

Furthermore, Ali Jookhun is of the opinion that there is room for improvement in terms of services for children with disabilities. *“It is also necessary to spur the parents about the various services available. Above all, we should not overwhelm them on the administrative plan. On the contrary, we must make their lives easier. Otherwise, it increases the risk that they do not accept the disability of their child.”*

Disabled and needy

Commenting on the plight of parents of children with disabilities, the social worker raises the case of those living in poverty pockets. He says that it is even harder for them: *“Being poor, they will not have the same facilities that wealthier parents can provide to their children. In addition, we often deal with single parent families. The father is gone or serving a prison sentence. The mother must assume both roles and at the same time work to feed the family. She has no choice but to leave her disabled child to a neighbour who is also needy. When you see this, you have a feeling of revolt that hits you in the guts. The worst part is that you are helpless and you wonder where our elected representatives are.”*

His own case

Ali Jookhun was himself the father of two girls with disabilities. Born on 29th of July 1993, Irfaanah and Umraanah were suffering from cerebral palsy. They died in 1999 and 2005 respectively. *“The hardest part, in my case, was to find available services. It was in the mid 90s and there was not much. Education proposed almost nothing for disabled children. Fortunately, I was lucky that a normal pre-primary school had accepted my two daughters. My wife and I were strong parents. We accepted our two daughters with their disability. Sometimes religious faith plays a role also. For us, it was a blessing. On 29th of July, my two daughters would have turned 23. I have fond memories and intense emotional moments of them,”* he says in a broken voice.

He added that parents are the best teachers for the children, including

those with disabilities. *“We always tend to think it is the mother who has to care for her disabled child. But the father must also contribute fully to his upbringing. I would say that the relationship between the spouses is doubly important. Often there are cases where the mother leaves the family home and it is the father who cares and vice versa. This further affects the child with disabilities. Anyway, the more harmony within the couple, the better the child will be taken care of,”* he argued.

The social worker recognises that it is



not always easy for some parents who finally snap. There are even some who have severe depression, especially those who have not obtained the necessary support.

Inclusive education

Ali Jookhun makes inclusive education his battle cry. Because he is convinced that the place of a child with disabilities is in a normal school. According to him, children learn by imitation. *“Those with disabilities will learn from other children and at the same time, their perception of disability will change. Unfortunately, we still have some way to go to that level. We must thank the former Minister of Education Vasant Bunwaree, who had developed the Resource Centre to tackle the problem at the source. The centre offered all therapies that were needed.”*

The president of U-Link regrets that nurseries hardly accept children with disabilities. He is pleased that the situation is better at pre-school level, despite the fact that there is more improvement to be made. Especially since, he says, there are parents who act as mediators to work to include more children with disabilities in regular primary schools.

Sexual abuse

Ali Jookhun reports sexual abuse suffered by children with disabilities. He says that those with mental disabilities are most at risk. He reveals that all reports confirm that very often family members are perpetrators of such abuse. *“They know perfectly well that the victim will be inconsistent in his testimony that will not hold up in court. So they can act with impunity. But the victims are also found in specialized centres. And you will find that often these abuses are not reported. First, these organizations value their reputation. Then, a case of sexual abuse may lead to the institution's closure. Besides that there are repercussions in enrolment,”* he insists.

As for the parents, Ali Jookhun argues, they face pressure so that they do not complain. Then, there is the following. If they denounce, the parents know they will not be able to send their child to the institution in question anymore...