

Past Connections New Directions

A report from a gathering to ensure QPPD's strong advocacy into the future

Queensland Parents for People with a Disability Inc

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It is good to have an end to journey towards, but it is the journey that matters in the end.

Ursula le Guin

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Background to this report

This year marks the 25th anniversary of Queensland Parents for People with a Disability. During this quarter century, QPPD has become known as a collective systemic advocacy organisation doing strong, relevant advocacy on behalf of people with disabilities. QPPD's mission highlights its role:

QPPD vigorously defends justice and rights of people with disabilities by exposing exclusionary practices, speaking out about injustices and promoting people with disabilities as respected, valued and participating members of society.

As part of our 25 year celebrations, parents and allies from around Queensland came together to talk QPPD about ways that could be strengthened in its ongoing work of doing systemic advocacy on behalf of people with disabilities. Together this council of the wise has demonstrated commitment to people with disabilities and collective heroism based on over 650 years of knowledge, wisdom and activism concerning the lives of people with disabilities.

One of the forms of heroism is the willingness to tolerate anxiety and uncertainty in the pursuit of our values, whether these values be played out in our work goals, the love of another human being, or the raising of a family.

Samuel Brandon

The gathering's purpose was threefold:

- to bring together old and new members of QPPD
- to connect with old friends and meet new ones
- to reflect on QPPD's past and contribute to its future.

The focus of the workshop's content was on the last of these three aims, considering ways that the organisation could move forward in its role of developing, maintaining and renewing its systemic advocacy work. The recommendations from the gathering were to be put to the management committee of QPPD to take on board to consider how they could be put into practice as we move into our next 25 years.

The gathering began by revisiting the organisation's history, celebrating its action and achievements, and honouring its people.

History is not just a name for the past. It is the name for the stories of the people.

A. J. P. Taylor

QPPD's History: 1981—1985

National women's conference 'My child was born disabled'	Queensland women decide to	The Community Living Movement and Wolfensberger's earlier visits had seeded ideas of rights, acceptance and quality lives for people with disabilities	
1981—IYDP	form a collective	people with disabilities	
International Year of Disabled Persons— changes attitudes		Queensland Parents of the Disabled (QPD) formed	
and expectations	Access 81 is held— QPD's first Conference	A few children with	
Clarity about being on behalf of people with disabilities		physical disabilities are accepted part time into regular state schools	
Legislation is currently funded	Clarity about parents supporting one another		
by Commonwealth—The Handicapped Persons Assistance Act		Regional parents consider ways of connecting in	
	Parents do whistlestop tours around Queensland	QPD is housed for free under the	
Branches are formed in some regional areas		Dutton Park School and survives on	
Commonwealth	Debate about branches and their connection with QPD	grants	
Handicapped Programs Review asks people with disabilities and families what		Clarity gained about being an advocacy organisation	
life should be like	Brochures, imagery and information produced	A bill about	
'You are not alone'— strength and knowledge in sharing		assisted decision making is introduced into	
New Directions—the	'The meat message'—state clearly what you want	State Parliament	
response to the Handicapped Programs Review gives hope for a		QPD runs a campaign around guardianship	
better life	QPD makes its values and people known to politicians	The Intellectually Handicapped Citizens Act is passed by the State with parents and	
The first resource book is published about strategies			
	Advocacy to influence—QPD is on many committees	allies on its first Council	

QPPD's History: 1986—1990

Access 86— QPD's second conference		The Commonwealth Disability Services Act 1986 is passed with principles and objectives affirming rights, acceptance and quality	
Funding for new	Launch of the Parent Resource Book	lives for people with disabilities	
services becomes available under the Act including funding		Public support of the new Disability Services Act	
for advocacy	QPD auspices a new advocacy group—QAI	Traditional services are	
QPD's Respite Policy to push for new forms		required to change their practices and to move away from provision of	
People living in nursing	Search workshop and auspice of CRU	congregated supports	
homes and other forms of congregated care begin to move to life in the		QPD's first Education Policy —lobbying and parent talks	
community	QPD gets demo funding to pilot systems advocacy	The State Government accepts	
Mission workshop and name change to QPPD		responsibility for education of students with disabilities and closes charity based special	
Visits by Gerry Provencale,	QPPD travels, talking with parents, sons, daughters	schools	
Jo Dickie, Michael Kendrick affirm families and bring new ideas of brokerage and		Book 1—Quality Lifestyles A Statement	
individualised funding	QL Conference with people with disabilities and allies	The Office of Disability produces	
Book 2—Quality Lifestyles, The Issues		the forward thinking kit, 'Disability Society and Change'	
State Govt still only	QPPD goes to Canberra to lobby on recommendations	and Change	
provides services to people with intellectual disability and to people		Workshops held around the state in 26 communities	
with impaired vision	Lobbying state and services about Quality Lifestyles	National Parent Information Project	
Travelling Advocacy Info Trunk goes around Qld		provides seeding money to enable	
	QPD has no funding and is inactive for a while	creative things to happen locally	

QPPD's History: 1991—1995

State wide committee, regional presidency, funding Commonwealth State Disability Agreement—funding passed over to the State—new State Disability Services Act 1992 State-wide Accommodation and Inclusive Living Network Community Safeguards Coalition—safeguarding what we had achieved prior to handover to the State Days of ideas, planning, witting Network State wide committee, regional presidency funding responsibility to people with disabilities New premises, new staff, new energy, new focus Inspiring visitors—Brian Salisbury, Bruce Uditsky Jeff Strully, Nicola Schaeffer, John O'Brien, Connie Lyle, Mel Ainscow, Michael Kendrick Policy—A bed in a house is not a home Policy—Inclusive education for students with disabilities Creative thinking with Marsha Forest and Jack Pearpoint— '			
Commonwealth State Disability Agreement— funding passed over to the State—new State Disability Services Act 1992 State-wide Inclusive Education Network State-wide Accommodation and Inclusive Living Network Community Safeguards Coalition—safeguarding what we had achieved prior to handover to the State Days of ideas, planning, Days of ideas, planning, Stories to inspire New premises, new staff, new energy, new focus Inspiring visitors—Brian Salisbury, Bruce Uditsky Jeff Strully, Nicola Schaeffer, John O'Brien, Connie Lyle, Mel Ainscow, Michael Kendrick Policy—Inclusive education for students with disabilities Creative thinking with Marsha Forest and Jack Pearpoint— Creative thinking with		away from its funding responsibility to people	
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State-wide Inclusive Education Network State-wide Accommodation and Inclusive Living Network Community Safeguards Coalition—safeguarding what we had achieved prior to handover to the State Days of ideas, planning, State-wide Inclusive Education Network Inspiring visitors—Brian Salisbury, Bruce Uditsky Jeff Strully, Nicola Schaeffer, John O'Brien, Connie Lyle, Mel Ainscow, Michael Kendrick Policy—A bed in a house is not a home Policy—Inclusive education for students with disabilities Creative thinking with Marsha Forest and Jack Pearpoint—	funding passed over to the State—new State Disability		
State-wide Accommodation and Inclusive Living Network Policy—A bed in a house is not a home Community Safeguards Coalition—safeguarding what we had achieved prior to handover to the State Inclusive Ed workshop and Inclusive Lives conference Days of ideas, planning, Strully, Nicola Schaeffer, John O'Brien, Connie Lyle, Mel Ainscow, Michael Kendrick Policy—Inclusive education for students with disabilities Creative thinking with Marsha Forest and Jack Pearpoint— '	Services Act 1992		
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Days of ideas, planning, Inclusive Ed workshop and Inclusive Ed works	what we had achieved		
Days of ideas, planning, Pearpoint — '	State		
the only chicha for	Days of ideas, planning, writing, sharing, meeting	Pearpoint — ' the only criteria for	
Amazing energy, focus and support for each other inclusion is breathing'	of support in regular schools, QTU backlash— 'we're not here for the kids,	inclusion is breathing	
schools, QTU backlash— 'we're not here for the kids, Creative live in workshops, courage and action			
only the teachers' National Alliance for Inclusion—rally and march Sharp increase in students	only the teachers		
Mothers in Arms meet with MPs, Ed bureaucrats, QTU with disabilities in regular schools including some with significant disabilities		schools including some	
CJC Inquiry into Together we are better			
Basil Stafford confirms 'An insidious culture of Inspirational annual AGM workshops	confirms 'An insidious culture of		
	abuse'	Deinstitutionalisation—started,	
properly, Campaign processes, some out some not	· ·	campaigns, started again, poor processes, some out some not,	
Postcard Campaign Don't turn back the clock		smaller institutions	

QPPD's History: 1996—2000

Education Provision for Students with Disability, Placement Policy			
Small personalised	Institutional Reform marches, vigils, parliament	increase in membership	
community based services, set up by parents and people with disabilities, are		Less energy in adult issues as families focus on services	
getting on with life	Work with allies—CRU, QAI—strategies, campaigns	The dark night of the	
State wide teleconferences on issues and strategies		innovators comes as government pulls back from promises to support	
Students with disabilities	TV, radio, press releases letters to the editor	community living	
begin to lose ground in regular schools, especially if they have		Funding stats—comparison with other states	
high support needs	Balancing the pushes and pulls—prioritising bushfires	Anti-Discrimination	
Conference with Bruce Uditsky—Lights to GO!		test case fought and lost concerning exclusion of a child	
Economic rationalism is	QPPD auspices Gold Coast Advocacy Group	from regular school	
firmly established with governments looking at unit costs of support and		Travelling Advocacy around Queensland communities	
advocacy	On many committees trying to influence inclusion	Wolfensberger's	
Bribie Workshop—revisiting who we are and setting our direction		week on dissecting advocacy	
Students with	Think tank on Advocacy— are we really doing it		
disability allowed to stay at school until the age of 18		\$ not the answer—talking with families, Unmet Needs Campaign	
	Coffee mornings introducing new families to QPPD	Change of	
Political information for families to use in discussions		government and the establishment of a new department—	
	Difficult times and conflicts of interest around priorities	Disability Services Queensland	

QPPD's History: 2001—2005

Organisational development project, new leadership, name		The state introduces individualised funding but confuses it with	
Gaining funding for	Anti–discrimination Disability Advisory Group	individualised support	
support is dependent upon critical need once people with disabilities'		Book—Daring to Dream Celebrating QPPD's 20 years	
lives are in crisis	Education Placement policy Phone in and report	The 2 roads of life are	
Ministerial Taskforce and later, Advisory Council on inclusive ed		becoming clearly defined again with \$ and ideology moving along the	
Predetermined	Education Queensland Summit on Inclusion	segregated road	
consultations—Funding Reform, Have Your Say, Disability Services		National and international conference presentations	
Act review	Politics, Partnership and Personalised Responses	New institutions are	
Towards a system of support, Dissenting funding reforms		called innovative housing, reinvention of the '4 pack' group home	
More people are living in	Community Connectedness and Quest for Belonging		
segregated and congregated care than ever before		Survey, focus groups, report Small choice in rotten apples	
0.01.201010	Young People in Nursing Homes campaign	Predominant response to	
Regional advocacy tour and development workshops		including students with disabilities becomes more special units in regular	
	Illusion of Inclusion and review of the Education Act	schools	
The Safeguards Coalition is reformed for collective action		Stimulating AGM workshops Fork dinner speakers	
	Organisational Peer review sets challenges for future	The State introduces a	
The pendulum is swinging back—workshop and report		new Disability Services Act with little reflection on the feedback from	
	Report on Community Investigation into Abuse	parents and people with disability	

Lessons from our past

From an analysis of our history, people identified 106 lessons that have been learnt from our involvement in QPPD. The lessons have a bearing on the future in that they have shaped the way that the organisation has operated and have held messages that are relevant for the future.

- 1. You are not alone
- 2. The importance of people coming together to hear new ideas
- 3. Raise expectation
- 4. Nurture hope and vision
- 5. Keep a State perspective
- 6. Two roads of life, exclusion and inclusion
- 7. Understanding the impact of the 2 roads
- 8. Segregated early life can often lead to segregated later life
- 9. The importance of advocacy 'for' people with disabilities
- 10. The focus of our 'meat message'
- 11. Keeping focussed and strategic
- 12. Plan, plan, plan
- Cultivate allies
- 14. Find allies in the bureaucracy
- 15. Remember this is systems advocacy
- Understand the framework of SRV
- 17. Know what you don't want
- 18. Dream and act on what you do want
- 19. Keep clear what the business of families is
- 20. Own money, more say with supports
- 21. Innovation can come from outside
- 22. One is never a prophet in one's own land
- 23. Talk with others about ideas and strategies
- 24. Be careful what you ask for
- 25. Avoid simplistic solutions
- 26. Know where to put focus on things that really matter

Do not seek to follow in the footsteps of those of old; but seek what they sought.

Matuso Basho

People make their own history more wisely when they know what their history has been about

Manning Clark

Lessons from our past (continued)

27.	Monitor what people say		
28.	Talking the talk versus walking the walk		
29.	You may have rights – the issue is if and how you achieve them		
30.	You can die with your rights on		
31.	Sustain the organisation		
32.	Continue to renew		
33.	Services should work to fit the individual not individuals work to fit the service		
34.	Have the focus on working towards a vision for son or daughter		
35.	The irony of doing extraordinary things to achieve the ordinary		
36.	Know the good stories		
37.	Demonstrate it does work		
38.	Build grass roots advocacy		
39.	Ask others to justify why exclusion should happen, not justify why inclusion should happen		
40.	Build community one at a time around individuals		
41.	Systems advocacy is complex – systems are complex – life is complex		
42.	Be clear about doing advocacy not just being advocacy		
43.	Consider what the alternatives would be if our advocacy did not happen		
44.	Ask others to support you		
45.	Seek commonality not difference	Not to transmit experience	
46.	Join with the wider network – be informed	is to betray it	
47.	Together we are better	Elie Wiese	
48.	Muster the support of allies		
49.	Parent discussion and action is important		
50.	Parents take leadership in many spheres of influence in community life		
51.	Keep hope alive		
52.	Keep supporting ordinary parents to do extraordinary things		
53.	Keep huge things manageable		
54.	The importance of the least dangerous, best interest assumption		

Lessons from our past (continued)

55.	Consider how we share the work		
56.	Continue to legitimise the authority of parents		
57.	Reasonableness and cooperation before confrontation		
58.	Cultivate and nurture allies within the system		
59.	Use the skills the staff bring		
60.	Use stories of real life to illustrate our advocacy		
61.	Be strategic		
62.	Never go alone		
63.	Our 2 reps policy		
64.	Know where to put energies		
65.	Say no to constant advisory committees without evidence of any outcomes		
66.	Learn so much by being on the management committee		
67.	Meet, plan, take action, review, write, follow up		
68.	Capitalise on opportunities		
69.	Look for win/win situations		
70.	Remember image in presentation – who goes – how presented – well thought through	History is a vast early warning system.	
71.	Develop counter-arguments Norman Cousin		
72.	Believe it is possible		
73.	Creativity doesn't necessarily cost more		
74.	Affirm your family beliefs are right for your son or daughter		
75.	Beware resignation that things wont change		
76.	A time to step back, a time to protest		
77.	Learn as you go – learning by doing		
78.	Involvement in broader systemic advocacy gives knowledge and strength to take up challenges for own son or daughter		
79.	No matter where people are on their journey, QPPD can help		
80.	Courage comes from support, knowledge and stories from life		
81.	Using connections to our benefit		

Lessons from our past (continued)

- 82. QPPD is a safe place where parents can let off steam, plot, plan and talk
- 83. Advocacy is always needed ongoing work
- 84. Parents are still isolated as in other generations
- 85. Part of a much wider movement
- 86. Use expertise of staff
- 87. Importance of good reporting of people's lived experience
- 88. Powerful storytelling
- 89. Importance of good analysis
- 90. Naming what it is
- 91. There are other people out there
- 92. Getting a sense of the bigger picture
- 93. A clear focus to advocacy work
- 94. The value of peer review
- 95. Country/city connectedness, each with a role to play
- 96. Continue to dare to dream on at different points throughout life
- 97. Sometimes the strongest opposition turn over the stone and become the greatest advocates
- 98. Sharing the passion of my own reality with people who understand and share the same dreams
- 99. Sponsoring people to workshops changes thinking
- 100. Gain support to make things happen
- 101. Consider wider opportunities and have the courage to ask
- 102. Ask others to justify their stance rather than having others ask us to continually defend ours
- 103. Seize opportunities at the right time
- 104. Good people are incredibly valuable and are to be acknowledged and valued openly
- 105. Remember to have fun along the way
- 106. Friends for life.

Those who cannot remember the past are content to repeat it.

George Santayana

Our hopes for the future

People who came together shared a common vision for life and want future generations of people with disabilities to:

- grow up in a world where they are not defined by their disability
- go to preschool with their neighbourhood friends
- go through the same enrolment processes as their brothers and sisters
- find that they are not assessed and placed in separate units or schools because they have a disability
- know that teachers have the same commitment to them as they do to other students
- grow up with typical expectations and prospects for adult life

Everything that is done in the world is done by hope.

Martin Luther

- have opportunities for continuing education
- have work or meaningful alternatives that are life giving
- have economic security to live and be part of community life
- have a home of their own
- know that they will not be congregated in situations with others they do not like or fear
- be free from abuse, neglect, exploitation and discrimination
- be able to move around their home and their community and to have adequate supports to do so
- experience welcoming communities that include them
- participate in and contribute to community life
- express their spirituality
- have relationships and people in their lives who love them
- have their parents share a vision of a good life with them
- not be reliant solely on parents for the rest of their parents' lives
- not be reliant solely on services for the rest of their lives
- be happy and content with life.

Our hopes for the future (continued)

Our hopes for the future are not pipe dreams. They are the same aspirations that most people hold for any son or daughter. Therefore it should not be seen as unusual or strange to hold these beliefs for a son or daughter with a disability. We know that with much work they can become reality. However we are quite realistic about such achievements. We know that it takes extraordinary time and effort for sons and daughters with disabilities to have an ordinary life.

This deceptively simple aim of people with disabilities living valued lives comparable to those on offer to most other citizens is, in fact, very complex to achieve. Many of the systems that support people with disabilities, although having admirable jargon and good intent, actually work against these aims. Through their values and practices, especially those that put resources together, people with disabilities are grouped and taken out of ordinary life.

The great thing in this world is not just where we stand, but in what direction we are moving.

Oliver Wendell Holmes

Changing these systems takes a long time, often meeting brick walls which require creativity and influence to dismantle. However, over the last 25 years, QPPD has made very significant progress in some areas for some people. We have enabled the gate to ordinary life to open for some, but many are still excluded behind it.

Progress is slow and there is always danger of moving backwards. This is especially so now, when the people who are making life defining decisions come and go with such rapidity through government and services, as well as through people's lives. They never get to understand people's realities or gain knowledge from the people who remain in their lives, who love them the most.

This is why advocacy will always be needed.

Parents will always have a role to play in being vigilant and in bettering the lives of people with disabilities.

Unfortunately a compelling lesson from history is that there will always be injustice and, if it is not addressed, then it will continue to grow unchecked.

As one gets older, one discovers everything is going to be very much the same, but with different hats on!

Noel Coward

Advocacy under threat?

For the first time since gaining recurrent funding as a systemic advocacy organisation under the Commonwealth Disability Services Act 1986, QPPD has been given temporary funding for 6 months. QPPD is not the only advocacy organisation in this situation, as it has been applied to all advocacy organisations who are funded by the Commonwealth.

Certain signs can precede certain events.

Cicero

This situation has arisen because we are waiting for the decisions from a review that the Commonwealth has held about the relevance of advocacy throughout Australia.

QPPD believes it is important to have a strong voice on behalf of people with disabilities at an individual level through individual and citizen advocacy, and at a systemic level through corporate and collective advocacy, all of which are funded to a limited extent here in Queensland. As part of this broad strategy, we also believe it is important to have a strong voice of parents on behalf of people with disabilities when people's rights are not achieved and when many people with disabilities are still not supported to belong to and be part of our communities.

Diversity is a safeguard

QPPD believes that the support of diversity is a safeguard for our communities. Just as it is important to embrace the acceptance and inclusion of the variety of people who live in our communities across the state, so is it to important to acknowledge the need for the variety of the forms of social advocacy that are required to uphold the rights, justice and quality of life for all.

We believe that in order to keep people safe, and for them to have a decent life comparable to other citizens, we need strong support of advocacy for individuals, done by family and loved ones, by paid advocates and by citizen advocates. Yet individual advocacy is not enough. Many issues faced by people with disabilities and their families are common and are inherent in the wider beliefs, structures and practices of our society and in the actions of our governments.

Systemic advocacy addresses these concerns in two ways by supporting people to come together to advocate on issues of commonality, as well as by having paid advocates who continue to address the injustice and complacency of the broader societal systems, so the needs of people with disabilities are met.

Advocacy in Queensland needs to remain strong and relevant so that vulnerable people with disabilities can have a strong voice on their behalf

Why parents make good advocates

Legitimacy and value of the parent voice in advocacy

Sometimes the role of the parent voice on behalf of people with disabilities is questioned by those who do not understand why people who have disabilities need strong advocacy. Yet most parents know that the effects of a person's impairment can be overwhelming, especially when it is coupled with complex support needs and the negative attitudes of others. On top of these, systems and services can make life-defining decisions that effect people's wellbeing and human rights.

A parent who is really a parent is never really free.

Honoré de Balzac

We believe that parents do have a recognised natural authority in the lives of their sons and daughters in our society. When the person is a child, their parents are their legal guardians. In adulthood the natural authority of parents can continue, especially when something goes amiss or when their son or daughter has ongoing support needs as a result of having a disability.

It is typical that parents:

- Have commitment and take great responsibility for the well being of their son or daughter
- Know their son or daughter the most from long term observation and insight
- Deep experience is never peaceful.

Henry James

- Are attributed decision making especially when the person has difficulty in doing so
- Have a stake in the outcomes and live with the consequences
- Bear witness to the performance of services
- Are there for the long haul and are more free of vested interests
- Bring talents, knowledge and experience
- Know the real life stories
- Are well positioned to see how life adds up
- Are well positioned to take action on their son or daughters behalf.

Why parents make good advocates (continued)

Additional strength in coming together as parents

Not only does the parent voice have a legitimate role, but also we are stronger when we come together to share our experiences and wisdom about what needs to happen on behalf of people with disabilities. We recognise that we are not alone and affirm that our knowledge, expertise and dreams are real. We hold the stories of lived experience through our sons and daughters and we gain greater understanding and strength in uniting for justice and decent lives.

Collective advocacy gives us opportunity to dream, to be inspired, to have information, to learn, to network, to have hope and to take action for a better future. Our advocacy enables creative thinking about what a better future might look like, as it inspires long term vision and action and re-energises us to continue to be there for the long haul. It helps us to keep hold of the bigger picture, and to be proactive and not focus on reactive, simplistic solutions that are of little value.

One of the best safeguards of our hopes is to be able to mark off the areas of hopelessness, to face them directly, not with despair but with creative intent of keeping them from polluting all areas of possibility.

William Lynch

Broader benefit of the collective parent voice to society

Parent advocacy forms an important part of the wider Community Living Movement. Not only does it support the view that the community is where people with disabilities belong, but it also promotes the acceptance of the diversity of our communities and the inclusion of all citizens in Australian life.

It also supports citizens who take responsibility for improving the lives of loved ones and recognises that parents work in many paid and unpaid roles in support of people with disabilities in the broader community.

It is always minorities that hold the key to progress; it is always through those who are unafraid to be different that advance comes to human society.

Raymond Fosdick

As such, parent advocacy is a training ground to deal with injustice and public life, where families can participate regardless of finances and political power, adding capability to the broader community. It is more than a personal quest for a son or daughter; it is part of the movement of creating a better and more just society for all.

Why allies are important

QPPD has always recognised the importance of our allies and have connected and joined forces with others in many different ways during our 25 years. Allies have been there in the good times, but often, more importantly, they have been there with us in the bad times; times when we have relied on the knowledge and strength of others to help us to move forward in our advocacy on behalf of people with disabilities.

Allies were identified as strengthening the work of QPPD by:

- Sharing their passion and concern for social justice in relation to the lives of people with disabilities
- Understanding and supporting the issues that parents face

The impossible is possible when people align with you.

Gita Bellin

- Sharing the values and vision of QPPD
- Supporting and encouraging the advocacy work of QPPD
- Working alongside parents and families to achieve QPPD's objectives
- Building links with others (individuals and organisations), for and on behalf of QPPD in order to advance our aims
- Providing an alternative perspective on issues
- Adding knowledge and strength to QPPD's work
- Joining in campaigns, subcommittees, steering committees of the organisation
- Being 'in the know' and providing us with the information we need
- Working as a back up behind the scenes
- Acting as mentors.

However participants recognised that allies need to be cultivated. Also on an individual level, allies could be other family members and people who have stepped forward to support a person with a disability in a freely given relationship. With these thoughts in mind, the following questions were identified for the organisation to explore further in the future:

- Where do brothers, sisters, other family members, support network members and other people who have a freely given commitment fit?
- How do we use our organisational allies better? other advocacy organisations, other agencies, networks, support groups
- How do we keep connection with the wider community living movement?
- How do we use our individual allies more strategically?

Priorities for development, strength and renewal

The gathering set these priorities for the organisation to take forward, so that strong relevant advocacy is developed, maintained and renewed.

Making Connections and Links

- Find hospitable ways to welcome new members
- Have regular group induction events with experienced members and guest speakers (supported regionally)
- Reintroduce identifying parent contacts throughout the state
- Support parent contacts actively and seek their information and feedback
- Utilise and follow up on regional advocacy development for new connections and links
- Continue to follow up written information and invitations with personal contact by phone
- Identify other individuals and groups with similar issues and strategic purpose and develop ways of connecting with them to support our advocacy
- Host a 5 yearly state wide conference.

Vision, Information and Knowledge

- Renew the vision with each new generation by explaining and sharing with new members and allies
- Revisit past advocacy efforts and successes with new members and new adversaries, as old issues come back
- Develop counter arguments to deal with the pressure towards stereotyped grouped responses (start early)
- Make contact and arrange to meet where parents gather to put forward alternative views and to question the pressures to follow exclusionary tracks
- Develop a range of ways for members to feedback information, as well as have contact with one another
- Give parents skills to understand the complexity of the jargon and systems they encounter
- Create opportunities to share information and stories
- Arrange and sponsor parents to events
- Don't assume parents know what the options are stimulate creative thinking
- Keep up informative Staying In Touch and the Newsletter.

Priorities for development, strength and renewal (con)

Nurturing the spirit of the organisation and the rah rah!

- Develop and support the passion about social justice in creative ways
- Organise personal opportunities for members to play a part in campaigns and to work together in a number of different ways
- Develop a spirit of welcoming, generosity and care for all involved
- Seek opportunities to renew, restore, inspire, enthuse members over the long haul
- Celebrate large and small gains
- Develop a process and make use of it, which deals with issues or conflicts quickly and professionally, so they do not escalate
- Build creativity, fun things and celebrations into collective events.

Action around systemic advocacy issues

- Remember the mission and core business of the organisation is systemic advocacy
- Encourage the spirit of doing strong advocacy with parents, staff and allies working together
- Support the efforts of the staff and use their skills to facilitate action
- Establish links with current and past members to help inform strategy
- Plan priority long term advocacy campaigns (eg five year)
- Organise and support a number of coordinated meetings in local areas on a particular issue
- Involve membership in priority setting—canvas ideas in conjunction with AGM gatherings to clarify where energy is
- Plan proactive action by inviting bureaucrats to discuss our priorities
- Demonstrate the positive outcomes of advocacy and its power to achieve change
- Renew alliances with other advocacy groups to share knowledge and broader priorities
- Maintain the clarity and balance of our systemic focus by not letting current active member issues be the only driving force of the organisation.

Priorities for development, strength and renewal (con)

Leadership of the content of advocacy

- Identify a range of ways members can have involvement in systemic work and support their development and growth
- Create a public presence and support parents representing the views of QPPD
- Identify and provide mentoring of key active members
- Provide professional supervision of staff involved in front line advocacy work
- Do good analysis, planning and reviewing by seeking input from staff and outside analysts
- Maintain contact with past active members who have stepped back to deal with other aspects of life as sleepers can awaken
- Hold a Past Connections, New Directions Workshop every few years
- Foster allies within the bureaucracy to help with understanding the complexity of government systems and feeding in our issues of concern
- Use the knowledge and wisdom of others on difficult issues by seeking out and developing links with other advocates and like minded people
- Remember to do everything together—at the least in twos.

Leadership and stewardship of the organisation

- Maintain the mission and focus of our systemic advocacy— the management committee is charged with this responsibility
- Have good induction processes, with opportunities to pass on knowledge, share experiences and have learning needs met
- Use the 2 vice presidency roles to induct the new, and support the president
- Seek opportunities for committee members tailored to roles and suiting talents
- Identify mentors for committee roles
- Consult mentors to help with clarity and advice and ideas about difficult issues
- Support members of the management committee to manage balanced commitment between committee work and family and personal life
- Ensure careful timing of membership events so that people can be involved in determining priorities and strategic organisational action
- Develop a 5 year plan for recruiting committee members, giving opportunity for knowing what the organisation stands for, how it works and expectations for succession.

Recommendations for first steps

Three key areas were identified for priority work around planning for organisational strength over time. These were to:

- 1. Invest in people
- 2. Choose solid, relevant priorities and practices
- 3. Work on organisational sustainability.

For purposes of action, nothing is more useful than clarity of thought combined with energy of will.

Henri Amiel

1. Invest in people

The strength of the organisation was seen to come from the people whom QPPD attracts and the relationships that are forged through its advocacy work. Therefore a major investment of the organisation was affirmed to be the development and support of the people involved in the advocacy work of QPPD, so that strong advocacy can happen across the state.

It was also acknowledged that QPPD is a training ground for other involvements as part of the wider Community Living Movement, with many parents being involved in progressing important agendas forward outside their role in QPPD at personal, local, regional and state wide levels. As such QPPD not only does strong systemic advocacy, but also develops and sustains strong parent leadership in many other roles that benefit people with disabilities.

The following recommendations were put forward:

Draw in New Parents

 Develop a planned strategy to seek out places and ways to draw in and welcome new parents so that they are inspired and not overwhelmed, allowing for where they currently are on their own journey.

Participants identified that QPPD currently makes connection with potential members in four main ways:

- By word of mouth and personal connection
- By parents phoning the office when in crisis
- By travelling to regional communities
- By inviting and welcoming people into QPPD's advocacy.

Recommendations for first steps (continued)

Suggestions for first step priorities for drawing in new members were:

- Send a small number of brochures to current members and other active parents encouraging them to distribute them at upcoming local AGMs or to give to parents that they know locally
- Develop a strategy for office staff to assist parents in crisis through a process of referring parents to identified members (parents and allies) who are prepared to talk with them by phone
- Set yearly priorities for a small number of 'out there' connections, with travel to regional communities and visits to parent groups (eg with those connected with services, SEDUs etc)
- Support a new focus group to do systems advocacy around a burning concern (three areas were suggested – young parents whose sons or daughters are being enrolled in SEDUs, transition from childhood to adulthood, and adults with aging parents, which could also include other family members and allies)
- Welcome parents where they are at on their journey and find ways for them to contribute to the organisation's work by linking a buddy or mentor with new parents locally in any advocacy involvements or regionally by re-establishing parent contacts.

Reconnect With People From The Past

 Reconnect with active people from the past who have a passion for the organisation, its values and its work

Participants at the gathering recognised that QPPD has many parents will link in and move back at different times during their lives and that it is important to allow this flexibility. Often parents will want to put their energies elsewhere in other roles. Rather than this being seen as negative, strategies need to be put in place to maintain connections in ways that people can still feel that they are part of the bigger picture, even if not contributing directly to it, or have options that draw on their strength and knowledge for particular organisational planning events.

Suggestions for first step priorities included:

- Identify parents and allies who have been active members in each regional community
- Personally invite them to be a part of the 25 year celebration AGM
- Identify a person in each region who is prepared to be a parent contact to welcome new members in the area

Recommendations for first steps (continued)

- Identify people who are prepared to be linked with one person at a time around an issue of concern
- Identify committee members from the past who are prepared to act as a mentor to a current committee member
- Each year, use the wisdom of older and newer members in setting the priorities of the organisation, in conjunction with committee and staff.

Develop a Succession Plan for Governance

Seek good people, make personal connections and ask personally

Participants indicated that the management committee members needed to take strong leadership and stewardship roles in relation to the organisation's governance and remain connected with what was happening in the organisation. They also affirmed that new committee members do not just appear by chance. Rather, as is usual practice in any organisation, good people are usually sought, encouraged or head hunted and drawn in personally.

First step priorities for a succession plan were:

- Identify potential people for this year's committee, given that some people will be leaving
- Encourage the use the positions of the 2 Vice Presidents for the succession of the next president and the support by the outgoing president, as was the original intent
- Develop an ongoing succession plan for the organisational leadership detailing ways of identifying people, connecting them in with steering committees or other QPPD work, as well as having induction, skill and guidance, mentoring and replacement strategies for committee members over time.

2. Choose solid, relevant priorities and practices

 Use collective mechanisms for determining priorities with clear focus on the systemic advocacy function

The suggestion here is that QPPD, as a state wide organisation, needs the input of its state wide connections. This acknowledges the wisdom and knowledge held by parents across the state derived from their own involvements in their regional communities. This is particularly so with active parents who have been in advocacy and other significant parent leadership roles.

Recommendations for first steps (continued)

This does not mean that the members decide priorities based on their own personal agendas. Rather an analysis is done of the current situation, with members identifying the systemic advocacy issues in line with QPPD's mission, which need attention strategically, given the resources and capacity of the organisation. The committee would then move these agendas forward in their governance role.

Suggestions for first step priorities were:

- Develop an Organisational Plan that puts into practice the suggestions for strengthening QPPD from this gathering of parents and allies
- Select key strategies that will be focussed upon for the next phase of the organisation's work around strengthening QPPD's membership
- Emphasise this strengthening role in the development of a new Strategic Plan.

In foresight, be a strategist

René Char

3. Work on organisational sustainability

Develop a planned strategy to deal with external threats

The gathering emphasised the need for people to know what is happening about the stability of the organisation and its funds. People were concerned that this is the first time in QPPD's history that our recurrent funding has been made non-recurrent, with the Commonwealth Government giving all advocacy organisations that it funds a 6 month contract following the National Review. Discussion continued about how advocacy had been threatened in the past and that it was only through proactive and concerted effort that the situation had reversed.

Suggestions for first step priorities were:

 Develop a planned strategy to deal with external threats: The future is not a gift—it is an achievement

Harry Lauder

- know what is happening
 - connect with other advocacy organisations in Queensland
 - connect with parent advocacy and other allies in other states to find out what they know
- be at the table in discussions with Commonwealth
- be involved in collective action.
- develop an action plan to marshal support from membership and allies which is ready to roll out if the threat of cutbacks or defunding of any advocacy in Queensland becomes real.