



Inquiry into health outcomes and access to health and hospital services in rural, regional and remote NSW - December 2020

Submission

Mid Coast 4 Kids – About Us

Mid Coast 4 Kids is a collective impact initiative designed to support Mid Coast communities to address long term, entrenched social issues that affect children, young people and families. Membership of Mid Coast 4 Kids is broad, covering the community, health and education sector including Aboriginal and Torres Strait Islander services.

This submission draws on the expertise and experience of our members, local professionals and parents, as well as contemporary evidence on screening and surveillance in early childhood health, with a particular focus on the link between early health screening and educational outcomes.

Executive Summary

This submission highlights concerns about the long-term health and educational outcomes for children on the Mid Coast due to inadequacies in screening and surveillance in early childhood health services. The submission further highlights gaps in service provision for children identified with needs related to hearing loss, vision impairment, speech and language delay and behavioural issues. The submission makes recommendations based on the principles of the [National Framework for Universal Child and Family Health Services](#), with a key emphasis on enhanced collaboration, service integration and greater flexibility and capacity in funded services.

The case for improvement

The *National Framework for Universal Child and Family Health Services* (NFUCFHS) asserts, “All Australian children benefit from quality child and family health services that support their optimal health, development and wellbeing” (2011 p.2). It is important that screening and surveillance is available and accessible to all children and families throughout a child’s development, principally across key transitions. This is particularly true for vulnerable families. Transition periods such as becoming a parent, early infancy, the toddler years and starting preschool and school represent critical developmental stages for children and families. Each of these transitions involves multiple social, cognitive, physical and emotional changes. Failure to make successful transitions puts children at increased risk of poor outcomes in the present and the future (NFUCFHS, 2011 p.7).

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There are 6,879 children (aged 0-5) on the Mid North Coast in the 'vulnerable young children group'. This is approximately 1 in 3. This means they do not have the skills (learning, socio-emotional, physical) to flourish at school (Edwards et al, 2020 pp.38). On average, these children are estimated to cost the NSW Government \$171,000 each for the key human services they use up to the age of 40. This is 2.9 times the average cost for all NSW children aged 0-5.

- 43% of these children have parents who have interacted with the justice system
- 35% of these mothers smoked during pregnancy
- 31% of these children had a concern report
- 24% of these mothers were aged 21 and under during child birth
- 8% of these parents have been in social housing

(Their Futures Matter Data Pack, Mid North Coast, 2019)

There is a strong economic argument for supporting children and families early. Benefits accrue to the whole of society, through enhanced human capital and capability, increased productivity, greater social inclusion and reduced expenditure in health, welfare and crime, related to disadvantage across the life span (NFUCFHS, 2011 p.7).

The *Australian Early Development Census* shows us there are a significant number of children on the Mid Coast starting school with vulnerabilities across a range of domains and there has been no significant change in this trend since 2009.

	Developmentally vulnerable in 1 or more domain/s	Developmentally vulnerable in 2 or more domain/s
Greater Taree	25.8%	12.3%
Gloucester	23.5%	10.0%
Great Lakes	19.9%	9.0%
NSW	19.9%	9.6%

Source: AEDC Data, 2018 <https://www.aedc.gov.au/data/data-explorer>

When universal population health services are available to all children and families in the population, the range of developmental outcomes narrows and more children approximate the average, that is, more children attain normal development. Further, the targeting of additional services and supports for children at or below the vulnerability threshold for normal development leads to a decrease in the number of children not attaining normal development (Hertzman and Power, 2004 pp.483-443).

Spotlight on the universal child health and development program on the Mid Coast

The Hunter New England LHD has a complex multi-layered system of funding and service delivery involving a range of government and non-government stakeholders supporting children and families. While there are examples of high quality service provision throughout¹, inconsistency and fragmentation of services across the service sector means many children and families, particularly those who are most disadvantaged, are not receiving the services they need, when they need them.

¹ An example of high quality service provision is the *Safe Start Program* that provides psychosocial, mental health and domestic and family violence screening to all women from the time of booking antenatal services. Women identified as potentially vulnerable are actively followed up by Maternity and Child and Family Health Nurses as well as a multidisciplinary team until those women are linked with adequate support for both themselves and their children (Maternal and Child Health Primary Health Care Policy, 2009).

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In NSW, early health and development screening is scheduled from birth to 5 years of age², as outlined in the Personal Health Record or “Blue Book”. The Blue Book is issued to parents of every child born in NSW to track individual health and development.

Mid Coast 4 Kids have identified significant numbers of children falling through the gaps, failing to access services; encountering significant wait times; and /or incurring substantial out of pocket costs to address such issues as hearing loss, vision impairment, speech and language delay and behaviour issues. This is mirrored across Australia, as demonstrated in the *2014 National Survey of Child and Family Health Nurses*, which revealed a rapid drop off in contact with Child, and Family Health Nurses after 6 months (Schmied et al, 2014). This means a significant number of children are at increased risk of not having issues detected early enough to seek support and intervention before commencing school.

In 2001, the *Get It Right for School* program was a near universal before school screening program provided by Child and Family Health Nurses through Community Health in Taree, Forster and Gloucester. This program packaged together a number of services and ensured children’s hearing, vision, weight, height, motor, speech and language development were screened. Local practitioners regard this program as the ‘gold standard’, most closely aligned with the integrated promotion, prevention and early intervention approach supported by the literature.

In 2016, this program was discontinued, the Lower Mid North Coast being the last in the New England Health District to move to Activity Based Funding, with before school screening now seen as a Primary Health Care role³. This current, more fragmented system, places the onus of responsibility on parents to navigate service provision across a range of domains and locations. This includes Child and Family Health clinics; GP clinics; immunisation clinics; audiometry clinics; and early childhood education settings (StEPS – Statewide Eyesight Pre-schooler Program).

For parents presenting to GP clinics, [Blue Book](#) Checks or the [Healthy Kids Check](#) are not consistently offered and where the check is undertaken, it is completed within a limited period of time. Access to the check has also been impeded by the removal of the Medicare Item number, which previously enabled generalist practice nurses to assist, providing less incentive for GP practices to undertake the checks.

“Had vaccinations with the GP who didn’t do any checks using the Blue Book. I feel sometimes it is just a tick and flick and not a full check-up”.

Early Childhood Screening Survey, Mid Coast 4 Kids, 2020

At Taree, Forster and Gloucester Community Health Centres, the immunisation clinic is coordinated by generalist nurses and operates independently of Child and Family Health Nurses who are

² The four-year health check can be supplied to any child, including children 5 years of age, up until they attend school.

³ Funding previously used to supply before school screening services were utilised to provide Forster with a Childhood Immunisation Clinic and to reduce Audiometry wait times in Taree by adding another clinic.

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specifically trained in developmental surveillance. Parents are required to make a separate appointment to access early childhood screening services.

The audiometry service provided at Taree is currently offered two days per week. The service only provides five appointments per day, and a single family can sometimes take multiple appointments. There is currently a wait list of four to six weeks to access this service. In saying that, community awareness of the clinic is low and were the service to be promoted, the wait list would grow with no capacity for the clinic to provide additional services.

Hearing loss affects both physical and psychosocial areas of development such as language, motor skills and parent / infant interaction. Early identification of any hearing loss must therefore be a priority for child and family health services. Targeted services are also required to provide support where an increased need or risk factor is identified (NFUCFHS, 2011 p.20).

Aboriginal and Torres Strait Islander children on the Mid Coast are better off. Hearing assessments are available through the local Aboriginal Corporation Medical Centre (Biripi and Tobwabba), with an Ear Nose and Throat (ENT) Specialist visiting the area once per month to provide specialist medical services. In saying that, children requiring further assessment or surgical intervention, are required to travel to John Hunter Children's Hospital in Newcastle, a two-hour drive, which incurs additional out of pocket expenses for families in the form of travel and accommodation.

Parents are currently being advised of wait times anywhere between 4 and 6 years...

Non-Aboriginal and Torres Strait Islander children, who require further assessment and intervention, have a different pathway. Parents are currently being advised of wait times anywhere between 4 and 6 years. Children who require surgery (e.g. grommets, adenoidectomy, and tonsillectomy) are required to travel to John Hunter Children's Hospital in Newcastle, most often following a significant wait period. With such long wait lists, children are missing opportunities for early intervention and in many cases have already started school without having their hearing loss being addressed. For parents who elect to pay for private services, costs are cited to be anywhere between \$2,500 and \$20,000 depending on the medical needs and ongoing supports required by the child or children.

"It shouldn't matter if you're in the public system, it should be covered for those that can't afford to go private. They did it for corona virus so why can't they do it for these important services that impact on so many different aspects of a child's learning and development. We don't live in America".

Amanda's Story

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Availability of allied health services, such as Speech Pathology, Occupational Therapy and Psychology, is a significant issue in this area. There are long waiting lists through the public system (12 months +). Children aged 0-6 are now eligible to access funding through the NDIS on the Early Childhood Early Intervention (ECEI) program. However, despite having access to generous funding packages, extensive waiting periods mean that children miss vital hearing, medical and other allied health services in the preschool years. NDIS funds are also being used as a 'stop gap' to access services while children wait for underlying issues to be addressed. Refer to Martha's story (Story 7), her child, confronted with a substantive wait time for ENT surgical services, was given access to a speech therapist. This afforded little to no benefit, as the underlying hearing issue had not been addressed. A grossly inefficient use of funds.

The Mid Coast is an area characterised by significant disadvantage (SEIFA, 2016 – 928.0 - 15th percentile), where many families face adversity and challenges including inter-generational trauma, domestic and family violence, mental health issues and unstable housing. For these families,

“It was important to me he had the ability to learn and hear when starting school. I did not want him to have to wait and spend 6 years with his head underwater, unable to learn as I know he is very smart. In 6 years, he would be nearly in high school, his schooling would be seriously affected, his mental health would suffer and my own as his main support”.

Martha's Story

navigating complex systems is challenging and often considered too hard.

“Working as a Learning and Support Teacher in the Taree area for a number of years, it has become increasingly frustrating not being able to access Speech Pathology services through Community Health. At the end of 2017, there were seven referrals made to Community Health for speech and language assessments of children who were to commence Kindergarten in 2018. The intake for that year was 34 children, which is nearly twenty percent of children enrolled. These seven children were identified as having difficulties while attending their Kindergarten orientation by teaching staff who have experience working with children who have developmental and speech delays.

The referrals were unsuccessful as the Speech Pathology department give priority service to children under school age. Being school age, these children fell through the gap in universal screening services and their learning was invariably affected. We had to negotiate training for staff to help up-skill them for children presenting with these deficits.

Speech Pathologists from Community Health have previously come to schools to implement individual programs with children. This generally occurs when there is no capacity for the children to attend Allied Health clinics. This has great outcomes for children, if parents can attend they do, but the best outcome is that the Student Learning Support Officers can attend and continue the program during the school week, which allows for generalised learning and practice of the tasks to assist with articulation and language. Again, Community Health do not have the capacity to attend schools any longer.

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Most schools have stopped referring to Community Health as the wait list is six to twelve months at best. Sometimes when families do obtain an appointment they forget to go, do not have transport, or in some cases, the children flatly refuse to go. As mentioned previously, schools are a place of security for some children and are therefore the best place for engagement with services.

This is just one school that has difficulty accessing speech pathology. Many parents do not have the capacity to attend a GPs office and request Enhanced Primary Care, or the finances to pay above Medicare rebates if they are successful in acquiring an EPC” (Lynn Brettle, President of the Manning River NSW Teachers Federation).

According to [Brighter Beginnings](#), the NSW Government “is committed to giving every child in NSW the best start in life.” Further, “making sure children are developmentally on track when they start school is the first step to achieving full participation and lifetime health, education, social and economic benefits.”

Timely access to developmental surveillance is a critical component of this initiative. However, this needs to be considered in the context of social determinants of health including housing stability, domestic and family violence and poverty. These risk factors contribute significantly to developmental vulnerability. Innovative, community driven solutions are required to address access to services in this community.

Recommendations

Mid Coast 4 Kids support the principles of the *National Framework for Universal Child and Family Health Services*.

Principle 1 - Access

- Universal screening services on the Mid Coast should be free, appropriate and accessible for all children and families and articulated where possible with other children’s services e.g. [Connected Beginnings](#), [First Steps Count](#)⁴

⁴ *Connected Beginnings* aims to support Aboriginal and/or Torres Strait Islander children in areas of high need, be well prepared for school by supporting Indigenous pregnant women, and Indigenous children from birth to school age. Over time, it is anticipated the program will contribute to reducing the difference in school readiness and education outcomes between Indigenous and non-Indigenous children. The Connected Beginnings Program is delivered on the Mid Coast through the Department of Education and Biripi APMC, with the lead school being Taree Public School. The Program provides outreach and support so more Aboriginal and Indigenous families get involved in early childhood services; and brings together early childhood and health services so Indigenous families have a place in their community for these services.

With construction of Stage 1 commencing early 2021, *First Steps Count Child and Community Centre* will be a unique facility in Taree, providing an integrated model of service delivery, coordinating programs and services for children, young people and families as well as serving as a thriving community hub. The Centre is targeting children aged 0-12, with a specific focus on ensuring that children and their families are supported and ready to start school, and that children are supported through critical periods of transition as they develop.

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- Increase in funded services to be provided through Community Health on the Mid Coast, this includes but is not limited to, audiometry services, psychology services, speech pathology and occupational therapy.
- Medical and allied health services should be localised, with health and education partnerships formed to encourage and support professionals to relocate to rural and remote areas where skill shortages are identified. There is a significant need for local Ear, Nose and Throat services in the Mid Coast region, as identified by the stories of our local families (Appendix 1).
- Services should be delivered flexibly how and where the family need it. Some families will need help to access services, therefore greater investment in integrated service hubs and

We need a well-trained ENT paediatric doctor who is based in our region so people can stay in their own area to access these services. To be able to see an ENT in your own region would make these treatments and surgeries much more comfortable and less expensive.

Alex's Story

intensive child and family support services (e.g. First Steps Count Child and Community Centre).

- Increased emphasis by GP services on the importance of the [First 2000 Days](#) and the performance of the Healthy Kids Check. This should include the reinstatement of the Medicare Item number for general practice nurses to assist, as well as comprehensive training provided for same.

Principle 2 – Equity

- Universal early and family health services play a key role in reducing inequalities between population groups. Greater flexibility in service provision to ensure population groups facing adversity can access services. This should include increased capacity for Child and Family Health Nurses and other allied health staff to make universal screening services available in early childhood settings and through integrated service hubs. Refer to [Thriving and on Track](#) and the [Rockdale Hub](#) as examples.

Principle 3 – A focus on promotion and prevention

- The primacy of health promotion, prevention and early intervention is recognised in service delivery. This should extend to the resourcing of ongoing, localised community campaigns and innovative programs that emphasise the importance of the [First 2000 days of life](#) and support families to access services and supports that build capacity in children and families.

Principle 4 – Diversity

- That the diversity of local families and communities is valued and services are sensitive and responsive to family, cultural, ethnic and socioeconomic diversity. In this regard, support the development of integrated models of care, where health, early childhood services and schools work together to increase access for vulnerable families to early childhood development surveillance (Edwards et al, 2020 p.6). On the Mid Coast, this means ongoing support for *Connected Beginnings*, *First Steps Count Child and Community Centre* and

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increased capacity and flexibility in Community Health services to deliver in a variety of settings.

Principle 5 - Collaboration and partnership

- Increase the capacity of child and family health services to work in partnership with primary, secondary and tertiary health services and the education, welfare and disability sectors to provide coordinated, multi-disciplinary care and integrated service delivery. On the Mid Coast, this means funding capacity within existing services to build and maintain multi-disciplinary care teams to ensure the continuity of care at key transition points is seamless.

Principle 6 – Evidence based

- Services should reflect the best evidence or harness practice wisdom where evidence is not available. Better-coordinated and integrated approaches to service models and collaborative ways of working are increasingly being recognised both nationally and internationally as the best way to meet the needs of children and families. This means partnership and collaboration across professions and traditional service boundaries and coordination of service delivery results through enhanced access to services, improved health outcomes, a wider choice for consumers; and a reduction in the use of inappropriate or unnecessary services (NFUCFHS, 2011 p.11).

Appendix 1: Stories of our children

Story 1: Alex and Heath

Alex White interview: ENT services in the Mid Coast

Cundletown 2430

We required ENT services when my son, Heath was four years old (he is now nine) and we noticed he had sleep disordered breathing. He needed to have his adenoids and tonsils out and we also found out he had a tongue tie which causes breathing problems. He now has an expander in to broaden his jawline.

All of these problems were initially diagnosed by our GP. We did not have to wait a long time to see an ENT because we decided to be treated as private patients but we did have to travel outside our area to Port Macquarie. We had private health insurance, however, we were still out of pocket because of the gap fees and travel expenses.

The two weeks after this surgery were agonising as we had to be alert for bleeds and were told to drive from Taree straight to Port Macquarie hospital if he was to have a bleed, as Manning Base did not have an ENT if he had to have corrective surgery to stop the bleeding.

Another 3 years on and Heath's breathing problems returned. We had to source another ENT out of the area - this time in Sydney. He had his adenoids removed for the second time and had his turbinates in his nose shaved, resulting in plastic cones in his nose that had to be removed. This was another long two weeks. Then he had to have the cones removed where the ENT accidentally clipped the skin inside his nose causing a nosebleed.

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We were even more out of pocket the second time round due to the longer stay and accommodation costs in Sydney.

I estimate we were out of pocket around \$3000 just for the first round of ENT services in Port Macquarie but all up after Heath required that second round of surgery in Sydney I think we've probably forked out around \$20,000 all up (included some orthodontics).

Heath's health is really good now and he's breathing well and sleeping through the night. Previously he had a lot of behavioural problems and we noticed the impact on his learning and development but now we're noticing a big improvement.

A very sad downside of all of these treatments that have had to take place outside our own home area is that Heath has since developed a fear of doctors. Sadly, we will be heading down that path again with our almost 3 year old daughter Mia as she has developed signs of sleep disordered breathing and will have to travel away again.

We need a well-trained ENT paediatric doctor who is based in our region so people can stay in their own area to access these services. To be able to see an ENT in your own region would make these treatments and surgeries much more comfortable and less expensive.

Story 2: Amanda and Lucas

Amanda Dickson Sinclair

Gloucester 2422

Lucas was four at the time and is now aged 7

Our family has found accessing ENT services in the Mid Coast region extremely difficult and near impossible without the necessary funds to pay as private patients.

When my son Lucas was aged four and started pre-school, he began getting lots of infections in his tonsils. Like many children, their immune system has to grow and develop some tolerance to infections but for Lucas his tonsils seemed to become a target.

The problem kept reoccurring with tonsil flare-ups at least every two months and a high fever for at least 3 days before the antibiotics would kick in. His throat was so swollen you could hardly see the back of his throat. That was just in his first year of pre-school which was such a crucial stage in his development.

Our local GP sent through a request for Lucas to be seen by an ENT at John Hunter Hospital so he could have his tonsils removed. We didn't have private health insurance or the financial means to pay privately so we were in the public health system. A year had passed with no word from John Hunter Hospital whatsoever and we were on a waiting list.

Because Lucas also has autism, when he was five he did a second year of pre-school. Because of his autism, he was sometimes non-verbal it was difficult for him to tell us when he wasn't feeling well so the ear infections would get ahead of us before we would know – kids with autism don't tell you when there's something wrong.

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It continued getting worse to the point that Lucas was continuously on antibiotics. This shouldn't have happened but it did. The GP said this was not ok and sent an urgent request to have his tonsils removed but yet another 6 months passed from that escalated request and yet the only contact I had to date from John Hunter Hospital was when they left a voicemail asking me if we would still like Lucas's name left on a waiting list.

So that was three years and just one communication response in the form of a voicemail from John Hunter.

The thing that bothers me the most about this, given that we know Lucas couldn't vocalise his problems because of autism, is that his throat could have completely closed up and major damage could have occurred and John Hunter Hospital knew that Lucas had autism.

It's not as though I didn't follow up with the hospital once we were placed on the waiting list – I was calling over those years with John Hunter and I just kept getting the same answer...we're on the waiting list.

John Hunter Hospital needs to do better with their communication around these waiting lists and they need to make sure that the kids are getting the health care they need. It shouldn't matter if you're in the public system, it should be covered for those that can't afford to go private. They did it for corona virus so why can't they do it for these important services that impact on so many different aspects of a child's learning and development? We don't live in America.

We also need ENT and paediatric services here in the Midcoast. Currently paediatric services only come to Gloucester on one day once a month from out of area. We're still on a waiting list for paediatric services. It's a lot to take children to Sydney every 6 months and we can't afford to stay so we do it in one day and that's gruelling.

Too many of us just sit quietly and try not to rock the boat and cause any ripples but it's just not acceptable.

Lucas's problems have still not been resolved and he's still getting infections 3-4 times a year. It's not quite as bad as it was but it's not good.

Lucas was almost non-verbal for his first year in pre-school because of his time away with the ongoing infections. This is a time when he needed social interaction and these problems impacted his learning and physical and social development. It has a huge ripple effect.

Story 3: a personal account of an experience trying to access ENT services in the Mid Coast

Taree 2430

I live in Taree and over the past two years have faced barriers in accessing Ear, Nose and Throat (ENT) services in the Mid Coast.

My son Luke, who's now seven years old, first began displaying learning and speech difficulties at the beginning of last year (February 2019). He was five years old at the time.

Luke was struggling with learning at school and there were issues at home, because we thought he wasn't listening to us.

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Luke was also having some speech issues with pronunciation so I started him with speech therapist and although we did notice some improvement there were still some sounds he couldn't pronounce.

We spent around six months doing speech therapy before it was recommended that we get his hearing tested, which we did, and it was at this point that we discovered he had mild to moderate hearing loss in one ear and moderate hearing loss in the other. He was diagnosed with glue ear so he was referred to see an ENT.

It was the hearing loss that revealed why Luke couldn't pronounce properly because he couldn't hear the correct sound. We needed a referral to see an ENT, but of course, there isn't one in the Mid Coast, so it was recommended that we try to get into see Dr Indu Gunawardena, an ENT from the Central Coast who visits the Mayo Private Hospital in Taree once a month for a clinic.

Once we got an appointment with Dr Indu, it became clear that Luke needed grommets put in and his tonsils and adenoids removed. Dr Indu does not do tonsils at the Mayo Hospital so we had to travel to Gosford Private Hospital in order to have this operation done in May last year.

Due to risk of bleeding with tonsils being removed we had to stay 14 days near a hospital with an emergency department and ENT services so that required two weeks of accommodation. We had to bear the cost of accommodation on top of the out of pocket expenses for Dr Indu.

Luckily, we had relatives in Sydney so we could stay one week in Sydney. We do have private hospital cover so that covered some of the costs but we were still out of pocket \$2.5k. We pay a hell of a lot of money for private health insurance but private surgeons can charge whatever they want above the recommended Medicare amount. So in total we had \$4000 in the Doctor's fees and then Gosford Private Hospital cost \$5000 with one overnight stay. Private health cover met the hospital stay fees, Medicare paid about \$500 in surgery costs and private health insurance paid about \$200 for surgery fees. The remainder we had to pay as private specialist fees.

In addition to the specialist Doctor's fees there was approximately \$150 in petrol costs and \$500 in accommodation costs. It would have easily been \$2000 if we had to stay the entire two weeks in Gosford and we didn't have the relatives we could stay with in Sydney.

If we didn't have private health cover then we would not have been able to have this surgery done.

Since Luke's had the surgery he's greatly improved. His speech is fantastic, we know he can hear us now and he's not below in any learning milestones.

I think my experience shows that the Mid Coast region, and every regional and rural hospital needs an ENT. The Manning Valley has a lot of kids and there's so many with this issue and it's not easy for everyone to travel in order to get the necessary treatment.

I had a friend whose daughter had to have the same thing done and she had to take out a loan in order to have the surgery done. It's an expensive surgery to have to pay for and unless you have the means then it's out of reach for many people. The additional costs of having to travel and stay for two weeks in accommodation is also an added cost burden.

Story 4: Breanna lives in Taree and has a six-year-old son Dexter who has suffered from ear infections since he was as young as one. Sadly, Breanna has been on what can only be described as a merry-go-round of ENT services due to the waiting periods and varying service levels across Mid North Coast locations.

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I first noticed problems when Dexter was just one year old when he would smack his ears a lot and he would also pull on them.

Dexter's problems became much worse after he turned three in 2017 when he experienced about three to four ear infections within six months and each time our GP prescribed antibiotics.

Because I had glue ear as a child I was concerned that this could also be the problem for Dexter so I asked our GP if we could see an Ear, Nose and Throat specialist. I was living in Kempsey at the time and it was recommended that we see an ENT in Coffs Harbour.

I didn't have any private health insurance but I didn't want to be put on a waiting list so we decided to just pay the extra costs. For the initial diagnosis we would have spent approximately \$50 on fuel, \$200 in accommodation and around \$200 to see the ENT.

The ENT looked in Dexter's ears and said there was a lot of ear wax but didn't check his hearing. I was also told to put olive oil in his ears to remove the wax. Unfortunately, the ear infections continued and we had to keep treating them with antibiotics.

When Dexter started preschool a teacher asked whether his hearing had been checked and suggested that this could be the source of some of his problems so I took him back to GP to get a referral to have a hearing test which was done in Port Macquarie and this cost around \$100. There was some hearing loss so I then took Dexter to an ENT in Taree (where we were living now) and Dexter was diagnosed with a low form of glue ear. The screening test revealed his left ear was the worst. We were also told that it was a problem that could go away on its own. This was another \$200 appointment when we were again told to wait four months to see if it settles down.

This ENT, Dr Phillip Michael, then left Taree and there was no ENT in Taree.

A number of months passed and then I saw another ENT that was visiting Taree, Dr Indu Gunawardena. She also said it was something that can go away on its own and again that we should wait six months. When we went back six months later she then recommended surgery.

Because Dexter had other blood disorder complications I wanted a test screen run before he had surgery to ensure that he would be able to withstand it. Unfortunately, Dr Indu lost these blood test results and a number of months went by waiting for this to be resolved.

Nine months had passed and then suddenly I heard from the Dr Indu who was pushing to have the surgery done quickly over an upcoming weekend in November.

I lost confidence in this ENT, given the lost blood test results so I then asked to see a different ENT. We were then referred to Dr McArthur who again told us to give it another six months to see if it would go away. I then discovered he was a convicted sex offender (see SMH story below).

<https://www.smh.com.au/national/nsw/convicted-child-sex-offender-quietly-exits-international-grammar-school-board-20171027-gz9i7u.html?fbclid=IwAR2zYB5wgXibb4apl8uddhpVCm7GM7CIW3ckFDI3dleIRS8JRyp904-ApAc>

Unfortunately, Covid19 then broke out and this has put a pause on everything. I have been referred to a fourth ENT specialist in Newcastle and again this will be in the private system and I'll have to pay more fees and travel expenses.

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Throughout these past few years, I am out of pocket thousands of dollars by having to pay privately for these ENT services, which still have not resolved Dexter's issues. Dexter still has hearing problems and I find I need to repeat things a lot for him. He also has behavioural problems and we do not know if that is linked with the hearing difficulties.

I wonder why these private specialists are pushing children back six months at a time. It's been three years and we've gotten nowhere. I didn't want to go through the public system because of waiting periods but as things have turned out I may as well have because I've not had Dexter's health issues resolved.

We need a dedicated ENT in this Mid Coast region and the costs need to be covered under the public health system. We simply can't afford to keep waiting for these services because too much is at stake for our children's health and wellbeing.

Story 5: Melissa is a proud mother of two beautiful girls. Melissa would like to share her "ear health journey" with her second daughter, Melinda.

Melinda was born in 2012 at Manning Base Hospital in Taree, NSW. A healthy baby, she underwent the standard health screenings in hospital including the State Wide Infant Screening Hearing (SWISH) program, which she passed.

Melinda was enrolled at Girrawong Preschool at Purfleet from the age of 2 ½. It was here, in 2015, that she had her first hearing check offered through Biripi Aboriginal Corporation Medical Centre as part of a routine screening program for Aboriginal children at preschool. This screening test found that she had Glue Ear (Otitis Media) and it was recommended that she be followed up with her local doctor and to have her hearing re-checked at the next screening. When Melissa reported these results to her mother (Melinda's grandmother) she discovered that her brother (Melinda's uncle) had glue ear as a child and needed grommets. This was the first time Melissa had ever heard of Glue Ear. She was given a factsheet and the doctor prescribed antibiotics – the first of many scripts for Melinda.

At a before school hearing screening assessment in 2016 for her oldest daughter at Hearing Australia, Melissa told the clinician that she was worried about Melinda. She always had a runny nose. Her speech was fine but Melissa had to repeat herself a lot when talking to Melinda. Luckily, Hearing Australia offered to do an assessment on the spot, without an appointment. The audiogram showed mild-moderate hearing loss in both ears and tympanometry showed that Melinda had fluid behind her eardrum (i.e. she had middle ear pathology).

Melinda needed to be seen by an ENT Specialist. It was hard to get on the ENT list here unless you have a lot of money.

Melissa asked her GP for a referral to the ENT clinic run monthly at Biripi. In June 2016, she got a place on the waiting list and had to sit in the clinic and wait for 3 hours to see the ENT. The Doctor was great but it was hard having to wait for so long as he had a lot of people to see.

The ENT asked if Melinda snored – yes, she did – so recommended that she have her adenoids out. Melissa stated that "he was talking all doctorly, he answered her question and concerns", he said she would hear from him soon and Melinda was added to the waiting list for surgery.

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In November 2016, Melinda had another hearing screening at Girrawong Preschool. Again, the assessment showed she had Glue Ear. She was followed up by the GP and prescribed more antibiotics for the infection. Melinda seemed to recover between times and her hearing fluctuated a lot. It was at this time that Melissa asked for a referral to a private ENT at the Mayo Hospital as she was so worried that Melinda was going to have really damaged ears if she had to keep waiting. She knew this was going to be very expensive.

Melinda was offered an appointment to have surgery at John Hunter Children's Hospital in Newcastle in April 2017, so she did not end up having to pay to see the private ENT. It was a big deal to drive to Newcastle, about 2 hours south of Taree. The appointment was scheduled for 9:15am so they had to leave at 6:00am. Melinda was 4, care needed to be organised for Melinda's sister and both Melissa and her partner were on their P plates so it was a stressful drive.

The doctors at the hospital were all really nice. Melinda was told she would have a sleep. She wanted her dad to go in to the operation with her so Melissa had to wait anxiously in the waiting room. They removed her adenoids and inserted grommets. Fortunately, they were able to come home the same day. They returned to Newcastle for a 4-6 week follow up with the ENT.

There was a specific care regime that Melinda and her family had to take with the grommets. Melinda was really worried about the grommets coming out but she did everything right and kept them dry. The teacher commented that she was more interactive in class. They just had to make sure the noise level wasn't too loud. The grommets came out naturally after 6 months.

Melinda had another hearing check through Biripi. She had more infections, more runny noses, more antibiotics.

Melissa had to explain to her extended family about the importance of blowing Melinda's nose. Some of her cousins were mean to her, saying she was deaf.

In June 2018, when Melinda was 6 years old, Melissa received a letter stating Melinda was on the waiting list for more surgery at Maitland Hospital. In October that year, where she had grommets inserted and prescribed a steroid spray as her nasal tubes were narrow.

Melinda was in Year 1 at Taree Christian College. Fortunately, her classroom teacher had a personal experience with grommets so was very mindful and attentive to Melinda's hearing. It was at this time that Melinda was referred to the Learning Centre as she was showing delays in reading and sound blending.

A hearing review at Hearing Australia in July 2020 showed that Melinda's hearing was normal. This was very confusing – how could that be? Her hearing was fluctuating so much.

At school, the support teacher wrote a letter of support suggesting that Melinda be seen by the local Itinerant Hearing Support teacher. While her hearing was normal on testing, she had significant scarring on her eardrums and the Itinerant Support teacher suggested she might have Auditory Processing Disorder. That same day, Melissa took Melinda straight to Hearing Australia to make an appointment for the Auditory Processing Disorder (APD) test. There was to be a \$170 charge.

At the assessment in October 2020, Hearing Australia was unable to conduct the complete APD assessment because Melinda was showing significant hearing loss on the left side. Hearing Australia did not charge the fee as the test was incomplete. She will try the assessment again in January 2021. It has been recommended that Melinda needs a hearing aid and teacher's microphone in the

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classroom. Fortunately, there is funding available to cover the costs of this equipment, which is about \$1600.

Melinda needs 1:1 support for learning at school. She finds it hard to read, she cries and says she doesn't want to go to school. She is a great visual learner and a good cook, is very hands on and a great artist. However, she struggles with academic work at school as a result of her hearing and processing difficulties.

Melissa found it difficult navigating the system and having to go to multiple places for different appointments. She would have liked more information to help her and less waiting time. She had to push a lot to get the services needed for her daughter and she imagines what it might be like for other parents who have no support and no car to travel to see specialists.

Story 6: A personal account of Lauren's experience trying to access ENT services in the Mid Coast

Wingham 2429

My daughter Katie is now six years old and first began experiencing breathing and sleep problems at the beginning of this year.

Katie has asthma, some learning disabilities (ADHD) and sensory issues but she began snoring and having additional breathing problems. We took Katie to our regular Laurieton-based GP who diagnosed breathing difficulties aside from her asthma and she also had enlarged tonsils.

Katie wasn't listening on top of her ADHD and this was impacting on her learning. Katie's school mentioned it so we got a hearing test done which revealed Katie's hearing was really bad in her right ear, half of normal hearing in her left and in her right ear hardly anything.

She was given a referral to John Hunter Hospital but we had to keep waiting initially in two-week blocks and then after a while I was told that there was a waiting list for two years just for an appointment to see the ENT specialist which was going through the public health system. It was at this point I then considered going to a private specialist.

I was told about *Dr Indu Gunawardena*, a specialist from Gosford who visited Taree once a month and it took us two months to get an appointment. Her costs were not cheap, approximately \$1770 for her and \$700 for the anaesthetic and another \$200 to stay overnight at Gosford Hospital. Then we had to pay another \$2000 for a hotel to stay, 7-10 days with food expenses. This stay was required because of the nature of the surgery and needing to be close to a hospital with ENT services in case there were post-operative complications.

During the surgery Katie had her tonsils removed and one grommet placed in each ear and two months ago. We were trying to go back for another visit because of some post-surgery problems (Katie developed some problems in her right ear - full of blood and wax, the grommet moved a fraction). This was another \$120 to get a script for eardrops, which cost \$40.

To cover the costs for Katie's surgery and treatment we've had to borrow \$4000 from family and we're still paying that off week by week. We were saving for a house and what savings we did have had to go towards this treatment.

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In total, Katie's treatment cost \$8000, which also included accommodation costs for a two bedroom self-contained hotel with laundry and kitchenette due to the length of our stay.

Since having the surgery Katie's been pretty good, I've noticed a difference in her hearing and breathing. The drops are finished now but you can still see the grommet. I'm concerned that she might need another follow up surgery and I just can't afford it.

I find it so frustrating that it's so hard to find an ENT in the Mid Coast region and in order to have the treatment you have to go private and not many people can do that. This region definitely needs an ENT specialist based here and the costs need to be more affordable through the public health system.

Story 7: My name is Martha Katsamangos. I have been asked to write about my experience with my 4-year-old son and our local rural health service.

Wingham 2429

When my son, Nash was a baby he presented as a normal baby. By age 3, Nash was diagnosed with a speech delay after being assessed by a speech therapist that visited the local preschool. He also was displaying behavioural issues and was roughly 12 months behind in his development.

This led to Nash being referred to a paediatrician and occupational therapist.

The paediatrician report said Nash appeared well and healthy and there was a probability that Nash had ADHD as well as a speech delay. He recommended Nash see an ENT to investigate further and a follow up appointment in about 12 months to see if his behaviour had improved with time before he was given a diagnosis.

Nash was continuing to receive fortnightly ½-hour appointments with the speech therapist that attended the preschool. Hunter Rural Health Service provided these appointments. 10 hours of service was funded through this program.

The preschool had numerous children with various issues and hosted a morning tea and information session on the NDIS hosted by Northcott. I was invited to attend. That day I started a claim for NDIS services for Nash.

I took Nash to an occupational therapist at a cost of \$170 and for another \$170; they wrote me a report to submit to the NDIS to support my claim. I submitted my claim with the assistance of Northcott and received \$20,000 to spend on therapies and the like. He is now on his second NDIS plan this one provides \$24,000 in support.

This should have allowed Nash to access weekly appointments with a speech therapist and an OT and to spend time with a disability support worker. However, there were no speech therapists available. They all had waiting lists of over 3 months and most were over 6 months.

It took about 5 months to get him in to see the speech therapist. Thank goodness, they prioritised him ahead of others or our wait would have been longer.

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Nash did not make a lot of progress with the speech therapist. His behavioural issues and medical issues were a huge barrier to his learning.

He had several hearing tests throughout the course of time and the nurse who did them told me Nash was fine, he did have some fluid in his ears, but to blow his nose every day until he was ten.

Nash had an appointment in the first half of 2020 to see the ENT Dr DeHaan. He is the only ENT within 2 hours drive. He works privately. I was told a free one was a 5-6 year wait and at least a 2-hour drive.

Then we had COVID-19 and the ENT appointment was cancelled indefinitely.

Nash finally attended an appointment in June 2020 and Dr Dehaan informed me he had received the hearing test results and Nash's ears were terribly blocked. He said, if you thought about the times when you had water stuck in your ears that is how Nash's ears were all the time. No wonder he was so frustrated and unable to learn, he had missed so much, it was as if he had his head underwater!

He told me he thought Nash's condition could be improved by a tonsillectomy and possibly his adenoids removed to let his ears drain. There were no guarantees it would work and Nash could require grommets after the tonsillectomy. Through Dr Dehaan, the surgery would not be free. He told me a rough estimate of around \$4000 for surgery and private hospital stay and a further \$1500 for grommets.

I did not have the money. I had to tell Dr Dehaan I would save up, come back, and book in then. If I had the money, they could have done the surgery the following week.

I went back to my GP to see if we could find any other options. As a single mother of 5, who was unable to work, I was really worried I wouldn't be able to get the money or get it in a reasonable time, I am embarrassed to say, my household lives week to week, pay check to pay check. There is usually nothing left to save.

He rang every option he could find and the quickest wait under public health was roughly 3 years and hundreds of kilometres away. Nash was due to start kindergarten in a few months - January 2021.

It was important to me he had the ability to learn and hear when starting school. I did not want him to have to wait and spend 6 years with his head underwater, unable to learn, as I know he is very smart. In 6 years, he would be nearly in high school, his schooling would be seriously affected, his mental health would suffer and my own as his main support.

I had to get the money as quickly as possible. I used my Centrelink mid-year lump sum after they balanced my payments, the \$550 coronavirus supplement payments for all my children, plus anything else I could put aside fortnightly until I saved enough. His father contributed some too.

In August 2020, Nash had his tonsillectomy surgery. He did not need his adenoids removed.

This made the total cost around \$2500. We had a follow-up appointment 2 weeks later and Nash's ears and hearing tested as normal!

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It's October now and the difference in Nash is amazing. He can hear, he is learning to talk and he has so much to say. It has made a huge difference; he is happier and is more engaged in life. He is able to make connections with people in a positive way and it has helped the whole family as well as Nash.

Nash does have more medical appointments to attend. He is due to go back and get his hearing tested again soon. With another follow-up with Dr Dehaan, I pray we are in the clear with his ears. His speech and occupational therapies are continuing and will for the near future.

I have found that my main barrier to accessing health services for Nash is cost and the lack of services, free or paid, in our area. I would love to see these issues addressed. I hate to think of all the kids waiting 6 years to be able to have a 45-minute operation, knowing how much it affects the child and their family.

Edit: 6 weeks after the surgery Martha has received an invoice from the anaesthetist for \$1200, additional to the expenses already paid. Martha has also been advised that further surgical intervention may be required in the near future.

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