
Review of health services for children, young people and families within the NSW Health system

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The silent partner in this Review was Ms Christine Farraway, from Health Connect Consulting, who provided wonderful support in conducting research, contributing to the writing of the report, subediting and providing invaluable feedback on my drafts, as well as the more mundane organising of appointments. She should not be held responsible for the recommendations that I made but she should be given credit for helping me to express my views with far more clarity than I would have achieved without her help. Only she and I truly understand the massive contribution that she has made to this Review.

Recommendations of the Review

Seventy-seven recommendations were identified through this Review. These recommendations, together with the issues that the recommendations are addressing, are summarised below. The key findings supporting the recommendations are presented in the body of this report.

Sections 4, 5 and 6: System wide governance and accountability



These recommendations link with the Secretary's priority to strengthening governance and accountability.

Issue: There exists inconsistency in the implementation of frameworks specific to children, young people and family health care and the development of accompanying outcomes measures. Additionally, the monitoring of implementation and outcomes is variable.

Recommendation 1: The development of every framework be accompanied by an implementation plan, by outcome measures and by monitoring of both implementation and outcomes.

Recommendation 2: The implementation of the Paediatric Service Capability Framework be incorporated as a key performance indicator in the Service Level Agreement of each Local Health District (LHD).

Issue: The effective operation of children, young people and family health services in NSW is dependent upon strong, visible clinical leadership at the highest level. There are currently insufficient levers to support the Chief Paediatrician to achieve the purpose of this role.

Recommendation 3: The Chief Paediatrician work with each LHD to support implementation of the Paediatric Service Capability Framework.

Recommendation 4: An annual report be made to the Deputy Secretary Health System Strategy and Planning, via the Executive Director Health and Social Policy on the strengths, vulnerabilities and opportunities in the implementation of the Paediatric Service Capability Plan for each LHD.

Issue: The current role of the Chief Paediatrician is primarily focused on acute and hospital paediatric care. A greater focus on community paediatrics and priority areas in child health is a necessary requirement to support care in the community and evolving priorities.

Recommendation 5: The role of the Chief Paediatrician be expanded to include a broad overview of paediatrics and child health. This would make it clear that the Chief Paediatrician has a role in working with others to improve healthcare in areas including (but not limited to) assessment and management of community paediatric issues such as behaviour disorders, developmental delay, as well as long term vital initiatives, for example the First 2000 Days.

Issue: Clarity around the governance of the Sydney Children's Hospitals Network (SCHN) was a key issue impacting this Review. Consultation confirmed that further expanding the governance of the SCHN to a state-wide remit would be challenging.

Recommendation 6: The current situation be clarified and reinforced that SCHN is not responsible for overall governance of paediatrics across NSW. In parallel, SCHN should not be held responsible for failure of implementation for matters for which it has neither authority nor budget.

Issue: Services do not always operate at their designated service level. Other LHD priorities often impact on the ability for an LHD to meet its objectives in relation to paediatric services. The tight-loose-tight model means that the Ministry of Health (MOH) sets a tight direction, allows a looseness about how objectives are achieved, and applies tight ownership and monitoring of deliverables.

Recommendation 7: Although LHDs have flexibility about how paediatric objectives are achieved, they should not have flexibility about whether paediatric objectives are achieved. NSW Health requires a system that monitors the achievement of paediatric objectives across all LHDs.

Recommendation 8: The MOH recognise that some paediatric decisions (outside the scope of those classified as supra-regional specialities) need to be considered across LHDs and the SCHN. These decisions should be referred to the NSW Paediatrics Executive Steering Committee for discussion and resolution.

MOH structures and governance

Issue: There is no systematic approach that drives decision making and provides focus and direction for children, young people and family health services. A committee that operates as the primary decision-making committee across all child, youth and family services is required.

Recommendation 9: The current NSW Paediatric Executive Steering Group be reconfigured to function as the peak decision-making committee across child, young people and family services in NSW to oversee new models of care, development of standardised guidelines and processes, statewide policy and planning, and monitoring of outcomes. Community representatives should be part of the membership.

Issue: Consultation identified that there are unclear pathways for escalating issues, decision making and approval of recommendations. This finding was consistent with the April 2019 Performance Audit Report¹ recommendation from the NSW Auditor-General about Governance of Local Health Districts that “more clarity around how the escalation process works and how escalation decisions are made”.

Recommendation 10: The Chief Paediatrician be given a key role in taking advice from MOH, LHDs and SCHN about the best way forward for paediatric decisions that need to be considered across LHDs and SCHN.

Recommendation 11: The Chief Paediatrician present the issues, options, and any recommendations, to the NSW Paediatric Executive Steering Committee.

Recommendation 12: The NSW Paediatric Executive Steering Committee consider and agree recommendations from the Chief Paediatrician and escalate committee decisions to the Deputy Secretary Health System Strategy and Planning.

¹ <https://www.parliament.nsw.gov.au/tp/files/75490/Governance%20of%20Local%20Health%20Districts%2018%20April%202019.pdf>

Recommendation 13: The Deputy Secretary Health System Strategy and Planning present relevant committee decisions to the senior executive team for approval.

Issue: The Performance Audit Report from the NSW Auditor-General raised issues about the relationships between the pillars and LHDs, suggesting that the MOH should “provide clarity on the relationship of the Agency for Clinical Innovation and the Clinical Excellence Commission to the roles and responsibilities of LHDs”. The recommendation in this Review is consistent with the Audit Report.

Recommendation 14: Relevant decisions from ACI or from CEC be referred to the NSW Paediatric Executive Steering Committee for advice and subsequent approval by the senior executive team (in line with the process outlined in recommendations 12 and 13 above).

Issue: Communication and information flows across committees, networks and stakeholders are inconsistent and reduce the ability for committees/networks to perform their core functions of oversight, monitoring and decision making.

Recommendation 15: Existing systems and processes for communication and transfer of information between and across committees/networks, system managers and operational managers be refined to support efficient information flows, decision making, implementation and monitoring.

Issue: There was evidence that many committees did not have terms of reference while others were outdated and/or unclear in their purpose, governance and process of evaluation.

Recommendation 16: All committees develop clear terms of reference that are updated at least biennially and include a clear purpose and functions, reporting lines and measures of effectiveness to periodically evaluate performance.

Children’s healthcare networks

Issue: Children from Central Coast Local Health District (CCLHD) frequently travel to Sydney for care. There is an opportunity to include the CCLHD in the Children’s Healthcare Network (CHN) Northern region, where appropriate, rather than flow to Sydney.

Recommendation 17: The Children’s Healthcare Network Northern region be expanded to include the Central Coast LHD.

Recommendation 18: Future subspecialty paediatric appointments to HNELHD consider a fractional component shared with CCLHD.

Issue: The effectiveness of the three CHNs and overall operational governance is variable. In some instances, this was thought to impact communication, patient management and quality improvement.

Recommendation 19: Future subspecialty appointments to the SCHN be shared with a Metropolitan Paediatric Level 4 (MP4) or Regional Paediatrics Level 4 (RP4) hospital.

Recommendation 20: A long term approach be considered for the Children’s Healthcare Network Western and Southern regions to be combined in a sector linked to the SCHN. An early priority be cross credentialing of staff involved in outreach activities.

Local leadership, governance and operations



These recommendations link with the Secretary's priorities for strengthening accountability and governance, patient safety and experience, value based health care and systems integration.

Issue: The deficiency of clinical leadership and a nominated 'Medical Lead' across many LHDs was thought to impact quality planning, delivery and monitoring of paediatric services locally.

Recommendation 21: Each LHD appoint a Medical Lead in paediatrics. In some LHDs, there will be a co-lead from nursing and in some cases the leadership will be across both paediatrics and child health. The overarching aims and functions of the role are described in the Framework.

Issue: In some instances, the number of paediatricians in a level 4 facility was considered insufficient for a sustainable 24 hour on-call access to a paediatrician. Additionally, level 4 paediatric facilities need to ensure that paediatricians do not work more than a 1 in 4 on-call.

Recommendation 22: The on-call roster for a level 4 paediatric facility be no more onerous than 1 in 4. The usual way to achieve this will be through a minimum of 5 paediatricians on the roster.

Issue: One of the essential criteria for meeting level 4 paediatric standards as described in the Paediatric Service Capability Framework is "provides non-inpatient child and family health services (e.g. developmental assessment, multidisciplinary assessment and treatment of psychosocial and behavioural problems)". Although some of these services will be offered in private practice, the public system also needs to provide services for those who cannot afford to be treated in the private system.

Recommendation 23: Level 4 paediatric facilities have an essential role in providing both acute and non-acute outpatient services. This might encompass activities such as offering care in the home. The responsibilities of paediatricians reflect this broad role, rather than a more limited focus on acute inpatient care.

Issue: Current transport procedures are not standardised, are complex and require collaboration across a range of service providers with varying capability.

Recommendation 24: Increase the clarity of protocols for consistent access to appropriate transport for sick children to higher level services and return transfers to local facilities. This will require engagement with Newborn and paediatric Emergency Transport Service (NETS) and NSW Ambulance.

Recommendation 25: Develop and implement protocols for reliable access to appropriate transport for children who need to be seen at a specialist children's hospital.

Issue: One barrier to providing outreach clinics to rural areas is the funding for the travel of the health professional team. By contrast, there is funding for children to travel to metropolitan specialist hospitals.

Recommendation 26: In order to facilitate outreach clinics to rural areas, a reverse Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) be developed, where the cost of sending health care workers to a rural centre be funded, analogous to patients and their families being funded for the costs of travelling to a tertiary centre for assessment and care.

Issue: A better understanding of appropriate safe care using telemedicine is required. This is an important issue in rural and regional LHDs. Potential exists to assess and review more children closer to home through the use of telemedicine and support sharing of clinical information and links between tertiary and smaller facilities.

Recommendation 27: Clinicians and administrators develop and implement agreed guidelines for the safe use of telemedicine in the treatment of children with acute and chronic medical problems to avoid the need for transfer.

Issue: There is significant variability in paediatric surgery undertaken across LHDs and SCHN. The Surgery for Children in Metropolitan Sydney Strategic Framework has not been implemented. The framework provides clear guidance around emergency surgery, planned surgery and the appropriate level of paediatric medicine service to support the surgical service.

Recommendation 28: The Surgery for Children in Metropolitan Sydney Strategic Framework (2014) be implemented, measured and monitored.

Issue: Navigation of the health system for children and their families with complex needs is challenging. The lack of enablers to support care coordination, such as a single medical records system across the LHDs and SCHN, suggests that the interim recommended solution of Care Navigator positions will be needed for many years.

Recommendation 29: Innovation funding be provided by the Paediatric Healthcare Team to LHDs for 2 years of funding of Care Navigator positions, conditional upon LHDs providing ongoing funding after the initial funding period provided that pre-determined agreed outcomes are achieved.

Issue: Nursing staff identified a need to develop greater capability to support the management of more complex patients. APLS and PLS are highly regarded courses and provide an opportunity to upskill the workforce. The provision of funding from LHDs is consistent with current industrial awards.

Recommendation 30: LHDs provide funding for nurses to attend APLS and PLS training courses.

Issue: Support for capability development of nursing staff was a recurring theme. The capability of many district hospitals to provide the level of care required to meet the standards of level 4 paediatric wards and level 4 special care nurseries remains challenging.

Recommendation 31: LHDs and SCHN implement systems for nurses to be upskilled by working in more complex clinical environments and by use of outreach education.

Issue: A limitation of functional space in some settings, impedes appropriate models of care. Outpatient care for children in public health facilities remains an important component of healthcare. Furthermore, multidisciplinary clinics are best practice in many of these situations. While the development of facilities is on a longer-term timescale these requirements should be considered in the design of future facilities.

Recommendation 32: Hospital planning recognise the need to construct facilities to enable the operation of multidisciplinary clinics for children and young people.

Issue: Numerous examples were presented to indicate that adults are residing in paediatric wards and child safe policies and guidelines are not always complied with.

Recommendation 33: LHDs implement the requirements for child friendly and child safe health facilities.

Section 7: SCHN governance



These recommendations link with the Secretary's priority to strengthen governance and accountability.

Issue: The governance of the SCHN is complex and a strategy for the way forward is required.

Recommendation 34: The Secretary of Health makes it clear that both CHW and SCH will be comprehensive specialist children's hospitals with tertiary and quaternary services on each site.

Recommendation 35: The Paediatric Intensive Care Units at CHW and SCH operate as a single service on 2 sites.

Recommendation 36: NETS transfers ensure that SCH receives a similar mix of the sickest children as CHW.

Recommendation 37: The Sydney Children's Hospital and the Children's Hospital Westmead remain in the SCHN.

Recommendation 38: The Chief Executive and the Board of the SCHN be made accountable for ensuring that these recommendations are implemented within 12 months.

Recommendation 39: The Chief Executive and Board of SCHN develop and implement a plan to increase cooperation between the two campuses. This will include acknowledging the cultural differences between the two hospitals.

Recommendation 40: The MOH convenes a meeting between key staff at SCHN and SESLHD to decide the principles and details of the costs of shared services at the Randwick campus. The resolution of these longstanding contentious issues will help to ensure that the focus of discussions between SCHN and SESLHD is around improving patient care, rather than who pays what share of the cost of delivering services.

Recommendation 41: Future enhancement funding be directed to areas where there is clear evidence of, and ongoing commitment to meaningful shared services between CHW and SCH, or shared services between SCHN and at least one LHD. This would include but not be limited to fractional appointments on more than one site. Cardiac services may need to develop in parallel due to irreconcilable conflict between CHW and SCH.

Recommendation 42: The Chief Executive and the Board of SCHN develop a new strategic plan that includes a vision, a strategy and an implementation plan for both CHW and SCH, as well as NETS, the Poisons Information Centre and the Western and Southern regions of the CHN.

Section 8: Neonates



These recommendations link with the Secretary's priorities to strengthen governance and accountability and patient safety and experience.

Issue: The operational governance and linkage between NICUs and SCUs was not always clear and a number of barriers to timely back transfer were highlighted.

Recommendation 43: In addition to the model of tiered neonatal networks, the plans for future governance need to provide coordination across the whole system to connect NICUs and SCNs.

Recommendation 44: The plans for future governance need to ensure that back transfers from NICUs to SCNs are managed across the whole system.

Issue: There is a need and desire for consistent education and training specific to critical care for NICU and SCU staff to support system capacity, capability and safety of patients.

Recommendation 45: Training and upskilling of staff caring for newborns in both SCNs and NICUs requires a state-wide approach.

Issue: Communication between providers can be inconsistent and transitions of care and protocols are frequently different across different sites and providers. This potentially impacts continuity of care, patient safety and patient flow.

Recommendation 46: The plans for future governance need to focus on the interfaces which can be problematic in the current system, such as interfaces between midwife and child and family nurse, obstetric services and general practice, and between neonatal services and specialist paediatric services in children's hospitals and LHDs.

Section 9: Community paediatrics and child health



These recommendations link with the Secretary's priorities for patient safety and experience and value based health care

Universal Health Home Visiting (UHHV)

Issue: One of the barriers to UHHV has been that the funding provided to LHDs to support it has not always been directed towards UHHV. The current plans to continue with UHHV, to have a shorter first visit, and to use the visit to identify those who need further visits is supported by this Review. This approach is recommended rather than universal contact.

Recommendation 47: Universal Health Home Visiting continue to be promoted, together with identification of those who need further visits.

Issue: One of the gaps in the current UHHV model can be the transition from maternity services. This Review has identified the need to socialise the midwife completing the maternity journey and providing active encouragement in handing over the family to both the child and family health nurse and the general practitioner.

Recommendation 48: Each LHD ensure an effective handover of the family from the midwife to both the child and family health nurse and the general practitioner.

Allied Health services

Issue: In a resource constrained environment, there will be pushback against any recommendation for an increase in allied health staffing. The Reviewer does not believe that the current system provides allied health disciplines with an equal opportunity with medicine and nursing in attracting a fair share of funding.

Recommendation 49: The Ministry of Health recognise that the demand for allied health services for children, young people and families far exceeds supply and adopts a long term strategy to address the staff shortages. Targets for investment include initiatives for the First 2000 Days, for mental health and for interventions for domestic violence.

Paediatric Rehabilitation

Issue: Delivery of services where both LHDs and specialist children's hospitals are both essential (often characterised as a tiered network) require a governance model that facilitates effective interaction. The MOH has a critical role in coordinating this process. This is another example of an area that is too small to be considered a supra-regional specialty but that needs central oversight.

Recommendation 50: The Ministry of Health works with specialist children's hospitals and LHDs to better coordinate paediatric rehabilitation services across NSW.

Developmental assessment and services

Issue: There appears to be wide variation in the intake systems, diagnostic assessment approach and rationale for developmental assessment, with limited agreement on the ideal model of care.

Recommendation 51: Intake systems for diagnostic assessment services should determine whether a detailed assessment is what is required. In particular, if a functional assessment for NDIS purposes is needed, a general paediatrician would be able to provide the report.

Recommendation 52: ACI undertake a project to determine the most efficient and effective way both to perform developmental assessment and to focus on increasing the capacity of families to adjust to and optimise management of their child's disability.

Recommendation 53: MOH initiate interagency discussions with areas such as Education and NDIS to clarify and simplify the assessment and information required for eligibility for services to support children with developmental needs.

Child Protection and Domestic Violence

Issue: Resources to provide support post screening are required to facilitate the necessary response to domestic violence.

Recommendation 54: The commitment to screening for domestic violence be accompanied by resources to assist women and their children.

Issue: Improved coordination and support is required for clinicians working in the area of paediatric forensic medical services.

Recommendation 55: The Ministry of Health works with the specialist children's hospitals and LHDs to better coordinate paediatric clinical forensic services across NSW. One component is that reports relating to alleged physical assault should not be submitted until they have been peer reviewed.

Section 10: Attention-Deficit Hyperactivity Disorder (ADHD)



These recommendations link with the Secretary's priorities for patient safety and experience and value based health care

Issue: There was a widespread view that a different delivery system of care needs to be considered for the management of ADHD.

Recommendation 56: Pilot studies across NSW implement ways for general practitioners to write repeat prescriptions for stimulant medication for ADHD.

Recommendation 57: If pilot studies are successful, general practitioners be allowed to receive prior general approval (known as Patient-Class Approval) to write repeat prescriptions for stimulant medication for ADHD.

Issue: The current NSW ADHD model of care, comprising a paediatrician responsible for all aspects of prescribing and monitoring need for, and response to stimulant medication, may not be the best system.

Recommendation 58: A group of clinicians experienced in management of children with ADHD consider whether a trial should be conducted to compare different service delivery mechanisms of care for assessment and management of ADHD.

Section 11: Young people



These recommendations link with the Secretary's priorities for patient safety and experience and value based health care

Issue: There is a requirement to build capacity and capability in the workforce across NSW so that more young people can access quality healthcare to meet their changing health needs and to avoid loss of the improvements in early childhood health.

Recommendation 59: The Ministry of Health support Royal Australasian College of Physicians (RACP) tier 1 and 2 training requirements in Adolescent and Young Adult Medicine (AYAM) for all general paediatricians/community child health/behavioural paediatricians.

Recommendation 60: The Ministry of Health build capacity among the AYAM workforce through funding of advanced training opportunities in adolescent medicine at the specialist children's hospitals and in metropolitan, rural and regional locations with appropriate supervisory arrangements.

Recommendation 61: The Ministry of Health work with relevant groups to develop training pathways and competency frameworks for clinical nurse consultants in AYAM, through dedicated clinical qualifications that provide more breadth and depth than the existing workshops and resources.

Recommendation 62: LHDs and SCHN provide dedicated training opportunities and ongoing support for nurses in adolescent inpatient and outpatient units and youth health centres.

Recommendation 63: The Ministry of Health work with primary health providers to identify opportunities for training and ongoing support for those working with young people.

Issue: There is an absence of meaningful feedback from both parents and young people about their experience and outcomes.

Recommendation 64: The Patient Reported Experience Measure (PREM) be modified so that both parents and young people can provide feedback, rather than one or the other.

Section 12: Mental health



These recommendations link with the Secretary's priorities for strengthening governance and accountability, patient safety and experience, value based health care and systems integration

Issue: Consultation identified that various services do not accept responsibility for assessment and/or ongoing management of children and young people with mental illness. The MOH needs to ensure that LHDs individually and collectively recognise the need to provide services.

Recommendation 65: The Ministry of Health oversees meaningful engagement between health care providers who are both inside and outside the mental health system to develop and implement a collaborative approach to addressing both mental health and the mental illness needs of children and young people.

Issue: Paediatricians are required to care for children and young people with acute behavioural disorders and with mental illness. Many paediatricians find themselves out of their clinical comfort zone with this group of patients. It is recognised that paediatricians require appropriate training, knowledge and experience to provide safe and appropriate care. One possible example is the development of “*entrustable professional activities*” by the Neurodevelopmental and Behavioural Society of Australasia.

Recommendation 66: Training programs be developed to provide paediatricians with a minimum standard of capability and qualifications to safely care for children and young people with acute behavioural disorders and with mental illness.

Issue: Most general paediatric nurses feel that they have limited capability for managing children and young people with acute behavioural disorders and with mental illness.

Recommendation 67: Training programs be developed for paediatric nurses to provide qualifications for managing children and young people with acute behavioural disorders and with mental illness.

Issue: There is a significant need to increase the numbers of allied health professional working in mental health.

Recommendation 68: The MOH recognise that the demand for allied health professional services in mental health far exceeds current supply and develops a targeted strategy to address the issue.

Issue: The Productivity Commission's Draft Report on Mental Health recommends five key reform areas, all five areas are relevant to children, young people and their families.

Recommendation 69: This Review welcomes the findings in the Draft Report from the Productivity Commission on Mental Health and commends the Draft Report to the MOH. One area to highlight is the need for early intervention in young people diagnosed with psychosis.

Issue: Providing GPs with enhanced skills to manage complex behavioural and mental health problems is being studied in the ECHO project in NSW. To participate in the panel discussion, GPs are using the Medicare item number for “case-conferencing”.

Recommendation 70: The MOH supports projects implementing and evaluating models of care increasing the skills of GPs in managing complex behavioural and mental health problems in children.

Section 13: First 2000 days



These recommendations link with the Secretary's priority for systems integration

Issue: Ongoing engagement, collaboration and investment across a wide range of stakeholders is required to achieve successful long term outcomes for the first 2000 days.

Recommendation 71: Health and Social Policy Branch in the MOH continue to develop the opportunities for the Centre for Population Health/Public Health Units and Primary Health Networks to engage fully with implementation of the First 2000 Days.

Recommendation 72: The Secretary, NSW Health engages with Secretaries of Departments such as Education and Communities and Justice to ensure high level cooperation and accountability across sectors responsibility for successful implementation of the First 2000 Days.

Recommendation 73: The Ministry of Health engages with Faculties of Health and Medicine and other educational bodies to ensure that the broad medical, nursing and allied health curricula recognise the lifelong importance of the first 2000 Days for the physical, cognitive, social and emotional health of the population.

Section 14: Measuring progress



These recommendations link with the Secretary's priorities for strengthening governance and accountability, patient safety and experience, and digital health and analytics

Measuring progress

Issue: There is an absence of data across all points of the patient pathway to monitor progress, measure success and facilitate a coordinated approach to strategic and operational improvements.

Recommendation 74: NSW Ministry of Health develop robust key performance indicators and outcome measures using a similar template to the State of Child Health Report 2017 from the Royal College of Paediatrics and Child Health, United Kingdom. Part of this process should be a data mapping exercise to identify both what is required and what is currently available.

Issue: Measures to support the implementation of the First 2000 Days Framework have not yet been determined. Data from AEDC can be used to target communities in greater need of focus, as well as to measure progress with achieving desired outcomes. This recommendation is not new. The Fifth National Mental Health and Suicide Prevention Plan 2017-2022 has a key outcome in the domain "Healthy start to life" as the proportion of children developmentally vulnerable in the Australian Early Development Index.

Recommendation 75: The Australian Early Development Census (AEDC) be used as a key outcome measure of the First 2000 Days.

Issue: The management of type 1 diabetes was raised by many of the interviewees. Type 1 diabetes is a life-long disease and currently there is no known way to prevent it or to cure it, however there is good evidence to demonstrate what works. There are serious long-term complications related to poor diabetic control, including blindness, kidney disease, limb amputations, heart disease and stroke.

Recommendation 76: HbA1c levels in children and young people with type 1 diabetes be used as a key outcome measure in LHDs and SCHN.

Issue: The NSW Youth Health Framework 2017-2024 has no accompanying implementation, monitoring and evaluation document. The Framework indicates that the MOH will identify state level priorities and that LHDs and SHNs have lead responsibility for the implementation of the Framework.

Recommendation 77: NSW Ministry of Health adopt a survey such as the Middle Years Development Index as a key measure of health, development and well-being of adolescents and guide comprehensive approaches to intervention programs.

Executive summary

A key priority for the NSW Health system is the design and delivery of high quality, effective and safe health care services for children, young people and families, from conception until 24 years of age.

This independent Review was announced by Minister Hazzard in February 2019. This Review focused on the current status of governance and the delivery of health services to children, young people and families within the NSW Health system. This Review provides an outline of current issues and challenges associated with the provision of care for this group of patients.

The key findings of this Review are based on a range of activities including over 250 stakeholder consultations, LHD site visits, and a range of submissions, previous reports and documentation. Many good practice examples were identified during the Review, and several are presented in this report. As far as possible, opportunities for input were provided to all key stakeholder groups including patients, clinicians from a range of disciplines, managers, non-government organisations and primary care, NSW Ministry of Health and Pillar staff, local health districts, the Sydney Children's Hospital Network and academics.

Taken together the key findings of the Review provide the basis for the recommendations presented in this report. These recommendations highlight opportunities for improvement and align with the strategic priorities of the Secretary, NSW Health, across the areas of governance and accountability, value-based health care, patient safety and experience, digital health and analytics, and systems integration.

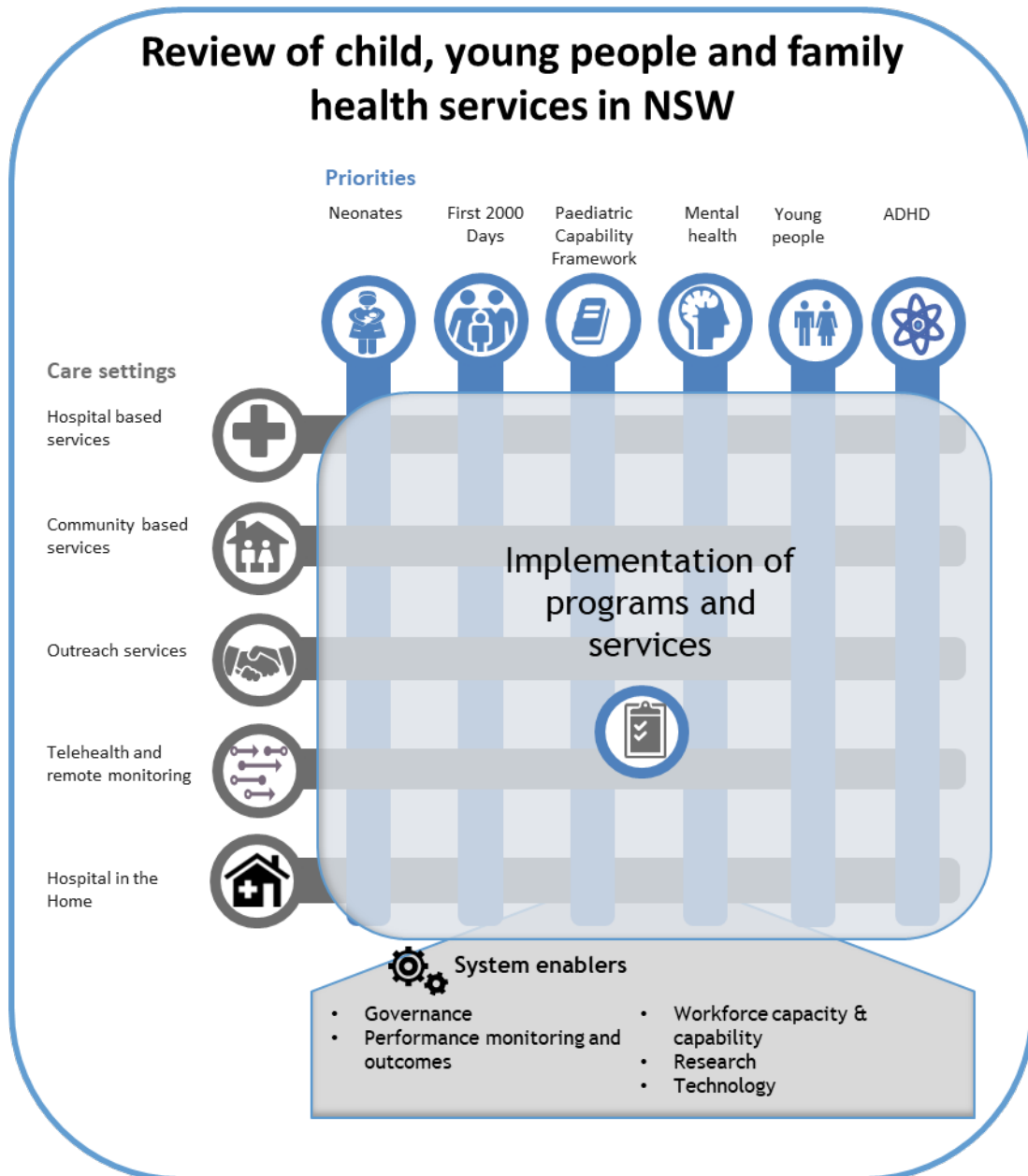
The NSW Health system of care for children, young people and families

This Review covered a diverse range of care settings, priority focus areas and system enablers that support service delivery for children, young people and families to meet the varying care needs of people as they move through different life stages. Figure 1 captures the three core elements of the Review as described below:

- 1. Care settings:** The Review encompassed all care settings where services are delivered including hospital based services, community based services, outreach services, telehealth and home monitoring and hospital in the home.
- 2. Priority areas:** Several priority areas were identified including neonates, the first 2000 days, the Paediatric Capability Framework, mental health, ADHD and young people. These priority areas relate to particular population groups or areas where a strong focus is required.
- 3. System enablers:** The system enablers describe the components that support service delivery including governance, performance monitoring and outcomes, workforce capacity and capability, research and technology.

It is important to acknowledge that no one element sits in isolation, rather elements are mutually dependent to improve the patient journey and achieve the desired outcomes.

Figure 1: An overview of the NSW Health system of care for children, young people and families in the context of this Review



Different perspectives and identified issues

This report attempts to present the broad views, perspectives and issues raised by stakeholders. For some interviewees, their focus was care of children in hospitals either in LHDs or in the SCHN; for some it was the care of newborns in SCNs and NICUs; for some it was child protection; for some it was child development; for some it was disability; for some it was behaviour disorders; for some it was mental health; for some it was young people.

The Reviewer identified a vast array of issues that were seen as the problem to be solved. The most common piece of data quoted to the Reviewer was that *'80% of Emergency Department (ED) presentations occur outside the SCHN'*. This was usually a segue into a comment that the attention needed to focus on the whole system of health services for children, young people and families and not just the tertiary services.

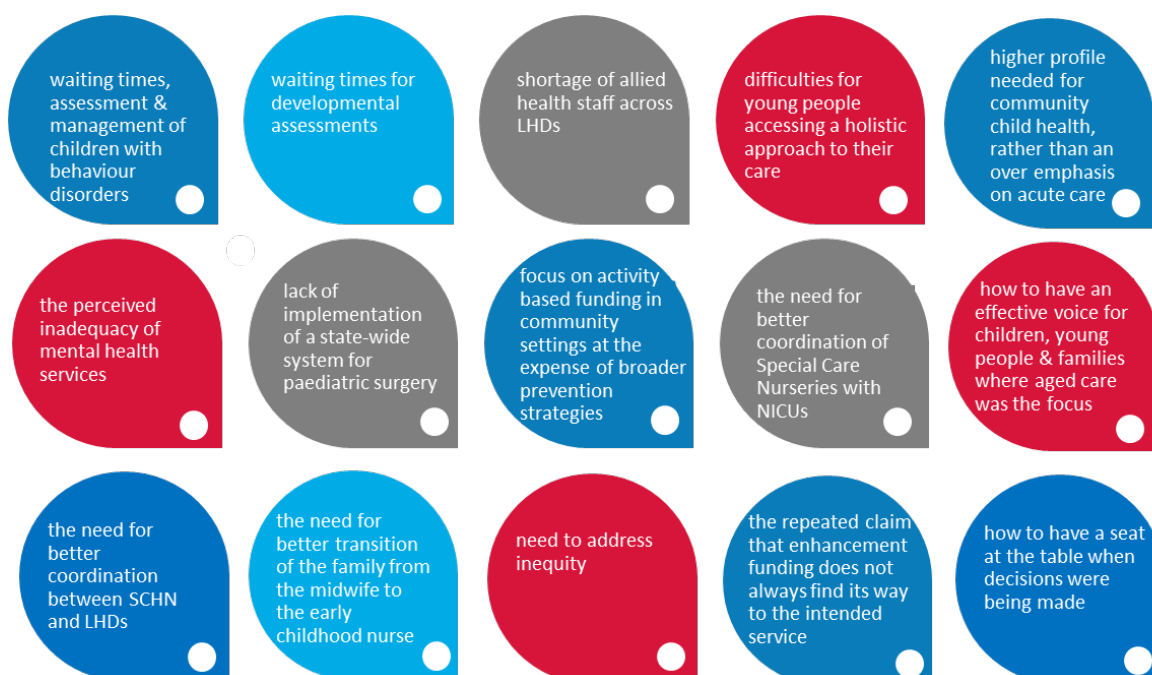
Identified issues can be summarised in six main categories:

- 1. Lack of clarity about decision making.** Although there were groups referred to as networks, committees with names that suggested specific functions and individuals with titles that suggested particular responsibilities, it was often unclear as to whether these individuals or groups had any authority to make decisions or any mechanisms to escalate issues.

2. **Challenges in implementation, measurement and monitoring of outcomes.** Excellent frameworks had been developed, such as Surgery for Children in Metropolitan Sydney Strategic Framework (2014) and the NSW Paediatric Service Capability Framework (2017) but these had not been implemented across LHDs.
3. **Perceived lack of integration of hospital and community paediatrics and child health.** Some LHDs had addressed this well, with portfolios with names like Kids and Families with responsibility to address the whole spectrum of care for children, young people and their families. Across the system, including the MOH and the pillars, narrow silos predominated.
4. **Limited, short term funding of new initiatives,** without clear mechanisms in place to ensure that there was ongoing funding of and widespread implementation of successful pilot programs. This seemed to be a problem for support projects for indigenous children and their families but was identified as a recurrent theme across the health system. The lack of either short or long term funding for implementation of the First 2000 Days Framework leaves serious questions about how it can fulfil its potential. All the evidence tells us that it should be a high priority.
5. **Models of care.** Issues related to models of care were twofold relating to the requirement for more resources to meet unmet demand and the requirement for service redesign to manage demand more effectively. The management of behaviour disorders, the approach to developmental assessments and the management of mental health issues are unlikely to be solved by attempting to scale up the services that are currently provided. For example, many LHDs have ongoing requests from their child health services for extra paediatricians who will address the currently unmet demand for assessing and managing children with behaviour disorders. Other LHDs have recognised to need to explore different approaches to the treatment model. One clinician indicated the need for a randomised controlled trial of service delivery mechanisms for children with behaviour disorders.
6. **Mental health.** In the general community, people talk about physical health and mental health. The mental health approach for children, young people and families in NSW was characterised by interviewees as addressing mental health issues of people with moderate to severe psychosis, rather than broader mental health. There was a turf war, not to claim territory but to indicate that a large segment of territory was not within scope for mental health services. Once again, meaningful solutions that benefit children, young people or families need to consider underlying assumptions about models of care. Strong partnerships with primary care to manage lower acuity mental health issues are essential.

More specific issues raised are illustrated in Figure 2 below.

Figure 2: Issues raised during the Review



Recommendations

The recommendations provide strategic advice to the Secretary, NSW Health about the delivery of services for children, young people and families in the NSW Health system for which there is good evidence, widespread support and clearly viable opportunities for improvement.

Seventy-seven recommendations have been identified and are presented in Table 1. These recommendations have been grouped in to short, medium and long term recommendations for implementation. There are:

- 34 short term recommendations to be addressed with 12 months
- 33 medium term recommendations to be addressed within 1 – 2 years
- 10 long term recommendations to be addressed within 5 years.

Table 1: Short, medium and long term recommendations

Short term recommendations within 12 months	Medium term recommendations within 1-2 years	Long term recommendations within 5 years
<p>Recommendation 1: The development of every framework be accompanied by an implementation plan, by outcome measures and by monitoring of both implementation and outcomes.</p> <p>Recommendation 2: The implementation of the Paediatric Service Capability Framework be incorporated as a key performance indicator in the Service Level Agreement of each LHD.</p> <p>Recommendation 3: The Chief Paediatrician work with each LHD to support implementation of the Paediatric Service Capability Framework.</p> <p>Recommendation 4: An annual report be made to the Deputy Secretary Health System Strategy and Planning via the Executive Director Health and Social Policy on the strengths, vulnerabilities and opportunities in the implementation of the Paediatric Service Capability Plan for each LHD.</p> <p>Recommendation 5: The role of the Chief Paediatrician be expanded to include a broad overview of paediatrics and child health. This would make it clear that the Chief Paediatrician has a role in working with others to improve healthcare in areas including (but not limited to) assessment and management of community paediatric issues such as behaviour disorders, developmental delay, as well as long term vital initiatives, for example the First 2000 Days.</p> <p>Recommendation 6: The current situation be clarified and reinforced that SCHN is not be responsible for overall governance of paediatrics across NSW. In parallel, SCHN should not be held responsible for failure of implementation for matters for which it has neither authority nor budget.</p> <p>Recommendation 9: The current NSW Paediatric Executive Steering Group be reconfigured to function as the peak decision-making committee across child, young people and family services in NSW to oversee new models of care, development of standardised guidelines and processes,</p>	<p>Recommendation 7: Although LHDs have flexibility about how paediatric objectives are achieved, they should not have flexibility about whether paediatric objectives are achieved. NSW Health requires a system that monitors the achievement of paediatric objectives across all LHDs.</p> <p>Recommendation 8: The MOH recognise that some paediatric decisions (outside the scope of those classified as supra-regional specialities) need to be considered across LHDs and the SCHN. These decisions should be referred to the NSW Paediatrics Executive Steering Committee for discussion and resolution.</p> <p>Recommendation 16: All committees develop clear terms of reference that are updated at least biennially and include a clear purpose and functions, reporting lines and measures of effectiveness to periodically evaluate performance. Children’s healthcare networks</p> <p>Recommendation 17: The Children’s Healthcare Network Northern region be expanded to include the Central Coast LHD.</p> <p>Recommendation 18: Future subspecialty paediatric appointments to HNELHD consider a fractional component shared with CCLHD.</p> <p>Recommendation 19: Future subspecialty appointments to the SCHN be shared with an MP4 or RP4 Hospital.</p> <p>Recommendation 21: Each LHD appoint a Medical Lead in paediatrics. In some LHDs, there will be a co-lead from nursing and in some cases the leadership will be across both paediatrics and child health. The overarching aims and functions of the role are described in the Framework.</p> <p>Recommendation 24: Increase the clarity of protocols for consistent access to appropriate transport for sick children to higher level services and return transfers to local facilities. This will require engagement with NETS and NSW Ambulance.</p> <p>Recommendation 25: Develop and implement protocols for reliable access to</p>	<p>Recommendation 20: A long term approach be considered for the Sydney Children’s Healthcare Network Western and Southern regions to be combined in a sector linked to SCHN. An early priority be cross credentialing of staff involved in outreach activities.</p> <p>Recommendation 22: The on-call roster for a level 4 paediatric facility be no more onerous than 1 in 4. The usual way to achieve this will be through a minimum of 5 paediatricians on the roster.</p> <p>Recommendation 28: The Surgery for Children in Metropolitan Sydney Strategic Framework (2014) be implemented, measured and monitored.</p> <p>Recommendation 32: Hospital planning recognise the need to construct facilities to enable the operation of multidisciplinary clinics for children and young people.</p> <p>Recommendation 49: The Ministry of Health recognise that the demand for allied health services for children, young people and families far exceeds supply and adopts a long term strategy to address the staff shortages. Targets for investment include initiatives for the First 2000 Days, for mental health and for interventions for domestic violence.</p> <p>Recommendation 58: A group of clinicians experienced in management of children with ADHD consider whether a trial should be conducted to compare different service delivery mechanisms of care for assessment and management of ADHD.</p> <p>Recommendation 59: The Ministry of Health support RACP tier 1 and 2 training requirements in AYAM in all general paediatricians/community child health/behavioural paediatricians.</p> <p>Recommendation 60: The Ministry of Health build capacity among the AYAM workforce through funding of advanced training opportunities in adolescent medicine at the specialist children’s hospitals and in metropolitan, rural and regional locations with appropriate supervisory arrangements.</p> <p>Recommendation 68: The MOH recognise that the demand for allied health</p>

<p>statewide policy and planning, and monitoring of outcomes. Community representatives should be part of the membership.</p> <p>Recommendation 10: The Chief Paediatrician be given a key role in taking advice from MOH, LHDs and SCHN about the best way forward for paediatric decisions that need to be considered across LHDs and SCHN.</p> <p>Recommendation 11: The Chief Paediatrician present the issues, options, and any recommendations, to the NSW Paediatric Executive Steering Committee.</p> <p>Recommendation 12: The NSW Paediatric Executive Steering Committee consider and agree recommendations from the Chief Paediatrician and escalate committee decisions to the Deputy Secretary Health System Strategy and Planning.</p> <p>Recommendation 13: The Deputy Secretary Health System Strategy and Planning present relevant committee decisions to the senior executive team for approval.</p> <p>Recommendation 14: Relevant decisions from ACI or from CEC be referred to the NSW Paediatric Executive Steering Committee for advice and subsequent approval by the senior executive team (in line with the process outlined in recommendations 12 and 13 above).</p> <p>Recommendation 15: Existing systems and processes for communication and transfer of information between and across committees/networks, system managers and operational managers be refined to support efficient information flows to support decision making, implementation and monitoring.</p> <p>Recommendation 23: Level 4 paediatric facilities have an essential role in providing both acute and non-acute outpatient services. This might encompass activities such as offering care in the home. The responsibilities of paediatricians reflect this broad role, rather than a more limited focus on acute inpatient care.</p> <p>Recommendation 29: Innovation funding be provided by the Paediatric Healthcare Team to LHDs for 2 years of funding of Care Navigator positions, conditional upon LHDs providing ongoing funding after the initial funding period provided that pre-determined agreed outcomes are achieved.</p> <p>Recommendation 30: LHDs provide funding for nurses to attend APLS and PLS training courses.</p> <p>Recommendation 33: LHDs implement the requirements for child friendly and child safe health facilities.</p> <p>Recommendation 34: The Secretary of Health makes it clear that both CHW and SCH will be comprehensive specialist children's hospitals with tertiary and quaternary services on each site.</p>	<p>appropriate transport for children who need to be seen at a specialist children's hospital.</p> <p>Recommendation 26: In order to facilitate outreach clinics to rural areas, a reverse IPTAAS scheme be developed, where the cost of sending health care workers to a rural centre be funded, analogous to patients and their families being funded for the costs of travelling to a tertiary centre for assessment and care.</p> <p>Recommendation 27: Clinicians and administrators develop and implement agreed guidelines for the safe use of telemedicine in the treatment of children with acute and chronic medical problems to avoid the need for transfer.</p> <p>Recommendation 31: LHDs and SCHN implement systems for nurses to be upskilled by working in more complex clinical environments and by use of outreach education.</p> <p>Recommendation 43: In addition to the model of tiered neonatal networks, the plans for future governance need to provide coordination across the whole system to connect NICUs and SCNs.</p> <p>Recommendation 44: The plans for future governance need to ensure that back transfers from NICUs to SCNs are managed across the whole system</p> <p>Recommendation 45: Training and upskilling of staff caring for newborns in both SCNs and NICUs requires a statewide approach.</p> <p>Recommendation 46: The plans for future governance need to focus on the interfaces which can be problematic in the current system, such as interfaces between midwife and child and family nurse, obstetric services and general practice, and between neonatal services and specialist paediatric services in children's hospitals and LHDs.</p> <p>Recommendation 48: Each LHD ensure an effective handover of the family from the midwife to both the child and family health nurse and the general practitioner.</p> <p>Recommendation 50: The Ministry of Health works with specialist children's hospitals and LHDs to better coordinate paediatric rehabilitation services across NSW.</p> <p>Recommendation 52: ACI undertake a project to determine the most efficient and effective way both to perform developmental assessment and to focus on increasing the capacity of families to adjust to and optimise management of their child's disability.</p> <p>Recommendation 53: MOH initiate interagency discussions with areas such as Education and NDIS to clarify and simplify the assessment and information required for eligibility for services to support children with developmental needs.</p> <p>Recommendation 55: The Ministry of Health works with the specialist children's hospitals and LHDs to better coordinate paediatric clinical forensic services across NSW. One component is that reports relating to alleged physical assault should</p>	<p>professional services in mental health far exceeds current supply and develops a targeted strategy to address the issue.</p> <p>Recommendation 73: The Ministry of Health engage with Faculties of Health and Medicine and other educational bodies to ensure that the broad medical, nursing and allied health curricula recognise the lifelong importance of the first 2000 Days for the physical, cognitive, social and emotional health of the population.</p>
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<p>Recommendation 35: The Paediatric Intensive Care Units at CHW and SCH operate as a single service on 2 sites.</p> <p>Recommendation 36: NETS transfers ensure that SCH receives a similar mix of the sickest children as CHW.</p> <p>Recommendation 37: The Sydney Children's Hospital and the Children's Hospital Westmead remain in the SCHN.</p> <p>Recommendation 38: The Chief Executive and the Board of the SCHN be made accountable for ensuring that these recommendations are implemented within 12 months.</p> <p>Recommendation 39: The Chief Executive and Board of SCHN develop and implement a plan to increase cooperation between the two campuses. This will include acknowledging the cultural differences between the two hospitals.</p> <p>Recommendation 40: The MOH convenes a meeting between key staff at SCHN and SESLHD to decide the principles and details of the costs of shared services at the Randwick campus. The resolution of these longstanding contentious issues will help to ensure that the focus of discussions between SCHN and SESLHD is around improving patient care, rather than who pays what share of the cost of delivering services.</p> <p>Recommendation 41: Future enhancement funding be directed to areas where there is clear evidence of, and ongoing commitment to meaningful shared services between CHW and SCH, or shared services between SCHN and at least one LHD. This would include but not be limited to fractional appointments on more than one site. Cardiac services may need to develop in parallel due to irreconcilable conflict between CHW and SCH.</p> <p>Recommendation 42: The Chief Executive and the Board of SCHN develop a new strategic plan that includes a vision, a strategy and an implementation plan for both CHW and SCH, as well as NETS, Poisons Information Centre, and the Western and Southern sectors of the CHN.</p> <p>Recommendation 47: Universal Home Health Visiting continue to be promoted, together with identification of those who need further visits.</p> <p>Recommendation 51: Intake systems for diagnostic assessment services should determine whether a detailed assessment is what is required. In particular, if a functional assessment for NDIS purposes is needed, a general paediatrician would be able to provide the report.</p> <p>Recommendation 54: The commitment to screening for domestic violence be accompanied by resources to assist women and their children.</p> <p>Recommendation 56: Pilot studies across NSW implement ways for general practitioners to write repeat prescriptions for stimulant medication for ADHD.</p> <p>Recommendation 64: The Patient Reported Experience Measure (PREM) be modified so that both parents and young people can provide feedback, rather than one or the other.</p>	<p>not be submitted until they have been peer reviewed.</p> <p>Recommendation 57: If pilot studies are successful, general practitioners be allowed to receive prior general approval (known as Patient-Class Approval) to write repeat prescriptions for stimulant medication for ADHD.</p> <p>Recommendation 61: The Ministry of Health work with relevant groups to develop training pathways and competency frameworks for clinical nurse consultants in AYAM, through dedicated clinical qualifications that provide more breadth and depth than the existing workshops and resources.</p> <p>Recommendation 62: LHDs and SCHN provide dedicated training opportunities and ongoing support for nurses in adolescent inpatient and outpatient units and youth health centres.</p> <p>Recommendation 63: The Ministry of Health work with primary health providers to identify opportunities for training and ongoing support for those working with young people.</p> <p>Recommendation 66: Training programs be developed to provide paediatricians with a minimum standard of capability and qualifications to safely care for children and young people with acute behavioural disorders and with mental illness.</p> <p>Recommendation 67: Training programs be developed for paediatric nurses to provide qualifications for managing children and young people with acute behavioural disorders and with mental illness.</p> <p>Recommendation 69: This Review welcomes the findings in the Draft Report from the Productivity Commission on Mental Health and commends the Draft Report to the MOH. One area to highlight is the need for early intervention in young people diagnosed with psychosis.</p> <p>Recommendation 70: The MOH supports projects implementing and evaluating models of care increasing the skills of GPs in managing complex behavioural and mental health problems in children.</p> <p>Recommendation 74: NSW Ministry of Health develop robust key performance indicators and outcome measures using a similar template to the State of Child Health Report 2017 from the Royal College of Paediatrics and Child Health, United Kingdom. Part of this process should be a data mapping exercise to identify both what is required and what is currently available.</p> <p>Recommendation 75: The Australian Early Development Census (AEDC) be used as a key outcome measure of the First 2000 Days.</p> <p>Recommendation 76: HbA1c levels in children and young people with type 1 diabetes be used as a key outcome measure in LHDs and SCHN.</p> <p>Recommendation 77: NSW Ministry of Health adopt a survey such as the Middle Years Development Index as a key measure of health, development and well-being of adolescents and guide</p>	
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<p>Recommendation 65: The Ministry of Health oversees meaningful engagement between health care providers who are both inside and outside the mental health system to develop and implement a collaborative approach to addressing both mental health and the mental illness needs of children and young people</p> <p>Recommendation 71: Health and Social Policy Branch in the MOH continue to develop the opportunities for The Centre for Population Health/Public Health Units and Primary Health Networks to engage fully with implementation of the First 2000 Days.</p> <p>Recommendation 72: The Secretary, NSW Health engages with Secretaries of the Departments such as Education and Communities and Justice to ensure high level cooperation and accountability across sectors responsibility for successful implementation of the First 2000 Days.</p>	<p>comprehensive approaches to intervention programs.</p>	
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Concluding remarks

To implement and realise sustainable change for the system and children, young people and families in NSW, it is vital that all stakeholders work together to achieve success. Services should not be competing with each other to keep or lose essential services. Equally services need to accept responsibility for helping to provide care from prevention, through community services to inpatient care, so that children, young people and families can receive the right care in the right place at the right time.

Section 1: Review background and approach

Introduction

The design and delivery of high quality, effective and safe health care services for children, young people and families, from conception until 24 years of age is a key priority for the NSW health system.

Following the 2011 governance review of NSW Health and more recent organisational changes there have been changes in the overall governance of services for children, young people and families.

As system manager, the Ministry of Health sets the policy direction, allocates resources and monitors performance across the system. Local health districts (LHDs) and specialty health networks (SHNs) provide services to meet the needs of their local community. They are supported by the Agency for Clinical Innovation (ACI) and the Clinical Excellence Commission (CEC) which provide guidance across a range of areas including standardisation of care, new models of care, supporting improved clinical care and safety and quality.

Review Terms of Reference

In February 2019, Minister Hazzard announced an independent review of paediatric services. Following consultation with key internal stakeholders it was proposed that the review focus on governance and the strategic delivery of health services to children, young people and families from conception until 24 years of age (referred to in this document as 'this Review').

The purpose of this Review is to provide strategic advice and recommendations to the Secretary, NSW Health about the current status of delivery of services for children, young people and families in the NSW Health system and areas for improvement.

This includes:

- how current services are delivered, noting any changes in clinical evidence that may provide an opportunity to identify new directions for system-wide activity.
- current governance arrangements in place in NSW Health to ensure they are sufficient to deliver evidence-based outcomes for children, young people and families across NSW.
- an assessment of how health services and partners are working together to achieve the shared goal of delivering healthcare in NSW that is safe, effective, integrated, high quality and continuously improving.
- the integration of care into the community including linkages with the primary health care sector.

The Children, Young People and Families Steering Committee were responsible for oversight of this Review. Refer to Appendix 1 for the Review Terms of Reference and Appendix 2 for the list of membership of the Steering Committee.

Review approach

The key findings of this review are based on a range of activities including key stakeholder consultations, site visits to local health districts, review of available data and documentation.

Over 250 stakeholder consultations were undertaken providing opportunity for input from all relevant organisations and individuals including: the NSW Ministry of Health and Pillars, local health districts, Sydney Children's Hospital Network, relevant discipline specific groups, non-government organisations and the consumers and families of NSW health services. Refer to Appendix 3 for the individual stakeholder consultation, group consultation and submissions list.

Section 2: Children, young people and families in a broader review context

Strategic alignment

The annual NSW Health Strategic Priorities 2019-20 outline how NSW Health work together to achieve its core objectives. It builds on and complements the State Health Plan: Towards 2021 as well as directly aligning with the NSW State and Premier's Priorities.

The Secretary's priorities as articulated in the NSW Health Strategic Priorities 2019-20 include:

- Patient safety and experience
- Value based health care
- Systems integration
- Digital health and analytics
- Strengthening governance and accountability.

The eight Strategic Priorities are aligned to the strategies of the State Health Plan, these include:

- Keep people healthy
- Provide world class clinical care where safety is first
- Integrate systems to deliver truly connected care
- Develop and support our people and culture
- Support and harness health and medical research and innovation
- Enable eHealth, health information and data analytics
- Deliver infrastructure for impact and transformation
- Build financial stability and robust governance.

Additionally, it is important to note that there is other work that staff undertake that is not specifically listed in the Strategic Priorities document but is equally important and reflects the need for good data systems and processes.

Value based health care

Value based health care is central to the provision of high quality and effective health care services for children, young people and families in NSW. There are significant opportunities to deliver value based health care and more closely align services for children, young people and families with this Secretary's priority. The objective of value based healthcare is to improve health outcomes that matter to patients by evolving how we receive and provide care. This will be achieved with a focus on delivering and measuring health outcomes and using insights to further inform expenditure, clinical models, and the experience of receiving and giving care.

Value based healthcare in NSW means delivering services that improve:

- the health outcomes that matter to patients
- the experience of receiving care
- the experience of providing care
- the effectiveness and efficiency of care.

Healthy, Safe and Well

In November 2014, the now disbanded NSW Kids and Families released a document, Healthy, Safe and Well, which is a strategic health plan for children, young people and families from 2014-2024. The status of this strategic plan in 2019 was unclear. It remains on the NSW Health website and was referred to by staff in the MOH and in the pillars, CEC and ACI. Staff in LHDs and SCHN did not regard it as a current strategy with an accompanying implementation plan. On the other hand, the life journey approach adopted in the document has been accepted widely and the underlying concepts have been incorporated in frameworks such as the First 2000 Days, the Paediatric Service Capability Framework and the NSW Youth Health Framework.

Recent reviews

In recent times there have been several other reviews that are relevant to this Review. All reviews occur in a context. Recent reviews include:

- **September 2018 Review of cardiac services across the Sydney Children's Hospital Network (unpublished).** A Cardiac Planning Steering Committee was established by the Chief Executive Officer of SCHN, with the remit to provide Executive with information on current cardiac services and in particular the barriers and issues associated with a 'one service, two-site' model for cardiac services.
- **April 2019 NSW Auditor General's Report on Governance of Local Health Districts.** This audit assessed the efficiency and effectiveness of the governance arrangements for LHDs. Recommendations focussed on decision making, principles of good governance and accountability and oversight mechanisms.
- **June 2019 Review of Governance for the Sydney Children's Hospital Network** conducted by Dr Kathy Alexander, Dr Peter Steer and Ms Sue Peter. The Alexander Review made some recommendations about the broader governance of health services for children and young people and for the need for "a clearly articulated strategy for paediatrics in NSW". The Reviewer was asked to address those recommendations.
- **December 2019 Review of health services for children, young people and families in the NSW Health System (this Review)** was conducted between July and December 2019. This Review was not a review of obstetric services. However, the critical interface between obstetric services and paediatric and child health services and the linkages between maternal health services and outcomes for children, such as the First 2000 Days Framework, necessitated some consideration of maternal health services.

Service for children, young people and families in NSW

The NSW Health system for the delivery of service to children and young people covers a large geographical area and includes multiple and diverse health facilities across metropolitan, regional, rural and remote regions. Within this system, the majority of paediatric acute care is delivered by facilities that are located away from the State's three specialist children's hospitals. Local Health Districts are responsible for determining the paediatric service capability level of their facilities, taking into account the clinical support services available. This is a complex and diverse network of services with many interdependent parts.

The Sydney Children's Hospital Network

- The Children's Hospital at Westmead (CHW) was relocated from Camperdown to Westmead in 1995. The hospital was established as its own area health service at that time and was purpose built for paediatric services. The now Sydney Children's Hospital Randwick (SCH-R or SCH) was originally part of the Prince of Wales Hospital (PoWH) and became an independent children's hospital in 1998 and was then part of the South East Sydney Area Health Service.
- In 2012, the CHW and SCH (along with some other state-wide paediatric services) integrated to form the SCHN.
- Together, CHW (including Bear Cottage) and SCH Randwick care for 151,000 sick children every year. In 2016-17 there was a total of 104,184 bed days at CHW and 49,135 bed days at SCH. CHW saw 57,676 ED presentations, while SCH saw 36,848 ED presentations.
- Non-admitted patient services across SCHN in 2017-18 were 863,114.

John Hunter Children's Hospital

- John Hunter Children's Hospital (JHCH) is a specialised tertiary referral paediatric hospital in Newcastle, providing complex medical, surgical, major trauma and neonatal care services for northern NSW.
- The Children's Hospital in Newcastle, one of three children's hospitals in NSW, will over the course of a year see almost 25,000 children and young people present to the emergency department, have 9,000 admitted to hospital and perform over 100,000 occasions of service through outpatient clinics.

Paediatric and neonatal intensive care services

Paediatric and neonatal intensive care services are identified as Supra-LHD services in the NSW Health Service Agreements. Responsibility for the planning of Supra-LHD services sits with the Ministry because of their state-wide role. SCNs are considered in the planning for NICU services due to their role in accepting back transfers within their tiered maternity and neonatal network. Other supra LHD services that are high cost and low volume include (but are not limited to) transplant, high risk maternity, burns and spinal cord injury services.

Maternity and neonatal services in NSW (and ACT)

There are more than 70 maternity services across NSW ranging from levels 1 (lowest) to 6 (highest)². Seven of these are co-located with a level 6 maternity service (refer Figure 3) and 2 are located within the SCHN.

Neonatal Intensive Care & Special Care Nurseries

The NSW birth rate has been stable for the past 10 years. The rate of admission to NICU appears to vary across NSW. Based on data on NICU stays across NSW public facilities from 2013-14 to 2015-16:

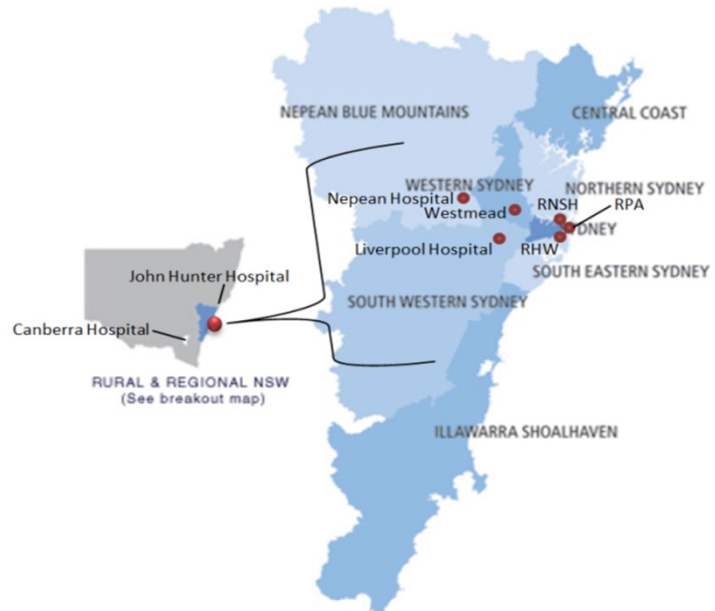
- 8% of babies were discharged directly from NICU
- 17% of all babies were stepped down to a different facility (of which 42% transferred to SCN in another facility, 58% transferred to a non-SCN unit).

There appears to be variability in the utilisation of SCN across the state, depending on a range of local and network factors.

Paediatric Intensive Care

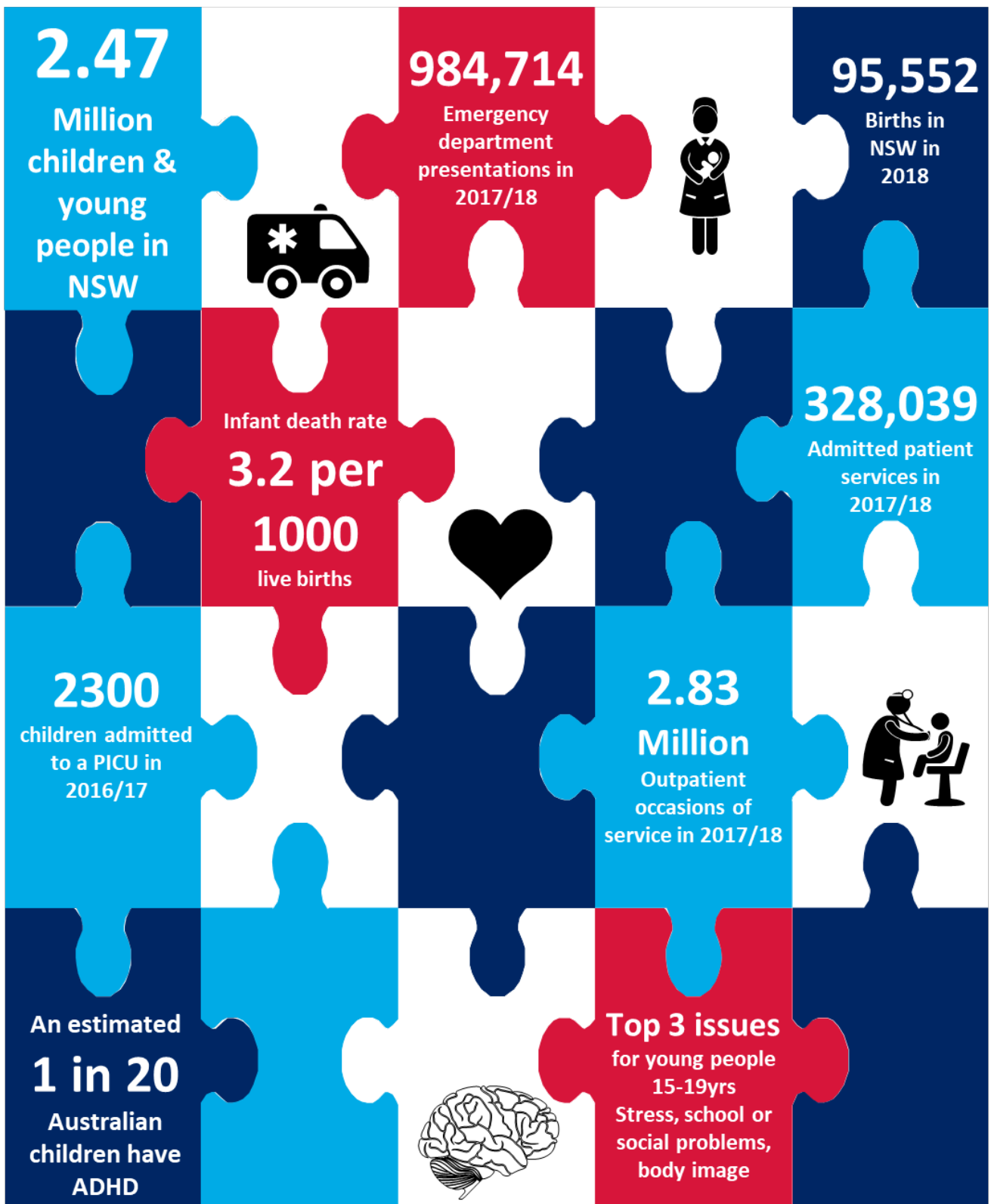
There are currently three paediatric intensive care units across NSW located at Children's Hospital Westmead, the Sydney Children's Hospital, Randwick (both managed by SCHN) and John Hunter Children's Hospital (managed by HNELHD). In 2016-17 only 1.9% of children admitted to hospital in NSW required access to paediatric intensive care services. This equated to 2,300 admissions to the three PICUs in NSW. 5% of paediatric ICU admissions occur outside the three PICUs. Between 2007 and 2017, half of all PICU episodes occurred at the Children's Hospital Westmead; around one third occurred at Sydney Children's Hospital; the remaining 10% occurred at John Hunter Children's Hospital.

Figure 3: location of NICUs in NSW



² NSW Health Role Delineation of Clinical Service provides a consistent language across NSW for describing clinical services and is a planning tool used in service and capital developments, it describes the minimum support services, workforce and other requirements for the safe delivery of clinical services

Snapshot of children and young people in NSW



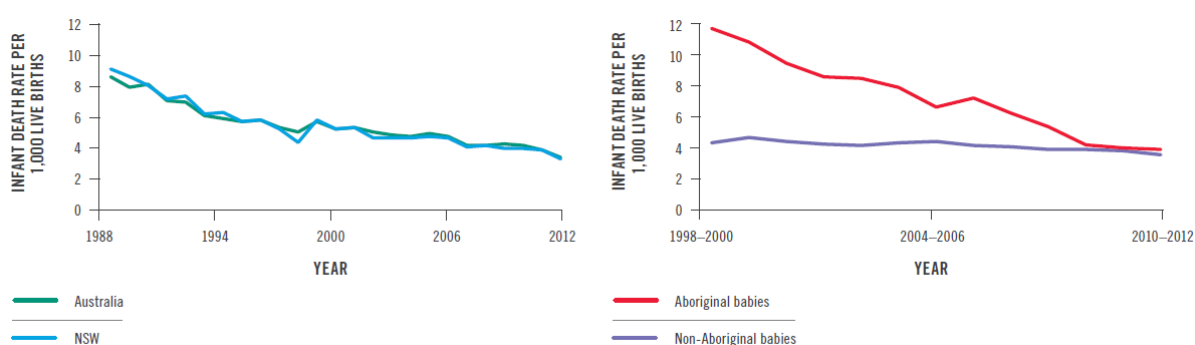
The total population of NSW in 2017 was 7,861,068, with children and youth comprising 31.5% of the population (2,474,337). In 2018, there were 95,552 births in NSW.

Current state services 2017-18	SCHN	All NSW public health services (excl SCHN)
Number of admitted patient services	49,790	278,249
Number of ED attendances	95,739	888,975
Number of non-admitted patient occasions of service	863,114	2,831,193
Number of ICU beds	CHW: NICU beds – 23 PICU beds – 22 SCH: CICU beds – 13 NICU beds – 4	JHH: NICU beds- 19 PICU beds – 4 Other NICU beds across NSW and ACT

Improvements in infant mortality

In late 1914 and early 1915, the first public services providing child and family health care to NSW children and their families opened their doors. The first Baby Health Centre opened in Alexandria in 1914, followed by Newtown and Darlinghurst. In addition, 20 bush nurses were funded in rural NSW by the Department of Public Health. At that time, more than 100 out of every 1000 children born alive died before their first birthday. A century later, the Chief Medical Officer presented the 2014 report³, The Health of Children and Young People in NSW, in which the 2012 infant mortality rate was 3.2 per 1000 live births. These enormous improvements are due to multiple factors, including raised living standards, better hygiene with clean water and sanitation, improved nutrition and high uptakes of immunisation. Infant death rates fell significantly between 1988 and 2012, from 9.2 to 3.2 per thousand live births. Maternal factors such as nutrition, health behaviours and access to medical treatment, the impact of neonatal care units and population health interventions such as sleeping position for infants to prevent sudden unexpected deaths in infancy have all contributed to the improvements. The gap in infant mortality rates between Aboriginal and non-Aboriginal infants has also closed in this period, although it is too early to claim complete success.

Figure 4: Trends in infant death rates, NSW



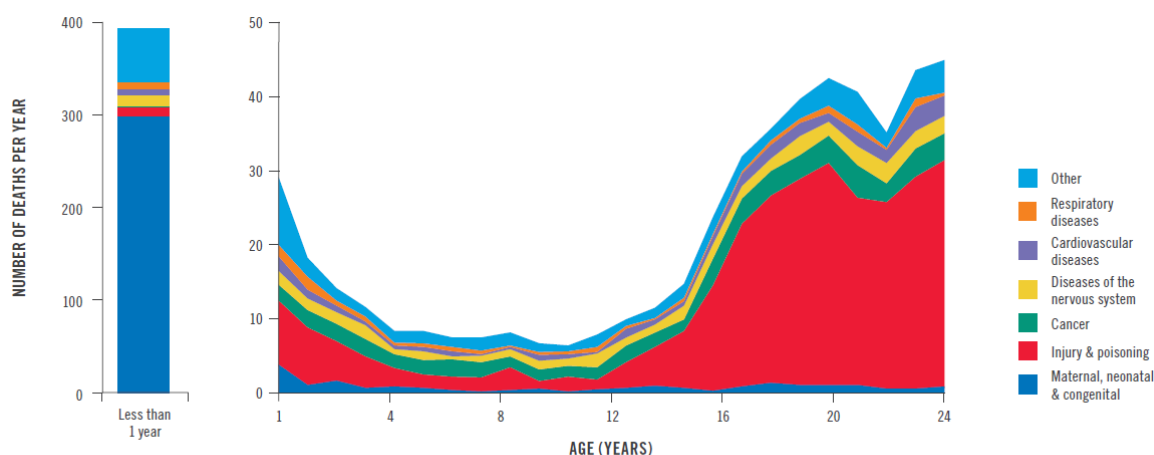
Source: ABS Deaths, Australia, 2012²⁶

Causes of death in children and young people

Death rates and leading causes of death continue to be important data sets. Figure 5 extracted from the Health of Children and Young People is reproduced here to show the numbers and leading causes of death in NSW from 2001-2011.

³ <https://www.health.nsw.gov.au/epidemiology/Publications/2014-cho-report.pdf>

Figure 5: Leading causes of death, NSW, 2002-2011



Source: Australian Coordinating Registry Cause of Death Unit Record File

Data was made available to the Reviewer for 2013-2017 combined. Both datasets show that the first year of life has the highest mortality, with the leading classification of death referred to as factors related to birth, complications in the neonatal period or congenital disease. Injuries and poisoning were the leading causes of death in children aged 1-14 years and young people aged 15-24. However, the nature of these were very different. In children aged 0-4 years, drowning contributed to almost one-third of injury and poisoning deaths, whereas motor vehicle accidents and suicides contributed to over half of all injury deaths in young people. Cancers were the second leading cause of death from 1-24 years.

Causes of admission to hospital in children and young people

In 2012-2013, the main causes of hospitalisation in children were infections and respiratory conditions, especially asthma and ear, nose and throat infections. In young people the leading cause of hospitalisation was mental health problems. Long term trends show a decrease in the importance of infections such as gastroenteritis and admissions due to asthma.

ADHD prevalence

Clinicians often talk about the new morbidity. In part this is reflected in common conditions, such as ADHD, seen in the community. In June 2015, the Drug Utilisation Sub-Committee (DUSC) reviewed the utilisation of PBS-listed medicines in the management of attention deficit hyperactivity disorder (ADHD). During the five year period 2010-2014, the number of patients treated with PBS medicines for ADHD rose steadily, with an annual increase of 5-8% and a 5 year growth rate of 31%. The rates of treatment in school-aged children are highest in ACT, NSW and Queensland.

The reported prevalence of ADHD is variable and may be influenced by the diagnostic criteria used. In the United Kingdom, the prevalence in school aged children and adolescence is between 3 and 9%. Kids Health Info from the Royal Children’s Hospital Melbourne indicates that it is estimated that one in 20 Australian children have ADHD. About one to two percent of Australian children are prescribed stimulant medication.

Health and wellbeing issues for young people

Approximately one third of Australia’s young people live in NSW. Twelve to 24 year olds make up 16.5% of the NSW population.

Young people experience a range of health and wellbeing issues that are distinct from those of younger children and the adult population. The NSW Youth Health Framework 2017-2024⁴ reports data from Mission Australia showing the top issues of personal concern for young people aged 15-19 in NSW, as per Figure 6 below.

Figure 6: Top issues of personal concern for young people aged 15-19 in NSW 2016

TOP ISSUES OF PERSONAL CONCERN FOR YOUNG PEOPLE AGED 15-19 IN NSW 2016¹⁷

ISSUE OF PERSONAL CONCERN	EXTREMELY CONCERNED OR VERY CONCERNED (%)
COPING WITH STRESS	44.5
SCHOOL OR STUDY PROBLEMS	39.9
BODY IMAGE	30.6
DEPRESSION	23.6
FAMILY CONFLICT	23.5
PERSONAL SAFETY	19.9
BULLYING/EMOTIONAL ABUSE	16.1
DISCRIMINATION	14.3
SUICIDE	13.4
DRUGS	8.9
ALCOHOL	6.8
GAMBLING	4.4

SOURCE: MISSION AUSTRALIA.

Prevalence of mental health

Mental health concerns are the predominant contributor to the burden of disease for young people. Depression, anxiety, behaviour disorders, eating disorders, self-harm and early psychosis are all important issues. Suicide is the leading cause of death among young people. Young people with complex mental health problems often have co-morbid health and psychosocial issues that need to be addressed, including substance abuse, homelessness, smoking and obesity. Further data about the health and wellbeing of young people in NSW is presented in section 11 of this report.

Inequalities in health of children and young people

Aboriginal and Torres Strait Islander children and young people have historically had worse health than non-indigenous children and young people, although the gap has narrowed for many indices. There are other disadvantaged groups and many key markers of risks for poorer health, such as overweight and obesity, smoking, drug and alcohol abuse and poor oral health are all more common in lower socioeconomic groups and other disadvantaged groups. Adverse childhood experiences, in particular, multiple adverse childhood experiences, also compound disadvantage. The SCHN Aboriginal Health Strategic Plan 2018-2021⁵ provides a broad overview:

“The social and cultural determinants of health are those factors that influence health status, risk of disease or vulnerability to disease, or injury amongst individuals and population groups. These factors include: education, employment, housing, and importantly, the consequences of colonisation – which have had a devastating impact on the social, economic and physical living conditions of Aboriginal people for over 200 years. The effects of racism experienced by Aboriginal people contributes to poorer mental and physical health and should therefore also be considered a social determinant of health. These factors directly contribute to the health disparities experienced by many Aboriginal people.”

⁴ NSW Youth Health Framework 2017-2024

⁵ SCHN Aboriginal Health Strategic Plan 2018-2021


Furthermore, a growing body of research has demonstrated that optimising child health and development has positive long-term benefits not only on future morbidity and mortality but also on educational and employment outcomes. Responsive parenting, healthy nutrition, quality early childhood education and developmentally appropriate psychosocial stimulation have powerful protective benefits which can off-set the adverse effects of early disadvantage.

Taken together, the NSW Health strategic priorities, previous Reviews and available data have informed the current state and provided the context of this Review. The key findings and recommendations for the future of child, young people and family health services in NSW as outlined in this report, are intrinsically linked to the current state and the complex environment in which we operate.

Section 3: Good practice examples

All Reviews of this type run the risk of focussing entirely on the deficiencies of the system and of failing to acknowledge the positives. The Reviewer had the privilege to talk to many highly motivated, talented and committed clinicians and administrators working tirelessly to deliver the best possible outcomes for children, young people and families. Overall the quality of care is very high, even if some people see this as despite the system, rather than facilitated by it.

Staff are passionate about what they do. The tables below share some of the good practice examples identified during this Review.

 **GOOD PRACTICE EXAMPLES**

<ul style="list-style-type: none">• First 2000 Days Framework <i>One senior administrator told me that she had burst into tears of joy when she realised that the Framework document for the First 2000 Days could change the lives of so many children.</i>• Successful family intervention <i>A nurse administrator in a regional LHD told me about a family intervention with a young baby and the Aboriginal father. He had a history of drug and alcohol abuse and was a single parent. In great detail, she worked through how a nurse had worked with the family to help the father address his drug and alcohol problems, how he had obtained employment and housing and how he was reading to his young child; and how the older children who had been poor school attenders were now attending school on a regular basis. She was proud of what her staff had achieved, excited for this family and desperate to ensure a continuation of the funding that had allowed this successful intervention, as well as ashamed that there were so many more families in her community who needed help and support.</i>• Partnerships in the First 2000 Days <i>A partnership between Tresillian, Northern NSW LHD, North Coast PHN and Bulgarr Ngaru Medical Aboriginal Corporation implements the first 2000 days. The focus is on wellness and early intervention, and the collaborative implementation of these strategies.</i> <i>Western NSW LHD has a Kids and Families Strategy and Operational Plans 2018-2021 which indicates strategy, operational plans, clear outcome measures and measurable targets.</i>	<ul style="list-style-type: none">• Adverse Childhood Experiences <i>Another person attended a meeting to tell me about Adverse Childhood Experiences (ACEs) and how vital it was that this Review emphasise how important it is for the health system to understand the significance of ACEs. When I asked her if she wanted to say anything more, she said that her sole aim was that ACEs were understood by me and highlighted in this Review.</i>• Continuity of Care <i>The head of an Aboriginal Medical Service had recognised the problem of lack of continuity of care when the midwife supporting the mother during pregnancy did not always achieve an effective handover of the family to the Early Childhood Nurse. He had introduced a system where the Aboriginal Health Worker, the midwife and the Early Childhood Nurse were all part of the same team and had ensured the seamless transition of care. In other LHDs, a similar problem had been recognised and addressed by the commitment of individuals to make a difference.</i>• Clear strategy and implementation <i>The Children's Healthcare Network of Clinical Nurse Consultants work together very effectively to support each other and to improve the care of children across NSW. This may be to decrease variation of care, to help ensure standardisation of equipment, or to upskill staff across the system.</i>• Aboriginal Parent Program <i>The Ngala Nanga Mai (we dream) pARenT Group Program uses art as a tool to facilitate access to health and educational services for young Aboriginal parents and their children. Its outcomes have been very positive.</i>
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2019 NSW Health Awards

- **Integrated Care: Creating Healthy Homes and Neighbourhoods (HHAN), SLHD**
HHAN is a population-based, family-centred, care-coordination network functioning across health and social care agencies to assist vulnerable families navigate the care system, keep themselves and their children safe, and promote social cohesiveness. This also won the Collaboration Award in the 2019 Prime Minister's Awards for Excellence in Public Sector Management.
- **Health Research and Innovation: Achieving Targets: Children with Type 1 Diabetes, HNELHD**
Prior to 2005, more than 80% of children attending the John Hunter Children's Hospital diabetes service failed to meet international targets for control of blood glucose levels, dramatically increasing the risk of development of complications from the disease. A new management program was introduced. The clinic now has the best control of blood sugar levels in Australia and New Zealand, with a mean HbA1c of 7.3% versus a national average of 8.3%.
- **Volunteer of the Year: Isabelle Wilson**
For her work in SESLHD as a consumer representative for Headspace Bondi Junction and a member of the Youth Reference Group. She has provided leadership to SESLHD, participated in consumer forums and provided ideas for the Youth Mental Health First Aid project.
- **Saving Lives – Priorities in Action, WSLHD**
Emergency Departments are the first point of contact for many young people and their families seeking mental health expertise in times of crisis. The Mental Health service in collaboration with the PHN introduced a child and youth mental health ED navigation pilot establishing a new model of care for under 18s. In particular, the risk lens was broadened to include a comprehensive trauma-informed needs assessment and short-term post-discharge involvement. The pilot suggested that is a very successful approach.
- **Young Mums, Dads and Bubs, MNCLHD**
A collaborative approach to care, this is a partnership between the Child and Family Health Nursing Service in MNCLHD and Headspace. The aim is to improve access to a range of services for high-risk new mothers under 25 years of age, fathers, babies and children.
- **Walking the Milky Way, NSLHD**
The neonatal intensive care unit at Royal North Shore Hospital implemented several strategies to introduce breast milk to the diets of the preterm babies in the unit, improving their nutrition at the same time as decreasing the risk of infections and the need for antibiotics.
- **The Online Choices Program, HNELHD**
This targets diet as a key factor in preventing obesity. The program involves the addition of behavioural prompts and information into an existing online lunch ordering system in school canteens to support parents and children selecting healthier food items. The results have been very impressive.
- **Koori Kids Futures: A High School Student Work Experience Program from NBMLHD**
This program offers a five-day immersion for secondary school students, providing a clear picture of the world of work and the skills required to make informed decisions about employment in the healthcare sector. Students observe, visit and participate in activities that showcase the clinical and clinical support roles associated with various health careers.



2019 Premier's Awards Finalists

- **High Flow Oxygen for Bronchiolitis from HNELHD**

The hospital treatment of bronchiolitis relies on optimal oxygen therapy until the child recovers. High-flow warm humidified oxygen (HFWHO) was introduced into Australian paediatric care without randomised control trial (RCT) evidence of safety and effectiveness. The study, now published in the Lancet, compared HFWHO with usual low flow oxygen therapy. No significant differences were detected in time on oxygen, length of stay and ICU admissions. HFWHO reduced the rate of treatment failure, supported children for longer, reversed the deterioration of most who failed the usual low flow oxygen therapy, and was preferred by parents for ability to feed and comfort.

- **Little Wings from SCHN**

A collaborative approach to care, Little Wings is a registered charity that provides transport for children with chronic disease and their families to travel to and from home to each of the three specialist children's hospitals. A typical scenario would be a child with cancer undergoing three-week courses of chemotherapy with a week's break between cycles. In that week off, road and air transport are provided so that the child and family members can return home and then back to hospital.

It would be wrong to conclude that these were the only examples of good practice identified. Furthermore, in addition to the examples that were identified and not highlighted above are undoubtedly numerous others which were not seen by this Review, due to the impossibility of learning about all the good practice examples in all the LHDs and in the SCHN.

Section 4: Governance and accountability

Key messages

1. Clear and transparent governance structures are essential in a complex system such as NSW Health. This Review reflects on strategic, operational and clinical governance in the context of the current system structure.
2. The Review references the tight-loose-tight approach as the foundation for improving governance. To more closely align with this approach, the system requires tighter governance through the streamlining of committees and networks, clearer processes for decision making and approvals, and the provision of consistent messages to support implementation at the LHD and the SCHN level. Additionally, it will require tight monitoring to ensure that implementation has occurred, and outcomes are achieved.
3. The effective operations of child, young people and family health services in NSW is dependent upon strong, visible clinical leadership at the highest level and support for the Chief Paediatrician to achieve the purpose of this role is required.
4. The future governance of the SCHN was unknown at the time of this Review.

Key findings

NSW Health structure and governance

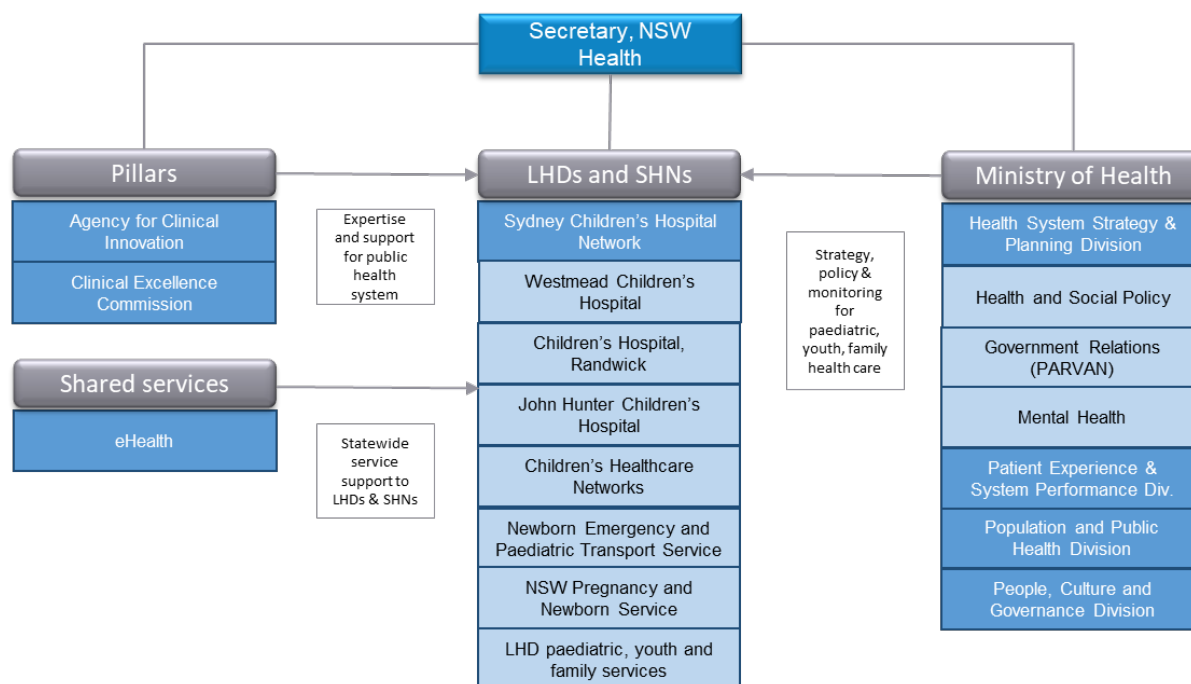
Following the 2008 Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals' (the Garling Inquiry), in 2011 NSW Health implemented structural and governance reforms across the Ministry, LHDs and other agencies within the NSW Health system. The reforms empowered LHDs by devolving some management and accountability from the Ministry for the delivery of health services in their area.

Additionally, these reforms were intended to deliver greater local decision making, including better engagement with clinicians, consumers, local communities, and other stakeholders in the primary care (such as general practitioners) and non-government sectors.

Under this model of governance, LHDs are accountable for meeting their annual obligations under the service agreements.

As a sub-set of the NSW Health system, child, young people and family health services in NSW are governed and managed across a range of NSW Health organisations and portfolios, as illustrated in Figure 7. Further explanation of these organisations is provided below.

Figure 7: NSW Health organisations governing and managing child, young people and family services



In late 2015 the former pillar NSW Kids and Families was dissolved and the process for transfer of responsibilities to other NSW Health entities was initiated. Responsibilities for paediatric healthcare were transferred to the Health and Social Policy Branch, Strategy and Resources Division (now known as the Health System Strategy and Planning Division), Ministry of Health, with further paediatric portfolio areas identified for alignment, including within the Agency for Clinical Innovation and the Clinical Excellence Commission.

Consistent with its system manager role, the Ministry is responsible for leading strategy, policy and monitoring for paediatric healthcare, and allocation of the paediatric funding portfolio, including current Children's Healthcare Network staff and identified projects.

The ACI is responsible for providing guidance to the NSW Health system on paediatric healthcare including standardisation of care, establishing models of care, clinical guidelines and running forums to bring clinicians and consumers together. The Children's Healthcare Network (CHN) supports clinicians providing healthcare to children to provide high-quality healthcare across NSW. The Clinical Excellence Commission provides leadership in safety and quality in NSW to improve healthcare and outcomes for patients and their families/carers.

The Health System Strategy and Planning Division is responsible for strategic health policy development, delivering better value health care that drives improvements in population health and the patient experience, inter-jurisdictional negotiations, funding strategies including Activity Based Management, system-wide planning of health services including mental health, capital planning and investment, systems integration, setting the strategic direction for maternal, child, youth and paediatric health policy and working across government agencies to respond to many intractable social issues. The Health and Social Policy Branch manages the Disability, Paediatric Healthcare and Youth Health and Wellbeing portfolio and the Maternity, Child and Family portfolio.

The Prevention and Response to Violence Abuse and Neglect (PARVAN) team was established under the Government Relations Branch to ensure NSW Health has appropriate systems in place to respond to the major government social policy reforms and other key policy drivers in the areas of sexual assault, child abuse and neglect, domestic and family violence, and in relation to children and young people with sexually harmful behaviours (under tens and 10-17 year-olds).

Mental Health-Children and Young People (MH-CYP) is a unit of the Mental Health Branch. MH-CYP leads strategic activities that support local health districts and speciality networks in service planning and policy development to address clinical services for infants, children, adolescents, young people and their families. MH-CYP oversees the implementation of high quality mental health services for children and young and their families.

The Patient Experience and System Performance (PESP) Division supports system purchasing, management, and monitoring of overall performance. PESP acts as a critical interface with local health districts, specialty health networks, the pillars and other agencies.

The Population and Public Health Division co-ordinates the strategic direction, planning, monitoring and performance of population health services across the state. Strategic areas of focus include alcohol and other drugs, tobacco control, overweight and obesity, HIV, sexually transmitted infections and viral hepatitis, end of life care, organ donation and data analytics that drive actionable insights. The division works in partnership with Aboriginal organisations and communities, and other parts of NSW Health to ensure the health system meets the needs of Aboriginal people, a priority population for NSW Health. The division responds to the public health aspects of major incidents and disasters in NSW and supports population health services to create social and physical environments that promote health.

The People, Culture and Governance Division undertakes a range of functions for the effective administration of NSW Health and implementation of governance frameworks. The Division leads the development, integration and review of capability-based talent management strategies and a values based cultural framework across NSW Health. The Workforce Planning and Talent Development Branch developed the Health Professionals Workforce Plan 2012-2022 that provides a blueprint to ensure NSW can train, recruit and retain doctors, nurses, midwives, oral health practitioners, allied health professionals and other clinical staff to provide health services for NSW communities.

In 2012, the Children's Hospital Westmead and the Sydney Children's Hospital, Randwick (along with other state-wide paediatric services including the Newborn Paediatric Emergency Transport Service (NETS), the Pregnancy and Newborn Services Network (PSN), the Children's Court Clinic (CCC), and Bear Cottage integrated to form the Sydney Children's Hospital Network.

eHealth NSW is responsible for providing direction and leadership in technology-led improvements in patient care across NSW Health in consultation with local health districts and specialty networks.

Chief Paediatrician and senior clinical advisors

The role of the Chief Paediatrician changed after the disestablishment of Kids and Families. The position description (updated 29 March 2017) has overall reporting to the Executive Director, Health and Social Policy Branch and day-to-day operational reporting (from July 2019) to the Director Disability, Youth and Paediatric Health. The position was 0.8 FTE but has been decreased to 0.6 FTE. The primary purpose of the position of Chief Paediatrician is:

"To improve the quality, safety, appropriateness, effectiveness, integration and efficiency of acute and related healthcare for infants, children, adolescents and their families in NSW through clinical advice, leadership and collaboration."

In addition to the Chief Paediatrician, a range of senior clinical advisors provide clinical advice and leadership in key portfolio areas including child and family health, youth health and wellbeing, obstetrics, PARVAN, neonatal care (via PSN), and New Street services. The Chief Psychiatrist provides clinical advice and leadership for child, youth and family mental health services.

Reflections about the structure

It is unclear to this Review what levers the Chief Paediatrician possesses to fulfil his role. For example, when he conducted the comprehensive self-assessments of Paediatric Service Capability Framework in the 15 LHDs, his primary task was to describe the situation and provide feedback to districts. The task did not extend to supporting districts in areas of local continuous improvement. The Chief Paediatrician does not provide input into the development of SLAs, so it is not surprising that implementation of the Paediatric Service Capability Framework has not been a key performance indicator in the SLAs.

The focus of the Chief Paediatrician position description on acute paediatrics represents a very narrow view of child health, rather than a broader role of paediatrics and child health that would cover the spectrum from the first 2000 days, through community paediatrics, outpatient care and acute care.

There is a lack of clarity about how the Chief Paediatrician should interact with other senior clinical advisors.

NSW Kids and Families

Many interviewees, especially clinicians, remained disappointed at the loss of the NSW Kids and Families pillar and some hoped that this Review would recommend a return to the previous structure. The main benefits that were perceived from Kids and Families were:

1. a strong voice for children, young people and families in a health system that was dominated by issues relating to adult care
2. easy access through a single-entry point in NSW Health on issues relating to children, young people and families
3. the belief that *“good things were starting to happen”*.

By contrast, senior executives were more likely to express the view that Kids and Families had not achieved its objectives. They saw Kids and Families as creating yet another silo in the system and that Kids and Families had worked in parallel with, rather than in concert with the rest of NSW Health.

It was not the purpose of this Review to analyse the strengths and weaknesses of Kids and Families. What was relevant to this Review was a widespread perception that there had been many changes in people and structures since the disestablishment of Kids and Families.

Governance of services

This Review commenced after a further restructure had occurred in June 2019. During this Review, there were ongoing discussions about possible new models of governance for the Pregnancy and Newborn Services Network and the Children’s Healthcare Networks, as well as unresolved recommendations from the Alexander report about the Poisons Information Centre, Newborn and Paediatric Emergency Transport Service and Bear Cottage. At the same time, the uncertainty in the governance of SCHN and indeed whether it would continue to include the two Sydney children’s hospitals was unsettling.

In this context, the key governance issues identified across NSW were not a determination of where cardiac surgery was performed or whether there was a SCHN or not. Of course, these needed to be resolved.

Outside the SCHN, the concerns about developmental assessment, behaviour disorders, mental health, paediatric surgery, outreach services from the tertiary hospitals and extra resources to fund the implementation of the First 2000 Days Framework were the key gaps in services to be addressed. Some people from within SCHN saw that SCHN had a broader governance role across the state. This Review revisited the 2012 report *“Future Governance Arrangements for Children and Young People’s Health Services in NSW”*, chaired by the Hon Ron Phillips AO. There is a detailed discussion of options for governance. Ultimately, the leadership model recommended and adopted was standards, policies and programs developed by a new statutory health corporation governed by a board, working within the new organisational relationships for NSW Health, without provision of services or centralised budget holding.

There are some key messages from the thinking of the Phillips’ Report that are relevant to this Review. That Report did not support the proposal that the SCHN be given a responsibility for managing paediatrics across NSW. Some interviewees for this Review had the mistaken belief that SCHN was expected to govern paediatrics across the state but had not been provided the necessary levers and authority so to do. Other interviewees were looking for this Review to recommend that the Board of SCHN would have the leadership role for paediatrics across the state. There was no support from outside the SCHN for this approach.

The lack of support for the broad governance role for SCHN was multifactorial:

1. Some people who thought that it was a good concept believed that the existing turmoil, low morale and lack of trust within the SCHN would take at least a decade to resolve and that an outward looking SCHN was not achievable in the short or medium term.

2. Whatever the merits or otherwise of cardiac surgery operating on one or two sites, individuals inside and outside the service had low confidence in governance which they understood as SCHN Board policy to have cardiac surgery on two sites and practice for cardiac surgery to be on one site.
3. Some people referred to the SCHN Strategic Plan 2017-2022 document. Although Bear Cottage, NETS, PSN and the Children's Court Clinic are all listed on page 4 of the document, there is no specific reference to any of them in the strategic plan. The Poisons Information Centre, which takes more than 100,000 calls per year, and which began at the Royal Alexandra Hospital for Children is not mentioned; and the Children's Healthcare Network, for which SCHN is responsible for the Western and Southern regions is not specifically mentioned, although there is a statement *"We'll collaborate with other health services especially Primary Health Networks and Local Health Districts to build capacity and networks within the primary and secondary services"*.
4. As the Nours report on Paediatric Outreach services from October 2014 noted, *"Over many years, the provision of paediatric outreach services has been a commitment of the three children's hospitals...These services have largely been driven by historical agreements and affiliations."* Some of these outreach services, such as burns, are regarded as best practice and have strong institutional and clinician support; other services, often valued just as highly by clinicians, have been dependent on personal relationships between clinicians. Sometimes these less formal services operate outside the hospital system, in private rooms, sometimes they are privatised clinics and sometimes they are embedded in the hospital system, with multidisciplinary clinics staffed by a combination of healthcare professionals from the local hospital and from the SCHN. There are also outreach services such as support to ensure local healthcare professionals can contribute to treatments including administration of IV chemotherapy. Undoubtedly the benefits to children, young people and their families have been enormous. There was another commentary delivered from both inside the SCHN and inside LHDs, summarised by the statement *"the real reason for outreach is referrals"*. Some believed that the dominant reason that the senior leaders at CHW and SCH supported outreach clinics was to protect the referral base to their individual hospitals. The Reviewer found no evidence to support that this is a contemporary reality, but it highlighted the deficiency of trust in the SCHN.
5. The role of the CHN Northern region was unclear in a central SCHN governance model. The Northern region was perceived to be functioning reasonably well and bringing it into a broader SCHN was seen to have more disadvantages than advantages. Furthermore, senior staff from John Hunter Children's Hospital indicated that their attempts to engage more broadly with SCHN had been postponed by their colleagues in SCHN because of the current environment.
6. The language of hub and spoke model was language which made many individuals in LHDs uncomfortable. Many of the clinical leaders in both paediatrics and child health are based in LHDs rather than SCHN and a broader role for SCHN would certainly need to consider major leadership roles for medical, nursing and allied health staff from LHDs rather than SCHN.
7. Another area of frustration was the perception that SCHN has made decisions about rationing of care that add to the workload of LHDs. *"The bugbear of LHDs is the propensity of SCHN to transfer services without proper consultation"* The Reviewer heard from many people in many LHDs about the process by which a decision was made that MRIs under general anaesthetic would be conducted in LHDs, rather than in the SCHN. The clear message for this Review was the need for effective processes for the SCHN to work with LHDs around delivery of clinical care.
8. Many paediatricians talked about the difficulties of making referrals to SCHN. Others spoke of their frustration about channels of communication through junior doctors rather than having access to their peer consultants. It was impossible in this Review to distinguish perception from reality but it was another reason to conclude that there is, at best, very limited support for SCHN to be given a governance role across the State.

Just as Phillips did in 2012, this Review does not recommend that the Board of SCHN has overall responsibility for a state-wide approach to paediatrics and child health. At the same time, if this is accepted, then SCHN cannot be blamed for failing to deliver state-wide services for which they have neither authority nor budget to deliver. For example, the paediatric ward at the new Blacktown Hospital has not been opened. The language being used is:

"The NSW Government has committed to the delivery of new paediatric services at Blacktown Hospital with the opening of the Acute Services Building; the building includes a paediatric ward, clinics and

dedicated, discrete paediatric treatment areas in the Emergency Department. The facilities are designed to meet current, and projected future, demand. The model of care and recruitment of additional specialised staff are continuing to be discussed, and paediatrics will potentially be introduced in a staged approach. Services will also be provided in a network fashion with Mt Druitt Hospital's existing services, and specialist children's hospitals."

This Review was informed of attempts by SCHN to negotiate with WSLHD, including training staff and shared appointments. The paediatric ward at Blacktown Hospital has not opened and there is a strong flow of children to CHW, who could be safely managed at Blacktown Hospital. This Review has sympathy for the difficulties that this creates for SCHN and reiterates that SCHN has neither budget nor authority to deliver services outside SCHN.

Major decisions such as whether or not a new paediatric ward is opened at Blacktown Hospital and how much paediatric surgery is planned for the new facility at Campbelltown Hospital require central input because neither the CE of SCHN nor the CE of the relevant LHDs sets the broad direction for paediatric services. Another example might be the implementation of the Metropolitan Paediatric Surgery Framework, which is discussed elsewhere.

LHD capacity and capability

The MOH has a general approach that LHDs are responsible for providing services within their capability to children, young people and families. One of the gaps in service delivery in many LHDs is paediatric surgery. If the surgery were performed in the LHD, funds would flow. However operating theatres are a finite resource and, in general, are heavily utilised. Adding paediatric surgery will probably increase waiting lists for surgery. Due to the importance that has been placed on surgical waiting lists by the Ministry, a disincentive for LHDs to undertake paediatric surgery is inadvertently created. The CE of SCHN can meet with the CE of an LHD to discuss provision of paediatric surgery inside the LHD and inside SCHN. A clear system wide mechanism to support negotiation (between districts and/or the SCHN) and achieve the desired outcomes is required.

One interviewee suggested that each SLA should quarantine some of the LHDs activity funding for a paediatric target (in some LHDs children are more than 20% of their population). For those districts that are not servicing children and young adults proportionally to their district population, either produce a plan to increase servicing of children and young people in desired areas (eg surgery and ED admissions) or move activity funding that they should already be providing to the LHD or SCHN receiving the flow of patients and who are doing the work and exceeding targets (unfunded).

An exciting new paediatric development is being constructed at Campbelltown Hospital, which will create a major paediatric facility for the state. One area where greater clarity is required, is what volume of paediatric surgical service will be provided. This would appear to be an excellent opportunity to maximise paediatric surgery, within the paediatric service capability. Clearly, there are paediatric surgical staff within the SCHN with the expertise to work with SWSLHD in making paediatric surgery as good as it could be, if provided with the required authority and budget.

Phillips recognised the need to have a central structure for developing policy and overseeing implementation. The Kids and Families structure that his committee proposed has come and gone. This Review accepts that there is no appetite in either the Ministry or in the LHDs for it to be recreated.

There are some paediatric decisions (not classified as supra-regional specialties) that need to be considered across LHDs and the SCHN. Some current examples include back transfer of babies and children from centres offering higher care (usually NICUs and ICUs) to those offering lower level care (usually level 4 facilities), implementation of paediatric surgery, and implementation of LHDs meeting their designated service capability framework. These are discussed in further detail later in this report.

Reflections of the Reviewer on Governance

A critical component of this Review relates to recommendations about the governance across NSW Health for delivery of quality services to children, young people and families. There are many components to governance. One aspect is the overall strategic framework, which includes the broad policy development for primary, secondary, tertiary and quaternary services for children and young people in the hospital and in the community. For many interviewees, this immediately led to a view that the solution was a return to Kids and Families, or a similar iteration, to ensure that the voice for children, young people and families was heard in a large health system in which paediatrics and child health is relatively small. Any effective solution needs to respect the system of governance between MOH, the Pillars, the LHDs and SCHN. What the Reviewer observed was talented and committed people meeting in committees and working in a variety of what were called networks, where there was no clarity as to how these committees and these networks intersected with and integrated with the health system. Interviewees characterised this as people and committees talking to themselves.

Another aspect is organisational structure. As the Alexander Report identified, entities such as NETS, PSN and Poisons information Centre sit within the SCHN. There is organisational logic in this approach. For example, NETS needs to employ and pay staff and requires an HR system. It also maintains a pharmacy, so it needs professional oversight of the system of storage and dispensing of drugs. There are many other examples of the need for what are often referred to as “back of office services”. It is far better to undertake these operational matters as part of a larger entity, such as SCHN, than for NETS to set up its own boutique systems. On the other hand, an enterprise such as NETS has an overall strategic importance way beyond SCHN. At the same time this Review was being conducted, planning was happening about back transfer of babies from NICUs to SCNs. The line managers of NETS, who are based at CHW, were engaged both actively and constructively in these discussions. However, the leadership team at NETS regarded the absence of references to NETS in the strategic plan of SCHN as an indication that NETS had operational rather than strategic line management to SCHN. The line managers were committed to a strategic role but did not see an opportunity for escalating strategic issues about NETS up the line.

Even if it were agreed that the line management was operational, there were questions about whether the available “back of office” functions were fit-for-purpose. Using the same recruitment model to employ medical staff for NETS as the model for recruiting medical staff for CHW and SCH has been challenging. The Poisons Information Centre (PIC), which takes 100,000 calls per year and requires a sophisticated system for diverting calls to minimise waiting times, also relates to the fit-for-purpose environment. A limited understanding of the operational requirements of the PIC to meet the strategy is an ongoing challenge.

The Children’s Healthcare Network, Western and Southern regions were not included in SCHN strategy. A significant proportion of interviewees in the SCHN were unaware of this Network or believed that the Network had been disbanded.

The Pregnancy and Newborn Services Network was another entity not included in the SCHN strategy. Stakeholders viewed that the PSN relationship with SCHN was for operational purposes.

Both Tresillian and Karitane are linked into the health system through formal relationships with an LHD. In one case, the relevant Chief Executive of the LHD emphasised the need to deliver within the strategic parameters for their LHD, whereas the other Chief Executive concentrated on a whole of state strategy.

In addition to strategic and operational governance, there is clinical governance. Clinical governance has been approached in many ways, including through clinical practice guidelines, standardisation of care, models of care, minimising variations of care and delivering better practice. Both ACI and CEC have important roles in clinical governance. Historically clinicians from NSW were 10 times more likely to access on-line guidelines from the Royal Children’s Hospital (RCH) Melbourne than the NSW Health guidelines. The decision has been made to have RCH work with NSW, Queensland and Victoria to develop guidelines for the East Coast. This is a positive initiative and provides an opportunity to decrease the industry of multiple people working on producing multiple almost identical materials. Nevertheless, in some instances there remains a mismatch between recommended and actual practice for common conditions such as children with bronchiolitis treated in ED and/or admitted to hospital. Reaching agreement on models of care for conditions such as type 1 diabetes and for assessment and management of children with developmental delay has also been challenging.

Populism offers simple solutions to complex problems. Many interviewees craved a benevolent dictator, based in the MOH, in control of the governance of the health of children, young people and families.

There was unanimous agreement from within and outside the SCHN of the statement made in the Alexander Report that “the potential of the network governance is unfulfilled”. There were many solutions suggested by Alexander and her colleagues. One was to broaden the role of the SCHN. Another was to improve SCHN Board governance practices. A third was to add resources to addressing the change management process applied to the SCHN. A fourth was the belief that SCHN was inadequately funded (14% lower cost than its nearest interstate counterpart) and that the funding model needed to be addressed.

Although there was clear acceptance of the need to improve Board governance, to more adequately acknowledge and address the different cultures at CHW and SCH, and to receive more funding, the broadening of the role of the SCHN was contentious. The Reviewer found no evidence and no opinion that supported the concept that expanding the role of the SCHN would make it more outward looking. Rather, a common view was that if the SCHN remained in its current form, it would take a decade for the “wounds to heal”.

The decision about the role of the SCHN, or indeed its continued existence, should not be determined by a popularity contest. However, the Reviewer did not believe that the broader role for the SCHN canvassed in the Alexander Report was acceptable to the LHDs or to the MOH.

Although many interviewees were looking to this Review to suggest a governance structure to guarantee effective functioning of the Western and Southern regions of the CHN, it seemed unlikely that any particular structure was likely to solve the underlying problems that these sectors were not seen as important to the strategy of the SCHN.

Clinicians participating in outreach clinics from the tertiary hospitals often did this through goodwill relationships established with local paediatricians, often resulting in lack of clarity about whether they had formal appointments and clinical privileges in the LHD in which they were conducting the outreach clinic. For example, a consultant conducting an outpatient service might be asked to consult on an inpatient but would not have an appointment with the privileges to allow that.

The required processes of administration do not recognise that health care workers are part of an overall system. Although there is talk about cross credentialing, its implementation has been challenging. For example, interviewees indicated requests for them to provide documentation in each LHD in which they work about matters such as immunisation status, medical registration, medical indemnity and working with children checks. For example, if a paediatrician from one of the specialist children’s hospitals is participating in outreach activities in the network that is associated with their children’s hospital, the LHD should define the local privileges and work with the specialist children’s hospital rather than the doctor about documentation of registration, etc.

Another issue was raised by many interviewees. They wanted this Review to be focussed on Women’s and Children’s Health services, rather than what they saw as an artificial separation. There was strong support at the Randwick Hospitals campus for Sydney Children’s Hospital and the Royal Hospital for Women to work together more closely and the SCHN was perceived to have made this more difficult and to have hampered what had been regarded as good historical relationships between SCH and the SESLHD, both in hospital and community health.

Whatever decision is made about the continuation of the SCHN, this Review does not support an enhanced governance role for the SCHN across the state. It does recommend clearer processes for how decisions are made about what SCHN (or its successors) are responsible for and what individual LHDs are responsible for.

Similarly, this Review does not recommend a separate stand-alone structure within the MOH or the Pillars for children and young people. It does recommend streamlining committees and networks, clearer terms of reference for committees and networks and processes for escalating matters, for their approval and for their implementation in LHDs and the SCHN. This is consistent with the tight-loose-tight approach but will require closer monitoring that implementation has occurred.

Section 5: Committees & networks related to child, youth and families

Key messages

1. Over 60 committees and networks related to child, young people and family services in NSW were identified as a component of this Review. The operation, purpose and effectiveness of these committees was variable.
2. Effective communication is essential in a complex system such as NSW Health. Systems and processes that provide committees and networks with the right information are needed to enable them to perform their core functions of oversight, monitoring and decision making. Subsequent information flow from committee members to management to frontline staff is also important.
3. The Children's Healthcare Networks are divided in to three regions: Northern, Southern and Western. The Northern region was viewed to be operating effectively while the strengths of the Southern and Western regions were viewed to be related to strong relationships between individual clinicians, rather than strong systems.

Key findings

Children, young people and family committees

A desktop review of relevant children, young people and family committees and networks was undertaken. Where available, terms of reference for the various committees and networks were reviewed. This included purpose, functions, membership, meeting frequency, reporting lines and measures of effectiveness.

Over 60 committees and networks related to child, youth and family services in NSW were identified as a component of this Review. Figure 8 and Figure 9 below provide a pictorial representation of these committees and networks.

Figure 8: NSW Health children, young people and family committee and network structure

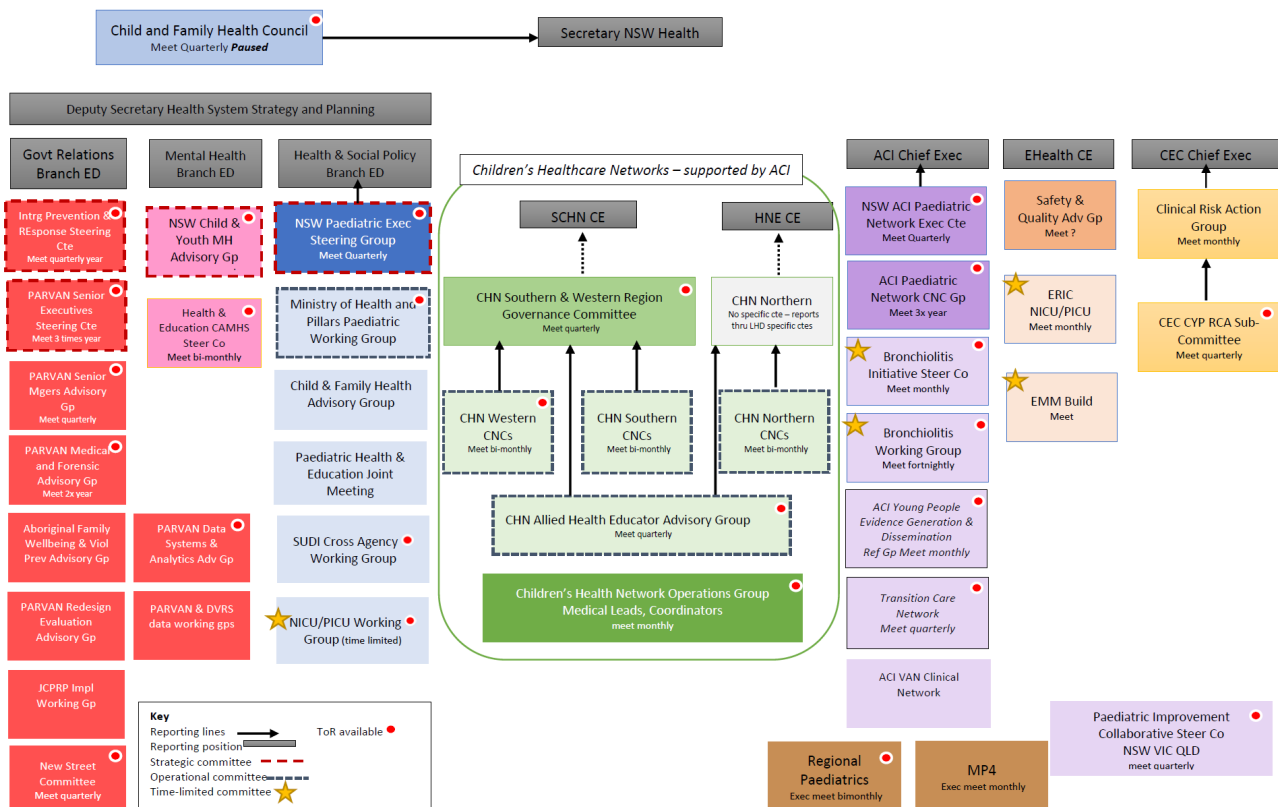
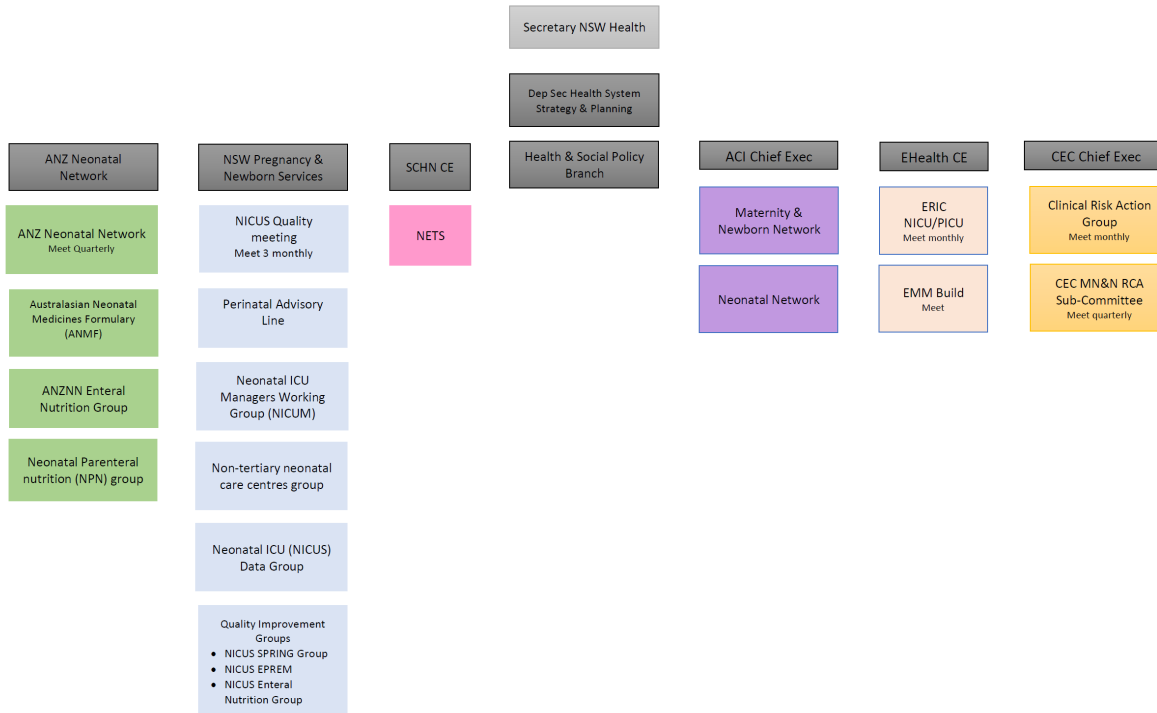


Figure 9: ANZ and NSW Maternity and Neonatal committee and network structure



An overarching formal state-wide committee for children, young people and family services does not currently exist.

Terms of reference were not available for all children, young people and family committees and networks identified. Furthermore, the age of the available terms of reference for committees and networks varied considerably. Most terms of reference that were reviewed identified the purpose, function and membership of the committee/network. Identification of reporting lines and measures of effectiveness of committees/networks were not commonly included in the terms of reference. The most common situation was that it was neither apparent to whom a committee reported nor what mechanism there was for escalating an issue from a committee.

The process for information flows between committees and responsibility for decision making was often unclear. Similarly, the process through which key actions for implementation could be approved was not evident.

Systems and processes to get committees and networks the right information are needed to enable them to perform their core functions of oversight, monitoring and decision making. Existing cross-committee information flows were informal and variable; cross committee membership is not enough to ensure efficient information flows. This is particularly relevant for a large complex system such as NSW Health where numerous issues are likely to arise and need to be formally referred across committees /networks.

In addition, the Ministry policy of identifying email addresses by the name of the individuals rather than their role provides challenges in record keeping and communication for external parties when people have temporary secondments or act in positions during annual leave.

Children's Healthcare Networks

It was reported that the operational effectiveness of the three Children's Healthcare Networks (CHNs -Northern, Southern and Western regions) was variable. In particular, the overall view was that the Northern region was functioning well; that the Southern region had functioned reasonably well as Greater Eastern and Southern Children's Healthcare Network (GESCHN) before the SCHN was formed but had been less effective as the Southern region as part of the SCHN; and that the Western region had struggled to be effective. For both the Southern and Western regions, the strengths were seen to be due to strong relationships between individual clinicians, rather than strong systems supporting those clinicians. "Phone a friend" was accepted as the most common process of engagement between a clinician in a regional or metropolitan level 4 facility and the tertiary facilities in Sydney.

CHN Northern region

The current CHN Northern region is functioning well. The Northern region has been embraced as part of the paediatric team in HNELHD. The Coordinator of the CHN Northern region is a member of the HNE Paediatric Executive Team. She also has direct and indirect management of the paediatric Clinical Nurse Consultants.

The CHN Northern region has had strong strategic leadership for many years, with leadership by example in providing services outside JHCH. The Northern region has five CNCs, who have a critical role in continuing education and upskilling staff across the region. The Reviewer was told that CNCs spend more than half their time educating staff in small regional hospitals. The CNCs were referred to as *“the foot soldiers who make it work”*. Medical leaders have also worked hard, not only to engage paediatricians but also to involve GPs. The emphasis has been on acute care, one example of which has been the deteriorating child. The Standard Paediatric Observation Chart (SPOC) helps to identify white, blue, yellow and red zones. This is one example of a project that has been implemented and embedded a sustainable model.

Notwithstanding the undoubted strengths of the CHN Northern region, there remains a tension around the current model of strategic leadership by influence. In particular, the CHN does not have operational management authority. It is a testament to leadership at multiple levels in the relevant LHDs that over 25 years the model of care for children and young people has continued to evolve from silos of care in hospital and community, to an integrated Children and Young People Health Network (CAYHNet) in Newcastle to a regional HNE network, to the proposed expansion of the looser CHN Northern region. All the LHDs in this CHN should be encouraged to maximise opportunities by continuing to work together.

There is an opportunity to include the CCLHD in the Northern region, rather than have patients flow to Sydney. The current Department of Education, Department of Communities and Justice, Primary Health Networks and the University of Newcastle linkages between Hunter New England and the Central Coast make this a natural liaison. This should be implemented in a planned fashion, with proactive planning about services and funding transfers. The agreement between HNELHD and CCLHD should capture the need for outreach services to be provided in the Central Coast, rather than an emphasis on children, young people and their families travelling to Newcastle.

CHN Western and Southern regions

The Northern region serves a defined geographical region with defined boundaries. It is far easier for this region to function well than either the Southern or Western regions. Positive efforts will be needed to make a difference from the current situation where the Children's Healthcare Networks have little visibility in SCHN. Realistically, this will always be a challenge in the Western region, with so many metropolitan hospitals and in an environment where the SCHN has no authority over the LHDs. In addition, the Reviewer was unclear regarding the priority of the Children's Healthcare Networks in the strategy of the SCHN.

Both the CHN Western and Southern regions have had a positive effect, particularly in bringing health professionals together around common issues. There is an ambiguity about what is part of CHN, what is part of RPNSW and MP4, and what sits within ACI.

One comment made was: *“The hub and spoke model which has been talked about for more than 20 years needs to be made a reality. The big district hospitals, such as Nepean, Liverpool, Campbelltown, Gosford, RNSH, St George and Wollongong, need to be enticed to take on more paediatric subspecialty work.”*

The current situation was seen as training of Fellows in subspecialty medicine, most of whom were left without a staff specialist position after completing their training. *“They are often left to their own devices, usually in private practice and suffer from a lack of peer review and interaction with academic units. Creating relationships between the specialist children's hospital and the district hospitals would provide better long term service for patients and doctors alike.”*

At Campbelltown Hospital, three part time staff specialists in paediatric endocrinology are connected clinically to SCH and work on the on-call roster at SCH. Feedback to this Review suggested that they value very highly the connection to a specialist children's hospital. However, they have neither formal cross appointment to SCH nor even a memorandum of understanding. A contributor to this Review made the diplomatic understatement that it was a bit “messy”. Another perspective was that *“structures, systems and processes support an isolationist approach”*.

Although many interviewees wanted this Review to emphasise the importance of the CHN Western and Southern regions, there are many factors limiting the cohesive operation of these networks. For acute referral made using NETS, the decisions about the hospital to which children are transferred is made by NETS and not by supposed networks. There is disagreement within SCHN about which hospitals sit within each network. Campbelltown is an example, with connections to both SCH and CHW. As noted above, the SCHN strategy does not specifically include CHN.

The CHN was established nearly two decades ago, with a focus on paediatrics rather than community child health. A key issue then was concern about the erosion of paediatric skills outside the specialist children's hospitals. If we revisit the purpose of a CHN in 2019, it would be to emphasise an outward looking service model that embraced the full spectrum of paediatrics and child health, rather than the narrow model of acute paediatrics. Furthermore, the SCHN did not exist when the CHN was established. This Review suggests that a two sector model is more logical than the current three sector model. The Northern sector would continue to be linked to John Hunter Hospital and would serve north of the Hawkesbury River; while the other sector would be Western and Southern and be linked to the SCHN.

A quick achievement for the new Western and Southern sector would be cross accreditation of staff involved in outreach clinics and other clinical service between SCHN and LHDs. Further planning would be needed to set up a small governance group that establishes strategy and holds accountability, that plans visits to LHDs, that manages staff in the CHN roles (coordinators, medical leads and allied health educators) and that is embedded as part of the SCHN Executive.

Section 6: Case study: Paediatric Service Capability Framework

The Paediatric Service Capability Framework is a 50 page document and the accompanying Companion Toolkit is 40 pages. These documents should be regarded as reference material to support the following commentary and recommendations.

Two key statistics are that 80% of Emergency Department presentations for children in NSW and 67% of inpatient separations occur outside the specialist children's hospitals.

Key messages

1. The key driver for the introduction of the NSW Paediatric Service Capability Framework (the Framework) was the requirement for local paediatric services to be delivered optimally; whether in rural, regional or metropolitan locations. The Review noted that the implementation of the Framework across LHDs was variable and a missed opportunity.
2. In 2017-18, self-assessments of the strengths, vulnerabilities and opportunities of the Framework for the LHD overall, and each hospital were conducted. The reports provide a rich source of information about each LHD and its hospitals, unfortunately these reports were not always made available within the LHD.
3. Common issues from the self-assessments included:
 - Lack of services or limited services for mental health and acute behavioural disturbance.
 - Lack of documentation of available paediatric surgical services and an absence of a proper process for involvement of paediatricians in the care of children admitted for surgery.
 - Limited availability of allied health services.
 - Delays in transfer of sick children.
 - The absence of a medical lead for paediatrics to support safe, reliable and effective care.
 - Complexities in maintaining a stable, skilled workforce.
 - Children not cared for in an environment separate from adult patients.

Key findings

Paediatric Service Capability Framework

In 2017, the Ministry of Health published the NSW Paediatric Service Capability Framework⁶ and its accompanying document Paediatric Service Capability Framework: Companion Toolkit⁷. The first paragraph of the Executive Summary of the Framework summarises the rationale:

“The NSW Health system covers a large geographical area and includes multiple and diverse health facilities across metropolitan, regional, rural and remote regions. Within this system the majority of paediatric acute care is delivered by facilities that are located away from the State’s three specialist children’s hospitals. The key driver for the introduction of the NSW Paediatric Service Capability Framework (Framework) was the need for local paediatric services to be delivered optimally; whether in rural, regional or metropolitan locations.”

The Toolkit consists of seven individual tools:

⁶ https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2017_010.pdf

⁷ <https://www.health.nsw.gov.au/kidsfamilies/paediatric/Publications/pscf-companion-toolkit.pdf>

1. Establishment and operation of paediatric short stay and acute review services.
2. Close observation and capability in paediatric wards.
3. Emergency surgery for children: Implementation of LHD designed surgical sites and the emergency department algorithm.
4. Paediatric Clinical Emergency Response System and beyond facility escalation process.
5. Involvement of paediatricians in the care of children in NSW hospitals.
6. Child friendly and child safe health facilities.
7. Children and adolescents in paediatric services requiring mental health care.

Paediatric Service Capability Framework self-assessments

In 2017 and 2018, the NSW Chief Paediatrician, Dr Matthew O'Meara, visited every LHD together with representatives from both the MOH and NSW Health. They met with LHD representatives, who participated in a self-assessment of the strengths, vulnerabilities and opportunities of the Paediatric Service Capability Framework for the LHD overall, together with an assessment for each of the hospitals in the LHD. A summary report was provided back to the LHD.

The reports provide a rich source of information about each LHD and its hospitals. Unfortunately, the reports were not always made available to key staff within the LHD. Indeed, some paediatricians reported that they had used this Review as a trigger to try to persuade management in their LHD to make available a copy of the findings.

Similar vulnerabilities were identified across multiple LHDs and multiple hospitals. The most common issues identified were:

1. Lack of services or limited services to meet the needs of children and young people with a mental health problem or an acute behavioural disturbance.
2. Lack of documentation of available paediatric surgical services and no proper process for involvement of paediatricians in the care of children admitted for surgery.
3. Limited availability of allied health services.
4. Delays in transfer of sick children, especially within the LHD, due to a shortage of availability and absence of clarity and coordination of transfer and retrieval options. Practical problems identified included the unavailability of pulse oximetry monitoring for young children in ambulances and the difficulties in transferring infants weighing less than 3kg.
5. The lack of a medical lead for paediatrics across the LHD to support the delivery of safe, reliable and effective healthcare in all facilities.
6. Difficulties in maintaining a stable, skilled workforce, including skills that are required to provide higher levels of care.
7. Children not cared for in an environment separate from adult patients.

Although these issues were described in the reports, there was neither a requirement to address vulnerabilities nor monitoring of whether improvements were made. This Review provided an opportunity to test what progress had been made. Although there were examples where positive initiatives had occurred, the overall conclusion from interviewees and the Reviewer was that the Paediatric Service Capability Framework review process represented a lost opportunity. *"It's a great document. There was a great launch. It was just shelved in my LHD. No state-wide summary was presented. It's a missed opportunity."*

Framework implementation and monitoring

The summary section of the document issued as the Framework reads as follows:

"This guideline provides guidance and support within a safety and quality framework for the provision of paediatric medicine and paediatric surgery services at site specific levels. This framework provides

guidance to Local Health Districts for admission, escalation and back transfer regarding paediatric medicine and surgery for children services.”

At the foot of the same page is a note from the Secretary which states that *“compliance with this directive is mandatory for NSW Health and is a condition of subsidy for public health organisations”*.

The language of guidance and support is very different from the language of mandatory and a condition of subsidy. Many interviewees made comments such as: *“They keep describing what we are doing rather than defining what we need to do and holding our LHD accountable”*.

The Framework is a case study of the governance issues that need to be addressed in NSW Health. The decision making is left to LHDs, with the MOH the funder of services and having its role under the Westminster system of providing advice to the Minister.

The Framework was one of many examples that has resulted in widespread frustration of clinicians looking after children, young people and families about the gap between a framework that is supported and subsequent implementation and monitoring.

Many of the vulnerabilities identified from the capability assessment exercise led by the Chief Paediatrician and from this Review require a state-wide approach. The issues around appropriate management of children and young people presenting with mental health issues and acute behaviour disorders is a systemic problem. Individual LHDs are vital contributors to achieving improvements but cannot do this without the support of an overarching system.

Paediatric surgery

Paediatric surgery requires a recognition of local circumstances. However, this should recognise the 2014 document from NSW Health, Surgery for Children in Metropolitan Sydney: Strategic Framework⁸. This Framework includes the statement:

“The recommended actions consider opportunities for a standardised approach within the current workforce context and, consistent with LHD domains of responsibility for their population, as the first stage of a state-wide planning process for sustainable services.”

And the Framework *“can be customised for use by any hospital in metropolitan and rural LHDs”*.

Paediatric surgery was a recurrent theme throughout the Review. Section 4.2 of the Framework addresses three key aspects of paediatric surgery outside the SCHN. The first is emergency surgery, the second is planned surgery and the third is the appropriate level of paediatric medicine service to support the surgical service. Issues relating to both emergency and planned paediatric surgery have been the subject of many reviews. This Review found that the Surgery for Children Framework had not been implemented across the NSW Health system. Numerous interviewees expressed disappointment, many stating that what was needed was implementation rather than further reviews.

The Framework self-assessment exercise identified vulnerabilities such as:

“Absence of documented scope and level of complexity of paediatric surgical cases that can safely be undertaken”

“Lack of documented process for involvement of paediatricians in the care of children admitted to surgical services, with reliance on nursing staff to escalate concerns to a paediatrician” and

“Lack of formalised model of care for acute review and follow up of paediatric surgical patients.”

⁸ <https://www.health.nsw.gov.au/kidsfamilies/paediatric/Publications/surgery-for-children-framework.pdf>

Transport systems

Section 5 of the Framework describes the networked approach to paediatric care. One aspect of this is the transfer of critically ill children to specialist children's hospitals. This is only one part of the jigsaw. Clinical emergency response systems need access to higher level services within the LHD network. For example, children in Wyong Hospital may need transfer to Gosford Hospital and children at Shellharbour Hospital may need transfer to Wollongong Hospital. In WNSWLHD, there are three base hospitals with level 4 paediatric facilities and more than 20 local hospitals that are part of clusters that are serviced by these three units. Transfer is one aspect of the clinical emergency response system. The self-assessment summaries from the Framework exercise raise issues from these and other LHDs such as:

"delays in transfer of sick children due to lack of availability and lack of clarity and coordination of transfer and retrieval options"

"lack of clarity of the role of patient flow services where paediatric patients require transfer"

"lack of protocols for consistent access to appropriate transport for transfer of sick children to higher level services and return transfers to local facilities"

"there is a gap between availability of NETS, ambulance capability and availability of local staff to escort the patient"

"there are particular issues in transfer by ambulance of infants weighing less than 3kg and younger children who require pulse oximetry monitoring"

The interviewees in the current Review all provided similar information about normal ambulances not being equipped to transport the cots for babies under 3kg and not equipped with the disposable finger probes to enable pulse oximetry monitoring in young children; that the NETS service is not designed for transfers such as Mudgee to Dubbo; and that if local staff are used for transfers within a LHD, there is a major loss of capability at the level 4 facility while staff are on the transfer. There are also issues about transporting infants who are too young to support their own head (with the possibility of airway compromise during transfer).

The challenges related to back transfers are even greater. For example, if a baby on CPAP is ready to be transferred from a NICU to the SCN close to home, the NETS team needs to balance the risk that there will be an emergency call for a retrieval while the back transfer is being undertaken. In children who are older, especially more than 10kg, back transfer should be easier but often does not happen.

This is a further example where the underlying problem would be more efficiently addressed centrally, rather than each LHD negotiating a solution with NSW Ambulance, NETS and other key parties. Interviewees for the Review also identified concerns about whether best practice was occurring for transport options for children who had sustained severe trauma.

NETS continue to provide a highly valued service across NSW. Back transfer of children is not being undertaken as frequently as it could be, partly due to lack of clarity around responsibility and partly for logistical reasons. The Deputy Secretary Patient Experience and System Performance in NSW MOH is leading a process to address the issues of back transfers.

Another transport challenge is children who require transfer, usually to a specialist children's hospital for a non-urgent investigation or assessment. For example, a child receiving supplemental oxygen therapy in a district hospital may have an outpatient appointment to be assessed by a cardiologist in a specialist hospital. At present there is difficulty in guaranteeing availability of transport on a particular day to ensure the child arrives by a particular time, to fit into the timeslot available for consultation and investigations.

Outreach services

There is strong support for planned outreach clinics but their development requires more than the goodwill and commitment of individual clinicians. Challenges in funding are often a consideration, especially when the outreach is in a regional centre. Although the privatised outpatient model with bulk billing is a common model, this rarely covers the direct costs, let alone the indirect costs, for non-procedural specialties. One possible consequence is

that families are expected to visit specialist children's hospitals rather than the services from specialist children's hospitals visit them.

Telemedicine

A core component to addressing the clinical emergency response is a consideration of the opportunities for telemedicine to be used in the acute situation. The Reviewer was taken through several cases where the paediatrician at the level 4 facility was able to talk to the local GP, the parents and the child, to observe the child and then to supervise the management using the videoconferencing system. In all these cases, this was not a single teleconference call but ongoing review of the child's progress. This is particularly relevant in the situation where there are large distances to be travelled and the child has a condition that is likely to respond quickly to treatment. Converting these anecdotal cases into agreed principles for use of acute telemedicine seems the logical next step.

Protocols concerning the need for paediatricians to assess and review children on a regular basis while they are inpatients were developed before the widespread availability of assessing and reviewing children through telemedicine. A better understanding of what is appropriate safe care is essential and an important issue in rural and regional LHDs.

Similarly, the optimal ways to use telemedicine for assessment and management of children and young people with chronic problems has not been defined clearly. Undoubtedly, the opportunities for using telemedicine in effective ways will increase. Many interviewees identified the added benefits in upskilling staff in regional communities.

Medical leads and medical staffing

In order to provide the required 24 hour on-call access to a paediatrician, at the same time as an acceptable on-call roster, level 4 paediatric facilities need to ensure that paediatricians do not work more than a 1 in 4 on-call. The usual way to achieve this will be to have at least five paediatricians appointed to each level 4 paediatric service. Some hospitals have achieved the 1 in 4 on-call by employing locum cover. This can work, although it may limit the capacity to provide follow up clinics to review children who are being treated at home and need follow up assessment, as well as providing other outpatient services.

Part of the responsibility of the paediatrician on-call is to be aware of children who need short-term follow-up after a visit to the Emergency Department. In some cases, appropriate follow-up will be a telephone call, an appointment with a GP, or review in the ED. Many level 4 facilities offer an acute review service adjacent to or within the paediatric ward. Clearly the on-call paediatrician needs to oversee any review service operating from the paediatric ward.

One of the essential criteria for meeting level 4 paediatric standards that is in the Framework is "*provides non-inpatient child and family health services (e.g. developmental assessment, multidisciplinary assessment and treatment of psychosocial and behavioural problems)*". Although some of these services will be offered in private practice, the public system also needs to provide a service for those who cannot afford to be treated in the private system.

A separate issue in senior medical workforce is how to provide 24 hour availability for subspecialists in paediatrics. This is a complex issue. One approach that could be adopted in many of the subspecialties is a statewide roster using staff from multiple hospitals.

Workforce

The Framework recognises the importance of the workforce:

"Attracting, training and keeping highly skilled personnel is key to all NSW Health services, but is crucial in paediatrics where the wide range of skills and geography covered necessitates a flexible, skilled and culturally competent workforce with ready access to training, best practice knowledge and specialist advice."

Senior staff, particularly nursing, emphasised that in many facilities the workforce is young and inexperienced and require opportunities for development.

Upskilling of staff is essential. One aspect of this broad area is ongoing training in the recognition of the sick and deteriorating child and the provision of paediatric emergency care. One highly regarded way of training staff to improve the early management of acutely ill and injured children is the Advanced Paediatric Life Support (APLS) course. Many interviewees indicated that their LHD did not provide financial support for staff to attend an APLS course and that nurses are often unable to access award-based study leave. The Reviewer agrees with the widely held view that LHDs should provide some financial support for nurses to attend APLS courses.

The Emergency Department at Campbelltown Hospital has made it an internal mandatory requirement for all medical staff to achieve APLS (3-day course) accreditation as well as senior nursing staff to achieve PLS (one-day) accreditation. The APLS provider course has been held locally in Campbelltown for the last ten years. ED and ICU registrars are reimbursed for registration costs of attending APLS.

Many staff also commented on the need for opportunities for nursing staff to gain experience by observing in a specialist children's hospital or in a neonatal intensive care unit. In theory these opportunities are available but in practice both funding and logistics mean that it rarely happens.

"There is a lot of talk about cross staffing in our clinical streams and networks but it never happens. Everyone says it's a good idea but there are always reasons not to do it"

"We need to be able to move money around. When we [specialist hospital] take a nurse she doesn't earn her salary and when we send her back she will help take patients away from us"

An investment in adequate training is required to support NSW Health to achieve the aspiration of managing more children and babies closer to home.

One of the most consistent suggestions made to this Review is not addressed in the Framework, namely a nurse for each LHD who was described using terms such as a care navigator or a care co-ordinator for children with chronic complex disease. A few LHDs have already recruited such a person. The role description varies, sometimes helping to navigate the health system and sometimes navigating across a broader portfolio of Health, Education, Communities and Justice, and Housing. One argument put to this Review was that the optimal approach is to work on systems to ensure care coordination rather than case management. However, the Reviewer found no evidence that there was an imminent solution to achieving care coordination through the system. The lack of basic achievements such as a single medical records system across the LHDs and SCHN suggest that the interim solution of care navigator positions will be a solution needed for many years.

The Reviewer has provided a discussion about allied health staffing in later in this report. The widely expressed concern about inadequate allied health staffing requires an understanding of what are appropriate benchmarks for staffing levels and would best be coordinated by the Chief Allied Health Officer in the MOH.

Child Friendly and Child Safe Health Facilities

It is totally appropriate to respect the need for LHDs and individual hospitals within LHDs to tailor their work to reflect the local circumstances; however it makes no sense for there to be 15 LHDs with 15 different policies on what is meant by "child friendly and child safe health facilities". This Review found widespread reporting across multiple LHDs of regular occurrences of adults being managed in designated children's wards. At the Ministry, there was a clear view that the practice was unacceptable.

Feedback to the review added extra evidence to the Paediatric Assessment Capability Framework that children and young people are not always managed in an environment consistent with the toolkit "Requirements for child friendly and child safe health facilities". In some hospitals, the pressure to manage the need for adult patients requiring admission is given a higher priority than the requirement that adults should not be admitted to paediatric wards.

"We all know that we shouldn't have adult patients in children's wards. But we are told that the Ministry can't tell LHDs what to do, it can just advise them"

"Why do we have a Ministry if it can't implement a simple policy around the safety and security of children?"

Facilities

During site visits conducted as part of this Review, the Reviewer was made aware that some level 4 facilities do not have adequate office space available to conduct outpatient clinics, particularly when multidisciplinary clinics are trying to operate. For example, when children and young people are attending an outpatient clinic for the management of their type I diabetes, the nurse educator and the dietitian need a private area to see the child and not consult in the waiting room area. Longer term planning is needed in the design of new and upgraded paediatric facilities to recognise that public hospital outpatients with multidisciplinary clinics is part of the standard model of care.

Mental Health

The management of mental health, both acute and chronic, the management of behaviour disorders and the contested debate about whose responsibility it is to assess and manage children and young people with a spectrum of presentations is addressed in more detail in sections 10 and 12.

Recommendations

The key findings as described in Sections 4, 5 and 6 provide a platform for new ways of working and opportunities for improvement. The recommendations that support these key findings are presented in four broad categories below:

- System wide governance and accountability
- MOH structures and governance
- Children's Healthcare Networks
- Local leadership, governance and operations.



These recommendations link with the Secretary's priority to strengthening governance and accountability.

System wide governance and accountability

Issue: There exists inconsistency in the implementation of frameworks specific to child, young people and family health care and the development of accompanying outcomes measures. Additionally, the monitoring of implementation and outcomes is variable.

Recommendation 1: The development of every framework be accompanied by an implementation plan, by outcome measures and by monitoring of both implementation and outcomes.

Recommendation 2: The implementation of the Paediatric Service Capability Framework be incorporated as a key performance indicator in the Service Level Agreement of each LHD.

Issue: The effective operation of child, youth and family health services in NSW is dependent upon strong, visible clinical leadership at the highest level. There are currently insufficient levers to support the Chief Paediatrician to achieve the purpose of this role.

Recommendation 3: The Chief Paediatrician work with each LHD to support implementation of the Paediatric Service Capability Framework.

Recommendation 4: An annual report be made to the Deputy Secretary Health System Strategy and Planning via the Executive Director Health and Social Policy on the strengths,

vulnerabilities and opportunities in the implementation of the Paediatric Service Capability Plan for each LHD.

Issue: The current role of the Chief Paediatrician is primarily focused on acute and hospital paediatric care. A greater focus on community paediatrics and priority areas in child health is a necessary requirement to support care in the community and evolving priorities.

Recommendation 5: The role of the Chief Paediatrician be expanded to include a broad overview of paediatrics and child health. This would make it clear that the Chief Paediatrician has a role in working with others to improve healthcare in areas including (but not limited to) assessment and management of community paediatric issues such as behaviour disorders, developmental delay, as well as long term vital initiatives, for example the First 2000 Days.

Issue: Clarity around the governance of the SCHN was a key issue impacting this Review. Consultation confirmed that further expanding the governance of the SCHN to a state-wide remit would be challenging.

Recommendation 6: The current situation be clarified and reinforced that SCHN is not responsible for overall governance of paediatrics across NSW.

Issue: Services do not always operate at their designated service level. Other LHD priorities, impact on the ability for an LHD to meet its objectives in relation to paediatric services. The tight-loose-tight model means that the MOH sets a tight direction, allows a looseness about how objectives are achieved, and applies tight ownership and monitoring of deliverables.

Recommendation 7: Although LHDs have flexibility about how paediatric objectives are achieved, they should not have flexibility about whether paediatric objectives are achieved. NSW Health requires a system that monitors the achievement of paediatric objectives across all LHDs.

Recommendation 8: The MOH recognise that some paediatric decisions (outside the scope of those classified as supra-regional specialities) need to be considered across LHDs and the SCHN. These decisions should be referred to the NSW Paediatrics Executive Steering Committee for discussion and resolution.

MOH structures and governance

Issue: There is no systematic approach that drives decision making and provides focus and direction for child, young people and family services. A committee that operates as the primary decision-making committee across all children, young people and family services is required.

Recommendation 9: The current NSW Paediatric Executive Steering Group be reconfigured to function as the peak decision-making committee across child, young people and family services in NSW to oversee new models of care, development of standardised guidelines and processes, statewide policy and planning, and monitoring of outcomes. Community representatives should be part of the membership.

Issue: Consultation identified that there are unclear pathways for escalating issues, decision making and approval of recommendations. This finding was consistent with the April 2019 Performance Audit Report recommendation from the NSW Auditor-General about Governance of Local Health Districts that “more clarity around how the escalation process works and how escalation decisions are made”.

Recommendation 10: The Chief Paediatrician be given a key role in taking advice from MOH, LHDs and SCHN about the best way forward for paediatric decisions that need to be considered across LHDs and SCHN.

Recommendation 11: The Chief Paediatrician present the issues, options, and any recommendations, to the NSW Paediatric Executive Steering Committee.

Recommendation 12: The NSW Paediatric Executive Steering Committee consider and agree recommendations from the Chief Paediatrician and escalate committee decisions to the Deputy Secretary Health System Strategy and Planning.

Recommendation 13: The Deputy Secretary Health System Strategy and Planning present relevant committee decisions to the senior executive team for approval.

Issue: The Performance Audit Report from the NSW Auditor-General raised issues about the relationships between the pillars and LHDs, suggesting that the MOH should “provide clarity on the relationship of the Agency for Clinical Innovation and the Clinical Excellence Commission to the roles and responsibilities of LHDs”. The recommendation in this Review is consistent with the Audit Report.

Recommendation 14: Relevant decisions from ACI or from CEC be referred to the NSW Paediatric Executive Steering Committee for advice and subsequent approval by the senior executive team (in line with the process outlined in recommendations 12 and 13 above).

Issue: Communication and information flows across committees, networks and stakeholders are inconsistent and reduce the ability for committees/networks to perform their core functions of oversight, monitoring and decision making.

Recommendation 15: Existing systems and processes for communication and transfer of information between and across committees/networks, system managers and operational managers be refined to support efficient information flows to support decision making, implementation and monitoring.

Issue: There was evidence that many committees did not have terms of reference while others were outdated and/or unclear in their purpose, governance and process of evaluation.

Recommendation 16: All committees develop clear terms of reference that are updated at least biennially and include a clear purpose and functions, reporting lines and measures of effectiveness to periodically evaluate performance.

Children’s healthcare networks

Issue: Children from CCLHD frequently travel to Sydney for care. There is an opportunity to include the CCLHD in the CHN Northern region, where appropriate, rather than flow to Sydney.

Recommendation 17: The Children’s Healthcare Network Northern region be expanded to include the Central Coast LHD.

Recommendation 18: Future subspecialty paediatric appointments to HNELHD consider a fractional component shared with CCLHD.

Issue: The effectiveness of the three CHNs and overall operational governance is variable. In some instances, this was thought to impact communication, patient management and quality improvement.

Recommendation 19: Future subspecialty appointments to the SCHN be shared with an MP4 or RP4 Hospital.

Recommendation 20: A long term approach be considered for the Children’s Healthcare Network Western and Southern regions to be combined in a sector linked to SCHN. An early priority be cross credentialing of staff involved in outreach activities.

Local leadership, governance and operations



These recommendations link with the Secretary’s priorities for patient safety and experience, value based health care and systems integration.

Issue: The deficiency of clinical leadership and a nominated ‘Medical Lead’ across many LHDs was thought to impact quality planning, delivery and monitoring of paediatric services locally.

Recommendation 21: Each LHD appoint a Medical Lead in paediatrics. In some LHDs, there will be a co-lead from nursing and in some cases the leadership will be across both paediatrics and child health. The overarching aims and functions of the role are described in the Framework.

Issue: In some instances, the number of paediatricians in a Level 4 facility was considered insufficient for a sustainable 24 hour on-call access to a paediatrician. Additionally, level 4 paediatric facilities need to ensure that paediatricians do not work more than a 1 in 4 on-call.

Recommendation 22: The on-call roster for a level 4 paediatric facility be no more onerous than 1 in 4. The usual way to achieve this will be through a minimum of 5 paediatricians on the roster.

Issue: One of the essential criteria for meeting level 4 paediatric standards as described in the Paediatric Service Capability Framework is “provides non-inpatient child and family health services (e.g. developmental assessment, multidisciplinary assessment and treatment of psychosocial and behavioural problems)”. Although some of these services will be offered in private practice, the public system also needs to provide services for those who cannot afford to be treated in the private system.

Recommendation 23: Level 4 paediatric facilities have an essential role in providing both acute and non-acute outpatient services. This might encompass activities such as offering care in the home. The responsibilities of paediatricians reflect this broad role, rather than a more limited focus on acute inpatient care.

Issue: Current transport procedures are not standardised, are complex and require collaboration across a range of service providers with varying capability.

Recommendation 24: Increase the clarity of protocols for consistent access to appropriate transport for sick children to higher level services and return transfers to local facilities. This will require engagement with NETS and NSW Ambulance.

Recommendation 25: Develop and implement protocols for reliable access to appropriate transport for children who need to be seen at a specialist children’s hospital.

Issue: One barrier to providing outreach clinics to rural areas is the funding for the travel of the health professional team. By contrast, there is funding for children to travel to metropolitan specialist hospitals.

Recommendation 26: In order to facilitate outreach clinics to rural areas, a reverse IPTAAS scheme be developed, where the cost of sending health care workers to a rural centre be funded, analogous to patients and their families being funded for the costs of travelling to a tertiary centre for assessment and care.

Issue: A better understanding of appropriate safe care using telemedicine is required. This is an important issue in rural and regional LHDs. Potential exists to assess and review more children closer to home through the use of telemedicine and support sharing of clinical information and links between tertiary and smaller facilities.

Recommendation 27: Clinicians and administrators develop and implement agreed guidelines for the safe use of telemedicine in the treatment of children with acute and chronic medical problems to avoid the need for transfer.

Issue: There is significant variability in paediatric surgery undertaken across LHDs and SCHN. The Surgery for Children in Metropolitan Sydney Strategic Framework has not been implemented. The framework provides clear guidance around emergency surgery, planned surgery and the appropriate level of paediatric medicine service to support the surgical service.

Recommendation 28: The Surgery for Children in Metropolitan Sydney Strategic Framework (2014) be implemented, measured and monitored.

Issue: Navigation of the health system for children and their families with complex needs is challenging. The lack of enablers to support care coordination such as a single medical records system across the LHDs and SCHN suggest that the interim solution of Care Navigator positions will be needed for many years.

Recommendation 29: Innovation funding be provided by the Paediatric Healthcare Team to LHDs for 2 years of funding of Care Navigator positions, conditional upon LHDs providing ongoing funding after the initial funding period provided that pre-determined agreed outcomes are achieved.

Issue: Nursing staff identified a need to develop greater capability to support the management of more complex patients. APLS and PLS are highly regarded courses and provide an opportunity to upskill the workforce. The provision of funding from LHDs is consistent with current industrial awards.

Recommendation 30: LHDs provide funding for nurses to attend APLS and PLS training courses.

Issue: Support for capability development of nursing staff was a recurring theme. The capability of many district hospitals to provide the level of care required to meet the standards of level 4 paediatric wards and level 4 special care nurseries remains challenging.

Recommendation 31: LHDs and SCHN implement systems for nurses to be upskilled by working in more complex clinical environments and by use of outreach education.

Issue: A limitation of functional space in some settings, impedes appropriate models of care. Outpatient care for children in public health facilities remains an important component of healthcare. Furthermore, multidisciplinary clinics are best practice in many of these situations. While the development of facilities is on a longer-term timescale these requirements should be considered in the design of future facilities.

Recommendation 32: Hospital planning recognise the need to construct facilities to enable the operation of multidisciplinary clinics for children and young people.

Issue: Numerous examples were presented to indicate that adults are residing in paediatric wards and child safe policies and guidelines are not always complied with.

Recommendation 33: LHDs implement the requirements for child friendly and child safe health facilities.

Section 7: The Sydney Children's Hospital Network

Key messages

1. Both CHW and SCH should be comprehensive, specialist children's hospitals caring for the sickest children.
2. CHW and SCH should not be competing with each other to keep or lose a service.
3. CHW and SCH should remain as a Network.
4. The CHW and SCH ICUs should operate as a single ICU service on two sites.

Key findings

A fundamental question that needs to be asked is whether Sydney should have two comprehensive specialist children's hospitals. Related to that is the question of what constitutes a comprehensive specialist children's hospital. For some, the answer is to look at models elsewhere, so centres such as The Hospital for Sick Children, Toronto or Great Ormond Street, London are seen as examples of comparators. When Ireland considered a tertiary children's hospital in "A National Model of Care for Paediatric Healthcare Services in Ireland", it was stated that the sickest children and young people have better clinical outcomes if treated in a tertiary hospital that has:

- high caseload volumes across at least 35 subspecialties of paediatrics
- advanced medical technology and information and communications technology
- child and family friendly facilities
- an integrated approach to innovation, service delivery, outreach, education and research
- a responsive paediatric and neonatal retrieval service.

Once again, the definitions are subject to interpretation. A subspecialty could be broad, such as respiratory medicine, or it could be narrower and include asthma, cystic fibrosis, sleep medicine and allergy as subspecialties. Even further, it could refer to highly specialised areas such as ciliary abnormalities. Similarly, terms such as high caseload volumes, advanced medical technology and an integrated approach are subjective.

For others, there is a somewhat circular argument that a specialist children's hospital is a hospital where the sickest children and young people are cared for.

CHW would regard itself as being a comprehensive specialist children's hospital but it has never performed heart transplants. Similarly, in the days when cardiac surgery was performed at SCH, the fact that liver transplantation was centralised to CHW did not cause concern about its status as a comprehensive specialist children's hospital.

Within the SCHN, one view presented to this Review was that CHW should become the sole children's hospital providing quaternary services. This seemed neither logical nor feasible. Large commitments for capital developments have been committed to both the Westmead and Randwick sites, with unequivocal political commitments to the importance of both specialist children's hospitals in the current and future plans for delivery of care to the sickest children and young people. Furthermore, the Reviewer was told by people inside and outside SCHN that CHW was "bursting at the seams" and was struggling to cope with its current workload, so the notion of down-skilling services provided at SCH did not seem to be in the best interests of children and young people. Secondly, one of the strongest paediatric oncology services in the country is based at SCH. Both State and Commonwealth Governments have committed \$600 million to a new development at SCH, a significant component of which is a Comprehensive Children's Cancer Centre, reinforcing the expectation of a major unit at SCH. Providing the best care for children with cancer requires multiple expertise and input from disciplines outside the subspecialty of oncology.

Some submissions sought to revisit the recommendation from the Garling Report that there would be a new facility, neither CHW nor SCH, which would be the premier facility for Sydney. That recommendation by Garling was not adopted years ago and a series of major capital investments at both campuses have reinforced that there is no intention to revisit that decision.

In addition, the Reviewer believes that specialist clinical services for children and young people should not be considered in isolation. In the same way that it is important to consider how primary, secondary, tertiary and quaternary services interface with each other and how community services interface with hospital services, it is also important to consider the interfaces with maternity facilities, with adult hospitals, with Medical Research Institutes and with universities. Both the Westmead and Randwick campuses are rich and expanding environments for research, education and clinical care. Paediatrico has provided an excellent example of discovery research and translational research operating together, with University of Sydney, UNSW Sydney, Children's Medical Research Institute, Children's Cancer Institute and Sydney Children's Hospitals Network combining in a large project delivering precision-based medicine. This has helped to unlock the full potential of strong research groups working together to achieve outcomes that would not have been achieved as individual institutions working independently. The NSW Government has provided strong support for this approach, including a large research grant.

This Review understands the importance of a strong voice for paediatrics, child health and young people. The cultural approach to presenting this voice has had a different emphasis at CHW and SCH. Royal Alexandra Hospital for Children, both when it was located at Camperdown and since it moved to the Westmead campus has emphasised the need for a separate paediatric identity and historically has run all its own back of office functions. It has also favoured an approach where those who deliver services have an exclusive paediatric practice. SCH has had a different approach. It began as part of an area health service and has always embraced a role as providing community child health and secondary paediatric health services to a local community, as well as tertiary and quaternary services to a broader population. It also shares services with the Royal Hospital for Women and the Prince of Wales Hospital, including but not limited to physical facilities such as operating theatre suites, services such as medical imaging and pathology, and staff who have expertise in both paediatric and adult medicine and surgery. Both the CHW and SCH approaches have delivered good care to children and young people.

The different philosophical approaches at CHW and SCH around how to deliver care to the sickest children and young people have made it more difficult to achieve a two-site single service, where staff from both hospitals have mutual respect for the work done at both hospitals. A common view expressed at SCH was the disestablishment of the SCHN, with SCH returning to what is now the SESLHD. The imagined solution was that funding would move with SCH from SCHN to SESLHD and that SCH would re-establish cardiac surgery services.

The Medical Staff Councils at SCH and RHW have held discussions at many levels, including with the Chair of the Board of the SESLHD, with UNSW Sydney and with Government and opposition politicians. The assumption was that with SCH reintegrated into its LHD, SESLHD had the authority to recommence paediatric cardiac surgery, that staff would be recruited and that the service would recommence.

The advice given to the Reviewer was that the fundamental assumption that the Board of SESLHD, with SCH as part of it, had the authority to decide that cardiac surgery would be undertaken at SCH was incorrect. That authority is held by the Secretary, NSW Health. Therefore, the decision about cardiac surgery on one or two sites is not resolved by SCH relocating governance to SESLHD. Similarly, decisions about whether SCH is a comprehensive specialist children's hospital does not rest with the Board of SCHN, if it remains part of the Network, and does not rest with the Board of SESLHD, if it moves to that LHD. This interpretation may be contested but was consistent with the understanding conveyed to the Reviewer by staff in the MOH.

Although the initial terms of reference for this Review were developed on the assumption that decisions about the SCHN would be made and announced before this Review was concluded, the Minister for Health and the Secretary NSW Health, determined that they would await this Review. Accordingly, the Reviewer regarded commentary about SCHN as within scope.

This Review concludes that both CHN and SCH should be tertiary children's hospitals and that both should also provide quaternary services. The mix of quaternary services at the two sites would be different. For example, there is no case to be made for cardiac surgery for hypoplastic left heart to be conducted on two sites and CHW would be the logical site; liver transplantation should be on one site and continuing at CHW should be non-controversial. A case can be made that surgery for brain tumours should be at the SCH site, together with CAR-T cell therapy and phase 1 clinical trials in paediatric oncology. However, the two sites should not be competing with each other to keep or lose a service.

A key requirement for SCH is to have an intensive care unit that can manage a complex caseload. Without that capability, the capacity to deliver the required specialist services to the children of NSW is compromised. Concerns

were expressed by some that the loss of cardiac surgery has resulted in loss of skills in the intensive care unit at SCH. The PICU at SCH is now accredited for 12 months training for specialists, rather than the 24 months that was the case and remains the situation at CHW. One way to address this would be to have a single intensive care unit operating on two sites. If SCH managed neurosurgery for brain cancer and for children who require surgery for epilepsy, and CHW managed more complicated cardiac surgery, then staff would need to rotate between both sites to obtain comprehensive training.

The Reviewer does not recommend consolidating other quaternary services at CHW. For example, the existing relationships between SCH and POW hospital and the current services at CHW support a continuation of renal transplantation on both sites.

However, it will need to be a priority that the Ministry gives clear indications to SCHN about the expectations of delivery of services on both sites and holds management and the Board to account to ensure that implementation occurs.

The Alexander Review identified the need to address the governance of Bear Cottage, NETS, the Children's Court Clinic, the Poisons Information Centre and PSN. This Review supports that need but suggests an alternate approach to that proposed by her Review. The way the NSW Health system is structured and funded means that, as an example, the NSW Poisons Information Centre needs to be located in the SCHN or a LHD for its funding to be allocated and managed, including back of office functions. It would be appropriate for the Poisons Information Centre to become part of SLHD and to have strong links to University of Sydney; it is equally appropriate for the Centre to remain part of the SCHN, provided that the SCHN recognises its responsibility to help the service to be as good as it can be. This would include providing the necessary infrastructure to support a call service that takes more than 100,000 calls per year.

The governance of NETS is more complex. Although it is part of a supra-regional specialty of PICUs and NICUs, NETS is managed as part of the SCHN. The leadership of NETS sees this as an operational connection and the failure to mention NETS in the 2017-2022 strategic plan of the SCHN is a curious oversight. On the other hand, the line managers of NETS in the SCHN believe that they should be helping to shape and support the strategy of NETS. These same line managers are appointed to key committees set up by the MOH to discuss the role of NETS in matters such as back transfer of children. This Review recommends that NETS remain part of SCHN and that the Chief Executive and the board include the strategy for NETS as part of the strategy for the SCHN.

Recommendations

The key findings as described in Section 7 above, provide a platform for new ways of working and opportunities for improvement.



These recommendations link with the Secretary's priority to strengthen governance and accountability.

Issue: The governance of the SCHN is complex and a strategy and operational plan that provides clear direction is required.

Recommendation 34: The Secretary of Health makes it clear that both CHW and SCH will be comprehensive specialist children's hospitals with tertiary and quaternary services on each site.

Recommendation 35: The Paediatric Intensive Care Units at CHW and SCH operate as a single service on two sites.

Recommendation 36: NETS transfers ensure that SCH receives a similar mix of the sickest children as CHW.

Recommendation 37: The Sydney Children's Hospital and the Children's Hospital Westmead remain in the SCHN.

Recommendation 38: The Chief Executive and the Board of the SCHN be made accountable for ensuring that these recommendations are implemented within 12 months.

Recommendation 39: The Chief Executive and Board of SCHN develop and implement a plan to increase cooperation between the two campuses. This will include acknowledging the cultural differences between the two hospitals.

Recommendation 40: The MOH convenes a meeting between key staff at SCHN and SESLHD to decide the principles and details of the costs of shared services at the Randwick campus. The resolution of these longstanding contentious issues will help to ensure that the focus of discussions between SCHN and SESLHD is around improving patient care, rather than who pays what share of the cost of delivering services.

Recommendation 41: Future enhancement funding be directed to areas where there is clear evidence of, and ongoing commitment to meaningful shared services between CHW and SCH, or shared services between SCHN and at least one LHD. This would include but not be limited to fractional appointments on more than one site. Cardiac services may need to develop in parallel due to irreconcilable conflict between CHW and SCH.

Recommendation 42: The Chief Executive and the Board of SCHN develop a new strategic plan that includes a vision, a strategy and an implementation plan for both CHW and SCH, as well as NETS, Poisons Information Centre and the Western and Southern regions of the CHN.

Section 8: Neonates

Key messages

1. The effective care of a neonate requires a broad range of clinicians across neonatology, paediatrics and other specialities. Care may be provided across many settings and involve many transitions dependent upon the needs of the neonate.
2. The importance of strong statewide and tiered network leadership and governance was recognised as a key element in delivering effective critical care services for neonates.
3. The availability of NICU beds was variable across and between tiered networks. The linkage between NICUs and SCNs was not always clear and a number of barriers to timely back transfer were highlighted.
4. There was a strong desire to upskill talented staff to develop greater capability in critical care and to support the management of back transfers or more complex patients.
5. The PSN currently sits within the SCHN. During the time of this Review a planning process was underway to determine the future of PSN. This Review was not provided access to these proposals.

Key findings

Care of the neonate

The usual situation after a delivery in hospital is that the baby rooms in with the mother, although sometimes this is combined with some form of hospital nursery. At the other extreme, very sick newborn babies require highly specialised care in a neonatal intensive care unit. A lower level of specialised care is provided in a special care nursery. Most of these services are provided in obstetric units of general hospitals or in a specialised women's hospital, the Royal Hospital for Women. Both the CHW and SCH have NICUs, commonly to manage neonatal surgery or other complex newborn conditions.

Most of the paediatricians working as specialist neonatologists are in the obstetric units outside the SCHN. General paediatricians also treat neonates and there is a considerable medical workforce in training that works in SCNs and NICUs as part of training in general paediatrics or as training to be a neonatologist. The nursing workforce to care for pregnant women are midwives. The nursing workforce in SCNs and NICUs come either from a midwifery or registered nurse background. Allied health staffing may be people from a generalist background or specialising in maternal health or paediatrics.

The involvement of paediatricians often begins in pregnancy, particularly when it is recognised antenatally that there are fetal abnormalities or when decisions are being made as to whether the baby should be delivered prematurely.

Transitions of care

The challenges of transition from neonatal to paediatric services and from midwifery to child and family were recognised. Part of this reflects the silos in the delivery of services but part may reflect models of care. For example, the transition from the midwife service to mother and baby to the child and family nurse has tended to be a hard stop. Some of the successful transitions have involved an Aboriginal health worker, midwife and child and family health nurse working together in a more seamless fashion. In this model, the child and family health nurse becomes involved earlier and the midwife stays involved longer.

The effective care of babies and their families requires many transitions of care. For example:

- when the baby in a NICU is well enough to be moved to a SCN, there is a transition from NICU to SCN, which often means moving from one hospital to another

- if the graduate of a NICU is left with ongoing issues such as chronic lung disease, there is a need to transition to the paediatric environment and/or a need to transition from care by the neonatologist to care by another paediatrician
- the transition from the care of mother and baby by the midwife to the child and family health nurse and the general practitioner
- babies of mothers who have taken drugs during pregnancy may need ongoing care for the withdrawal symptoms that they experience.

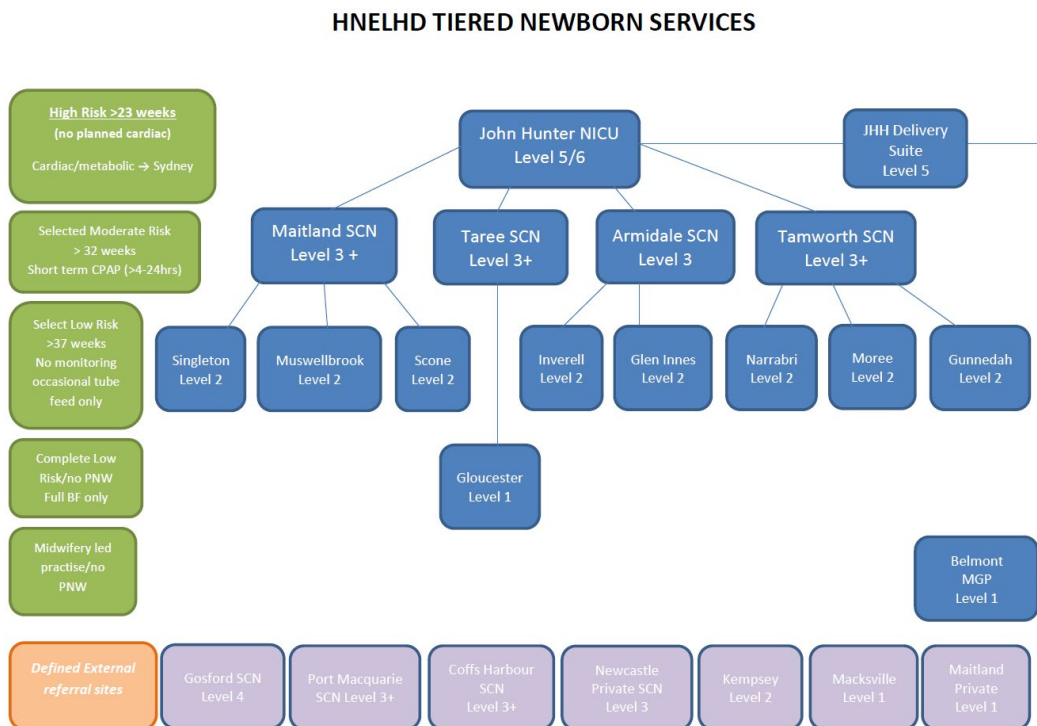
Tiered networks for neonatal intensive care services

The delivery of neonatal intensive care is coordinated across NSW (and the ACT) and the NICUs and PICUs are regarded as supra-regional services within the MOH. There are also a series of tiered networks, by which NICUs are linked to SCNs and lower level facilities. The tiered networks each have a NICU, namely Centenary Hospital for Women and Children (ACT), John Hunter, Liverpool, Nepean, Royal Hospital for Women, Royal North Shore, Royal Prince Alfred and Westmead. The tiered networking arrangements for perinatal care in NSW were published on 5 November 2019.

The Review identified that the Neonatal Intensive Care Units were well connected. What was more ambiguous was how the SCNs were linked together and how decisions were made about which babies should be managed in NICUs and which babies should be managed in SCNs.

One example of a tiered network of neonatal services is the HNE network. Figure 10 shows the delineated service capability for each of the units and the high-level summary of the babies able to be managed in each facility, including when babies need transfer to SCHN.

Figure 10: HNELHD Tiered newborn services



The NICU Director is also the Director of Newborn Service for HNE. Every four months, they meet with all SCNs and ensure that each service is working at service capability. John Hunter Children's Hospital has strategic responsibility and operationally, as an example, the Tamworth Director would be responsible for any required action. Both Gosford (part of CCLHD) and the Mid North Coast units also attend the meeting. There is no line management authority with these other LHDs. JHCH has provided transport services, some education and the ability for their staff to attend the NICU for upskilling. There is operational separation and this model relies on goodwill rather than any formal agreement.

Bed availability

NICU beds are not always available in an individual tiered network. Liverpool has a particular problem because of its huge and growing catchment area in south west Sydney. Respondents supported the tiered network system but indicated that, in addition, there needed to be an overall view.

Some of the unresolved issues relate to demand for NICU beds. Both birth rate and rate of prematurity are stable. However, tiny babies have increased survival rates. For example, five babies of 25 weeks gestation who survive will use one NICU bed for a year. Projections are that premature babies of even lower gestational age will be long term survivors. Central planning that uses population growth as its main driver for resource allocation has challenges in planning for the increased survival of more premature babies. *“In the past, this would have been on the radar of the PSN/statewide services.”*

A major potential for maximising the use of resources is timely back transfer of babies from the hospitals with a NICU to SCNs in other hospitals. Although there was total support for the concept, some barriers existed:

- in some cases, there had been a cultural tendency to keep the baby in the hospital with the NICU
- in some cases, there was delay in the receiving hospital accepting the back transfer, usually because it required a need to surge up the nursing staffing to meet the demand
- in many cases, there were logistical issues with a lack of availability of NETS services to perform the back transfer.

At the time of this Review, these matters were under consideration, particularly the role of NETS in performing the back transfers.

Management of premature babies

Some submissions to this Review were looking for a recommendation that SCNs should manage premature babies as low as 28 weeks gestation, rather than the current 32 weeks. The Reviewer considered this proposal and was shown data that indicated that this would be associated with significantly worse outcomes for babies. Although each individual tiered network makes its own decisions about a role delineation model such as this, many individuals lamented the loss of a centralised system for dealing with this in an efficient evidence-based manner.

Workforce

A component of a review of service capability for obstetric services, by the Senior Clinical Advisor in Obstetrics NSW MOH, included a review of SCNs across the state. Those observations, combined with the observations from this Review, highlight the challenges of staffing and upskilling the staff in SCNs, in regional but also in many metropolitan hospitals. Some tiered networks and the SCHN offer training opportunities. However, nurses in leadership positions across the state identified challenges about how to upskill talented but inexperienced junior nursing staff.

Pregnancy and Newborn Services Network

The Pregnancy and Newborn Services Network sat within the SCHN at the time of this Review. However, a planning process was underway to determine future plans for PSN. This Review was not provided with access to the draft proposals. As noted earlier, PSN was not included in the strategy for SCHN 2017-2022. Many individuals talked about the late Emeritus Professor Henderson-Smart and his leadership of PSN, with major initiatives in clinical care, education and research. In that era, the PSN worked with state-wide services in NSW Health on state-wide guidelines and had major roles in education and in research.

Recommendations

The key findings as described in Section 8 above, provide a platform for new ways of working and opportunities for improvement. Planning for the PSN were occurring during this Review and the future governance proposals were unclear. It was also unclear whether the issues identified below would be managed through PSN or whether a different form of governance would be needed to oversee them.

These recommendations link with the Secretary's priorities to strengthen governance and accountability and in patient safety and experience.



Issue: The operational governance and linkage between NICUs and SCNs was not always clear and a number of barriers to timely back transfer were highlighted.

Recommendation 43: In addition to the model of tiered neonatal networks, the plans for future governance need to provide coordination across the whole system to connect NICUs and SCNs.

Recommendation 44: The plans for future governance need to ensure that back transfers from NICUs to SCNs are managed across the whole system.

Issue: There is a need and desire for consistent education and training specific to critical care for NICU and SCN staff to support system capacity, capability and safety of patients.

Recommendation 45: Training and upskilling of staff caring for newborns in both SCNs and NICUs requires a statewide approach.

Issue: Communication between providers can be inconsistent and transitions of care and protocols are frequently different across different sites and providers. This potentially impacts continuity of care, patient safety and patient flow.

Recommendation 46: The plans for future governance need to focus on the interfaces which can be problematic in the current system, such as interfaces between midwife and child and family nurse, obstetric services and general practice, and between neonatal services and specialist paediatric services in children's hospitals and LHDs.

Section 9: Community paediatrics and child health

Key messages

1. Care delivered in the community includes a diverse range of service providers and funding and payment systems across the public, private and non-government sectors. The current system has developed over many years to support strong and effective responses for children who need access to care.
2. Some of the main pressure points in the delivery of community health care services for children, young people and families were identified as:
 - the management of children and young people with mental health disorders
 - the variation in the approach to assessment and management of developmental delay
 - the challenges in ensuring that the NDIS meets the needs of children and their families
 - the demand for allied health services far exceeding the supply of services across the system.

Key findings

Overview of the current system for community care

Community paediatrics and child health is a very broad area. Normal growth and development, developmental assessment and treatment, assessment and treatment of behaviour disorders, mental health, disability, child protection and population health strategies such as immunisation and prevention of Sudden Unexpected Death in Infancy, provide a brief snapshot of some of the coverage of community paediatrics and child health.

Although this Review is about services for children, young people and families in the NSW Health system, this must be considered in the context of all other service providers that contribute to the health and wellbeing of children, young people and families. General practitioners work closely with and interact with NSW Health funded services but most of the funding for general practice is independent of NSW Health. The availability and affordability of specialist services offered by paediatricians, allied health professionals and nurses in private practice has always been a vital component of service delivery for children. Non-government organisations such as Barnados Australia, Benevolent Society, Headspace, Tresillian and Karitane continue to work closely with NSW Health and to be integrated into service delivery models. Some Aboriginal health services receive a component of Commonwealth funding. Departments such as Education and Justice and Communities have direct and indirect roles in both promotion of health and in interventions for children with identified problems.

It is of limited value to consider how many allied health professionals are needed in NSW Health without a broader overview of how many allied health staff work for other NSW Departments, how many work in NGOs and how many are in private practice. When a major change to the system occurs, such as the implementation of the NDIS, there are challenges and disruptions to NSW Health which are both hard to predict and hard to plan for.

As well as complicated interfaces between NSW Health and other systems, there are complicated interfaces within NSW Health. Newborn babies start their health journey under the supervision of midwives, who need to work effectively to ensure a handover to early childhood nurses. For indigenous babies, this might be facilitated by an Aboriginal health worker. Every child should have a general practitioner and some of these babies will be referred by an obstetrician to a paediatrician, who may be employed as a staff specialist or work in private practice. If there are major sleeping or feeding issues, NGOs such as Karitane and Tresillian may become involved. Mental health problems in the family may lead to engagement of mental health services. Child protection issues and violence abuse and neglect may introduce other agencies.

Fortunately, the system has developed in a robust manner over many years, so that the children who need to access services usually have mechanisms for doing that, irrespective of whether the service sits inside or outside NSW Health. Unfortunately, the system often has low visibility. Media coverage of health issues is often dominated

by measurements of waiting times in emergency departments, together with associated bed block, and waiting times for elective surgery. The benefits to individual children, young people and families and to society in general of investing in ensuring that children have access to health services in an equitable way and are able to fulfil their potential is accepted conceptually but it is sometimes hard to identify the levers in the system which hold LHDs accountable for this.

Universal Health Home Visiting

A number of interviewees commented on Universal Health Home Visiting (UHHV) policy. A mandatory component of the provision of primary health care to parents caring for a new baby is that every family in NSW is offered a home visit by a child and family health nurse within two weeks of the baby's birth. Linked to this is the requirement that each LHD ensures that there are sufficient staffing levels to provide UHHV for its population. The clear intention of UHHV was to form part of the continuum of care and network of services for families and young children, beginning in pregnancy and extending through early childhood. If the UHHV identified "vulnerability", then it may be deemed beneficial to provide ongoing support and active follow up, or in more concerning situations, coordinated team management and review. In the absence of "identified vulnerability", there would be further assessments at 6-8 weeks and 6-8 months. The original policy also referred to Sustained Health Home Visiting (SHHV) and indicated that this was not mandatory.

An example of a sustained home visiting service is the Sustaining NSW Families program (SNF), which is offered in some geographical locations to *"families who meet eligibility criteria, which include mothers experiencing mild anxiety and or mild depression and circumstances which are known to have an impact on the family."* Each SNF team has a nurse coordinator, child and family health nurses, a social worker and other allied health professionals.

Some of the comments about UHHV were that the single home visit had been intended as the plank which would then lead to sustained home visiting, to providing support to all families and extra support to vulnerable families. These interviewees were disappointed that the focus on a single process indicator meant that the underlying strategy had been misplaced. Others contended that in a resource constrained environment, in which there were insufficient resources to undertake both targeted and universal home visiting, the priority was to have targeted visiting. A variation of this argument was that children's health services are competing to retain their funding with other areas of clinical need and that it is a more powerful cost benefit to opt for targeted home visiting rather than UHHV. The opposite perspective was also presented, namely that if a single universal home visit ceased to be mandatory, some services would cease UHHV but not redirect the resources to targeted home visiting.

One approach that was promoted by some interviewees was that UHHV should be replaced by Universal Health Contact, providing the option of telephone contact rather than a home visit.

One of the barriers to UHHV has been that the funding provided to LHDs to support it has not always been directed towards UHHV. The current plans to continue with UHHV, to have a shorter first visit, and to use the visit to identify those who need further visits is supported by this Review.

A workshop has been held to promote discussion on UHHV and the reported consensus outcome was reinforcement of the importance of UHHV. This Review identified that some LHDs are struggling to achieve UHHV, that UHHV is not being conducted in all LHDs and that some of the reporting of UHHV is misleading because it represents a home visit by a midwife rather than a child and family health nurse.

One of the gaps in the current model can be the transition from maternity services. This Review has identified the need to socialise the midwife completing the maternity journey and providing active encouragement in handing over the family to both the child and family health nurse and the general practitioner.

Some LHDs have used Aboriginal health workers to coordinate the seamless transfer of the baby and family from the obstetric service to the child health service. Another LHD ran a successful trial of English language education in mothers whose first language was not English. This was undertaken in pregnancy to help mothers to navigate the health system after their babies were born. Unfortunately, budget challenges led to the cessation of the initiative. The engagement of the family GP as well as the child and family nurse has been challenging in some areas.

Allied Health

The models for allied health staffing across the LHDs vary markedly. Some services provide allied health staff whose job is in child health, while others have mixed roles, caring for adults and children.

Interviewees provided a prevailing message of demand for allied health services far exceeding available supply. Typical comments included:

“Allied health services that meet the needs of the population are not consistently available”

“Limited access to allied health services, including outpatients and ambulatory care”

“Limited access to allied health services, particularly psychology and social work”

“Access to allied health services is limited by NDIS processes and the lack of private options”

“12 month waiting time for speech pathology” and

“Lack of access to paediatric allied health services”.

The shortage of allied health resources was perceived by some to be too big a challenge to be solved. Examples arose in multiple areas covered in this Review. Examples include:

- The extra pressures and demands for allied health staff such as occupational therapists and physiotherapists with the introduction of the NDIS.
- The progressive introduction of screening for domestic violence without the social work and other allied health workforce to help in the management of those identified by the screening.
- The long waiting times to access speech pathology services for children with speech delay, when there is strong evidence for the cost benefit of early intervention. The important role of developing strong early language skills as part of the first 2000 days has created an additional concern about the tension between providing early input for the first 2000 days versus providing intervention for children who have presented with established speech delay.
- The need for effective interventions by dieticians for children and young people who are overweight and obese.
- Unmet demand for children and young people with mental health problems and with acute behaviour disturbance.

These are a small set of examples of pressure points. The Reviewer looked for benchmarks to describe allied health staffing levels by discipline needed to serve a particular population of children and young people. These are difficult numbers to obtain. For example, Cartmill and her colleagues (2012) reviewed nine allied health professions in the Australian setting and concluded that *“The evidence for use of staffing ratios for allied health practitioners is scarce and lags behind the fields of nursing and medicine”*.

The situation is further complicated by the need to understand how many allied health staff work in agencies such as Education and Communities and Justice. Cutbacks in allied health services provided in Education does not change total community demand but does put extra pressure on Health. Some local councils have adopted a whole of sector approach, where it has been possible to have an overall view of services available across government departments, non-government organisations and private practice. This maximises efficiencies but also highlights that there are real gaps.

This Review hesitates to quantify the level of the gap between available services and reasonable demand. However, all the material presented support the case that allied health staffing levels have been inadequate for many years and that there is a widening gap between demand and supply. The current budgetary pressures and the need for “efficiency gains” seem to affect community staffing more than staffing for acute services and allied health staffing more than medical and nursing.

One of the reasons presented to the Review was that many of the improvements in medical and nursing staffing had resulted from industrial pressure for payment for overtime, for a focus on safe working hours and for appropriate nurse/patient ratios. There does not appear to have been the same breakthrough moments for allied health staffing, or indeed for most staff in community settings. Although this section is part of community health, the shortages in allied health apply in both inpatient and outpatient settings and across all age spans including

newborn care, children and young people, as well as for physical and mental health. The Reviewer was told about the recent funding of an acute care facility, where a certain amount of funding had been allocated for staffing. Once the agreed medical and nursing staffing had been provided, the only money left was enough to provide a 0.5 allied health worker. The discussion was about which allied health discipline should receive the 0.5 rather than the unfairness of the relative distribution of funding.

Historically, allied health has been less likely to have a seat at the management table than medical and nursing staff. This has started to change. However, the recurrent narrative across LHDs was that allied health disciplines were least likely to benefit from funding enhancements and most likely to be affected by budget cuts compared to medicine and nursing. Usually there was also very limited clerical support available, so that precious time was diverted away from direct clinical care to clerical duties that would be performed more quickly and cheaply by others.

There was also a widespread perception that the funding of the system relied on episodes of care and that community group activities were unfunded. The Reviewer was shown that this was not the way funds were allocated to LHDs. It is possible that LHDs may not pass on funds in the same way that the funds are received and there were certainly examples of targeted funding not being used to fund the target.

National Disability Insurance Scheme

The implementation of the NDIS has ongoing challenges. One interviewee summarised it as:

“It’s been a frustration bouncing between the boundaries of Health and NDIA. We need to hold the agency and ourselves to account”

The communique of the October 2019 meeting of the COAG Disability Reform Council acknowledged this:

“the Council maintained momentum in resolving long-standing issues regarding the interface between the National Disability Insurance Scheme (NDIS) and mainstream service systems”

“The Council agreed to an approach to improve the access and experience for participants with psychosocial disability in the NDIS and to address the interface between the NDIS and mainstream mental health systems”

and *“The Council agreed the National Disability Insurance Agency (NDIA) will introduce Justice Liaison Officers (JLOs) in each state...providing a coordinated approach to supporting NDIS participants in youth and adult justice systems”*

The NDIS has had a huge impact on allied health staff across the state.

Paediatric Rehabilitation

The NSW Paediatric Rehabilitation Model of Care project has been led by the three tertiary Paediatric Rehabilitation Services (PRS) – Kids Rehab, CHW; Rehab2Kids, SCH; and HNEkidsRehab, HNELHD. Funding provided to the MOH by the Minister for Health provided an enhancement of services and also funded a review of paediatric rehabilitation services, which was undertaken by Nexus Management Consulting from 2016-2017 and completed in February 2017. The key focus was defining the profile of the three Paediatric Rehabilitation Services.

Further work was conducted with funding from SCHN and HNELHD to look more broadly at both NSW PRS and state-wide services, looking at solution design, recommendations for implementation and design, and documentation of a model of care. This was undertaken from 2018-2019 and was completed in September 2019.

The third phase began in October 2019, with two key areas of focus. The first are initiatives that develop greater consistency and unity between the three NSW PRS to enhance access to specialist paediatric rehabilitation care for children and young people with complex rehabilitation needs. The second are initiatives that strengthen partnerships in care across sites, services and sectors to provide and support rehabilitation care as close to home as possible. This represents a phased approach to redesigning and strengthening paediatric rehabilitation service provision within NSW and the ACT. This can be shown diagrammatically in both Figure 11: Pyramid of care and Figure 12: Continuum of care.

Figure 11: Pyramid of care



Adapted from VPRS model of care

Figure 12: Continuum of care

NSW PAEDIATRIC REHABILITATION CONTINUUM OF CARE						
	Focus of Care	Funding Body	Facilities/Services	Services provided	Continuum of Rehabilitation Care	Enablers
PRIMARY 	Supports to maintain everyday living	State Government	<ul style="list-style-type: none"> Department of Education Family & Community Services Department of Housing Juvenile Justice 	<ul style="list-style-type: none"> Educational support Social care Child Protection Home Care Housing 		<ul style="list-style-type: none"> 'Empowering Child & Family' <ul style="list-style-type: none"> Info from child/family* 'Tell their Story' Info for families* Family/Parent support* Peer support Engagement strategies for priority pop's* Cultural Sensitivity* Interpreters* Telehealth* HealthPathways PHNs Social services Child protection* School Liaison* 'Go Local' <ul style="list-style-type: none"> Outreach - Regional Hubs, Clinics Telehealth - Inpt / Outpt advice, Education NSWPRS Consultancy Workforce capacity* Education & training* LHDs BIRPs PSOS CHNs LHD Care Coordinators ACI Transition Care Coordinators iCare NODIA Adult Rehab Services HITH
HOME <i>Rehab in Everyday Living</i>	Health services in local community	Federal Government State Government	<ul style="list-style-type: none"> General Practice Aboriginal Health Services Early Intervention Services Maternal/Child Health Youth Health Services 	<ul style="list-style-type: none"> Care Co-ordination Monitor & review Allied health 		
LOCAL						
SECONDARY 	Disability support in community	National Disability Insurance Scheme (non-compensable)	<ul style="list-style-type: none"> Non-Government Organisations (NGO) Allied Health ECEI 	<ul style="list-style-type: none"> Disability supports Maintenance supports Early Intervention 		<ul style="list-style-type: none"> '3 as 1' - PRS Working as One Governance Referral Criteria/Process* Consistent clinical practices Ease of appointments Data management* Workforce capability* Clearly defined Roles* Care co-ordination* PRS Info & Promotion Research & QI Infrastructure Tech & Equipment Other specialist services Transition Care* Hospital school
COMMUNITY <i>Shared Rehabilitation Care</i>	Rehab needs can be met in the local community	NSW Health iCare Lifetime Care (compensable only)	<ul style="list-style-type: none"> NSW Base Hospitals Brain Injury Rehabilitation Programs (BIRPs) Paediatric Spinal Outreach Service (PSOS) 	<ul style="list-style-type: none"> Paediatrician review 		
REGIONAL						
TERTIARY & QUATERNARY 	High complexity rehabilitation needs Intensive specialist rehabilitation New Injuries Intermittent or Continuous engagement	NSW Health	<ul style="list-style-type: none"> NSW PRS 3 PRS linked with 3 NSW Children's Hospitals Allied Health Departments linked with 3 NSW Children's Hospitals 	<ul style="list-style-type: none"> Day Rehab Intensive ambulatory rehab Specialist outpatient clinics & programs In reach to acute-consultation Inpatient Rehabilitation 		
HOSPITAL <i>Specialist Rehabilitation</i>						
STATE						

"the right rehabilitation care, at the right time, with the right team, in the right place"

*Denotes enablers present across the continuum

There are a number of challenges for the project:

- Although MOH was involved in the first stage, when funding was allocated by the Minister, currently there is no link between the Rehabilitation Model of Care Project and the MOH, a link which is required for the implementation phase. Specifically, there is no MOH sponsor.

- NSW PRS has no mandate to engage in communication with LHDs and to work in partnership to establish mechanisms to support rehabilitation care close to home. Implementation of the NSW Paediatric Rehabilitation Model of Care will require partnerships with key players from all LHDs. Despite the provision of care as close to home as possible being reflected in all major strategic planning documentation from the Ministry of Health, there does not appear to be a requirement for LHDs to provide services for children and young people such as rehabilitation.
- In rural and remote areas, there are often limited resources and development of capability requires a role for tertiary services to provide professional support for staff. However, funding for this upskilling does not seem to be available.
- There are opportunities to address limited services in regional, rural and remote areas through use of telehealth however this is currently unfunded for nursing and allied health staff.
- A specific issue has also been identified for young people transitioning to adult rehabilitation services, with a gap in the provision of botulinum toxin for the cohort that requires it.

This is another example where it is difficult to see that the needs of children and young people can be served in a coordinated manner if each individual LHD functions totally independently from the three specialist children's hospitals. Assigning governance for paediatric rehabilitation to the SCHN would be equally ineffective to the current model, because there would be no mechanism for operational control of staff or resources within the LHDs.

Developmental Assessment and Services

A widespread concern expressed by general practitioners and general paediatricians was the difficulties in accessing services for children with Autism Spectrum Disorder (ASD) and with global developmental delay. Part of the confusion for those requesting the services is that some diagnostic assessment units assess three children a day, others one child a day and sometimes one assessment might take a week. Some of this apparent variation is explained by services that are purely assessment versus those that also include patient management. However, most of the variation appears to relate to different models of assessment adopted by different assessment units. No evidence-based gold standard was apparent.

Concerns were also expressed that sometimes the pivotal problem was regarded as the diagnosis, rather than patient management; and that in some situations the developmental assessment was to meet criteria required by the Department of Education or by NDIS. Of course, if a particular form of assessment is required to access services, then it is clear why diagnostic assessments would take that form.

The Reviewer was told that that access to the NDIS is based on function not testing, so that if a 3-year-old child is recognised by a general paediatrician as having global developmental delay, the child does not need to be seen by a Developmental Assessment Unit to access the NDIS. This would suggest that some of the referrals may not be necessary, if the primary reason for the referral is to document eligibility for NDIS.

Intake criteria for diagnostic services vary widely. Some services are using triage to offer tiered services to better tailor the needs of the child and family to the services offered. This seems a promising approach, which could be more broadly adopted.

Child Protection and Domestic Violence

Violence, abuse and neglect (VAN) is used by NSW Health as an umbrella term to describe three types of interpersonal violence:

- all forms of child abuse and neglect
- domestic and family violence
- sexual assault.

Due to the high degree of connection and overlap in the experiences of, and responses to, these issues, the decision was made to include child protection creating PARVAN (Prevention and Response to Violence Abuse and Neglect). This is in the context of the Royal Commission report into Institutional Responses to Child Sexual Abuse. The Ministry has developed a Framework, Integrated Prevention and Response to Violence, Abuse and Neglect

(August 2019)⁹. Figure 13: Integrated Prevention and Response to Violence, Abuse and Neglect Framework and Figure 14: Violence, abuse and neglect: the case for change are taken from the executive summary of that Framework.

Figure 13: Integrated Prevention and Response to Violence, Abuse and Neglect Framework

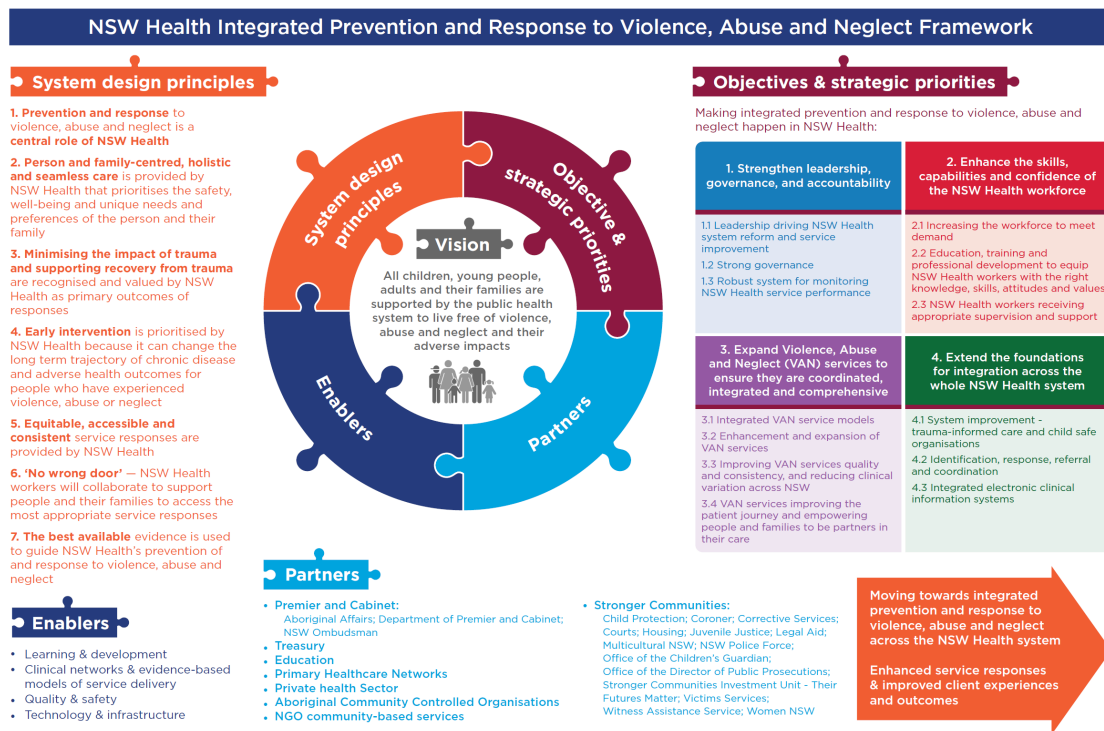
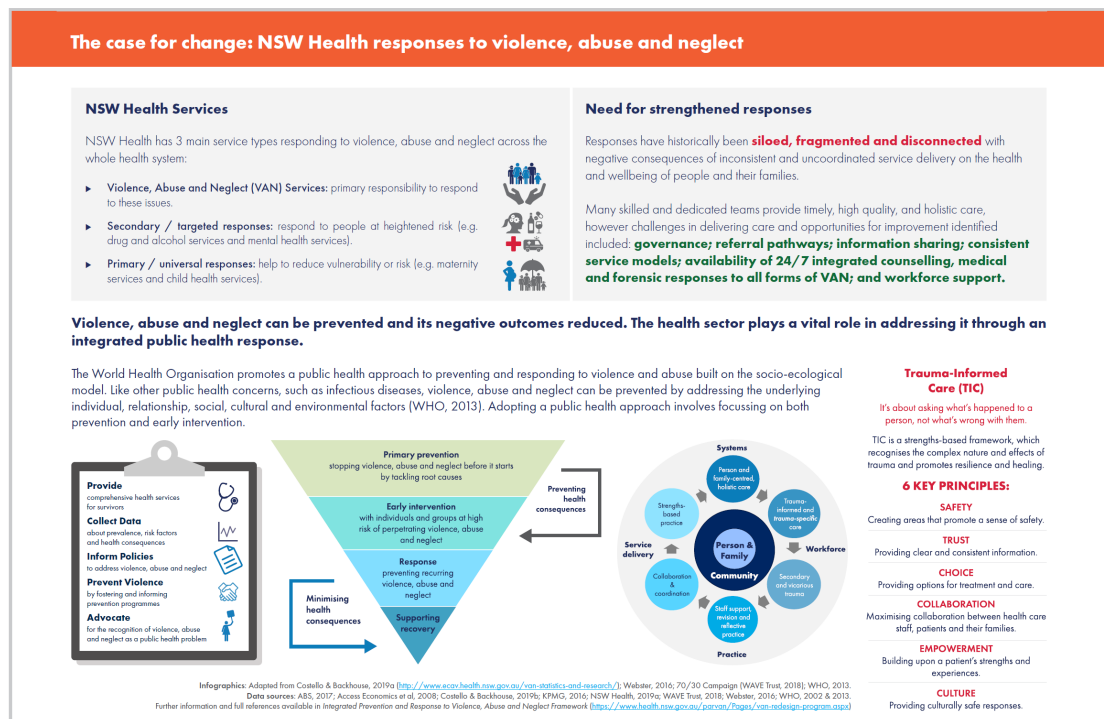


Figure 14: Violence, abuse and neglect: the case for change



⁹ <https://www.health.nsw.gov.au/parvan/Publications/iparvan-framework.pdf>

The Framework has been accompanied by a funding enhancement. Governance has been strengthened, clinical gaps have been identified and there has been progress on increasing capabilities. An implementation road map to build services has been accompanied by clear plans to monitor outcomes and to hold LHDs and SCHN accountable.

A number of interviewees commented on the challenge to thinking for the NSW health system.

“The rigid nature of the medical model doesn’t even allow us to understand the issues”, “It’s a very big change for the Ministry, the Pillars and Districts to embrace the violence abuse neglect perspective” and “We’re not funded to do early intervention”.

Despite these reservations, there was acknowledgement of the progress that had been made. The Senior Executive Forum has been involved in key discussions and implementation is occurring in LHDs. An ongoing challenge remains the shortage of staff to provide effective intervention when women are identified by a positive response to screening questions, conducted in the emergency department setting, about domestic violence. One children’s ward in NSW has implemented screening for domestic violence as a routine part of inpatient assessment and has appropriate resources to act upon a positive screen; the rest of the system is wrestling with how to ensure that resources are available, not just to screen but also to provide support.

Another issue raised related to the delivery of paediatric forensic medical services across NSW, especially for cases of suspected Physical Abuse and Neglect of Children (PANOC). In children with suspected abusive injuries, a paediatrician is expected not only to assess the child and family (usually through history, examination and appropriate forensic examinations) and manage the complex interagency investigation response but also to provide a clear, logical, evidence-based forensic opinion that is useful to the court, police, statutory agencies, other health workers and the child and family. In the initial stages this opinion may be provided orally but, in most cases, a written report or expert certificate is required. Furthermore, paediatricians may be called to court to give oral testimony as expert witnesses on the basis of their written opinions.

Clearly, this is a complex and nuanced process, particularly for paediatricians who do not regularly undertake this work and who may have had minimal formal training and experience. A poorly-formed opinion may have major consequences for the child, family and community, e.g. missed opportunities to prevent further harm, children unnecessarily removed from their family’s care, or parents or carers wrongly accused of harming children. The nature of this work has a tendency to attract a high level of judicial and public scrutiny.

The provision of this forensic medical service for children outside the specialist children’s hospitals is provided by local paediatricians. This may occur on an ad hoc basis with minimal peer review, supervision and clinical oversight. Understandably, local paediatricians are reluctant to undertake this work. There are neither established mechanisms nor clinical guidelines in place to ensure that forensic assessments for PANOC cases are standardised, nor are there any requirements for paediatricians to ensure that their reports have been appropriately peer reviewed and are of acceptable standard, prior to submission.

In NSW, most of the paediatric forensic expertise is currently held by a small number of paediatricians working within the Child Protection Units (CPUs) at CHW and SCH. While the two CPUs do provide advice and consultation to paediatricians outside the SCHN, there are no formal processes in place and no system to ensure an equitable service of high standard. There is also a Child Protection Team in HNE.

NSW Health has set up a telephone hotline, which is staffed by paediatricians from the three specialist children’s hospitals and is designed to provide clinical advice and consultation for forensic medical services in NSW. The opinions expressed to this Review was that, while this service was of value, it did not adequately address the complex issues related to the provision of complex forensic opinions by paediatricians who need significant support throughout the entire process. Ideally, the delivery of a telephone hotline should be embedded and delivered through a centrally based clinical forensic service for children. This would allow coordination and standardisation of services across NSW, enable formal processes for peer review of expert certificates and forensic reports, and facilitate the establishment of clinical guidelines. Statewide services currently exist in Victoria and Queensland, with the Victorian Forensic Paediatric Medical Service operating as a hub and spoke model and a Child Protection and Forensic Medical Service based at Queensland Children’s Hospital. Comparisons of governance across Australian states are problematic. The specialist children’s hospitals in NSW need a mechanism to work with LHDs to provide optimal forensic services.

Recommendations

The key findings as described in Section 9 above, provide a platform for new ways of working and opportunities for improvement. The recommendations that support this are presented below.



These recommendations link with the Secretary's priorities for patient safety and experience and value based health care

Universal Health Home Visiting

Issue: One of the barriers to UHHV has been that the funding provided to LHDs to support it has not always been directed towards UHHV. The current plans to continue with UHHV, to have a shorter first visit, and to use the visit to identify those who need further visits is supported by this Review. This approach is recommended rather than universal contact.

Recommendation 47: Universal Health Home Visiting continue to be promoted, together with identification of those who need further visits.

Issue: One of the gaps in the current UHHV model can be the transition from maternity services. This Review has identified the need to socialise the midwife completing the maternity journey and providing active encouragement in handing over the family to both the child and family health nurse and the general practitioner.

Recommendation 48: Each LHD ensure an effective handover of the family from the midwife to both the child and family health nurse and the general practitioner.

Allied Health services

Issue: In a resource constrained environment, there will be pushback against any recommendation for an increase in allied health staffing. The Reviewer does not believe that the current system provides allied health disciplines with an equal opportunity with medicine and nursing in attracting a fair share of funding.

Recommendation 49: The Ministry of Health recognise that the demand for allied health services for children, young people and families far exceeds supply and adopts a long term strategy to address the staff shortages. Targets for investment include initiatives for the First 2000 Days, for mental health and for interventions for domestic violence.

Paediatric Rehabilitation

Issue: Delivery of services where both LHDs and specialist children's hospitals are both essential (often characterised as a tiered network) require a governance model that facilitates effective interaction. The MOH has a critical role in coordinating this process. This is another example of an area that is too small to be considered a supra-regional specialty but that needs central oversight.

Recommendation 50: The Ministry of Health works with specialist children's hospitals and LHDs to better coordinate paediatric rehabilitation services across NSW.

Developmental assessment and services

Issue: There appears to be wide variation in the intake systems, diagnostic assessment approach and rationale for developmental assessment, with limited agreement on the ideal model of care.

Recommendation 51: Intake systems for diagnostic assessment services should determine whether a detailed assessment is what is required. In particular, if a functional assessment for NDIS purposes is needed, a general paediatrician would be able to provide the report.

Recommendation 52: ACI undertake a project to determine the most efficient and effective way both to perform developmental assessment and to focus on increasing the capacity of families to adjust to and optimise management of their child's disability.

Recommendation 53: MOH initiate interagency discussions with areas such as Education and NDIS to clarify and simplify the assessment and information required for eligibility for services to support children with developmental needs.

Child Protection and Domestic Violence

Issue: Resources to provide support post screening are required to facilitate the necessary response to domestic violence.

Recommendation 54: The commitment to screening for domestic violence be accompanied by resources to assist women and their children.

Issue: Improved coordination and support is required for clinicians working in the area of paediatric forensic medical services.

Recommendation 55: The Ministry of Health works with the specialist children's hospitals and LHDs to better coordinate paediatric clinical forensic services across NSW. One component is that reports relating to alleged physical assault should not be submitted until they have been peer reviewed.

Section 10: ADHD

Key messages

1. The diagnosis of ADHD and subsequently the increased workload for paediatricians in the public system has increased considerably in the last decade.
2. The increasing demand for services and some variation in the management of ADHD warrants a review of the model of care for ADHD service delivery.
3. The prescription of stimulant medications, roles, responsibilities and protocols is an area for further investigation.

Key findings

ADHD was perceived as a major issue throughout this Review. It is hard to obtain valid data but the Reviewer was told regularly that 50-70% of the workload of a paediatrician in private practice was for children whose problems included ADHD. Similarly, staff specialists reported that the demand on outpatient services both in hospitals and in the community was far more than they were able to meet. When the Reviewer was shown lists of patients attending clinics, it was clear that ADHD was a dominant diagnosis.

Three main issues were identified as being responsible for the gap between demand for service and availability of supply.

1. There is a drift away from private practice as the model for consultant paediatricians, so that the demand was moving towards public services. This was also reported to be compounded by a financial issue that many families were unable to afford the gap payment between the Medicare benefit and the cost of consultation in private practice.
2. ADHD has become more common and is more complex, often being associated with comorbidities. The data section of this report supports the increase in prescribing of stimulant medication.
3. The model of care in NSW does not allow general practitioners to write initial prescriptions for stimulant medication and there is restricted capacity for them to write repeat prescriptions after there has been an assessment and initiation of treatment by a paediatrician.

Different practitioners have attempted to manage the gap between supply and demand in different ways. One common approach was the development of a business case to employ extra paediatricians in the public sector to see these children. Although this was an understandable approach at an individual facility or LHD level, across the system the Reviewer saw this as neither likely to be funded nor likely to meet demand.

Another approach was to ration services. An example of this was a metropolitan hospital that has indicated that it will not accept any child referred for assessment and treatment of ADHD. This approach increases inequity in the system because parents who can afford care in private practice are able to access care for their children.

Another approach was to revisit the model of care. The Reviewer looked for evidence of the benefits of stimulant medication. The Cochrane Library is a trusted source of data from randomised controlled trials. A review of “*Benefits and harms of methylphenidate for children and adolescents with attention deficit hyperactivity disorder (ADHD)*” was published by Storebo et al. in 2015. The key results were:

“Findings suggest that methylphenidate might improve some of the core symptoms of ADHD – reducing hyperactivity and impulsivity and helping children to concentrate. Methylphenidate might also help to improve the general behaviour and quality of life of children with ADHD. However, we cannot be confident that the results accurately reflect the size of the benefit of methylphenidate.”

Their conclusion began:

“At the moment, the quality of the available evidence means that we cannot say for sure whether taking methylphenidate will improve the lives of children and adolescents with ADHD...”

The Royal Australasian College of Physicians released draft Australian guidelines on ADHD in November 2009 and they remain on their website. These guidelines were developed in accordance with NHMRC guideline development requirements. However, the draft guidelines were considered but not approved by the Council of NHMRC in December 2011.

The National Institute for Health and Care Excellence (NICE) published its guidelines on the diagnosis and management of ADHD in March 2018, with an updated version in September 2019.

These guidelines include recommendations about appropriate service organisation and training, including:

“People with attention deficit hyperactivity disorder (ADHD) would benefit from improved organisation of care and better integration of child health services, child and adolescent mental health services (CAMHS) and adult mental health services.”

And *“Trusts should ensure that specialist ADHD teams for children, young people and adults jointly develop age-appropriate training programmes for the diagnosis and management of ADHD for mental health, paediatric, social care, education, forensic and primary care providers and other professionals who have contact with people with ADHD.”*

In a section on why the committee made its recommendations is the following statement about medication for children 5 years and over and young people with ADHD:

“Evidence showed the benefit of medication in this age group in improving ADHD symptoms and this was in line with the committee’s experience. The committee acknowledged there are concerns about recommending medication for ADHD and particularly the uncertainty over the long-term adverse effects of medication in growing children. However, the committee agreed that untreated ADHD can have far-reaching, long-lasting negative impacts on a child or young person’s life (for example, affecting academic performance, interpersonal relationships, work, personal issues, substance use and driving). Medication offers a better balance of benefits and costs than non-pharmacological interventions, so the committee agreed to recommend it when ADHD symptoms are persistent and still causing a significant impairment in at least one domain of everyday life despite the implementation and review of environmental modifications. The committee was aware of the implications of medication in this young population and made several recommendations to ensure its responsible use.”

The management of ADHD across NSW has some variation of care but clinicians tend to follow the NICE guidelines. The more specialised community child health units are more likely to have a multidisciplinary team and less likely to prescribe medication without a behavioural intervention. Both in private practice and in public clinics, the patient load created by reviewing children on medication limits the capacity to see new patients. However, the problem appears greater in the public system, particularly because of the comorbidities that many of these children have.

Prescribing stimulant medications

One possible solution is to incorporate general practitioners in the process of reviewing children and writing repeat prescriptions. Any medical practitioner can prescribe PBS ADHD medicines, as long as prescribing is also in accordance with State or Territory law. Nurse practitioners can prescribe continuing therapy for all ADHD medication except atomoxetine providing they also comply with State/territory law. Many interviewees for this Review quoted the situation in Queensland, where GPs have been permitted to write repeat prescriptions. Many interviewees proposed pilot studies in NSW, in which GPs would be supervised by paediatricians to review children with ADHD and provide repeat prescriptions if that was appropriate.

In fact, the provisions for issuance of authorities to prescribe psychostimulants for children do not exclude general practitioners. An individual GP, with a letter of support from a specialist, can apply for an authority for a named child for 12 months. Each child requires a separate approval. Appendix 5 provides the details. Unfortunately, this is a cumbersome system because it does not allow a GP to seek a more general approval to treat a series of children with ADHD (a Patient-Class Approval). This patient-class approval system operates in Queensland.

Another community paediatrician has been considering a revised service delivery model of either a CNC or a GP working in a shared care clinical model with a paediatrician in the initial and follow up assessment.

Consultation reflected a widespread view that a different delivery system of care needs to be considered for the management of ADHD. A number of sites indicated their willingness to participate in a trial of supervising and supporting GPs to write repeat prescriptions and an expression of interest to LHDs would be likely to result in many positive responses from suitable units. One possible model would be that the local Director of Paediatrics would work with PHNs and local GP practices to identify appropriate GPs. GPs would be eligible if they held Fellowship of the Royal Australian College of General Practitioners or Diploma of Child Health or equivalent and agreed to training. Success would be measured by monitoring that the GPs measured height, weight and blood pressure and documented in the child's medical record response to therapy and the absence of significant side effects. A likely model would be that paediatrician and GP use the same proforma for documenting outcomes.

In the likely scenario that the pilot studies were effective, accredited general practitioners should receive prior general approval (known as Patient-Class Approval) to prescribe repeat scripts for stimulant medication, as is the case in Queensland.

The current NSW model of care, with a paediatrician responsible for all aspects of prescribing and monitoring need for and response to stimulant medication may not be the best system. For example, clinical nurse practitioners working in a shared care model, general practitioners working in a shared care model, or indeed various combinations are possible service delivery mechanisms. If this is regarded as worthwhile pursuing, it is likely that a multicentre study across Australia would be the optimal study design.

Some work is already being done. The Enhancing Child Health Outcomes (ECHO) project in Queensland for ADHD aims for early identification of developmental problems by engaging parents in the GP clinic waiting room and linking them up with state services and pathways to care. In Victoria, Professor Harriet Hiscock has a project on strengthening primary care for children through an integrated paediatrician-GP care model. The details are shown in Appendix 4. Many of these children had ADHD.

Recommendations

The key findings as described in Section 10 above, provide a platform for new ways of working and opportunities for improvement. The recommendations that support this are presented below.



These recommendations link with the Secretary's priorities for patient safety and experience and value based health care

ADHD

Issue: There was a widespread view that a different delivery system of care needs to be considered for the management of ADHD.

Recommendation 56: Pilot studies across NSW implement ways for general practitioners to write repeat prescriptions for stimulant medication for ADHD.

Recommendation 57: If pilot studies are successful, general practitioners be allowed to receive prior general approval (known as Patient-Class Approval) to write repeat prescriptions for stimulant medication for ADHD.

Issue: The current NSW ADHD model of care, comprising a paediatrician responsible for all aspects of prescribing and monitoring need for, and response to stimulant medication, may not be the best system.

Recommendation 58: A group of clinicians experienced in management of children with ADHD consider whether a trial be conducted to compare different service delivery mechanisms of care for assessment and management of ADHD.

Section 11: Young people

Key messages

1. At SCHN and John Hunter Children's Hospital, Adolescent Medicine provides holistic multi-disciplinary care to adolescents who have a range of complex health and social vulnerabilities. Young people living outside these areas experience barriers to accessing healthcare that meets their needs, as there are very few clinicians skilled in youth health.
2. Other major themes were that:
 - young people commonly use digital technology to look for health information and information about health services, but the majority of young people believed that visiting a health professional was better than the internet
 - marginalised young people perceived and experienced multiple forms of discrimination
 - the complexity and fragmentation of the health system can be mitigated by system knowledge and by support in navigating the system.
3. There is a limited capacity and capability to manage young people and a requirement for more accessible training in this area to upskill the workforce.

Key findings

At SCHN and John Hunter Children's Hospital, Adolescent Medicine provides holistic multi-disciplinary care to adolescents who have a range of complex health and social vulnerabilities. The models of care are innovative and draw on best practice, with clinicians who are recognised specialists in adolescent medicine and health. Elsewhere across the state, young people experience barriers to accessing healthcare that meets their needs, as there are very few clinicians (such as general practitioners, paediatricians or nurses) outside the metropolitan area who have competency and interest in youth health. Access 3, published by Kang et al, explored health access and health system navigation for young people aged 12-24 years, with a focus on several marginalised groups, specifically Aboriginal and Torres Strait Islander, homeless, refugee background, living in rural and remote NSW, and sexuality and/or gender diverse background. Health and wellbeing were poorer when compared to a nationally representative sample of Australian young people. A majority had had recent contact with the health system, especially general practice. Cost was the most frequently cited barrier to accessing health care.

A smaller group of marginalised young people were followed for a year. Difficulties with access and navigation of the different parts of the health system were common. The report describes that:

"Structural and system factors could impede smooth movement through the health system, while accessing any individual service at a particular point in time (including follow up care) often only occurred after the young person weighed up a range of factors, such as direct and indirect costs, convenience, previous experience, and competing priorities...Health professionals similarly reported that services may not always have the capacity (through lack of experience, or expertise, as well as bureaucratic factors) to meet the needs of young people who belong to more than one marginalised group."

Other major themes were that:

1. Young people commonly use digital technology to look for health information and information about health services, but the majority believed that visiting a health professional was better than the internet.
2. Marginalised young people perceived and experienced multiple forms of discrimination.
3. The complexity and fragmentation of the health system can be mitigated by system knowledge and by support in navigating the system.

Many interviewees highlighted the issue that young people do not sit comfortably within paediatrics and similarly do not fit comfortably within adult services. One example is the Patient Reported Experience Measure (PREM), which is designed to be completed by the adult patient or the parent of a child but not by both parents and young people. Work is underway to enable reporting on a single hospital experience from the perspectives of both young person and parent.

This Review noted the limited capacity and capability to manage young people. There are very high quality services but their reach is limited. Similarly, there are excellent examples of programs transitioning young people from paediatric services to adult care but more work remains, particularly in the transition of young people with developmental delay.

There has been an unwarranted assumption that adolescents and young adults enjoy good health and that they have limited need for health services. The limited morbidity and mortality measures that we have indicate that not only is this incorrect but also that appropriate intervention in young people can have major long-term benefits. These benefits are not limited to health and include educational outcomes, employment and avoiding the justice system. The second decade of life provides an important opportunity to intervene to establish favourable lifelong health trajectories.

In the same way that cross accreditation has been identified as an issue for staff involved in outreach clinics, there is a need to recognise the importance of cross accreditation of staff to manage the interfaces between paediatric and adult care. Similarly, the benefits of care navigators identified in Recommendation 29 also apply to young people, for transition to adult care and for working across the complex systems of mental health, drug and alcohol services and chronic medical care services.

Recommendations

The key findings as described in Section 11 above, provide a platform for new ways of working and opportunities for improvement. The recommendations that support this are presented below.

Young people



These recommendations link with the Secretary's priorities for patient safety and experience and value based health care

Issue: There is a requirement to build capacity and capability in the workforce across NSW so that more young people can access quality healthcare to meet their changing health needs and to avoid loss of the improvements in early childhood health.

Recommendation 59: The Ministry of Health support RACP tier 1 and 2 training requirements in AYAM in all general paediatricians/community child health/behavioural paediatricians.

Recommendation 60: The Ministry of Health build capacity among the AYAM workforce through funding of advanced training opportunities in adolescent medicine at the specialist children's hospitals and in metropolitan, rural and regional locations with appropriate supervisory arrangements.

Recommendation 61: The Ministry of Health work with relevant groups to develop training pathways and competency frameworks for clinical nurse consultants in AYAM, through dedicated clinical qualifications that provide more breadth and depth than the existing workshops and resources.

Recommendation 62: LHDs and SCHN provide dedicated training opportunities and ongoing support for nurses in adolescent inpatient and outpatient units and youth health centres.

Recommendation 63: The Ministry of Health work with primary health providers to identify opportunities for training and ongoing support for those working with young people.

Issue: There is an absence of meaningful feedback from both parents and young people about their experience and outcomes.

Recommendation 64: The Patient Reported Experience Measure (PREM) be modified so that both parents and young people can provide feedback, rather than one or the other.

Section 12: Mental health

The term mental health is used by some people to refer to a state of health and by others to a state of illness. In particular, when people talk about the need to address the mental health of children, young people and their families, there is an enormous difference between a broad focus on emotional well-being and focussing on those who have psychotic illnesses. Both approaches are very important.

Key messages

1. The epidemiology of the onset of psychotic mental illness indicates that 75% appears by the age of 25, with a surge from puberty. Early intervention has an enormous return on investment, interrupting the traffic to welfare, increasing the likelihood of getting young people back to education and increasing the likelihood that they will gain employment.
2. Mental illness and in particular severe mental illness, requires person-centred, integrated care across multiple services, providers and settings. Service demands and pressure on the mental health system and workforce are significant and increasing.
3. There is a need to improve capability training and structures to support a skilled and effective workforce (broader than the mental health workforce) that is in contact with people with mental health issues.
4. The NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022 provides overarching strategic actions in the areas of perinatal care and early intervention for children and young people.
5. The key points and recommendations of the Productivity Commission's Draft Report on Mental Health are all relevant to children, young people and their families.

Key findings

Mental illness and behavioural issues

Throughout this Review, it was often unclear whether interviewees were talking about mental health or about mental illness. Similarly, there was a wide disparity between what mental health professionals regarded as within the domain of mental health compared to the beliefs of those outside mental health. Although many interviewees wanted to discuss both those with acute mental illness and those who had acute behaviour disturbance as an overall problem, others had a very different perspective. In addition, for the many individuals with a combination of physical and mental illness, there were many ambiguities about how health professionals should work together in a holistic way.

The management of children and young people with mental health problems and acute behavioural problems was a major vulnerability identified across LHDs. The volume of comments was massive. Typical quotes were:

"Lack of appropriate model of care and facilities for children and young people with acute behavioural problems"

"Limited capability to meet the needs of children with complex social problems and mental health issues"

"Limited access to psychiatrists, paediatricians provide care to mental health patients with support from mental health consultants"

"Access to psychiatric consultation and liaison services is inconsistent"

"The lack of consistent, coordinated mental health services and models of care at LHD level"

"Lack of services that meet the needs of children with a mental health problem"

These difficulties were also heard in the Review from clinicians in most LHDs and were raised by representatives of children and young people, as well as by bodies such as the Australian Medical Association (AMA).

Workforce capacity and capability

Both paediatricians and general practitioners reported their discomfort at treating acute behavioural disorders and mental illness in children and young people because they did not believe that they had the appropriate skills and qualifications. The Reviewer is aware of a failed attempt in the past between the RACP and the Royal Australian and New Zealand College of Psychiatrists (RANZCP) to train general paediatricians as child psychiatrists.

Arguably, the program was too ambitious, with the expected outcome of individuals with dual qualifications in paediatrics and child psychiatry. Some paediatricians in this Review indicated their enthusiasm for formal training that would better equip them to participate in the management of children and young people such as those who attend the ED with bleeding arms after self-injury. Currently, many of them find themselves out of their clinical comfort zone as the doctor under whom the child or young person is admitted.

Most saw the ideal model as a combination of upskilling on their behalf combined with mental health support from someone such as a clinical psychologist. The Reviewer does not purport to have the knowledge and skills to do any more than suggest the notion of training programs.

It is clear from the Review that access to telephone advice from a mental health professional to a paediatrician is perceived by both parties to provide enhanced care to children and young people with behaviour disorders and mental illness. However, most paediatricians who supported the concept of formal training imagined a 6-12 months course rather than something more limited. It may be appropriate for GPs to undertake this training as well.

Clearly there is a big mental health agenda and a complex set of moving parts. However, on the ground, what child health professionals see is a demand for mental health services that far exceeds the capacity of the available service providers.

In a few cases, this Review identified a culture of *“collectively it’s our problem”* with people working together constructively. More commonly, there was limited engagement and often it was unclear what levers there were to improve levels of collaboration. This Review recommends reconsideration of models of care for children and young people with mental illness and with acute behaviour disorders.

The NSW Service Plan for People with Eating Disorders 2013-2018 noted the historical *“lack of clarity about which clinical system holds primary responsibility for care of people with eating disorders”* and provided a tiered structure for care. Interviewees indicated service gaps, significant difficulty in finding an available bed for children and young people with serious disease, and some LHDs that were unable to meet their expected service delivery capabilities.

NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022

The NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022: A Framework and Workforce Plan for NSW Health Services¹⁰ highlights the policy context of the NSW Mental Health Reform, with the first strategic direction of strengthening prevention and early intervention, with a stronger focus on services for children and young people. The framework notes that intervening early in children and young people *“provides an opportunity to positively affect the life trajectory of children and young people”* and that for women in the perinatal period and their infants *“intervening early and ensuring partnerships and coordination with maternity, child and family health, mental health and other relevant support services is essential for women in the perinatal period and their infants and families”*.

The implementation plan¹¹ highlights the need to enhance the mental health workforce in mental health leadership, in medical, nursing and allied health, in mental health community support services and *“supporting capacity in partner workforces”*.

The Strategic Framework also highlights the fact that mental health clinical and community support services are delivered across a range of service settings and by a variety of providers, including:

- community managed organisations

¹⁰ <https://www.health.nsw.gov.au/mentalhealth/resources/Pages/mh-strategic-framework.aspx>

¹¹ <https://www.health.nsw.gov.au/mentalhealth/resources/Publications/sfwp-implement-plan.pdf>

- Aboriginal Community Controlled Health Services
- general practitioners
- primary health networks
- private providers
- private hospitals
- local councils, public and community managed organisations also offer health promotion, prevention and early intervention programs.

Productivity Commission enquiry in to mental health

In October 2019, the Productivity Commission released its Draft Report on Mental Health. In the key points is the following:

“The treatment of mental illness has been tacked on to a health system that has been largely designed around the characteristics of physical illness. But in contrast to physical health conditions

- *mental illness tends to emerge in younger people (75% of those who develop mental illness, first experience mental ill-health before the age of 25 years) raising the importance of identifying risk factors and treating illness early where possible.*
- *There is less awareness of what constitutes mental ill-health, the types of health available or who can assist. This creates the need for not only clear gateways into mental healthcare, but effective ways to find out about and navigate the range of services available to people.*
- *The importance of non-health services and organisations in both preventing mental illness from developing and facilitating a person’s recovery are magnified, with key roles evident for – and the need for coordination between – psychosocial supports, housing services, the justice system, workplaces and social security.*
- *Adjustments made to facilitate people’s active participation in the community, education and workplaces have, for the most part, lagged adjustments made for physical illness, with a need for more definitive guidance on what adjustments are necessary and what interventions are effective.”*

The Draft Report recommends reform in five areas:

1. Prevention and early intervention for mental illness and suicide attempts.
2. Close critical gaps in healthcare services.
3. Investment in services beyond health.
4. Assistance for people with mental illness to get into work and enable early treatment of work-related mental illness.
5. Fundamental reform to care coordination, governance and funding arrangements.

All these key points and reform areas are relevant to children, young people and their families. The Productivity Commission makes numerous specific recommendations about what should be started now. These will not be repeated in this Review.

Recommendations

The key findings as described in Section 12 above, provide a platform for new ways of working and opportunities for improvement. The recommendations that support this are presented below.



These recommendations link with the Secretary’s priorities for strengthening governance and accountability, patient safety and experience, value based health care and systems integration

Mental health

Issue: Consultation identified that various services do not accept responsibility for assessment and/or ongoing management of children and young people with mental illness. The MOH needs to ensure that LHDs individually and collectively recognise the need to provide services.

Recommendation 65: The Ministry of Health oversees meaningful engagement between health care providers who are both inside and outside the mental health system to develop and implement a collaborative approach to addressing both mental health and the mental illness needs of children and young people.

Issue: Paediatricians are required to care for children and young people with acute behavioural disorders and with mental illness. Many paediatricians find themselves out of their clinical comfort zone with this group of patients. It is recognised that paediatricians require appropriate training, knowledge and experience to provide safe and appropriate care. One possible example is the development of “entrustable professional activities” by the Neurodevelopmental and Behavioural Society of Australasia.

Recommendation 66: Training programs be developed to provide paediatricians with a minimum standard of capability and qualifications to safely care for children and young people with acute behavioural disorders and with mental illness.

Issue: Most general paediatric nurses feel that they have limited capability for managing children and young people with acute behavioural disorders and with mental illness.

Recommendation 67: Training programs be developed for paediatric nurses to provide qualifications for managing children and young people with acute behavioural disorders and with mental illness.

Issue: There is a significant need to increase the numbers of allied health professional working in mental health.

Recommendation 68: The MOH recognise that the demand for allied health professional services in mental health far exceeds current supply and develops a targeted strategy to address the issue.

Issue: The Productivity Commission’s Draft Report on Mental Health recommends five key reform areas, all five areas are relevant to children, young people and their families.

Recommendation 69: This Review welcomes the findings in the Draft Report from the Productivity Commission on Mental Health and commends the Draft Report to the MOH. One area to highlight is the need for early intervention in young people diagnosed with psychosis.

Issue: Providing GPs with enhanced skills to manage complex behavioural and mental health problems in children is being studied in the ECHO project in NSW. To participate in the panel discussion, GPs are using the Medicare item number for “case-conferencing”.

Recommendation 70: The MOH supports projects implementing and evaluating models of care increasing the skills of GPs in managing complex behavioural and mental health problems in children.

Section 13: First 2000 days

Key messages

1. The first 2000 days is a critical time for physical, cognitive, social and emotional health. What happens in the first 2000 days of life has been shown to have an impact throughout life.
2. Most interviewees identified a clear understanding of the importance of the first 2000 days and an intention to change the focus of services to identify and assist the most vulnerable families. There is further work to engage not only the maternity and paediatric clinicians but also those working with adults to understand the importance of early life issues for long term outcomes in adults.
3. To fully realise the goals of the First 2000 Days Framework and implement sustainable change for the system and improved outcomes for children and families, it is vital that government agencies and other organisations work together to achieve success.

Key findings

The First 2000 Days Conception to Age 5 Framework

Research findings about the significance to both children and adults of the first 1000 days of life have been published widely and are well known in the paediatric community. Most researchers would refer to the Barker hypothesis on the fetal origins of adult disease as the beginning of a major shift in our understanding about the role that early life plays in the health and wellbeing of adults. In 2017, the Australian Centre for Community Child Health at the Murdoch Children's Research Institute published a comprehensive review on the evidence of the importance of the First Thousand Days. NSW Health has made the decision to broaden the focus to the first 2000 days to include the evidence that quality education in the preschool years also has a strong impact on long term outcomes.

The First 2000 Days Conception to Age 5 Framework¹² was published in February 2019. The executive summary makes the case clearly:

"The first 2000 days is a critical time for physical, cognitive, social and emotional health. What happens in the first 2000 days of life has been shown to have an impact throughout life. For example, early life experiences are:

- *strongly predictive of how a child will learn in primary school*
- *a predictor of school performance, adolescent pregnancy and involvement with the criminal justice system in the adolescent years*
- *linked to increased risk of drug and alcohol misuse and increased risk of antisocial and violent behaviour*
- *related to obesity, elevated blood pressure and depression in 20-40 year olds*
- *predictive of coronary heart disease and diabetes in 40-60 year olds*
- *related to premature ageing and memory loss in older age groups."*

Interventions

In particular, the Framework emphasises that exposure to particular stressors before birth and exposure to adverse experiences in childhood increases the likelihood that an individual will have poor health and wellbeing later in life. The higher the number and severity of stressors and the higher the number of adverse experiences in the early years of life, the greater the risk to long term health and wellbeing. Adverse childhood experiences include emotional, physical or sexual abuse, physical or emotional neglect, presence of domestic violence,

¹² https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2019_008.pdf

household substance abuse, household mental health issues, parental separation or divorce and a household member who is in prison.

Fortunately, some interventions have been shown to help protect and buffer these adverse childhood experiences, such as:

- parenting support programs
- social support for parents
- support programs for young people
- programs to prevent teenage pregnancy
- support and treatment for substance abuse
- support and treatment for mental health issues
- high quality childcare
- income support for lower income families
- prevention of domestic violence
- home visiting for at risk families with newborns.

Implementation

If successfully implemented, the First 2000 Days would have a greater impact than curing childhood cancer.

This Review was not a review of maternity services, except for the relevance of the periconception period and pregnancy to the first 2000 days. The NSW Health Strategic Priorities 2019-2020¹³ has a strategy under Population and Public Health to “Support pregnancy and the first 2000 days”. The executive sponsor for this strategy is the Health and Social Policy Branch, whereas every other Population and Public Strategy has Population and Public Health as the sponsor. During visits to LHDs in the early part of this Review, Public Health Units did not appear to be actively engaged with plans for implementation of the strategy for the first 2000 days and stated that this was out of their scope. Later in this Review, the mood had changed and the opportunities with embracing the first 2000 days had been recognised.

There is a risk that the importance of the first 2000 days is limited to maternal and child health services. Just as immunisation programs conducted in children and adolescents against Human Papilloma Virus (HPV) target the prevention of cervical cancer in adult women, the first 2000 days should be viewed in a similar way as a long-term investment, notwithstanding its immediate short-term benefits.

The Reviewer was informed that antenatal services will place greater emphasis on identification of families with vulnerabilities and that resources would be concentrated on them. The limited engagement that this Review had with maternity services indicated a clear understanding of the importance of the first 2000 days and an intention to change the focus of services to identify and assist the most vulnerable families.

In Community Child Health, the importance and potential of the first 2000 days was embraced widely. *“It’s a game changer”* was a common response. There was excitement about the potential to make a huge positive long-term impact on children, not only during their childhood but also into their adult lives. There was some concern that the resources to implement would not be available in the tight financial environment.

The MOH has an extensive program of education so that *“All staff in the NSW health system understand and promote the importance of the first 2000 days and the best opportunities for action.”*

The message has certainly been heard and embraced by Chief Executives in LHDs and, as indicated above, there has been progress in engaging Population and Public Health and Primary Health Networks. There are many opportunities to spread the message more widely among health professionals whose main work is in the field of adult medicine. This Review also identified the need to ensure that all those who educate health professionals understand and teach their students that the importance of the underlying concepts about the importance of the first 2000 days for physical, cognitive, social and emotional health are not seen as only paediatric issues or only issues for pregnancy but form part of a framework for understanding the importance of early life issues for outcomes in adults.

¹³ <https://www.health.nsw.gov.au/priorities/Documents/strategies-priorities.pdf>

Cross agency collaboration

A whole of government approach is strongly supported by each of the main players in the system. The Review found political recognition of the importance of departments working together.

Some NGOs reported that Health, Education and Justice and Communities were each engaging them to do work towards meeting targets for the first 2000 days but that there were unrealised opportunities for the three departments to work together more cooperatively. It was difficult to reach a firm view on the extent to which this perception was a reality. What was very apparent was the fact that the first 2000 days was embraced widely across government departments and that there was high individual ownership of the concepts.

Recommendations

The key findings as described in Section 13 above, provide a platform for new ways of working and opportunities for improvement. The recommendations that support this are presented below.



These recommendations link with the Secretary's priority for systems integration

First 2000 Days

Issue: Ongoing engagement, collaboration and investment across a wide range of stakeholders is required to achieve successful long-term outcomes for the first 2000 days.

Recommendation 71: Health and Social Policy Branch in the MOH continue to develop the opportunities for The Centre for Population Health/Public Health Units and Primary Health Networks to engage fully with implementation of the First 2000 Days.

Recommendation 72: The Secretary, NSW Health engages with Secretaries of the Departments such as Education and Communities and Justice to ensure high level cooperation and accountability across sectors responsibility for successful implementation of the First 2000 Days.

Recommendation 73: The Ministry of Health engage with Faculties of Health and Medicine and other educational bodies to ensure that the broad medical, nursing and allied health curricula recognise the lifelong importance of the first 2000 Days for the physical, cognitive, social and emotional health of the population.

Section 14: Measuring progress

Key messages

1. Measurement and monitoring are critical to understanding trends and making improvements. Current measurement and monitoring for LHDs/SCHN is primarily through activity based funding and Service Level Agreement Key Performance Indicators (KPIs). While these are important measures, they provide only a limited picture of the system.
2. It was noted that many initiatives were developed without clearly defined criteria for success. The system needs to consider measures for all initiatives to track progress, make changes over time based on results and monitor outcomes.
3. Numerous examples of good practice were cited during consultations, however broadly sharing this good practice was noted to be more difficult. Better data sharing is a powerful tool to drive improvement in outcomes for children, young people and families and support a learning culture.
4. Key performance measures must align to the vision and strategy we are trying to achieve. This will require monitoring focused more on 'outcomes' and 'impacts' rather than 'inputs' and 'outputs'. Examples of recommended KPIs have been presented below.
5. A data mapping exercise to compare what data is required and what data is available would be beneficial.

Key findings

Measuring progress

The NSW Ministry of Health has various ways that it signals to LHDs and SCHN what it regards as important. One way is through financial signals. The emphasis on funding activity may appear self-evident and entirely logical but it does drive particular behaviours. For example, a widespread narrative in community settings in LHDs was that the emphasis on activity-based funding had the effect of directing activities towards individual consultations and away from group-based prevention programs. Many interviewees focussed on the importance of setting up services in a way that enabled activity to be recorded. They also described the user-unfriendly information technology systems for recording occasions of service. One unit had moved a clinician away from seeing clients to a desk job of cleaning up data that was incomplete so that the work that had been done would qualify for funding under the activity based funding formula.

Another signal that the system sends to clinicians and administrators are the key performance indicators. Waiting times for elective surgery and time to be seen in the emergency department have become measures that are emphasised so strongly and reported so widely by the media that they become surrogate measures of the success of the health system.

Clinicians reported to this Review many initiatives of which they were proud. Frequently, they added a comment such as *"but it won't shorten surgical waiting lists"* or *"this has made a big difference for children but it doesn't cut exit block in the ED"*.

Many themes about measuring progress emerged from this Review. The first and dominant one was that many initiatives were developed without clearly defined criteria for success. As noted above, the belief was that high quality Frameworks are developed, without a clear implementation strategy and without measurement and monitoring of implementation. A common MOH response to these observations was that LHDs are responsible for local implementation. This Review understands that approach but reiterates the concerns of interviewees that the MOH needs to have measurements of whether local implementation is occurring and hold LHDs accountable.

The message from the Secretary in NSW Health Strategic Priorities 2018-2019 makes the intended approach clear:

“Ultimately we are reinforcing our ‘tight- loose-tight’ performance system that sets a tight direction, allows a looseness about how the objectives are achieved to encourage innovation and continuous improvement, and applies tight ownership and monitoring of deliverables”.

A second theme was that the key performance indicators that are set tend to be very conservative and reflect what has already been achieved or will be easy to achieve, rather than what real success would look like. Challenges such as improving health outcomes for disadvantaged groups are complex. The system needs to consider reasonable interventions, to implement them, to measure outcomes, to adjust or indeed to change direction based on results and to have a continuous improvement cycle. Of course, there are many examples where this is what does occur, but the argument was that this was because of the leadership of individuals rather than the culture of the system. The Reviewer was told about the bronchiolitis project as part of Leading Better Value Care. The key aims of the project were to reduce routine X rays, to reduce routine pathology tests for viruses and to reduce ineffective bronchodilator therapy. The Reviewer was provided with data about the poor outcomes in one particular setting and told that the person involved had been instructed to deny the existence of the data and not to provide this data to the Chief Paediatrician who was overseeing the project. The Reviewer confirmed that the Chief Paediatrician had not seen the data.

Another theme was how to track progress in a way that addresses rather than widens inequity. The health system tends to offer appointments at a particular time on a particular day. If a family does not attend, a follow up is offered and then a third appointment. After the third non-attendance, the family is blocked from accessing the service. The system tends to be poor at understanding the absence of public transport to the health service, the lack of money to pay for transport, the competing demands of other children and indeed the whole set of circumstances why the referral was made in the first place. Progressive health services understand these complexities and are changing their models of care (such as drop-in clinics, co-location with other services such as playgroups) to try to ensure increased access of vulnerable groups to their services. One possible approach to putting a spotlight on inequalities would be to ask each LHD to provide data that demonstrated an area where improvement was needed, together with a plan for targeting that vulnerable group.

Another theme was that the current system has many examples of good outcomes for children, young people and their families in individual LHDs. Many of these could be adopted successfully in other LHDs. Interviewees felt that the current systems were poor at sharing good practice. Using data from individual LHDs to show progress needs to be shared more broadly within the system to encourage more generalised uptake. Similarly sharing failed initiatives should be encouraged, not to embarrass individuals but to help create a climate of understanding that we can all learn from initiatives that have been unsuccessful.

Using data

Using data can be a powerful tool to drive improvement in outcomes for children, young people and their families. The nature of the data that we collect comes in many forms. Occasions of service data tells us about the quantity of service but is unlikely to help us understand quality or whether the desired outcome has been achieved. Shortening surgical waiting lists comes with the expectation that more people will receive beneficial care in a timely fashion. Ensuring that junior medical staff do not work onerous hours comes with the expectation that this is good for the wellbeing of the staff and will be good for patient care.

One key process to follow is to understand what we are trying to achieve. If the aim is to eradicate measles through immunisation, the key outcome measure will be how many people are diagnosed with measles. However, we know that measles eradication requires about 95% of the population to be immune, so an immunisation rate of 85% might sound a good number but would be regarded as inadequate. If we have 95% of the whole community immunised against measles but pockets of much lower immunisation in certain areas, we know that there are still vulnerable communities. We might survey why there are poorer immunisation rates in some areas and tailor interventions to determine if the immunisation coverage improves.

Sometimes we are clear in what we need to achieve and how to achieve it. More commonly, we can expect that progress will be incremental, with some relatively unsuccessful interventions and the need for reconsideration of strategies. Addressing a large public health issue, such as childhood obesity, will inevitably be challenging. Bridging the gap in health and social outcomes for indigenous people has been very difficult, neither for lack of funding nor commitment to make progress.

Example: key performance indicators to measure progress

The Royal College of Paediatrics and Child Health, United Kingdom (UK)

Many interviewees have thought deeply about the use of key performance indicators for children, young people and families. There was very strong support for the approach taken in the UK by the Royal College of Paediatrics and Child Health.

The Royal College of Paediatrics and Child Health released a document, State of Child Health Report 2017. Included in that report were 25 indicators to measure the health of infants, children and young people. Not surprisingly these included indicators relating to mortality, to conception, pregnancy and infancy, to early years, to school age/adolescence, to family and social environment, and to health conditions of childhood. For each indicator, there was a detailed analysis, namely:

- key messages
- what is the indicator showing us?
- data availability and comparability
- why is the indicator important?
- where are we now?
- spotlight on inequalities
- what does good look like?
- how can we improve?
- key actions
- additional note

Table 1 shows the indicator set nominated for child health in the UK.

Table 2: State of Child Health Report 2017 indicators

Indicator	Indicator definition
Mortality	
1.1 Infants (under one year)	Number of infant (under one year) deaths per 1,000 live births
1.2 Children (one to nine years)	Annual deaths of children aged one to nine years per 100,000 population
1.3 Young people (10 to 19 years)	Annual deaths of young people aged 10 to 19 years per 100,000 population
Conception, pregnancy and infancy	
2.1 Smoking and pregnancy	Proportion of mothers recorded as smokers at time of delivery or at first post-natal visit
2.2 Breastfeeding	Proportion of mothers recorded as breastfeeding at six to eight weeks post birth
2.3 Immunisation	Proportion of children who received the full course (three doses) of the 5-in-1 vaccination by 12 months
Early years	
3.1 Healthy weight when starting school	Proportion of children at a healthy weight during their first year of primary school
3.2 Healthy teeth and gums	Proportion of children with no obvious tooth decay at age five
3.3 Hospital admissions due to non-intentional injury	Rate of hospital admissions for non-intentional injuries in children under five years
School age/adolescence	
4.1 Healthy weight at Year 6 (10 to 11 years)	Proportion of children at a healthy weight during their final year of primary school
4.2 Human Papilloma Virus (HPV) vaccination	Proportion of girls who have received the completed Human Papilloma Virus (HPV) course of immunisation

4.3 Smoking in young people	Proportion of regular smokers aged 15 years
4.4 Alcohol and drug use	Proportions of regular alcohol users and drug users aged 15 years
4.5 Wellbeing	Proportion of young people aged 15 years who report high life satisfaction, by gender
4.6 Suicide	Suicide rate amongst young people aged 15 to 19 years per million
4.7 Road traffic injuries	Number of car drivers or passengers aged 17 to 19 years reported killed or seriously injured
4.8 Sexual and reproductive health	Number of conceptions per 1,000 females under 18 years of age
Family and social environment	
5.1 Child poverty	Proportion of children living in households with income less than 60% of the median
5.2 Children in the child protection system	Number of children subject to child protection plans or on the child protection register
5.3 Counselling sessions by Childline	Percentage of Childline counselling sessions by primary concern across UK
Health conditions of childhood	
6.1. Asthma	Number of emergency hospital admissions for asthma for children and young people under 19 years of age
6.2 Cancer	Proportion of children (0–14 years) surviving five years following a diagnosis of cancer
6.3 Diabetes	Proportion of children with Type 1 diabetes meeting recommended targets for blood glucose control
6.4 Disability and additional learning needs	Percentage of pupils with Special Educational Needs and Disabilities / Additional Support Needs
6.5 Epilepsy	Number of emergency hospital admissions for epilepsy for children and young people under 19 years of age

The UK approach for each indicator resonated strongly with interviewees in the current Review. This Review does not recommend that each UK indicator should be a NSW Health indicator but it does recommend the format of the dot points of the detailed analysis listed above.

The Australian Early Development Census

At the time of the Review, NSW Health had released The First 2000 Days Conception to Age 5 Framework. The implementation plan and outcome measures were still in development. One possible outcome measure involves the use of the Australian Early Development Census¹³ (AEDC). The AEDC is a nationwide data collection of early childhood development at the time children commence their first year of full-time school. The AEDC is held every three years, with the 2018 AEDC data being the fourth collection. The research tool used is the Australian adaptation of the Early Development Instrument. It collects data relating to five key domains of early childhood development, namely:

- Physical health and well being
- Social competence
- Emotional maturity
- Language and cognitive skills
- Communication skills and general knowledge.

These domains predict later health, wellbeing and academic success. In the 2018 census, 19.9% of NSW children were developmentally vulnerable in one or more domains and 9.6% were developmentally vulnerable in two or more domains. Data can be viewed by state, by community and by local community. For example, the data for

¹³ <https://www.aedc.gov.au/>

Campbelltown community showed 25.4% of children were developmentally vulnerable in at least one domain and in the local community of Claymore 54.7%.

Data from AEDC can be used to target communities in greater need of focus, as well as to measure progress with achieving desired outcomes.

This recommendation is not new. The Fifth National Mental Health and Suicide Prevention Plan 2017-2022¹⁴ has a key outcome in the domain “Healthy start to life” as the proportion of children developmentally vulnerable in the Australian Early Development Index.

Diabetes

The management of Type 1 diabetes was raised by many of the interviewees. Type 1 diabetes is a life-long disease and currently there is no known way to prevent it or to cure it. There are serious long-term complications related to poor diabetic control, including blindness, kidney disease, limb amputations, heart disease and stroke. Poor diabetic control in children and young people sows the seeds for these complications in adult life. On the other hand, children and young adults with good control of their diabetes are less likely to develop these complications in later life. There is a good measurement for control of diabetes, the blood test for HbA1c, which is performed routinely as part of standard management.

Data from the National Diabetes Register showed that in 2013 there were 6091 children in Australia aged 0-14 years with type 1 diabetes (a rate of about 1 in 720) and in 2017 the number was 6500.

Good management of type 1 diabetes in children and young adults requires a multidisciplinary team approach. When HbA1c data is used as the measure of diabetes control, there are wide variations in control across different clinics in NSW. The best control in Australia is achieved in a large metropolitan centre in NSW. This clinic has a different model of care from the clinics in the SCHN. Paediatricians in metropolitan and regional areas are aware of the variations in HbA1c data and believe that the differences in models of care are an important component of the marked differences in diabetes control between clinics. One way to address the issue is to use HbA1c data as a key performance indicator across LHDs and the SCHN.

Feedback to this Review from some in MOH expressed concern that this recommendation was too specific. Notwithstanding that opinion, the Reviewer noted:

- that this recommendation is very similar to a Royal College of Paediatrics and Child Health measure
- optimal diabetic control in children and young people will contribute to long term benefits for adults
- currently the HbA1c outcomes across NSW show large variation between clinics
- the Secretary, NSW Health showed the importance of this issue by bestowing an award in 2019 to the clinic with a model of care with the best results in Australia.

Youth Health

In 2017 the NSW Ministry of Health published the NSW Youth Health Framework 2017-2024¹⁵. There is no accompanying implementation, monitoring and evaluation document but there is a section in the Framework that indicates that the MOH will identify state level priorities and that LHDs and SHNs have lead responsibility for the implementation of the Framework. The issue of Key Performance Indicators is more problematic. In particular, headline indicators for youth health that allow meaningful comparisons nationally and internationally are not in place. NSW Health Epidemiology and Evidence Branch does its own Health Behaviour Survey in schools, which covers drugs and alcohol extensively and also includes sun protection, nutrition, exercise and mood. There are obvious gaps, such as sexual health, sexuality, gender identity, relationships, social media, bullying and key measures of mental health. It is difficult to harmonise data and to explore associations across health domains when the measures are not consistent, or samples recruited in the same way (for example, via social media versus school based).

¹⁴ <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-fifth-national-mental-health-plan>

¹⁵ https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_019.pdf

There is a role for separate surveys to capture more detailed information in specific domains but there should be consistency with key measures to be included across all surveys and methodology to allow comparison of data. A tool like the Middle Years Development Index (developed in Canada and being used in South Australia) would provide an understanding of the bigger picture of health, development and well-being of adolescents and guide comprehensive approaches to intervention programs. There is also a WHO survey which has merit. There was a National Youth Indicator Group for AIHW but funding is no longer available for the National Youth Data Group.

Other indicators

Data relevant to the health and wellbeing of children and young people is available from many sources. This Review found it a time-consuming task to identify what data was available. The Reviewer was made aware that a data mapping exercise of the datasets for children and young people is being undertaken by researchers. This will be important to identify what is currently collected and where the gaps are. For example, it is simple to ask a question such as “what is the dental health of children and young people across NSW?” but it is much more difficult to be certain about what would be the best measurement and what is the best available information.

Recommendations

The key findings as described in Section 14 above, provide a platform for new ways of working and opportunities for improvement. The recommendations that support this are presented below.



These recommendations link with the Secretary's priorities for strengthening governance and accountability, patient safety and experience, and digital health and analytics

Measuring progress

Issue: There is an absence of data across all points of the patient pathway to monitor progress, measure success and facilitate a coordinated approach to strategic and operational improvements.

Recommendation 74: NSW Ministry of Health develop robust key performance indicators and outcome measures using a similar template to the State of Child Health Report 2017 from the Royal College of Paediatrics and Child Health, UK. Part of this process should be a data mapping exercise to identify both what is required and what is currently available.

Issue: Measures to support the implementation of the First 2000 Days Framework have not yet been determined. Data from AEDC can be used to target communities in greater need of focus, as well as to measure progress with achieving desired outcomes. This recommendation is not new. The Fifth National Mental Health and Suicide Prevention Plan 2017-2022 has a key outcome in the domain “Healthy start to life” as the proportion of children developmentally vulnerable in the Australian Early Development Index.

Recommendation 75: The Australian Early Development Census (AEDC) be used as a key outcome measure of the First 2000 Days.

Issue: The management of type 1 diabetes was raised by many of the interviewees. Type 1 diabetes is a life-long disease and currently there is no known way to prevent it or to cure it, however there is good evidence to demonstrate what works. There are serious long-term complications related to poor diabetic control, including blindness, kidney disease, limb amputations, heart disease and stroke.

Recommendation 76: HbA1c levels in children and young people with type 1 diabetes be used as a key outcome measure in LHDs and SCHN.

Issue: The NSW Youth Health Framework 2017-2024 has no accompanying implementation, monitoring and evaluation document. The Framework indicates that the MOH will identify state level priorities and that LHDs and SHNs have lead responsibility for the implementation of the Framework.

Recommendation 77: NSW Ministry of Health adopt a survey such as the Middle Years Development Index as a key measure of health, development and well-being of adolescents and guide comprehensive approaches to intervention programs.

Appendix 1: Review of health services for children, young people and families within the NSW Health system – Terms of reference July 2019

Background

The design and delivery of high quality, effective and safe health care services for children, young people and families, from conception until 24 years of age is a key priority for the NSW health system.

Following the 2011 governance review of NSW Health and more recent organisational changes there have been changes in the overall governance of services for children, young people and families.

As system manager, the Ministry of Health sets the policy direction, allocates resources and monitors performance across the system. Local health districts (LHDs) and specialty health networks (SHNs) provide services to meet the needs of their local community. They are supported by the Agency for Clinical Innovation (ACI) and the Clinical Excellence Commission (CEC) which provide guidance across a range of areas including standardisation of care, new models of care, supporting improved clinical care and safety and quality.

In February 2019, Minister Hazzard announced an independent review of paediatric services. Following consultation with key internal stakeholders it is proposed that the review focus on governance and the strategic delivery of health services to children, young people and families from conception until 24 years of age.

The review will be undertaken by an independent reviewer with contemporary knowledge of governance and clinical care for children, young people and families.

Purpose of the review

The review will provide strategic advice and recommendations to the Secretary, NSW Health about the current status of delivery of services for children, young people and families in the NSW Health system and areas for improvement.

This includes how current services are delivered, noting any changes in clinical evidence that may provide an opportunity to identify new directions for system-wide activity.

It will consider the governance arrangements in place in NSW Health to ensure they are sufficient to deliver evidence-based outcomes for children, young people and families across NSW.

This review will provide an evaluation of how health services and partners are working together to achieve the shared goal of delivering healthcare in NSW that is safe, effective, integrated, high quality and continuously improving.

The review will consider the integration of care into the community including linkages with the primary health care sector.

Scope of the review

The review will cover the following areas.

1. Evidence that the NSW health system incorporates key plans and frameworks related to children, young people and families into service planning and delivery.
2. The extent to which the strategic and operational governance currently in place supports NSW Health to address priorities with a particular focus on:
 - Priority areas including the NSW State Health Plan; NSW Premier's and Government priorities and NSW Health strategic priorities.
 - Addressing emerging issues raised from within the NSW health system that relate to children, young people and their families.
3. Assessment of how the strategic directions, objectives and strategies outlined above have been implemented. This will include achievements and identification of emerging priorities and gaps.

4. Recommendations regarding future governance that will provide the required system direction and guidance on planning and delivery of health care services for children, young people and families to 2024. The recommendations will focus on ensuring effective communication and sufficient support across the system to deliver outcomes.

Review Oversight

The review will be led by an independent, appropriately qualified person with contemporary knowledge of governance and clinical care for children, young people and families.

The Children, Young People and Families Advisory Council will oversee the review.

The final report and recommendations will be provided to the Secretary, NSW Health for consideration.

Health and Social Policy Branch will provide secretariat and management support to the review. Additional resources may be engaged to support the reviewer in undertaking research, consulting with stakeholders, data analysis and the delivery of the final report.

Proposed methodology

The review will consist of three phases, a draft and final report:

5. Preliminary service mapping and assessment including:
 - a) A high-level desktop mapping of structures, standards, guidelines, quality frameworks, networks, service capability development within the NSW Health system and their implementation.
 - b) The 2014 Report of the Chief Health Officer on the Health of Children and Young People in NSW.
 - c) Review of other relevant information such as the NSW Legislative Assembly Committee on Community Services 2018 report Support for new parents and babies in New South Wales and any relevant recommendations in the Sydney Children's Hospitals Network Governance Review.
 - d) Identify current activity including work undertaken across LHDs, the Ministry, ACI, CEC, other human services agencies, whole of government initiatives to develop a clear cohesive map of initiatives and strategies that align with priorities.
6. Qualitative consultation:
 - a) Site visits to facilities in identified LHDs including tertiary, metropolitan, regional and remote health services.
 - b) Targeted workshops.
 - c) Consultation with key stakeholders.
7. Quantitative evaluation:
 - a) Consider a range of data sources that measure progress, outcomes and activity to inform the review.

Timeframe

The independent reviewer will provide a report to the Secretary, NSW Health no later than six months from the start date of the review.

Appendix 2: Review Steering Committee membership

A steering committee for the Review of Health Services for Children, Young People and Families in the NSW Health System, was convened to:

- provide advice to, and oversight of, the Review and to consider the findings of the Review, and
- provide advice to the Secretary, NSW Health regarding the system level response.

The members, appointed by the Secretary NSW Health, of the steering committee included:

- Dr Paul Craven, Co-Chair, Executive Director, Children, Young People and Families, Hunter New England LHD
- Dr Nigel Lyons, Co-Chair, Deputy Secretary, Health System Planning and Policy, Ministry of health
- Ms Janet Cormick, District Manager, Integrated Child, Youth and Family Wellbeing, Mid North Coast LHD
- Professor Valsa Eapen, Chair, Infant Child and Adolescent Psychiatry, University of New South Wales
- Ms Elizabeth Geddes, Chair, Family and Consumer Advisory Council, HNE Kids and Families
- Ms Jenny Martin, Director Allied Health, Central Coast LHD
- Ms Helen McCarthy, Director of Nursing and Midwifery Services, Royal Hospital for Women, South Eastern Sydney LHD
- Adjunct Associate Professor Cheryl McCullagh, Chief Executive, Sydney Children's Hospitals Network
- Professor Peter McDougall, Retired, Former Chief medical Officer and Executive Director of Medical Services & Clinical Governance at The Royal Children's Hospital (RCH) Melbourne
- Mr Michael Morris, Acting Chair, Sydney Children's Hospitals Network Families and Consumer Council
- Dr Matt O'Meara, Chief Paediatrician, NSW Health
- Ms Fiona Renshaw, Director Integrated Care and Allied Health, Murrumbidgee LHD
- Professor Kate Steinbeck, Chair, Adolescent Medicine, Centre for Research in Adolescent Health, University of Sydney
- Ms Tish Bruce, Executive Director, Health and Social Policy Branch, MoH (observer)
- Mr Paul van den Dolder, A/Director Disability, Youth and Paediatrics, HSPB, MoH (observer)
- Ms Janice Oliver, Manager, Paediatric Healthcare Team, HSPB, MoH (secretariat)

Appendix 3: List of stakeholders & groups interviewed and individuals who made submissions to the Review

1. AMA NSW combined face to face and teleconference.
2. Dr Lisa Amato, Staff Specialist in Paediatric Endocrinology, Campbelltown Hospital, SWSLHD.
3. Analytics Assist, NSW Ministry of Health
4. Ms Josey Anderson, Clinical Director, Royal Far West.
5. Dr Teresa Anderson AM, Chief Executive, SLHD.
6. Dr Ramprasad Attur, Consultant Psychiatrist, Gna Ka Lun, SWSLHD.
7. Ms Ruth Baker, Director of Allied Health, SCHN; Manager, Orthotic Shared Services, Sydney Children's and Prince of Wales Hospitals.
8. Professor Amanda Barnier, Associate Dean Research, Faculty of Human Sciences, Macquarie University; Professor, Department of Cognitive Science, Macquarie University.
9. Ms Jennie Barry, General Manager, Prince of Wales Hospital, SESLHD.
10. Mr Bruce Battye, Director Pharmaceutical Regulatory Unit, NSW Ministry of Health.
11. Professor Louise Baur AM, Head of Child and Adolescent Health, University of Sydney; Head, Children's Hospital Westmead Clinical School, University of Sydney; Consultant Paediatrician, Weight Management Services, The Children's Hospital at Westmead.
12. Dr Andrew Berry, State Director and Consultant, NETS.
13. Ms Elizabeth Best, Manager, Aboriginal Maternal and Infant Health Service, NSW Ministry of Health.
14. Ms Pauline Best, Paediatric nurse educator, St George Hospital.
15. Ms Vicky Blight, Nurse Manager, Child and Family, SWSLHD.
16. Dr Deepak Bhonagiri, Director Critical Care, SWSLHD.
17. Ms Danielle Bos, Paediatric Clinical Nurse Consultant, SNSWLHD; Chair ACI Paediatric Network Clinical Nurse Consultant Group.
18. Ms Pip Bowden, Principal Psychologist, ISLHD Allied Health Services, ISLHD.
19. Dr Tara Brown, Staff Specialist in Paediatrics, Liverpool Hospital, SWSLHD.
20. Ms Tish Bruce, Executive Director Health and Social Policy Branch, NSW Ministry of Health.
21. Ms Janet Burke, Manager, Child Life and Music Therapy, SCH Randwick, SCHN.
22. Mr Adam Bryant, Operations Manager, Office of Director of Mental Health, ISLHD.
23. Associate Professor Adam Buckmaster, Consultant Paediatrician; Conjoint Associate Professor, School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle.
24. Ms Katherine Burchfield, Health Director, Royal Far West.
25. Dr Vicki Burneikis, Consultant Paediatrician CCLHD.
26. Ms Elizabeth Burnheim, Health Service Manager, Coonamble, WNSWLHD.
27. Ms Paula Caffrey, Director Child and Family Health Services, Community Health, SLHD.
28. Dr Neil Caplin, Co-Department Head, Medical Imaging, CHW.
29. Child and Family Health Advisory Group, NSW Health
30. Ms Lindsay Cane AM, CEO Royal Far West.
31. Dr Kathryn Browning Carmo, Senior Staff Specialist Neonatal Intensivist, Grace Centre for Newborn Intensive Care, CHW; Acting State Director NETS; Chair Medical Staff Council CHW.
32. Ms Kim Casburn, Research and Innovation, Royal Far West.
33. Ms Angela Casey, Network Clinical Program Director, Critical Care, SCHN.
34. Dr John Cass-Verco, Deputy Area Clinical Director Women's Health, Neonatology and Paediatrics SLHD; Acting Head of Department Paediatrics RPA Hospital; Staff Specialist in Paediatrics, RPA Hospital.
35. Dr Raymond Chin, Paediatric and Neonatology Stream Director, SWSLHD.
36. Ms Mia Chong, Paediatric CNC, SWSLHD.
37. Ms Jenny Claridge, Co-Director Kids and Families ISLHD; Service Lead Paediatrics and Child Health.
38. Ms Vanessa Clements, Director, Specialty Service and Technology Evaluation Unit, Strategic Reform and Planning Branch, NSW Ministry of Health.
39. Associate Professor Ruth Colagiuri AM, Co-founder Juvenile Arthritis Foundation of Australia (JAFA); Menzies Centre for Health Policy, University of Sydney.
40. Professor Stephen Colagiuri AO, Co-founder Juvenile Arthritis Foundation of Australia (JAFA); Professor of Metabolic Health, University of Sydney.
41. Dr Alison Colley, Senior Staff Specialist in Clinical Genetics, SWSLHD.
42. Professor Clare Collins, Professor in Nutrition and Dietetics; NHMRC Senior Research Fellow; Director of Research, School of Health Sciences; Deputy Director, Priority Research Centre in Physical Activity and Nutrition, Faculty of Health and Medicine, University of Newcastle.
43. Community Health Directors at Community Health Peak Forum.
44. Ms Julie Cooper, Executive Director, Integrated Care Directorate, WNSWLHD.
45. Ms Tracey Couttie, Paediatrics Triage CNC, Paediatrics Triage, Emergency Department Wollongong Hospital, ISLHD.
46. Ms Cathryn Cox PSM, Executive Director, Strategic Reform and Planning Branch, NSW Ministry of Health.

47. Professor Maria Craig, School of Women's and Children's Health, UNSW Medicine, UNSW Sydney; NHMRC Practitioner Fellow; Paediatric Endocrinologist, St George Hospital and The Children's Hospital at Westmead; Academic Co-Director Charles Perkins Centre Westmead.
48. Dr Paul Craven, Executive Director, Children, Young People and Families Directorate, Hunter New England Local Health District; Director of Newborn Services, HNELHD; Conjoint Senior Lecturer, School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle.
49. Dr Matthew Crawford, Specialist in anaesthesia, intensive care and pain management at SCH, POW Public and POW Private Hospitals.
50. Mr Anthony Critchley, Director Mental Health CCLHD.
51. Ms Leanne Crittenden, Coordinator, Children's Healthcare Network Northern Region, HNELHD.
52. Ms Jacqui Cross, Chief Nursing and Midwifery Officer, NSW Ministry of Health.
53. Ms Mary Crum, Paediatric Network Manager, Agency for Clinical Innovation.
54. Ms Donna Curtis, Manager Violence, Abuse and Neglect, CCLHD.
55. Professor Kate Curtis, Professor of Trauma and Emergency Nursing, Sydney Nursing School, University of Sydney; Emergency Services ISLHD.
56. Ms Rochelle Darby, Manager, Child Protection, Diagnostic and Assessment Wollongong, ISLHD.
57. Ms Debrah Davies, Principal Strategy Manager, Kids and Families, Integrated Care Directorate, Western NSW LHD.
58. Ms Fiona Davies, CEO Australian Medical Association (NSW).
59. Mr Andrew Davison, Chief Allied Health Officer, Health System Strategy and Planning, NSW Ministry of Health.
60. Professor Andrew Dawson, Director, National Poisons Register and Clinical Toxicology, RPAH; Clinical Director, NSW Poisons Information Centre, SCHN; Clinical Professor of Addiction Medicine, Sydney Medical School, University of Sydney; Conjoint Professor, School; of Medicine, WSU; Conjoint Professor, School of Medicine, UNSW.
61. Ms Nguyet de Mello, Acting Manager, Child and Family Health, Health and Social Policy Branch, NSW Ministry of Health.
62. Dr Mark de Souza, Consultant Paediatrician, Nowra, ISLHD.
63. Ms April Deering, currently Principal Policy Officer, First 2000 Days; Manager, Child and Family Health, Health and Social Policy Branch, NSW Ministry of Health.
64. Ms Laura Dent, Community Health Manager, Coonamble, WNSWLHD.
65. Ms Emma Dickens, Integrated Care Lead, SCHN.
66. Dr Katrina Doyle, Head of Department, Paediatrics, Bankstown Hospital, SWSLHD.
67. Ms Erica Drew, Integrated Care, Central Coast Health Alliance and Health Pathways, PHN.
68. Professor Valsa Eapen, Chair of Infant, Child and Adolescent Psychiatry, UNSW; Head, Academic Unit of Child Psychiatry, South West Sydney; Infant, Child and Adolescent Mental Health Services, SWSLHD.
69. Associate Professor John Eastwood, Executive Clinical Advisor Clinical Services Integration and Population Health; Co-Chair Institute for Women, Children and their Families; Consultant Paediatrician and Public Health Physician SLHD; Conjoint Associate Professor UNSW; Adjunct Associate Professor University of Sydney.
70. Professor Michael Edye, Divisional Medical Director, Surgery and Anaesthetics Blacktown and Mt Druitt Hospitals; Chair of Surgery, School of Medicine, Western Sydney University; Senior Clinician in Surgery at Blacktown Mount Druitt Hospitals; VMO North Shore Private, Macquarie University and Norwest Private Hospitals.
71. Mr Stephen Ella, Manager Nunyara Aboriginal Health, CCLHD.
72. Mr Josh Emanuel, Operations and Facility Manager, NETS.
73. Ms Louise Everitt, Clinical Midwifery Consultant, Complex Pregnancy Care, St George Hospital; Honorary Associate UTS; PhD student WSU.
74. Ms Ruth Evans, Team Leader for Allied Health, Division of Kids and Families; occupational therapist, ISLHD.
75. Ms Bridget Farrell, Paediatric to Adult Transition Coordinator, SWSLHD.
76. Dr Marino Festa, SCHN Critical Care Clinical Program Director (Medical) SCHN; Paediatric Intensive Care Specialist; Honorary Fellow, Critical Care and Trauma Division, The George Institute.
77. Ms Laura Finn, Nurse Unit Manager Paediatrics, St George Hospital.
78. Ms Angela Firth, Associate Director Allied Health, Allied Health and Innovation Directorate, WNSWLHD.
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Appendix 4: Stimulant medication for children in NSW

The provisions for issuance of authorities to prescribe psychostimulants for children do not exclude GPs, but under the advice of the Stimulant Subcommittee of the Medical Committee guidance for the Delegate has been developed which assists to deal with the clinical complexity of appropriate care of these children. These criteria are published:

- <https://www.health.nsw.gov.au/pharmaceutical/doctors/Pages/prescribe-psychostimulant.aspx> and
- <https://www.health.nsw.gov.au/pharmaceutical/Documents/adhd-criteria-child.pdf>

Prescribe psychostimulant for a child

Specialists (e.g. paediatricians, child and adolescent psychiatrists) and other designated prescribers may apply for authorisation to prescribe psychostimulant medication for the treatment of ADHD in a person aged under 18 years by submitting an [Application for Authority to Prescribe a Psychostimulant for ADHD in a Child or Adolescent](#).

To prescribe children doses greater than:

- 1mg/kg daily or 50mg daily of dexamfetamine
- 2mg/kg daily or 108mg daily of methylphenidate
- 70mg daily of lisdexamfetamine

Submit an [Application for Authority to Prescribe a Psychostimulant in a High Dose for the Treatment of ADHD in a Child or Adolescent](#)

To prescribe psychostimulant medication to a person aged under 18 years for all other diagnoses submit an [Application for Authority to Prescribe a Schedule 8 Drug – Psychostimulant](#).

Requirements for the authorisation and prescribing of psychostimulants for the management of ADHD in children are described in [Criteria for the Diagnosis and Management of Attention Deficit Hyperactivity Disorder in Children and Adolescents \(TG181\)](#).

General practitioners

General practitioners may apply for authorisation to continue to prescribe a psychostimulant for a person aged 18 years or over by submitting an [Application for Authority to Prescribe a Schedule 8 Drug – Psychostimulant](#).

Note: GPs seeking authorisation to prescribe psychostimulant medication for a patient must provide a supporting letter from the patient's current specialist with their application.

A general practitioner may apply for a person aged under 18 years in certain circumstances by submitting an [Application for Authority to Prescribe a Psychostimulant for ADHD in a Child or Adolescent](#).

Appendix 5: Strengthening Primary Care for Children through an integrated paediatrician-GP care model

Professor Harriet Hiscock, Associate Director of Research at the Centre for Community Child Health, Consultant Paediatrician and NHMRC Practitioner Fellow.

Abstract

1. Introduction

In Victoria, the healthcare system for children is overburdened by increasing general practitioner (GP) referrals to hospital emergency departments (EDs) and outpatient clinics. GPs could be supported to manage children closer to home.

2. Practice change implemented

We co-designed and implemented a GP-paediatrician integrated care model comprising: weekly paediatrician-GP co-consultation sessions at the GP practice; monthly case discussions; and phone and email support for GPs.

3. Aim and theory of change

The model was designed to support GPs to deliver higher quality of care, with greater confidence for a broader range of childhood health concerns. We measured: model feasibility and acceptability; GP confidence, referrals and care quality; family experience and preference for care; and costs.

4. Targeted population and stakeholders

Population: 49 participating GPs from 5 GP practices (2 metropolitan and 3 regional); and their patients aged 0 – 17 years, and families; and 2 Paediatricians.

Stakeholders: The Royal Children's Hospital; Sunshine and Werribee Mercy Hospitals; North Western Melbourne Primary Health Network (PHN); and the Victorian Department of Health and Human Services.

5. Timeline

12-month intervention.

6. Highlights (innovation, Impact and outcomes)

The model was feasible and acceptable to GPs, families and paediatricians with 624 children seen in the co-consultations and 50 case discussions conducted. In pre-post testing, there was a 7% absolute reduction in ED referrals, 20% reduction in GP low value care; increased GP confidence in paediatric care (88% to 100%); and family confidence in GP care (78% to 94%). Families reported ease and comfort of receiving paediatric care closer to home. Model costs as implemented were \$172 over and above usual care, per child seen in the co-consults. However, in an idealised implementation scenario, the model has the potential to be cost saving for families, state/federal governments and hospitals.

7. Comments on sustainability

Sustainability planning was completed in partnership with the PHN and the practices; two have hired paediatricians, with others exploring options for access to paediatric support and learning (e.g. webinar program). The research team plan to complete a larger, multi-site multi-state trial to rigorously evaluate effectiveness and cost-effectiveness of the model in high referral areas.

8. Comments on transferability

This integrated care model could be replicated for chronic complex care that burdens the hospital system, or implemented in service hubs with co-located paediatricians, or extended to include telehealth for rural/regional hubs.

9. Conclusions (key findings)

Developing and embedding a GP-paediatrician integrated model of care in Australia's primary health

care system is feasible and acceptable; improves GP confidence and quality of paediatric care; benefits families and children; and may reduce referrals to hospital services.

10. Discussions

Truly integrated care, delivered as a collaboration between hospitals, health networks, GPs and their practices has the potential to shape a health system in which children can receive higher quality, timelier care, closer to home.

11. Lessons learned

Co-design and initial onsite-support were crucial e.g. billing; data collection; co-consult structure and purpose. The drive and desire to provide better care for children is the strongest motivator for change.

Biography

Professor Harriet Hiscock is Associate Director of Research at the Centre for Community Child Health, Consultant Paediatrician and NHMRC Practitioner Fellow. She is Director of the Royal Children's Hospital Health Services Research Unit, Group Leader of Health Services at the Murdoch Children's Research Institute, Director of the Australian Paediatric Research Network, and Principal Fellow, Department of Paediatrics, University of Melbourne. Her research focuses on common child health conditions, in particular (i) developing and trialling integrated care models, to reduce hospital burden; (ii) reducing low value care (i.e. unnecessary imaging, pathology testing and medication); (iii) optimising care for common mental health conditions such as ADHD and anxiety. She is also interested in improving child health outcomes through paediatric, secondary care-based research including e-health. She is driving this research through the Australian Paediatric Research Network – a research network of 550 paediatricians. She is assisted by a team of about 15 researchers and students.

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Appendix 7: Glossary and abbreviations

ACE Adverse Childhood Experience
ACI Agency for Clinical Innovation
ADHD Attention-Deficit Hyperactivity Disorder
AEDC Australian Early Development Census
AEDI Australian Early Development Index
AIHW Australian Institute for Health and Welfare
AMA Australian Medical Association
APLS Advanced Paediatric Life Support
ASD Autism Spectrum Disorder
AYAM Adolescent and Young Adult Medicine
CAYHNet Child and Youth Health Network
CCLHD Central Coast Local Health District
CEC Clinical Excellence Commission
CHN Children's Healthcare Network
CHW The Children's Hospital at Westmead
CNC Clinical Nurse Consultant
DCH Diploma of Child Health
ECHO Enhancing Child Health Outcomes
FRACGP Fellowship of Royal Australian College of General Practitioners
FWLHD Far West Local Health District
GP General Practitioner
HNE Hunter New England
HNELHD Hunter New England Local Health District
HPV Human Papilloma Virus
IPTAAS Isolated Patients Travel and Accommodation Assistance Scheme
ISLHD Illawarra Shoalhaven Local Health District
JHCH John Hunter Children's Hospital
KPI Key Performance Indicator
LHD Local Health District
MLHD Murrumbidgee Local Health District
MNCLHD Mid North Coast Local Health District
MOH Ministry of Health
MP4 Metropolitan Paediatrics Level 4
NDIA National Disability Insurance Agency
NDIS National Disability Insurance Scheme
NETS Newborn & paediatric Emergency Transport Service
NHMRC National Health and Medical Research Council
NICU Neonatal Intensive Care Unit
NNSWLHD Northern NSW Local Health District
NSLHD Northern Sydney Local Health District
PANOC Physical Abuse and Neglect of Children
PARVAN Prevention and Response to Violence Abuse and Neglect
PHN Primary Health Network
PIC Poisons Information Centre
PICU Paediatric Intensive Care Unit
PLS Paediatric Life Support
PoW Prince of Wales
PRS Paediatric Rehabilitation Services
PSN Pregnancy and Newborn Services Network
RACP Royal Australasian College of Physicians
RANZCP Royal Australian and New Zealand College of Psychiatrists
RIDBC Royal Institute for Deaf and Blind Children
RHW Royal Hospital for Women Randwick

RNSH Royal North Shore Hospital
RPA Royal Prince Alfred
RP4 Regional Paediatrics Level 4
RPNSW Regional Paediatrics New South Wales
SCHN Sydney Children's Hospitals Network
SCH-R and SCH Sydney Children's Hospital Randwick
SCN Special Care Nursery
SESLHD South Eastern Sydney Local Health District
SHN Specialty Health Network
SLA Service Level Agreement
SLHD Sydney Local Health District
SNSWLHD Southern NSW Local Health District
SWSLHD South Western Sydney Local Health District
UHHV Universal Health Home Visiting
UK United Kingdom
UNSW University of New South Wales
USyd University of Sydney
UTS University of Technology Sydney
VAN Violence Abuse and Neglect
WHO World Health Organisation
WNSWLHD Western NSW Local Health District
WSLHD Western Sydney Local Health District
WSU Western Sydney University