

**We dedicate this report to Jenny Fitzgerald,
Marcus, Ajit and Krishna. We send our deepest love
and affection to you at this time that it may
strengthen and nourish your courage and devotion**

Introduction

This Annual Report covers the period from 1 July 1998 until 30 June 1999. 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 Objects

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 objects are:

1. To affirm and put first people with disability in Queensland.
2. To do 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 do 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 organisation.
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/or which is actually, or very likely to be, "costly" to the actor, eg in terms of

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

and 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.
being mindful of the most vulnerable person.

- ❖ Systems advocacy is a particular form of advocacy that focuses on influencing and changing "the system" (as in 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

This report was presented to the Annual General Meeting of QAI on 18 September 1999.

I would like to welcome everyone to the 12th Annual General Meeting of Queensland Advocacy Incorporated.

This is my first year as President of QAI and my first attempt at writing a report of this nature. This role has placed me on a steep learning curve, one in which I hope that I have served people with disability well.

The 1998-1999 year has been very busy as usual for all involved with QAI. QAI continues to be challenged by the many competing demands placed upon us by the 'sector', the 'wider community' and of course, the people we are here to serve, 'the most vulnerable people with disability' in Queensland.

QAI issued challenges of our own to government of all levels, the disability sector itself, the wider community, our membership and other interested stakeholders to become more involved in the lives and issues that impact on the lives of people with disability who are most vulnerable. The detail of this work is explained throughout the Annual Report, the report will be circulated today to AGM participants and by mail to all members over the next couple of weeks.

Thank you

There are so many people to thank for what seems to be their endless and tireless contributions to the work of QAI that it's hard to know where to begin.

The QAI Management Committee takes this opportunity to publicly thank everyone the organisation has had contact or communication with throughout this past year. Your continued support and contributions to QAI is vital to our success into the future.

One of the cornerstones to QAI's success is the continuing commitment of my colleagues, the members of the Management Committee – Mike Duggan, David Swift, Donna Best, Doug Eldridge, Marg Schroder and Deborah White. These people individually and collectively bring the huge task that is QAI's work into a sharp focus called the Operational Plan. These people give so much of themselves in terms of time, knowledge and skills and I want to thank each of them for supporting me in my role as QAI President, and without them my efforts would be average. One member, Deborah White, left QAI in October 1998. Deborah is a parent of a young boy with disability and decided to be on the committee of Queensland Parents of People with Disability (QPPD). The insights Deborah brought to the values workshops from a parent's perspective were invaluable to developing our understanding. QAI wishes Deborah well.

Staff Changes

The one major staff change that has taken place during the year was the resignation of QAI's Director, Jeremy Ward in October 1998. Jeremy's commitment to the

work, mission, vision, principles and values of QAI is unquestionable. His clarity of purpose is an inspiration to many people within Queensland and throughout Australia. QAI held a farewell party in October to celebrate his involvement as a systems advocacy lawyer and later appointment as Director of QAI over 11 years.

This made finding Jeremy's replacement an interesting challenge and Christine Douglas filled in as acting director for 8 weeks. During the selection process, Christine was the convener of the process and did an outstanding job during a difficult time for QAI.

Kevin Cocks was appointed in late October and commenced in the first week of November as QAI Director.

The one other comment I need to make about QAI staff is how they are an incredible group of individuals who choose to give so much of themselves to the work of QAI. Much more than their job description requires of them to achieve the mission of QAI. A big thankyou to their family members must also be extended, for allowing the flexibility of the staff to do their work, often after hours.

Post-Evaluation

Much of the year has been utilised by all at QAI with implementing many recommendations of QAI's second evaluation with workshops, meetings and discussions on leadership, quality, vulnerability, review of planning processes and continuing policy review.

Another area of work was the completion of QAI's values statement which is now available for members' consideration. The values statement has enabled QAI to have a foundation to ground our work for balance and consistency and to make sure that work is in the best interests of the most vulnerable people with disability in Queensland.

QAI has undergone a major restructure looking at issues such as decision-making, meetings – purpose and duration, the development of the Strategic Plan Manual and the Committee Development Framework. Many of the mechanisms have been implemented to guide QAI's human resources and our work in the 21st Century.

Annual Fund

The QAI committee has established an Annual Fund Breakfast Committee. This committee has been chaired by Sean Reidy over the last 12 months and was attended by Jeremy Ward and then Kevin Cocks as the Director of QAI. John Rigby, who is the QAI fund raising consultant also participated in committee activities.

The inaugural Annual Fund Breakfast held on the 20th November 1998 was a very successful and important time for QAI. This was one of our very first public attempts at engaging with the broader community and engendering awareness around the importance of independent, social advocacy in the lives of vulnerable people with a disability.

The guest speaker was Justice Margaret McMurdo and the audience was made up of representatives from law firms and individual lawyers as well as supporters of QAI.

Sean Reidy has been the Chairperson of the Annual Fund Committee for the past two years and is standing down this year. On behalf of the Management Committee, staff and members of QAI, I would like to congratulate Sean on the tireless and excellent job he has done to give shape, direction and vision to the committee and the ongoing future of the Annual Fund. Thank you Sean.

Queenslanders with Disability Network (QDN)

QAI has auspiced the Queenslanders with Disability Network (QDN). During 1998, the government of the day called for expressions of interest in developing a network or coalition of people with disability which would respond to the government on a whole range of issues relevant to people with disability and their lives. An interim Steering Committee of the Queenslanders with Disability Network submitted a proposal to form a network.

In June 1999, QDN was successful in obtaining recurrent funding to develop the network. This network is expected to play a very important role in informing people with disability in this State about the expectations and opportunities for better lives that is inherent in the Queensland Disability Services Act.

This developmental project is focussed on people with disability as distinct from service providers, parents, families and carers of people with disability. QDN takes the view that this project is focussed on developing a voice and avenue for Queenslanders with disability. The organisation developed with this funding will enable Queenslanders with disability to express their views on what services are needed, how those services are delivered and the accompanying policies and mechanisms needed to support the principles and objectives in the Disability Services Act 1992.

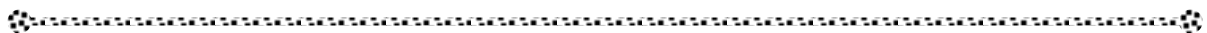
Additionally, Queenslanders with disability will also have an opportunity to voice concerns and views about those things that affect their lives that cannot be provided by services, and which need to be encouraged and fostered within the community.

QDN is committed to ensuring that the Network will include all people with disability including:

- people living in isolated, rural and remote and regional parts of Queensland
- people who experience profound disabilities
- the diverse range of disability experiences across the State
- people from indigenous and non-English speaking backgrounds.

If QAI members wish to know more about QDN you can contact them on 07 3236 3398.

Thank you
Nigel Webb



Treasurer's Report - Donna Best

This report was presented at the Annual General Meeting of QAI on 18 September 1999.

I take great pleasure in presenting the financial report for QAI for the financial year 1998/99. QAI's audited financial statements were prepared by Hayward, Gesch & Dorge, chartered accountants and are attached at Appendix B of this report.

In 1998/99 the Gaming Machine Community Benefit Fund gave funding to QAI to document the Maryborough Disabled Persons' Ward story.

The fundraising activities of QAI generated a small income through the inaugural Annual Fund Breakfast that was held in November 1998.

The Queenslanders with Disability Network (QDN) received funding from the Queensland Department of Families, Youth and Community Care in July 1999. QAI and QDN have entered into an auspice agreement for 1999/2000.

The Queensland Law Society granted QAI \$ 18 500 which has been used to fund the legal advocacy work of the Law Project.

The Gaming Machine Community Benefit Fund granted QAI \$ 7500 in June 99 for office equipment, which includes a laptop computer.

QAI's expenditure in 1998/99 was in excess of its received income. The deficit was covered from QAI's accumulated funds.

INCOME

In the past financial year, QAI received our recurrent operating grant from the Commonwealth Department of Family and Community Services. Total Funds available to QAI in 1998/99 were as follows:

QAI Grant(DFCS)	\$ 323 452
Queenslanders with Disability Network (DFYCC) (unexpended)	\$ 64 000
Queensland Law Society (unexpended)	\$ 18 500
Gaming Machine Community Benefit Fund	\$ 10 000
Gaming Machine Community Benefit Fund (unexpended)	\$ 7 500
TOTAL	\$ 423 452

In addition to the grants, QAI received income from the following sources:

Book Sales	\$ 560
Interest	\$ 3 047
Membership & Donations	\$ 4 714
Sundry	\$ 130
Fundraising initiative	\$ 1 295
TOTAL	\$ 9 746

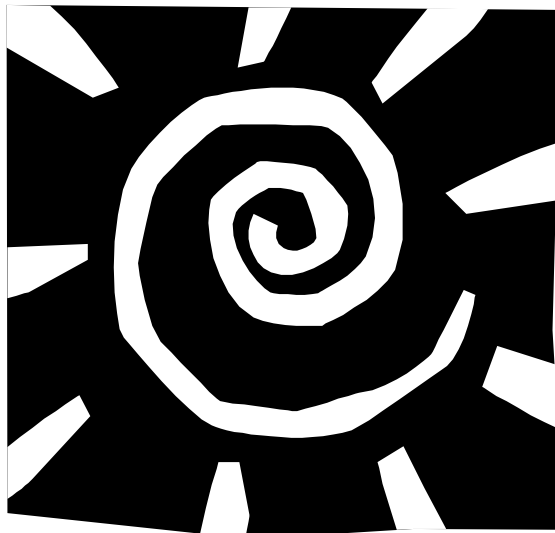
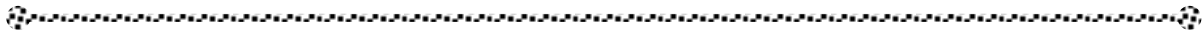
EXPENDITURE

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	\$ 19 030
Postage Printing & Stationery	\$ 9 722
Office Occupancy Costs	\$ 36 000
Salaries	\$ 231 694
Travel & Conferences	\$ 24 586

I would like to thank all the staff for their support during 1998-1999 and Peter Gesch from Hayward, Gesch and Dorge Chartered Accountants for auditing QAI's books and for his helpful advice throughout the year.



QAI Organisation

QAI is an incorporated association with members and a management committee. QAI must abide by its rules of association and certain regulations set out by the State. These require that:

- restrictions be placed on the activities that an incorporated association can carry out
- an annual meeting for members must be held every year and the QAI committee must meet at least every month
- proper records of members and minutes must be kept
- the accounts of the association must be open to public scrutiny and audited annually.

Members

QAI has a membership of 436 individuals, not all of whom are currently financial. Members are asked to join QAI because they endorse the organisation's values and principles and believe in QAI's Mission and Objects. During the past year members have supported QAI's work by:

- paying a membership fee and electing a committee at the Annual General Meeting on 19 September 1998
- assisting in the work of the organisation by participating in sub-committees and in campaigns on issues
- participating in workshops with committee and staff to increase the understanding and application of QAI's philosophical base,
- assisting QAI to be accountable by attending the presentation describing QAI's work at the AGM and by reading the Annual Report - subsequently questioning and commenting on some of QAI's actions
- becoming informed about QAI's policies and work and talking about QAI to family, friends, neighbours - thus raising the profile of the most vulnerable people with disability and their issues
- recruiting new members to add to the voice of people supporting QAI's values and work
- keeping QAI informed about happenings in local communities eg by sending in newspaper articles and by contacting QAI staff and committee and discussing situations with them.

Members of QAI do not receive any special services from QAI. However, QAI has endeavoured to keep members informed of the issues via the Newsletter and Annual Report. Four editions of the Queensland Advocacy Incorporated *NEWSLETTER* were produced in 1998/99 and sent to over 850 individuals and organisations. The Newsletter is also available on the QAI website. Audiotapes were available to those members who requested them.

Management Committee

There were seven people elected to the management committee at the AGM on 19 September 1998. One member resigned during the year. Committee members attended and participated in numerous meetings and workshops throughout the year.

The committee and staff met 12 times for formal management meetings. Two special meetings of the management committee were held to discuss budget and goal priorities. An induction workshop and two committee development workshops were held for the new committee. Planning meetings for 1999-2000 attended by staff and committee resulted in revised goals and objectives for the next three years and a new operational plan for 1999-2000.

In addition to formal meetings of the committee, various sub-committees consisting of staff and management committee met regularly throughout the year to discuss issues and undertake any planning around these issues. These included:

policy sub-committee (4 meetings), AGM sub-committee (4 meetings), post-evaluation sub-committee (11 meetings).

Staff and committee members attended various workshops throughout the year. These included:

Post evaluation workshops (4), Values workshops (5), Management committee development workshops (3), Planning workshops (5).

QAI's President met at least weekly with the Director, to deal with any issues that came up in between meetings of the committee, to discuss and sign correspondence and to set agendas for meetings. Other staff met with the President as required to discuss issues relevant to their particular projects. The Treasurer met fortnightly with the Administrator to authorise payments, sign cheques and check budgets.

The committee and staff met with the Department of Family and Community Services project officers in the past year to discuss funding issues, current work of QAI and the Commonwealth Advocacy Program Review.

The committee was informed about the work of staff via monthly written or oral reports from each staff person and by informal meetings with staff at the office. Staff reports were discussed in some detail at committee meetings. At least one (and sometimes more than one) committee member read over any submissions and written material prepared by QAI, and had input into the final drafts.

Committee members also took part in reference groups and in organising events around QAI's work. Committee members accompanied staff to meetings with Government Ministers and on most occasions to meetings with senior bureaucrats.

Committee members also participated in teleconferences of the funded advocacy groups in Queensland, and attended consultations such as those relating to the Commonwealth Advocacy Program Review.

Staff

Founding member of QAI and Director, Jeremy Ward, resigned in September 1998. Jeremy has taken up a position as a member of the Veterans' Review Board.

Kevin Cocks joined QAI as its new Director in November 1998.

Kathleen Dare, Legal Advocacy Development Worker, went on extended maternity leave in January 1999.

Josie Nolan, who for many years has ensured that QAI's offices are spick and span, resigned in January 1999 for health reasons.

At 30 June 1999, full time staff employed were:

Director	Kevin Cocks
Administrator	Sharyn Pacey

Part time staff were:

Systems advocacy worker (9 days/fortnight)	Christine Douglas
Bioethics Systems advocacy worker (3.5 days/week)	David Turnbull
Individual legal advocacy worker (3 days/week)	John Stannard
Legal advocacy development project worker (3 days/week)	Kathleen Dare
Administration assistant (22 hours /week)	Julie Granger
Administrative assistance (1 day/week)	Bobby Noone

Funding

QAI continued to be funded by the Department of Family and Community Services (DFCS).

Apart from interest from investment of funds, book sales, donations and membership fees, in 1998/9 QAI raised additional income through grants and the Annual Fund.

Complaints about QAI

No formal complaints against QAI were received during 1998/9.

In 1994/95 a commitment was made by the committee that an independent person would examine the operation and outcomes of the QAI Complaints System each year, after the Annual General Meeting. The independent person who was appointed to examine the Complaints System after the AGM in September 1998 was Lex Weddell who will be asked to continue this function after the AGM in September 1999.

Planning, Review and Evaluation

In response to recommendations from the external evaluation QAI staff and committee conducted five full day workshops with staff and committee to develop a values statement. This significant document which will guide and direct QAI's work is attached at Appendix A.

QAI staff and committee documented our decision-making procedures and how we work together in *Our Charter*.

New goals and directions were set during our planning workshops around the strategic plan for 1999-2000. The focus of QAI's work for the next three years is set around the following goals:

Goal 1: To advocate for systems and practices that eliminate abuse and oppression of people with disability.

Goal 2: To take an active leadership role in the development of social advocacy

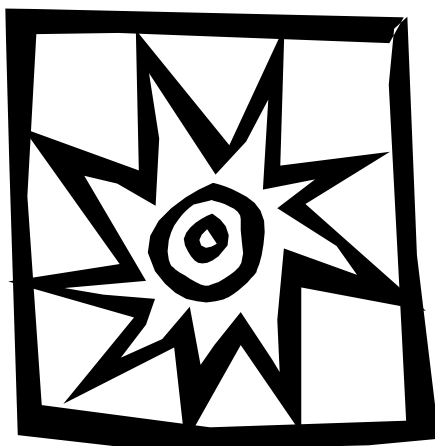
Goal 3: To actively promote the provision of appropriate individual legal advocacy

Goal 4: To pursue our advocacy goals, QAI will conduct an efficient and accountable organisation.

Staff Performance Appraisals were carried out in April/May 1999, involving all staff meeting with Director to develop assessment and training needs.

Queenslanders with Disability Network

This new network was successful in receiving recurrent funding from the Queensland Department of Families, Youth and Community Care. The network will be auspiced by QAI and will be located in QAI's offices initially.



Advocacy Development and Support

During 1998/1999 QAI advocacy development and support remained an area of priority for QAI. This work came within the role of QAI Director, Kevin Cocks, though a number of other staff assisted with different tasks.

Information on Advocacy

QAI received numerous requests for information on advocacy. These requests came from people with a disability, family or friends of people with a disability, direct service workers and students. The information provided was mainly drawn from the advocacy information sheets produced by the Action for Advocacy Development and the chapter on advocacy in QAI's book *Include Me In*. This information was made available free of charge.

National Advocacy Alliances

Members are aware that QAI has been an active member of the Australian Advocacy Network (AAN) and this past year has been no different. The main area of work undertaken by AAN was around the National Advocacy Program Review, the consultation process and the process leading up to the final report.

QAI along with many advocacy groups around Australia were very concerned on a number of aspects relating to the process, objectivity and time frame leading up to the final report. AAN on behalf of its members lobbied both the bureaucracy and the Minister to extend the time frame for the consultation process; the time frame was eventually extended.

Additionally, AAN carried out a Freedom of Information search; the search focused on all of the submissions, relating to the National Advocacy Program Review, which were submitted to the Office of Disability. AAN analysed over 160 submissions. This action revealed that the draft report of the advocacy review did not truly reflect the information presented to the Office of Disability by way of submissions from advocacy groups and other interested parties around Australia. AAN produced a paper with its analysis of the information provided in the 160 submissions to the Office of Disability. Armed with this information AAN made a number of delegations to the Minister responsible for the National Advocacy Program Review, Senator Jocelyn Newman. Additionally, members of the Community Affairs Legislation Committee (CALC) and members of the Community Affairs References Committee (CARC); including Senator Gibbs, Senator Evans, Senator Bartlett, Senator Eggleston, Senator Knowles, Senator Harradine and Senator Margetts.

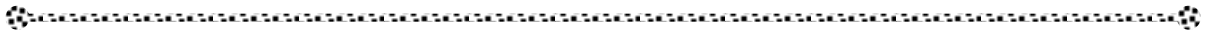
AAN also made delegations to Hon. Warren Truss' office. AAN sent out over 300 Alternative Draft Analysis of the submissions received to its members around Australia for them to provide comment and feedback to the inter-consultation process.

Erik Leipoldt, who has been the convenor for AAN for the past four years, has stepped aside as the convenor. On behalf of QAI and its members I would like to congratulate Erik on the work that he has undertaken with AAN members and in

particular in ensuring that advocacy was represented to the powers that be in a vigorous manner at a national level.

Advocacy Development Network

QAI has continued to participate in the support of the Advocacy Development Network (ADN) throughout the year, in particular the lead up to the successful ADN Conference in March. QAI has also assisted Mary, the convener of ADN, in developing and presenting advocacy workshops in particular to the Department of Housing's 'Housing Resource Officers'. QAI Director, Kevin Cocks has been invited to participate in the advocacy development network's focus group. The focus group is charged with supporting the convener of the Advocacy Development Network to implement ADN's operational plan.



Bill and Lee Garsden of Queenslanders with Disability

Closure Of Institutions/Community Living Project

QAI spent a challenging year working on this project in an environment that was in direct contrast to the previous 12 months. Last financial year there was a Coalition government, this year a Labor government; last year we had little to no policies and even less growth monies, this year a plethora of emerging policies, working groups and consultations and an allocated \$30 million in additional funding for disability.

Coupled with this contrast, however, were a number of significant similarities that continued to impact on the lives of people with disability in Queensland. They were the continuing ascendancy of the notion of choice, group living - albeit reduced from the 6-pack arrangement to the 3-pack - and an emphasis on the family and family support. The latter, while wonderful in themselves and fully supported by QAI, have seemed to come at the expense of independent advocacy for individuals with disability and a discounting of the legitimate role it plays in the lives of people with disability

QAI's task in this area has largely been one of trying to identify and monitor the changes in terms of their effectiveness and relevance to the needs and lives of people with disability. Thus QAI's core work has remained virtually unchanged in an environment seemingly full of change.

Bringing People Together

In keeping with QAI's tradition of bringing people together around pertinent issues, QAI organised a number of meetings with key people from the community and government disability sector, to monitor and discuss the setting up of the Disability Services Agency. This was a timely and crucial piece of action as the community sector was in serious danger of being excluded from the early, but highly important, exploratory and planning processes. QAI has continued to play a role via the Ministerial Reference Group set up and ongoing dialogue at the informal but the nevertheless strategic level. The reference group comprises government and community representatives and has appointed a Strategic Leader, produced a consultation paper and engaged the views of the community about the structure of the new agency and its Strategic Plan, set to forge the direction of Disability Services Queensland for the next five years.

QAI has also played a leading co-ordination role in bringing the wider sector together to form a community coalition around the changes that have been occurring in the field over the past 12 months. The coalition is barely in its infancy stage and will be the subject of next year's Annual Report.

Submissions/Consultations/Reference Groups

Whilst there is always debate about the dilemmas participation in bureaucratic and service delivery processes pose for advocacy groups, QAI has engaged in a number of them in this 12 month interval. In order to determine QAI's involvement, a number of filter questions are asked. E.g. Does it fit with QAI's Operational Plan? Will our involvement conflict with QAI's mission and values and the principles of advocacy? Can similar information be obtained elsewhere? Who else will be the voice for the most vulnerable people with disability? The answers to these questions

are not always easy or clear-cut, but on that basis QAI has also refused many invitations.

Priority Determination Panels & Registration of Need

QAI, along with other members of the Combined Advocacy Groups Queensland, was one of the few voices that questioned the validity and effectiveness of the Priority Determination Process in delivering an open, timely and defensible mechanism for funding people with disability in Queensland. QAI wrote a submission to government, attended a public forum and engaged in continuing dialogue with the department about the philosophical and operational complexities and inconsistencies of the program. QAI also published an analysis of the program in its December 1998 *Newsletter* in an attempt to raise debate within the sector. In the absence of universal entitlement, any scheme established to distribute poor levels of funding would be inadequate.

As a tool for quantifying need and informing future planning and budget estimates, a needs registration process has a long overdue place. While QAI supported the overall concept we also argued to have the process separated out from the priority determination process and for the department to monitor the effectiveness of the format and content of the actual Needs Registration Form. The collecting of data is based wholly on a deficit model, placing individuals with disability, families with members with disability and others who may fill out the form in the insidious position of painting the person in the blackest terms possible in order to attract a high rating.

Other areas of involvement include:

- Local Area Co-ordination: Written submission and participation in a community consultation forum (DFYCC)
- Prevention of Abuse Assault and Neglect Project: Reference Group member, attendance at a community consultation forum (DFYCC)
- Community Visitors Program: Reference Group member (Office of the Adult Guardian)
- Behaviour Support Project: Written submission and participation in a community consultation day (DFYCC)

Closure of Institutions

QAI continued to call for an advocacy support program for the former residents of Challinor and current residents of Basil Stafford, to complement the family support project that was created to assist the families who had members in those centres. Both the Minister and the department have been reluctant to support an advocacy component to operate alongside its other relocation planning and operational processes. Without such an opening, access to proper information, residents and families is severely curtailed. QAI did not achieve the level of involvement it hoped to reach this financial year.

This year QAI also witnessed a number of institutional reform packages come asunder with enormous and sometimes tragic consequences for the people concerned. Such examples reflect the inability of ceiling packages and grouping of individuals based on dollar equations to provide a meaningful and sustainable life for people with disability. The harmful and long term impacts that institutional living has on the

people who lived in them cannot be underestimated and compensation to redress the imbalances must be included in any funding arrangement. QAI continued to raise these issues in a variety of ways throughout the year in an effort to break down the impasse that is being created via the department's equity policy.

The determination of the government to build two new centres for those families who did not want their family member to live in the community continued unabated throughout this period. The closure of Challinor was dampened by the knowledge that two more centres would take its place. The question as to whether these centres will house only those for whom they are originally intended, for the life span of those centres, remains unanswered.

Closure of Institutions Reference Group

Although in recession for the past 6 months the Reference Group has provided QAI with an important information and resource base. The expertise in the group has been particularly useful in identifying and analysing the associated political, social and bureaucratic dimensions of the issue and identifying under and unutilised opportunities for furthering our understanding and sphere of influence.

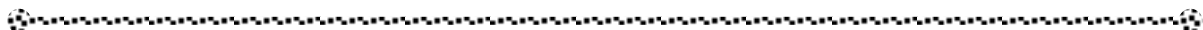
Tapping Into Local Energy

With the relatively successful closure of the Disabled Persons Ward at the Maryborough Regional Hospital, QAI harboured hopes that similar moves might occur in other hospital wards akin to DPW Maryborough, scattered throughout Queensland. Two years down the track, however, there has been little to no indication about the future of these hospital wards. QAI commenced inquiries at a governmental level in this regard and has been in the process of gauging local interest in the Baillie Henderson Units in Toowoomba, and the Birribee Unit in Rockhampton. QAI is willing to offer support and information to local individuals or groups in these areas who may have an interest in the current and future status of the residents of these wards.

Disabled Persons Ward (DPW) Maryborough

QAI was fortunate in securing a \$10,000 grant from the Community Gaming Benefit fund to employ a consultant to write the DPW story. Since that "story" has many, many themes and layers it was decided to begin with the people themselves. Six individuals were finally chosen to be the focal point of the research. A series of interviews have been undertaken with the selected residents where possible, their families where willing and able, their current and past carers, relevant departmental players past and present, and again where feasible their friends and advocates. The story is now in the first draft stage and makes for very powerful and moving reading. QAI is hoping to publish and launch the work sometime late in the year, or early next year.

QAI is also hoping to attract more funds to present a further in-depth analysis of the DPW Story from a bioethical, legal and social advocacy perspective.



Bioethics Advocacy Project

1998-1999 was the first full year of work by the bioethics advocacy project worker. As it eventuated, the year built on the work already done in the project as planned, yet even after this year the work is still very much in its formative stages. There are a number of reasons for this, not the least being the huge scope of bioethics as a field of knowledge, and its problematic nature in addressing issues regarding disability.

The field of bioethics presumes to

- encompass the whole of human life, from the genetic stage, to the prenatal, to the neonatal and beyond, finally to the stages of aging and death
- deal with issues from the philosophical, ethical and cultural, to the professional and technical arenas.

What bioethics does in QAI's view, is display an attitude of professional superiority towards the decisions that ordinary citizens must make regarding the lives of people with disability. Bioethics has not yet sufficiently embraced in terms of research, specific issues to do with disability, and has not elicited the stories relevant to these issues from people with disability. Hence we find extremely arrogant pronouncements coming from the writings of many prominent bioethicists about the lack of worth in having a life with a disability.

A number of factors have shaped, and continue to shape the direction of the QAI bioethics advocacy project.

1. Advocacy for people with disability continues to be disregarded in the dominant bioethics literature and the need to develop a broad 'values' base that richly embraces the views, longings and aspirations of people with disability becomes more urgent.
2. Advocacy in the bioethics area is a huge task. For the sake of manageability the tasks of advocacy have needed to be organised around specific themes, and strategic foci created to enable advocacy responses to be made.
3. Institutions such as those created by the medical profession are conducted behind doors that are, by and large, professionally closed to public scrutiny. For advocacy to gain access to these institutions allies are needed and provocative statements need to be made in key areas to draw professionals out of their secrecy.
4. The people who make decisions regarding the lives of people with disability are often unwilling to talk about them for personal reasons. This often however, is not just an issue of confidentiality. It is an issue of hiding decisions that are ethically questionable from scrutiny.
5. The technological innovations of the present era are being applied without sufficient regard for their ethical implications. Yet the pressure is on in all corporate arenas to be seen to be ethically responsible. This corporate pressure is the greatest asset that advocacy has and provides avenues for critical challenges to be made that draw out the responses we need in order for the project to

proceed. This report will deal with each of these points in turn.

1. QAI spent a great deal of painstaking time in articulating its own values in the latter part of 1998. These values have been used in the bioethics project to inform and provide the justificatory basis for the work. They have been indispensable, providing a filter through which the work has been evaluated, alongside the filters regarding advocacy and the organisational filters of QAI. Working out how these values may be applied in a variety of situations has been an ongoing and challenging task.
2. The bioethics project has been divided into three themes around which issues may be grouped. The themes are
 - Eugenics in genetic, prenatal and neonatal medicine
 - Health and wellbeing
 - Euthanasia

These themes focus, somewhat appropriately, on issues to do with the beginning, the middle and the end of life. What they do is name the primary issues that the bioethics project deals with. Using these themes, QAI has been on the lookout for strategic situations that can become the focus of advocacy efforts.

3. By the end of the year of 1998 QAI was in a position to make the first approaches to a major institution. Approaches by way of a bioethicist working in a Brisbane hospital were repelled. The message was clear. *This is difficult work. Leave it to the (one and only) ethics professional.* The big problem with this response for QAI is that this professional has a conflict of interest, being employed by the hospital. Advocacy principles demanded that this response be challenged yet without burning the bridges of negotiation. In the meantime Lisa Bridle, who is researching prenatal diagnosis of Down syndrome, was proving a worthy ally. Understanding of the issues in prenatal medical interventions was developing. As readers of the QAI newsletter will be aware, QAI wrote letters, published articles, and eventually gained access to powerful policy making bodies within the hospital. The work continues.
4. QAI realises that many people with disability and those who provide them support have in their stories, indispensable pieces of information that are vital as we seek to oppose biotechnological threats. This year saw the beginning of what we hope may lead to many contacts with 'lay' people who can tell us stories that will continue to inform the project. As well, QAI is seeking out people from within the biomedical professions to become allies in the struggle against continued injustices, abuse, oppression and discrimination.

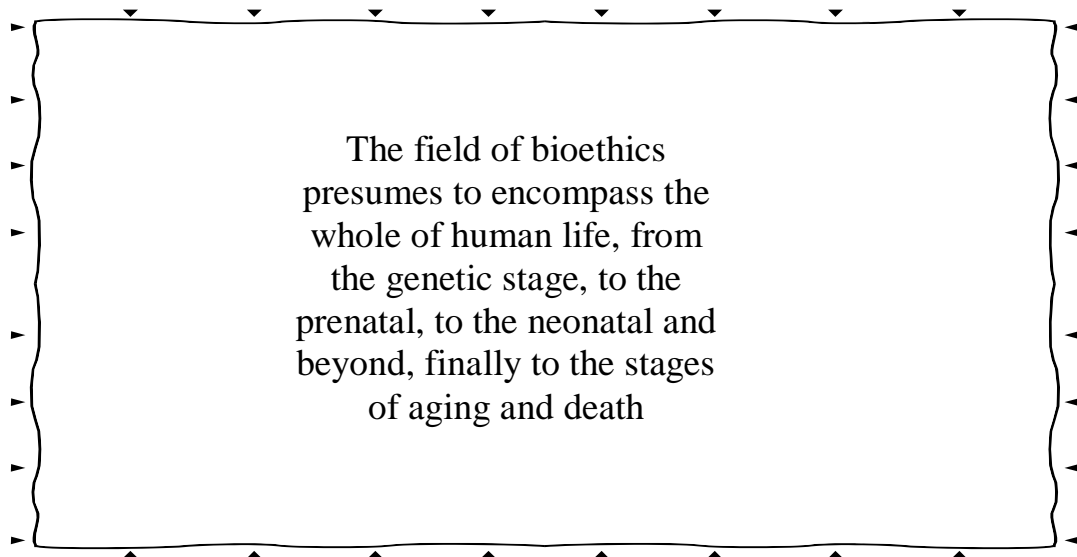
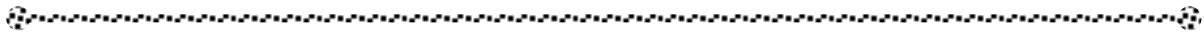
Valuable allies did appear during this year to assist with the direction of the work. Special mention must be made of Christopher Newell, a researcher and teacher in ethics who produces research papers at a wondrous rate, and never fails to send them on. He is a source of valuable information in every area of bioethics research into people with disability. Elspeth Douglas, a retired bookseller, has been an invaluable source of data collection. Every month she sends on relevant articles from her wide sources of reading. Adam Hildebrand, from Citizen Advocacy in USA, has also provided valuable support and intellectual assistance. There are others who gave inspiration and support, for whom space here is

insufficient to mention, but for their efforts also, gratitude is deeply felt.

5. The issue of ethics and technology, spurred on by what QAI is finding out about genetic and prenatal technology is looming as a significant focus for future work. The reliance by biomedicine on technology means that ordinary human communication is being avoided wherever possible. This kind of communication is time-consuming and unpredictable. It is easier for biomedicine to adopt technical solutions conveyed in technical language as these are administratively simpler and give the profession greater control. The gateway to a more sophisticated eugenics is open.

In conclusion, 1998-1999 was a formative year, a year full of research, thought and writing and making valuable contacts. Highlights of the year were

- delivering a paper at the Australian bioethics conference in Hobart in October
- the 'values' workshops and deepening liaisons with the QAI management committee
- the staff retreat for the deepening and expansion of relationships and ideas
- meeting allies and potential allies
- finally getting the attention of a major medical institution.



The Law Project - Legal Advocacy Development

This report for the year covers a six-month period from 1st July 1998 to end of December 1998.

During this period the following activities were undertaken by the Legal Advocacy Development Worker.

Training

Training for the legal profession and other workers has been a major feature of the advocacy relating to this project. The project funded and conducted training in Cairns and Townsville, these sessions were attended by solicitors in private practice, community legal centre workers and advocacy workers and were very enthusiastically received.

The project worker also presented a seminar for the Queensland Law Society Continuing Legal Education Program where there was a very good attendance.

Law Reform Submissions

A joint submission with Cairns Community Legal Centre and Townsville Community Legal Service on the *Coroners Act Amendment Bill* was written by the project worker. This submission was supported by the joint advocacy network. As a result of the joint lobbying, the proposed amending legislation was not pursued and we were advised by the Attorney's-General Office that our submission will be considered as part of a whole review of the *Coroners Act*.

Other Submissions

The Law Project wrote to and lobbied the Department of Families, Youth & Community Care concerning the Forde Inquiry's terms of reference. This inquiry was established to inquire into the abuse and neglect of children in institutional settings in Queensland, but the terms of reference directly discriminated against children with disability. Despite our submissions, the terms of reference were not widened to include children with disability.

Funding Submissions

After a number of detailed submissions to the Queensland Law Society requesting funding for the writing and publishing of a manual for lawyers on acting for clients with disability, we were finally successful in receiving a grant of \$18,500.

This research element of this work has commenced and the writing will be conducted in the 1999-2000 financial year.

Annual Fund Breakfast

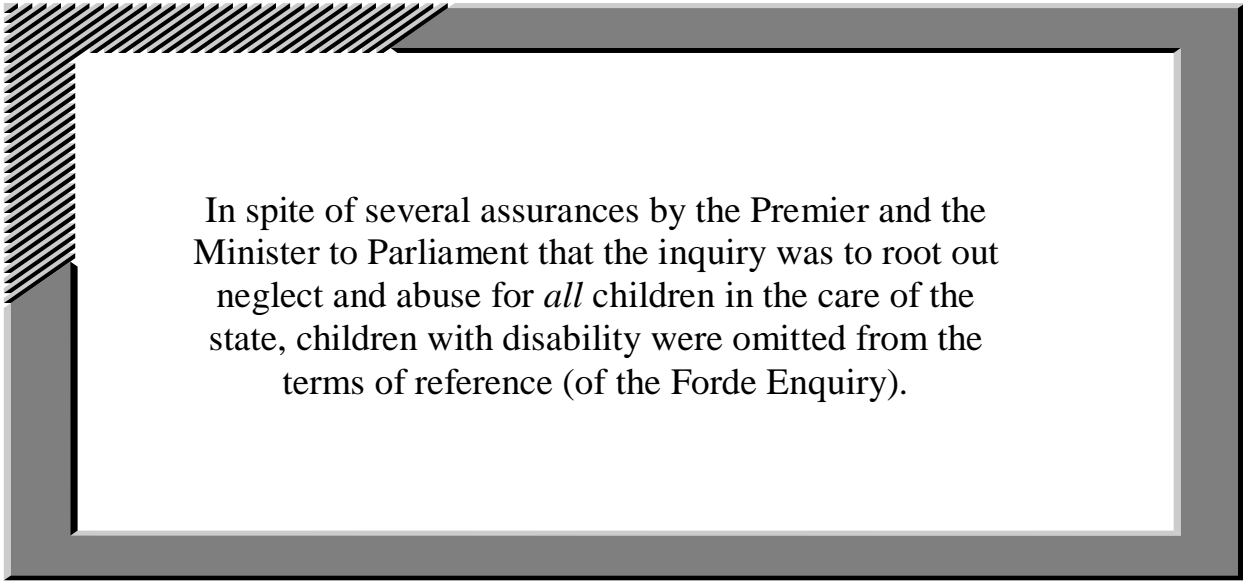
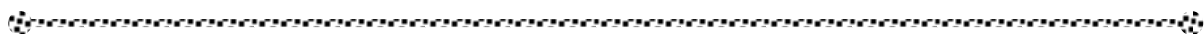
The legal advocacy development worker wrote and gave a speech for the Annual Fund Breakfast in November 1998.

Judicial Education

The Annual Fund Breakfast was well attended by the legal profession, including the judiciary. Justice McMurdo, the president of the Court of Appeal, and the then Deputy Stipendiary magistrate, Di Fingleton both initiated dialogue regarding judicial training on disability and this has been followed up with further correspondence.

Case Work

While the legal advocacy development worker is not primarily responsible for casework, assistance in the provision of advice and casework for the law project was provided.



In spite of several assurances by the Premier and the Minister to Parliament that the inquiry was to root out neglect and abuse for *all* children in the care of the state, children with disability were omitted from the terms of reference (of the Forde Enquiry).

The Law Project - Individual Legal Advocacy

The Law Project has experienced an exciting and eventful year. The quotient of lawyers at QAI experienced a, some would say healthy, drop from around half to perhaps one sixth of staff as Jeremy Ward left and Kathleen Dare took maternity leave with the gorgeous Arabella, already showing excellent communication skills. The Legal Advocacy Worker has covered some of the training, advocacy and submission writing of the Legal Advocacy Development worker during her maternity leave.

In the event, much has been achieved and more will come to fruition in the next year. QAI has taken a great leap out of introspection, the external review process being now largely implemented, and toward creating a big, bright future for people with disability, or at least a little less abuse and oppression.

Legal Advice

The legal advice statistics, attached at Appendix C, reveal that while the number of cases undertaken remains almost unchanged, the number of requests for assistance with guardianship issues is significantly increased although total legal advice is down somewhat. Guardianship has come into a new focus with the introduction of the *Powers of Attorney Act* and the start-up of the Adult Guardian's office. This, of course, is the inexpensive end of the Queensland Law Reform Commission's 1995 draft decision-making legislation. We now have an Office of the Adult Guardian, and we have a right to a statutory health care attorney. However, alone in Australia, Queenslanders with disability await legislation to assist with decision-making, a Guardianship Tribunal and a comprehensive Community Visitors Scheme for people who are unable to plan for the onset of a decision-making disability.

Forde Inquiry

This must get a mention as one of the major disappointments for people with disability in the last year. In spite of several assurances by the Premier and the Minister to Parliament that the inquiry was to root out neglect and abuse for *all* children in the care of the state, children with disability were omitted from the terms of reference. QAI's requests for widening of the terms of reference or otherwise for inclusion were completely ignored as were both of QAI's submissions to the inquiry on abuse and neglect of children with disability residing in institutions.

The report and recommendations make no reference to children with disability apart from appropriate access to education within the juvenile justice system. It seems that Queensland's children with disability in institutions are either transparent or insufficiently at risk within those government and private institutions to require an inquiry into the conditions of their lives.

Out And About

As well as the Forde Inquiry, submissions were made in response to government papers on the now anticipated guardianship legislation, the review of the Children's Commissioner and Children's Services Appeals Tribunals Act, the review of the Mental Health Act, and review of the Freedom of Information Act.

Support was also given to the Queensland Association of Mental Health Legal Advocacy Pilot in the first half of 1999. This was done by way of training of volunteers and participation on the reference group. A peer advocate position has been funded and materials prepared for submissions for recurrent funding for statewide advocacy.

The worker also presented a paper on the issue of abuse and oppression at the Voices Conference organised by the Community Living Program, attended the National Community Legal Centres' Conference, the Community Resource Unit Conference, a real high-light of the year and now in print, and a three-day Social Role Valorisation course.

As well, we all saw the growth of QAI's Values Statement over five difficult days, the implementation of the external review through a process of Saturday meetings, and the staff retreat was of course anything but a holiday away from QAI.

Work was also begun on an important part of the Law Project for 1999-2000 - the Gap Analysis Plan which will work towards assessing the situation for people with disability who require access to the legal system. Stay tuned for developments on this one. It has, as they say, real potential to be big.

It has been a challenging and rewarding year. QAI has this ability to expand horizons and re-frame views in ways that one was not aware were even possible and Kevin Cocks has certainly carried this aspect of QAI forward, constantly causing us to challenge our thinking and the basis for our actions. I have learnt not to assume where the work will lead me. I look forward to an opportunity to work to root out abuse and oppression wherever it may be found in the coming year.

