Background to QPPD

Queensland Parents for People with a Disability (QPPD) is a parent-based, statewide advocacy organisation with over 200 financial members as well as strong networks with allies and extended family members. QPPD has been a strong force for systems change in Queensland since its founding in 1981.

QPPD's mission is to vigorously defend justice and rights for people with disabilities by exposing exclusionary practices, speaking out against injustices and promoting people with disabilities as respected, valued and participating members of society.

Since 1990 QPPD has been funded under the Disability Services Act from the Commonwealth Government to do statewide systems advocacy on behalf of people with disabilities. In addition to this systems advocacy focus, QPPD continues to develop a wide membership of families and friends across Queensland who remains in contact with the organisation. As well as personally supporting one another, these families take up issues collectively on behalf of sons, daughters and others.

Preface

While many of the concepts presented in this paper refer to "families" we also acknowledge these principles apply to unpaid carers, extended networks and circles of support, particularly where people do not have family or supports, together with the diverse family structures in indigenous and culturally and linguistically diverse communities.

QPPD believes that the foundation of a lifelong care and support scheme for people with disability must be firmly grounded in the Principles of the United Nations Convention on the Rights of Persons with Disabilities. As the UN has recognised, this requires a major "paradigm shift" where people with disability will no longer be seen as objects of pity or charity and considered burdensome to families and communities. Instead, people with disability must be seen first and foremost as **citizens** with an equal right to access the goods of our society as well as equal opportunity to contribute. Thus, the scheme must be based on an entitlement to adequate supports to enjoy a lifestyle and level of community participation which resembles that of other citizens.

QPPD strongly supports the concept of a national disability insurance scheme because it provides not just an opportunity for more funding to be made available for people with disability but gives attention to how this funding should best flow to individuals in order to uphold genuine citizenship rights. Thus, we believe that there is a need for the Lifelong Care and Support Scheme to be linked explicitly to a National Disability Strategy which is underpinned by the tenets of the Convention on the Rights of Persons with Disabilities.

A National Disability Strategy, presently a commitment of the Federal Labor Party, would require all Australian governments to recognise and respond to the impacts of historical and ongoing discrimination and through legislation and policy, dismantle societal barriers (including out-dated service models) which entrench disadvantage and oppression of people with disability. A new scheme should allow people with disability to be actively involved in designing the supports they need to enable them to live as valued, contributing citizens and provide redress and restoration for the abuses and neglect of past and current policies and practices.

QPPD also expects that a disability support scheme must be located within both national and state social inclusion agendas. This means that people with disability should no longer face a situation of “social apartheid” (Goggin and Newell, 2005) but be routinely present and included in ordinary community settings – from birth and throughout their lifetimes.

Who should be the key focus of a new scheme and how they may be practically and reliably identified

The key focus of a new scheme should be people with impairment. While entitlement should be on the basis of disability and impairment, our membership is concerned about the process of determining eligibility i.e. assessment.

Assessment for eligibility currently depends on a model of families painting the worst possible picture of their family member, what some members have called “the misery Olympics”. This causes untold damage to family relationships as well as disadvantaging those families who decline to ‘play this game’. QPPD strongly contends that any new scheme must recognise that the person with disability is not the problem nor “burdensome” but rather that it is the social impacts of living with disability – societal barriers, prejudices and attitudes, as well as lack of supports – which cause burden. For this reason, some of our members are concerned about how a disability support scheme is identified. They are uncomfortable with the language of “insurance” as it might reinforce the idea that impairment itself is an unwelcome event (akin to a fire, flood, or natural disaster), thereby masking the socially constructed nature of disability and how an impairment can be more or less disabling depending on the social environment.

It is crucial that the assessment process at point of diagnosis is simple and provides access to a basic level of service. Once impairment is identified, the person and or their family should be provided with a level of support to ensure that they can come to terms with the diagnosis, know about the range of services available and be assisted to overcome negative conceptions of disability and regain a positive sense of the future. This model is likely to involve some initial identification by medical specialists or other professionals who would then link the individual and family to peer support services, such as those currently operated by diverse organisations such as the Down Syndrome Association of Queensland, Parent to Parent, Spinal Injuries Association and family advocacy organisations.

Assessment of eligibility for ongoing support needs to be flexible and transparent. It is unlikely that any one “tool” will render a sufficiently well rounded account of the impact of disability, and a combination of “tools” may prove onerous, intrusive and continue to focus attention on the deficits rather than the potential of people with disability. Assessment of need must go hand in hand with working alongside families to build capacity and to envision future possibilities which stress “ordinary life” rather than dependency. We believe that an assessment process which is relational, strengths-based and capacity building is more likely to yield cost-effectiveness than any attempt to find a one size fits all “assessment tool”. It is also important that individuals and families do not face the current multiple, periodic assessments which rely upon providing information again and again to numerous government departments. While people with lifelong disability may face changing support needs, an entitlement based system would allow families to have greater certainty about support availability, particularly at key transition points (entry to school, post-school, retirement etc.). Clearly there is value in a nationally recognised assessment process as people with disability need portability and equitable access to support regardless of where they live. In particular, families do not want assessment processes which emphasise “failure” and deficits, because such assessments have a damaging impact on perceptions. Indeed, we would argue that many individuals have had their life opportunities dramatically impacted upon by perceptions created by an IQ score.

Example:

The transition to school which should have been a time of excitement was for us absolutely demoralising. It seemed that we spent 6 months collecting reports from a variety of specialists to show how very, very intellectually disabled our son was (in order to access support). While I tried to ignore the low IQ scores which he received and the pages on how developmentally delayed he was, the impact was devastating. It eroded our optimism for the future and I had to fight my preoccupation with horrible negative thoughts. Nowhere could I recognise the wonderful boy we knew, a child who tried so hard and was to us a complete joy. It seemed almost l often thought that if any “ordinary” person had such unbalanced, misleadingly negative reports written about us, we would consider them libellous and seek legal remedy. The worst, of course, was that we had to go through this same process every 2 or 3 years, including getting the paediatrician to sign off that he still had Down syndrome!

We believe there is:

- A need to ensure that assessment processes are based on principles of entitlement and attempt to minimise administrative burdens, intrusiveness and the traditional focus on deficit models of assessment.

- A danger that the ascribed authority of medical or professional experts will over-ride the natural authority, personal knowledge and expertise of people with disability and their families. Thus, assessment processes must be collaborative and potentially make use of community panels which include people with lived experience of disability.
- An approach that takes into account the multiple disadvantage and access issues for people with a disability who are:
  indigenous
  culturally and linguistically diverse
  living with dual or multiple diagnoses
  living in rural and remote areas
  homeless
  lesbian, gay, bisexual, transgender

  These typically hard to reach groups are often disadvantaged in generic service systems and will require a targeted approach to redress the barriers to appropriate assessment and services. Assessments may be more appropriately targeted if carried out by agencies who have existing knowledge and expertise in providing services these disadvantaged population groups. This would require agency staff to be trained and audited against assessment standards, enabling these groups to participate in, rather than reject assessment processes.

People with a disability, particularly those who have impaired decision making capacity or communication challenges are over-represented in other government and community service systems due to the lack of appropriate interventions and support. These include:

- Homelessness Services
- The Criminal Justice System (Police, Courts and Prison and Probation and Parole)
- Domestic Violence and Sexual Assault Services
- Drug and Alcohol Services
- Child Protection Systems
- Gambling Services

- Hospital and Health and Mental Health Services
- Welfare and Emergency Relief Agencies

The high cost of not providing adequate support and resources to citizens to enable them to be included and participate is directly linked to the additional costs to society in the above service systems. The costs of people with a disability in these systems need to be scoped along with the savings which would be achieved by the provision of appropriate supports.

Which groups are most in need of additional support and help?

QPPD recognises that the impact of impairment on an individual and family relies upon a variety of social factors, and that many individuals and families lack the financial or social resources to "cushion" the impact of impairment. There is a risk that assessment processes which focus too narrowly on a biomedical or diagnostic approach to determining eligibility will disadvantage individuals. In particular, QPPD recognises that people who might be considered to have a mild intellectual disability should not be ruled out of this system. These individuals require support in order to avert homelessness, mental health issues and imprisonment. A scheme which fails to recognise the vulnerability of this group by ruling them ineligible will end up transferring the costs to other social spending areas. Thus we would argue for a scheme which has wide coverage to include those individuals with cognitive impairments who currently are ill-served within models which determine eligibility on a sole factor such as IQ.

A small amount of investment and the ability for someone to "walk" with individuals over time may assist people to move out of, and away from dependency models and take up valued roles in the community e.g. employment.

Who makes the decisions?

People with a disability should be able to determine what supports and services best meet their needs.

For children with a disability and adults who have impaired decision making ability it is often the family who are best able to make appropriate decisions on behalf of an individual.

Families are frequently disenfranchised in current service models. Their natural authority is undermined and service inflexibility has resulted in families not having a voice in how services are delivered to their family member. The natural authority of families will be upheld where a model of lifelong planning is able to be implemented.

Michael Kendrick, an international consultant in the delivery of quality services to people with a disability, describes some key points of this natural authority of families. These principles may also be applied to unpaid carers, extended networks and circles of support, particularly where people do not have family or supports, together with the diverse family structures in indigenous and culturally and linguistically diverse communities. The key points are:

1. The public generally recognises the primacy of families in terms of their responsibility for a person's wellbeing. In this way, families have the authority to be highly engaged because they also tend to have greater responsibility for the wellbeing of their family members.
2. Families have authority (normally) arising from knowing their family member the most fully and over the longest period of time. In this way they have the authority that arises from long term observation, insight and personal relationship.
3. Families typically care about or love their relative more than would be true of others, however committed the others may be. Not only do families usually care more but they are also expected to care more.
4. Families have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves.

5. Families are expected to advocate for their own members. Not uncommonly, they are granted considerable presence in the decision-making processes affecting their family members, even where legal formalities do not require it.
6. The family is an authoritative witness to the performance of professionals and systems and may have special (though not necessarily exclusive) insight into events that take place.
7. Family members bring to their role a wide range of talents and experiences which can give them additional authority on many matters. For example, a parent might also be an expert educator.
8. Families are often best positioned to see how everything, in its entirety, adds up in a person's life. For this reason they can often see the incongruence of different interventions.
9. Family members are often free of the vested interests which call into question the credibility of other parties. Frequently family members are granted a degree of independence which highlights their credibility and purity of motive.

QPPD therefore would want a position adopted that allows for a range of options in the way funding is allocated to meet need including the ability to self or family manage funds and outcomes for their family member.

The kinds of services that particularly need to be increased or created?

The current service system has built up a menu of service types which bear little resemblance to people's actual needs. No-one NEEDS a "day service", no-one NEEDS an "accommodation service". Instead, people with disability – like other Australians – need real homes and something meaningful to do in their day, ideally a job which provides them with an adequate income. We therefore need to re-imagine our service system.

QPPD believes that the opportunity for individuals and families to self-manage supports and funding should be a prime feature of any disability care and support scheme. This will require more creative responses than most people with disability currently can access, and may require support for individuals and families to consider what supports might best meet their needs. It will also require a shift of thinking to how people with disability can occupy valued social roles and contribute to society, rather than being seen only as service recipients.

QPPD considers that we need services which will:

- Build capacity of families and people with disability themselves to envision good lives characterised by equal citizenship and the opportunity to contribute and participate in their local communities
- Provide access to the safeguards of independent advocacy
- Use community building approaches built on principles of social inclusion in order to identify opportunities for education, work, leisure etc within their local community. This may be achieved by documenting good community building practices as well as providing pilot funding for additional efforts, particularly in the area of employment where people with disability continue to face significant disadvantage
- Provide access to some specialised disability supports (aids, equipment, early intervention, communication supports, access to specialist assessment and health care etc)
- Employ community navigators who would help families to consider how to best access services while harnessing ordinary community resources.
- Allow specific attention to transition times (to school, from primary to high school, post-school etc) where currently people with disability face significant barriers to social inclusion.
- Ensure that where there is multiple disadvantage systems are resourced to respond

Ways of achieving early intervention

Currently families are either directed into specialised services (e.g. early intervention therapies) or offered no support. There is a tendency for families to see their child as fundamentally broken and on a “different path”. We believe that this contributes to a more costly disability service system as families are discouraged from having needs met within generic, “ordinary” community settings and there are negative impacts of early social exclusion. A guiding principle must be that supports are only as special as necessary.

It is crucial therefore that any NDIS has the flexibility to both provide access to the specialist services or equipment which may be required as well as supporting families to access generic services (recognising that historically people with disability have been socially excluded and barred from many of the ordinary places – regular schools, community sporting and recreation clubs, etc.) QPPD believes that it is crucial that “early intervention” is offered within a “strengths based model” where disability is not viewed as something to be “fixed” but rather the individual’s right to a lifestyle like their age-based peers is recognised, nurtured and facilitated by a mix of specialist and generic services and community based supports.

Early intervention requires not just a timely response so that early learning and developmental opportunities are available to the individual but also an approach of investing in family capacity, upholding the right of the family to also enjoy a lifestyle resembling that of other Australian families and to reclaim ordinary dreams that may have been called into question by a diagnosis of disability. These supports, when offered at the transitional points of a person’s life, would enhance the lives of people with disabilities, safeguard families, and communities would be diverse and vibrant.

How a new scheme could encourage the full participation by people with disability and their carers in the community and work

Investment in innovative pilot programs in employment, in order to assist individuals with disability into the range of employment options enjoyed by other Australians (public service, private enterprise employment, as small business owners etc.).
Facilitate ongoing community education campaigns that focus on the ordinary lives of people with a disability and the real challenges they face.

A key feature of this is to move away from the dichotomy of the superhero, ‘achieving incredible feats against all odds’ or the dehumanising images of people with disabilities as ‘burdens of care’ to people living ordinary lives in families and communities as students, workers, partners, parents, volunteers, employers and so on.

How to give people with disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong)

People with disability and their family members must have the opportunity to plan their individual budgets, with transparency about accountability requirements and their obligations. They must have the ability to decide who will support them and to dismiss any employee whose conduct is unacceptable or who lacks the capacity to work in support of the person’s individual goals.

Safeguards will include that people with disability and their families will have access to planning support, the opportunity to envision a good life and stories and examples from those who have developed good quality personalised services.

Complaints mechanisms and an independent ombudsman, and increased access to individual and systemic advocacy are crucial.

How to improve service delivery — including coordination, costs, timeliness and innovation

A concerted effort to provide support to families and people with disability from the time of diagnosis, and at appropriate levels during important stages of a person’s life, is a matter of human rights, a necessity and not an act of charity. Timely, appropriate supports to ensure the family and the person are known, included and valued in their local community would facilitate optimal opportunities for freely-given and natural supports and with less dependency on paid support.

There is an urgent need to ensure that individuals can choose the most flexible and cost-effective support options, rather than being locked into expensive "disability support models". It is crucial that new service models maintain people with disability in culturally valued "ordinary" lifestyles rather than entrenching a disability client identity.

Where generic supports can be purchased in a way that meets the person's needs in a timely, cost-effective and non-stigmatising way, this is preferable. Currently support is equated with "support worker hours" even though this may not be the most effective way of providing support – and indeed, such models often isolate the individual from other citizens. Support for an individual to attend a community gym, have a meal at a community club or use a generic cleaner is frequently more cost-effective than the "disability service model". Similarly, there has been a tendency for the supports requested by families to manage a disability to be denied as "income support", even where denial of that support plunges the family into crisis, with the person with disability then becoming relinquished to child safety or disability service systems.

QPPD strongly believes that we need a model where families are resourced to be involved in planning for the future for their sons and daughters. For many families, planning and managing their own supports will require the following underlying supports:

- Access to networks of experienced users/families through a family support/resource hub
- Leadership Development
- Training and Education on how to administer funding
- Mentors (on call, attend meetings)

- Navigators (who assist people through disability, healthcare and generic service systems and connect people to generic and specialist supports)
- Information – materials, publications
- Planning and implementation assistance
- Recruitment assistance
- Assistance with payroll and all related administrative responsibility.

While the establishment of such resource centres involves some costs, we consider these costs minimal when compared to the inefficiencies within current service models. This small amount of resourcing supports personalised, self managed services, allowing for better outcomes for individuals and their families.

The practical aspects of a scheme that will make it work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services

While recognising the legitimate concern that any scheme which is introduced is not subject to disproportionate "cost blow-outs", QPPD would point out that the current system is expensive and yet fails to meet the needs not only of those who are denied support but also delivers very poor outcomes to many of those who are "lucky" enough to receive a funded service. The experience of people with disability and their families to date has been that the criterion for support is one of crisis. Currently a family breaks down; vulnerable people are at risk of homelessness, abuse, assault or neglect, before supports are made available to them. The costs to the community in reparation are enormous, and the costs to the lives of people are devastating. A different model of support – one which works with people and their families to envision good lives and draw upon natural community resources, would ultimately result in less demand for respite and emergency funding.   Without expecting some disability utopia, we can expect that the current 'unmet need' would largely be able to be met, and 'aging carers' would no longer pose such a crisis as families are supported at an earlier stage to consider how their sons and daughters with disability would be supported to have a life of their own.

The current disability system is based on a false assumption of “economies of scale” which has driven group home models, congregated day services and special education. The evidence against the “economy” of these models is substantial, particularly if we look at quality of life, wasted life opportunities and the professional wages bought in when things go awry. No-where is this more apparent than in the industry which has been built up to manage “challenging behaviour”. In Queensland, the Positive Futures Initiative is a case in point, in terms of the financial investment in mopping up from service models which have failed to meet the needs of individuals with complex needs.

The new scheme would necessarily challenge models of service provision which fail to meet Australia’s obligations under the UN Convention on the Rights of Persons with Disabilities. Certainly disability service models which continue to isolate individuals from the community and drive out informal supports must evolve to meet the obligations of the Convention.

There is a need to dismantle institutional and other models which are built on forced congregation of people with disability, though it is recognised that achieving this may take time. Of urgency, however, all state and federal governments must be required to stop directing funding to building new congregate accommodation and day service models.

Better wages in the disability sector are clearly needed in recognition of the skill and complexity of the work. The facilitation of opportunities for disability workers, the people they support and their families to come together to reflect on and improve responses will be critical. While this may include formal training, support and mentoring and opportunities for workers to be involved in more meaningful community development work than currently possible will also be of benefit in attracting new workers.

Living in poverty is a common experience for many people with a disability and their families. This is also evidenced by the volume of people on a disability support pension or carer payment or sole parent benefit.

Barriers to employment participation are a key feature of how service systems are currently structured. Many parents are unable to work as there are no appropriate care options for their family member, or because services rely on parents to prop up under resourced systems. The system currently relies on unpaid care by family members with the only option for funded support being to relinquish the care of their family member. A much less cost effective alternative than the provision of appropriate support.

There is an imperative that any new system acknowledges the contribution of families and provides supports for both people with a disability and their carers to engage in work and meaningful activity and provides sufficient supports for a quality of life to be sustained.

Example:

A person with a disability was married, living independently receiving 9 hours / week funding from Disability Services. At 30 she had a stoke resulting in an acquired brain injury and physical disability. She has all the associated mental health issues of anyone coming to terms with their acquired disability. Additional hours of support were sought and this resulted in less than 3 hours of paid support being provided on a daily basis. The mother of the person had to leave work in order to provide full time care in the absence of any alternatives. The cost of full time care would be much higher than a benchmark of 8-10 hours per day which would enable the parent to continue employment and them both to have a more fulfilling life.

Example:

A child with a disability is attending a regular school under Queensland’s Inclusive Education Policy. The parent however is required to attend the school up to three times per day to toilet their child. Teacher’s aides may toilet children but it is at the discretion of the Principal. This common practice means that unlike most parents who can re-enter the workforce when their children attend schools some parents of people with a disability are unable to do so because of practices which prevent this.

The ability to be included in mainstream education and other programs should not be dependent on a person being continent. For many people with disabilities there are continence issues which need to be managed in order for full participation to occur, and this needs to be factored into support systems.

How long would be needed to start a new scheme, and what should happen in the interim?

QPPD believes that it is important for extensive consultation to occur after drafting a response, and therefore implementation should occur after that time.

In the meantime the establishment of Family Resource Centres and assisting small networks of families to trial self-managed funding within the proposed model of life-long planning would pave the way for a smoother introduction of the new scheme.

Lisa Bridle
PRESIDENT

Mark Reimers
DIRECTOR