

Additional information to inquiry into over representation of Indigenous people in the criminal justice system from phoenix consulting.

## 27-06-10

The following is a letter written by an Indigenous mother about her and her families experience with ear infections and hearing loss. It highlights background stress on families because of hearing loss, that contribute indirectly to involvement in the criminal justice system. This mother wished not to be identified by name.

"I am the parent, partner, granddaughter and sister of people with CSOM, or, "chronic long-term Glue Ear,' auditory processing delay(CAPD) and fluctuating and permanent hearing loss. My family and ancestry, is fractured and while I can safely blame a variety of social reasons, the common thread among them is CSOM.

Survival of the broader problems that stem from fluctuating hearing loss and poor auditory processing is more difficult because of the lack of acceptance by government agencies of what is an ongoing and life-time affliction that affects justice, social, health, education and employment outcomes.

The recommendations of the recent Hearing Inquiry offer a bit of hope for fairer interactions with the justice, child protection and education systems. The idea of additional supports for people who have different academic needs has come a long way in the last two decades. However, acceptance or understanding of the complexities behind Glue Ear are still virtually nil, meaning that at present teachers and advocates have to seize on limited or leftover support available under funding for other learning and health problems, to assist people with long-term glue ear.

As a young mum, I knew little about my family background and CSOM, so my son was seven before it was diagnosed and it was only discovered after visiting his estranged grandmother in regional WA. He experienced many years of pain and confusion before he began receiving any treatment, which was worsened by a lack of continuity in medical care due to life on the run, escaping family violence. As the man of the house, emotionally, he took on the responsibility for being strong and subsequently internalized a lot of pain, worsening his isolation.

Knowledge among the community and their support, can save children with CSOM a lot of suffering and prevent risk of abuse. Greater community awareness allows earlier health and

education intervention and this has a flow-on effect whereby children are less obstructed in disclosing abuse, and in being more alert and aware of the environment around them. It also allows them a chance to have closer, stronger relationships that are more conducive to domestic harmony and protective behaviours.

Families with kids with CSOM can suffer relationship breakdowns, re-partnering is exceedingly difficult and the poor education and employment opportunities available to them with no systemic recognition and support, create a lifetime of adversity, anti-authoritarianism, transience and a subsequent lack of continuity in ear care. Family relationships can be volatile because of poor communications, more misunderstandings, and fatigue. Fatigue affects the parents who cannot sleep when their child is wailing with pain. It affects the child who cannot go to school because each time he lies down to sleep is when the pain hits. It also affects his siblings, who not only have to vie for parental attention but who also cannot sleep due to the crying, but do not have the excuse for their teachers that they were sick. Eventually, in adult years, long-term glue ear patients who have fluctuating or permanent loss or auditory delay, can have problems with a lack of confidence and insomnia.

Effective treatment for children with CSOM, hearing loss and auditory processing delay needs a sustained and multi-pronged approach. As complex as the problems are the solutions must be equally comprehensive, including support and education for struggling parents and siblings. Children with long-term pain also need a range of therapies that go well beyond prescription medication. If parents are shown massage and can use steamers they can lessen inflammation, congestion and referred pain. Accommodation needs to be free of smoke and allergens, and that poses insurmountable difficulties for some families and they need help and support. Educators also need support to deliver schooling in a more flexible way to affected families.

From my work as a journalist, I have learnt that in the northern and central parts of Australia recurrent middle ear disease can be as common as 85-90% of Indigenous children under four. This age is pivotal for development of the auditory link with the brain. The prevalence of middle-ear disease in these regions at that age is a harbinger of radical, worsening outcomes for generation after generation and a systemic approach to treatment, education and awareness is essential immediately.

The recent Senate Hearing Inquiry also heard evidence that 90% of Indigenous inmates at Darwin Correctional Centre have hearing loss. These children who are to become long-term sufferers of this condition will be over-represented in statistics as both victims and offenders, just as they are in my family and in my partner's family, and poor communication and no supports will exacerbate the terrible inequities already existing within the justice system for Indigenous youth.

I consider that projects raising community awareness and supporting families, teachers, advocates and health workers can mean that less Glue ear sufferers will slip through the gaps, and will facilitate earlier intervention in areas of health, justice and education. Greater community support also lessens the stress on individuals and families from poor communications and long-term ill-health associated with CSOM and reduce relationship breakdowns.

In the course of my research, I found Damien Howard's website and was really surprised that there was someone who specialized in this field that affected my family so badly for generations. While we had to struggle through and find ways of dealing with the illness and the problems it can cause, if any of my family or my partner's family had this knowledge or his support it could have prevented years of heartache, discrimination and confusion."