

STEERING YOUR OWN SHIP?

**Assisting people who are unable
to make decisions
for themselves**

An Issues Paper

**Queensland
Law Reform Commission
1991**

The Queensland Law Reform Commission held a public forum on 27 May 1991 at Education House. The forum (and this issues paper) forms part of an inquiry resulting from a reference received from the Attorney-General to review laws affecting people with a disability.

This issues paper records statements and opinions held by people who participated at the public forum. The truth of each of these statements and opinions cannot be checked by the Commission, as most participants gave their comments and observations anonymously. Rather than taking each comment as factually accurate, the Commission sees workshop statements as a valuable tool in identifying the perceptions held by people directly affected by the laws in this area about the systems designed to give them assistance.

The Commission would like to expand upon three points in the paper which may require clarification.

First, assistance can presently be given to "intellectually disabled citizens" through the Intellectually Disabled Citizens Act. The range of people who are classifiable as "intellectually disabled citizens" has not been exhaustively listed in this paper. Examples of the types of people who are covered by the legislation are used in the text. For instance, a person whose functional competence is limited by brain damage caused through illness or injury can seek the assistance provided under the Intellectually Disabled Citizens Act. The paper has used a person with brain damage caused through a car accident injury as but one example of the wide range of people in this category.

Secondly, page 15 of the paper says that the Legal Friend may give consent to medical procedure or treatment to a person who has no other functional disability other than the fact that he or she has been rendered unconscious. The law in this area is not as clear as it might be. This proposition maybe too broadly stated. The question is whether the person has limited functional competence by reason of intellectual impairment. If the unconscious person cannot be categorised in this way, then the Legal Friend cannot consent to medical treatments or procedures on his or her behalf. For further information, please see sections 4 and 5 of the Intellectually Disabled Citizens Act.

Thirdly, the quote which is third from the bottom of page 28 may be ambiguous. It may be clearer if "[at 18]" is added to the end of that quote.

The short citation for this discussion paper is Q.L.R.C. I.P.1
Published by Queensland Law Reform Commission, August 1991
Copyright is retained by the Queensland Law Reform Commission
Printed by Westminster Classic Printing

ACKNOWLEDGMENTS:

The foundation of this issues paper is the views expressed by the participants at the Commission's public forum, held on 27 May 1991, who are too numerous to name.

Special thanks to the Community Justice Program and those of its mediators who facilitated workshops - Mieke Brandon, Margaret Collins, Carol Greenwood, Mary-Ellen Hempel, Charles Linsley, Kate McCormack, Ruth McDonald, Dian Meiklejohn, Melda Morris, and Leigh Robertson.

Special thanks also to Kelie Walsh and Nelsina Barnard for their untiring typesetting efforts.

ISBN: 0-7242-4606-1

Queensland Law Reform Commission

P.O. Box 312, North Quay, Brisbane, Q. 4002.
Phone: (07) 227 4544 Fax: (07) 227 9045

Dear Reader

This issues paper reflects the views of over 200 people who attended a public forum called "Looking after the affairs of people with a disability."

The public forum was held on 27 May 1991 at Education House. The forum program can be found on the last two pages of this publication.

As you will see from the program, the main theme explored at the forum was when and how the law should intervene in decisions about the lives of people with an intellectual or mental disability.

In advertising the forum, the Commission targeted the people affected by the present legislation about intellectual and mental disability.

The Commission was particularly concerned to learn of any concerns held by these groups of people about the existing laws, and their suggestions for improving the present system.

Where the comments made in this paper came from

You will also see from the program that two workshop sessions were held on the day. There were fourteen workshop groups. Ten small workshop groups comprised people who had a disability and their carers. Four larger groups comprised professionals and policy makers working in the field of intellectual or mental disability.

Each group was taped. Due to a problem with the recording equipment, the taping of two of the twenty-eight workshop sessions was not successful. This aside, the other tapes provided over 25 hours for transcription.

The transcribed comments made by both main speakers and workshop participants form the basis of this issues paper. The Commission has edited the transcripts under topic headings for easy reference.

Some features of existing legislation excited a lot of comment. Other features did not. In introducing topics with an explanation of the law, the Commission has concentrated on the issues raised in the forum. Therefore, the information about the law contained in this paper is explanatory only - it is not intended to be a comprehensive statement of the law in the area of substituted decision-making.

The focus of this paper

This paper focuses upon people **aged 18 years or more** who are unable to make decisions for themselves without some type of assistance.

How to read this paper

Introductory comments and brief explanations about the existing legal system are in normal type. These comments and explanations have been inserted by the Commission.

Comments made by the main speakers at the public forum - speeches and comments from the main platform to the audience - are in bold italics.

Comments made in workshop groups are in italics, but are not bolded. When a dot appears prior to a statement, this identifies a new speaker. More often than not, the new speaker will have been in a different workshop group to the previous speaker.

Types of comments made in the workshop groups

By its nature, public forums often attract people who believe that the system has treated them or their loved ones badly or inappropriately.

This in no way derogates from the very legitimate concerns that were expressed at the public forum.

It does, however, mean that comments expressing support for the system by people directly affected by the laws in this area, were not prevalent.

Where do we go from here?

The Commission has recently started work on developing a number of different models to reform or streamline the law in Queensland dealing with when and how the law should intervene in decisions about the lives of people with an intellectual or mental disability. The Commission hopes to have a paper about these options by December, 1991. All people who have been sent this issues paper will also receive this next publication.

This issues paper has been prepared to identify problems with the existing law. The comments made at the public forum will help the Commission to prepare appropriate models for change.

Submissions or comments from the community are always welcomed by the Commission. However, the most important time for individuals to comment during the Commission's review will be after the release of the Commission's second paper in December. Should you wish to address any of the issues contained in this paper, please send your comments to -

**The Secretary
Queensland Law Reform Commission
PO Box 312
NORTH QUAY Q 4002**

Contents

INTRODUCTION	1
1. THERE ARE A NUMBER OF TYPES OF DECISIONS THAT PEOPLE WITH A DISABILITY MAY NOT BE ABLE TO MAKE ON THEIR OWN.....	2
<i>Financial.....</i>	<i>2</i>
<i>Making a Will.....</i>	<i>3</i>
<i>Medical.....</i>	<i>3</i>
<i>Lifestyle.....</i>	<i>5</i>
2. THE LAW GIVES DECISION MAKING ASSISTANCE TO PEOPLE DEPENDING UPON THEIR DISABILITY	7
<i>Should there be one set of rules that apply to all?</i>	<i>9</i>
3. DIFFERENT BODIES AND PEOPLE ARE RESPONSIBLE FOR DECIDING WHETHER PEOPLE WITH DISABILITIES NEED ASSISTANCE IN MAKING DECISIONS	12
<i>The Intellectually Disabled Citizens Council</i>	<i>13</i>
<i>Doctors.....</i>	<i>15</i>
<i>The Public Trustee</i>	<i>17</i>
<i>The Supreme Court</i>	<i>18</i>
<i>Should the bodies and people who decide whether people with disabilities need assistance in making decisions -</i>	
<i>have direct experience with the type of disability that they are dealing with?</i>	<i>20</i>
<i>include lawyers?</i>	<i>20</i>
<i>comprise one or three members?</i>	<i>22</i>
<i>allow people about whom decisions are being made to be represented by a lawyer?</i>	<i>23</i>
<i>be able to compel people to attend a hearing?</i>	<i>23</i>
4. DIFFERENT BODIES OR PEOPLE ARE GIVEN RESPONSIBILITY FOR PROVIDING DECISION MAKING ASSISTANCE TO A PERSON WITH A DISABILITY	24
<i>The Legal Friend</i>	<i>27</i>
<i>Doctors caring for patients under the Mental Health Services Act</i>	<i>30</i>
<i>Committees under the Mental Health Services Act</i>	<i>31</i>
<i>The Public Trustee</i>	<i>32</i>
<i>Should different people make different kinds of decisions for the same person?.....</i>	<i>36</i>
<i>Do the actions of substitute decision-makers need to be scrutinised by an independent source?</i>	<i>37</i>
<i>Should the range of substituted decision-makers be widened?</i>	<i>39</i>

5. THE BODIES AND PEOPLE WHO ARE RESPONSIBLE FOR DECIDING WHETHER PEOPLE WITH DISABILITIES NEED ASSISTANCE IN MAKING DECISIONS APPLY DIFFERENT RULES	41
<i>Clear principles are needed</i>	<i>41</i>
<i>Least restrictive alternative</i>	<i>41</i>
<i>Encourage disabled to achieve their potential</i>	<i>42</i>
<i>Provide assistance only on an as needs basis</i>	<i>42</i>
<i>Presume competency</i>	<i>43</i>
<i>Substituted decision-makers must give people with a disability a say in what happens</i>	<i>43</i>
6. THESE BODIES ALSO HAVE A RESTRICTED POWER TO TAILOR ORDERS TO SUIT THE NEEDS OF A PERSON WITH A DISABILITY	44
<i>People are different</i>	<i>44</i>
<i>In some legislation these distinctions are recognised</i>	<i>45</i>
7. THE ROLE OF THE MEMBERS OF THE FAMILY	47
<i>Present involvement of the family in decisions made for a family member with a disability who needs assistance in making decisions -</i>	
<i>by the Public Trustee</i>	<i>48</i>
<i>by the Intellectually Disabled Citizens Council</i>	<i>49</i>
<i>Should substituted decision makers be required to consult with family members before making decisions?</i>	<i>50</i>
<i>When decisions are being made for a person by somebody outside the family, this affects the family and spouse of that person</i>	<i>50</i>
<i>Should the law allow family members to be substituted decision makers?</i>	<i>51</i>
<i>Arguments for generally</i>	<i>52</i>
<i>Arguments for in medical procedures</i>	<i>53</i>
<i>Arguments against</i>	<i>54</i>
8. OVERALL COMMENTS ABOUT THE EXISTING SYSTEM	56
<i>There is a lack of understanding</i>	<i>56</i>
<i>There is a lack of information</i>	<i>57</i>
<i>Laws about people with intellectual and mental disabilities should be presented more clearly</i>	<i>58</i>
<i>There is a lack of services</i>	<i>59</i>
<i>A complaints mechanism to ensure proper standards is needed</i>	<i>60</i>
<i>There are cases of inappropriate institutionalisation</i>	<i>64</i>
<i>Reform and the reform process</i>	<i>65</i>
PROGRAM FOR THE PUBLIC FORUM HELD ON 27 MAY 1991	67

Introduction

An important way in which people maintain freedom in and control over their lives is by making decisions and having these decisions acknowledged and acted upon. The decisions that people make in their lives, steer their destiny.

Withdrawing decision-making power can diminish a person's self respect and dignity. The opinion held by that person may become less important to the people with whom that person comes in contact. As a result, the person's status in society can diminish.

As far as possible, the law should act to allow individuals to preserve their decision-making power.

However, in some cases this is not possible. For instance, a person who has had a severe intellectual disability since birth may never be capable of making the decisions that affect his or her life. Another person, who has made very competent decisions throughout his or her life, may have suffered a deterioration of their intellectual competence through dementia or trauma to an extent where decision-making is no longer possible.

In other cases, it may not be desirable. For instance, a person who has been involved in a car accident and suffered extensive brain damage may be entitled to a substantial damages claim, but may not have sufficient intellectual capacity to protect the damages received from others who are tempted to take advantage of the person. A person suffering a brief psychotic episode may make harmful or life-threatening decisions during the psychotic period.

In other cases, people have mental or intellectual impairments which enable them to make some, but not all, of the decisions in their lives.

The Queensland Law Reform Commission is reviewing when the law should intervene in a person's power to make decisions, and when and how this should occur.

In performing this task, the Commission is mindful of balancing two sometimes competing interests - the need to maximise the control by people of the decisions that affect their lives, and the need to protect people from abuse and exploitation.

There are many grey areas in the existing law about substituted decision-making. More certainty in this area of law is needed not only for people with intellectual and mental disabilities, but also for the people who care for them and for the people who deal with them.

***1. There are a number
of types of decision that
people with a disability may
not be able to make on their own***

FINANCIAL

For a financial transaction to be valid, each party must understand the general nature of what he or she is doing by participating in that transaction.¹ The more complex the transaction, the greater the intellectual capacity that will be required.

If a person wishes to open and operate a bank account, then he or she will need to understand that the bank holds some money on his or her behalf which the person can withdraw. This does not require a high level of intellectual capacity.

By contrast, a person who is buying a car may sign an agreement that requires the person to make monthly payments to a financial institution. The agreement may say that, if payments are not received by the financial institution, the financial institution has the right to take back the car. A complex list of rights and responsibilities may be contained in the agreement. If the person can understand the purpose of the contract when it is explained, then the person will be bound by the agreement. However even if the purpose of the contract was not understood, the person may still be bound by the contract if the other contracting party did not know, or have reason to know, that the person had a mental or intellectual disability.²

Some contracts will be binding upon a person with an intellectual or mental disability even though the transaction was not understood by that person. The law says that a person with a mental incapacity who buys necessities (things that are necessary to maintain the person's normal standard of living, such as renting a flat or buying groceries from a supermarket) must pay a reasonable price for them.³

Generally, someone dealing or trading with a person, who does not know about the disability will not be disadvantaged - any contract that is signed with the person who has the disability will be valid. However, the contract may not benefit the interests of the person who has the mental or intellectual disability. The person with the disability may need protection from their own lack of good judgment.

¹ Gibbons v Wright (1953) 91 C.L.R. 423

² Imperial Loan Company v Stone [1892] 1 Q.B. 599 at 602-3, approved by the High Court in Gibbons v Wright [1954] 91 C.L.R. 423 at 441; See Commercial Bank of Australia v Amadio (1983) 151 C.L.R. 447.

³ Section 5 Sale of Goods Act of 1896.

Provision may also be needed against unscrupulous people who, befriending a person with an intellectual or mental disability, influence the disabled person to give money to them.

In a case of severe mental or intellectual disability, a person may have no understanding of the financial decisions that need to be taken to maintain them. Where people are incapable of managing their financial affairs, a substituted decision-maker needs to be appointed to manage the person's financial affairs.

MAKING A WILL

I've got a cousin who is retarded and this person from the Public Trustee said he will have to make a will out. His mother had died and he is quite incapable, severe case. There was no way he could do that. He just isn't capable.

To be able to make a will, the person must have an understanding greater than the general nature and effect of making a will. A person who wishes to make a will must be able to remember the property which is to be disposed of by the will, the people to whom the property is to be left, and the way in which it is to be distributed amongst these people.⁴

In addition, the person making the will must be of sound mind, memory and understanding at the time the will is made.⁵

This assessment is generally made by the person or organisation which has been asked to prepare the will.

You must be able to go to somebody who can say "yes, this person has the capacity to make a will or the power of attorney".

When people die without making a will, their property is distributed amongst their living relatives through a set formula.⁶

MEDICAL

Doctors, dentists and other healthcare professionals cannot give a person treatment or operation involving the application of physical force, however small, without first obtaining the patient's consent. Healthcare professionals who apply force without a patient's consent can be sued,⁷ and may be guilty of a criminal assault.⁸

4 Harrison v Rowan 3 Washington at page 585, cited in Banks v Goodfellow [1870] L.R. 5 Q.B. 549 at 567.

5 Smith v Tebbitt [1867] L.R.1 P.&D. 398; Harwood v Baker [1840] 3 Moore PC 282; 13 E.R. 117.

6 The Succession Act 1981-1987.

7 In such circumstances, the healthcare professional commits the tort of trespass to the person. Collins v Wilcock [1984] 3 All E.R. 374.

There are some exceptions.

First, a doctor may be confronted with a patient who needs surgery to save or prolong life. If the patient is incapable of consenting to the surgery, and a relation of the patient is not available to consent to the procedure, the medical superintendent of the hospital can consent to the surgery on behalf of the patient.⁹

Secondly, where a person is in charge of another who (because of age, sickness, unsoundness of mind or any other cause) is unable to arrange medical care necessary to preserve his or her life, then that person must provide the other person with necessary medical care.¹⁰

Thirdly, a casualty surgeon may wish to perform an urgent operation on an unconscious patient where there are no next of kin available. Although neither the patient nor next of kin have consented, the surgeon can proceed with the operation free from fear of being sued or charged with assault.¹¹

In England, a possible fourth exception has been raised. In a recent case, it was said that a patient who, because of a mental or intellectual disability could not understand the nature or purpose of an operation or treatment, could be operated on without consent being given if the operation was carried out either to save the patient's life, or to improve or prevent a deterioration in the patient's physical or mental health.¹²

Australian courts may be less likely to condone this exception.¹³

The other issue is "sterilisation" for people in institutions or people who are over 18. There are people who can speak up for themselves, may be able to get married and have children. But a person who has been assessed as low - the mental age is between 5, 12, 18 months - shouldn't have to go through what a woman goes through every month because they can't handle it. They don't know what to do.

8 Section 245 of the Criminal Code.

9 Section 52 Medical Act 1939-1988.

10 Section 285 of the Criminal Code; Chubb J in *R.v Macdonald & Macdonald* [1904] St.R.Q. 151 at 178-9.

11 *Wilson v Pringle* [1987] 1 Q.B. 237 at 252, approved by Nicholson CJ in *Re Jane* (1988-1989) 85 A.L.R. 409 at 418; section 282 of the Criminal Code.

12 *In re F. (Mental Patient; Sterilisation)* [1989] 2 W.L.R. 1063 in particular the judgment of Lord Brandon of Oakbrook at 1067.

13 For example, see the comments made by Nicholson CJ in *Re Jane* (1988-1989) 85 A.L.R. 409. The case considered whether a sterilisation procedure could be undertaken on an intellectually disabled girl. At 435, the Chief Justice of the Family Court expresses doubt about whether the medical profession should be entrusted not to engage in improper or unethical conduct in making surgical decisions when the consent of the patient is absent. At 439, he points out that the parents of intellectually disabled persons cannot be expected to be dispassionate or impartial because of their intimate involvement with the problem, and says that serious decisions such as sterilisation require the approval of a court. Although the case concerned a girl, the Chief Justice's consideration of *parens patriae* could equally apply to adults.

This comment was made in a workshop. The participants in this workshop group agreed that the issue was very sensitive and required careful scrutiny. A professional working with schizophrenia gave the following example -

There is a case at the moment where a young couple both have schizophrenia. The girl is very ill with [it]. Yet they are both getting married and the first thing she wants to do is have a baby. And there would be a very high chance of them having a child with schizophrenia. But on the other hand by the time that child has grown to adulthood or the age where they would have it, they possibly by then would have better medication or have even found a cure. The girl I would think is so ill she wouldn't be able to look after the child. That is a very difficult case. You can't just tell her she can't have a child. It's a matter of rights and ethics.

In most cases in Queensland, a sterilisation operation should not be performed on an adult who cannot competently consent to the operation because of a mental disability, without the Supreme Court's approval.¹⁴

In certain circumstances, the Legal Friend can consent to a sterilisation operation being performed on a person with an intellectual disability.¹⁵ The Supreme Court may also approve sterilisation of a person with an intellectual disability.

In all cases, careful scrutiny will be given to the necessity for the operation.

LIFESTYLE

The current legislation does not deal with accommodation or lifestyle issues. ... Consideration should be given to these. ... It should be stressed that both are very very sensitive areas in which we should tread very lightly and very carefully.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

As an issue for reform, ... lifestyle issues are quite clearly an agenda item that needs redress. ... I play no role in those sorts of decisions. ... There is nobody apart from the Supreme Court who can play that role on the behalf of an adult person who because of their degree of intellectual disability are unable to make those sorts of decisions for themselves. I am talking about issues such as

¹⁴ The Supreme Court in exercise of its parens patriae jurisdiction. The Queensland Supreme Court has power to authorise what is for the benefit of people of unsound mind ("natural-born fools, lunatics and persons deprived of understanding") - see section 22 of The Supreme Court Act of 1867 and *Re Magavalis* [1983] 1 Qd.R.59. A doctor would need substituted consent to perform a sterilisation operation upon a person who was incapable of giving that consent. When the person has a mental or intellectual incapacity, the Supreme Court has power to decide whether or not the operation should be performed - see *Wellesley v Wellesley* (1928) 2 Bli. N.S. 124; 4 E.R. 1078. In those rare cases where the Supreme Court appoints a committee of the person, that committee can give consent on behalf of the person with a mental disability for whom the committee was appointed - see page 31.

¹⁵ Sections 26(3) and 31A(4)(b) Intellectually Disabled Citizens Act 1985-1989. See page 27 for a fuller explanation of the role of the Legal Friend.

accommodation, activities and sexuality. Those things are simply not dealt with under existing legislation in Queensland.

(Hugh Carter, the Legal Friend.)

Later, in a workshop, the Legal Friend expanded on his previous statement -

The great gap which exists in Queensland law at the moment certainly lies in the area of persons who need substitute decisions in the lifestyle area. ... For example, a young adult man with an intellectual disability: his parents are divorced, the straight-out issue [is that] mum wants him to live with her, dad wants him to live with him. Who is able to resolve that when the young man is unable to make that decision for himself?... That adult should be able to make those decisions for themselves. But if that person can't, then currently the law doesn't recognise any other avenue of dealing with that apart from through the Supreme Court. That is an expensive process and [involves] full confrontation in the court system. It really isn't a practical, cheap and accessible way to resolve that. That is the only way it can be resolved and it is not appropriate.

Other professionals working with people who have a mental or intellectual disability said -

I actually work in the field of aged care and often come into contact with demented people... We often come across people who live alone and don't have any relatives, who actually aren't capable of caring for themselves and who are very resistant to accept any support services to help them safely stay at home. We don't actually seem to have legislation to cover those people when they are no longer capable of making decisions themselves about are they safe or should they stay at home, and yet they're refusing to leave home. Sometimes they refuse services and refuse to leave home and we have to walk out.

We have a similar situation where we can offer services to people but if they are over the age of 18 they have the right to refuse our services even if it really is in their best interest to accept - our hands are tied the same ways yours are in that situation.

2. The law gives decision-making assistance to people depending upon their disability

A person with an intellectual disability since birth or early childhood can, if the Intellectually Disabled Citizens Council approves, -

- . be given supportive assistance in personal and social activities through the appointment of a volunteer friend.¹⁶ The volunteer friend is recruited through a scheme administered through the Intellectually Disabled Citizens Council. Volunteer friends provide concentrated, one-to-one support to people with intellectual disabilities. In May 1991, the scheme had 144 volunteer friends;
- . be given free assistance by the Legal Friend. The assistance may be the provision of information about options and services available to the person with the intellectual disability. It may be liaison with a government department on behalf of the person.¹⁷

The law also gives people with impaired intellect due to brain damage or illness, and people with Alzheimer's disease access to these types of assistance.¹⁸ The law does not give people with other mental disabilities similar forms of assistance.

When "intellectually disabled citizens" are unable to give medical consents, the Legal Friend may be able to give consent on behalf of the citizen. When a person with a mental disability is unable to give medical consent to a medical procedure other than one which would save, prolong¹⁹ or preserve²⁰ life, then substituted consent can only be given by the Supreme Court or by a committee appointed by the Supreme Court to attend to the personal affairs of that person.

The law allows for a committee²¹ of family or friends to be appointed to either manage the financial affairs or make decisions about the care and comfort of a person who is mentally ill and incapable of managing his or her estate.²² This avenue is not

16 Section 31A(4)(c) and Part IV Intellectually Disabled Citizens Act 1985-1989.

17 Section 26 Intellectually Disabled Citizens Act 1985-1989.

18 Section 4 Intellectually Disabled Citizens Act 1985-1989.

19 Section 52 Medical Act 1939-1988.

20 See footnote 10.

21 A committee can comprise one or more people.

22 This mechanism is, however, rarely used. Application is made to the Supreme Court under Sch 5 clause 4 Mental Health Services Act 1974-1989. There have only been 42 applications made to the Supreme Court since 1968.

available to people with Alzheimer's Disease.²³ It may, however, be available to people with an "intellectual handicap".²⁴

Any laws in this area are trying to address the very difficult and complex issue of what happens when somebody cannot make certain decisions by themselves. Who should the law be for? ... Our laws should address the needs of everyone who requires that sort of assistance. We may have different views on certain people or certain groups of people. ...

If we start by saying that we need laws for people with an intellectual disability or psychiatric disability or people with dementia then we have immediately fallen into the trap of tailoring our laws according to the imprecise and often inaccurate labelling that professionalism of disability has left us with. ...

The issue is not why someone can't make a decision, not what label we have given them. .. The reason for someone's inability to make certain decisions should not determine whether they have access to our legal system and to our laws. If they do then our laws have simply discriminated. ...

When it comes to other types of decision-making - the non-financial, the personal lifestyle type decisions - many people simply miss out. The rarely used Supreme Court procedure under the Mental Health Services Act is an ancient form of guardianship. It is basically restricted to the mentally ill (whatever that term actually means in the legislation). ...

[The Mental Health Services Act] deals with what the Act calls the mentally ill. There is no definition in the Act, except to say that for the purposes of the Act, mentally ill or mental illness is said to include intellectual handicap and drug dependence, neither of which are defined. ...

The Intellectually Disabled Citizens Act can certainly provide a mechanism for appointing a substitute decision-maker in some ... decision-making areas (for example consent to treatment) but it is of course restricted to those who fit within the definition of intellectually disabled citizen. ...

In the area of financial and property management, those different laws probably cover everybody - at least the definition of protected person and protection order probably does.

(Jeremy Ward, Queensland Advocacy Inc.)

Who should the law be for? There shouldn't be any division. It should be one law for all. ... So maybe even look at [whether] people with disabilities - whether physical or intellectual - have the same rights as everybody else, rather than have a classification of an intellectual disability or a classification

²³ Re Warby and the Mental Health Services Act 1974-1989 (Qld) Unreported decision Queensland Supreme Court McPherson SPJ, delivered 9 May 1991 [91/123].

²⁴ Section 5(2) and sch 5 Mental Health Services Act 1974-1989.

for a physical disability. The laws of the country [should] apply to general people - a nondiscriminating law.

SHOULD THERE BE ONE SET OF RULES THAT APPLIES TO ALL?

It makes sense to have one consistent set of rules in this area. ... Our legal system is complicated enough without having different laws for different groups of people administered by different bureaucrats all trying to deal with the same issues.

(Jeremy Ward, Queensland Advocacy Inc.)

Opinion was divided about this issue. One view put by people affected by the present laws was that the same decision-making rules should apply in all situations. They said -

- . I'm a carer of a daughter with mental illness, she has slight schizophrenia. ... It is very difficult to say something specific about how the law has affected me, because the psychiatrically disabled are actually not included in a lot of the legislation which mainly centres upon the intellectually handicapped and physically handicapped. We find that we are always one or two very small voices in any discussion or seminar or conference which is for the disabled.*
- . It always seems to be centred around the intellectually handicapped, the physically handicapped and listening to them this morning I realised that our problems are really all much the same.*
- . There seems to be some discrimination by the very fact that we have a Mental Health [Services] Act and also the Intellectual[ly] Disabled Citizens Act because once you have had any dealings underneath either of those Acts it more or less labels you as being either intellectually disabled or mentally ill. When Jeremy was speaking this morning I could not help but think that he had a very good point when he said would it be better to have one law across the board rather than having separate laws for all.*
- . We do need to protect people at certain times in their lives and I think that if we can say which particular people we need to protect, it means that matter hasn't got to be spread over everyway.*
- . Even if you wrote it that this was for a particular thing all it takes is for people to say that they fall into that category. Making it specific doesn't really alter it. All you do is make them say you fit into that specific category; you can make a person fit into the category wherever you want. It does not take much - somebody writing it on a bit of paper. It's like saying you fall under the Mental Health [Services] Act because we have verification from these eminent people. We can make you fit into anything. You have to make it broad enough so that it covers everybody, specific enough so that people cannot be fitted in if they don't fit in tight.*

Legislation mainly deals with categories of people in certain circumstances. That assumes that people remain stationary. Now if they keep shifting in or out of the categories these people [would be] actually moving from one legislation to another. There would have to be an ongoing system.

Perhaps we should not be defining [people in] terms of their illnesses but in terms of someone who is not capable of taking decisions.

The [Acts] talk about people's personal life - decision-making doesn't include a provision for substitute decision-making for people with a psychiatric disability. ...

There is nothing to cover a person with psychiatric disability who may not be able to make a decision.

We haven't got access to the Legal Friend.

We need to be under the umbrella of something...

I think we should have the same services provided for us - the psychiatrically disabled - as the intellectually disabled.

Other people consider that a set of uniform rules could not adequately cater for the needs of people with different disabilities.

The following conversation took place in one of the workshops for people affected by the present legislation -

The Mental Health Services Act ... was designed to pick up people, with both intellectually disability and with psychiatric illnesses... And look at the havoc that that piece of legislation has wrought.

I come from the Alzheimers Association and the concerns we have with the current legislation is that it focuses on intellectual disabilities and mental illnesses and psychiatric disabilities. Dementia does not really fit between the two. We don't fit into psychiatric disabilities and we don't fit into intellectual disabilities. People with Alzheimer's Disease have very different needs.

Government officials working in the area of disability agreed with this last comment. They explained that -

An elderly person with dementia who has a spouse doesn't have the same needs as a young person who was born with a disorder. The young person needs encouragement to develop their full potential whereas the elderly person going through dementing processes will in fact just deteriorate. Their needs are obviously different and the philosophical base for assistance I think also need to be different. You need a different approach. That elderly person might have a spouse, have a family, and would be going through the shared responsibilities that married people do. Yet at the same time a young adult, maybe 19, has lived with their family most of their lives and needs to have the opportunities to express their individuality and may sometimes need assistance

in having their rights and responsibilities recognised by other people in the community. They are very different needs and yet at the moment all those same persons have been picked up under the one piece of legislation and perhaps that really isn't all that appropriate.

Within the area of intellectual disability, at some point [adults with an intellectual disability] may be able to participate more and more in the decisions. In the psychiatric area [you are] talking about a population where the person may duck in and out, if you like, of being able to make a lot of fairly active decisions in their life, but then for part of their life they're not able to - they need a lot of support. Then the people with dementias may well be progressively declining. I think it is almost impossible to have only one encompassing body to try and deal with three categories of people. I see that as a real danger.

The frail elderly would be very upset if they were classified in the same barrel as the intellectual handicapped. They don't see themselves as that, some of them don't even see themselves getting a bit slow.

3. Different bodies and people are responsible for deciding whether people with disabilities need assistance in making decisions

Imagine someone with dementia. If, as sometimes happens, that person is admitted to one of our State psychiatric hospitals purely because there is no suitable alternative accommodation, an "authorised medical practitioner", who does not need to have any expertise in the area of dementia, may certify that that person is incapable of managing their money. Just because they are living in a psychiatric hospital, that certificate alone is enough to authorise the Public Trustee to take over management. That person's family need not and may not be consulted.

Or, let us say that an application is made to the Supreme Court for a protection order. On the Court being satisfied that the person cannot manage their money, the Court can order that the Public Trustee takes over. The Court will normally require reports from two medical practitioners, though again, there is no requirement that they have any expertise in the area of dementia.

Finally, the definition of "intellectually disabled citizen" is sufficiently wide to allow an application to be made to the Intellectually Disabled Citizens Council. The Council, none of the members of which currently have expertise in the area of dementia, makes a decision on a range of information. In doing so the Council must ensure that it considers certain factors, such as the individual circumstances of the person in question, and their express wishes, but need not base its decision on any particular expert opinion. In practice, the Council listens to family members and relevant workers and professionals.

The quite different processes and the use of quite different expertise with each demonstrates the confusion and inconsistency with our current laws. One procedure requires one medical certificate; another requires an application to the Supreme Court; the third requires an application to a Tribunal with special expertise but only in the area of intellectual disability.

(Jeremy Ward, Queensland Advocacy Inc.)

- . Why can't we have just one body to deal with instead of all the different ones?***
- . I really think you need to have one body or one set of legislation which covers a whole wide range of people but assists them individually.***
- . The thing that struck me... is the ease with which someone can be condemned as intellectually handicapped and the affairs of the family taken over by an outsider.***

THE INTELLECTUALLY DISABLED CITIZENS COUNCIL

The Intellectually Disabled Citizens Council was originally conceived to put people who had had an intellectual disability since birth or early childhood, into contact with mechanisms that could support and assist them. The membership of the Council reflects this aim. The overwhelming majority of Council members have had direct experience in assisting or caring for people with intellectual disabilities.

The present Council currently stands at 9 members, 4 of whom are parents with adults with intellectual disability, 2 of whom are siblings of people with intellectual disability, 3 are psychologists (including one of the parents), and one is a lawyer. ...

The Council is not a Court and doesn't function like a Court. Our aim is to avoid being an adversarial forum.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

However, the **Intellectually Disabled Citizens Act 1985-1989** also gives to the Intellectually Disabled Citizens Council the responsibility of assessing the support and assistance needs of people with a short-term or long-term intellectual impairment caused by illness, injury or natural deterioration.²⁵ This means that, in addition to people who have had an intellectual disability since birth or early childhood, the Council also deals with -

- . people who have dementia (including Alzheimer's Disease); and
- . those who have suffered brain damage caused through a car accident.

The Chairman of the Council estimates that about 60% of applications currently being handled by the Council concern people with dementia.

Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council, described the Council's function at the public forum. He said -

Access to the Council's services is by written application lodged either by-

- . ***the person with the intellectual impairment, called the citizen, on his or her own behalf;***
- . ***a relative who has attained the age of 18 years;***
- . ***a member of the Police Force;***
- . ***an officer of the Department of Family Services and Aboriginal and Islander Affairs, so authorised by the Department's Chief Executive;***
- . ***or***
- . ***any other person who has attained the age of 18 years and who satisfies the Council that he or she has a proper interest in the well-being of the citizen.***

Applications are processed through the office of the Council, and scheduled for consideration by a board or panel of three council members. Council members travel throughout the State to conduct proceedings. Notice of proceedings is given to -

- . the citizen named in the application;**
- . the applicant, if the applicant is not the citizen;**
- . the nearest relative to the citizen; or**
- . any other relative or person who has attained the age of 18 years and appears to the Chairman to have exhibited a continuing interest in the well-being of the citizen.**

The purpose of the proceedings is to consider the application -

- a) to ascertain whether the citizen is competent in law to provide valid consent for medical, dental, surgical or other professional treatment and care, to identify the citizen's need for support in giving such consent, and to approve the least restrictive means of support in accordance with the options set down in the legislation;**
- b) to ascertain whether the citizen is without social and inter-personal support to an extent where he or she has unmet needs, and to nominate the citizen to the Volunteer Friends Programme when this is required; and**
- c) to review the arrangements in place for the management of the citizen's financial and estate affairs, and where these arrangements are not in the best interests of the citizen, and an appropriate alternative arrangement is not available, to issue a notice to the Public Trust Office to manage the affairs.**

The Volunteer Friends programme is described on page 7.

The Council can also approve of support and assistance being provided to the citizen by the Legal Friend (see page 27).

People affected by this legislation said -

- . I am quite sure that the present Board would consult us if necessary and that they would have due regard to whatever we had to say and provided it made common sense I am sure that they would make no attempt to upset us.**
- . There isn't a person that knocks on your front door on the afternoon of your child's 18th birthday and says "now I own that person". That ... doesn't happen. If a person needs some help in medical consent, in money matters or is lonely and has no friend then the Intellectually Disabled Citizens Council can be involved. ... There are thousands, tens of thousands of families and people who don't need any of that and it doesn't happen. If you don't want to get this Council involved you don't have to unless something happens with your son where he is unable to say, "Yes I want this to happen to me and I know what the risks are." Then you do have to have the Council involved to decide.**

Commenting about the speed with which the Intellectually Disabled Citizens Council makes its decisions, one person said -

- . *If it is a person that has already been referred to the Council and the Council has deemed [them] to be assisted then the information is there and they already know some of what is happening. It can happen very quickly. I know from personal experience of it happening very quickly.*

DOCTORS

On page 3, the need for doctors, dentists and other healthcare professionals to obtain consent for surgical and other medical procedures was discussed. With limited exceptions, these healthcare professionals must obtain the consent of their patient before performing any procedure which requires the application of force. If they do not obtain their patients' consent, they may be sued by their patients and, in addition, by guilty of criminal assault.²⁶ A healthcare professional confronted with a person who has an intellectual or mental disability may not be confident that the person understands the nature or extent of the operation or treatment proposed. In such cases, the doctor may decide to obtain the consent from another lawful source.

To avoid the risk of being sued, healthcare professionals can contact the Legal Friend to seek and, where appropriate, obtain lawful consent to undertake a medical procedure or treatment on "intellectually disabled citizens" including -

- . a person who has had an intellectual disability since birth or early childhood;
- . a person suffering from dementia (including Alzheimer's Disease);
- . a person with brain damage caused through a car accident; and
- . a person who has no disability, but has been rendered unconscious and would benefit from surgery or another medical procedure prior to regaining consciousness.²⁷

This procedure is not available for patients who cannot consent because of a mental illness.

- . *I think lawyers and doctors need to be informed. I didn't realise that [when] you go to hospital they are too frightened to do any procedures at all. They are frightened to even speak to a disabled person, they speak to the parent.*
- . *It has gone the pendulum where the parent got all the say in everything to the doctors now needing the permission of the Legal Friend. ... I'm just saying*

²⁶ See pages 3, 4 and 30 of this paper.

²⁷ Sections 26(3) and (9) Intellectually Disabled Citizens Act 1985-1989.

that the pendulum has swung. The doctors are consulting with parents [of children] up to 18 but ... they show no knowledge of what goes on with people over 18. Consequently they think they have got to go straight to the Government or the Legal Friend. What happens if my child, well actually adult, was rushed in quickly for an operation?

The involvement of the Legal Friend is by way of request of a doctor whose opinion is taken as being infallible, without verification by any other uninvolved medical practitioner. As a result the patient is deemed to be intellectually disabled and treated as such until such time as can be proved otherwise. This is contrary to our basic democratic and judicial practices.

What worries me is that all any doctor has to do is say, "Okay, this person has a mental problem - refer that person to the Legal Friend with total disregard for the family."

A doctor who is related to the patient should definitely not be able to suggest involvement of the Legal Friend and the Intellectually Disabled Citizens Council. If the doctor is not the patient's doctor he or she should definitely not be able to involve the Legal Friend and the Intellectually Disabled Citizens Council.

Doctors can also decide that the Public Trustee should step in and take over the management of a person's financial affairs. Two mechanisms allow this.

The first mechanism applies to -

- a person with an intellectual disability who enters the Basil Stafford or the Challinor Centres; and*
- a person who is admitted to a psychiatric hospital or ward, whether that person suffers from a mental illness, senility or dementia.*

The Public Trustee becomes responsible for the estate management of these people once he is notified that a designated medical practitioner or a psychiatrist believes that the person is mentally ill and incapable of managing his or her estate.²⁸

A professional working with people who have a mental disability commented -

One of the dilemmas is the irreversibility of that whole system. Whereas at least the Intellectually Disabled Citizens Act is able to serve to prevent that to an extent, we can't save some of those individuals that come directly under the Mental Health Services Act.

Secondly, if the Public Trustee is satisfied that a person is either -

- . totally or partially unable to manage his or her affairs; or
- . someone to whom undue influence is or may be applied in managing or disposing of property or money -

because of age, illness mental incapacity, physical or mental deterioration, or drug or alcohol abuse, and the estate of that person is not more than \$10,000 in value, the Public Trustee may file a certificate of disability in the Supreme Court. This will empower the Public Trustee to take over the estate administration of the person concerned. Before a certificate of disability can be filed, the Public Trustee must see the reports of two medical practitioners. In addition, the Public Trustee cannot file the certificate of disability if the affected person objects.²⁹

- . *The Public Trustee can act on the word of the doctor. It does not have to go through any tribunal or anything else. The doctor can say, "Oh yes he is spending too much money on this and that - he can't control his money." [The] Public Trustee takes over without any consultation.*

THE PUBLIC TRUSTEE

The Public Trustee can initiate an application to the Supreme Court to be given decision-making and administration power over the financial affairs of a person. If the Supreme Court is satisfied that, because of the person's age, illness, excessive alcohol use, drug use, physical or mental deterioration, or mental incapacity -

- (a) the person is unable to manage all or part of his or her affairs; or
- (b) undue influence is or may be applied to the person in administering his or her financial affairs -

then the Court may appoint the Public Trustee to manage the person's estate.³⁰ The Public Trustee can also apply for a Court-directed investigation to find out whether a person fits into one of the above categories.³¹

Only one comment was made about this aspect of the Public Trustee's many roles -

- . *[The] Public Trustee only wants to come in when there's been money awarded in the Court. They don't want to look after people with no money or no property.*

²⁹ Section 70 Public Trustee Act 1978-1990.

³⁰ Section 65 Public Trustee Act 1978-1990.

³¹ Section 66 Public Trustee Act 1978-1990.

THE SUPREME COURT

The Supreme Court has a general power to protect people who are "of unsound mind" (including those with an intellectual or a mental disability who cannot understand or reason) and their property.³²

Effectively, the Court is the overseer of people who cannot take care of themselves.³³

The overseeing power extends "as far as is necessary for protection and education."³⁴ It is wide enough to allow the court to approve medical procedures such as blood tests³⁵ and sterilisation procedures.³⁶

In addition to this general power, the Supreme Court can also -

- appoint the Public Trustee as manager of the financial affairs of those -

- (i) who are unable to manage all or part of their financial affairs; or
- (ii) to whom undue influence is being or may be applied in disposing or managing property or money -

because of age, illness, physical or mental deterioration, mental incapacity, or drug or alcohol abuse. Normally, the Public Trustee will apply to be appointed as estate manager. However, if the Court is awarding damages for personal injury to a person who falls into the above category (for example, to a person who has sustained serious brain injury in a car accident) it may appoint the Public Trustee to manage that person's financial affairs (and, therefore, the monetary award) without receiving an application to do so.³⁷

- appoint one or more persons to form a committee to manage the financial affairs, or to make personal decisions for people who are mentally ill and cannot manage their financial affairs;³⁸

- hear appeals from decisions to provide, terminate, vary or refuse assistance under the **Intellectually Disabled Citizens Act 1985-1989**,³⁹

- hear applications brought by someone affected by an act or decision of the Public Trustee, the Legal Friend or the Intellectually Disabled Citizens Council, that in acting or making the decision, one of these bodies or people have acted improperly or outside their legal authority;⁴⁰

32. *Re Magavalis* [1983] 1 Qd.R.59.

33. *Wellesley v Duke of Beauford* [1827] 2 Russ 1; 638 E.R. 236

34. *Wellesley v Wellesley* [1828] 2 Bli.N.S.124; 4 E.R. 1078 at 1083

35. *Re S v McC. and M: W v W* [1972] A.C.24

36. *Re Jane* (1988-89) 85 ALR 409

37. Sections 65-67 Public Trustee Act 1978-1990

38. Sch 5 cl 4 Mental Health Services Act 1974-1989.
See page 31 for a fuller explanation.

39. Section 43.

40. Order 81 Supreme Court Rules.

- . hear applications to remove the Public Trustee as manager of a person's financial affairs and re-instate the person as estate manager.⁴¹

Generally, people affected by the present legislation thought that the Supreme Court was out of their reach -

- . *The person that was dissatisfied... was told that they had recourse to the Supreme Court. I don't know if there is anybody here that would have the finances to approach the Supreme Court. It would be a monstrous expense. You would lose your house and everything.*
- . *Apparently it takes about six years to get something through the Supreme Court.*
- . *Most of us just couldn't appeal because of time and financial constraints.*
- . *This Supreme Court business is nonsense for an ordinary person.*

A worker made this comment about the wife of a client who contested that her husband's affairs should be managed by the Public Trustee -

- . *The wife took it to the Supreme Court and won the appeal. She now has control over their affairs. It was very expensive and took about three years to go through the process.*

A guest speaker at the public forum, Tony Lawson, thought that a challenge to the Public Trustee's authority was beyond most people -

The problems in Victoria [before the Guardianship and Administration Act was passed] were not dissimilar to the situations that you have described here. ...

The fourth area was that the accountability of appointed decision-makers was inadequate, irregular and difficult to invoke. In particular in Victoria where the Public Trustee was appointed to manage a person's financial affairs, if you wished to challenge their authority you had to take that to the Supreme Court. Now I suspect that the same is true of the Supreme Court in Queensland as it is of the Supreme Court of Victoria. You either have to be very rich or very poor to go to that body. Very rich - you can afford anything. Very poor because you might then qualify for legal aid. And the rest of us be damned! That is the reality in regard to access to justice.

(Tony Lawson, President of the Guardianship and Administration Board (Vict).)

41 For protected persons, section 69 Public Trustee Act 1978-1990; for patients under the Mental Health Services Act 1984-1989, sch 5 clause 6(iii) Mental Health Services Act 1984-1989; when the Public Trustee is appointed through the Intellectually Disabled Citizens Act 1985-1989, section 34 or section 43 Intellectually Disabled Citizens Act 1985-1989; when the Public Trustee becomes manager of the estate upon the filing of a certificate of disability, section 73(3) Public Trustee Act 1978-1990.

Similar views were expressed about contesting the decisions made under the Intellectually Disabled Citizens Act -

. *He said, "We do have a cause for recourse - we can go to the Supreme Court." I mean, who can afford that? There is no place you can go to for help questioning the power of the Legal Friend.*

. *It was said in there that if you didn't agree with the decision of the Legal Friend then the next step was the Supreme Court. Well, let's face it, who can afford that? The law has to be changed where there is some other person, some other shield.*

ooo0ooo

SHOULD THE BODIES AND PEOPLE WHO DECIDE WHETHER PEOPLE WITH DISABILITIES NEED ASSISTANCE IN MAKING DECISIONS...

...HAVE DIRECT EXPERIENCE WITH THE TYPE OF DISABILITY THAT THEY ARE DEALING WITH?

The definition of "intellectual impairment" in the legislation is wide enough to encompass the dementia area as well as congenital intellectual impairment. People who are appropriately placed to deal with issues with congenital intellectual impairment are not necessarily the appropriate people to deal with the issues of the dementia area. The legislation needs in some way to reflect this.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

...INCLUDE LAWYERS?

Thankfully the Queensland legislation does not provide for the mandatory inclusion of lawyers as Council members or as members of boards or panels.

The Council is not a Court and doesn't function like a Court. Our aim is to avoid being an adversarial forum. On the basis of what I am told by lawyers and others about the Queensland legal and justice system's inappropriate handling of people with intellectual impairment, it seems to me that few members of that profession have any understanding of, or interest in, or acceptance of, the philosophies and concepts and principles which people active in the area of intellectual disability regard as important and essential. The last thing people with intellectual disability and their families of this State need is to be dominated by a group of lawyers and doctors.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

- . *It seems to me that you can't know something unless you have some experience of what's going on or some commitment to someone if we're talking about people's lives. And I don't really accept the notion that the best decisions are made by those who are detached and supposedly objective and know nothing about the circumstances and rely on what people bring to them - which is obviously the way the traditional court system works.*
- . *I think it should be someone who has had dealings with the handicapped in a real sense.*

I acknowledge that the growth of specialist tribunals is here. They are important. But there is a danger with specialist tribunals - that they become reflective of a particular philosophical approach to issues.

When you set up a tribunal and you compose it not of judges but of people appointed from the community there is always a problem of encompassing an appropriate range of views and approaches. While [the Victorian Guardianship and Administration] Board does have a wide range of views, one question can be asked - [are] most of those people, indeed all those people, on that Board because of their social welfare or disability background? Is that the appropriate, objective input that is needed in questions concerning the individual liberty of people and the management of their estate? That is a question that I think will need to be confronted.

(Kevin Martin, the Public Trustee.)

- . *If there is going to be a Council, I question the qualifications. In situations where help is needed we need people on these Boards with either legal background or some formal education.*
- . *These people [on the Intellectually Disabled Citizens Council] are looking at it [from] a caring parent point of view rather than looking at it from a legal stance. I think in this situation legality is essential and we need professional people who know the law, who know the rights of the intellectually disabled, and who can work on that basis.*
- . *I think the Board at present is very very sympathetic towards the parents of children who are mentally handicapped. My main concern is that people could be appointed to that Board who do not have that same broad and general outlook that these folk have.*
- . *The medical profession... have got no idea. ... A doctor comes along who has no practical knowledge or experience with people with an intellectual disability and he is considered to be an expert. I've had 16 years practical hands on experience and I would not be considered to have the same professional quality.*

A conversation in one workshop about this topic -

- More than one person to make the decision. Maybe a board of people to make the decision, instead of just one person.*

That board should have different people on it, different representatives on it.

As that man said, not necessarily doctors or lawyers - they should be consumers.

The [Intellectually Disabled Citizens] Council has a lot of people like that. This hearing we went to they said, "None of us are doctors... none of us are."... They were totally hostile to us right from the start. So that didn't work either - they are not doctors or professionals.

...COMPRISE ONE OR THREE MEMBERS?

Thankfully, unlike the Victorian legislation, the Queensland legislation does not provide for single member boards or panels, and I hope it never does.

... I am certain that Queensland families do not want or would not tolerate determinations dealing with the human rights of their family members made by single member boards or panels. My own view is that three member boards or panels are the absolute minimum safeguard.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

Despite Lionel's comment about single member tribunals I believe that if you choose your Boards carefully, if you get a range of skills, and you get good quality leadership of the tribunal then you won't have the sort of problems which have occurred in the Courts in relation to gobbledegook, poor service standards, the alienation of people, slow delivery of service and expensive service. Those are things that shouldn't be present in any reform proposal that you organise.

And the fact the tribunals sit in either one or three member boards [means]... in our tribunal, more complex matters are dealt with by three member boards chaired by a lawyer and two other members. Single member boards, chaired by both lawyers and non-lawyers, perform very well indeed. You really ought take confidence in the experience of other tribunals in this area throughout Australia in terms of reform and the body that you organise.

(Tony Lawson, President of the Guardianship and Administration Board.)

...ALLOW PEOPLE ABOUT WHOM DECISIONS ARE BEING MADE TO BE REPRESENTED BY A LAWYER?

There is a view that lawyers when they get involved in this area, simply muddy it up and I as a lawyer certainly agree that that is a big issue and an important one to come to grips with. Nevertheless, I think we have to ask ourselves if we are giving anyone - whether it is a court or a tribunal - the power to say that you or I or anyone else can't make certain decisions for themselves, should they have a right to be represented and have their point of view protected in that process? And only the Supreme Court process at the moment allows that but that is probably the only positive feature about that process.

(Jeremy Ward, Queensland Advocacy Inc.)

I would like to see the right of the citizen whose application is being considered to legal representation at no cost to himself or herself reintroduced into the legislation.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

...BE ABLE TO COMPEL PEOPLE TO ATTEND A HEARING?

Sometimes people with intellectual impairments are unable to attend when their application for the Council's services is being considered because the family member or carer upon whom they rely to bring them refuses to do so. I would like to see provision to order such attendances in some circumstances.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

4. Different bodies or people are given responsibility for providing decision making assistance to a person with a disability

People can choose who will make decisions on their behalf if they should ever lose legal capacity, by making an enduring power of attorney.

Through an enduring power of attorney, a person can nominate one or more people to make decisions on his or her behalf. The nominated person or people need not be a lawyer - a family member or friend can be an "attorney."

Enduring powers of attorney were only recently introduced in Queensland.⁴² Unlike powers of attorney, they do not lapse when the person who gave the power becomes legally incapacitated because of injury (for instance, brain damage), mental deterioration (for instance, dementia) or some other cause.

The types of decisions that people making an enduring power of attorney give to another to make on their behalf is not clear. Presently, an enduring power of attorney authorises the person named as the substitute decision-maker "to do anything that I may lawfully authorise an attorney to do".⁴³ Certainly, this encompasses the full range of decisions about financial, monetary and business transactions.

However, can decisions about accommodation, care, and day-to-day activities be given to an attorney? Can an attorney be entrusted to make medical, dental and healthcare decisions on another's behalf?

An attorney is a person who can stand in the place of another.⁴⁴

There are some decisions that, because of their personal nature, cannot be made by another - a decision to marry or to have sexual intercourse with another.

Accommodation, care and life-style decisions can probably be given to an attorney. Many of these decisions will have a financial component to them.

However, consent to medical and healthcare treatments and procedures can probably not be made by an attorney. Many of these procedures are intrusive. Some involve force. The decisions in this area have a more intimate and personal effect.⁴⁵

⁴² Through the Property Law Act Amendment Act 1990.

⁴³ Second Schedule, Form 16A Property Law Act 1974-1990.

⁴⁴ See Stroud's Judicial Dictionary of Words and Phrases (5th Ed) Sweet & Maxwell London 1986 at page 223.

⁴⁵ The Australian Law Reform Commission agreed with this conclusion in its Discussion Paper No 33 "Community law reform for the ACT: Enduring Powers of Attorney" October 1987 at page 6. However, no reasoning is given in the paper for how this decision was arrived at.

Unless a person who has become legally incapacitated has made an enduring power of attorney, organisations or individuals not of the person's choosing may be appointed to make decisions for that person.

I have been retired for about 5 years, after nearly 25 years as a trust officer, with one of the trustee companies. Just after my retirement my wife, Joyce, began having very simple problems such as telling the time, cutlery being placed incorrectly on the table, and so forth. Then she began to lose her skills such as sewing, knitting and playing the piano. Choosing clothes to dress herself became a problem and after 3 years Alzheimer's Disease was diagnosed.

Joyce now has no significant abilities whatever. When it became difficult for Joyce to sign her name, I hurriedly organised a simple form of power of attorney in my own favour. ... I did not foresee the need for a witness to my wife's signature to be a Justice of the Peace. ... Complete loss of signing ability soon followed. ... I had enough other troubles in taking over the running of the house, washing and cooking and doing the laundry etcetera. without having to worry about the legality of my power of attorney. ...

I think I state the existing law closely enough when I say that [when] the donor of the normal power of attorney becomes incapable of giving instructions on the use of that power or of ratifying the attorney's actions, then that power is now void. This is the position that I was, and am still, in. So are many other thousands like me.

So, do I follow the law? Do I invite the Public Trustee to take control of my wife's interests? Or do I continue to use my invalid powers as the interest of no other powers are involved - we have no family. I choose to break the law. I choose to remain in control. ...

Even though it is highly unlikely that my actions will be challenged by anybody the knowledge that I am using a void power of attorney does not sit easily. The whole situation is further pointed up when it became necessary to consider the sale of jointly held real estate.

We had a deteriorating care situation. Day respite care simply had not worked - after several attempts my wife would not even get out of the car at the centre. The opportunity arose to obtain the very last of 11 x 2 bedroom independent living units at an Anglican Church facility. The advantages were quite obvious - reduced home maintenance for me and most importantly 24 hour access to [the] nursing care required.

I had to act quickly as the units were in great demand. To be able to sign a real estate transfer for and on Joyce's behalf my power of attorney had to be registered in the Real Property Office. However, the witness to my wife's signature was not a Justice of the Peace or otherwise suitable qualified person for the purposes of the Real Property Office.

I thought that the Public Trustee might be prepared to act in just this one transaction but when approached he wanted to take out a Protection Order and asked for details of all assets that Joyce and I had an interest in.

I was fortunate that in the assistance of a colleague from working days we found that one section of the Real Property Act allowed the registration of my power of attorney if the non-qualified witness were now to make a declaration before a Justice of the Peace. This was done and, within the full knowledge that I should not sign as Joyce's attorney, I sold the house to secure - in joint names I should point out - the independent living unit. This has proved to be the very best decision I have ever made since the onset of my wife's illness.

I have related the above saga to point out the situation of a spouse and carer under existing legislation before the enduring power of attorney became law. Even though I have not acted according to the letter of the law I will continue to act for my wife until I am challenged. I can show that I have acted in her best interests at all times. ...

I do understand the absolute need for the legislation enabling the Public Trustee to take over control of the affairs of a person with a disability, particularly where that person has no close relatives or the relatives have conflicts of interest etcetera. I did not want to give up the power of sole determination of the future of our assets. The enduring power of attorney seems to me to be the greatest single advance in our area of concern for many years. But it was too late for us. I have since arranged one for myself. Now there must be many thousands of people whose impaired abilities arose too prior to the passing of this legislation. ...There will undoubtedly be thousands more, as many will not even know what an enduring power of attorney is until it is just too late to act.

(Part of a speech given at the public forum.)

This chapter looks at the organisations and individuals who can be appointed to be substitute decision-makers for a person who loses legal capacity when medical consent is needed. For the many who are not legally capable and have either not signed, or were never competent to sign an enduring power of attorney, this chapter also looks at the main organisation which is given substituted decision-making power for financial and estate management.

When speaking of people with disabilities -

"the greatest barrier in the pursuit of equity is that they are forced to rely on a system which encourages decision-making from persons or organisations once removed from their particular plight."

(Opening address by Queensland's Attorney-General, The Hon Mr Dean Wells.)

THE LEGAL FRIEND

Queensland's Legal Friend presently provides free services to and for a range of "intellectually disabled citizens" including those with -

- . an intellectual disability since birth or childhood; or
- . dementia (including Alzheimer's Disease); or
- . brain damage caused through a car accident.⁴⁶

If the Intellectually Disabled Citizens Council (or, in an emergency, the Chairman of that Council) approves, the Legal Friend currently provides a free advice⁴⁷ and liaison service about -

- . making a will;
- . accommodation alternatives;
- . whether a contract is binding;
- . defending a criminal charge;
- . Social Security and Medicare entitlements.

In providing any of the above forms of advice or liaison, the Legal Friend must carry out the wishes of the person being assisted, or, if that person is unable to express his or her wishes, in a way that the Legal Friend considers that person would have acted.⁴⁸

If the Legal Friend believes that financial affairs of any of the people with a disability listed above require urgent protection, the Legal Friend can notify the Public Trustee. Once the Public Trustee receives this notice, he then takes over the management of the person's financial affairs. The Intellectually Disabled Citizens Council can assess whether the intervention of the Public Trustee is desirable at a hearing held not more than 28 days from the date of the Legal Friend's actions.⁴⁹

It is only in the case of providing doctors, dentists and other care-givers with consent to medical, dental, surgical or other professional treatment or care that the Legal Friend can be placed in the shoes of a person with a disability listed above, and make that decision for that person. In giving this consent, the law requires the Legal Friend to take all reasonable steps necessary to consult with relatives, and to give consideration to the views expressed by these relatives.⁵⁰

⁴⁶ Section 4 Intellectually Disabled Citizens Act 1985-1989.

⁴⁷ Under section 26(1)(a) Intellectually Disabled Citizens Act 1985-1989, the Legal Friend may "obtain for or provide to an assisted person ... information with respect to the citizen's legal rights and legal procedures and specialized services that are available to give the citizen assistance."

⁴⁸ Section 26 Intellectually Disabled Citizens Act 1985-1989.

⁴⁹ Section 32 Intellectually Disabled Citizens Act 1985-1989.

⁵⁰ Section 26 Intellectually Disabled Citizens Act 1985-1989.

The Commission has been told by the Legal Friend that, from October 1990 to July 1991, 80% of his work has focused upon giving medical consents. He estimates that 55%-60% of the medical consents that he has given over this period were for people with dementia.

The nature and extent of the services provided by the Legal Friend are scrutinised by the Intellectually Disabled Citizens Council. If the Legal Friend provides any of the services described above in any emergency situation, he can only do so with the prior approval of the Chairman of the Intellectually Disabled Citizens Council and must, after providing the service, put the matter before the Intellectually Disabled Citizens Council for its later consideration.⁵¹

The Legal Friend is a lawyer. He is assisted in performing his duties by another lawyer.

Whilst the Legal Friend's office is in Brisbane, he is able to appoint other lawyers to act in the capacity of Legal Friend in areas outside Brisbane. Fifteen lawyers are presently authorised to act in the capacity of the Legal Friend. Each of these lawyers provides support and assistance to only one person with an intellectual disability.

The overwhelming concerns expressed about the Legal Friend by people affected by present legislation involved consents to medical procedures.

- . *See, the Legal Friend is a total monopoly and while he says he only becomes involved when it is necessary or asked for, that is totally wrong. If any disabled person has to have an operation in the State then he has to give consent. The doctors can't proceed because they could be liable. If my daughter was 18 and a doctor went and operated on her I could sue the doctor because he did not have the consent to do the operation unless he has Hugh Carter's signature.*
- . *He doesn't want the Legal Friend. He wants his family to make the decision up until he is 18 or if he is 18. He doesn't want to be handed over to a legal friend.*
- . *Legally the Legal Friend in conjunction with, and in close co-operation with, you will give permission for this procedure. You can understand why the law is in place because it is a protection for the disabled. You could be not available and not be able to talk about it; a person could go in for a medical procedure which was very restrictive or could for example do ... harm. So who is to make the decision? The doctor can't make that decision.*
- . *The Legal Friend should definitely not have the power to give a doctor permission to carry out a major operation or any operation on an elderly person, particularly when this is totally against the wishes of a patient and of the family.*

⁵¹ Section 26(9) Intellectually Disabled Citizens Act 1985-1989.

The Legal Friend should definitely not have the right to allow, during an interview by a doctor... of an elderly patient, the presence of [another] doctor:

- * when that doctor is related to the patient;*
- * [when that doctor] is not the patient's own doctor;*
- * when this doctor has made application to the Legal Friend to have the person classed as intellectually disabled;*
- * when that same doctor who is related asks questions of the patient during the same interview.*

The Legal Friend has unlimited powers with no formal accountability. Without accountability there is no avenue for repair on a decision or action that is taken.

[At] the last meeting I went to they said that if an elderly person was a little bit not with it [and] had to have an operation, the relative could not give permission for the anaesthetic - it had to be the Legal Friend.

What is probably needed here is things like minor surgery or up to certain levels that the Legal Friend may give back to the care of the relative.

And this Legal Friend works in with doctors. ... He sends this letter out to all doctors telling them what he can do for them. This more or less says, "I'll help you put someone away" - that's really what it says.

There is probably a need [for the Legal Friend] but most of the time I am sure that the families want what is best for the child so why shouldn't they be allowed to make the decision. If there is disagreement or something, well then as a last resort, call on the Legal Friend.

I've looked after my handicapped daughter for 41 years and she is really handicapped. Say for example she had to have surgery and we needed the permission of the Legal Friend. Who is the one who is going to stand beside the bed and make the decisions on the spot? You don't have the Legal Friend there. There is a definite conflict between my decision-making and theirs.

We've had Hugh Carter out to speak to us at a group. ... A couple of cases he claims success, we know the other side of it and we claim failure in those cases where he claims success.

I have a son who is 18 and we might say for his benefit, and for his pleasure or whatever, that he has a vasectomy. Now if somehow the Legal Friend was notified of this operation taking place, he would be requested by the person notifying him that he step in to see it was being done for proper reasons etcetera. I felt that was saying to me, "Well, we are taking away that family decision to have that done."

Dialogue in one of the workshops -

The lady who just spoke about not being able to get a tooth extracted without the permission of the Legal Friend: this seems to me where the problem is. How we solve that problem, I don't know; but this is a concern.

But that is probably more the application of the law, isn't it?

Just take her out for the day and take her to the dentist. End of matter.

But that is not the correct thing to do.

It is, actually.

These comments can be contrasted with dialogue later during the public forum -

I am much more comfortable, particularly after Hugh Carter spoke to us. I think he made some very positive statements and I am afraid we have heard all kinds of things - I think that has given me a lot of comfort of what he said was his role.

Yeah, I don't think he is the big boogey we thought he was.

Why do you think this has happened?

Because of lack of information. It doesn't get out from the original source to the community. I don't think I have ever seen a document that states the law and what his job is.

Also compare this comment made in a workshop group -

I think a lot of us are unaware of the reality of the position of the Council and the Legal Friend as it is at the moment. I think maybe we have all heard stories down the track and have become very confused and afraid of what we have heard and what can happen. I am going away feeling a lot happier about it.

DOCTORS CARING FOR PATIENTS UNDER THE MENTAL HEALTH SERVICES ACT

When my husband was in Baillee Henderson there was no accountability. I was never consulted about the medication and I know he was given a lot of

extra sedation. There didn't seem to be any extra accountability or consultation of what was dished out. I know they are supposed to be acting in the patient's best interest but often [it is] more that it is the last resort for the staff. ... I could never find out what doses he was receiving or what he was being given. There was just no accountability.

For ten years I could not scratch myself, I was on high doses of Largactyl, and they wouldn't take me off it. I finally found out that the reason they wouldn't take me off it, was because it was cheap. I read an article in New Science Magazine about the use of Largactyl for social control. I complained to my doctor at Lawson House about it but he wouldn't change the medication. I looked up the equivalent medical registers and found a drug called Modecate which suited me and I put myself on it with the help of a private doctor. I've been right ever since. That was ten wasted years.

On page 4, the circumstances in which a medical procedure or treatment can be given to people without their consent was outlined.

These circumstances also apply to regulated and voluntary patients under the **Mental Health Services Act 1974-1989**.

However, a regulated or voluntary patient who has been admitted to a psychiatric institution or ward cannot be forced to undertake a course of treatment or medication. A doctor who forces a patient to take medication or undergo treatment after that patient has refused it may be guilty of a criminal assault upon the patient.⁵² In addition, the patient may be able to claim damages.⁵³

COMMITTEES UNDER THE MENTAL HEALTH SERVICES ACT

If a person is proved to be mentally ill and incapable of managing his or her estate, the Supreme Court can appoint a committee of one or more people⁵⁴ -

- (1) to manage the financial affairs of that person. For a committee to be appointed instead of the Public Trustee, a sufficient reason must be provided (usually by the person or people seeking to become the committee) to show why the committee should be appointed instead of the Public Trustee;⁵⁵

52 Sections 245 and 246 of The Criminal Code; "Commission of Inquiry into the care and treatment of patients in the psychiatric unit of the Townsville General Hospital between 2 March 1975 and 20 February 1988 - Report" (The Carter Inquiry Report) Vol 1 Govt Printer Brisbane February 1991, chapter 18.

53 For the tort of trespass to the person.

54 Sch 5 clause 4 Mental Health Services Act 1974-1989.

55 Sch 5 clause 4(5) Mental Health Services Act 1974-1989.

- (2) to attend to the personal care of the person.⁵⁶ Whilst the committee can arrange accommodation and nursing care for the person, it has been doubted that this power extends to arranging for the person to be admitted to and detained in a psychiatric hospital.⁵⁷

The committee may comprise members of the family or friends of the person with the mental disability.

This avenue is not available for people with intellectual disability. Nor can a committee be appointed for someone with Alzheimer's Disease.⁵⁸

The procedure is rarely used - there have only been 42 applications for the appointment of a committee since 1968. Forty of these applications concerned management of financial affairs.⁵⁹

No one in the public forum workshops commented about committees.

THE PUBLIC TRUSTEE

A combination of laws allows the Public Trustee to be given decision-making and administration power over the financial affairs of people with intellectual or mental disability. These laws were summarised on pages 14, 16, 17, 18, and 27.

With some exceptions, once the Public Trustee takes over the management of a person's estate, the Public Trustee can do anything with the estate that the person could have done with it.⁶⁰ An important exception is that the Public Trustee cannot sell a house or land worth more than \$50,000 which belongs to a person whose estate is being administered by the Public Trustee except with the consent of the Supreme Court.⁶¹

Once the Public Trustee takes over the management of the estate of a person with an intellectual or mental disability, any contract made by the person (other than for necessities) can be avoided.⁶²

⁵⁶ The breadth of this duty of committees was discussed by Power J in *MN v AN* (1989) 16 N.S.W.L.R. 525 at 534-537.

⁵⁷ *MN v AN* (1989) 16 N.S.W.L.R. 525.

⁵⁸ *Re Warby and the Mental Health Services Act 1974-1989* (Qld) Unreported decision Queensland Supreme Court McPherson S.P.J., delivered 9 May 1991 [91/123].

⁵⁹ Information provided by Mr Bruce Nickell of the Public Trust Office.

⁶⁰ Section 80(1)(d) Public Trustee Act 1978-1990.

⁶¹ Section 80(3) Public Trustee Act 1978-1990.

⁶² Section 83 Public Trustee Act 1978-1990.

Heather Thorne, whose husband was left brain damaged after a car accident six years ago, explained the concern she felt about the administration of her husband's estate by the Public Trustee -

[Before the Public Trustee took over Bill's affairs] I could find out very little about what having our funds managed by the Public Trustee would actually mean in our lives. All assets purchased with the compensation money were to be purchased in Billy's name, only for his protection. If we purchased a house, would I be permitted to live in it if he had to go into a nursing home? I wanted honest and direct answers about what would be happening. I didn't know what I could expect from anyone and I still don't

[Now] I feel that my rights have been ignored by the system. If I want anything I have to ask the Public Trustee for it and I have to justify my request. ... The funds are Bill's alone, granted to compensate for loss of earning, yet if he hasn't been injured then I as his wife would have had equal shares in his earnings.

For the first time in 30 years we have separate bank accounts. For the first time in 30 years things are bought in separate names. I live in Bill's house with no guarantee that I can continue to live in it if the Public Trust Office decided otherwise. Things are no longer ours but his and hers. If I divorced Bill I would be entitled to half his assets and maintenance but because I stay married I am not considered an equal partner and yet when I inquired at Social Security about a benefit because I was not able to work and had no income of my own, I was told that I would not be eligible because they would consider that half of Bill's money was mine. ...

When Bill had his accident I lost enough but when I saw that I would have to give over control of our family affairs to [the] Public Trust Office I felt that we were being stripped of our rights and privacy. We took a vow 30 years ago to stick together through good times and bad and our commitment to this vow has been ignored by the system.

- . I think quite frankly that the existing legislation is quite adequate to handle the financial affairs of our intellectually disabled people.**
- . I'm quite happy with the Public Trust. I believe that they are the better person out of the solicitors, accountants and all these people.**
- . The accountability of the Public Trustee! The power they have is too great - like God Almighty.**
- . I have a 26 year old quadriplegic and my concern is definitely with the Public Trustee. On numerous, numerous, numerous, numerous calls to the Public Trustee of trying to give rights to my son on paper work, what assets he has got, things that he is able [to] see, photocopy of the contract of powers, everything, they just say, "No we are in control, you have got no say, he's got no say, ... he's just a vegetable."... I say, "Well can I bring him in and can we do it from there?" "No, you can't. We have got control of everything." It's just so frustrating to see this boy - he has been assessed by [an organisation that says] that he has got the highest IQ that comes through there for a boy who**

is quadriplegic - say "Son, you just... can't open up a bank account, you can't open up nothing." His mind is just as capable as anybody else.

I have a son. He had an industrial accident. He finished up with subsequent brain damage. He has been in hospital ever since - five years ago. ... They handed all his affairs to the Public Trustee. They never bothered to tell him, or us. He was receiving Worker's Compensation at the time. The Worker's Compensation Board paid out the affairs. The Public Trustee - they still didn't bother to notify my son or myself that this had in fact happened. ... It was two months after the Public Trustee had taken over my son's affairs that I found out. I only found out because the Workers Compensation Board's cheque stopped coming to my house.

In one group of people affected by existing legislation, the following conversation occurred -

Can't we get better access to what is going on? ... If you are the family trying to make your way through the Public Trust system to see why a particular thing is happening, it's horrific.

... Usually you end up with cap in hand and saying, "Sorry, sorry, but I must ask a question."

Well I've worked with a lot of families (I'm a parent as well as a professional) and the most anger with families has been towards the Public Trust Office and that basic accessibility. They say, "No" - why do they say "No"? Why do they say "No"? How dare they say "No"!

Is the Public Trustee really the "baddie"? He seemed all right out there today but when you actually go to them with a problem you don't get anywhere.

Well actually whenever I've gone to the Public Trust - I have found them very helpful.

We have had a friend who has the Public Trust looking after her affairs and she is quite happy with the results.

Can I say that I am actually scared to go to them?

It must depend on the person who serves you.

A professional working with people who have an intellectual disability suggested that the Public Trust Office could offer a more supportive role -

One of the most positive things we should look at [in] dealing with people with intellectual disabilities is that these people have an ability to learn and to be able to take control and to manage in many ways as somebody with a degenerative illness may not have. ... Any support which is given in decision-making to someone with an intellectual disability should realise there is a very real potential for that person to be able to take over the decision-making process, the budgeting process, and handling their financial management and

decision-making themselves. ... The biggest problem now is that you go to the Public Trust Office but they tend to take control. The Public Trust Office won't offer training for an intellectual[ly] disabled person to handle the budgeting or make the decisions or to help with the money management where officers of perhaps our department - Family Services - or support agencies that provide services to intellectually disabled people, will do.

A professional working with people who have a mental disability said that -

I found [in] my dealings with the Public Trustee that it is a matter of who you get on to. You need to make a few established contacts so that you are speaking to that person all the time. I found that you are always talking to the juniors and they become terribly officious. If it is "How much do they have in their account? Can they afford to go on a holiday?" - there is no response. "It has got nothing to do with me." If I want to buy them clothing it is a matter of my taking them down to the department store, getting a chit for how much it is going to cost and taking it back to the Public Trustee to draw a cheque on their behalf and then back to the store again. And I found most of them terribly impassive in that they have not got that same contact as the normal carers do have. It simply comes down to it is a bureaucracy. They're handling somebody else's money and I feel that they take the attitude that it is their money and not the person's whom they are looking after. But then if they weren't anonymous then they would have to think a lot more clearly before they gave you an answer. In one case a client gave half a million dollars in with the Public Trustee and wanted to draw out one hundred dollars for a pair of shoes and was told it was too much; he could get a much cheaper pair. Then again, on the other side, you look at my present contacts. Terrific! It is just a matter of asking and they leave enough to your own discretion to do the right thing.

Where we consider that management is no longer necessary or no longer in the best interest of the individual concerned, we can surrender our management role and indeed our basic philosophy is, in those cases where it can be established that a person can properly look after their affairs, we seek to withdraw.

(Kevin Martin, The Public Trustee.)

Once the Public Trustee is managing the financial affairs of a person, there are many mechanisms which allow for the financial management role to be returned to that person if the person regains competency. With the exceptions of withdrawal by the Public Trustee, these mechanisms are not explored in this issues paper.

If the management of the person's financial affairs came to the Public Trustee through the filing of a certificate of disability or under mental health legislation, the Public Trustee can withdraw without obtaining authorisation by a court or another body.⁶³

⁶³ Section 73(i) Public Trustee Act 1978-1990 - the Public Trustee must withdraw if satisfied that he should no longer manage the estate at any time after a certificate of disability has been signed; Sch 5, clause 6 Mental Health Services Act 1974-1990 - the Public Trustee ceases to manage when satisfied that a patient under this Act is able to manage his or her estate.

When the Public Trustee is appointed through the Intellectually Disabled Citizens Act 1985-1989, the Public Trustee investigates the existing arrangements for the financial management of the person's estate. Where adequate arrangements exist, the Public Trustee can withdraw as estate manager by notifying the Chairman of the Intellectually Disabled Citizens Council that adequate existing arrangements (such as a valid enduring power of attorney or an existing discretionary trust) make the Public Trustee's intervention unnecessary.⁶⁴

By contrast, if a person's financial affairs are being managed by the Public Trustee under a protection order made by the Supreme Court, then the Public Trustee's authority to manage can be removed only by the Supreme Court whilst the person is alive. This can be achieved through an application to the Supreme Court by either the Public Trustee or the person whose estate the Public Trustee is managing.⁶⁵

ooo0ooo

SHOULD DIFFERENT PEOPLE MAKE DIFFERENT KINDS OF DECISIONS FOR THE SAME PERSON?

There is an artificial separation between lifestyle issues, known as guardianship (for instance, consenting to medical treatment and deciding where a person should live) and financial issues, known as administration. ... In reality, when we make decisions about lifestyle matters, we are often making decisions about financial issues and vice versa. For instance, if I lived in Brisbane and the issue was, "Where do I live? Do I live on Southbank in one of those expensive apartments or do I live in a less expensive suburb, perhaps out at Wynnum or Manly?" I have to make a decision based upon a lifestyle issue. What sort of image do I want to project about myself? How close to the shops or the city do I want to be? Do I want to live in a built-up suburb? But equally I need to look at what is in my wallet. Am I able to afford to either buy or rent in one of those suburbs? When I am making that financial decisions about where I live, I am making a lifestyle decision as well. Any mechanism that you establish ought recognise that they have to deal with the totality of the circumstances of an individual, rather than being able to cut up the person into compartments or elements and have them dealt with by different places and different organisations.

(Tony Lawson, President of the Guardianship and Administration Board (Vict).)

There are two aspects which one looks at. One looks first of all at the guardianship of the person and one also looks at the guardianship of the estate. The issues arising from both those approaches are not necessarily the same. Intertwined surely - you cannot look at one without looking at the other. But the principles that guide the approaches society should adopt to both guardianship

⁶⁴ Section 32(3) Intellectually Disabled Citizens Act 1985-1989.

⁶⁵ Section 69 Public Trustee Act 1978-1990.

of the person and guardianship of the estate of that person, don't always intermesh well. ...

Whilst there is an inter-relationship between lifestyle issues and financial issues, this is not always the case. Issues of financial management and responsibility are the fundamental issues of administration. At times these can be in conflict.

One of the problems we always face is, "Should a person with a disability be permitted to adopt a lifestyle which will result in the rapid depletion of their economic resources so that in the long run they become a burden on the State and society?" People not under a disability can go out and waste their resources and demand that the society then pick them up. Do we adopt the same attitude towards people with a disability or do we step in to manage their affairs?

(Kevin Martin, The Public Trustee.)

. *I couldn't see how you can separate the guardianship role and financial because they are so dependent on each other.*

One professional working with people who have disabilities pointed out that -

. *Access and guardianship, especially with older people - it's a very off-putting kind of thing. People might relate to it with kids perhaps, but [to] ordinary people... the guardian means someone who has the care of a child.*

DO THE ACTIONS OF SUBSTITUTE DECISION-MAKERS NEED TO BE SCRUTINISED BY AN INDEPENDENT SOURCE?

Two areas of review were identified by forum participants.

First, an automatic review of the need for a substituted decision-maker after a fixed period of time. At present, only the appointment of substituted decision-makers through the **Intellectually Disabled Citizens Act 1985-1989** (such as the Public Trustee or the Legal Friend) is reviewed automatically after a set period of time.⁶⁶

Secondly, a review of the conduct of substituted decision-makers was thought necessary. This could be assessed through either an automatic review, or an application by a person who was concerned about the way in which the substituted decision-maker was handling their power over someone else's financial or personal affairs.

At present, the Supreme Court can hear allegations that substitute decision-makers have abused or overstepped their power, or acted improperly. This Court can then make orders to rectify the situation. In addition, if the complaint concerns a public servant, then the Parliamentary Commissioner can investigate (see page 60), but cannot himself overturn the decision or action.

⁶⁶ Section 28. The "kind and extent" of assistance given under the Act is reviewable by the Intellectually Disabled Citizens Council at least once every five years.

If the complaint concerns a substituted decision-maker appointed through the **Intellectually Disabled Citizens Act 1985-1989** (for instance, the Public Trustee or the Legal Friend) then the Intellectually Disabled Citizens Council has the power to review.⁶⁷

However, if the substitute decision-maker was appointed through an enduring power of attorney or by the Supreme Court, then the Supreme Court is the only body that can take away the substituted decision-maker's power.⁶⁸

Comments were made at the forum about the desirability of being able to review a number of substitute decision-makers appointed under present legislation - the Public Trustee, the Legal Friend and people nominated to make decisions under an enduring power of attorney. One speaker noted that if the range of substituted decision-makers is widened to include, for instance, family and friends, there will need to be a mechanism to make these people accountable.

We are an accountable organisation, we are accountable to the individual, the Government, to society as a whole, through the courts.

(Kevin Martin, The Public Trustee.)

The problems in Victoria [before the Guardianship and Administration Act was passed] was not dissimilar to the situations that you have described here. ... The fourth area was that the accountability of appointed decision-makers was inadequate, irregular and difficult to invoke. In particular in Victoria where the Public Trustee was appointed to manage a person's financial affairs, if you wished to challenge their authority you had to take that to the Supreme Court. Now I suspect that the same is true of the Supreme Court in Queensland as it is of the Supreme Court of Victoria. You either have to be very rich or very poor to go to that body. Very rich - you can afford anything. Very poor because you might then qualify for legal aid. And the rest of us be damned! That is the reality in regard to access to justice.

(Tony Lawson, President of the Guardianship and Administration Board (Vict).)

It seems to me that in the past that there is a problem with only one person having control of everything. ... I mean it is either the Public Trustee controls everything and doesn't tell the next of kin or the next of kin controls everything and there is no independent person looking on from outside to look after to see that nothing is done wrong.

There is still the matter of the review of the enduring powers of attorney. I would think that, because for some reason people become more lucid, every three years or something somebody might have to come and say, "Do you want that continued?" They may be able to review something.

⁶⁷ Section 27(3).

⁶⁸ Enduring powers of attorney - section 175B Property Law Act 1974-1990; committees under the Mental Health Services Act - Sch 5 clauses 4(3) and 6(2) Mental Health Services Act 1974-1989; the Public Trustee appointed through a protection order - section 69 Public Trustee Act 1978-1990.

One suggestion that has [been] mentioned is the appointment of persons other than a government agency as administrator of the person's estate. It is interesting to note that from the figures in [the 1989-90 Guardianship and Administration Board] Annual Report, State Trustees of Victoria were appointed administrator in 60% of the cases, relatives and friends in 33-35% of the cases and others - the solicitors, the accountants, the public trustee companies - in 5-7% of cases. One of the great problems that society is going to have to confront if it appoints other persons as administrators is the maintenance of the necessary input and control over the way in which those people carry out their duties.

(Kevin Martin, The Public Trustee)

Dialogue in a workshop discussing their concerns about existing legislation -

. *Maybe we should be looking at putting a few restraints on this Legal Friend.*

So who is he responsible to?

The Minister.

The Minister! When I rang up the Minister, I was told Hugh Carter is doing his job. End of story. I have written to her again and anyone you can think of. You walk round in circles looking for someone to help you.

And another comment -

. *And I see as very important a review process that is accessible, and I guess to be accessible in the situation of disability and mental health it has got to be free.*

SHOULD THE RANGE OF SUBSTITUTED DECISION-MAKERS BE WIDENED?

Our laws should be enabling the best substitute decision-maker to be appointed in the particular circumstances. ... We need our laws to have sufficient flexibility to allow that. ...

In the area of money management only the process involving the Supreme Court allows for someone other than the Public Trustee to be appointed, but the rules are very much worded in favour of the Public Trustee. ... The appointment of anyone other than the Public Trustee is quite unlikely. ...

Is the fact that the Public Trustee will sometimes be the best person, any basis for an assumption that they will always be the best choice? ...

Where the Intellectually Disabled Citizens Council is asked to decide that a substitute decision-maker is required to consent to professional or other treatment or care, the Council has no alternative than to appoint the Legal Friend or perhaps another specifically nominated lawyer. ...

Those who believe that the Legal Friend or another lawyer is always the best person to make professional consent decisions make a similar assumption that no one else could do that job as well or indeed better in many circumstances.

(Jeremy Ward, Queensland Advocacy Inc.)

- . *I still tend to swing towards the Victorian situation. I think that is a very positive situation in that... the best person for the job is chosen to represent the person with the disability and I think that in any situation we couldn't ask for more than that.*
- . *The major way forward that I see is freeing up the system so that there are more choices available in the system such that at least a relative or friend can be appointed as a guardian, ...that there be more choices available for the financial administration in addition to the Public Trustee, basically a guardian or a private trusteeship company.*

Many people at the public forum felt that the range of people authorised to make decisions for a person unable to do so should be extended to include family members. Their comments can be found in Chapter 7 of this paper.

5. The bodies and people who are responsible for deciding whether people with disabilities need assistance in making decisions aren't bound by the same rules

CLEAR PRINCIPLES ARE NEEDED

In our laws addressing how decisions should be made, ... clear principles should be inserted so that people who are making these decisions have some guidance. Only the Intellectually Disabled Citizens Act does that at the moment.

(Jeremy Ward, Queensland Advocacy Inc.)

Other decision-makers are not required by law to be guided by the types of principles in this chapter. However, that does not mean that principles do not exist. Take, for example, the Public Trust Office -

The philosophy of approach is often times more important than the strict legality that can apply. ... At the offices of the Public Trustee -

- * we seek to be consultative***
- * we provide expertise***
- * we provide professional advice***
- * we seek to manage on an individual basis not in accordance with any sort of general formula but looking at each case***
- * we seek to be caring***
- * we seek to be nonintrusive into the affairs of individuals***

(Kevin Martin, The Public Trustee.)

LEAST RESTRICTIVE ALTERNATIVE

When we are talking about the laws entering into the personal lives of individuals, that should only happen when there is absolutely no alternative. ... It is in effect a decision to take away their rights.

(Jeremy Ward, Queensland Advocacy Inc.)

Legislation, as I see it, is a complete deprivation of a person's civil liberties in that it is not giving the person with the disability the right to make their own decision.

Assistance provided under [the Intellectually Disabled Citizens Act]... is provided in the least intrusive way. It is based on the philosophy ... that all persons with

an intellectual disability are deserving and have the same rights as anyone else within the community and that those rights need to be recognised. This legislation does recognise the abilities of persons with an intellectual disability and provides substitute decision-making only as a last resort.

(Hugh Carter, The Legal Friend.)

We've heard about the least restrictive alternative. ... That is certainly a very very important feature of that [Intellectually Disabled Citizens Act]. But it doesn't exist in the other legislation which we have heard about.

(Jeremy Ward, Queensland Advocacy Inc.)

Referral to the Public Trust Office is seen as the most restrictive alternative and is not done if an appropriate alternative arrangement can be arranged or is in place. Referral to the Public Trust Office through this legislation, unlike protection orders or the Mental Health Act referrals, is not on the basis of incapability, but on the basis of need.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

ENCOURAGE DISABLED TO ACHIEVE THEIR POTENTIAL

[The Intellectually Disabled Citizens Act] was designed specifically to support persons with an intellectual disability. ... The legislation was carefully thought out and designed to encourage persons with an intellectual disability to achieve their potential.

(Hugh Carter, The Legal Friend.)

PROVIDE ASSISTANCE ONLY ON AN AS NEEDS BASIS

The assistance provided under the Intellectually Disabled Citizens Act is very importantly only provided on an as needs basis.

(Hugh Carter, The Legal Friend.)

It is only in limited circumstances where we intervene. We do not seek to adopt a general attitude of intervening in the affairs of intellectually disabled people. Indeed the Public Trust Office fully supports the concept that intellectually disabled persons or persons with a disability should enjoy the full rights and privileges of any person in the community, and it should only be in a case where it has been proven that assistance is necessary, that our organisation should become involved in managing their affairs. ...

Where we consider that management is no longer necessary or no longer in the best interest of the individual concerned, we can surrender our management role and indeed our basic philosophy is, in those cases where it can be established that a person can properly look after their affairs, we seek to withdraw.

(Kevin Martin, The Public Trustee.)

PRESUME COMPETENCY

In all considerations of applications the Council approaches the issues on the basis that the citizen is presumed competent until the contrary is demonstrated.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

SUBSTITUTED DECISION-MAKERS MUST GIVE PEOPLE WITH A DISABILITY A SAY IN WHAT HAPPENS

Bodies and Courts which make decisions about people with a disability must hear and take account of those people. This is not necessarily the case for substituted decision-makers.

When the Legal Friend acts as a substituted decision-maker (in giving medical consents) he is required by law to ensure that, as far as possible, the wishes of the person with an intellectual disability are taken into consideration.⁶⁹ Other substituted decision-makers are not required to take the affected person's wishes into account.

It is really [about] the person with the disability having a say in what happens. For example, whether or not they stay with their families. There needs to be a respect for the disabled being able to make their own decisions.

A hypothetical example given by a schizophrenic who has been a patient in a psychiatric hospital exemplifies the previous comment -

I'm in the Schizophrenic Fellowship and I am in the social club and I have noticed one fact: 75% of the members smoke. Say you've got money in trust and you want to get a packet of tobacco. The medical profession are embarked on a crusade to stop people smoking. Is it their right at the present moment to say, "You cannot have the money to buy your tobacco because we know better than you, and you shouldn't smoke." I used to smoke. I don't anymore.

⁶⁹ Section 26(5)(d) Intellectually Disabled Citizens Act 1985-1989.

6. These bodies also have a restricted power to tailor orders to suit the needs of a person with a disability

You've got to define first of all who the laws are for in order that you can define your laws. And then, your laws would have to be tailor-made to suit a number of different people who really need to be cared for.

There needs to be something in place which is tailor-made to suit the individual - more flexible.

PEOPLE ARE DIFFERENT

[One] of the difficulties in Victoria [before its present legislation was passed], was that the decision to appoint a substitute decision-maker often involved an all or nothing approach. There was little or no capacity to tailor-make the intervention to fit the actual needs of the particular person, acknowledging the person's capacities as well as their incapacities. I want to quote one example which I don't think is dissimilar to the situations that have occurred in Queensland.

Before guardianship legislation came in in Victoria [with] all persons who were made involuntary patients in psychiatric hospitals, automatically their affairs went under the Public Trustee. It was based upon a simple argument that the label of the mental illness ought to be sufficient to invoke an all-enveloping protection mechanism to protect that person with a mental illness from themselves and from being taken advantage of by other people. The label of the disability was the criteria that the law had used to assign the management of that person's financial affairs to the management of some other person - in this case the Public Trustee.

A case that arose soon after our Tribunal was set up involved an inner suburban psychiatric hospital. A woman had been admitted with a psychiatric illness and was being treated involuntarily. She was there against her will. Staff became concerned that she was in the process of selling her house and might be taken advantage of in that process. The law as it had previously applied, whereby automatically her affairs went under the Public Trustee - that was abolished with our legislation. So the hospital made an application to our Tribunal for an emergency order to be made appointing the Public Trustee (since renamed the State Trust Corporation) to manage her financial affairs. We held a hearing that day. At the hearing it became apparent that this woman over a period of five to six years had been in the process of buying and selling five to six houses. She had actually made a profit on every transaction, and if I was as astute as she was in relation to real estate transactions, I wouldn't be the President of the Guardianship and Administration Board. Yes, she was incapacitated. She wasn't

able to have sufficient insight into her psychiatric illness to seek and receive appropriate treatment. But the evidence showed that there was no need to intervene in the management of her financial affairs. Incompetent in one area of her life. Competent in the other area. And in that particular case the application was dismissed.

The guardianship legislation allows the tailor-making of orders that fit the particular need or the circumstances of the individual. Legislation needs to be flexible.

(Tony Lawson, President of the Guardianship and Administration Board (Vict).)

- . *I have seen some of my mates being made intellectually disadvantaged. Because of their low education, it has been classified as an intellectual disability and that is where I think there is a big problem.*
- . *This is the problem with the Bureaucratic: they blanket us so much that I fit in the same [category] as my friend down here, and his needs are not the same as my needs. We have to make sure that if there is a general classification that these sorts of people don't suffer.*
- . *There needs to be some mechanism from severely disabled intellectual to mild intellectual. They are all categorised as severely disabled no matter how mild they are.*

Professionals working with people who have an intellectual or mental disability agreed-

- . *We need to ... encompass several different things - those people who are intellectually handicapped, those people who have some type of dementia, those people who are maybe head injured and maybe able to handle some of their affairs. So it needs to be a fairly broad spectrum of what you are looking at, to be able to consider all of these fairly, and take into consideration not only the person's concern, but also the immediate family as well and what their concern is.*
- . *Everyone has their individual needs and they have to be assessed as an individual, whether they be suffering from Alzheimer's or intellectual disability or [a] psychiatric condition.*

IN SOME LEGISLATION THESE DISTINCTIONS ARE RECOGNISED

We need laws that allow for orders appointing substitute decision-makers to be tailor-made to the abilities of the particular individual and the particular circumstances. ... Under our current laws only the Intellectually Disabled Citizens Council has any degree of flexibility in this regard.

(Jeremy Ward, Queensland Advocacy Inc.)

Perhaps one of the issues to do with the Intellectually Disabled Citizens Act that isn't well understood is that, to an extent it is tailor-made in that the Legal Friend doesn't have to intervene every time, and even if somebody has received the assistance of the Council for a medical consent in one situation, it doesn't mean they will need it next time.

7. The role of members of the family

. One of the difficulties that we have is trying to come to grips with whose responsibility it is that our daughter is handicapped. Is it our responsibility? Or does the community have a responsibility to care for her? As we see it, the community has a responsibility and we have some responsibility. If we felt a responsibility we think we should have some rights too. The community, the government, is trying to push all the care onto us. They are withdrawing services that are available and saying we can't have these services. ... So, the parents are going to have to look after them, and if the parents are going to look after them, they need some rights.

. The Federal Government policy is that carers should care at home. In the area of the frail aged, the Commonwealth policy is, only 10% of the 70 years age bracket [should be] cared for in residential care. There are more than that number of Alzheimer's patients in the over 70 years age group, so Alzheimer's patients alone could not be placed in residential care. Thus, unfortunately it is absolutely essential that our carers survive and that their rights are enshrined in the legislation. ... So what [the Federal Government] is saying is, "Care in the home because we cannot provide a State instrumentality to look after your loved one, but we will manage your affairs for you." The extraordinary frustration of that contradictory situation simply compounds the stress of caring.

. I'm a carer of a daughter with mental illness. She has slight schizophrenia. ... I have been told many times that the parents have actually no rights whatsoever.

. I am the father of a 13 year old daughter who is intellectually handicapped. ... I can see no reason for the Legal Friend or Public Trustee to be involved in the care of our daughter when she turns 18. ... I have no bothers with having a counsellor or something there where a caring parent or sibling would demonstrate to that Body that they have the ability and welfare of the intellectually handicapped person as their primary concern. ... But I do have a bother about not being able to justify it to anybody and having it automatically taken out of our hands when she turns 18.

. Treat each family on its own merits.

My husband, Bill, and I have been married for 28 years, have 4 children, until 6 years ago we had a pretty good life. It wasn't always easy but we shared the ups and downs. We were both employed for one purpose - our family and our home. Never was it his money or my money, but our money. Never was it his decision or my decision, but our decision. All of this changed in an instant when the car Bill was driving, with my daughter in it, was hit by a semi trailer. ...

We exhausted every legal avenue to keep Bill's money out of the hands of the Public Trustee but it ended. We had no choice. This decision was based on a

blanket assumption - that people with head injuries cannot manage their own affairs. It was also based on the need as the Public Trustee sees it, to protect the person from unscrupulous relatives. I felt outraged that I was being judged on the basis of other people's behaviour and not as myself. ...

We married for "better or for worse, for richer or for poorer, until death do us part". My husband is still alive and these vows still count to us. I want Billy's right as a thinking, feeling person respected as well as his wishes that our marriage continue as a joint partnership as it always has been. ...

If the law dictates that monies must be given to the Public Trustees I do not understand why the commitments to the marriage by both partners are not taken into account. Why can't the money be divided and the wife given her share to contribute equally to the family costs, or at least managed by the Public Trust Office in both names, so that purchases are made in joint names? People would be able to go on as normal as possible in their own lifestyle.

(Heather Thorne, a public forum guest speaker.)

PRESENT INVOLVEMENT OF THE FAMILY IN DECISIONS MADE FOR A FAMILY MEMBER WITH A DISABILITY WHO NEEDS ASSISTANCE IN MAKING DECISIONS BY THE PUBLIC TRUSTEE

A hand-out prepared by the Queensland Law Reform Commission observed -

Although decisions about the property can be legally taken without consulting the family of the person, the spouse of the person is usually consulted. Further, the Public Trustee is not legally required to be swayed by or account for, the wishes of the person for whose estate the Trustee is managing.

Kevin Martin, the Public Trustee, replied -

Now that's a theoretical legal position. The practical position is... that we seek to make those decisions after the widest possible consultation with the family, carers, spouses and also the person concerned themselves.

In a workshop, Jeremy Ward, a solicitor with Queensland Advocacy Inc, was asked what type of obligation the Public Trustee has to involve the family of people whose estates were administered by the Public Trustee -

As far as I am aware there is really nothing that is spelt out. ... By contrast if you look at the Intellectual Disability Citizens Act you will see that when the Legal Friend is making a decision involving consent [for example, to medical treatment] that there is an obligation that he must take all steps to fully consult with the family. I am not aware of anything in the Public Trust legislation about that.

A representative of the office of the Public Trustee responded -

I don't know anything about the actual legislation but in practice they are always taking into account - always - the wife, the children, the family. ... They always have been - they always will be. All I can go on is my personal dealings with them.

PRESENT INVOLVEMENT OF THE FAMILY IN DECISIONS MADE FOR A FAMILY MEMBER WITH A DISABILITY WHO NEEDS ASSISTANCE IN MAKING DECISIONS BY THE INTELLECTUALLY DISABLED CITIZENS COUNCIL

The role of the parent [is] somebody whom at every stage in any decision-making process is consulted throughout the whole process. The [Intellectually Disabled Citizens] Act very clearly says that when the Legal Friend is making decisions on medical or treatment matters he must consult with the family if they are reasonably accessible. We invite family members to considerations of applications. We listen to them. We take their views into consideration when we arrive at our decisions. Often, where we believe that the person with the intellectual disability doesn't have the capacity to take an informed and valid decision, we will say to the parent, "Do you believe that if you explain the situation to him or to her sufficiently that you would be able to give them sufficient insight to make that decision?" If the answer is "yes" and the parent, the family member, is willing to accept that responsibility, we are happy to give it to them. The longer I am associated with this organisation, the more I try to stretch that particular aspect of the legislation. If there is a chance to give that parent that role, I lean towards doing that. The Act says we must and we do try to consult with parents in every decision that we take.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

There should be more consultation with the family to allow the family to have at least some input. At the moment, the family can be ignored entirely and in actual fact [the Intellectually Disabled Citizens Council] are missing out on very valuable information because the family members are the ones who are most competent to give concrete information as to what is happening with the disabled person.

I did speak to Mr Rackley [Chairman of the Intellectually Disabled Citizens Council] and what we said this morning is very relevant - that the families and parents have got to be given more consideration. I said, "Why don't you bring families into it more?" He said, "No, the law does not allow that", but that he as Chairman falls over backwards to give the family and the relatives as much say as he possibly can and he'll do it more. But that isn't what the law tells him to do.

SHOULD SUBSTITUTED DECISION-MAKERS BE REQUIRED TO CONSULT WITH FAMILY MEMBERS BEFORE MAKING DECISIONS?

- . *Because a family isn't involved in the day-to-day care of their child, then it's assumed that they are no longer part of the family unit and that families no longer need to be involved in their decision-making. And that is not the case at all. But that tends to be the assumption so decisions are made by service providers which don't include the families at all. And what we are saying is that families have a right to be involved regardless.*
- . *I'm afraid the law to some extent shuts out families and relatives in making a lot of decisions. I'm not saying they are going to take our relatives away from us, but I think the family and relatives should have more say in the decisions that are made for their handicapped relatives.*

One workshop group of people affected by the present legislation was more adamant-

- . *Consultation with the whole family - everyone involved in that person's life.*

Consultation is very important. It should be a top priority.

You must underline, and in block letters: "consultation".

WHEN DECISIONS ARE BEING MADE FOR A PERSON BY SOMEBODY OUTSIDE THE FAMILY, THIS AFFECTS THE FAMILY AND SPOUSE OF THAT PERSON

I have got to say this. The interests of the family of that person, the carer or the society as a whole (as important as those issues and interest may be) must ultimately be subordinate to the interests of the person with the disability.

(Kevin Martin, The Public Trustee.)

I resented the invasion of a third party in my marriage - marriage is personal and private, a joint partnership.

During our marriage we were joint trustee of our own affairs and nobody questioned our abilities or our motives. Suddenly, neither of us were considered capable enough of managing our own affairs.

Even though Bill's role before the accident was to support his family, the family rights became uncertain. The focus was on Billy only. ... The disabled person is not the only person in the relationship - the whole family is affected.

(Heather Thorne, whose husband was left brain damaged after a car accident six years ago, talking about her feelings about her husband's financial affairs being given to the Public Trustee.)

A person presently affected by disability legislation suggested -

- . *I feel that counselling is a great idea, because the rest of the family ... are affected, let's face it. It doesn't happen to one person it happens to everybody associated with it.*

A professional working with sufferers of Alzheimer's Disease and their families said -

- . *I have been around the State in the last month and I have been able to consult about 100 of our families that we work with. In every case - whether they come from a professional background, whether they have come from a working class background, in every case in spite of their career history - under the burden of care, they simply cannot cope with bureaucracy. Under normal circumstances, the Public Trust Office wouldn't be considered to be bureaucracy. I am sure they are sensitive and efficient. But, under the burden of care, even minor obstacles become life threatening, in the sense that the family is seen to be threatened. ... On the part of the husband and wife who may have... operated in the setting of a marriage for 40-50 years, the presumption is in fact that they are no longer competent and they are frail aged themselves - they are probably 60-70-80 years [old]. But they have jointly managed their affairs and planned their retirement for 40-50 years. In rare cases perhaps they have only been married 20 years.*

A Public Trust Office official, who was in the same workshop as the person that made the last comment, said -

- . *Probably the Alzheimer's Disease cases where you have husband and wife - where the husband has always looked after the funds etcetera - are the most difficult under the present legislation. I guess any thinking person would have to say that there ought to be some mechanism whereby Public Trustee management can be relinquished to an individual person, particularly a wife.*

SHOULD THE LAW ALLOW FAMILY MEMBERS TO BE SUBSTITUTED DECISION-MAKERS?

On the question of delegating to parents and family members of people with intellectual impairments a larger role of substituted consent, ... I am aware that consideration of that option must include the consideration of the good parent-bad parent issue. My face to face experiences with family during my first term as Chairman of the Council tells me the issue will not be easily or quickly dealt with. Again if that option is to be included in the provisions of the legislation, there will need to be very clear guidelines spelt out both for parents and families and for Board and panel members.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

ARGUMENTS FOR GENERALLY...

As the Court case for Bill's compensation drew nearer, suddenly things changed. For six years no one had cared how I looked after him or whether I would leave him or not. Nobody wanted to take responsibility for him then - that was mine alone. Suddenly Bill's welfare became everybody's concern and my rights and my role as his partner in the past and in the future disappeared. His affairs would be looked after by the Public Trust Office.

(Heather Thorne.)

- . *I take care of a child who has problems and my concern is with this magic age of 18. I mean to say, he only has 2 to 3 years to go. ... I've looked after him up until now. Somebody is going to take an interest in him all of a sudden and decide to say I can't take control of him now. All of a sudden the parents are no good. We have looked after him for 18 years. If there aren't any problems why not leave it the way it is? Fair enough if the parent has died, or if the parents can't cope anymore. But why can't it be left the way it is?*
- . *I really can't understand why I can't continue to go along on the same vein when she has been bought up in a loving, extended family, because I am a single parent. I just feel threatened. She is 18 in 1993 and so it's a significant year. It seems to be coming very fast.*
- . *If you look at, say, the animal kingdom, a tiger will look after its cub. It will teach it to hunt and fend for itself right throughout its life and the cub would then start to pick up survival instincts it has picked up from its mother. It would not pick up those same instincts from somebody else. It comes from the family environment.*
- . *I've looked after an intellectually handicapped person for 40 years now. If I didn't love that person I could [have] put them in a residential home when she was 20 years old. The [Intellectually Disabled Citizens] Council and the government don't consider that I am doing it because I love the child and I have given half my life. And I would say my life revolves around our handicapped person's needs. ... But the Council is saying that the doctor or someone can say that her affairs should be taken away. What I'm saying is, it doesn't matter at what stage in life it is, it is too easy to take over a person's affairs.*
- . *If the family is not doing the right thing there ought to be some kind of counselling saying, "This is why we think you're wrong." But they don't even give you the chance.*
- . *We might be only 10% wrong but it's better than being told you are 100% wrong if you're not in it. At least there is an attempt to say, "Well you're a part of the treatment," and they have got their part and we have ours.*
- . *I can't understand why this lady who has probably looked after her mother for donkey's years - has catered for all her needs - suddenly has that all taken away from her.*

- . *I firmly believe in the family being the best. Most families would want the best interests of the child or person and that, you know. Unless it is absolutely necessary, why are government departments brought in to take these decisions away from the family?*
- . *With the situation with me and the boys' bank accounts - they're both over 18 years of age, I don't actually handle their money, but I'm helping them handle their money because they don't really know what they are doing. I take them to the bank and they make their marks on the withdrawals but they don't really know what is going on. What am I supposed to do, go and get Power of Attorney? I am literally doing it outside the law. I was told, "Yes, that is right, but all the other parents are too."*
- . *It just seems to me that we have them all our lives, we have all the responsibility for them and have done our best for them, and then the minute they are 18 I am [acting] against the law because I still handle their money and everything. It really needs to be clarified where I stand.*
- . *The fact that the Victorian legislation allows for a parent to put themselves up to be that advocate is where we fail here. ... If the parents are bad parents then the Tribunal will make that decision.*

ARGUMENTS FOR IN MEDICAL PROCEDURES...

- . *If I was in that situation I would expect my next of kin to make decisions if I couldn't make them for myself. If there was nobody else there, then that would be understandable - that is, [for the Legal Friend to make decisions]. But why would you need to have a Legal Friend when you have next of kin?*
- . *I'm her daughter and if she needs a tooth extracted I should have the right to say, "Yes, she can have it done." You know, she never has been classed as a mental patient - she is just old, she's 89.*

In one workshop session, **Hugh Carter, the Legal Friend**, observed -

- . *In relation to the quality of the decision there has never been a question in my mind or certainly raised in the legislation that the Legal Friend makes a better decision than family members. Families are obviously deeply involved and legislatively involved. I must, under the legislation, take all reasonable steps to consult with that person's family. So families actually have a recognised legislative base in playing a part in that decision-making.*

(Hugh's comment applies to decisions about all professional treatment and care.)

SHOULD THE LAW ALLOW FAMILY MEMBERS TO BE SUBSTITUTED DECISION-MAKERS?

ARGUMENTS AGAINST

People affected by the laws said that -

- . *A lot of people with intellectual disability cannot reason for themselves and to a lot of parent's minds they remain children.*
- . *I have a 24 year old who would be equal to a ten year old. So what is he but a child? He is a big kid and he will be a big kid for all his life. He has progressed as far as he can.*
- . *Anyone turns 18 has their own rights. You cannot continue to make legal decisions for them. At 16, a person becomes entitled to a pension and some parents/carers do not always place the whole of that to the benefit of their child/person they are caring for. This is a protection to enable the pension money to be used for the child.*

Professionals working with people with an intellectual or mental disability said that -

- . *There is the other side of the coin that there are families who haven't got the person's best interest at heart; they do things for their own benefit and interpret the law for their good.*
- . *With a lot of brain damaged people ... you can see that they're quite intelligent and they know what they want, but they act like children at home because that's the way they're easily handled at home. Sometimes emotionally they're too frightened to speak out and say, "I am an adult and I do know what I want", because it's not in Mum and Dad's interests for them to follow their heart. I know there are some of our consumers who would like to do work, but Mum and Dad feel that possibly it would be degrading - they wouldn't get paid properly for it. But what they are not considering is that the person wants to contribute in a physical way but they are not being allowed to. ... [The parents say], "I don't want them to go into a workshop area. I don't want them to be abused." But what they are actually doing perhaps, in some cases, is abusing them themselves by withdrawing that attention, withdrawing that love, and not really giving them the motivation or support they need.*
- . *They say to me, "I want a hair cut" or "I want a new dress" or "I want whatever" and the way it usually has to be is that the association writes to the Legal Friend or writes to a parent. In a lot of cases the parents attitude is, "Why should I waste \$10 on a haircut?" It is just too easy for a carer/parent/Legal Friend to step in and stop the disabled person's independence.*
- . *There have been documented cases where the capable one has access to the funds, has not worried about the incapacitated person, put them in a home, [and] gone off with someone else - with a third party.*

When discussing the role of the Public Trustee in estate management of people with brain damage, a Public Trustee official commented -

In severe traumatic brain damage situations, the effect on marriages can be traumatic because they are not the same people anymore. Those who can last: it's absolutely wonderful. But it's at least 75% that fail.

8. Overall comments about the existing system

THERE IS A LACK OF UNDERSTANDING

- . *The session we have just had has highlighted just the confusion and the lack of informed knowledge about the present laws and how they work. ... That discussion has shown how the system at present can be confusing even though you might have been in it and been part of it.*
- . *The law is there, but you have to be a lawyer and know double dutch and know Latin to understand it. Why can't they put it in plain simple English?*
- . *The law doesn't seem to be spelt out. We really don't know that it means and what our rights are.*
- . *There has never been a clear definition of the law in regards to mentally ill people.*
- . *There has never really been a clear definition when he came to be disabled. Maybe if this was made clear then we would avoid a lot of the problems that are arising.*
- . *We don't know what the law is and we don't know our rights.*
- . *Until this incident happened with my grandmother, I had never heard of Hugh Carter or the Intellectually Disabled Citizens Council. We knew nothing about it - we still really don't know.*

A professional working with people who have a mental or intellectual disability said -

- . *[With] some of the clients which I come in contact with - if you follow all their points -the basic thing that comes out time and time again is that they don't understand what is being said. The jargon and the literature is just way over their heads. And perhaps if that was made a lot more everyday, simple language, the professionals and the people with whom they are dealing with would be more appropriate to help them and know which way to send them, rather than have them come back time and time again to try and find out what is meant by that bit of paper. And some of the clients I see just can't be bothered after the first couple of times because they don't understand it and they don't have input into it. They can't stand up and say, "This is what I want", because they feel they don't understand the jargon.*
- . *The Act that I know best is the Mental Health Services Act which is written in fairly archaic language and is most difficult to understand. That applies to doctors who use [it] and not just clients who come under its divisions.*

Up to today I didn't know we had people [like the Legal Friend] and I mean I have worked in the community for 13 years. I work with frail aged, disabilities and I should have known about it, but I didn't.

THERE IS A LACK OF INFORMATION

- . *We need written out in black and white terms: this is what will happen, this is what might happen.*
- . *We need information regarding enduring powers of attorney and things that are really going to affect a person's lifestyle. This should be readily available through support organisations or I guess you could go on indefinitely trying to supply information and it still might not ever reach the people.*
- . *There seems to be a general lack of information getting out to people with disabilities or elderly people on what their rights are.*
- . *How do we find out about our legal options?*
- . *I have a 35 year old mentally and physically disabled son. ... I feel that there is not enough knowledge given to us about what is happening regarding what his and our rights are as parents. I have just recently heard about what happens if he needs to go to hospital. You just can't find out enough. Where are you to go to find help? I've just heard today about the [Intellectually Disabled] Citizens Council.*
- . *I think perhaps there should be a lot of parents that are frightened of the Intellectually Disabled Citizens Council and perhaps they could send out literature in more simple terms to explain some of the things.*
- . *We have another group ... operating on the power of attorney before a person becomes demented - the old type of power of attorney. So few people know about the enduring power of attorney. ... I mean, I know [the Public Trust Office] are not an advertising agency, but not many people know about this enduring power of attorney.*
- . *A lot of parents and carers of these kind of people are not advised of their rights or the rights of the people concerned. I think that is where the information part should come in.*
- . *Give us a booklet we can read to say, "What is the law"... We have to go to a hot-shot solicitor to find out where we stand with the law. Why can't we get a book?*

Commenting on the lack of knowledge held by members of the community about current legislation covering people with intellectual disability and the need for community education, **Lionel Rackley, the Chairman of the Intellectually Disabled Citizens Council** said -

It should have happened when the Council was first inaugurated in 1986. It didn't happen. In fact at that stage, the Council was told by senior officials of the Department, "Stop doing all this community education work. Too many people are getting to know about the legislation. We don't have the resources to cope with this." The Council's resources to do community education has been limited since the word go. That is why there is no point in having this sort of legislation unless it's well resourced.

LAWS ABOUT PEOPLE WITH INTELLECTUAL AND MENTAL DISABILITIES SHOULD BE PRESENTED MORE CLEARLY

- . *The Bible has been written into plain English - why can't the book of law?*
- . *I would like to make a statement/recommendation for future policy and changes and that is the adoption of plain English. ... It makes it easier for you and I to read changes in the new policies, new laws, legislation.*
- . *Legal jargon is often difficult to interpret. It needs to be fairly plainly put. Things like availability of information - it should be easily available - and education right down the line.*
- . *It is clear policy of the Attorney-General to re-write every law concerned in easy language. But what we want in the meantime is some user-friendly leaflets to tell you simply what is going on.*
- . *It's hard to interpret and it's hard to find your way around it. So it needs some way of being available, being accessible both in terminology and availability and where to go for resources and direct information. It should be available to all, not just special people.*

People affected by the present legislation said in one workshop -

- . *Another concern of mine is why is it so hard to extract information from these Acts? Why do they have to be so hard to understand? ...*
- They give three pages of definitions and then just carry on.*
- They could simplify it.*
- Maybe even examples need to be given so it is easier to know how the laws apply.*

THERE IS A LACK OF SERVICES

- . *This legislation is all good and well but the services aren't there to keep up pace with the changes - people are encouraged to go and live on their own but there is nobody there to regulate support or even counsel parents.*
- . *Apparently as the law stands now, once my child turns 18 I don't have any legal rights as a parent. Okay, that is fair enough but on the other hand they don't provide the services to give [to] those people. ... They are putting all the laws in but no action. I would dearly love my daughter to go into independent living and she could if there was the support and accommodation, but obviously there isn't the funding. So why do they have to make parents feel as if they are committing a crime?*
- . *My husband received head injuries 8 years ago and I took him out of the institution because it wasn't looking after him well. ... But all my doctor and specialist kept telling me (and I'm a trained nurse) was I can't look after him at home. ... My husband has done well. But I lived in dread for the first 6 months that someone would walk into my house and tell me I wasn't coping. I didn't have any support at all from the institution I took him out of.*
- . *I cared also for my mother this year and she died in my home. I had to do everything for her. Yet when she wanted to come out of hospital to live with me, I had to ring the Legal Friend to find out where she stood with making her own choice to come to my home or to have the rest of my family put her in a nursing home to die. And that was a great mess up. Once she got to my home and I needed the assistance to care for her, it stopped there. Everyone seemed to want to make the decision for her but no one wanted to follow up who was caring for her or how the caring was going. There were no support services for the carer.*
- . *As a parent it is assumed that even when our child turns 18 we will stay at home and look after them, but when it comes to the rights of our son then all of a sudden [he] can't go to work or anything.*
- . *Seeing the position is so bad regarding housing for people with an intellectual disability, I feel it should be legislated for. ... I'm talking as a parent only. ... There must be some way where there is a law that says that if they need assistance to find accommodation or suitable accommodation [then that can be provided]. There is a terrible lot of trouble going on with people with dementia now. There isn't enough accommodation.*

In a workshop group comprising people with a mental disability, this conversation occurred -

- . *I was feeling down and feeling psychotic and went to the PA psychiatric centre and said, "Can you admit me?" They said, "You are too sane [for us] to admit you." When I don't want to go in they want me in - when I want to go in for a rest they don't want me. ... I'm a diagnosed schizophrenic. When I get psychotic, I recognise my illness. I know when I'm likely to do danger to*

myself or anybody else. That's the point. They don't recognise that you are compis mentis enough to know when you are in a bad way.

What do you think the resolution of that is?

More beds.

Well, if I go to Royal Brisbane and say "I need help will you admit me?" and they say, "No, we have only got 1000 beds and there are 1500 people", do you think I should be able to complain to somebody about that?

I do, yes. It is a matter of finances. It boils down to how much the government can afford.

No legislation, no matter how close to the ideal it is, will succeed unless there is long term Government commitment to adequate resourcing.

(Lionel Rackley, Chairman of the Intellectually Disabled Citizens Council.)

A COMPLAINTS MECHANISM IS NEEDED TO ENSURE PROPER STANDARDS

Queensland's Parliamentary Commissioner can investigate complaints by people who are affected by the decisions or acts of officers or employees of the Public Trust Office or the Departments of Health, and Family Services and Aboriginal and Islander Affairs.⁷⁰

This means that people who believe that they have been treated unfairly, improperly or incorrectly by the Public Trustee, the Legal Friend or public servants in the Health or Family Services Department have a body to which they can have their complaint investigated.

Written complaints must normally be made by the person affected by the decision or act, but if a person for any reason is unable to make a complaint then a representative of the person may make a complaint on their behalf.⁷¹

The Commissioner need not investigate complaints that he believes to be trivial, unnecessary, frivolous or vexatious.⁷² However, most other complaints must be investigated. If the Commissioner finds at the conclusion of the investigation that the act or decision was, for instance, unlawful, discriminatory, unfair or wrong, the Commissioner can report and make recommendations to the head of the relevant Office or Department. If the head of the Office or department appears to have failed

⁷⁰ Sections 4, 12 and 13 Parliamentary Commissioner Act 1974-1988.

⁷¹ Section 16(2) Parliamentary Commissioner Act 1974-1988.

⁷² Section 17 Parliamentary Commissioner Act 1974-1988.

to have taken appropriate action within a reasonable time, the Commissioner may send the report to the Premier and have the report tabled in Parliament.⁷³

The Commissioner must confine his investigations to the public sector. His investigations focus upon an individual complaint.

Two other avenues for complaint exist under present legislation.

The Legal Friend is not explicitly given power to investigate abuse, unlawful detention or endangerment of "an intellectual disabled citizen" (for instance, a person who has had an intellectual disability since birth or early childhood, or an Alzheimer's disease sufferer). However, if he becomes aware that an intellectually disabled citizen -

- . is being held against his or her will, he can instruct a solicitor to apply for a court order commanding his or her release;⁷⁴
- . has been physically harmed, he can arrange for a police officer to take that person to a nursing home or a hospital;⁷⁵
- . may be sick or physically harmed, he can enquire about that person's health, and whether medical, surgical, or other professional treatment or care is desirable.⁷⁶

Official visitors appointed under the **Mental Health Services Act 1974-1989** provide another possible avenue for complaint. Official visitors are required to visit the training centres or psychiatric hospitals or wards to which they were appointed at least once each month. During these visits, they must inspect records containing medical recommendations and applications for the admission of regulated patients. They can also inspect, and visit residents of, the centre, hospital or ward. After each monthly visit, the official visitors must report to the relevant departmental Director.⁷⁷ They do not have power to rectify a complaint after they report.

At the public forum, a need for a specialist overseer of the system was identified - someone who would not focus on the resolution of individual complaints but who could look at institutional and departmental procedures, practices and policies and negotiate to make existing systems work better.

People affected by legislation about mental disability said -

- . *The thing that I would like, and see as being vital, is an independent point of review - an ombudsman or whatever you would like to call him.*

73 Section 24 Parliamentary Commissioner Act 1974-1988.

74 Through a writ of habeas corpus and section 26(1)(b) Intellectually Disabled Citizens Act 1985-1989.

75 Through the use of sections 26(3) and (9) Intellectually Disabled Citizens Act 1985-1989.

76 Section 26(5)(b) Intellectually Disabled Citizens Act 1985-1989.

77 Sections 13 & 14 Mental Health Services Act 1974-1989; clause 12 Mental Health Services Regulations 1985.

- . *When I was at [a psychiatric hospital] I saw many bashings out there by male nurses, for ridiculous reasons. I would like them to be subjected to the same psychiatric criteria as the subject patients are, to weed out any unsuitable elements, such as people suffering from masochistic complexes like this.*

When commenting about the Ward 10B inquiry a person with a mental disability said -

- . *People were complaining [for] about 20 years. That's terrible. 20 years! They had so many people saying that definitely, definitely something was wrong and so many people knew about it. How bad do things have to get before something is done? How many people had to die that shouldn't have died?*

Professionals working with people who have intellectual or mental disabilities said -

- . *We have something like that already for the nursing homes, because there is advocacy for the aged which has just been set up and that is there specifically to advocate for people living in nursing homes.*

But that advocacy for the aged doesn't have a statutory base and I think that what you're looking [for] is some sort of statutory base.

A broadening of the official visitors perhaps or a rethinking of the official visitors.

Or the replacement. The official visitor comes in, walks out and does nothing from the time he arrives to the time he goes out, except have a cup of tea and a sandwich.

- . *There is an enormous need, in my view, for some sort of agency to be able to do a lot of systems' change work. It just isn't happening in Queensland - there simply isn't anyone around. I think the easiest answer is to look at what the Public Advocate does in Victoria. ... I do have problems, however, with the dual role of the Public Guardian and Public Advocate. Sure, guardianship takes an advocacy role. But, at the same time, I would have thought a Public Advocate would from time to time seek to address his or her concerns at the Public Guardian role under that legislation.*

- . *I worked in a privately run hostel in Brisbane for three years. I left there on 27 November 1990. 45 residents lived there. Their living conditions are sub-standard, their furniture sub-standard. Some of the residents there are covered by the Public Trust. There are other residents there that should have a carer or someone from Psych Services to make sure that their money is being looked after properly. Some of them cannot even write and yet the people who own the place just have them sign papers. They were actually charging the residents for services which they never ever received. I did write to the local member of Parliament and Psych Services and they said the issues I raised were rectified. That was as far as it went. Nothing was done about it.*

I did get a call the other day from a man in Townsville who was in a situation where he was looking after his wife, and had been for 30 years. He reached the point where he felt he couldn't do it any longer. What he said to us was that he couldn't bear to put his wife in the local hospital because he thought that the conditions there - the hygienic conditions - were such that he wouldn't want to put her in this particular mental hospital. ... There doesn't seem to be any place where that man can go to protest about the facilities that are available where he lives.

Where I work we can write submissions which we do constantly. But you need someone who's got the authority and the status to be able to go along to the Commissioner of Police in a way quite different than I could, to say, "Listen, we need to do something about the whole process of interviewing people with disability." We need someone who can go along to other senior people within the criminal justice system and be able to negotiate at that senior level, to get some changes to happen.

By contrast, a representative of the Department of Family Services and Aboriginal and Islander Affairs said in a different workshop group -

People may not know we have working arrangements with the Police Force, assignments on how they should treat intellectual[ly] disabled people - a whole range of [things] that is never talked about.

A person working with people with an intellectual disability said -

We've got one issue in our area (Ipswich) where they are starting to put "time out" rooms in some of the houses. That is a room where they put them when they claim they have been playing up. They basically lock them in a room until they behave themselves. There are no handles on the inside of the doors. These people are all adults - mid 30's to mid 40's. The thing is that the men that rent the house are the ones paying rental, not the department, so it is their house. They are intellectually disabled people. Moderate to severe, mainly severe. They have rented the house off us. It is their house as far as the lease goes. But the support, the people who look after them, comes from the Family Services - Department of Intellectual Disability Supports. If the person is playing up a little bit and disrupting somebody they could take them for a walk. But you can't just lock someone in a room. It is very inappropriate. They are put in this small room and they have no way of getting out no matter what happens. There are no activities in there or anything. They are just locked in there on their own. It doesn't make sense because these people should have rights. I think they have taken the rights away. It has started already. They have got the room built and from what we have been led to believe, so far they haven't actually used the room, but how could we be there all the time to know whether or not they have actually used the room. The thing is that if they get one of these rooms in a house they will end up in all the houses. The thing is they say they live in the community and it is their right, yet they are taking away that right by locking them in the room.

Balance this last comment with an observation from a person working with people who have an intellectual disability -

I often find that care-givers are placed in the situation where, for one reason or another, ... they may need to restrain a person from running on a road or entering a dangerous situation. ... There is perhaps a duty of care, [placed on] a care-giver to perhaps place a physical restraint on someone with an intellectual disability. There is no law that protects that care-giver in terms of how far and what types of areas he can go into to place a restraint on that [person]. ... I can't try to get a legal friend on the phone to give me some sort of authority in order to restrain that person from doing that act.

We need ... in place when we are looking at this type of legislation, some agency, some mechanism so that the whole system, if you like, can be monitored, so that we can have someone keeping an eye on it. ... We need to give consideration to some sort of special ombudsperson or public advocate, such as exists in some other jurisdictions, who can keep an eye on the big picture, who can do systems' advocacy and perhaps who can also resource, and develop and stimulate the development of independent advocacy supports for people throughout this State.

(Jeremy Ward, Queensland Advocacy Inc.)

THERE ARE CASES OF INAPPROPRIATE INSTITUTIONALISATION

A carer of a person thought to have a mental disability said that -

The only thing I didn't like when Barry became ill - they just grabbed him and threw him in jail in a padded cell. And if it wasn't for the fact that there was some friends there that knew us we would never had known. ... But the law says they can take them from the street, put them in jail in a padded cell, until assessed, then put [them] into hospital, given very strong drugs that zonks them completely out. So they have no right to ask for help - they want to know if their family is there or what. That is something I do think has to be changed. I think the first thing that should be done is they should be given the right to make a phone call and they should contact the family immediately. Not throw them in a padded cell where he was absolutely terrified. ... He was so terrified he didn't even know anything. ... I think there should be some way they can automatically contact the families.

Other people involved with people who have intellectual disabilities said -

I have seen too many of [my] friends classified as intellectually handicapped when they weren't. They might have been physically handicapped or slow learners but they definitely weren't intellectually disabled. That girl who spoke last, she was a slow learner. She was never given the opportunity. Just shove them all into the spastic centre without any consideration to the disabled.

(This person was referring to Lyn Dommett.)

I am a founder of the Endeavour Foundation. They were formed as the Queensland Subnormal Childrens Welfare Association. When they branched out into the country they were getting a terrific lot of help of funding from the government and because of that funding the government said, "You have got to take all disabled people, particularly in the country areas." They did this because they wanted to keep their funding. Unfortunately because of that people like Lyn Dommert and hundreds of others came in. They were not really intellectually handicapped in the true sense of the word, with the result that they feel as they did, rightly, about it. But that is the problem - there are hundreds and thousands of really intellectually handicapped (what we term and what we formed it for) who are looked after all the time and they need it.

REFORM AND THE REFORM PROCESS

We need to critically evaluate whether we need to build a new bureaucracy or whether we need to, in a very dogged manner, ensure that those systems that are already in place for the community as a whole, work for the whole community, and not simply for people who are more advantaged than others.

(Ms Ruth Matchett, Director-General, Dept. of Family Services and Aboriginal & Islander Affairs)

There is no difference in philosophy I believe between what has occurred in Queensland and what has occurred in Victoria. Both legislative schemes, at the moment, seek to maximise freedom for the person with the disability.

The question for us in Queensland is, do we create new structures as Victoria, South Australia and Alberta have, or do we improve, mend, fix up, streamline the existing structures that have been developed in Queensland?

(Kevin Martin, The Public Trustee.)

Do we need to build a new bureaucracy? Legislation [is] already in place to allow people to have control of their own lives and one has to be careful that you don't have this perpetual child image - that you are protecting people too much that you don't allow them to grow and have some control over their own lives.

Now, I'm not standing up saying that the [Intellectually Disabled Citizens] Council is a wonderful thing. I'm saying it's better than what we had before, because what we had before is nothing. But we should be looking at what happens in other States and how we can make that work better for us. We all have experiences where things happen and they go wrong, and there aren't the safeguards in there to protect what we want.

Recognise that in dealing with law reform, laws have got to be written to encompass all of the people, with all of the sorts of situations and problems and difficulties that occur.

Laws, if they are going to be balanced, need to take into account the healthy situations which occur - the positive situations and the supportive situations that occur in families in the community - and the need to respect individuals. ...

For us to arrogantly say that we will invent something new or, alternatively, that we are not prepared to look and listen to what people have done elsewhere, is stupid.

(Tony Lawson, President of the Guardianship and Administration Board (Vict).)

PROGRAM

Introduction

Queensland's Attorney-General, Mr Dean Wells, will open the public forum. 10.00 - 10.05am

Existing laws in Queensland - in theory and in practice

- . Kevin Martin, the Public Trustee 10.05 - 10.15am
- . Lionel Rackley, Chairman of the 10.15 - 10.27am
- Intellectually Disabled Citizens Council
- . Hugh Carter, the Legal Friend 10.27 - 10.33am
- . Jeremy Ward, solicitor, Queensland 10.33 - 10.50am
- Advocacy Inc

Questions

10.50 - 11.00am

Problems with the existing law from the perspective of those who the law affects

- . Heather Thorne, a carer of a spouse 11.00 - 11.12am
- with brain damage
- . Noel Harris, a carer of a relative 11.12 - 11.24am
- with dementia
- . Lyn Dommett, advocacy officer with 11.24 - 11.40am
- Speak Up for Yourself
- . Comments from other participants who 11.40 - 12.00pm
- are affected by the present laws

Workshop

Participants at the forum will divide into groups and expand upon the material raised in the first two hours. The topic theme is whether existing Queensland legislation adequately deals with decisions made about the rights and needs of people with a disability.

12.00 - 1.10pm

LUNCH

1.10 - 2.30pm

Who should assist people with a disability to make decisions?

Main Forum Speaker:

Mr Tony Lawson, President, Guardianship & Administration Board (Vic) 2.30 - 3.20pm

Comment:

Mr Kevin Martin, The Public Trustee 3.20 - 3.30pm

Ms. Ruth Matchett, Director-General, Dept. of Family Services and Aboriginal and Islander Affairs 3.30 - 3.40pm

Workshop 3.45 - 4.45pm

Participants at the forum will be divided into groups and discuss their ideas about how the present laws and structures concerning decisions made about people with a disability can be improved. Discussion can focus upon ideas for the improvement of the present system or ideas for models to replace the existing system.

IDEAS FOR CHANGE 4.45 - 5pm

Our roving reporters will report back to everyone about ideas that were raised by each of the workshop groups.
