Draft National Standards for Disability Services (LINK)

Comments by

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The more things change the more they are the same

The proposed National Standards for Disability (NSD) seem to be a revised version of the Disability Standards that are in force nationally, and in the states and territories. They have been around in various forms for many years, and are a variation on a common theme. The National Standards for Disability are an intrinsic part of a failed system of service delivery, and it seems unlikely they will make more than a minor contribution to the paradigm shift called for by people with disabilities and the Productivity Commission. To achieve this far more comprehensive and strategic support for the disability sector is required.

The following paragraphs outline some of the outcomes the report prescribes, some of the impediments to achieving them, and some suggestions on how to move forward.

The sector's failure in supporting people with disabilities and carers has been reported on anecdotally and through enquiries over many years – the most recent the 'Shut-out report'[1] - but little has changed. The 'Shut-out' report identified two major areas where the sector has failed people with disabilities:

Social inclusion and community participation: 56% People with disabilities and their families, friends and carers reported daily instances of being segregated, excluded, marginalised and ignored. At best they reported being treated as different. At worst they reported experiencing exclusion and abuse, and being the subject of fear, ignorance and prejudice.
Disability services, 56%: More than half of the submissions received said that services and programs act as a barrier to, rather than a facilitator of, their participation. Many said that the system is characterised by a one-size-fits-all approach that offers very little choice or flexibility. Programs and services were built around organisational and system needs rather than the needs of clients.[2]

Current dogma and practice

For several centuries disability support's underlying values were about 'doing good deeds' which is the foundation for the 'alms for the deserving poor' charity model of welfare. When Mohammed Yunis[3] said that "Charity maintains poverty", he was not thinking about money but about inequality. Charity demands that the giver is more equal than the receiver, creating an unequal disempowering relationship. This class distinction (power differential) was enshrined in the 'social construct of disability', which led to normalisation, and the bio-medical, deficiency based model of disability. It gave justification for excluding the disabled from mainstream life and transferring care from the broader community to institutions, workhouses, asylums and prisons (Ariotti 1999, p. 216).[4]

MacIntyre (cited Leipoldt 2000, p. 4)[5] offers an enlightening perspective as he explains disability' to be part of the human condition. However, after almost two hundred years of separation, society no longer has a collective experience of disability being part of life and community. Our current level of thinking has placed an artificial divide between the disabled and the community.[6] Systemically and systematically people with disabilities have been

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[1] Shut Out, National People with Disabilities and Carer Council, 2009

[2] Shut Out, National People with Disabilities and Carer Council, 2009 (p 2)

[3] Mohammed Yunis, founder of the Grameen Bank of Bangladesh, Noble Peace Prize winner in 2006

[4] Ariotti, 1999, p. 216, cited Wiltshire, D., The Social Construction of Disability, 2004

[5] MacIntyre, cited Leipoldt, E., 2000, p. 4

[6] Paton, S., Homan, J., Learning with Amanda, 2006

isolated, stigmatised and discriminated against. They have been denied equity in their own life and with it empowerment.

The current top down contractual system of disability support has to this day maintained this divide, and the culture that supports it. Its dominant feature is the ‘purchaser/provider split’. Vern Hughes observes that in this model, the supply-side funder is simultaneously the purchaser, buying the provision of services to a range of client groups on a contract basis. Providers, being contracted to the funder/purchaser, are accountable to the purchaser, not to their ‘clients’.[7] People with disabilities have little if any control over their own lives, it is controlled by the professionals, the gate keepers, funding bodies and service providers. Until there is a structural change in the relationships between funders, service providers and people with disabilities little will change, and people with disabilities will remain isolated from community and disempowered.

Social Role Valorisation (SRV), an other name for normalisation, is a fashion that became popular in the eighties. It has influenced thinking and belief to the point it influenced legislation, and to this day has been an impediment to inclusion. It is the deficiency based bio-medical model of disability by an other name. It aims to change appearance and behaviour, so differentness will go unnoticed. Szivos observed that one of the central contradictions of normalisation [“SRV”] is that while it purports to re-value people with disabilities, it is rooted in a hostility to and denial of “differentness”. (1992:126) [8]

A paradigm shift

The Productivity Commission in its final report said that:
“The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports”,
It then proposes a radical new direction, a paradigm shift. It does not precisely identify ‘the end in mind’, but provides enough clues in its report to be able to extrapolate what defines a ‘good life’.

The Productivity Commission states that:

- *“there should be a new national scheme”.*
- *“the main function of the (new National Disability Insurance Scheme) NDIS would be to fund long-term high quality care and support for people with significant disabilities”.*
- *“it would aim to better link the community and people with disabilities”.*
- *“people would have much more choice in the proposed NDIS. Their support packages would be tailored to their individual needs. People could choose their own provider(s), ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options”.* [9]
- *an ‘individual choice’ model, in which people with a disability (or their guardians) could choose how much control they wanted to exercise.*[10]
- *Local Area Coordination (LAC) and development, which are broad services, including individual or family-focused case management and brokerage. They aim to maximise people’s independence and participation in the community.*[11]
- *people could choose their own provider(s), ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options.*[12]

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[7] Hughes, V., Breaking the Mould – Empowering Individuals and Families to Shape Systems, 2003

[8] Szivos, 1992:126, quoted Campbell, F. A., Social Role Valorisation Theory as discourse: bio-medical transgression or recuperation?, 2000

[9] Productivity Commission, final report Disability Care and Support, Key Ppoints, 2011

[10] Productivity Commission, final report Disability Care and Support, Overview, 2011, (p 33)

[11] Productivity Commission, final report Disability Care and Support, Overview, 2011, (p 23)

[12] Productivity Commission, final report Disability Care and Support, Key Points, 2011, (p 3)

In these simple paragraphs the Productivity Commission has prescribed a major culture change. It demands the sector makes a complete U-turn, and relegates the charity model of disability to the dust bin of history.

It is a change that takes the sector out of its comfort zone of experience and values that it understands, into a new and strange territory where each organisation has to re-invent itself – and get it right – if it is to be relevant in this ‘new world’. Carl Poll observes that: *“Those providers that continue to design services on a take-it-or-leave-it basis may find themselves without a role in the future system”.*[13]

Culture change

A culture or paradigm shift is a new way of thinking about old problems that brings a dramatic change in our perceptions. Notable examples of this would be the move from “flat earth” to “round earth” thinking, or the shift from believing that the earth is the centre of the universe.[14] A culture change involves shifting the context of our point of view entirely. One question to ask is: “How do we decide what is right?” It requires an examination of underlying values and principles. It examines the inter-relationship between problems and solutions. Understanding the values and assumptions that lie below the patterns of actions. This allows examination if these values and assumptions give cause to a recurring cycle in which today’s solutions become tomorrows problems. It is a learning process that can create transformational change. It may also lead us to understand that an organisation where its governance’s values are incompatible with those that support good service user outcomes will fail.

Supporting the sector to change

This required culture change is ‘unchosen change’. Resistance to unchosen change is natural, as in early stages of dealing with change, anxieties and insecurities abound.

The Productivity Commission proposes a national service provider strategy (capacity building and attitude change) and workforce development strategy.[15] This is a major initiative, complementary to a National Disability Service Standard. It is most likely prompted by the Productivity Commission‘s observation that: *“While some governments have performed much better than others, and there are pockets of success, overall, no disability support arrangements in any jurisdiction are working well in all of the areas where change is required”.*[16]

Few, if any, service providers have the capacity to turn their organisation’s Titanic around without support. The Department of Communities (DoC) in Queensland developed and implemented, and funded a multi faceted approach towards managing change in the community services sector. It launched the ‘Community Door’ website,[17] now auspiced by the Queensland Council of Social Services (QCOSS) As part of its ‘Strengthening Non-Government Organisations project’[18] the DoC provided a full set of policy templates with advisory guides.[19] Also, as part of the program, the DoC appointed a number of Sector Development Workers throughout the state. Information gives knowledge, mentoring gives understanding. Understanding of how the policy framework supports our vision of a good life, an inclusive and meaningful life, not just for our service users, but all of us, can be transformational.

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[13] Poll, C., KeyRing Living Support Networks, Co-Production and Personalisation in Social Care’, 2007

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Paton, S.,Building partnerships and managing change, Institute For Sustainable Regional Development, Central Queensland University, Rockhampton, 2000. (p 55)

[15] Productivity Commission, final report Disability Care and Support, Overview, 2011, (p 36)

[16] Productivity Commission, final report Disability Care and Support, Overview, 2011

[17] http://www.communitydoor.org.au/

[18] http://www.communities.qld.gov.au/communityservices/community-support/strengthening-non-government-organisations-ngos

[19] http://www.communitydoor.org.au/documents/quality/policy/standards.documents1-6.zip

Community Development is based on the belief that within any community there are assets such as knowledge and experience which, if successfully tapped into, result in enhanced participation that can be directed into collective action to achieve the communities' desired outcomes.[20] These principles are equally applicable to assist and mentor organisations, and individuals towards reaching their full potential.

Giving people with disabilities more choice, including the authority to manager public monies, signals a major delegation of power, which changes the relationship between the NDIS (the funder) and service user from a top down one into a collaboration, facilitating the best possible 'good life'. It also changes the role of the NDIS, which now - through the Local Area Coordination - becomes a facilitator, and evaluator of services provided.

When the Productivity Commission said that: "*approaches to delivery of supports and administrative processes are only weakly evidence-based, despite the billions of dollars given to such services each year",*[21] it indicated that accountability in the sector was found wanting. This would indicate that outcome based evaluations will inevitably replace input or output based ones.

In the disability sector service providers will need to be as good as they can be, not only to survive, but to become 'service providers of choice' for service users. To achieve this its governance's values must not only be compatible, but also in practice support the values that lead to good service outcomes: a 'good life', for its service users.

A good life

The opening paragraph of the 'Shut Out' report expresses a vision that we all share:

"Ideally, we want to live in a dignified and simplified society where we have the confidence and self esteem to speak our mind and have the opportunities that everyone has". [22]

Relationships and networks are the foundation stones and building blocks of community, and living a valued life. For relationships to have value and be valued, they must be respectful and trusting. Happiness and well being does not come from our freedom to break free of bonds but instead to commit ourselves to relationships. (Happiness Paradox) [23]

There is overwhelming evidence, through research, experience, and anecdotally, that the best outcomes in the human services sector – including disability – are based on community development principles and are powered through relationships.

Through developing relationships people become the centre of their individual communities, of which there may be many, serving different purposes and interests; all interwoven and overlapping the communities built by others. These relationship communities may range from quite small to a wonderfully complex tapestry, rich in texture and colour.[24]

We all aspire to having a 'good life'. The building blocks that make for a good life are varied and personal, however there are some common element:

Inclusion in community,

- *Valued relationships and networks,*
- *Empowerment,*
- *Choices,*
- *Challenges.*
- *Opportunities to contribute, and*
- *Security for the future,*

Most, if not all, of these features are important issues with all people to a greater or lesser degree, not just with people with disabilities. They are all part of an organic holistic system, and thus interconnected and interdependent.

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[20] Paton, S., Regional Sector Development Hand Book, Queensland Alliance, 2010

[21] Productivity Commission, final report Disability Care and Support, Overview, 2011, (p 7)

[22] Shut Out, National People with Disabilities and Carer Council, 2009 (p1)

[23] Leadbeater, C., **With** Relationships and The Public Good, 2008

[24] Homan, J., Community access, 2003

Staff selection.

The relationships between support workers and service users is the ‘canary in the mine’. Staff selection is usually based on an applicant’s skill sets and experience which are easily measured. Rarely is a person’s value base evaluated when selecting staff. It is either ignored as not important or, as it is an abstract, considered too difficult to assess. However if that box is not ticked then a disconnect between the values of the organisation and staff may initiate Steve Simpson’s UGR’s (Unwritten Ground Rules) that may be seriously damaging to the organisation and its service users. Eddie Bartnik and Ron Chalmers observe that a program is only as good as the individual LAC (support staff) that the person has, hence staff selection, quality and consistency is critical.[25]

Operating on a traditional paradigm, many support services and government departments actively discourage, or forbid, the development of close personal relationships between support workers and service users. It is seen, as ‘not professional’ and creating a ‘conflict of interest’. The institutional, neo-medical model assumes that the disabled either do not require love or friendship or that they are able to meet these needs outside the care network.[26] This is flat earth thinking. Bramston Training and Consultancy in “Healthy Boundaries” puts forward a compelling argument that professional and personal relationship can be rich and rewarding, and can co-exist without creating conflict of interest. It states that:
“*There are differences between relationships that are formed in our personal lives and those that are formed with people being supported. It is important to highlight these differences, as they are the defining features that separate and create the* ***boundaries*** *within which support relationships are formed”.*[27]

Many risk averse organisations discourage or outright forbid support staff from inviting service users into their homes or taking them to the homes of family or friends. It is considered high risk. May be. Without accepting and managing risk innovation is not possible, and life becomes a sterile landscape. A life without innovation becomes a prison centre where people behind a one meter fence are as isolated as they were in institutions behind a two meter wall, a life without meaning, without choices, challenges or hope!

The trend in service provision to people with disabilities has been to give up on their potential, and just fill in time between meals. Again flat earth thinking. By carefully matching support staff with a service user can lead to rich and mutually rewarding relationships. It can also initiate and grow an empowering environment, the key to self actualisation, and a person realizing Maslow’s: “What a man can be, he must be.”[28] The Productivity Commission supports this when it says that “supports would focus on learning and life skills development, including continuing education to develop skills and independence in a variety of life areas (for example, self-help, social skills and literacy and numeracy) and enjoyment, leisure and social interaction”[29].

Again, relationships are the key. To mentor and teach, build social and other skills that will enhance self-esteem and self-confidence, is exciting and challenging. The growth in maturity will earn the person a more valued role in community. This is not charity by community. Inclusion is earned through building capacity and thereby reducing dependence. It realises Pat Deegan’s vision when she said:

“We don't want to he main-streamed. We say let the mainstream become a wide stream that has room for all of us and leaves no one stranded on the fringes”.[30]

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[25] Bartnick, E., Chalmers, R., It’s about more than the money, Local Area Coordination Supporting People with Disabilities, ‘Co-Production and Personalisation in Social Care’, 2007

[26] Paton, S., Homan, J., Learning with Amanda, 2006.

[27] Bramston Training and Consultancy, Getting it right, Workshop for service leaders, 2008/09

[28] MASLOW, A., A THEORY OF HUMAN MOTIVATION, 1943

[29] Productivity Commission, final report Disability Care and Support, Key Points, 2011, (p 23)

[30] Deegan, P.,(prominent American psychologist with serious mental health issues), Recovery as journey of the heart, 1995

Enhanced capacity has several other dimensions. The Productivity Commission says that *"People would have much more choice in the proposed NDIS".*[31] However people with disabilities have by and large been marginalised to the point where they have been excluded from most decisions that affect them. For more choice to become more than a tokenism, people with disabilities need to build their understanding of risk and their ownership and responsibility for decisions made.

Capacity to contribute and respond to challenges are other dimensions to building skill and capacity in community, and capacity to manage risk. They are all interconnected with relationships and inclusion.

Security for the future is not just about money, but also about relationships. Of course funding through the Disability Support Pensions (DSP) and National Disability Insurance Scheme (NDIS) are important, however as important are being valued in our community, a sense of belonging, respect, and love.

It is clear that the closer a person comes to reaching his potential, the greater his capacity to live a 'good life' and the more inclusion in community becomes a win-win for the person with a disability and community.

Consistency

For the NDIS to be a national system it needs to be consistent throughout the nation. The Productivity Commission is well aware of this when it says: the Commission is proposing a National Disability Insurance Scheme (NDIS), overseen by a new organisation, the National Disability Insurance Agency, that would oversee a coherent system for all Australians, regardless of their jurisdiction.[32] Its first option for funding the NDIS is consistent with this: The Commission recommends that the Australian Government would take responsibility for meeting the entire funding needs of the NDIS. This would provide certainty, clear lines of funding responsibility.[33]

The Productivity Commission offered a couple of other funding options. The second one, although 'workable', it showed no enthusiasm for.

The third option on the other hand:

"The third and most inferior option of a 'federated' NDIS. In which the Australian Government would provide additional disability funding to state and territory governments and stipulate some common national features, but would otherwise leave state and territory governments in control of their own systems. This would be better than current arrangements.

However, the system would remain fragmented, and the support received would retain features of the postcode 'lottery'. Moreover, such an arrangement could easily revert to the current dysfunctional and unfair system, with 'agreements' breaking down into disputes about relative contributions, special variations and carve-outs. A loose arrangement would expose Australians to significant risk.

A federated scheme would not offer people the assurance of high-quality long-term" care and support".[34]

There seems to be a genuine fear that this third option may well be the government's preferred one. If that were to happen the "coherent system for all Australians, regardless of their jurisdiction"[35], may never become a reality, and the result may be the current system with some more money.

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[31] Productivity Commission, final report Disability Care and Support, Key Points, 2011, (p 3)

[32] Productivity Commission, final report Disability Care and Support, Overview, 2011, (p 37)

[33] Productivity Commission, final report Disability Care and Support, Overview, 2011, (p 33)

[34] Productivity Commission, final report Disability Care and Support, Overview, 2011 (p37)

[35] Productivity Commission, final report Disability Care and Support, Overview, 2011 (p 37)

There is compelling evidence that the Disability sector needs to effect major change, at a national and service provider level if the objectives for people with disabilities expressed by the Productivity Commission are to be realised.

There is also compelling evidence that if change at the national level become fragmented through the introduction of a federated system, this will put success seriously at risk.

There is also compelling evidence that if service providers fail to understand the proposed paradigm shift, and hence change their value and on the ground systems, then they not only seriously fail people with disabilities, but also run the risk of failing as an organisation through lack of relevance.

Recommendations

- That the issues about a federated system for the NDIS be addressed at the political level,
- That comprehensive support systems, beyond a set of service standards tuned to the needs of the new systems, be put in place to guide and mentor organisations to build capacity for them to effect the paradigm shift with confidence.

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