A debt acknowledged – on a positive note

Nobody likes to dwell on negative things, and nobody wants to project their self image as that of a snarling dog too often kicked in the belly. We sense that our government after so many investigations is well and truly "over" these sob stories. Of course, let's forget about guilt trips and "move forward"...although how can that happen without looking at what has been neglected in the past and what historical inequity there has been, because it does seem from reading some of the submissions that there is a huge discrepancy between states, regions and even within the same area. Indeed families in some states have done it really tough compared to those who cite comparatively good funding, which still hasn't met their needs. No doubt there was a point when we were "over" any wholesale disregard for minority groups, yet the throw-away line is perhaps hardest to bear because we should feel solidarity with the inexhaustible hours worked and the strength of character of our fellow carers - old and young. I can't understand why those who work and also care for someone manifesting with a severe disability today receive the least empathy or support -does anyone comprehend that they have the hardest life of all carers? I'm sure they would like the time to do the role of carer fulltime but have to juggle a job of some description shouldering extra guilt and longer hours and then have less eligibility for funding or time for advocacy - talk about a no-win situation, especially for the people with a disability for whom they attempt to care. This comment is however meant to say something positive about a NGO who has done an excellent job for whatever reason.

By moving forward we can compose a "wish" list of what we might have if we were better funded, but the idea of 'wish' implies that it can be done without, whereas our families more often don't have the means to purchase life saving equipment nor sanity saving respite for the carer – that is the trouble with projecting our wishes forward, without fully appreciating the "before scenario" and the differences that these measures will make to our present quality of life – for the person with a disability and carer are inextricably linked. Care isn't like medical research. With research we know we are probably talking about improving the next generation not the current one because science moves slowly. With proven international treatment standards, we are inhumane if we do not aim to improve the situation for this generation who are right now dysfunctional.

Nevertheless, in the spirit of moving forward I would like to record some grateful and positive things about what has been done really well to assist my son and his family and by default all the Queensland families affected by the dystrophinopathies – the most common and severe muscle pathology of childhood affecting 1 in 3,500 males of all races.

Often we don't acknowledge the good things because we just accept them as a given – the benefits seem to fall out of the sky it seems. The more seamless the service, the less thought we give to who is providing the service or the money or the equipment or the educational event we are attending, we don't think about the work behind the scenes because there's been no hassle for us – nothing dramatic to imprint in our memory what has occurred because someone else had deep knowledge and predicted our needs prior to any struggle. I know this first hand as a founding director of the voluntary Duchenne Foundation, formerly Parent Project Australia. And, that's the irony in all domains - those who do their job well and succeed at supporting people with disabilities are taken for granted sometimes for decades...which is OK by them, because the reason they do their job well is because they have a solid inner core – they are motivated only by doing what is right rather than looking for PR opportunities. The trouble with being overlooked is, increased demand and expansion can't be sustained and then your service cannot be adequately funded and maintained.

There is one very marginalized and taken for granted agency in Qld... I am talking about MontroseAccess, Corinda, Brisbane – the state centre of excellence for a variety of childhood disorders but in particular Duchenne muscular dystrophy, which is the most common muscle pathology of childhood. This former sanatorium, clinic and school for "crippled children" on the banks of the Brisbane River has an ingrained stewardship for disorders like DMD and was well appointed to take responsibility for the state-wide Duchenne population in terms of therapy services – 1 in every 3,500 males and their families.

Today this agency, which has never enjoyed sufficient public funding, have come upon hard times & recent service modifications have been received with ingratitude by some, because Montrose has been humming along supporting families and making it look like it takes so little effort for decades – because they have a deep understanding of the disorder including current international standards and what families go through...and why would they demand tribute from an already overburdened group of parents and guardians, these things they also deeply understand.

From the moment my son was referred to MontroseAccess, information and equipment was a given when needed. They applied on our behalf for subsidies and prescribed exactly what was needed and they monitor our children very closely, more closely than clinicians often. Our therapy regimes were all drawn up for us and we only had to learn and execute them. Our child's wheelchair was prescribed to prevent contractures, scoliosis and delay respiratory problems. Indeed the saving to society must be substantial because my 22yr old son has not had spinal surgery (whereas it is commonplace elsewhere). Nor is he using nocturnal ventilation, something hitherto unheard of , which is generally required in one's mid-teens. There must have been forms for us to sign, but I don't recall I had to fill in many forms. The therapists were always one step ahead with predicting my son's needs. We never waited for something we needed. We never asked a question via phone or email that went unanswered. When we needed a place to stay in Brisbane because a family member was hospitalized or for a school excursion, the arrangements were easy to make. Out of all the community service providers we have known in nearly 20 yrs, this centre of excellence with a deep understanding of our single disorder, cared and continues to care for the dystrophinopathies to such a standard that MontroseAccess therapists are in constant demand as international speakers for the care and treatment of Duchenne.

It would seem to me that this international standard service which has produced therapists who have taught the world about holistic care, would be rewarded with incentives? These ambassadors of excellence in treatment should have been rewarded by allowing them to have job security, higher wages, the means to implement the services and facilities they envision? The saving to society for maintaining those with Duchenne so well, should have been rewarded. This has not been the case. MontroseAccess has never been able to boost the number of physiotherapists to acceptable caseload levels because the public hospital system and private practices can pay so much better wages. MontroseAccess has not been able to build independent living facilities for over 18's on the rambling grounds or provide adequately for the young men who are now living longer because of their excellent service, Montrose has not had sufficient stocks of equipment to enhance quality of life on an individual basis. Our state government has taken this high standard of service very much for granted. MontroseAccess have a business case before the state government as part of the newly formed Queensland Neuromuscular Alliance to enhance therapy services at the moment in connection with the movement of their neuromuscular clinic to the hospital setting – a clinic that only they knew years ago would bring Qld children into line with international standards of clinical care but now has fallen behind again due to the ingratitude of our health system towards this service provider.

In summary, whilst I believe that individuals should be able to prioritize their own funding to cater to their needs, the best service providers with solid evidence of success rather than self-reported evidence, need to be rewarded with support and these MUST be the clinical and information services that specialize because they have a deep knowledge of what is needed and when, and can empathize with families based on the facts rather than by comparing disorders on appearances and allocating support based on perceptions or prior experiences across a broad range of disorders – comparing apples and oranges .

MontroseAccess staff may be paid in a not-for-profit organization, but along with unpaid carers nationwide, this wonderful service for Queensland children and youth with severe life-limiting neuromuscular disorders has been sorely neglected and underfunded. More funding must be provided to “centres of excellence” for specific disorders to recognize international leadership and to give them the incentive to keep abreast of cutting edge treatment and care and in doing so, continue to reduce public costs through preventative care. More importantly, they look at the whole child/teen/adult and their family and community and the cascading effect is improved physical and emotional quality of life for the extended family. Adequate funding for such service would be truly visionary because networking centres of excellence or information services inhabited by lifelong holistic learners are not just about providing state-of-the-art treatment in a reciprocal network for one child and family or even state and national families but children and youth across the world.