Research and Practice in Intellectual and Developmental Disabilities, 2015
Vol. 2, No. 1, 37–44, http://dx.doi.org/10.1080/23297018.2015.1036769

Routledge
Taylor & Francis Group

Factors that Underpin the Delivery of Effective Decision-making Support for People with Cognitive Disability

Jacinta Douglas, Christine Bigby*, Lucy Knox & Michelle Browning

Living with Disability Research Centre, La Trobe University, Melbourne, Victoria

(*Accepted 29 March 2015*)

Over one million Australians have some form of cognitive impairment due to intellectual disability or acquired brain injury and require significant levels of support for decision-making. To date, the range and quality of support available has been poor, often tending toward undue paternalism, with deleterious consequences for the individual's sense of identity and quality of life. Efforts to rectify this situation have recently been championed by law reform commissions, which have focused on establishing new legal structures for support with decision-making. However, the crucial issue of how decision-making support is delivered *in practice* – in terms of quality and effectiveness – remains in urgent need of attention. The aim of this article is to describe four empirically based propositions that characterise effective decision-making support; orchestration by the primary supporter; commitment to person; support principles; and a repertoire of strategies that can be used flexibly depending on the type and context of particular decisions. These propositions are based on evidence from a series of qualitative studies conducted by the authors. Results of these studies enabled the identification of factors that underpin delivery of effective support and can be utilised to develop capacity-building education programs for people providing decision-making support to those with cognitive disability, either intellectual disability or acquired brain injury, which will substantially improve the quality of support given.

Keywords: decision-making; human rights; cognitive disability; supported decision-making

The exercise of individual choice and control is central to contemporary disability policy and the Australian National Disability Insurance Scheme (NDIS). The right to make one's own decisions is embedded in the United Nations Convention on the Rights of Persons with Disability (UNCPRD) to which Australia is a signatory. This right realises the philosophical value of self-determination associated with the health and wellbeing of individuals. The move to individualised funding and market-driven models of human service delivery, as exemplified in the NDIS, means that people with cognitive disability are confronted with more choice-making situations, and an increase in the range and complexity of decisions they are expected to make (Carney, 2013).

Over one million Australians (5% of the population) have some form of cognitive impairment due to intellectual disability or acquired brain injury (Australian Institute of Health and Welfare, 2013).These people are high users of disability services and, in turn, constitute over 60% of participants in the NDIS. This large group requires significantly

*Correspondence to: Professor Christine Bigby, Director, Living with Disability Research Centre, School of Allied Health, La Trobe University, Bundoora, Victoria, 3016. Email: c.bigby@latrobe.edu.au

more support for decision-making than other adults in the community. In the context of the Australian dedifferentiated disability policy and service system, the importance of tailoring either individual support or wider social change to take account of the specific issues created by different types of impairment is often neglected. Nevertheless, it is also important to highlight similarities between people with varying types and severity of impairment. In this article we focus on people with cognitive disabilities, using the term to refer to people with either intellectual disabilities or acquired brain injury, as both groups have a stable rather than declining level of cognitive impairment, and experience difficulties with executive function, self-direction, and communication of varying type and severity.

Support for decision-making has not been done well. Research points to people with cognitive disabilities having very limited or no involvement in either the major or minor decisions that affect their lives (Antaki, Finlay, & Walton, 2009; Bowey & MvGlaughlin, 2005). Traditionally, there has been an unsatisfactory choice between the extremes of appointing a guardian or unregulated informal support for decision-making. Guardianship orders authorise substitute decision-making that takes account of the preferences and best interests of the support receiver. However, its guiding principles do not meet the expectations of the United Nations treaty-monitoring body. Provision of unregulated informal support places few expectations on supporters and offers little guidance about supporting decision-making. At times, this has led to confusion about the legal standing of informal supporters; a tendency to resort to informal substitute decision-making or undue paternalism; and decisions that reflect the values of others, which are made in haste, are driven by resource issues, or are contrary to values and rights embedded in policy (Bigby, Bowers, & Webber, 2011; Bowey & McGlaughlin, 2005; Kohn & Blumenthal, 2014).

Growing acceptance of the broad concept of supported decision-making is creating opportunities to inject new expectations into the practice of support for decision-making. The foci of Law Reform Commissions in Australia and internationally (Australian Law Reform Commission, 2014; Law Commission Ontario, 2013, 2014; Victorian Law Reform Commission, 2012) have been on new structures to enable people with cognitive disabilities to access good support for decision-making without removal of their rights (Power, Lord, & deFranco, 2013). In Australia, clear expectations have been placed on nominees under the NDIS legislation, proposed Victorian reforms will create the role of "supportive guardians", and the Australian Law Reform Commission (2014, para 1.4) has proposed reform of all Commonwealth nominee provisions in line with four national decision-making principles: the right of all persons to make and have decisions respected; to be supported to make decisions; for supported decisions to be directed by the "will, preferences and rights" of the person; and for provision of appropriate safeguards.

Delivering Support for Decision-making

The creation of appropriate legal structures is essential to implement the right to make one's own decisions and consequently much attention has been paid to developing such structures. However, in comparison the crucial issue of the actual practice of delivering support for decision-making in whatever context has been severely neglected. A systematic review of the peer-reviewed literature between 2000 and 2014 about processes of support for decision-making of people with either intellectual disabilities or acquired brain injury found only a small body of literature reflecting a weak evidence base, with few robust designs or large scale studies (Bigby, Douglas, & Whiteside, 2015). Choice and decision-making were often used interchangeably and very few of the 54 studies

reported focused specifically on processes of support for decision-making, but rather included these as one of many factors investigated. For example, Ellem, O'Connor, Wilson, and Williams (2013) included support for decision-making as part of their study of social work practice with marginalised groups, and Beadle-Brown, Hutchinson, and Whelton (2012) included data on choice as one of a number of domains that have better outcomes as a result of staff practice being based on active support.

Indeed, former Chief Justice Mason of the High Court warned of the dangers of "experimental law-making" (Mason, 2013, p. 173) before gathering rigorous evidence on what works in terms of ensuring that the desires of people with cognitive disabilities are *actually* at the centre of decision-making. Early adopters of supported decision-making, such as Sweden and Canada, provide little evidence on the operation of mechanisms, such as micro boards, Sweden's *Godman*, or the practice of decision-making supporters (Boundy & Fleishner, 2013; Browning, 2010; Then, 2013). In fact, serious doubts are raised about the capacity of such schemes to deliver their intended benefits (Browning, 2010; Carney, 2013; Carney & Beaupert, 2013; Kohn & Blumenthal, 2014; Law Commission Ontario, 2014), or cater for all groups of people with cognitive disabilities, regardless of cultural background (Law Commission Ontario, 2014).

Within Australia, several small projects have piloted approaches to support for decision-making (Carney, 2014). Although not subject to rigorous research, they are internationally recognised for providing some insight into the conditions for effective support (Law Commission Ontario, 2014). They point to the need for decision-making supporters to have positive expectations about involvement of the support receiver; and for support to extend beyond the exercise of choice to the actual implementation of decisions. The authors' qualitative studies in respect of people with intellectual disabilities have revealed multiple factors that impact on the process of providing support and afforded insights into why existing practice has delivered only limited outcomes. For example, temporal constraints placed on many decisions and the dilemmas experienced by family members have been uncovered, such as balancing the practical and ideal, risks against protection, and differing perspectives about what might constitute "best interests" (Bigby et al., 2011; Bigby, Webber, & Bowers, 2014). Behaviours used by decision-making supporters to shape the choices and decisions made by people with cognitive disabilities have been identified (Bigby, Whiteside, & Douglas, 2015; Bigby, Frawley, & Phillips, 2014; Knox, Douglas, & Bigby, 2015a, 2015b). These findings suggest that the interests of supporters can consciously and unconsciously dominate decisions. Indeed, supporters receive little guidance to grapple with tensions between paternalism and dignity of risk, even in supported decision-making schemes with clear expectations that the desires of the support receiver be at the centre of decisions (Browning, Bigby, & Douglas, 2014). These studies are also the first to investigate the nature of support for decision-making available to people with acquired brain injury, which enables comparison to experiences of people with intellectual disabilities. For example, spouses are rarely decision-making supporters for people with intellectual disabilities; knowing a person with acquired brain injury well, involves knowledge about their life both pre- and post-injury, whereas such a significant marker is not present in the lives of people with intellectual disabilities.

These studies have identified a diverse range of support strategies and decision-related contextual factors that can affect strategy selection for supporters. Highlighted is the centrality of familial or social relationships between those who provide and those who receive support, and different approaches to support used by spouses, parents, other family members, clinicians, and service providers, with varying degrees of success (Bigby et al., 2015; Knox, Douglas, & Bigby, 2013, 2015a, 2015b). These studies have also

demonstrated that people with cognitive disabilities have a "positive" or "successful" experience of decision-making support if support is provided by one or more individuals with whom they have a trusting relationship; who have a knowledge of their history and goals (including previous decisions and outcomes), and the nature of their impairment and level of functioning; who are flexible, and use variable strategies to tailor their support to the unique needs and characteristics of each individual; and who collaborate with the individual to reach their desired outcome.

Exploring Factors that Underpin the Delivery of Effective Support

Using evidence from these studies (Bigby et al., 2015; Bigby, Frawley, & Phillips, 2014; Bigby, Webber, & Bowers, 2014; Douglas, Drummond, Knox, & Mealings, in press; Knox et al., 2015a, 2015b), the Australian pilot studies (Carney, 2014), and the literature on maximising choice at a micro level for people with cognitive disabilities (Willner, Bailey, Parry, & Dymond, 2010), empirically based propositions have been developed that describe factors in four broad areas with implications for practice: (a) orchestration, (b) commitment, (c) support principles, and (d) strategy development. At this stage, the evidence suggests that factors within these domains appear to be common across people with varying severity of acquired brain syndrome and intellectual disabilities, in different contexts, and with different relationships to supporters.

Orchestration captures the importance of two aspects of the role of a primary supporter in the delivery of support for decision-making. First, a primary supporter needs to have a relationship with the person with a cognitive disability. The relationship does not have to be "excellent" or "perfect" but rather it needs to be "good enough"; that is, characterised by trust, genuine positive regard, and honest interpersonal interactions. Second, a primary supporter needs to recruit or orchestrate the involvement of other supporters, both formal and informal, around the person with the cognitive disability, and identify and resolve conflict among them.

Commitment is the key to effective delivery of support for decision-making. Effective supporters recognise that having knowledge of the person's history, the dynamic nature of their preferences, and the effect of their specific cognitive impairments on their decision-making needs is crucial to the process. They are committed to developing this knowledge, continually learning about the person with cognitive disability, and changing their own expectations based on new knowledge.

Support principles lay the foundation for effective support. These principles relate equally to collective and individual approaches to support and they represent essentials of practice for those providing support. Several principles can be drawn from examples of "effective" support and "good" experiences: recognise that the decision-making agenda is based on the desires of the support receiver and that these can be realised in many different ways; be cognisant of one's own values and their potential impact on the support process; understand risk and its potential costs and benefits and use rights as a touchstone for weighing these; preserve the self-identity of the person being supported; and be able to articulate the reasoning processes involved in supporting and reaching a decision with a person.

Finally, effective delivery of support rests upon *strategy development*. Effective supporters need to develop a repertoire of flexible strategies that they can call upon readily as personal and contextual demands vary. Strategy use depends on time; situation; the significance, scope, and nature of the decision; and who else might be involved in or affected

by the decision. Strategies include: use of supporters as a sounding board for issues; provision of information; testing options and potential experiences that might result from a decision; introducing and nurturing the seeds of ideas about options; bringing in others to trial a situation; creating distance to enable greater autonomy; breaking a decision into smaller components that are shared across the person and supporter; imagining or re-imagining the future; teaching skills; and considering choice options within defined boundaries or parameters.

Building Capacity for Effective Decision-making Support

From the perspective of self-determination, it is clear that good support for decision-making is crucial. It enables the will and preferences of people with cognitive disabilities to be central to their decisions and increases their control over their own lives. In turn, this can positively affect the self-identity, psychological wellbeing, and quality of life of people with cognitive disabilities (Brown & Brown, 2009; Nota, Ferrari, Soresi, & Wehmeyer, 2007). The introduction of the NDIS within Australia has further emphasised the need for provision of effective decision-making support. In the NDIS, decisions about the value of individual support packages will be based largely on the goals articulated by participants. In turn, decisions about types of services purchased with package funds will rest firmly with participants. The majority of adult participants in the NDIS will have some form of cognitive impairment and consequently will require support with the decision-making process, and many people with cognitive disabilities have no strong informal relationships through which support for decision-making occurs.

New strategies are being piloted to recruit, train, and support community volunteers to be involved, either individually or as part of a decision-making support group around an individual without informal support. Although in its early stages, and resembling to some extent a long tradition of private legal and financial advice, there are also moves to establish private fee-for-service programs to support people with cognitive disabilities with decision-making about aspects of their lives. The existing challenge faced by disability service providers in facilitating support for everyday decision-making will be exacerbated as their long-term clients become participants in the NDIS, and have to make major life decisions and choose service providers. The new expectations of nominees for NDIS participants and other decision-making supporters will also generate demands on the National Disability Insurance Agency, Guardianship Tribunals, Public Trustees, and Public Advocates to provide effective education and support of supporters.

Developments such as these demonstrate the need for evidence-based and effective resource and training materials that have applicability across the diverse informal and formal contexts in which support for decision-making occurs. Availability of demonstrably effective training may also offer the potential to reduce the need for formal guardianship by providing "gatekeepers" to applications, such as Public Advocates and service providers, with alternatives to redress perceived shortcomings with informal decision-making support. There is further potential to assist Tribunals in framing orders about provision of informal support by inclusion of capacity-building provisions for training of supporters.

Until now, limited empirical investigation into the practice of support for decision-making has meant that our current tools to guide support are largely untested and based primarily on ideology, principles drawn from social, health, and legal professional practices, or practice wisdom rather than empirical evidence (Department of Human Services,

2014; Watson & Joseph, 2011). However, it is essential that capacity-building education programs are evidence-based and rigorously evaluated in terms of impact and potential to change the attitudes and behaviour of decision-making supporters and thus the sense of control of those in receipt of support. The factors that the authors have proposed as underpinning delivery of effective decision-making support (orchestration, commitment, support principles, and strategy development) provide the foundation for further research on effective support for decision-making, training and resource development, and for evaluation.

Conclusion

The NDIS has added urgency to the quest that had already begun to find workable ways of supporting people with cognitive disabilities to exercise choice and control through making their *own* decisions or *being involved* in decision-making processes. The recent Inquiry into the United Kingdom's Mental Capacity Act 1995, and significant evidence from previous disability reform and other sectors, clearly demonstrates that legislation and policy principles must be backed up by strong implementation strategies to change culture and practice in formal and informal spheres if philosophically driven and well-intentioned reform is to change people's lives. The promise of rights and wellbeing of people with cognitive disabilities encapsulated in the UNCPRD and NDIS will be jeopardised if insufficient attention is given to implementation issues and ensuring access to ongoing and effective support for decision-making.

Acknowledgements

The authors thank Professor Terry Carney for his helpful advice on the development of this article.

This is a revised version of a paper delivered at the 8th Annual Roundtable on Intellectual Disability Policy, "Supporting People with Cognitive Disability with Decision-making: Learnings from recent Australian research and international experiences", La Trobe University, 10 December 2014.

References

Australian Institute of Health and Welfare. (2013). *Australia's welfare 2013*. Canberra: Australian Institute of Health and Welfare.

Australian Law Reform Commission. (2014). *Equality, capacity and disability in Commonwealth laws (DP 81)*. Sydney: Australian Law Reform Commission.

Antaki, C., Finlay, W., & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday pPractice. *Journal of Policy and Practice in Intellectual Disabilities*, *6*, 260−266.

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centred active support - Increased choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities, 24*(5), 291−307

Bigby, C., Bowers, B., & Webber, R. (2011). Planning and decision-making about the future care of older group home residents and transition to residential aged care. *Journal of Intellectual Disability Research*, *55*(8), 777−789.

Bigby, C., Frawley, P., & Phillips, L. (2014). "Well hang on, that's sort of not right": Family and staff perspectives on "Cultures of Respect" in supported accommodation services for people with intellectual disability, La Trobe University On-line Repository http://hdl.handle.net/1959.9/308905.

Bigby, C., Webber, R., & Bowers, B. (2014). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work*. Advance online publication. doi: 10.1080/0312407X.2014.950678

Bigby, C., Douglas, J., & Whiteside, M. (2015). Processes and dilemmas in support for decision making. Report to Scope. Melbourne: Living with Disability Research Centre, LaTrobe University On- Line Repository. [link to be provided]

Boundy, M., & Fleischner, B. (2013). *Supported Decision Making Instead of Guardianship: An international overview*. Washington: TASC, National Disability Rights Network.

Bowey, L., & McGlaughlinm A. (2005). Assessing the barriers to achieving genuine housing choice for adults with a learning disability: the views of family carers and professionals. *British Journal of Social Work*, *35*(1), 139−148.

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 11−18.

Browning, M. (2010). *Report by Michelle Browning 2010 Churchill Fellow To Investigate New Models of Guardianship and the Emerging Practice of Supported Decision Making*. Retrieved from https://www.churchilltrust.com.au/media/fellows/Browning_Michelle_2010.pdf.

Browning, M., Bigby, C., & Douglas, J. (2014). Supported Decision-Making: Understanding how its conceptual link to legal capacity is influencing the development of practice. *Research and Practice in Intellectual and Developmental Disabilities*, *1*(1), 34−45.

Carney, T. (2013). Participation & service access rights for people with intellectual disability: A role for law? *Journal of Intellectual & Developmental Disability*, *38*(1), 59−69.

Carney, T. (2014). Clarifying, operationalising and evaluating supported decision making models. *Research and Practice in Intellectual and Developmental Disabilities*, *1*(1), 46−50.

Carney, T., & Beaupert, F. (2013). Public and private bricolage-challenges balancing law, services & civil society in advancing CRPD supported decision making. *UNSW Law Journal*, *36*(1), 175−201.

Department of Human Services. (2014). *A guide to supporting people with a disability to make their own decisions*. Melbourne, Victoria: Department of Human Services.

Douglas, J., Drummond, M., Knox, L., & Mealings, M. (in press). Rethinking social-relational perspectives in rehabilitation: traumatic brain injury as a case study. In K. McPherson, B. E. Gibson, & A. Leplege (Eds.), *Rethinking rehabilitation theory*. Boca Raton: CRC Press.

Ellem, K., O'Connor, M., Wilson, J., & Williams, S. (2013). Social work with marginalised people who have a mild or borderline intellectual disability: Practicing gentleness and encouraging hope. *Australian Social Work*, *66*(1), 56−71.

Knox, L., Douglas, J., & Bigby, C. (2015a). "I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents. *Neuropscychological Rehabilitation*, doi:org/10.1080/09602011.2015.1019519

Knox, L., Douglas, J, & Bigby, C. (2015b)."The biggest thing is trying to live for two people": Spousal experiences of supporting decision-making participation for partners with traumatic brain injury. *Brain Injury*, doi:10.3109/02699052.2015.1004753

Knox, L., Douglas, J. M., & Bigby, C. (2013). Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury. *Disability & Rehabilitation*, *35*(22), 1926−1932.

Kohn, N. A., & Blumenthal, J. A. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disability and Health Journal*, *7*(1), S40−S43.

Law Commission Ontario. (2013). *Capacity of adults with mental disabilities and the federal RDSP*. Toronto: Law Commission of Ontario.

Law Commission Ontario. (2014). *Legal capacity, decision-making and guardianship. discussion paper may 2014*. Toronto: Law Commission of Ontario.

Mason, A. (2013). Foreword. *University of New South Wales Law Journal*, *36*(1), 170−174.

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self−determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research 51*(11), 850−865.

Power, A., Lord, J., & deFranco, A. (2013). *Active citizenship and disability*. Cambridge: Cambridge University Press.

Then, S.-N. (2013). Evolution and innovation in guardianship laws: Assisted decision-making. *Sydney Law Review*, *35*(1), 133−166.

Victorian Law Reform Commission. (2012). *Guardianship: Final report*. Melbourne: Victorian Law Reform Commission.

Watson, J., & Joseph, R. (2011). *Listening to those rarely heard*. Melbourne: Scope Victoria.

Willner, P., Bailey, R., Parry, R., & Dymond, S. (2010). Evaluation of the ability of people with intellectual disabilities to 'weigh up' information in two tests of financial reasoning. *Journal of Intellectual Disability Research*, *54*(4), 380−391.