Executive Summary

In 2020 the Health Board (HB) identified a number of concerning patient experience indicators within the Community Childrens Nursing (CCN) Team and agreed to commission an Independent Review of the Service. This was undertaken between March and September 2021 and covered the period April 2019 to September 2020. A total of 20 children receiving Continuing Care during the period covered by the review were included.

The reviewers have focused on and structured the report to reflect the key areas identified by the HB:

- The culture of care, particularly focussing on family involvement;
- Direct experience of children and families using the service;
- Direct engagement with staff within the service;
- How professional nursing standards are delivered.

In undertaking the review, it was clear that this is a service that is essential for families caring for a child with complex health needs. The reviewers spoke to dedicated skilled nurses and support workers, most with many years' experience. However, limitations were identified that prevented families from receiving the standard of service that would have been expected or which fully represented the HB values.

Governance arrangements for the CCN Service were ambiguous and lacked clarity. The team felt undervalued and distant from other children and community services within the HB. The governance team structures were unclear and did not support easy oversight or the ability to identify concerning trends which were arising. It was therefore not possible to see how the Board could be assured as to the standards or safety of the service being provided.

Concerns appeared to be managed internally with no robust consistent processes in place for reporting, or monitoring them[1]. This led to missed opportunities to identify trends, to consider how to address issues in a timely manner, or to support decisions made. The result of this is that 90% of the families the reviewers spoke to had concerns that had not been addressed to their satisfaction.

Some immediate issues of concern were identified as part of the review work; these were highlighted to the HB as soon as they were identified and were addressed at the time they were raised.

The Service Model implemented provided services for three distinct categories of children but Continuing Care was the primary focus and formed the basis of the funded establishment for the whole Service. The use of key management data to capture and identify trends and to support the further development of the service as a whole was

[1] Formal complaints that were made to the HB were managed in line with HB and policy requirements.

very limited. No performance or trend data was collected for two of the three cohorts of children receiving support. The accepted practice at that time of not reporting concerns via the Datix process also served to conceal the emerging trends from the wider HB.

The service design itself had built in challenges:

- The length of time taken to deliver a package of care once it had been deemed appropriate;
- The inherent challenge of operating a service where Registered Nurses (RNs) work office hours Monday to Friday whilst the Health Care Support Worker (HCSW) workforce operated mostly at night;
- Having to deliver a service that met the child's needs when the family home was also the HCSWs workplace.

Partnership working with parents including a co-production approach to determine the type, frequency, and level of care families felt they needed was not evident. The '*what matters to me'* and *'voice and control'* requirements that underpin the *Social Services and Well-being (Wales) Act (2014)* do not appear to have been reflected in the way services have been developed and offered.

There was little evidence of the families being seen as partners in the delivery of care for children who require clinical care delivery and/or health monitoring 24 hours a day in the community. The parents form part of the team, providing the same level of care during the day as the HB staff do overnight. The HB staff were providing a night shift of care to the child not simply allowing parents to sleep. It does not appear that this was fully understood by the CCN Service.

The review identified parents who wanted to work with the HB but were frustrated due to poor communication and relationship management from the leaders of the Service. This led to relationships that fractured easily and repaired poorly which, combined with a perception of sanctions being imposed should families complain, led to a lack of trust for many families and a total breakdown in relationships with some.

The culture of care within the team was complex, the leadership style appeared inflexible with innovative ideas neither encouraged nor taken forward. Some staff spoke of feeling demoralised and frustrated having reported concerns with regards to their workload and the ability to sustain a safe service during the COVID-19 pandemic. There was no evidence that these concerns were appropriately addressed or resolved.

The service focused primarily on Continuing Care to the detriment of developing the wider Childrens Community Service. The role of the Matron appeared to span both operational practice and strategic development and while her main focus appeared to be Continuing Care, the reviewers found evidence of decisions made outside of the Welsh Government (WG) guidance and a team structure which no longer reflected its requirements. There is also concern relating to the quality assurance processes and

the decision making Panel which uses of the Adult Panel within the Health Board to agree the care provision; limiting the paediatric knowledge and skills required to support decision making. There also appeared to be a lack of knowledge and understanding of the Continuing Care process within the wider HB management and governance arrangements, which reduced the ability to audit and monitor the implementation of the WG guidance to provide adequate assurance to the Board.

The experiences of the children and families were fundamental to the review and the meetings with the families were powerful and moving. It is important to note that none of the families were critical of the CCN Service as a whole and many praised aspects of the service but there were concerns about specific issues, which were not appropriately addressed. A number of themes were identified that recurred for many of the families receiving care relating mainly to:

- The Continuing Care assessment process;
- The time between agreement and provision of care;
- Cancellations of care;
- Concerns and complaints including professional practice;
- Record keeping and documentation; and
- The process adopted to calculate the amount of care required.

Many families spoke positively about the HCSWs that actually delivered the care and of RNs who helped them and supported them to navigate the process to access care.

The views of the CCN Team were also sought and reviewers met with all RNs and a cross section of HCSWs. In analysing their views and responses, it is clear staff are aware of the challenges and issues faced by the families and are keen to help resolve them. Indeed, the reviewers met with staff who were caring and committed and had innovative ideas that could help to shape the team moving forward.

There were several key factors which led to the team being unable to fully deliver to the HB standards and values:

- The lack of clear governance systems;
- A focus on Continuing Care rather than the service as a whole;
- The leadership model;
- The lack of engagement and partnership working with families;
- The Bridgend transfer; and
- The wide ranging impacts of the Covid-19 pandemic.

However, it was pleasing to note that many positives were also identified from discussions with the CCN team. These provide significant opportunities to review and develop the service model so that it reflects what families need and want rather than expecting them to fit in to ‘what we offer’. By the completion of the review many families

already spoke of a significant improvement in both communication and service delivery.

It is therefore hoped that the recommendations within the report will support continued improvement and accelerate the pace of that improvement for the benefit of all concerned.

The Reviewers would like to express their gratitude and appreciation to all families who participated in the review even though for some it was an emotional and difficult process. Similarly, the reviewers wish to extend their thanks to the staff of the CCN Service specifically and to the wider Swansea Bay UHB staff who supported the review and responded positively and helpfully to queries and requests for information.

The Recommendations

Assurance

The HB should:	
5	Ensure that the CCN Service is supported in developing effective relationships with pathways of care developed to enable all relevant services to work together successfully.
34	As required in *A Healthier Wales*[2] ensure a compassionate leadership model is put in place for the CCN Service and that the HB demonstrates its recognition of the significance and value of the Service.
23	Develop robust pathways for communication and service delivery with adult community services as well as acute paediatric services.
1	Consider whether additional work is undertaken to seek and capture the views of the families of the cohort of children that transferred to Cwm Taf Morgannwg UHB during 2019.
2	Consider whether to make contact with the parents who wished to participate in the review anonymously but were unable to do so for this review.

Compliance

The HB should:	
6	Ensure that the storage of health care records is in accordance with the HBs Policy and allows for access to records for children on the active caseload.
7	Ensure that any future move to online records is managed in line with all legislative, regulatory, national and local policy requirements including consideration of extending the development of the patient portal.
8	Ensure that the CCN Service continues to report issues/concerns via Datix.
9	Ensure that concerns and complaints are captured and managed in line with all relevant policies and National Guidance.
14	Track the resource provided for the Nurse Assessor posts and ensure it is utilised in line with the requirements of the WG Policy Guidance with the correct expertise, knowledge and skills in place to perform this function.
15	Review the current processes for quality assurance and multiagency decision making to ensure they are managed in line with WG Guidance.
16	Ensure that the CCN Service is fully compliant with the HBs Lone Worker Policy.
17	Consider scope to develop wider HB community management for out of hours and lone working services.

[2] *A Healthier Wales: long term plan for health and social care,* Welsh Government, 2019
Detailed guidance on compassionate leadership advice is available from HEIW via the following link: https://nhswalesleadershipportal.heiw.wales/compassionate-leadership

21	Ensure that the leadership style for the CCN Service is participative, and complies with all relevant HB policies and National Guidance.
24	Ensure that safeguarding is managed and overseen in line with the Wales Safeguarding Procedures.
26	Ensure appropriate audit processes for Children and Young People Continuing Care are in place that measure compliance with the WG Guidance.
27	Ensure concerns and complaints processes: ➢ are managed in accordance with HB and national policy requirements; ➢ responses are appropriate and proportionate with any sanctions only applied with the agreement of senior HB managers.
31	Ensure staff are fully aware of the HB Policies and any relevant professional regulatory requirements regarding the use of various social media apps to communicate with each other.

Service Development

The HB should:	
10	Identify a dataset of key management information related to the CCN Service.
11	Consider whether the current skill mix and staffing establishment is sufficient to meet the demands placed upon all elements of the service including step down services if a child is no longer deemed eligible for Continuing Care.
18	Explore alternative options to deliver more flexible and timely care including a review of the bank and agency processes.
19	Ensure a multiagency approach to develop local pathways agreed and jointly owned by the HB and its partners.
25	Ensure the skill mix model of 24 hour service delivery is reviewed with benchmarking models across other HBs in Wales.
30	Ensure the leadership of the CCN Service is one which is participative and continues to engage with families.
32	Ensure a more streamlined process is in place to link the CCNs with their team of HCSWs to ensure appropriate delegation, competence and assurance mechanisms are in place.
33	Review the roles undertaken by the various bands of staff and ensure that staff skills and abilities are utilised to their full potential.

Partnership and Engagement

The HB should:	
12	Ensure that working in partnership with parents becomes a fundamental principle applied by the CCN Service.
13	Develop a comprehensive 'Parental Agreement' that sets out the role and expectations of both the HB and the parents working in partnership.
22	Support the CCN Service in moving to a partnership approach ensuring the 'what matters to me' requirement is embedded in all processes.
28	When addressing concerns and complaints, from a family perspective, ensure: ➢ the needs of the child continue to be safely met; ➢ that all feedback is timely and appropriate; ➢ compassionate care forms the basis of interactions with families regarding concerns and complaints.
29	Consider undertaking engagement events, which includes senior HB representation.

Strategic Planning

The HB should:	
3	Consider the most appropriate position for the CCN Service within the HB structure.
4	Develop clear and effective governance arrangements for the CCN Service that includes adequate resource allocation from the governance team.
20	Continue to build upon regional work including multiagency service planning to address consistent and recurring gaps in universal and specialist services. To support this the HB should consider sharing the recommendations with LA partners.