children with a diagnosed moderate to severe disability in foster care placements in Ireland. These children represented approximately 8% of the foster care population yet neither Tusla nor the HSE had a good enough system in place to ensure adequate supports were being provided to these vulnerable children, and their carers. We were concerned that this meant these children were not provided with every opportunity to reach their full potential and could also result in foster family placements ending prematurely and children with disabilities being placed in institutionalised care from which they may never leave.

As a result of our investigation, both the HSE and Tusla made a number of significant and ambitious commitments and we have been engaging with Tusla and the HSE on their progress towards fulfilling these commitments. In early 2019, the Ombudsman for Children's Office met with the Tusla and HSE National and local teams responsible for the implementation of the recommendations. At the conclusion of these meetings, both Tusla and the HSE requested an additional 12-months to ensure the full realisation of the commitments entered into as a consequence of the Molly investigation. We published an update on Molly's Case in January 2019 and continued to monitor progress since that time.

This report outlines what has happened over the past twelve months, as well as the overall changes that have taken place since Molly's Case was first published in 2018.

# **Recommendations & Commitments**

#### **OCO Recommendation 1**

Both Tusla and the HSE formally engage with their respective government departments with regard to the findings of this investigation. Formal engagement with their respective government departments would determine how the current gap in the provision and co-ordination of services and supports to children with a diagnosed moderate to severe disability in foster care can be addressed by legislative, regulatory, policy and/or budgetary means.

#### **Progress by TUSLA, the Child and Family Agency**

In 2018: Tusla told us they would submit a business case to Government to explore the introduction of an enhanced support payment for vulnerable children in their care. They told us they were fully committed to formal engagement with the Department of Children and Youth Affairs to discuss and determine both the current and future service delivery for this cohort of children.

In 2019: Despite this commitment in 2018 we found that Tusla did not make any business case to the Government as regards enhanced support payments for foster carers of children with a moderate or severe disability. As discovered in Molly's case, extra financial payments remained at the discretion of Tusla Area Managers and approved through the care-planning process.

In 2020: The Chief Executive at Tusla told us that each Tusla region is assessing current provision of therapeutic supports to children in foster care to inform planning for children with complex needs.

As regards enhanced payments he advised that Tusla has in place national guidance relating to the provision of enhanced payments for foster carers and that this is an appropriate mechanism to ensure that enhanced payments are provided on the basis of the needs of each individual child and their respective carers. However, the Chief Executive has requested a detailed briefing on this guidance and, more importantly, the application of enhanced payments to foster parents in case there are any limitations to this approach due to a now more informed view arising from the OCO investigation. Any such limitations will be addressed at the earliest opportunity.

Tusla actively advocates with state agencies for children to ensure they receive required supports such as special needs assistants, and the housing adaptation grant<sup>1</sup>.

The Chief Executive also advised that Tusla continues to engage with the Department of Children and Youth Affairs in relation to producing legislation to support and mandate multi-agency working and that a paper on this issue was submitted as part of the Expert Assurance Group process arising from the HIQA Investigation Action Plan<sup>2</sup>.

<sup>1</sup> Tusla advised that the foster care allowance is not included in the means test for housing adaption grants, the income of foster carers is considered as reported in the statement of the OCO

<sup>2</sup> This group was established by the Minister for Children and Youth in 2018 in response to the "Report of the investigation into the management of child sexual abuse against adults of concern by the Child and Family Agency (Tusla) upon the direction of the Minister for Children and Youth Affairs", as published by the Health Information and Quality Authority (HIQA).

### **Progress by the HSE**

In 2018: At the time of publication the HSE told us they made a substantial bid in their 2018 estimates to the Department of Health for respite services and they successfully obtained an extra €10 million to develop respite services across the country for persons with disabilities.

In 2019: HSE told us that they opened 10 new purpose designed respite centres in 2018. They were also able to provide more in-home respite hours as well as respite sessions in the evenings and during holidays. However, they were unable to be specific about how much of this budget was allocated to expand children's respite services. They estimated this figure to be approximately 20% or €2 million but couldn't outline the number of respite hours allocated to children. Both HSE and Tusla told us that they could not make joint submissions together for additional monies for respite services for these children because of the legislative structure of their departments. However, they told us that one HSE area, CHO5, were being actively supported by their local Tusla social work team in their budget submission for improved respite services for children in care with a disability for their area.

In 2020: The HSE Director General advised that the Department of Health and the Department of Children and Youth affairs are engaged on matters relating to the Joint Tusla & HSE Protocol arrangements. A joint meeting of the Department of Health, the Department of Children and Youth Affairs, the HSE and Tusla is also expected to take place in early 2020 to further discust his.

He confirmed that the HSE has engaged with the Department of Health regarding investment in new service developments, including respite and home supports into the future. The Director General also stated that the HSE's Community Operation's Team will work with Chief Officers and Heads of Social Care to ensure that there is a specific and ring-fenced proportion of available resources delivered to children with disabilities in foster care as part of their commitment under the HSE National Service Plan (2020)<sup>3</sup>.

Finally he confirmed the desire by both himself as the Director General of the HSE and the CEO of Tusla to work collaboratively and to strengthen relationships at local level to meet the needs of vulnerable children and young people.

#### View of the Ombudsman for Children

Of note is that, for the first time, this office has received agreed commitments from both the CEO of TUSLA and the Director General in the HSE to ensure the necessary leadership to give effect to the recommendations arising from this investigation. Despite the lengthy delay in this occurring, this is to be warmly welcomed.

Also of significance is that all of the key decision makers including the Department of Health, the Department of Children and Youth Affairs, HSE and TUSLA are, at long last, coming together to work collaboratively to meet the needs of these vulnerable children in the care of the state.

<sup>3</sup> HSE National Service Plan 2020: Action: In partnership with Tusla, fully implement recommendations arising from the Children's Ombudsman Report. This is inclusive of the need to identify, within existing budgets, supports to respond to the needs of children and young people in foster care arrangements that have been assessed as having a moderate to profound disability

We recognise that making changes takes time, but clear action is long overdue from, all leaders, to effect real and sustainable changes within both systems, because childhood is short. We welcome the inclusion of the commitment to implement the recommendations from the investigation in the HSE National Service Plan and we expect that this will be a mechanism for the government to hold both agencies to account for their progress in this area.

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

### **OCO Recommendation 2**

Tusla and the HSE should systemically review the current supports and services being offered to this child to ensure she reaches her full physical, cognitive and educational potential.

## **Progress by Tusla, the Child and Family Agency**

In 2018: Both the HSE and Tusla told us at the time of the investigation that the Joint Protocol for Inter-Agency Collaboration between the HSE and Tusla would greatly assist with a systemic review of the current supports and services being provided to Molly. Tusla expressly stated their commitment to ensuring that she reaches her potential.

In 2019: We found that the social work department made significant progress in re-assessing Molly's needs and working with the HSE in order to put in place the therapeutic supports and services which might enable her to reach her full potential.

Amongst other actions Tusla arranged for an independent two-week residential assessment of Molly's needs, a National Educational Psychologist Service (NEPS) assessment with respect to Molly's educational needs and a dietician was assigned to Molly's school and helped develop a new dietary plan for Molly.

Care plan review meetings were held and notably Tusla invited a wide range of professionals involved in Molly's life to attend her care plan review meeting along with her foster carers. This meant that, for the first time in her lifetime, her foster carers and all other adults providing services to Molly sat down together to discuss what needed to happen to help her reach her potential.

However, we found that Molly's foster carers continued to face financial challenges. For example, when Molly was placed in a residential centre for two weeks for an assessment her carer's Foster Care Allowance was deducted for these two weeks. This was despite the fact that they transported her to and from the residential unit, and visited her on three occasions. There were also still issues in relation to funding for child-minding

services. Tusla reduced funding for child-minding services from €150 to €100 per week on the basis that six hours Home Support hours and additional respite had been assigned by the HSE. This deduction occurred even though the family were not receiving these supports from the HSE, as they were unable to identify a service provider.

In 2020: The CEO of Tulsa stated that the foster carers receive a high level of support and monitoring from the social work teams. He stated that Tusla continues to provide €100 per week for child minding/housework and that respite has increased from one to two nights per month, funded jointly by Tusla and the HSE. There is also the provision of 6 hours home support per week, some of which has been "banked" to address the period when home support staff were unavailable. Banking the hours means that the home support owed to Molly and her carers, which they could not use as staff were not available, could be accumulated and used at a later date when staffing was in place.

Molly's case is also discussed at care plan review meetings and at monthly interagency meetings between the HSE and Tusla in the local area. High levels of support are provided by the social worker, social work team leader and the principal social worker. The social work department was managing concerns regarding Molly's classroom mix and staff ratio with her carer and relevant stakeholders. They were addressing concerns with the foster carers about the change in use of nutritional supplements with Molly. There are also plans, in partnership with the HSE, to support Molly's attendance at swimming on a weekly basis once a service provider had been identified.

The CEO advised that given the involvement of her carers, and the importance of continuity of the relationship for Molly while she was in residential for two weeks, carers should be reimbursed their Foster Care Allowance for those two weeks. In addition, he stated that the loss sustained by the foster carers by the reduction in enhanced payments, when Home Support was not yet in place, should also be restored retrospectively for that period. However, when we spoke with the foster carers as part of this follow up they had not yet received this reimbursement. We sought clarification from Tusla who subsequently advised that due to an oversight in the local area this had not occurred but the monies were immediately refunded to the carers.

The foster carers also told us that they remained unhappy with their engagement with Tusla and their relationship with the social work department remains difficult. This is because they do not feel their views are fully considered with respect to Molly's speech and language therapy, paediatric care and dietary needs. They were also recently informed that they would be getting a new Link Social Worker, despite requesting that either, their current Link Social Worker remain on, or their previous one be brought back, in order to ensure a continuity in support. Tusla social work department advised that they were unable to allocate their previous link social worker due to the staff member's workload. They also advised that they were unaware of the request to maintain their current link worker but will seek to ensure that consistency in support remains the same.

At the moment (following a long delay due to provider staff shortages) the foster carers have home support of six hours per week. While Tusla and the HSE agreed that the foster carers could use a certain amount of 'banked' Home Support hours (in addition to the six hours per week) upon the resumption of the service, unfortunately the new provider was unable to fulfil these additional hours.

The foster carers told us that they understood that these 64 'banked' Home Support hours would not carry over into 2020. This was confirmed by Tusla. The foster carers confirmed that they have received two nights respite per month.

#### **Progress by HSE**

In 2018: Both the HSE and Tusla told us at the time of the investigation that the Joint Protocol for Inter-Agency Collaboration between the HSE and Tusla would greatly assist with a systemic review of the current supports and services being provided to Molly.

In 2019: The HSE confirmed that a disabilities case manager had also been assigned to Molly to help co-ordinate her care with her foster carers, the various HSE services and with Tusla.

In 2020: The Director General HSE stated that the Disability Case Manager attends and participates in joint child care meetings. He stated that Molly was offered two to three nights of respite care per month in 2019. He stated that Molly's school is working with her SLT, Paediatrician and Dietician regarding her feeding regime and is coordinating with her Disability Case Manager and Social Worker. He stated that from March 2019, an average of six hours of Home Support per week has been provided. He stated that there is a request for additional Home Support, in order to bring Molly to swimming, that this is currently under review by the HSE and Tusla, and that it will depend upon access to transport and staff availability.

#### View of the Ombudsman for Children

There is no doubt that both the HSE and Tusla locally are working much more closely together than ever before to meet Molly's needs and we welcome in particular that professionals from a range of disciplines continue to be actively involved.

Molly has complex health and educational needs and it is important the right people are working together at the right time to meet these needs. Of note is that Molly's foster carers believe the provision of education to Molly has improved, which is key factor in helping her reach her potential.

Tusla has played a key role in co-ordinating everyone's efforts and most importantly, in building positive relationships to ensure good communication and helpful interactions between professionals across all agencies. It appears that significant progress has been made in the local area with regular meetings between Tusla and the HSE to discuss, not only Molly's case, but other similar cases. This is to be commended especially as other HSE areas around the country have only made limited progress in this regard.

Maintaining relationships between foster carers and their network of support is hugely important and it is regrettable that both their link social worker and Disability Manager are changing. Every effort should be made to maintain consistency in such relationships and the views of foster carers actively considered when changes are being made.

Both the foster carers and Tusla understood that the carers would be losing their 'banked' home support hours for 2020. However, the HSE clarified with us that this was not the case and these hours remained available to the foster carers. The HSE advised us that they would contact both the foster carers and Tusla to clarify this. They also advised that the current weekly six hour home support is continuing but as the foster

carers requested additional support a business case was required in accordance with standard HSE processes.

A key issue arising from our investigation was that Molly's foster carers carried the burden of seeking services and support for Molly. While there has been obvious improvement it is disheartening that two years later there is a lack of clarity between the HSE with the foster carers and Tusla as regards home support.

Molly's needs are predictable and therefore services should be able to work together to ensure foster carers are fully informed about available support and the care planning process should be the mechanism to consider whether support may need to be increased over time following assessment. Any lack of certainty is unfair, not just on Molly but also on the foster carers who care for her each and every day.

#### **OCO Recommendation 3**

If, as proposed, this child is moved to another care placement, that Tusla and the HSE put in place the necessary supports so that she experiences a stable transition from her current to her future home.

## **Progress by Tusla, the Child and Family Agency**

In 2018: Tusla told us that they remained fully committed to their statutory responsibility to Molly and this includes ensuring that all care planning decisions (including placements) are guided by the best interest of the individual child. This includes a commitment that any placement moves would be underpinned by stability and minimum disruption to the child's life through the provision of identified appropriate supports and joint professional liaison where necessary.

In 2019: Tusla re-iterated their commitment to Molly and to provide continued support to her carers to maintain the stability of her placement.

In 2020: We found that Molly remains living with her foster carers and there are no plans to move her to another placement. We understand that everyone is committed to help support Molly and her carers so that she can remain living in her family home.

#### **Progress by HSE**

In 2018: HSE told us that they remained fully committed to do a joint review of this case with Tusla, the Child and Family Agency. Support will be provided by HSE Disability Services as it is required and this has been agreed with Tusla.

In 2019: HSE re-iterated their commitment to work closely at local level with Tusla to provide continued support to Molly and to her carers.

In 2020: We found that Molly remains living with her foster carers and there are no plans to move her to another placement. We understand that the HSE is committed to continue to provide the necessary supports to help Molly and her carers.

#### View of the Ombudsman for Children

When Molly's case was first published in 2018 serious consideration was being given to moving her to residential care. This was not something that her foster carers wanted. The enormous amount of work that has taken place, by the HSE and Tusla, to address the OCO recommendations has changed Molly's situation and she is thankfully still at home in a loving family setting. There is no doubt that this has been to Molly's benefit and it has also resulted in a significant saving for the exchequer. The savings were generated because there is approximately €90,000 difference in the cost of foster care compared to HSE disability residential care per year⁴.

It is a concern that the relationship between the social work department and the foster carers remains fraught. Oftentimes when relationships between adults become difficult, it can inadvertently have a negative impact on the child. Molly is a child with complex needs and there is no doubt that she requires extra care and support to reach her potential. Tusla, in caring for Molly, must also continue to provide appropriate care to her foster carers with these considerations in mind, so that they feel valued and supported in their parenting. The commitment and love provided by Molly's foster carers over the almost 17 years she has been in their care, must also be recognised. As Tusla have the statutory responsibility for Molly and the foster carers have the parenting responsibilities it is completely understandable that views can differ about what is best for Molly. However, every effort must be made to resolve disagreements and seek to understand each other's views, to ensure that everyone agrees on what is in Molly's best interest both now, and into her adulthood.

## **OCO Recommendation 4**

Tusla and the HSE should systemically review the supports and services being offered to approximately 471 other children with a moderate or severe disability in foster care in the State within 12 months of the date of issuance. The output of this review should inform the development of the local case management model, currently proposed in the Joint Protocol. The review should also inform the development of specific performance metrics and outcome measures for this cohort of children, as well as wider inter-agency and departmental engagement.

#### **Progress by Tusla, the Child and Family Agency**

In 2018: Tusla stated that they issued a communication to all staff to ensure that they were fully aware of the Joint HSE/Tusla protocol and of the undertaking given to the Ombudsman for Children to ensure systemic review of the supports and services being offered to children in care with a moderate to severe disability. They advised that that these systemic reviews would occur under the statutory care planning functions as per the Child Care Act 1991. They also advised that the Service Directors for each region would collate the data from the systemic review to inform any future development of

<sup>4 &</sup>quot;A Time to Move On from Congregated Settings",(HSE 2011) found that while costs varied from centre to centre, the average payment per person by the Health Service Executive was €106,000. Source www.gov.ie. Foster care allowance is €325 per week for child under 12 years of age and €352 for child over 12 years of age. Child benefit is €1,680 per year.

specific performance metrics and outcome measures for this cohort of children. In addition, Tusla would identify these children to their colleagues in the HSE in order to facilitate the preparation for involvement in care planning and joint working for these children.

In 2019: Notable progress was reported in implementing the Joint Protocol for Interagency Collaboration, which has been in force since March 2017. Tusla told us that its Chief Operations Officer and the HSE's Head of Operations for Disability Services now meet quarterly under the National Joint Protocol Oversight Committee. Every area now has an Area Joint Working Group, and the relevant HSE Head of Service from each Community Healthcare Organisations (CHO) area meets with the relevant Principal Social Worker monthly, to review the cases of all children in care with a diagnosis of moderate or severe intellectual disability.

Tusla has stated that there is an expectation that decisions regarding the provision of access to appropriate, available services will be made at local team level. However, there is now a clear escalation policy for complex cases that cannot be resolved at local level. According to Tusla, Joint Protocol workshops have been held at local level and a directive has been issued by both Tusla and the HSE that the protocol must be used. Furthermore, all social work team leaders have been informed that HSE staff members involved in a child's case must be invited to Child in Care Reviews.

In addition to the Joint Protocol, Tusla has conducted an internal audit in order to identify children with a moderate or severe disability in foster care and to determine the additional supports required by them. Data returned from the Tusla areas in November 2018 showed that there were 483 children in care with a diagnosis of moderate or severe disability. Of these, Tusla stated that 407 have had their Child in Care Reviews within the statutory time frame. Of the 76 who have not had their Child in Care Review within the statutory timeframe, there are dates set for 69 reviews. Tusla stated that performance metrics and outcome measures were still being developed for this cohort of children, and that specific research into how Tusla measures success is being commissioned.

Tusla told us there is now a central national database for this cohort of children, which will allow Tusla and the HSE to plan at an earlier stage for the children's transition to adult care. While we welcome this positive development of a central database we note that HSE could not confirm that each of the CHO local areas have identified these children.

In 2020: The CEO of Tusla advised that Tusla is committed to implementing the HSE-Tusla joint protocol with regard to children with a disability by (1) allocating a senior Tusla staff member at Area Manager level to have national oversight of compliance with the protocol, (2) organising joint HSE-Tusla workshops across the country to brief senior staff in Tusla areas/HSE CHOs, (3) establishing Area Joint Working Groups with an escalation mechanism (although he states that challenges exist regarding both agencies capacity to fund and support individual cases in accordance with multiple statutory obligations), and (4) establishing a National HSE-Tusla group to provide national oversight and governance with regard to implementation of the protocol.

He stated that the routine inclusion of HSE Disability Managers in care plan reviews for children with a disability is an example of Tusla and the HSE's close working relationship. He stated that these reviews occur at a minimum annually, and the HSE is invited to

participate in this process either by attending the meeting or, where appropriate, by providing a report with relevant updates.

He confirmed that, the figure of 471 children referenced in our investigation statement was based on figures provided by Tusla from 2015. He further advised that at the end of September 2018, the number of children in care with a diagnosed disability was 477. He is aware that there remain concerns about the process for agreeing this number with the HSE but provided assurance that more clarity will be brought to this issue between the two agencies. Notwithstanding this he has advised that the focus should remain on the children known and agreed with HSE counterparts at local level, ensuring the maximum possible response to them. He stated that Tusla's National Childcare Information System (NCCIS) is now live in all 17 areas, and that this system has the capacity to record data in respect of children in foster care with a mild, moderate, and severe disability, and to generate reports to inform service planning.

#### **Progress by HSE**

In 2018: HSE committed to working collaboratively with TUSLA to systemically review the needs of this vulnerable group and to have concluded this process within 12 months of the date of issuance. This commitment was made subject to Tusla, as the statutory lead, convening and leading this process as per their statutory remit and through the agreed structures under the Joint Protocol.

In 2019: There was a significant lack of progress on the commitments made by the HSE. The HSE told us that disability managers in the various CHOs did not have the capacity to undertake case management roles. The HSE stated that the case manager role, now assigned to Molly's area, is not in every area and that each of their nine CHO areas are proceeding at a very different pace in terms of Joint Protocol implementation. In addition, the HSE indicated that not all areas and front-line staff members fully understood their roles and responsibilities under the protocol. The HSE stated that not every area was aware of the Molly investigation and the recommendations agreed upon by the HSE. The HSE believes stronger communication was required between the national and local teams.

According to information submitted by the HSE, only four Area Joint Working Groups had identified their cohort of children with moderate or severe disability in foster care. The remaining five CHOs working groups are still 'in progress' to identify these children. The HSE contends that the data received from Tusla was incomplete because there's no consensus between the HSE and Tusla as to what constitutes a moderate to severe disability. The HSE has stated that it was undertaking a validation exercise at CHO level to determine the children's names and conditions.

Moreover, the HSE did not know how many of the children identified had Tusla care plan review meetings informed by the HSE services or how many of these children had individualised plans to meet their needs from the HSE. The HSE acknowledged that of the nine CHO areas only one area reviewed the needs of these children through the care planning process. The HSE stated that two areas had not even begun planning for the systemic reviews committed to at the time of publication.

In 2020: The CEO of the HSE stated that the HSE is continuing to implement the Joint Protocol via the 17 HSE/Tusla Area Joint Working Groups throughout Ireland.

He stated that the investigation statement's reference to approximately 471 children came from a September 2015 Tusla data source that did not include the children's names or identifiers. He stated that, given that this database used a broad definition of disability (including children with mild disability and/or a physical or sensory disability) and included children who had yet to be assessed, the HSE contends that the figure of 471 children with moderate to severe disability cannot be relied upon.

However he advised that Statutory Children in Care Reviews are progressing at local level with a view to ensuring that there is an active care plan in place that guides all stakeholders in supporting each child and his/her carers. According to information provided by the HSE, five of the nine CHOs have identified the cohort of children with a moderate to severe disability in foster care and this work is in progress in the four remaining areas. This is just one additional CHO area than in 2019.

Only three out of nine CHOs have worked with Tusla through the care planning process to review the identified children's care plans. There are two additional CHO areas compared to 2019. This work is in progress in five other areas and has not yet started in CHO 7 (Kildare/West Wicklow, Dublin West, Dublin South City and Dublin South West).

He stated that if areas of concern arise, these can be addressed via the 17 HSE/ Tusla Area Joint Working Groups and, if necessary, the nine HSE/Tusla Community Healthcare Organisation Joint Working Groups, or the HSE National Director and Tusla Chief Operations Officer. The HSE has also drafted a local case management model and KPIs (including outcomes) for children with complex needs in statutory care as a result of their on-going reviews.

At a national level the HSE has worked with Tusla to identify children with a moderate to severe disability in care, including foster care, who will turn 18 years in 2019/2020, and has submitted an estimate of the funding required to support these transfers to the Department of Health via the 2020 budget estimates process.

#### View of the Ombudsman for Children

Two years on it is obvious that these vulnerable children are no longer invisible to the HSE and Tusla, the Child and Family Agency. The Chief Executive Officers of both agencies re-iterated in their most recent correspondences their shared commitment to work together to meet the needs of these children. Both the Department of Health and the Department of Children and Youth Affairs have a critical role to support this commitment through specific actions and we note the HSE included the commitment to meet the recommendations of the investigation in their HSE Service Plan 2020 which was approved by the Minister for Health in December 2019.

There is no doubt that there is much more to do. At the most basic level it is incomprehensible that two years on the HSE has still not managed to come to an agreement with Tusla to identify the children in state care with moderate to profound disabilities. Together the HSE and Tusla have 17 Joint Area Working Groups and a series of national, regional and local processes have been introduced to deal with this small and very specific cohort of children. Despite this impressive new network, the HSE and Tusla cannot come to an agreement about the number of moderate to severely disabled children in care. There also remain significant and inexplicable disparities across the

nine HSE CHO areas in relation to their engagement with Tusla's care planning process to meet the needs of these children.

The HSE and Tusla are proud of the fact that they have worked together successfully to identify the children in this cohort who will turn 18 in 2019/2020, and that is good. However, is it not possible that the same process could be used to identify younger children and plan for their care from as early as possible? A failure to do so suggests a focus on the financial implications to their budget when they take over the care of an individual, rather than a drive to plan for and provide the best care for children when they need it.

# Conclusion

Molly is still happily living with her foster carers and is receiving greater input and support from a wider range of services than two years ago. Her educational experience has improved according to her carers and respite is provided on a much more frequent basis than two years ago. This is a welcome outcome from this investigation and all the HSE and Tusla professionals involved with Molly in the local area should be proud of this. However, the foster carers still faced delays in securing promised financial reimbursements and flexible home support remains an on-going challenge. All of these factors appear to have affected the quality of the relationship between Tusla and the foster carers, which is deeply regrettable, and renewed efforts must be made by all adults involved to improve this in order to protect Molly.

The working relationship between Tusla and the HSE, and the impact that this is having on the care of children with disabilities who are in state care, is still of concern. The implementation of the Joint Protocol for Interagency Collaboration has progressed but there is still a long way to go.

The Government has an important role to play in providing strength and support to the Joint Protocol for Interagency Co-operation. A specific, bespoke approach is necessary to adequately support and provide for this cohort of children in the care of the state. The Government can take the lead to make this happen, and consideration should be given to providing a protected budget for this cohort of children to meet their predicted needs. However, it is an absolute necessity to budget for these children from birth, or the first day they enter state care, and to acknowledge that there is a known and ongoing commitment (in terms of finance and human resources) required from the state.

It is imperative that every effort is made to support exceptionally committed foster carers that are looking after children with moderate to severe disabilities. Key practical changes would make significant differences to foster families around Ireland including the provision of flexible home support, enhanced payments to meet the financial implications in caring for a child with disabilities, and greater respite care. The regular and on-going use of specific business cases for the attainment of services for children is a significant burden on foster carers. If the children are known by virtue of the fact they are in State care then their identified needs are somewhat predictable.

There must be a better way to support foster parents who provide such invaluable love and care to our most vulnerable children. Without these foster carers there is no doubt that these children would grow up in institutions and remain there. Ireland has no desire to return to the widespread institutional care of children especially children with disabilities.

There is a unique opportunity here for the Department of Health through its work to implement the UN Convention of the Rights of People with Disabilities in Ireland to work alongside the Department of Children and Youth Affairs to protect and enshrine the rights of children with disabilities so that they are always seen as children first.

Therefore, in conclusion, it is my intention to submit a copy of this report to both the Oireachtas Joint Committee on Health and the Oireachtas Joint Committee on Children and Youth Affairs to highlight the limited progress to date in response to the recommendations by both the HSE and Tusla, the Child and Family Agency. In an effort to mirror the level of cooperation required for this case, I will be urging the two committees to come together to review the report and address the issues arising.