

Queensland Advocacy Incorporated

ANNUAL REPORT 2001 - 2002

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Management Committee 2001 - 2002

President	Nigel Webb
Vice-President	Bernadette Scalora
Secretary	Michael Duggan
Treasurer	Robert Reed
Member	Michael Fisher
Member	Lisa Lehmann
Member	David Paterson

Queensland Advocacy Incorporated (QAI) is an independent community based systems advocacy organisation for people with disability in Queensland.

QAI advocates for the fundamental needs, rights and lives and protection of the most vulnerable people with disability in Queensland. QAI does this by engaging in systems advocacy work - through campaigns directed to attitudinal, law and policy change, and by supporting the development of a range of advocacy initiatives in this State.

QAI is funded by the Department of Family & Community Services under the Commonwealth Disability Services Act and is run by a management committee, the majority of whom are people with disability.

Introduction

This Annual Report covers the period from 1 July 2001 until 30 June 2002. 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 pleased to welcome everyone to the Queensland Advocacy Incorporated fifteenth Annual General Meeting held at the Riverglen Conference Centre in Indooroopilly on the 19th of October 2002.

I am honored to present my fourth Annual Report to the QAI membership. The QAI Committee has continued to steer QAI in proactive directions. This year can be split in two major parts as far as I can see in terms of reporting to the members.

In July through to August 2001, QAI continued its involvement in Action Forum 2001. The four-day event held at the Brisbane Convention Center was well attended with more than 200 participants. The dinner held in conjunction with the forum was also a success with many more members from the community and business sector engaging with QAI and our work. As a result of Action Forum 2001 many participants gave an undertaking to continue much of the discussion generated from the event. A number of on-line groups have been formed and are continuing the commitments they started. QAI has undertaken some of the work from the forum and is using a lot of the information gathered at a systems level.

From October 2001, through to about February 2002, QAI then went through a period of organizational debriefing trying to absorb, collate and distill much of the learning from Action Forum 2001. Of course, QAI undertook many functional and operational activities at the same time like the Annual General Meeting, the Annual Fund Breakfast, Planning days and the Quality Self-Assessment and a well-earned Christmas and annual leave break.

QAI came into the New Year in 2002 with some vigor, planning for some staff changes, contributing towards Advocacy Development and continuing to explore the development of a model of governance for QAI.

A number of the advocacy groups attended the Regional Advocacy gathering hosted by Mackay Advocacy Inc. in Mackay over three days during February/March 2002. This gathering proved to be very successful and was focused on regional and remote issues for the advocacy movement across Queensland. The Director and I represented QAI at the gathering and came away with a renewed sense of collaboration between colleagues. The Public Advocate was invited to participate; his contribution was well received.

The Committee was asked to convene, review and implement a staff selection process when we were sadly informed about the resignation of QAI's long serving Systems Advocacy worker Christine Douglas who made an outstanding contribution for almost eleven years. The selection process culminated in March with different Committee members being involved in short-listing and interview processes. QAI developed an innovative way of assessing and meeting all short-listed applicants. By inviting them to spend the day together to consider and comment on a range of issues that the person in the position would come across in their work for QAI before a formal interview process was undertaken. The standard of applicants was impressive and their engagement in the day made for a tough decision for the interview panel members. QAI decided to appoint Melinda Ewin as Systems Advocacy worker.

The Combined Advocacy Groups of Queensland (CAGQ) met on the 11th June 2002 for three days in a workshop/ gathering atmosphere to discuss the future of advocacy in Queensland and steps to keep the momentum going were put in place. Most QAI Management Committee and Staff members attended all or part of the gathering. The first day of the meeting was a plenary session hosted by Dr Michael Kendrick. I think most who participated gained a great deal from the knowledge and experience Michael had to offer on the subject of advocacy – in every aspect. The next two days the CAGQ members set about reaffirming the CAGQ Charter and committing to the “Right Relationships” between members. Overall the meeting was deemed very much a success with many new connections forming across the state.

One important event was a soiree (held at the QUT Art Museum) and Bioethics workshop held at Queensland University of Technology – Gardens Point campus. QAI was one of the co-hosts along with B.E.I.N.G (organisers) of the event. Dr. Jane Clapton was invited to give the inaugural “Jennifer Fitzgerald memorial address”. Dr. Jane Clapton was a close friend and co-professional with Jenny. She gave a moving and provocative address. Jenny was the original bioethics worker at QAI and the author of our book “Include Me In”. The bioethics workshop brought together a wide audience including academics, government, professionals and people with disability to openly discuss and debate an array of issues within bioethics and biotechnology. Our thanks to David Turnbull for putting this together. I am sure he has much food for thought.

Over the past two years QAI has been exploring different models of governance as a way forward for QAI into the future. We want to move away from the traditional notions of management to allow the Committee more flexibility in its strategic thinking, visioning and planning. QAI will be better able to serve our constituents and have a greater role in setting strategic direction, ensuring QAI’s practice is focused on the achievement of our mission; advocacy for the most vulnerable Queenslanders with disability so that vulnerable people with a disability are seen and treated as valued citizens within our society. We are deliberately moving through this process slowly learning from the experiences of others as we go. QAI wishes to thank Mike Nelson and the Board members of PQAQ for their assistance to date. This work may lead to changes being made to QAI’s constitution and model rules next year.

Obviously, I have only highlighted some activities with my report. Members will note there has been, for some time, a section within the QAI newsletter where different Committee members write about current issues and activities on behalf of the committee. Members and other interested persons are encouraged to keep up-to-date by using the Web site www.qai.org.au

EVALUATION

We have begun planning to undertake our third 5-yearly independent external evaluation at QAI. This allows us to examine all facets of QAI’s policies, practices, procedures, values and vision to ensure we remain on track and true to our mission. We remain committed to the principles of independent evaluations. This evaluation is a clear demonstration that QAI is open, transparent and accountable to a wide range of stakeholders in the community. An external team is currently being formed to make recommendations that will bring about long-term improvements for QAI based on issues raised throughout the evaluation process. Members will be given the opportunity to contribute to the evaluation through a questionnaire circulated in the December 2002 newsletter.

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.

The QAI Management Committee is a remarkable group of people whose long-standing commitment is always appreciated. Bernadette Scalora, Robert Reed, Mike Duggan, Michael Fisher, Lisa Lehman and David Patterson are my colleagues who have given so much of themselves and learned so much while discharging their duties and helping QAI towards our vision. I would like to thank each member for their ongoing support especially during the tough times when the important decisions are usually the hardest to make. One member of the Committee, David Patterson resigned in August for health and personal reasons. QAI thanks David for his contribution and wishes him well along with his family. Michael Fisher has decided not to re-nominate because of upcoming study commitments next year. Good luck! Your efforts were valued and fantastic.

The QAI staff members and their families, who are the most unique group of people, always seem to pull it together in spectacular fashion. I would like to particularly thank the QAI Director, Kevin Cocks. I simply can't explain how you do it but we know you do it well.

There are a couple of well-earned thank you's to acknowledge. To Steven Tonge from Flower and Hart for his ongoing support and legal advice with the QAI lease agreement. Also, I thank Donna Best and Brian Woods for their ongoing commitment to ensuring the newsletter is collated and mailed to all our members.

STAFF CHANGES

The staff and management of QAI said farewell to staff member Christine Douglas, at a great QAI party (with karaoke). Her years of dedication to the growth of QAI, her steadfast belief in the principles of advocacy and values of QAI and her personal commitment to people with disability are now legendary across the sector. Christine is quite simply a delight to all that know her. QAI extends its warmest wishes to Christine and her family.

QAI welcomed Melinda Ewin, who is settling into the role of Systems Advocacy worker – Community Living and has become part of the “family” in no time at all! Welcome Melinda! I know we are enjoying working with you, as are many others.

At the time of my last report Julian Porter had been seconded to replace John Stannard as QAI's legal advocate and I noted John's subsequent resignation from QAI. Julian has now been appointed to take on the legal advocate role on a permanent basis so we welcome him to the "family" too.

QAI ANNUAL FUND

I would like to acknowledge the work of the Annual Fund Chairperson Mr. Ron Ashton and his associates at Minter Ellison. The Annual Fund Breakfast was a great success and we were excited that Mr Noel Pearson agreed to be guest speaker. His speech was thought-provoking and inspirational and the breakfast was well attended by various QAI stakeholders and friends including a large number of law firms. The Annual Fund

Committee (and Mr Robert McRae, a Partner at Bain Gasteen) are now planning a dinner (with another high profile guest speaker) and in the coming year they will be reviewing QAI's fundraising strategies in some depth.

COMMITTEE MEMBER REFLECTIONS

This year Committee Members were invited to offer some reflections on their involvement and participation within QAI.

Robert Reed - Treasurer

This was my first year as a member of QAI's Management Committee although I had been working a few years beforehand closely with QAI staff through my role as Director of the Community Benefits Program at Minter Ellison, Lawyers. I was very proud to be asked to take on the role of Treasurer during the course of the year. I have also joined the Finance Subcommittee and the Governance Subcommittee as well as continuing my work with QAI staff in my Minter Ellison/Annual Fund Committee capacity.

My involvement with QAI this year has for me meant a very steep learning curve and a lot of hard work but it has always been extremely worthwhile and inspiring. Through the committee induction sessions I have gained a better understanding of QAI's long and distinguished history and of advocacy principles in general. It has been exciting to be involved in the intensified efforts to move QAI towards a new Governance Model and I have learnt a lot about organisational structures, procedures and policies from this work.

Most importantly, I have thoroughly enjoyed working with the people at QAI (staff and committee members) under the leadership of a fantastic Director and President. These are professional, dedicated, down-to-earth and fun people and I am looking forward to continuing to work with them in the future to help in whatever way I can to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Lisa Lehmann – Committee member

Well hi, my first year as a committee member of QAI is drawing to a close, so what a perfect opportunity to reflect on the year that was, one of my most constructive and exciting periods to date. For me personally it has been a great learning curve with a few adventures along the way...

I had the opportunity to attend a number of conferences and meetings throughout the year on various issues and topics. The knowledge and references gained through these events has been very a useful tool for me in my role as board member of QAI. I think back to the first conference I attended representing QAI and although I did gain a lot of knowledge from it I wish I had the knowledge and personal courage I have gained through out the year from fellow board members of both QAI and other advocacy organizations. Through my work with QAI I have also been given the opportunity to be a panellist at a facilitated public discussion, which was held in my local area. I feel I have gained a greater sense of self worth and inner strength to be able to represent QAI on a professional level, and I feel I did this to the best of my capacity, when I have attended such events in my role as committee member.

In the past year the knowledge, courage, and wisdom I have both gained and embraced with enthusiasm, has given me greater insight into what human rights really means, and the injustices that are still happening to humans.

I would like to be given the opportunity to continue in my position on the management committee to further utilise the knowledge I have gained in my first year and look forward to extending my understanding and knowledge of formal advocacy, to be able to represent QAI in an even higher professional capacity. I also look forward to being a part of the big picture of QAI, in the overseeing of the growth, stability, and evolution of the organization as part of my role on the management committee.

David Patterson – Committee member

My name is David Patterson. I have a psychiatric disability - bipolar disorder. My daughter has been diagnosed ASD - now we are looking at de-labelling her. I am a capitalist developer.

My experience with QAI has been great. I count it as one of the proudest times in my life. I encourage everyone to do what they can to help themselves and QAI. Together we make each other strong. I know of no other organisation so open, so accountable and so moral. However, my family and my health come first. It is time for me to be a little selfish. I have a mathematical theory I wish to publish - Match theory. I want to use my / our skills to redevelop hostels / boarding houses, so that they are fit places for my friends to live. I want to be a fundraising consultant to others. I want to publish my work - eighty8strings.com.

I have been institutionalised again recently - involuntary treatment order. This is why I have resigned - potential conflict of interest problems. Many people say I am a worry - including family and friends. I say tell someone who cares...

Your friend, David Patterson.

THE LAST WORD

There are a number of standing committees within QAI whose function it is to get into, understand and recommend the appropriate course of action for the organisation and advise the committee. At times the schedule is very demanding and the decisions fraught with danger so, to those who've taken the risks enjoy the rewards. These committees include; finance, governance, AGM, external evaluation and staff selection.

Thank you

Nigel Webb
President QAI Committee

Treasurer's Report - Robert Reed

I take great pleasure in presenting the financial report for QAI for the financial year 2001/2002. QAI's audited financial statements were prepared by Hayward, Gesch & Dorge and are attached at Appendix A of the Annual Report.

QAI's expenditure in 2001-2002 was in excess of its received income. The deficit was covered by QAI's accumulated funds.

In terms of outlays this year we continued to meet expenses related to the Action Forum. Other major outlays related to QAI's involvement in Combined Advocacy Groups Qld events and the Bioethics functions.

This is my first year as Treasurer of QAI taking over the role from Bernadette Scalora in February (who had up until then been acting as both Vice President and Treasurer). I would like to thank all QAI staff and committee members who have greatly assisted me in 'learning the ropes' and trying to fill the shoes of Donna Best! Particular thanks to Bernadette and Rose who 'clued me up' at the start and to the hard-working members of the finance subcommittee (Nigel, Kevin and Mike Fisher). One of our most exciting initiatives this year was to strategically invest some of QAI's funds with a view to creating a future source of income while keeping QAI's funds secure.

INCOME

In the past financial year, QAI received its recurrent operating grant from the Commonwealth Department of Family and Community Services as well as funds from DSQ. Total Funds available to QAI in Financial Year 2002 were as follows:

Disability Service Queensland	40000.00
Department Family & Community Services	364407.00
Interest Received	927.28
Auspice Fee	9000.00
Annual Breakfast	8047.27
Membership	82.00
Donations	3672.77
Sundry Income	4215.32
Fundraising	3172.09
Action Forum	19485.01
Traineeship	7135.00
Legal Aid Queensland	765.00
TOTAL	460908.74

EXPENDITURE

The *Statement of Income & Expenditure* prepared by QAI's auditor details the combined expenses incurred by all the projects throughout the year.

Major expenses for the year were:

Consultancy	\$40995.12
Postage Printing and Stationery	\$16060.41
Office Occupancy Costs	\$37138.06
Salaries	\$203510.33
Website Maintenance	\$1086.36
Worker's Compensation	\$990.74
Travel Expenses	\$13346.87
Superannuation	\$17117.42
Repairs and Maintenance	\$1418.32
Insurance	\$2706.64
Computer Expense	\$5443.13
Committee Expenses	\$3026.62
Conference and function expenses	\$102394.67
Other associated expenses (attached auditor's report)	\$33347.49
TOTAL	\$478582.18

I would like to thank Peter Gesch from Hayward, Gesch and Dorge Chartered Accountants for auditing QAI's books again this year. I would now like to appoint Peter Gesch as the auditor for next year 2002-2003.



Director's Report – Kevin Cocks

It is with great pleasure that I present my fourth annual report to the members of Queensland Advocacy Incorporated.

This report reflects upon the work carried out by the QAI staff in the financial year of 2001-2002 and I would like to thank all of the staff and committee of QAI for their ongoing commitment to protecting the most vulnerable people with disability in Queensland, but on a personal note, I would like to thank them for their continued support throughout the year.

The beginning of this financial year was mainly concerned with the winding up of the Action Forum 2001. As a result of the Action Forum 2001, QAI established specific processes to strengthen its advocacy efforts particularly in the area of bioethics; review of the Disability Services Act Qld; younger people in nursing homes and other health facilities; indigenous people with disability; economic justice for people with disability and story writing. David established an email discussion group called *Talk Bioethics*. David expands upon the *Talk Bioethics* discussion group in his project report. Even though the review of the Disability Services Act Qld was one of the Labor party's election commitments, to date, very little has occurred, however, the success of the email discussion groups throughout the Action Forum 2001 provided QAI with some future strategies in engaging with its membership with respect to the debating and informing people of the critical issues that may arise around the DSA review when it finally occurs. Melinda will expand upon the activities of the younger people in nursing homes and other health facilities.

An exciting outcome of the Action Forum 2001 was a mandate for QAI to explore issues for indigenous people with disability. As a result of this mandate, and a forum hosted by North West Advocacy Mt Isa in October 2001, QAI developed a three-phase proposal. In this phase QAI aims to build relationships with indigenous people with a disability, their families and networks within targeted indigenous communities. Additionally, we aim to develop a common understanding of a) the situations that indigenous people with a disability and their communities are experiencing; b) how decisions are made about people with a disability in the context of their needs, families, communities and government services; c) who has power, authority and influence over the way indigenous people with a disability live.

We approached the Minister for Disability Services and Aboriginal and Islander Affairs, the Department of Community & Family Services Indigenous Health and the Aboriginal and Torres Strait Islander Commission along with a number of philanthropic bodies to seek funding for the 1st phase. In June 2002 we were successful in receiving funds from Perpetual Trust to the tune of \$30,000 to carry out the 1st phase of this project.

Unfortunately, we have not made many advances on the issues of economic justice for people with disability nor story writing, but these things are still important to QAI and we will continue to seek opportunities to further these issues.

In November 2001 Christine Douglas announced her intentions to retire from QAI to leave in April 2002. Christine has been a long-term staff member for QAI and committed ten years of her work-life to advocating for people with disability to have a better life. It was with great sadness that we accepted Christine's resignation, however, we realize that she would not be walking away from QAI or people with disability, she was just

beginning a new chapter in her life and in the lives of people with disability and their families and friends.

It is with great pleasure that I introduce you to Melinda Ewin, the person who has taken Christine's place and is now QAI systems advocacy worker. Melinda's main focus is around the community living project and all that entails. Melinda began working with QAI in April and has already made her mark in the team at QAI and I look forward to a long and fruitful contribution from Melinda to QAI's advocacy efforts.

Additionally, Julian Porter was seconded for 6 months in the beginning of this financial year and was made permanent in February 2002. Equally Julian has made his mark within the culture of QAI staff and definitely has brought a great contribution to the legal advocacy project.

On a personal note I would like to reflect upon the significant contribution made by all staff members in their respective roles. I am deeply honored and QAI is deeply blessed to have such dedicated, committed and valuable staff.

QAI has continued its advocacy efforts around hostel and boarding houses, or in government terminology, the private residential services industry. We have continued our advocacy focus on those people who have been or will be inappropriately placed in hostels and boarding houses. There are a group of people for whom this form of accommodation will never be appropriate, no matter how physically improved hostels and boarding houses may become because of the accreditation and standards that will be required to be met due to the Residential Services Act that was introduced on the 25th August 2002. You may recall QAI's advocacy around hostels and boarding houses commenced with the call for a Coronial inquest into the death of Lynette Daemon who at the time was living in a hostel in Ipswich. In January 2002, the final Coroner's report was handed down. The Coroner recommended that DSQ review its system of referral of people with disability to hostels and boarding houses. The Minister committed to consult with QAI in developing terms of reference for that review. As at June 2002 the review has still not been carried out. QAI has taken this matter up with the Minister and the process of the review appears to be having renewed commitment from the department.



Community Living Project – Melinda Ewin

The baton for systems advocacy worker was passed along this year within the ranks of QAI.

The lull in the push for equality and rights for people with disability generated by department personnel and politicians alike has heightened the need for advocacy. This pause, without effective advocacy, may induce a backsliding to the "old ways" of thinking renamed under the guise of "new models". In particular are 1. notions around "limited responsibility" and 2. inappropriate accommodation that is a form of

reinstitutionalisation, both need to be addressed to stem this backsliding.

The term, “limited responsibility”, is used by government officials to determine when enough is enough. That means that when approaching solutions for people with disability, the dollar is the bottom line. What may truly serve the best interests of the individual is not considered, what is in the individual’s best interest is determined totally by the monetary situation. What has changed, you may ask? Calling the process “limited responsibility” has now put the agenda in the open, there is now no pretences that individuals come first.

Seriously worrying is the move to re-institutionalise people with disabilities. This trend is seen in the lack of appropriate supports for young people with disabilities. The lack of availability of appropriate support limits housing and care options and the right to live independently in the community, and puts young people at risk of placement in aged care facilities. Similarly, the alarming rate of younger people with disabilities being placed in aged care facilities as the first option corroborates the impetus of the acceptance of institutional settings as suitable for people with disabilities.

QAI’s history of advocacy that is grounded in the fight to protect vulnerable people with disabilities has continued this year through the Community Living Project. QAI has advocated for equality and rights on behalf of people with disabilities in the following projects:

- Younger people in aged care alliance
- Baillie Henderson Hospital Campaign
- Halwyn Centre
- Boarding House and Hostels Campaign
- Attend reference group for Community Visitors Program.

1. YOUNGER PEOPLE IN AGED CARE ALLIANCE (YPACA)

The Alliance has forged ahead since its inception 18 months ago.

During the year QAI attended, 1 full day workshop, 9 group meetings, 3 story telling meetings, the Victorian Younger People in Nursing Homes Summit, 3 individual meetings with people living in nursing homes and one teleconference meeting with a person in threat of entering a nursing home.

This participation has seen the strengthening in agreement of the group to a common commitment that advocates against the use of institutionalised practices as solutions for young people with disabilities and promotes innovative initiatives that encourage community participation. Further, the opportunity to network with inter state organisations has instigated a loose coalition of state entities to take action on a national basis.

The Younger People in Aged Care Alliance meets every 3rd Tuesday of the month. For more information please contact Melinda Ewin at QAI.

2. BAILLIE HENDERSON HOSPITAL (BHH)

The year has seen this group grow in number from 4 to 21 with community participation

including members from the local Social Justice Group, Project 300, Catholic Church, family members and local community members. Baillie Henderson Hospital is a psychiatric facility run by the department of health. It has been home for decades to about 40 residents who have physical and intellectual disabilities. in various degrees of complexity.

The residents are housed in a dormitory like situation. Individuals residing in BHH receive limited if any community access. The aim of the community group is to gain community access for the residents in the short term whilst the long term vision is to see the residents living with appropriate support in the community.

During the year QAI has met with DSQ staff on 3 occasions. Three joint meetings with DSQ, BHH, Cerebral Palsy League and family members produced a submission to DSQ for Community Access funding, 2 visits with staff followed by a full day visit with a formal meeting with staff and spending time with residents and 4 regular monthly meetings since inception of the group.

The community support group usually meets on the 2nd Monday in the month, if you would like further information or would like to attend the meetings please contact Melinda Ewin at QAI.

3. HALWYN CENTRE

QAI lodged a formal complaint on behalf of family members about the practices occurring within Halwyn Centre. This formal submission was a significant piece of work carried out by Christine Douglas. It involved 6 meetings with families, 5 interviews with individuals to gather information that would identify and verify concerns and complaints raised by family members, current and ex-staff from Halwyn and Disability Development Unit. The submission was then presented to the relevant authorities for investigation. As an outcome of QAI's advocacy efforts the Department of Health has instigated a series of reforms within the Halwyn Centre. Despite the encouraging rhetoric surrounding the reforms, QAI believes true reform will only come when individuals are supported as individuals and their relationships with families are nurtured in a community setting.

A submission for funding for Community Access was developed and submitted. In the formulation of the submission, QAI consulted with DSQ staff, Office of the Public Advocate and Adult Guardian. Meetings with the families of residents were held to discuss: 1. strategies, 2. the progress of the Community Access submission, 3. the submissions implementation and follow up which is ongoing.

4. BOARDING HOUSE AND HOSTELS CAMPAIGN

The first phase of the campaign around the ongoing issues of the inappropriateness of vulnerable people with disabilities with high or complex support needs residing in boarding houses or hostels was completed this year.

QAI's position paper, Opening Doors, was presented formally to the Premier's Hostel Task Force, to Merri Rose the Minister for Fair Trading and the Minister's Policy Advisor from DSQ. A total of 500 papers were distributed to government departments, service providers and the community. Three meetings were held with Speaking Up For You and one meeting for government consultation.

Phase 2 of the project commenced in May 2002. This phase will collate information and produce a report that will form the basis for the direction of QAI's advocacy in the future year. QAI has engaged Jan Dyke to assist with this campaign.

5. COMMUNITY VISITORS PROGRAM

Two meetings of the Community Visitors Program reference group were attended by QAI to provide feedback on the Community Visitors Program Information paper and job requirements of the position.



Bioethics Project - David Turnbull

This annual report demonstrates the actions for 2001-2002 taken in accordance with the Bioethics Project plan.

1.4.1.1 To work with the Younger People in Aged Care Alliance around health and wellbeing issues

Tasks of the bioethics project worker for the Alliance were to attend meetings, take and distribute notes and contribute to research. The project worker attended several meetings up until April 2002. The main role of the bioethics project worker was to assist with QAI's involvement in the Alliance and to promote understanding of any bioethics issues arising. With the involvement of Melinda Ewin taking place from May 2002, and with her strong leadership capacities becoming evident, and given the workload increasing from other aspects of the bioethics project, the bioethics part of QAI's involvement in the Alliance was greatly reduced.

1.4.1.2 Conduct bioethics interviews, forums, workshops and focus groups around beginning and end of life issues

The key to QAI's work in this area of the project was in the formation of the Biotechnology and Ethics Interest Group (BEING). The group was formed out of the biotechnology/ethics discussion group that QAI convened in mid 2001. The formation of the group was greatly enhanced by the involvement of Prof Wayne Hall and colleagues (Office of Public Policy and Ethics, Institute for Molecular Bioscience, University of Qld), Dr Mal Parker, Mr Andrew Taylor, Ms Jennifer Fleming (Australian Institute for Health Law and Ethics), Mr Ray Campbell (Queensland Bioethics Centre) and Dr Barbara Hocking and colleagues (Faculty of Law, QUT). A series of planning meetings from November 2001 onward gave the impetus needed for QAI to hold a number of key forums and workshops in association with BEING.

At the June 19, 2002 BEING workshop convened by QAI, Dr Jayne Clapton delivered the inaugural Jennifer Fitzgerald Memorial Address. This was an enormous success, and the address was also printed in the QAI July 2002 newsletter. The workshop was attended by 65 leaders in the fields of ethics and biotechnology. The soiree, held in conjunction with the workshop, was attended by 70 people.

Another event, during this reporting period I spent time planning for was a significant workshop entitled *Genetic and Disability: Different Spaces, Different Futures*. This event was jointly planned with Community Resource Unit consultant Lynda Shevellar. The key speakers for the proposed event were Prof Sohail Inayatullah (international futurist) and Dr Christopher Newell (UTAS). David Turnbull (QAI), Dr Jennifer Kromberg (Queensland Clinical Genetics Service), Dr Sandy Taylor (UQ), Lisa Bridle (UQ), Rikki and Julie Chaplin (QAI&QUT), Dr Lynn Gillam (University of Melbourne), Dr Mal Parker (UQ), Dr Michael Gattas (QCGS) and Dr Jayne Clapton (GU). QAI in conjunction with BEING, also planned for a hypothetical "GOING FOR GOLD", with Dr Norman Swan (ABC TV& Radio health presenter) and a distinguished panel. These events have and will place QAI as a leader in the community response to ethical issues arising from genetics and biotechnology. The foundation has been well and truly laid for QAI's ongoing work in this field.

1.4.2.1 To work with relevant groups to promote the social determinants of health model

As reported in previous Annual Reports QAI has engaged Qld Health workers outlining a collaborative approach to social issues regarding health. An invitation from Qld Health to QAI to facilitate a further collaborative discussion between health workers around the social determinants of health was not followed up by those making the original proposal. Given the pressing nature of QAI's other work, there has been no opportunity to find out why this proposal languished or to press for a greater involvement by QAI in promoting this concept. However QAI remains committed to this aspect of health, particularly as it impacts on wellbeing issues for people with disability in remote communities. But for this year, no significant work on this aspect of the project has occurred.

1.4.2.2 To work with relevant groups to address the ethical implications of biotechnology for people with disability

This aspect of the project signals the ongoing work of QAI in beginning and end of life issues. QAI's bioethics project has, for a number of years, had some involvement in the Down Syndrome Association of Queensland, mainly through contact with Lisa Bridle and Sue Boyce. This year the new president of the DSAQ, Emma Bennett was invited to the October 7 workshop. A number of other specific disability support groups have been contacted through the workshop, and this work is now ongoing. Other relevant groups include biotechnology research and industry groups, and also clinical services. Great strides have been made towards ongoing dialogue with Queensland Clinical Genetics Service (QCGS), the UQ Institute for Molecular Bioscience, The UQ Faculty of Medicine, The Australian Institute for Health Law and Ethics, The Queensland Bioethics Centre, The Mater Hospital, The Uniting Church Centre for Social Justice and Uniting Health Care.

QAI was instrumental in getting Prof Noel Preston's report into conflicts of interest in biotechnology released from the Qld government, which had withheld it despite repeated claims involving "freedom of information". Finally, with a little impetus from a Courier Mail article, the report was released. QAI managed, despite these difficulties, to establish a congenial relationship with the Qld Minister for Innovation and Information Economy (DIIE), Paul Lucas, and members of his staff. The DIIE will be a sponsor for the October 7 workshop and the October 8 hypothetical, this sponsorship reflects a vote of confidence from the Queensland Government in community participation in biotechnology and QAI's leadership role in this field.

In January 2002, QAI wrote a submission to the Australian Law Reform Commission—Australian Health Ethics Committee *Inquiry into the Protection of Genetic Information*. In the September 2002 publication of the findings of this Inquiry, QAI's submission was quoted as having summed up particularly well, the complex ethical and social issues arising out of biotechnology. QAI's concerns have been noted and acknowledged by the leaders in biotechnology policy making in Australia.

1.4.2.3 To work with relevant groups to address threshold-based approaches to medical decisions in the lives of people with disability

In May 2002, QAI hosted a seminar about ‘wrongful life’ in conjunction with Griffith University. 25 people attended the seminar addressed by Fiona Campbell, lecturer in disability studies at GU. ‘Wrongful life’ and ‘wrongful birth’ claims both have a significance for medical decisions that could lead to decisions to terminate pregnancies or withdraw treatment, and to political/social decisions that may minimise or deny adequate support to people with disability.

1.4.3.1 To consult with a reference group concerning relevant themes in bioethics

BEING meetings have provided most of this contact, with Wayne Hall and colleagues proving to be very supportive. Also there were regular discussions and exchanges between the “old faithful”, Mike Duggan, Christopher Newell, Jayne Clapton, David Massey, Lisa Bridle, Rikki Chaplin and Julie Webb. Of great significance also were the inputs by Ray Campbell, Mal Parker, Naomi Sunderland, Erik Leipoldt and Sohail Inayatullah. The membership of the reference group reflects QAI’s growing state, national and international networks.

1.4.3.2 To contribute to and be informed by bioethics and disability discussions and research

Following the Action Forum in 2001, QAI hosted a email bioethics discussion group, “talkbioethics”. This has created the opportunity for people in areas remote from Brisbane, as well from interstate and internationally, to contribute to QAI’s discussions. Conversations have been quite well supported, particularly by Erik Leipoldt in WA and Dr Christopher Newell in Tasmania. There have been several engagements with up an coming bioethics graduates (PhD) students, that have been quite significant in helping QAI establish its position in the field.

Several QAI newsletter articles have been written as well as draft articles and a book chapter for publication. A paper “Genetic Manipulation and Duties to Posterity” has been accepted by Monash Bioethics Review for publication.

The bioethics worker attended the “vulnerability” workshop at West End, October 2001. Along with several people with disability supported by QAI, he also attended a Biomedica Conference at UQ Ipswich in July 2002. He presented a paper on eugenics at the Environment Conference at UQI earlier that month. Another paper was presented at an ethics seminar at QUT Carseldine in August 2002.

Law Project – Julian Porter

This was a significant year for the Law Project.

Firstly, it saw a changeover in the person undertaking the Legal Advocacy Worker position. John Stannard left after several years of enthusiastic service to pursue new challenges at the Office of Public Advocate and Julian Porter, who has a background in quasi-criminal and administrative law with the State government, joined the team.

Secondly, after a period approaching two years of the Legal Advocacy Worker attempting to carry out the dual roles of Individual Legal Advocacy Worker and Legal Advocacy Development Worker while employed part-time, the decision was taken by the Committee to suspend the telephone advice line service, part of the Individual Legal Advocacy role. As hard a decision as it was it made sense as the reality of the situation was that the worker was too often getting caught up with the minutiae of a small number of individual cases (often with little legal element to them) while the goals at which the Legal Advocacy Development project was aimed, and other systemic work, were given less priority and eventually ignored.

Changeover

Not coming from the disability sector, the new Legal Advocacy Worker spent the beginning of the period reading and familiarizing himself with issues and concepts in relation to disability and with the values and objectives of QAI. He was briefed by each of the other project workers on the nature of their roles within the organisation and by the previous incumbent of the position in relation to the existing files. The process of applying for a principal's practicing certificate from the Qld Law Society was also time consuming.

Individual Legal Advocacy

The suspension of the telephone advice service came into force in January 2002 so the legal advice statistics *attached* relate largely to the period from July 2001 to December 2001. In the first half of 2002 however the suspension was enforced loosely only so some assistance has been given in particular cases right up to the present. Hence the total number of advices for the year is down but not as dramatically as if no advices were given after December 2002.

Of course the advice line is only one aspect of the Individual Legal Advocacy work carried out. Another large element is the resulting casework. Often, problems emerging from telephone enquiries are not actually legal problems as such and may require advocacy is not of a strictly legal nature. A preferred approach of referral of this type of case to a geographically appropriate social advocacy group or support group has been adopted and in return the strategic plan for this position now specifically allows for provision of assistance to social advocacy groups when in advocating for a client they find they require legal advice or assistance.

In the period in question four significant legal matters were initiated in association with social advocacy groups:-

- A judicial review application in relation to a funding matter has gone to the Supreme court with the assistance of a barrister working pro bono. This was the single biggest piece of work undertaken.
- In another funding matter it was decided to enter into a dialogue with the Minister against a background of a threatened Judicial Review and what seemed to be exceptional circumstances. Almost a full year later a satisfying compromise has been reached.
- Still in the preparatory stage is a matter in which strategic advice has been provided to a social advocacy group in relation to potential complaints to the Ombudsman and civil action in relation to repeated abuse in a share-house.
- A disputed guardianship matter where DSQ saw fit to send legal representatives to argue against the appointment of *any* guardian for a person living in the ALS system.

Another matter upon which the Legal Advocacy Worker was focused in the middle of the year, again with the assistance of a pro bono barrister, was an ongoing Administrative Appeals Tribunal case. The case ran for two days and there was no social advocacy group involved to provide support and to do the “legwork”. Again there has been no result handed down. While it was appropriate to run this matter due to the client’s particular vulnerabilities and the opportunity to vastly improve the client’s life if successful the amount of time expended on preparation for this matter is a reminder of the rationale for taking the majority of our matters from social advocacy groups and not from the general public.

On occasion a social advocacy group will contact the legal advocacy worker for assistance in obtaining a solicitor or barrister, often on a pro bono basis, to handle a case for a client who doesn’t fall within QAI’s guidelines or capacity to handle. An example was a matter before a magistrates court where a person with severe intellectual disability may have been jailed for repeatedly breaching conditions of bail. Had no appearance been entered on their behalf and no explanation of efforts towards solving the problems in their life less disruptively been given this well could have been the result.

Other Advice work/Assistance

The Legal Advocacy Worker is often called upon to give advice on a more general topic than comes within the realm of individual legal advocacy. This is recognised in the latest strategic plan which anticipates the worker “will provide legal support for the objectives of QAI’s projects” and that this will be done not only through individual legal advocacy but also “provision of legal advice and assistance to other QAI projects and social advocacy groups where relevant”. Such work is often done on an informal basis such as to defray reporting upon but significant matters have included vetting a report by a social advocacy group for defamatory matter and assisting the bio-ethics project with an eventually successful appeal in relation to a Freedom of Information Application. The worker has on occasion been invited to add a legal perspective to meetings of groups doing work around the Halwyn Centre, Basil Stafford and the hostels campaign and advice as to ramifications of planned action has on occasion been required.

Funding – Legal Aid

Clearly it would be ideal for the Law Project to return to at least one full-time or two part-time positions focusing on the two areas of individual legal advocacy and legal advocacy development. With QAI's Commonwealth funding actually reducing in real terms the likelihood of this occurring without sourcing other funding is not good. Hence significant effort has been expended through the past year towards making application on two occasions for amounts of non-recurrent Community Legal Centre funding from Legal Aid Queensland. These applications have been unsuccessful but it is hoped that eventually this agency will face up to its responsibility to disadvantaged people with disability in this State. Legal and political processes by which this may be achieved are being considered presently.

Coronial Finding/Inquiry into Hostel Placement

In January 2002, the findings of an inquiry into the death of Lynette Deamon, at Palmville Court hostel in Ipswich, were handed down by the Ipswich coroner. From one perspective this brought to an end a major focus of work of the Legal Advocacy worker over the past two years, first of all lobbying for the inquiry, then ensuring that the voice of vulnerable people in hostels was heard at the lengthy hearing. The Coroners findings however have given rise to further systemic work. While she did not recommend that criminal charges be brought against anybody in relation to the death she did make two riders to her findings as to the cause of death. Firstly that Disability Services Queensland should consider undertaking a review of the system whereby people with disability are placed into private hostels, and secondly that the matter should be referred to the Nurses Board for consideration as to whether disciplinary action (such as deregistration) should be taken against hostel manager and registered nurse Roseanne Brown. The Legal Advocacy worker was instrumental in ensuring wide press coverage of the findings. As a result the Minister committed the Department to carrying out the aforementioned review. The worker, along with the QAI director has been involved in settling terms of reference and identifying a suitable person to undertake the review. It is disappointing that at the time of this report the review is yet to begin. The Legal Advocacy worker has also maintained contact with the Nurses Board and is aware that an investigation is presently underway into Ms Brown's conduct.

Law Reform

Throughout the year the Legal Advocacy worker has considered it necessary to contribute submissions, in the project's role of involvement in implementation and reform of legislation relevant to the objectives of QAI projects, to processes in relation to the following legislation:-

- Guardianship and Administration Act
- Residential Services Act and Regulation
- Personal Injuries (Proceedings) Act and Commonwealth Review of the Law of Negligence.

While it is difficult to quantify the value of making such submissions and to what extent they are taken into account when it comes to drafting legislation it is clear that proponents of opposing or inconsistent views will continue to be a part of these processes and that their views need to at least be balanced by contributions from us.

Preliminary meetings and discussions have begun in relation to QAI's approach to contributing to the review of the Disability Services Act, to take place over the next six months.

Legal Profession Development – Training package and resources for profession

In association with Minter Ellison Lawyers much has been done in the past months towards reviving the idea of a Legal Profession Training Package in relation to disability issues and legal issues in relation to disability. Considerable work was put into such a project several years ago by the Legal Advocacy Development project but a certain amount of updating of the content and modernizing of the style of presentation is now planned. Funding is being sought to employ professionals to assist with the packaging and style of presentation as well as with planned consultations with stakeholders as to content.

QAI is also committed to updating it's contributions to the valuable publications published by Caxton Legal Service – the Qld Law Handbook and the Lawyers Practice Manual. The process for this updating will coincide with the updating of content for the Training Package by the Legal Advocacy Worker.

Continuing Legal Education/Conferences/Networking

- Attendance by Law Project Worker at Queensland Association of Independent Legal Services annual conference, Caxton Legal Centre Access to Justice Conference, Inclusion International Congress
- Involvement in national Disability Rights Network.
- Attendance at various functions, dinners, presentations, AGM's etc held by QAI and allies and within the community, government and private legal sectors.

The value of maintaining a visible presence within a number of communities through such activities is often as significant as the information taken away and the contacts made.



LEGAL ADVICE STATISTICS 2001 - 2002

TABLE 1 – Type of Advice

What people asked about	Total number of inquiries
Guardianship (excluding financial matters)	9
Inclusive Education	6
Consent to Medical Treatment	4
End of Life Decisions	0
Rights and Care in Institutions and Group houses	1
Rights and Care in Psychiatric Units	6
Death of a Person with Disability	0
Victims or Witnesses of Crime	0
Assault or Abuse	7
Care within Educational or Health Services	0
Children with disability in state care	1
Other	1
Not specified/ Advice not given	65
Total	100

TABLE 2 – Who asked for advice

Contact by **Number of persons**

Person with disability	37
Relative/Friend	35
Advocacy Group	9
Solicitor	3
Other Worker	16
Other	0
Total	100

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	27
Physical	20
Sensory	1
Psychiatric	18
Multiple	1
Brain Injury	9
Other	3
Unknown	21
Total	100

ATTACHMENT

Attachment A – QAI Financial statements for the year ended 30th
June 2002