



## **Long-term care for people with severe disability — Amar-Singh HSS**

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APRIL 15 — Children and people with disabilities and their families go through many struggles in life. Broadly outlined a child or person with disability (PWD) goes through five key stages in life; five major challenges. In the initial stage, when parents realise there is something wrong, it is vital that they get an early and professional assessment to reach a diagnosis and rehabilitation. The most important thing we can do for them, is to put them in touch with another family with a similar condition who have made progress. This dramatically changes outcomes and provides vital emotional support. We then come to the preschool period where we need to prepare the child for school and develop their living and communication skills. Here early intervention is crucial and this is often done with the help from EIP centres run by non-governmental organisations (NGOs). We often also require many therapists (OT, PT, Speech, etc). We then come to the third major challenge of entry into school, hopefully into an inclusive education environment where the child with a disability can be accepted by her/his peers. Teachers play a vital role here to integrate the child into the class and work with the family to achieve the best outcomes possible.

Then comes the very difficult transition of moving out from school into either university, vocational training or some form of sheltered training with a view to employment. While many of us have worked hard to develop services for the first three challenges, the fourth is poorly developed in our country. Employment, and training for employment, at the present moment is extremely poor for PWD. The supportive structure, the availability of crucial individuals like Job Coaches, the acceptance of the employment community is all seriously lacking. We need to create many, many varied opportunities for training and employment of PWD. All this starts with transition planning, long before the PWD leaves school.

Difficult as all these stages were, the fifth stage is the hardest to face especially for families where the PWD requires life-long support. PWD can have many different outcomes. Some may have significant improvement with therapy and be fully integrated into society. Others may acquire the abilities for independent living and be fully employed in the marketplace but have some social adjustments. Yet others require sheltered employment and supervised living. Finally some require life-long support for everyday daily living tasks. These last two groups of PWD are the ones that need the most support. They keep their parents awake at night wondering and asking themselves repeatedly “what will happen to my child when I am gone?” There are no easy solutions to this painful question. Government, private and NGO facilities for long-term residential care of PWD who require life-long support are limited in number and poor in quality. Not all parents have the financial resources to face this future. Not all families have siblings or relatives who can or want to shoulder this burden when parents die.

For far too long much of the responsibility to care for these long-term needs has been placed on shoulders of parents and NGOs. It is time that we as a community come on board and take responsibility for this area. It is heartening to see the new government openly wanting to be involved. We however cannot just push all of this to our Welfare Department that is grossly understaffed and over-worked. What is required is a number of strong initiatives. We need to create extensive infrastructure and facilities. But even more importantly we need to generate right-hearted persons as carers; people who will be there to support these PWD long-term. One of the best workable models in the world is by Jean Vanier who runs L’Arche. He created communities that care and live together as families with PWD. We must avoid creating institutions but develop caring communities and group homes. In addition, for PWD who have some abilities or can work in sheltered environments or have relatives who want to support them, we need day-carers who can come in and provide support. Transport, assistance with day living, financial support, etc all goes a long way to alleviate the weight of care and make the long term living meaningful and enjoyable.

I ask that we as a new government and community work seriously to develop the services that a segment of our population requires. We have lapsed for quite some time and there is much to do.

While we endeavour to finally make some significant change in the long-term outcomes of PWD, let us not do this thinking we are the only ones who are giving. We are receiving at the same time from the PWD. As Jean Vanier say so insightfully: *“In our fragmented, often broken societies, in our towns made of steel and glass and loneliness, people with disabilities can act as a kind of cement that binds people together. This is their role in society. They have a special part to play in the healing of hearts and in destroying the barriers which separate people from one another and prevent them from living happily and humanly.”* PWD help to integrate and unify the community. They offer communities an opportunity to find purpose and hope and joy. And especially, in our lost and frantic world, they offer meaning to relationships and life.

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