Queensland Parents of People with Disabilities (QPPD), Australia

Striving for Inclusive Education for All

"Our children just want to be cool, to be one of the group and to be treated the same as everyone else"

"Our group is about our individual talents being pooled to create this very strong and energetic force!"

# Experiences of Education

## Some very positive.....

"Sam makes it known that he just wants to be like everyone else. He's on the same timetable as everyone else and included in the same things in the class. He knows that some of the work he is given, and the expectations of project work, might be different. but as far as joining in all class activities and being part of the class it's just what he expects."

Another parent struggled to obtain inclusive education for her son with multiple disabilities. She succeeded in transferring him from a special school into the last year of the local primary school:

"It was the best year that Chris had ever had in his life because he was able to enjoy doing what other kids had done all their lives. Initially there was a lot of hesitation and negativity from the school who had never met anyone like him before. However we were very fortunate that we had a principal who was very open and a teacher who was prepared to give it a go.

Attitudes changed dramatically in the first year. Although they were initially very afraid, they soon realised that he had different gifts and talents and that he was a young boy after all. They learnt to see that the disability wasn't Chris, but that Chris was an individual who had a personality, and who had the same likes and dislikes as other children of his own age. It was a learning curve for the whole school! Chris was a pioneer. He was the one who made the journey."

## And others not so positive.....

"My son, who has severe multiple disabilities, was refused a school place by the State Education Department. They told me that my only option was to teach him at home. I finally managed to persuade a private school in the Catholic education system to accept him for 3 days a week."

"Since our family moved 100km away from Brisbane our experience of our daughter's schooling has dramatically deteriorated. In Brisbane her self-esteem and confidence grew dramatically, particularly in the last two years. She was valued, given jobs that no one ever expected she'd be able to do, like taking a note to the school Principal. Now she's not given anything to do; she's considered to be the poor little kid with the disability who can't do anything."

"To be valued equally is a real struggle"

"Our child was moved, against our wishes, from mainstream primary school to a special education unit. In mainstream she was expected to do a lot of things for herself as there were no teachers' aides, so she did not become too dependent. Now that she's in a special education unit, my daughter expects that, when the going gets tough, the teacher aide or some adult will do it for her and the learned dependency is a constant bugbear. She certainly doesn't have a teacher aide at home! If they don't insist she does more for herself she's going to be an imperious little thing who thinks she can order adults about as her own personal slaves."

# How we started QPPD

As part of the International Year of the Disabled Person (IYPD), a national women's group organised an Australian Women's Conference in 1980. A few women from Queensland followed this up by holding a workshop which provided the first opportunity for about 150 parents from all over Queensland to come together for 3 days to talk about our family situation and the fact that we had a child with disability and what a difference it made to the family. There were a few men at the conference, but the majority of parents were women, and it was certainly mothers who probably had the main caring role.

The conference was very emotional. People who spoke were very angry about many issues. We felt that this energy needed to be channelled constructively. At the end of the conference there was unanimous agreement to set up a Queensland organisation to lobby around issues that were relevant to our children and families. It was a reaction against the feeling of being powerless to influence service provision and government decisions. QPPD, the Queensland Parents of People with Disability, was set up to be an umbrella organisation for all disabilities to cover the whole area of Queensland.

The plan was to have a group of parents in Brisbane (the state capital) to communicate with parents all around the state. The parents' group would:

* monitor services and legislation;
* consult with service providers and policy makers about needs and rights;
* liaise with other parents and consumer groups.

The unique thing was that parents spoke to parents. It started out as a reactive organisation to check out what was happening and try to exert influence at various levels to make change.

We succeeded in getting a small donation from some government departments to enable two parents to travel around the state for three weeks to publicise the organisation. They stopped off at different places on the coast and walked around with big red QPPD badges. They stopped people to ask them, "Do you know of any people who have children with a disability in this town?" They talked on local radio, visited local schools and hospitals, wherever we thought disabled children might be and wandered around looking for them. They tried to include any family they came across with any disabled child.

From the first QPPD was inclusive of families from all backgrounds and all disabilities because every type of disability was represented at the original workshop and no one wanted to be left out. There was no money to start with and all the planning was done in the homes of people on the committee. There was only a small number of members in Brisbane.

# Our role in Education

The QPPD Education sub-committee was set up in 1986-7. The Commonwealth government commissioned the committee to set up a demonstration project. Two parents worked tirelessly to compel the Education Department to take responsibility for the education of students with intellectual impairment. Prior to this students with this impairment were ignored by the system. Privately run segregated 'sub-normal centres' were the only form of stimulation that a few children were receiving. This was the focus of 'inclusion' at the time - getting the government to take responsibility for all students. Special schools existed, but had primarily supported students with physical disabilities.

QPPD had representatives on about 19 state education committees, including advisory committees. They mainly worked at obtaining information and learning how to lobby and advocate.

A milestone came in the early 1990s when we became very concerned that a considerable number of disabled children were being excluded from their local schools. In response, Jane Sherwin, a facilitator from Community Resource Unit invited a Canadian parent working in community education, Bruce Uditsky, to run a 3-day workshop. The first two days were a huge event. There was great interest from teachers, workers in the disability field and parents. The third day was for parents only. Bruce sat in a circle and challenged, encouraged, and inspired us.

A meeting was called for all the parents who told their stories and described their dreams for their children. It was an informal group of interested people who wanted change in the education of children with disabilities. We drew strength from each other and got to the point of trying to clarify our vision and our values. We developed a collective voice to try to influence government and the policies of the day.

**"All children with all disabilities should attend their local school. The only criterion was that they could breathe, whether assisted or unassisted. In other words, just the fact that they were alive!"**

# The Inclusive Education Network was born.....

"I remember the electric feeling of fresh enthusiasm from these parents. All of a sudden a window has opened and they see so much potential and a path they can follow. The energy was just amazing and seemed to flow into the individual and give that extra bit of energy to fight their own particular battle. People would come up with unique approaches for research and various projects and it was fun too! Each person kept a check on different things. For example, my thing was to keep the focus on the child in the discussion, so every now and again I would say, ' Hang on a minute, what about the kids?"

Our parents wanted the same for all their children, whether disabled or not and that is mainly to be accepted at the school as an individual within their own uniqueness; to be welcomed and given the same opportunities as others; to be valued for who they are and not cast aside because of their label.

In order to ensure that the group was self-sustaining, the position of chair was rotated and the parent members started to take more control and ownership of the process and to take greater leadership roles. At the start we tried to increase awareness and arouse interest by word of mouth and by circulating a newsletter.

We operated on two main fronts. The first was dealing with and trying to influence the Education Department and the other was to strengthen the group itself and the individuals within it. Some parents brought considerable experience and wisdom to the group and could be asked for practical advice, such as how to respond when teachers or head teachers raise difficulties.

The group now has eighty members and holds monthly meetings by tele-conference. Ten members come together on a monthly basis by phone from all around the state of Queensland to share their experience, the challenges, and what is happening in their locality.

# Some examples of activities include.....

## A public rally

We organized a city centre rally with press releases, literature, and a banner made up of all the faxes sent in support of students' desire to go to an ordinary school. It was huge, there were hundreds of faxes. We drew on the Salamanca Statement of 1994. The rally culminated in a march to the Education department building and its leaders tried to present the statement to the Minister.

## National Alliance for Inclusion

A group of us formed the National Alliance for Inclusion, which includes professionals. This alliance is nation-wide although most activity takes place in Brisbane. The National Alliance published a book written by a teacher who was also the parent of a son with disability entitled, "Strategies for Inclusive Schooling". It is a collection of parent stories and information from parents as well as from teachers who were supportive of inclusive education.

Strengths of the Group

* Great clarity about what people want, and great passion;
* Great courage and commitment. People are willing to support each other outside as well as inside meetings. There is intense interest in the "journeys" of individual families;
* Willingness and ability to work both at a systems level and as a lobby;
* Group-generated motivation.

"It was something different. There was always someone with a new story - often something very exciting that they had achieved or that their child had achieved beyond expectation. The stories are probably where I gained a lot of strength and what gave the group a lot of strength".

# Views of Other Family Members

Fathers and men in QPPD mainly support their wives by doing the practical tasks with the children to enable them to attend meetings and participate. "Though we have males who hold office in the organisation as far as the nitty-gritty and the everyday discussion of education is concerned and the people who front up to the school with their kids, it's usually the mothers."

Brothers and sisters express individual views about inclusion for their sibling with disabilities. The younger sister of Chris, a multiply disabled boy who succeeded in remaining in mainstream school until he was 18, was extremely positive and changed her primary school so that she could be at school with her brother. His older brother had greater difficulty in coming to terms with it and only in adulthood realised the benefits.

# Challenges and difficulties that we face

**"Our main struggle is against hostility to inclusion"**

* In 1994 some members of the group were invited to speak to parents at a special school who were very pro-segregation. We encountered considerable hostility and verbal abuse but it was an important learning experience.
* At a forum on Special Education two representatives of QPPD had a similar experience. Because of the strength of feeling against inclusion they felt too threatened to be able to express the arguments in favour.
* Another crucial challenge became a test case in Australian education law. One family, experienced members of QPPD, challenged their local school's right to exclude their daughter, after a long struggle during which they tried to work in collaboration with the school.
* "We plodded on and kept trying to work with the school and the teachers, encouraging them, informing and educating them along the way because they were quick to point out that they had no knowledge of anyone like my daughter. Initially our daughter was only allowed to attend regular school on a part time basis, with two days in a special unit. In her second year she was allowed to attend the regular class full-time but after 6 months they excluded her for behaviour that is prejudicial to the good order and conduct of the school'. They objected to her singing in class and having to be taken to the toilet on an hourly basis. In spite of the fact that our daughter did not have a severe disability and we had been told that we had a good case, we lost our court case. We were very upset!
* Another family decided against court action in spite of being blatantly discriminated against in relation to enrolment in the local high school. A place was promised for their child but on the day she started they were turned away on the grounds that she had special needs.
* QPPD launched a document called INCLUSIVE LIVES in 1994 at about this time and had a public campaign about inclusive education. This led to a strong backlash from the Queensland Teachers' Union who started their own active campaign against the Inclusion of students with disabilities in mainstream schools.
* The vitriol that the group experienced surprised us at the time. We were just some people who wanted better lives for our sons and daughters. We've learnt from that about the ebb and flow that movements experience.

# Strategies we have developed to address the challenge

* QPPD members always attend meetings as a small group;
* Preparation for meetings with professionals and statutory bodies, such as the education department,
* De-briefing meeting afterwards to develop our lobbying strategies;
* Our message is consistent;
* A paid worker is employed by the group to support its activities;
* Keep abreast of policies;
* Leadership roles are shared and rotated, so that there can be continuity and to ensure that newer members can also develop these skills;
* There is a continuing programme of information mornings to encourage parents to understand what inclusion involves for their particular child and also to join into the broader work of systems advocacy;
* Widening the membership.
* More positive publicity, such as public rallies.
* Publications with a positive message.
* Sustaining the commitment. Members are very passionate about the cause and what they believe in and about their dreams for their children.

# Looking to the Future

We see a number of tasks ahead:

* Promoting inclusion and resisting segregation. Currently, although there are more policies and legislation supporting education for children with disabilities, there is again a trend towards segregation. This is because of the way in which resources are being directed. Resources are now provided mainly in separate settings or in small settings on mainstream school campuses. The rationale is that resources need to be clustered but that means that students too must receive their education at designated sites. So one of the main tasks of QPPD will be to "stem the tide".
* Seeking support from wider groups, including professionals, both academics and educators.
* Liaising with similar groups internationally to "lend credence" to our own goals. If it's known that perhaps there is inclusive schooling in less developed countries then there seems to be less excuse for our country not to do it.
* Looking at the notion of lifelong learning beyond primary and secondary education and beyond schools altogether. Young people may seek a home of their own in the community or may stay at home for many more years. They have needs for leisure, recreation, sport and community access, employment and further education.
* Challenging the barriers in further education. Most Technical And Further Education (TAFE) courses for people with disabilities are inappropriate and of poor quality - similar to the life-skills commonly delivered in special schools. Each TAFE campus is autonomous and usually inadequate and there is no over-arching umbrella governance. We have much work to do here.

QPPD tries to set priorities and goals each year. These are driven by the experiences, needs and wishes of the parent members and where their energies lie while at the same time keeping the big picture in mind and trying to work at a systems level.

We have to be alert to where there's an opening in the door to give an opportunity to influence the kinds of programmes, services or courses available. For example, where before there were no further education opportunities for students with intellectual disabilities there are now at least some courses on offer. Similarly, work opportunities were limited to training centres and sheltered workshops. These should be seen as windows of opportunity and chinks in the armour to bring about change.

# Our advice to other Parent Groups

* Coming together to discuss things informally to start with gives incredible strength;
* Sharing experiences and clarifying a common cause enables people to work together;
* Workshops, guest speakers and conferences give inspiration;
* Bringing in people from outside is a kind of reality check and helps us to reflect and move on;
* Joint planning and doing things in pairs and groups strengthens individuals as well as the group;
* The group reaffirms that parents are the experts on their own child;
* Work at developing a constructive relationship with official departments;
* Learn to deal with people at different levels and talk appropriately to different groups of people within the system;
* Always treat people with respect and be polite;
* Be consistent in your message and aims;
* Be firm, honest and positive in what you believe;
* Remember that parents' voice is legitimate and has great integrity;
* It is important to make time for yourself and to have fun;
* Keep your dreams for your children; they give you the passion that drives the work towards inclusion.

# Sources:

A group of parent members of Queensland Parents of Disabilities (QPPD) held a meeting to discuss the questions outlined by EENET's Family Involvement project. They sent a tape of their discussion as well as a number of documents produced by QPPD.

**Time-line:**

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| **1980** | National Women's Conference; |
|  | Queensland disability workshop; |
|  | QPD established; |
| **1981** | Access '81 Conference, "The Future Should Be Theirs"; |
| **1982** | QPD became an incorporated body |
| **1983-84** | Received funding for travel, produced newsletter, communication and lobbying workshops |
| **1984** | QPPD Education sub-committee established |
| **1985** | Office provided by Department of Education, submissions written for funding and employment of a staff member |
| **1986** | International Year of the Family; |
|  | Access '86 Conference; |
|  | QPD members involved in federal consultations which formed the Commonwealth Disabilities Services Act. |
|  | QPD Education sub-committee was born; |
|  | Pressurized government to take responsibility for all students' education. |
| **1987** | Changed name to QPPD; |
|  | Conducted consultations of 200 people for "Quality Lifestyles"; |
|  | Moved to new premises. |
| **1988** | QPPD developed 2 other organizations: Queensland Advocacy Incorporated (including legal advocacy) and Community Resource Unit (including education and training for the service sector). |
| **1989-90** | Two year "Quality Lifestyles Project, including "Quality Lifestyles" conference; |
|  | produced 2 booklets: "The Statement" and "The Issues"; |
|  | moved to new premises. |
| **1991** | 3-day workshop run by Canadian parent and advocate, Bruce Uditsky; |
|  | Inclusive Education Network established; |
|  | Recurrent funding to do advocacy. |
| **1992-93** | Teleconferences and networking statewide; |
|  | "Access '93" conference, with emphasis on inclusive education. |
| **1994** | "Inclusion in Life" activities. |
| **1995** | "Inclusive Lives" campaign; |
|  | subsequent backlash from Queensland Teachers' Union; |
|  | students excluded from school which provoked national rallies and protests across the state; |
|  | work continued to focus on defending justice and exposing exclusionary practices and segregation; |
|  | Institutional reform was one of those activities |

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**QPPD: Guiding Principles For The Organisation's Work**

1. **ENRICHMENT BY DIVERSITY:** Society is enriched by the diversity of its members and their shared humanity.
2. **PARTICIPATION AND CONTRIBUTION:** People with disabilities are members of society and, like everyone else, need opportunities to participate in and contribute to ordinary life.
3. **POSITIVE FUTURES:** The future of people with disabilities and their families lies in the willingness of all of us to find better ways of supporting ordinary life.
4. **RECOGNITION OF VULNERABILITY:** People with disabilities are more vulnerable when they are not supported to belong to families, neighbourhoods and wider communities.
5. **SPEAKING OUT FOR OTHERS:** Advocacy provides a voice for people with disabilities when they face ignorance, fear, abuse, and rejection of their community membership.
6. **STRONG INDEPENDENT ADVOCACY:** Advocacy is strengthened when it is independent and as free as possible from conflicts of interest.
7. **FAMILY LEGITIMACY:** Parents have a natural vested interest and a legitimate role in safeguarding the lives of family members and can be effective advocates for them and with them.
8. **JOINING TOGETHER:** Parent advocacy is established and strengthened by sharing ideas and experiences, supporting one another and working towards a common vision for sons and daughters.
9. **COLLECTIVE STRENGTH:** The collective voice of families, joined together in advocacy, influences the direction of governments, services, and wider community attitudes and responses.
10. **JOINING WITH ALLIES**: Joining with others with a similar vision strengthens the advocacy voice of people with disabilities and their families.

**QPPD: ORGANISATIONAL GOALS AND OBJECTIVES**

1. Staying in touch with the grass roots;
2. Advocacy development with families;
3. Systems advocacy;
4. General advocacy development;
5. Management and accountability.

**QPPD: What Inclusion Means To Children**

* being able to enrol at the local neighbourhood school;
* sitting in regular classrooms beside children the same age who don't have disabilities;
* making friends with other children at school;
* gaining support from teachers and children to be included into the life of the class and school;
* having curriculum adapted where necessary;
* participation in the classroom in group and individualised instruction;
* having additional resources such as teacher aide time and equipment;
* belonging to a group;
* growing in self confidence;
* assisting other children to understand and celebrate differences;
* having the same opportunities as others.

**QPPD: Strategies Parents Can Use**

* check out what others know about the local schools;
* got to your local schools well before you want your child to start (6 months);
* talk with the principal and the person directly responsible for educational services for your child;
* always take a friend or ally with you for support;
* emphasise your child's strengths and talk about their needs. It may be useful to make a list beforehand;
* act confident, look at people, sit straight;
* talk about the support your child will need;
* talk about what inclusion means to you and your child;
* talk about rights and expectations of education for your child;
* repeat your main message if there are excuses or evasions;
* consider taking issues higher if you do not get what you want;
* ask lots of questions about the school and what it does;
* take notes in meetings; check what is agreed or not agreed;
* read about inclusion so you can state a few facts;
* talk about ways in which inclusion can work;
* network with other parents;
* identify your allies in the education system and enlist their support;
* enlist wider advocacy support;
* consider a support group to help you with strategies;
* always tell people when things are going well;
* give positive feedback, affirm their efforts, assistance and support;
* tell positive stories.

**Reference:**
**Title:** Striving for Inclusive Education for All: Queensland Parents of People with Disabilities (QPPD), Aus
**Author:** QPPD
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