

**STANDING COMMITTEE ON SOCIAL ISSUES**  
**Inquiry into substitute decision-making for people lacking capacity**

**QUESTIONS ON NOTICE**  
**(Remaining from questions sent pre-hearing)**

**Intellectual Disability Rights Service**  
Submission 3

**Trustee and Guardian functions**

1. In your submission to this inquiry you suggest that the former Office of the Protective Commissioner was so poorly funded it could not comply with certain human rights principles, including the presumption that an adult has capacity in a certain area and that all persons have the same human rights regardless of capacity.<sup>1</sup> Can you elaborate on how the Office of the Protective Commissioner was not able to comply with these principles?

**IDRS:** Based on our clients' complaints (listed below) it is clear in many cases the OPC could not meet the principles of the Act, in particular section 4(d) that *the views of such persons in relation to the exercise of those functions should be taken into consideration*.

Common complaints include:

- use of 'client service teams' leading to no particular person being responsible or accountable for any particular client, for clients with intellectual disability this makes communication very unsatisfactory
- inconsistent service delivery and information to clients which understandably leads to incredible levels of stress and frustration for those clients;
- slow (to no) responses to requests from clients;
- bills not being paid;
- slow decision-making;
- an unwillingness to spend the time needed to understand the needs, changing circumstances and idiosyncrasies of clients;
- a lack of individualised service to the needs and wishes of each client;
- clients being left for extensive periods of time 'on hold' when they telephone the offices and being forced to leave voicemail messages that do not get returned or answered, and
- concerning cynical and pejorative attitudes displayed by some of the staff in

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<sup>1</sup> Submission 3, Intellectual Disability and Rights Service, p 4

these offices to their clients and to disability generally.

IDRS finds that it is rare that a the people with intellectual disability who contact us with complaints about the Office of the Protective Commissioner (now Public Trustee) have had their views sought in a meaningful way.

2. In your submission you propose that one of the guiding principles in the area of substitute decision-making should be that “the wishes, opinions and choices of the person must always be sought and considered.”<sup>2</sup> In your experience, what are the circumstances in which this has not occurred?

**IDRS:** This is primarily based on the concerns and complaints noted above in relation to financial management by the OPC/NSW Trustee. Due to a lack of resources/staff/etc few, if any, clients under the financial management of the OPC have individualised financial plans and budgets developed with them and specifically tailored to their lifestyle needs and aspirations. Few clients have regular direct personal contact with staff, and for those reasons it is not possible for the OPC to really know if the person’s assets are being used for their benefit or in their best interests, let alone genuinely taking into account the person’s views for financial decisions made or refused.

### **Tribunal processes**

3. In your submission to this inquiry you refer to factors the Guardianship Tribunal takes into account when considering whether to make a financial management order in respect of a person. You state that the ‘test for a person to be drawn under a financial management order is much less onerous than the test that needs to be satisfied by a person to get out of a financial management order...’<sup>3</sup> Could you explain in more detail what you mean by this statement?

**IDRS:** in our view the ‘test’ a person needs to satisfy for revocation of a financial management order under section 25P of the NSW Act (and the evidence they need to present) is too onerous, particularly when compared to the ‘test’ needed to be satisfied to put the person under the financial management order in the first place. This should not be the case. Sub-section 25P(2) of the NSW Act says that the Guardianship Tribunal may revoke a financial management order only if:

- a) it is satisfied that the protected person is capable of managing his or her affairs, or
- b) it considers that it is in the best interests of the protected person that the order be revoked (even though it is not satisfied that the protected person is capable of managing his or her affairs)

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<sup>2</sup> Submission 3, Intellectual Disability and Rights Service, p 4

<sup>3</sup> Submission 3, Intellectual Disability and Rights Service, p 11

It is starkly unfair that there is no alternative limb in this test allowing the applicant to argue there is no longer a 'need' for their affairs to be managed by another person, even though there is a 'need' limb in the test to determine whether that person should have been under the financial management order in the first place. In other words, in New South Wales, it is easier to be put under a financial management order than it is to be removed from one. It is submitted that section 25P(2) should include a 'no longer needs' alternative limb, with wording like:

- c) it is satisfied that there is no longer a need for another person to manage the affairs (currently under management) on the person's behalf.

These lopsided entry and exit 'tests' may also arise in other jurisdictions. Also, given the complexity of properly preparing and making revocation applications, there is a need for applicants to be offered the assistance of legal support and, where necessary, legal representation. While we acknowledge this often happens in practice, The Act should include a positive duty on the tribunal to appoint a legal representative to assist a person applying for revocation of a financial management order.

4. In your submission to this inquiry you raise some concerns about the factors the Guardianship Tribunal considers when deciding whether a person is in need of a Guardian.<sup>4</sup> You recommend that the Tribunal should consider whether or not all "informal arrangement" for supported decision-making for the person have been considered and exhausted. Could you elaborate on this and give some examples?

**IDRS:** In the experience of IDRS the Guardianship Tribunal generally does consider the possibility of informal supported decision making in deciding whether or not a guardianship order should be made. However, it would be preferable if the Act included a Principle to this effect in S4.

IDRS considers that the multi disciplinary nature of the Guardianship Tribunal in NSW is an important factor which equips the NSW Tribunal to fully consider this issue in determining whether a guardianship order should be made.

### ***Public Guardian functions***

5. The Public Guardian has recommended that section 21A of the *Guardianship Act 1987*, allowing the Public Guardian to authorise members of the NSW Police Force to move a person under a guardianship order from one place of residence to another, be amended to specify that the Police may use "all reasonable force."<sup>5</sup> Can you comment on this proposal?

**IDRS:** IDRS acknowledges that it may be necessary in some situations for the Public Guardian to authorise police to use some force to move a person under guardianship

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<sup>4</sup> Submission 3, Intellectual Disability and Rights Service, p 10

<sup>5</sup> Submission 7, Office of the Public Guardian, p 19

from one place to another. IDRS has no objections to this being made express in the legislation. It is essential that this power is only given to a guardian to be used as a last resort and where the circumstances warrant this action for the person's safety.

6. The Public Guardian has recommended that the *Guardianship Act 1987* be amended to allow the Public Guardian to pro-actively investigate matters where it becomes aware a vulnerable person may be in need of a guardian.<sup>6</sup> Can you comment on this proposal?

**IDRS:** IDRS supports this power being added and made express in the Act. IDRS would suggest the power could also be utilised where there is no one else willing or available to raise, make an application or to otherwise investigate a vulnerable person's situation.

7. The Public Guardian has recommended the *Guardianship Act 1987* be amended to allow the Public Guardian to assist people with decision-making disabilities without the need for a guardianship order.<sup>7</sup> Can you please comment on this proposal?

**IDRS:** IDRS does not understand entirely what is contemplated here and in what circumstances the Public Guardian might become involved in assisting without the need for a guardianship order. IDRS is wary of adding a bureaucratic layer of formality to informal arrangements.

If the proposal aims to assist or support people with disability in decision making and advocating to meet their needs, IDRS believes that extending funding to more community based disability advocacy providers is likely to be a more effective way to achieve good outcomes for people with intellectual disability. Disability Advocacy Organisations are undertaking this role daily but most have long waiting lists and in some areas there is no advocacy available at all. The Disability Advocacy sector would require additional funding in order to meet the demand in this area.

The expertise of the Office of the Public Guardian is necessarily on decision making on behalf of people under guardianship, based on consultation with the person. Community based advocacy services are more accessible, skilled and philosophically committed to standing beside clients to assist them in decision

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<sup>6</sup> Submission 7, Office of the Public Guardian, p 14

<sup>7</sup> Submission 7, Office of the Public Guardian, p 13

making and achieving the assistance they need. Perhaps there is a role for the OPG to help out to advocate for broader options and systemic outcomes – this role could also be fulfilled by the creation of an Office of the Public Advocate.

If it is proposed that the Public Guardian have the role of making decisions on behalf of people who do not have capacity to manage their own life decisions without a guardianship order, IDRS would have some concern and believes this role is best carried out within the context of a guardianship order where the authority of the guardian is defined and the order is subject to review.

## **Records**

8. In your submission you recommend that “records must always be kept about supported and substitute decision-making arrangements...”<sup>8</sup> What are the circumstances in which records are not kept? In these circumstances, what information are you proposing should be kept?

**IDRS:** IDRS does not see this as a big problem, although it is one that is difficult for our centre to measure or audit. We would see records as most important for financial management arrangements; and both for formal and informal arrangements. Records of conversations/views of the protected person and any relevant support people/family should be kept, along with records of transactions. Private managers are already audited on their records under the legislation.

## **United Nations Convention on the Rights of Persons with Disabilities**

9. In your submission you state that Australia’s ratification of the United Nations Convention on the Rights of Persons with Disabilities and adoption of its Optional Protocol indicate recognition in Australia of the rights of persons with a disability to “freedom to choose their residence, on an equal basis with others.”<sup>9</sup> Do you see any potential for conflict between this right and guardianship orders, given the Public Guardian’s power to authorise members of NSW Police to move a person under a guardianship order from one residence to another? If so, how might such a conflict be resolved?

**IDRS:** IDRS acknowledges that ‘rights’ will sometimes conflict with one another. This has occurred with other human rights instruments and can be seen with

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<sup>8</sup> Submission 3, Intellectual Disability and Rights Service, p 5

<sup>9</sup> Submission 3, Intellectual Disability and Rights Service, p 6

examples like: a taxi driver of a particular religion refusing a blind person to travel in their taxi with a Guide Dog.

IDRS acknowledges that there will be times (emergencies, last resort) when Police will need to move a person from one place to another against their wishes in order to protect the person even when it is against their wishes. In some cases to neglect to take such action may conflict with the person's right to be free from abuse or to live in a safe environment.

Once you acknowledge this, then you acknowledge the right to determine where one resides or to be in a particular place is not an absolute right in all situations. IDRS sees conflicts of rights as a reality but submits that the protections below be in place to ensure conflicts are genuine and fairly dealt with. Intervention, especially authorising the police to intervene, should be:

- the least intrusive measure as possible
- exercised with sensitivity and maintaining the dignity of the person
- exercised with consideration of all possible alternatives and, if a decision has to be made against a person's wishes, done so as a last resort and/or only to protect a person's health/wellbeing
- recorded in official records
- subject to judicial review and/or appeal

**From questions to all witnesses:**

***Assisted/Supported decision-making versus substitute decision-making***

1. In relation to 'assisted' decision-making as opposed to 'substitute' decision-making, there is a question as to whether an assisted decision-maker would make decisions that they (the assisted decision-maker) thought were right, or that were the wishes of the person being assisted. The second of these alternatives is sometimes referred to as respecting the person's right to make bad decisions.

- Can you comment on this issue?

**IDRS:** IDRS sees (informal) assisted decision-making as the person ultimately making the decision themselves – after consultation; advice; etc. This should be the goal for all people with disability. For a person with intellectual disability capacity will vary depending on the complexity of the decision and the support available to them.

The other form of informal decision-making (where a person does not have capacity) is informal substitute decision-making – for example, where a service provider contacts a person's parent to see whether it is okay for the person to go on a holiday. IDRS acknowledges that informal substitute decision-making occurs and needs to occur. The Guardianship Act should and generally does have the function of providing for a formal decision maker to be appointed if anyone, including the person, has concern that the informal decisions being made are not in the interests of the person or if decisions are being forced upon the person with any coercion.

Assisted decision-making is always at the discretion of the person assisting and how much 'assistance' is given/enforced as part of the decision-making process.

To the extent that a decision does not immediately and significantly physically, psychologically or financially harm the person or another person, then a 'bad' decision should be respected – assuming this occurs after significant consultation; being satisfied that the person has an understanding of consequences, etc - so long as the person can see the alternatives and weigh up the consequences of the decision they make.

Enabling assisted decision making also requires that those working with or assisting the person then work flexibly and co-operatively with the person to minimise any risks associated with their decision. For example, if a person chooses to travel independently to work understanding there are some potential risks and against the recommendation of others, then all effort should be made to accommodate the decision and to reduce the perceived risks rather than waiting for the person to fail.

- If legislation providing for assisted decision-making were to be introduced in NSW how do think it should address this issue?

**IDRS:** IDRS does not see a need to legislate in relation to assisted decision making. If it were, IDRS would submit it should not be overly prescriptive and should not create a whole new level of bureaucracy that would delay and frustrate decisions being made for people with disability. Such legislation should only deal with instances where there is an issue as to whether the person does have capacity to make their own decisions **and** where there is an issue as to whether the assisted decision making is counter to the person's interests and welfare.

General Principle 9 in Schedule 1, Part 1 of the *Guardianship and Administration Act 2000* (Qld) provides some useful principle-based guidelines on this topic.

## **9 Maximum participation, minimal limitations and substitute judgment**

- (1) A person's right to participate, to the greatest extent practicable, in decisions affecting the person's life, including the development of policies, programs and services for people with decision-making disability for a matter, must be recognised and taken into account.
- (2) Also, the importance of preserving, to the greatest extent practicable, a person's right to make his or her own decisions must be taken into account.
- (3) So, for example –
  - (a) the person must be given any necessary support, and access to information, to enable the person to participate in decisions affecting the person's life; and
  - (b) to the greatest extent practicable, for exercising power for a matter for the person, the person's views and wishes are to be sought and taken into account; and
  - (c) a person or other entity in performing a function or exercising a power on that person's behalf must do so in the way least restrictive of the person's rights.
- (4) Also, the principle of substitute judgment must be used so that if, from the person's previous actions, it is reasonably practicable to work out what the person's views and wishes would be, a person or other entity in performing a function or exercising a power on that person's behalf must take into account what the person or other entity considers would be the person's views and wishes.
- (5) However, a person or other entity in performing a function or exercising a power on behalf of the person must do so in a way consistent with the person's proper care and protection.
- (6) Views and wishes may be expressed orally, in writing or in another way, including, for example, by conduct.

The other concern with assisted and substituted decision-making is to ensure others do not impose their own opinions, morals, religious beliefs, etc on decisions being made with or for a person with disability. Just because a person does not agree with



the decisions another person is making on moral, religious, political or opinion-based grounds, this should not prevent the latter person making a decision and being supported in so doing. If a person wants to spend their money on sex services on a weekly basis or they want to have a certain boyfriend or girlfriend, they should be entitled to do so. IDRS has been contacted by parents of adult children with intellectual disability, saying they want to gain guardianship to stop their children associating with a person or spending their money on sex services.

Subsection 91(1) of the *Powers of Attorney Act 2006* (ACT) lists things that alone do not indicate impaired decision-making capacity and these are the sorts of things IDRS submits should not be influencing assisted decision-making – that “the person (a) is eccentric; (b) makes unwise decisions; (c) does or does not express a particular political or religious opinion; (d) has a particular sexual orientation or expresses a particular sexual preference; (e) engages in or engaged in illegal or immoral conduct; or, (f) takes or has taken drugs, including alcohol.”

## Capacity

2. It has been suggested to the Committee that decision-making capacity should be regarded as a spectrum with complete autonomy at one end and substitute decision-making at the other.<sup>10</sup>

- Who do you believe is qualified to assess where on this spectrum a person may be and what information is required in order to make this assessment?

**IDRS:** Whether a person has capacity is best assessed by people who know the person – for example, family, friends, advocates, psychologists and doctors. Capacity is not determined solely on a medical assessment or report. Medical assessments and reports from general practitioners and specialists will play a part and should be sought, but they should not be considered the sole determinant of whether a person has capacity or not.

- In practice, how could substitute decision-making arrangements be constructed to accommodate the fact that a person’s capacity may vary from time to time and situation to situation?

The simplest answer to this is that which (in principle) should be occurring under the present regime based on the Principles of the Guardianship Act– that is, that the capacity of a person to make a decision and the views of that person needing to make the decision should be considered and assessed as each new decision arises. There should be no presumption that a person with decision-making disability does not have legal capacity to make decisions about their lives or to look after their own affairs. To do so may offend against Federal and State disability discrimination laws. Sometimes some people with decision-making disability need help and support, on an informal or formal basis, to make some decisions in their lives. The ‘some’ adjectival qualifier here is the essence of ensuring a fair and meaningful supported and substitute decision-making system.

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<sup>10</sup> Submission 3, Intellectual Disability and Rights Service, p 3

### ***Public Advocate***

3. It has been proposed that an office of the Public Advocate be established in NSW to promote and protect the interests of people with disabilities, such as exists in some other Australian jurisdictions.

- Could you comment on this proposal

**IDRS:** IDRS strongly supports the proposal for a Public Advocate in NSW to provide valuable systemic advocacy for issues affecting people with decision-making disabilities for example, claims of systemic inadequate care or abuse in services, policies in relation to managing people with challenging behaviour. IDRS does not believe a Public Advocate's resources are best used by pursuing individual cases. Community based advocates who are able to know the person as an individual are better equipped for the individual advocacy role. Of course, more funding for these organisations would enhance this capacity.

There should be statutorily-based public advocate as exists in South Australia, Western Australia, the Australian Capital Territory, Victoria and Queensland to act as an independent and powerful voice for vulnerable people with disability. The public advocate could scrutinise and take action to promote and protect the rights of persons under guardianship and financial management.

The functions of the Public Advocate in Queensland described in the Guardianship and Administration Act are worthy of consideration:

- Promoting and protecting the rights of adults with impaired decision making
- Promoting the protection of the adults from neglect, exploitation or abuse
- Encouraging the development of programs that foster and maximise the adults autonomy
- Promoting services and facility provision
- Monitoring and reviewing service facility delivery
- From your knowledge of the role such an office would perform, how would such an advocate interact with existing entities in NSW such as the Guardianship Tribunal, the Mental Health Review Tribunal, the NSW Trustee and Guardian, the Public Guardian and the NSW Ombudsman?

**IDRS:** IDRS is not entirely sure about this, but presumably they would need to interact with a range of government department, agencies, government-funded

NGOs, people with disability and families, etc, in addition to all of the agencies listed in the question. The question does arise as to whether the Public Advocate function should be independent of each of the offices listed above in order to be able to raise systemic issues which may arise in relation to these agencies and their roles.

Ideally the Public Advocate would be an independent body.

- Are any of the functions such an advocate would perform currently being performed by other entities in NSW?

**IDRS:** There are community organisations and individuals across NSW advocating for solutions to systemic problems affecting people with disability. It could be argued that the Community Services Division of the NSW Ombudsman's Office under the Community Services (Complaints Appeals and Monitoring Act) has some functions in relation to examining systemic issues which affect people with decision making disabilities in the use of services. However, this role falls short of the role of an independent public advocate whose responsibility would be to act at a systemic level to protect the **human rights and interests** of people with decision making disabilities. A Public Advocate exists in addition to the Ombudsman in most states of Australia.

IDRS believes the role of a Public Advocate will be vital to the successful implementation of the United Nations Convention on the Rights of Persons with Disabilities in NSW.