

WORKING TO END FOETAL ALCOHOL SYNDROME

Presented by Hanlie Snyman from the Institute for Disability Innovation, Carnarvon, Northern Cape, South Africa on 6 November 2014, Cradock Karoo Parliament

When we started Grade 1 or in my time Sub A, we were so proud to write our names, some of us could even bring our mothers 2, 5 or 10 potato's, we could count!

In Carnarvon Primary School, we have 220 learners this year. 60 learners are from the previous year, they failed. How on earth can 60 learners fail? 8.4% of our learners are school drop outs, 20% do not have any schooling, 35% have Grade 7 or some schooling, and 12% have Grade 12 or Matric. Stats SA 2013 says that our unemployment rate in Carnarvon is 25% our youth unemployment rate is 32%. This is so sad our youth in Carnarvon does not have a bright future, why not?

I am Hanlie Snyman from the Institute for Disability Innovation, Carnarvon, Northern Cape, and thank you so much for inviting me this year again! Our topic this year is WORKING TO END FOETAL ALCOHOL SYNDROME. I thought to myself how can we end it? In Carnarvon I do not even know how many people of our community are suffering from this syndrome, because only professional's may perform screenings and evaluations.

There are not any professionals to perform screenings or diagnostic evaluations in Carnarvon. Therefore is it very difficult to tell exactly how many people in Carnarvon are suffering from this syndrome. I am asking: Why can't we only equipped health professionals to do the necessary screening and to perform the evaluation diagnosis correctly? Now we, the community, teachers, parents and families are labelling the children wrongly.

When I'm asking the Department of Education this question, they react very negative; in fact they make themselves very clear that I'm a very cruel person.

Isn't everybody's right to know if they have a disability and what kind of disability? If you know your disability then you understand yourself, and it make it easier for you to cope and live with it.

I am a hearing impaired person. During my school career I did not know I could not hear, each day was so difficult, I struggled. I was labelled as a very average child that doesn't have a bright future. If only I known that I have a hearing disability it would be much easier

for me and my teachers. I completed my degree at the University of the Free State, on my own, I could still not hear in the classes. When I started working, I realised that I cannot hear, I received hearing aids, a new world opened for me. Years later I worked at the National Institute for the Deaf, College in Worcester, as their Project Manager and I was part of the management of the College. My boss often tells me I am a very clever deaf person!

I'm asking again, isn't it everybody's right to know there disability?

Alcohol prevention programmes has failed totally in Carnarvon. Alcohol use/misuse did become a culture, a social status symbol, it gives people power. What is the solution, how are we working to end Foetal Alcohol Syndrome?

We have a commitment from the Centre of Development Support from the University of the Free State to help us create a FAS screening tool that is legally acceptable for use in the Carnarvon community. We have Carnarvon Primary School on board for the research work, they are helping us with the Department of Education in the Northern Cape, but we need the Department of Health also to take part.

In my heart I believe that if the children do know they have a syndrome, and if they do know their learning abilities, it will be easier for them to take full ownership for their future. It will help the parents to know their children's abilities and why they cannot be like a normal child. This will help the teachers to understand their learners learning barriers and to maybe focus more on skills.

When I'm holding a toddler in my arms and I can see that this child is special, I want so desperately a future for that child, because they did not ask to be a FAS child, their mothers make the decision and now they have to live with it. Please let us take hands to help FAS children to know their abilities; they deserve to be treated as a clever unique human being accordingly to their ability and not a person with behavioural problems, as a school drop-out, a trouble maker with the law, rapists or alcoholics.

As you can see, there is still a lot to do, so if anybody wants to take our hands in this project please I beg you join us and let us make a difference in our FAS children's lives and future.

I thank you.