

NATIONAL DISABILITY INSURANCE SCHEME
QUALITY AND SAFEGUARDING FRAMEWORK – CODE OF CONDUCT
SUBMISSION TO PUBLIC CONSULTATION JUNE 2017

Please accept my comments on the proposed Code of Conduct.

SUMMARY

The proposed code does not specifically refer to the 'dignity of risk'; the right for people with a disability to take reasonable risks in the conduct of their lives. This right is referred to in the NDIS general principles (4) and should be also referred to in the code of conduct. Service provider 'risk aversion' has the real potential to negate the basic principle of NDIS to allow participants to exercise choice and control over their lives.

Additionally the proposed code summary does not specifically refer to the issue of communication.

DISCUSSION – DIGNITY OF RISK

The discussion paper about the proposed code has a nine point summary with the following sections:-

1. *Promote individual rights to freedom of expression, self-determination and decision-making;*
4. *Provide supports in a safe and ethical manner with care and skill.*

The code of conduct is intended to reflect the general principles under the NDIS Act. These include the following nine principles relating to rights of action, decision making, assistance and self-worth:-

4. *General principles guiding actions under the National Disability Insurance Act 2013*

- (1) *People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.*
- (2) *People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.*
- (4) *People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.*
- (5) *People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.*
- (6) *People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.*
- (7) *People with disability have the same right as other members of Australian society to pursue any grievance.*
- (8) *People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.*
- (10) *People with disability should have their privacy and dignity respected.*
- (11) *Reasonable and necessary supports for people with disability should:*
 - a) *support people with disability to pursue their goals and maximise their independence; and*
 - b) *support people with disability to live independently and to be included in the community as fully participating citizens; and*
 - c) *develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.*

The discussion paper does not mention and therefore fails to reinforce the right of people with a disability to the 'dignity of risk' as referred to in principle (4) '....exercise choice, including in relation to

taking reasonable risks ...'.

The proposed Code of Conduct referred to in the Quality and Safeguarding Framework (9 Dec 2016) does refer to:-

1. *Respect the rights and dignity of all NDIS participants, including their right to choice and control and to take reasonable risks.*

However the reference to 'risk' is missing from the later Code of Conduct discussion paper.

Why is failing to reinforce the 'dignity of risk' important?

Service provider paranoia

Experience in Victoria is that service providers can have a paranoid attitude to risk aversion resulting in people with a disability being denied the right to informed decision making unless the service provider unilaterally decides there is absolutely no risk of them being accused of wrong doing in allowing the decision. This abrogation of rights can range from relatively minor issues such as denial of food choice to more serious impositions such as application of medical and allied health advice contrary to the wishes of the person with a disability.

There is no reason to believe this attitude by service providers of denying people with a disability the right to choice and control because of an often imaginary risk is restricted to the state of Victoria.

Avenues of complaint

In the event of complaints about unreasonable restrictions being unresolved with service providers, Victoria has safeguards including the Disability Act (DA) and the Charter of Rights and Responsibilities (the Charter). Both purport to uphold the dignity of risk. Complaints can be made via the Community Visitors scheme operated by the Public Advocate; the Ombudsman supposedly upholding aspects of the Charter (applicable only to public authorities); and the Disability Services Commissioner constituted under the DA. Consumer experience is that risk aversion overrides all else with these bodies contrary to their responsibility to protect the rights of people with a disability. This paternalistic 'we know best attitude' can also be seen in some advocacy organizations. The futility of such complaints about being denied the right to take reasonable risks is often described by consumers as 'you have rights, just don't expect to exercise them here'.

The NDIS Quality and Safeguarding Framework has a recognition of the right to take 'reasonable' risks (1.5 Framework Principles). This is similar to the wording of legislation in Victoria but there 'reasonable' is seldom acknowledged on behalf of the people with a disability. 'Reasonable' on the other hand can be offered by the system as 'reasonable' to apply restrictions on rights, regardless of how unreasonable and often petty the restriction is to the person with a disability.

It is hoped that the NDIS Quality and Safeguarding Framework and the associated NDIS Quality and Safeguards Commission will uphold this right of the consumer to assume risk under the NDIS. Specifically referring to this right in the code of conduct will reinforce to all that this is to be considered seriously.

Excuses for denial of rights

The literature is endless in explaining the right of a person with a disability to take personal risks. Apart from many references in NDIS writings and the National Standards for Disability Services; there is, for instance, the Victorian DHHS Disability Services 30 page publication 'Supporting decision making - A guide to supporting people with a disability to make their own decisions'

Yet Service providers can and do quote corporate policies or head office advice or 'one size fits all' practice manual requirements to excuse their behavior. They can also deny the people with a disability their right to choice by stating they are performing a task to 'best practice', or insist that things suggested or recommended in professional training of support staff are strictly adhered to regardless of people with a disability preference. However it can also simply just be the personal ignorance or preference of a support worker.

Code of Conduct requirements can conflict

When safety is referred to as in point 4 in the discussion paper summary (*4. Provide supports in a safe and ethical manner with care and skill*) this can be interpreted as mandatory by service providers to make their own decision about what is safe for the people with a disability, regardless of the wishes of the person. Service providers and complaints bodies will say no right is absolute and it must be balanced with their responsibility to provide a safe service. Thus the right of the people with a disability to self-determination can be expunged. This should be balanced in the code of conduct by also referring to the right to take risks.

Effects of this culture

This risk aversion culture of service providers has the potential to negate almost all of the nine general principles of the NDIS relating to rights of action, decision making, assistance and self-worth; which are listed above.

For the people with a disability being denied this right can not only restrict their choices in life but being presented with a culture of paternalism is belittling and demeaning and in no way can be considered to enhance their potential for intellectual development. Where the person has the capacity to make informed decisions, to assess risks for themselves and to act independently this can be psychologically crushing. This is recognized and discussed in the Quality and Safeguarding Framework.

Capacity for making informed decisions

The varying capacities of people with a disability to make informed decisions and can be difficult to negotiate by service providers. However the rights of the people with a disability should be considered as more important than service provider paternalistic culture. Additionally where there are other supports such as family and friends or advocates involved the decision about risks should be a collaborative process rather than a unilateral service provider decision.

Having principle (4) '*....exercise choice, including in relation to taking reasonable risks ...*' referred to in the code of conduct summary would give this right an emphasis which is missing when it is not stated.

CONCLUSION – DIGNITY OF RISK

Suggested addition to proposed code

I believe the right to the dignity of risk should be included in the code of conduct. It is not stated what form the final code will take, however if it is modeled on the discussion paper this could be added by amending sections 1 (summary) and 2 to include the following italicized text:-

1. Promote individual rights to freedom of expression, self-determination, decision-making *and risk taking*.
- 2.1 Promote individual rights to freedom of expression, self-determination, decision-making *and risk taking*

This obligation includes the following expectations:

- *Support people with a disability to explore and understand any real risks associated with their*

decisions and respect and accept their right to take such risks with their life choices.

An appropriate scenario depicting a typical situation of a person with a disability accepting a risk associated with a life decision to be supported by a service provider should be included.

DISCUSSION – COMMUNICATION

The ability to communicate is fundamental to everyone's life. Impediments to communication can be due to culture or language (CALD) or directly due to a disability such as cognitive impairment or physical difficulties leading to being non-verbal or sensory impaired.

The proposed Code of Conduct referred to in the Quality and Safeguarding Framework (9 Dec 2016) refers to:-

6. Communicate in a form, language and manner that enables the participant to understand the information provided and make known their preferences .

The proposed Code now does not mention communication directly but incorporates it into *2.1 Promote individual rights to freedom of expression, self-determination and decision-making*

Since effective communication is fundamental but so easily over-looked or ignored because it is difficult, it should be reinforced by being specifically mentioned in the Code of Conduct summary.

The NDIS is based on principles of choice and control by the person with a disability receiving support that is reasonable and necessary. It is fundamental that communication for this is necessary and it is incumbent on service providers to facilitate both communication and understanding.

CONCLUSION – COMMUNICATION

I believe the right to communication and understanding should be included in the code of conduct summary as a separate point. It is not stated what form the final code will take, however if it is modeled on the discussion paper this could be added by including in the summary the wording discussed above:-

6. Communicate in a form, language and manner that enables the participant to understand the information provided and make known their preferences.

Yours faithfully



Cliff Stephens
16th June 2017