Our ref: JC:MLM

Intellectual Disability Rights Service
Criminal Justice Support Network

P.O Box 3347, Redfern
NSW 2016
t - (02) 9318 0144
f - (02) 9318 2887
e - info@idrs.org.au
w - www.idrs.org.au
ABN- 11 216 371 524

NSW Law Reform Commission
GPO Box 31
SYDNEY NSW 2001

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By e-mail: nsw_lrc@agd.nsw.gov.au

Dear Commissioners,

IDRS Preliminary Submission on the Review of the *Guardianship Act 1987*

About the Intellectual Disability Rights Service

The Intellectual Disability Rights Service ('IDRS') is a community legal centre and disability advocacy service that provides legal and other advocacy for people with intellectual disability throughout New South Wales. IDRS advocates for policy and law reform and undertakes a range of community education with a view to advancing the rights of people with intellectual disability. IDRS also operates the Criminal Justice Support Network ('CJSN') which supports and advocates for people with intellectual disability when they come into contact with the criminal justice system as victims or defendants.

General Comments on the Review

IDRS believes that the *Guardianship Act* (the Act) and related legislation in NSW has not kept pace with changes in attitudes towards people with limited or impaired decision-making capacity and welcomes the review of the Act.

The focus of IDRS's submission is on people with intellectual disability.

IDRS notes that one of the complexities of guardianship legislation is that it attempts to cater for people with a broad range of decision-making incapacities. This includes people whose decision-making incapacity may be temporary, people whose decision-making incapacity may be cyclical, people who may currently lack capacity but have the potential through learning to improve their capacity for specific decision-making and people whose decision-making capacity may be in gradual decline due to conditions such as dementia who, in NSW, are most often subject to guardianship legislation.

In reviewing guardianship legislation, it is essential that the complexity of decision-making incapacity is kept in view to ensure that the interest of all are actively considered and that there are no unintended negative consequences for any particular group.

IDRS is in favour of the adoption of supported decision-making whenever possible for a person has limited or impaired decision-making capacity. IDRS, however, supports the retention of a substitute decision-making regime as a last resort, recognising that some people will always need decisions made for them and that substitute decision making is sometimes required to ensure the safety and personal well-being of people with decision making incapacity.

IDRS is largely in favour of the National Decision-Making Principles set out by the Australian Law Reform Commission (ALRC) in its report dated August 2014 on Equality, Capacity and Disability in Commonwealth Laws (ALRC Report).

IDRS supports changes that will:

- introduce more gradated options in decision making, both prior to and following the appointment of any substitute decision-maker;
- set out principles applicable to supported decision-making;
- better regulate the appointment of guardians and financial managers;
- provide for a register of guardians and financial managers;
- ensure that an appointed substitute decision-maker uses a supported decision-making approach whenever practicable;
- require a more individualised approach to the administration of financial management orders; and
- better regulate restrictive practices.

Supported Decision-Making

The ALRC Report recommends the use of both formal and informal supported decision-making. Under the ALRC's decision-making model, a formal supporter is 'an individual or organisation appointed by a person who may require decision-making support to enable them to make a decision' (ALRC Report para 4.33 at p82). The formal supporter 'may play a range of roles, including in relation to information, advice or communication' (ALRC Report para 4.34 at p82). Importantly, a key element of the ALRC's proposal for the introduction of formal supporters is that the supported person 'is able to exercise choice and control in relation to the appointment, or revocation of the appointment, of their supporter or supporters' (ALRC Report para 4.43 at p85). The ALRC acknowledges that informal supporters and support networks 'play a vital role in decision-making of people with disability' (ALRC Report para 4.36 at p83) and stated that in its view 'the introduction of formal supporters should not diminish the involvement of, or respect for, informal support, including in relation to decision-making' (ALRC Report para 4.39 at p83).

IDRS's experience in working with people with intellectual disability has been that informal supporters and support networks can be highly effective in assisting people with limited or impaired

decision-making capacity to understand the choices they have, weigh up potential consequences and communicate decisions. Consequently, IDRS is wary of measures that might create pressure to over-formalise existing informal support mechanisms that are already working well. IDRS is also cautious of legislative measures that might impose onerous duties on informal supporters, causing them to be reluctant to continue providing decision-support.

However, IDRS is in favour of measures which promote responsible informal supported decision-making that maximises the ability of supported persons to 'make, communicate and participate in decisions that affect their lives' (ALRC National Decision-Making Principle 2). IDRS believes guidelines for informal supported decision-making are appropriate and that practical information and education is essential to build the skill of informal supporters to fulfil this role.

IDRS also acknowledges that many people with intellectual disability do not have people in their lives who can assist them with informal decision-making support.

Appointment of guardians and financial managers

Currently, in NSW, a guardian is appointed where a person, because of a disability, is totally or partly incapable of managing his or her person. A similar provision applies to the appointment of a financial manager in relation to a person's financial affairs. The current process makes a clear distinction between capacity and lack of capacity. It does not recognise options other than substitute decision-making and in particular it does not test whether supported decision-making can be put in place to assist the person making the decision instead of appointing a guardian or financial manager.

IDRS supports the inclusion in the legislation of a clearly prescribed process which provides that a substitute decision-maker will only be appointed as a last resort and after:

- actively considering what decisions are necessary;
- actively considering whether supported decision-making options are available and appropriate;
- being satisfied by the applicant that adequate attempts have been made to put appropriate decision making supports in place,
- being satisfied that decision supports that are available or could reasonably be put in place will be insufficient, and
- being satisfied that informal substitute decision-making that has been occurring will be insufficient or is inappropriate in all the circumstances.

This supports the approach of the ALRC to ask, at the outset, what level of support or what mechanisms are necessary, to support people to make decisions (para 4.13 of ALRC Report). With adequate and appropriate support, a person may be able to retain control of the decisions they make instead of having the decision-making process taken away from them.

IDRS considers that a court or tribunal that appoints a substitute decision-maker must be able to make lapsing orders of appointment in appropriate cases, and must be able to limit the decision making scope of a substitute decision-maker to what is necessary.

IDRS notes that urgent action is sometimes needed to appoint substitute decisions makers for people with intellectual disability where there is evidence that their own decisions or influence of others places their safety and well-being at imminent risk. For example, the person may be living in an abusive situation and unable to take action to protect her/himself or may be financially exploited by a carer without the person realising or believing this. It is important that courts or tribunals maintain the ability to act on an urgent basis to appoint a substitute decision maker where necessary to prevent or address serious harm to a person with decision making incapacity.

Formal Recognition of Informal Decision Making Support and Representation

IDRS supports the introduction of a mechanism which allows for the formal recognition of informal carers in limited circumstances.

Many support networks operate in an informal way outside of the guardianship and financial management legal framework. Often this arrangement works well and should not be disturbed. However, in the experience of IDRS informal decision making support and representation has become more restricted and less accepted as risk management and privacy concerns have received greater recognition and priority.

Parents and other carers of persons with intellectual disability regularly seek the assistance of IDRS to get institutions and other organisations to deal with them on behalf of a person with severe disability and clear decision making incapacity who is in their care. It is not uncommon for health insurance providers and banks to refuse to give a carer any access to information. There is an impasse which is often to the detriment of the person with intellectual disability.

The carer cannot be appointed as the attorney or enduring guardian as the relevant person did not have the capacity to do so. The Guardianship Division may question the merits of making an order as extreme as appointing a financial manager to arrange health insurance or roll over a term deposit when there should be another way of doing this.

Under sections 9(2)(a) and 154 of the Queensland *Guardianship and Administration Act 2000*, a process is provided for the tribunal to ratify or approve matters by an informal decision maker for an adult with impaired capacity for the matter. This does, however, require a hearing before the tribunal.

IDRS supports a mechanism which makes it easier than an application to the Guardianship Division of NCAT to allow a parent or carer to take the necessary action to obtain information or to operate an account in trust for a person for whom there is evidence of clear and permanent decision-making incapacity. Any such appointments should be subject to strict safeguards including being limited in their application and as to time.

Case Study

Olivia is 22 years old. She has a severe developmental delay which her doctor says makes her unable to understand issues or make decisions for herself. She is totally and permanently unable to manage her own affairs. She is also unable to sign anything. She lives with her mother and father. They are her carers. Her mother is also her Centrelink Nominee. Olivia is on the family Medicare card. She is also covered by the family's private health insurance policy.

Olivia's mother asked the private health insurer for a statement of benefits regarding Olivia's health care services. She told the insurer's employee that Olivia was unable to understand health insurance, and unable to ask for the information herself, because she had a disability. She handed the employee a copy of a confirmatory letter from Olivia's doctor, and proof that she was Olivia's Centrelink Nominee. These documents confirmed Olivia's severe disability.

The health insurer's employee told Olivia's mother that the insurer would not give her the information because she did not have a power of attorney to act on behalf of Olivia, and she did not have an order from NCAT (Guardianship Division) appointing her as Olivia's financial manager.

Unfortunately, Olivia's disability means that she does not have capacity to grant a power of attorney, nor is she able to ask NCAT for a financial manager to be appointed.

Therefore neither Olivia, nor her mother, is able to get the statement of benefits paid for Olivia under the health insurance policy without applying for an order from NCAT.

Conceptual Language

IDRS considers that the definition of 'a person who has a disability' in s3(2) of the Act is inappropriate. In keeping with contemporary thinking, the focus of the legislation should be on 'decision-making capacity', any support a person needs to maximise that capacity, and any absence of that capacity, rather than on a person's disability.

IDRS supports the language of 'supporter', 'supported person', 'representative' and 'represented person'. IDRS believes that this change in language will promote a shift away from the traditional paternalistic approach towards people with limited decision-making capacity.

Register of supporters and representatives

Clients of IDRS have often been made the subject of a guardianship or financial management order many years before they seek our assistance. These orders were usually made because of the lack of supports available to the person at the time the order was made. It is not unusual for a client of IDRS to be unaware of the forum in which the order was made. Before a person can seek to have that order revoked or altered, the relevant forum in which the order was made must be ascertained

either by that person or anyone providing assistance. It would be easier for either the individual or any person assisting to initiate a process of review or revocation if relevant parties had access to an online register of all appointments, including the relevant jurisdiction in which the order was made.

Guidelines for Supported and Representative Decision-making

IDRS calls for more comprehensive guidelines to assist decision making supporters and to ensure that appointed substitute or representative decision makers comply with defined principles of decision-making.

In IDRS' experience, there has been a tendency for public decision makers to apply objective criteria and not to give weight to the wishes and general well-being of the person at the centre of the decisions being made. In our experience this applies particularly to the operation of the NSW Trustee and Guardian as a financial manager. For example, IDRS has assisted people who have had requests for funds declined in the following situations:

- to engage a solicitor to defend a matter to keep the person out of jail when Legal Aid was denied due to the means test;
- to go on a holiday, even though the person had a substantial reserve of funds for future needs;
- to make repairs to the house in which the person lived on a long-term basis, albeit that the house was owned by someone else. This person later died with over $300,000 in the bank.

In the experience of IDRS, some people under financial management orders in NSW lead impoverished lives week to week even though they have considerable funds under management.

Legislative requirements that require that:

(a) a decision maker consider all factors relevant to the individual, and
(b) a decision maker account for his/her decisions,

are more likely to result in people with intellectual disabilities having everyday experiences enjoyed by the general population.

Particular Guidelines for Substitute Decision-making

IDRS proposes that any principles to guide substitute decision-making proceed in accordance with the following hierarchy:

- firstly, a substitute decision-maker must consider the will, preferences and rights of the supported person. This is in line with ALRC Recommended Guideline 3-3 (2)(a) for representative decision making;
- if a person's will, preferences and rights cannot be ascertained, IDRS supports an approach which not only tries to ascertain the person's likely will and preferences but looks more broadly at the personal and social wellbeing of the supported person. In simply ascertaining a person's will and preferences, a substitute decision maker may not be required to take these broader considerations into account. For example, a supported person's environment

may be limited in some way, the person may rely completely on the views of one person or may be unaware of opportunities available to them;

- any decision should promote the option which is least restrictive of the supported person's rights but must also consider likely harm to the person. The ALRC Recommendations do not define harm. The parameters of harm should not be left open to interpretation and should be defined. Physical, emotional and psychological harm must be considered. For example, a financial decision maker should not be able to determine that the preservation of a person's assets is the overriding factor in determining harm.

Section 7A of the *My Health Records Act 2012* sets out how a representative must exercise their duty to ascertain a recipient's will and preferences. Section 7A(5) provides that if giving effect to a recipient's will and preferences would pose a serious risk to the person's personal and social wellbeing, the representative must act in a way which promotes the personal and social wellbeing of the recipient.

Further it should be a requirement that where a substitute decision is made, the decision and the reasons for that decision, be recorded.

Financial Management Orders

Clients of IDRS often seek assistance to alter or revoke financial management orders. Often these financial management orders have been made decades ago or when the circumstances of the person were such that they didn't have the necessary supports around them. There is no provision for automatic review of FMO's in NSW. All other states and territories, other than the Northern Territory, provide for automatic review of FMOs.

Although the legislation allows the Guardianship Division to order a review when making a financial management order, this does not happen often and only a small proportion of orders are reviewed. In practice, it is up to the person under management or their representative to seek review or revocation of an order.

Further, a financial management order is only revoked if the tribunal or court is satisfied that the person is capable of managing his or her own affairs or it is in their best interests to alter or revoke the order. There is no provision allowing for the revocation of an order on the basis that there is no longer a need for a person's affairs to be under management. This may arise in a number of circumstances including where a child becomes an adult or where a person, who previously did not have supports, is now able to manage their affairs with the help of a support network.

IDRS believes that the court or tribunal which appoints a financial manager should regularly review the order so as to establish whether the order is operating in the interests of the person under management, whether the person has developed or regained their capacity whether the financial management order is still required and whether there is any less restrictive order or option is available.

Many clients of IDRS find the restrictions of being under a financial management order extremely distressing, frustrating and detrimental to their lives, particularly where the NSW Trustee and Guardian has been appointed. In these circumstances there is no positive duty for a tribunal or court to actively consider the quality of life of a person under a financial management order. This should be prescribed by the legislation. See for example SCQ [2015] NSWCATGD 28 where the NSW Trustee and Guardian reported that 'the Trustee and Guardian's (TAG's) experience has been that the financial management order has been difficult to manage and causes [Mr SCQ] extreme frustration to the point where he claims that he is 'forced' to commit crime because of TAG's involvement.'

At present all private financial managers appointed in NSW are subject to the directions and oversight by the NSW Trustee and Guardian. IDRS supports a change which allows the option to appoint a private financial manager without requiring oversight by the NSW Trustee and Guardian where the Tribunal is satisfied that the relationship and other safeguards are such that oversight is considered unnecessary. Examples may be where the relationship is between parent and child or husband and wife and the court or tribunal is of the view it is clear that the safeguards offered by third party oversight are unnecessary.

IDRS supports amendments to legislation:

- which require that financial management orders are usually time limited and automatically reviewed by the court or tribunal which made the order
- which require financial managers to actively consult the person under management and any relevant parties, relatives, service providers and other members of the person's support network, in the development of the person's annual budget and priorities;
- to incorporate a provision which allows for the revocation of financial management orders where there is no longer a need for a person's affairs to be managed; and
- which enable the court or tribunal, in certain circumstances, to appoint a financial manager without requiring oversight of the NSW Trustee and Guardian.

Decision-making and the NDIS

Many clients of IDRS will be the beneficiaries of the National Disability Insurance Scheme. Many of these same people may at times be 'a person in need of a guardian' or a person for whom financial management is appropriate. If both terminology and approach are consistent across all jurisdictions this will assist people with intellectual disability to be able to access, make sense of and to fully utilise the supports open to them, including safeguards of their rights.

Supporting the recommendations of the NSWCID, IDRS proposes that if a person requires a nominee to manage their services, and if there is a guardian with authority to make decisions about services, that guardian should be automatically appointed the nominee of the individual for the purposes of the *National Disability Insurance Act* (NDIA). This is because the processes for appointing guardians are more rigorous than the administrative processes under the NDIA to appoint a nominee. This should also apply to any guardian appointed after a nominee appointment has already been made.

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Regulation of Restrictive Practices

The regulation of restrictive practices should be included in legislation.

Any such regulation needs to be considered in light of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector and the National Decision Making Principles to ensure consistency in approach and to embed safeguards for those subjected to restrictive practices.

The starting point must be that the use of restrictive practices is exceptional, short term and must be justified as necessary to protect the safety and interests of the person with disability. Such legislation must ensure that the process is not simply a 'rubber stamp'. Any system of regulation of restrictive practices must include clear criteria which must be positively satisfied to justify approval.

The regulation of restrictive practices has two elements:

- professional or clinical regulation so that any proposed restrictive practice is critically examined for its justification, appropriateness and validity in the person's circumstances and
- regulation to ensure legal and human rights protection for the person.

Both elements must be contained in any legislation which has the effect of authorising use of restrictive practices.

Currently in NSW, the Behaviour Support Policy of Ageing Disability and Home Care (ADHC) has been the key document which deals with restrictive practices in the context of behaviour support in NSW. This policy applies to both ADHC provided and ADHC funded services. The policy has no basis in legislation.

This ADHC policy defines 'prohibited' and 'restricted' practices (pp 10 -13). Restricted practices must be approved through an *'internal Restricted Practice Authorisation Mechanism'.* In ADHC the mechanism is the Restricted Practices Authorisation Panels. The policy simply says that ADHC funded services are expected to maintain a similar authorisation mechanism. These authorisation panels focus on 'professional /clinical regulation'. It is unclear to IDRS whether the Restricted Practice Authorisation Mechanisms are established in most funded services or what form they take.

IDRS submits that internal authorisation mechanisms, such as these, are not independent and are not sufficiently removed from those proposing the restricted practice. There are obvious and real conflicts of interest in this arrangement. This internal process does not ensure a sufficiently 'expert' critique of the proposed restricted practice in the context of the individual's circumstances.

The policy also refers to the need for a legally valid consent to use the restricted practice. This includes substitute consent if the person with disability does not have the capacity to consent.

The Guardianship Division of NSW Civil and Administrative Division (NCAT) plays a role in regulation of restrictive practices in NSW in response to applications for the appointment of a guardian with

specific authority to make decisions about proposed restrictive practices for a person with disability. This process involves a hearing, participation by the person with disability wherever possible and hearing of evidence. These applications are decided in the context of the Guardianship Act, including the Section 4 Principles of that Act.

The need for the consent of an appointed guardian if restrictive practices are to be used for a person with disability is not explicit in guardianship legislation. IDRS is not convinced that guardianship legislation is the best legislative base for protection of the human rights of people for whom restrictive practices are proposed. However, until a better legislative base is available, the review of guardianship legislation should explicitly require consent of a guardian if restrictive practices are proposed for a person who is incapable of providing an informed decision about the proposal.

The Victorian Act has a lot to offer but it focuses primarily on the clinical regulation of restrictive practices and does not seem to adequately deal with the human and legal rights protection of the individual. For example, it does not appear to require that the person concerned be notified or that their views are considered or represented in the process leading to decisions about approval.

The Queensland *Disability Services Act* requires expert approval of the use of the proposed restrictive practice by the 'chief executive' as well as consent of a guardian in most instances. This is similar to the unlegislated practice in NSW.

IDRS proposes that important elements of any system to regulate the use of restrictive practices must ensure

- independent expert approval and oversight
- regular independent review
- time limited authorisation and demonstrated active planning toward terminating the restrictive practice
- examination by a body that has statutory independence and is bound to adopt processes which protect the human rights of the person with disability,
- that the use of restrictive practice is authorised and consented to only on the basis that it is necessary for the safety and interests of the person the practice will be applied to.

Education

Education to raise awareness of significant change is important to the success of the change. The House of Lords conducted a Review of the United Kingdom *Mental Health Act 2005*, an Act which had undergone significant change in its approach to decision making. The House of Lords Select Committee found that "while in the main, the Act was held in high regard, it suffered from a lack of awareness and a lack of understanding. '[T]he prevailing cultures of paternalism (in health) and risk aversion (in social care) have prevented the Act from becoming widely known and embedded. The rights conferred by the Act have not been widely realised. The duties imposed by the Act are not widely followed.'

This may explain why the Queensland Office of the Public Advocate has initiated a research project looking at systemic enablers and barriers to protecting and supporting people with disabilities to make their own decisions. Although Queensland has tried to promote a regime which prefers supported decision making the number of applications for guardianship has continued to grow. This may be partly the result of lack of awareness of the options available and a reluctance to embrace a different approach.

We thank you for the opportunity to make this submission.

Janene Cootes

Executive Officer

Margot Morris

Principal Solicitor