

**Submission by the Office of the Public Advocate-Queensland  
To Australian Commission on Safety and Quality in Health Care  
Draft National Patient Charter of Rights  
March 2008**

---

**Interest of the Public Advocate**

The Office of the Public Advocate was created under the *Guardianship and Administration Act 2000* to provide systemic advocacy for adult Queenslanders with a decision-making disability.<sup>1</sup> Section 209 provides that the role of the Public Advocate is to:

- *promote and protect the rights of adults with impaired capacity for a matter*
- *promote the protection of the adults from neglect, exploitation or abuse*
- *encourage the development of programs to help the adults to reach the greatest practicable degree of autonomy*
- *promote the provision of services and facilities for the adults*
- *monitor and review the delivery of services and facilities to the adults.*<sup>2</sup>

As outlined above, broadly the functions of the Office of the Public Advocate are to protect and promote the rights and interests of adults who have impaired decision-making capacity (IDMC). This cohort includes people with mental illness, intellectual disability, acquired brain injury and dementia. The Office makes this submission to the Australian Commission on Safety and Quality in Health Care (ACSQHC) to promote and protect the rights and interests of these adults.

**General comments about the Draft National Patient Charter of Rights (the Draft Charter)**

The Office of the Public Advocate supports the development, implementation and monitoring of a National Patient Charter of Rights. As a general observation, it is considered that the Draft Charter adopts an appropriate tone. Some suggestions are made below for improving the suitability of the Draft Charter and Principles for adults with IDMC.

It is suggested that the Draft Charter does not sufficiently cater for health service users who have IDMC. A significant proportion of the population is comprised of people living with mental illness (approximately one in five Australians will have a mental illness during their lifetime), dementia (increasing along with the ageing population), acquired brain injury, and with intellectual disability (people in this cohort are now living longer than in previous generations) some of whom will have IDMC for at least some health care decisions from time to time. Accordingly, people with IDMC comprise a significant portion of the client base of health service providers. It is suggested that the Draft Charter should recognise this reality. This could be achieved in the overarching statements made in the preamble to the Rights.

---

<sup>1</sup> *Guardianship and Administration Act 2000* (Qld), Chapter 9.

<sup>2</sup> *Guardianship and Administration Act 2000* (Qld), s 209.

Specific comments are made about the articulated Rights and Principles and the explanatory comments in respect of each. References are made to Queensland legislation: each state and territory has its own arrangements. The numbering and headings in the Draft Charter are adopted in this submission for ease of reference. Accordingly, each is not repeated in full and the Draft Charter and this submission must be read together.

## **Patient Rights and the Explanation of Each Right**

### **1. Access**

Complex and subjective judgments are regularly made by health service providers about distribution of treatments which are in limited supply and in respect of which access is therefore limited. Notions of distributive justice are relevant. According to the Draft Charter, such treatments should be distributed according to clinical need. Given that in some cases, the need allocated will mean the difference between life and death, the issues are serious indeed.

Unfortunately, not uncommonly, people with disability and especially IDMC have reported/experienced subjective judgments of health professionals and others, that their lives are not worth living because of their disability. Quality of life judgments are made by health professionals to inform decisions about who receives scarce treatments and who does not. People with IDMC are often unable to complain if they are disadvantaged in such processes and the consequences may be dire. This may be so despite the person with IDMC living a good quality of life. It may be difficult for health professionals with little understanding or experience of the lives of people with disability to understand that quality of life is not necessarily dependent on intellectual and/or physical prowess.

Accordingly, it is suggested that the Draft Code be amended to clarify that people with IDMC are not to be disadvantaged when resource distribution is considered.

### **2. Respect**

It is undoubtedly the case that the most effective way for patients and health providers to interact is in a spirit of cooperation and mutual respect. However, adults with IDMC sometimes behave in a way that may appear disrespectful as a result of their impairment. Health service providers should be well placed to recognise their limited ability to comply with a requirement for mutual respect and consideration. Nevertheless, anecdotally, it appears that this is often not so.

To be useful, the Draft Code must articulate clearly an understanding that people with IDMC are in a different position and cannot be expected to comply with such requirements when their capacity does not allow them to do so. Health service providers must understand and acknowledge that this is so and services must cater for the needs of this group, who by virtue of their conditions causing IDMC (which often also predispose the person to other conditions) may require more regular health care than many members of the general population who do not have IDMC.

### **3. Safety**

No comments.

#### 4. Communication

To be useful, and able to be acted upon by patients, communication must occur and information must be presented in a format which the patient can understand and is appropriate given the characteristics of the particular patient. For many people with IDMC, some conventional approaches to communication and provision of information will be of limited use and could not be considered meaningful communication to the health service user. There must be some reasonable adjustment to information provision made in practical terms. This must be recognised and provided for generally in the Draft Charter as a responsibility of the health service provider. Language per se is not the only issue.

Anecdotally, it seems clear that health service providers are not infrequently unable, presumably due to inadequate professional training and/or interpersonal skills, to communicate in a meaningful way with adults with IDMC. Rectifying this system deficiency probably requires at least significant changes to tertiary curricula and continuing education programs which are outside of the ambit of the Draft Charter. Nevertheless, it is worthwhile establishing standards about appropriate communication within it, for the benefit of both health service users and providers.

#### 5. Information

Again, information must be provided in a format and style which is useful and appropriate given the characteristics of the health service user, including health service users with IDMC. Information may be given for different purposes. It is necessary to inform decision-making by a health service user. In the case of a person with IDMC, this may not be the health service user personally- a guardian, enduring attorney for health matter or a statutory health attorney may be the decision-maker. Comments made below (in respect of the right of participation) about the nature and extent of the information which must be given are relevant.

When information is provided to the decision-maker to inform the health care decision-making process, the actual patient must nevertheless be prepared for the procedure to be undertaken, so meaningful and respectful communication and provision of information to the actual patient remains essential. There would be limited usefulness in providing a highly technical explanation in medical terminology of, for example, a proposed complex surgical procedure to a person with significant cognitive impairment. The manner and format of the communication should be respectful of the health service users' characteristics.

#### 6. Participation

The right to autonomy or self-determination is fundamental to health law.<sup>3</sup> At common law, a patient who has capacity may refuse treatment, even life-saving

---

<sup>3</sup> *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1, 72 E; *Airedale NHS Trust v. Bland* [1993] AC 789, 864C; *Re A (Children)* [2000] Lloyd's Rep. Med 425, 494. See also discussion about the history of development of autonomy as a central idea in medical law, for example, in Derek Morgan and Kenneth Veitch, *Being Ms B:B, Autonomy and the Nature of Legal Regulation* [2004] Syd. L Rev 6 <http://www.austlii.edu.au/cgi-bin/disp.pl/au/journals/SydLRev/2004/6.html/query=gaa>.

treatment.<sup>4</sup> A patient with IDMC has the same right.<sup>5</sup> Under Queensland law, there is some limited statutory provision for health care to be provided without consent; for example, under the *Mental Health Act 2000*<sup>6</sup> and the *Guardianship and Administration Act 2000*.<sup>7</sup> Under the common law, an exception to the requirement for consent exists in the case of necessity.<sup>8</sup> There is doubt that the common law with respect to exception/s applies in Queensland.<sup>9</sup>

Accordingly, the drafting of the ‘right’ to participate in decision-making as articulated in the Draft Code appears misleading. More properly, in most instances health service users have the right to accept or refuse health care (rather than a right to participate in the decisions and choices about care).

The reference in the explanation of the right to participation to informed consent is noted. The intention may be to convey to health service users the need to consider material information when making decisions about whether to accept or refuse health care. The level of sophistication of an individual patients understanding of their health situation will no doubt impact on the information they require to make the decision, but an appropriate level of information must be given by the health service provider to every patient about proposed health care.<sup>10</sup>

---

<sup>4</sup> Patients who have capacity decide for themselves whether to accept or refuse recommended medical treatment, not their doctors. The right of a person with capacity to refuse treatment has been recognized in a variety of jurisdictions including the United States (*Schloendorff v. Society of New York Hospital* 105 NE 92 (NY) 1914)), Canada (*Nancy B v. Hotel-Dieu de Quebec* (1992) 86 DLR (4<sup>th</sup>) 385; *Ciarlariello v. Schactr* (1993) 100 DLR (4<sup>th</sup>) 609 (SCC); *Malette v. Schulman* (1990) 67 DLR (4<sup>th</sup>) 321), New Zealand (s. 11 Bill of Rights; *Re G* [1997] 2 NZLR 201; *Auckland Area Health Board v. Attorney General* [1993] 1 NZLR 235); and the United Kingdom (*Re B (Adult refusal of medical treatment)* [2002] 2 All ER 449; *Re C (Adult refusal of medical treatment)* [1994] 1 All ER 81; *Airedale NHS Trust v. Bland* [1993] AC 789; *Re T (Adult: refusal of medical treatment)* [1992] 3 WLR 782. In Australia, there has been scant judicial confirmation of the common law position. However, it appears to have been implicitly accepted by the High Court in *Secretary, Department of Health and Family Services v. JWB and SMB (1992) 106 ALR 385* (‘*Marion’s Case*’) 390,392 (where the majority endorsed the principle of bodily inviolability) and by the Queensland Supreme Court in *Re Bridges* [2001] Qd R 574. Ambrose J (when declaring that an adult did not have capacity to make decisions about health matters,) appears to have accepted a common law right to refuse treatment.

<sup>5</sup> *Airedale NHS Trust v. Bland* [1993] AC 789. Lord Goff quoted with approval *Superintendent of Belchertown State School v Saikerwicz*<sup>5</sup> [1977] 370 NE 2d 417, 428 in which the Supreme Court of Massachusetts said:

To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person by placing a lesser value on his intrinsic human worth and vitality.

<sup>6</sup> This legislation provides for the treatment of people meeting the requirements of the Act without consent: *Mental Health Act 2000* s 517.

<sup>7</sup> See ss 62-64 in respect of urgent and minor or uncontroversial health care.

<sup>8</sup> *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1. Some academics argue that the common law also provides for exceptions in respect of other circumstances, for example, Loane Skene *Law and Medical Practice: Rights, Duties Claims and Defences* 93-97; 115-116.

<sup>9</sup> *Guardianship and Administration Act 2000* prescribes an offence for giving health care to an adult with IDMC other than as provided for in that Act: s79.

<sup>10</sup> *Rogers v Whittaker* [1992] HCA 58.

There are two separate legal concepts which appear relevant in respect of this articulated right and the explanatory comments. Firstly, a valid consent must be obtained or giving of health care will potentially represent a trespass to the person, for which there may be civil and criminal law consequences.<sup>11</sup> To be valid, as discussed earlier the person must have capacity to give it. It must also be voluntary<sup>12</sup> and must cover the procedure undertaken.<sup>13</sup> However, even though a consent may be valid, if insufficient information is provided to the patient about the material risks, the patient may have an action against the health care provider in negligence in the event of an adverse event.<sup>14</sup>

In respect of negligence actions in the leading case of *Rogers v Whittaker*<sup>15</sup>, the High Court of Australia said

*15. ...Anglo-Australian law has rightly taken the view that an allegation that the risks inherent in a medical procedure have not been disclosed to the patient can only found an action in negligence and not in trespass; the consent necessary to negate the offence of battery is satisfied by the patient being advised in broad terms of the nature of the procedure to be performed ((37) Chatterton v. Gerson (1981) QB, at p 443). In Reibl v. Hughes the Supreme Court of Canada was cautious in its use of the term "informed consent" ((38) (1980) 114 DLR (3d), at pp 8-11).*

*16. We agree that the factors referred to in F v. R. by King C.J. ((39) (1983) 33 SASR, at pp 192-193) must all be considered by a medical practitioner in deciding whether to disclose or advise of some risk in a proposed procedure. The law should recognize that a doctor has a duty to warn a patient of a material risk inherent in the proposed treatment; a risk is material if, in the circumstances of the particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it.<sup>16</sup> This duty is subject to the therapeutic privilege.<sup>17</sup>*

Health service users cannot be expected to know what is meant by an alleged requirement on them to give *informed consent*. The health service provider must provide the material information to the health service user, to place the user in a position to give informed consent. Unless the explanation refers to the relevant

---

<sup>11</sup> *Department of Health and Community Services (NT) v JWB (Marion's Case)* (1992) 175 CLR 218 at 232.

<sup>12</sup> For example, see *Norberg v Wynrib* (1992) 92 DLR (4<sup>th</sup>) 449 (Can SC); *Appleton v Garrett* (1997) 8 Med LR 75.

<sup>13</sup> For example, it is suggested that consent to a hysterectomy for endometriosis would not constitute consent to an abortion. See for example, *Rogers v Whittaker* [1992] HCA 58

<sup>14</sup> *Rogers v Whittaker* [1992] HCA 58.

<sup>15</sup> *Rogers v Whittaker* [1992] HCA 58.

<sup>16</sup> Emphasis added.

<sup>17</sup> [1992] HCA 58 [15-16].

requirements, they will generally not understand what is meant. Also, it is to the benefit of health service providers to be clear about their obligations. These comments are also relevant to the right to information and the explanation about the information which must be given.

In Queensland, when a health service user has IDMC for the health matter under consideration (unless limited exceptions apply),<sup>18</sup> a health service user must seek the consent for the health care from the appropriate SDM. It is an offence to give health care to an adult with IDMC without authorisation.<sup>19</sup> Most commonly, authorisation will be required to be obtained through consent. The Draft Charter does not appear to recognise these realities. It is suggested that a broad overarching statement could be added: perhaps, to the preamble to the rights which acknowledges the special position of people with IDMC, in the same way that reference is made to cultural and social diversity.

## 7. Privacy

Unfortunately, anecdotal reports suggest that privacy requirements are frequently cited as a reason not to provide information to guardians and other substitute decision-makers who are the formally empowered decision-makers for an adult with IDMC, even though they can produce documentation confirming their appointment and who have a legislative right to obtain the information.<sup>20</sup> In respect of statutory health attorneys who can make most health care decisions for adults with IDMC in Queensland and whose appointment occurs by operation of law (as opposed to appointment by a tribunal or under an enduring power of attorney),<sup>21</sup> this issue may be exacerbated.

It would be proper to recognise the need for information to be given to substitute decision-makers.

## 8. Redress

The comments made earlier about information provision are relevant. To be an effective mechanism for people with IDMC, complaints processes must facilitate and support the person and their support network (if they have one) through the process. Without such an approach, the 'right' articulated is meaningless for this vulnerable group of people who will effectively be precluded from accessing and navigating the process. Once again, it is suggested that the Draft Charter should specifically acknowledge and provide for this vulnerable group.

## **National Patient Charter Principles**

Again, It is suggested that people with IDMC and the role of substitute decision-makers should be recognised in the preamble.

---

<sup>18</sup> For example, see *Guardianship and Administration Act 2000* ss 62-64 in respect of urgent or minor and uncontroversial treatment; and *Mental Health Act 2000* s 517.

<sup>19</sup> *Guardianship and Administration Act 2000* (Qld) s 79.

<sup>20</sup> See for example, *Guardianship and Administration Act 2000* (Qld) s 44.

<sup>21</sup> *Powers of Attorney Act 1998* (Qld) ss62-63, 75, 81.

The comments made above in respect of each of the articulated rights are again relevant. The following additional comments are also made about the Principles.

1. Access

Programs for promoting health and preventative screening are often not well used by people with IDMC. They are reliant upon others to access the services. Unlike people with capacity, advising them of the existence of the service, providing them with a brochure, or relying upon advertising of the programs will usually be inadequate as a means of facilitating access. Proactive responses from health professionals (and of course, others who support the adults) will likely facilitate greater take-up rates. It is suggested that support to access public health programs appropriate to meet the needs of adults with IDMC is another principle which the Draft Charter could adopt.

2. Respect

As noted, people with IDMC may not, and may not be always able to, accord respect dignity and consideration to their health care providers in the usual manner. This should not affect the regard a health care provider shows the patient, or affect the provision of appropriate care and treatment.

3. Safety

No comments.

4. Communication

In keeping with comments made above, information should be provided, not only in a language that is understood, but in a manner that is meaningful and can be understood (of course, it is acknowledged that there are different levels of understanding) having regard to the characteristics of the recipient, including adults with IDMC.

5. Information

Again, the role of substitute decision-makers for adults with IDMC could be usefully acknowledged. The role, as discussed above, is fundamentally different from the role played by support persons.

The expectation that adults with IDMC will follow plans ‘as agreed with the health care provider’ will, at least sometimes, be unrealistic, unless adequate support is available or provided to the adult. The Principles could usefully alert health care providers to this and provide for such support as may be available through the public health system to be made available.

6. Participation

Please note again the comments above about the right to accept (consent) or refuse health care and material information which will inform decision-making. It is suggested that some amendments are required to the current wording to reflect this position.

Also, it is again suggested that the role of substitute decision-makers should be specifically acknowledged. They have a different role to play than ‘family, carers or

other nominated support people.’ A person with capacity may well have support people, as will adults with IDMC. The same people will not necessarily be substitute decision-makers (although sometimes they will be).

#### 7. Privacy

Please note comments above. It is suggested some rewording is required to adequately address the requirement for information to be made available in appropriate circumstances to substitute decision-makers.

#### 8. Redress

As discussed above, it is suggested that the principles should include provision of support for vulnerable adults if it is to be a meaningful right for adults with IDMC.

### **Rights and Responsibilities**

It is suggested that in most respects (comments have been made specifically above where considered not so) an appropriate balance between roles, rights and responsibilities is struck by the Draft Charter. No greater emphasis on patient responsibilities is warranted. Where greater responsibilities of patients are articulated (in other codes), it is sometimes suggested that health service provision is contingent on the health service user fulfilling their responsibilities. There are often no existing legal obligations on patients in accordance with so-called responsibilities. The approach has no legal basis.

It is of particular concern when the articulated responsibilities may be such that vulnerable people with IDMC may not be able to understand that there is a responsibility, and yet may be at risk of being refused service because they cannot comply. By virtue of psychotic or manic symptoms, intellectual disability, dementia or traumatic brain injury, a person may behave in ways that are undesirable and difficult to manage. In a person with intellectual disability, aggression may be a means of communicating extreme pain. In a person with mental illness it may be a result of symptoms of psychosis. A person in such circumstances is not less deserving of appropriate health care, than someone who has read and complied with a Code of expected behaviour.

In such circumstances, substitute decision-makers and support people do not have a role or the power to ensure the responsibilities is met (notwithstanding that support people may use their best endeavours to achieve compliance). To be useful, the Draft Charter must articulate clearly an understanding that people with IDMC cannot be expected to comply with such requirements when their capacity does not allow them to do so. Health service providers must understand that this is so and services must cater for the needs of this group, who by virtue of their conditions causing IDMC (which often also predispose the person to other conditions) may require more regular health care than many members of the general population who do not have IDMC.

It would be of significant concern that the Draft Code could apparently act to provide a basis for health service staff to deny or delay treatment to a person in dire need of it.

## **Existing Charters**

Charters within Australia should support and be consistent with any National Charter. Otherwise, confusion will occur.

## **Possible Uses of the Charter**

Good policy is often not translated into practice on the ground. A Charter, no matter how appropriate, which is not implemented will have no impact on service delivery within the health system and therefore be of no benefit. Accordingly, implementation is key.

Implementation must be driven from the highest level. With respect to public health services, ideally, all Health Ministers would agree upon a National Patient Charter of Rights and undertake to implement it in their state or territory through development of consistent policy and practice. Then to ensure implementation, arrangements can be made for each health area manager and district manager (or equivalent) to assume responsibility for implementation and independent audits can be undertaken to assess implementation and drive continuous improvement. In respect of the private sector, responsibility for implementation will be more fragmented. Legislative amendment would be required to mandate adoption of the Charter and an auditing process with respect to compliance. Non-compliance could affect on-going accreditation and/or funding arrangements.

The Charter could inform/underpin national standards of service delivery.

## **How the charter applies in different sectors and settings**

Adaptation to meet the specific setting should be possible provided the guidance given by the Charter is sound and detailed sufficiently. However, if there is too much detail in the Charter, it will not be user friendly.

It is suggested that the Charter should properly be the document from which other policy work can flow, to provide additional guidance in respect of specific issues.