Disability Care and Support

Submission

My story is one of experience. I have a disabled sister who has had her condition from birth. Life has always been hard and a struggle just trying to cope with the day to day care needs. From a young age I always remember my mother completing form after form and not understanding why she always seemed exhausted and frustrated all the time.

A little bit about my sisters disability.

1. Occipital Encephalocele
2. Hydrocephalus which is shunt dependent
3. Spasticity in the lower limbs and in the right upper limb
4. Syringomyelia
5. Seisures
6. Developmental delay

DS deem that my sister has a neurological disorder that manifests as a physical disorder. This is an opinion noted by non professional DS staff. I believe that this is not correct and feel that the department does not understand enough about my sister disability in order to deem what care she actually needs resulting in lack of goals achieved and the decline in her overall health.

I was naive to think that the government supported those who are in need of support and those who do not have a choice will be supported for lifetime. I now understand that support is not an entitlement to my disgust!

My sister seemed to have a fulfilled life. She seemed happy during the early stages of her life whilst participating at her special school. The school had a good understanding of Xxxx’s abilities and Xxxx had friends. Since moving on from school the support almost ceases.

If the department says they are about integrating my sister into the community not assisting her to make friends with those who have like abilities. I think that this needs to start a lot earlier and a lot more invested in education for younger children about those less able. I also feel that it is important for those with a disability to have a support network with people with like abilities so they can lean on each other as well as the special school environment supported.

My mother was not coping since my sister left school and the department refused to listen or ignored the pleas and reports from professionals such as councilors from CPL league. As a result my mother continued to struggle until she could no longer and I was then engaged to demand the handover of Xxxx's care to DS.

NOTE: I was blown away that there was no plan for Xxxx to be moved to an independent living home. I thought that this was a natural progression!! I thought that it was in the department's best interest to help Xxxx be more independent because the reality is that my mother is not going to be around forever and how much harder would it be for her to transition to be more independent if she stayed there until my mother was almost at her death bed. I think Xxxx has been disabled her whole life. It's not like it's a surprise! Why is the department not ready?

DS made my mother sign a letter/form/statement confirming that she had abandoned her daughter. DS and other support services did not engage my mother with any decision making process for placement.

My sister was placed on emergency funding and stuck in an unsuitable respite facility (this facility was not equipped for full time care or Xxxx's physical needs) with children who had behavioral problems. She stayed there for a period of 8 months until bad treatment was proven.

I moved to the area to assist my mother in coping with placement of Xxxx and also to help Xxxx cope in DS services etc.. I have watched my sisters overall health decline since Xxxx has been in DS's care.

DS finally engaged Bay Support to rescue Xxxx from her current situation due to the proven bad treatment. Xxxx was placed in a shared house with two x males who have severe Cerebal Palsy and can only communicate through assisted communication.

Xxxx lived with two x males for over 8 months. This was always meant to be a temporary arrangement as this was the only option available to Xxxx. It was not until we had reported that one of Xxxx's flat mates was sent home for palliative care and was in pain making very loud distressed noises constantly. It took 3 months of complaints from myself and my sister to DS before another temporary arrangement had been made in which Xxxx was to be placed for 1 month until her new suitable accommodation had been arranged which we had been discussing.

Xxxx moved into Yyyyyyy Court the commencement of April 2010. At this point we were told that Xxxx would be suitable for a placement in Zzzzzz Court. All we were waiting on was 1 gentleman to move out and then they would join two other gentlemen together leaving a unit vacant for Xxxx and her new proposed flat mate. Xxxx is still within the proposed temporary arrangement.

We have just been advised that it has taken 4 months for the department to work out they cannot fit the two men into the apartment together. I feel that this is another example that the department is not working effectively and to not identify this issue prior to even presenting it to my sister is ridiculous.

Seriously this department has a caseload of around 150 people and they cannot even pair them up appropriately!!!!

Another issue about DS and their lack of funding is what the staff are doing in order to manage the lack of funds. The department is meant to be person centered case management arrangements however they are currently placing people into block funded arrangements. This is the reason that Xxxx was placed with the 2 x boys with high care needs to start with because Xxxx required someone to be at hand 24 hours a day however was not given enough funding for that so needed to piggy back off the boys funding.

Currently the funding for the block arrangement is given to the service provider and the service then arranges the care that they think is needed. I cannot even get a clear answer as to the provision of service from either the department or the service provider. I keep asking them what services did you say were going to provide as part of your tender? Does the service just look after bathing and feeding?? If this is the case then I will seek finding elsewhere for mental health issues..friends networks and activities etc etc I cannot get a clear response. The staff at the house say they have no time and that they should not need to help Xxxx with money management etc etc

Funding needs to be individualized based on the persons needs. The department’s assessments are not appropriate. A complete skills and abilities analysis (matrix) should be done to identify the care needs and them a provision of service be created from this information. All care plans should promote independence. There is currently no focus in this area and everything is voluntary. Personal development for independence should not be negotiable. If they can do it they do it!!

EG: Xxxx is considered to be her own decision maker. The family thinks this is ridiculous and feels that there is enough evidence to prove otherwise however the department has not done anything as they feel that there is no evidence to even suggest further investigation by professionals. I have been asking for them to do a cognitive and psyche assessment since August 09 in which the department agreed to organize as a matter of urgency that has still not been completed. I have a copy of documented meeting minutes which say that DS has agreed to do this on 18.08.09. This is neglect as far as I am concerned. On the other hand as she is considered her own decision maker the carers had been advised that the must do what Xxxx asks of them which meant that Xxxx did nothing for herself and became more dependent on staff. This would have contributed to the weight gain also. So by the department not pairing Xxxx with like abilities, not understanding the complexity of her condition, they have actually made her more dependent on care then assisting and encouraging independence…….crazy!!!!!

My concern is not only for my sister but it is for everyone else who has just been shoved anywhere. There is a lot more to independence than putting people in a house.

I want to highlight the youngcare set up as a great way to provide a support network and an environment which will promote friendships and independence. This is not a nursing home it is like a retirement village set up for those with a disability to live independently however the care is not far away when needed.

I have been fighting the system for over 12 months now. As a result I have had to use the government's health care plan in order to get some counseling to help me cope with the amount of mistakes the department is making resulting in health issues for my sister. The current system is a disgrace and the complaints process is designed not to listen.

I thought that the purpose of a complaints department was to identify issues through complaints lodged in order to improve the services and care. You are to jump through so many hoops in order to get anything investigated. You need to write escalated letters every time you need to go up the ladder. This process is designed to turn people away. Those who care for family members with a disability have enough stress in their lives without having to tell their story over and over again for no one to listen anyway. I thought a complaints process was designed to review and improve the services.

EG… I submitted a complaint to the department of communities about the department's mistakes and lack of action on 24 March 2010. The department responded with an incorrect summary of my complaint in which I corrected the next day. I then continued to follow up a response from this department however only received a response from them mid July. I then escalated the complaint to the Queensland Ombudsman who advised they would investigate only the last 12 months once I had an authority from my sister. The last complaints department took 4 months to give me a response and I could not escalate the complaint until I had a response therefore this process is designed to not even investigate the original complaint in full due to a technicality.

It is through this process that I now understand that everything that has happened in terms of my sister's care has been centered around the lack of funding available and not what support she actually needs. This is why we require a national disability insurance scheme.

THIS IS WHY WE MUST HAVE A DISABILITY INSURANCE SCHEME!!!!!!

☐It's time to change the way services for people with disabilities are funded and structured in Australia.

☐It's time to make services for people with disabilities and their families effective, equitable and efficient.

☐Almost every Australian has cared, or is caring, for a family member with a disability, or knows of a family doing so. Many of these families fall through a huge gap in Australia's social services network.

☐Those who acquire a disability through a workplace or a motor vehicle accident generally receive financial support. However, for those who acquire permanent disabilities in other accidents, are born with a permanent disability, acquire a permanent disability through a medical condition or have a permanent mental illness, there is no automatic support to meet their needs.

☐This is a national disgrace and an issue for every Australian.

☐It's time to introduce a new national safety net, ensuring peace of mind for all Australians should they or someone they love become severely disabled.

☐In place of Australia's current crisis-driven, outmoded welfare-based approach to disability services, it's time for a modern, forward-thinking National Disability Insurance Scheme.

☐Governments are already spending billions of dollars on disability services. A national insurance approach with its inbuilt focus on lifetime needs and claims management would be much more effective and efficient, as well as fair.

☐With the number of Australians with a severe physical, intellectual and/or behavioural disability increasing, and the community's capacity to provide informal care declining, it's time to start planning properly for the future, as Australia did in the 1980s when compulsory superannuation was introduced.

It's time to cement a National Disability Insurance Scheme as a central plank of Australia's social and economic policy framework.

As much as I advocate for the government to stand up and put appropriate funding structure in place, I also feel that persons with a disability should have the same expectations that anyone else. To contribute to the community in some way to their capacity. People who receive benefits normally have to prove that they are looking for a job in order to get their benefits or do something that is to ensure personal or professional development and so should those with a disability. Their voluntary capacity should be assessed and they should have to volunteer to their capacity. You would find that anyone who should not be entitled to a DSP who may have fallen through the cracks would then remove themselves as it is no longer a free ride and the benefit of working and earning money is understood and appreciated.