# Western Australian Auditor General's Report



# Improving Aboriginal Children's Ear Health



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\*Cover photo courtesy of the Child and Adolescent Health Service.



The Office of the Auditor General acknowledges the traditional custodians throughout Western Australia and their continuing connection to the land, waters and community. We pay our respects to all members of the Aboriginal communities and their cultures, and to Elders both past and present.

The Office of the Auditor General wishes to thank Justin Martin for painting this bespoke Aboriginal artwork to reflect the work of our Office. The black dots symbolise the Auditor General as an integrity institution working with people and government entities throughout Western Australia. In Noongar and Yamatji Country, the black dots represent a black crow, who also has a role to oversee the countryside.





THE PRESIDENT LEGISLATIVE COUNCIL

THE SPEAKER LEGISLATIVE ASSEMBLY

#### IMPROVING ABORIGINAL CHILDREN'S EAR HEALTH

This report has been prepared for Parliament under the provisions of section 25 of the *Auditor General Act 2006*.

Performance audits are an integral part of my Office's overall program of audit and assurance for Parliament. They seek to provide Parliament and the people of WA with assessments of the effectiveness and efficiency of public sector programs and activities, and identify opportunities for improved performance.

This audit assessed the whether state government entities are effectively reducing the burden of ear disease for Aboriginal children.

I wish to acknowledge the staff at the Child and Adolescent Health Service, the WA Country Health Service, the Department of Health, the Department of Communities and the Department of Education for their cooperation with this report.

CAROLINE SPENCER AUDITOR GENERAL

12 June 2019

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## **Auditor General's overview**

This report presents the findings from my performance audit of whether key entities are effectively reducing the burden of ear disease for Aboriginal children in Western Australia.

Undiagnosed or untreated hearing problems can create challenges that last for life. They can delay speech development, making it harder to learn. Hearing loss and educational deficits can make work and social interaction more difficult, and cause problems in interactions with government services and authorities.



While most children will experience an ear infection, the situation is much worse for Aboriginal children. The World Health Organization has found the rate of chronic middle ear infection in Australian Aboriginal children was among the highest in the world. For non-Aboriginal Australian children, the rate is one of the lowest.

This is a complex problem with many contributing factors, and identifying and treating the problem involves many entities. State-funded health services must work alongside educators and housing entities, as well as Commonwealth-funded primary health care and non-government Aboriginal health services. For state entities to be effective partners and providers they need good information, clarity on roles and responsibilities, and a clear approach to working together with Aboriginal people to design and deliver the services they will use.

# **Executive summary**

#### Introduction

The objective of this audit was to assess whether state government entities (entities) are effectively reducing the burden of ear disease for Aboriginal children. In this report we use the term 'Aboriginal' to include all Aboriginal and Torres Strait Islander people.

Our audit mainly focused on health services provided by the Department of Health, the Child and Adolescent Health Service and the WA Country Health Service. We refer to these entities as 'WA Health' throughout the report. We also included the Department of Communities and the Department of Education in the audit to provide broader context.

## **Background**

Otitis media (OM) is a treatable inflammation or infection in the middle ear that is very common in children. Most children will develop OM at least once in their first 3 years. Early detection and treatment can prevent the condition becoming chronic and severe. Frequent or severe episodes can lead to permanent ear damage and hearing loss, affecting learning as well as education and life outcomes. Some children with OM feel discomfort or pain, but others show no obvious symptoms.

Chronic suppurative OM (CSOM) is the most severe form of the disease, and is defined by continual ear discharge through a persistent hole in the eardrum. In 2004, the World Health Organization<sup>1</sup> found that Aboriginal children have rates of CSOM so high they indicate a significant public health problem in need of urgent attention. In contrast, it noted that the overall Australian rate was amongst the lowest worldwide.

Even temporary hearing loss can seriously impact many parts of life (Figure 1). It can slow down speech development, especially in the vital early years. If not diagnosed or treated, hearing loss makes it harder to learn effectively and do well at school, which has many serious effects on later life. Children that cannot hear well do not always respond to verbal instructions. This can lead to a misplaced reputation for misbehaving at home and school. Children with hearing loss can also have a hard time learning social skills and forming good relationships with their peers.

As well as the development and social issues illustrated in Figure 1, hearing loss can make it harder for Aboriginal children to learn cultural lessons and stories from elders and others in the community. For many Aboriginal people, having a strong culture is a vital aspect of wellbeing.

WA Health has recognised that co-designing services with Aboriginal people is the best way to support them. Co-design involves government developing policies, programs and services with the community to make them more effective and culturally appropriate. It can also help empower socially disadvantaged communities and build programs that reflect their values and needs. The WA Aboriginal Health and Wellbeing Framework and the Sustainable Health Review both cite co-design as a useful approach to improve Aboriginal health in Western Australian (WA).

World Health Organization (2004). Chronic suppuratives otitis media; Burden of illness and management options. Geneva, Switzerland: World Health Organization.

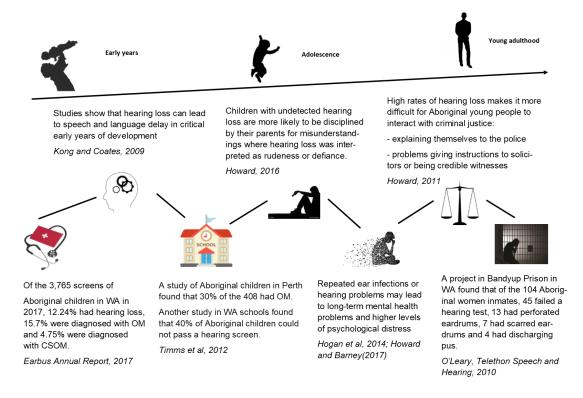


Figure 1: Some possible effects of hearing loss over time

Key entities involved in monitoring, treating and improving ear health of Aboriginal children are listed below.

Source: OAG

- WA Health, including the Child and Adolescent Health Service (CAHS) and the WA Country Health Service (WACHS): Have a role in preventing and detecting potential ear problems in young children. They also provide specialist and hospital treatment when ear problems are severe. The Department of Health (DoH) funds Aboriginal environmental health services in regional and remote areas.
- Department of Communities: Provides housing to many Aboriginal families and plays an important role in reducing environmental risk factors associated with OM. Having access to clean running water and uncrowded houses can help prevent OM.
- Department of Education: Focuses on minimising the impact of OM in classrooms by building staff capacity to support children with hearing loss, including the use of amplification systems in classrooms and additional educational support staff.

Many other stakeholders and service providers are involved in this area. The Commonwealth government funds primary care, including general practitioners (GPs) and Aboriginal Community Controlled Health Services (ACCHS) to provide front-line diagnosis and treatment. The Commonwealth has also funded specific ear health projects and programs over time. Various non-government organisations do research and provide medical services to help Aboriginal families with their children's ear health.

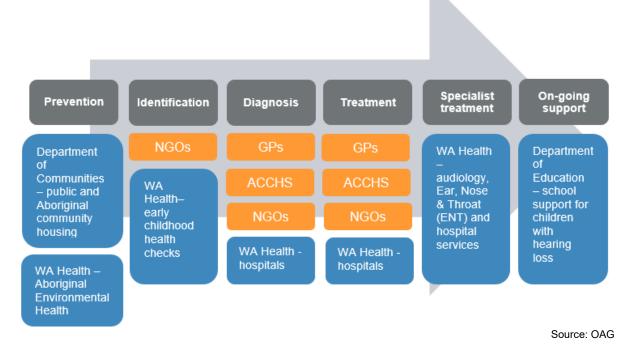


Figure 2: Prevention, detection and treatment of ear problems and key parties involved (state entities in blue)

## **Audit conclusion**

WA Health and other entities have recognised that the high rate of OM in Aboriginal children in WA is a complex problem with serious health, social and economic consequences. There are some local examples of good practice in preventing, detecting and treating OM in Aboriginal children, but there are still a number of barriers to reducing rates of the disease and its impact.

WA Health does not have adequate information on prevalence, assessment or treatment. Nor is there an effective system of co-designed and collaborative care. The current general approach to preventing, detecting and treating OM has not worked for many Aboriginal children. This means that the audited entities cannot demonstrate that they are effectively reducing the burden of ear disease for Aboriginal children.

Identifying the problem has largely relied on standardised child health screening that does not include physical ear checks. Programs developed specifically for Aboriginal children that include ear checks do not reach most Aboriginal children. Other checks take place when children start school, but by this time many children will already have hearing loss and developmental delays.

Service delivery remains ad hoc. The release of a WA Child Ear Health Strategy in 2017 was a step forward in the effort to tackle OM in Aboriginal children. However, entities still do not know who is ultimately responsible for implementing the strategy, and there are no specific plans or targets for them to measure progress and success.

There is evidence that co-designing services is important to ensuring their success in Aboriginal communities. However, the ear health services offered to Aboriginal children and families generally are not the result of effective co-design. Meaningful co-design will need to be a key part of implementing the strategy for it to effectively improve Aboriginal children's ear health.

## **Key findings**

# WA Health's data does not give a clear picture of Aboriginal children's ear health

WA Health do not track or analyse the rate of OM in Aboriginal children, nor do they know if efforts to reduce the burden or severity of ear disease are working. There are a number of gaps in WA Health's data linkage and information. For instance, they collect data on instances of care such as Universal child health checks (Universal checks). But these checks don't reach many Aboriginal children, and there is no linkage to subsequent diagnosis, treatment and outcomes.

Entities do not use existing data to build a clear picture of the prevalence of OM. Researchers, government entities and non-Government organisations (NGOs) all collect some data, but this is rarely shared. Without a coordinated and collaborative approach to data sharing it is difficult to evaluate what programs work best and where, and to provide an accurate picture of OM in the State.

Based on our review of the available research, Aboriginal children experience OM more regularly and suffer longer than non-Aboriginal children. It tends to present at a younger age and is more likely to result in hearing loss. The Telethon Kids Institute performed research in the Goldfields that found Aboriginal children had OM at more than double the rate of non-Aboriginal children (55% compared to 26%)<sup>2</sup>. This indicates a continued disparity between Aboriginal and non-Aboriginal children.

#### Programs to identify OM don't reach most Aboriginal children early enough

Early detection and treatment is the most effective way to avoid hearing loss and developmental problems, but WA Health are missing key opportunities early in children's lives to find out if they have OM. The main health screening program for children are the Universal checks from birth to 2 years. But these checks do not focus on ear disease and there is no physical examination inside of a child's ears unless parents have raised concerns. Further, the Universal checks do not reach most Aboriginal children. Our analysis of CAHS child health data in 2017-18 found that 43.9% of Aboriginal children in Perth received a health check.

Screening also occurs when children start school, an approach that is effective in reaching a lot of children. CAHS data for school screening in 2017 showed that 94% of Aboriginal children entering pre-primary in the metropolitan area had a health check. In addition to school entry, they also screened 1,260 Aboriginal children at 151 primary schools in 2018. However, because this testing comes when children are 4 to 5 years old and above, many will already have hearing loss and development delays from repeated or persistent OM.

The school testing also comes after the most important period when children develop neural pathways for language and hearing. While screening helps identify children who need support in learning, earlier intervention would be more effective in ensuring Aboriginal children are not already disadvantaged before they start school.

The main program specifically targeted at Aboriginal children has a limited reach. The Enhanced Aboriginal Child Health Schedule (EACHS) program is an extension of the Universal checks designed for Aboriginal children, and includes regular physical ear checks. While it appears to work, EACHS has not reached all at-risk Aboriginal children. In 2017-18 there were 1607 EACHS tests in the metropolitan area. CAHS believes this represents

<sup>&</sup>lt;sup>2</sup> Lehmann, D., Weeks, S., Jacoby, P., et al. (2008). Absent otoacoustic emissions predict otitis media in young Aboriginal children: a birth cohort study in Aboriginal and non-Aboriginal children in the arid zone of Western Australia. BMC Pediatrics 2008; 8: 32.

meeting 29% of Aboriginal families. There is no reliable data for non-metropolitan EACHS tests.

The EACHS checks program is being revised by WACHS and by CAHS, but in different ways. WACHS plans to keep the schedule but remove the focus on Aboriginal children, so it is for all at risk children and rename it the Enhanced Child Health Schedule. This could impact how much service Aboriginal families can access if resourcing does not change. CAHS has replaced EACHS with a system of tiered Universal checks based on assessed individual and family need. Families using the Aboriginal Health Team services will be offered an extended service that includes physical ear checks. However, it is unclear how both approaches will improve the reach of ear screening to Aboriginal children.

#### Services have not been co-designed, making them hard for Aboriginal families to use and limiting their effectiveness

To date while WACHS and CAHS have partnered with consumers in the design of some services, these approaches have not been consistently applied to ear health. Broader stakeholder collaboration and coordination is also limited. The State has recognised the benefits of co-designing Aboriginal services in the DoH's Aboriginal Health and Wellbeing Framework. The medical model of care identifies coordinated healthcare as key to reducing rates of OM. However, co-design has not been mandated by WA Health. When services are not designed for communities, they are less likely to be effective.

Services offered to Aboriginal families once children are diagnosed with OM are generally standardised and are not designed to encourage Aboriginal people to use them. Aboriginal families told us that the system is often difficult to navigate, particularly when they are referred from one service to another. Each referral increases the risk of missing an appointment or disengaging, and leaving OM untreated. Some families are uncomfortable or unable to deal with mainstream services, and some told us they believe that seeking care for persistent ear problems could result in them being 'reported to child protection'.

There are good examples of how changing service delivery can make them easier for Aboriginal families to use. The Pina Karnbi pilot project in Kalgoorlie has used immunisation as an opportunity to check children's ears and a nurse works with families to navigate services where a problem has been identified. The development of the Kimberley Regional Ear Health Strategic Plan involved collaboration between WACHS and the Kimberley Aboriginal Medical Service (KAMS). Learning from what is already working would enable continuous improvement in outcomes.

#### There is now an ear health strategy, but many of the conditions for its successful implementation are not yet in place

In 2017, the WA Minister for Health released the WA Child Ear Health Strategy (the Strategy) but the priorities set out in the Strategy have not been translated into specific actions with timelines, measures and resource requirements. The Strategy is silent on how it will be funded and who is accountable for its implementation. Working groups created under the Strategy have enabled relationship building across the sector, and may assist future partnerships, but they are yet to deliver any tangible actions.

There are broad socio-economic and environmental factors in Aboriginal ear health that involve stakeholders beyond those partnered in the strategy. Environmental health issues, such as overcrowding in housing, access to clean running water, poor nutrition and poverty are key factors and will require collaboration across entities not currently involved in the working groups.

#### Recommendations

The Department of Health, WA Country Health Service and Child and Adolescent Health Service should work together to:

- 1. actively work with stakeholders to progress the priorities of the *WA Child Ear Health Strategy* by:
  - a. agreeing and assigning accountability
  - regular public reporting on progress and results of the relevant areas of responsibility in the Strategy
  - c. formally agreeing data sharing arrangements

**DOH response:** Accepted

**WACHS response:** WACHS supports working with key stakeholders to progress the implementation of the Strategy to ensure a collaborative and consistent approach to tackling ear disease in WA.

**CAHS response:** CAHS agrees that greater clarification around areas of responsibility and accountability will assist in progressing the Strategy, and is committed to working actively with all stakeholders, but it has no mechanism (such as authority or funding) to direct other organisations.

Implementation timeframe: July 2021

The WA Country Health Service and Child and Adolescent Health Service should work together to:

2. design and implement a process for developing co-designed services for implementing the WA Child Ear Health Strategy

**WACHS response:** WACHS supports this recommendation.

**CAHS response:** For CAHS, this recommendation aligns with other work planned in reviewing aspects of service delivery to Aboriginal families and will be integrated into this broader body of work.

Implementation timeframe: July 2020

3. leverage existing contact with Aboriginal families to increase early detection of OM through opportunistic ear checks. This should include offering all Aboriginal children physical ear checks through the Universal Child Health Checks or equivalent.

**WACHS response:** WACHS is currently implementing the Enhanced Child Health Schedule (ECHS), which will see all vulnerable children (including Aboriginal children) offered additional child health checks, over and above the universal child health checks, which will include provision of ear health checks.

**CAHS response:** This recommendation is supported. For CAHS, this will require:

- policy review (in progress);
- development of a sustainable education program to upskill staff; and
- additional equipment to increase capacity across the Aboriginal Health team and universal child and health services' nursing workforce (in progress).

Implementation timeframe: December 2019

## **Entity responses**

## **WA Country Health Service**

The WA Country Health Service has a strong commitment to enhancing the health and wellbeing of Aboriginal people and considering the unique needs of children. WACHS has developed a specific Aboriginal Health Strategy and a Healthy Country Kids strategy which combine to articulate our service focus for Aboriginal children in country WA. Key focus areas of the Aboriginal Health Strategy include maternal health and parenting, child health and development, and creating healthy environments.

The provision of ear health services to Aboriginal children is complex and challenging, with Government, private GPs/clinicians and Non-Government organisations (NGOs) involved in providing services from prevention through to treatment.

WACHS acknowledges that to make an impact on ear health in Aboriginal children a coordinated approach across the patient journey is required, including operational service coordination across the Federal and State Governments and the Non-Government sector to reduce service fragmentation and gaps. In this regard, WACHS supports a recommendation that relates to progressing the implementation of the WA Child Ear Health Strategy (the Strategy) to ensure a collaborative and consistent approach to tackling otitis media (OM) in WA.

WACHS has a well-established history of partnering with consumers and service providers in the design, delivery and evaluation of services. Since 2013-14 WACHS has worked with the Aboriginal Community Controlled Health Sector (ACCHS) and NGOs, providing funding via Grant Agreements to provide child and school health services in Aboriginal communities. In 2018, WACHS has established five year service agreements to guide the delivery of these services.

WACHS is also committed to working with consumers and key stakeholders to ensure their success in Aboriginal communities. WACHS will continue to partner and work collaboratively with the ACCHS, NGOs, private GPs, clinicians and community members to ensure ear health service delivery is flexible and meets community needs.

Important steps have already been taken by WACHS to leverage existing contact with Aboriginal families to increase early detection of OM through opportunistic ear checks. In 2019, WACHS will implement the Enhanced Child Health Schedule (ECHS) which will see all vulnerable children (including Aboriginal children) offered additional child health checks, over and above the universal child health checks, which will include provision of ear health checks.

#### Child and Adolescent Health Service

CAHS acknowledges the importance of progressing the implementation of the WA Child Ear Health Strategy with the aim of improving outcomes for Aboriginal children in the vital area of ear health. The impact of otitis media on the health and developmental outcomes of this vulnerable group of children are well documented. CAHS is committed to improving service delivery and making a difference in this area.

CAHS is committed to the provision of culturally safe services and seeks to actively partner with communities in ensuring that services meet the needs of Aboriginal and Torres Strait Islander people. CAHS welcomes the recommendation to co-design ear health services for Aboriginal children. This will build on work already underway in relation to Aboriginal specific community based services.

The opportunity to increase ear health surveillance through opportunistic ear health checks has been recognised and CAHS Community Health is currently conducting a review of policy and practice to identify potential ways to enhance existing service provision.

Whilst acknowledging the significant role of CAHS, in providing a universal screening service for Aboriginal children within the metropolitan area and tertiary level specialist services within Perth Children's Hospital, it is important to acknowledge that there are many other healthcare providers (Government and Non-Government organisations) delivering ear health services as part of the broader health system. The complexity of this system has been recognised and CAHS staff are committed to supporting clients to navigate the system and ensure their ear health care needs met.

CAHS is also committed to actively working with stakeholders to progress the priorities of the WA Child Ear Health Strategy, responsible for ensuring it is providing a service that meets the needs of its own clients and supporting the broader health system to implement the priorities of the Strategy.

## **Department of Communities**

The Department of Communities acknowledges the recommendations made and the significant role it plays in the broad socio-economic and environmental health issues identified, including the provision of housing (to reduce overcrowding) and access to clean running water.

The Department looks forward to working more collaboratively with the Department of Health and other stakeholders to support improved ear health for Aboriginal children.

#### **Department of Education**

The Department of Education would like to acknowledge the significant work completed by the Office of the Auditor General (OAG) in assessing current services available to support the ear health of Aboriginal children.

It is essential to work with other Government agencies, non-government providers, families and communities to support health, wellbeing, participation and achievement of Aboriginal children and young people.

The Department supports the OAG recommendations for extensive collaboration between health providers when implementing the WA Child Ear Health Strategy. The Department would welcome future opportunities to further engage in collaboration with health providers and communities to co-design effective and sustainable strategies to improve the ear health of Aboriginal children.

The Department will continue to provide public schools with professional learning, advice and guidance to ensure that ear health approaches are culturally responsive and informed by the Department's Aboriginal Cultural Standards Framework.

The Department promotes the use of a two-way approach in its design, planning and delivery of services for/impacting on Aboriginal people. Strengthening collaboration between schools and communities and across Government must incorporate both Aboriginal and non-Aboriginal perspectives.

# Audit focus and scope

The audit assessed whether entities are effectively reducing the burden of ear disease for Aboriginal children. It focused on 2 key questions:

- 1. Has WA Health helped reduce the incidence and severity of OM in Aboriginal children?
- Are entities partnering effectively to ensure strategies work for Aboriginal families? 2. In conducting the audit, we:
- reviewed agency policy and key documents
- examined records of 140 child health checks at CAHS and WACHS
- examined records of 43 enhanced Aboriginal child health schedule checks at CAHS and WACHS
- analysed data on child health checks, hospital waiting times, School of Special Needs: Sensory (SSEN: S) clients and public housing crowding rates
- interviewed management, clinical and other staff from WA Health, including Kalgoorlie, Halls Creek and Armadale child and community health clinics and the Aboriginal health team's clinic in Kelmscott
- interviewed staff from the Department of Education including staff from SSEN: S and principals at schools in Kalgoorlie, Coolgardie, Halls Creek and Armadale
- consulted with key stakeholders in Perth, including:
  - Aboriginal Health Council of WA
  - Derbarl Yerrigan Health Service 0
  - Earbus Foundation of WA
  - Moorditj Koort Aboriginal Health and Wellness Centre
  - Rural Health West 0
  - Telethon Kid's Institute
  - WA Primary Health Alliance
- consulted with key stakeholders in regions:
  - Bega Garnbirringu Health Service in Kalgoorlie
  - Kimberley Aboriginal Medical Service in Broome
  - Yura Yungi Medical Service in Halls Creek
- spoke to Aboriginal mothers, caregivers and community members in Kalgoorlie, Leonora, Halls Creek, Armadale and Kwinana.
- reviewed research and literature.

This was a broad scope performance audit, conducted under Section 18 of the Auditor General Act 2006 and in accordance with Australian Standard on Assurance Engagements ASAE 3500 Performance Engagements. Performance audits focus primarily on the effective management and operations of agency programs and activities. The approximate cost of undertaking the audit and reporting was \$520,000.

# **Audit findings**

# WA Health's data does not give a clear picture of Aboriginal children's ear health

#### OM affects Aboriginal children at a higher rate than non-Aboriginal children

Although there is no conclusive and comprehensive data, the weight of research shows that OM is a significant issue for Aboriginal children. It shows that OM appears at a younger age, is more common and more likely to result in hearing loss in Aboriginal children than in non-Aboriginal children. High rates of OM were first recognised in WA by the Deputy Commissioner Public Health in 1957.

Aboriginal children have some of the highest rates in the world of CSOM, a severe form of OM that is a major cause of hearing loss. A 2004 WHO paper reported the issue for Australian Aboriginal children was 'a massive public health problem' (Figure 3). In contrast, it noted that the overall Australian rate was amongst the lowest worldwide.

Prevalence of CSOM	Nation / population group
Highest (>4%) – urgent attention needed to deal with a massive public health problem	Tanzania, India, Solomon Islands, Guam, Aboriginal Australians, Greenland
High (2-4%) – avoidable burden of disease must be addressed	Nigeria, Angola, Mozambique, Republic of Korea, Thailand, Philippines, Malaysia, Vietnam, Micronesia, China, Eskimos
Low (1-2%)	Brazil, Kenya
Lowest (<1%)	Gambia, Saudi Arabia, Israel, <b>Australia</b> , United Kingdom, Denmark, Finland, Native Americans

Source: WHO: Chronic suppurative otitis media; Burden of illness and management options

#### Figure 3: CSOM prevalence

A 2004 Telethon Kids Institute (TKI) survey<sup>3</sup> of parents and care-givers of Aboriginal children found that high rates of Aboriginal children reported runny ears or recurrent ear infections. When ears are runny, OM is severe and the eardrum has been perforated. Results varied by region, but 10-25% of Aboriginal children (0-17 years of age) experienced runny ears or recurring ear infections.

Another TKI research project regularly examined 100 Aboriginal and 180 non-Aboriginal children from birth to the age of 2 in the Goldfields. This study found that the rates of OM in Aboriginal children were more than double that of non-Aboriginal children (55% of 184 examinations in Aboriginal children compared to 26% of 392 examinations in non-Aboriginal) (Figure 4).

<sup>&</sup>lt;sup>3</sup> Zubrick, S., Silburn, S., Lawrence, D. et al. (2005). The Western Australian Aboriginal Child Health Survey: The Social and Emotional Wellbeing of Aboriginal Children and Young People. Curtin University of Technology and Telethon Institute for Child Health

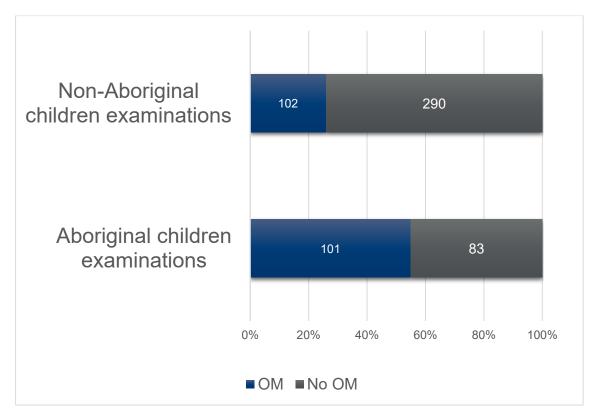


Figure 4: Rate of OM in Telethon Kids Institute Study 2008 Source: Telethon Kids Institute

Aboriginal children in WA have higher rates of presentation at hospital for OM than non-Aboriginal children. Commonwealth data from 2004 to 2015 showed that Aboriginal children in WA were hospitalised more often than both non-Aboriginal and Aboriginal children from the rest of Australia. Another TKI study<sup>4</sup> of children born in WA between 1996 and 2012 found Aboriginal children 10 times more likely to present at hospital with OM.

We reviewed regional hospital data and found that Aboriginal children presented at emergency departments with OM more often than non-Aboriginal children. Of 1,157 OM presentations from 2012 to 2017, 72% were Aboriginal, supporting these findings.

A study<sup>5</sup> of Aboriginal children in Perth from 1998 to 2004 found high rates of OM. The study found hearing loss evident in 40.9% of the children aged between 4 and 7 years - right at the beginning of formal education.

#### WA Health does not have a clear view of how bad the problem is or if initiatives are successful

Although entities collect case by case information on children's ear health, they do not collate it to provide a more complete picture of incidence and severity. They also cannot access primary health records of diagnosis. As a result, WA Health does not know exactly how many Aboriginal children are diagnosed with OM, how often they are diagnosed or where it is most prevalent.

<sup>&</sup>lt;sup>4</sup> Westphal, D., Lehmann, D., Richmond, P., Lanningan, F., Williams, S., Moore, H. Epidemiology of Otitis Media hospitalisations in Western Australia: a retrospective population cohort study (1996-2012). Telethon Kids Institute, National Centre for Epidemiology and Population Health, Australian National University, School of Paediatrics and Child Health, University of Western Australia, Princess Margaret Hospital for Children

<sup>&</sup>lt;sup>5</sup> Williams, C., Coates, H., Pascoe, E., Axford, Y., Nannup, I. (2009) Middle ear disease in Aboriginal children in Perth: analysis of hearing screening data 1998-2004, MJA Volume 190 Number 10

Because entities don't have a robust baseline, it is very difficult for them to demonstrate what kind of treatments, programs and services work best to reduce the burden of ear disease for Aboriginal children in WA communities. Nor can they identify where the problems are greatest so they cannot efficiently target initiatives and funding where they are likely to have most impact on ear health outcomes for Aboriginal children.

The many entities, organisations and medical practices involved in identifying, diagnosing and treating OM in Aboriginal children across WA collect their own specific data. However due to privacy concerns, they do not share patient information, even at a de-identified and aggregated level. There isn't one entity responsible for collecting, evaluating and reporting the data. Because the data is not shared, no one knows how bad the situation is for Aboriginal children at a whole of state level at any specific point in time, and there is no baseline to measure performance.

While WACHS and CAHS collect some data, they do not use data or information to track children's journeys through the system or their ear health outcomes. For example, they record instances of health checks through the Universal checks and the EACHS program but do not link this data with hospital or ear, nose and throat (ENT) specialist records. They cannot use the data to identify patterns in OM or test the success of regional programs. Whether a child with suspected OM actually gets that problem resolved or treated is not known or routinely analysed.

## Programs to identify OM don't reach most Aboriginal children early enough

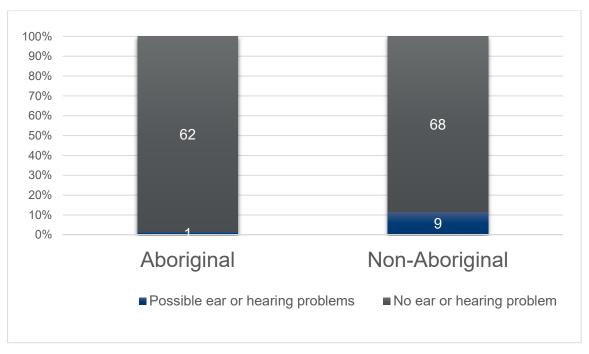
#### Early childhood health checks do not effectively identify OM

WA Health currently offer 5 child health checks from birth until the school entry check. These Universal checks are usually delivered by nurses in a clinic and are currently the main service offered that could pick up ear health problems. In the 2017-18 financial year there were 102,890 checks performed in WA, with 4,497 checks of Aboriginal children

While the Universal checks are designed to assess a child's overall health and development rather than specifically identifying OM, they are the best opportunity for early detection and intervention. The checks do not include a physical ear check which is the best method of detecting OM and instead rely on parental observations of development. This means WA Health is unlikely to detect OM early and OM is only likely to be identified if the child's development has already been affected.

Our review of Universal check files in Halls Creek, Kalgoorlie and Armadale found the rate at which Aboriginal children were identified with ear or hearing problems was much lower than would be expected based on published research. This demonstrates problems with the effectiveness of the testing regime in identifying potential hearing problems in Aboriginal children. We reviewed 140 files of children (63 Aboriginal and 77 Non-Aboriginal) who had received at least one Universal check. We found only 1 case where an ear or hearing problem was found in an Aboriginal child, but 9 in non-Aboriginal children (Figure 5).

This would suggest that the major problem was in the non-Aboriginal population, but this does not match the research data, WA Health and NGO data and experience, or what people told us of their lived experiences. Such a significant discrepancy with the research and data would suggest that WA Health needs to review the effectiveness of the checks in identifying OM.



Source: OAG

Figure 5: Number of potential ear problems identified during standard (Universal) child health checks in 3 locations

The Universal child health checks are achieving limited coverage among Aboriginal children. Our analysis showed that only 4% of Universal checks in 2017-18 involved Aboriginal children, even though the ABS national census data indicates that they make up 7% of all children in WA. We note that there is no simple agreed way to identify the number of Aboriginal people, and that this can affect data analysis.

Our review of CAHS Universal checks data for the period 2013-2018 found that Aboriginal children were almost 3 times as likely to not attend an appointment as non-Aboriginal children. The data showed a 'did not attend' (DNA) rate of 28% for Aboriginal children against 11% for Non-Aboriginal. When families do not attend an appointment this is a missed opportunity to detect problems.

#### Aboriginal specific services that should identify ear problems are not offered to all Aboriginal children

WA Health offers the EACHS program which are culturally appropriate health checks that are dedicated and designed to improve the level of engagement with Aboriginal families. Our analysis of metropolitan EACHS data showed a much lower rate of non-attendance for appointments than the universal checks, at 10% compared to 28%.

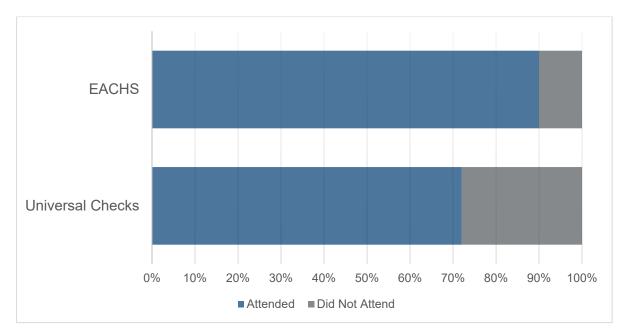


Figure 6: Attendance rates for child health checks

Source: OAG analysis of CAHS data

- CAHS Universal checks Jan 2013 Jun 2018
- CAHS EACHS May 2016 Jun 2018

The EACHS is a more intensive version of the Universal checks and are better at identifying OM. They are usually delivered by Aboriginal health nurses and include physical ear screening rather than relying on parent's observations. Our file review found EACHS identifies more potential ear issues (11 of 43 checks we reviewed) than the Universal checks (1 of 63 checks of Aboriginal children we reviewed), although we concede the EACHS cohort is more likely to have a higher rate due to their more complex needs.

EACHS is only offered to children that a nurse assesses at risk, even though Aboriginality in itself is a risk factor for ear disease. In some areas, such as in Kalgoorlie, nurses have chosen not to offer EACHS at all.

The EACHS checks program is being revised by WACHS and by CAHS, but in different ways. WACHS plans to keep the schedule but remove the focus on Aboriginal children, so it is for all at risk children and rename it the Enhanced Child Health Schedule. This could impact how much service Aboriginal families can access if resourcing does not change. CAHS has replaced EACHS with a system of tiered Universal checks based on assessed individual and family need. Families using Aboriginal Health Team services will be offered an extended service that includes physical ear checks. However, these changes will not increase the availability of the targeted services to Aboriginal children and without the focus on Aboriginality may result in fewer Aboriginal children receiving ear screening.

In Perth, the CAHS Aboriginal Health Team also run two ear clinics for Aboriginal children – one north of the river, one south. The clinics improve access to timely treatment by cutting down the waiting time to see ear health specialists. For example, an Aboriginal family who attends the ear clinic can see an ENT specialist within a month or two, while the median wait time is 105 days (in 2017, all children) to see one at Perth Children's Hospital's outpatient clinics.

The ear health clinics however have a limited reach. Clinics only have a small number of appointments available, for instance 14 per month at Armadale, and funding is partially external and subject to budget fluctuations. As a result, there is unmet demand for these services.

## Services have not been co-designed, making them hard for Aboriginal families to use and limiting their effectiveness

#### There are often barriers that can prevent Aboriginal families from receiving appropriate and timely treatment

The referral-based system of care can be difficult for Aboriginal families to navigate in many ways. Each time a family is referred to a different service, there is a risk of missing an appointment or disengaging. The rates of child ENT patients who miss their appointments is more than double for Aboriginal children (35% in 2017) than non-Aboriginal children (16% in 2017). If a family miss multiple appointments, they can miss out on treatment altogether.

Aboriginal families can miss appointments for different reasons, including:

- not all health services are culturally appropriate, which can make families uncomfortable and reluctant to engage.
- Aboriginal families have cultural obligations that can take precedence over a medical appointment, such as assisting other family members in crisis, and attending funerals and sorry business.
- appointment letters may be sent to outdated addresses, especially for people with a transient lifestyle.
- SMS reminders are sent in English, but English is not the first language of all Aboriginal people.
- health services use communication methods that families do not engage with such as hardcopy letters. Young parents are now more engaged with digital and mobile communications.
- socio-economic disadvantages, such as lack of transport, can also make it difficult for families to attend appointments.

If a client misses 3 appointments, it is WA Health policy to take them off the waiting list altogether. For vulnerable children, whose families cannot navigate a sometimes complicated system, this policy is likely to result in diagnosis and treatment delays. These delays put an affected child's development at risk.

Within the ACCHS sector we found examples of organisations that are actively dealing with these barriers. We spoke with Moorditi Koort, an ACCHS in the Kwinana area, who explained to us how they help Aboriginal clients navigate services and overcome barriers to treatment.

#### Helping Aboriginal families access services: Moorditj Koort

Moorditj Koort is an ACCHS with a clinic in Perth's southern suburbs. During our visit, the organisation told us about how it provides flexible, culturally competent support to its clients. It offers transport to help families get to appointments. It also offers non-judgmental support that recognises the traumatic history many Aboriginal families have dealing with government entities. Moorditj Koort also helps families navigate mainstream services. We spoke to a number of women who were clients of the organisation. One mother of a child with OM told us her child's grommets needed replacing and her child had suffered repeated ear infections. Their school reported the child's ear problems to the Department of Communities (Child Protection). Moorditj Koort supported the mum to get her child back on the waitlist for surgery, which the mum assumed had already been done. They also helped her talk to Child Protection despite her fears. Because of this contact, Child Protection wrote a letter of support for surgery.

Figure 7: Example of actively overcoming barriers to accessing services

# WA Health has not consistently co-designed services with Aboriginal communities so that services work for them

Child ear health services are largely standardised across the State and co-design with Aboriginal people has not occurred in a consistent way. The co-design of services with its users is best practice and recognised in both the *Sustainable Health Review Report* and WA Health's *Aboriginal Health and Wellbeing Framework 2018-2030*. Co-designing services is a way to empower socially disadvantaged communities and ensure programs reflect their values and needs. When services are not designed for communities they are less likely to be usable or meet needs and more likely to be ineffective.

We spoke to Aboriginal people from different areas who told us the different priorities they had for their communities:

- In Kalgoorlie, women told us they were keen to have Aboriginal people involved in health service delivery, so that families felt welcomed and safe using the services. Ideally, they wanted a health service that was run as a partnership between Aboriginal and non-Aboriginal people, using the strengths and expertise of all.
- In Halls Creek we spoke to elders whose main concern was the effect of alcohol and drug use on young people's parenting skills. They worried that this stopped young parents from focusing on their children's ear health.
- In Perth, one mum told us young women mainly use mobile phones and are unlikely to read posters or pamphlets. But she thought they might use a culturally appropriate mobile phone app to learn about, monitor and report on their child's ear health. We were also told that it is possible to incorporate a basic hearing test in a mobile app, which could further help parents monitor their children.

We found no clear examples of an accepted best practice worldwide approach to the prevention, detection and treatment of OM. Success in this area relies on regional approaches that reflect the distinct local issues in those communities. Our discussions confirmed that community needs differ and so the approach to services should be tailored to be effective and achieve consistent outcomes. Getting the design right will therefore depend on effective local engagement with the users of services.

#### Better collaboration among agencies and stakeholders is required to improve Aboriginal children's ear health.

Aboriginal children's ear health is influenced by the social, economic and physical environment and to address all of these factors requires cross-entity collaboration, which is currently limited. For instance, entities do not coordinate ear health screening with housing environmental health checks or providing co-ordinated education about prevention. Health services are key to reducing the burden of ear disease through effective detection and treatment, but will have limited impact if known risk factors such as overcrowded housing and poor sanitation are not addressed at the same time.

Poor environmental health, particularly overcrowded housing, is well-recognised as a contributing risk factor for OM. In New Zealand, improved housing conditions and access to health care halved the incidence of CSOM in rural Maori children between 1978 and 1987. The Department of Communities is responsible for the housing of many Aboriginal communities as well as Aboriginal people living in mainstream public housing. Its data shows overcrowding occurs in 8% to 21% of tenancies in remote Aboriginal communities, although overcrowding is historically under-reported. Sharing information about these cases with WA Health would make it easier to design better programs.

Collaboration between WACHS and local ACCHS occurred in 2 of the 3 regions we visited in our audit. The Sustainable Health Review has called for long term funding of ACCHS to create partnerships in prevention and early intervention in Aboriginal health. Using the expertise of ACCHS where available may limit barriers to service and provide better outcomes.

In Perth, CAHS does not collaborate with other entities on Aboriginal children's ear health except for school entry checks and the school ear health program, which as noted earlier is too late to prevent early childhood learning and development delays. However, schools told us they were not informed of the result of children's ear tests and therefore could not provide assistance in the classroom or to families.

The Department of Education provides assistance to around 850 Aboriginal students (as at May 2019) with conductive hearing loss through its School of Special Needs: Sensory (SSEN: S). This is approximately 2% of all Aboriginal school students in WA. Based on our analysis of prevalence, this likely leaves many undiagnosed children without support to learn. SSEN: S can only support students who have been diagnosed with hearing loss, showing the need to coordinate with WA Health and other screening services.

The Department of Education has to manage the challenges associated with children's hearing loss to ensure they are still able to learn at school. Schools also provide an opportunity to educate families as well as children in healthy behaviours and awareness of OM and its causes and treatments. While this is happening in some schools, there is no coordinated approach to identifying the schools where this approach might be most needed and have most impact.

#### WA Health built important relationships developing a strategy for Aboriginal children's ear health, but successful implementation is hampered

Both WACHS and CAHS partnered with key stakeholders to develop the WA Child Ear Health Strategy 2017-2021 (the Strategy). Their partners include the Aboriginal Health Council of WA, Rural Health West, TKI and the WA Primary Health Alliance. Prior to 2017, although there was a model of care for OM, there was no strategy either within WA Health or across this broader group of stakeholders to improve Aboriginal children's ear health.

The development of the Strategy has built good relations between the stakeholders. These relationships will be crucial for the implementation of the Strategy, which will need to involve sustained improvement in a complex environment. However, good relationships alone will not be sufficient to implement the strategy effectively.

The Strategy set out a comprehensive set of priorities that need to be addressed to improve child ear health in WA. These priorities are:

- enhanced prevention
- standardised surveillance
- consistent treatment
- workforce development
- program evaluation
- coordination and partnerships
- comprehensive evidence.

The Strategy provides a clear direction for stakeholders to work towards but does not include specific actions, timelines, responsibilities, performance measures, financial requirements, funding or sources. There is no single organisation accountable for driving action on the Strategy. Since its release in late 2017, 5 working groups have been established to work out how to implement the Strategy. However, the working groups are yet to make recommendations, and changes to services on the ground to achieve improved ear health have not progressed significantly.

Environmental health is a key missing element in efforts between stakeholders to accomplish the Strategy. Poor environmental health is a risk factor for OM. The Department of Communities is responsible for the housing in many Aboriginal communities whilst the DoH helps to maintain environmental health standards for Aboriginal people in regional and remote WA. Neither are part of the working groups to improve child ear health. It is important that these 2 entities are included in plans for improving ear health to ensure that housing conditions are not contributing to high rates of OM.

#### While system-wide improvements have not yet been made, there are examples of effective local initiatives across the State and other jurisdictions

Although the priorities identified by the Strategy have not yet progressed to actions, during our audit we saw examples of initiatives and activities in the places we visited that were working well. In order to continuously improve services on the ground, it is important that entities learn from what is already working and share those learnings. There are also examples of effective initiatives in the non-government sector and other states.

#### Kalgoorlie's Pina Karnbi pilot project

In Kalgoorlie, WACHS has partnered with a local ACCHS, Bega Garnbirringu, and other stakeholders to try a more proactive way of screening Aboriginal children for ear disease.

The Pina Karnbi project is a pilot initiative that upskills nurses to offer ear checks and health promotion information when children are immunised. There are a range of incentives for parents to have their children immunised, including financial penalties for not doing so, so the immunisation rate is high.

The project creates many more opportunities for extra checks of Aboriginal children's ears. It means more extensive checks are offered at 2, 4, 6, 12, and 18 months of age, and at 4 years. A physical check is done rather than just a discussion with parents, and it includes tympanometry. Tympanometry is an assessment of middle ear function and the mobility of the ear drum.

The project also includes a new service to help families navigate the health system if a problem is identified. A nurse works with families, GPs and specialists to promote a smooth and consistent service for the family.

As of December 2018, Pina Karnbi had 180 children participating and the project confirmed the high rates of ear problems in young Aboriginal children in Kalgoorlie. Fortyseven percent of tympanometry results were abnormal and 6 children had undergone or were scheduled for grommets as a result.

The project was due to be evaluated in February 2019 with a view to rolling it out further across the Goldfields.

#### Figure 8: Pilot project to increase ear checks

Another example of good practice is demonstrated by SSEN: S, which is implementing new ways to better support Aboriginal children with fluctuating and undiagnosed hearing loss.

#### The SSEN: S program in the Ngaanyatjarra Lands

Because the eligibility for SSEN: S services rely on having long-term hearing loss and a formal diagnosis, it is likely that many Aboriginal children are missing out. In recognition of this, the SSEN: S has recently piloted a project in the Ngaanyatjarra lands near the Northern Territory border, to provide more help to students with fluctuating and/or undiagnosed hearing loss.

As part of this program 123 students (primary and secondary) were screened with 82 students (67%) exhibiting either OM or conductive hearing loss. These hearing impairments were previously undiagnosed and the SSEN: S was then able to provide assistance to the schools which the children would not otherwise have received.

Figure 9: Example of school-based screening

#### Local strategy in the Kimberley

In the Kimberley, WACHS had partnered with the Kimberley Aboriginal Medical Service to develop a child ear health strategy for the region. Two dedicated ear health coordinators, 1 from WACHS and 1 from KAMS, worked in partnership to write the strategy and implementation plans. WACHS has now employed a second ear health coordinator in the Kimberley and together, the 3 Kimberley ear health coordinators are tasked with working out a 3-year action plan.

#### Figure 10: Example of a local strategy to improve services

Apart from specialist support from the SSEN: S, the amount of support that students receive varies from school to school, depending on the resources of the school and how it prioritises hearing. We visited 4 schools, each with a high number of Aboriginal children – East Kalgoorlie Primary School, Coolgardie Primary School, Halls Creek District High School and Neerigan Brook Primary School in Armadale. East Kalgoorlie Primary School provides students with a lot of extra help in relation to their ear health and hearing, while Coolgardie Primary School, which is a much smaller school, did not have the same level of resources available.

#### **East Kalgoorlie Primary School**

East Kalgoorlie Primary School recognises that its students' wellbeing has a big influence on their education, so puts a lot of effort into making sure kids are as healthy as possible. Some examples include:

- all classroom teachers using sound-field systems that amplify the teacher's voice and help the whole class to hear and understand the teacher
- engaging a private family support worker as well as speech and occupational therapists
- a breakfast program and showering and laundry facilities for students that may need them.

Figure 11: Example of additional school-based support

#### **Queensland's Deadly Ears Program**

The Queensland government has developed the Deadly Ears Program that leads the implementation of Deadly Kids Deadly Futures: Queensland's Aboriginal & Torres Strait Islander Child Ear & Hearing Health Framework 2016-2026, which is a 10-year plan for improving health, early childhood development and education outcomes in that state. It is jointly owned by the Department of Health and Department of Education.

The framework outlines shared goals, actions and how progress will be measured. Each year an action plan is released that details the specific activities service providers and stakeholders will undertake and the outcomes are provided in a summary report.

The program has increased rates of attendance at audiology from 53% (2014) to 94% (2018). Rates of children fitted with hearing aids has increased, particularly among the critical 0-3 age group. It has also developed resources to assist the hearing diagnosis in children 0-2, increasing the rate able to have a diagnosis from 49% to 65%. The program aims to be a culturally competent workplace and this helps the engagement with families accessing the program.

Figure 12: Interstate example

# **Appendix 1: References**

Area	Evidence	Source
Health	Of the 3,765 screens performed (children were screened multiple times) on Aboriginal children by the Earbus in 2017:  12.24% had hearing loss  15.7% were diagnosed with OM  4.75% were diagnosed with CSOM.  Pilbara had the highest rates of ear disease, followed by Goldfields, while the South West, where a very small number of kids were screened, had the lowest rates. Rates remained steady throughout the year.	https://teams.oag/PA/HearingLossAC/Documents/6.%20Evidence/Earbus%20statistics%202017.xlsx?Web=1 Source: Earbus Annual Report 2017, p.11
Development	The end result of RAOM, OME and CSOM, when not treated adequately, is significant conductive hearing loss with a resultant speech and language delay, especially where English may be a child's second or third language. This results in educational problems, social isolation, truancy and ultimately early school-leaving and difficulties gaining employment.	Natural history, definitions, risk factors and burden of otitis media  Kelvin Kong and Harvey L C Coates  Med J Aust 2009; 191 (9 Suppl): S39.    doi: 10.5694/j.1326- 5377.2009.tb02925.x Published online: 2009-11-02
School	A recent study of children in Perth found that 30% of 408 school aged Aboriginal children have OM.	Timms, Grauag and Williams (2012) Middle ear disease and hearing loss in school aged indigenous WA children, Asia Pacific Journal of Speech, Language and Hearing 15 277-90
Behaviour/ family	Anecdotal evidence on the impact of hearing loss on Indigenous family functioning was submitted to the Northern Territory Royal Commission. Children with undetected hearing loss were more likely to be disciplined by their parents for misunderstandings where hearing loss was interpreted as rudeness or defiance.	Royal Commission into the Child Protection and Youth Detention Systems of the Northern Territory, Transcript, Thursday, 13 October 2016, p.244. (Dr Damien Howard).
Mental health	Children were more likely to have abnormal/borderline psychosocial outcomes at 10/11 years of age if they had been reported to have ongoing ear infections or hearing problems when they were 4 to 5 years old. When looking at the younger cohort however, poorer psychosocial outcomes were only documented at 6 to 7 years for children reported to have hearing problems at 0 to1 years, not for those who were reported to have ongoing ear infections.	Psychosocial outcomes of children with ear infections and hearing problems: a longitudinal study. Hogan A¹, Phillips RL, Howard D, Yiengprugsawan V.  https://www.ncbi.nlm.nih.gov/pubmed/24593675  BMC Pediatr. 2014 Mar 4;14:65. doi: 10.1186/1471-2431-14-65.

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Court interactions	<ul> <li>Once Indigenous hearing impaired people come into conflict with the criminal justice system, there are a number of issues that then place them at increased risk of continued adverse contact with the system, including:         <ul> <li>difficulties in explaining themselves to the police, with the result that they are more likely to be arrested and charged</li> <li>problems giving instructions to solicitors or being credible witnesses in court</li> <li>management difficulties for corrections staff</li> <li>problems coping, both socially and emotionally, in correctional settings.</li> </ul> </li> </ul>	Doing Time – Time for Doing: Indigenous youth in the criminal justice system, House of Representatives, Standing Committee on Aboriginal & Torres Strait Islander Affairs, Damien Howard, Phoenix Consulting, submission 87, p.1.  https://www.aph.gov.au/binaries /house/committee/atsia/sentenci ng/report/fullreport.pdf p.109
Justice	As well as their work with Indigenous children, Telethon Speech and Hearing has just become the first non-government entity to screen the entire Indigenous population of a jail. From April to June 2010, Anne O'Leary personally tested 104 Aboriginal women at Bandyup Prison, on the outskirts of Perth.  Of 104:  45 failed a hearing test and needed a referral  13 had perforated eardrums  7 had scarred eardrums  4 had ears discharging pus.	See above.  Also referenced in OICS Report of Inspection at Bandyup p.84: http://www.parliament.wa.gov.au/publications/tabledpapers.nsf/displaypaper/3814072a4e7c48650df0e2164825792d0026c7b4/\$file/4072.pdf

# Auditor General's Reports

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3	Implementation of the GovNext-ICT Program	30 August 2018
2	Young People Leaving Care	22 August 2018
1	Information Systems Audit Report 2018	21 August 2018





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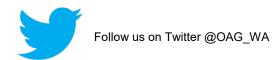
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