MontroseAccess

Response to the Productivity Commission Draft Report

Disability Care and Support

MontroseAccess - Background

MontroseAccess is a specialist disability service provider located in Brisbane providing services to children and young adults, their families and their carers throughout Queensland. MontroseAccess provides therapy, respite and recreation services to children and community access, independent living skills, pre-employment skills and respite to young adults. MontroseAccess has service delivery teams comprised of allied health professionals (Physiotherapy, Occupational Therapy, Speech and Language Pathology, Social Work and Psychology), Recreation Officers, Therapy Assistants and Disability Support Workers located at the Gold Coast, in metropolitan Brisbane, Strathpine and the Sunshine Coast. Outreach services are provided to regional and rural Queensland.

MontroseAccess is an independent not-for –profit organisation with tax deductibility status. Income is received from return on investments, corporate and individual donations and State Government funding.

MontroseAccess provides services to approximately 600 clients, their families and their carers. MontroseAccess provides holistic services underpinned by the principles of family centred, community based, interdisciplinary, strengths based practice. As a specialist disability service provider MontroseAccess works with clients with predominantly physical disability, including neuro-muscular conditions, juvenile idiopathic arthritis, acquired brain impairment, cerebral, spinal and skeletal conditions and a number of rare syndromes. Due to their disability and the specialist nature of the support package required, MontroseAcess is the only available service for most of the children and young adults it supports.

Response to Report

MontroseAccess welcomes the review of the current disability support system and the goal of developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers. It also agrees with the Commissions description of the current service system as underfunded, unfair, fragmented and inefficient. Further, MontroseAccess supports the introduction of a National Disability Insurance Scheme that provides cover for all Australians in the event of significant disability.

The comments provided in this response have been developed in consultation with families and staff and are based on over 75 years of experience. MontroseAccess is of the view the report does not adequately distinguish the needs of children with disability. The report places emphasis on including the person with a disability in decision making about their assessment, needs and support package. Whilst this approach is suitable for an adult with a disability it is the parent, adult family member or carer of a child with a disability who needs to be involved in these processes. Another significant difference is the child’s circumstances and their support needs change as they achieve (or do not achieve) developmental milestones and move through key transition points in their life. A child’s circumstances also change in response to a degenerative condition. This will have implications for the frequency a child's needs are reassessed.

MontroseAccess strongly recommends the high level task force on implementation includes representatives from the children's disability sector, providers, parents, carers and advocates to ensure the needs of children with disability are adequately considered.

Chapter 3 Who is the NDIS for?

Many of the children supported by MontroseAccess have degenerative conditions or disabilities that significantly impact their physical, social and emotional functioning. Early diagnosis, referral and intervention are critical to prevent or reduce physical deformity, loss of function and psychological harm. Failure to intervene early is likely to lead to increased care requirements and reliance on the service system in the future and a reduction in the potential for people to live economically and socially independent lives. At the time of diagnosis the disability may not appear significant however our experience is that early intervention is essential to prepare the child with the disability and their family. Early intervention includes a range of services dependant on the nature of the condition and varies from client to client. It may include provision of direct therapy, information and counselling to parents about the pathway of the condition, peer support and preparation. For example, a newly diagnosed four year child with Duchene muscular dystrophy (DMD) may not appear to have a significant disability. DMD is a degenerative neuro muscular, life limiting condition that leads to significant disability during the person's life. Generally children lose muscle strength as their condition deteriorates and by the time many of them reach their teenage years they are unable to walk, weight-bear or manoeuvre themselves independently in bed. Respiratory muscles weaken over time making breathing more difficult whilst lying down (as gravity cannot assist the diaphragm). Evidence demonstrates the benefits of early intervention in literacy and language skills and preparation for families about the progression of the condition. As the condition degenerates the need for supportive intervention becomes more obvious. MontroseAccess also supports children with Juvenile Idiopathic Arthritis (JIA) a disability that can cause significant pain, loss of function, social isolation and extended periods of school absence if untreated. MontroseAccess runs a clinic for children with JIA which provides regular review by an interdisciplinary team. A child with JIA who is well supported by a package of intervention may incorrectly appear not to have a significance disability. MontroseAccess wants to ensure children currently receiving early intervention and or assistance whilst their condition is stable will continue to be eligible for a funded support package under the NDIS.

MontroseAccess recommends the scope of the individuals receiving assistance under Tier 3 needs to be sufficiently broad to ensure children currently receiving assistance continue to be eligible for support under the proposed NDIS. As these children often have complex medical conditions associated with their disability it is important the interface with the health and palliative care sectors works effectively. It is also not reasonable to assume that the health system adequately caters for their needs.

Chapter 4 What individualised supports will the NDIS fund?

MontroseAccess agrees with the range of supports recommended in the report and would like to see the following supports added to the scope of what is provided under the NDIS:

- Interventions that build family resilience and assist families remain intact. The rate of divorce within families who have a child with a disability is significantly higher than for the general population. Montrose Access provides a number of interventions specifically targeting at supporting and building family resilience, e.g. sibling groups, parent retreats, peer supports
- Interventions that assist families adapt their routines around the needs of the child with a disability
- Recreation services to develop and enhance social and leisure skills
- Tailored information about the specific condition and its impact on the child as they develop
- Orthotics for children with physical disability to prevent contractures and improve function and comfort
- Attendance and review at specialist clinics for example wheelchair clinics, JIA clinics and neuro muscular clinics
- Transport assistance to participate in the support package funded under the NDIS

MontroseAccess agrees in principle with recommendation 4.4 however makes the observation that for many of the therapeutic interventions provided the evidence base does not exist or is limited as the research has not been undertaken. MontrosaeAccess is fully committed to contributing to the research agenda and collecting the evidence to support clinical benefit.

The Commission seeks feedback on arrangements that should apply in relation to higher electricity costs that are unavoidable and arise for some people with disability. Montrose Access strongly supports this approach and confirms that it is a real additional expense. Many children with disability need an air-conditioning unit for increased comfort and are reliant on technology that requires a power source for charging. It is suggested an electricity rebate is introduced.

Chapter 5 Assessing care and support needs

Montrose Access supports the concept of the NDIS providing assessed care and support activities across a broad range of life activities tailored to the individual's aspirations and circumstances. The recommendation to employ trained assessors is also endorsed. Montrose Access does however have some concern about the knowledge and skills base required of assessors in understanding the complexities of many of the disabilities that will be assessed. In our experience parents are often a well informed source of information about their child's needs and should be included in the assessment process.

It is recommended parents and carer's views are sought as part of the assessment process. As a specialist service provider we encourage NDIS to consider outsourcing assessments to organisations that have a detailed understanding of the disability, for example there is strong evidence for early intervention in literacy and language development for children with Duchene muscular dystrophy that may not be immediately obvious to an untrained assessor or parent. This would not prevent the assessor making the determination with the child and their family, about the individualised support package to be funded by the NDIS. It would mean the identification of reasonable need would be made with input from assessors with a detailed knowledge of the disability.

As a specialist service provider Montrose Access has well established referral networks ensuring that most children and families are referred early after diagnosis**. It is recommended the NDIS adopts a *'no wrong door policy'* that means individuals can receive services immediately, if appropriate, rather than having to wait for the outcomes of an NDIS assessment for referral to a service provider. Montrose Access is able to respond quickly and flexibility to these early referrals providing specialist information and advice. It is recommended that that an arrangement is established to fund service providers to provide this type of service prior to formal assessment by the NDIS.**

Montrose Access strongly supports recommendation 5.6 to assess the needs of the carer where they provide a substantial share of the care package to determine the sustainability of the arrangements. In our experience, parents or a family member of children with disability are the primary care giver and do provide significant amounts of unpaid care for their children. For example, children with Neuro Muscular conditions generally lose muscle strength as their condition deteriorates and by the time many of them reach their teenage years they are unable to walk, weight-bear or manoeuvre themselves independently in bed. Respiratory muscles weaken over time making breathing more difficult whilst lying down (as gravity cannot assist the diaphragm). MontroseAccess has clients with other conditions (e.g. transverse myelitis, cervical spine trauma, Peliezius Merzbacher, Fibrodysplasia Ossifficans Progressiva) who also require intensive carer support to sustainably remain at home. Parents transfer their teenage and young adult children into/out of bed using a hoist and manually manoeuvre them to dress in bed. As their children weaken, parents need to turn them in bed, move them up and down the bed and assist them to sitting. Ankle, knee and hip contractures and scoliosis frequently make bed an uncomfortable place and is often so compromised that parents report they regularly rise during the night to turn their children or move them to a more comfortable position. This happens on average 3- 4 times a night but we recently had a mother who reported that she rose 20 times a night for this purpose. This example highlights the demands of caring for a child with high physical support needs has on families and therefore the importance of carer assessment and support and also interventions that build family resilience.

The Commission seeks feedback about if the front-end deductible should be waived in consideration of the value of natural supports. MontroseAccess strongly supports this principle in recognition that caring for a child with a disability places significant economic burden on families. Many families live on a single income as one parent is a full time carer which prevents them participating in the paid workforce. Purchase of disability equipment, modification of vehicles for transporting children, modification of bathrooms and bedrooms and purchase of medications are expensive and are additional costs not borne by families who do not have a child with a disability.

Chapter 6 Who has the decision making power?

MontroseAccess supports the right of children and adults with disability to exercise choice in deciding the most appropriate service provider. Many of the families of children, whom we support, have however expressed anxiety at the prospect of self-directed funding and their capacity to exercise **informed** choice. Families do not necessarily perceive themselves as 'experts' on their child's health and needs. A parent, for example, said she would not have known about the positive role a piece of equipment would have for her child, without being advised by a therapist or understand the ways in which the work of a speech pathologist and occupational therapist complement each other without seeing them work as a team. MontroseAccess offers holistic, coordinated care and support that may be undermined, if under self-directed funding individuals purchase Occupational Therapy from one agency and Physiotherapy from another. There is a risk the significant benefits of coordinated care for children with complex, multi sector needs (education, health and palliative care sectors) may be diminished and become fragmented.

MontroseAccess has recommended the high level task force on implementation includes representatives from the children's disability sector. It is further recommends the task force considers the implementation of self-directed funding for children and seeks advice from parents and advocates.

Chapter 7 Governance of the NDIS

MontroseAcces provides services to children and young adults through out Queensland. The model of service delivery is community based providing services in the child's local environment. Outreach services are provided to rural and regional Queensland. Given its model of service delivery travel forms a significant component of the cost structure.

MontroseAccess recommends in determining the price paid to service providers the NDIA factors in travel costs.

The report also appropriately places emphasis on establishing benchmarks and quality assurance.

MontroseAccess recommends the cost of compliance and record keeping is factored into the price paid to service providers by the NDIA.

Chapter 10 Collecting and using data under the NDIS

The report recommends considerable investment in the design and establishment of extensive and robust data systems and associated supportive technologies.

MontroseAccess recommends the cost of IT investment is factored into price paid to service providers by the NDIA.

Chapter 13 Workforce issues

Attracting and retaining suitably trained and empathetic support workers is a critical success factor to support the expanded need for services under the NDIS. The report correctly recognises many of the work force challenges in the current system. Many organisations have explored and introduced options for staff retention given labour shortages. Currently low wage rates are a deterrent to attracting and retaining suitable people. MontroseAccess supports strategies that will increase the employment pool of disability support workers.

Chapter 17 Implementation

MontroseAccess supports the recommendations in this section of the report. The introduction of an NDIS is a significant change for the disability service system and there is considerable risk that if implementation is under resourced and or rushed that people with disability may be further disadvantaged. Queensland is currently undergoing significant reforms including Growing Stronger and Outputs based funding. Despite the best intentions there are challenges with implementation and long waiting lists exist in many areas for referral, assessment and packages. It is important the NDIS learns from the experience of other jurisdictions in the resourcing and planning implementation.

MontroseAccess strongly recommends that adequate resources and planning are allocated to implementation.