



Intellectual Disability Rights Service

Submission on NDIS Quality and Safeguarding Framework May 2015

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About Intellectual Disability Rights Service (IDRS)

Intellectual Disability Rights Service is a community legal centre and disability advocacy service working with and for people with intellectual disability in NSW. We deliver

- Legal advice and casework
- Advocacy and support for people with intellectual disability in contact with the with the criminal justice system
- Advocacy and legal assistance for expectant parents and parents with intellectual disability at risk of having their children removed
- Rights training and self-advocacy development
- Policy and law reform to protect and advance the interests of people with intellectual disability

Intellectual Disability Rights Service (IDRS) attended the National Roundtable on Quality and Safeguarding and People with Intellectual Disability held by NSW Council for Intellectual Disability in March 2015. IDRS endorses the position statement of NSW Council for Intellectual Disability on NDIS Quality and Safeguarding Framework. This submission is written to add to the key points made in the NSW Council for Intellectual Disability paper and does not address every question in the discussion paper.

Many people with intellectual disability are isolated

IDRS emphasizes that many people with intellectual disability are isolated and have little or no natural supports of family and friends in their lives. This includes

- people who were placed in residential care, often institutions, as young children in accordance with government policy of the time and lost contact with family early in life
- people whose parents have passed away and who have no other involved family
- people who are struggling to live independently in the community, despite the challenges of their intellectual disability, with little or no service or family support. In our experience many of these people, almost inevitably become socially isolated and many become involved in minor matters (often repetitive) as defendants in the criminal justice system
- people who have grown up in out of home care and have little or no natural support systems in their adult lives

A significant proportion of the people that IDRS works with have little or no natural support in their lives. People with intellectual disability are expected to make up over 60% of participants in the NDIS. It is imperative that the future quality and safeguarding framework improves on the current systems to provide real safeguarding for people who are isolated and most vulnerable and that the system isn't reliant on family systems to raise issues on behalf of people with intellectual disability. It is important that safeguarding is person centred like the new service system and doesn't just replicate current inadequate safeguards.

Information systems

- communication needs of people with intellectual disability are commonly overlooked
- people with intellectual disability generally need someone to listen to them and talk to them in order to benefit from information so that they can apply information to their own circumstances
- IDRS stresses the need for any agencies tasked with safeguarding people with disability to ensure that those who need assistance are able to talk to a 'real person' without having to navigate an on-line application or numbered options on automated phone answering systems. These systems are barriers to information for people with intellectual disability.
- IDRS encourages systems to enable participants to share information through online forums, including consumer ratings. This information should be easily available and displayed for example in Australian Disability Enterprises, residential services, NDIA.

There should also be an option so that people with disability who are limited in accessing on-line information should be able to call to speak with someone to get this information.

- IDRS stresses the importance of provision of information being independent and free from conflict of interests.

Building Natural Safeguards

- The level of safeguarding available to people with disability should be graded depending on their vulnerability. IDRS believes that a person who has little or no personal supports is more vulnerable than someone who has natural supports and that the level of safeguarding should be greater and have an outreach approach rather than relying on response to problems raised to that vulnerability
- IDRS believes that people with disability and particularly those who have no natural supports should have an entitlement to an advocate. For example, The Care Act 2014 (UK) (**Care Act**) requires local authorities to arrange for an independent advocate to represent and support and person subject of a safeguarding enquiry or review.
- Citizen Advocacy programs, a few of which are still funded by Department of Social Services, have provided an opportunity for people with disability to establish relationships with a citizen advocate, enhancing personal natural safeguards for some people with disability
- Building of natural safeguards is dependent of people with disability living more visible and connected lives. This will be enhanced by safeguarding processes insisting that services meaningfully link people to their communities and to people outside of the service world
- Families of people with disability would benefit from support and information about how to build natural supports into the lives of their sons and daughters with disability in their planning for the future
- Choice and Control are unfamiliar concepts to people with intellectual disability who are isolated in residential services or on the fringe of their communities. Safeguarding must include outreach education and peer support programs to build the skills of people with intellectual disability to recognize abuse and denial of rights and what they can do.

Advocacy

- Advocacy is an essential part of the safeguarding framework particularly for people with intellectual disability who have no natural supports.
- Key to the value of advocacy is that it is independent of service provision, avoiding potential conflict of interest, and that it is community based. The proposed design of the Information Linkages and Capacity Building aspect of the NDIS at this stage does not appear to provide an alternative to advocacy.
- Much of the work of advocacy is assisting people with disability to access complaint and safeguarding mechanisms and to assist people with disability to resolve a myriad of high

risk difficulties that arise with disability and with mainstream government and non-government agencies eg with Centrelink, housing, health, employment, criminal justice agencies, taxation, finances, fines etc. This is particularly the case for people with intellectual disability who are often unable to resolve these difficulties alone. Advocacy provides persistent, person centred, problem solving assistance at the same time building the capacity of the person to deal with future issues.

- IDRS specifically provides advocacy to people with intellectual disability at crisis points in their lives when they are involved with the criminal justice system as defendants or victims. IDRS also provides advocacy for expectant parents and parents who have intellectual disability again at times of crisis when they are preparing for birth or are at risk of having their children removed. It is unclear how this sort of crisis advocacy will be available in the future as safeguards for these usually isolated people with disability.
- IDRS has been audited for assessments against 4 sets of standards applying to disability services and community legal centres. IDRS does not have confidence that the current standards and the audits conducted to for accreditation are in any way an effective safeguard for people with disability using the service. They reflect theory rather than practice and have limited impact in terms of safeguarding.

Person-Centred Oversight of services

- IDRS would support the need for providers of services to vulnerable people to be registered.
- IDRS emphasizes that type of service is not the key indicator of degree of oversight and level of safeguards required. In the NDIS which is designed to be person centred, safeguards should also be designed around the individual person with disability. Some people will need access to greater safeguards than others. A person with physical disability who is well connected with their community, living in their own home and managing their own package and supports will potentially need less safeguards than a person with severe intellectual disability, who lives in a group home, is dependent on others for mobility and feeding, who has limited communication and no active natural supports in their lives. Indicators of the level of safeguards needed would be the how dependent the person is on services, whether they are able to recognize abuse and neglect, whether they have the capacity to seek help on their own behalf and whether there are non-service provider people actively involved in the person's life who would pursue and problems on their behalf.
- IDRS supports the need for a scheme similar to Community Visitor schemes. However, unlike most current community visitor schemes, we propose that the focus of the Community Visitor should be on the individual and how the service is working for the individual person rather than a general overview of the service itself. The service may work well for some but not for others. To achieve real change safeguards need to be person centred as well as service.

Complaints Mechanisms

- Existing procedures for people with disability to complain about disability services are inadequate. Their effectiveness typically relies on co-operation from the service provider to comply with recommendations after often lengthy investigative processes. There is no power to enforce recommendations
Investigation often cannot achieve outcomes for the person with disability.
- IDRS The complaints mechanism in the new safeguards framework should be focused on welfare and outcomes for the person with disability. People with disability need a simplified process within which binding decisions can be made within a reasonable time frame. In addition the complaint handling body should have a responsibility to report to the NDIS if it is found that the person's welfare and goals are not being advanced by their service providers so that a review of that person's plan can be undertaken. It is important that all of this can be achieved in a short time frame depending of the level of neglect or risk for the person.
- The handling of complaints, like the NDIS, should be person centred rather than assessing the service provider performance it must assess the adequacy of the service for the particular individual.
- The complaints mechanism should include an adjudicator which has the power to issue infringement notices that could include warnings, requirements for apologies, set time limits for action and impose financial penalties. In the UK, the Care Quality Complaints Commission is an independent body with power to hold care providers accountable to their failings by issuing cautions and fines.
- Traditional ombudsman structures are not sufficient to provide adequate safeguards for people with disability.

Ensuring staff are safe to work with participants

IDRS Client Case Studies

Case study 1 Financial exploitation within a group home

Elise has lived in a group home with several other people for 10 years. She is middle aged with intellectual disability and has difficulty with communication. She receives DSP paid into her personal bank account and staff take her to the bank to withdraw her DSP which is then paid into the household working account run by the group home. Two years ago it was discovered that \$9,000 was not able to be accounted for by the group home. Elise needed her advocate to help her complain. The advocate sought assistance from IDRS. Initially the NGO promised financial statements but then said the matter would be investigated by its own auditors. The matter was reported to the police. Five months later there were still no accounts and the NGO refused to answer questions posed by the advocate. In the end it was a year before any accounts were provided. The police advised the advocate that so many people had access to the account that they did not have enough evidence to charge anyone. When the police asked to interview staff, they refused to be interviewed. Some of Elise's money was finally reimbursed but no account was given of how the reimbursement was calculated. The advocate believed the amount was at least \$1,500 short. No-one was charged by police. No action was

taken against the service provider. The advocate suspected there were 5 other residents with similar stories.

Case study 2

Steven is an adult with intellectual disability and epilepsy. He uses a wheelchair and is incontinent. He is non-verbal and is dependent on carers for meals and hygiene. A carer at his day program was seen by another staff member to grab his hair, throw his head back and shake his head from side to side and was heard to say 'you bite me and I'll bite you'. Steven was observed to have marks on his arms.

The carers employment was terminated. His mother reported the matter to the police. After 4 months IDRS wrote a letter to the police asking why no statement had been taken from the witness and whether the carer had been charged. There was no response and a IDRS made a phoned the police to find that there was no event number and no record of the assault. Eighteen months later and after 2 further letters, Steven's mother received a letter stating that due to statements had been contradictory and Steven's inability to make a statement sue to his disability, there would be no prosecution.

Case Study 3

Mark lives in a group home. His behaviour support plan advises staff that he should be plenty of time to get up in the morning and should not be rushed as this is recognized as causing him distress. The group home support worker was running late and did not follow the usual routine, waking Mark physically and forcing him out of bed. Mark lashed out hitting the worker who twisted his arm behind his back and threw him on the floor. Other staff heard what happened but did not see. The worker called police in relation to Mark's behaviour. The police indicated that Mark would be charged with assault. Later that day it was found that Mark's arm was broken. Police then indicated to Mark's mother that they would charge the worker. The worker chose to leave his employment. Police dropped the charge against Mark. Months later IDRS pursued the matter with police who said that it had been decided to withdraw the charges against the worker. There had been no consultation with Mark or his mother.

- Under current systems in NSW each of these disability workers will probably have gone on to work with and possibly steal from and assault other people with disability. IDRS supports a requirement for working with vulnerable people clearances to apply to staff who have client contact. In our experience charges rarely result from situation such as these. Clearly National Police Record checking is not sufficient to prevent staff who have exploited or abused people with disability continuing to work in the sector.

Reducing and eliminating restrictive practices

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 or human rights protection for the person

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

- independent expert authorisation approval and oversight
- regular independent review
- time limited authorization 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 only authorised and consented to on the basis of the safety and interests of the person the practice will be applied to

IDRS emphasizes that it is totally inappropriate for decisions about the use of restrictive practices to be authorized by a service provider who is applying for authorization or an authorization panel which representatives of the organization.

People with disability must have the right to make their views known to any authorizing or monitoring body and should be provided with advocacy or representation to facilitate this.

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