



**Review undertaken in respect of a death of a young person who
was known to the Child Protection & Welfare Agency**

Brian

Executive Summary

APRIL 2018

Introduction and Summary

This review concerns the death of a thirteen year old boy with autism, here called Brian who lived with both his parents. Brian was described by those who knew him as intelligent and articulate, quiet and with a keen sense of humour and liking to display his intelligence orally. While he had numerous talents and skills, he was very uncomfortable in situations that were not entirely in his control and slow to trust people. He had few friends and felt socially excluded. He was aware of his own complex needs and wanted his situation to improve but found change very difficult.

Brian had special needs from an early age and received services from a number of different HSE departments including child and adolescent mental health, psychology, speech and language and occupational therapy. His middle childhood years were relatively unproblematic, but his behaviour became challenging from the time he was nine years of age. He was diagnosed with Asperger's Syndrome and began to receive autism services in addition to psychology and child and adolescent mental health services. The social work department (SWD - then part of the HSE) later became involved with his family after referrals were made about the risk he posed to himself due to his aggressive behaviour. The SWD conducted a partial assessment and found no child protection concerns. The case was closed when Brian was 11 on the basis that his parents were coping. He was referred again to the SWD by mental health and autism services when he was 12 and a family support worker was then allocated. As time went on, Brian received significant support from his primary and secondary schools as well as the autism and child and adolescent mental health services. Numerous interdisciplinary meetings took place to try and plan for him.

None of the services appeared to be successful in helping Brian to manage his own behaviour and his parents became increasingly stressed and exhausted. He became virtually house bound. He was unable to access respite care in a disability setting locally. Youth support services tried to help with social integration, but progress was very limited. An application for a special needs assistant in secondary school was turned down on the basis that he did not qualify. There was an overall lack of clarity about which service should take the lead role in co-ordinating the case, and Brian consequently appeared to fall between services. As he got older, his weight increased significantly and he became aggressive and very uncooperative with services, including the home based autism service. He was unhappy and frustrated; he put himself into several dangerous situations and expressed suicidal ideation from time to time. He rarely went to school after the transition to secondary level, would not take his prescribed medication and his parents were unable to manage him. There was a debate between professionals about whether the case needed to be categorised as a child protection case because of the escalating riskiness of his behaviours, but this was not

accepted by the SWD. By the time Brian turned 13, a decision had been made to source residential placement for him in a specialist centre for children with autism. However, no placement for a child with his needs was available in Ireland. His parents were reluctant to agree to a placement in another jurisdiction, expressing a preference for home based tuition. Brian said he would kill himself if he was sent abroad. Plans went ahead for a home tuition arrangement but he died before they could be put into operation.

1. Findings and Conclusions

The review found that a number of services tried very hard to assist Brian and his family, particularly his schools and the psychiatrists who worked with him. However, no one service had a lead role, nor did any single service have the capacity to address his very complex needs. Interagency boundary tensions were evident with some services asserting that they did not have responsibility in relation to children diagnosed with autism. Services came in and out of the case, notably the SWD and the psychology services. There was no procedural framework for responding to children whose at risk status stemmed from a health or developmental or disability issue. Some services looked to the SWD to provide the lead role in managing the case, but this was rejected by the SWD. The legal and administrative process for the residential treatment option abroad was complicated. There was, in the assessment of the review team, the possibility of SWD involvement in care proceedings. The lack of clarity about leadership in the case contributed to a delay of up to a year in starting the process for planning residential treatment.

The review also found that while there was a lot of emphasis on efforts to manage Brian's behaviour and access services for him, there was less focus on understanding the experiences of his parents, who had to deal with enormous stress, interact with numerous services and endure frustration when a care package to meet Brian's needs could not be established.

The specific conclusions of the report are as follows;

- Brian was a child with a very high level of need from the time he was 10 onwards, and was a child at risk of significant harm from the time he was 11 because of a number of indicators including his repeated threats and acts relating to self-harm. The severity of his difficulties were highly unusual and complex.

- He did not meet the threshold for child protection intervention by the SWD because his indicators, including repeated threats and acts of self-harm, were seen as primarily related to his diagnosis of autism, and not related to parental omission.
- There is no single point at which the timing or circumstances of his tragic death could have been foreseen or prevented.
- The overall HSE service¹ response to the needs of Brian and his parents was obstructed by issues concerning service remits and boundaries which caused delay.
- There was no clear procedural guidance to ensure timely resolution of how to respond to cases where children are at risk of significant harm primarily because of complex health or developmental or disability needs.
- HSE service responses in this case to referrals (including the SWD) were generally timely.
- Appropriate assessments of Brian's individual needs were carried out in the HSE by CAMHS, the speech and language therapy service, the autism service, the occupational therapy service and the child psychology service.
- The services which provided the most consistent and sustained support to Brian and his family were the autism service, CAMHS and the two schools, all of which worked closely to try to ensure that he received the best possible support. All three services were alert to his needs and the escalating risks.
- The SWD was not compliant with its obligations under Children First to complete an initial assessment of the case
- There was no single integrated report or reports from any service at any time to draw together all of the available assessment data on Brian and his family. This finding illustrates the lack of coordination in the case.
- There was no assessment of parental capacity or family functioning despite repeated references to the fact that Brian's parents felt under constant pressure to manage him appropriately.
- Whilst there is considerable evidence of inter-agency activity through telephone contacts, letters, discussions and meetings, the recording of exchange of information and of decisions is poor, and the purpose and frequency of meetings lacked clarity.
- Whilst CAMHS had clinical responsibility for this case, the service did not believe that it had the organisational mandate or a clear organisational pathway to lead on legally complex and

¹ Note that the term 'HSE service response' includes the actions of the SWD at this time, which occurred prior to the establishment of Tusla in 2014

resource intensive aspects such as access for Brian to services in a specialist residential centre outside the state.

- The recommendation for a specialist therapeutic placement outside the state reflected the unusual nature and complexity of Brian's needs. Clear and accessible guidelines were needed regarding the procedures to be followed when CAMHS (or another HSE service) is seeking to access such a placement outside the jurisdiction. It is the view of the review team that the absence of such guidelines added significantly to the delay in starting the process in this case.
- The SWD rejected a leadership role in the case because it felt that the resolution of the needs of a child with a severe autistic spectrum disorder lay outside its primary remit, which was child protection.
- The case was managed by the SWD as a 'child welfare' case, which meant that it was not prioritised because of resource pressures on the service. It was not allocated to a dedicated social worker for assessment and was inappropriately closed when Brian was 12. When re-opened later that year the SWD still did not assume a lead role in co-ordinating the case but provided a sustained and narrowly focused family support input until Brian's tragic death
- The categorisation of the case as 'child welfare' by the SWD was maintained even after the need for treatment in a specialist residential centre outside the state came on to the agenda. Whilst such an application did not per se require the involvement of the SWD, the review team considers that the possibility of care proceedings was an issue for consideration at the time, in the circumstances of this case. The level of risk to the child, the level of the difficulties experienced by his parents, and the absence of guidelines for this type of case, should have ensured that the SWD took the lead.
- Both CAMHS and the SWD had opportunities to highlight the unique needs and risk profile of this case organisationally, and to draw attention to the emerging difficulties, through completion of integrated assessments of need and risk, which were not taken.
- The HSE, as the corporate body at the time, did not react to the emerging needs and risk profile of this case by clarifying leadership and by establishing a clear pathway for resolution of the emerging difficulties
- There is repeated evidence in this case that access for children and young people on the autistic spectrum to services is problematic, and that the dedicated autism service, despite the best efforts of its staff, worked with significant deficits in multi-disciplinary support, HSE guidance, management and resourcing.

14 Key Learning Points

- **Understanding of autism;** Brian's needs were very specific and complex. The case history establishes that most services were unprepared and struggled, both in terms of knowledge and procedural guidance, to respond to his needs. Some had to learn to manage as his needs escalated whilst others stepped back because they felt that they lacked the expertise and/or did not see autism as their priority. His parents, in most instances, felt unsupported. Whilst this report has identified a number of practice and policy issues, there is an overall need for a better level of awareness and understanding across all professions and agencies of the range of presentations and needs of children and young people on the autistic spectrum
- **Children at risk of significant harm associated with disability/mental health needs;** The principle of the paramountcy of the child means that in practice responses by child care social workers must always be centred on the assessed needs of every child and applies fully to cases where the risk of significant harm related to disability, mental health or autism exceeds the capacity of responsible parents. There needs to be greater clarity in procedural guidance about lead responsibility for the management and co-ordination of such cases, as well as clear escalation processes when risk increases.
- **Parental capacity and family functioning;** The capacity and functioning of responsible parents can be stretched by children and young people with high levels of additional needs. The lead service for such cases needs to be able to assess parental capacity and family functioning as well as the needs of the child.
- **SWD Initial assessments;** SWD initial assessments are stipulated in Children First to be multi-disciplinary in nature. In practice this means not only consultation with partner agencies in the development of the assessment, but active sharing of conclusions. This is particularly important where the initial referral has been instigated by partner agencies.
- **Management, recording and documentation by HSE agencies of multi-agency assessments;** Where the needs of a child require multi-agency assessment processes by the HSE, good governance requires that there is clarity and agreement about the lead agency and the procedures to be followed. These include arrangements for the common recording and dissemination of assessment information, action plans and care plans.

- **Management by the HSE and Tusla of service boundary tensions;** It is essential that the corporate risk and quality assessment processes in the HSE and Tusla have the capacity to identify and address cases where children or young people with high levels of need have experienced delay or lack of resolution because of service boundary disputes, and to take quick remedial action. It is also incumbent to the individual service managers to take action to identify such impasses to their senior managers. Processes for resolution of disputes are now addressed in the Tusla – HSE Joint Protocol 2017².

15. Recommendations

Under its remit, the NRP makes its recommendations to Tusla for implementation. The needs of children with complex autism do not fit easily within existing Departmental and service boundaries, as illustrated by the circumstances of this case and the needs of this child. A number of the recommendations in this report relevant to the protection and welfare of such children lie outside the sole remit of Tusla and are not within its capacity to implement. One of the recommendations requires to be considered jointly by Tusla and the HSE through the Joint Protocol National Oversight Group. Three can be implemented by Tusla. It is the intention of the review team that the remaining recommendations be brought to the attention of the Department of Children and Youth Affairs (DYCA) (see Recommendation 8 below).

1. The pathway for management of cases where children/young people with needs related to mental health, disability or autism are at risk of significant harm needs to be specified in relevant guidance. Examples of such cases are where parental abuse or wilful neglect does not exist but where parental capacity to meet the child's needs is compromised to the point where the child's safety and welfare is in jeopardy. This should be specifically referenced in the Tusla Guide for the Reporting of Child Protection and Welfare Concerns and any other relevant documentation issued under Children First 2017.

² Joint Protocol between the Health Service Executive and Tusla Child and Family Agency to promote the Best Interests of Children and Families V1.0 (March 2017)

2. Tusla and the HSE need to evaluate the 2017 Joint Protocol for Inter-agency Collaboration between the HSE and Tusla to Promote the Best Interests of Children and Families with specific reference to this case, in order to clarify pathways for the management of cases of children/young people at risk of significant harm where there are needs related to mental health, disability or autism, and where there is not a context of wilful parental neglect. The protocol needs to address arrangements for identification of the lead service for HSE led multi-disciplinary assessments (eg CAMHS, psychology, autism, disability etc) and for consultation with Tusla as required, as well as arrangements for assessment of parental capacity and family functioning and provision of support to parents in HSE led cases.
3. The HSE needs to develop procedural guidance for the management by its services of cases of children/young people at risk of significant harm where there are needs related to mental health, disability or autism, and where there is not a context of wilful parental neglect. This guidance should address the role and responsibilities of the lead agency, the scope of assessments, review arrangements, recording and documentation etc. It should also address procedures to be followed in circumstances such as this case, when a service is seeking access to specialist residential treatment outside the jurisdiction.
4. Tusla should ensure that the pathway for management of cases of children/young people at risk of significant harm where there are needs related to mental health, disability or autism, and where there is not a context of wilful parental neglect, as developed in recommendations 2 and 3 (above), is referenced in the next edition of the Child Protection and Welfare Handbook.
5. There is a need in Ireland for a dedicated autism service to cater for children's needs in the community through multi-disciplinary support and education, and, where required, through the provision of specialist residential services. The review team notes the work that has already been undertaken on a national autism delivery model, and a recent review of this by the HSE. It is recommended that the HSE publish an update on progress in the implementation of the national autism delivery model, that it ensures strengthened, consistent and properly resourced autism

support services locally for children and families, and that no child should have to travel abroad in order to access specialist residential services.

6. The Department of Education and Skills needs to consider revision of the current NCSE criteria for the SNA service in order to address the needs of children with complex autism, and must have greater flexibility (both in access criteria and in employment practices) to cater for the specific needs of individual children. Schools also require greater clarity about co-ordination between the school and outside agencies in complex cases.

7. This review illustrated a deficit of awareness and knowledge about autism on the part of Tusla staff, including a lack of understanding about the impact on a family of having a child with autism and the risks to which autistic children may be subject. It is recommended that Tusla, as part of its professional development strategy, makes specific reference to autism when delivering modules related to disability, mental health and behavioural issues.

8. It is recommended that the Department of Children and Youth Affairs identify a mechanism through which recommendations made by the National Review Panel that are outside the remit of Tusla will be progressed and monitored.

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