



Johnny

- 7 years old
- Primary school student
- Has atresia on his left side without a formed pinna (outer ear)

Bio

Johnny was born with atresia which means that he is unable to hear from one side. Doctors told his parents that there was not much to do about it, because the inner ear would also be unformed and the ear canal was blocked. He would be able to go through life quite well hearing from one side only. However, not having pinna leaves children open for ridicule because of not being 'normal'.

Seven years later, his parents convinced the doctor that further tests were needed. Imaging showed that the hearing system was intact, and even just opening up the ear canal would allow the sound to get to the inner ear. Doctors are discussing providing him with a prosthetic pinna, so that he will be able to live with less of a stigma. But for the tenacity and networks of the parents, Johnny would be consigning to hearing with one side only and will deal with the stigma. This in fact happened when Johnny went to school.

Services to counsel and guide Johnny and his parents were never offered. His mum noticed the situation may have been affecting his behaviour and relationships with other kids, but did not know how to deal with it.

Motivations

- to hear with both ears
- to be accepted by other children
- to overcome stigma

Frustrations

- being unable to hear from one side
- being stigmatized
- his relationship with other kids is affected negatively

Needs & Expectations

- counselling and guidance services to help him deal with the stigma
- prosthetic pinna to live with less of a stigma
- doctors to actually do further tests on other children's ears
- spread awareness about ear health to other communities to develop understanding

Goals

- receive counselling and guidance services
- communities to understand and accept him
- stigma on himself to be removed



Sally

- health worker
- tasks include checking ears of children and those around in the remote community

Bio

Sally is an Indigenous health worker in a remote community. A few times a year a team comes to check the ears of the kids, and those who are around are seen. Their hearing is checked, a doctor looks in the ear, and medications and surgery is organised. However, some kids were not around to be seen. The visiting team barely had any time to share anything with Sally, other than provide a list of kids who were seen and what they found. Sally was not empowered to help, and did not feel equipped to help the kids on a continuing basis.

On one occasion, Briyanna comes in with her 6 month old child Gemma. Her 5 year old son Brian has also come along. Gemma is crying a lot and pulling at her ear. Both Briyanna and Sally do not know what is wrong, but she remembers that a child pulling at their ear means something. She does not remember what it was and is not sure who to ask.

She notices that Brian has a discharge from his left ear. She knows what to do for him –try to clean it out. Antibiotics may be needed, but she can't give these without a doctor having a look in the ear. The doctor will not be around for another couple of weeks. She could take a picture, but how can she organise someone to look at it? At some stage Brian will need surgery at the hospital (6 hours away), but he'll need to see the surgeon first, then book the surgery and find a way to get Brian and his mum there and back. Where can she turn to for help?

Motivations

- to be empowered and equipped to help the community
- to treat all ear health problems in the community

Frustrations

- visiting team barely shares any information with Sally
- she does not feel empowered to help
- she does not feel equipped to help kids on a continuing basis
- she needs to wait for a doctor to check the patients before making any decisions when it comes to medications or surgery

Needs & Expectations

- full transparency of information to be given from the team
- doctor to be readily around so she can make decisions faster
- more training on ear health and the community so she is better equipped in this field

Goals

- receive training on ear health and community
- receive all relevant information from the team
- have an efficient method to communicate with the doctor if the doctor is not physically present