Concise Child Practice Review Report

CYSUR 3/2021

Date report presented to the Board:

15th January 2024

Child Practice Review Report

CYSUR: Mid & West Wales Safeguarding Children Board

Concise Child Practice Review Re: CYSUR/3/2021

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*
- *The time period reviewed and why*
- *Summary timeline of significant events to be added as an annex*

Legal Context

A Concise Child Practice Review was commissioned by CYSUR, the Mid and West Wales Safeguarding 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[1] (2014 Act); *Working Together to Safeguard People Volume 2 – Child Practice Reviews*[2] published 2016 (updated, 2021); The Safeguarding Boards (Functions and Procedures) (Wales) Regulations 2015[3].

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

This Child Practice Review identified learning that will benefit future practice. It involved practitioners, managers and senior officers who explored the detail and context of agencies' work with Child A and her family. The review's outcome will generate professional and organisational learning to promote improvement in future interagency practices with children and families. It includes the circumstances that led to the review, highlighting effective practice and consideration of how to improve future practice (Working Together to Safeguard People – Volume 2 – Child Practice Reviews (Welsh Government, 2016[5])).

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

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[1] Social Services & Well-Being (Wales) Act 2014

[2] Working Together to Safeguard People – V2 – CPRs (Welsh Government, 2016)

[3] The Safeguarding Boards (Functions and Procedures) (Wales) Regulations 2015

[4] 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

[5] Working Together to Safeguard People – V2 – CPRs (Welsh Government, 2016)

Preamble

The distressing nature of Child A's avoidable suffering and subsequent death is an inescapable truth at the core of this Child Practice Review. Throughout the review process, all concerned have ensured that Child A's life, relationships, and the nature of her death were treated with the utmost dignity. The legacy of Child A must be more than the memory of how she died. We can achieve that by harnessing what we learn from how this tenacious child faced the world amidst compounding health and social inequalities. Child A deserved our sincere, thoughtful and critical examination of the multiple hierarchical interrelated and complex factors that contributed to her lived experience. Equally, we should be willing to gaze upon and celebrate her vibrant life and the positive impact of her family and public services. In doing so, this review will help make sense of how a child who was loved and cherished by her family, who had notable potentiality, died prematurely in a state of chronic neglect.

Circumstances resulting in the review

In October 2020, the Ambulance service informed the police that they had attended the family home of 16-year-old Child A and sadly found her to be deceased. The condition of her body was a source of anguish and indicative of chronic neglect. There were also significant concerns about the unhygienic and unkempt condition of Child A's immediate living environment. There was a sense of shock, distress and anger regarding what Child A had experienced, particularly in the months, weeks, and days before her death. A post-mortem examination was completed. Child A was found to be grossly obese and immobile; consequently she had extensive inflammation and infection leading to her suffering and ultimate death. The absence of parental intervention to seek medical assistance for Child A lacked explanation and hindered immediate comprehension.

The period reviewed and why

The review's Panel and Independent Reviewer convened before suspending its activity pending the outcome of criminal proceedings. The Panel agreed to extend the standard 12-month timeline to 24 months from 10th October 2018 until 10th October 2020 to include an understanding of Child A's lived experience before the onset of the COVID-19 pandemic. That contrast is important as the pandemic created unprecedented demands on all public services. The pandemic highlighted our depleted and unprepared human and physical resources[6] and its impact on children's education[7]. Across the public sector, local authorities, education, health and the police demonstrated a remarkable ability to pool their resources and find innovative solutions.[8]

Furthermore, the review received contextual background information to assist its understanding of the impact of historical events on Child A's needs. The review has benefitted from valued contributions from Child A's family. Additionally, the knowledge and skill of the Panel's members, practitioners and service managers to critically examine Child A's lived experience helped co-produce the learning presented within this report.

An introduction to Child A and her parents

Child A was the fifth of six children born to their parents in rural Wales. At the time of her birth, Child A's mother, Ms B, was 22 years old, her father, Mr C, was 27, and they had five children under the age of 5. Child A was described as a wonderful, determined, fun, and headstrong girl who, despite her significant congenital disabilities, wanted to be treated as 'normal.' Child A loved being active; she could perform what seemed like handbrake turns in her wheelchair and excelled when playing sports. Reportedly, given the right opportunities and support, Child A could have been a future Paralympian.

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[6] COVID-19: Impact of the pandemic on healthcare delivery (bma.org.uk)

[7] COVID's impact on education: Worst for the most vulnerable | World Economic Forum (weforum.org)

[8] COVID-19: good council practice | Local Government Association

She was born with spina bifida (SB), a complex and lifelong disability. This congenital condition is one of the most complex permanently disabling conditions, affecting most areas of a child's functioning[9]. Consequently, Child A had hydrocephalus, significant bladder and bowel difficulties, paralysis of her legs and was wheelchair-bound. Child A had multiple surgical operations throughout her life and required access to expert treatment and support from various health specialists in Wales and England. These specialists included, but were not exclusive to, community paediatrics, consultant paediatrics, urology, orthopaedics, physiotherapy, occupational therapy, continence, and dietetics. Child A had numerous appointments over her lifetime with these health professionals. However, it is recognised that many were also missed.

When their daughter was younger, Ms B and Mr C each assisted with complex and intimate care, including catheterisation. They attended primary school trips with Child A to remove barriers to her inclusion by supporting her care needs. Child A had surgery that enabled her to self-catheterise and self-manage her bowel programme. Although these daily tasks were burdensome and time-consuming, they increased her experience of self-efficacy, privacy and dignity. While sustaining Child A through complex reconstructive urological surgery, Ms B and Mr C supported their daughter's wish to be 'normal.'

In an ableist world[10], Child A wanted to live her life like any other child and have others treat her as 'normal.' Child A enjoyed good intelligence and attended mainstream primary and secondary schools. Positively, with the support of professionals and her family, Child A gained control of her body and was encouraged to enjoy a positive self-identity. Mr C explained that as Child A grew older and required greater privacy and autonomy, he appropriately withdrew assistance for his daughter’s personal care. In 2016, at the age of 12 years, Child A had successfully transitioned from primary to secondary school and enjoyed sports and other social activities. There were no safeguarding concerns about Child A at that time. She was developing a strong sense of independence as she entered adolescence. In 2017, the Integrated Disability Service discharged Child A from their service in agreement with her parents. The Local Authority did not receive a multi-agency referral form (MARF) to request a care and support assessment or to raise any concerns about her well-being prior to her death.

Timeline of events

This section of the report provides an overview of interactions between Child A and public services within the two-year timeline of the review. The information presented will be analysed and discussed in later sections of this report.

Notably, at the beginning of 2019, Child A had 98% school attendance and was a valued member of her school community. She received frequent support from a school-based Youth Intervention Service (YIS) worker after experiencing bullying on a social media platform. Although Child A found it difficult to articulate her feelings, the YIS worker gained some insights and recorded concerns about A's emotional well-being.

In February 2019, Child A had swelling to her left knee and was experiencing intermittent pain; the symptoms were noted to be minimal, and her parents received medical advice for her to take paracetamol when needed. In March 2019, Ms B contacted out-of-hours triage to seek advice regarding Child A, who was experiencing abdominal pain and nausea. Ms B was advised to continue with the pain relief and to contact the service again if symptoms worsened. As the school year ended in July 2019, Child A's attendance had dropped to 89%, but this figure was also impacted by an authorised family holiday that took place during term time.

In August 2019, a paediatrician wrote to the school nursing service to request that Child A's weight and height be recorded. Upon receipt, the referral form was annotated to record that the appropriate equipment was not available to the school nurses; as such, the request was passed

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[9] Holmbeck et al. (2006) https://doi.org/10.1097/00004703-200606000-00012

[10] Daalen-Smith (2007). https://www.tandfonline.com/doi/abs/10.5172/conu.2006.23.2.262

to the community children's nursing service. However, there is no written evidence of that request within Child A's health records. In September 2019, paediatric urology decided not to offer further appointments after Child A was not brought (WNB) to five previous appointments. However, that decision was later reversed, and Child A was seen virtually in May 2020.

Child A's parents continued to raise health concerns and took Child A to the General Practitioner (GP) in October 2019. At that time, Child A was experiencing a swollen foot and leg with accompanying flu-like symptoms. The GP records report that Child A had an elevated temperature, and her leg was swollen and inflamed. Additionally, there was a scab on her toe. Child A and Ms B were advised to continue with pain relief and provided with information to assist their monitoring of Child A's condition. The GP records note 'worsening advice given including sepsis.' Four days later, Child A was brought by Ms B to the pre-planned six-month review with the Orthopaedic Consultant. At that appointment, there was concern that the pressure area on Child A's toe had caused low-grade cellulitis[11] in her leg. It was noted that Child A had completed the course of antibiotics, and her condition was improving. Advice was provided to Ms B to examine Child A's feet daily and to keep her leg elevated.

Later that week, Child A was brought by Ms B to the district nurse's clinic, where it was recorded she had lymphoedema[12] in both legs. Lymphoedema is a chronic condition, the treatment of which the NHS states should include wearing compression garments, taking good care of your skin, moving and exercising regularly, having a healthy diet and lifestyle, and using specialised massage techniques. Child A and her parents required advice about how to manage lymphoedema, and the district nursing service noted the presence of support in the local community known as 'Leg Club.' However, although there was a recording for the district nursing service to discuss Child A's needs with the lymphoedema service, it is unclear if that discussion occurred. The importance of the appropriate maintenance of professional documentation will be discussed in a later section of this report.

In mid-November 2019, the school wrote to Ms B and Mr C as Child A's attendance had dropped to 70.8%. Both parents attended a meeting at the school, and Ms B explained her daughter's recent health needs and the bullying Child A had experienced in school. The school provided informal counselling to assist Child A and her friendship group. Child A's school attendance quickly improved to 82%.

Child A was seen by a Physician Associate (PA) over the Christmas holidays and received treatment for an acute ear infection. The last occasion Child A was seen in person by a health professional took place in early February 2020 as a follow-up appointment following treatment for an ear infection six weeks earlier. Child A was not brought to the outpatient appointment at the Community Nursing Continence Clinic in mid-February 2020. There is no evidence the Powys Teaching Health Board's Was Not Brought Policy was followed on that occasion.

Following the onset of the COVID-19 pandemic, Child A was identified as a vulnerable pupil; she last attended school in person in March 2020. Due to shielding, Child A could not attend the school's well-being hub. Instead, the school organised weekly well-being calls from senior leadership or well-being team members during the lockdown period. Two such calls took place with Ms B in March 2020. In April 2020, the Team Around the Family (TAF) ceased its involvement with Child A, recording she had been allocated to the Youth Intervention Service as a single agency support.

Throughout April 2020 and July 2020, the school staff telephoned Ms B weekly during term time. Most of those calls were answered by Ms B. Although numerous references are made to Child A's thoughts and feelings during these calls, there are only two recordings where it was explicit that Child A was spoken to directly.

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[11] Cellulitis - NHS (www.nhs.uk)

[12] Lymphoedema - NHS (www.nhs.uk)

In May 2020, a change in health practices enabled Ms B to participate in a telephone consultation with the hospital urology department. There is no mention of Child A being included in that consultation, where it was reported there had been no urinary tract infections, and Child A's self-catheterisation continued to be managed well. That was the last recorded interaction with a health agency before Child A's death.

On 17th July 2020, Child A's annual review of Special Educational Needs provision took place by phone. Child A engaged in that discussion (in the background), voicing concerns about her limited career opportunities. The careers service attended the call to help assist Child A with follow-up activities.

From the 3rd September 2020 to the 9th October 2020, the school maintained daily contact with Ms B, who described Child A as suffering from various ailments, including a cold and diarrhoea. A phased return to school was planned with Ms B to commence on the 7th October 2020. Further calls took place in the days before Child A's death, with Ms B reporting that Child A was too unwell to be in school and was too anxious about coming to school. The school were the last agency to speak to Ms B regarding Child A.

Practice and Organisational Learning

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

The learning identified within this section is derived from the timeline, Agency Analysis, Learning Events, an online health discussion and contributions from family members. Paralleling the legislative and ethical framework of the *National Review of Early Help, Care and Support and Transition for Disabled Children in Wales* report, published by Care Inspectorate Wales in 2021[13] (CIW 2021 report), this Concise Child Practice Review incorporated the social model of disability[14], the United Nations Convention on the Rights of Persons with Disabilities[15] (UNCRPD), the United Nations Convention on the Rights of the Child[16] (UNCRC), Rights of Children and Young Persons (Wales) Measure 2011[17], Equality Act 2010[18], Well-being of Future Generations (Wales) Act 2015[19] and Social Services and Well-being (Wales) Act 2014[20].

The review formed two overarching learning points which overlap to contextualise aspects of Child A's experiences that were not readily visible in the timeline. The first was how a child with a chronic disability could receive coordinated care and support if they were not assessed for or in receipt of a care and support plan. Secondly, was the context of Child A living in the rural location of Powys.

The importance of coordinated 'care and support' to help a child with a lifelong and potentially life-limiting chronic disability live a 'normal' life.

The importance of co-ordinated 'care and support' for a child with a lifelong disability such as spina bifida is an overarching learning point from this Child Practice Review. A key challenge has been to interrogate the experience of Child A, her parents and professionals to help make sense of how services could have operated differently in their support for Child A's wish to have a 'normal life.' Child A did not want to be defined by her disability; as such, it was important any structural and organisational barriers were identified and addressed.

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[13] National Overview Report in relation to Disabled children (careinspectorate.wales)

[14] Social model of disability sets out a different way to view disability – rather than defining people as disabled by their impairment (i.e. the medical model of disability), people with impairments are considered to be disabled by physical, attitudinal and organisational barriers created by society.

[15] Convention on the Rights of Persons with Disabilities | OHCHR

[16] UN Convention on the Rights of the Child - UNICEF UK

[17] Rights of Children and Young Persons (Wales) Measure 2011 (legislation.gov.uk)

[18] Equality Act 2010 (legislation.gov.uk)

[19] Well-being of Future Generations (Wales) Act 2015 (legislation.gov.uk)

[20] Social Services & Well-Being (Wales) Act 2014

There was a change in the legislation defining services for children with disabilities during Child A's life. The Welsh Government's commitment to providing sustainable health and social services for children, adults and families[21] was realised in the Social Services and Well-being (Wales) Act 2014[22]. Regarding children, the 2014 Act repealed or amended numerous aspects of existing primary legislation[23], including the concept of a 'Child in Need"[24] within the Children Act 1989. Prior to the enactment of the 2014 Act in 2016, Child A was, under the Children Act 1989, classified as a Child in Need and was entitled to services[25]. In 2017, the Integrated Disability Service discharged Child A from its provision with the agreement from her parents. At that point in time, there were no identified unmet needs.

The Social Services and Well-being (Wales) Act 2014[26] presumes a child with disabilities will have needs, and there is a duty on the Local Authority 'to assess a child who appears to need care and support in addition to, or instead of, the care and support provided by their family.' Child A was not subject to a care and support plan and, therefore, was not 'open' to receiving services from the Integrated Disability Service. The importance of transition planning for children with disabilities and the actions required by both Local Authorities and Health Boards in Wales has been defined in the CIW 2021 report. However, without a care and support plan or a request for an assessment, Child A and her needs and those of her parents as carers were not visible to the Local Authority.

Additionally, the 2014 Act makes provision for a disability register[27], the maintenance of which is now linked to the Care and Support Census[28]. The CIW 2021 report found that not all Local Authorities had complied with the requirements of the 2014 Act and states this information is crucial to plan for services that meet current and future needs. Child A had a chronic disability, but it is unknown if she was a child included in the disability register or what impact that might have had on her ability to receive services. Notably, registration is voluntary, and registers may, therefore, represent an underestimation of the number of children with disabilities.

The review recognised the challenging working conditions of those who continue to deliver our public services. The commitment of practitioners and managers to deliver the best health, education and social care they can was abundantly evident. However, a repeated narrative shared by managers and practitioners as part of the learning events was the insufficient number of practitioners across services, including community paediatricians[29], specialists in congenital urology[30], GPs[31] and school nursing[32]. Notably, there are some strategies in place designed to respond to effective workforce provision, including the introduction of Physician Associates (PAs) in contemporary general practice[33,34].

Family Perspectives and Reflections

Child A wanted to be treated as normal. She was determinedly independent. Child A's mother and father accept responsibility for not consistently providing adequate care and support for their daughter.

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[21] Sustainable Social Services for Wales: A Framework for Action (gov.wales)

[22] Social Services & Well-Being (Wales) Act 2014

[23] Table_of_Amendments_and_Repeals.pdf (socialcare.wales)

[24] Table_of_Children_Act_1989_Destinations.pdf (socialcare.wales)

[25] Children with disabilities were entitled to services under schedule 2 part 1 paragraph 6 of the 1989 Act.

[26] Social Services & Well-Being (Wales) Act 2014

[27] https://www.gov.wales/local-authority-registers-disabled-people-31-march-2022

[28] Wales Children Receiving Care and Support Census: as at 31 March 2021 | GOV.WALES

[29] Kindregan (2023). 798 The role of advanced clinical practitioners in triage of referrals to community paediatricians. Archives of Disease in Childhood, 108(Suppl 2), A67–A68

[30] Payne, et al., (2023). Stress among UK consultant urologists and factors influencing when they leave full-time NHS practice. Journal of Clinical Urology.

[31] Majeed (2017). Shortage of general practitioners in the NHS. BMJ (Online), 358, j3191–j3191. 1

[32] School nurses stretched to breaking point despite pledge: RCN survey reveals reduced investment in training and development for school nurses resulting in shortages. (2009). Primary Health Care, 19(8), 4–4. 3

[33] Salisbury (2023). Physician associates in general practice BMJ 2023; 382 :p1596 doi:10.1136/bmj.p1596

[34] Ali (2023). Physician associates in general practice: a GP registrar's perspective BMJ 2023; 382 :p1960

Learning Events Perspective and Reflections

All Agencies

1. Child A was not subject to a care and support plan, akin to Section 21 of the Social Services and Well-being (Wales) Act 2014 at the time of her death. Although multiple health professionals participated in the delivery of her complex health care, this was not coordinated by a single agency or practitioner who had a holistic understanding of her complex health and care needs.

2. Agencies rely on each other and a child's parents to request a care and support assessment.

3. Child A would have benefitted from an assessment to identify her care and support needs.

Local Authority

4. It was unknown if Child A was included in the disability register and the learning event attendees were unclear if or how inclusion would have directly benefitted Child A.

5. The Local Authority should have a system that identifies the children with disabilities in their region who are likely to need care and support. This information should be used to shape allocated resources and the services available to children in Powys.

Health

6. Child A's changing health and physical needs could have been predicted, and for that reason, a regular review or assessment may have helped proactively identify these.

Agency Perspective and Reflections

Health

1. There is a void in current provision for children and their parents with identified chronic disabilities who are not subject to a formal care and support plan to ensure periodic reassessment of changing needs.

Local Authority

2. The pre-timeline decision to withdraw services was, at that time, not informed by a current assessment of developmental need. Any decision to withdraw services where a child has complex needs should be a multi-agency decision based on an up-to-date holistic assessment of need.

3. Parents of children with chronic disabilities should be offered a carers assessment.

The context of living in Powys

Child A lived in one of Powys' most poor rural areas, where 60% of the population experienced at least one dimension of deprivation at the time of the 2021 census. Children living in Powys have access to community-based health services to meet their needs. However, in the absence of a general hospital, all acute and many specialist services are commissioned from other health providers, often resulting in children and their families having to travel to access these services. Positively, there is notable expertise in both local and commissioned health services however, cross-border working can create challenges in communication between health professionals.

Child A's chronic disability required her to receive specialist treatment. Her urological and orthopaedic appointments were held at different hospitals in England, both a significant distance from her home. Research[35] shows access to paediatric urology can create a financial burden on any parent who must take time off work and self-finance transportation, but it can be a greater concern for families on a low income. Despite the challenges of attending these appointments, Child A was taken by her parents to many urological and orthopaedic appointments, although a number in her life were missed. The introduction of remote consultations for urology in May 2020 helped to remove some of the practical challenges to attend in-person appointments.

A final aspect to discuss as part of Child A’s life in Powys was that her family home was at the top of a steep hill. The house location meant Child A could not independently travel to and from her home. Although she was described as fearless as she wheeled downhill, slowing her progress by grabbing onto a lamppost, that was not without risk. Despite her soaring spirit, Child A was unable to wheel herself back up the hill, and family members would take turns to propel her wheelchair. Notably, the family home interior had some adaptations in Child A’s bedroom and bathroom. Child A could be agile, and when inspired to obtain some out-of-reach sweets, she could use her wheelchair to climb onto the countertop. However, the kitchen was full height and was not adapted to assist Child A in developing her independent living skills.

Family Perspectives and Reflections

Engagement with the family reflects they welcomed relationship-based practice with local professionals in whom they could trust. Child A engaged with various practitioners and received support from family members. However, travelling to hospitals in England put additional pressure on Child A’s family and their financial resources.

The family was glad to receive a house adapted to accommodate Child A and her wheelchair. It was explained that the hoist in Child A's bedroom had been installed for the previous occupant, but Child A had been able to self-transfer and had not used it. Ms B described how Child A would whizz down the hill at great speed in her wheelchair when going to school or out as a family. The family members would then take turns pushing Child A’s wheelchair up the hill to return home.

Learning Events Perspective and Reflections

<u>Housing</u>

1. Housing did not receive a referral to assess the suitability of the family home to meet Child A's needs as she grew older.

<u>Health</u>

2. There was agreement that there are challenges to the provision of health services when areas of expertise are cross border. These include communication, variations in policy and processes and the distance that children and their families may need to travel to access services.

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[35] Bator, et al., (2015). The burden of attending a pediatric surgical clinic and family preferences toward telemedicine. Journal of Pediatric Surgery, 50(10), 1776–1782.

Agency Perspective and Reflections

Health

1. Information sharing and communication between the English hospitals, the local hospital, the GP and the parents could have been more robust to establish why Child A was not brought to appointments. That could have been explored further to identify any safeguarding concerns or offer any further support to the family, particularly concerning the distance the family had to travel to appointments.

The importance of monitoring weight and physical activity for children with spina bifida

The monitoring of Child A’s weight as part of an ongoing care and support plan could have provided an opportunity to support her and her parents with weight management and early identification of any developing concerns. It is acknowledged that there were accessible weighing scales within a few hundred metres from her high school, however, the awareness of that equipment and how it could be used was not maintained and known by all health practitioners involved in providing her with health care services. Although the scales accommodated a wheelchair, when she was physically strong, Child A could have transferred herself from her wheelchair to the ground and back again.

Child A's weight had been a longstanding concern, which is unsurprising as obesity is often associated with spina bifida due to the limited ability of paraplegic children to burn calories. Contextually, it is known that 25% of school-aged children in Powys are overweight. As she transitioned to high school, Child A was supported by a physiotherapist to build her upper body strength, which enabled her to self-transfer from her wheelchair and increased her independence. Her new abilities enabled her involvement in wheelchair basketball and other physical activities, and these sports assisted in her weight management. The physiotherapy service was closed once Child A was physically independent and all her care aims were met. Child A was not re-referred to the physiotherapy service by any agency. When inactive, such as through illness, Child A could have soon lost the upper body strength that enabled her to self-transfer, and her subsequent increase in weight would have exacerbated that.

The Reviewer learned Child A and her parents engaged well with local practitioners with whom they could build trusting relationships. For example, the family viewed one dietitian who supported a whole family approach to eating well, as an asset. However, Child A found some dietary advice to be condescending and pre-timeline there is evidence of multiple appointments where she was not brought to see a dietitian. That was regrettable, as research[36] suggests the transition from adolescence to adulthood often marks the beginning of obesity for many people with spina bifida. There is no evidence that Child A or her parents fully understood the complexity of spina bifida and obesity or the interventions that could assist.

As a teenager, Child A might have been more body-conscious and had unanswered questions about her emerging maturity and what that meant for her future. Had there been a relationship-based practice approach to monitoring her weight, this might have helped to bridge any reluctance to engage with what she may have found to be unhelpful dietary advice.

Family Perspective and Reflections

Child A was skilled at overcoming debilitating aspects of her disability. She was determined to manage her complex private health needs, although there were times when this became challenging for her. Child A did not welcome dietary advice when she found it delivered

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[36] Rendeli, et al., (2020). Dietary approach to prevent obesity risk in Spina Bifida patients. Child’s Nervous System, 36(7), 1515–1520.

condescendingly. Ms B recalled the good relationship she and her daughter shared with an engaging dietitian with whom the family built a level of trust. However, in later times Ms B explained they felt agencies were less concerned about Child A's diet.

Learning Events Perspective and Reflections

Health

1. There was practice knowledge that Child A was on an increasing weight trajectory with limited physical ability to burn calories. However, there was an absence of oversight and review of her weight management akin to her changing needs and disability.

2. The physiotherapist identified that Child A was not re-referred to their service by any agency or the family when her activity levels were reduced due to illness. As a direct result of this learning, they have now adapted and improved their recording practice upon case closure by detailing the circumstances by which a child should be re-referred to this service.

Agency Perspective and Reflections

Local Authority

1. Before the Integrated Disability Service discharged Child A in 2017, one of their roles had been to monitor Child A's weight. Prior to the timeline, regular discussions were held about Child A's weight gain, but there was little consideration about at what point it would be appropriate to escalate to this being a matter of child protection.

Health

2. During the timeline, there were no recordings or assessments of Child A's weight and its impact on her well-being. Routine height and weight are not undertaken at Orthopaedic Clinics unless there is planned surgery. However, children under paediatric care should have routine height and weight monitored, bearing in mind the need and availability for specialist equipment for some children.

3. It has been recognised at an All Wales level that there is a need to address childhood obesity; Wales published its All Wales Obesity Pathway in 2010, which has been superseded by the development of an All Wales Weight Management Pathway[37] for children, young people and families published by the Welsh Government in 2021.

All Agencies

4. Prior to the onset of the COVID-19 pandemic in March 2020, Child A was seen at school and by health professionals, but there was no reference made regarding her weight.

The importance of monitoring skin conditions for children with limited mobility

Another key health factor that relates to Child A’s weight and lack of mobility was the need to care for and monitor her skin. There was an episode of deterioration in her skin condition towards the end of 2019, for which her parents sought and received medical attention. There is evidence Child A and her parents received advice regarding the initial treatment for lymphoedema and the condition was noted to be improving. However, the timeline showed no evidence of Child A being offered a follow-up appointment following the identification of lymphoedema. Notably, apart from

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[37] All Wales Weight Management Pathway 2021

the paediatric request for Child A to be weighed in August 2019 (which did not occur), the monitoring of Child A's weight and skin care was not included in other health appointments that were attended.

Learning Events Perspective and Reflections

Local Authority

1. If Child A had a care and support plan and was thus open to the Integrated Disability Service, they would have understood the importance of her receiving care for lymphoedema and helped to coordinate that.

Health

2. Once Lymphoedema or any health condition has been identified that could impact skin integrity or reduce mobility in a child with a disability, the opportunity should be taken to consider assessing a child's skin from this point. A clear pathway could have identified this and helped access the appropriate service.

Agency Perspective and Reflections

Health

1. Once Lymphoedema had been diagnosed, there was an opportunity to monitor Child A's skin from this point, however, there was not a clear pathway to identify and access the appropriate service to do this.

Local Authority

2. On reflection, the Integrated Disability Service's systems and processes in place prior to the timeline under consideration were not sufficiently robust, and its decisions were not always informed by an up to date multi-agency assessment of need.

Transitioning from childhood to adulthood with spina bifida

This theme has two aims; one is to contextualise Child A's experience as an adolescent, and the second is to reflect on the importance of transition planning for children with spina bifida. Medical advancements over recent decades have increased the life expectancy of people with spina bifida. Thus, our understanding of the complexity of living with spina bifida through adolescence and adulthood continues to develop[38]. Adolescence and the early onset of puberty for girls with spina bifida can coincide with a sudden deterioration in bladder and kidney function[39]. Further research[40] shows that for girls with physical disabilities, managing menstruation at school can be particularly challenging.

Family functioning when a child has spina bifida is a topic of research and evaluation[41] aiming to understand the interrelating biological, neuropsychological and social factors. Research suggests that a child with a chronic condition such as spina bifida will, in adolescence, increasingly believe

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[38] Phillips, et al., (2017). Spina Bifida Management. Current Problems in Pediatric and Adolescent Health Care, 47(7), 173–177. 7

[39] Tong & Tanaka, (2021). Let's Talk About Sex: Special Considerations in Reproductive Care and Sexual Education in Young Women With Spina Bifida. Urology (Ridgewood, N.J.), 151, 79–85.

[40] Streur, et al., (2023). "They had the lunch lady coming up to assist": The experiences of menarche and menstrual management for adolescents with physical disabilities. Disability and Health Journal, 16(4), 101510–101510. 0

[41] Holmbeck et al. (2006) https://doi.org/10.1097/00004703-200606000-00012

that they are the decision-makers when it comes to managing their illness. A longitudinal study[42] of 140 children with spina bifida from ages 8 years to 23 years demonstrates how the transfer of care from parent to child is a complex and essential part of transitioning into young adulthood. Research supports parents facilitating their child's independence within their child's developmental abilities, while recognising expectations are subject to fluctuation as children with spina bifida become emerging adults[43].

The complexity of Child A's health, education and social care needs required the coordination of multiple agencies to aid transition to adulthood successfully[44]. In school, Child A was receiving support to think ahead about study and career options. In her annual Special Educational Needs Review convened by phone in July 2020, Child A voiced concerns about her limited career opportunities.

Multiple agencies had discharged Child A from their service, and there is no evidence of any consideration to initiate an assessment of her needs to enable that coordinated transition to adult services. If the planning for transition to adulthood is inadequate, it can increase health and social needs[45]. Transition to adult care for children with spina bifida has multiple challenges, including neurocognitive and neuropsychological functioning issues. For example, research suggests many people may demonstrate medical post-traumatic stress disorder, which can make them less likely to commit to medical treatments, even when there are no other options.

Learning Events Perspectives and Reflections

Health

1. Child A should have had access to transition planning. Many of her needs could be predicted, but the overarching coordination of services was not consistently available.

2. Child A benefitted from advances in urological care which can prevent avoidable premature death for children with spina bifida.

3. Health promotion for children with spina bifida is a huge challenge as they begin to take responsibility for their care while coping with the complexity of adolescence compounded by their disability.

4. A child with significant and chronic disabilities such as spina bifida should not be discharged from services if that limits the transitional support they need from paediatric to adult care.

Education

5. The school positively worked with Child A and her family to explore her future education and career options, and completed her annual Special Educational Needs Review in July 2020 by phone.

Local Authority

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[42] Stern et al., (2021). Medical responsibility growth in youth with spina bifida: Neuropsychological and parenting predictors. *Health Psychology, 40*(10), 692-701.

[43] Holbein, et al., (2017). Milestone achievement in emerging adulthood in spina bifida: a longitudinal investigation of parental expectations. Developmental Medicine and Child Neurology, 59(3), 311–316.

[44] Roth, et al., (2023). Transitioning Young Adults with Spina Bifida: Challenges and Paths to Success. Journal of Pediatric Urology.

[45] Jenkins, et al., (2021). Adolescents and Young Adults With Spina Bifida Transitioning to Adulthood: A Comprehensive Community-Based Needs Assessment. Academic Pediatrics, 21(5), 858–867.

6. If the Integrated Disability Service had been involved with Child A as a child with a care and support plan, they could have supported her and her parents in planning for transition.

Housing

7. Housing did not receive a referral to assess the suitability of the family home to meet Child A's needs as she grew older.

Agency Perspective and

Health and Local Authority

1. Child A should have had access to transition planning. Many of her needs could be predicted, but the overarching coordination of services was not consistently available. Transition planning could have helped consider her changing needs as she moved into adulthood and support her increasing independence, while recognising the complexity of her disability. If a child with a lifelong disability is discharged from services without any oversight it limits the vital cohesive, holistic care, treatment and support they need from paediatric to adult care.

Recording the child's voice and sharing information to facilitate coordinated care

At times, good information sharing regarding Child A's needs was evident, particularly at a local level. There were occasions when Child A's contributions were recorded, and that allowed us to reflect on her views at those times. The review learned Child A was a private child and rarely shared within school, information about her home life. The YIS worker had gained her trust, and Child A felt able to share some of the vulnerability she experienced, and used the tools available to record her degree of emotional well-being. However, at times, the recording and storing of information was insufficient; on occasion written recordings were incomplete and one health service could not locate its records. When Child A was brought to appointments, there were occasions when her views were not explicitly recorded.

While recognising the multiple challenges that can be barriers to attending appointments, a theme throughout Child A's life was the inconsistent attendance at health appointments. However, there is little evidence that the professionals involved recognised these inconsistencies across all services. Powys Teaching Health Board has a Was Not Brought Policy developed in 2013 and amended in 2019 to include vulnerable adults. This document was updated in 2022 following an internal audit. The current policy placed the responsibility to explore the missed appointment in more detail on the practitioner whose appointment was missed. That responsibility includes the need to consult with any other practitioners involved with the child and complete and document a risk assessment detailing the next steps to be taken. Additionally, the referrer is also to be made aware of the failed appointment and actions to be taken. All occasions where a child was not brought to an appointment must be recorded as a significant event, which is monitored and audited by Team Leads.

Child A required an ongoing holistic assessment of her needs that was detailed within a multi-agency care and support plan. Such a plan would need to be facilitated by a care coordinator to bring multi-disciplinary practitioners, the family and Child A together to help identify current and any potential future needs[46]. In the absence of a designated care coordinator for children with complex care needs, there is the presumption that the parents will fulfil that role. However,

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[46] Myers (2022). 887 Care Co-ordination for children with a disability or developmental difficulty empowers families and reduces the burden on staff supporting them. Archives of Disease in Childhood, 107(Suppl 2), A75–A76.

research suggests a care coordinator serves to support and increase family engagement, and can ease the pressure on professional services that have limited staff capacity.[47]

Learning Events Perspective and Reflections

Health

1. There was evidence of good practice between locally based practitioners when they were simultaneously engaged with Child A and her parents.

2. There was an absence of multi-agency working, and someone identified as coordinating the care Child A required.

Agency Perspective and Reflections

Local Authority

1. There should be a willingness from other agencies to hold multi-agency meetings and bring involved parties together; there should not be a sole reliance on the Local Authority to organise.

Health

2. The 2022 WNB Policy has been shared across the Health Board, and training was provided, but it is acknowledged that it is still being embedded in practice. There is an ongoing audit process to monitor, identify challenges and improve its application in practice. The audit includes policy compliance, identify areas of good practice, the challenges in its application and identifying improvements in practice, where required. There are challenges as different health providers use their own WNB Policies, which may have different processes to follow when a child is not brought to an appointment. This could result in information not being shared with the right practitioners, leading to gaps in knowledge about the holistic needs of the child, their ongoing or missed assessments and care planning.

3. The hospital and other health records did not consistently capture Child A's voice to help understand her presenting health needs, wishes and feelings.

4. Processes in place to store and record key health information were not sufficiently robust, leading, on occasion, to incomplete recordings and an inability to locate Child A's podiatric records.

Education

5. Child A had a Statement of Special Educational Needs to respond to her physical disability needs.

6. Child A had significant support to aid her transition to high school, but the emphasis was on her physical needs rather than social concerns.

7. The school did not consistently capture Child A's views and record explicitly when they had spoken with her during her period of shielding.

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[47] Care coordination for children with a disability or developmental difficulty….. Wiley Online Library

The context of the COVID-19 pandemic

Prior to the onset of the pandemic, research knowledge revealed that parents of children with spina bifida can experience poor physical and mental health and difficulties within their relationships[48]. Further research[49] that identified a high prevalence of depressive symptoms in parents of children with spina bifida recommended parents be offered screening to identify their mental health needs. Ms B explained how the family endeavoured to ensure their family life was inclusive of Child A, which occasionally created some limitations and at times excluded her siblings' interests. Research[50] into the lived experience of siblings of a child with spina bifida echoed that of Ms B, with these relationships being particularly treasured and depicting a range of emotions, including love, affection, pride, concern and sadness.

In March 2020, the country responded to the COVID-19 pandemic with a swathe of emergency legislative and policy measures. Health and social care resources were often redirected to respond to unprecedented needs. In accordance with government guidelines, Child A was identified as someone who needed to shield as a means of protection during the pandemic. When she was in good health, Child A's attendance at school was excellent and reports reflect, with aside of occasional friendship difficulties, she enjoyed being at school. However, there was no assessment of the likelihood that she could suffer significant harm during the pandemic due to the potential physical and mental effects of restrictive movement and isolation.

The COVID-19 strategies within the family home were successful, as Child A did not appear to contract the COVID-19 virus. However, isolating at home also restricted her mobility, which resulted in significant consequences. The pandemic did spur innovations in virtual clinics,[51] of which Child A participated in May 2020.

Research[52] into the experiences of parents of a child with disabilities during the pandemic has demonstrated the reduced mental and physical health of parents who had a significant reduction in their social support. Parents who experience an imbalance in their abilities and the chronic[53] demands upon their resources are at risk of severe exhaustion, termed parental burnout, when exposed to ongoing parental stress. There is no evidence that either Ms B or Mr C received an assessment of their support needs to care for their daughter, Child A.

At the time of her death, Child A had been socially isolated for six months per governmental guidance to reduce transmission of the COVID-19 virus. Child A was worried about the virus, and her family were able to ensure she remained free from the virus. The nature of social isolation means we have a limited understanding of Child A's day to day experience during that time. However, the evidence of the way she died permits us to conclude the contributory impact of extended quarantine for Child A was multiple and complex, exacerbating her vulnerabilities and reducing the supportive infrastructure upon which she relied[54].

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[48] Ulual, et al., (2023). Relation between marital adjustment and somatic symptoms on parents of children with Spina Bifida. European Psychiatry, 66(S1), S588–S588.

[49] Ridosh, et al., (2017). Depressive Symptoms in Parents of Children with Spina Bifida: A Review of the Literature. Comprehensive Child and Adolescent Nursing, 40(2), 71–110. https://www.tandfonline.com/doi/full/10.1080/24694193.2016.1273978

[50] Bellin, et al., (2008). Risk and Protective Influences in the Lives of Siblings of Youths with Spina Bifida. Health & Social Work, 33(3), 199–209. https://academic.oup.com/hsw/article-abstract/33/3/199/817911?redirectedFrom=fulltext

[51] Dicianno, et al.,. (2022). Innovations in Telemedicine Services in Spina Bifida Clinics in the U. S. During the Covid-19 Pandemic. Technology and Innovation, 22(2), 157–164.

[52] Fortin-Bédard et al., (2023). Being a Parent of Children with Disabilities during the COVID-19 Pandemic: Multi-Method Study of Health, Social Life, and Occupational Situation. International Journal of Environmental Research and Public Health, 20(4), 3110

[53] Mikolajczak, M., & Roskam, I. (2018). A theoretical and clinical framework for parental burnout: The balance between risks and resources (BR). Frontiers in Psychology, 9, 886–886. https://www.frontiersin.org/articles/10.3389/fpsyg.2018.00886/full

[54] Stiles-Shields et al. (2021). https://academic.oup.com/jpepsy/article/46/9/1040/6341660

Family Perspective and Reflections

Child A was concerned about becoming infected with COVID-19, and she and her parents agreed to withdraw her from school before the first Lockdown. Quarantine or shielding was physically restrictive as the family only had a small garden. The location of the family home was on a steep hill; as such, Child A was unable to get up and down the hill on her own safely.

Learning Events Perspective and Reflections

1. When Child A was in school, it was her happy place, and she had people to support her. The rules regarding COVID-19 were changing daily; it was a difficult circumstance that nobody was prepared for, and schools became hubs in a matter of days.

2. The YIS worker continued informal involvement with Child A up until the pandemic. The worker reported to the school monthly. The YIS worker would check in with Child A weekly, but this might not always have been recorded, as it could be a quick conversation in the corridor. However, that practice has now changed, and all these conversations are recorded.

3. Prior to disruption created by the COVID-19 pandemic, the charity Shine assisted in a multi-disciplinary team approach, in the England hospital based urological service.

Agency Perspective and Reflections

<u>Education</u>

1. The school followed all the Welsh Government guidance on supporting families during the COVID-19 lockdown period from March 2020 to July 2020. They maintained contact with Child A and her family every week.

2. Until the lockdown period, the school supported Child A to maintain her expected academic progress, and she displayed a positive attitude to her education.

3. The support provided by the school for Child A's specific needs was appropriate, as demonstrated by the annual reviews in 2019 and 2020.

4. The Youth Intervention Service ceased providing counselling services to support Child A with friendship issues and emotional development in April 2020. There was no ongoing referral for her emotional needs during the pandemic.

5. The family experienced issues using Microsoft Teams for the annual review in July 2020. The school could have offered support to set this up with the family to ensure visual contact was made with the family. The school did not expect Child A to attend school until September due to her medical needs and the fact that she was shielding. Plans were agreed upon with Ms B to reintroduce Child A into the school from the 7th October 2020. That was a phased return due to the COVID-19 situation and Child A being at risk as she had been shielding.

6. The school has strengthened its guidance for responding to incidences when pupils have not been seen. A new ‘eyes on’ policy, developed by the school in which Child A attended, means if a child has not been seen for two weeks, a heightened state of alert could elicit a visit to the family home or, if deemed necessary, raise a safeguarding concern with the relevant agency. Additionally, in a future pandemic, schools will ensure vulnerable learners can access IT applications, so children are seen and heard to help

monitor their well-being and education progress. As such, the school’s weekly contact sessions will include visual and verbal contact with pupils, either over Teams or through a physical visit to the home (depending on Welsh Government guidance at the time).

Local Authority

7. The Local Authority’s Children's Integrated Disability Service ceased its involvement on 27 April 2017, when Child A was aged 12 years.

Health

1. A virtual urology appointment was completed via telephone due to the COVID-19 pandemic, which was a missed opportunity to see how Child A presented at that time. Virtual appointments have been identified as a positive additional option to children and families who are required to travel to appointments frequently.

Improving Systems and Practice

To promote the learning from this case, the review identified the following actions for the Board and its member agencies and anticipated improvement outcomes:

(What needs to be done differently, and how will this improve future practice and systems to support practice?)

1. Local Authorities to ensure care and support assessments are consistently offered and subsequent plans are strength based and outcome focused and comply with the relevant codes of practice. Quality assurance systems should be effective in driving continuous improvement and compliance with statutory requirements.
2. The Local Authority and Health Board to jointly review the systems, processes and pathways that are in place for children with chronic disabilities. That joint review should confirm arrangements are adequate and sufficiently robust to ensure:
    - Children’s complex care needs and the services they receive are overseen and coordinated by a single designated agency or practitioner. This must include children who may not be subject to formal care and support plans akin to Section 21 of the Social Services and Well-Being (Wales) Act 2014.
    - There are sufficient checks and balances in place to support opportunities for the reassessment of a child’s changing needs, including transition arrangements and planning.
    - Appropriate systems must be in place to capture and record the number of children with identified disabilities in the Local Authority area, in accordance with Section 18 of the Social Services and Well-Being (Wales) Act 2014.
    - Relevant practice guidance to ensure children and their families consistently receive the right information, advice and assistance at the right time. There should be ‘no wrong door’ for children with disabilities and their families.
    - Practitioners and statutory agencies are aware of the support available from third sector and charities for children and their families with complex disabilities, and are able to signpost families to these services as appropriate to need.
3. All agencies to undertake a review of their existing training programmes and policy guidance to ensure the duty on all practitioners, regardless of barriers, to speak to and

communicate directly with children, is understood. Their responsibility to engage with and accurately record any communications must be explicitly clear and understood by those responsible for delivering and providing services to children and their families.

4. Powys Teaching Health Board to raise awareness, implement and embed the updated All Wales Weight Management Pathway for children, young people and families published by Welsh Government in 2021.

5. Powys Teaching Health Board to review the availability of and access to lymphoedema services for children living in Powys. To clarify or create a protocol regarding the regular monitoring of the skin condition of children with complex health needs and mobility limitations, including spina bifida.

6. Powys Teaching Health Board to further embed the Was Not Brought policy and to consider cross-border involvement.

7. The Local Authority to review case closure practice guidance for Integrated Disability Services (IDS) and IDS Early Help to ensure all closures involve contact with other professionals and clarity on the process of re-referring, including for transition needs to adulthood, when required.

8. The Local Authority to review the IDS Early help offer to ensure it has sufficient resource to deliver a meaningful and effective service. That review to include effective communication and information sharing and the development of Practice Guidance for recording contacts with children and families by the Youth Intervention Service.

9. Consideration should be given to rolling out and embedding the ‘Eyes On’ policy implemented by the school in which Child A attended across the Local Authority area as a model of good practice.

Statement by Reviewer(s)

Reviewer 1	Dr Donna Peach	**Reviewer 2** *(as appropriate)*	N/A

Statement of independence from the case *Quality Assurance statement of qualification*	**Statement of independence from the case** *Quality Assurance statement of qualification*
I make the following statement that before my involvement with this learning review: • I have not been directly concerned with the child or family, or have given professional advice on the case. • I have had no immediate line management of the practitioner(s) involved. • I have the appropriate recognised qualifications, knowledge, experience, and training to undertake the review. • The review was conducted appropriately and rigorous in its analysis and evaluation of the issues set out in the Terms of Reference.	I make the following statement that before my involvement with this learning review: • I have not been directly concerned with the child or family, or have given professional advice on the case. • I have had no immediate line management of the practitioner(s) involved. • I have the appropriate recognised qualifications, knowledge and experience and training to undertake the review. • The review was conducted appropriately and was rigorous in its analysis and evaluation of the issues as set out in the Terms of Reference.
Reviewer 1 *(Signature)*	**Reviewer 2** ……………………………………………… *(Signature)*
Name *(Print)* Dr Donna Peach	**Name** *(Print)* ………………………………………
Date 29th January 2024	**Date** ……………………………………….

Chair of Review Panel *(Signature)*

Name *(Print)* Jayne Butler

Date 29th January 2024

Child/Adult Practice Review Process

To include here in brief:

- *The process followed by the Board and the services represented on the Review Panel*
- *A learning event was held and services that attended*
- *Family members had been informed, their views sought and represented throughout the learning event and feedback had been provided to them.*

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 agencies, all of whom had had an involvement with the individuals at the centre of this review:

- Local Authority Children Services
- Health
- Education
- Police

The Reviewer is grateful to the Panel for their commitment and expertise to support the learning review process across agencies. In total, 11 panel meetings were held.

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 benefitted from the kind participation and thoughtful reflections of Child A's family members, to whom the Reviewer wishes to extend sincere condolences and gratitude for their valuable and child-focused contributions to the learning process. These views are presented throughout this report.

The Learning Events and Health Discussion

All agencies were invited to attend two all-day Learning Events; one convened for practitioners on 20th September 2023 and one for managers held the following day. In all, 27 professionals attended and embraced the critically reflective process. Unfortunately, one health professional could not attend due to work commitments, and the Reviewer convened an online discussion with them.

The time that had passed since the death of Child A did not lessen the challenging nature of reflecting on the events at the centre of this review. At each Learning Event, practitioners and managers shared their insights into the lived experience of Child A. Attendees valued the opportunity to listen, share and learn from their different involvement and great care was taken to retain the dignity of Child A during every conversation. It was evident that for many years, professionals had worked extremely hard to support Child A and to ensure she had access to as full a life as her condition would allow. The Reviewer is grateful for the invaluable contributions of everyone who participated in the learning process. The willingness of all to engage in critical reflection and seek solutions built on a shared understanding is commended.

Family declined involvement: no

For Welsh Government use only

Date information received: ……………………………………… *(date)*

Acknowledgement letter sent to Board Chair: ………………………………………*(date)*

Circulated to relevant inspectorates/Policy Leads: ………………………………………*(date)*

Agencies	**Yes**	**No**	**Reason**
CSSIW			
Estyn			
HIW			
HMI Constabulary			
HMI Probation			

Appendix 1: Terms of Reference

Terms of Reference for Concise Child Practice Review

CYSUR 3 2021 (Powys)

- **Nominated Safeguarding Lead** – Holly Gordon
- **Review Panel Chair** – Jayne Butler
- **Independent Reviewer(s)** – Dr Donna Peach

Core Tasks:

- Determine whether decisions and actions in the case comply with the policy and procedures of named services and Board.
- Examine the effectiveness of inter-agency working and service provision for the child and family.
- Determine the extent to which decisions and actions were in the best interests of the child and outcome focused.
- Seek contributions to the review from appropriate family members and keep them informed of key aspects of progress.
- Take account of any parallel investigations or proceedings related to the case.
- Hold a multi-agency learning event for practitioners and identify required resources.

In addition to the review process, to have particular regard to the following:

- Whether previous relevant information or history about the child and/or family members was known and taken into account in professionals' assessment, planning and decision-making in respect of the child, the family and their circumstances. How that knowledge contributed to the outcome for the child.
- Whether there were obstacles or difficulties in this case that prevented agencies from fulfilling their duties (this should include consideration of both organisational issues and other contextual issues).

Specific tasks of the Review Panel

- Identify and commission reviewers to work with the *Review Panel* in accordance with guidance for extended reviews.
- Agree the time frame.
- Identify agencies, relevant services and professionals to contribute to the review, produce a timeline and an initial case summary and identify any immediate action already taken.
- Complete additional information regarding Independent Reviewer and Panel membership
- Produce a merged timeline, initial analysis and learning outcomes.
- Plan with the reviewers a learning event for practitioners, to include identifying attendees and arrangements for preparing and supporting them pre and post event, and arrangements for feedback.
- Plan with the reviewers contact arrangements with the individual and family

members prior to the event.
- Receive and consider the draft child practice review report to ensure that the terms of reference have been met and any additional learning is identified and included in the final report.
- Agree conclusions from the draft report and an outline action plan, and make arrangements for presentation to the Practice Review Sub Group for consideration and agreement.
- Plan arrangements to give feedback to family members and share the contents of the report following the conclusion of the review and before publication.
- *Review Panel* members will adhere to the principles of the Data Protection Act 2018 when handling personal information as part of the Child Practice Review process (see section on Information Sharing & Confidentiality).

Specific tasks of the Practice Review Sub Group:

- Agree and approve draft ToR for each case recommended for CPR.
- Agree conclusions from the draft report and an outline action plan, and make arrangements for presentation to the Board for consideration and agreement.
- Monitor CPR action plans to ensure all recommendations are carried out on behalf of the Board.

Tasks of the CYSUR Safeguarding Children Board

- The Business Unit, on behalf of the Board, will inform Welsh Government of the undertaking of a CPR.
- Will adhere to timescales for completion, as per statutory guidelines.
- Receives and formally approves the final CPR report and action plan.
- Consider and agree any Board learning points to be incorporated into the final report or the action plan.
- Confirm arrangements for the management of the multi-agency action plan by the Review Sub-Group, including how anticipated service improvements will be identified, monitored and reviewed.
- Plan publication on Board website for a minimum of 12 weeks after completion.
- Agree dissemination to agencies, relevant services and professionals.
- The Chair of the Board will be responsible for making all public comment and responses to media interest concerning the review until the process is completed.

Information Sharing and Confidentiality

Ownership of all information and documentation must be clarified in order that the appropriate permission is obtained from the relevant organisation prior to sharing. Organisations can only share information that is owned or originated by them.

Responsibility for requesting information from each organisation (including from independent providers) should be clarified and agreed by the Panel, as appropriate.

A statement of confidentiality (as below) will be signed at each Panel meeting by all attendees to reaffirm the boundaries within which information is being shared:

- In working with sensitive information in relation to a Child Practice Review, all agencies have agreed boundaries of confidentiality. This process respects those boundaries of confidentiality and is held under a shared understanding that:

- The Panel meeting is called under the guidance of *'Working Together to Safeguard People: Volume 2 – Child Practice Reviews'* from the Social Services & Wellbeing [Wales] Act 2014.
- The disclosure of information outside of the Panel beyond that which is agreed at the meeting will be considered as a breach of the subject's confidentiality and a breach of the confidentiality of the agencies involved.
- If consent to disclose is felt essential, initial permission should be sought from the Chair of the Panel, and a decision will be made on the principle of 'need to know'.
- However, the ultimate responsibility for the disclosure of information to a third party from the Multi-Agency Panel rests with the Mid & West Wales Safeguarding Board and must be referred to the Board Business Manager for authority to disclose.