PERSONAL RESPONSE

I am the carer/parent of a young man (28 years old) with an intellectual disability.

We fostered this lad from 3 years of age and he is still very much part of our family although now living in supported accommodation.

He came to us with developmental delay but no actual diagnosis of his problem.

Without any recognition of his disability we struggled for help and support in the early years and were forced to become a “squeaky” wheel to get people to take his problems seriously.

Finally at age 7, I accidentally discovered the reason for his problems when by chance I read an article about children who suffered from a particular rare genetic syndrome. He certainly ticked all the boxes and further investigation through the medical field confirmed my diagnosis. Knowing what we were facing and having a name to put to his difficulties was very helpful. It didn’t mean we would give up on assisting him but we knew the areas which would cause problems, we were able to work on his strengths and we had a “condition” to fill in on the paper work.

Over the years we have worked hard to get the support he needed and the proper schooling and training for adulthood. It was often a battle with bureaucracy and red tape but we researched his disability, got involved with a support group and advocated strongly for his needs. We had very little support from disability services and without our friends and supportive schools it would have been very difficult as he was not an easy child to raise.

The result is a confident young man, a great sportsman, who works in sheltered employment which he loves and now lives in supported accommodation with 80 others which suits his outgoing “people person” nature.

From my experiences with this lad I have a number of concerns which I feel need addressing for any new scheme.

- Regardless of diagnosis or not, any child with developmental delay needs recognition, testing and appropriate intervention. Not all children will get a “name” to their disability. It is alarming when actual conditions ((eg Down syndrome, autism, fragile x) are named for support money etc when there are so many others who may miss out because either they aren’t diagnosed or they don’t fit into the nominated disability.

  Often the well known disabilities have funded support organisations but those with no diagnosis or rare disabilities have very little support and information.

  All children with developmental delay need appropriate testing and intervention services.

- The proposed National Insurance Scheme recognises “significant disability” as its criteria. This is commendable, but those with perhaps less obvious significant disability often have huge needs too, but in a different way. I hope that the emphasis on significant disability will not exclude assistance for others who also need appropriate services to become successful members of the community. Without access to appropriate services they could become the forgotten strata of disability when in fact many, with appropriate support, could lead very useful lives.

  All people with disability need assistance and services to meet their needs.

- Intellectual disability is often misunderstood in the community and when disability is mentioned we often see pictures of people in wheel chairs etc.

  The disability field needs to recognise intellectual disability and the difficulties these people and their families face.

  Many official forms for support and financial assistance (eg Centrelink Carers allowance/pension) do not adequately account for intellectual disability and therefore many people may miss out on appropriate support and assistance.

  Whilst many with intellectual disability may not need 24 hour support for their physical needs they certainly need 24 hour support/supervision to live safe and successful lives in the community and their families are certainly greatly affected by their disability.

  Intellectual disability needs to be better understood and recognised to ensure that people with intellectual disability and their families are equally supported.

- People with intellectual disability have difficulty making choices because of the nature of their disability. The notion that adult people with intellectual disability can make informed decisions is not helpful. From my experience this often sets them up for failure and the confidentiality laws put people in a very vulnerable position if family and carers who know them well are not allowed/encouraged to be involved.

  It is ridiculous that families who have often been very involved in decision making for their intellectually disabled child are suddenly left out when the young person reaches adult age. Chronologically they may be that age but developmentally and intellectually they may still be functioning at a much younger level.

  Families/carers need recognition as advocates for people with intellectual disability and their experience and knowledge recognised and respected in decision making.

- Lack of information about services etc is a major problem for disabled people and their family or carers. It is often only through word of mouth or accident that people discover services which might help.

  Many families are so busy just surviving that they are too weary or do not have the necessary skills to fight their way through official channels and red tape.

  Many don’t even know where to start and the literature available if you can find it is often so general as to be of little help.

  Information provided by the disability sector is sometimes sent only to the disabled person. If they cannot read, they pay little attention to the written information and fail to pass it to their carers who may have found it useful.

  Especially in the area of intellectual disability the person concerned is often unaware of their needs and ignores the information pertaining to them.

  Better information services are essential so people know where to access information and the information needs to be useful.

  Families/carers should be kept informed of any information sent to clients of Disability SA. Perhaps a nominee scheme which nominates a support person for each person (who needs assistance to understand information) could assist the proper dissemination of information.

- Help is often only available in time of crisis. Usually there is no one who regularly checks on families and assists them to make future plans in readiness for the next transition phase.

  Unless I make contact with a disability service they would have no idea of my sons needs or what he requires for the future.

  Surveys cannot be accurate if the very people they are planning for are not known and asked their opinion.

  More staff and services to help all people with disability and their families/carers are needed, so that they have regular contact with disabled services without being crisis driven.

  This would enable people to make informed plans in advance and also give Governments numbers and information about possible services which might be needed in the future.

  Statistics would more likely to be accurate for future planning if all people with disability are known to the system and given an opportunity to contribute and have their needs known.

- Services seem to be more readily available for children, but once the disabled person reaches adulthood their services are often more limited. Their disabilities do not go away at age 18. Many will remain “children” forever.

  In fact disabilities sometimes become more obvious as they struggle to fit into the general adult community which is not always as accepting as the school system. Often the gap caused by their disability becomes wider on reaching adulthood and yet the services reduce, putting great stress on families if activities are no longer available during the day.

  Adequate and appropriate services are necessary for adult people who are disabled.

- Accommodation is scarce for people with disability who need support as they grow older. People with disability need opportunities to leave home as the general community does. Respite etc is a good stop gap for the family but to be truly independent disabled people need a variety of accommodation options so they can choose a living style which suits their needs so they too can move out of home and grow.

  There should be a variety of accommodation options available to suit individual needs.

  All disabled people should have the opportunity to move out of home if they wish to.

- The whole notion of disability and inclusion in the community is another area which needs understanding. Whilst I agree that disabled people need to be included in the community, in my experience the community, especially as the child grows older, is less sympathetic and accepting of disability and “difference”.

  After trying the inclusion model for a number of years in his early schooling my son moved into special schooling and was very happy and successful. He was taught appropriate life skills (not a useless negotiated “academic” curriculum) and now he enjoys supported employment, accommodation and sporting opportunities.

  Although he is happy and able to participate well in the general community it is in the “special” environment that he finds his true friends, has fulfilling social opportunities and where he feels really accepted.

  Disabled people should have the opportunity to mix where they feel most comfortable, without any stigma. A variety of education, social, sporting, employment and accommodation opportunities is needed. No one size fits all.

Like many families we have battled for support and services over the years and my comments come from my experiences and observations as we have progressed through the disability arena. We are currently fairly stable and things are going well but you never know what is around the corner and can never be complacent. Tomorrow the whole thing could change when someone gets a new idea about disability, services lose funding, policies change, or governments alter their focus and support.

For the sake of many disabled people’s lives and those of their families and carers, it is important to get this right.

Barbara Smith