

# **The External Review of Swansea Bay UHB Children's Community Nursing Service: The One Year on Report**

Carol Killa  
Gaynor Williams  
July 2023

## Contents

Section	Page
Executive Summary	3
Section 1: Purpose and Methodology	8
Section 2: Governance and Leadership	11
Section 3: Staffing, Skill Mix and Demand	15
Section 4: Stakeholder Views and Perspectives	19
Section 5: Progress in Implementing the Improvement Plan	29
Section 6: Conclusions	36
Appendix 1: Staffing Establishment over Time	38

## Executive Summary

In 2021, in response to a number of concerning patient experience indicators, Swansea Bay University Health Board (SBUHB) commissioned an External Review of the Childrens Community Nursing Service (CCNS). A final External Review Report with 34 Recommendations was submitted to the Health Board (HB) in October 2021.

One year on from the initial Report, the reviewers were asked to consider progress on delivering the Recommendations and the implementation of the HB Improvement Plan.

### Governance and Leadership

There is now a clear governance and assurance structure in place that provides a continuous flow of information and a communication pathway between the CCNS, the Service Group, and the Board. Increased resourcing of the Governance team to support the work has been helpful. The meeting Minutes reviewed confirmed regular and appropriate reporting of progress against the requirements of the 2021 Report.

The Risk Register had been actively updated over time to include progress reports relating to the staffing establishment and relevant expertise. The level of resource required has been considered and a Business Case process was evident to address this. There continues to be some level of short term risk related to the substantial turnover of staff and some posts still vacant at the point of reporting. Incidents reflecting the range of service provision are now consistently reported, with cancellation of care being the primary issue reported via Datix. The incident reports are subject to senior level oversight through the governance structure demonstrating a clear learning focus.

The senior level leadership model has changed since the 2021 Review, with a Deputy Head of Nursing post with a wider portfolio of responsibilities replacing the previous Matron post. The HB will need to carefully monitor this to ensure the CCNS has access to appropriate senior operational leadership. At the Team Manager level there is short term instability, with the interim Team Manager leaving for a post in another HB and the role being covered temporarily by the Clinical Educator. This has led to a short term limitation on the ability to deliver on all training and development requirements. Whilst governance training appears to have been well embedded, the roll out of Compassionate Leadership training has been limited to date due in part to staffing changes.

A key issue in the External Review Report was that staff felt they were isolated from other services working with children and families within the community; a review of where this service is best sited was recommended. There appears to have been limited progress to date to consider where the CCNS best sits within the HB structures, they interact with a number of services that sit within different Service Groups and different geographical locations. It is hoped there will be further work undertaken to ensure the services that collectively form the care pathways for the same group of

children are able to communicate and interact effectively so that families and partner agencies can engage easily with them.

## **Staffing, Skill Mix and Demand**

Significant staff changes have taken place since late 2021, with most of the CCNS registrants in post at the time of the External Review having left to take up posts elsewhere. These posts have now been recruited to, with additional posts being added to provide registrant cover into the evening/twilight hours. Two Nurse Assessors have also been appointed; this represents a significant step forward in supporting the team to undertake its role effectively and also ensuring compliance with the WG policy requirements for Children and Young People's Continuing Care.

The Registered Nurses (RNs) are enthusiastic and motivated, the new RNs recognise they have limited experience in both community nursing and Continuing Care and will require ongoing support and guidance as they develop and settle into their new roles.

The Team Manager in post during 2021/23 was pivotal in taking the team through the turbulence of the past year, seeking to change the team culture and the way services were provided whilst also coping with a period of significant staff turnover following the Review. The Clinical Educator has also made a significant contribution to supporting the Service and developing the new team of registrants.

The HCSW establishment continues to be calculated based upon the number of Continuing Care children and the amount of hours required to put in place the package allocated to each child. This does not reflect the role of HCSWs in providing support for the acute and chronic cohorts of children also supported by the Team or in building some resource into the establishment to allow for training and development to take place. This increases the risk of cancellation to care or delay in providing care packages. A new nurse bank model has been introduced but this will need to be monitored until the Board is assured that there is no increase in care cancellation or delays to care package provision. The staffing establishment and skill mix has fluctuated over the past year as the HB sought to appoint new members of staff and maintain the service. The HB will need to monitor this to ensure there is sufficient senior level leadership and guidance for the Service as a whole.

In 2021 the inability of the CCNS to capture and monitor activity and trends in both referrals and demand was identified as a risk. There has been progress in that some activity is now entered onto PIMS+ but the system is still relatively new to the team and there is at this point limited ability to interrogate PIMS+ to extract activity and trend data. Further work will be required to develop effective dashboards and reporting processes.

## **Stakeholder Views and Perspectives**

The views of parents and the CCNS staff were fundamental to the 2021 External Review and remained a key focus for the One Year on Report. Without the CCN Service, it is difficult to see how children with such high levels of care could be maintained and cared for at home. It is therefore positive to find that both families and

the CCNS team report a major change in culture. There is now a partnership approach, with evidence of trusting relationships between the families and the CCNS that can withstand individual concerns that may occur over time.

#### Culture:

There is a clear view from the parents that the culture had changed since the Review, with:

- Improved relationships and no acrimony: this was viewed to be welcome and positive. The relationships between families and the CCNS team were described as much improved and there had been no mention or consideration of withdrawal of care.
- Issues reported by families are now being dealt with effectively and in a professional manner, with timely feedback, giving more confidence in the service.

#### Communication:

Communication related issues formed a key theme of the 2021 External Review but significantly different views were expressed this time, with families reporting:

- Improved communication and contact from office based staff. This included more visibility of senior managers, which was welcomed.
- Improved processes to inform families of cancelled care and a reduction in the incidents of cancelled care.
- New routes to communicate introduced including: a QR code to support ease of feedback from families; the production of a monthly newsletter; and consideration of events that could bring families together for mutual support.

Staff also reported improved communication within the Service, with a weekly *huddle* and *lunch and learn* sessions now in place. There is also evidence that operational staff are more involved in the Governance processes with team leads attending the local quality, safety and risk meetings.

#### The Service Model:

The service model has developed over the past year and the families appreciated efforts made to maintain the 'team around the child' approach adopted during the COVID-19 restrictions.

#### Leadership:

Discussions with the CCNS team clearly identified and recognised the support provided by Service Group leads. In summary, it was clear from discussions with both families and the CCNS Team that this is a service that has seen a fundamental change to its culture and its approach to delivering care; there is a much more positive approach, with recognition that care is delivered in partnership.

There has been less progress in joint working with partners; the Regional Partnership Board transformation work does not appear to have progressed as expected and will need to be advanced. The reviewers were informed of the recent commencement of

a series of Vanguard workshops, it is hoped that this work will support partners to address improved inter-agency working in order to provide co-ordinated care services for this small but complex group of children and their families.

## Progress in Implementing the Improvement Plan

Only three of the 34 recommendations were judged to remain RAG rated as red, indicating less progress than would have been expected at this stage. They relate to multiagency working and compliance with WG policy requirements. With regards to multiagency working, the Vanguard workshops underway would be expected to lead to improved multiagency service delivery. The HB needs to ensure an ongoing commitment to address these issues.

Regarding compliance with WG policy requirements, there were three main issues identified where the service had moved away from policy:

- The removal of the Nurse Assessor posts;
- The use of the Adult Panel to consider cases;
- The long period of time following confirmation of eligibility before a package of care was implemented.

Actions and improvements have been progressed in all these areas meaning the HB can now review the assessed progress and score accordingly.

In relation to the remaining recommendations, the reviewers have noted significant progress and a drive to improving service delivery. Ongoing work is necessary to ensure the progress is maintained.

## Conclusions

Almost two years since the External Review work commenced and four years since the experiences of parents led to the concerning patient indicators that initiated the commissioning of the External Review, the CCNS has developed and is now in a very different place.

Having reviewed the Improvement Plan in detail the reviewers can confirm there has been significant progress made. The culture within the CCNS team is now one of compassion and professionalism, with a 'can do' attitude. There is more visibility and proactive communication between the managers and families and there have been no circumstances where withdrawal of care has been considered since the 2021 Report. The leaders of the service and Health Board leads have made it very clear to the reviewers that this would now only ever be considered with executive level oversight and a full risk assessment of the case.

The families now speak of a caring and compassionate service delivering excellent care in the community and the CCNS team has created an environment where change is welcomed and can take place. With adequate access to leadership and expertise this bodes well for the future service provision of Children and Young People's Continuing Care in the community.

The CCNS team provide an invaluable service to those families with children who have highly complex health needs. Without this service families would struggle to keep their children at home in the family environment. This One Year on Review has demonstrated how much families appreciate the service. There remain some ongoing issues to resolve as part of the Improvement Plan to allow the CCNS to achieve its full potential but from the progress made to date, the Reviewers are confident that continued progress in implementing the findings and Recommendations of the 2021 External Review will ensure a CCNS that can thrive and is fit for purpose.

The CCNS provides a service that when functioning well is virtually invisible, but should it fail the consequences would be far reaching and very visible. Over the past two years the service has undergone a transformation, with a mostly new team of staff and a culture that is open and seeks to engage positively with the families of children with very complex needs. It has been a pleasure and a privilege to see the CCNS overcome the initial turbulence that followed the External Review Report and develop and change to the extent it has.

## Section 1: Purpose and methodology

### 1. The Purpose: Setting the Scene

In 2021, in response to a number of concerning patient experience indicators, Swansea Bay University Health Board (SBUHB) commissioned an External Review of the Children's Community Nursing Service (CCNS). The Review involved extensive analysis of documentation, policies and processes along with meetings and discussions with CCNS staff, the parents of children receiving Children and Young People Continuing Care (CYPCC), and other stakeholders. A final External Review Report was submitted to the Health Board (HB) in October 2021.

The Review Report included a total of 34 Recommendations, grouped based on the following themes:

- Assurance;
- Compliance;
- Service Development;
- Partnership and Engagement;
- Strategic Planning.

The External Review Report was subsequently considered by the SBUHB Board on 25 November 2021. The Board accepted both the findings and Recommendations in full and subsequently requested the reviewers undertake more detailed work focusing on three key areas:

- A review of checklists where the outcome was the child would not proceed to a full CYPCC assessment;
- A review of risk assessments which involved the threat to withdraw care or resulted in the actual withdrawal of care;
- The management of transition from CYPCC to adult services.

These three pieces of additional work were undertaken and Reports were provided to the HB on 13 January 2023<sup>1</sup>.

One year on from the initial Report, the reviewers were asked by the HB to consider progress on delivering the Recommendations and the implementation of the HB Improvement Plan. In undertaking the work and in drafting this Report, the reviewers recognise this has been a challenging time for the CCNS; the HB generally, and the CCNS Team specifically, have had to continue to provide a service during a period of upheaval and change. It is to the credit of the current CCNS team, their Team

---

<sup>1</sup> An anonymised Executive Summary was also provided for each Report.



Manager<sup>2</sup>, the Children's Services Head of Nursing, and the Service Group Head of Quality Improvement, that they have ensured safe standards of care whilst driving forward the change process and developing improved and trusting relationships with families.

The reviewers wanted to record at this early point the positive and professional impression given by all members of the CCNS team and their managers. Families spoken to currently in receipt of care expressed a significantly more confident and positive view of the CCNS team and the services they provide than was the case previously; relationships and interactions with families now appear to be much more open and trusting. The recent loss of the Team Manager to take up another post elsewhere is disappointing; her contribution towards changing the culture and the way services were provided over the past year to meet the HB values was significant.

## **2. The Scope**

The scope set out by the HB covered:

- The current management structure and governance processes.
- The staffing establishment, skill mix, capacity and demand trends.
- The views of key stakeholders including: the current CCNS team members, families of children in receipt of service; and service managers.
- Progress in implementing the Improvement Plan.

The Report has been structured to reflect this scope. The timescales for completion were amended during the course of the work with the agreement of the Commissioners<sup>3</sup>.

## **3. The Methodology**

As with the initial Review, a mixed methodology was adopted:

- (i) A review of Health Board documentation including the Improvement Plan and the minutes of relevant Board and Committee meetings.
- (ii) A review of the current management structure and governance processes against those in place previously.
- (iii) A review of the current staffing establishment and sickness/absence data.
- (iv) A series of meetings/discussions with the CCNS team, including individual discussions with all registrants<sup>4</sup>. These meetings focused on progress, staff morale and perceptions of changes and improvements, including whether staff felt they had a credible voice within the service.

---

<sup>2</sup> The post holder recently left the HB to take up another post.

<sup>3</sup> The need to review timescales was due to additional work undertaken on the Follow on Reports including reviewing Subject Access data as an additional route to locating relevant records.

<sup>4</sup> One registrant was off sick and was unable to meet with the reviewers. The offer of a meeting when the person returned to work was extended but not taken up.

- (v) Communication with the families of those children currently in receipt of CYPCC services via the CCNS<sup>5</sup> to seek their perceptions of the service one year on and to identify any outstanding concerns. The form of communication offered was based upon the wishes of the families and included:
  - in person meetings;
  - Microsoft Team meetings;
  - Emails or other written correspondence.
- (vi) A process, as required by the HB, to ensure feedback to both families and staff who engaged with and participated in the One Year on Review<sup>6</sup>.

## **4. The Cohort**

SBUHB provided the reviewers with a list of children currently receiving CYPCC support via the CCNS; this identified a total of 18 children<sup>7</sup> in scope. Fourteen of these were children who formed part of the original External Review cohort, with an additional four children having been identified as eligible for Continuing Care since the dates covered by the External Review work<sup>8</sup>. The reviewers sought to engage with all of these families.

## **5. The Report Structure**

This Report has been structured to reflect the requirements and scope determined by the HB. The analysis and information are provided within the following sections:

- Governance and Leadership including the line of sight from the CCNS through to the Service Group and Executive Board.
- Staffing, Skill Mix and Demand compared to 2021.
- Stakeholder Views and Perspectives including those within the CCNS, the wider HB, families and Local Authority (LA) partners.
- Progress of the Improvement Plan, based upon the findings set out in the initial three sections.
- Conclusions.

---

<sup>5</sup> This included some families who had been involved in the initial External Review along with new children now in receipt of support.

<sup>6</sup> To be provided following the submission of the final Report to SBUHB.

<sup>7</sup> This does not reflect the totality of the services provided by the CCNS. In addition to CYPCC the CCNS also supports a number of children and young people with long term needs and a cohort with acute needs.

<sup>8</sup> Three of the new CYPCC children require support for school based needs, there is one package of care at home being progressed for a young child with complex needs.

## Section 2: Governance and Leadership

### 1. Previous Findings

The 2021 External Review identified several concerns regarding governance, including:

- No reference to the CCNS specifically or to paediatric services more generally within the HB Annual Report<sup>9</sup>.
- Limited evidence of strategic level awareness within the HB of developing concerns, with no apparent line of sight from the CCNS through to the Executive Board.
- Limited access to governance focused input and support.
- No reference in the HB wide Risk Register and limited reference in the Paediatric and Community Paediatric Risk Registers to risks related to the CCNS.
- The methods of record keeping.
- The lack of recording and the poor management of incidents, concerns and complaints.

### 2. The Current Position

#### (a) Governance

The Service Group Director and Director of Nursing for Neath Port Talbot and Singleton remain accountable for the service delivery of the CCNS Team which forms part of the wider women and children service provision. This currently includes:

- Gynaecology and Maternity services
- Neonatal and children's services consisting of:
  - the Neonatal Unit;
  - the acute Paediatric Wards;
  - Paediatric Outpatient and Assessment Units ;
  - the Children's Community Nursing Service and specialist nurses

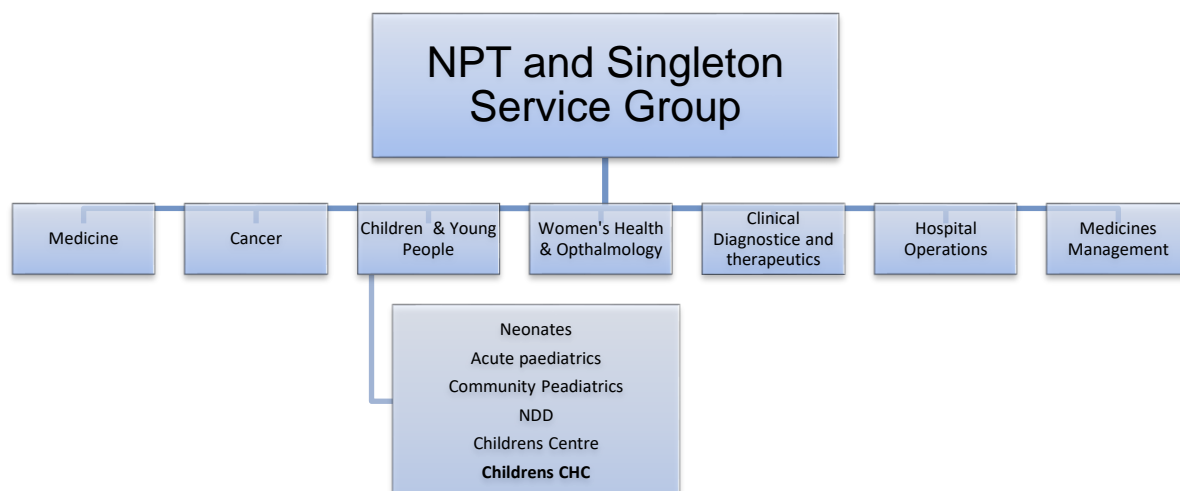
Governance reporting is via the Service Group Quality, Safety & Risk Group, reporting through to the Health Board Quality and Safety Committee, which itself reports into the main Board. This structure appears robust, providing oversight of reporting procedures intended to effectively monitor the safety of the CCNS service provision, which had been identified as having limited assurance only in the External Review Report.

---

<sup>9</sup> apart from an issue relating to paediatrics within Morriston Hospital Emergency Department (ED)

Increased resourcing of the Governance team to support the work was viewed to be helpful and the meeting Minutes reviewed confirmed regular and appropriate reporting of progress against the 2021 Recommendations.

In the initial External Review the CCNS team described feeling isolated from the wider HB, and in particular the wider community services. In response to this a review of where this team sits within the organisational structure was recommended in the 2021 Report, however it is understood the organisational structure for the Service Group remains unchanged from that presented in 2021, as set out below:



## (b) Risk

The Paediatric Risk Register was provided in late 2022 for consideration as part of the One Year on Review. This identified two actions that referred specifically to the CCNS:

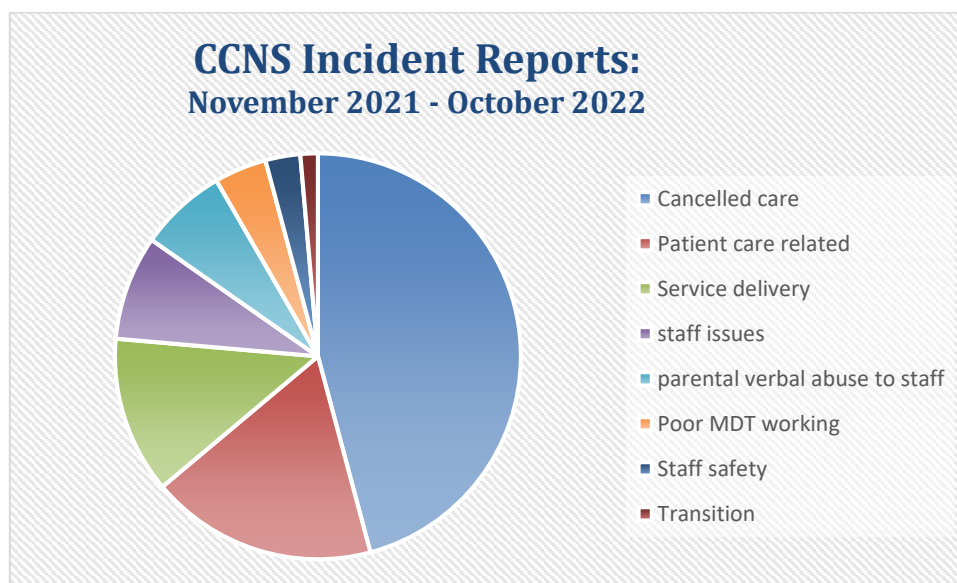
- (i) Difficulties in sustaining safe service provision linked to a number of staff leaving following the External Review.
- (ii) Children not being able to access a service in line with WG policy requirements, specifically regarding the two Nurse Assessor posts.

It was noted that the Risk Register had been actively updated over time to include progress reports relating to the staffing establishment and relevant expertise. The level of resource required has been considered and there was evidence of a Business Case to address this. Short term risks continue related to (i) the loss of current expertise linked to the substantial turnover of staff and (ii) the newly appointed registrants having limited experience of community and Continuing Care practice.

## (c) Incident Reporting

The HB confirmed that all incidents are now reported via the Datix incident reporting system. Analysis of the incidents reported for the November 2021 to October 2022 period confirmed that incident reporting is taking place to a much higher degree than

previously. The analysis of the 72 Datix reports made during that year indicated that 33 (46%) related to cancelled care.



Further analysis identified that 88% of cancelled care occurred on weekends (i.e. Friday through to Monday) due primarily to staff sickness, with only 12% of cancellations occurring during midweek nights. This may be an area that requires further scrutiny by the HB.

It is clear from the incidents reported that a wide range of other issues are also captured that reflect the range of service provision. This is now subject to senior level oversight through the current governance structure and demonstrates a change towards using this information to support continuous learning and service development.

#### (d) Leadership

The leadership style adopted for the time period covered by the 2021 External Review by the then CCNS leaders appeared directive in nature. Staff described how they found it hard to express alternative views and the overall approach led to difficulties in relationships with parents and staff alike. The Review recommended a more inclusive approach based on the Compassionate Leadership model advocated in *A Healthier Wales*<sup>10</sup>. It is understood progress in delivering formal Compassionate Leadership training has been limited due to the inability to release staff.

The senior level leadership structure has changed since the 2021 Review, with a new substantive Head of Children's Nursing appointed. The HB has decided not to include the CCNS Matron post<sup>11</sup>; instead the Reviewers were informed that the intention is to create a Deputy Head of Nursing post with a wider portfolio of responsibilities. This

<sup>10</sup> A healthier Wales: long term plan for health and social care, Welsh Government, updated November 2022. [A healthier Wales: long term plan for health and social care | GOV.WALES](https://gov.wales/a-healthier-wales-long-term-plan-for-health-and-social-care)

<sup>11</sup> This alternative model was considered due in part to limited applicants despite two advertisements.

appointment has now taken place and will need to be monitored to ensure appropriate operational senior leadership and support is available to the CCNS Team.

### (e) Assurance

The reviewers are now assured that there is a clear governance structure in place, with the Executive Nurse Director having overall accountability for the Improvement Plan and the Service Group Nurse Director responsible for leading and implementing the agreed changes.



This continuous flow of information should drive a clear monitoring and communication pathway between the Service Group and the HB Board.

Some actions do remain outstanding. There has been:

- A lack of clarity regarding who leads on the totality of children's services within the organisation with service provision spread across several Service Groups and geographic locations within the HB. This can make pathways of care difficult to navigate for families and stakeholders alike. At a strategic level it poses challenges for the HB in developing co-ordinated services across the Swansea Bay area. It is understood the Executive Director of Nursing has been asked to review current arrangements.
- Limited progress in reviewing where the CCNS would best be positioned within the organisation to ensure co-ordination across all related services and to improve pathways of care.

## Section 3: Staffing, Skill Mix and Demand

### 1. The Team

Significant staff changes have taken place, with most of the CCNS registrants in post at the time of the 2021 External Review having left to take up posts elsewhere. The majority of these vacated posts have now been recruited to, with the two Nurse Assessor appointees having recently joined the CCNS at the point of reporting.

At a **senior/leadership level**, the Service Group Head of Children's Nursing and Head of Quality Improvement provide direct leadership and guidance, acting as an ongoing source of advice and support; this has been recognised and welcomed by the CCNS team.

**The Team Manager** has been pivotal in taking the team through the turbulence of the past year, seeking to change the team culture and the way services are provided whilst also coping with a period of significant staff turnover following the Review.

In addition to leading the CCNS through this period of change the post holder continued to (i) provide oversight and supervision of the Continuing Care process, in line with previous responsibilities as the Continuing Care lead, and (ii) remained the 'go to' expert for Children's Continuing Care expertise within the wider HB.

Following the Team Manager's recent move to another HB, the HB has taken steps to fill the post on a secondment basis initially, in order to ensure there is no gap for this key role whilst recruitment takes place for a permanent appointment.

The loss of the Matron post<sup>12</sup>, to be replaced by a broader Deputy Head of Children's Nursing role, will need to be monitored closely over the next year. There needs to be sufficient senior leadership for the service as a whole as well as senior operational support available to the CCNS Team.

**The Clinical Educator** role has developed further since the 2021 Review. The post holder now works some evening and night shifts in order to allow for training and development work with HCSWs in the child's home. Weekly lunch and learn sessions have been developed and are valued by the team who have been supported by the clinical educator as they take on their new roles with limited community experience. This is in addition to ongoing responsibilities for training across the CCNS team and holding a small caseload of CYPCC children. The post holder is currently acting up on a secondment basis into the Team Manager role; this will impact on the ability to

---

<sup>12</sup> The HB has advised that the Matron post for Children's Community Services, Clinical Nurse Specialists, Neuro Developmental disorder team and outpatient's children's centres across the Health Board was advertised by the CYP Division but failed to attract any interest. As a result a Deputy Head post, as described in the CYP Division Workforce plan was advertised and an experienced Childrens Nurse with community experience appointed.

deliver on training and competency requirements and the HB will need to consider how best to mitigate this short term risk.

The **registrants** are enthusiastic and motivated, the new RNs recognise they have limited experience in both community nursing and Continuing Care and will require ongoing support and guidance from the HB as they develop and settle into their new roles.

The recent appointment to the two new **Nurse Assessor** posts is a positive and welcome development that will release the registrants to focus on case management and supporting the families through the assessment and care delivery processes. The length of time taken to put these two key posts in place has impacted on the ability to deliver a more effective team structure that is compliant with the extant WG Policy Guidance sooner.

It appears the **HCSW** establishment is still calculated based upon the number of Continuing Care children and the amount of hours required to put in place the package allocated to each child. This model does not reflect the role of HCSWs in providing support for the acute and chronic cohorts of children also supported by the Team or in building some resource into the establishment to allow for training and development to take place. A nurse bank model has been established and is currently building up resource to help with this. This will require ongoing monitoring.

## 2. The Establishment and Skill Mix

During the period of this review the staffing establishment had been fluid and subject to change as the Business Case requirements were implemented. At a senior level a decision has been made to remodel the senior structure moving away from Matron post to a Deputy Head of Nursing with wider responsibilities. It is to the credit of the Head of Nursing and the CCNS senior team that they have managed to navigate the service through a period of complexity and change, maintaining standards and improving relationships with service users. At the time of writing this Report, the senior management/leadership structure consists of a substantive newly appointed Deputy Head of Nursing and an interim Team Manager role provided by the secondment of the Practice Educator. This will limit in the short term the ability to support training requirements including the rollout of Compassionate Leadership training.

This current limited senior staffing model is new and untested and will need to be monitored and risk managed until it is fully embedded; the improvements in the quality assurance processes will support this.

While the HB has taken steps to progress a revised establishment for the CCNS, with Business Cases developed and approved, the team expressed some concerns that the process of approval for the new appointments has been made in a phased manner and over an extended period of time. This was due to affordability impacted on by the scale of funding required. While there has been an increase in posts into the CCNS, there is a need to be mindful that the Service will extend out of hours and the workload/workforce balance will need continued monitoring.



The Table at **Appendix 1** sets out the funded and actual establishment position as at March 2023<sup>13</sup>. Future changes are likely to mean the establishment as set out in the Table will have changed further by the time this Report is considered by the HB.

It appears from the information provided in March 2023 the CCNS had less registrants funded than 2021, with 0.6WTE drop and an overall 1.69WTE gap between the staffed and actual establishment. This has now improved with the introduction of the two Nurse Assessor posts, but still limits the actual CCN posts at a time when they are extending the service to ensure the safety of staff and quality of care out of hours.

There has also been a 23% reduction in Band 4 posts and a corresponding increase of 25% in Band 3 posts, reducing the senior non-registrant workforce. It had proved more challenging than anticipated to appoint to Band 4 vacancies, linked in part to the development of the role and its essential criteria requirements. This may have contributed to the corresponding increase in the number of Band 3 posts.

Regarding therapy input, the Reviewers were informed that 1WTE Band 6 post is currently being used to fund 35 hours of occupational and/or physiotherapy and 2.5 hours of speech and language therapy but these hours are not always accessible or prioritised despite the funding commitment from the CCNS budget, this agreement needs to be revisited.

### 3. Trends and Demand

The number of children receiving Continuing Care support via the CCNS appears to be relatively stable over time; whilst children have left the service since 2021 they have been replaced by others meaning the numbers have remained generally consistent. However, Continuing Care reflects only one element of the CCNS workload, the others being the acute and chronic cohorts who are also supported by the team.

The 2021 Report identified a lack of key management information on referrals and demand for service support. This impacted on the ability of the CCNS to profile demand and evidence any increase against a fixed establishment of RNs. Recommendation 10 referred to the development of a dataset for the CCNS that covered all three cohorts of children – acute, chronic and continuing care. Whilst work has been undertaken to include activity on PIMS+ it has proved difficult for the team to access information requested by the reviewers. It appears that as the system was relatively new to the CCNS there is, at this point, limited ability to interrogate PIMS+ to extract activity and trend data across all three cohorts of children. This will require further work to develop effective dashboards and reporting processes.

In summary, it is clear that:

- The HB has taken steps to address the staffing issues identified in the 2021 External Review.
- The appointment of two Nurse Assessors is a significant step forward.

---

<sup>13</sup> As provided by the HB

- From information provided it appears the Business Case process has led to an additional £430k investment in the Team to date<sup>14</sup>.
- The ability of the CCNS and HB managers to access and interrogate essential management information on activity and trends to support service development and oversight is still in its early stages. The move to a digital solution needs to continue to be progressed.

---

<sup>14</sup> As identified in the 26<sup>th</sup> January 2023 Board Paper.

## Section 4: Stakeholder Views and Perspectives

The views of parents and the CCNS staff were fundamental to the 2021 External Review. At that time, parents expressed concerns about aspects of their child's care package and/or their relationship with the CCNS managers. Many members of the CCNS team had also recognised similar issues and wanted to be part of a service that worked more in partnership with families. They were keen to co-produce the care that was essential to support the profoundly complex needs of these children.

Without this Service, it is difficult to see how children with such high levels of care needs could be maintained and cared for at home. It is therefore welcome to find that both families and the CCNS team report a positive change in culture. The focus is now one of partnership with parents, developing trusting relationships that can withstand individual concerns that may occur over time.

There were residual trust issues expressed by one family that continue to impact on their relationship with the Service, but even for this family there was recognition that things are improving, it was reported that '*communication is 100 times better than before*' and '*there are no problems with the care delivered*'.

Two statements from a parent who experienced significant issues previously demonstrate the improvements achieved over the past year:

*The staff do an incredible job, they are our lifeline and they keep our children alive. We have to build relationships, don't be scared be proud as a team that is trusted by vulnerable families.*

*Things have improved. I can now express views and concerns about a staff member and not be afraid that care will be pulled. There is no mention now of withdrawal of care or threats.*

### 1. Views of Parents



As part of the 2021 External Review, the reviewers were able to meet or communicate with 13 of the 23 families identified as in scope. This provided a good sample from which to draw key themes, ensuring family voices were reflected throughout the Report.

For the One Year on Review, the same approach was adopted; families were contacted by the HB via letter, informing them of the work and inviting them to meet with the reviewers to provide their views. This was followed up by a second letter and then a text directly from one of the reviewers; this resulted in contact from four families who expressed a wish to meet and discuss their experiences since they were last interviewed in 2021.

Whilst lower in number, comprising only 22% of the cohort of 18 children, the reviewers are satisfied that appropriate efforts were made by the HB to contact and engage with the families. The limited responses could indicate that families had no concerns and felt it unnecessary to engage further, however it is acknowledged that parents of children with complex health needs often have difficulty engaging due to time constraints. There is ongoing work underway by the HB to explore how best to communicate with and engage families to assist the HB in improving services and maintaining relationships. This is a positive development.

A key issue in the 2021 Report was the assessment process for CC eligibility, in the interim period four new children were found eligible for CC. The reviewers discussed with the HB the feasibility of meeting with these families, but it proved not possible to schedule meetings to review their experiences<sup>15</sup>. This is an area that the Service Group may wish to review as part of the ongoing engagement work with families.

The issues identified during the meetings with families were analysed and a number of themes identified. These demonstrated generally positive and improved views of the Service that included:

#### (a) Culture

There was a clear view from the parents that the culture had improved since the Review.

*Things are so different now, things are 100 times better than they were*

*The staff do an incredible job. They keep our children alive*

*The team should be proud of what they do, they are trusted by families*

*The team are awesome, they are absolutely fantastic*

Analysis of the responses provided by parents identified three main areas relating to team culture and compassionate care:

---

<sup>15</sup> Three of the children were identified as in need of school based support. One child requires a complex package of care that is currently under development.

- Improved relationships with no acrimony; this was viewed to be welcome and positive, the relationships between families and the CCNS team were described as being much improved.
- No threats to withdraw care; this was confirmed by both of the families interviewed who had been subjected to that process previously.
- Issues reported being dealt with effectively in a professional manner, and with timely feedback, giving more confidence.

One parent gave an example of a recent issue she had raised about a HCSW and how differently it had been managed compared to previously. Before, the HCSW would have been moved to work with another child and the parent would be left feeling the concerning behaviour had just been transferred to another family. The parent spoke very positively about how the recent issue had been addressed; this had resulted in resolution in discussion with the HCSW, who subsequently continued to provide support for the child with no residual animosity.

## (b) Communication

Problems with communication formed a key theme of the 2021 External Review; with families expressing concerns about relationships with the office based team and also with staff visiting their home in pairs<sup>16</sup>. There were significantly different views expressed this time:

*Lots more contact from the office now, we are informed in advance of any changes*

*I can contact my CCN and they go over and above to be helpful*

Five main areas were identified relating to communication, all of which demonstrated a more positive experience:

- Better 'office' contact in contrast with previous experiences.
- Improved visibility of senior managers: The efforts made by the Head of Children's Nursing to visit families when children were admitted to hospital was viewed very positively. They were clear that *this would never have happened before*. Families also welcomed the efforts made by the Team Manager to meet with them in order to build relationships.
- Improved processes to inform families of cancelled care: parents generally reported less cancelled care, although one parent noted this had increased again recently. When care was cancelled families are made aware as soon as possible and given the relevant information.

---

<sup>16</sup> Due to some perceived risk to the staff rather than because the child's needs indicated two members of staff were required

- Improved communication: families are contacted at the beginning of each week and informed of the names and cover for the week.
- Introduction of a QR code as an additional route to communicate – three families were aware, two of these had used the code. One parent was not aware of it<sup>17</sup>.
- The production of a quarterly newsletter, providing information and updates to families.

### (c) Service Delivery

The service model is recognised as being challenging to deliver. It involves primarily evening and night time cover delivered by HCSWs in the child's home whilst the registrants worked mainly during the day. Plans are underway to provide enhanced evening RN cover, ensuring access to registrants out of hours. The move towards working some night and evening shifts by the Clinical Educator was viewed positively by both the team and families<sup>18</sup>.

The parents felt the service had improved and they could see a difference from that which they had received previously. Efforts had been made to maintain the 'team around the child' approach adopted during the COVID-19 restrictions, which was appreciated by the families. Families also acknowledged the need to accept additional staff to develop experience and knowledge of the child to enable them to provide short term cover should that be necessary.

Specific areas of improvement mentioned by both staff and families were:

- Allowing CCNS staff who usually provide care in the home to follow children into hospital and ensure continuity of care.
- HCSWs being able to administer some forms of medication, based upon training and competency assessment.
- Improved speed of response, particularly from the office based staff and the child's nurse.
- A reduction in the number of children requiring 2:1 care, releasing more capacity to allocate to others and reduce cancellations of care.
- Improved continuity of care through the 'team around the child' model.
- A more proactive response, working together with families to prepare and pre-empt issues rather than responding later.

---

<sup>17</sup> This was fed back to the HB and rectified immediately

<sup>18</sup> This had been proposed previously but the proposal had been rejected.

Families spoken to all welcomed these improvements:

*Our CCN is great and goes over and above*

*The team around the child model is great in providing continuity*

*Allowing staff to follow the child into hospital is invaluable; it allows us some time to go home for short periods*

*The team are incredible, they do their best to ensure continuity*

*The care provided has changed our lives*

Whilst the feedback was generally positive and indicative of an improved approach to working in partnership with the families, there were four issues identified as areas that could be further improved. These were:

- One parent discussion identified a late approach to transition planning.
- Two families felt that joint working with social care services could be improved.
- Despite recognising the improvements over the last year, one parent still felt a residual lack of trust; the parent was able to reflect and recognise that this was based on historic issues which may take some time to resolve.

One family raised a concern about access to residential respite care, noting that whilst there was local access to residential respite care for children with less complex needs (such as at Tŷ Laura), accessing respite care for children with more complex needs involved travel out of area to Tŷ Hafan. The amount of respite care available at Tŷ Hafan was very limited and only available for those children deemed to be life limited.

## **2. The Views of Staff**

### **(a) The CCN Staff**

The Reviewers have met with all the registrants as part of the evidence gathering work. The Team Manager acknowledged the high level of demands on her time; she undertook:

- The role of manager supporting the implementation of the Improvement Plan.
- The operational delivery of the CCNS.
- The role of 'go to' expert for CYPCC, due to her previous role as Continuing Care lead not being replaced.
- Supporting the Head of Nursing with senior operational leadership previously provided by the Matron.

The team's Clinical Educator undertakes the role in addition to holding a small caseload of Continuing Care children. The role has been adjusted to allow the educator to be more flexible and accessible during evening and night time hours and this allows the post holder to work with HCSWs in their workplace (the child's home) to develop their skills and assess competencies. The totality of this role in having responsibility for training in addition to having a caseload of Continuing Care children is challenging; this was also noted by families and staff. The need to second the Clinical Educator to cover the Team Manager role means the short term loss of a dedicated education and development role, posing a short term risk that the HB will need to manage and mitigate.

The reviewers met with all the registrants and found them to be professional, keen and enthusiastic. They spoke positively of both the Team Manager and the Clinical Educator, acknowledging the high levels of support they received from them. In the meetings the reviewers were informed that on occasions they were reluctant to approach the Team Manager with a query or issue because they were concerned about her workload and of putting additional demands onto her; despite this they all appeared to be settling well into the new posts. The Reviewers were informed of new ways of working already being implemented; this included joining the daily ward round at the Morriston site.

From the meetings with the team a number of issues were identified and are listed in the table below:

Concerns:	Positives:
<ul style="list-style-type: none"> <li>➤ Leadership structure, including the Team Manager workload</li> <li>➤ Limited community based expertise across the registrant team</li> <li>➤ The lack of experience in Continuing Care</li> <li>➤ Limited ongoing contact with wider HB senior managers apart from the Head of Children's Nursing and Head of Quality Improvement.</li> <li>➤ The continued focus on Continuing Care rather than a rounded view of demands on the totality of the services provided</li> </ul>	<ul style="list-style-type: none"> <li>➤ New ways of working, including the Ward Round pull model, both for the early identification of likely referrals and improved relationships and communication with the ward based teams and families</li> <li>➤ Improved communication and feedback between the CCN Service and families</li> <li>➤ The reduction in cancelled care and the speed and effectiveness of communication with families when cancellation was unavoidable</li> <li>➤ The team culture has improved</li> </ul>



<ul style="list-style-type: none"> <li>➤ The length of time taken to recruit to the Nurse Assessor posts.</li> <li>➤ Registrants feeling under pressure due to limited experience and insufficient resource</li> <li>➤ Limited time for case supervision and caseload review</li> <li>➤ Meeting statutory and mandatory training needs along with all other training requirements linked to complex care provision</li> </ul>	<ul style="list-style-type: none"> <li>➤ The value of the <i>huddle and lunch and learn</i> sessions</li> <li>➤ The development of the bank to support short term cover</li> <li>➤ Access to the Guardian Service was viewed as helpful and positive</li> <li>➤ The team value each other and operate well as a cohesive group</li> <li>➤ HCSWs caring for a child whilst in hospital to begin to develop relationships with the family and assist with skills development prior to discharge.</li> </ul>
---	---

The reviewers made several attempts to meet with the HCSW workforce to seek their views, including: an in person meeting; an open invitation to HCSWs to contact the reviewers individually; and finally a late afternoon session via Microsoft Teams. Whilst only one HCSW opted to participate by providing feedback via email the reviewers are confident that the HB made every effort to support a discussion so that the HCSW views could be heard.

### **(b) Wider HB leadership and support**

In discussions with the CCNS Team they clearly identified and recognised the support provided by both the Head of Children's Nursing and the Service Group Head of Quality Improvement. However, the fragmentation of children's services across the HB continues to contribute to the CCNS feeling isolated. The team noted that various other children's services are working with the same group of children but are located in different Service Groups and in different locations across the HB estate, limiting the communications between them.

Some staff expressed ongoing disappointment at the way the 2021 External Review Report had been reported by the media; they described feeling unprepared and vulnerable when exposed to the media scrutiny that resulted from the publication of the initial Review.

### **(c) The Views of Local Authority Partners**

In the 2021 External Review, the reviewers were informed of transformation work, planned under the Regional Partnership Board (RPB), to review and improve partnership working. There was a dedicated work stream relating to children with

complex needs identified with a clear plan to take this forward; it was disappointing to hear that there had been limited progress with this. The Reviewers were informed that recent Vanguard workshops held in February and March 2023 may form the basis of a focused move to address improved multi-agency working. Multiagency discussions have identified some specific concerns<sup>19</sup> related to:

- A perceived lack of inter disciplinary working within the HB, for example between learning disability services, children's services and long term care.
- Difficulty in identifying a single point of contact who would undertake a care co-ordinator role on behalf of the HB, meaning the LA *get bounced around*;
- A lack of co-ordination between the CYPCC, Looked After Children (LAC) and children within the Children's Disability Team (CDT) even though these services were sometimes involved with the same children at the same time.
- Difficulties in agreeing funding responsibilities leading to delays in the provision of services. *Things get tense when finance is discussed.*
- The lack of a resolution process that could rapidly address disagreements. *Do we look to external arbitration?*<sup>20</sup>
- The underpinning ethos of working together around the child getting lost in the bureaucracy.
- Placements made in an emergency seeming to fall to the LA to manage with protracted discussions afterwards regarding funding.
- The recognised impacts of some placements which are very high cost and may be out of area leading to increased difficulties in monitoring and review.
- Meetings between partners are not attended by HB professionals at a level that allows for timely decision making, *things usually need to get taken back for further discussion on both sides.*
- A view that packages of care appeared to be turned down at the Quality Assurance stage with any peer review *always* supporting the HB view.
- The checklist step is unnecessary *as everyone proceeds to full DST*<sup>21</sup>.

Some concerns were identified regarding more strategic issues:

- The focus appeared to be on reacting and managing the issues today on a child by child basis meaning there was little room for forward thinking on how

---

<sup>19</sup> Some of these issues relate not to CYPCC but to other groups such as Looked after Children.

<sup>20</sup> In this statement 'we' referred to both the LAs and HB

<sup>21</sup> This is not supported by the Follow on Work which identified several children where checklists had not resulted in proceeding to a full assessment and DST completion.

collectively agencies could work together and change or further develop the model.

- The growing number of young people with ongoing needs now approaching adulthood and needing assessment and commencing the process of transition planning. The LA noted there are circa 50 young people identified who will need to be managed through to transition to adult services over the next few years. This will place significant new demands on both those assessing and on those providing services for a growing number of young adults with complex needs.
- Access to respite locally for children with more complex needs.

On a positive note:

- Staff attitudes and behaviours were felt to have improved and are *no longer an issue*.
- The Community Learning Disability Team have a model in place that was felt to be positive, consistent and fair.
- The Vanguard events have helped to highlight some issues and are beginning to work through what and how things need to change.

Whilst the views expressed referred to a much wider group of children and young people than CYPCC, there were clear views that the processes adopted by the HB can be fragmented and would benefit from a single point of access, leading to a single point of contact management model, with signposting to all relevant HB services.

An analysis was also undertaken of Panels held during 2021/22. These identified recurring themes that provide evidence of progress in developing more robust working relationships between Health and Social Care.

Areas of concern identified were:

- The checklists not being shared with LA partners '*as it's a health document*'.
- Whether the LA should be involved in completing the checklist.
- Whether families should be involved with the checklist completion.
- Young people being referred to the CCNS very near their 18th birthday. This appeared to be a route to ensure an assessment of need had been undertaken to support consideration of adult CHC. This involved the CCNS undertaking assessments on young people who were not previously known to the service<sup>22</sup>.

The improvements noted were:

---

<sup>22</sup> This is a wider issue that appears to be occurring in many parts of Wales.

- The significant progress made in recent months, both regarding engagement and in ensuring that Panels are now inclusive.
- LAs are now represented at Panels.
- Learning opportunities are identified and acted on.
- Escalation of issues within the HB appears now to be taking place where appropriate.

In summary, it is clear from discussions with both families and the CCNS team that this is a service that has seen a fundamental change to its culture and its approach to delivering care; there is a much more positive approach, with recognition that care is delivered in partnership. The Team Manager has met with all the Continuing Care families in order to establish a relationship that will allow all parties to have confidence in the way services are delivered and how queries or issues of concern will be dealt with.

There have been no unacceptable behaviour letters or threats to withdraw care since the initial External Review and there is a clear directive that such communication would not now take place without executive director level agreement. Whilst there is confidence that the culture has changed, there continue to be risks relating to the length of time it has taken to recruit to key posts leading to a temporarily fragile leadership structure, currently placing increased pressure on the team.

The limited progress regarding multiagency working is of concern and the complexity in negotiating children's services remains a challenge for our partners and families alike.

## Section 5: Progress in Implementing the Improvement Plan

The preceding Sections of this Report have provided an update on the key themes identified in the 2021 External Review Report. To address the issues identified and progress the 34 Recommendations the HB developed a comprehensive and co-ordinated Improvement Plan.

This Section of the Report reviews the progress on its implementation.

### 1. Management of the Improvement Plan and Organisational Scrutiny

The External Review undertaken in 2021 provided a total of 34 recommendations. There are clear reporting processes in place, and SBUHB Board formally received reports and considered progress at:

- the HB Quality and Safety Committee on seven occasions<sup>23</sup>;
- the HB Management Board on three occasions<sup>24</sup>;
- The HB Board on two occasions<sup>25</sup>.

RAG Rating of all Recommendations = 34		
	No.	% Compliance
Red	3	9%
Amber	14	41%
Green	17	50%

Of the 34 recommendations made by the reviewers, only three had not progressed to the extent that would have been expected. The reviewers were informed that the HB had deferred progress on engagement related actions whilst the review was underway in order to build any further findings into their Improvement Plan.

### 2. Assurance and Compliance related Actions

Total Recommendations relating to Assurance and Compliance = 18		
Red*	2	11%
Amber	6	33%
Green	10	55%

\*The red scores relate to:

- (i) Multiagency working in Recommendation 15. Some of the actions under this recommendation were scored green
- (ii) Recommendation 26 regarding compliance with the WG Policy Framework.

<sup>23</sup> On: 21/12/21; 1/2/22, 22/2/22, 1/4/22, 26/4/22, 23/8/22, and 4/1/23

<sup>24</sup> On: 1/2/22, 10/8/22, 20/12/22

<sup>25</sup> On 25/11/22, 26/1/23

In relation to Assurance and Compliance, two areas remained red indicating there had been little progress identified. These related to multiagency working and compliance with the WG policy requirements.

Partnership working was to be developed via the Regional Partnership Board (RPB) collaboration process but the reviewers were advised that this has not progressed to the extent that all partners would have liked; it appears that the level of strategic partnership working in children's services remains limited. This was the common theme among all stakeholders involved in this review and is disappointing. This would benefit from intervention at a strategic level to ensure this work is progressed.

While the Vanguard workshops, commenced in February 2023 provide an opportunity to progress some of these issues, a strategic level commitment from all partners is necessary to ensure an agreed framework is in place committed to improved multiagency service delivery.

Compliance with WG policy requirements is an area noted to have made little progress and had been rated as red. However, the recent appointment to the two Nurse Assessor posts is a significant step, which along with work recently undertaken to reduce the delays in delivering a package of care will allow the HB to review the assessed RAG rated position.

The length of time taken to provide a package of care once a child had been assessed as eligible for CYPCC was a key concern in the 2021 Report. This was often due to:

- (i) The time it took to agree eligibility for CYPCC.
- (ii) The lack of staff available within the core service to meet the assessed needs.
- (iii) The process to employ staff which only began once eligibility was agreed.
- (iv) The necessary induction and training required before the HCSWs could actually provide care.

Collectively this led to delays in providing care that routinely extended into several months. Changes have now been approved that support an 'agreement in principle' earlier in the process, meaning work could begin to provide the required package of care. This is a significant improvement and makes the process much more efficient and less bureaucratic for the families involved.

Six Recommendations were rated as amber:

- Compassionate leadership with support from the HB Workforce and Organisational Development team, bespoke training has been developed, the plan being to roll this out across the whole Team. The ability to roll out training across the CCNS Team has been hindered by an inability to release staff at this point in time<sup>26</sup>.

---

<sup>26</sup> In addition to an inability to release staff from the roster to undertake compassionate leadership training, one member of the CCN team also indicated that she was unable to continue with the planned MSc due to operational workload pressures.

- Online records - a digital app is being finalised prior to roll out, with training needs identified to support this. In the meantime an asset register has been established and assurance audits are undertaken and reported to the Service Group Quality and Safety Meetings on a regular basis. This ensures records are now safely stored and accessible when necessary.
- Nurse assessors are now appointed and in post. This is a significant step and will allow the HB to revise the progress and scoring on this.
- Lone worker management is progressing, with the buddy system established and progress made in working towards a registrant covering evening hours.
- Out of hours –The HCSW workforce remains the backbone of the CYPCC provision, working both a day roster and supporting the overnight packages of care. The roles and governance around this have been reviewed with a new Standard Operating Protocol for Out of Hours working implemented with agreed processes for reporting to the new Band 4 and planned future Band 6 posts.
- Leadership style – while steps have been taken to develop additional leadership expertise, the current decision not to appoint a Matron for the CCN Service, instead appointing a Deputy Head of Nursing with wider responsibilities will pose some risks for the CCNS which will need to be monitored.

It is pleasing to see the ongoing progress and improvements in relation to governance and assurance. These include:

- The development of a Business Case to increase the service resource, which is monitored through governance processes.
- The provision of governance training which has increased the use of Datix to report incidents, including cancellations of care, with evidence of regular monitoring and reporting of practice into the Service Group Quality and Safety Committee.
- Operational leads now attend weekly multidisciplinary incident review meetings chaired by the Head of Nursing.

Finally, one of the most upsetting issues identified in the 2021 External Review Report was the way some families had been labelled as 'difficult'. This manifested in them being risk assessed<sup>27</sup> and receiving communications from the CCNS that included a 'cease and desist' type of letter, the result being a threat to withdraw care. The threat to/actual withdrawal of care was enacted for several vulnerable children leading to high levels of risk; it also caused significant distress for families who were already under pressure caring for a child deemed life limited and possibly under palliative care. The HB confirmed such actions are no longer permitted. This is a very welcome development.

---

<sup>27</sup> The Follow on Report on the use of Risk Assessments as part of a consideration of withdrawal of care identified little if any consideration of the risks to the child and their wider family if care were to be withdrawn or any alternative pathway through which care could be provided.

Collectively these actions provide assurance of an improved governance focus with a clear line of sight from the CCNS to the Board and a change in culture within the team.

### 3. Service Development

Total Recommendations relating to Service Development = 8		
Red*	1	12%
Amber**	4	50%
Green	3	38%

\*The red score relates to multiagency pathways in Recommendation 19. Some of the actions under this recommendation were scored green

\*\*Two of the amber scores included some of the embedded actions scored as green.

In relation to this theme, only one element has not made the progress expected; this relates to developing multiagency pathways (Recommendation 19). As with Recommendation 15, the lack of progress in this area is disappointing and the HB needs to consider at a strategic level how best to address this. There is a need to develop effective and robust processes with their key partners.

Four Recommendations were rated as amber for this theme:

- **Dataset of management info/trends**: To ensure the CCNS has access to key management information and the ability to capture trends in demand the division has developed children community specific datasets reportable via PIMS+. There has been some progress with this, with activity data now captured. However it has proved difficult to access and interrogate the data held on PIMS+ due in part to the CCNS and managers not yet being able to familiarise themselves with the system and how to extract data. This meant the reviewers had difficulty in accessing this information and the CCNS were unable to be clear on activity profiles. The RAG rating on this action may need to be reviewed.
- **Skill mix and establishment** whilst a workforce plan is in place and there has been progress in rotational posts between the hospital and community it is disappointing that the HCSW establishment is still calculated based upon the number of CYPCC children receiving support rather than the work undertaken by the CCN Service across all three cohorts.
- **24/7 skill mix** – whilst business plans have been developed that recognise the need to increase the registrant establishment in order to provide an out of hours presence, this has not yet translated into all posts being filled.
- **Leadership and engagement with families** there has been progress in ensuring the CCNS senior team engage more effectively with families. This has included the Team Matron meeting with each family to begin to develop trusting relationships. Further work is currently on hold in order to build the feedback from this One Year on Review into the programme of work.



Other positive improvements include:

- CCNS registrant attendance at the daily Ward Board round in order to enhance the review of care for those children who may have a community package of care or who may be likely to need community support on discharge. This is viewed by staff and families to be a significant improvement. It is essential to ensure that the CCNS resource remains at a level that allows this model of good practice to continue.
- The team did consider the possibility of staff transitioning into adult services to ensure smoother handover of care for young people during transition, however this was not deemed feasible at this point in time.
- A review of the staffing rosters was undertaken to allow for the observation and support of HCSW practice out of hours; the Nurse Educator now supports the HCSW workforce with training and assessing competencies out of hours; this change is seen as a significant improvement by both the HCSWs and the families. The HB will need to be assured that this will continue with the secondment of the Nurse Educator into the Team Manager post.
- The Band 3 and Band 4 portfolios and competencies have been reviewed and an agreed workforce and development plan is in place to ensure staff are working within the full extent of their banding with the required competencies. All HCSW's are supervised by their named CCN; the ability to align the individual workers to the children cared for by the CCN has not yet been possible. Benchmarking this across Wales has also yet to happen.

While there has been significant progress relating to the service model, the HB will need to consider:

- The immediate risk associated with the interim Team Manager arrangements in place. Until a replacement substantive Team Manager is appointed the CCNS is operating at a reduced level of senior leadership expertise and this will need to be managed and mitigated on a short term basis.
- The Improvement Plan highlighted the use of peer review of the standards and practice against the WG CYPCC Guidance. This was intended to be taken forward by the all Wales CYPCC Group and peer review Terms of Reference had been agreed to support the disputes process.

## 4. Partnership and Engagement

Total Recommendations relating to Partnership and Engagement = 5		
	No.	%
Red	0	0%
Amber*	2	40%
Green	3	60%

\*Two recommendations identified as amber had component within the actions that were green

This theme relates to partnership and engagement between the families and the CCNS; there has been significant improvement with partnership working with families, moving closer towards a co-design and co-production model. A more flexible approach to planning and managing packages of care, with improved systems for feedback and engagement are now in place. It is clear that extensive work has been undertaken to ensure families are aware of, and feel confident to use, these new ways of communication.

Two Recommendations are identified as amber:

- **Partnership approach including the 'what matters to me' discussion** – the HB has identified the need for training sessions and the development of a video to support training, working with the patient feedback team. The Implementation Plan indicates that the training programme completed in May and training commenced in June 2023.
- **Engagement events** – an Engagement Plan has been developed but the work has been deferred until after the reviewers had spoken to families as part of the work for this Report. The feedback from families was that some form of session where they could meet up would be helpful. They suggested a 'coffee morning' type session based either in Ysgol Crug Glas or a local meetings facility could be considered.

In relation to engagement work, new developments include:

- A weekly *huddle* session.
- A weekly *lunch and learn* Thursday session, where information can be shared.
- The creation of a *what's the noise* app for HCSWs to use (anonymously if preferred) to escalate any issues. Whilst staff spoke positively about this it was noted that the app does not apply to RNs; some felt this was a missed opportunity and it may be useful to consider extending the app to all CCN staff to use.
- A new parental agreement form has been developed and shared with families.
- A newsletter to parents providing updates and sharing relevant information.
- The creation of a QR code to provide immediate access to the CCNS in relation to any concerns or comments parents may have.

## 5. Strategic Planning

Total Recommendations relating to Strategic Planning = 3		
	No.	%
Red	0	0%
Amber	2	66%
Green	1	33%

None of the actions identified for this theme are reported to be red.

Two Recommendations are scored as amber:

The siting of the CCNS within the HB structure: The reviewers would query the amber score attached to Recommendation 3 which refers to where the CCNS is best positioned within the HB. The Head of Children's Nursing has attended a meeting to consider the position of the services within the wider HB; it is hoped this will continue to be progressed. The current structure does not enable families to negotiate pathways of care for children with complex needs effectively or easily with children accessing several elements of Children's Services managed within different Service Groups. A key example of this is the Child Disabilities Health Visiting Service who consistently work with the same families as the CCNS, often at the same point in time yet sit within differing Service Groups. This hinders effective service planning and creates frustration for those managing service areas.

Discussions with the CCNS team and wider HB services indicated a preference for the service to be linked more formally with other community paediatric services, ensuring a more cohesive approach. The Head of Children's Nursing has advised that she now sits on the Transformation Board, representing Children's Nursing Services; it is hoped this will provide a focus that will accelerate work on this.

Access to adequate governance support – there has been a small increase in the governance support available to the CCNS; the reviewers were informed of plans to further increase the staffing resource to support effective governance.

## Section 6: Conclusions

Having reviewed the Improvement Plan in detail it is heartening to see the progress made. The culture within the CCNS team is now one of compassion and professionalism, with a 'can do' attitude. There is more visibility and proactive communication between the managers and families and there have been no circumstances where withdrawal of care has been considered since the 2021 Report.

The reviewers have been assured that a withdrawal of care would never be considered without Director level approval and would need to be supported by robust and appropriate risk assessments and planning.

The families spoke of a caring and compassionate service delivering excellent care in the community and the CCNS team were unanimous in their feedback that they had a supportive Team Manager and a Head of Children's Nursing who listened when they expressed concerns. The CCNS team, although mainly new with limited experience in community and Continuing Care, has created an environment where change is welcomed and can take place. With appropriate leadership and expertise this bodes well for the future service provision of Children and Young People's Continuing Care in the community.

The team provide an invaluable service to those families with children who have highly complex health needs. Without this service families would struggle to keep their children at home in the family environment. This One Year on Review has demonstrated how much families appreciate that.

There has been a welcome resource investment in the team, and a focus on addressing the Recommendations in the 2021 External Review through the implementation of the Improvement Plan. The loss of the Matron post from the CCNS will need to be monitored to assure the HB that there is sufficient senior nurse oversight for this small but essential Service.

The Improvement Plan continues to identify three actions RAG rated as red. The HB will need to consider how best to accelerate actions to progress these. In addition, there has been limited progress on Recommendation 3, currently scored as amber, relating to where the CCNS is sited within the organisational structure. There should be consideration given to rescoring this until progress is made in this area.

Looking ahead, discussions with HB staff and stakeholders identified the prospect of increasing referrals of children and young people with complex physical, behavioural and developmental needs. The HB will need to consider this not only as part of its ongoing service planning for children's services but also regarding the impact of the increased numbers expected to transition into adult services.

The use of the all Wales CYPCC Group to progress work appears to have been limited. However, an all Wales approach would be beneficial in developing consistency in implementing the Framework. This would need to be undertaken in partnership with

other HBs across Wales and would require work to ensure a robust governance framework is in place should the HBs collectively wish to pursue this.

There remain some ongoing issues to resolve as part of the Improvement Plan to allow the CCNS to achieve its full potential. From the progress made to date, the reviewers are confident that the HB has acted upon the findings and Recommendations of the 2021 External Review. It is hoped this level of commitment will continue to support the HB in addressing the outstanding issues.

It has been almost two years since the External Review work commenced and four years since the experiences of parents led to the concerning patient indicators that initiated the commissioning of the External Review. The CCN Service has developed and is now in a very different place.

The CCNS provides a service that when functioning well is virtually invisible, but should it fail the consequences are far reaching and very visible. Over the past two years the CCNS has undergone a transformation, with a mostly new team of staff and a culture that is open and seeks to engage positively with the families of children with very complex needs. It has been a pleasure and a privilege to see the CCN Service overcome the initial turbulence that followed the Review Report and develop and change to the extent it has.

**Carol Killa  
Gaynor Williams  
July 2023**

## Appendix 1: Changes to CCNS Establishment over time

Band		Pre Bridgend Transfer WTE	Post Bridgend Transfer WTE	Staffed Establishment as at March 2023 WTE <sup>28</sup>	Actual Establishment as at March 2023 WTE <sup>29</sup>	Funded v Actual Gap WTE
8		1.0	1.0	0	0	-
7		1.0	1.0	2.0	1	+1
6		10.6	8.6	8.32	7.91	- 0.41
5		3.08	2.2	1.89	1.72	- 0.17
4		19.5 HCSW	14.25 HCSW	16.02 HCSW/Nursery Nurse	12.19	- 3.83
3		15.25 HCSW 1.0 Admin = 16.25	14.12 HCSW 1.0 Admin = 15.12	14.56 HCSW 0.6 Admin = 15.16	18.32 0.6 Admin = 18.92	+3.76
2		0.8 Clerical Support	0.8 Clerical Support	0.8 A&C	0.8	-
Total		51.69WTE	43.69WTE	44.23 WTE	42.54WTE	-1.69

**Report Ends**

<sup>28</sup> As provided by the Team Manager on 11 April 2023

<sup>29</sup> As provided by Team Manager on 11 April 2023