Determining service provider effectiveness: a response to the NDIS quality and safeguard framework

The Council of Australian Government's public consultation about the proposed framework for quality and safeguards for the National Disability Insurance Scheme (NDIS) is welcomed. The consultation paper (National Disability Insurance Scheme 2015) offers a detailed discussion of components of the framework and outstanding questions. The consultation paper explores 'the best ways to ensure all NDIS registered providers offer services that are safe and effective, while ensuring participants have choice and control when choosing a provider' (COAG Disability Reform Council, Media Release, 16th February, 2015.) Key elements of the quality and safeguarding framework are, provider registration; systems for handling complaints; ensuring all staff are safe to work with participants; safeguards for participants who manage their own plans; and reducing and eliminating restrictive practices in NDIS funded supports.

Knowing the quality of support provided by organisations providing disability support is critical to meeting the individual and collective outcomes for the NDIS. This paper considers service effectiveness and how information about service effectiveness can be available to individuals and their families when choosing and reviewing their support arrangements. Attention to service effectiveness would also provide an impetus to strengthen internal provider governance processes including support product definition. (For further details see Implementing a service effectiveness framework, Department of Communities and Social Inclusion, Disability SA 2015 (final release pending Ministerial sign off).

The following discussion describes why quality and safeguarding measures are so important for many people with an intellectual disability; how and why previous approaches to quality and safeguarding have failed to reliably improve the quality of services provided particularly for people with an intellectual disability; and how to redress the lack of information within services available to regulators and to people with an intellectual disability and their families about how recognise a 'good service'; that is a service that can demonstrate it is making a difference in people's lives.

The importance of the quality and safeguarding for people with an intellectual disability

There are high hopes for the potential of the NDIS to transform the lives of people with an intellectual disability by emphasising social and economic participation, and choice and control. Worldwide people with an intellectual disability, particularly those people who will be participants in the NDIS, are significant users of disability support services for significant parts of their daily lives and throughout their lives. People with an intellectual disability consistently experience diminished rights; isolation from the community; institutionalised rather than personalised support; exposure to restrictive practices; and decision making by others which have limited life's possibilities. There are ongoing challenges understanding the perspectives of individuals who do not communicate with words; and maintaining attention to restraint and seclusion (Hayes, Joyce & Couchoud 2003); abuse and neglect; and how to ensure oversight in community settings. People with disabilities and their families in Australia have expressed frustration about the quality of disability support (Productivity Commission 2011). There is concern that quality systems and compliance approaches have not been sensitive to the experience of the individuals receiving support or to the approaches taken by staff delivering that support.

The NDIS framework has many positive elements for people with an intellectual disability: it is based from a person centred perspective; there is attention to support quality *and* safety, and to the performance of support providers, with observation as well as paperwork-based accountability. The framework is concentrating on the dual risks relevant to people with intellectual disability, that they '*could receive poor quality services that do not help them to achieve their goals, and that ...people could be harmed in some way' (p10).* The framework is pitched towards '*areas where dangers are greatest and the consequences (p10) of harm most severe…. Therefore providers of support types where there is potentially greatest risk to participants will have to comply with a stronger regulatory framework (p10).*

Challenges for the NDIS framework for people with an intellectual disability and their families are, how quality and safeguarding can be best pursued in a market place of support providers; how individuals and families can know what support product they are choosing; and how support product effectiveness – what difference support makes in people's lives - can be determined and by whom.

What's happened so far in the pursuit of quality services

The Quality and Safeguarding Framework (the framework) is a divergence from years of attention to meeting disability standards that has resulted in improvement in organisational processes but has not automatically contributed to improvement in staff support practice or changes in people's lives. Despite enthusiastic and widespread uptake across many sectors, there has been limited research about implementing quality monitoring systems including standards (Douglas 2013). Regulation in general can 'increase compliance, reducing risk and raise standards' but regulatory mechanisms alone are not sufficient to ensure service quality (Haines 2011). Experience is suggesting that the 'regulated and the regulator are drowning in paper so no one can see what is really going on' (Mansell 2006). The framework's goal to reduce unnecessary administrative demands on providers is consistent this.

What has been required for services to meet standards is not the same as providing evidence for outcomes being achieved for individuals receiving support; and does not reflect people's experiences of the support received. While the organisational processes are able to replicated, what is being assessed has been too far removed from service delivery (for example, Clegg 2008). Quilliam and Wilson (2011) note that there can be 10-20 evidence indicators per standard which comprise a *mix* of outcome, satisfaction and process measures with a bias to process measures and therefore confuse outcome measurement. McEwen et al (2015) analysed the 387 indicators listed in the Victorian Disability Standards to provide evidence required to determine compliance with the four standards. Over 80% these indicators required a review of written information, such as a support plan or client file note, and just less than 20% requires observations of staff practice or interviews with service users and staff.

Overemphasis on individual outcome measurement can reduce outcomes to simple goals and activities and thereby neglect many areas of quality of life; assign organisational outcomes as if they have the 'same weight' as outcomes for people with disabilities (rather than being a means to achieve personal outcomes) and thereby distract organisations from service delivery; or service providers are judged accountable for outcomes beyond their control.

How organisations approach reaching compliance can be influenced by many factors including the likelihood of detection; or competing organisational objectives and costs (Mansell 2006). Auditing and monitoring regimes are 'vulnerable to ritual compliance'

(Haines 2011 p26) whereby the focus is on what is measured rather than on the risk itself, leading to unintended consequences such as analysis of minutiae when things do go wrong; lack of attention to systemic failures; and the dominance of financial audits (Clegg 2008).

Risk management in human services has emphasised risks to staff and to organisations rather than risks to service users or their families not receiving quality services (Mansell 2006). Services and individuals and families frequently describe examples where health and safety requirements take precedence over their quality of life. As Mansell graphically describes:

> *'….where the risk of extended inactivity or being cooped-up all day to a person with intellectual disability may not be considered, but the risk of their challenging behaviour to the member of staff going shopping with them will be'.*

The expansion of home and community-based services offers greater possibilities for people with intellectual disability wanting services and this should increase competition between service providers as they devise ways to provide relevant and personalised support. However community based service delivery may also serve to further shield service delivery from quality assurance and improvement processes if service delivery becomes 'hidden'. New ways are needed ascertain the impact of support services on people's lives.

New directions in determining quality services

A shift is occurring from standards and compliance based measures of quality to a focus on 'is the person better off as a consequence of the service?' (Dutton 2003). For example, Kimmich (2003) reviewed the disability sector quality systems in seven US states. The features of these systems were: longitudinal evaluation of service outcomes based from interviews with consumers and primary support staff and home observation; diverse monitoring teams undertaking observation and interview; citizen monitoring; quality improvement systems including management planning, self-survey and outcomes review; onsite assessment of agency compliance by government staff team with standards including observation, interviews and records review; individual-based outcome monitoring system including assessment, service planning and implementation completed by direct care staff. Similar findings were described by Feinstein & Caruso (2003) where comparative information about service effectiveness identified and promoted best practices; issued performance profiles of providers, reporting strengths, areas for improvement and emphasising continuous quality improvement and enhancement. This created a process to ensure change at a (national), state and provider level through attention to public information about service effectiveness.

Measures of effectiveness take into account needs, desires and perceptions of individuals receiving services and support; consumer choice and satisfaction; and how people are treated and supported. Attention is needed to which organisational and staff practices contribute to outcomes for individuals, such as the influence of organisational culture, structures, and processes on staff practices (Bigby et al in press; Mansell & Beadle-Brown, 2012; Mansell, Beadle-Brown, & Bigby, 2013; Ripley 2013).

These developments require significant changes in 'who does monitoring, who responds to questions asked by monitors, what questions are asked, what is done with the information collected' (Feinstein & Caruso 2003). Directions for the future of quality systems include individuals and families becoming 'wise shoppers' by gathering formal and informal information about service effectiveness. Individuals and families 'need and expect information about provider capacity, service availability, past service accomplishment, comparative cost effectiveness, and consumer satisfaction' (Dutton 2003).

Observation is critical to determining the quality of staff practice and the lived experience of people with an intellectual disability, particularly those with severe and profound disability who cannot easily represent themselves (Clegg 2008, Mansell 2006). Staff in services often work in relatively unsupervised situations, have wide latitude and have to exercise considerable judgment in their work. As a first step, someone other than the person with an intellectual disability (who may not in any case be able to voice their concerns) 'needs to notice whether things are going well or badly' (Mansell 2006). Observations cannot be misrepresented in the same way as has occurred in paperwork (for example, Department of Health 2012: Victorian Ombudsman, 2011).

The NDIS framework does include the option for observation of staff practice and the experiences of individuals. Observation about the nature and consistency of staff practices can accompany inspection of paperwork and interviews with staff and people using services as the basis for judging service effectiveness. Observations can be undertaken by individuals and families, internal staff and external monitoring teams, depending on who needs the information. There are examples in other jurisdictions of independent monitoring teams including people with cognitive impairments (Feinstein & Caruso 2003), or experts with experience (UK Quality Care Commission 2014) including people with disabilities, families and professional with experience at service level. That is, people who know what to look for and what to ask people receiving support and their direct support staff. What to observe and ask during visits includes: how engaged and involved people are; how do staff and people supported describe what they are doing and why; are some people getting too much support when they could be acting more independently; and what is happening for people with the highest support needs: as they need the most support. It is necessary to be able to define what expected outcomes look like, in what context and for which people (for example, Bigby et al in press; UK Quality Care Commission 2013).

The role of independent third party accreditation is also changing. There is opportunity for accrediting bodies to continue to refine their role to remain relevant and to help providers to be sustainable and competitive with attention beyond organisational processes to satisfaction, quality of life, and service improvement measures and observations (Wiener et al 2007).

The missing dimension: information about service effectiveness

Many individuals with intellectual disability and their families receiving services have little sense of the effectiveness of the support received, except perhaps the achievement, or not, of short term goals. As a consequence of different priorities and personal experiences, people can be satisfied with vastly differing circumstances and service delivery quality.

Many service providers talk about their mission to, for example, increase social inclusion of people with disabilities – but do they? When it is known that having friends, family and community members in people’s lives increase their emotional, physical and mental well-being and when the NDIS is looking to build natural supports and safeguards: it is timely to ask services claiming to do this, how effective are they? Boards or government providers rarely receive performance data and information about program quality effectiveness in the same way that financial data might be routinely scrutinised. Few organisations report internally or externally against their mission. What suffices in many governance processes are reports about program quality centred on ‘one off’ agreeable stories about what is happening for specific individuals; the numbers of people in particular program types; or frequency of adverse events. Such descriptors are not irrelevant as examples of program effectiveness and quality but are not enough on their own.

Until the NDIS, there has not been a mechanism to pay attention to the lifelong impact of support (except through the compensable disability system). The NDIS framework recognises the importance of '*high quality'* information to individuals with intellectual disability and their families to enable them to meaningfully choose between support providers and to know how the chosen provider performs (p12). Therefore, individuals and families need information about what to ask to know if a provider is effective, that is, have experience achieving what is claimed.

Informed individuals and families are essential to the operation of the NDIS. One of the challenges for the NDIS with a market approach to support products is ensuring that individuals and families can benefit from the competition and variability of support offerings between providers. Providers have the opportunity to develop distinctive responses not limited by previous program and funding reporting and boundaries (for example, day options, shared supported accommodation). However, even more varied descriptions, like home handy man or holiday assistant, give no clue as to how well that support is provided, that is, is the service effective?

Information about service provider effectiveness would enable organisations to be confident the support they provide makes a difference in people's lives; individuals can know the strengths of organisations and compare between organisations in the context of their own personal priorities; and the NDIS can be sure systemic goals are being progressed. Service effectiveness can attend to different aspects of service quality important to individuals and families via outcomes (for example, 'we support people to be employed') and/ or outputs (for example, 'our staff arrive on time').

Summing up

Supporting people with an intellectual disability does require attention to the concurrent challenges of maximising people's opportunities *and* protecting people's vulnerabilities often throughout life. Effective services provide support which increases opportunities for choice and control and individualised lifestyles, increase life quality *and* establish safeguards for people with intellectual disability living in the community. People with an intellectual disability who are more engaged in their preferred daily activities, can do more for themselves and have more friends, family and community members are less vulnerable to the effects of social isolation and diminished lives. People who are socially linked can make better use available resources, and for some people their formal support requirements will reduce (with greater capability) or change (though support to community, friends and family, rather than directly to the person).

Service level performance data is additional to information about individual outcomes and is rarely available from providers or sought by regulators, accreditors or individuals and families. Information about service effectiveness describes the overall performance of a service by considering what has happened for many people being supported, against set indicators and over time. These indicators will vary between organisations depending on what support is being offered. How each organisation provides this information will be determined by how it defines its support products.

NDIS participants will be better placed to make meaningful choices if they are informed by their personal preferences; satisfaction of those who have used the provider *and* evidence for service effectiveness.

NDIS will not achieve as much as it could if individuals and families don’t have information about what constitutes good support and about the overall performance of providers. Without information about service effectiveness, it is difficult to imagine how organisations can define their support products for the NDIS and how individuals and families can meaningfully choose between the options. There is also potential to use this information more formally as part of provider registration.

References

References can be supplied on request.

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