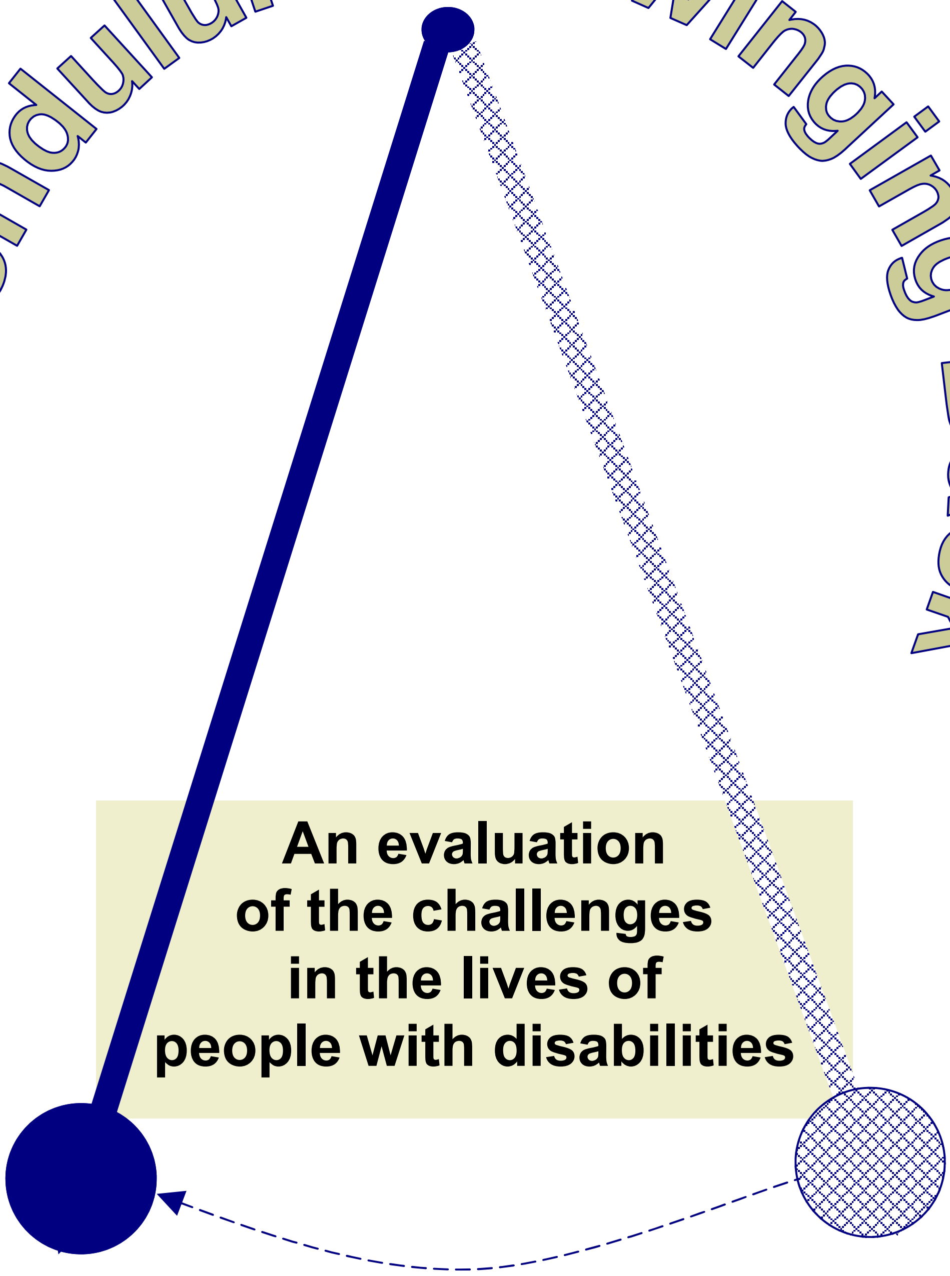
Queensland Parents for People with a Disability

The Pendulum Is Swinging Back



An evaluation of the challenges in the lives of people with disabilities

Group Placement, Vacancy Management,
Congregation, Isolation, Control, Abuse,
Services supporting quality assured
devalued and wasted lives

Personalised Approaches, Flexibility,
Participation, Contribution, Innovation,
Services supporting a good life
in one's home and in community

February 2005

Queensland Parents for People with a Disability vigorously defends justice and rights of people with disabilities by exposing exclusionary practices, speaking out against injustices and promoting people with disabilities as respected, valued and participating members of society.

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QPPD acknowledges the wisdom and support of all the people who attended this gathering and extends thanks for their participation and valuable contributions.
This report was facilitated and written by Jan Dyke.

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SUMMARY OF THE KEY CHALLENGES

On the basis of the evaluation of the losses and gains that have been identified in relation to the lives of people with disabilities, the following challenges are put to the Queensland Government, Disability Services Queensland and the disability sector as a whole. We ask that these challenges become the focal points for discussion, debate and action during the remainder of the State Government's term of office and that mechanisms are put in place to address the issues raised.

KEY CHALLENGE 1.

Even though people with disabilities and their families are not likely to have enough funding to fulfil all their needs in the foreseeable future, the vision of community life and citizenship should not be undermined or compromised by ill thought through, quick fix economic solutions that re-establish our own form of apartheid for people with disabilities here in Queensland. This is the vision we are heading back towards, with some of the old congregated solutions being re-established, promoted, strengthened and condoned by current policy and practice.

Positive imagery and a personalised vision of a good and valued life need to be developed and strengthened so that people with disabilities can achieve positive futures as adults, included in family and other important relationships, at home, in the neighbourhood and in community life.

KEY CHALLENGE 2

The wisdom about local responses and solutions, and how to connect with one another does not lie with the bureaucracy, but rather it lies at the heart of community. Communities need to be supported to relate to and include people with disabilities and to find their own solutions about how they can participate and contribute to the rich fabric of community life. However to do this well, they need relevant, practical and timely information, strengthening and connections, and funding and support at the local level.

The building of the capacity of communities needs to be supported from within, with practical ways of connecting, strengthening and supporting people to respond and to meet the needs of people with disabilities.

KEY CHALLENGE 3

The core business of service provider agencies is to enable people with disabilities to get on with living their life, regardless of the nature of their disability. However the current service system operates in a range of different ways from provision of segregated institutional care to the provision of personalised supports at home and in community. Queensland's history and knowledge base dictates that energy and funding should not be put into the creation and maintenance of outmoded and inappropriate congregated supports and services that take people with disabilities out of life and heighten their vulnerability considerably. Instead, priority needs to be given to the creation and support of small personalised services that keep decisions close to the people they serve and act as a buffer from the requirements of bureaucracy, with investment in developing clarity about ways of supporting people with disabilities to live valued lifestyles as contributing members of their families, neighbourhoods and communities.

The focus of energy and funding needs to be on creating and maintaining personalised supports and services that enable a valued lifestyle and are built around a culture of right relationships, which keeps the decisions close to the people involved and embraces their authority to direct and influence their own lives.

KEY CHALLENGE 4

The constant changing of bureaucracy with the subsequent loss of history, vision, connections, knowledge and practical skills has meant the lead agency responsible for enabling good lives for Queenslanders with disability has not delivered. When this loss is coupled with tight bureaucratic control and little investment in people, the lives of people with disabilities become worse. Perhaps the most concerning result is how the system is reinventing itself. The same congregated options are being repackaged, just with different language and spin, moving back towards a one size system fitting all. The images of our past are becoming the images of our future.

The work of bureaucracy needs to focus on investment in people, not only in complex tools and procedures, which means that vision, creativity, connections, knowledge and development need to be supported at all levels of the system, from people with disabilities and families, to communities, to service workers, to senior public servants.

HOW THIS DOCUMENT CAME ABOUT

Information came from people who have remained faithful to people with disabilities and to improving their lives over decades.

The information contained in this report came from a small gathering of people who have remained faithful to people with disabilities and committed to improving their lives over decades. During this time, they have taken on a wide range of leadership roles, some in different parts of the state, and have continued to speak out on behalf of people with disabilities about the issues that affect their lives.

Some participants have been involved or associated with QPPD for a very long time and were part of the development of earlier policy documents, such as *Quality Lifestyles* in 1988 and *A Bed in a House is not a Home* in 1992. These documents set out clear expectations about adult life from the perspective of people with disabilities and their families. Other participants were part of a group who came together in April 2001 to identify the challenges that presented in the new millennium, following the creation of Disability Services Queensland.

One outcome of the 2001 gathering was to name the concerning agendas and twenty challenges that were beginning to permeate and influence the lives of people with disabilities and their families. These concerns were publicised in QPPD's report, *Politics, Partnership and Personalised Responses*, which has helped to inform people of the broad systemic issues and to focus QPPD's agenda on behalf of adults with disabilities over the past few years.

They revisited the 20 challenges put forward in 2001

At this most recent gathering in February 2005, people met for two days to take stock of what is happening in the lives of people with disabilities. The first day, titled *Hindsight, Insight, and Foresight* forms the content of this report. The process allowed for an analysis of what we know from history, what this means for people and their families, and what key advocacy issues need to be driven forward on behalf of people with disabilities. As part of the process, participants began by revisiting the same twenty challenges that were identified in 2001 to analyse what has transpired in the last few years and to consider what had been gained and lost.

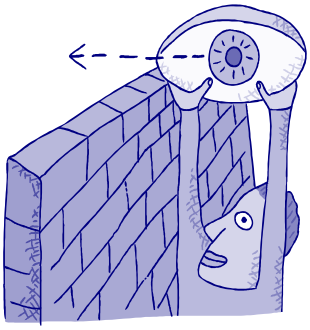
The gains and losses relating to the twenty challenges have been summarised into four key challenges in this document. Although some things may be moving forward for a few, the consensus was that many gains are being lost, as the political momentum swings back towards outmoded and dangerous models of care and control.

Sadly, as identified by all, the pendulum is swinging backwards.

Key Challenge 1.

STRENGTHENING POSITIVE VISIONS AND PLANNING FOR ADULT LIFE WITH ADULTS WITH DISABILITIES AND THEIR FAMILIES

Strengthening Positive Visions and Planing—Why the challenge back then?



The areas of strengthening positive visions and planning for adult life were seen as a key challenge in 2001 because many people with disabilities, in the cold light of reality and in comparison with other citizens, did not have a good life. Often their and their family's original vision of adult life was displaced by what was on offer by a service, or alternatively, no supports were available, so that any hope and vision about anything different soon became too hard.

Although most people and their families were willing to look beyond what was offered, little support was available to plan to do so. Those who had tried, were often labelled as ungrateful or unrealistic, when all they wanted was to achieve a decent life.

The ordinary vision of having a good life is knocked out of people.

Strengthening Positive Visions and Planning—What has been gained?

Over the past few years, a few formal opportunities have been made available to support people with disabilities and their families to hold and work towards a positive vision for adult life. Although this has been on a very small scale, nevertheless it has created opportunity for those people to come together, to share information, and to embark upon or continue a journey towards having a good life with a secure future.

Some opportunities to strengthen a personalised vision are available on a small scale

Opportunities for some people to come together to rekindle their dreams and to strengthen their vision for life have continued to be available through the work of the Community Resource Unit, Queenslanders with Disability Network, Queensland Parents for People with a Disability and Parent to Parent, as well as some other grass roots based groups. This important function is also encouraged by some services such as Mamre, as well as by some Local Area Coordinators (LACs) and small personalised support services that do this as part of their routine work with each person and their family.

New funding has allowed a number of very small family driven responses that have encouraged families to consider what the present and the future could look like for and with their family member. Small projects such as Pave the Way, Pathways to Possibilities, Positive Futures and the Homes West Experience have created much wider ripples of interest and the call for more opportunity for people to think and plan outside their formal service systems.

A small amount of non recurrent funding has rekindled creativity and new ideas.

Interestingly these approaches are considered innovative with several being funded by small non-recurrent Innovative Funding grants. This implies that the roles of strengthening positive visions and planning for ordinary life are not seen as a regular features of support, worthy of recurrent funding and external to the dominant service system. However the success of these projects should prove otherwise.

The heightened interest in planning for the future has been fuelled by the stark realisation that many people are unlikely to attain any funding in the long term, or they have had their expectations of service fidelity torn to shreds by some service providers closing their doors. Therefore they are desperately seeking alternatives. Others are growing older and are aware that few supports and safeguards are in place for when they die, leaving their son or daughter in a very vulnerable position.

The reality is that the future is not secure.

Also, many young adults who have grown up included in their families and local schools and neighbourhoods are now expecting to have a regular adult life. Their vision of life is very ordinary—a home of one’s own and involvement in community life with a range of relationships, from known acquaintances, to friendships, to intimacy. They do not want to remain forever as an add-on to their parents’ life or to have to be placed in a vacant bed in some group facility when living in their parental home is no longer an option.

Personalised alternatives have been embraced with relationships at their heart.

This interest has led to local creative responses by some people and their families that break the stereotype of an unfulfilled adult life. As a result a range of personalised living alternatives including share housing, flatmates, attached units, adopted families and cooperatives are now being embraced. These have relationships at their heart rather than merely shelter. There has also been increased effort to foster ordinary relationships in the lives of people with disabilities, some of whom are choosing to live alone.

These situations have created interest and investment in broader community based solutions, with consideration being given to ways that a positive future can be guaranteed by bringing in extended family members and committed others into the lives of people with disabilities to safeguard the positive vision for adult life. Some families are considering how support networks or circles can be created, as well as establishing safeguards through wills and trusts to continue the positive vision and future for the life of a family member with disability following the death of parents.

Such responses can assist a person to remain as a valued community member, often in their own home and in community life. Other examples of bringing ordinary citizens into the lives of people with disabilities have been in a small area of work around people with a psychiatric disability the creation of a new Citizen Advocacy Agency in Brisbane.

Relationships with people without disability have proved to be potent safeguards.

Strengthening Positive Visions and Planning—What has been lost?

The general consensus of the gathering was that, despite the gains for some people, the vision of a congregated life is alive and well and has slipped back to being the dominant solution for supporting the lives of people with disabilities. This is despite the intent of the Commonwealth and Queensland Disability Services Acts and all the individualised rhetoric to the contrary, put out by the current government and many service providers.

The vision of a congregated life has slipped back to being the dominant solution for supporting people with disabilities.

Support for the great majority of people with disabilities has returned to being conceived as moving out of ordinary life into a service based alternative, where workers take control and where the important relationships with family, friends and community are left behind. The bricks and mortar facility is once again the dominant focus point and place of support, with centre based respite, group housing, day services, hostels and nursing homes all clearly back on the agenda and establishing a very different, lonely culture away from the typical relationships of ordinary life. These options are put forward to people with disabilities and families as a choice, when in reality, so few real alternatives to this same dominant model are available.

There is no choice when only more of the same flawed model is on offer.

Money is promoted as the solution to having a good life

The change in Disability Services Queensland's funding program has also resulted in funding packages being promoted as the solution to getting a good life and to accessing services. This means that in order to be eligible for support, families have to compromise all positive imagery and expectations, as they are encouraged to portray sons and daughters in the worst possible light, as tragedies and burdens to their lives. They, as well as people with disabilities, are expected to beg and paint the most negative pictures of themselves, as being inadequate, desperate or non-coping in order to be considered for any type of support or funding. This process can best be described as humiliating and cruel.

The major individual funding arrangements, now the essential mechanism for gaining access to any supports, have become 'extreme crisis' based with few mechanisms of attaining any support unless people fall further into degradation and highest vulnerability and lay their private life open in great detail. Families are being pitted against family, and person against person, as they attempt to prove that they are more needy than anyone else. Some have even taken to extreme and dangerous action in order to have their plights recognised.

Such a response is not surprising given that people with disabilities and families have so few opportunities to gain any support to build a positive vision about adult life or to be assisted along the way with strategies or supports, even when the going gets extremely tough. Many have difficulty in knowing where to start and, as their situation gets worse, they have little capacity, creativity or energy to step back and to rethink about what a positive life could look like.

Money may only buy a vacant bed.

Attaining the magic funding package, in reality, may often only buy a vacancy in an existing group based service, one that is highly unlikely to 'fit' with the person's needs or their positive vision for life. Yet, when an inappropriate option is offered, especially when extreme crisis has been reached, who would want to turn an offer down? Something, after all, has to be better than nothing. Yet the option on offer may not be in the best interest of the person with a disability and can be quite unacceptable by ordinary community standards. In these ways the vision of a positive future is constantly compromised and driven out of the realms of possibility for many people with disabilities and members of their family.

When it comes to the crunch, something is seen as better than nothing, even when it is highly inappropriate.

The segregated track can be firmly set for life from infancy.

In many instances the negative, special burden role is now being reinforced in babyhood, with families captured by the system early, so that any vision and expectations are firmly set on a segregated track for life. This raises vulnerability and increases the cost of support considerably over the long term. In this way the person may never be appreciated in their family, nor are their gifts and competencies sought. They are also never known in their own local community, making informal connections and relationship building nigh on impossible.

Also the segregated track can congregate families together via their connection with a service which is providing an alternative life for the person elsewhere. This may mean that they share similar experiences and frustrations with a service they have complaints about. However, any threat to the service's sustainability will bring them together in support of a system that few really want, yet to lose it would mean that their son or daughter is left back on their door step without any other viable alternatives on offer.

Planning is often confused with assessment and placement.

The notion of planning is also being confused with assessment and placement. Planning should not be service-bound, but rather be done in the context of an ordinary life with the planning for the service component being only one part of life, albeit often an important one. Much of the work that is now happening with service providers is to ascertain whether or not a person will fit into what they have on offer. If they do not, the person is either refused service or they are expected to fit into a vacancy and take what the service says it can provide.

Old terms such as vacancy coordination, placement and service viability have reappeared in departmental vocabulary after being discarded over two decades ago. These negative concepts form the basis of the illuminating vision being promoted in the current *Have Your Say* document put out by government, with the expectation of a positive reaction by people with disabilities and their families.

When funding is not forthcoming, greater reliance falls to other parts of the system, especially health and aged care services. Some Aged Care Assessment Teams (ACAT) have no qualms suggesting that a vision for the future of a young person with a disability is in a congregated facility, together with older people. In this way, Home and Community Care (HACC) services such as day respite centres, as well as residential care in private hostels and nursing homes get put forward as acceptable ways for young adults to live.

Other systems are picking up the slack and offering inappropriate solutions.

Seeding grants and pilot projects are no longer on the funding menu.

Small amounts of money as seeding grants or pilots have not been forthcoming over the last decade. This has seen the capacity of people with disabilities and families to connect with one another and to share ideas reduced significantly. Families in regional areas can be further disadvantaged because they do not have mechanisms to connect to hear about or trial new ideas in country towns or in rural or remote areas. This has meant that positive visions of life have not been able to be shared easily, nor have many new supportive small grass roots services been developed with the ethos of personalising supports.

Another backward step has been that the collective dissenting voices of people with disabilities and their families have been pushed from centre stage dialogue with government. In their place are political appointments and other content free decision makers who have little understanding of the realities of life with a disability, yet they set the vision and agenda of how people's lives will be directed and played out.

Whilst some previous Ministers and bureaucrats have given support to the vision of community living and the move towards individualised supports, the current establishment now appears to have turned back the clock to reinvent the vision of congregated housing and 'innovative' lock down centres as the state of the art here in Queensland. When we consider all the heartache, abuse, energy and money these systems have expended in the past, why would a Smart State even be considering redeveloping these dinosaurs when there are far better and more humane ways of supporting people?

Restating the key challenge

Even though people with disabilities and their families are not likely to have enough funding to fulfil all their needs in the foreseeable future, the vision of community life and citizenship should not be undermined or compromised by ill thought through, quick fix economic solutions that re-establish our own form of apartheid for people with disabilities here in Queensland. This is the vision we are heading back towards, with some of the old congregated solutions being re-established, promoted, strengthened and condoned by current policy and practice.

Positive imagery and a personalised vision of a good and valued life need to be developed and strengthened so that people with disabilities can achieve positive futures as adults, included in family and other important relationships, at home, in the neighbourhood and in community life.

Key Challenge 2.

BUILDING THE CAPACITY OF LOCAL COMMUNITIES TO BE MORE RESPONSIVE TO THE NEEDS OF PEOPLE WITH DISABILITIES

Building the Capacity of Local Communities—Why the challenge back then?

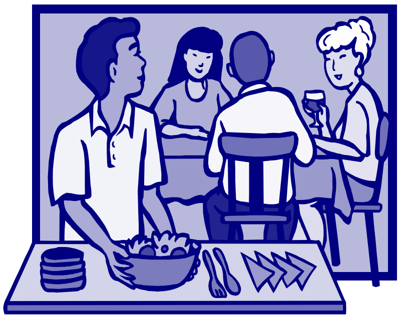
The area of community capacity building was seen as a key challenge in 2001 because the lives of people with disabilities were often played out well away from the lives of the rest of the community. The great majority of adults who still lived with family members were usually included in their lives, but they rarely had the opportunity to participate with their own age group or to contribute their own gifts and talents to a wider social group, and nor did families have opportunities to be involved in life without them.

Although other adults with disabilities might have moved out of their parental home, the majority were congregated together in a serviced house in a suburban street, where they were usually not known and were not part of what was happening in their local neighbourhood. Despite their being seen out and about together in a group, any relationships were distant and they had few opportunities to get to know others or to contribute to their local community in a valued way. Such marginalisation only reinforced the stereotype of people with disabilities being better off with their 'own kind', rather than challenging this assumption and reframing for community that their own kind is, in fact, all of us.

The stereotype of them and us is reinforced in daily life

Building the Capacity of Local Communities—What has been gained?

Some people have managed to live rich and meaningful lives connected with and contributing to the ordinary life of their community. These lifestyles have often developed following earlier inclusion as students in regular schools and/or later having opportunity to connect with others in creative community pursuits or work. This has been more likely to happen when people have had less significant disabilities and has often been driven by families who have sought and encouraged opportunities. However, it is important to recognise that many people have remained included in aspects of life by being supported to continue to play a valued role in their family, if not in their wider community.



Some families have shown tremendous tenacity and courage personally to ensure that their family member remains included

People with more complex needs have continued to have fewer opportunities to be part of wider life, as connections and ongoing relationships require much greater intent and support. Yet despite this, some very positive examples of the intentional involvement of community have taken place. In order for this to happen, some people with disabilities and their families have shown tremendous tenacity and courage, with people doing all they can personally to ensure that the person remains in community and as part of it.

For some people with disabilities, this happened by families drawing people in around them, or by workers staying on in the life of a person with a disability in a freely given relationship after they have completed paid employment with them. For others, connections have happened personally where people have been drawn in as part of an intentional circle of friends or a support network.

Some good examples of ordinary citizens being involved in the lives of people with disabilities have happened with the creativity of families and workers in small personalised services. They have found that when encouraged and supported, some communities have had the capacity to come up with solutions and to be responsive to the needs of people with disabilities.

Some wonderful outcomes have happened when the person becomes known well, is appreciated for who they are and what they contribute, so that genuine relationships have developed over time. Where success has been achieved, ordinary citizen involvement and understanding has been supported and intentional strategies have been used to enable further connections into people's lives where they have been nurtured, strengthened and also renewed.

People continue to share good stories, experiences and strategies

Although building the capacity of community has not been high on recent political or funding agendas, some development and maintenance of interest in the area has continued informally. This has happened through the sharing of stories, experiences and strategies via the networks of people who continue to do this, as well as through the support of training and leadership by community based groups such as Community Resource Unit, Values in Action and some family or people with disabilities based groups.

Some great examples of community capacity building have happened through the routine work of a few well connected Local Area Coordinators and service workers who know their local community well and find creative ways of connecting people. These workers have developed skill in harnessing local responses and inviting ordinary citizens into a person's life. Citizen Advocacy Programs also have done this in a very particular way, as have some individual advocates who have managed to turn life around for a person who has been very vulnerable and totally isolated.

For people involved in these efforts, this has been a wonderful and rewarding experience. These examples demonstrate that energy and creativity continue to bubble under the radar and that the skills, friendship and decency of ordinary people can be tapped, nurtured and strengthened, although it is clear that such wisdom is not being supported and used more widely.

The friendship and decency of ordinary people can be tapped, nurtured and strengthened

Building the Capacity of Local Communities—What has been lost?

Many people with disabilities have continued their life's journey on a segregated track, where they have not only lost connections with ordinary life, but also have often lost connections with their family and their families' links with the wider community. This is particularly so when people with disabilities have been placed into residential care situations where they are congregated together on the basis of their disability.

Although many of the forms of group living are said to be in community, they are not really part of community, as life is not played out much in typical ways in the public gaze. When people do connect with other citizens they do so in groups which immediately highlights their difference and separation. Groups also attend stereotyped places and activities where they can be managed by one worker. Usually in these places there is little real connection with anyone else.

Although the numbers of workers supporting people in community life has increased, many tend to have very little understanding or skill in how to go about connecting people. The mechanism of 'community tourism' is rampant where people with disabilities are bussed around in the name of community access, but never really make any connection with anyone else. In this way, the stereotyping of people with disabilities is reinforced by the imagery these services project in public with the people they support.

Groups may live in community but are not part of community

Inclusion is now being seen as innovative and the exception rather than as the rule. It is also being misinterpreted as groups of people just being there, rather than individuals participating and contributing to the rich fabric of community life. Many workers have no theoretical framework and very little opportunity to connect with community members in ways that people with disabilities ever get known or appreciated. Even with some individualised arrangements, workers remain velcroed to the person's side and become the conduit for any conversation and community activity, instead of supporting the person and other community members to become connected by looking for ways that regular contact can be made, or where the person's contributions can be given and appreciated.

Some workers remain velcroed to the person's side

Good workers are having more difficulty now too, and for many it has become too hard. Some staff can't use their own cars, can't travel on public transport, can't help to lift a person into someone else's car, yet their role is community access. More and more, rules are being used to justify why people need to be grouped and why ordinary citizens cannot be involved in their lives. When natural links are attempted, they are often rejected. There is no ability to be spontaneous or to follow up on invitations, or to take advantage of natural connections, because workers get caught in the red tape and risk factors associated with duty of care, blue card checks, workplace health and safety and shift changes, so the opportunity and the connections are immediately lost.

Absence of meaningful relationships with people with significant disability are becoming even harder with proposed centralised funding solutions and decision making about how people with higher support needs will be able to live their lives. Disability Services Queensland systems are returning to heavy promotion of the 'special' label and the need to group these people together for specialist care and economic reasons. This continues to support the myth that people with severe disabilities are too disabled and cannot be included, nor can they be expected to offer anything in a relationship with a person without a disability.

In these ways people with disabilities have their citizenship denied and instead, it is interpreted as being as a consumer of specialised services, not as a person who, like any other, needs a range of relationships with people who are not paid to be in their life. In line with this thinking, investment is in grouped services, not at the community end where it is most needed.

Investment is with grouped services not with life at the community end

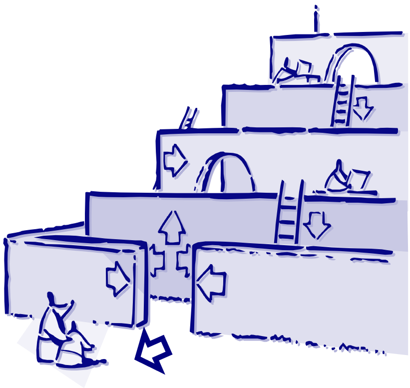
Few mechanisms therefore exist to educate communities about the value of people with disabilities and their individual contribution as citizens to the richness and diversity of community life. There is little effort to build their capacity to be more responsive especially when the focus of funding is on neediness and superficial congratulatory activity, such as can happen in Disability Action Week. When funding is not available, few opportunities exist for small amounts of money to be used flexibly and those that are available are being tightened to fit more rigid government and service requirements.

The whole idea of development and support of grass roots initiatives has also disappeared. Without recognition and support of local leadership of people with disabilities, families, workers and local community members, identification and support of new leadership for the next generation has not been happening.

Top down approaches have limited mechanisms for grass roots involvement and creativity

This means that the next generation of people with disabilities and their families is heading towards an even leaner time, as the wisdom of local communities is being lost with little opportunity for people to connect, expand knowledge or take on new leadership roles. When there are few mechanisms, no seeding money, few ways to bring people together, no support to work things through, and no local development, the quality of life of people with disabilities in Queensland will reduce further.

Whereas input from all stakeholders was welcomed and encouraged at the time when Disability Services Queensland was first established, people with disabilities and families are now being expected to rubber stamp already decided government agendas and decisions. This has been confirmed repeatedly in government consultations that have been used to elicit ideas from communities. These have given rise to great hope, but have resulted in much heartache.

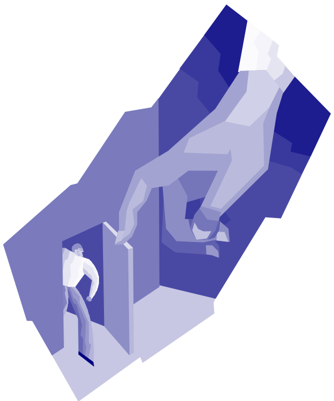


Top down approaches have also had effect on the role and functioning of the State and Regional Disability Councils. At their establishment, these councils were seen to be one of the many mechanisms that devolved the power downward and outward to local communities by establishing conduits for advice, discussion and debate. Although advice may be sought, there appears to be little interest in local responses so that some people feel that they have no influence, especially when many decisions have already been taken prior to approval being sought.

Current mechanisms of consultation and influence imply tokenism

A new assumption is that communities will have all the information they need by their members sitting at a computer and accessing the internet. Although this is a great source of knowledge, people have to be able to have the time, technology, skills and energy, as well as know what it is that they need to be looking for, how it is classified, how they find it and when it is available. Even so, much of the content is centralised and systemic information, with little that links into the practical knowledge that individuals or communities might need at a local level.

If all these issues are considered in the context of contemporary times, it is little wonder that very little positive activism about better lives for people with disabilities is being engaged in by communities. Many people are feeling quite disempowered and unable to influence ways that local communities can be more responsive to the needs of people with disabilities. People are far more likely to accept their lot in life when few opportunities are available for people to connect and learn from one another around values that relate to social justice and life at grass roots, or to share strategic ways to go about understanding the political system and influencing positive change.



Lack of community capacity building has led to the loss of Queensland's development as a civil society

With corporate models of leadership and achievement being dominant and rewarded, important connections between all the key stakeholders does not happen. This has divided the disability movement and has ensured that the connection between the disability sector and other social movements has been severed. This is not only a loss to people with disabilities and their families, but also to social justice and Queensland's continuing development as a civil society.

Restating the key challenge

The wisdom about local responses and solutions and how to connect with one another does not lie with the bureaucracy, but rather it lies at the heart of community. Communities need to be supported to relate to and include people with disabilities and to find their own solutions about how they can participate and contribute to the rich fabric of community life. However to do this well, they need relevant, practical and timely information, strengthening and connections, and funding and support at the local level.

The building of the capacity of communities needs to be supported from within, with practical ways of connecting, strengthening and supporting people to respond and to meet the needs of people with disabilities.

Key Challenge 3

PROVIDING PERSONALISED SUPPORTS WITH PEOPLE WITH DISABILITIES AND THEIR FAMILIES

Providing personalised supports—Why the challenge back then?

The provision of personalised supports in adult life was seen as a key challenge in 2001 because many services seemed to be losing the focus that their core business was to support people with disabilities to have a good life with similar standards and opportunities as other Queenslanders. These services were struggling to move away from their stereotyped grouped responses, where people were taken out of life to receive their support. In many instances the power to drive all life's agendas was vested in the one service. They not only provided support where the person lived and went during the day, but also often controlled a person's housing and whether or not they would be accepted or rejected as a client.

Any changes towards more personalised supports would require a very different approach. Service providers would need to understand that life needed to be supported where it happened, not away from regular life. They would need to embrace the authority of people with disabilities and/or their families to direct and influence their own lives and would acknowledge that people would need to be supported and enabled to do so in uniquely different ways. They would also need to recognise that their formal service role was only one part of life and that to be of good service meant decisions about how each person's life would be played out would be kept as close as possible to the person whose life was being supported.

Providing Personalised Supports—What has been gained?

Small pockets of personalised services that are governed by people with disabilities or by family members have been allowed to coexist with the traditional service system for many years. These small services have continued to work towards the deceptively simple aim of people with disabilities living valued lives comparable to those on offer to most other citizens. They have continued to do good work despite many obstacles, and have delivered in relation to people with disabilities having good lives.

These services have clarity about what is service business and what is personal and/ or family business

These small services tend to have a number of things in common, including having clarity about service governance and of the positive role that people with disabilities and families play, valuing their involvement and decision making in relation to the direction of supports in their lives. Their small size allows them to know all the people well and to be able to solve any issues quickly, because decisions are kept close to the people they serve with minimal organisational layers.

The connections of these small agencies and the personal networks of people with disabilities and family members have allowed the sharing of knowledge and experiences amongst one another. Recently, families who did not have personalised supports but who were interested in having better lives for their sons and daughters also had access to this knowledge through a small innovative funding grant allowing families to share the Homes West Experience.

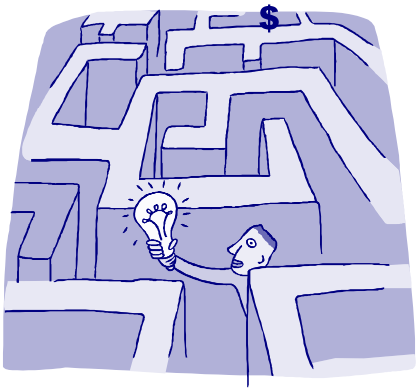
Because of the success of these small personalised services, two community based responses have been generated recently. One is to ensure that these services are safeguarded, so that the expectations and requirements of government and bureaucracy do not threaten their sustainability. The other is to develop a new service arrangement using a host agency, where all the positive aspects of the governance and practice of a personalised service are maintained, but without people with disabilities or their families having to be responsible for all the administrative, legal, employment or funding arrangements. The catalyst for this new approach was a number of people with disabilities with significant support needs who had individualised funding, yet despite this, could not get any personalised service or be supported well by the traditional service system.

The Disability Sector Training Fund has allowed for greater opportunity for people to develop better understanding and work skills with the opportunity to access knowledge and funds for training, not only for workers but also allowing people with disabilities and families to be involved.

Some services are prepared to have external evaluations and invite the scrutiny of others in how they go about their work. This too is happening in small pockets and is often dependent upon good values based leadership.

Good service is usually dependent upon good values based leadership

Providing Personalised Supports—What has been lost?



Many of the small, personalised services were developed in Queensland around a decade ago. Despite their proven record since then, little support has been given to their sustainability or to any new developments. The excitement and challenge, which people with disabilities and their families felt with the opportunities to create and influence those new ventures, have now gone. With few opportunities for people to get together and funding arrangements not supporting the development of new services, the leadership and creativity that was shown in getting these services up and running is no longer valued. People with disabilities and families are left to do it all alone.

Competition, resentment, confusion and lack of choice are fostered by the current system

Competition and resentment have been fostered by the current system, with those families or people with disabilities who have funding and those people who have struggled to develop good supports being seen as the lucky ones.

Confusion is rife between personalised services or supports, (supports provided *with* a person and/or their family, based on and fitting with their unique needs and aspirations for life) individualised services, (stereotyped or prescribed services provided on an individual basis) and individualised funding (money attached to an individual for meeting defined need). Whilst individualised funding has helped some people to obtain personalised supports, much of the money has been put into the traditional service system where people use their funding to buy congregated care. Again this is because there is no real choice. Little new personalised service development has been supported to happen.

In order for any funding to be given, a recognised service provider must be nominated. Because choice for personalised options has not been available without development money or supported infrastructure, people with disabilities or family members either have had to establish new incorporated bodies to provide personalised services or have had to set up a private company to take the funds. Although these set ups usually work very well for the people whose funds they hold, they require intensive work, as their governance requires people to develop, run and maintain the service, be the employer, fulfil legal, funding and insurance requirements and much more.

People have to set up, run and maintain their own services in order to get what they need

Currently Queensland has no alternative service models where people can have good personalised supports, yet be shielded from these onerous bureaucratic, administrative and legal responsibilities of running the service.

Many services see their core business as running a facility, not supporting a person to have a good life

So why are people with disabilities and families taking the drastic steps of setting up their own services? They do this because many of the traditional services have reverted to seeing themselves as running a facility, rather than supporting people to have a good life. They still operate with people having only what is on offer, where the person is expected to fit what they provide, along with others. This leads to people with disabilities having prescribed and regimented lives with the one approach fitting all.

Many people's homes and community based respite centres operate like small institutions with similar atypical and often abusive cultures and routines. Funding policy is supporting this more and more by promoting mechanisms for people to live together. Residents are expected to fit in with one another, otherwise they are not welcomed and are expected to find a vacancy where they can be placed elsewhere. Therefore ordinary community living is not an option.

Over the last few years, young people with disabilities have returned to total institutional life in greater numbers than ever before, only now they are living hidden in nursing homes, private hostels, boarding houses and congregated group homes. This reversal is happening with no recognition of the inappropriateness of such wasted lives, or the abusive history of such places. This trend is incomprehensible, given all the recent work of community and government over the last three decades in getting people out of such places. In the past, particular funding initiatives recognised the need for restorative justice for the people who had been sent away from community. This no longer exists.

Institutions are hidden and called euphemistic names like hostels and innovative housing

Other reversals are apparent with the building of centralised institutional responses such as the 'behavioural control unit', euphemistically called 'innovative housing' by the current government. Again this makes no sense when all the evidence is against such approaches. Trans-institutionalisation is also back in vogue with people moving out of one institutional facility, but into another congregated setting.

Many workers do not know how to support families or other important people who have a commitment to the person with a disability, when they live with family members or in grouped living situations. Paid workers often drive out family and other informal supports. They are made to feel not welcomed, there are no valued roles for them or the person with a disability to play, or they are turned away by sheer dismay of what they find when they visit. Staff describe their roles inappropriately as people's house parents or their friends and lack understanding of the importance of maintaining the relationships with the key people who care the most about the people they support.

For people who challenge the service, the situation becomes even more difficult. When families make suggestions about providing more appropriate personalised or responsive supports to meet their family member's needs they get labelled as difficult, rather than considering how the service can be more flexible and do a better job. It is even more rare that people with disabilities themselves are talked with about how they want to live their life. Usually things happen around them and to them rather than with them. In this way the roles that people with disabilities and family members play in directing what happens in life is devalued with workers taking an overly professional stance of knowing what is best.

The focus of support has become to fulfil the service's needs not to fulfil the person's needs

The new forms of deficit assessment and ranking do not help people with disabilities get the services they need, as people are being expected to fit into a service vacancy and to bring money in to prop up its viability. The prime concern becomes to fill the vacancy, no matter how inappropriate the service may be, how incompatible the people with disabilities are and how awful life becomes. This raises the question of why is the service there. Is the focus of support to fulfil the service's needs or to fulfil the person's needs?

No transition mechanisms exist to move to small personalised approaches

The vacancy coordination approach is now condoned as the new way forward, supported by notions of placement into a service. This is alien to people having a life which is supported in ways that suit their personal needs and aspirations. The intent of the principles and objectives of the legislation no longer drive these decisions. Also having transition processes and funding to enable these large services to devolve the power to smaller groupings and to move to more personalised and local approaches has been lost.

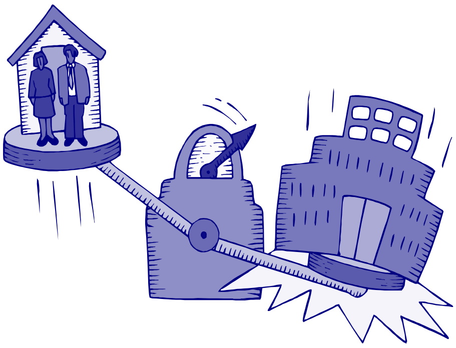
Now flexible dollars buy less support

Small organisations with poor base funding are also finding service provision more difficult as each year their flexible dollars buy less. Although services are given the Consumer Price Index increases, in real terms wages and other overheads are outstripping this meagre rise. These effects are compounded for services in rural and remote areas because of the time and distance to make personal connections and to provide support.

The increased requirement to do more administrative and paper work has also resulted in the hours of support to individuals being reduced in real terms. Poor base funding puts even greater stress on those services that are governed by people with disabilities or family members, who are also trying to deal with increased demands for paper work around the things that happen naturally in the way they provide supports.

Different funding mechanisms also exist, depending upon when the service or person was funded. This can be an administrative nightmare with different funding forms and with the percentage for administration being much less in earlier grants. This has lead to some services being seen as under threat or as being non-viable, especially when bureaucratic decisions and judgements rule quality criteria, and their requirements are not seen to be fulfilled.

Increased demands to account to bureaucracy are leaving some small services under threat



Because of little support of new small service development, the large organisations have grown by taking on individualised funding packages to become even greater monopolies, which operate and provide services in similar bureaucratic ways to the state. This growth in the size of old services in turn, has led to dollars not being left at grass roots level. Their growth has led to an increase in middle management in service structures as well as the development of a greater depth of hierarchies. Therefore service provision is more rigidly controlled with decisions being made further from people with disabilities and families, with little knowledge of the person or their situation because of the layers of decision making.

Concern has been raised about the loss of principled frameworks from which policy and service provision are suspended. These give clarity and understanding to guide ways that people with disabilities are supported and how their services are managed.

Good values and frameworks are not seen as important

These frameworks also apply to on the job training and support where there appears to be little promotion or internal support of what it means to be of good service. In many cases trained staff have learnt theory, but lack the practical know how to enable them to do the skilled work. Many have difficulty in translating planning into actions that lead towards achieving a good life. Some services go through the motions of doing the right things on paper, but when the practice is viewed from the perspective of people with disabilities and families, sometimes it is seen to get no further.

Workers find themselves in services where what they say they do and what they really do are very different

Many workers are well meaning and come with good ideas, but find their creativity is not valued or harnessed. They can be caught in a system that has little coherency between what they say they do and what they actually do. Their good intent is not developed or allowed to be played out, resulting in disillusionment and leaving their job, and often, leaving the sector. High staff turnover also means people with disabilities and families have to retell their stories constantly. Growth in the employment sector and lower unemployment now means it is harder to attract good staff with good values. Also poor pay in the sector can attract other needy people.

Support workers and coordinators with good vision and values also struggle with making the work on the ground coherent with their good intentions, and are often unable to come up with the goods. This leaves people with disabilities and family members demoralised because workers can talk the talk, but not walk the walk.

In general, staff training and development is given lower priority now that individualised funding has taken prominence. In the past the expectation was that a certain percentage of funding went to supporting staff development, but without proper infrastructure for services this has not happened easily, sometimes not at all.

Where staff development is on the agenda, little relationship seems to exist between staff development and competency development. Loss of support of networks for new workers and absence of informal learning and development has meant that new service leadership is not supported or mentored. This is in keeping with the loss of support of an active learning culture of reflective practice with many services not analysing or evaluating their work.

Many services do not encourage an active learning culture or reflective practice and evaluation of their work

Skills have no currency without good values

The current baseline expectation for workers is now being put forward as Certificate III in Disability Studies. Yet practice has shown that good values are the keys to people being supported well. Skills can be learnt, but without a good values base, skills have no coherency with what is required in the practice of supporting life. This is how most people with disabilities and family members make the decision when selecting workers. They agree that the most important criterion is to have good values about the people they are working with, and that workers can be taught the specific skills they need on the job in relation to the person they are supporting.

Governance boards of some service organisations now have more board members with little understanding or contact with the lives of people with disabilities. They focus on being a business, having lost touch with the people they serve. In addition they are also employing executive staff with technical or business skills, but without any framework of good values to guide their decision making. This content free management is also mirrored in government, so that little understanding is held by any key decision makers.

Many workers also lack depth of understanding about life with a disability and have never spent time with a person trying to listen and to understand what their life's journey has been like or what their daily life is like from their perspective. Managers are more likely now to have no knowledge of the people that the service supports They arrive in an organisation at a middle management level and direct staff to do things they have no understanding of, cannot do, or have never done themselves. In these situations poor managers have tremendous effect on the organisation as a whole and on the morale of all, and yet in many instances they are rewarded. Little investment is put into thinking and judgement. Instead the sector is now investing in a culture of rulers and followers.

The sector is now investing in a culture of rulers and followers

Over rigorous workplace health and safety, privacy and risk assessments have now taken over and stifled the flexibility of many work situations, with appalling consequences to the ordinariness of everyday life. Awards and union demands have also caused similar problems for some people, especially where life is divided and controlled by shift changes. These are now being used to justify why the most ordinary and reasonable things cannot be done, with many examples of rules being taken to utterly ridiculous conclusions.

Common sense is no longer used, with people's bodies and their private homes turned into industrial worksites

These originally helpful pieces of legislation have lead to over control by many managers and workers and have resulted in mantras of excuse for not doing ordinary things. Dignity of risk, once an important developmental principle, has left the agenda, as has working in good faith and using common sense. These are confused with safety of an individual and cotton wool versions of duty of care, and have been fuelled by the growth of fear of litigation leading to greater control over what happens in people's lives. People's bodies and their private homes have been defined as industrial worksites and in some instances families have been asked to sign indemnity forms to take away any rights of the person with a disability who is supported by a service.

Misuses are covering gross abuse and neglect

Now service is refused because of improper use of workplace health and safety, or privacy is used to hide poor service, or consumer choice is used to justify not having to deal with the moral dilemmas of working in the best interest of a very vulnerable person. These misuses are only covering gross abuse and neglect of people with disabilities.

Restating the key challenge

The core business of service provider agencies is to enable people with disabilities to get on with living their life, regardless of the nature of their disability. However the current service system operates in a range of different ways from provision of segregated institutional care to the provision of personalised supports at home and in community. Queensland's history and knowledge base dictates that energy and funding should not be put into the creation and maintenance of outmoded and inappropriate congregated supports and services that take people with disabilities out of life and heighten their vulnerability considerably.

Instead, priority needs to be given to the creation and support of small personalised services that keep decisions close to the people they serve and act as a buffer from the requirements of bureaucracies, with investment in developing clarity about ways of supporting people with disabilities to live valued lifestyles as contributing members of their families, neighbourhoods and communities.

The focus of energy and funding needs to be on creating and maintaining personalised supports and services that enable a valued lifestyle and are built around a culture of right relationships, which keeps the decisions close to the people involved and embraces their authority to direct and influence their own lives.

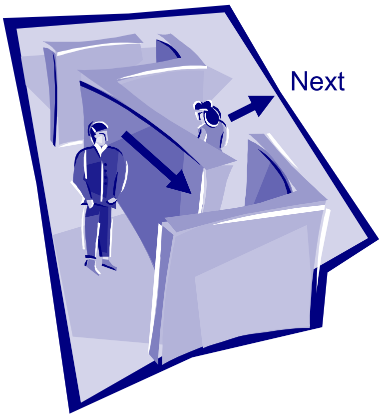
Key Challenge 4

INVESTING IN PEOPLE RATHER THAN IN COMPLEX BUREAUCRATIC TOOLS AND PROCEDURES

Investing in people not bureaucracy—Why the challenge back then?

The focus was on developing rules and on paper policies and procedures

The area of investing in people rather than in complex bureaucratic tools and procedures was seen as a key challenge in 2001 because technocratic business models were beginning to take over centre stage and influencing how government was operating with community. Instead of developing enabling relationships, the focus was on developing more rules, policies and procedures. This was having direct effect on disability services, limiting their flexibility and responsiveness. However, bureaucratic complexities also were beginning to permeate the lives of people with disabilities and their families adding to their already complex lives.



The new wave of top down political decision making, filtered via content free managers, was leading to gross incoherency between policy and practice and instead of supporting better lives, this was complicating lives even further. People involved in the top jobs in government never stayed long and with each new restructure the history of the predecessors was lost. New work happened in a vacuum and created its own understanding of what was required, based on the personal values of those involved. Unfortunately for many people with disabilities and their families, this was often not what they valued or required, nor did they know how to influence or go about getting what they needed, because the goal posts kept changing and the mechanisms became more and more complex.

Investing in people not bureaucracy—What has been gained?

Since 2001, the community has become much wiser about the government's use of rhetoric and how on paper rules, policies and procedures do not guarantee a decent life for people with disabilities, nor do they necessarily make people less vulnerable. Therefore they are not putting their trust in these tools and mechanisms as easily as they did when changes were first mooted.

Community is wise to the rhetoric as well as the fallibility of paper based policy and procedures

However despite the flawed processes, people with disabilities, families and service providers are required to follow these complex procedures in order to have recognition of what they require and what they do. Some good connection and work is happening at middle and lower levels of the public service where some workers are helping people with disabilities and families to understand and negotiate what is needed.

Some individuals who are willing to blur the lines in order to get good things happening in people's lives are hungry for support of their actions and viewpoints from their managers, because they are being of good public service and doing the right thing by people, and yet are not working outside government policy. These workers are enabling and doing everything they can to make things work for people, not using every rule and procedure to justify why things cannot be done. Good outcomes can and do happen when a worker is creative and is prepared to find ways to work with a person with a disability or a family, rather than putting their allegiance with the system.

Good workers are servants of the public with an allegiance to the people they serve rather than to bureaucratic red tape

Some really important breakthroughs have happened in people's lives when people with disabilities or families have had flexible use of direct payment and discretionary funding which has been available in the more creative options such as Local Area Coordination, Family Support and Project 300. This has also happened with some individualised funding particularly when money has been held by those small agencies with flexible responsive approaches.

Investing in people not bureaucracy—What has been lost?

The constantly growing and shifting bureaucracy continues to make connection and relationships with decision makers extremely difficult, not only for people with disabilities and their families but also for service providers. Workers in Disability Services Queensland and other government departments constantly move on to improve their status and career, leaving behind people in acting positions or new workers who often have limited knowledge and understanding of their role, the policies that govern their work and with whom they are working. Most workers have no connection with the real life of the people they serve and do not get to understand the impact that their changes make, nor of the impact of the decisions they do and don't make.

Constant movement and restructuring makes relationships and understanding difficult

People with disabilities and family members have difficulty in forming relationships with key bureaucrats at all levels of the department because of this constant movement and the expectation of having to tell ones story and bare one's soul over and over with each new person. When people do have good workers in their lives, they are not encouraged to stay on, nor is their work acknowledged or rewarded.

Constant changes also mean the loss of corporate history with workers having difficulty interpreting what has happened prior to their arrival. They are constantly changing what they can and can't do, and are unclear about what they can or can't tell people with disabilities or families. This lack of clarity is also mirrored in not knowing where policy and procedures are heading. Workers say they feel they cannot discuss anything because of the imposed culture of a ruled regime. This has led to loss of courtesy of front line people who don't answer phones and don't call back, or don't know, but don't find out.

There is also loss of understanding as to why Disability Services Queensland was established as a stand alone department. At that time, positive development of the sector was needed because of the poor history, funding and support to people with disabilities by successive Queensland governments in the past. The creation of the department was in recognition of the need for positive discrimination and restorative justice for the many neglected people whose lives had been congregated, isolated or wasted. Apart from getting an injection of funding, these ideals have not been driven forward with the sector or in the lives of people with disabilities in the spirit of the Disability Services Act.

Disability Services Queensland was established because of the recognised need for positive discrimination and restorative justice

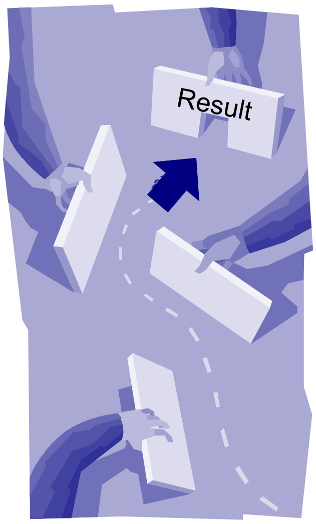
The current Minister seems to be paying little attention to the intent of the principles and objectives of this Act which governs his and others' decision making. Unfortunately, the language of community is being used now by government to promote its ventures, but many actions are contrary to the values of the legislation and the spirit of cooperation. The positive attempts of collaboration in the early part of the development of the new department have now slipped back into political expediency and greater systemic inflexibility. The sector is being blamed for this being labelled as 'divided'. This is to be expected when the option of congregation is the only one supported for people with disabilities with complex support needs. For them, there is little movement forward or support of ordinary life, yet the current system appears to have difficulty in understanding this reality. There is no choice.

Work is now driven by reactive crisis management to avert political fallout

A lack of corporate planning is evident, as well as an absence of understanding and detail as to how positive agendas can be moved forward in a non-regimented way. Departmental program areas now seems to be driven by reactive agendas, as well as reactive crisis management to avert any political agitation or disgrace.

Despite this Disability Services Queensland presumes it knows the answers to what makes a good life and the best ways to achieve it. The thoughts and ideas of people with disabilities continue to be devalued as do those of their families, if they are saying anything against what is currently on offer. With most of the government advisory processes, the decisions appear to have been made before the advice is sought, with the expectation that the community will condone such processes and rubber stamp the bureaucratic thinking.

Attempts at community consultation have been poorly done with the language of the bureaucracy being beyond the scope of average people. Content and processes also predetermine the anticipated outcomes. When information is put forward from people with disabilities and families, it does not appear to be used and is not released to a wider sector audience. The funding reform has not produced major changes as suggested by community and nor has the Disability Services Act review. In the current consultation *Have Your Say*, little has been done to redress the issues raised continually in early reviews. Although bureaucrats do lots of nodding, many people with disabilities and families feel patronised because their concerns are not heard or understood, let alone acted upon. This lip service smacks of tokenism with no intent to follow up with action.



Good internal departmental work does not appear to be valued either with few opportunities for creative thinking or action. Instead, workers' efforts are channelled into the production of technocratic processes assessments, agreements, forms, models and papers. These workers have to learn to fly below the radar in support of people with disabilities and their families, but are lost to the sector when they become disillusioned with their inability to influence positive outcomes.

An over-reliance on paperwork has surfaced

Over the last few years the over-reliance on paperwork has surfaced with this now being the major mechanism for funding and evaluation. This significantly disadvantages the small services and individuals who do not have the administrative infrastructure or sophistication to deal with the expectations.

Despite all the paper work there is little action around good service. The new quality assurance system, the recipient of millions, has had its roll out only with service providers. Its requirements do not have a clear value base and they do not sit within a framework of having a good life. The expectations are only of minimum service standards. The funding program is not encouraging creativity or development at grass roots either, with the exception of a very small bucket for innovation.

On the whole, there appears to be little understanding of building from where people are at and enabling and supporting things to happen well. If people cannot play the bureaucratic services game then they tend to miss out. The emphasis is on keeping tight control and only working in encapsulated service models. Government is also ignoring the benefits of some of the good work that is being done by the Disability Services Queensland flagships of the Local Area Coordination Program and the Family Support Program. With increasing suspicion about people with disabilities' and families' capacity to handle money, these more flexible options are also losing their capability by becoming more rigidly controlled.

The department has lost its enabling role

On the service side of bureaucracy, the transition of Disability Services Queensland's own services into less institutionalised options has not eventuated. In fact the old Intellectual Disability Service models such as the Alternative Living Service (ALS) are now being promoted and re-created in different forms again in community. This trend is most worrying.

Restating the key challenge

The constant changing of bureaucracy with the subsequent loss of history, vision, connections, knowledge and practical skills has meant the lead agency responsible for enabling good lives for Queenslanders with disability has not delivered. When this loss is coupled with tight bureaucratic control and little investment in people, the lives of people with disabilities become worse. Perhaps the most concerning result is how the system is reinventing itself. The same congregated options are being repackaged, just with different language and spin, moving back towards a one size system fitting all. The images of our past are becoming the images of our future.

The work of bureaucracy needs to focus on investment in people, not only in complex tools and procedures, which means that vision, creativity, connections, knowledge and development need to be supported at all levels of the system, from people with disabilities and families, to communities, to service workers, to senior public servants.