

**"They help him understand what's happening ..."**  
**- The use of social narratives to support adults  
with intellectual disability**

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NSW, Australia

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# Acknowledgement of Country

Acknowledging that this work took place on unceded Dharawal land  
(50 km south west of Sydney, NSW)

Acknowledge elders past and present, and pay respects to Aboriginal people  
Acknowledge the harm caused by British/ European Colonisation of Australia

# Intellectual Disability

Global Prevalence of intellectual disability	Functional issues
<p>10.37 per 1,000 population (Dew and Gaskin, 2020),</p> <p>*rates are higher in 'high-income' countries (including Australia)</p>	<ul style="list-style-type: none"><li>• Cognitive, functional, and adaptive difficulties --&gt; difficulties in self-care, household management, employment, community participation (Boat &amp; Wu, 2015; Smith et al., 2015)</li></ul>

- Lifelong condition
- Supports may be lifelong- but supports look different in adulthood
- People with ID can participate if well supported (Nijhof et al., 2024; Samuels & Stansfield, 2011)

# Communication Supports

- Difficulties expressing and understanding information (Marrus & Hall, 2017) - can communicate and comprehend information if supported
- Visuals, diagrams, photos preferred (Brown et al., 2017)
- Communication supports a priority – necessary for everyday participation (García et al., 2020)
- Adults with ID may require additional supports to live independently (Bridges et al., 2019)



# Social Narratives (Social Stories)

- Visual supports presenting information about various social situations as stories
- Describe what and when particular behaviours should be displayed and what can be expected in certain situations (Zimmerman & Ledford, 2017)
- Widely used with autistic children to support communication, - improved social understanding/ functioning, behavioural outcomes (Steinbrenner et al., 2020; Whalon et al., 2015)



The nurse cleans my arm with a cotton bud.



The nurse puts the needle in my arm. I might feel a little sting.



The nurse puts a band on my arm. It may feel tight.

## Where are the gaps?

- Limited evidence on use of social narratives for adults with intellectual disability
- Research predominantly on use with autistic children

### **Research Aims**

1. Explore the experiences and perceptions of adults with intellectual disability and their carers on the use of social narratives to support participation.
2. Explore the design and implementation of social narratives in the context of use with adults with ID.

## Research Design

**Qualitative case series** – in-depth exploration of participants within their context (Yin, 2018)- multiple information sources

Multiple case studies grouped together to present common findings among the group

## Research Paradigm

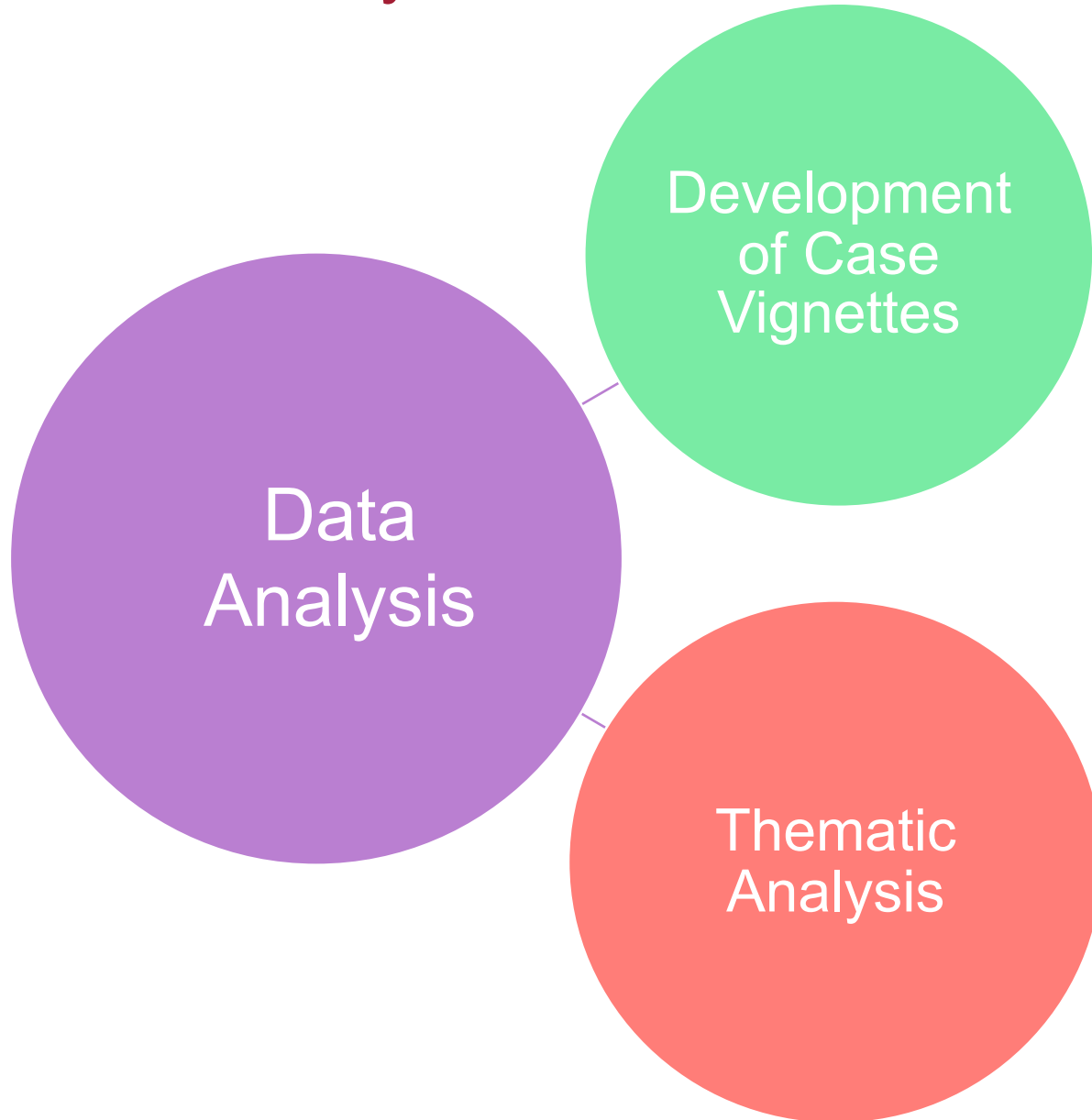
**Pragmatism** – investigates consequences and implications of research to inform practice and solve practical problems (Allemang et al., 2021)

# Participants and Data Collection

- Five semi-structured interviews:
  - ❑ 5 adults with diagnosed intellectual disability who had used social narratives
  - ❑ 6 carers of adults with intellectual disability providing at least 20hrs of care per week
- Interviews recorded and transcribed verbatim for analysis
- Multiple sources of information – participants' medical files and social stories collected
- Two researchers present at interviews

South Western Sydney Local Health District (SWSLHD) –Specialist Intellectual Disability Health Team (SIDHT- and Senior Clinician for Intellectual Disability and Mental Health). – Ethical approval obtained from SWSLHD Human Research Ethics Committee

# Data Analysis



- Personal story about the five participants with ID- their context, their needs and their supports
- Six stages of Thematic Analysis (Braun & Clarke, 2021)
- Combined transcripts from all interviews

# Results Overview



*\* Names are  
pseudonyms*

*All had ID,  
'Charlotte and  
Brandon' were  
also autistic*



Participant  
vignettes\*

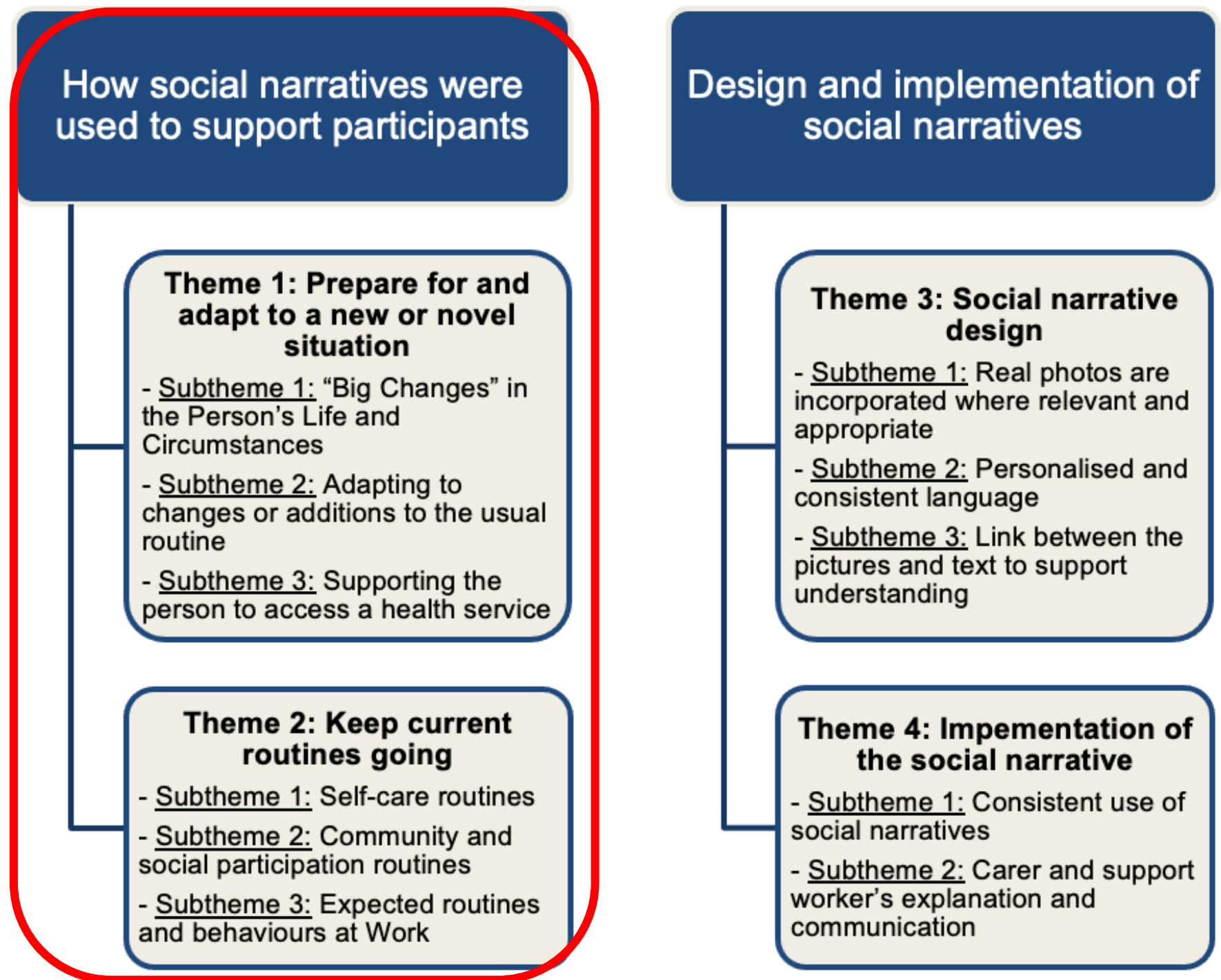
1. Charlotte (42y F)    Alissa
2. Jordan (24y M)    Karen
3. Odette (24y F)    Brenda
4. Brandon (36y M)    Phillis
5. Imran (47y M)    Troy & Molly



Four  
Themes

1. Supporting adults with ID to prepare for and adapt to a new or novel situation
2. Supporting adults with ID to keep their current routines going
3. Social narrative design
4. Implementation of the social narrative

# Thematic Map



# Theme 1: Prepare for and adapt to a new or novel situation

- **Subtheme 1: “Big Changes” in the Person’s Life and Circumstances**

- Events or situations with substantial impacts on their lives

- Adapting to a new living environment/arrangement

*“I’ve actually had to create [social narratives] to assist him to **understand the process of moving from one house to the other**, knowing what the next house is going to look like and things like that, and who’s going be working with him.” (Phillis, carer of Brandon).*

- Adapting to changes in employment

*“**One to explain what their work contract is.** ... about break time, start time, finish time, toilet breaks, and some safety and stuff like that ....” (Karen, carer of Jordan).*

# Theme 1: continued...

- **Subtheme 2: Adapting to changes or additions to the usual routine**

- One-time activity or change / unfamiliar setting
- Smaller, temporary changes – can be significant

*“We used to just absolutely hate public holidays, especially on a Monday because that threw her routine out completely. **But she’s getting a bit more accepting of that, as long as she knows exactly what’s happening, and that’s where the social stories [social narratives] are just excellent.**” (Alissa, carer of Charlotte).*

- **Subtheme 3: Supporting the person to access a health service**

- Preparing for new/unfamiliar health service or procedure

*“[A social narrative] helps him prepare for **particularly unexpected circumstances**, such as [when] going to hospital for appointments, especially if he hasn’t experienced an appointment like that before.” (Phillis, carer).*

# Theme 2: Supporting adults with ID to keep their current routines going

- **Subtheme 1: Self-care routines**

- Support engagement in self-care; act as a reminder of task and steps
- Encourage participation in non-preferred self-care routines

*“The self-care one – the idea was that every evening the staff member looking after him would go through it with him **because it talks him into having a shower the next morning.**” (Molly, carer of Imran).*

- **Subtheme 2: Community and social participation routines**

- Prepare participation in regular events in the community or involving others

*“[Day program created social narratives] for **going out to the park, and they’re going to have a barbecue.**” (Phillis, carer).*

# Theme 2: Supporting adults with ID to keep their current routines going

- ❑ Reinforce expected behaviours at home with housemates

*“... just little things like, instead of just going into another person’s room, knocking on the door first, she had to have social stories [social narratives] in regard to that.” (Alissa, carer).*

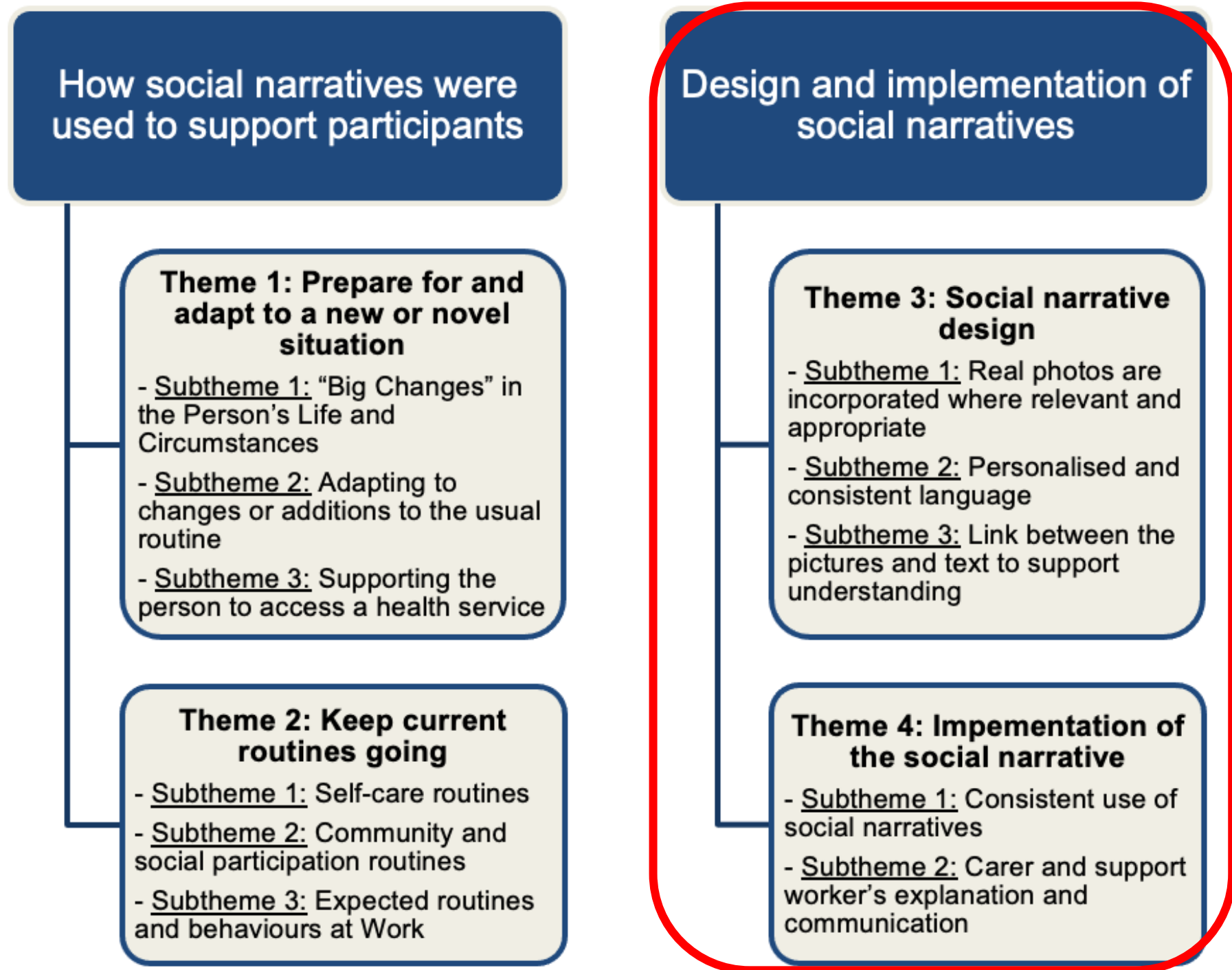
- **Subtheme 3: Expected routines and behaviours at work**

- ❑ Remind the person of routines and behaviours at work

- ❑ Remind the person of expectations of work for ongoing participation

*“They have done social stories [social narratives] **regarding her behaviour at work** because she can be absolutely beautiful one minute and you don’t know what anybody has said or done, but the next minute she could be screaming and not very happy at all.” (Molly, carer).*

# Thematic Map



# Theme 3: Social narrative design

- **Subtheme 1: Real photos are incorporated where relevant and appropriate**

- ❑ Real photos including of the person and actual tasks

*“... real-life photographs are more familiar to him, and I try and put photos of him in the social story [social narrative] **so he sees the connection**.... I think it’s been more successful for him to understand and relate.” (Phillis, carer).*

- **Subtheme 2: Personalised and consistent language**

- ❑ Sentences containing person's name – linking it to action

- ❑ Meaningful and individualised language

*“**We’ve learned that saying the word ‘shower’ is not helpful for him. ... it’s little things like, ‘get cleaned, look nice, smell nice.’** That has really helped with consistency of language in ways outside of the written language in social stories [social narratives].” (Molly, carer).*

# Theme 4: Implementation of the social narrative

- **Subtheme 1: Consistent use of social narratives**

- Regular and consistent use and training across supporters perceived to impact long-term success and efficacy

*“I met with a handful of nurses, gave them education about how and when to use a social story [social narrative].” (Molly, carer).*

- **Subtheme 2: Carer and support worker’s explanation and communication**

- Role in reading through the narrative and explaining its content
- Used or revisited closer to the event in question

*“So, if we were going to an appointment, **I’ll take it with us in the car, and we might sit in the car and read through it before we go in.**” (Phillis, carer).*

# Discussion

- Limited literature in the adult space (Samuels & Stansfield, 2011) findings align with work with children.
- Social narratives (social stories) facilitate **participation in meaningful activities** through promoting relevant social skills, expected behaviours, and emotional regulation- in line with autism literature (Smith et al., 2021; Rutherford et al., 2019)
- Supports can work if they are individualised to a person's own need and context (Chinn & Homeyard, 2016) and if they are used consistently/ regularly (Zhou et al., 2024).
- People with intellectual disability still need to be supported in adulthood – social narratives and visual supports are part of this.
- Social narrative use should be extended to adults – guide practice for adults with intellectual disability to support participation in various contexts

# Implications, Limitations & Recommendations

- Limited sample size- case series method- consider more involvement of people with ID
- This was not an efficacy study- a different method would be needed for this
- Explore in-depth the use of social narratives for adults with ID within specific contexts, (i.e., self-care, health service access, community participation, and leisure – identified as key areas of participation for adults with intellectual disability)
- Explore of the creation of social narratives for adults with intellectual disability for development of guidelines/standards
- Co-design with people with intellectual disability to help focus and guide the research – they are experts in their own experiences

# Advice for Developing and Using Social Narratives

- Personalized to the context of use, depending on the person's need(s)
- Real photos, including photos of the person- increase understanding and practicality of the content- check meaning
- Careful consideration of language use in social narratives (consistent with the person's learning style and preference)
- Photos and text or descriptions should match (clear link)
- Read to / with the person close to the event in question
- Use it consistently- build it into routine/schedule- repetition
- Use with verbal explanation from a carer or guardian (trusted person)
- Revise over time to ensure they meet the person's needs (variations as required)
- High tech (on a device/ app) or low tech (paper/ drawing) can be used



# Conclusion

- Social narratives are perceived to be successful in supporting participation for adults with ID
- There are considerations for design and use.
- Work is ongoing.

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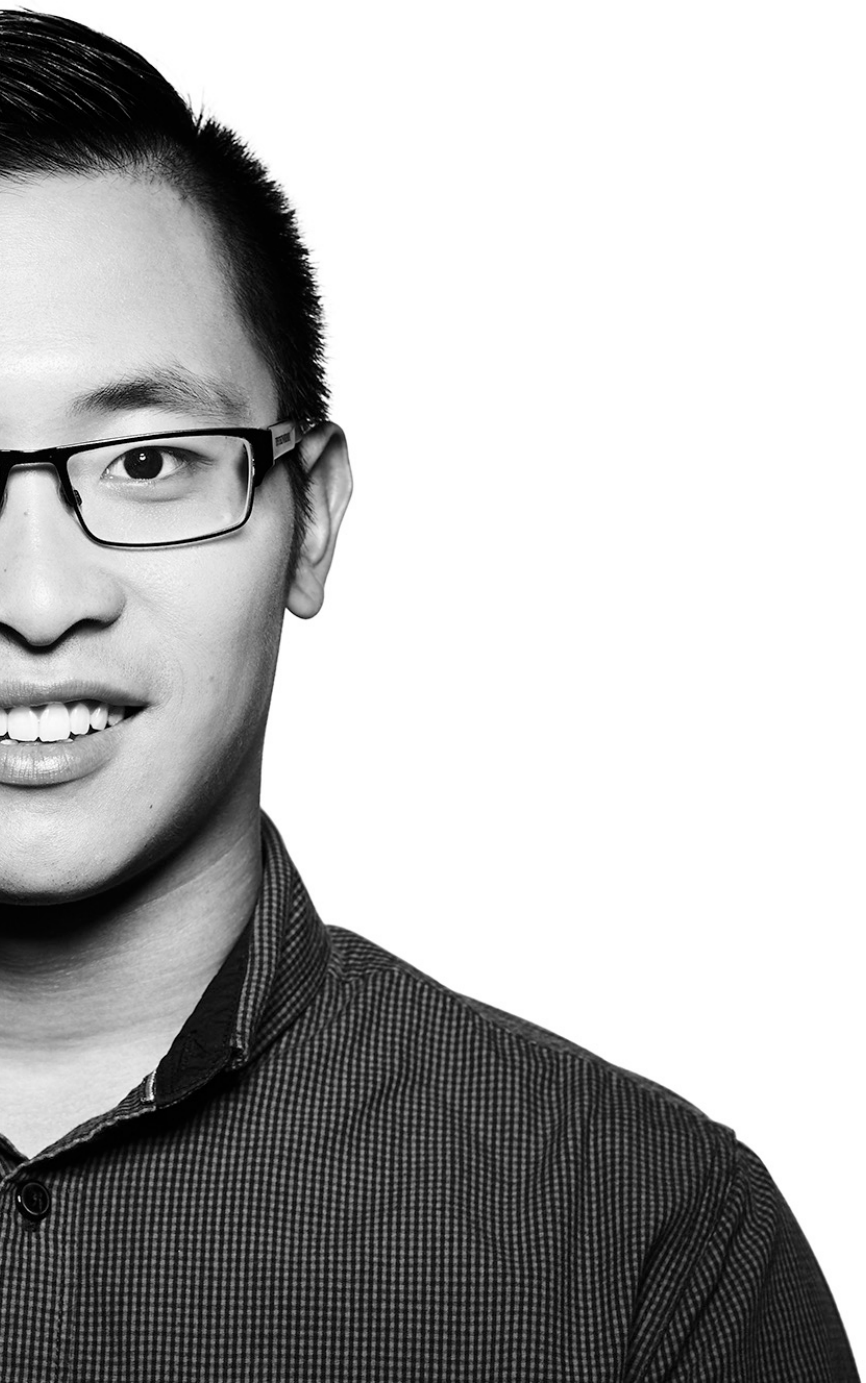


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