

Being a pioneer: A qualitative study of the experience of moving into new specialist disability accommodation (SDA) from the perspective of adults with neurological disability

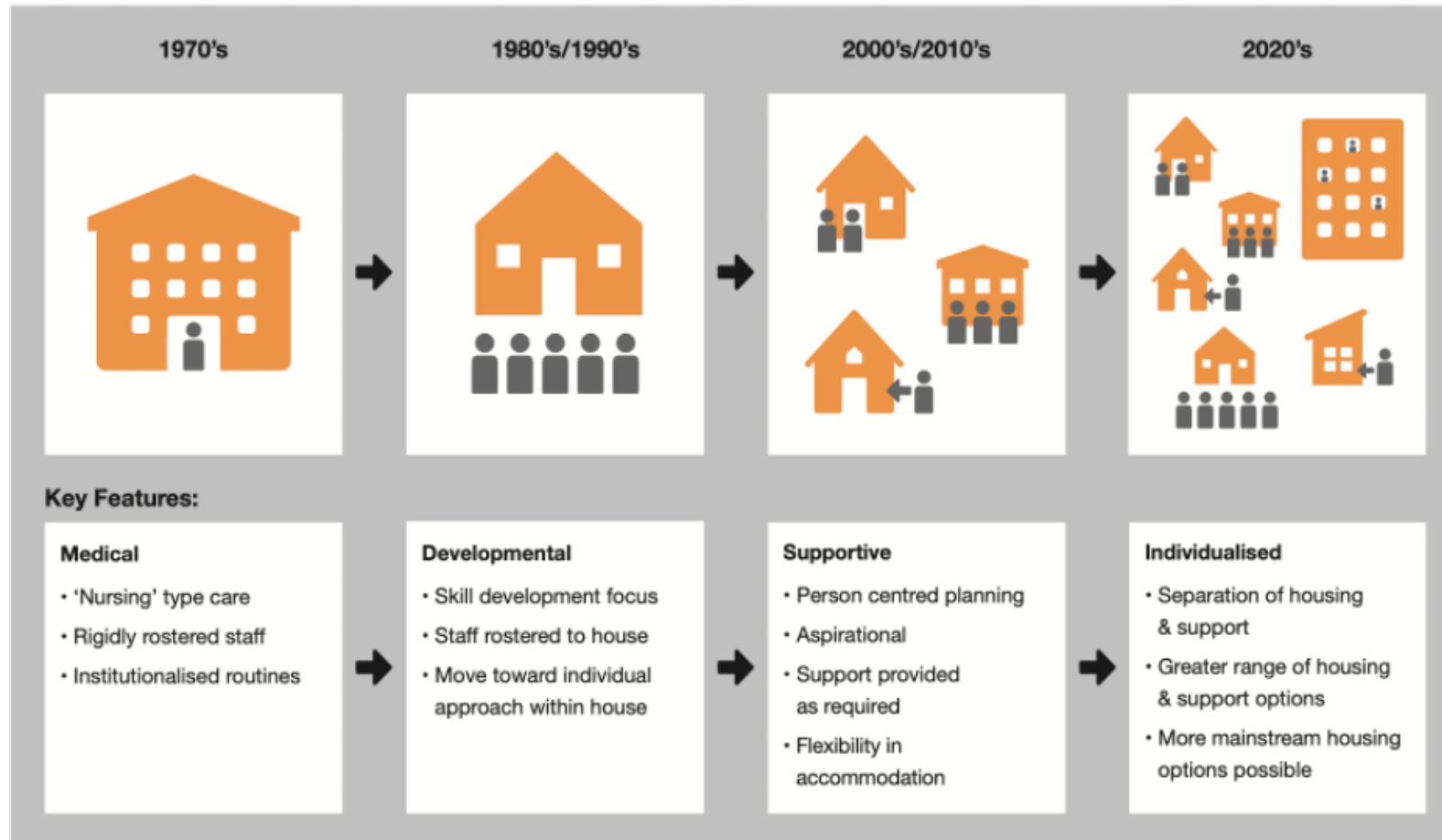
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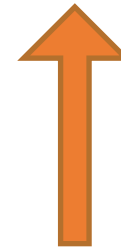
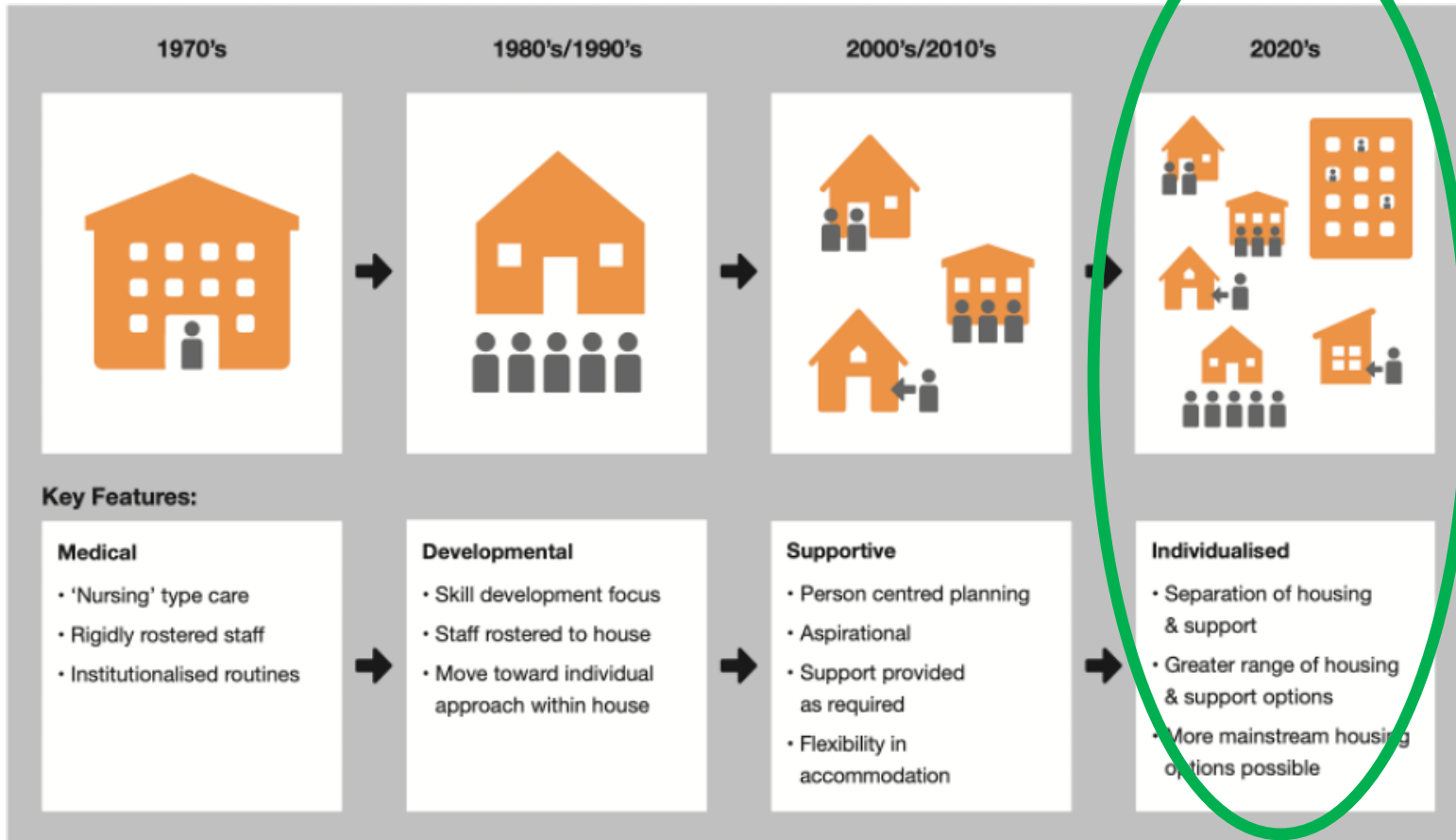
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Background



Background



Self-determination, autonomy, home and community participation, mood & social relationships.¹

Gap in research evidence: experience of people with acquired complex disability¹

Research Aim

To better understand the experience of moving into individualized housing from the perspective of people with disability

Specialist Disability Accommodation (SDA): government funding for housing that is available to some people with disability and complex care needs who require housing specifically designed to maximise independence

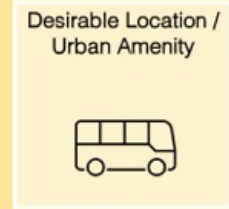
Focus: moving into new home



Setting: SDA funded 10 + 1 apartments



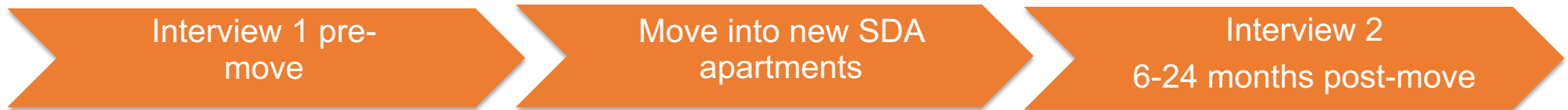
Research Aim: 10+1 model



New SDA Apartments



Constructivist grounded theory methodology



- Adults ranging in age from 30-57 years (6 male; 4 female)
- Acquired Brain Injury (3); Cerebral Palsy (3); Muscular Atrophy (1); Other Neurological (1); Multiple Sclerosis (1); Muscular Dystrophy (1)
- Shared Supported Accommodation (3); Residential Aged Care (3); Living with Parents (3); Private Rental (1)

- Interviews were transcribed and analyzed verbatim
- A total of 20 transcripts (pre-move and post-move) across 10 participants
 - Initial 5 participants were double coded by two authors
 - Remaining 5 participants were coded individually

Analysis¹

- Constant-comparative method of constructivist grounded theory
- Two main phases
 1. Data-driven open coding (line by line)
 2. Focused coding
- Axial coding explored relationships across participants

Results: Qualitative Analysis

Pre-move: not a good fit

Feelings of hopelessness

1. Lacking autonomy and opportunity in everyday activities
2. Missing meaningful social relationships
3. Having limited housing choices

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Moving in the right direction

1. Building a support team
2. Navigating new responsibilities
3. Making a home

Lacking autonomy and opportunity in everyday life

- Lack of privacy, rigid routines, limited or no choices

“They put you on a timetable. And your time to have a shower is at 8.30...you’ve got to have a shower then otherwise you don’t get a shower at all” (Darren)

Missing meaningful social relationships

- Friends unable to visit
- Unable to plan social activities

“ I struggled a lot. I think while I was in aged care my friend came once - one friend once...and that I felt really awkward about it” (Peter)

Having limited housing choices

- Pre-move environment as only option
- Pressure to accept pre-move housing vacancy
- Not a long-term option

“They next got back to me and said, “We've found a bed for you.” Notice the language. “We've found a bed for you.” (Susan)

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"SDA is new. It's not something that many people know about" (Andrew)

Results: Qualitative Analysis

Pre-move: not a good fit
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Post-move: being a pioneer
Moving in the right direction

“That's what I want to do, moving in here. I wanted to be able to grow in independence, and not need so much help. I'm looking forward to you know, just that next step of being able to be a bit more independent” (Susan)

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Building a support team

- Recruiting support workers that suit individual needs and preferences

“We do have our own team of workers so everyone’s got their own team and different times they come in. I have a really great team.... You know, because we’re within our rights to say if we don’t want that person, we can choose to dismiss them.” (Mary)

Building a support team

- Support workers contribute to daily quality of life

"I'm feeling valued. Rather than just a job or a chore to be done. I feel like these people who are helping me get ready, are invested in the fact that I feel ready to go out. And it changes your outlook on facing the day" (Susan)

Building a support team

- Difficulties finding the right support workers
- Ongoing monitoring of support arrangements

"My support arrangements are more settled, but it would be reasonable to say that it's always evolving and always fluctuating." (Kara)

Navigating new responsibilities

- Managing increased responsibilities can be challenging

“If we want maintenance done, we organise it...I don’t have to wait for somebody else to do it or their approval to do it” (Kara)

“It’s allowed me to grow. Like with confidence, and you know, being able to manage things. I feel like I can do a lot more for myself” (Sammy)

Navigating new responsibilities

- Life is busy and settling in takes time

"I still don't feel completely settled. I've still got boxes of stuff that I can't find homes for...those kinds of things overwhelm me" (Susan)

"I can't get into the fridge... There's so many things I can't do because it's not designed for me" (Lisa)

Making a home

- Enjoying new choices and autonomy

“ I like to be able to set it all up myself and then I can do what I need to do and there’s no-one stopping me from doing it.” (Kara)

Making a home

- Experiencing increased privacy and safety

“I feel like I’m having more time to myself, which is really what I enjoy.” (Sammy)

Key messages

- A positive shift from pre-move to post-move
- Having choices and autonomy in daily lives
- Key points of challenge include having the right support and tailoring the environment to individual needs
- Significant change and period of adjustment; focus is still on getting set up and making a home

Implications and limitations

- Opportunities to consider the best way to support people during this significant life event
- Longitudinal study to build on initial findings and better understand long term benefits and challenges

Thank you

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