



LA TROBE
UNIVERSITY

**Living with
Disability**
RESEARCH CENTRE
Supporting inclusion of people
with cognitive disability



The Process of Supported Decision Making: Learning from the Experiences of People with Intellectual Disabilities and their Supporters in Canada

Michelle Browning, Christine Bigby, Jacinta Douglas
Living with Disability Research Centre
La Trobe University

Why explore supported decision making?

There are strong ethical and philosophical reasons to promote the development of supported decision making as an alternative to legal regimes such as guardianship.

However, there has been little research conducted in the area which can inform the development of policy and legislation internationally.

Little is understood about what supporters actually do when they assist people with intellectual disabilities to make decisions. This research sought to explore this and develop a theory which could explain the process of decision-making support.

My research

Qualitative research using a grounded theory methodology

Aimed at understanding the process of supported decision making in the context of two legal structures in Canada:

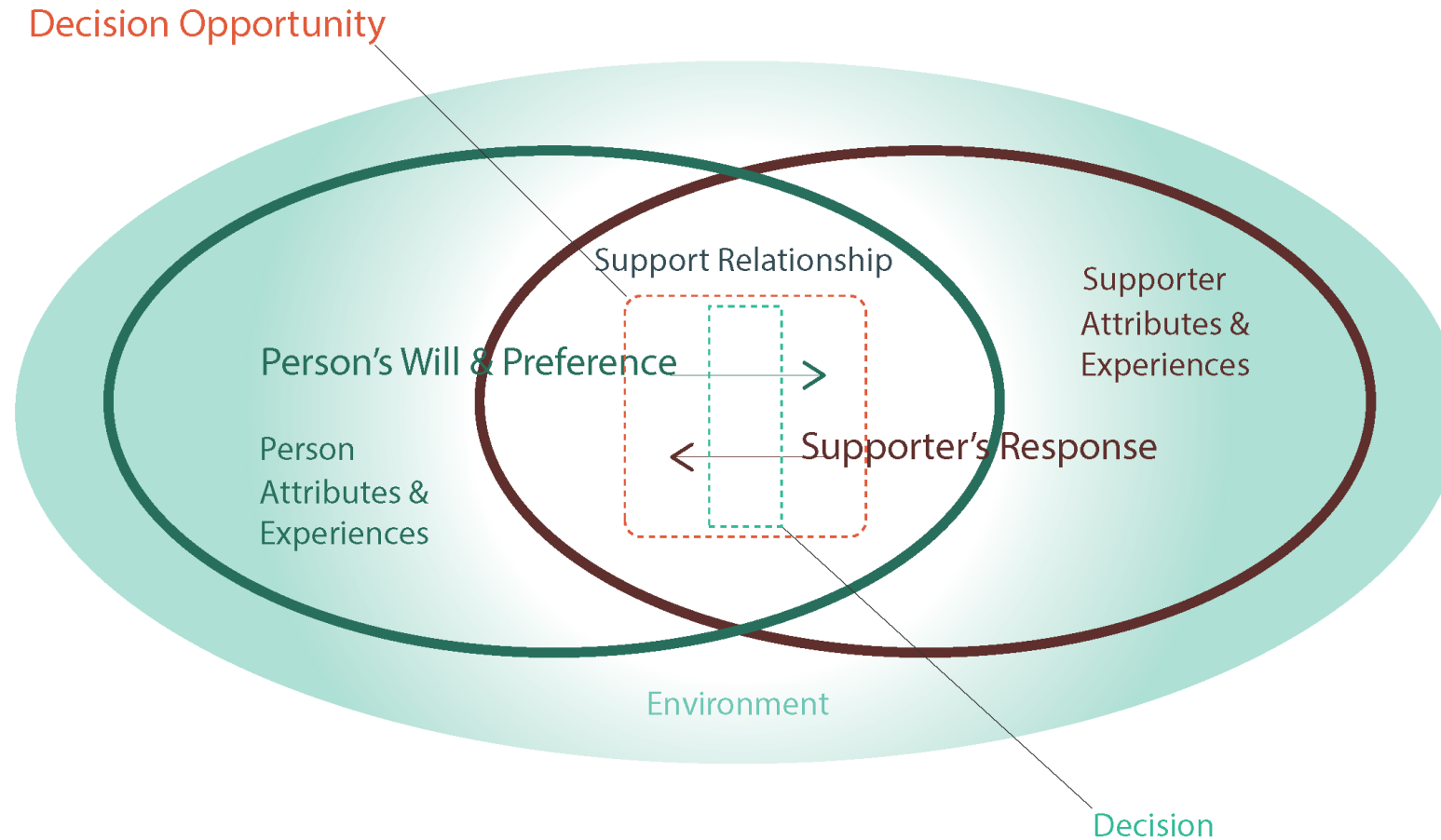
1. Microboards
2. Representation Agreements

Recruited 7 central participants with intellectual disabilities and their support networks (6 in BC, 1 in Ontario)

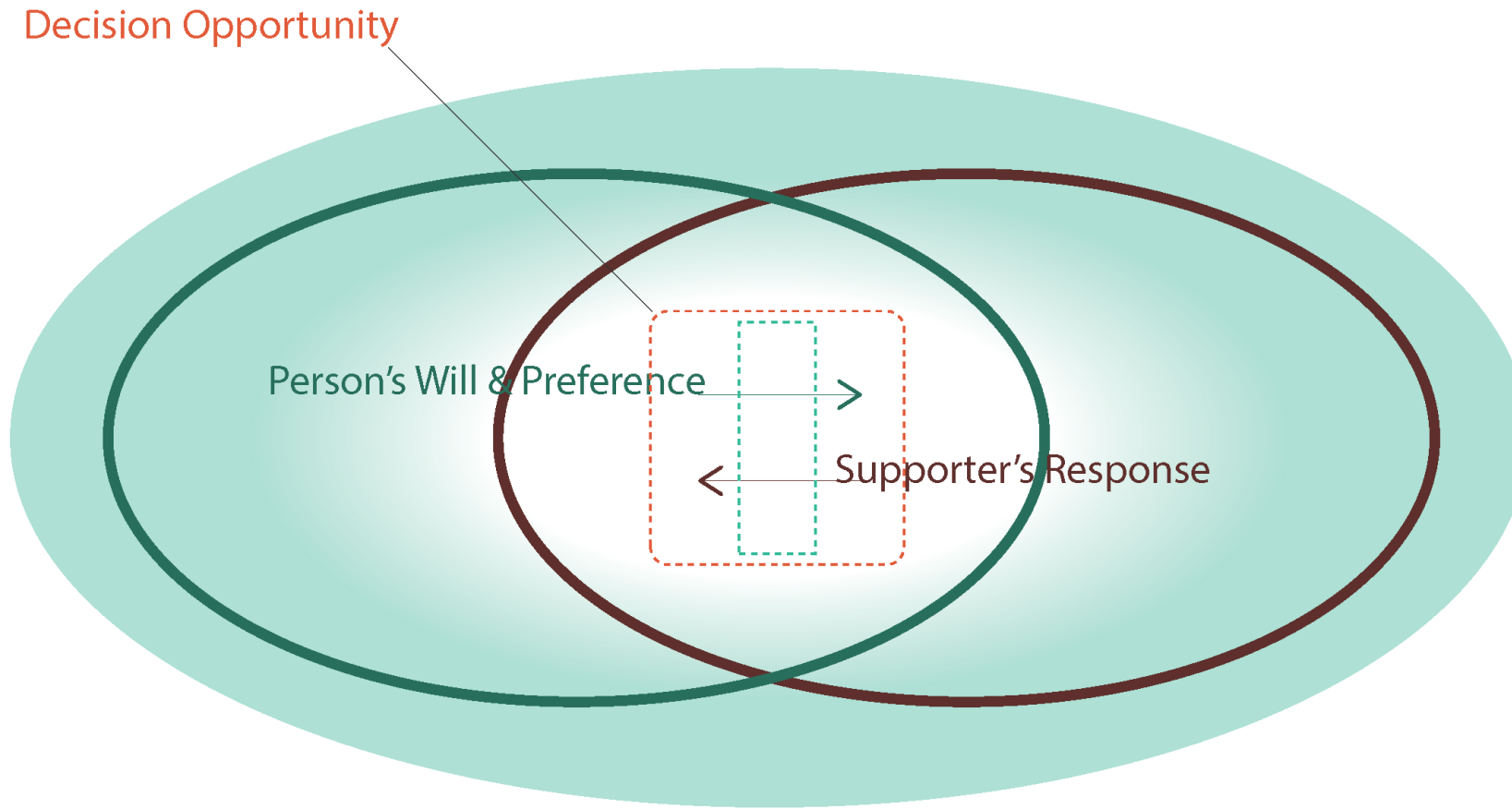
Conducted 34 semi-structured interviews (family members, friends, paid staff) and over 100 hours of participant observation

Data analysis involved initial, intermediate and theoretical coding of interview transcripts and observation field notes

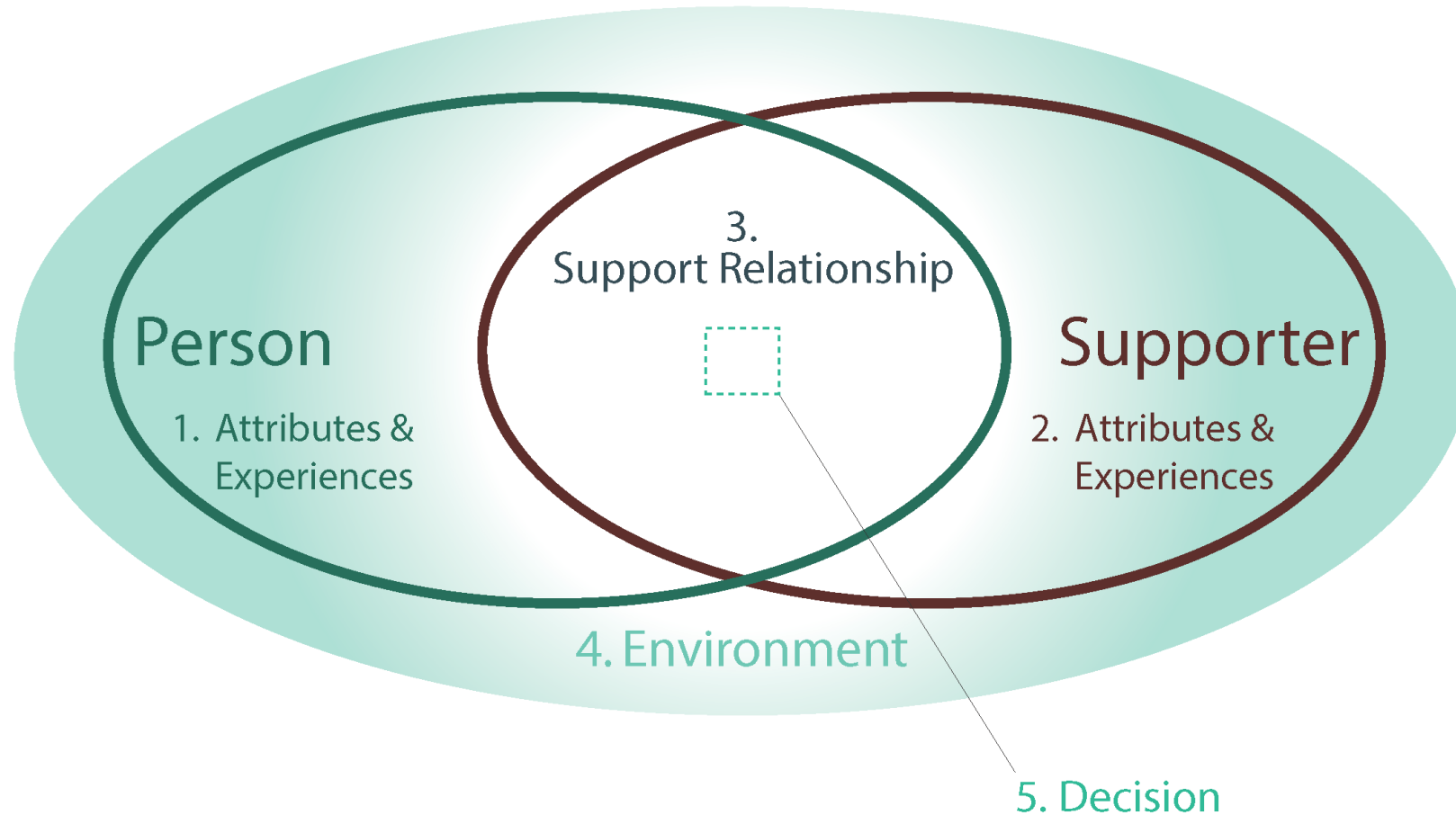
A model of the process of decision-making support



The process of decision-making support



The five factors which shaped the process



The process of decision-making support was dynamic

The process of decision-making support always involved the elements identified in the model but because the nature of each changed, as did the way they interacted for each decision, the support provided and the outcomes varied enormously.

Support that worked for the same person in one situation did not necessarily work in a different situation. And a certain type of support could be enabling in one situation and restrictive in another.

The process discovered in this research could not be described as a series of specific steps, or the implementation of specific strategies because it was not a linear, static process. Rather the process was multifaceted, dynamic and recursive.

Decision-making participation of people with intellectual disabilities needs to be understood in the context of a complex, dynamic process

The model of decision-making support developed from this research provides a unique understanding of the multitude of factors which shaped the ability of central participants to engage in decision-making.

Historically, the law, policy makers and practitioners have been overly focused on the impact of a person's cognitive ability when considering their ability to participate in decision-making.

This research demonstrated there were a broad range of factors which significantly shaped the ability of central participants to engage in decision-making, many of which had nothing to do with their cognitive ability. Existing research has identified some of these things individually, such as the influence of supporter beliefs and expectations on a person's opportunities to engage in decision-making. The unique contribution of this research is in understanding that it is the complex interaction of individual, relational, decisional and environmental factors which together shaped the person's ability to participate in the process of decision-making support.

Implications for how we think about decision-making ability

In this research, the participation of people with intellectual disability reflected the social model of disability (Shakespeare, 2006) in that a range of factors which sat outside the person with disability shaped their inclusion in decision-making.

The model of decision-making support developed from this research challenges thinking about decision-making ability which tries to locate that ability solely within the cognitive capacities of the person. Decision making ability also needs to consider things such as prior experiences, values, beliefs and expectations of the person and their supporter, stress and health, relational quality, environmental constraints and decisional consequences.

Future legislation and policy which promotes supported decision-making will need to ensure it views decision making ability in a much broader way than 'mental capacity.' Decision making ability is so much more than a person's autonomous ability to understand and appreciate the consequences of a decision.

The provision of decision-making support needs to be understood in the context of a complex, dynamic process

The provision of decision-making support also needs to be understood in the context of a complex, dynamic process.

Some research has pointed to the importance of relational quality as a significant contributor to quality decision-making support (Knox et al., 2015; Knox et al., 2016a; Knox et al., 2016b; Watson, 2016b).

Other research has suggested supporters need to be aware of their own values and how they shape their perception of the consequences of decisions including the assessment of risk (Bigby et al., 2017).

This research suggests a multitude of factors which include personal attributes of both the person and their supporter, their relationship, the decision, and a range of environmental factors will shape how supporters provide support in the decision-making process. Therefore, it may be unhelpful to try and single out only one or two factors as primarily influencing the provision of support.

Implications for practice

It seems highly likely that supporters will benefit from developing a greater understanding of the wide range of factors shaping how they respond to the person's will and preferences in the decision-making process.

Developing the ability to step back from the process and examine the individual, relational, decisional and environmental factors at play would likely help supporters reflect on the type of influence they have over the person's participation in the process and the outcome.

For example, self-reflection may assist supporters to develop an awareness of the personal attributes such as the values, beliefs, goals and priorities they bring to the process. Self-reflection may also help supporters identify the assumptions they have about the person's decision-making ability, the expectations they have regarding their role as a supporter and their beliefs about what constitutes a good life or good decision-making outcome.

Risk of oversimplification

This research suggests it is important not to underestimate the complexity and dynamic nature of providing decision-making support. It is difficult and taxing work.

Those that underestimate the complexity, risk oversimplifying the solutions to challenges experienced within practice. For example, Arnstein-Kerslake suggests undue influence occurs when the support relationship is characterised by “domination” (p.13). Defining undue influence according to a particular characterisation of the support relationship does not reflect the complexity of the relationships encountered in this research. It also does not reflect the range of other factors which shaped how supporters responded during the process.

It is hoped this model assists practitioners, policy makers and those engaged in law reform to better understand the process of decision-making support and the importance of respecting the complexity and dynamic nature of its implementation when crafting supported decision-making legislation.

References

- Arnstein-Kerslake, A. (2014). An empowering dependency: exploring support for the exercise of legal capacity. *Scandinavian Journal of Disability Research*. doi: 10.1080/15017419.2014.941926.
- Bigby, C., Whiteside, M., & Douglas, J. (2017). Providing support for decision making to adults with intellectual disabilities: perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disabilities*, doi:10.3109/13668250.2017.1378873
- Knox, L., Douglas, J.M. & Bigby, C. (2015). 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI. *Brain Injury*, 29(6), 745-757. doi:10.3109/02699052.2015.1004753.
- Knox, L., Douglas, J.M., & Bigby, C. (2016a). Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury. *Research and Practice in Intellectual and Developmental Disabilities*, 3(1), 12-21. doi:10.1080/23297018.2015.1077341
- Knox, L., Douglas, J.M., & Bigby, C. (2016b). "I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents. *Neuropsychological rehabilitation*, 26(2), 236-260. doi:10.1080/09602011.2015.1019519.
- Shakespeare, T. (2006). *Disability Rights and Wrongs*. Abingdon: Routledge.
- Watson, J. (2016b). Assumptions of decision-making capacity: The role supporter attitudes play in the realisation of article 12 for people with severe or profound intellectual disability. *Laws*, 5(6), 1-9. doi: 10.3390/laws5010006.

Thank you

Michelle Browning

mjbrowning@students.latrobe.edu.au

