



Reflecting on your role as a decision supporter

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Outline

1. Provide an overview of supported decision-making.
2. Learn about the importance of the quality of the relationship you have with the person you support.
3. Explore the role you have responding to the person's will and preferences.



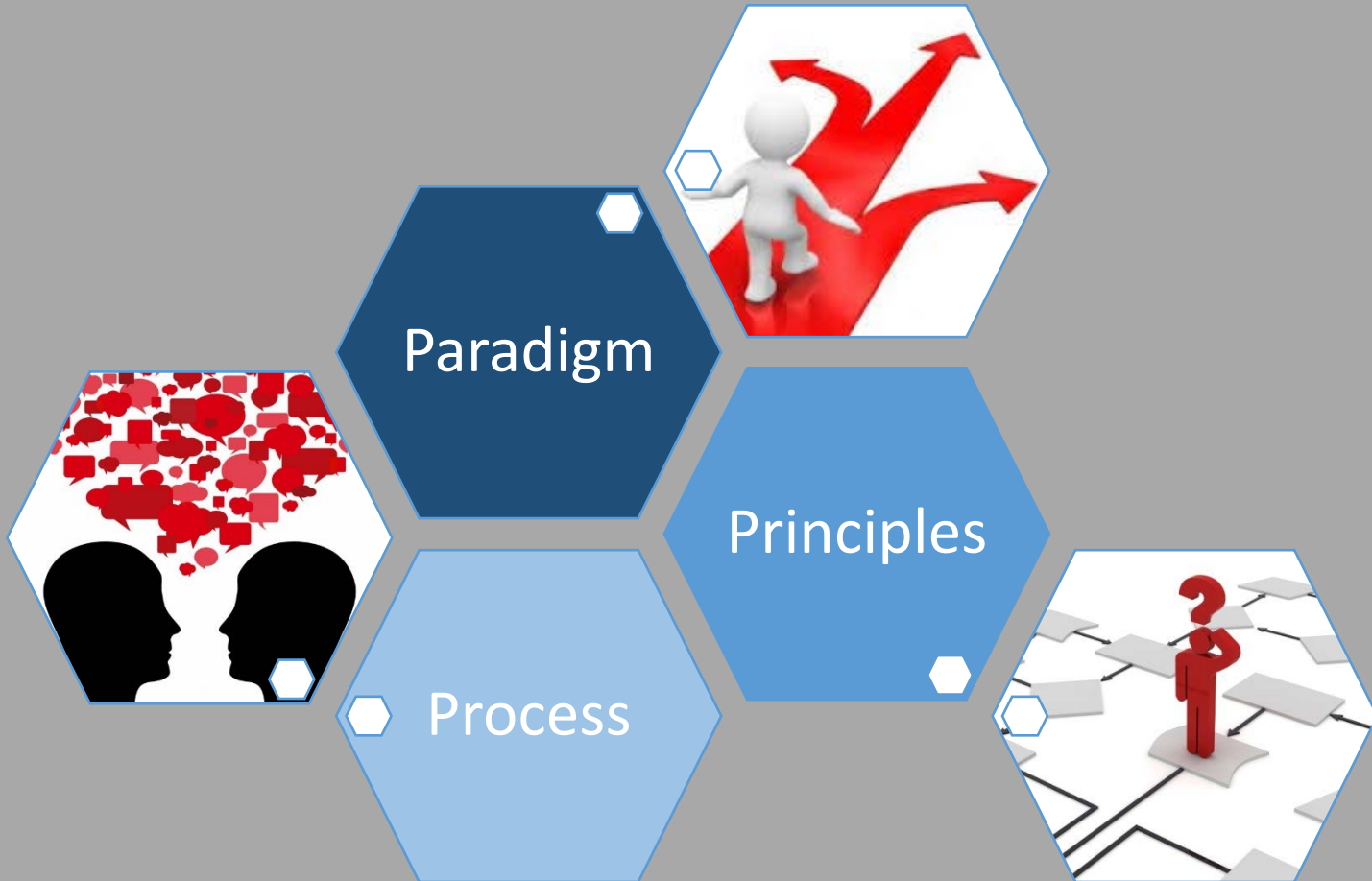
I'VE GOT MY THINKING CAT ON



What is supported decision-making?



What does the literature say?



A means of obtaining important human rights

“...all human persons, regardless of their decision-making capabilities, should enjoy “legal capacity” on an equal basis...”

Article 12 calls for not only the respect for legal capacity on an equal basis but also places an obligation on states to provide access to the support necessary for the exercise of legal capacity.

This requires the replacement of substituted decision-making regimes with supported decision-making ones.”

(Flynn & Arnstein-Kerslake, 2014).

A legal process based on a set of principles

Supported decision-making emphasizes the person's right to **self-determination and autonomy**, the presumption of **capacity**, and the right to **decision-making supports to enable equality**.

(Bach, 1998)

Support process leading to self-determination

Supported decision-making is assisting a person with disability **to make their own decisions, make choices about their life and exercise control over things that are important to them**

(NSW Family & Community Services, 2015)

Supported decision-making is a range of practices whereby people with disabilities are assisted **to make or implement** their own decisions

(WAIIS, 2013)

Why is supported decision-making important?

practical assistance



self-determination

exercise legal capacity



personhood



MICHAEL BACH

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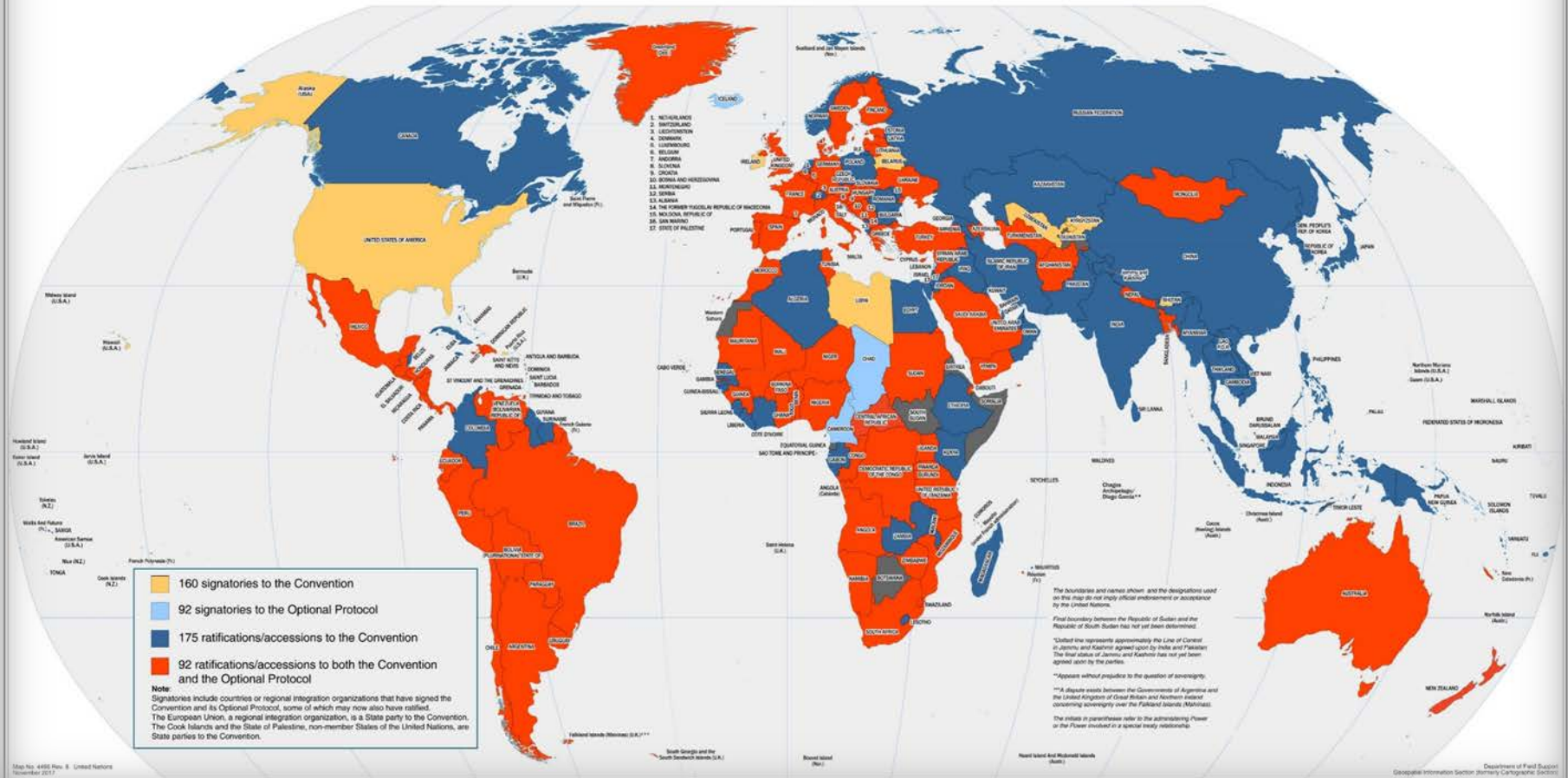
Enabling an important human right



CRPD and Optional Protocol Signatures and Ratifications

Not Signed
 Signed Convention
 Signed Convention & Protocol
 Ratified Convention
 Ratified Convention & Protocol

As of 19 September 2017



**What does all this mean for you as a
decision supporter?**



Reflection Exercise 1

Think of a time when you needed support to make a decision. What was the decision?

How much support did you need? What type of support did you need to make the decision?

Was the support provided helpful to you? Why or why not?

What did your experience teach you about providing someone else with decision support?

There is a growing body of research exploring supported decision making

- 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
- Bigby, C., Douglas, J., Carney, T., Then, S., Wiesel, I., & Smith, E. (2017). Delivering decision-making support to people with cognitive disability – what has been learned from pilot programs in Australia from 2010-2015. *Journal of Social Issues*, 52(3), 222-240. doi: 10.1002/ajs4.19
- Knox, L., Douglas, J., & Bigby, C. (2013). Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury. *Disability and Rehabilitation*, 35(22), 1926-1932. doi:10.3109/09638288.2013.766270
- 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.
- Knox, L., Douglas, J.M., & Bigby, C. (2016c). "I've never been a yes person": Decision-making participation and self-conceptualisation after severe traumatic brain injury. *Disability and Rehabilitation*, doi:10.1080/09638288.2016.1219925
- Knox, L. (2016d). *The experience of being supported to participate in decision-making after severe traumatic brain injury* (Doctoral dissertation). La Trobe University, Melbourne.
- Watson, J. (2016a). *The right to supported decision-making for people rarely heard* (Doctoral dissertation). Retrieved from https://www.researchgate.net/profile/Joanne_Watson/publication/258997358_Thesis_The_right_to_supported_decision-making_for_people_rarely_heard/links/5751420a08ae17e65ec149cf.pdf
- 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.

This research says the quality of your support relationship is important



Supporters with a positive relationship...

- Understood the consequences of the brain injury
- Appreciated what was important to the person
- Had a positive approach to risk

Knox, Douglas & Bigby
(2015; 2016a; 2016b; 2016c; 2016d)

Knowing the person

- History, life story, self narrative
- Health, abilities, defining qualities
- Communication style
- Values and beliefs
- Goals, priorities and expectations

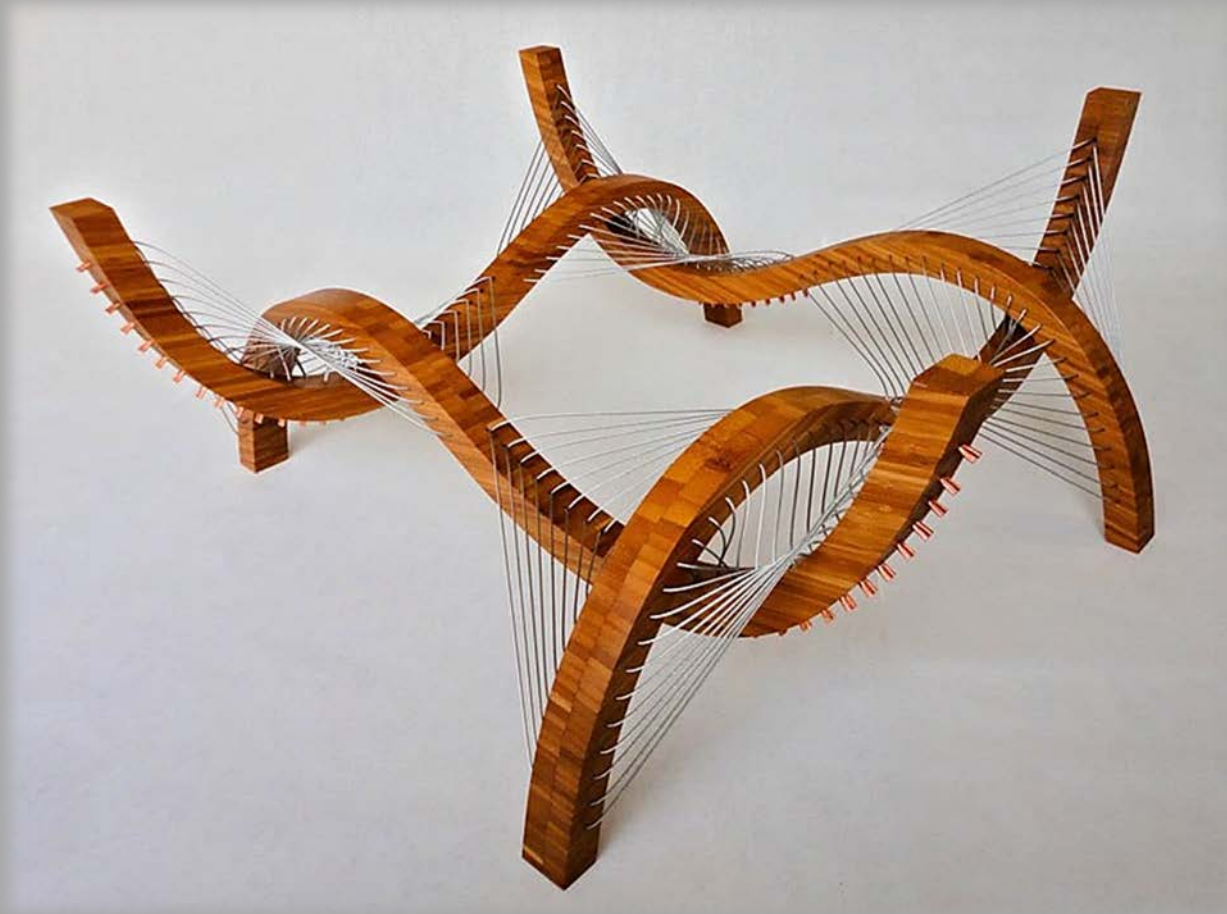
“...generally the **closer** supporters’ reported their relationship to be with the person they were supporting, the **more likely** they were to be **responsive** to that person, in terms of acknowledging, interpreting and acting on their expression of preference” (p.337).

Watson (2016)

Closeness more important than role



Dilemma of practice



Case study: exploring relational closeness and neutrality

Ben has expressed a strong desire to move out of the family home where he lives with his parents. Ben is twenty five and has a mild intellectual disability and episodic periods of severe depression. As a result of his depression Ben has been unable to maintain regular employment since leaving school. Ben's parents do not support his desire to move out because they believe his mental health is not stable enough. Their knowledge of Ben's cycles of depression and his inability to identify the warning signs of an episode lead them to believe living independently is not achievable for him at the moment. Ben has sought the support of an advocate to help him achieve his goal of living independently. The advocate believes Ben is capable of moving out of the family home with the right support.

What does relational closeness offer in this situation?

What does neutrality offer in this situation?

How do you think relational closeness and neutrality should impact on the support the advocate and parents provide to Ben in this situation?

Family members had **an overarching vision** for their family member's life.

Workers did not hold visions for the people they supported but saw their support as being **guided by** ideas of **being neutral**.

Bigby, Whiteside & Douglas (2017)

Something to consider...



Morning tea



Reflection Exercise 2

What are some things you do in your role as a decision supporter?

What do you consider to be the most important aspect of your role?

What are some of the things that make providing decision support difficult?

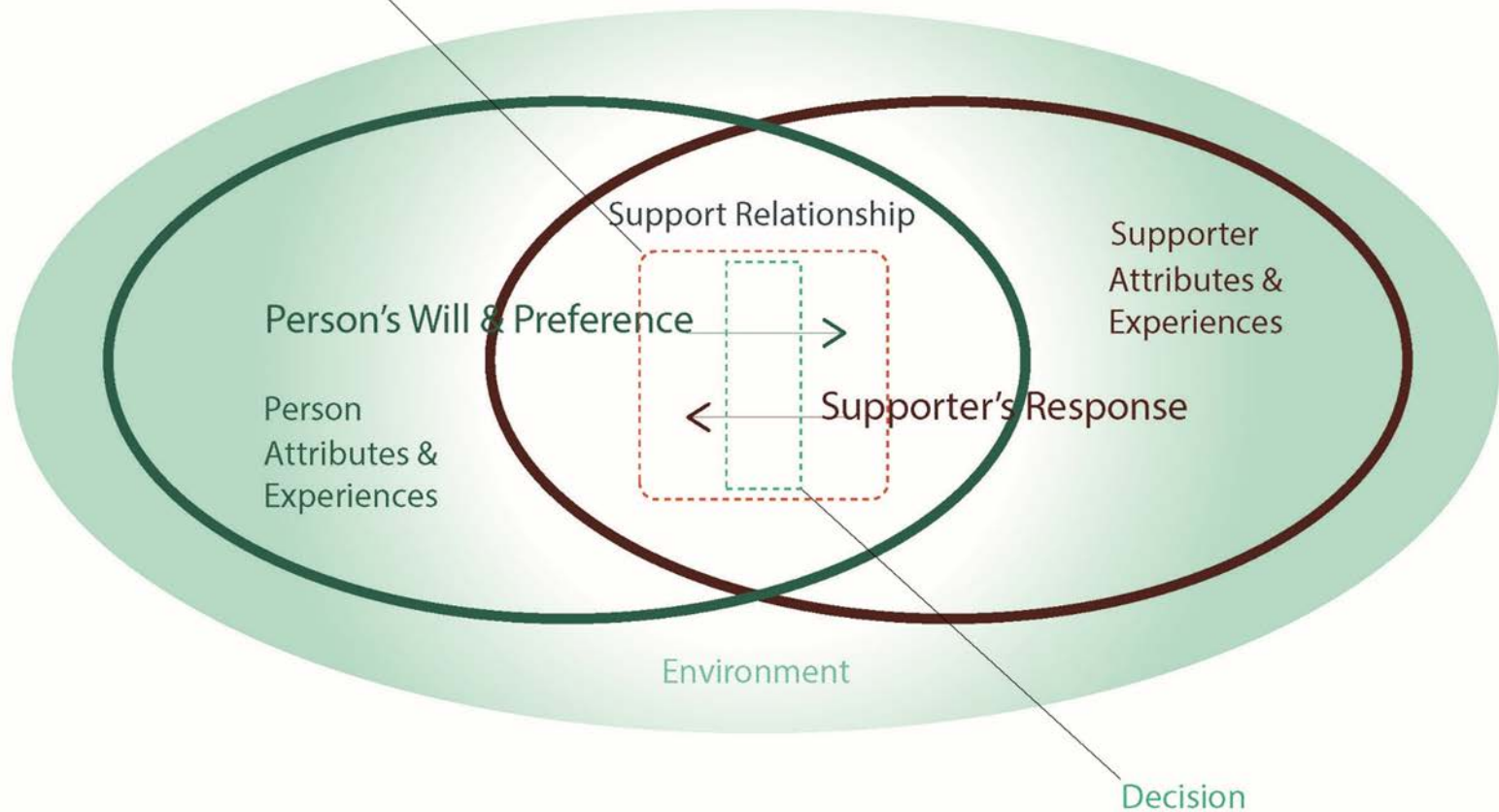
How do you define success as a decision supporter?

Key role of decision supporters

- The key role of decision supporters is to respond to the person's expressions of will and preference.
- A person's will motivates and initiates their actions.
A person's preferences are the things they like and dislike.
- Decision supporters may need to support the person to be able to express and clarify their will and preferences.

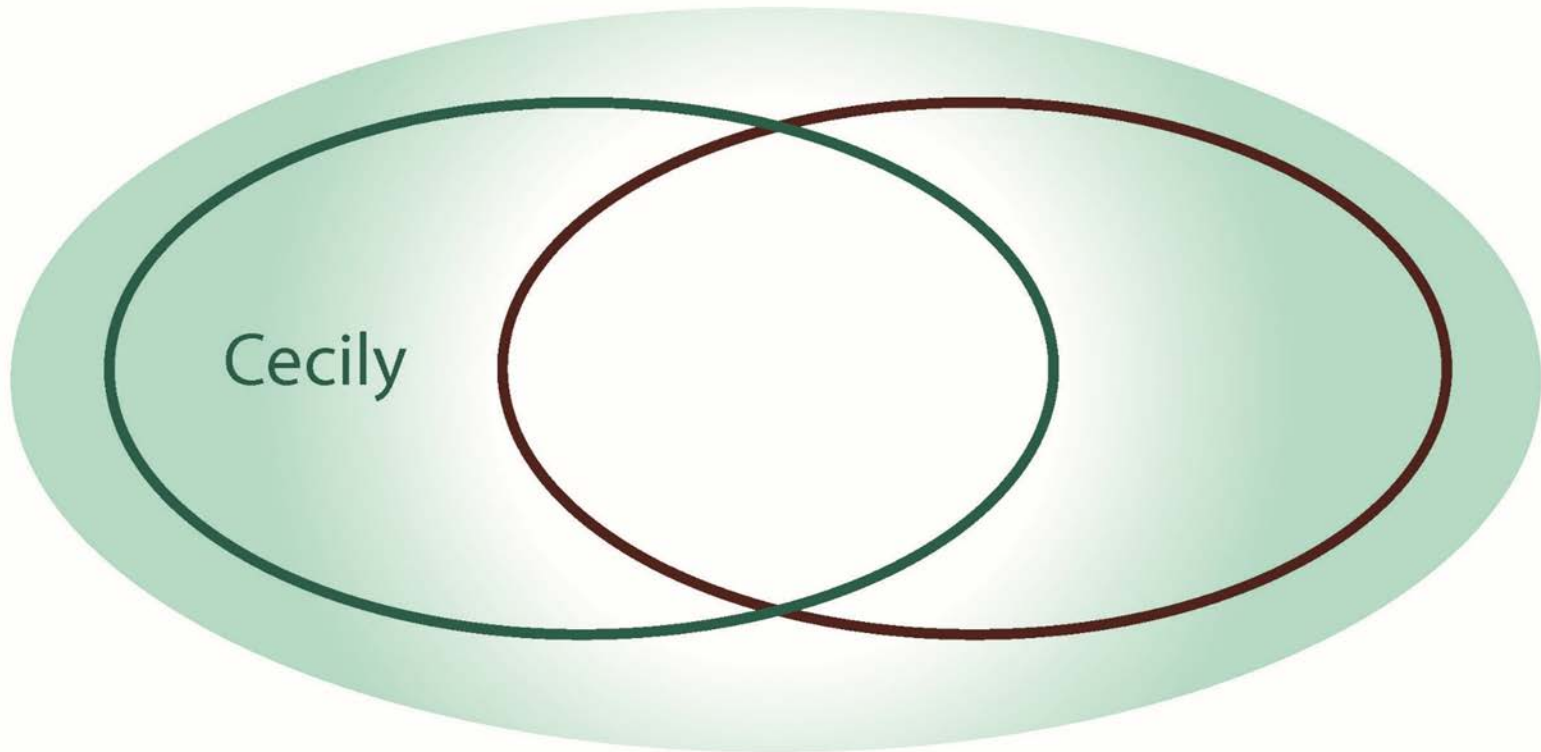
A model of the process of decision-making support

Decision Opportunity

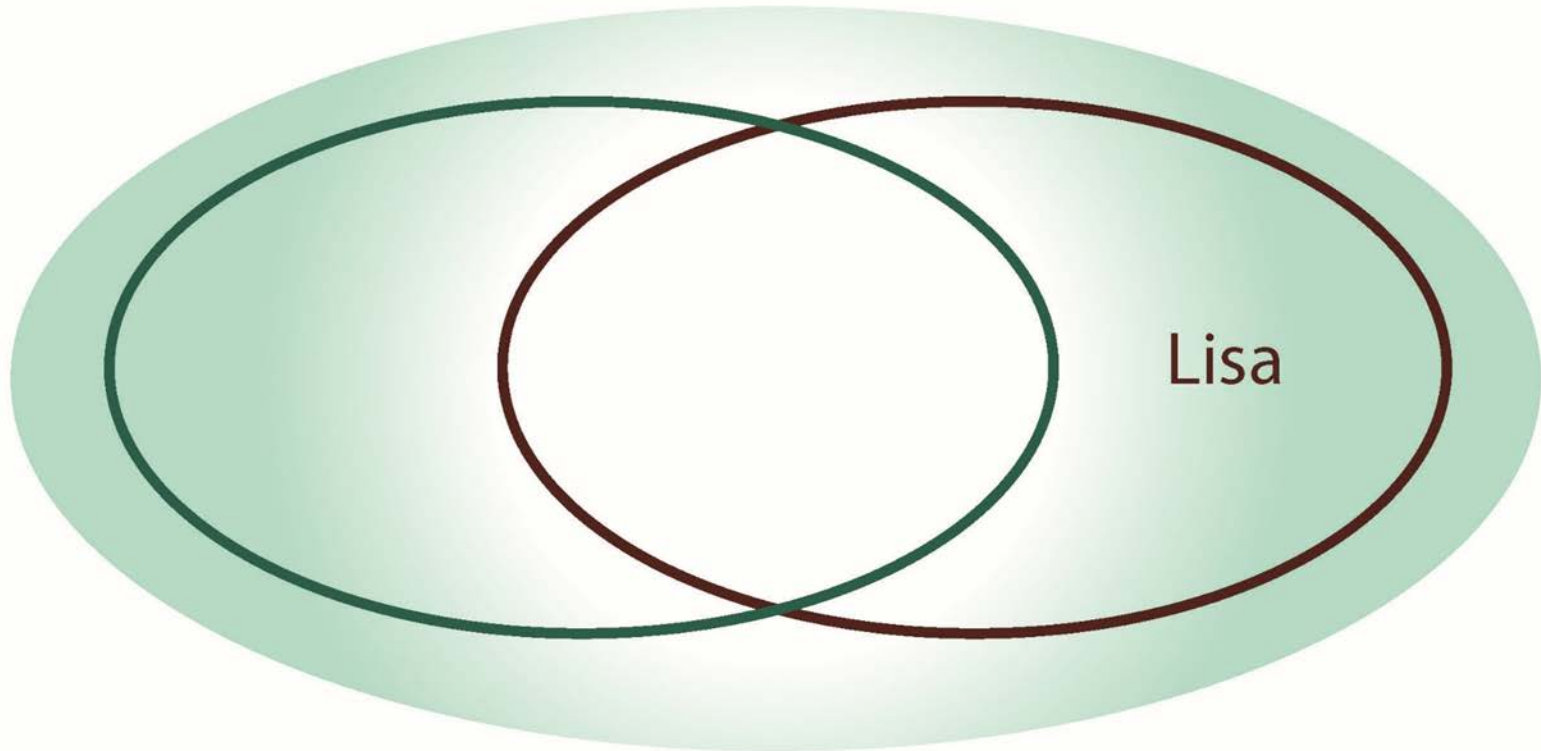


Browning (2018)

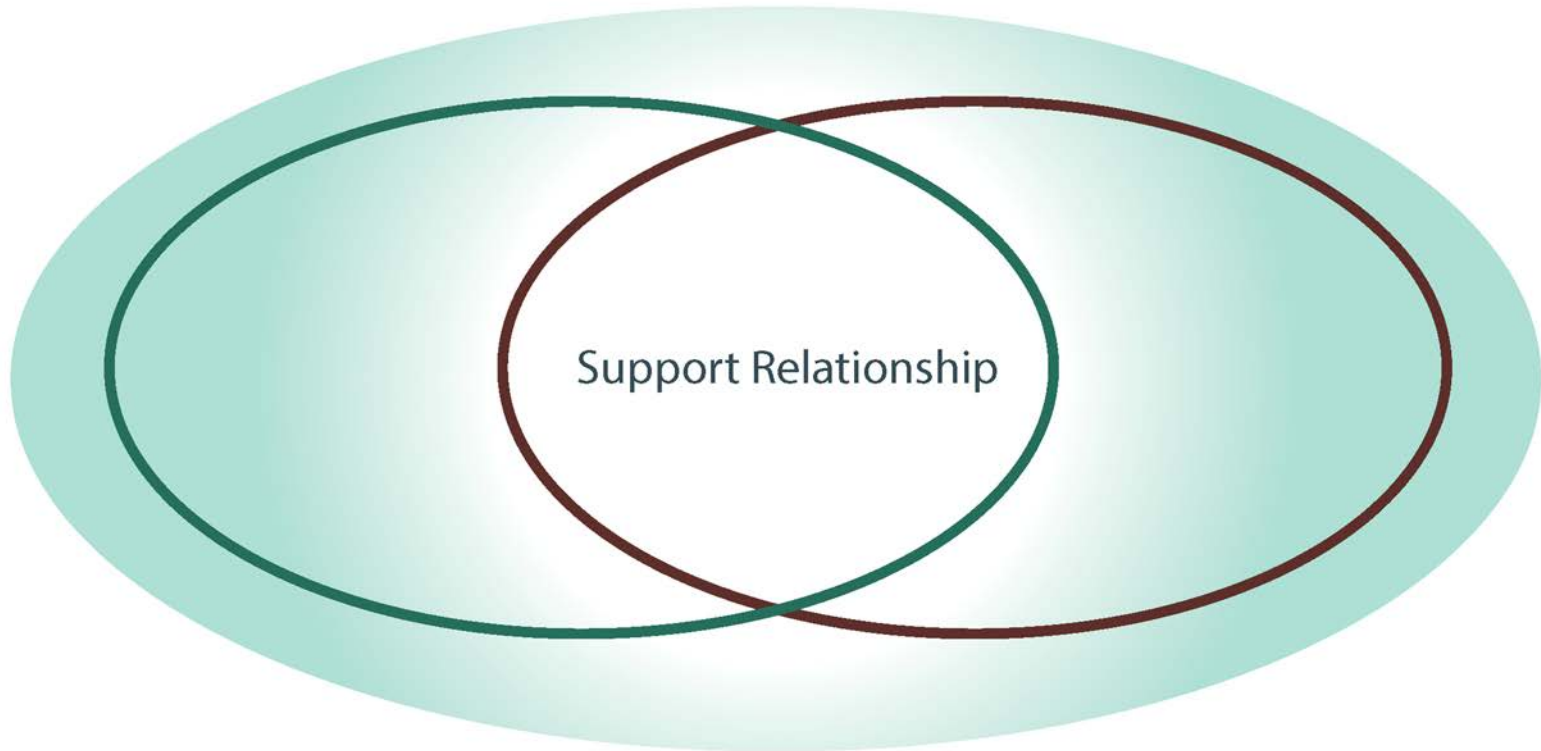
Cecily's attributes and experiences



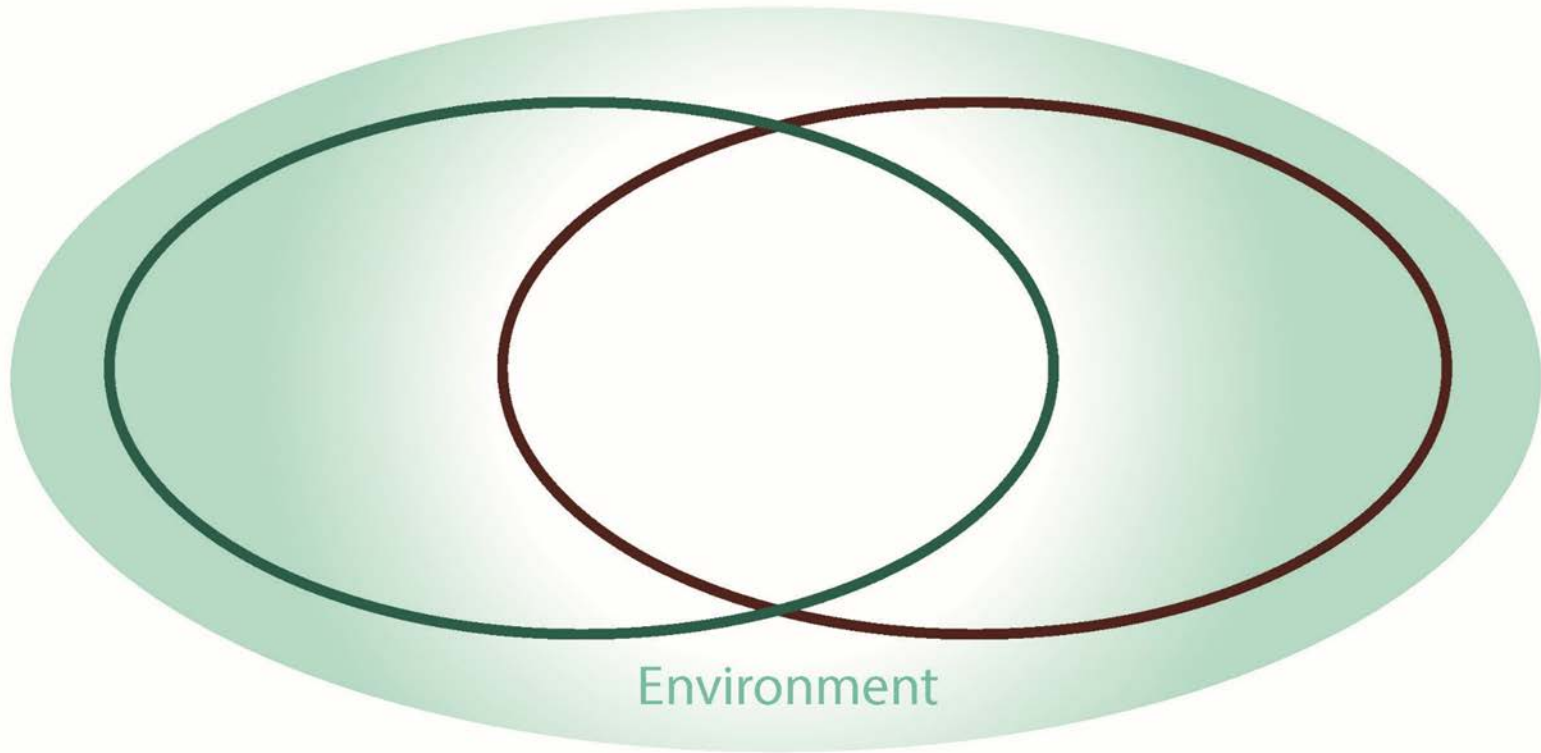
Lisa's attributes and experiences



The support relationship

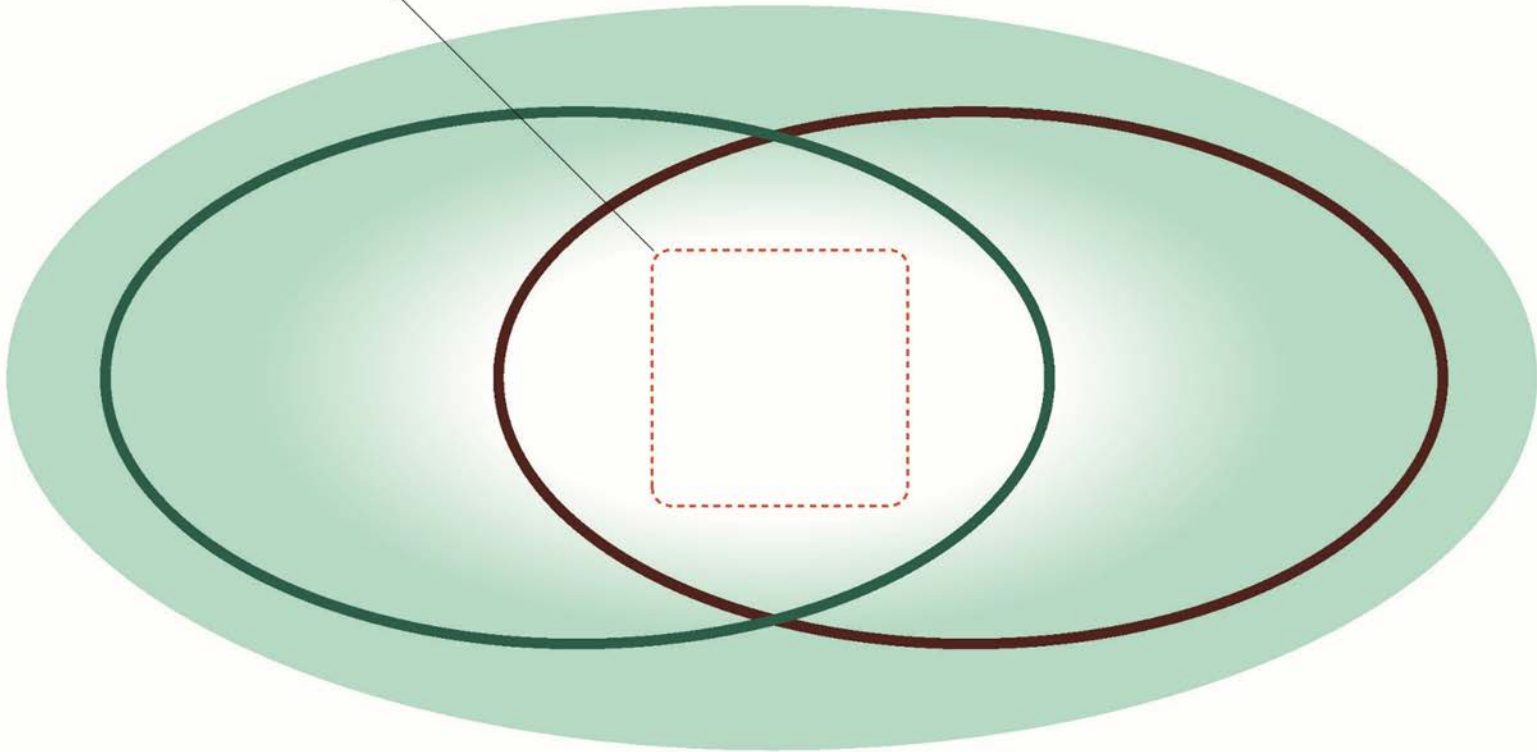


The environment

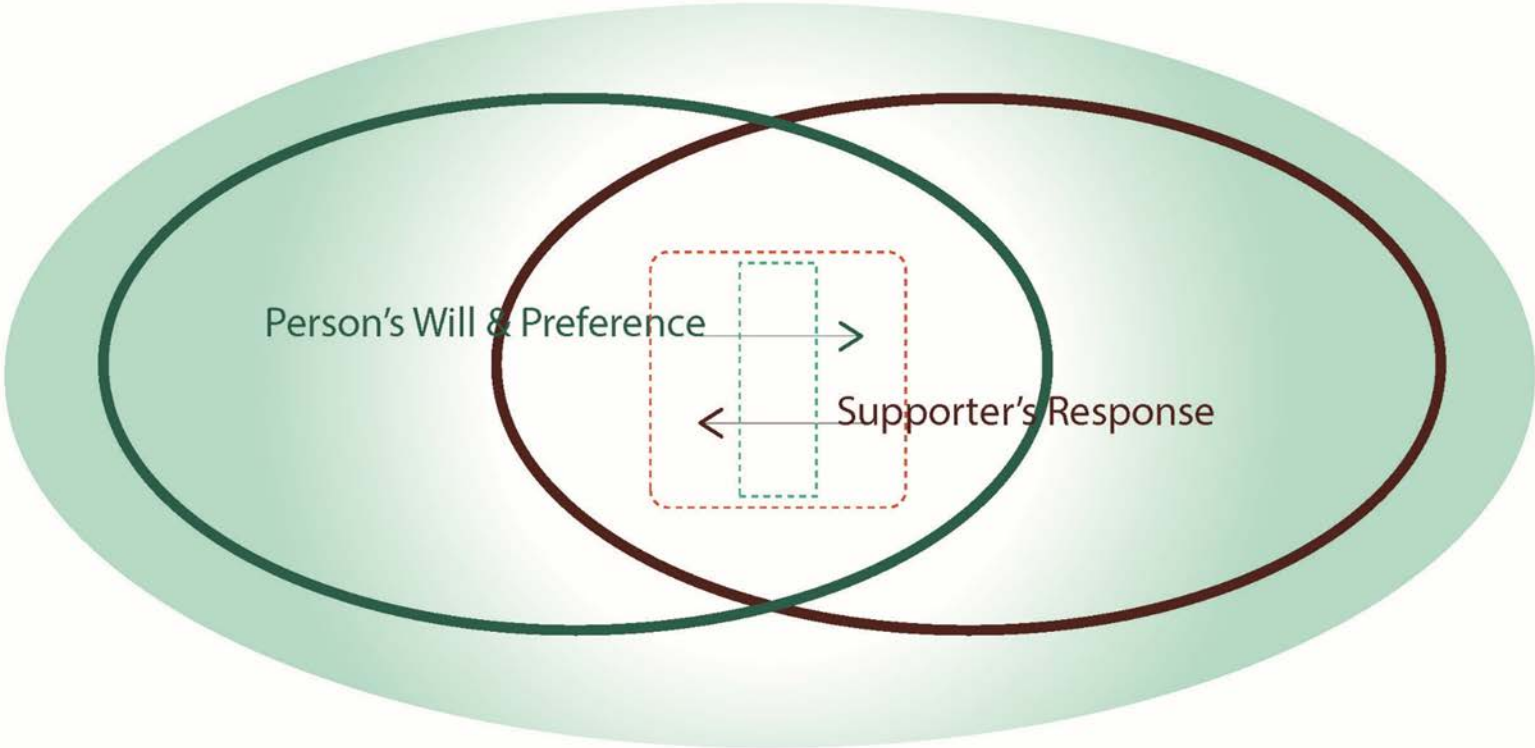


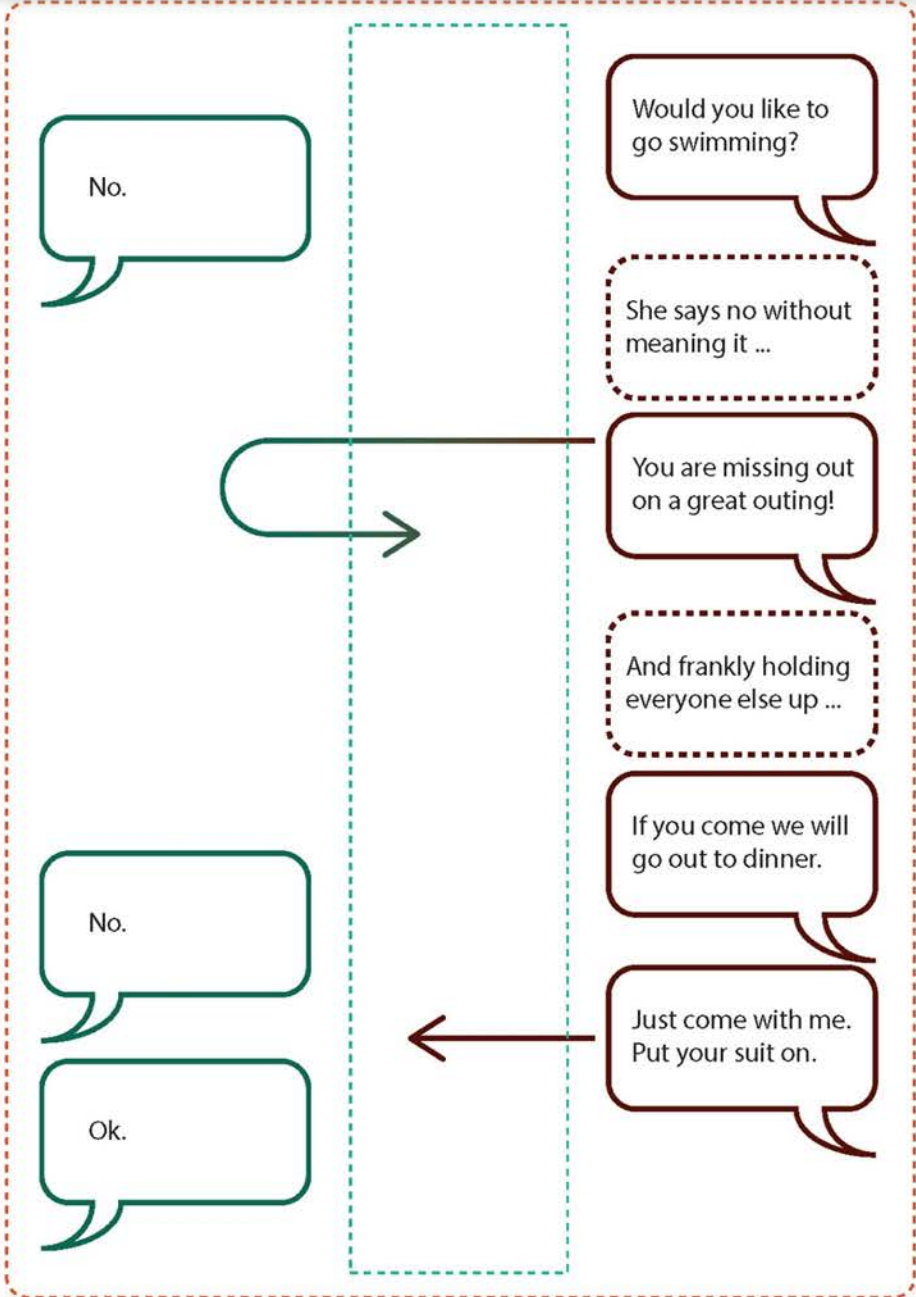
Decision opportunity

Decision Opportunity

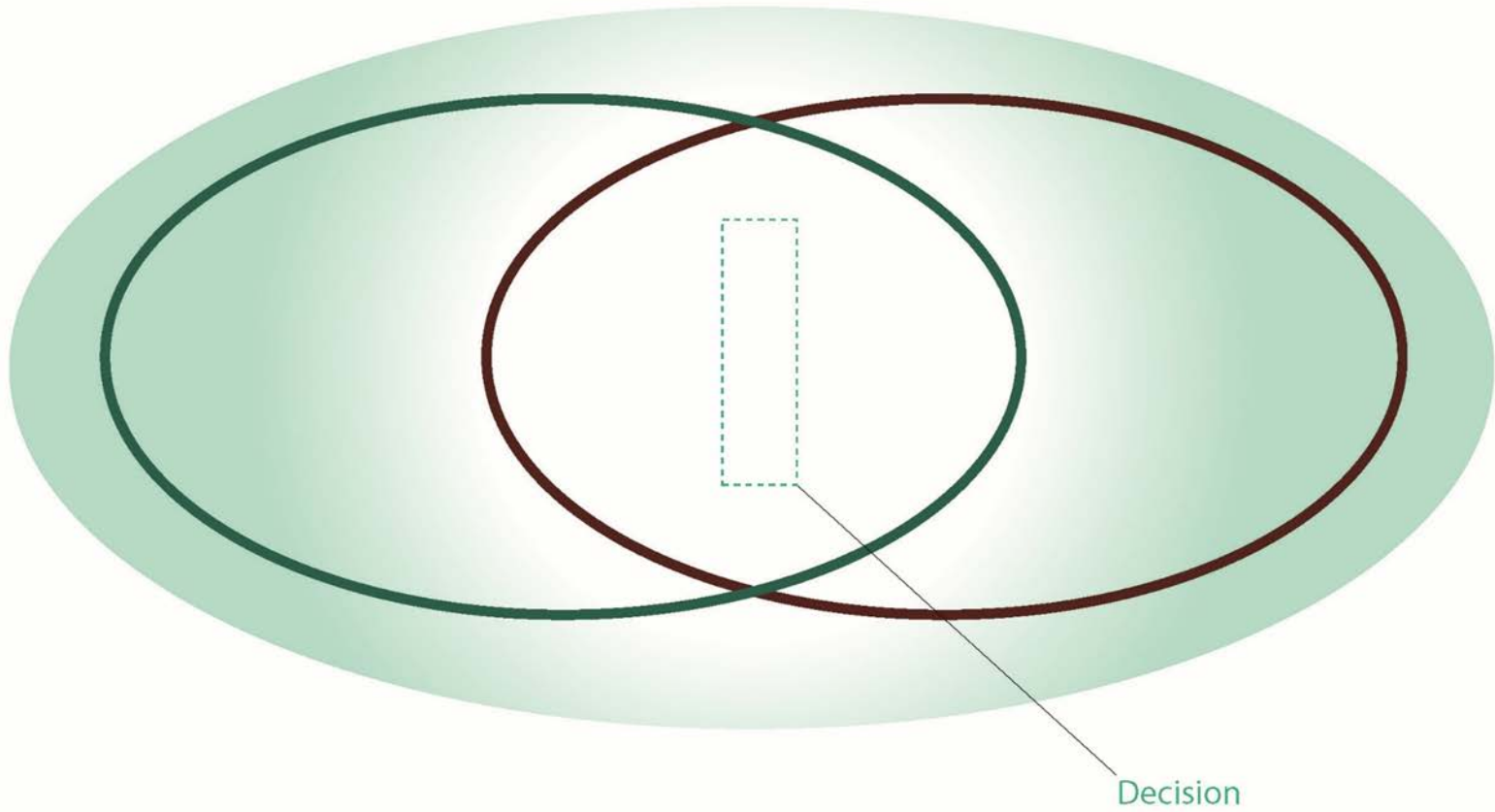


Cecily's will and preferences & Lisa's responses

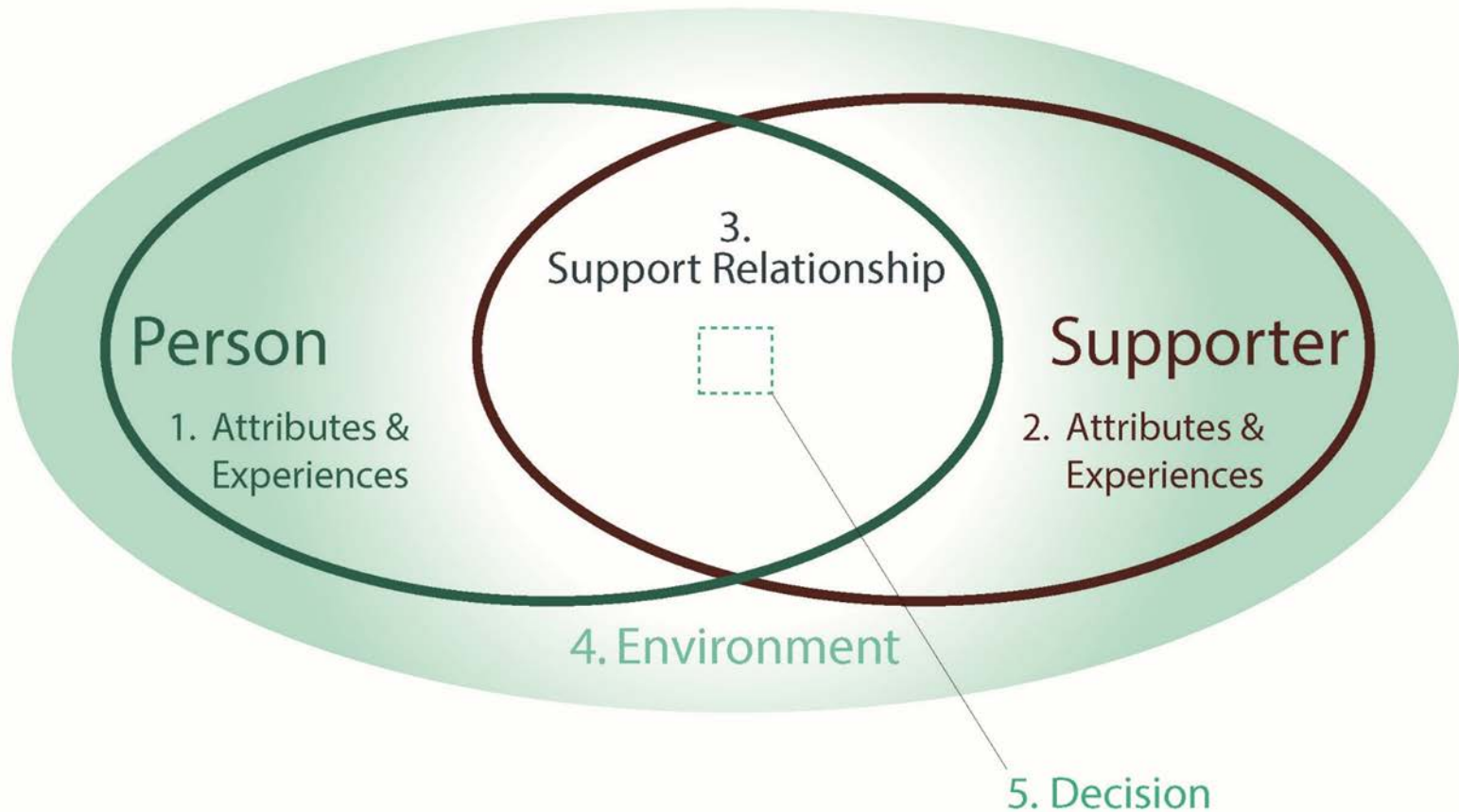




The decision



The five factors which shaped Lisa's support



How could understanding the process of supported decision-making help you in your role as a decision supporter?



Three ideas to take home

- 1) The **quality** of your relationship is important.
- 2) The tension between relational **closeness** and **neutrality**.
- 3) The **five factors** which shape the process of decision-making support.



Thank you

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