



Photo: Tanja Bause

'WE ARE ALSO PEOPLE' ... Some of the children with Down Syndrome who will benefit from the new organisation.

New group raises awareness of Down Syndrome

• **TANJA BAUSE**

THE Down Syndrome Association of Namibia was launched in Windhoek last week.

It is estimated that one out of every 650 babies born in this part of the world has the extra chromosome which causes Down syndrome (DS). That one extra chromosome is the cause of much havoc in the person's body, from serious medical problems to a whole range of developmental challenges.

"Unfortunately society does not see the person, they see DS. They see a person who looks different, speaks perhaps not so clearly or not at all, a person with less social filters who expresses him or herself emotionally more freely. They see the Down syndrome and not the person, although people with DS are people just like you and me," says Eline van der Linden, a

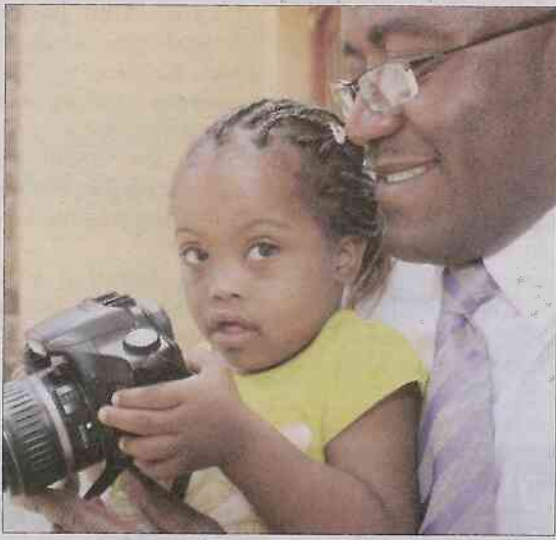
founding member of the association and mother of five-year-old Namashiku, who has DS.

If one in 650 children born in Namibia has DS, there should be about 3 400 people with DS in the country. But with the current lack of information, advocacy and medical care, only 35 percent of these children will live beyond the age of two. Considering these statistics there are currently about 1 000 people with DS in Namibia.

"There is so much opportunity in Namibia to make a difference for people with DS and to create openness in society about DS," van der Linden says.

The Down Syndrome Association of Namibia hopes to help create that openness in society.

"In Namibia we can jump the learning curve, finding applications that work for us, drawing from achievements of Down syndrome associations



'YES I CAN' ... Marcha Pescha and her dad, Marvyn Pescha, at the launch of the Down Syndrome Association of Namibia.

the world over and Down Syndrome International, which brings us all under one umbrella," she says.

They aim to get to a point where a person with DS can say: "Down Syndrome, yes I have that, but it did not stop me from living my life to the best of my ability.

I was looked after by health professionals who knew what to do with me. I was welcomed by my local kindergarten and also at our local school. I learned how to read and write and many other important things. I have friends and family who care about me. It is not

about what I cannot do, but what I can do."

The association will reach out to the government, private sector and the public to change perceptions about people with Down syndrome. They will facilitate opportunities for self-advocacy by people with DS.

They will also facilitate parent-to-parent or caretaker support. They will grow the support network, helping each other by sharing experiences, contacts of service providers and emotional support.

The Association will continue to have dialogue with education professionals, institutions and the government on inclusive and integrated education models. They will also organise fun social activities for people with DS and their families, caretakers and friends.

People who want more information can visit the website www.downsyndromenamibia.org.