

Queensland Advocacy Incorporated

ANNUAL REPORT 2000 - 2001

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Annual Report 2000-2001

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Management Committee 2000 - 2001

President	Nigel Webb
Vice-President	Bernadette Scalora
Secretary	Michael Duggan
Treasurer	Donna Best
Member	Michael Fisher
Member	Amy Stockwell
Member	David Paterson (August 2001)
Member	Julie Conway (Oct 2000 –Feb 2001)

Introduction

This Annual Report covers the period from 1 July 2000 until 30 June 2001. It describes in detail the efforts of QAI to be a strong and effective systems advocacy organisation, committed to its mission of promoting, protecting and defending through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI's Mission and Objectives

QAI's mission is:

“To promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland

QAI's objectives are:

1. To affirm and put first people with disability in Queensland;
2. To undertake systems advocacy that strives to promote, protect and defend the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland;
3. To undertake legal advocacy that strives to promote, protect and defend the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland;
4. To take an active leadership role in advocating for the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland;
5. To support, promote and protect the development of advocacy initiatives for the most vulnerable people with disability in Queensland;
6. To be accountable to the most vulnerable people with disability in Queensland;
7. To conduct an efficient and accountable organization; and
8. To adhere to and constantly reaffirm the following beliefs and principles:
 - ❖ All human life has intrinsic dignity and worth;
 - ❖ People with disability must positively and actively be accorded worth, dignity, meaning and purpose through being included in and with their community;

- ❖ Social Advocacy is functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous and is likely to be 'costly' to the actor in terms of:

- time or other resources;
- emotional stress;
- bodily demands;
- social opprobrium, rejection, ridicule;
- self-esteem, self certainty;
- socio-economic security, livelihood; and
- physical safety, life.

The essential elements of Social Advocacy are:

- strict partiality;
- minimal conflict of interest;
- emphasis on fundamental needs and issues;
- vigorous action;
- cost to the advocate;
- fidelity; and
- being mindful of the most vulnerable person.

- ❖ Systems advocacy is a particular form of advocacy that focuses on influencing and changing 'the system' (that is, the whole of society and the various systems operating within) in ways that will benefit people with disability as a group within society. Systems advocacy includes, but is not limited to, policy and law reform activities.



President's Report - Nigel Webb

I am delighted to welcome everyone to the fourteenth (14th) Annual General Meeting of Queensland Advocacy Incorporated - 20 October 2001 at the premises of the Paraplegic and Quadriplegic Association, Kangaroo Point.

This is my third year as President of QAI and it's my privilege to present the 14th Annual Report. This year the QAI Committee has overseen some significant changes in aspects of QAI's work and development as an organisation. A dedicated piece of work was QAI's involvement in the issues around hostels and boarding houses for groups of vulnerable people with a disability. This attracted considerable community support and media attention. QAI successfully co-ordinated a hostels forum in March 2001 where residents were given the opportunity to speak freely of their experiences.

During the 2000-2001 period QAI continued to operate well in an extraordinary environment of internal and external pressures and continued its organisational growth. QAI maintains a very professional profile in all areas of its work. The Community Living Project with its added scope of promoting advocacy issues for people with disability in regional centres and remote communities; the Law project: from QAI's beginnings this has seen a continuing demand: probably a highlight would be the introduction of the Guardianship and Administration legislation and subsequent appointment of the Guardianship Tribunal and the Office of the Public Advocate. QAI has made a significant contribution to the issue of Guardianship for people with impaired decision making capacity and will continue monitoring progressive developments; the Bioethics Project, where the major influence has been in genetics and the health and well being arenas, has involved plenty of reading, writing and speaking in preparation for future activities. This is only a thumbnail sketch of some reflections, more detail of QAI's work is presented in the staff's section of the Annual Report.

THANK YOU

QAI is very much a team effort, there are so many people who give of themselves willingly and tirelessly to make the QAI experience a rewarding one for everyone involved. We can only hope that all who give of themselves with such enthusiasm are aware of how important their contribution is to our Mission. Special thanks to Stephen Tonge for his support and advice to QAI concerning negotiation of the Lease agreement.

The QAI Management Committee is a remarkable group of people whose long standing commitment may never be fully recognised. Bernadette Scalora, Donna Best, Mike Duggan, Michael Fisher, Amy Stockwell, Julie Conway and David Patterson are my colleagues who have given so much of themselves and learnt so much while guiding QAI towards its collective vision. I would like to thank each member for his/her ongoing support especially during the tough times when important decisions are usually the hardest to make. One member of the Committee, Julie Conway resigned in April 2001 so as to minimise conflicts of interest with her work within the Department of Housing. Julie made an important contribution particularly in policy development and beginning QAI's understanding of what a future governance model might look like. As a result of Julie's resignation the committee advertised for expressions of interest from its members

to fill the committee vacancy, David Paterson answered the call and filled the vacancy. David is a parent of a young child with disability. David has made a significant contribution to QAI and I look forward to working with David in the future.

It is with mixed emotions that I write this particular acknowledgement to Donna Best. Mixed in the sense that Donna is going to leave a huge void at committee meetings and in the daily work that Donna carried out as a committee member as she steps down at the end of this financial year: yet the need for renewal and rest I can empathise with fully. Donna has been a long-standing committee member, in fact since QAI's first steering committee meeting in August 1987.

Donna has served in many roles, more recently as the treasurer. Her other activities have included attending conferences throughout the years on behalf of QAI, carrying out a major role in the distribution of the Newsletter 4 times a year, participating in project reference groups and management committee subcommittees, attending meetings with government and community people, keeping QAI informed of events taking place in the media – monitoring articles in newspapers and sending them into QAI and ringing us if any disability issues are on the radio. In particular Donna played a significant role in the planning for QAI's Action Forum 2001. On behalf of current and past committee members and staff I wish Donna all the best and look forward to seeing her regularly around 'the traps'.

STAFF CHANGES

A few staff changes have taken place during the year. Firstly, Kathleen Dare - Legal Advocacy Development worker - resigned. Kathleen has since been appointed to the Guardianship and Administration Tribunal. Kim Moody also resigned as Administrator in August 2000 for personal reasons. QAI took the opportunity to reconsider its administration needs, hiring both Rose Cenita and Shelley Brook to provide more flexible administrative supports. Along with Julie Granger, these three ladies have held QAI together through another hectic year. John Stannard was seconded by the Office of the Public Advocate for a period of six months and commenced that position in July 2001. Julian Porter replaced him for the six month secondment period.

(P.S. John has subsequently resigned from QAI due to perceived conflict of interest).

QAI ANNUAL FUND

I would like to acknowledge the work of the Annual Fund Chairperson Mr. Ron Ashton and his company Minter Ellison for their ongoing support. The success of the Annual Fund breakfast continues to grow. This year QAI was fortunate to have Justice Marcus Einfeld as its guest speaker. We had to put out the "full house" sign with more than 220 guests, as unfortunately the Novotel hotel could not accommodate a larger audience. Through the Annual Fund and membership of the Friends of QAI, we raised just over \$10,000.00. All money was allocated to the Action Forum 2001 to assist people with disability to participate. QAI thanks everyone for their generous donations throughout the year.

COMMITTEE MEMBER REFLECTIONS

This year Committee Members were invited to offer some reflections on their involvement and participation within QAI. It is important particularly in the International Year of the Volunteer that we acknowledge and support individual contributions.

I was a management committee member during 2000/2001 - a time that has been particularly exciting for QAI and an important learning time for me. I am disappointed to be resigning from the committee after such a brief time to take up employment interstate, but I have sincerely appreciated the support of the management committee and staff who have continually encouraged my understanding of advocacy. The start of my term as a management committee member was a steep learning curve, but throughout the year I have learnt an enormous amount from my involvement in committee development evenings, regular monthly meetings, sub-committee involvement and strategic planning days.

The 4 Days in July and the Action Forum as a whole, in addition to the Phone In/Email In and the Hostel Forum, have provided a wealth of information and networks to inform QAI's efforts to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland. I am honoured to have played a (very) small role in achieving this mission.

I hope to continue to be involved with QAI in the future, even if from afar for the next few years. I would like to take this opportunity to thank the staff and particularly the Director, the President and the members of the management committee for their friendship and professionalism which have made my time on the committee a very valuable and enjoyable experience.

Amy Stockwell
Committee Member

One of the most significant things about the last 12 months at QAI, for me, is a better appreciation of the varying personalities, experiences and skills of the people who constitute it. From staff and Management Committee members, old and new, to consultants who fill varying roles, allies, clients, and participants of the Action Forum, to the key roles of the Director and President. What a wellspring of diversity to draw on and learn from! I have been awed, sometimes touched, by people's commitment and by their passions. In one way or another, you have all contributed to QAI's work and to its progress. Thank you.

Bernadette Scalora -Vice President

I certainly learned that QAI is continually working hard to promote advocacy for the most vulnerable. To that end, there are many workshops for the Management Committee to attend i.e.: Committee Development, Social Advocacy, Conflict of Interest, and Operational Plan. Items such as the Commonwealth Self-Assessment

Survey and the Consumer Assessment for Disability Services Standards, helped to keep us busy. QAI staff showed their commitment to advocacy by all the effort that was put into both the 'hostel campaign' and the "Action Forum" and particularly the "4 Days in July."

Mike Fisher
Committee Member

THE LAST WORD

At this time we are in the midst of a Federal Election, while QAI is not aligned to any political organisation, I feel it is important that as President of QAI I take the opportunity to make a few observations. QAI encourages all elected officials at all levels of Government, Federal, State and local candidates to consider their policy positions and issues in the light of what is needed by people with disability, their families and advocates. One in five Australians is identified as having a disability as articulated in legislation. People with disability and their families make important contributions to our society. QAI calls on the Federal Government to continue its commitment to funding the National Advocacy Program with real increases to help many advocacy organisations get on with the business of advocating for vulnerable people.

Since 1994 and many attempts by consecutive administrations to carry out the advocacy review there has been no increase in the overall National Advocacy Program's budget. In real terms QAI has effectively had a 15% decrease in funding. This places great pressure on QAI's and other advocacy organisations capacity to address the advocacy needs of vulnerable people with disability in Queensland, as management committees need to balance the administrative/operational costs and project costs, to ensure we have the appropriate infrastructure to support our advocacy efforts. Some examples of substantial operational/administrative cost increases include fixed costs such as Leases, the Social and Community Services Award obligations, the impact of the Goods and Services Tax on the not for profit organisations and the increasing demand for advocacy actions and efforts.

Nigel Webb
President



Director's Report – Kevin Cocks

It is with great pleasure that I present my third annual report to the members of Queensland Advocacy Incorporated. This report reflects upon and highlights the work carried out in the financial year of 2000/2001. I would like to thank all of the staff and committee of QAI for their commitment, dedication to people with disabilities, for their sense of humor and particularly their support during the past year.

This year QAI undertook many activities one of which was Action Forum 2001. I would like to thank the Planning Committee; Bob Dick, Elizabeth Synnot, Donna Best, Mike Nelson, Mike Duggan, and John Rigby for their voluntary commitment, their wisdom, energy and dedication over a twelve month period to making the Action Forum a successful event.

In the first nine months of this year much of QAI's work continued to focus on the hostel campaign. The campaign received significant media coverage and unsolicited public response to QAI with a range of information, including evidence of '**People Trading**'. Relevant information was given to *Taskforce Argos* and much of the information is still being investigated by the taskforce. Additionally, submissions were made to the Premiers Hostel Task Force, meetings were conducted with the then Minister for Disability Services Queensland, Anna Bligh, and the Minister for Fair Trading, Judy Spence, and relevant departmental officers. The key messages contained in submissions to respective ministers, departmental officers and the general community emphasise that government can not just focus on fixing the boarding house and hostel infrastructure. QAI advocated that the focus had to be on the people who have been inappropriately placed or dumped in the hostels industry. No matter how improved the hostel and boarding house system is, this system is totally inappropriate for people with high and complex support needs. The longer government ignores the fundamental needs of vulnerable people within the hostel and boarding house industry the longer vulnerable people will be subjected to daily experiences that are oppressive and abusive.

In March 2001, QAI held a hostel forum, gathering together people with disability living in hostels, advocates and other concerned citizens. As a result of this forum and work with other advocates and support agencies QAI produced a position paper titled *Opening Doors to Life*. This position paper outlines how government could respond to the fundamental needs of the most vulnerable people with disabilities living in the hostel system.

Opening Doors to Life advocates for effective systemic reform within the hostel and boarding house industries, in conjunction with government legislation, policy and programs. The latter need to ensure:

1. Separation of competing agendas, separating the issues of the boarding house and hostel owners and operators from those of vulnerable people with disability with high or complex support needs.
 - Separating the provision of housing from the provision of support to people with disability with high or complex support needs.
2. A Moratorium on placement
 - Placing a moratorium on housing people with disabilities with high or complex support needs in boarding houses and hostels.

3. Safeguards
 - Establishing safeguards for those people with disabilities with high or complex support needs at a high risk now living in boarding houses and hostels.

4. Thoroughly considered service responses through Pilot Projects
 - trialing and evaluating a process of working toward desirable futures with 40 people with disabilities with high or complex support needs living in boarding houses and hostels that incorporate;
 - a. immediate crisis responses
 - b. personalised planning
 - c. development of individualised responses and supports
 - d. community development work to establish and embed responses in the local community

5. Ongoing commitment to change
 - on the basis of the pilot project, implementing a personalised process of moving people with disability with high or complex needs out of boarding houses and hostels.

The outcome to date of our hostels campaign is two-fold. First, significant increase in public awareness around the abuse and neglect that has evolved by consecutive governments not providing the appropriate resources to support vulnerable people with disabilities to maintain relationships with their families and friends and to be embedded in the community free from neglectful and abusive situations. Second, a continued commitment of government to the regulation of the hostel and boarding house industry. Hopefully this regulation will at least ensure tenancy rights in the future for residents living within the hostel and boarding house industry.

Other major advocacy efforts carried out by QAI include a statewide phone-in/email-in and work around the Halwyn Centre, Red Hill. These are reported under the Community Living Project section.

ACTION FORUM 2001 MAY 2001 – AUGUST 2001

The Action Forum 2001, hosted by QAI, was an exciting, innovative event, held for the first time in Australia and involved people with disability, their families, friends and concerned citizens from Queensland, Australia and overseas.

- The Action Forum 2001 facilitated energetic discussion, challenges and opportunities for many people who otherwise would not have the chance to be involved in this event. The event design was a process in itself using the Internet and face-to-face activities.

- The Action Forum included three major stages:
 1. Electronic Action Forum using the Internet and an email mailing list
 2. Four day face to face event
 3. Celebration Dinner

Stage 1 *Electronic Action Forum May to Mid June 2001*

This stage was an electronic action forum using the Internet and email mailing list from May to August 2001. During these first six weeks, people with disability, their families and concerned citizens posted stories highlighting their issues, concerns and questions relevant to their experience of living with disability. 225 people participated in this active and lively email discussion list. Postings were received from people in the United States of America, India, New Zealand, rural, regional and urban Queensland and Australia. Over 500 postings were received by June 30th.

Electronic Action Forum Mid June to 13th July 2001

Keynote presenters posted presentations on the Internet, scoping the historical and lived experience of people with disability and their families. The presentations focused on Community Living - Abandoned or embedded?; Policy Making; Bio-Ethics and Justice for All. For a copy of the full text of the presentations go to <http://www.qai.org.au/forumindex.htm>.

In another first QAI and a number of people with intellectual disability developed a presentation using advanced information technology provided by Learning Network Queensland. This presentation developed using audio graphics and video camera technology and is available on QAI's website. Without this assistance, this group of people would have been excluded from participating in this very important part of the Action Forum 2001. Participation in the presentation provided a unique opportunity to people with an intellectual disability from Townsville and Toowoomba to communicate and exchange experiences, ideas and concerns about their life experience, their hopes and dreams for the future and their contribution to realistic and informed policy regarding services and societal change. To read this report in full go to

[A focused discussion by people with disability about their lives](#)

At <http://www.qai.org.au/learningonline.cfm>

Stage 2 *'4 Days in July' 15th July to 18th July 2001*

This face-to-face event was held at the Brisbane Convention Centre from 15th July to 18th July 2001. Participants drew on the discussions, concerns and issues raised on the email discussion list, and established a sense of community and identity. A search-based process was used to define the 'people's record' of what a civil society would look like for all people, taking other likely developments into accounts that would enhance or threaten the realisation of people developing a shared vision for a civil society.

This process was also designed to provide an opportunity for people with disability, families, friends and concerned citizens to interact, exchange ideas, develop knowledge and greater understanding about the lived experience of people with disability and their families. All processes were participant driven, finally people developed action plans for the future. In all, 18 Action Plans were developed. Six of those coincide with the areas of work that QAI identified in its yearly planning process - this year conducted after the Action Forum – and are as follows:

1. Bioethics
2. Review of the Disability Services Act Queensland
3. Younger people in nursing homes and other health facilities

4. Indigenous people with disability
5. Economic Justice for people with disability
6. Story writing

Stage 3 Celebration Dinner 16th July 2001

This stage of the Action Forum celebrated, acknowledged and appreciated the contribution of people with disability to community life in our Australian society. Matt Laffan presented his life story which provoked thought and discussion for the urgency of timely intervention by people with disability themselves in creating a more accepting and just society. Prominent public speaker and author Peter Fitzsimons, who highlighted the benefits of a civil society where diversity and difference are welcomed and valued, joined Matt.

Awards were made to:

- Angus Downie, a person with disability who has made a significant contribution to the growth of a civil society in Australia;
- Sue Tuttle, on behalf of Far North Queensland Information Alliance, a community effort by family members of people with disability that has given significant support to the growth of a civil society and
- Members of Rebels with Attitudes and the Schools Group who have been supported by the Community Living Program. This award was for an organisational effort that has worked collaboratively with people with a disability in promoting the growth of a civil society.

The Celebration Dinner attracted 330 people including key leaders and members of the corporate sector including legal, medical, and government sectors as well as prominent citizens and community sector leaders.

Expectations of Action Forum 2001, were that:

- The personal experience and acquired knowledge of people with disability and families will be recognised and legitimated.
 - Participants will be better equipped to make disability a public issue in ways that will move the issues forward.
 - Participants will identify how the justice system can be more responsive and equitable.
-
- The knowledge and experience gained from Action Forum 2001 will better equip participants to actively engage in discussions and direction setting with service providers, community services and Disability Services Queensland departmental officers.
 - Issues of Bioethics including genetic technology that discriminate against people with disability will be placed on the public and political agenda.
 - Action Forum 2001 will provide an opportunity for preliminary development of a social model of disability. This model, once developed, will help construct a practical social policy framework and can be used to influence future social and economic policy development.
 - QAI will build stronger networks and promote social advocacy through the internet, primarily QAI's web-site.

Some statistical data regarding the use of the Electronic Forum between May and August 2001:

	May	June	July	August
Number of hits on QAI web site: (includes times pages on the site were opened)	17 869	10 728	11 793	10 470
Number of people who logged onto the QAI Web site:	930	972	861	1 957

The number of subscribers to the Electronic Forum: 227

The number of emails generated on the Mailing List: 724

Countries of origin of web site visits and emails:

India; Japan; Thailand; China; Korea; Hong Kong; Indonesia; Turkey; Netherlands; Germany; UK; NZ; Guam; Canada and the USA.

Categories of Electronic Forum Topics:

- Bioethics
- Community living including:
 - Access Issues
 - Employment
 - Funding Issues
 - Support Issues
 - Carer/Worker Issues
 - Education
 - Discussion of Community Living Presentation
- Justice for All Presentation
- Transcending Rhetoric

For people interested in the proceedings of the 4 Days in July, please go to QAI Web site <http://www.qai.org.au/peoplesrecord.cfm>, the People's Record.



Community Living Project – Christine Douglas

The Community Living Project faced another challenging year as the struggle for a meaningful, adequately resourced and safe life for people with disability took a battering from the over emphasis on service viability and the tricky demands of Disability Services Queensland (DSQ) Priority Determination process. Alongside the new encounters and welcomed energy that the Action Forum 2001 engendered and the real difference that some Adult Lifestyle Support packages are making in people's lives, there is a sense of tiredness and despair that runs deep: we cannot ignore this. QAI's advocacy efforts must and will continue in earnest, even as advocacy itself is increasingly threatened and underrated on many fronts.

Advocacy efforts around the Community Living Project fell into four areas of work and are as follows:-

THE COMBINED ACTION GROUP (CAG)

The two tasks identified by the CAG for this period - namely a statewide phone-in and 3 story-writing workshops - were carried out.

STATE-WIDE PHONE-IN

On the 27th March 2001, QAI conducted a statewide phone-in/ email-in over a period of 12 hours. The phone-in/ email-in was widely advertised, and people with disability, family members and other committed people from all areas of Queensland were invited to contact QAI to talk about what was happening in their lives. 110 people participated in the phone-in, and each call took an average 45 minutes.

The phone-in assisted QAI in building a picture of what experiences people with a disability and their families were having, particularly in the areas of community participation, relationships and service provision. QAI staff, committee and volunteers from the Combined Action Group (CAG) manned the phones over this period. There was also an opportunity for people to respond via email if they so desired.

The responses received provided a snapshot of the general concerns of Queenslanders with disability, their families and concerned others. It also revealed the general policies and practices of "the system" that impact upon real life and leave people in situations where they can become or are vulnerable. The data also builds upon information collected during QAI's trips out west, workshops with people living in the hostel system and inquiries to QAI for legal advice or general advocacy advice.

The majority of respondents maintained that the services they receive are either inappropriate, could be improved upon or are insufficient. The key issues identified to improve the quality of services were more flexibility and greater personalisation, that took into account the different needs and uniqueness of each individual.

The phone-in produced rich yet disturbing information about people's level of poverty, isolation, impoverished relationships and concerns about service provision. The calls also canvassed people's views about what a desired life could look like. The profound simplicity of their answers is something that service providers, funding bodies and government policy makers would do well to heed. The phone-in Report *About Life 2001* will be available on QAI's website: <http://www.qai.org.au> under the 'Learning On Line' extracts of the report will be published in the December Newsletter.

STORY WRITING WORKSHOPS

Although stymied by lack of resources to proceed in Brisbane, QAI was able to go ahead on the Gold Coast due to the generosity of a local writer who offered to assist and guide a small number of people through the process. Using the contacts and support of Gold Coast Advocacy, three sessions were organized and conducted. An invitation was extended to participants, if ready and willing, to post their stories on QAI's Action Forum 2001 Email Discussion or Learning on Line. A number of people did this, much to our benefit and learning, and QAI greatly appreciates their courage and generosity.

The CAG will regroup after many months' hiatus to determine its future status and activities. The story-writing component has the capacity to be taken up by the Writer's Group that emerged as one of the Actions Plans from the *4 Days in July* Event and one which QAI is willing to support provided it focuses on life stories by and about people with disability.

CLOSURE OF INSTITUTIONS

In keeping with the guiding advocacy principles of fidelity and heightened awareness of the most vulnerable, QAI renewed its commitment and increased its efforts around advocating for people with disability living in institutions, particularly those in health facilities.

HALWYN CENTRE

In July 2000 QAI began a course of action around the Halwyn Centre, Red Hill, in conjunction with a number of families from Halwyn who approached QAI via the Disability Development Unit (DDU). The majority of families had already removed their family members from Halwyn, due to unresolved grievances they had with the centre, but were looking for a forum to express their concerns and prevent ongoing detrimental practices.

QAI was advised to place all concerns before the *Operational & Audit Branch* of Queensland Health who would determine whether or not there was an official misconduct case to answer. QAI followed due process and mounted a substantial submission, incorporating the individual complaints of families with its systemic issues, in April 2001. Complaints included poor medical practices resulting in gross neglect; poor levels of information and communication; poor dietary requirements; unexplained injuries; impoverished living environment; inappropriate management of resident's finances and lack of effective grievance mechanisms.

Not surprisingly the *Operational & Audit Branch* found there was no official misconduct case to answer and referred us back to the unit that referred us to them! In the latter part of 2001, QAI will again consult with interested families and other relevant stakeholders with the view to determining what responses are the most appropriate, effective and feasible, given QAI's limited human and financial resources. Obvious starting points are the Offices of the Public Advocate and the Adult Guardian.

BAILLIE HENDERSON HOSPITAL

QAI's focus on Tredgold and Rush (now a brand new unit named Morris-Mouatt) Houses at Baillie Henderson Hospital, Toowoomba strengthened during this period. QAI has been visiting these wards on a monthly basis since December 2000, getting to know individuals and engaging in dialogue with the hospital staff with the view to attracting community access dollars to begin the complex, but increasingly imperative, task of moving people into the community. These two particular units house people with intellectual and physical disability of varying degrees of complexity: all have lived on the Baillie Henderson Psychiatric Hospital site for decades. Since Queensland is one of the last states to house people with intellectual disability in mental health facilities, QAI will be using that fact to bolster its arguments. QAI is also exploring the interest and capacity of local Toowoomba citizens to support the systemic work of QAI, including taking a personal interest in one or more of the people living in the wards.

Whilst the primary focus is on Baillie Henderson Hospital, QAI is also mindful of people with disability living in similar situations throughout Queensland (eg Birribi Unit at Rockhampton Base Hospital and Mossman Hall at Charters Towers).

YOUNG PEOPLE IN AGED CARE FACILITIES

In February 2001 QAI, together with a number of other key groups, met to form the *Young People in Aged Care Alliance*. The Alliance is based on the common agreement that '...aged care facilities and services are inappropriate for younger people with disability.' Meetings to date have aimed at building the evidence, and identifying and exploring the pathways that lead to young people being placed in nursing homes and other aged care facilities. The Alliance has been steadily growing in numbers over the months and will form a significant part of QAI's advocacy in the next financial year. Younger people with disabilities (under 65) are increasingly incarcerated in nursing homes and other aged care and hospital facilities due to the lack of suitable alternatives, flexible support packages and the political will to ensure that such horrendous practices are discontinued.

The *Younger People in Aged Care Alliance* meets every 3rd Monday of the month. If you would like to know more about the alliance contact Christine Douglas at QAI.

TRAVELLING ADVOCACY PROJECT (Trip Out West)

In keeping with QAI's pledge to return out west, QAI revisited Toowoomba, Tara Chinchilla, Mitchell, Roma and Dalby in November 2000. Unfortunately due to time and resource constraints QAI was unable to include Charleville, Cunnamulla and St George in its itinerary. Efforts were made to link these towns into QAI's Action Forum 2001, particularly the e-mail discussion forum, by way of compensation. QAI's second visit concentrated on exploring the capacity of local communities to support people with disability living in their midst. This was a particularly painful exercise at times, as the lived experience of many people with disability and their families spoke to their daily isolation and discrimination and constant struggle to find the resources and supports they need. At the same time participants felt the meetings were timely and acted as a useful leverage to bring people together again, to refocus and re-energise.

QAI did not write a formal analysis of this phase of the Travelling Advocacy Project, however the material generated from each workshop was documented for participants to build on. Certainly QAI's experience of these visits reinforced the conclusions it reached in its August 2000 *Trip Out West Report* with greater intensity and urgency.



Bioethics Project - David Turnbull

What has the QAI bioethics project done in the past year by way of advocacy for the lives of the most vulnerable people with disability in order to protect and defend them? Sometimes it seems that progress has been very slow. People who understand what it takes to develop a project over the long term have remarked that the QAI bioethics project is still in its infancy, still at the beginning. What is hoped over the next few years is for it to develop into maturity and to strengthen some of its early initiatives.

The bioethics project nevertheless has had a number of practical outlets in the past year for acting, speaking and writing. Before going on to tell of specific instances of QAI's work, it is worth reflecting more generally on acting, speaking and writing in bioethics.

ACTING

Acting in bioethics means that QAI has to be involved in a broader community response to issues such as biotechnology. In this response, QAI seeks to put issues of conflict of interest within the biotechnology power elite, economic injustice in the health system and genetic discrimination high on the agenda. But this response has not just to be directed at biotechnology, but also at the alternatives to biotechnology, including alternatives for people with disability. This means acting with a sense of justice, which is often a pathway of balance between oppressive extremes. Just as the biotechnology quest must not become pre-eminent, neither is there any other singular path that can be recommended for society's response to disability in all circumstances. Rather there must be many paths with in-built limits – paths that offer cures for people, and paths for lives that fall or move outside the scope of those cures. Finding out what pathways are ethically viable for vulnerable people with disability means listening to the voices and stories of vulnerable people with disability.

SPEAKING

QAI also recognises that many of the most vulnerable people with disability do not have a voice within current political debates. Neither has this voice been present historically. Changing this means going against long established patterns of political behaviour to allow the voice of the most vulnerable people with disability and those speaking up for them to be heard and respected. This also means inviting a *wide* range of people into the advocacy project, to listen, to appreciate and to understand *outside* their particular circumstances, and allow for the discovery of each particular life as part of a larger and diverse social and spiritual whole. It is the need for people to be given opportunities to make this discovery that has to be spoken about most of all.

WRITING

Writing continues to play a major part of the activities of the bioethics project. This has been through the use of print and electronic media. Writing is necessary for clear and accurate communication, for persuading others of the advocacy perspective, for staying in touch with other people over vast distances.

However writing is also a major limitation because it expresses the particular style of an author. Not everyone can get the most from any one author, and this author is well aware of those limitations.

But it is always a challenge to grow as a communicator with the written text and to be immersed in the challenge of writing to particular *and* diverse audiences.

This is getting to the heart and soul of the QAI bioethics project. The bioethics project has to be immersed with all its limitations in both particularity and diversity, in the lives of people and their struggles: to put it in one word, in *life*. That is the fullest meaning of the word, *bioethics*. Life has many aspects and differences, and discrimination on the basis of those differences is unfair, so the bioethics project must be prepared to speak out against the discrimination of people with disability. And because bioethics is a field of concerns extending over *the whole of life*, the task is huge, and QAI is always on the lookout for allies, for fellow travellers to help with aspects of the work. This has meant having a collaborative approach to the work.

THE PLAN FOR 2000-2001

In 2000-2001, the plan was to bring about collaborative growth in three ways. First it was to grow through being linked to QAI's other work. Second it was to grow through making connections to work being done outside QAI. Third it was to grow through exploring particular pathways in bioethics and to write articles for a wider audience that signal concerns that QAI has in this field. This plan has worked and continues to provide a practical framework for our activities.

The linking to QAI's other work has been done through being part of the 'Trip out West', through participation in the Hostels forum, the State-wide phone-in, the QAI Action forum, the Combined Advocacy Group Qld, and the Younger People in Aged Care Alliance. Through this linking, important contacts with families and allies have been made. One of these contacts, a family near Toowoomba, has provided the content for one of the conversations transcribed on to "Learning on-line" on the QAI website. The conversation is entitled "Genetic Doctors" and provides a very disturbing account of the aftermath of neglect following genetic diagnosis in the life of one young boy with disability.

It is worth reflecting on the reasons for selecting a story like this to be transcribed. Bioethics stories are often by their very nature personal, private and involve confidentiality. They often involve end of life or near death experiences that expose people to heightened vulnerability, not just in the experiences, but also in telling the story to others. But sometimes people do want to tell their story because it relates something about their experiences that others may find helpful. In this case the story exposes deep inadequacies in the medical system, and the family particularly wanted it told. Transcribing a taped conversation was a way of allowing people to tell the story in their own words. So putting the story on the QAI website was keeping faith with the family, as well as using the story to ask systemic questions, and to provide an inspiration for others to come forward with their own stories. There are great systemic implications for the telling of individual stories.

One example of linking the bioethics project to work being done outside QAI occurred through the reference group of the "Health Advocacy" project of the Developmental Disabilities Unit (DDU).

In another initiative, links were made with the Community and Public Health Planning in Rural and Remote Areas project, which is part of Public Health Services in Qld. There was an invitation to QAI to attend a Social Determinants of Health working group, and this work is ongoing. The social and community-based approach to health informs the Rural and Remote Areas project. What is exciting about this approach, are the implications for the recognition by the Health Department, of the social determinants of health for people with disability in Queensland. As well, a project was begun to work with people from the universities, community, government and health sectors to consider the implications of the Code of Ethical Practice for Biotechnology in Queensland. This work is also ongoing and sits within the stream of QAI's work that addresses the implications of biotechnology on the lives of people with disability both now and into the 21st century.

The third aspect of the bioethics project work was to write articles for publication. Two papers were written and published in international journals. A milestone of the year was the setting up of "Learning on-line" on the QAI website. A number of articles and interviews were written and placed there to give people an introduction to QAI's bioethics work, and to challenge a deeper critique amongst policy makers, researchers and practitioners.

These three streams of work, alongside the QAI Action Forum 2001, represents a broad-based initiative, one that seeks to connect with the experiences of people with disability and also to address matters of systemic concern. This broad approach to bioethics is planned to continue well into the future.



Law Project – Julian Porter

This was the second year where one lawyer attempted to cover the roles of Individual Legal Advocacy Worker and Legal Advocacy Development Worker. This task was made all the more difficult by the economic necessity for the part-time position to be reduced from 4 days (32 hours) to 3 days (24 hours) per week during the period.

INDIVIDUAL LEGAL ADVOCACY

Providing legal advice and assistance to individuals with disability and ongoing casework for persons in circumstances of particular vulnerability remained the focus of the Law Project.

Statistics detailing the type of advice requested, who requested it and the nature of the disability of the person requesting the advice, or whom advice was requested on the behalf of, are *attached*. It can be seen that, in total, advice or assistance was provided on 152 occasions, a remarkable number given the other work the Law Project worker was involved in throughout the year, as detailed below. As in past years it can be observed that the area of law most commonly dealt with, by some margin, was that of guardianship, followed by assault or abuse, inclusive education and rights and care in institutions and group-houses. From these queries 19 matters were identified within the legal advice guidelines as requiring ongoing casework and the opening of a file.

The casework component of the Law Project worker's practice included identifying and coordinating barristers and solicitors from the private bar to assist with individual matters where possible on a "pro bono" basis (ie at no cost to QAI's client). Five matters in the period were handled in this manner.

The above figures do not include regular referrals provided by the Law Project to other Community Legal Centres and private practitioners more properly equipped to deal with particular queries which is another important service provided on a daily basis by the Law Project.

CORONIAL INQUIRY/ CORONERS ACT REFORM

During July, August and September 2000 the Law Project Worker was kept busy by work in relation to the resumption of the coronial inquiry into the death of Lynne Deamon at Palmville Court Hostel in Ipswich. This was a matter which QAI had lobbied extensively for there to be a hearing in relation to. The current Coroners Act does not require an inquiry to take place on every occasion when there is a death in a hostel unlike the situation for deaths in government-run "institutions". At the time of writing no findings had yet been made by the coroner.

The Law Project worker finalized a submission in February 2001 regarding potential amendments to the Coroners Act.

LEGAL AID POLICY REFORM

After a period of research throughout February into comparative levels of funding by Legal Aid of legal matters on behalf of people with disability, the Law Project worker met with the Criminal Justice Commission in March and April 2001 to raise concerns in relation to apparent inequities.

INSTITUTION OF GUARDIANSHIP AND ADMINISTRATION ACT

Over many years QAI has regarded obtaining workable guardianship legislation for Queensland as an absolute priority. With the *Guardianship and Administration Act* coming into effect during the past year the Law Project worker has continued to work towards a system that delivers upon the promise of the legislation.

In particular QAI has taken an interest in the first steps of the Office of the Public Advocate with its stated function (amongst others) of “doing systemic advocacy towards promoting and protecting the rights of adults with impaired capacity for a matter”.

In September 2000 the Law Project Worker and Director met with the Attorney General and Director General, Department of Justice regarding issues of concern in relation to the process of appointment of the Public Advocate.

In March and June 2001 the Law Project Worker and Director met with the Public Advocate regarding the role that his office intends to play and the relationship of his office with the Public Trust Office and the Guardianship and Administration Tribunal.

COMMUNITY LIVING PROJECT

The Law Project worker assisted with legal advice in relation to the submission made by QAI in relation to the Halwyn Centre in April 2001.

CRIMINAL LAW AMENDMENTS

In December 2000 the Law Project Worker completed an article on Criminal Law Amendments in relation to disability. In conjunction with Minter Ellison QAI produced a discussion document on Criminal Code and People with Disability for discussion in focus groups at the *4 Days in July* component of Action Forum 2001. The Law Project Worker was also involved in Department of Justice interdepartmental working group into the Criminal Code and people with intellectual disability.

PEOPLE WITH DISABILITY IN THE CRIMINAL JUSTICE SYSTEM

In December 2000 the Law Project worker attended a seminar on the Queensland Correctional system and prepared an internal briefing paper on people with disability in Prisons.

CONTINUING LEGAL EDUCATION/ CONFERENCES/ NETWORKING

The Law Project worker attended the annual Queensland Community Legal Centres conference and the Queensland Law Symposium both held over several days as well as three professional development seminars.

QAI maintained an involvement with Queensland Association of Independent Legal Services (QAILS) particularly in relation to their involvement in agreements for Legal Aid funding and also regarding professional indemnity insurance arrangements organised through them. These links were utilized to organize the annual cross-check of files by a colleague from another Community Legal Centre.

INTERNAL INFORMATION TO QAI

The Law Project worker provided advice on issues including defamation, leasing and insurance law for the information of the Director and Management Committee.



LEGAL ADVICE STATISTICS 2000-2001

TABLE 1 – Type of Advice

What people asked about	Total number of inquiries
Guardianship (excluding financial matters)	41
Inclusive Education	14
Consent to Medical Treatment	8
End of Life Decisions	0
Rights and Care in Institutions and Group houses	11
Rights and Care in Psychiatric Units	4
Death of a Person with Disability	3
Victims or Witnesses of Crime	3
Assault or Abuse	15
Care within Educational or Health Services	8
Children with disability in state care	4
Other	19
Not specified	22
Total	152

TABLE 2 – Who asked for advice

Contact by	Number of persons
Person with disability	33
Relative/Friend	57
Advocacy Group	31
Solicitor	8
Other Worker	23
Other	0
Total	152

TABLE 3 – Disability of Person about whom the advice was requested (including where a people with disability made the request)

Nature of disability	Number of persons
Intellectual	34
Physical	20
Sensory	8
Psychiatric	18
Multiple	20
Brain Injury	7
Other	1
Unknown	44
Total	152