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Value creation by mothers of primary school-aged children with intellectual disability using the NDIS

Jane Adams, UNSW Sydney
Professor Leanne Dowse, UNSW Sydney
Professor Angela Dew, Deakin University
Dr Alison Wannan, UNSW Sydney
Associate Professor Jung-Sook Lee, UNSW Sydney

Background

- Mothers of children with intellectual disability navigate complex service systems and support networks and engage in trade-offs as they use their available resources to meet the needs of their child, family, and their broader networks.

- There is a significant body of literature focused on parents' experiences of working with services for their child with disability (Hodgetts et al., 2014; Ingólfsdóttir et al., 2017; King et al., 2017; Moynihan & Illsley, 2022; Østerud & Anvik, 2024; Pozniak et al., 2023).

- There is less research examining how mothers of children with disability use services and supports under a personalisation framework, such as individualised funding packages under the NDIS.
  - Experiences of families with children and young people of varying ages (Loadsman & Donelly, 2021; Prowse et al., 2022; Simpson & Douglas, 2016; Tracey et al., 2018)
  - Some research primarily on early childhood (Howard et al., 2015; Ranasinghe et al., 2017)

- There is little research that focuses specifically on the experiences of parents of primary school-aged children with intellectual disability.

Middle childhood as a focus of this study

Middle childhood (6-12 years of age) – given little attention in research and policy (Bessell et al., 2024).

NDIS outcomes reporting (e.g. NDIA, 2022) shows:

A lack of progress in key domains for children in middle childhood and early adolescence in key areas:

- Social relationships
- Community participation
- Inclusion

Persistent issues experienced by carers and families of children in middle childhood/ early adolescence:

- Perceived lack of support
- Deterioration in the social participation of families and carers since they accessed the scheme for their child

The definition of middle childhood is generally accepted to be 6-12 years (Collins, 1984; Daly & Walsh, 2023). However, the NDIS data age group that encompassed most primary school-age children was 7-14 at the time of this study (NDIA, 2024). It is acknowledged that NDIS data on this group also includes children in early adolescence.

Research Questions

In a personalisation model such as the NDIS:

- **How do mothers of primary school-aged children with intellectual disability engage in value creation using their available resources?**
- **How do mothers create and use complex personal ecosystems of services and supports?**
- **How is value created and/or eroded as mothers work with a personalisation scheme such as the NDIS?**

Qualitative multiple case study research

- **Qualitative multiple case study design**
- **5 mothers of primary school-aged children with intellectual disability**
- **Short-term longitudinal study over 6 months**

Policy review to understand how value is present in NDIS legislation and policies

Using the concept of value

Value has been described as:

> "Perhaps the most ill-defined and elusive concept in service marketing and management" (Grönroos & Voima, 2013, p. 134).
>
> "Under-theorised and poorly understood" (Osborne et al., 2021, p. 642).

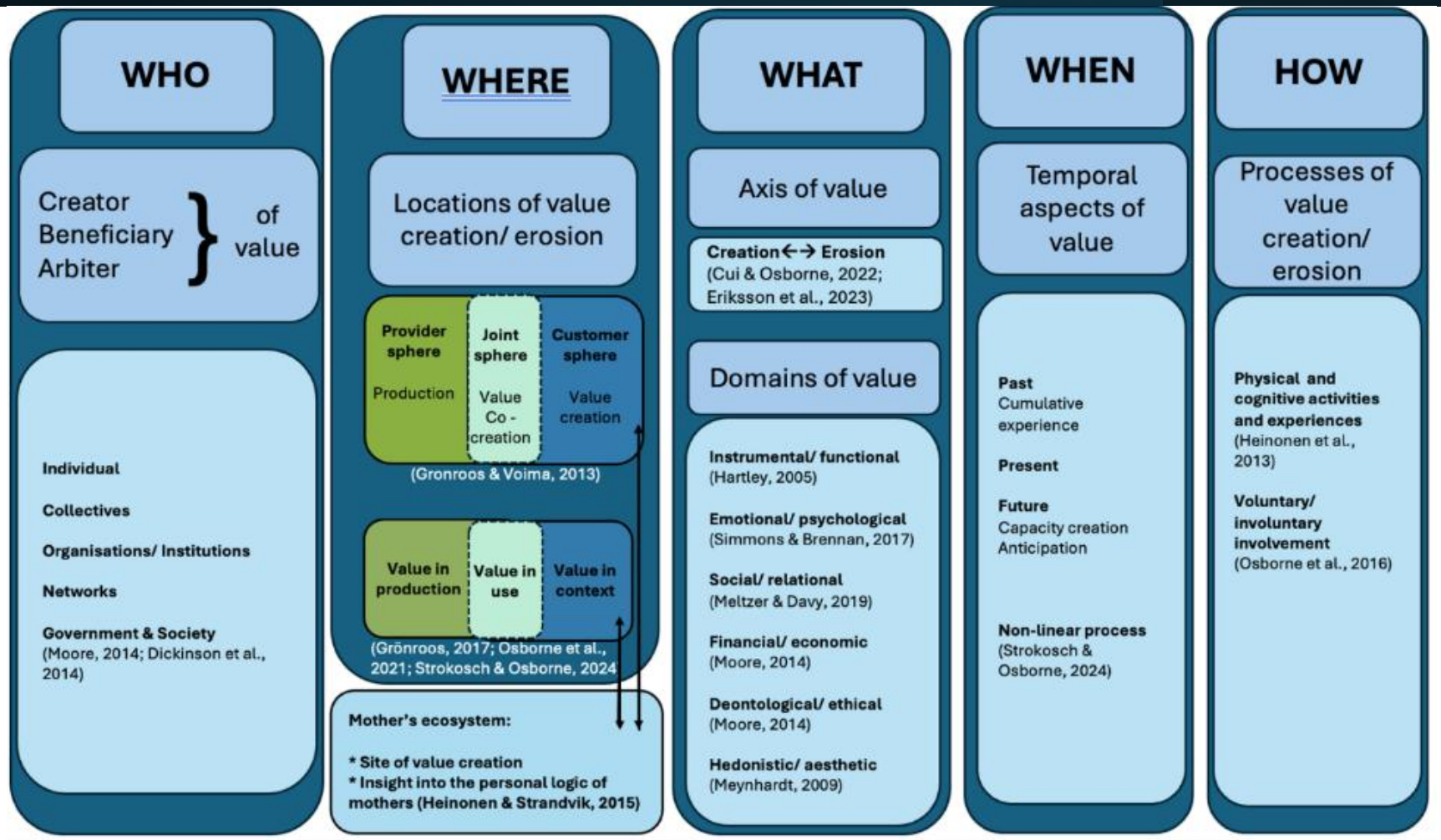
Public (societal) value aims of the NDIS.
Public value insufficient for understanding the value creation that mothers contribute to. More recent recognition of how individual value creation relates to public/ societal value creation (Yates et al., 2023).

Value as a multidimensional and subjective concept.
This is a shift away from defining value solely in terms of financial value or value for money.

How value creation aligns with the principles underpinning personalisation.
Seeks to understand the person's life in order to understand the role that services may play in supporting it.

Value co/creation: Recognises recognising that in services for children there is not always a clear boundary between parents/ carers' value creation in interaction/ outside of interaction with services.

A Framework of Value



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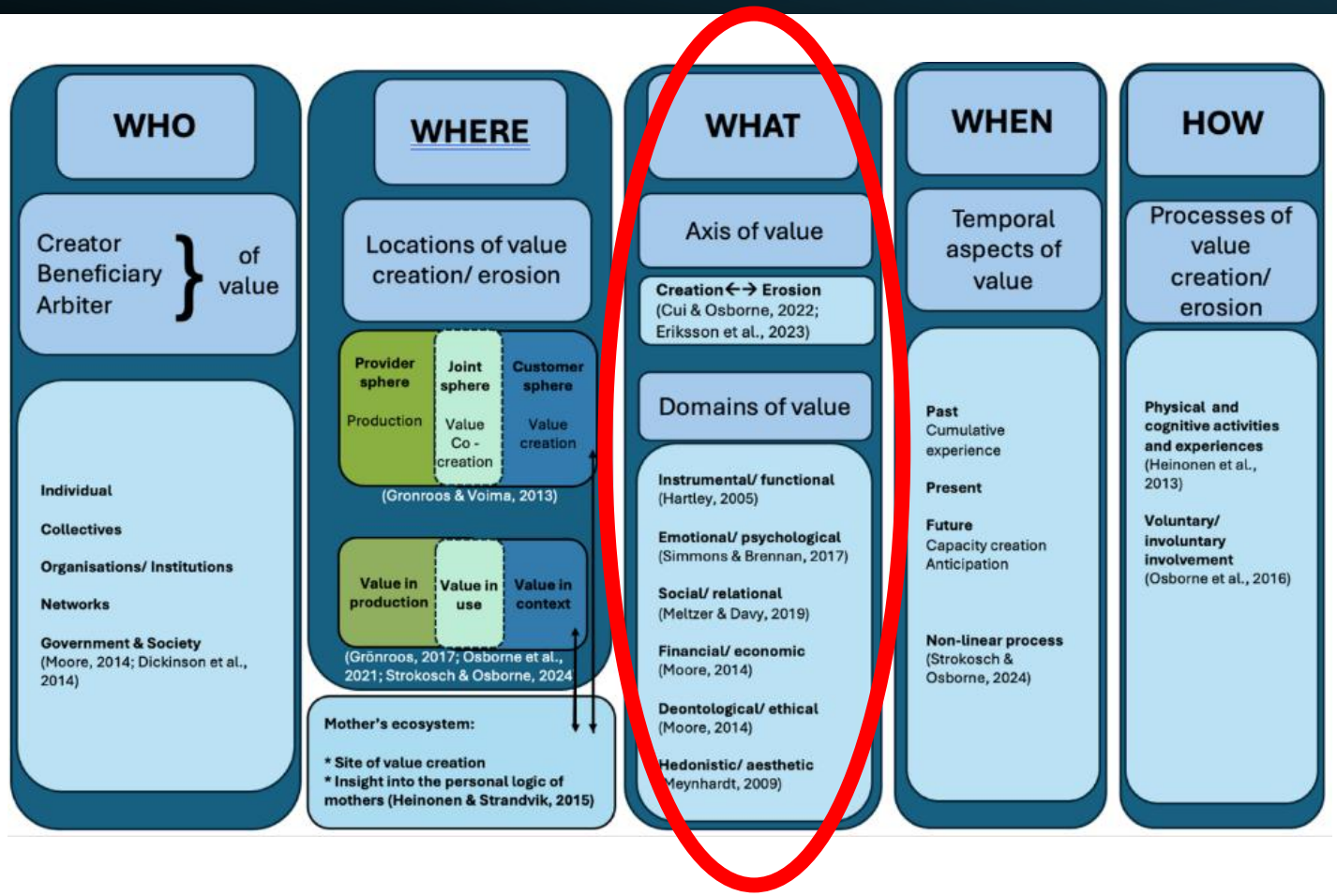


Domains of value

Instrumental/ functional
(Hartley, 2005)

Emotional/ psychological
(Simmons & Brennan, 2017)

Social/ relational
(Meltzer & Davy, 2019)

Financial/ economic
(Moore, 2014)

Deontological/ ethical
(Moore, 2014)

Hedonistic/ aesthetic
(Meynhardt, 2009)

How is value present in NDIS legislation/ policies?

Public value aims specific to children in NDIS legislation and policies

- Deontological value by upholding children's rights
- Financial value by bounding the Scheme's responsibilities for children
- Future value creation by building the capacity of children

NDIS policy silences about children and families

- Social and relational value for children
- Managing the personal cost of public value
- Role of primary caregivers in creating instrumental and functional value

	Legislation And Legislative Instruments [a]
1	National Disability Insurance Scheme Act 2013
2	National Disability Insurance Scheme (Children) Rules 2013
3	National Disability Insurance Scheme (Support for Participants) Rules 2013
4	National Disability Insurance Scheme (Complaints Management and Resolution) Rules 2018
	Operational Documents [b]
5	NDIS Operational Guidelines – Planning
6	NDIS Operational Guidelines – Including Specific Types of Supports in Plans
7	NDIS Operational Guidelines – Child Representatives
8	NDIS Operational Guidelines – Review of Decisions
	Other
9	NDIA submission to the Productivity Commission Issues Paper on NDIS Costs (2017)

Methods: Data Collection

1. Interview that focused on understanding family life, activities, routines, culture and priorities.

“Personalization, unlike consumerism, focuses on life, not on services.” (Needham 2011, p. 58)

2. Participatory network mapping: Services and informal relationships, how the network was developed and maintained.

6 months

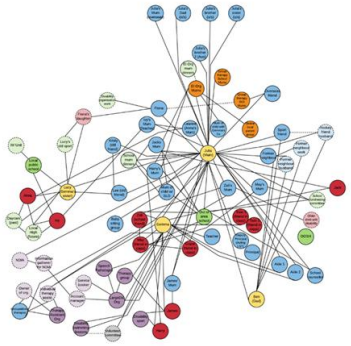
Documents if mothers chose to share those.

3. Update the network and explore changes that have occurred for them over time. Clarify initial analysis of each mother’s ecosystem.

Methods: Data Analysis

Individual cases

- Reflexive thematic analysis
- Qualitative structural analysis of network
- Network → networked ecosystem



Individual case reports

Cross-case analysis

Reflexive thematic analysis across cases

Findings: Instrumental Value

Mothers co/created instrumental value by choosing services that supported outcome attainment

Evaluating services to ensure they add value, beyond families' existing skills and resources

> "I know some of that sensory stuff looks like play, but honestly Ethan was calling the shots. He could have got the same benefit from me taking him to the park. There was not really a therapeutic benefit happening." (Jenny)

Knowing what a good service looks like for their child, and sharing strategies between providers

> "Now I'm better at going 'this is what Ethan needs' or 'this works well for him' … Now I can tell a new therapist, 'that's a strategy that works really well for him, you don't have to use it, whatever works for you, but this might be something'. (Jenny)

Missed opportunities for instrumental value creation – e.g. for mothers to build capacity to manage funding

> "[Ryder has] never had holiday programs, [the NDIA] have never approved that but with the [local disability organisation] holiday programs they actually put it through therapies because they were able to manipulate it in a way that they could code it to come out of the therapy budget." (Michelle)

Findings: Functional Value

Mothers co/create functional value by giving feedback to improve the quality of services

Individual and collective dissatisfaction in complaint-making

> [M]ost of the parents in the support unit are all in a Facebook group that I created for this unit. There [were] quite a few comments on our group page about the way this teacher was treating the kids and speaking to them. … I said, 'I'm not the only one that's got concerns about the way you're talking to and treating the kids.' (Michelle)

Feedback pathways (indirect/ management/ writing)

> I generally don't like face-to-face confrontation. I'd just prefer not to argue with somebody. I'd walk away from that, and I'll put it in an email and send it to them. 'You've got a copy of this; I sent you this on this date at this time'. (Michelle)

Missed opportunities for functional value co/creation through NDIA evaluation processes

> "It's a lot of numbering. 'Do you think that your daughter has benefited from this?' On a scale of what? What are these answers? What do these questions relate to? […] But they're generic questions. Not tailored to her. …'What's changed now that you've got that NDIS?' 'Well, we can continue on with our weekly therapy sessions.' 'Has she improved in this?' 'No, it's the same." (Tamara)

Findings: Deontological/ ethical value

Mothers co/create deontological value, associated with upholding their child's rights

> "When I book in therapy they think you can do two appointments in one day with Riley, whereas [he needs] one appointment then a day to get over that. …You just let him do his own thing and go at his pace and introduce it that way. (Megan)

Deontological/ ethical value in how mothers use NDIS funding

> " I'm not someone who's just going to risk that and do the wrong thing and use funding for things that's not supported. … He can't go and have magnet therapy or Himalayan salt therapy, or whatever, like you know, we're talking about proper mainstream accepted therapies" (Jenny)

Missed opportunities for deontological value co/creation in planning processes

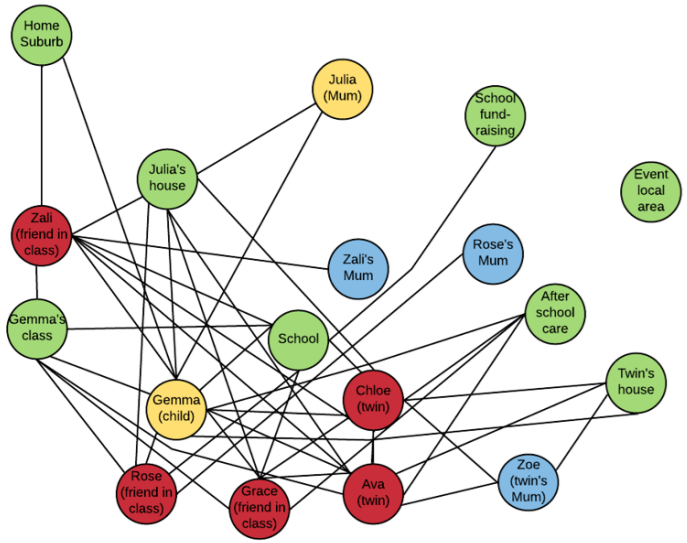
> "Ethan was in his first meeting … there's chairs set up at the table and there's toys in the room, and he's like, 'Where's my chair?'. … [Teenage daughter] didn't want to be in her meeting. [She] came and sat in the meeting room, but she didn't want to be there at all." (Jenny)

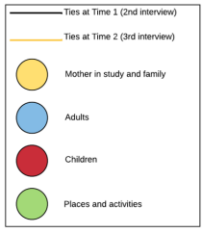
Findings: Social and relational value

Mothers fostered the conditions for social/ relational value creation for their child

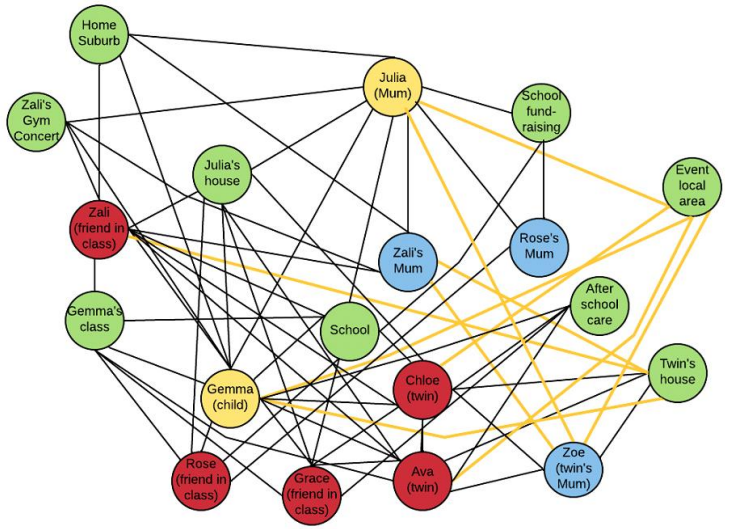
> "She had me over with [Zali's Mum] a few weeks ago on a Saturday night. We just went over for an early dinner at her place and she cooked something and we took something over and left at 7:30 to come home with the girls." (Julia)

Direct Connections Between Gemma's Peers





Connections of Mothers and Children in Julia's Ecosystem



Findings: Social and relational value

The subjective work of fostering social and relational value through parent connections

> [Keeping in touch] is hard work; it is really hard work … I want to, but finding the time, and they're all going out [for dinner] … I just can't do it, but I'd love to. But it's hard work. (Julia)

The evolving role of disability in mothers' social/ relational value creation

> I'm not bothered about [socialisation in the pool]. I want [Gemma] to swim. … [They told me] you've got to arrange a picnic or something. … I don't want to go and do a social thing. I don't think Gemma's bothered about being presented with a certificate with a load of people that she does not know at all. (Julia)

Distanced everyday lives as a barrier to social/ relational value creation

- **Out of area schooling:** "it's quite hard because I'm not in [school suburb], so they can pop over to each other's houses … they'll probably run into each other a little bit more" (Julia)
- **Routines dominated by disability-specific activities:** "[We] wouldn't be running into each other as much. Not at the same activities" (Julia)

Emotional Value

Emotional value erosion for mothers when required to be the expert

> "[Workers have said] 'I'm new to this, you probably know more than I do'. I don't want someone to say that to me, and they've said it to me a lot, especially through the NDIS. Having the [LAC] come out, 'You probably know more than I do'. I'm like, 'That *does not* make me feel very good, because how are you going to get me what I want?' (Tamara)

Emotional value erosion for mothers - being required to repeatedly tell their story

> "…. it's hard to just keep talking about the same thing over and over again. You have to do it with the NDIS to get the NDIS. It's hard to do that every year. I find it really difficult to just keep saying the same things over and over again." (Tamara)

Emotional value erosion for mothers when expectations do not meet reality

> "I thought she was going to be good, but then she just dropped off the face of the earth. … Didn't help me with *anything* … I haven't heard from her since, even though I texted her and called her. And now it's in the hands of [the NDIA] and that's all I know … I know they're just so busy, everyone's *busy*. But it's kind of just 'You've got [funding] now, we don't need to help you anymore.' (Tamara)

Interaction between value creation and erosion

Emotional value erosion for mother undermines the instrumental value of service

> "It was a really, really easy shift [working with Ethan]. [Support worker] came back and all I got was bad feedback like 'Ethan didn't do this or didn't want to do this or didn't participate with this or didn't help clean up', or whatever else. I don't get that from anyone else … None of it was big, none of it was important. If there had been a proper incident that I needed to know about, sure, …but this was all just random whinging." (Jenny)

Emotional value erosion for mother as a barrier to future access to support for family

> "This lady helped her so much, she was really good. I couldn't believe it. […] but then she left. *Everybody leaves!* We tried another lady but that just didn't work out. So, I never tried respite after that because I thought it just chopped and changed too much, and it wasn't someone where I could get the same person to come in all the time." (Tamara, Interview 1)

Emotional value creation for mother resulting from relational and instrumental value in services for child

> "I sit on the chair and I'm just like 'Yes!' I don't have to be running around the room and apologising … It's actually nice just to go and sit and watch him play and have [physio]therapy. It's amazing." (Megan)

Implications

Tell complex stories about value creation and value erosion.

- Non-linear/ incremental changes (e.g. social and relational value)
- How value creation and erosion interact (e.g. between domains/ between beneficiaries)

Funding allocation makes claims on the hypothetical ecosystem of mothers.

- Missed opportunities for value co/creation when mothers do not have these assumed resources
- Lack of understanding and support for the work mothers engage in (e.g. to establish social connections)

Framework of value as a potential tool for examining tensions in policy objectives.

- Tension between domains of value
- Tension between value created for children in the present, and value created for children as future adults
- Tension between value created/ eroded for various actors (e.g. children, mothers, society)

Recognise mothers as initiators of value co/creation

- Much value creation happens outside of interactions with services, and this needs to be better understood.

Examination of how value co/creation at an individual level contributes to achieving public/ societal value (Yates et al., 2023)

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Contact details

Jane Adams

Bachelor of Applied Science (Speech Pathology) - University of Sydney
Master of Health Science (Developmental Disability) – University of Sydney
PhD Candidate - UNSW

jane.adams@unsw.edu.au

www.linkedin.com/in/jane-adams-1019bb1ab

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