Bringing life to legislation: building a strong legislative framework for and with people with disability

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Building a strong legislative framework for and with people with disability

Submission to the Hon Warren Pitt, Minister for Communities, Disability Services and Seniors regarding legislative changes to the Queensland Disability Services Act (1992)

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This report brings together the findings of an extensive process of engagement and consultation about the review of the Queensland Disability Services Act (1992).

The information has come from people with disability, family members and those who support them in diverse communities across the state.

Their information forms a submission to be presented to the Hon. Warren Pitt, Minister for Communities, Disability Services and Seniors, giving an independent perspective which will further inform and influence the current Disability Services Queensland review of the legislation.

Clear themes have emerged from the meetings, interviews and discussions held with people around the State, and these are reflected in the report.

Where possible, the views of individuals and groups are expressed in their own words. Where several sets of information are being drawn together, individuals are not quoted, although the discussion is directly reflective of the views expressed to the consultants.

The vignettes which illustrate several sections of the paper are true stories related during the consultation process, although the names of individuals involved have been changed.

Each person who participated in this process has been offered the opportunity to view the draft report and provide feedback on it prior to its submission to the Minister.
Executive summary

This report develops and makes explicit recommendations for change to the Queensland Disability Services Act. The report is structured in the same way as the current Act, in order to make clear links between the points made by people with disability, families, service providers and advocates around Queensland and the current legislation.

The report is divided into three sections.
1. Overarching legislative issues
2. Issues directly relating to the current Act
3. Description of the Engagement Project

The first section addresses overarching issues which have direct impact on the development of disability legislation.

In this section, a much clearer articulation of the Act is recommended to ensure that it relates to all Queenslanders with disability, not just those people who receive services funded by Disability Services Queensland.

A revised Act needs to address the needs, goals and aspirations of people with disability in Queensland more effectively by demonstrating the relationship of this Act with other pieces of legislation, other government jurisdictions and other bodies and agencies in the broader community.

The Disability Services Act needs to express and encourage a strong and enforceable vision for the lives of people with disability, which is built from the expectations and experiences of people with disability and their close supporters.

A commitment to developmental, progressive planning and implementation of flexible supports over the lifetime of a person with disability, must be included in a revised Act, so that they become available as and if they are needed.

Strong, effective and independent complaints mechanisms and quality assurance systems, based on the expectations of the Act, need to be spelt out more strongly.
The Act needs to be enforceable with sanctions for non-compliance on a range of levels, from breaches which affect individuals, to systems breaches which result in government departments or other legislations relating ineffectively or unjustly with the Disability Services Act.

The second section of this report details responses of participants to particular components of the existing act, including recommendations for additional inclusions.

A clearly identified need was expressed for the purposes, principles and objectives of the Act to relate visibly and unambiguously to one another, so that a coherent path is developed between vision and practice, which can be clearly followed.

Specific recommendations are put forward in this section about maximising the active participation and meaningful involvement of people with disability and families. Particular areas for inclusion in the Act are around choice and decision making; minimum restriction of rights and opportunities; the role of families and supporters; addressing abuse and neglect; focus on the development of the individual; participation in service development, implementation and planning; and access to independent advocacy and support.

The final section details the process of consultation and engagement with people with disability, families, advocates and service providers that drives this report.

139 people across five communities in Queensland gave generously of their time, wisdom and expertise to meet and discuss issues of legislation and life for people with disability. Their views and experiences are the backbone of the report.
Thirty eight recommendations have come from the engagement process with people with disability, families and people who support them.

Recommendation 1.

That the descriptive title and sub-title of the Act be reworded to ensure greater clarity about the scope and breadth of the Act.

Recommendation 2.

That the Act be significantly expanded, either as one piece or a suite of legislations, which addresses:
- the rights of all Queenslanders with disability
- relationship of this Act to other legislation
- relationship of this Act to generic community and government agencies
- requirements of disability services
- complaints
- monitoring of services
- prevention of abuse and neglect

Recommendation 3.

That the Act be retitled to exclude the word ‘services’.

Recommendation 4.

That the Act make explicit the inclusion of all people with disability, regardless of age including:
- children with disability
- people with disability over sixty five years of age

Recommendation 5.

That the Act make explicit the expectation that all services provided to people with disability comply with the legislation including those developed, funded or provided by:
- Disability Services Queensland
- Other public sector departments
- Community agencies
- Private, non funded residential services and facilities (the private for profit sector)
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<td>6.</td>
<td>That the Act contain reference to other relevant legislations and make the relationship between them explicit.</td>
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<td>7.</td>
<td>That the Act include mechanisms for ensuring the rights of people with disability are held in equal regard to the requirements contained in other legislation. This must include enforceable penalties for non-compliance.</td>
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<td>That the Act include a strengthened requirement for all State government departments to develop, implement and review a disability plan. This must include measures for recognising and reinforcing good practice and enforceable penalties for non-compliance.</td>
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<td>9.</td>
<td>That the Act include an overarching statement at its outset, which outlines the primary vision and ambition of the legislation. This may replace the current sub-title.</td>
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<td>10.</td>
<td>That the Act include a specific commitment about its promotion to people with disability, families, advocates, service providers, government and the broader community.</td>
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<td>11.</td>
<td>That the Act include a principle about ensuring the developmental, progressive implementation of supports as and when they are needed by people with disability and families.</td>
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<td>12.</td>
<td>That the principles of the Act include the right to pursue independent resolution of grievances and the objectives include the tracking of complaints, proactive investigation of issues of concern and monitoring of expectations of change.</td>
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<td>13.</td>
<td>That the Act include the establishment of an independent complaints and monitoring body which has powers to undertake investigation and gain compliance. The development of such a body must include further discussion with people with disability, families and the broader sector about what is needed.</td>
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<td>14.</td>
<td>That the Act include an explicit commitment to the development of localised information and resource points, and the promotion of these, to people with disability and families across the state.</td>
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<td>15.</td>
<td>That the Act explicitly include reference to the Disability Services Standards as the minimum standards for service evaluation. This should be done in such a way that it does not preclude the development of quality assurance mechanisms over time.</td>
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<td>16.</td>
<td>That quality assurance mechanisms be developed that are seen to be different from minimum standards. These would be grounded in the perceptions of people with disability and their families and focus on the quality of the relationships and support of services in their lives.</td>
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<td>17.</td>
<td>That provision be made within the Act for regular evaluation of the implementation of the Act in relation to how life for people with disability is played out. Such evaluation must be conducted external to the funding body and must actively include the perspectives of people with disability and their supporters.</td>
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<td>18.</td>
<td>That the Act be constructed in a manner which provides a clear and linear path which shows how the vision, purposes, principles, objectives, funding and operational requirements and powers of the Chief Executive interrelate.</td>
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<td>Recommendation 19.</td>
<td>That an additional purpose be drafted into the Act to set out the requirements and responsibilities of government and community agencies in providing services to people with disability.</td>
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<td>Recommendation 20.</td>
<td>That the purpose relating to funding reinforce the intent of the principles and objectives of the Act, with the emphasis being on flexible funding supporting the achievement of an ordinary life at home and in the community.</td>
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<td>Recommendation 21.</td>
<td>That the Act contain more explicit statements about how innovation is determined, encouraged and supported with emphasis on personalised responses that improve people’s lives and the nature of the supports they receive.</td>
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<td>Recommendation 22.</td>
<td>That the Act include a mechanism for determining eligibility for support based on need, which includes individuals who do not easily fit into the current diagnostic categories, and is not reliant on fitting artificial funding criteria.</td>
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<td>Recommendation 23.</td>
<td>That the Act include a new principle on the right of people with disability to be free from all forms of abuse and neglect.</td>
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<td>Recommendation 24.</td>
<td>That the Act include a new principle on the central importance and authority of committed families of people with disability, that acknowledges the role they play and their importance in safeguarding the fundamental human rights of their family member.</td>
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<td>Recommendation 25.</td>
<td>That a new principle be formulated around the entitlement to restorative justice, with the acknowledgement that people with disability living in institutional forms of care be given their due recompense.</td>
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<td>That the Objectives of the Act be retitled to become the Objectives for the development, implementation and evaluation of disability programs and services with people with disability.</td>
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<td>That the language used in the objectives be strengthened to reflect the fact that these are enforceable obligations, not aspirations.</td>
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|                | That the Act contain a new objective which specifies that services are designed and implemented to ensure that:  
- the incidence and likelihood of abuse and neglect of people with disability is recognised  
- preventative safeguards are established with strategies put in place to protect people with disability from abuse and neglect  
- mechanisms are put in place to respond effectively and appropriately to incidents and suspicions of abuse and neglect. |

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|                | That a new objective be included in the Act which focuses on the need for services to encourage and support the decision making and choices of people with disability in:  
- Day to day choices  
- Major decisions  
- Lifestyle choices. |

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<td>That the Act include an objective which requires services to ensure workers are appropriately trained and supported in carrying out their jobs.</td>
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<td>That the Act preclude the provision of service to young people with disability by services designed and used by aged people.</td>
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<td>Recommendation 32.</td>
<td>That the objective relating to information provision be expanded to include the provision of information to any interested person in formats which are easily accessible to them, and the provision of information about community resources and supports external to the service.</td>
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<td>Recommendation 33.</td>
<td>That the objective relating to advocacy support be expanded to include the requirement for services to ensure people with disability have access to independent support where desired in order to make decisions about the service they receive, about significant decisions in their lives and in making complaints.</td>
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<td>That the objective relating to participation in planning of services be expanded to include participation in the development, implementation and evaluation of services.</td>
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<td>Recommendation 35.</td>
<td>That the objective relating to family relationships be reworded to reflect the importance of the mutuality of the relationship between people with disability and families.</td>
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<td>Recommendation 36.</td>
<td>Any funding grants be given out and used in ways that mirror the Principles and Objectives of the Act, so that no new services are developed, which do not fit with the Act’s intent.</td>
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<td>Recommendation 37.</td>
<td>That the Act contain a range of sanctions for non compliance. Such sanctions must be consistent responses to particular breaches, rather than the imposition of a blanket solution such as defunding. Breaches of the Act which result in harm or negative outcomes to people who use services should attract severe sanctions.</td>
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<td>Recommendation 38.</td>
<td>That good practice, creativity and leadership are publicly acknowledged and shared.</td>
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Section One: Scope of the Act

The central theme of all the group meetings and several individual interviews in this process concerns the scope of the Act. Although the Act may state that it covers all public sector programs and services, the way it has been perceived and the way it has been enacted gives the impression that it only relates to some services funded by Disability Services Queensland.

While the Act may be thought to imply the view that the principles of the Act relate to all Queenslanders with disability, this is not the way the Act is understood by a large proportion of participants in this process. The strongly held and well developed view of people with disability and those who support them is that the Act needs to enable and protect the rights of all Queenslanders who have disability, and not be seen to be restricted to those who are in receipt of funding from Disability Services Queensland (DSQ).

The words ‘An Act relating to provision of services to people with disabilities’ which sit directly under the title of the Disability Services Act indicate to many that the content of the Act relates only to those people who are currently receiving services which are disability specific and funded by DSQ.

Recommendation 1.

*That the descriptive title and sub-title of the Act be reworded to ensure greater clarity about the scope and breadth of the Act.*

The Act needs to encompass the essence of personhood, citizenship and what leads to having an ordinary and decent life in the community. There needs to be a clear link between the purposes, principles and objectives with the Act being a useful guide for all people to use, showing how the principles and objectives relate to real life. It needs to reflect a broad perspective of life, with one of the important aspects being the provision of good quality services.
Several people drew the parallel with the *Americans With Disabilities Act*, which is much broader in scope than this Act. The general consensus was that the current Act and its interpretation have in many ways unintentionally continued the mindset and preservation of segregation of people with disability.

A number of different groups raised the idea of more encompassing legislation. This was seen to take two forms:

Either: A broader Disability Act, which includes a vision and principles that relate to all Queenslanders with disability, regardless of whether they receive funded services or not. Within the Act, specific sections would relate to the funding and operation of disability services, complaints, abuse protection and monitoring.

Or: A suite of specific legislations which together form a framework of enablement and protection for people with disability. Such legislations would include a Disability Citizenship Act which details the rights and principles of inclusion, a Disability Services Act which delineates the funding, development, operation, and monitoring of services and a Disability Protection Act which provides legislative structure for complaints, prevention of abuse and neglect and service monitoring.

**Recommendation 2.**

*That the Act be significantly expanded, either as one piece or a suite of legislations, which addresses:*

- the rights of all Queenslanders with disability
- relationship of this Act to other legislation
- relationship of this Act to generic community and government agencies
- requirements of disability services
- complaints
- monitoring of services
- prevention of abuse and neglect
“The Act needs to put the person with the disability and the family as the focus rather than service provisions because life should not be embedded in service delivery.”

“The Act needs to put the person with the disability and the family as the focus rather than service provisions because life should not be embedded in service delivery.”

“Life should be set in the usual flow of things – family, home, work, being out and about.”

“Life should be set in the usual flow of things – family, home, work, being out and about.”

“Relationships are the most important things in life. Services are about helping ordinary things to happen around those relationships”.

“Relationships are the most important things in life. Services are about helping ordinary things to happen around those relationships”.

“It is very important the Act promotes people with disability as contributors in community life, not just as recipients or burdens.”

“It is very important the Act promotes people with disability as contributors in community life, not just as recipients or burdens.”

Regardless of the shape of the Act, the word ‘services’ needs to be removed from its title. Many people articulated very clearly how services do not form a life, and that life should not be seen in this context. Therefore services were not seen as a goal in themselves but rather as a means of enabling life, and when working well, they can support and make a full life possible.

No participants questioned the need for legislation which governs, directs and monitors disability services. They do, however, question the rationale behind the Act relating only to services.

**Recommendation 3.**

*That the Act be retitled to exclude the word ‘services’.*

The breadth of the Act’s engagement with people with disability was also seen to need expansion to include:

- children with disability who are not seen to be catered for by the current act, especially when at school, or if they do not yet receive DSQ funded services
- people with disability who are over sixty five years of age, particularly given the increasing longevity of the population at large and of people with disability in particular.

**Recommendation 4.**

*That the Act make explicit the inclusion of all people with disability, regardless of age including:*

- children with disability
- people with disability over sixty five years of age.

The current Act does not cover all services that provide supports to people with disability. Many people use services that are not funded by DSQ, instead using other government and/or community based services.
The Act does not cover all services that support people with disability

Georgina is a young woman of 18. She cannot talk or move much, and she lives in a nursing home for aged people. When we visited, Georgina had just arrived home from school. She had been put back to bed, in a room shared with three aged people. Two have Alzheimer’s disease and are quite noisy. The other does not speak the same language as Georgina. Because she cannot move her head much, she was still lying in the position where she was put, looking at a bare patch of besser brick wall. She cannot move herself into a position where she can see the window or doorway or any activity in the room. She is not regularly turned or positioned so she can use what little movement she has and remains like this most of the time, unless she is being fed, washed or dressed.

In rural and remote areas disability services are scarce, with many services funded by the Home and Community Care program or by other areas of health, often in aged care day respite. Concern was also raised about the non-inclusive practices of private organisations that operated without the guiding values and expectations of the Act.

The Act needs to spell out much more clearly the regulations that cover all public, community and private sector organisations and companies that support people with disability.

Recommendation 5.

*That the Act make explicit the expectation that all services provided to people with disability comply with the legislation including those developed, funded or provided by:*

- Disability Services Queensland
- Other public sector departments
- Community agencies
- Private, non funded residential services and facilities (the private for profit sector)
Interaction with other legislation

The Act needs to engage coherently with other legislation

“It is essential that the Act sets expectations for other pieces of legislation affecting health, education, housing, guardianship, public trustee, transport and the private corporate sector and so on, stipulating that people with disability have equal rights with regard to the implementation of specific acts.”

There are several other pieces of legislation which impact significantly on the lives of people with disability. The Guardianship Act, Disability Discrimination Act, Workplace Health and Safety Act, Mental Health Act and building access and consumer protection legislations are of particular relevance in the lives of people with disability, particularly those who engage with services. A number of these have been enacted after the DSA, and as such have not been considered in the development of the Act.

The Act needs to engage coherently with each of these. It also needs to engage coherently with the Commonwealth Disability Services Act and other Commonwealth legislation which impacts on people with disability, particularly those Acts which direct the provision of financial supports and pensions and employment. Importantly, the Act needs to ‘marry in’ with Commonwealth legislation so that there is entitlement to a certain standard of living. The Act also needs to consider its interaction with the proposed UN Convention on the rights of people with disability (currently in negotiation).

**Recommendation 6.**

*That the Act contain reference to other relevant legislations and make the relationship between them explicit.*

Beyond a rational and explicit relationship with other legislation, the issue of the status and enforceability of the Disability Services Act was raised repeatedly across the State. On a number of occasions, people talked about the way in which other legislation had been interpreted as more important than the DSA.

Workplace health and safety is a prime example with significant impact on people’s lives. Several examples were provided during the consultation process where workplace health and safety legislation was held by services to be more important than the DSA, resulting in the following situations as described.
“Obligations under the Act need to be strengthened with this Act being seen as having impact over other acts so that people’s lives and homes are not taken over by inappropriate standards or bureaucracy.”

Interaction with other Government Departments

- a person being refused service in their own home when their bathroom did not conform to workplace requirements,
- a person being refused service because a balcony did not have safe railings (although the service to be provided was all inside the house)
- people with physical disability being refused a service because of a ‘no lifting policy’
- staff working in a person’s own home being required to wear closed toed shoes and hairnets when preparing meals in the home kitchen.

There are also many complicated interactions between industrial legislation, policy and the Disability Services Act. Considerable work needs to happen to make these interactions explicit and to safeguard against people with disability being made vulnerable to mistreatment.

For example, industry awards require workers to be given numerous warnings before termination for ineffectively carrying out their jobs. People with disability who have made complaints about workers which have resulted in disciplinary action may become vulnerable to mistreatment by that worker in the event they continue to work with that individual.

**Recommendation 7.**

*That the Act include mechanisms for ensuring the rights of people with disability are held in equal regard to the requirements contained in other legislation. This must include enforceable penalties for non-compliance.*

In the course of the consultation process, numerous examples were related of repetitive and frustrating contacts with different government departments which could be minimised by a common understanding of disability and a consistent and openly articulated approach to meeting the needs of people with disability.
Coordinated approaches are essential

Need to build a picture of need over life with seamless changes from one life stage to another

A person who uses a wheelchair can be seen as having high support needs if the Medical Aids Scheme only subsidises a home based manual wheelchair. Because they cannot move around easily at home or in their local community, they may need assistance with cooking, washing and cleaning as well as going shopping, banking, to the video shop, recreation, having a taxi subsidy, and generally moving around their community. A large individualised funding support package would need to be considered to pay a worker, plus there would be many other costs, such as for taxis every time the person moved out of their home. Yet if that same person had a motorised chair or scooter, or even a loan through Medical Aids Scheme to buy a motorised vehicle and pay it off, then the person does not need these forms of support as they are able to access their home more easily without using up all their energy, as well as having the freedom to access their local community without paid support. They may still need accessible transport if they wished to go to places that were not in driving distance, but they would have the capacity to meet their basic needs locally without paid support, especially when they are known and supported by the local shop keepers and businesses. Surely this is far better use of money.

The Act needs to have mechanisms that influence other departmental policies and value and encourage the expectation of continuity of service to build a picture of need over life. This should be seamless from one life stage to another over all life changes. People should not have to be reassessed continually and reapply for support. If government departments and agencies develop better planning processes, sharing of basic data and information, understanding of disability issues and more constructive communication processes, this can be minimised. No matter how this interaction is managed, the focus must remain on a collaborative approach with all participants and stakeholders.
Strengthening the current disability reporting mechanism on disability plans of government departments is a way in which the impacts of this problem may be alleviated. Several options were put forward in the consultation process:

- DSQ not only takes a lead agency role, and also takes the values leadership role as specified by the principles and objectives of the Act. It needs to engage leadership and commitment across Government and have the authority to expect and to make things happen for people with disability.
- An independent disability Ombudsman or Commissioner role is created to address a broad range of complaints, quality and monitoring issues (see later). This role is responsible for leading and enforcing the development, implementation and evaluation of disability plans across government departments and agencies.
- Local Councils are tied into the act with expectations that they develop a proactive community plan for/with people with disability, as in the Western Australian Act.
- Formalising a memorandum of understanding between State and Local Government to build the capacity of local communities to be more responsive to the needs of people with disability.

One of the ways in which effective communication across government on disability issues could have great impact is through addressing the extra cost of disability comprehensively. Medicines, equipment, technology, travel and the extra use of services all combine to mean that many people with disability are faced with significantly higher costs of living than people without disability. The development of a cross government support system to minimise and streamline extra costs would make an enormous difference to the poverty of people with disability and the associated social and physical isolation that accompanies it. This is particularly so for people who live in rural and remote areas.
Another possibility raised by participants was the development of a system whereby people can claim back the cost of necessary equipment and disability related expenses through the taxation system.

“We have to drive a thousand kilometre trip, stay overnight, and travel back. We can’t get support for our other children, so have to take them with us. My husband must take time off work to travel as a family. This is so hard when a child has high support needs. If you want to fly you can’t get support for other members of the family. Families are not seen to have wider needs than just the issues around the child with the disability. There is no subsidy for families to get an accessible vehicle to move around our local community or to get to appointments required by specialists at the coast or in Brisbane.”

Recommendation 8.
That the Act include a strengthened requirement for all State government departments to develop, implement and review a disability plan. This must include measures for recognising and reinforcing good practice and enforceable penalties for non-compliance.

Participants commonly felt that the Act does not have a clear vision which forms an umbrella under which all legislative, policy and operational action operates. The principles of the Act indicate good intent and are thought by some to form a vision, but others feel this vision is not sufficiently clear nor sufficiently understood and carried out in practice.

The view is put strongly that the Act needs a clear and guiding vision about people with disability and the nature of their lives. This must be expressed from the perspective of people with disability.
Clarify the vision that drives the intent of the Act

“The Act has moved from a vision about life and how services support that vision, to picking up issues for service providers and meeting the needs of DSQ.”

The Act needs to be promoted

Disability legislation is strongly supported and has certain expectations

Recommendation 9.
That the Act include an overarching statement at its outset, which outlines the primary vision and ambition of the legislation. This may replace the current sub-title.

Around half of the people who participated in the process acknowledged their limited understanding of the specifics of the Act, its scope and its purpose. People frequently expressed the need for more promotion of the Act and its intent, so everyone sees it as a guiding tool for the way in which services are structured and operated to support people’s lives. In keeping with a broader conception of the Act, it would serve as a guiding tool for inclusion and engagement in the general community.

There is undoubtedly strong support for the need for legislation relating to the lives of people with disability and the services that support them. About a third of the people who participated in the process expressed the view that the Act had enabled significant difference in their lives. People who have been engaged in the disability community for over a decade all said they had seen important change during that time. Even among those who did not have detailed understanding of the content of the Act, it is seen to be symbolically important.

People are strongly supportive of the continuation of disability legislation, and see it as vital that the Act is enabling and empowering legislation which sets people with disability at its heart.

The Act must:
- set a framework and tools for life
- hold a shared vision about how people can be supported and included in community life
- set expectations about the nature of the services that support people with disability to have a life
The Act should set a framework, vision, and belief, with lifelong possibilities and expectations for a quality life with the support of services.

- establish and fund services to do what they are supposed to do
- emphasise quality of life, the same as others without disability
- help people believe it can happen
- expand the vision of everyone about lifelong possibilities as it sets them on life’s journey.

Build on the lessons learnt and become a living law.

Impact of the Act on the lives of people with disability

When the Act was written in 1992, Queensland had a long history of congregate models of service provision and the dominance of a small number of large service providers. It also had a small number of examples of innovative service development and practice from which to build. While many of these elements remain today, the advances which have been made over the past twelve years provide an opportunity for the new Act to build on the lessons learnt, and to become a living law which leads to, encourages, promotes and enforces the development of services and supports which assist people with disability to be fully included and respected citizens.

Recommendation 10.
That the Act include a specific commitment about its promotion to people with disability, families, advocates, service providers, government and the broader community.

People who have had a long involvement in the disability movement talked about their understanding of the way the original Commonwealth Disability Services Act, followed by this State Act, had changed the expectations for people with disability in Queensland. Some people saw the enactment of the law as a symbolically important moment which resulted in a greater public awareness of issues concerning disability. Others do not share the view that the Act has provided leadership and direction to the community in general. However, there is a high degree of consistency of response to the question of whether the Act has impacted on the lives of people with disability.
The most common comment was that the implementation of the Act has resulted in three distinct groups:

1. A small group for whom life has changed significantly with the introduction of individual funding and the use of new, innovative, flexible, personalised support services.

2. A larger group that remains in the same situation as prior to the introduction of the Act, some with significant and costly resources that are not used well. This group includes those people with inadequate amounts of funding and those using congregate facilities such as group based homes, hostels and day services, aged care day respite or nursing homes, etc.

3. A very large group of people with no resources and no services and nothing happening to address their current situations or their future.

This means that most people with disability are missing out supports which sustain a decent life, especially adults. The result is greater cost in the long run if people are only funded by a large package when the situation has reached crisis later on when everything breaks down. This can also result in very poor support being available.

Alice had been asking repeatedly for support for her daughter Theresa for several years. Theresa had been assessed as eligible, but they had been unsuccessful in obtaining any funds. Life has continued on for the family, growing steadily more difficult as Alice aged and Theresa’s needs increased over time. Alice had a bad accident which resulted in her spending time in hospital, needing a lengthy recuperation period and with a permanent disability herself. This crisis led to emergency funding becoming available, which resulted in Theresa leaving the family home and being placed in a group home without adequate time for her mother to train staff about her very specific needs. After some months, staff are reluctant to believe or address Alice’s concerns about Theresa’s needs, despite clear evidence that her health and wellbeing are suffering.
A lot of discussion was held in different parts of the State on the need for the provision of small amounts of responsive and proactive support to people with disability and families as needs arise. While this is in many ways an issue of implementation, it also has great relevance to legislation, in terms of the development of principles which encourage and enable a proactive, developmental approach to service provision which supports the maintenance and growth of people’s informal supports and networks. This point is picked up again in the section of this paper which discusses the principles of the Act.

The Act needs to encourage, support and lead the development of sustainable, responsive communities around people with disability. People with disability and their families generally do not want services to provide all the supports in their lives, or to provide the life. The development and continuity of informal supports as well as proactive planning and forward looking supports put in place as needs arise were commonly seen to be a way of both supporting people with disability to fulfil valued roles in their communities and also a way of using limited resources more wisely.

When funds are used in this way it becomes a win-win situation, with the cost to government minimised by the reduction or delay in need for intensive funded support services and the personal cost to the people themselves greatly reduced. Participants also spoke of the need for services to be available to assist families in supporting their family member with disability, not to replace their relationships or the person’s informal networks.

**Recommendation 11.**

*That the Act include a principle about ensuring the developmental, progressive implementation of supports as and when they are needed by people with disability and families.*
Complaints and Monitoring Systems

A key issue raised without exception was the area of compliance with the principles of the Act that relate to the pursuit of grievances. The existing complaints systems in place now do not adequately and expeditiously protect and uphold the rights of people with disability as contained in the Act.

A number of groups put forward the view independently that the Act should make provision for a complaints body which is external to the body which funds and provides disability services. Concerns were raised repeatedly about the conflict of interest which is inherent in the current arrangement where complaints are dealt with inside DSQ. A commonly held assumption is that, as the service provision arm of DSQ does not comply with the Act itself, the funding arm cannot expect or demand that others in the community sector must do so.

A number of examples of complaints which were poorly dealt with by services and also by DSQ were related in the consultative process. Many told of their reluctance to make complaints, based on their fear of possible retribution. The situation was described where people with disability and families are hesitant to stand up and complain when some service providers can respond vindictively and take the service away, and there is no recourse. This situation is compounded in rural and remote areas where there may only be one service, but this feeling was also common in cities where movement and portability of funding is also an issue.

In addition to resolving individual complaints, many people indicated a need for a system which tracks complaints and poor service provision. (Issues would also be identified through quality assurance systems and service evaluation.) This process would ensure follow up on positive action to remedy the situation and be responsive to emerging negative trends about particular services or models of service delivery.
Retribution is happening

An independent Ombudsman or a Disability Commissioner

“We need a one stop place with legislative powers to take action and require compliance”

Yolanda’s parents had serious concerns about the way support was being provided to their daughter in a group home. Their concerns were raised many times with the service, but Yolanda’s situation was never addressed. Relations between Yolanda’s parents and the service became adversarial, and the service took them to the Guardianship Tribunal to have their decision making authority removed. The Tribunal did not do so, but did put conditions around their role in making decisions on behalf of their daughter. The distress and frustration this has caused them has impacted badly on their own wellbeing, and Yolanda continues to live a less than optimal life.

Recommendation 12.
That the principles of the Act include the right to pursue independent resolution of grievances and the objectives include the tracking of complaints, proactive investigation of issues of concern and monitoring of expectations of change.

A large proportion of participants in the consultation process saw the necessity for an independent Ombudsman or a Disability Commissioner who may have a comparable role to that of the Children’s Commission, and somewhat similar to those in some other states of Australia. The development of such an Ombudsman or Commissioner role would meet a number of identified needs. It would enable:

- Response and independent investigation of individual complaints
- Identification of multiple complaints around the same service or issue and action to redress the situation
- Imposition of sanctions on services as consistent with the Act
- Identification of systemic issues of concern and the development of policy responses to resolve such issues
Identification and tracking of complaints and abuse

- A proactive education function which informs people with disability, families, advocates, service providers about their rights and obligations regarding complaints
- Resourcing of and information gathering by Community Visitors.

The Community Visitors scheme could logically operate within such a framework. This would provide a source of information to the Ombudsman or Commissioner on the individual and systemic issues occurring within services. A strong and resourced Community Visitor team also provides a valuable opportunity for the identification of abuses and practices of concern which individual people with disability or families may feel too vulnerable to raise through complaints.

Recommendation 13.
That the Act include the establishment of an independent complaints and monitoring body which has powers to undertake investigation and gain compliance. The development of such a body must include further discussion with people with disability, families and the broader sector about what is needed.

During the consultation process, an overwhelming concern for people with disability and families was the struggle to find information and to find out when information changes.

No people involved in the process felt they were linked in to information provision which kept them up to date with the various funding opportunities, services and support available, and information about various issues concerning disability.

It was also pointed out that people did not have the capacity, time or energy to search the internet to gain information on a frequent basis, especially if they were not aware of what they should be searching for.
At best, the search for information is frustrating and time wasting. At worst, this state of affairs is dangerous, as families struggle on in situations where they do not have knowledge of useful connections, the equipment necessary to care safely for people with high support needs, or access to responsive solutions that may be helpful locally.

Many people felt they remain unsupported and under great strain, and they do not have opportunity to access supports which would improve the quality of life of the person and their family.

The Local Area Coordinator’s (LAC) role was mentioned a number of times as a very useful and supportive innovation on the part of DSQ, although there is not coverage of LACs across the state and the role was seen to be at high risk of being subverted.

**Having had contact with several of the LACs in the Far North, it is clear they have made a huge difference to the way programs and services have been provided. Their networking provides a comforting bank of resources and information on which they can draw, in their endeavour to cope with the many complex issues. The LAC program is probably one of the most innovative moves the Government has made in the field of disabilities in a long time.**

While there is strong support for this role, many participants also expressed the view that a one stop shop for disability information is needed, which is accessible and independent of government and services providers in order to maintain integrity of information provision.

**Recommendation 14.**  
*That the Act include an explicit commitment to the development of localised information and resource points across the state, with the promotion of these, to people with disability and families.*
Disability Services Standards

“Clear Standards on which services are built, maintained and evaluated need to be included in the Act”.

Quality Assurance

“Whilst the paper work may be a necessary part of the process, it could be streamlined somewhat to allow those at the coalface to get on with the real purpose of the task in hand.”

About service responsiveness and enabling what needs to happen in life

Disability Services Standards need to be written into the Act explicitly, and directly linked to the principles and objectives of the Act. The monitoring and auditing processes which support the implementation of the Standards must also be laid out in the Act. The failure of services to meet the minimum requirements of the Standards needs to activate the sanctions in the Act, as referred to above.

It is critical that the Standards cannot be used as a ‘tick and flick’ tool which enables services with good on paper rhetoric and policy, yet poor practice, to pass an audit.

Recommendation 15.

That the Act explicitly include reference to the Disability Services Standards as the minimum standards for service evaluation. This should be done in such a way that it does not preclude the development of quality assurance mechanisms over time.

In addition to auditing of the compliance of services with the Standards and the Act, broader evaluation processes should be in place to measure the impact of the Act on the lives of people with disability and their families.

People strongly supported reflective practice, continuous improvement, action learning and sharing of information about good and innovative practice in order to build a good quality service system. The inclusion of a quality assurance system is therefore seen to be a critical part of the Act, with people with disability and families having a powerful role within the quality assurance framework where they have influence over participation, contribution and outcomes. This role should not require people to have onerous bureaucratic engagement but rather enable people to talk about their relationship with services that support them and the responsiveness of those services to enabling what they need to happen in life.
“Becoming caught up in administrative procedures takes away people and time to continue the work of developing and enhancing the lives of people with disabilities. People suffer because valuable resources are taken up by the procedural process.”

“We need to create new ways of doing things that still ensure accountability, but to people with disability and their families, rather than to corporate norms.”

The quality assurance system contained within the Act also needs to give consideration to the workload on services, especially small local ones, and assess practice as well as policy in such a way that workers are not removed from their core business for lengthy periods in order to satisfy paper based policy requirements of an evaluation process.

“Avenues for appealing the outcomes of evaluations need to be included in the Act. Consideration also needs to be given to the development of measures which are consistent across different government departments, so that diversity of funding does not require agencies to complete multiple evaluations in order to acquit their funding.”

Recommendation 16.
That quality assurance mechanisms be developed that are seen to be different from minimum standards. These would be grounded in the perceptions of people with disability and their families and focus on the quality of the relationships and support of services in their lives.

Systematic analysis of how services are being implemented and the critical issues emerging through evaluation, both positive and negative, is required. The information which emerges from this analysis links directly to how government policy and programs are developed.

Recommendation 17.
That provision be made within the Act for regular evaluation of the implementation of the Act in relation to how life for people with disability is played out. Such evaluation must be conducted external to the funding body and must actively include the perspectives of people with disability and their supporters.

Regular external evaluation of the implementation of the Act
### Section Two: Purposes of the Act

**“I would like to think that the Act will never become static but be an evolving piece of legislation which allows room for reasonable and innovative change.”**

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<tr>
<th>Interrelationship between vision, purposes, principles, objectives, funding, requirements and powers</th>
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#### Purpose (a) – Affirming rights

Participants feel that the purposes of the Act are clear and mostly unambiguous. It is the implementation of the purposes of the Act which is more at issue. A significant amount of discussion was held around the coherency of the principles, objectives and powers of the Chief Executive and the purposes of the Act. A significant number of participants felt that the primary elements of the Act need to interrelate more consistently. In effect, the purposes should provide a clear statement of intent, clearly supported by the principles, objectives, funding structures and powers. Through this, a clear policy direction for government and funded services becomes explicit.

**Recommendation 18.**

_That the Act be constructed in a manner which provides a clear and linear path which shows how the vision, purposes, principles, objectives, funding and operational requirements and powers of the Chief Executive interrelate._

There is strong support for this purpose. As detailed earlier, the Act requires a clearer articulation of the fact that the fundamental rights statement applies to all Queenslanders with disability.

In keeping with the recommendation to broaden the scope of the Act, the purposes of the Act need to be expanded to formalise the requirement for other government departments to develop and implement disability plans, to be monitored by DSQ as lead agency.

This purpose must be supported by strong and enforceable provisions in the legislation which require other departments to give due consideration and allocate appropriate resources to the development and implementation of disability plans.
This may require a broadening of the existing purpose (b) to include more explicitly the parts of the public sector which provide services which are generic in nature and used by people with disability (such as transport, education, housing and health services), or it may require the addition of an another purpose.

**Recommendation 19.**

*That an additional purpose be drafted into the Act to set out the requirements and responsibilities of government and community agencies in providing services to people with disability.*

Many participants consistently expressed the view that there are several omissions in the existing objectives of the Act. These are addressed in detail further in this paper.

The clear view of people involved in this process is that the current Act has not achieved the purpose of creating flexible funding mechanisms which assist people with disability to lead a similar quality of life, equal to others in the local community, and to participate and contribute as members of society.

Any funding mechanism must ensure individuals with disability and their families determine flexible funding supports, which become available through different ages and stages of life, not only at times of crisis. They also must direct how funding is used to support their engagement in ordinary life.

**Recommendation 20.**

*That the purpose relating to funding reinforce the intent of the principles and objectives of the Act, with the emphasis being on flexible funding supporting the achievement of an ordinary life at home and in the community.*
Purpose (d) – Innovation

“The Act needs to set clear expectations for change in the service sector, with appropriate resources to move towards implementing the vision of the Act.”

“One positive aspect is that the Act has allowed some small, responsive, flexible community based services to get going. It has provided affirmation of their ideas [and they do] use the principles and objectives as the basis of their support. It has allowed them to get some funding as they abide by the intentions of the Act. It is hard to get others up as now funding is only to selected individuals.”

However the general consensus was that the Act has not created or encouraged much innovation in mainstream service provision.

The Act needs to have clarity around decision making in relation to what is innovative support, and what is not and who makes the call. Consideration should be given to establishing a diverse group, including individuals whose lives are affected, representatives of organisations and the research community in decision making and agenda setting around encouraging, supporting and sharing innovation. The focus should be on supporting creative thinking, connecting, and action at grass roots level, enabling people with disability and family members to be strengthened and supported, and communities to be more responsive to the needs of people with disability. The focus needs to be on people with disability and their families and supporters.

**Recommendation 21.**

*That the Act contain more explicit statements about how innovation is determined, encouraged and supported with emphasis on personalised responses that improve peoples lives and the nature of the supports they receive.*
Basic Concepts

Definition of disability and access to support

Labels do not determine need

Aims are different in different parts of the service sector

A number of family members who participated in the process described the difficulties in accessing services due to the fact that their son’s or daughter’s disability was not included within the definition of the Act. People with behaviours that are challenging, especially those with labels such as Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder have been repeatedly told they do not meet the criteria for funding or service allocation, despite the presence of a very real need for support.

“The current labelling of disability is too narrow. It excludes people who are on the disability support pension who have very challenging behaviour with the labels ADD or ADHD. They and their families can get no supports as adults, yet are in critical situations at home, where violence is often rife and where families are breaking down. The impact on life is more important than the label. You don’t have to include these labels but rather somehow need to acknowledge the individuality of such situations and the critical need for support.”

By the age of six, Jed’s parent’s marriage had fallen apart and his father had left home. His grandmother moved in to help until he was 13, during which time he attended 16 different schools and special education units, because he was expelled and moved on, being seen as being too disruptive and a danger to others. Disability Services Queensland (and its earlier equivalent) was not interested in Jed’s situation, because they said he had not been given the specific label of intellectual disability or psychiatric disability, and therefore they are not able to help him.

People with psychiatric disability have not been well considered in the development of the Act. There are complex relationships between people’s mental health and their disability, and the aims of service provision in the mental health arena are often different from those of the disability sector in significant ways.
Responsive to need not label

Funding categories should not drive the availability or nature of supports

Principles of the Act

The episodic nature of mental illness may mean that many people have no disability when well, while the impact on others may leave them with psychiatric disability which changes over time but still results in their having ongoing support needs, or the need for critical periodic supports. Current interpretation of the Act often leaves these people without any mechanisms for gaining support because they have been deemed not to fit the criteria, have been given a label that does not fit, or assessment of their needs does not relate to the mechanisms for allocation for funding. The Act needs to be responsive to meeting the needs of all people with disability in assessment and support.

In many instances, the consultants were told of situations where funding was used to drive the nature of supports, where people with disability were expected to fit into categories required for funding and/or services, which did not correlate to their needs. Their view is that funding agreements are used to justify why services cannot be flexible and responsive to the needs of people they support. This approach results in not having fundamental needs met or being grouped to get service provision which does not meet individual needs and does not connect with typical roles and relationships in community life.

Recommendation 22:

That the Act include a mechanism for determining eligibility for support based on need, which includes individuals who do not easily fit into the current diagnostic categories, and is not reliant on fitting artificial funding criteria.

The consistent view of participants is that the Act needs to be more clearly and explicitly seen to be relevant to the lives of people with disability beyond the parameters of DSQ funded service provision. To this end, there is strong support for maintaining the principles of the Act. It is necessary that the language used in the Principles promotes and sustains a view of people with disability as citizens with equal rights.
The principles of the Act are seen as important guiding values, which are not sufficiently strongly supported in the objectives of the Act. A clearer relationship between the objectives and the principles is necessary. As has been detailed above in discussion of the scope of the Act, the principles are generally worded, and could apply to anyone with disability, regardless of their relationship to funded services. However, the objectives of the Act clearly relate only to funded services. There is a lack of understanding about whether the principles do in fact relate to all Queenslanders with disability, or just those who are in receipt of funded services.

Major issues arise, however, in discussion of whether the principles of the Act have been put into practice. It is strongly felt that the intent of the Act is not seen as relevant by many service providers in daily practice. People’s experiences are testament to the fact that many of the principles in the Act are not being upheld. The next example is representative of stories told through the individual interviews held with people around the State.

Most of the examples we heard from people detailed treatment by services which was not in keeping with the principles of the Act, and which indicated that neither government nor services were using the Act as a guiding tool. Indeed, a number of the service providers we spoke with had a limited understanding of the content and scope of the Act, and how it related to them as service providers.
The principles are not enumerated in this paper. Rather, those principles where change is required and the areas in which new principles are needed are detailed below.

**Peter, a man with quadriplegia, was moved from a hospital rehabilitation unit to transition housing 400 kilometres from his previous community and his family. After two years, he remains in transition housing, as there is nowhere else for him to live. There is no foreseeable change to his circumstances. He has no links in his current community apart from the other people who live in his house and the staff who provide care. He finds his current living arrangement difficult, as it “becomes a routine of fitting in with others who have similar needs and issues. It’s not an ordinary life”.

An additional principle is required in a new Act, relating to abuse and neglect of people with disability. While the right to be free from abuse and neglect is a basic human right, and as such included in the first principle, the experience of people with disability is frequently that this right is not enabled, protected or defended, leaving them highly vulnerable, particularly if their situation is not open to scrutiny.

**Recommendation 23.**
*That the Act include a new principle on the right of people with disability to be free from all forms of abuse and neglect.*

At present, the principle around attaining quality of life and participating in society also includes reference to families. An additional, separate principle is required which addresses the important role that families and committed others play in the lives of people with disability.

“*Regardless of capacity or skill, families do have a natural authority and are entitled to influence the direction of their family member’s life if they have remained faithful and committed to the person with disability and their well being.*”
Committed families are often the greatest safeguard

“The Act needs to acknowledge and value the vital role and authority of family members and informal supports in the lives of people with disability, especially those with high or complex support needs. Having committed people in their life is often their greatest safeguard. This can happen by listening, not patronising, supporting and doing what it takes to enable a good life with people and their families and including them, not replacing them.”

Recommendation 24.
That the Act include a new principle on the central importance and authority of committed families of people with disability, that acknowledges the role they play and their importance in safeguarding the fundamental human rights of their family member.

Restorative justice

Several people raised the issue of people with disability being caught in outmoded, and often very costly, systems of support where they had no opportunity to leave or to change their life situation. As they are in receipt of services, they are not a priority for access to new forms of support.

“Joanna lives such a wasted life. She has stayed with 26 other people in the same place for 38 years. Her life is regimented and operates around very atypical routines. She is up at 6.30, is put to bed following lunch and is bathed mid afternoon and put into her pyjamas ready for dinner at 4.30. She has few possessions, and those she does own are quickly lost or broken. Her diet has been reduced to pureed food, yet I can remember her loving to eat a steak. She has had in applications for funding to move out since 1999, but continues to be rejected. As her sister, it breaks my heart.”

Recommendation 25.
That a new principle be formulated around the entitlement to restorative justice, with the acknowledgement that people with disability living in institutional forms of care be given their due recompense.
The need for flexibility of supports was raised again and again by participants in all areas. The impacts of living in rural and remote areas and the need for episodic supports for people with psychiatric disability or people in crisis were given frequently as examples where flexibility of support makes an enormous difference to short and long term outcomes for people with disability.

Emma has received a small funding package to provide personal support to live in her own home. She requires support to get up, shower and dress and then she can go about her day unassisted until going to bed. The service provider who administers the package is medical model based and only works on week days. This means Emma has no service on weekends, early morning or at night and must stay in the same clothes from Friday to Monday because she has no assistance then. This is not conducive to her health or comfort when temperatures soar over 40 C. Her worker does not arrive at any specified time each day, as her support has to fit in with others who need nursing care in the community, which means that she often has to greet friends and family arriving at her home in her night wear. Although the funding package gives Emma some support, enabling her to live independently, her life is still very much dictated by the availability of the service. What she does has to fit around when the service is available to get her ready to live her life.

The Act needs to encourage quick, creative, local decision making and problem solving about life close to the people who live it.

“The expectation should be of flexibility in funding and supports to deal with people’s changing needs at different points in life, with information and support based on the rhythm of life – infant years, preschool years, primary school years, high school years, work and alternatives, early adulthood, a home of one’s own, middle adulthood, life without family, older life – all with a basic support entitlement.”
Objectives of the Act

There is a need to embed change and to strengthen the Act to give greater clarity and so that those services which are not flexible, responsive, innovative or forward looking are encouraged, supported and compelled to make changes to their operations. This will result in better support for people who use them.

The objectives for services set in the Act need to focus the role of services and supports in enabling ordinary life to happen, by ensuring:

- They are available to support ordinary life when and where it happens
- They meet people’s needs
- They are safe
- They address barriers
- They enable personal, social and economic participation and contribution.

The majority of the objectives of the Act are supported and it is recommended that they be retained, but updated, so that they include appropriate language and expectations of quality support.

“Clarify what is known about good service provision and set these expectations in the objectives of the Act – local, small, flexible, responsive, timely, person centred, individualised and personalised, portable, keeping the choices, decisions and solutions close to the people involved, recognising their authority to decide and influence what happens in their life.”

Recommendation 26:
That the Objectives of the Act be retitled to become the Objectives for the development, implementation and evaluation of disability programs and services with people with disability.

The language contained in the objectives is of concern to many people. The objectives of the Act need to form the basis on which services are monitored and assessed for compliance with the Act.
It is in no way appropriate that the objectives include the word ‘should’. The language used in the objectives must ensure that clear expectations of compliance with the spirit and specifics of the Act are expected and will be enforced.

**Recommendation 27.**  
*That the language used in the objectives be strengthened to reflect the fact that these are enforceable obligations, not aspirations.*

As with the discussion of the principles, the objectives of the Act are not enumerated in this paper. Those requiring alteration and the addition of new objectives are detailed below. The issues central to several of the objectives have already been raised in this paper, and so will not be repeated here.

They include the objectives concerning:

- Integration with generic services
- Taking into account additional disadvantages
- Including people in local community life
- Promotion of competency, positive image and self esteem
- Inclusion in community
- Grievances

The Act needs to include specific reference to the vulnerability of many people with disability and the reality of their experience of abuse and neglect. It also needs to include a framework of safeguards and an effective response to occurrences of abuse and neglect and when services are involved. This objective needs to relate coherently to the new principle around abuse and neglect put forward earlier in this document.

“This counsellor ended up breaking down and talking about her feelings for me and sexually abusing me. I told mental health and they did nothing. I felt so let down. I got depressed and suicidal and had panic attacks if I left home.”
Recognising vulnerability and safeguarding against abuse

Choice and Decision Making

“Power is usually centralised with services where there is no expectation of developing the type of relationships with people with disability and their families that give them the authority to decide what types of supports they need and how best this can happen.”

Recommendation 28.
That the Act contain a new objective which specifies that services are designed and implemented to ensure that:

- the incidence and likelihood of abuse and neglect of people with disability is recognised
- preventative safeguards are established with strategies put in place to protect people with disability from abuse and neglect
- mechanisms are put in place to respond effectively and appropriately to incidents and suspicions of abuse and neglect.

Currently no objective requires services to enable, promote and support choices and decision making by or with people with disability about day to day and lifestyle choices. The Act needs to promote choice and decision making as central features of service provision, from the choice of breakfast cereal to the choice of living arrangements and workers.

There is a need for the addition of an objective which draws the control of decision making back to the person with disability themselves and which safeguards decision making by involving those with closest commitment to the person. This objective also needs to develop clarity about what is service business and what is personal or family business.

Recommendation 29.
That a new objective be included in the Act which focuses on the need for services to encourage and support the decision making and choices of people with disability in:

- Day to day choices
- Major decisions
- Lifestyle choices.
The values base and skills of workers are critical to the quality of support people with disability receive from services. It is essential that staff, particularly those who work with people with complex or high support needs, have adequate training and are equipped to do their jobs effectively. However, strong concerns were raised by some people about the concept of setting mandatory levels of qualifications for support workers such as at a Certificate III level.

A number of examples were raised in the consultation process where people with challenging behaviour were exited from services, as the service found their behaviour too difficult to deal with and other people were put at risk, often because the service was grouped. This left people at home full time with their families, without support. Families told of being left exhausted and frustrated at the failure of formal services to provide them with any assistance when it was clearly greatly needed. These families were of the clear view that other models of service provision and training and support for staff to work effectively and actively with their family member would have resulted in a different and better outcome.

<table>
<thead>
<tr>
<th>People who are seen as challenging are often not supported</th>
</tr>
</thead>
</table>

“Sometimes it is better to pick people with good values about people with disability and to train them on the job, by or with the person they support.”

“Quality service provision is not necessarily related to having qualifications.”

“If he is only given some support, and he is given time to grow, he will eventually fit into society. He has such poor self esteem, no friends, and has little understanding of the consequences of his actions. He needs his family environment and we love him dearly and do the best we can, but we need support and he needs to do something with his life. People need to recognise how vulnerable this young man really is. Max needs others around him who will support him. He needs good role models and the support of a young man who could take him out on weekends and help him enjoy ordinary life. He needs to be around other young people and do what other kids do. Given a few years he will mature, but he needs support to hang in there now, otherwise he will be lost to the criminal justice system or to the grave. In his heart, he wants a normal life too.”
Focus on the development of the individual

An individual funding package but no individualised supports

An individual funding package creating a meaningful life

### Recommendation 30.
The Act include an objective which requires services to ensure workers are appropriately trained and supported in carrying out their jobs.

There is a need for a clearer understanding about what individualised service provision means.

Bruce receives an individual funding package and is living in a group home with three other people who also have individual funding. Their combined funding is sufficient to employ staff, as long as none of the people living together move out. This results in a situation where a package which is intended to be flexible in fact locks Bruce into a foursome, as to move would be to greatly disadvantage others. The service provided to each of the people living together is congregate in nature. There is little evidence that the packages of each person are being used to support them to follow their own path or develop different supports and living options which may suit them far better.

Ben loved being driven around. His family knew he would enjoy working in this way, so they found work experience for him accompanying a van driver on his route. As this was successful, they created a viable work option for him by using some funding to go towards buying a van to operate a small business. Ben employs a worker who enables his involvement in his own business, the profits from which go towards paying both his and his worker’s wages. To many people, Ben would be considered person with high support needs incapable of holding a job, gaining a wage, let alone contributing to paying the wage of another person and having his own business. By using his funding creatively his family have built on his gifts and enabled him to have a real and positive work life, and he has contributed to paying tax, decreasing the employment statistics, and decreasing the costs of his own support.
This objective needs to link to the purpose on innovation as well as a number of the principles, and be implemented creatively by service providers and the funding body to ensure that service delivery to people is truly individualised.

The objective that relates to meeting individual need should be placed immediately following that on development of the individual, as they closely interrelate.

Gordon was referred by Mental Health to a sheltered workshop where he had nothing to do. “I watched TV all day. I could do that at home. I had no help to do things. When I complained and asked for something to do I got into trouble, so I walked out and didn’t go back.”

Several examples were given to highlight the problems of people with disability being supported in ways that were inappropriate to their needs and age. This was particularly so where services were medical model based or in conjunction with aged care.

“All Shirley’s possessions remain in a small plastic carry bag in the bottom of her wardrobe, with nothing hung up or put in the drawers, so she is unable to access them. One of her cupboards has a sign on it indicating that housekeeping items are stored in there for staff. There is nothing on show to personalise her bedroom area.”

“I think it is really important to have some form of planning and supports happening in a continuous way across the different life ages and stages.”
The clear view of participants was that the objective has not been upheld. Several examples were provided highlighting where the one service provider held the control of whole of life service provision. Some of these were outside metropolitan Queensland centres, while other examples were from large cities. All situations described resulted in the choices and breadth of life experiences of the people using those services being significantly contracted.

When people discussed this objective they referred to the control of life being with the one service, rather than only having one service. The difference, and the exception, lies with the small number of services set up around particular individuals. These services were seen to provide support to the person to live a full and rich a life as possible, and do so by providing supports across any necessary domains of that person’s life. There are clear differences in the philosophies and structures of these services, not least in the facts that the authority to make decisions and the control and governance of the service rest far more closely with the person with disability and/or with their family.

The development of new models of support, which work with individuals and not over groups of people, needs to be acknowledged and supported.

This objective currently relates to services making information about their own service available. It needs to be expanded to include a requirement for services to make this information available to any interested person, in formats which are easily accessible to them. It also needs to include making information available to people with disabilities and families about resources, connections and supports outside of the service.

Recommendation 31.

That the Act preclude the provision of service to young people with disability by services designed and used by aged people.
Ensure access to independent advocacy and advocacy support

Cannot access independent advocacy and advocacy support when it is not available

Participate in the planning and operation of services

Recommendation 32.
That the objective relating to information provision be expanded to include the provision of information to any interested person in formats which are easily accessible to them, and the provision of information about community resources and supports external to the service.

Access to resourced, independent advocacy (working on behalf of the person) and advocacy support (supporting the person or their family to take up issues themselves) were raised many times by people during the consultative process. While this is more an issue of implementation, the current lack of access to independent advocacy and advocacy support has implications for the legislation. A requirement for people to have access cannot be effectively monitored if independent advocacy or advocacy support are not available.

Beyond this existing requirement for support to participate in decisions around the service, there is a need for services to play an active role in ensuring that independent support is available for people wanting assistance in making choices and decisions about other issues in their lives, and in making complaints.

Recommendation 33.
That the objective relating to advocacy support be expanded to include the requirement for services to ensure people with disability have access to independent support where desired in order to make decisions about the service they receive, about significant decisions in their lives and in making complaints.

The active participation of people with disability and families in the way in which their services are developed, implemented and evaluated is seen to be a critical component of good service practice.
“There needs to be clarity about what is service business and what is personal or family business, with decisions relating to support and how life is to be played out being made by either the person themselves or by close family.”

Services need to look more at how decision making and relationships are supported not thwarted.

This objective needs to be strengthened in order to require services to comply effectively with quality assurance processes which build on the engagement of people who use services.

“I think relationships are the most important things in life. Services should be about helping ordinary things to happen around those relationships. They should not control me, or take over, or interfere with my private or family life. I should have a choice about who works with me. My support worker needs to be there for me.”

Amanda lives on an isolated property. She has a dream for her life. She wants a home of her own in the town, either living by herself or with another person with whom she gets on well. She sees herself as needing some supports, especially with managing daily life – the cooking, budgeting and shopping. She also would like to meet new people and to try new things, as well as have a holiday. She has a strong interest in people from different cultures and would love to make new contacts. Amanda is very clear about what she does not want and how her supports would operate. She said, “I really don’t want to be lonely or unhappy. I live a long way from town, I don’t know people there. I want to be part of the community, but I don’t want the government people or other workers coming in and taking over my life.”

People with disabilities and their family and supporters must be the primary impetus to evaluate current services with the opportunity to be included in developing, implementing and evaluating future services.

Recommendation 34.
That the objective relating to participation in planning of services be expanded to include participation in the development, implementation and evaluation of services.
While supported in principle, the wording of this objective needs alteration to better reflect the role and context of families that the relationships between their members are mutually dependent, and that people with disability are important contributors to the fabric of their families.

**Recommendation 35.**

*That the objective relating to family relationships be reworded to reflect the importance of the mutuality of the relationship between people with disability and their families.*

People recognise the advances that have been able to be made under the Disability Services Act with individual funding and the creation of small, responsive service options which operate in more personalised ways.

They also highly value the flexibility of the funding approaches of some small service providers, Local Area Coordinators and family support workers who have access to small amounts of money that can do what it takes to meet people’s needs. These forms of funding are seen to be essential. However, concern was raised about their sustainability and therefore for their mechanisms to be safeguarded by the Act.

People also see the need for a range of funding options which support the development and implementation of services, as well as strengthen people with disability and their families and build the capacity of local communities to be more responsive to the needs of people with disability.

Some unintended consequences of the newer funding approaches do need to be considered, however. Many of the individual funding packages are used in traditional ways with their being added to block funding grants with people being attached to what already is on offer, so that the person gets the same congregative service regardless of the funding type.
For the smaller personalised services, there may be very little capacity for development of important service infrastructure such as provision of training opportunities for their staff and management, developing organisational vision and policy or for doing formal evaluations, given the small budgets with which they are operating.

The need exists for the Act to enable consideration of the positive ways of supporting such infrastructure with some forms of shared block funding to support the development, training, networking, research and innovation and other important aspects of small responsive service provision which enables more flexibility and good practice.

The current requirements for accountability of funds are onerous. They are governed by the inflexible and outmoded practices of other departments and do not give the flexibility needed to live life. While it is essential that proper accountability for the use of funds is in place, it is not reasonable to expect a three monthly acquittal of funds with expectation of exact spending of money in this timeframe.

The Act needs to ensure safeguards are in place to make certain the effective use of funding packages, but these need to be counterbalanced with mechanisms which do not unfairly impact on the lives of people with disability.

More flexible ways of using and holding funding need to be written into the Act, in order to support and enable a wider range of options and choices that give people with disability more flexibility.

The Act needs to include mechanisms for funding allocation, including opportunity for individuals to hold and use their own money.

Expectations and parameters need to be set for the use of funding for private for profit agencies and generic services who take on a support role with people with disability.
Appropriate timing of the receipt of funding was seen as a crucial issue that needed reflection in the Act. People saw the emphasis of the funding program being on crisis and driven by the historical legacy of under-funding. This was seen as being inconsistent with the principles and objectives of the Act.

“There is no cohesive planning over life and needs are not seen in context. This creates a false economy of savings. We need to look at long term investment in people. That would bring about much better use of money and much better quality of life.”

Decision making about funding was seen to be depersonalised and done at a great distance from the people who are applying for it. Some solutions to this were seen to be:

- Proper devolution of policy implementation and funding to the local level
- Funding being allocated on a shire basis with emergency funding being held by local councils.

Mechanisms for fairness and equity also need to be included, particularly in the allocation of funds. Of particular concern are poor services that continue to get significant amounts of funding as well as additional funding without strings attached.

Recommendation 36.

*Any funding grants be given out and used in ways that mirror the Principles and Objectives of the Act, so that no new services are developed, which do not fit with the Act’s intent.*

The Act also needs to consider a way of resolving the problems people with disability face in the financing of essential items. An interest free loan scheme, for example, would alleviate some of the pressure on people who require particular equipment in order to live their lives. Although these examples are from Health Department funding, their operation should be able to be questioned under this Act.
Power of the Chief Executive

Sanctions for non-compliance with the Act

“The DSA needs to be strengthened to enable its assertions to become requirements.”

“Support the legislation with strong and appropriate regulations, so that policy may be reviewed continuously and revised in the light of experience.”

Grace is a young girl who is unable to speak, but an electronic speech facilitator will open up her world dramatically. This equipment will enable her to communicate her own needs, to develop written language, to form conversational relationships and to attend her regular school. This equipment costs $14,000. Her family was able to obtain a $3,000 subsidy from the government, but had to get the rest of the money through fund raising and a great deal of family sacrifice. As some of the money was contributed by government, the equipment is seen to belong to the government, despite the fact that the family contributed most of the cost.

There was strong support for sanctions against services that do not conform to the Act. The current inclusion of defunding was seen to be an inadequate response.

Participants were of the firm view that the Act must “have teeth” and be enforceable in order to make real and positive change in the lives of people with disability and in order to create a coherent, quality service system.

A number of options for sanctions were raised by participants in different forums, including fines, demerit points, transition plans and processes, and defunding.

Transition processes for services to comply with the Act need to be built in, is similar ways to the original Commonwealth Disability Services Act (1986) in such a way that clear expectations are provided and enforced.

People raised a number of concerns about defunding services with this seen as a last resort when other transition processes or sanctions had failed. They are clear that, if defunding does happen, people with disability are not further harmed by the loss of service and that proper process are put in place so that their needs are met.
It is important that there are differing responses to different sorts of breaches of the Act, according to how severely the breach impacts on the lives of the people who use the service. For example, services that have limited policy and procedures, but which are audited and found to be providing a good quality service to clients may be subject to a requirement to develop policy within a certain period of time and may be provided with resources to assist them to do so. A service which is found to have failed to act on reports of abuse of clients, however, must be subject to severe sanctions.

Specific sanctions must address specific breaches of standards. For example, if the breach relates to poor financial management of an organisation, several options would be considered. Again these would depend on the seriousness of the offence, with the response ranging from having support for the board of management to get their act together, to a requirement for the board to be replaced which would be imposed on the service.

The possible sanction of issuing fines for non compliance was raised. This option is supported by a number of people. One model proposed is similar to that of the fire safety framework which is being implemented in respite services (among others) which are classified as budget accommodation services. This is dealt with in the Building and other Legislation Amendment Act (2002), where a system of penalty points are referred to for breaches of specific conditions, to a maximum number of penalty points for each breach. Another example raised was the penalty system within the Workplace Health and Safety Legislation.

In some instances, small service providers indicated they would struggle to comply with the Act, due to a lack of resources. While these services may be providing high quality support to people with disability, the lack of staff or infrastructure may result in their being at risk of non compliance.
A concern raised about fines is that small services, if not given support to have documented policy and infrastructure, would have very limited capacity to pay fines due to the low percentage of their budget which goes to administration and operating overheads. It would be unlikely, according to several participants, that such services could sustain a system of fines without their viability being called into question over fairly small breaches.

> "Often service departments and organisations become bogged down in red tape and lose sight of the task they were originally set up to perform. To reach a peak, working for people with a disability, one doesn't want to be snowed under by huge avalanches of paper work, however this always seems to come with the territory and is I believe the biggest drawback to those who are trying to provide quality services to those in dire need." 

It is important that the Act recognise the limitations placed upon different sizes of service and service types, incorporate a transition period, and make resources available for those organisations which require assistance in order to meet minimum requirements.

The issue of transition was also raised in relation to positive change, including the importance of the devolution of large, congregate services to smaller, local, personalised ones. Transition plans guided by the intent of the Act may require extra funding but clear specification of the expectations should be made so that the extra funding does not just provide more of the same.

People felt that the evaluation of services needs to be external, strong and enforceable, and linked to sanctions. Systems need to be in place to avoid the process being dependent on the integrity of the individuals involved in the evaluation process. The complaints system of an Ombudsman or similar should be also linked to this.
Some ideas were put forward about the importance of positive sanctions and acknowledging, rewarding and sharing good practice, creativity and leadership.

“There also needs to be a range of encouragements and incentives for service innovation and good practice and these need to be celebrated and shared with others.”

Recommendation 37.
That the Act contain a range of sanctions for non compliance. Such sanctions must be consistent responses to particular breaches, rather than the imposition of a blanket solution such as defunding. Breaches of the Act which result in harm or negative outcomes to people who use services should attract severe sanctions.

Recommendation 38.
That good practice, creativity and leadership are publicly acknowledged and shared.
# Description of the Engagement Project

Facilitating the input of people with disability and those who support them in the review of the Disability Services Act (1992)

The project was steered by a committee made up of people associated with several key network, advocacy and peak bodies who have come together at significant points during the process.

The consultants met individually with several members of the steering group as well as two pilot groups comprising 14 people who were identified as having longevity, commitment to people with disability and a keen interest in the reform of the legislation. This process gave insight into the previous consultation about the Act and aided the development of this engagement process. They also gave direction to the development of a short discussion paper to be sent out with invitations, and identified the content of the guidelines for an engagement strategy which was presented to Disability Services Queensland.

People living in five diverse communities across Queensland were invited to be part of the process, as detailed below. In each area, a small, targeted focus group was run which included specifically invited people who have long standing or strategic involvement in the lives of people with disability. Additionally, a more widely promoted public meeting was held in each area. This meeting aimed to draw a wider representation of people with divergent experiences and interests.

To make the consultative process as inclusive as possible, a minimum of three individual interviews were held in each area. These interviews were with or about people with high and/or complex support needs. The experiences of these people are used within this report to highlight and illustrate the principles and concepts raised in the other information gathering sessions.

### Methodology

| Direction and development of the project and discussion paper |
| Selected people, open meetings and individual discussions about life |
| A Steering Committee |
Participants in the process were actively supported to attend through coverage of travel costs where required, the provision of support workers, interpreters, computer aided real time transcription, information in alternative formats and flexibility of approach in gathering information, and through payment for their participation in the case of people who were participating in an unpaid capacity.

Attempts were made to personalise the process especially with the focus groups, by individual invitation and connection, linking via people’s known networks and sending thanks to people. All participants had the opportunity to see and comment on what has been written in this report, prior to its final form.

<table>
<thead>
<tr>
<th>Community</th>
<th>Focus group</th>
<th>Public meeting</th>
<th>Individual interviews</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brisbane</td>
<td>26</td>
<td>9</td>
<td>9</td>
<td>43</td>
</tr>
<tr>
<td>Cairns</td>
<td>13</td>
<td>25</td>
<td>3</td>
<td>41</td>
</tr>
<tr>
<td>Mount Isa</td>
<td>14 (combined)</td>
<td>7</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>Roma</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Mackay</td>
<td>8</td>
<td>5</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>65</strong></td>
<td><strong>47</strong></td>
<td><strong>27</strong></td>
<td><strong>139</strong></td>
</tr>
</tbody>
</table>

Note:
- The total for Brisbane includes the two small pilot focus groups
- On local advice, only one meeting was held in Mount Isa, and extra interviews were conducted in this community instead.

The review process has involved the participation and contribution of 139 people through a combination of focus groups, small public meetings and individual interviews. As can be seen in the tables below, a substantial proportion of participants were people with disability, family members who supported people with disability, and advocates.
A thorough cross section of the community is represented in the breakdown of the types of disability participants had, and there was an effective representation of both men and women. Representation from indigenous Australians was a little lower than expected, and representation from people from culturally and linguistically diverse backgrounds was significantly lower than expected, despite considerable effort being put into engaging with people in both of these areas.

<table>
<thead>
<tr>
<th>Gender:</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal and Torres Strait Islander</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Cultural and Linguistically Diverse Background</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with Disability</td>
<td>54</td>
</tr>
<tr>
<td>Family members</td>
<td>58</td>
</tr>
<tr>
<td>Advocates</td>
<td>46</td>
</tr>
<tr>
<td>Service Providers</td>
<td>27</td>
</tr>
<tr>
<td>Key organisations</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
</tr>
</tbody>
</table>

Note:

- A significant number of participants fulfil more than one role. Where this is the case, each role has been noted in the table above.
- *People with Disability* refers to people who identified themselves as such to the researchers. There may be several people within the cohort who have a disability but who did not discuss this with us.
- *Families* refers to parents and siblings.
- *Advocates* refers to people who are formally engaged with advocacy organisations as either paid workers or management committee members.
- *Service Providers* refers to people who are engaged in direct service provision to people with disability.
- *Other* includes resource groups, networks, state and regional Disability Councils and local Councils.
Diversity of participants with disability

<table>
<thead>
<tr>
<th>Disability type</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>29</td>
</tr>
<tr>
<td>Cognitive</td>
<td>12</td>
</tr>
<tr>
<td>Communication</td>
<td>8</td>
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<tr>
<td>Sensory</td>
<td>10</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>12</td>
</tr>
</tbody>
</table>

Note:
- A significant proportion of participants have more than one impairment. Where this is the case, each type of impairment is counted, resulting in a large total figure than the number of participants.
- *Cognitive disability* includes people with intellectual disability, acquired brain injury and learning difficulty
- *Sensory disability* includes people with vision impairment, people who are blind, and people with hearing impairment
- *Psychiatric disability* does not distinguish between people with mental illness and people with psychiatric disability

Thanks must be extended to the many people who gave generously of their time, expertise and energy in contributing to this process. It is hoped that this document accurately reflects the wealth of information, wisdom and experience which was shared with us.

Sally Robinson and Jan Dyke.