Submission re Advocacy Framework; July 2015

Thank you for the opportunity to provide insights from lived experience of advocacy. We are parents of an adult person with significant intellectual and communication impairment. As such, our family member has compromised capacity to make many decisions and difficulty in imparting those decisions that can be made independently.

Four points we note regarding advocacy in general:

1. Disability covers a broad spectrum of functioning capacity. Our experience indicates that intellectual disability cannot be successfully represented by a peak body serving all disability; intellectual disability has unique issues. People with physical disability do not have credibility for families of persons with intellectual disability.
2. While inclusion is a very worthwhile and valid desire for people with a disability there are individuals who do not exclusively seek inclusion at all times; their desire is to mingle amongst their specific peer group; they are understood, they understand and seek such companionship. Likewise people with professional expertise choose to mingle amongst their own specific peer group. Inclusion should be a matter of choice; options to be included should be available; options to seek companionship in more segregated environments should be regarded as appropriate by advocates.
3. People with disability, like all individuals deserve privacy; there is no argument about this. However, the current systems mean, that processes to protect privacy, especially those employed by the corporate sector actually act to increase the vulnerability of people with disability. This matter is discussed below.
4. The legal system makes it virtually impossible for people with impaired decision making capacity to enter into any contract or make a will. In the NDIS environment it will be increasingly desirable for people with disability to become lessees or home owners in their own right. It will also be necessary for them to become parties to contracts around energy use, telecommunications and banking. Currently the systems are simply not available to meet this expectation. Trusts can be instituted but such a system requires sufficient capital to be efficient; that capital may not be available for many people with disability though they may have the capacity to purchase into a congregate community (similar to a retirement village)

We see advocacy, impaired decision making capacity, privacy and guardianship all closely interwoven. The purpose of advocacy is to support people with disability to be as independent as feasible and, thus, to be involved in decisions around their own lives to the greatest possible extent.

Currently privacy laws (and their interpretation by the corporate sector) often mitigate against this very desirable outcome of advocacy. In Queensland there exists a process termed Informal Substitute Decision Making; there is a designated hierarchy of persons who can act to support the decision making of a person with disability and, indeed, act on their behalf when necessary. However, the corporate sector tends to disregard this process and requires formal Guardianship or Administration before they will accept a third party acting on behalf of the person requiring a service. This places imposts on families and Government; applying for Guardianship is a long, convoluted process costing energy and time (and possibly legal expense) for families and resources for Government. Further the formal appointment is a general appointment which can effectively reduce/remove the freedom of the person with disability to make their own decisions; the power of decision making is vested in an entity who can use that power to reduce options for the person with disability.

Under an NDIS these matters are going to become more frequent and disruptive of the aspirations of the very people NDIS is meant to support. There needs to be thought to developing systems that facilitate people with disability to live ordinary lives with support and remove the barriers that currently create hassles and are demanding formal procedures that can increase vulnerability.

Recommendations:

Disability advocacy ensures:

1. that persons with impaired decision making capacity are represented by independent advocates in interactions with Government regarding policy.
2. the rights of people with impaired decision making capacity have the right to supportive representation in dealings with government and corporate organisations. This is a higher right than the right to privacy.
3. the rights of people with impaired decision making capacity to enter into contracts and to make a will. This requires long term consultation and the development of a legal framework.