



## Child Practice Review Report

North Wales Safeguarding Children's Board

Concise Child Practice Review

Re: NWSCB/1/2022

### Brief outline of circumstances resulting in the review

To include here: -

- Legal context from guidance in relation to which review is being undertaken.
- Circumstances resulting in the review.
- Time period reviewed and why.
- Summary timeline of significant events to be added as an annexe.

### Legal Context

A Concise Child Practice Review was commissioned by North Wales Safeguarding Children's Board on the recommendation of the Child Practice Review Sub-Group in accordance with the Guidance for Child Practice Reviews. The criteria for this review are met under the Social Services and Well-being [Wales] Act 2014<sup>1</sup> ; Working Together to Safeguard People Volume 2 Child Practice reviews<sup>2</sup> published 2016 (updated, 2021); The Safeguarding Boards (*Functions and Procedures*) (Wales) Regulations 2015<sup>3</sup>.

The criteria for this review are met under Chapter 6, Concise Child Practice Reviews:

A Board must undertake a Concise Child Practice Review in any of the following cases where, within the area of the Board, abuse or neglect of a child is known or suspected, and the child has:

- Died; or
- Sustained potentially life-threatening injury; or
- Sustained serious and permanent impairment of health or development; **and** the child was neither on the child protection register nor a looked after child on any date during the 6 months preceding –
- The date of the event referred to above; or

<sup>1</sup> [Social Services & Well-Being \(Wales\) Act 2014](#)

<sup>2</sup> [Working Together to Safeguard People – V2 – CPRs](#) (Welsh Government, 2016)

<sup>3</sup> [The Safeguarding Boards \(Functions and Procedures\) \(Wales\) Regulations 2015](#)

- The date on which a Local Authority or relevant partner<sup>4</sup> identifies that a child has sustained serious and permanent impairment of health and development.

The purpose of this child practice review is to identify learning that will benefit future practice. It involved practitioners, managers, and senior officers who explored the details and context of agencies' work with Child A and her family. The outcome of the review will generate professional and organisational learning to promote improvement in future interagency practices with children and families. It includes the circumstances which led to the review, including highlighting effective practice and considerations about what needs to be done differently to improve future practice (Working Together to Safeguard People – Volume 2 – Child Practice Reviews (Welsh Government, 2016<sup>5</sup>).

The Terms of Reference for this Concise Child Practice Review are in **Appendix 1**.

## **Preamble**

This Child Practice Review is centred on Child A, an inspirational young person whose life brought much joy but was marked by the profound impact of the rare mitochondrial disease and an even rarer *POLG* mutation. The consequences of the disease extend beyond the physical devastation on the body, encompassing every aspect of both Child A's and her parents' lives. With the dedicated care of her parents, family and multiple agencies, Child A faced the expectation of not getting better. However, a critical aspect of the analysis was the intersection of Child A's care and support requirements and the government policies implemented to curb the spread of COVID-19, particularly the mandated hotel-based quarantine requirements during the summer of 2021.

## **Relevant Contextual Information**

### **Introduction to Child A and her family**

Child A was the beloved daughter and the only child of her parents, Mr and Mrs A. She was bright, beautiful, resilient, inspirational and unforgettable. Child A was confident and cognitively able; she communicated well, and everyone enjoyed her 'superb sense of humour'. She loved school and would commit 100% when she had the physiological ability to engage. Her interests and hobbies include going to the cinema, pantomimes, reading, computers, TV, books and swimming. As a teenager, Child A could become bored, but she enjoyed applying make-up, watching music videos, and having her hair braided. Her mum described Child A to the reviewer as a "girly girl". Child A enjoyed affectionate relationships with her parents and enjoyed family holidays in Europe. Additionally, Child A valued her relationships with her global family both in the UK and Pakistan. She was particularly close to her paternal grandmother and maternal grandfather and loved spending time with them when she and her parents made their annual visit to Pakistan.

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<sup>4</sup> Local Authority or relevant partner means a person or body referred to in S.28 of the Children Act 2004 or body mentioned in s.175 of the Education Act 2002

<sup>5</sup> [Working Together to Safeguard People](#) – V2 – CPRs (Welsh Government, 2016)

Sadly, Child A was born with a rare and life-limiting mitochondrial disease. Additionally, she was also diagnosed with a rarer *POLG* mutation<sup>6</sup>, which created secondary health conditions and limited the effectiveness of some medications. Mitochondria impacts the body at a cellular level, preventing the cells from having enough energy to work properly. Its impact on the body can be different for every person. Regrettably, there is a high rate of mortality for children with mitochondrial disease, with research<sup>7</sup> reporting a mean/median age of death as <10 years in 74%, <5 years in 57% and <1 year in 13% of the disease. Mrs A reports that when her daughter was diagnosed with Mitochondrial disease, a doctor advised her not to research the condition; as such, she did not consider her daughter's condition would impair her life so significantly.

When she was three years old, Child A was diagnosed with epilepsy. When she was aged six, Child A could only walk a few steps; her balance was affected, and she became tired easily. By seven years of age, she had become more independent and could occupy some of her time with toys and puzzles. By eight years, it would take her longer to eat due to swallowing difficulties; her eyesight was poor, which meant Child A took time to process what she saw and needed more time to reply.

At the age of ten years, Child A experienced a series of significant seizures, and a paediatrician reported Child A was reluctant to leave the house due to her seizures and ataxia – poor coordination and speech. The contextual information provided to the review reflects that when his daughter was 10 years old, Mr A hoped for a miracle to enable her to walk again. However, at that time, Child A and her mother began to question if she was going to get better. A family safety plan was agreed upon that outlines the roles of the parents and agencies in supporting Child A's health and well-being. The plan included Child A receiving psychological support and Mrs A receiving counselling support. In July 2019, 11-year-old Child A's health conditions were multiple. They impacted every aspect of her being, which presented significant challenges to Child A, her parents, and the multi-agency practitioners supporting them. The rarity of the disease means that most practitioners will have no previous experience of working with a child with mitochondrial disease.

There were multiple health and Local Authority practitioners involved in Child A's care who regularly convened as a multidisciplinary team. In addition to multiple planned health appointments, Child A would often require emergency hospital and clinic visits in response to urgent symptoms arising. To provide some context of the multiple and complex needs of Child A, in July 2019, her health conditions were identified as follows:

1. *POLG* mutation-positive
2. Focal seizures
3. Ataxia (degenerative disease of the nervous system, leading to poor muscle control that affects coordination, balance and speech)

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<sup>6</sup> Uusimaa, J., Gowda, V., McShane, A., Smith, C., Evans, J., Shrier, A., Narasimhan, M., O'Rourke, A., Rajabally, Y., Hedderly, T., Cowan, F., Fratter, C., & Poulton, J. (2013). Prospective study of *POLG* mutations presenting in children with intractable epilepsy: Prevalence and clinical features. *Epilepsia (Copenhagen)*, 54(6), 1002–1011. <https://doi.org/10.1111/epi.12115>

<sup>7</sup> Senger, B. A., Ward, L. D., Barbosa-Leiker, C., & Bindler, R. C. (2016a). Stress and coping of parents caring for a child with mitochondrial disease. *Applied Nursing Research*, 29, 195–201. <https://doi.org/10.1016/j.apnr.2015.03.010>

4. Gross and fine motor coordination problems
5. General hypotonia and some increasing weakness (decreased muscle tone)
6. Sensory neuropathy (can include pain, tingling, and burning sensations)
7. Visual disturbances, impaired vision, wearing glasses, photophobia (bright lights hurt or irritate the eyes)
8. Chronic retching/vomiting due to helicobacter gastritis (abdominal pain, heartburn, loss of appetite, and, in severe cases, loss of weight).
9. Achalasia cardia, three balloon dilations most recently August 2015 (a swallowing disorder that makes it difficult to push food down into the stomach)
10. Small stature
11. Special educational needs
12. Significant weight loss requiring percutaneous endoscopic gastrostomy (PEG) milk feeds

#### **Circumstances resulting in the review.**

At the end of March 2021, Child A and her parents travelled to Pakistan to visit their relatives. They intended to return to the UK at the end of May 2021. However, they returned later than planned in June 2021. In February 2021, the UK government responded to concerns regarding the COVID-19 Delta variant by imposing social restrictions that required those arriving in the country to remain in a hotel for a period of quarantine. At the start of June 2021, Mrs A sought and was provided with a letter of support from the paediatrician requesting an accessible quarantine facility or permission for the family to quarantine at home. The request was denied. Mrs A actively pursued other avenues of appeal to no avail.

On 5<sup>th</sup> July 2021, Mrs A raised concerns about her daughter's health, reporting pressure sores and pain since being isolated in the hotel. After returning to the family home, Child A was found to have suffered extensive deterioration in her health, with a significant loss of weight and a worsening of her physical symptoms, including the presence of pressure damage. The GP responded quickly, and a multidisciplinary health management plan was introduced. By the 9<sup>th</sup> July 2021, there were signs of improvement in the area of pressure damage, although Child A continued to be frail and at risk of further skin damage. There were also concerns raised about Child A's emotional well-being. Mr and Mrs A took their daughter for a health assessment on the 12<sup>th</sup> July 2021, and x-rays were taken. A further home visit was made by an occupational therapist at home on the 13<sup>th</sup> July 2021. The chronology reflects Mrs A had sought professional advice about food and medication prescriptions before they visited Pakistan. Mrs A reported to professionals that her daughter had eaten well during the first two months in Pakistan, but then her appetite had waned.

A multi-agency meeting was convened on 21<sup>st</sup> July 2021, where concerns were shared. It was advised that the deterioration in Child A's well-being may have occurred in the hotel during quarantine. Attendees had different views on whether a safeguarding report should be made to examine if quarantine or parental care had contributed towards the deterioration of Child A's health. An action was created for the health service to make the safeguarding report. Additionally, it was agreed referrals for psychological support for Child A and Mrs A would be actioned. The following

day, Mrs A advised one of her parents had died. The bereavement compounded the complexity of the professionals' concerns, as it further impacted the emotional well-being of Child A and her mother, who deeply felt the loss of their family member.

Health professionals met on the 28<sup>th</sup> July 2021 to review the presenting factors. The outcome of that meeting was a decision to continue with the health management plan and closely monitor Child A's well-being. Those in attendance agreed to review Child A's progress before deciding whether to make a safeguarding report. The health professionals shared their decision with other agencies, advising that their decision did not prevent any other organisation from making a safeguarding report. Multi-agency practitioners continued to provide care and support to Child A and her parents.

Regrettably, Child A contracted COVID-19 in August 2021 and sadly died in September 2021 aged 13 years. Child A was much loved and is wholly missed by everyone who knew her.

### **Time period reviewed and why**

It was decided the standard twelve-month time period for a practice review would not provide an understanding of Child A's care and experience six months prior to the onset of the COVID-19 pandemic. The review panel, therefore, agreed the timeline would extend to two years, from 1 September 2019 until 5 September 2021. The timeline was supplemented by contextual background information that assisted the review in understanding the impact of events on Child A's needs. Those submissions were discussed in detail during meetings of the Panel and at the Learning Event and, alongside the contributions of Child A's mother, have informed the learning included in this report.

### **The process followed by the Board and the services represented on the Review Panel**

A Panel Chair and an Independent Reviewer were commissioned, who were, per the guidance, independent of the case management and had the relevant experience, abilities, knowledge and skills as required by the case and circumstances under review. The Review Panel consisted of representation from the following services, all of whom had had an involvement with the individuals at the centre of this review:

- Local Authority Children Services
- Health
- Education

In total, the Panel met on seven occasions. During this review, several Panel members, including the independent reviewer and independent chairperson, attended the North Wales Safeguarding Board Cultural Diversity and Harmful Practices Training, which they found beneficial. That training assisted the Panel's reflections on the learning in light of Child A's experience, and its usefulness for all professionals working in safeguarding is reflected in the recommendations.

### **Family involvement in the review**

Participating in a child practice review when a child has died is an incredibly difficult and sensitive process for any parent or family member. This review has benefitted from the kind participation and thoughtful reflections of Child A's mother, to whom the reviewer wishes to extend their sincere

condolences and gratitude for her valuable contributions to the learning process. These views are presented in later sections of this report.

### **The Learning Event and Health Discussion**

A Learning Event was convened on 11th January 2023, and practitioners from all key agencies were invited. Unfortunately, an unforeseen bereavement and public sector strike action led to the absence of education and one of the two health practitioners. At the Learning Event, practitioners shared their insights into the lived experience of Child A. It was evident that professionals had worked hard to support Child A and to ensure she had access to as full a life as her condition would allow. The time that had passed did not lessen the challenging nature of reflecting on the deterioration in Child A's health. Some attendees regret that a safeguarding report was not made, and this weighed heavily on them as it left any understanding of the impact of the hotel-based quarantine and parental care unresolved. It was evident that professionals had worked hard to support Child A and ensure she had access to as full a life as her condition would allow. The Learning Event provided an opportunity for the practitioners who attended to share their experiences and reflections. However, that process was limited by the absence of education and one of two health practitioners. Fortunately, shortly after the Learning Event, the reviewer convened an online video discussion with a key health professional. Health services remained clear in their analysis of the multiple complex needs of Child A and their decision-making processes to give the health management plan time to demonstrate effectiveness.

The reviewer is grateful to those who participated in the learning process for their invaluable contributions. The Learning Event raised difficult feelings which it was unable to resolve fully. Notably, the role of the Panel has been crucial and extensive in sharing and extending the learning process across agencies. The willingness of all to engage in critical reflection and seek solutions built on a shared understanding is commended.

### **Practice and organisational learning**

*Identify each individual learning point arising in this case (including highlighting effective practice) accompanied by a brief outline of the relevant circumstances*

Two overarching themes were drawn from the chronology, multi-agency analysis, Learning Event, health discussion and the kind contribution from Mrs A. The reviewer did not meet with Mr A and was unable to establish his use and understanding of English or his views about the review. However, although Mrs A took the parental lead with agencies regarding the care of her daughter, the review was able to gain insights into Mr A's views regarding his daughter's health and well-being. The first theme is the importance of a multi-agency approach to working with a child with a life-limiting condition and their global family. That theme also captured a holistic view of Child A's needs. Secondly, the impact of the COVID-19 pandemic was an important, if not devastating, factor in Child A's experience. In particular, the impact on her health during the UK Government imposed hotel-based quarantine and the decision to deny Mrs A's requests for reasonable adjustments.

### **A multi-agency global family approach to working with children with life-limiting conditions and their families**

Research<sup>8</sup> suggests a global perspective of care is required as the factors that constitute 'quality of life' vary between ethnic, religious, personal and community standards. As such, opportunities for inclusive discussions with Child A and her family regarding their feelings about crucial matters were vital. Anti-racial discrimination practice requires practitioners from the majority white population to consistently adopt a critically reflective lens to raise self-awareness of the experience of intersectional oppression<sup>9</sup>. A failure to do that can perpetuate the experience of structural racism. There was notable good practice in that regard from all agencies who worked to support Child A and her parents to maintain strong relationships with their families in Pakistan. However, there were also occasions when there was scope for a greater intersectional understanding and appreciation of a global family.

#### Family Life with Mitochondrial Disease

The rare, extensive and unpredictable health needs of Child A defined much of how she and her parents lived their lives. Mrs A states that she was advised not to research the disease. Indeed, the manifestations of the disease are unique to everyone, but a greater understanding of the disease would arguably have helped prepare Mr and Mrs A for the unexpected challenges<sup>10</sup>. The limited understanding that the review had regarding Mr A's knowledge came from Mrs A. The level of Mr A's understanding of English remained unclear. Practitioners who met Mr A when visiting the family home described him as an attentive father whom Child A was always excited to see. Mr A may have been more included in the discussions about his daughter's care if he had received information about the disease in his first language or if an interpreter was available. Notably, the rarity of the disease and the high mortality rate for children also means that most practitioners would not have experience in caring for a child with mitochondria.

As is common with Child A's health condition, maintaining her weight required medical intervention<sup>11</sup> and she was fitted with a PEG tube that enabled liquid food to be inserted directly into her stomach. For children and parents, PEG feeding has benefits such as removing the stress of administering oral medications. However, the frequency of feeding and overnight feeds often means parents, usually mothers, are providing 24-hour care<sup>12</sup>. That was the case for Mrs A, who would sleep on the sofa next to her daughter's bed in a downstairs room so she could administer night feeds and respond to any seizures. Mr A made adaptations to the family home and designed a wet room that would accommodate his daughter's bathing needs. He worked long hours so they could travel business class to ensure their daughter had sufficient space for her health needs while maintaining important familial relationships. As parents, Mr and Mrs A were on call to respond to any seizures that Child A might have at school and were always prompt in collecting her.

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<sup>8</sup> Saneto, R. P. (2016). Alpers–Huttenlocher syndrome: The role of a multidisciplinary health care team. *Journal of Multidisciplinary Healthcare*, 9(1), 323–333. <https://doi.org/10.2147/JMDH.S84900>

<sup>9</sup> Nayak, S. (2022). An intersectional model of reflection: is social work fit for purpose in an intersectionally racist world? *Critical and Radical Social Work*, 10(2), 319–334. <https://doi.org/10.1332/204986021X16555682461270>

<sup>10</sup> Price, J., Hurley, F., & Kiernan, G. (2022). “Managing an unexpected life - a caregiver’s career’: Parents’ experience of caring for their child with a non-malignant life-limiting condition. *Journal of Child Health Care*, 136749352211329–13674935221132920. <https://doi.org/10.1177/13674935221132920>

<sup>11</sup> Wolfe, L.A., Regier, D., Saneto, R., Parikh, S., Goldstein, A., & Boerkorl, N. (2013). Failure to thrive in children with mitochondrial diseases, *Mitochondrion*, 13(6), p935-<https://doi.org/10.1016/j.mito.2013.07.094>.

<sup>12</sup> Brotherton, A. M., Abbott, J., & Aggett, P. J. (2007). The impact of percutaneous endoscopic gastrostomy feeding in children; the parental perspective. *Child : Care, Health & Development*, 33(5), 539–546. <https://doi.org/10.1111/j.1365-2214.2007.00748.x>

Mothers of children with a life-limiting illness are significantly more likely to experience depression, anxiety and serious mental illness than other mothers (Fraser et al., 2021)<sup>13</sup>. Additionally, there is evidence their physical health is impaired. However, they visit the doctor less regularly, and the incidence of death was also 50% higher in this population of mothers.

A multi-agency approach was vital to support the complex individual care and support needs of Child A and her parents. Throughout Child A's life and during the timeline, there is abundant evidence that the multidisciplinary team worked well to meet the unpredictable and significant health needs caused by mitochondrial disease. There is evidence of detailed health action plans, and the Local Authority completed and updated a care and support assessment. The social worker beautifully and sensitively presented the depiction of Child A's abilities and needs.

Mrs A was the primary link with professionals, and she was supported to learn the skills required to deliver a high level of care to her daughter at home. There were occasions when Mrs A became exhausted and experienced pain due to the impact on her physical health. Positively, the Local Authority responded by completing a carer's assessment. To assist with Mrs A's physical needs, she was encouraged to accept the use of a hoist to help in the care of her daughter. Mrs A had initially agreed to a hoist, but she and Mr A had reached a stage where they thought caring for their daughter would require a bigger house, and they did not want the installation of equipment to hinder any potential sale. However, once the installation was explained during an in-person visit by the occupational therapist, Mrs A readily agreed to the hoist, which was fitted.

The review learned that Mr and Mrs A did not take up the Local Authority's offer of respite care. However, they did seek and accept support facilitated by all agencies to receive periodic care and support from their family members. Mrs A explained how she gained support for caring for Child A from their family during their annual visit to Pakistan. Their visit took place during the UK winter season, which provided much-needed respite from the cold for Child A. Additionally, Child A loved spending time with her relatives in Pakistan, with whom she shared close attachments. The support for Child A and her parents to spend time with their global family was consistent, and all agencies facilitated that by assisting Mrs A's preparations.

Within the chronology, there are occasions when Mrs A requests support with the daily activities of caring for her daughter and a desire for her daughter to attend school for a half day in the afternoon rather than the whole day. As the requests were being explored, the COVID-19 pandemic began, and Child A was clinically vulnerable and required to shield. Positively, the social worker completed a care and support review by telephone at the start of the pandemic and provided support that enabled Mrs A to access support from family members.

There was the scope for Child A's wishes and feelings to be formally documented. However, the contributions from Mrs A and the practitioners who had been involved with Child A reflect she had a meaningful impact on them, she could be strong-willed and able to assert her needs and wishes. Notably, the deteriorating health that Child A experienced prior to her death was also particularly devastating for those who provided her with care and support.

### School-Based Provision

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<sup>13</sup> Fraser, L. K., Murtagh, F. E., Aldridge, J., Sheldon, T., Gilbody, S., & Hewitt, C. (2021). Health of mothers of children with a life-limiting condition: a comparative cohort study. *Archives of Disease in Childhood*, 106(10), 987–993. <https://doi.org/10.1136/archdischild-2020-320655>



Child A loved school and indicated she wanted to attend whenever she could. She enjoyed her educational achievements as well as her relationships with teachers and school friends. Equally, they cherished her, and a particularly lovely home-school report captures the spirit, ability and educational potential of Child A. The contextual information suggests Child A's attendance at primary school was not problematic, and when she was too unwell to attend school, she was provided with home education.

School attendance enabled Child A to engage with stimulating learning and have her eating and weight independently monitored. However, the first six months of the timeline reflect Child A's poor attendance at high school, with reasons given being based on health needs, which were reportedly exacerbated by the cold weather. The chronology demonstrates Child A continued to enjoy high school when she attended. However, Mrs A expressed concern for her daughter's well-being when attending school due to the impact on her mitochondrial symptoms, such as tiredness and seizures. MacKinnon (2023)<sup>14</sup> suggests it is best to avoid the 'boom and bust' phenomenon for children experiencing fatigue created when levels of activity are too high and lead to greater exhaustion. The complexity of mitochondrial disease made assessment of Child A's needs and ability to attend school regularly more challenging. For example, Child A had drug-resistant epilepsy and would experience fluctuations in seizure control and changes in medication. The chronology reflects more frequent visits to the hospital when Child A was attending school, although Child A was not always required to be admitted to a ward.

Mrs A requested that her daughter attend only half days in the afternoon to enable Child A to recover from the tiredness she experienced after her morning routine. That request was eventually agreed upon as the school recognised that, on occasion, Child A did require sleep during the school day. However, the lack of attendance at school also reduced Child A's access to the services she required, such as physiotherapy, which was delivered on the school premises. The last physiotherapy session Child A had at school was in February 2020. In March 2020, concern was expressed about Child A's posture, and she was referred to an orthopaedic surgeon for further assessment.

There is frequent mention of Mrs A's anxiety in the timeline, and the reviewer formed the view that Mrs A feared not being present when her daughter needed her. Research<sup>15,16</sup> suggests parents of children with mitochondrial disease face unique challenges and experience a heightened sense of responsibility for their child.

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<sup>14</sup> MacKinnon, L. (2023). Management of fatigue in children and young people. *Paediatrics and Child Health*, 33(10), 305–312. <https://doi.org/10.1016/j.paed.2023.07.003>

<sup>15</sup> Senger, B. A., Ward, L. D., Barbosa-Leiker, C., & Bindler, R. C. (2016a). Stress and coping of parents caring for a child with mitochondrial disease. *Applied Nursing Research*, 29, 195–201. <https://doi.org/10.1016/j.apnr.2015.03.010>

<sup>16</sup> Senger, B. A., Ward, L. D., Barbosa-Leiker, C., & Bindler, R. C. (2016b). The Parent Experience of Caring for a Child with Mitochondrial Disease. *Journal of Pediatric Nursing*, 31(1), 32–41. <https://doi.org/10.1016/j.pedn.2015.08.007>

### **Family perspectives and reflections**

Child A was loved and spent her life with her family. Mrs A shared a video of Child A's 13<sup>th</sup> birthday party with the reviewer, showing her surrounded by family and enjoying their expressions of love, birthday gifts and fun. The reviewer was unable to meet with Mr A as he was in Pakistan for a period of mourning the loss of his daughter. Child A is buried in the family graveyard at the family home in Pakistan. Mrs A kindly showed the reviewer a film of Mr A commemorating his daughter by undertaking a graveside ritual.

Mrs A explained she wanted her daughter to have a normal life, and they had enjoyed numerous family holidays. Mrs A queried the pressure she experienced for her daughter to attend school when she had a life-limiting condition. Mrs A did not take up the offer of respite care as she did not want to be separated from her daughter overnight.

Mrs A particularly complimented the support she and her daughter received from the health professionals, whom she felt supported her in managing her daughter's complex medical needs.

Finally, Mrs A described in detail the support that she, her husband and Child A received during the last days of her life provided a lasting and protective memory that everyone did what they could to meet Child A's needs.

### **Learning Points**

- Children's wishes and feelings should consistently be documented whenever possible.
- Care and support plans to include arrangements to weigh children with life-limiting conditions who require independent weight monitoring, when they are not attending school.
- Care and support plans to include alternative arrangements for children who receive physiotherapy in school when they are not in attendance.
- Providing information regarding a child's health and social care needs in a parent's first language and consideration of the use of an interpreter could encourage their understanding and engagement in decision-making.

### **Good Practice**

- There are multiple examples of evidence of good communication between agencies and with the family.
- There was prompt follow-up of medical information to Mrs A to ensure the correct medication dosage was being provided to Child A at home.

- There was evidence of sensitivity in appreciating the relationship shared between Mr A and his daughter on the occasions when they were observed together.
- The family were supported by the Local Authority and Health, who wrote letters of support to permit relatives to extend their stay in the UK to support Mrs A in caring for her daughter.
- Regular multidisciplinary team meetings took place with Mrs A.

### **The progressive nature of mitochondrial disease amidst the impact of COVID-19**

In March 2020, the UK responded to the onset of the COVID-19 pandemic with a multitude of emergency legislative and policy measures. Health and social care resources were often redirected to respond to unprecedented demands. Children with mitochondrial disease are at significant risk of morbidity from viral infections having one or more risk factors<sup>17</sup>. In accordance with government guidelines, Child A was identified as clinically vulnerable and was, at times, required to be shielded as a means of protection from the virus. Mr and Mrs A and the MDT were faced with competing and conflicting demands when balancing how to prevent Child A from contracting the virus and ensure she had access to necessary treatment for the effects of mitochondrial disease.

#### Protection from the virus

The impact of COVID-19 underpins 18 months of the timeline for this review. It reflects the complex and highly skilled practice required in an effective multi-agency response to a child with mitochondrial disease during an unprecedented pandemic. The care and support assessment review undertaken by the social worker records the measures taken by Mr and Mrs A to protect their daughter from the virus. These included Mr A isolating himself within the house and the use of sanitising methods to limit the potential of him bringing the virus home. During this period, practitioners were providing services within the family home. At times within the chronology there appeared to be assumptions made about a global family, such as their use of space.

The management of Child A's inherent fatigue was a key factor in ensuring her level of activity optimised her health. Notably, Between February 2020 and October 2020, Child A gained three kilograms in weight, rising to 26.6kg. During that period, there were no urgent presentations at the hospital or clinic. Child A's epilepsy was stable, as was her food tolerance and retching. However, other aspects of her health and social needs were restricted due, in part, to the need to shield. Mrs A's request for support for a sessional worker to take Child A out in the community was agreed upon, provided she was well enough to participate. However, in July 2020, the agency providing sessional care determined it was too high risk to send sessional workers into the family home while the government shielding policy was in place. At that time, the shielding policy was in place until the 16<sup>th</sup> August 2020.

<sup>17</sup> Gordon-Lipkin, E. M., Marcum, C. S., Kruk, S., Thompson, E., Kelly, S. E. M., Kalish, H., Bellusci, L., Khurana, S., Sadtler, K., & McGuire, P. J. (2022). Comprehensive profiling of the human viral exposome in households containing an at-risk child with mitochondrial disease during the 2020–2021 COVID-19 pandemic. *Clinical and Translational Medicine*, 12(11), e1100-n/a. <https://doi.org/10.1002/ctm2.1100>

### Responding to concerns regarding Child A's posture

The Local Authority and Health agencies maintained regular contact with Mrs A to review her daughter's needs. In August 2020, Mrs A took Child A to attend an appointment with a specialist health consultant in the North of England. A medication review led to Child A being prescribed Baclofen, used to relieve rigidity and stiffness in muscles. The following day, a multidisciplinary team (MDT) meeting was held, which appeared to be the first MDT since October 2019. The professionals met before bringing Mrs A into the meeting. The MDT noted the ongoing concern about Child A's posture, weight and social isolation. It was arranged for a specialist chair to be moved from the school to the family home. However, there was some delay in the chair being set up as Child A was sleeping when it was delivered.

On balance, the MDT thought Child A should return to school in September 2020 after the shielding period to allow her access to physiotherapy and hydra sessions. Soon afterwards, Mrs A began to report an increase in her daughter's mitochondrial symptoms, which was judged to be due to anxiety rather than a deterioration in Child A's general health. Mrs A agreed to her daughter's return to school, but difficulties with the education transport provision and the wait for a part for the wheelchair created further delays. Then, the Welsh Government imposed a two-week 'firebreak' lockdown period from 23 October 2020 to stem the spread of the virus.

In late 2020, Child A was receiving physiotherapy at home, and concerns regarding her posture continued. A profiling bed for Child A was requested. Mrs A reports giving her daughter regular massages and using knee cushions. Child A required support to wear splints, and it was unclear from the chronology whether she or her parents understood the use of splints and their anticipated success, given the nature of Child A's condition at that time. In January 2021, there was a recording that Mrs A was struggling with providing physiotherapy to her daughter, which she found 'too hard'.

The appointment with the orthopaedic surgeon was rearranged from 13 November 2020 to 12 February 2021 as Mrs A was suffering from neuralgia, and there was no one else to take Child A to the appointment. The February appointment was attended. Mrs A had reportedly asked the sessional worker to assist with Child A's leg exercises, but it was outside of their remit and expertise. The request again suggests Mrs A felt in need of support with Child A's exercises. However, she was later advised not to ask other workers to assist. There was no recording of what discussions took place with Mrs A to explore the difficulties she was experiencing with providing her daughter with physiotherapy exercises and what support she needed. Saneto (2016)<sup>18</sup> asserts communication is key as mitochondrial disease progresses and medical needs change. He notes that although unpredictable losses of function occur, a multidisciplinary team approach can foster individual care for the child and their family.

On 23 February 2021, an MDT meeting was convened, and concerns regarding Child A's posture were raised. It was recognised that although the scoliosis was expected to worsen given the progressive nature of her condition, it would not have deteriorated to this extent at this time if she had had consistent physiotherapy and stretching exercises. Mrs A advised the MDT that she did

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<sup>18</sup> Saneto, R. P. (2016). Alpers–Huttenlocher syndrome: The role of a multidisciplinary health care team. *Journal of Multidisciplinary Healthcare*, 9(1), 323–333. <https://doi.org/10.2147/JMDH.S84900>

physiotherapy to the best of her ability with her daughter every day. The MDT heard that the physiotherapy plan was to reduce physiotherapy in the home as their involvement should be school-based.

Following that meeting, a family safety plan was agreed and two weeks later a detailed and largely sensitive care and support plan reflects the complexity of the needs of Child A and the care she receives is completed by the social worker. It highlights the limitations and barriers to meeting her complex needs. The plan recognises Child A can be too unwell to attend school and that not engaging is part of what she can control in her life. Additionally, there was a plan to offer Mrs A an updated carer assessment, the last one being completed in 2018.

#### Sessional support within the home

The sessional support was an important opportunity for social and cognitive stimulation for Child A during the pandemic. The reports from the sessional worker provide illuminating insights into the experiences of Child A during those visits. Child A was described as having fun with a sense of determination to complete tasks that might be difficult and shared her feelings about missing her grandmother. Both Child A and her mother advised the social worker in November 2020 that these sessionals were enjoyable for her, although she could be quite tired at the end of the two hours. Additionally, once the sessional worker was able to respond to Child A's seizures, her presence provided Mrs A the rare opportunity to run errands. The sessional worker continued to provide support, including when Child A's health had significantly deteriorated, providing valuable and sensitive interactions at a time when Child A was also experiencing grief following a close bereavement. The chronology notes the provision of sessional hours to Child A was time-limited as the demand for its service outweighed the provision.

#### The impact of hotel-based quarantine and significant deterioration in Child A's health

In February 2021, the UK government responded to the concern of the COVID-19 Delta variant by imposing social restrictions that required those arriving in the country to remain in a hotel for a period of quarantine. In March 2021, the Welsh government began to ease restrictions<sup>19</sup>, including removing the restrictions that closed schools. Advice for those shielding was to ensure additional risks were considered when outdoors. Child A and her parents left the UK at the end of March 2021 for their annual visit to see their family in Pakistan.

By May 2021, the Welsh government was bringing forward its dates for relaxing social restrictions, including the resumption of indoor activities for children. However, concern regarding a new COVID variant, B.1.617.1, led to the Welsh government postponing the lifting of restrictions for four weeks. The family had been due to return to the UK at the end of May 2021. On the 2<sup>nd</sup> June 2021, the paediatrician requested an accessible room in a quarantine facility or to permit the family to quarantine at home as per Mrs A's preference. The request was denied. Mrs A advocated for her daughter and appealed for alternative quarantine arrangements, to no avail.

Upon her return to the country, Mrs A emailed the occupational therapist on the 21<sup>st</sup> June 2021, explaining they were in quarantine and asking for him to arrange for hoist slings to arrive so that

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<sup>19</sup> [Coronavirus restrictions review March 11 2021: summary impact assessment | GOV.WALES](#)

they could return to the family home on the 2<sup>nd</sup> July 2021. Also, on 21<sup>st</sup> June 2021, Mrs A contacted the social worker and reported Child A had stayed well during their stay in Pakistan and had had no problems. There is no recording of a practitioner speaking directly to Child A at that time. However, by 5<sup>th</sup> July 2021, Child A was complaining of leg pain and had concerning pressure damage; Mrs A believed the deterioration in her daughter's health was due to the restrictive conditions during quarantine. Upon examination, the deterioration in Child A's physical health was of grave concern and was upsetting to the practitioners who worked closely with her. Her weight had dropped to 22.9kgs, there was a loss of muscle mass, and she had pressure damage and was experiencing pain. The subsequent decisions of the MDT members are described at the start of this report and constitute the basis of the review.

### **Family perspectives and reflections**

Mrs A questioned whether she could have done more as she balanced her daughter's quality of life and need for normality with the challenges of meeting her complex needs and knowing they were life-limiting. Mrs A described how she and her husband devoted their lives to their daughter and witnessed her suffering.

Mrs A felt that in signing the family agreement, she was perceived to be agreeing with a view that she was neglecting her daughter.

Mrs A was concerned about the impact of quarantine and contacted health professionals for support to quarantine at home. Mrs A also pursued other routes to advocate for her daughter by highlighting her concerns regarding the impact of quarantine.

### **Learning Points**

- The impact of the COVID-19 pandemic meant there was an insufficient number of support workers available to the Local Authority. Risk assessments were undertaken before any support was withdrawn.
- During the COVID-19 pandemic, governments, agencies and families were responding to complex and competing needs. Learning was a constant feature as they tried to make sense of new information.
- Future practice will benefit from the availability of accessible quarantine facilities or other methods of determining safeguarding adjustments for clinically vulnerable children.
- A video or phone call at the start of or during quarantine would have enabled a practitioner to speak directly to Child A.

- A risk assessment to ensure appropriate safety measures were in place for Child A undertaking international travel during a pandemic could have highlighted the potential impact of quarantine.

#### **Good Practice**


- The family were supported by the Local Authority and Health, who wrote letters of support to permit relatives to extend their stay in the UK to support Mrs A in caring for her daughter.
- Agencies recognised the contribution the risk of COVID-19 had upon Mrs A's anxiety about her daughter attending school.
- Health supported Mrs A's request for advocacy and wrote a letter requesting an accessible room in a quarantine facility or permitting the family to quarantine at home.

#### **Improving Systems and Practice**

*In order to promote learning from this case, the review identified the following actions for the Board and its member agencies and anticipated improvement outcomes: -*

1. All professionals working with children and families to receive cultural diversity and intersectionality training with a specific focus on working with global families whose children have life-limiting conditions.
2. Information about a child's significant health condition and prognosis should be provided to parents in both their first language and English.
3. To request the Chair of the North Wales Safeguarding Children's Board write to the Welsh Government to consider how future quarantine facilities will be suitable for children with life-limiting complex health needs.
4. Consideration to be given to alternative provision of school-based health services when children are absent from school or a period that would impinge on their health and well-being.
5. Promotion of counselling and well-being support to be provided and promoted for practitioners who are working with children with life-limiting conditions.

#### **Statement by Reviewer(s)**

<b>REVIEWER 1</b>		<b>REVIEWER 2</b> <i>(as appropriate)</i>	
<b>Statement of Independence from the case</b> <i>Quality Assurance statement of qualification</i>		<b>Statement of independence from the case</b> <i>Quality Assurance statement of qualification</i>	
<p>I make the following statement prior to my involvement with this learning review: -</p> <ul style="list-style-type: none"> <li>• I have not been directly concerned with the individual or family, nor have I given professional advice on the case.</li> <li>• I have had no immediate line management of the practitioner(s) involved.</li> <li>• I have the appropriate recognised qualifications, knowledge and experience and training to undertake the review.</li> <li>• The review was conducted appropriately and was rigorous in its analysis and evaluation of the issues as set out in the Terms of Reference.</li> </ul>		<p>I make the following statement that prior to my involvement with this learning review: -</p> <ul style="list-style-type: none"> <li>• I have not been directly concerned with the individual or family, nor have I given professional advice on the case.</li> <li>• I have had no immediate line management of the practitioner(s) involved.</li> <li>• I have the appropriate recognised qualifications, knowledge and experience and training to undertake the review.</li> <li>• The review was conducted appropriately and was rigorous in its analysis and evaluation of the issues as set out in the Terms of Reference.</li> </ul>	
<b>Reviewer 1</b>		<b>Reviewer 2</b>	
<i>(Signature)</i> 		<i>(Signature)</i> .....	
<b>Name (Print)</b> Dr Donna Peach		<b>Name (Print)</b> .....	
<b>Date</b> 07.02.2024		<b>Date</b> .....	

<b>Chair of Review Panel</b>	
<i>(Signature)</i>	
<b>Name</b>	Ann Griffiths
<i>(Print)</i>	
<b>Date</b>	07/02/2024



**For Welsh Government use only**

Date information received .....

Date acknowledgment letter sent to Board Chair .....

Date circulated to relevant inspectorates/Policy Leads .....

<b>Agencies</b>	<b>Yes</b>	<b>No</b>	<b>Reason</b>
CSSIW	<input type="checkbox"/>	<input type="checkbox"/>	
Estyn	<input type="checkbox"/>	<input type="checkbox"/>	
HIW	<input type="checkbox"/>	<input type="checkbox"/>	
HMI Constabulary	<input type="checkbox"/>	<input type="checkbox"/>	
HMI Probation	<input type="checkbox"/>	<input type="checkbox"/>	