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An Investigation by the
Ombudsman for Children's Office

Molly's* case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State

January 2018

*Not her real name

The issue:

Molly

Molly is a teenager. She was born with Down Syndrome and severe autism, and was abandoned at birth by her biological parents. She has grown up with her foster family after being placed there when she was a baby. Molly is dependent on her foster carers in all areas of her care, including feeding, toileting, bathing, and dressing. She requires a wide range of therapies and services to help with her health and developmental needs. Molly's foster carer, who complained to us, made clear that Molly has brought love and positivity to their lives, but she is also completely dependent in all areas of her care.

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. During our investigation Molly's foster carer was told that Molly would have to be moved to a full time residential placement.

Our findings:

We investigated Molly's case and found that the administrative actions of both Tusla and the HSE had a negative effect on her. There was a lack of co-ordination between the two agencies which meant that services and supports provided by both organisations were insufficient.

We found that 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.

This meant that Molly did not have the opportunity to reach her full potential. 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.

We found that neither Tusla nor the HSE had a good enough system in place to ensure adequate supports were being provided to these vulnerable children and to their carers. We were concerned that this meant these children were not provided with every opportunity to reach their full potential.

Our recommendations:

- Address the current gap in the provision and co-ordination of supports and services to children with a diagnosed moderate to severe disability in foster care through legislative, regulatory, policy and/or budgetary means.
- Review the current supports and services being offered to Molly to ensure that she reaches her full physical, cognitive and educational potential.
- If, as proposed, Molly is moved to another care placement, ensure the necessary supports are put in place so that she experiences a stable transition from her current to her future home.
- 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. The output of this review should inform the development of the local case management model, the development of specific performance metrics and improve wider inter-agency and departmental engagement.
- Devise a respite action plan for children with a disability in the care of the State, as well as children with a disability in the community at large.

This statement and our recommendations have implications, not just for Molly, but for approximately 471 other children with a moderate or severe disability in foster care in the State.

Tusla has accepted the recommendations made by the OCO as a result of this investigation and will formally engage with the Department of Children and Youth Affairs concerning the findings of this investigation.

A commitment has also been made by Tusla to undertake a systemic review of the supports and services being offered to children in their care with a moderate to severe disability. In addition, Tusla will identify these children to the HSE in order to facilitate care planning and joint working for these children. They also agreed to collate data from this systemic review to inform any future development of specific performance metrics and outcome measures for this cohort of children.

The HSE accepted the recommendations and committed to working closely with Tusla to review Molly's case as well as the other 471 children. The HSE also committed to include these vulnerable children in state care in their performance indicators under Progressing Disability Services, and to ensure that any assessment procedures have regard to their specific vulnerability as a child in care. The HSE has also sought additional funding from the Department of Health to improve the provision of respite services.

The Ombudsman for Children welcomes the commitments from both agencies and hope their actions will allow other children like Molly to grow up in families and to reach their full potential.

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Abbreviations

Ombudsman for Children's Office	OCO
Tusla - Child and Family Agency	Tusla / CFA
HSE Disability Services	HSE*
Intellectual Disabilities Liaison Nurse	IDLN
Occupational Therapy	OT
Memorandum of Understanding	MoU
HSE Integrated Service Area	ISA
Principal Social Worker	PSW

*Where 'HSE Child and Family Services' (the precursor to Tusla) is referred to, the entire phrase is used.

1. The Complaint

1.1. We received a complaint from Molly's foster carer, on behalf of Molly who is a teenager and who had been living with her foster carers since she was a baby.

1.2. Molly was born with Down syndrome and severe Autism Spectrum Disorder. Abandoned at birth, her biological parents have no contact with her. Legally she is in the care of Tusla.

1.3. Molly is dependent on her foster carers in all areas of her care, including feeding, toileting, bathing, and dressing. She requires a wide range of therapies and services to help with her health and developmental needs.

1.4. Molly's foster carer entered into a standard fostering contract[1] in 2003, when Molly first came to the family. She says that she was told at that time that all Molly's needs would be taken care of by the then Local Health Board, now Tusla and she accepted this.

1.5. Molly's foster carer says that at the time of the placement, she was informed that Molly had a mild disability; however, within three years of her placement they were informed that her condition had become more severe.

1.6. Molly's foster carer raised concerns about the supports and services provided to her and her family in order to meet the needs of both Molly, the subject of the complaint, and another foster child, who has mild Autism Spectrum Disorder. This foster child is now an adult and continues to live with the foster family. He is not the subject of this complaint.

1.7. Molly's foster carer says that Molly has brought nothing but love and positivity to their home and that she is a beautiful human being who needs extra care and attention. However, she told us that she is financially, emotionally, and physically drained, which she states is a result of a lack of support. She described feeling 'emotionally destroyed' but nevertheless she says she 'had to keep trying to find a way to fight for' her foster daughter. She equates her situation to being kept 'like a prisoner' in her own home at times. Molly's foster carer has also described the immense toll on her immediate family as a result of the care and advocacy required by Molly.

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[1] In its response to the draft investigation statement, Tusla has stated that 'this is not unusual as the child's needs are identified through the care planning process'.

2. The Investigation

2.1. Our role is set out in the Ombudsman for Children Act, 2002.[2] 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 2016, following a preliminary examination of the complaint[3], we advised Tusla and the HSE that we intended to proceed to statutory investigation with regard to the agencies' engagement with the foster family, and with each other, in respect of Molly.

2.4. We investigated the administrative actions of Tusla with respect to the following terms of reference:

- The advocacy undertaken by Tusla regarding additional financial support available to the family in respect of Molly's needs, particularly in relation to housing adaptations and transport;
- The information provided to, and communication with, Molly's foster carer in relation to additional supports available to them and how to apply for these; and
- The assessment and planning by Tusla for Molly's on-going and changing needs, including the need for adequate respite care and a co-ordinated approach with respect to her foster brother.

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[2] Ombudsman for Children Act, 2002, sections 8-16.
[3] Ombudsman for Children Act 2002, Section 8

2.5. We investigated the administrative actions of the HSE with respect to the following terms of reference:

- Current supports provided to Molly, including home supports and respite;
- Support to the family in identifying and providing for Molly's identifiable and changing needs, including adaptations to the house, equipment etc.;
- Engagement with Tusla in respect of planning for, and meeting, Molly's needs now and into the future; and
- Current working protocols and procedures for engagement between the HSE' Disability Services and Tusla in respect of children in care with a disability.

2.6. The investigation involved a review of all the information and files received in relation to the complaint. Investigation meetings also took place with the relevant local staff and national representatives of Tusla and the HSE, who had particular knowledge of Molly and/or the matters being investigated.

2.7. These meetings allowed us to acquire further information in relation to the complaint. The meetings also afforded Tusla and the HSE an opportunity to comment and provide any other information, which may assist in our understanding of the matter.

2.8. In accordance with Section 6(2) of the 2002 Act, this Office also considered meeting with Molly. Molly was present when we met with Molly's foster carer; however, she is non-verbal and has severe communication challenges. We, therefore, determined that it would not be possible, in the circumstances, to ascertain her views on matters under investigation.

3. Law and Policy

3.1. We review public bodies' administrative actions against relevant international and national legislation and policy, alongside local policies and procedures. It is not practical to list all the law, policy and procedures related to this complaint; however, we consider those referred here as particularly relevant to a complaint concerning a child with a disability in foster care.

3.2. International Standards

3.3. 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 fulfill the rights of all children, as outlined in the UNCRC, including children with disabilities. Article 3 emphasises that "the best interest of the child shall be a primary consideration" in all actions concerning children undertaken by "administrative authorities", such as the two public bodies involved in this investigation. Article 23 further recognises 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 disabilities.

3.4. *Paragraph 46 of UNCRC General Comment No. 9 (2006)* on *The rights of children with disabilities*[4] provides that 'Recognizing that the foster family is an accepted and practiced form of alternative care in many States parties, it is nevertheless a fact that many foster families are reluctant to take on the care of a child with disability as children with disabilities often pose a challenge in the extra care they may need and the special requirements in their physical, psychological and mental upbringing. Organizations that are responsible for foster placement of children must, therefore, conduct the necessary training and encouragement of suitable families and provide the support that will allow the foster family to appropriately take care of the child with disability'.

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[4] http://www.refworld.org/docid/461b93f72.html

3.5. The *Committee on the Rights of the Child's Concluding observations on the combined third and fourth periodic reports of Ireland*[5], call on the government to '16(d) Define specific budgetary lines for Traveller and Roma children, as well as children with disabilities who may require affirmative social measures, and ensure that those budgetary lines are protected in situations of economic crisis' and raised concern that '47(b) There are inadequate measures for facilitating the care of children with disabilities in the home environment, where possible or appropriate, in lieu of hospitalisation or institutionalization'. The Committee called on the government to '48(a) Adopt a human rights-based approach to disability and establish a comprehensive strategy for the inclusion of children with disabilities'.

3.6. Domestic Law and Policy

3.7. 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, Article 41A of the Irish Constitution places an onus on the State to recognise and affirm the natural and imprescriptible rights of all children. Section 8(8) of the *Child and Family Act 2013* makes a commitment that Tusla "shall facilitate and promote enhanced inter-agency cooperation to ensure that services for children are co-ordinated and provide an integrated response to the needs of children and their families."

3.8. *Better Outcomes Brighter Futures: The National Policy Framework for Children and Young People 2014 – 2020*[6] 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 across the five national outcomes'. The five national outcomes include 'Achieving full potential in all areas of learning and development' and 'Safe and protected from harm'.

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

[6] See https://www.dcya.gov.ie/documents/cypp_framework/BetterOutcomesBetterFutureReport.pdf

3.9. *Better Outcomes Brighter Futures* further prescribes that the diversity of children's experiences, abilities, identities and cultures is acknowledged, and reducing inequalities is promoted, as a means of improving outcomes and achieving greater social inclusion. It envisages that 'Inequalities are addressed across all sectors, including health, education and justice. Children and their parents do not face discrimination of any kind, irrespective of membership of the Traveller community, race, colour, gender, sexual orientation, gender identity, civil status, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status. All children in need have equality of access to, and participation in, a range of quality public services'.

3.10. The National Disability Strategy Implementation Plan 2013 - 2015[7] 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 of the mainstream community' and objective 2(b) provides that the 'move from congregated settings to live in community' be supported (at page 6).Progressing Disability Services for Children and Young People is the HSE's vision to make disability services equitable and consistent for all[8].

3.11. Finally, we reviewed specific policies and schemes such as the *Child Care (Placement of Children in Foster Care) Regulations 1995;*[9] the *National Standards for Foster Care (2003);*[10] the HSE's *Guidance on the Purpose and use of the Foster Care Allowance (2013);*[11] and the HSE's *National Policy and Procedure on Respite Care in Foster Care Settings (2013)*

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[7] http://www.justice.ie/en/JELR/NDS_ImplementationPlan_FINAL.Pdf/Files/NDS ImplementationPlan_FINAL.Pdf

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

[9] Available at: http://www.irishstatutebook.ie/eli/1995/si/260/made/en/print.

[10] Available at: https://www.dcya.gov.ie/documents/publications/National_Standards_for_Foster_Care.pdf.

[11] Available at: http://www.ifca.ie/files/1814/3324/2640/IFCA_insert_part_1.pdf.

4. Findings

4.1. The findings of our investigations relate to whether public bodies' administrative actions have adversely affected Molly. We also addressed the other approximately 471 children with disabilities currently in the care of the State.

4.2. Our findings against Tusla can be summarised as follows:

i. **The failure by Tusla to put specific training and qualified support in place at the time of placement is, given Molly's known diagnosed disability, contrary to fair and sound administration**

Although the social work teams assigned to Molly and her foster family over a 14-year period demonstrated high levels of motivation and, in some cases, engaged in exhaustive advocacy, their efforts were hampered by the lack of specified training and instruction on how to access appropriate supports and services. International standards recognise that children with disabilities pose a challenge in the extra care that they may need in their physical, psychological and mental upbringing[12], which can create reluctance among foster carers to accept these children. In order to militate against the inability to place, a child with disabilities in foster care, the breakdown of their foster placement, and a reversion to residential care, there should be streamlined additional and appropriate supports and services for children in care with a moderate to severe disability. However, at present Tusla does not make any distinction for this cohort of children in care, or the challenge presented by their extra needs.

Molly's foster carers were approved by the HSE Local Health Board, now Tusla, as appropriate carers for Molly's age group, not necessarily her particular needs. They did not receive any specific training or support with regard to parenting a child in care with a severe intellectual disability. However, Tusla insists that a foster carer's particular practical experience of the child's behaviours means that it is their role to articulate the child's needs to the social worker. This rationale may hold for able children in care who might experience behavioural shifts during their placement, but it does not hold for carers of a child with a moderate or severe disability who have no specific training or knowledge in caring for a child with complex needs.

Molly's foster carer could not rely on the social work team for advice, guidance and training in order to bridge this competency gap, as the social workers, by their own account, did not have, and were not required to have, any training or experience of children with a moderate, severe, or profound intellectual disability.

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[12] See paragraph 46 of UNCRC General Comment No. 9 (2006) see 3.1 above

Several social workers interviewed described feeling ill-equipped with regard to supporting Molly and her foster family. One social worker interviewed suggested that children in care with a disability should be entered into a special category when placed so that they automatically get access to greater financial assistance and respite, given the extra care required[13]. Indeed, eight social workers[14] commented to us that foster carers of children with disabilities needed more support services from the outset.

At interview, Tusla stated that the professional qualification of social workers covers all client groups, and they do not see the need for specialist teams for disability because social workers work in collaboration with other agencies. Therefore, collaboration with the HSE is essential in order to ensure that the rights and entitlements of children in care with a disability are fully and systemically realised at a local level.

Tusla stated that there is 'no evidence of how the lack of specified training and instruction has hindered access to specialized supports'. We accept that Molly'sfoster carer was proactive in seeking therapeutic supports for her foster daughter, which prevented poorer outcomes for Molly. However, Molly's foster carer experienced difficulties and delays in accessing day-to-day supports and services. This represents an unjustified barrier to a child in care with a disability reaching their full potential. Also, as outcomes for this cohort of children are not measured by Tusla, it is not possible for us to say conclusively what Molly's outcomes would have been had day-to-day supports and services been streamlined.

ii. Tusla does not make any distinction with regard to the categorisation, placement and provision of supports and services to a child with a disability in foster care, which is contrary to fair and sound administration

In an interview with us, Tusla management stated that the *equity of care principle* means that a child with a disability gets exactly the same service as another child in foster care. Tusla stated that no distinction is made with regard to a child in care with a disability, however, if that child needs a service, they will advocate strongly for it.

Despite numerous requests for documentation, which stipulates Tusla's equity of care principle and its application, none has been provided. Tusla stated that the equity of care principle is enshrined in the vision statement that '*All children are safe and achieve their full potential*' in the Tusla Corporate Plan 2015-17.

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[13] Interviewee 7

[14] Interviewees 5,6,7,8,9,11,12 and 13

Tusla has further stated that ‘Put simply, Tusla’s focus on the assessed needs of the child takes cognisance of the disability. It is the role of the social worker to ensure access to specialist services. Advice on managing a child with disability is usually and correctly provided to a carer by the therapist providing services. The foster carer, as the person caring for the child on behalf of Tusla, has particular practical experience of the child’s behaviours and as part of the fostering task has a role in articulating these behaviours to the child’s social worker in order that the social worker can seek access to specialist services’. We believe it is not sufficient to simply ‘take cognisance’ of the complex needs associated with a moderate or severe disability such as Down Syndrome combined with a diagnosis of severe Autism. This may imply that a minor adjustment to the norm is sufficient, which is clearly not the case, thus perpetuating the disadvantage experienced by this cohort of children in care.

iii. **Tusla’s current system of request for each funding requirement as it arises places an undue financial, administrative and, potentially, psychological burden on the foster carers of the child. Such a system unfairly militates against the fostering of a child with a disability where such routine costs are not provided for, or the repayment of routine costs is delayed, and is contrary to fair and sound administration**

Molly’s foster carer has had to present and request each funding requirement as it arises, assuming a substantial financial burden. She detailed to us her extra expenditure to date, which is attributable to Molly’s disability. She states that:

They have incurred and, for the most part, will continue to incur, costs associated with travelling from their rural home to attend regular appointments with the physiotherapist, SLT and OT; quarterly appointments with the dietician; regular appointments with the pediatrician, and for hearing and eye tests; follow-up visits to the ENT Department in another county hospital; multiple visits to GP services when she suffers infections, dehydration or severe constipation; and overnight stays with Molly in their county hospital. A return trip from their home to attend the physiotherapist, SLT, OT, dietician and GP services is 38kms, to attend the pediatrician and health centre is 54kms, to attend their county hospital is 96kms, and to attend another county hospital for specialised treatment is between 160kms to 208kms.

They provide Molly with a special liquidised diet as advised by the dietician and other over the counter medication which is not covered by Molly's medical card. Molly was initially in receipt of Dietary Allowance, however, this ended when Molly's foster carer began receiving the pension and no longer satisfied the means test requirement.

Molly's foster carer also provides specialised clothing, bed clothing and supplies including nappies, baby powder, Sudocrem, and baby wipes, which Molly will require long-term. The necessity for constant clothes washing and ensuring that their home is warm enough for Molly, has resulted in extraordinarily high electricity[15] and home heating bills. These are costs that would not occur with a non-disabled child of similar age. The 'Guidance on the Purpose and use of the Foster Care Allowance'[16], while not exhaustive, does not list any of these whole life additional expenditures.

They pay for HSE Disability Services respite for two weekends a year and five days in the summer at a cost of €15 per night. The local social work team contacted the financial department of the HSE Child and Family Services querying why Molly's foster carers had to pay respite to an organisation funded by the HSE generally. The budget holder said that HSE Child and Family Services would not be able to fund Molly's respite as HSE corporate, which was the corporate parent at the time, is not set up as a foster carer and 'that type of payment was usually made at local level'. The argument advanced by the HSE Child and Family Services, in this instance, suggests an abdication of their duty as corporate parent to the foster carer concerned.

Molly's social work team advocated and were successful in obtaining funding for the cost of adapting Molly's bedroom (€627.97) and for a car swivel seat (€2,213.25) from HSE Child and Family Services, the precursor to Tusla.[17] The social work team also contacted their budget holder, now Tusla, regarding Molly's foster carers concerns about additional costs. They were told that there was no scope to refund additional costs accrued as a result of Molly's disability. Tusla stated that the foster carers were in receipt of €16,900 per annum Foster Care Allowance, €1,560 per annum Child Benefit, and approximately €3,714 per annum Domiciliary Care Allowance. This was deemed sufficient by Tusla.

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[15] From ESB bills provided by the complainant, the average monthly cost of electricity between August – December 2016 was €248

[16] Available at: http://www.ifca.ie/files/1814/3324/2640/IFCA_insert_part_1.pdf

[17] In its response to the draft investigation statement, Tusla asks that this Office note the 'long home visits' attended by social works as evidence of support received.

Molly’s foster carer was told by her fostering link social worker to document what expenses were not being covered by the Foster Care Allowance and to send this information to the Minister or to the Ombudsman for Children’s Office as they are ‘unable to change things like this at [their] level and it needs to go higher up for any policy change’.

Following the transfer of Molly’s case to another Tusla area and in order to relieve Molly’s foster carer’s load, the social work team agreed to provide funding for a cleaner at a cost of €200 per week for four weeks and €110 per week thereafter; to be reviewed in six weeks. The social work team subsequently agreed at a Professionals Meeting to increase support for a carer and a cleaner to €240 per week on an assessed needs basis.

This funding of €240 per week ended in January 2017 after Molly’s foster carer stated that the private carer and cleaner, who were sourced by her, were no longer able to attend. The principal social worker (‘PSW’) stated that funding would recommence once Molly’s foster carer sourced an alternative provider[18]. The PSW also stated that additional funding for overnight care may be approved if Molly’s foster carer can identify someone to care for Molly, in order to allow her and her husband a night away together every two to three months. The PSW stated that this funding would need to be approved in advance, in line with national financial regulations and the scrutiny of the auditing committee.

iv. Tusla does not streamline appropriate supports and services or have any specified scheme or budgetary line for the foreseeable additional supports and services, including spending requirements, of foster carers of a child with a disability. This is contrary to fair and sound administration

Tusla told us that should a child in care with a disability present a funding requirement, social workers would have to make their case for resources as before and that each case would be judged on its merits. The budgeting for such foreseeable expenses does not appear to form part of any planning process with respect to a child who is in the care of the State. From our investigation it appears the current system of presenting and requesting each funding requirement as it arises, requires an excessive amount of advocacy and administrative work by the foster carers, and has jeopardized the stability of the placement.

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[18] In the notes to the Disabilities Professional Meeting dated the 22.10.16, the PSW clarified that Tusla offered to contract in the cleaning service from an agency but the complainant opted to receive the money from Tusla and buy in the additional help herself. The complainant was advised that a private arrangement would be more cost effective.

A wealth of independent research points to the extra cost of living for people living with a disability in Ireland. A 2010 study estimating the spending needs that arise due to disability found that 'The cost of disability for households containing an individual with a severely limiting disability is estimated at 30.4% of average household income'[19]. Therefore, based on the most recent census figures, the extra cost of having a household member with a disability is approximately €11,158 per annum.[20]

Having regard to Tusla's obligations under domestic law and international guidance on the matter, we consider that the current system unfairly militates against the fostering of a child with a disability.

In their response to us, Tusla stated that: 'As a result of recommendations made by the Comptroller and Auditor General in their 2015 Management Letter, and also due to the recommendations made in recent Internal Audit reports by Tusla, a requirement for a standardised cash allowances payment process to be implemented to enhance the controls and governance with regards to all cash allowance payments being made by the Agency (e.g. Foster Care Payments, Respite, Aftercare, Supported Lodgings) was identified. A new suite of forms is being introduced to standardise the process of initiating a cash allowance payment to ensure regular validation of payments being made and to ensure all care arrangements are captured by separate GL codes. One of the forms created is a 'request for additional support form'. As the name suggests, this payment initiation form will be used to authorise an additional financial support payment where deemed necessary (as per Policy, relating to additional Medical/Educational need). The payment will be reviewed on a monthly basis. This form will be based on identified need of the child rather than on a particular category of child such as a child with a particular diagnosis. This is totally consistent with the National Standards for Foster Care, which state: 'Children and young people are provided with foster care services that take account of their age, stage of development, individual assessed needs, illness or disability, gender, family background, culture and ethnicity (including membership of the Traveller community), religion and sexual identity'. The needs of a child with a particular condition may vary significantly from another child with the same diagnosis'.

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[19] See Cullinan J, Gannon B, Lyons S (2011), Estimating the Extra Cost of Living for People with Disabilities, Health Economics, 20, 582-599

[20] This is based on CSO figure for Average Weekly Earnings in the Irish Economy for Q2 2016 - €705.82. http://www.cso.ie/en/releasesandpublications/er/elcq/earningsandlabourcostsq22016finalq32016preliminaryestimates/

The proposal to standardise the 'request for additional support form' is positive. However, children in care with a moderate to severe disability require the streamlining of foreseeable additional supports and services. Therefore, the issues raised in this investigation and which we raised in a previous investigation[21] should have triggered a greater policy response from HSE Child and Family Services/Tusla with regard to the lack of funding and support for such children in foster care with special needs.

As a result of our previous investigation the HSE Child and Family Services made a series of commitments including:

- To revise the fostering arrangement and care planning to ensure that issues such as the procurement of specialist equipment and therapies which may be required for the child/young person are discussed and recorded at time of placement. In that way any ambiguity with respect to the role and responsibility of each party to the agreement may be avoided. Equally this would also have the beneficial effect that the child at the centre of the fostering arrangement would not have specialist therapies or equipment delayed or denied as the issue gets resolved;
- The HSE to devise a separate administrative scheme to ensure that funding, advice and assistance is made available to identify and address the special transport needs of those children. The HSE will establish a working group to (1) review the existing policies and (2) develop a standardized national policy for the provision of foster care services for children with special needs;
- To prioritise the provision of services and therapies for children with special needs in the care of the State in fostering arrangements

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[21] "Statement based on an investigation into the provision of supports and therapeutic services for a child with special needs in foster care" August 2011, see https://www.oco.ie/wp-content/uploads/2014/03/OCOInvestinservicesforchildinFosterCare.pdf

In its correspondence, the HSE has stated that it was unable to establish progress in relation to previous commitments. Tusla told us that the commitments entered into were by the HSE Child and Family Services, the precursor to Tusla and, therefore, a separate agency. There remains no effort to streamline appropriate supports and services, no specified scheme, and no budgetary line set aside for the apportionment of reasonably foreseeable expenses that are essential to the development, health and welfare of a child with a disability in foster care. It appears that if another child with this level of need entered the fostering system today, there would be no guarantee of any type of additional assistance. Any assistance would again be assessed on a case by case basis.

From a review of Tusla's Policy, Procedures and Guidance for Children in Care, Tusla operates standard care planning processes in relation to this category of children with a diagnosis of moderate, severe, or profound intellectual disability. This represents a failure to make reasonable adjustments from standard procedures that would give these children an equal opportunity to reach their full potential.

In its response to us, Tusla has stated that there is no evidence to support the finding that 'the current system of request and advocacy for additional services has led to undue financial, administrative and, potentially, psychological burden being placed on the foster carers'. We have examined the testimony of, and documentary evidence provided by, Molly's foster carer as well as the testimonies of 14 front-line staff and determined otherwise.

4.3. Our findings against the HSE can be summarised as follows:

i. **HSE respite services and facilities, and qualified intellectual disability support, is in severe shortage, exacerbating the challenges experienced by foster carers of children with a disability. This can result in the destabilisation of an otherwise sound fostering arrangement and is, therefore, undesirable administrative practice.**

As a child born with Down syndrome and severe ASD who was abandoned by her biological parents at birth, Molly required the intervention of both Tusla and HSE Disability Services ('the HSE') after the disaggregation of the Child and Family Agency from the HSE in 2014.

Tusla makes no distinction with regard to children with a disability in foster care, and does not provide any specialist social support to families who foster children with a disability. Therefore, Molly's social workers, and foster carers must rely on support from the HSE to bridge this service gap.

In an interview and correspondence with us, the HSE stated that the position of Intellectual Disabilities Liaison Nurses (IDLN) does not exist everywhere in the country, since it was not a protected position during the moratorium on public recruitment[22]. With regard to Molly, the IDLN was initially only required to visit her once a year, rising to once every 6 months as a result of her needs. One interviewee[23] recalled that Molly did not receive any home visit for a 14-month period between 2006 and 2008.

Through home visits, the IDLN assesses a child's needs and requests services. Significantly, and contrary to government policy which 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 across the five national outcomes'[24], the HSE looks solely at the child's disability and not at her particular vulnerabilities as a child in care, in assessing and allocating equipment and respite. The IDLNs[25] stated that there is a wait-list for most of these services, which are in short supply.

In interviews with this office the IDLNs[26] explained that for Molly to receive respite with another foster family in the area - which was not forthcoming - that family would need all the specially adapted equipment Molly requires. They stated that this is very difficult to find. A foster family was eventually identified for respite; however, they were based 88km away. Molly's foster carer refused this respite as impracticable.

The Residential Unit used by the HSE for respite for Molly provides a mix of two night breaks from after school and Saturdays. Molly is eligible for 168 hours in each six-month period allocation and is on the cancellation list, should any extra respite become available. There is another Residential Unit in the county; however, Molly's foster carer refuses to allow Molly to go there after she arrived at school in a disordered state following a previous stay. Molly's foster carer was also in receipt of six hours home support per week from the HSE; however, she could not leave the house while the home support worker was there. This home support ended in January 2016.

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[22] In response to the draft investigation statement, the HSE stated that 'the implementation of Progressing Disability Services (0-18s programme) envisages having in place a network consisting of Multi-disciplinary teams in order to meet the needs of the child/ young person (see http://www.hse.ie/eng/services/list/4/disability/progressingservices/faqs/ for further details).

[23] Interviewee 1

[24] Better Outcomes Brighter Futures: The National Policy Framework for Children and Young People 2014 – 2020

[25] Interviewees 1 and 2

[26] Interviewees 1 and 2

In their response to us, Tusla stated that it ‘acknowledges that the current respite at 3 times per year is inadequate to meet both the child’s needs and those of her carers. However, this is her entitlement as identified by the HSE Disability Service for a child with the child’s needs’.

The IDLNs interviewed suggest a much more flexible respite system, or the provision of finances for buying in those services from private providers is required. According to the HSE budget holder[27], Molly is getting the maximum level of respite they can give with the level of resources they have. They can only look within their area’s allocation, and redistribute it, not add to it. Molly would get the same respite allocation even if she was not a child in care.

Under the current system, children in care with a disability, such as Molly, compete with other children in the community for access to those resources.

The Government’s National Disability Strategy Implementation Plan 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. However, in interview with us, HSE management stated that ‘Children with disabilities want to remain in the mainstream – and that’s government policy – but the [State] system isn’t geared up [for that]’.

4.4. Our findings against the HSE and Tusla together can be summarised as follows:

i. **Tusla operates a standardised approach to children in foster care, regardless of whether they have a disability. Similarly, the HSE operates a standardised approach to children with a diagnosed level of disability, regardless of whether they are in State care. Such a siloed approach to a vulnerable cohort of children, which results in a competition for resources from both agencies, is undesirable administrative practice.**

ii. **The lack of interagency collaboration at a local and operational level between Tusla and the HSE, has had a negative impact on the provision of services for Molly, and is undesirable administrative practice.**

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[27] Interviewee 3

In November 2014, 11 months after the transfer of statutory responsibility for child welfare and protection services from HSE Child and Family Services to Tusla, Tusla undertook an internal review of the January 2014 HSE/Tusla Memorandum of Understanding. This internal review recommended that 'future iterations of the agreement should include clearer specification, standardisation and process redesign', that 'each service element of the MoU is underpinned by specific activity schedules', that 'a structured process of monitoring and reporting of the implementation of the MoU within Directorates' is established, and finally that 'a structured process of dispute resolution under the terms of Article 6 of the MoU' is established.

In addition, the HSE and Tusla jointly carried out their own review of inter-agency cooperation. This review commenced in July 2015. The resulting document entitled '*Review of the Memorandum of Understanding and Joint Protocol between the Health Service Executive and the Child and Family Agency agreed in January 2014*' was prepared and agreed by each agency's representative.

With regard to inter-agency collaboration at a local and operational level, the review states that:

> *'Evidence would appear to suggest that whilst the CFA ['Tusla'] are drivers of this protocol at a high level, CFA staff at operational levels are not implementing or adhering to the protocol. As a consequence, significant challenges are emerging within local areas for children presenting with a disability……In addition, the CFA has developed a framework describing the categorisation of need for children. This appears to discriminate against children with a disability and may exclude them from accessing child protection services……Disability Services have the expertise to manage the presenting disability of a child but services are not charged with the management of Child Protection and Child Welfare issues as this lies within the remit of the CFA…….In conclusion, there is a major failing between the documents which promote collaboration, cooperation, proactive responses and that which is current practice'.*

Concern is expressed from Disability Services that there appears to be a 'concerted effort' from Tusla that where a child presents with a disability it is the disability services responsibility to manage. The legislation is to protect all children regardless of presenting need and a child with a disability should have access to protection, expertise, ongoing monitoring that Tusla confers on other children in similar circumstances'.

With regard to inter-agency cooperation, both Tusla and HSE front line staff interviewed were aware of a memorandum between the two agencies - an agreement in principle to work with each other – however, they pointed out that the steps required for engagement and procedure are not laid down. The majority interviewed stated that there needed to be clarity between the HSE and Tusla especially at a local level as there is no guidance available to them to understand their roles, or the manner and frequency of interaction between them.

At present, Molly's allocated social worker must identify and contact the specific person in the HSE to advocate for supports; and meetings with the HSE are requested on a case per case basis. While the IDLN is invited to the annual review and professionals meetings, attendance is voluntary and hampered by bulging caseloads and travel restrictions[28].

From our investigation it appears that while Tusla recognises the child's protection and welfare needs, no distinction is made with regard to their particular disability requirements, and while the HSE recognises the child's disability needs, no distinction is made with regard to their protection and welfare vulnerabilities as a child in care.

Finally, it is concerning that, from interviews we conducted, Tusla management had no knowledge of the HSE's strategic plan for 'Progressing Disability Services for Children and Young People'[29]. Equally, while the vision of 'Progressing Disability Services for Children and Young People' is that each and every child or young person with a disability is supported to achieve their full potential, it makes no reference to children with a disability in the care of the State, fostered or otherwise.

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[28] Interviewees 1 and 2

[29] Progressing Disability Services for Children and Young People is the HSE's vision to make disability services equitable and consistent for all: http://www.hse.ie/progressingdisabilityservices/.

The standardised approach adopted by Tusla with respect to all children in care, regardless of whether they have a disability, and by the HSE with respect to all children with a diagnosis of moderate, severe, or profound intellectual disability, regardless of whether they are in State care, has resulted in both agencies engaging in undesirable administrative practice with respect to children with a disability in foster care.

Tusla and the HSE have stated that they are seeking to ensure greater inter-departmental cooperation and coordination through the 'Joint Protocol for Inter-Agency Collaboration between the Health Service Executive and the Child and Family Agency to Promote the best interests of Children and Families' which was submitted to us in April 2017[30].

While the Joint Protocol was signed by the respective agencies on the 29th March 2017, we have been informed that it will not be fully operational until the end of January 2018.

4.5. Adverse effect

i. **During the course of the investigation, Molly's placement has destabilised. Residential care is now considered by the principal social worker as 'the most suitable caring environment' for Molly, who has been with her foster carers since she was four months old, a time-span of over 14 years.**

As a non-verbal child with severe communication challenges in the care of the State, Molly's voice and participation in the care process was provided for directly by her foster carers. In her complaint to us, Molly's foster carer told us that Molly has 'brought nothing but love and positivity to our home' and that she is a 'beautiful human being who needs extra care and attention'. However, she says she is financially, emotionally, and physically drained, which she states is a result of a lack of support. Molly's foster carer has also described the immense toll on her immediate family as a result of the care and advocacy required by Molly.

In interviews with us, several Tusla and HSE front line staff[31] asserted that the stability of Molly's placement is at risk as a consequence of the financial, emotional, and physical strain on the family unit.

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[30] In its response to the draft investigation statement, the HSE stated that 'the recently adopted Interagency protocols should facilitate information sharing between the HSE & Tusla'.

[31] Interviewees 1, 2, 4, 5, 6, 7, 9, and 11

During the course of the investigation, Molly's placement has, in fact, destabilised.

In January 2017 the PSW wrote to Molly's foster carer expressing concern that "the provision of services over the past year has not decreased the stress in [Molly's foster carer's] home and has not made the caring task of [Molly] more manageable. [Molly]'s current and future care plan is regularly reviewed and it is now considered that the most suitable caring environment for [Molly] would be residential care. [Molly's] needs will continue to be complex and she now requires a team caring approach. [The PSW] understands from [their] conversation that [Molly's foster carer does] not agree that this would be in [Molly's] best interest. [Molly's foster carer] informed [her] that the last 13 years have been the best years of [her] life and [she] has talked about the joy [Molly] brings to [her] life". The PSW stated that she has requested that Molly's social worker commence the process of making applications to private residential care settings to provide full-time care for Molly as this process can be lengthy'.

Conclusion

In accordance with Section 8 of the Act we found that Molly has been adversely affected by the administrative actions of Tusla and the HSE in the planning for, and provision of, supports to meet her needs as a child with a disability in foster care. Furthermore, we have found that those actions were:

- Contrary to fair and sound administration; and/ or
- Based on undesirable administrative practice

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. This investigation highlighted a particular gap in the provision and co-ordination of supports and services by Tusla and the HSE to children with a diagnosed moderate or severe disability in foster care. This gap represents a failure to make reasonable adjustments from standard procedures that would give these children an equal opportunity to reach their full potential.

5.3. For their part, both Tusla and the HSE have recognised, in their responses to us, that greater planning and coordination is required. Significantly:

- Tusla states that 'Recognising the particular vulnerabilities of children in the care system, Tusla is conducting an assurance review of any allegations made against carers of young people with a disability'.
- Tusla 'recognises that there is a need to make services for children in care with a disability more responsive to the needs of the child and that the additional needs that result from the disability may place extra demands on the carers. Tusla would welcome engagement with stakeholders and government departments to examine in a comprehensive, inclusive and considered manner how best to deliver services for children and young persons with disability, both in and out of the care system. Tusla believes that it would be useful to consider whether the manner in which services have been disaggregated is in the best interests of children, and would be open to looking at how services might be delivered differently'.

5.4. Both agencies also contend that the formulation of a separate administrative scheme for children with a disability in foster care would require input from their respective government departments. Significantly:

Tusla stated that:

- 'Care planning is a statutory requirement specified in legislation. Even if Tusla were of a mind to introduce such a scheme, the revision of legislation is outside of the remit of Tusla'.

- ‘During the recent budget estimates process, Tusla submitted a business case to Government to explore the introduction of an enhanced support payment for vulnerable children in care… the matter, merit, and manner of such a payment could be explored and consideration could be given to the role of the Department of Social Welfare in the provision of payments’.

The HSE stated that:

- A new ‘policy would have to be formulated by the National Division to ensure consistency. Social Care Divisions Operational Plan 2017 sets out the work plan for 2017. The creation of a separate policy for children with a disability in care is not in that plan but the HSE will engage further with Tusla to see how such a plan could be written in 2017 for 2018’.
- ‘There is no budgetary scope in the 2017 service plan to fund an increase in Children’s respite services. If funding was available, there is limited capacity to provide an increase in the level of respite services. The HSE is governed by the National Service Plan and committed to defined resources. No additional resources have been made available in 2017 to accommodate the resourcing and provision of reliable and responsive respite for children with a disability in the community. However, we will examine our capacity to scope out what is currently being provided and make a submission as part of the Estimates process for 2018’.

5.5. Recognising the significant effort made by both agencies to ensure structured operational coordination and cooperation via the Joint Protocol, we recommend that, in the first instance, 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.

5.6. We also recommend that the following actions take place by Tusla and the HSE:

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

b. If, as proposed, Molly 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.

c. Tusla and the HSE should systemically review the supports and services being offered to approximately 471[32] 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. [33]

d. The HSE to immediately devise a respite action plan for the resourcing and provision of reliable and responsive respite to children with a disability in the care of the State, as well as children with a disability in the community at large.

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[32] 'The number of children aged under 1 to 17 years who are in care (under the Child Care Act, 1991) who have been diagnosed by a clinical specialist as having a moderate to severe disability', September 2015

[33] See previously Recommendation 1 of "Statement based on an investigation into the provision of supports and therapeutic services for a child with special needs in foster care" August 2011 with respect to all children with special needs in foster care: 'The HSE is to systematically review the status of all such foster children with special needs to ensure that each child has an assigned social worker to advocate on their behalf'.

6. Public bodies' Response to the Recommendations

Tusla

6.1. Tusla has stated that the agency agrees and accepts the recommendations made by the OCO. In particular, with regard to the recommendation that Tusla formally engage with the Department of Children and Youth Affairs concerning the findings of this investigation - Tusla has responded as follows:

> *'Tusla had submitted a Business Case to Government to explore the introduction of an enhanced support payment for vulnerable children in our care. We remain fully committed to formal engagement with the DCYA to discuss and determine both the current and future service delivery for this cohort of children. We anticipate that the commitment to the joint protocol from the respective government departments will assist with this engagement.'*

6.2. In response to the recommendation that Tusla and the HSE systemically review the current supports and services being offered to Molly to ensure she reaches her full physical, cognitive and educational potential, Tusla has stated:

> *'We envisage that the Joint Protocol for Inter-Agency Collaboration between the HSE and Tusla will greatly assist with a systemic review of the current supports and services being provided to this child and we are committed to ensuring that she reaches her potential. Tusla will communicate our agreement to this recommendation to the relevant Tusla staff to ensure operational governance of same.'*

6.3. In response to the recommendation that if Molly is moved to another care placement, Tusla and the HSE should put in place the necessary supports so that she experiences a stable transition from her current to her future home, Tusla has stated:

> *'We remain fully committed to our statutory responsibility to this child 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.'*

6.4. In response to the recommendation that Tusla and the HSE should systemically review the supports and services being offered to approximately 471[34] other children with a moderate or severe disability in foster care in the State within 12 months of the date of issuance, Tusla has stated as follows:

> *'It is [our] intention to issue a communication to all staff to ensure that they are fully aware of the Joint HSE/ Tusla protocol and of the undertaking that [we] have given to the Ombudsman for Children to ensure systemic review of the supports and services being offered to children in our care with a moderate to severe disability. [We] envisage that these systemic reviews will occur under our statutory care planning functions as per the Child Care Act 1991. A copy of this correspondence will be forwarded to the Ombudsman for Children's office.*

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[34] 'The number of children aged under 1 to 17 years who are in care (under the Child Care Act, 1991) who have been diagnosed by a clinical specialist as having a moderate to severe disability', September 2015

> *[We] will also ensure that the Service Directors for each region collates the data from the systemic review to inform any future development of specific performance metrics and outcome measures for this cohort of children.*
>
> *In addition, Tusla will identify these children to our colleagues in the HSE in order to facilitate the preparation for involvement in care planning and joint working for these children.'*

The HSE

6.5. The HSE Disability Service has confirmed that:

> *'The HSE will respond to these recommendations in the context of the agreed Interagency Protocol, note we (i.e. Tusla and HSE) have advanced in terms of the plan to roll out and have an established National Group to deal effectively in this area. This detailed protocol provides for structures at "area, "Regional" and "National" level where both case management and resource issues can be responded to'.*

6.6. In response to the recommendations with respect to the supports and services being offered to Molly, the HSE local office has stated:

> *'As a result of this report a joint meeting is scheduled [...] which is jointly convened by the Principal Social Worker Tusla and the Acting Disability Manager [HSE] Disability Services. The purpose of this meeting is to do a joint review of this case focusing in the first instance on the individual case and also on the joint learning for this and future cases... Support will be provided by [HSE] Disability Services as it is required and this has been agreed with Tusla.'*

6.7. In response to the recommendation concerning the review of supports and services being offered to approximately 471 other children with a moderate or severe disability in foster care in the State, the HSE has stated as follows:

> *'[The] HSE understands that Tusla have indicated that there are 471 children in this category. HSE commits to working collaboratively with Tusla to systematically review the needs of this vulnerable group and to have concluded same within 12 months of the date of issuance... this is subject to Tusla as the statutory lead (and the holder of the relevant clinical/ support information relating to this cohort) convening and leading the process as per their statutory remit and utilising the agreed operational structures as detailed in the Joint HSE/ Tusla Protocol. Specifically, HSE will need to assess the detail held by Tusla in this regard and to have validated same notwithstanding the absolute commitment to this recommendation as referred to above...*

> *[The HSE has] already developed performance outcome indicators relevant to Progressing Disability Services and are also implementing a state wide Management Information System [MIS] that will a) support case management and b) utilisation of data as an MIS for service planning purposes [Note: this is subject to GDPR]. [The] HSE has committed to further developing the suite of performance indicators and will ensure that we include vulnerable children with a disability in state care as an integral element of same. We will include both Tusla and [the Ombudsman for Children's Office] in this important endeavour…*
>
> *[The] HSE's assessment process/ procedures will require/ ensure that frontline HSE services will specifically take into account/ have regard to the needs of children in state care that have a moderate to high level of disability.'*

6.8. In response to the recommendation with respect to respite, the HSE local office has stated:

'[The] HSE has made a substantial bid as part of the 2018 estimates process relative to "Respite" services. This is a very important point to emphasise as Social Care would have undertaken this approach in 2016 also, the point being to underscore HSE's commitment in this area which is ultimately resource dependent. .. The level of funding afforded to Disability Social Care relies entirely on the current statutory service planning process in respect of resource allocation which can only be based on the Letter of Determination from D/ Health. Therefore, [the HSE is] not in a position to affirm what level of resource will be made available for this category of service until the HSE's Service Plan [2018] has been formally adopted.'

Molly's Foster Carer

6.9. At the conclusion of the investigation, Molly'sfoster carer requested that it be noted that the support of €240 per week, which she had been in receipt of prior to January 2017, had in fact allowed her and her husband a measure of freedom that they hadn't had since they had taken Molly into their care.

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