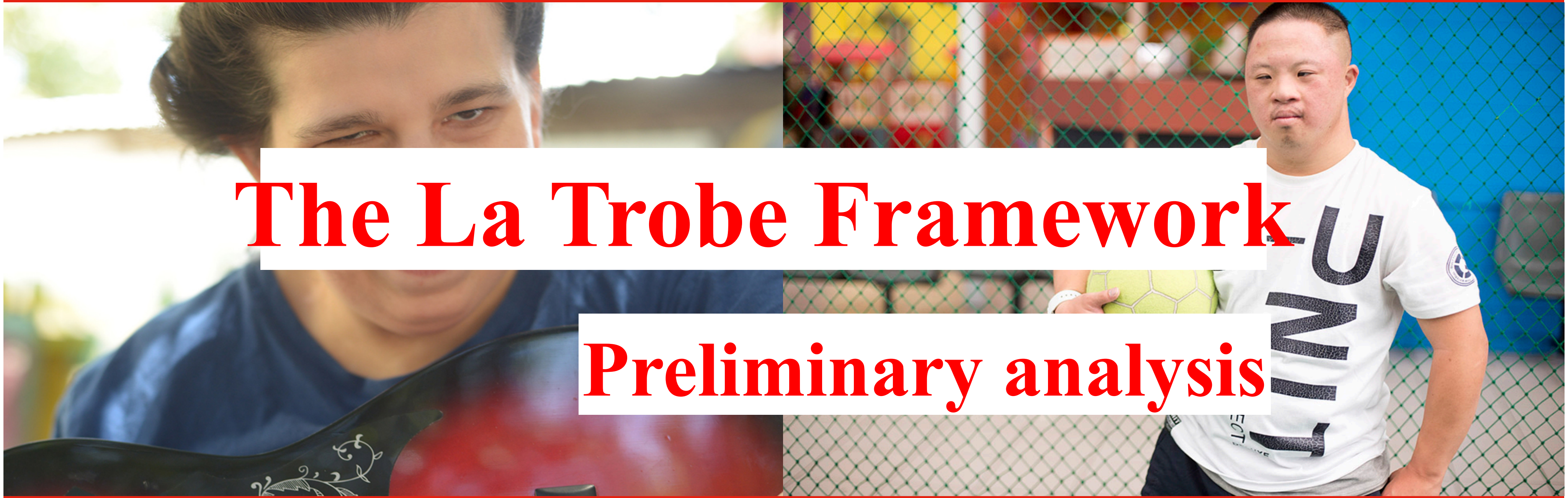
LA TROBE UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE



The La Trobe Framework

Preliminary analysis

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Overview – of the ARC project

- A four year project funded by an ARC Linkage Grant and 12 Industry Partners (2016 – 2020)
- Four Universities: La Trobe University, University of Sydney, University of Melbourne, and the Queensland University of Technology
- A semi-blinded randomised control trial looking at the effectiveness of a training package for decision supporters
- Includes two arms: people with mild to moderate intellectual disability and their supporters and people with acquired brain injury and their supporters
- Supporters can be family, spouses, friends, or paid workers who know the person well
- Half of the supporters get the training package early on and the other half at the end of their participation in the research
- Both supporters and decision makers participate in 3 or 4 interviews over a 12 month period
- **Aim – to see if the training package affects the way that decision support is provided and/or received**

Preliminary analysis

Research Question: What insights into The Framework can be gleamed from the pre-intervention interviews?

Three aspects of the framework

- Knowing the person
- Identifying the decision
- The principles of commitment, orchestration and reflection & review

Pathways to knowing the person

Intellectual disability	Acquired brain injury
Person less likely to give detailed descriptions of self	Person more likely to give rich details about self
Getting to know someone (both directions) takes time and shared experiences	Getting to know the person’s particular impairment from brain injury is important to providing decision support

Interviewer: It’s hard to describe people isn’t it?

Aria: Yeah. If they haven’t known me for a long time it’s really hard to know. Like Freya’s been through [things] with me and I know supporting me with things … like she’s always doing work with me like supporting me with my driving work and helping me get some work. Sometimes she’s nice to me and sometimes she’s not.

Interviewer: Would you say that she knows you well?

Aria: Yeah. A little bit very well. Still want to get to know her a bit more.

(Aria, decision maker, early 20s, intellectual disability cohort)

Freya: If anything, I think we know each other too well … [other people will] meet extreme stubbornness and blankness … or if she's pretty sure what is correct she'll go all out to make sure she has done it correctly. I'll get the Aria, which is, "I'm hungry and bored". So we have that level of relationship which I think in terms of supported decision making stuff, the decisions happening with someone like me is really good.

(Freya, Supporter, paid tutor and friend, intellectual disability cohort).

Kate: I would say that I would know him better than I know anyone else and I think that would be because of the time we've spent together. I think that it's all about hanging out, and because there have been times when I haven't left his side for a year … So it goes beyond spoken communication. And he doesn't really have that with anyone else.

(Kate, supporter, mother, intellectual disability cohort).

Lee: I’ve kind of lost my identity. It’s been lost in what I’ve categorised myself as, or allowed myself to be categorised as, which is an ABI patient.

But of recent times an ABI patient with some severe vulnerabilities when it comes to socialising. But with all that in mind, I don’t forget the positive – I guess I started off saying a creative person. I love artwork, making it ... Socialising is somewhat creative as well really, but that I find fulfilling I guess. So I’m a nice guy … I have goals and I also have deficits that I’m aware of, and one of the deficits is in fact amnesia. (Lee, early 30s, decision maker, ABI cohort).

Karen: He’s explained it to me a bit with the amnesia, he has the thought that, “I could eat something or I could go to the toilet, but I don’t know because I’ve got amnesia”. … I’ve just sort of gotten into the habit of deflecting it back … and bringing it back to himself and how he is feeling.

(Karen, supporter, partner, ABI cohort).

Identifying the decision: size and significance

Supporters need to think about what is most important for the person.

Samuel: There's some decisions without consequence and I'll let him do it. So making a decision on a meal, it's up to him totally. Making a decision about a credit card or spending money on various things, yes I will help him."

(Samuel, supporter, father, intellectual disability cohort).

Eda: But with something that is big like this, I just feel very hesitant in making that final decision …

The neighbourhood. I always say to her, have a look ay the houses around you. Are they well-kept? Or are they overgrown and broken windows and that … so is this the right thing?

(Eda, supporter, mother, intellectual disability cohort)

Bernice: In the hurry to get things done in a very tight timeline, I just sometimes don’t – I hardly even involve her in the decision. It’s just like, you know, have your breakfast, there are no choices about breakfast, just eat it.

I’ll talk about another decision about moving to a share house in due course. Because that’s far more complicated. And that does – and I have involved Sally a lot in that conversation.

(Bernice, supporter, mother, intellectual disability cohort).

Adhering to the principles is hard work

PRINCIPLES

Commitment
to the person and their rights

Orchestration
of others involved in the person's life

Reflection & Review
on your own values, influence
and support

Commitment to rights and reflection on values

Katrina: I’m aware that it is difficult to transition from being a parent of a child to being a parent of an adult, because she is not capable of being fully adult-like, but legally, she is of age and people expect her to make her own decisions and be responsible for herself. So funny things happen like when you go to the doctor, the doctor wants to speak to her alone but I feel concerned that the doctor might not understand that Svetlana answers questions in the way that she thinks you want to hear the answer. So I’m very protective, I guess.

(Katrina, decision supporter, intellectual disability cohort)

Commitment to orchestration

Kate: Well, there was his school group leader who's basically like his home room teacher, and also the program manager from [day program], we had four of us met, including Jasper. I've always taken him to all his meetings at school because he needs to speak for himself, at least it's not just about me interacting with people, so he was talking to them as well. I usually give my husband a bulletin but he doesn't get involved in any of this stuff, any of his health management or anything, nothing, so really it's just the people at the day service. And I chat to the carers and say, "Well, what do you think he's capable of? And what do you think he's not capable of? And what do you see his skills are?"

(Kate, mother, supporter, intellectual disability cohort)

Reflection on influence

Carol: Jasmine’s the youngest, but sisters in their late 20’s/early 30’s, it’s lovely for them to have that relationship. So it has been a good decision I think, and it’s probably made us realise how much we were controlling the way Zara lived her life

(Carol, supporter, mother, intellectual disability cohort).

Commitment to support

Nicole: He doesn’t like to rely on me [for decisions] because he knows that I’m busy and I don’t have a great deal of time … But, there are times when he’s in a lot of pain [and] just really needs it. So we always juggle. I’ve got to try and think about whether or not I’ve got the time to help, or even if I’ve got the emotional energy to deal with it myself at the time. And I’m finding these days I’m not because I have to switch off, emotionally, so that I don’t just fall apart … So anytime I get upset …I’ve just got to swallow it and keep pushing through.

(Nicole, supporter and wife, ABI cohort).

Balance of will, preference and rights

Pam: Initially Lila stated, ‘I don’t need a lawyer, I’m going to represent myself, they talk bullshit, they’re against me, I’m not going’ … ‘okay Lila yes you have court coming but don’t forget where you were a year ago. You’re the person who was laying in the gutter with the police dragging you into the back of the van, screaming abuse at everybody. You’re now somebody that people are proud of, they want to hear what you have to say, you’re a valuable member of society’ If her frame of mind was very angry and negative, I wouldn’t even touch on that subject. But grab it when the time’s right and she’s actually talking about progressing her life”

(Pam, supporter, paid worker).

Take home messages

Knowing the person

- Getting to know someone with an ABI in order to support them effectively with their decision making involves learning about the specific effects of their head injury on their decision making experience
- Getting to know a person with an intellectual disability may take more shared time and experiences – this may also be true for the decision maker getting to know the supporter

Identifying the decision

- Decision significance is relative to the person
- ‘Smaller’ decisions may have a higher significance for decision makers and therefore may require more input from supporters

Following the principles

- Following the principles is hard work

References from project

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Thank You

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