

Families for Change

Promoting and defending the rights and interests of people with a developmental disability.

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family

ADVOCACY

Activism needed. Apply here!

The political environment, in which we currently exist, has done much to silence and still the activists amongst us. A number of recent reports and articles have pointed to the 'silencing of dissent' across the not for profit sector in Australia. As the heavy hand of government is being felt across many quarters and the public purse strings are pulled ever tighter, so too are the lips that used to form the words of activism. They are falling silent for a number of reasons - fear of funding loss, frustration at calls for change falling on the deaf ears of governments, unwieldy and unresponsive bureaucracies, and 'biting the hand that feeds you' syndrome.

However, as the articles in this edition of *Families for Change* highlight, it has been activism that has brought about the changes within the disability sector over the past 20 years - activism, which in the main, has been led by parents, families, people with disability and their allies. It has not been governments, it has not been service providers, it has not been public servants who have stuck their necks out and risked everything in the struggles to acquire something better for people with disability. They have joined in at some point, willingly or otherwise, as the tide of change enveloped them, but the tide was turned by the activism of an often small number of committed people.

Family Advocacy by its very nature as an advocacy agency, undertakes activism on an almost daily basis. Some of our activism has contributed towards a number of very significant changes within the disability sector. In the 1992 Annual Report, a mention is made of the *Commonwealth/State Disability Agreement* (CSDA) as it was then known. The CSDA called for State legislation to compliment the *Commonwealth Disability Services Act* 1986. Family Advocacy became a member of a community reference group providing input into the form of legislation

required. The resulting New South Wales *Disability Services Act* 1993 was the culmination of many hours of work by a small group of people and was at that point, the strongest bit of State legislation to be implemented.

In 2004, Family Advocacy's activism came into play again around the proposed changes to the Post-School Options Program/ATLAS. The Government announced funding cuts, a move away from individualised funding and the creation of two new programs. Family Advocacy joined forces with many families, other advocacy groups and service providers to 'stare down' the Government and oppose the changes. The ensuing battle resulted in an increase in funding, a review of the process by a Parliamentary Committee and created an opportunity for on-going debate on the need for individualised funding as opposed to block funding.

Family Advocacy has also used the time leading up to a State election a number of times over the years to successfully gain support for significant issues. In 1995, it was the *Kids belong Together* campaign which triggered the commissioning of the *McRae Report* which highlighted the inequity of funding for children with disability in regular classes and led to what we now have in NSW - funding that currently supports 25,000 children with disability in the regular class of their local neighbourhood school.

Once again, in the lead up to the 2007 State election, Family Advocacy is running the *Help where it's Needed* campaign calling on the NSW Government to provide a skilled and experienced specialist teacher in every school to provide direct support to students with additional needs and to build the capacity of teachers to support all students.

The articles published in this journal focus on changes that have occurred over the past 20

years in the areas of inclusive education, supported living and open employment. The authors have all been key players in their areas of expertise and they too have brought activism to their work. Trudy van Dam worked in the area of supported living for much of this time and details the legislative changes that occurred and the subsequent changes to the way accommodation supports were being provided. Bob Jackson writes of the huge changes that have occurred within the education system for children with disability since the late 1970s. Phil Tuckerman, who started the first open employment agency in NSW for young people with significant disability, has identified the enormous changes that have occurred due to vigorous activism over the years.

People with disability will always need dissenters and activists in their lives - people prepared to name things for what they are and to push for change. Activism may seem like a scary word to many but it is an absolutely essential element within today's social climate.

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20 Years of supported living in Australia

Trudy van Dam

Trudy van Dam is the co-coordinator and a lecturer in the Habilitation programs at the Australian Catholic University. Previous to taking up this role she worked for over 20 years in service provision in the disability field. Her expertise has included: employment support; devolution of institutions; support of individuals labeled as having challenging behaviours; development of systems for assisting individuals develop and maintain social relationships, and the development of highly flexible and individualised support systems.

In 1984 when I first began working in the disability field it was an exciting time, full of hope for the future. The *Richmond Report* had been adopted by the New South Wales Government the year before. The Report committed the Government to the development of community based accommodation services and strengthened the inroads already made by early pioneers who had been setting up community based houses as early as the late 1970s. We are fortunate to still have the expertise of some of those early pioneers such as John Le Breton, Phillip Morath and Mary Ellen Burke who worked to demonstrate that community living was not just an idea but could be a reality. They worked alongside parent activists such as Jane Fraser, Jeanette Moss and Judy Ellis and many others who worked tirelessly to raise issues with politicians and bureaucrats and disseminate information to families and the community.

It was through strong activism by people with disabilities, families and professionals, supported by some bureaucrats and politicians, that a major review and consultation process of disability services across Australia was undertaken. The disability community owes a particular debt to Senator Don Grimes who was the then Minister for Community Services. Senator Grimes was particularly strong in his belief that major reform must take place in disability services and through his efforts, and that of many others, the Commonwealth *Disability Services Act* (DSA) was introduced in 1986.

The DSA promised a new era that would see people with disabilities take their rightful place as full participating members of the community. Existing disability services were required to prepare a transition plan outlining how they would change their services so they met the Principles and Objects of the DSA and the promise was that within five years of the introduction of the DSA all services would comply.

“The DSA promised a new era that would see people with disabilities take their rightful place as full participating members of the community”

To learn more about what it was going to take to develop community based services, demonstration projects were funded across Australia to spearhead the development of new services. An example of these projects was the funding of the Hornsby Branch of the Challenge Foundation of NSW to close its hostel and move all residents to community based accommodation. In 1987 its doors closed. Whilst some of the women who moved from there have since passed away, those remaining have continued to live successfully in the community.

In 1992 the introduction of the Commonwealth *Disability Discrimination Act* (DDA), strengthened the rights of people with a disability. The other significant legislative change was the introduction of the *Commonwealth State Disability Services Agreement* (CSDA) and the subsequent transfer of responsibility for all accommodation support services to the state governments in 1993. Strong activism was again crucial at this time to influence the development of the NSW *Disability Services Act* 1993, which was a requirement of the CSDA. The lobbying in NSW was very strong and many individuals contributed tirelessly. The Disability Safeguards Coalition was formed to galvanise and focus the efforts of activists. The coalition included advocacy agencies, service providers and other interested people. The lobbying particularly influenced the introduction of the *Complaints, Appeal and Monitoring Act* (CAMA) which provided an avenue for ensuring that the DSA was implemented appropriately.

Significant advances have been made in the development of community based supported living options. At the time of the introduction of the DSA, almost 100% of people with a disability living away from the family home were accommodated in institutions. Today 72% of people supported by accommodation services do so through community based options such as group homes, in-home accommodation support and other arrangements (AIHW:2006).

The DSA did not specify exactly how accommodation support services needed to look. It was envisaged that people would need flexible and individualised supports in order to meet each person's particular needs. However, in the 20 years following the introduction of the DSA, group homes have become the most dominant form of supported accommodation. They account for 68% of all non-institutional accommodation support services (AIHW). This has been a significant problem in meeting the individual needs of people with a disability. Group homes have been found not to provide the flexibility and range of options needed by many people.

Whilst some group homes do provide quite individualised arrangements, many problems have arisen in homes that are operated using highly structured rosters and routines. These homes meet the service's needs for routine and predictability rather than meeting the needs of the people living in the home. In such homes there is a tendency to operate the home on the basis of the group needs rather than meeting the individual needs of residents. Excessive staff presence and control have limited the ability of residents to develop their individual interests and to take control of their lives. Incompatibility of residents has also proven to be a significant problem in group homes and this has been exacerbated by reluctance of services to change living arrangements when residents don't get along.

Whilst group homes have flourished, some services have developed more individualised options. These services inevitably have small groupings of residents which allows for the pursuit of individual goals and meets the challenge of incompatibility because it is easier to find two or three people

who get along well than it is to find four or six. Some services have developed co-residency arrangements which involve the person with a disability sharing their home with a person without a disability. This option has proven to provide a sustainable living option for many people (Cameron-McGill and van Dam; 2000)

Some services have also formed strong alliances with people with disabilities and their families and devolved much of the control for the person's support to the person and their family.

A focus of many individualised support services is assisting people with a disability to develop skills and take greater control of their lives. These services are based on the developmental model which was a strong underpinning principle of the DSA. It is based on the knowledge that all individuals, regardless of ability, will continue to grow and develop for all their lives and that it is the responsibility of the support service to facilitate and support this development through specific skill development and the provision of growth opportunities. Unfortunately, the focus on the developmental model has largely been lost in accommodation support services. The focus tends to be on 'care and protection' and this stops the individual from experiencing new opportunities. Whilst the loss of focus on the developmental model has been a feature of accommodation services for a long time, it has been exacerbated in recent years by the approach of services in complying with occupational health and safety legislation. The dominant approach is that people with disabilities must be prevented from taking any risks rather than supported to take reasonable risks. This has resulted in the

prevention of people with a disability having pets (in case they, or staff, fall over the animal), prevented individuals from accessing local community facilities because a risk assessment hasn't been carried out on the particular shop or park the person wishes to attend. The clash of occupational health and safety legislation and the DSA has presented a major threat to meeting the needs of the people with a disability.

In the 1970s and early 1980s supported living was an idea that was slowly being tried. Now after more than twenty years, the benefits of community living are clear. We know from evidence from around the world that:

- Community based supported living is either cheaper or no more expensive than institutions.
- Community based supported living produces far better outcomes in every area of life than institutions do.
- The smaller the living unit, the better the outcomes are for the people living there.
- Any accommodation option that congregates people with disabilities together such as clustered living arrangements and 'village' communities produce poorer outcomes than small scale housing options dispersed throughout the community.
- Smaller scale housing options are associated with the greatest amount of interaction between staff and residents.
- Grouping people who have 'challenging behaviour' produces poor outcomes for those individuals.
- Living in institutions produces poor outcomes for people with 'challenging behaviour' (Epstein-Frisch, van Dam, Chenoweth; 2006).

“Some services have also formed strong alliances with people with disabilities and their families and devolved much of the control for the person's support to the person and their family”

With all this available knowledge about what ‘works’ and what ‘doesn’t work’, one would imagine that the field would be moving to smaller scale living options and more flexible arrangements. What we find, however, is that there is a tightening of the options available and even moves to establish services which will congregate people with disabilities such as the redevelopment of institutions into services for people with ‘challenging behaviour’ and older people.

The biggest challenge that is to face the supported accommodation area in 2007 is to ensure that what has been learned from the last 20 years is put to good use. There is so much evidence and experience that clearly demonstrates that the move to community living and smaller living situations is clearly better for all people with a disability regardless of their support needs, yet proposals to retreat to practices and models of the past continue even though they are masqueraded as new ideas. We find that the field is inundated with the rhetoric of community living but at the same time practices and options are proposed that are based upon discredited models of the past.

The promise that all services would comply with the DSA made 20 years ago has long since faded and there are currently almost 2000 people still living in institutions in NSW. There are many people desperately in need of accommodation support and we find ourselves fighting to maintain the gains that have been made in the past 20 years.

The passion and enthusiasm that saw alliances between people with disabilities, families, advocates, service providers, bureaucrats and politicians create major changes 20 years ago have long since gone, but the field desperately needs that passion now to ensure that the advances made don’t trickle away, and to ensure that progress continues. None of the advances that have been made in the last 20 years would have come to fruition without the vigilance and hard work of activists. We need that vigilance now more than ever. We all need to be aware of what research and evaluation of services has shown works and what has been shown not to work. We need to keep the fight going and bring to account those who seek retreat to practices that we know will not benefit or will even harm people with disabilities.

Australian Institute of Health and Welfare (AIHW) (2006) *Disability Support Services 2004-2005: National data on services provided under the Commonwealth State/Territory Disability Services Agreement*. Cat. No. Dis. 46. Disability Series. Canberra: AIHW

Cameron-McGill, F., van Dam, T., (2000) “Shared Living: having a life, not a model of support”, Conference paper delivered at 2000 ASSID Conference, Fremantle, October 2000

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“None of the advances that have been made in the last 20 years would have come to fruition without the vigilance and hard work of activists”

Inclusive Education in Australia – Parent Power at Work

Dr Bob Jackson

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Up to 1976 children with a significant intellectual impairment were not allowed by law to go to ANY school, segregated or included. The responsibility for their education was left to parents, but the Education Department could monitor the quality of this to ensure that it was done properly. This was the situation in Western Australia with other States varying somewhat, but overall they were very similar. To go from this situation to one where all over Australia children with very significant impairments are attending their neighbourhood school is simply, a revolutionary change.

As I am not an historian and have been mainly based in WA I do not have all of the relevant information to provide a sequence of events, so I apologise to those that I omit who have been key to changes in individual States. There are, however, some giants activating for change that I would like to acknowledge at the risk of leaving out others who may have been equally significant.

One of the pioneer activists in the education of children with disabilities was Jennie Guhl, a mother of a child with an intellectual impairment who found that her son was denied education in the early 1970s. She formed a mainly parent group called 'Watchdog' that lived up to its name and harassed both the Education Department and the local disabilities department in WA to get the law changed, refusing to accept that her child (or any other) was 'ineducable' or 'untrainable'.

Simultaneously in the 1970s, at several institutions around Australia some exciting work was occurring on educating these 'untrainable children'. At Marsden Hospital in New South Wales, Pyrtton Training Centre in Perth and no doubt other places, children with very significant impairments were being taught to read and do mathematics – debunking the whole 'untrainable' myth. Macquarie University, in Sydney, did some world leading research on early intervention and academics from around the world such as Baer, Stokes, Maggs and Birnbrauer worked in Australia demonstrating rapid learning for people with significant impairments.

All this exciting work however, would likely have come to nothing without the pressure of families. The first court case that I know of in Australia was about 1976 in Bunbury in WA. A family challenged the right to an education for their child in the Magistrate's Court – and won! The local Catholic school had agreed to take the child, so the Magistrate ordered that as the State school was unwilling to take the child, the child could go to the Catholic school with the costs of his education paid for by the State. A victory for common sense but alas it did not last. It ended up in the High Court where the issue being decided was the extent of Ministerial power. As the original reason for the case had been lost, and in the face of such massive opposition to a side issue, the parents pulled out. It should be noted that the family was supported in the trial by other parents who organised world experts in education to come to

WA to give evidence as well as local identities such as Dr Birnbrauer of Murdoch University and Darrell Wills who worked with the families. It was around this time that the parent group Parent Learning and Development Education Group (PLEDG) was started – a group that still today successfully accelerates the learning of children using parents as teachers.

“All this exciting work however, would likely have come to nothing without the pressure of families”

In WA, some changes in the law were made in 1976 that made very little difference in practice so the pressure continued. Eventually the State Government responded by setting up a review, where the committee brought down a report (the *Jecks Report*) recommending that the IQ be used as the method for determining a child's suitability for education, with those below specified IQ levels deemed 'ineducable' or 'untrainable'. Obviously there would be no point in trying to educate the 'ineducable' or 'untrainable', so they were to go to Activity Therapy Centres in the community or institutions. This method of determining education based around categorisation of intellect or other medicalised label was described by critics as being as logical as determining medical treatment on the basis of educational prowess.

A local academic, Dr Trish Formentin, went public and criticised the *Jecks Report* on the front page of the local newspaper – an action that rebounded on her for the remainder of her career. The *Jecks Report* was ultimately buried by the government who later set up a separate committee to recommend on ‘special education’ (the *Shean Report*).

In 1983 the government in WA had set up an investigation into education in general. This was published in 1984 (the *Beazley Report*) and was mirrored by similar reviews of education in other States. The *Beazley Report* was possibly the first in Australia to recommend inclusion as one option for children with an intellectual disability, and recommended that the basis for determining the education for all children should be educational need rather than medicalised category. The *Beazley Report* stopped short of taking a ‘rights’ perspective on the need for regular class access for children with impairments, in effect leaving it up to the goodwill of the Education Department and schools to implement the recommended changes.

In 1996 in WA the *Shean Report* was published. It stated that ALL children could be educated and had a right to education in the State system. It recommended a range of education options with totally segregated Special Schools; Education Support Centres on the grounds of the local school but with a separate principal and administration; and Education Support Units which were any combination of special classes or groups of classes on the grounds of the local school with the same principal as the regular school. Inclusion in the mainstream was also an option, although it was implied that this would be only for those most capable. Children were placed primarily on ascertained levels, mainly determined by IQ testing. As such it failed to follow the lead of the *Beazley Report* and instead relied on the old ‘cascade model’ based around the least restrictive alternative. However the *Beazley Report* did break new ground by strongly recommending training of teachers to work with children with impairments. It also allowed for a semi-independent mediation if there was an unresolvable conflict between parents and a school on the appropriate

placement. This was a major breakthrough and resulted in a few parents successfully challenging their child’s placement.

In other States the names of the arrangements varied but similar principles were followed. One exception seemed to be Queensland where they tried for ‘cluster schools’. The logic was that if all of the children with a physical disability only attended a few schools, there could be major savings on building modifications. Similarly, grouping other disabilities in certain schools could assist in centralising expertise. The down side of such groupings seems to have avoided scrutiny as this model existed for some time and still exists in a modified form to this day. It is interesting to note that even though the Commonwealth *Disability Discrimination Act* had been passed in 1992, the State Education Acts around the country failed to acknowledge the changes and left the right to determine placement in the hands of the Education Department, even though this was not in accord with the new Commonwealth law. As Commonwealth legislation over-rides State law, the lack of coherence between the various Acts was extraordinary.

This overall model of physical placement, depending on ascertained ability, still failed to satisfy many parents. It was not inclusion in the mainstream of the local neighbourhood school and the children were still congregated around a label.

Two milestone pieces of Commonwealth legislation had a huge impact on inclusion. The first was the *Disability Services Act* 1986, which was brought in by Senator Grimes – another unsung hero. One point not generally known is that a parent of a child with a disability, Judy Ellis, was extremely influential in the drafting of that legislation, still recognised through the world as a very progressive Act. This legislation was described as a ‘new direction’ – integration rather than segregation and congregation. The second major piece of legislation was the *Disability Discrimination Act* 1992 (DDA), which made it illegal to discriminate on the basis of disability, and moreover mandated that if

adaptation or support was necessary for a person to access regular education, this had to be provided. The States also brought in their own complementary legislation in the form of equal opportunity laws. School inclusion was now a right under law for all children. Of course to have a right is meaningless if it is ignored – a reality discovered by many families (and unfortunately still experienced today in some cases).

Numerous families took action under the DDA or equivalent State legislation. One of the first cases was lost in a judgment that reflected the prejudices of the time. The case was the ‘L’ case where a girl with multiple impairments was excluded from school and the parents took a case under disability discrimination legislation. The reason given for the judgment against the child was that her presence at the school had caused ‘unreasonable hardship’ for the teachers! I wonder if the same

“School inclusion was now a right under law for all children”

judgment would have been allowed if the teachers had found it too hard to teach boys. Another case (unreported) was lost for similar reasons involving a child with difficult behaviour in Townsville, even though the weight of evidence indicated that the school itself had caused the difficult behaviour. On the other hand other cases were settled out of court and some were won. However, a survey in NSW of families of children who were included indicated that even though 70% had experienced discrimination, *no one* who had gone through the discrimination commission system would do so again – even if they had in fact been successful. Parents report that the process has not improved, although education departments are more likely nowadays to yield earlier in most States, so less cases seem to go to actual Commission hearings.

Queensland Parents of People with a Disability and Queensland Advocacy Incorporated, Independent Advocacy in

SA, Star in Victoria and Family Advocacy (NSW) strongly supported many of these cases and other groups were probably involved as well. In all of these court cases parents suffered immensely as they were forced through huge emotional and financial trials in an attempt to achieve a basic right of all other children – to attend the local neighbourhood school. Some cases were well publicised such as Scarlett Finney and Daniel Purvis, but many parents remain unsung heroes, building the path for the next generation. Some cases were lost despite heroic efforts by the families involved – Daniel Purvis’s case was taken by his foster family to the High Court and lost on a technicality. The Purvis case broke new ground however, in that the original judgment found in favour of the child, found suspension to be discriminatory and indicated that good intentions were insufficient to avoid a charge of discrimination. In addition, a Federal Appeals court judge saw the DDA as trying to remedy a perceived *social evil* (i.e. discrimination). What a shift from the old ideas of ‘untrainable’, ‘ineducable’ and compulsory segregation! The era of education in the neighbourhood school as a right for all children was being endorsed by the highest courts in the land.

The view from the outside of the education system was that the litigation seemed to have had minimal impact on education departments. In reality though it was becoming clear to governments that they were going to have to yield on the issue. In the Salamanca Statement of 1990, the United Nations had recommended inclusion as the best educational option for children with impairments. The USA had mandated inclusion as the first option since 1974, Italy had been fully inclusive for several years and many third world nations were starting to implement full inclusion policies. In 1996 WA implemented a project of fully inclusive schooling for up to 50 children with severe intellectual impairment, with the results independently assessed by Edith Cowan University. The report concluded that inclusion was a very positive experience for the child with a disability, the other children and schools generally. Wills and Jackson

published a paper defining inclusion, with the intention of ensuring that governments could be held to account against a published standard. In Victoria, Joan Kirner’s Government was supportive of inclusion, a position that was supported also by the Kennet Government as an issue of parent choice. Unfortunately, the policy, funding and staff training necessary to make it a reality seems to have been limited with the result that the newly won ‘right’ was difficult to achieve in practice.

The year 2000 saw some major developments. The United Nations approached the National Council on Intellectual Disability for a report on how well inclusion was going in Australia for the 10th anniversary of Salamanca.

The National Council on Intellectual Disability approached Darrell Wills of WA who arranged with academics and students in each State to give up their time to carry out a sampling of their State on the ratings of families, teachers and principals on how well each State and Territory was going on school inclusion. These results were publishedⁱ and copies sent to each Minister of Education. One Minister was reliably heard to say “I’m not having our State scored as 3Ds”. An international conference on inclusion was organised for Melbourne in 2002 with many world experts on inclusion attending. WA and Tasmania set up major investigations with reports written in support of parents having a range of options including full inclusion in the neighbourhood school. WA and Tasmania stand out as the States that have thought the issue through with inclusion receiving policy, training and financial support. Queensland is also moving, with the other States agreeing in principle but without the same level of support apparent. Educational Standards have been implemented although it is unlikely they will have a major impact except on the most recalcitrant schools and States.

For many, many children in primary school, inclusion is now a reality with teachers increasingly supporting the idea. High Schools are also taking it on and the move now is for people with an intellectual disability to attend

university. All rosy now ...? You don’t get a society to change from strong rejection of a group to easy acceptance of sharing the classroom in one decade or even one generation – I think it will take at least three generations, but we are moving and after more than 30 years working on the issue, I can now say I am excited by what is happening.

“For many, many children in primary school, inclusion is now a reality with teachers increasingly supporting the idea”

As partnerships develop between parents and teachers examples of world standard inclusion are appearing. Reviews of the literature have been published showing that children who are included do significantly better academically and socially. This has opened up other avenues for legal appeal through litigation for poor professional advice if segregated schooling was recommended by professionals or administrators. Such litigation would be under civil law and not restricted as it is under the DDA. Time will tell if such avenues have a large impact – at the moment the major gains are being made where partnerships are built between schools and parents.

How did we get here? No simple answer but it is clear that without the actions of many families, we would not be where we are now. The other aspect that I believe has been important is the coalition of dissident professionals, supportive teachers, principals, bureaucrats, academics and families – but with the *families driving the agenda*. We have shown we can move mountains together.

ⁱ Wills, D., & Jackson, R. (1996). *Inclusion: Much more than being there*. *Interaction*, 10(2), 19-24.

ⁱⁱ *Interaction*, Volume 14 Issues 2&3, 2001.

OPEN EMPLOYMENT FOR PEOPLE WITH A MODERATE TO SEVERE INTELLECTUAL DISABILITY:

THE REALITY AND THE PROSPECTS

Phil Tuckerman

Phil Tuckerman has worked in the area of open employment for over 20 years and established a demonstration project in the early 1980s (Jobsupport) to show that open employment was realistic, for people with intellectual disability in Australia in the early 1980's. He has written a work experience manual for the New South Wales Department of Education and Training and an open employment manual for the Commonwealth Department of Health and Family Services. Phil has also participated in a cost benefit analysis that demonstrates open employment is the most cost effective option to government for people with high support needs.

This article tracks the progress made in getting people with disabilities into open employment, using Jobsupport's programs as an example, but highlights that there is no room for complacency and that activism is urgently needed to ensure a higher level of employment opportunities for people with moderate to severe intellectual disabilities.

In the early 1980s, employment opportunities for people with a moderate to severe intellectual disability were extremely limited. Employment in sheltered workshops was the norm: open employment (that is, regular jobs in regular, non-segregated workplaces) was rare.

From 1986, this employment pattern showed some significant changes. Employment in sheltered workshops (more recently known as Business Services) decreased markedly; open employment grew; and for school leavers, non-vocational Post School Options/ATLAS programs rapidly gained popularity.

STATISTICS

Student Destinations	80/82	90/92	93/95	02/04
Remaining Home	27%	37%	20%	15%
Sheltered Workshops	59%	25%	18%	14%
Open Employment	4%	16%	17%	22%
Post School Options			38%	39%

Some information about these changes is available from a series of surveys conducted by Jobsupport about the destinations of students leaving 'IO' classes – that is, classes for students with a lower mild, moderate or severe intellectual disability – in the Sydney metropolitan area.

CAUSE FOR CONCERN

The current pattern of destinations for school leavers with a moderate to severe intellectual disability is a cause for concern. First, non-open employment destinations are still the norm. In the early 1980s, it was sheltered workshops; now it is Post School Options/ATLAS. Second, the plateau of about 20% reached by open employment is a disappointment. This is especially the case for those who can recall the Commonwealth Government's optimistic aspirations two decades ago in its *New Directions Report* (1985).

Nevertheless, the relatively minor role of open employment still has some positive people with a moderate or severe intellectual disability can successfully enter the open workforce and remain there. We also have very good evidence about the conditions for success in open employment and the means by which these conditions can be brought about.

OPEN EMPLOYMENT – A VIABLE OPTION

The possibility of open employment and the conditions for its success are illustrated by the approach and achievements of Jobsupport.

Jobsupport began in 1986 as a Commonwealth-funded demonstration project aimed at examining whether open employment for people with a lower mild, moderate or severe intellectual disability was a viable prospect under Australian conditions (open employment had already been established in a number of locations in the United States).

The achievements of Jobsupport’s open employment services, with over 450 people in open employment, have demonstrated the viability of open employment for people with a moderate to severe intellectual disability. As well as being viable, open employment for this group of people makes sense economically. Research by Econtech in 2005 showed that open employment is a far cheaper option for government funding than Business Services and a very much cheaper option than Post School Options/ATLAS. Econtech’s 2006 research showed that significant recurrent savings would be achieved if Post School Options/ATLAS clients moved to open employment.

MORE ACTION NEEDED.....

Nevertheless, despite its advantages, the development of open employment in Australia for people with a moderate to severe intellectual disability has hovered at a relatively low level for many years. Dealing with this impasse is going to require some changes to the system of service delivery. Some of these possible changes are lightly sketched in the following few paragraphs.

1. In the United States, there are some excellent technical assistance programs based in universities. These programs have identified best practice. They review services on request, identify opportunities for improvement and put the reviewed service in touch with best practice examples. *Australian services would gain a lot from the introduction of similar programs within Australia.*
2. The proposed Commonwealth Department of Workplace Relations *star rating system* for open employment services could be used to identify good practice and inform a technical assistance program in Australia.
3. The introduction of ‘*report cards*’ for open employment services would enable people with an intellectual disability and their families to make informed choices between services.

4. The *Commonwealth State/Territory Disability Agreement* – which governs Commonwealth and State funding arrangements for various services – requires much greater flexibility than it currently has. *There should be more liberal right of return to State funded Community Participation and Transition to Work programs as a safety net for people who unsuccessfully attempt open employment.* At the moment, uncertainty about right of return is enough to deter some people from attempting open employment. Furthermore, *the restrictive cap on the number of places in each Commonwealth funded open employment service is counter-productive and should be lifted.*

If such system changes are not attempted, it is predictable that the current relatively low level of open employment for people with a moderate to severe intellectual disability will persist. In that event, an important group of Australian citizens will be the losers.

“We have very good evidence that people with a moderate or severe intellectual disability can successfully enter the open workforce and remain there”

Resources from the Inclusion Collection

Below is a selection of resources about the topic of this issue, activism. You can order articles, books, videos and kits from the Inclusion Collection online at www.family-advocacy.com or by phone on (02) 9869 0866 or 1800 620 588 (for non-metropolitan callers).

Sue Rubin speaks out **File: 10670**

This is an excellent article by a young political activist who also has autism. She writes about her decision (which in some ways seems more like an obligation) to organise people with autism in order to advocate for their human rights - particularly in relation to the use of aversive behaviour 'therapy', which she argues is actually a euphemism for 'abuse'. The strengthening element of this piece is her clarity of thought and her methods of activism - for example, finding a role model and using his work as a framework for her own.

Activism and life learning **File: 10966**

Diana Qian understands what it is like to have a physical disability and at the same time come from a non-English speaking background. In this short article she shares some of her experiences, including her struggle to go to university. Driven by her personal experiences and by her sense of social justice, Diana deals with negative attitudes by turning them into a driving force for her activism.

Some Ideas for Lobbying **File: 10137**

This is a list in point form of techniques for lobbying bureaucracies, adapted from a list put out by the Co-ordination Council for Handicapped Children, USA, in 1971. Council for Intellectual Disability (CID) has added four of its own and stresses that people who are taking on this kind of work should enlist the support of advocates.

Lobbying: The Politics of Change **File: 10536**

A really thorough compilation of issues that any lobbyist (remembering that anybody can take on a lobbying role) should have knowledge of. The author talks about many things; how to create a climate of change, how to structure and deliver a message, how to use the media, ideologies (both societal - such as liberalism and socialism - and party political) networking, understanding your 'enemy' and being prepared for the long haul involved in any attempt to radically change the status quo.

Guide to Lobbying: a guide to support strong advocacy by parents who have a son or daughter with a disability **File: 10912**

This easy-to read guide to lobbying is designed to assist parents in their advocacy role. It emphasises the strength of joining with others in lobbying, as well as giving useful and practical tips on lobbying. It has specific information on such areas as writing letters, meeting with politicians, attending meetings and consultations, identifying allies, and using the media.

The Community Action Book **File: 3145**

While quite dated, this book is a non-threatening and "comprehensive guide to community action in NSW". It contains information from how to get organised and active, to how to use the law. There are stories by community activists which show how this general information (for example

lobbying) has been applied in real life. These stories also have another great benefit; they show that while there is a broader knowledge to be gained and many links between different groups and political action, every case is going to be different. There is no one way to success, and nor is success or social change likely to happen overnight. The information within the book also forms a framework within which individuals and groups can take a closer look at structures of power in society. Family Advocacy has a kit called *Step by Step* and these two resources would work well together.

Step by Step: A kit for families working for an inclusive community

Step by Step is a resource especially made for parent groups who are:

- wanting ideas on ways the group can influence their community
- looking for helpful hints on some of the practical issues facing their group
- It is designed in such a way that it can be incorporated into your regular meetings over a period of several weeks and includes material on:
 - increasing networks
 - planning public meetings
 - dealing with the media and other members of the community.

The Odyssey

A journey of enrichment
and possibility

25 & 26 October 2007

Mark your calendar for Family Advocacy's first national conference – ***The Odyssey – a journey of enrichment and possibility***. The conference will be in Sydney on 25 and 26 October 2007.

The conference will cover the everyday joys and challenges experienced by people with disability at significant milestones in their life. Its purpose is to invigorate interest in NSW and Australia around people with disability having a good life - at all stages of their journey. More specifically, it is hoped that people will go away with ideas, contacts and references to promote positive change in the life of their family member, friend or the people they serve.

The conference will bring together speakers who have something fresh to say or examples to share from overseas, interstate and from within NSW.

There will be topics of universal interest as well as concurrent sessions that traverse topics of relevance to people during a particular stage of life.

More details soon.



PO Box 502 NSW 1710 Email: familyadvocacy@family-advocacy.com
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If undeliverable, return to:
The Institute for Family Advocacy
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familyadvocacy@family-advocacy.com

We're on the web!
www.family-advocacy.com

Family

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