

## The Get Building SDA Conference, 2019, Melbourne

### Who is Specialist Disability Accommodation (SDA) For?

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I'd like to thank the Summer Foundation for asking me to speak today on this very important topic.

No matter who is deemed eligible for Specialist Disability Accommodation, we must uphold the sanctity of home - what it means to have a **real** "home".

"A real home is not solely one's dwelling place, but rather a key crucible in life that helps sustain and uphold much that is deeply personal, private and intimate about ourselves and reflects our deep identity, values and preferences for a good life."

Dr Michael Kendrick (2008)

Although market and commercialised factors are important, we cannot be driven by these forces alone as we can lose sight of the actual person and the typical principles and practices of home.

Home can become **distorted** with well-intended system efforts which can further marginalise people with a disability and foster notions of difference. For example, finding a home could become limited to finding a vacancy, an option to "fit" into, congregations of people who share the same diagnosis, a service setting, facility or residential service, a place to live or find shelter or a commercial activity driven by staffing concern, rules and regulations. Even the term accommodation sets people apart - I don't know about you but I only look for accommodation when I go on holidays. It's short term, transient and hopefully somewhere exotic! And I can't wait to get back home!

To prevent us drifting too far away from what the concept of home is, it's helpful to think about what home means to you. Then compare your list to what you have created or plan to create. What are the differences? For example, do people have a say over the design or who they live with? Is there a staff room? Are meal or bed times at a set time? Do people have a front door key etc.

Our efforts at Belonging Matters stemmed from the extreme dissatisfaction and experience of people predominantly with developmental disabilities who had few choices other than congregate group homes. With capacity building investments, close to 40 people with developmental disabilities now live in their own home with personally directed and tailored support.

Our efforts were inspired by a world-wide movement and recently backed up by an Australian research report called *Quality and outcomes of individual supported living (ISL) arrangements for adults with intellectual and developmental disabilities* (Cocks et al, 2017). The study, a joint

research project by Curtin University, University of Melbourne and the University of Sydney, examined a total of 130 *Individualised Supported Living (ISL)* arrangements in three Australian States. A number of people with a disability and families associated with Belonging Matters contributed to the study and it provides a practical framework to guide our efforts.

According to McVilly et al (2017) the underpinning assumptions of the study are that people with a disability:

1. Can live in their own home with appropriate support,
2. Do not have to live with other people with disability, or people with whom they have not specifically chosen to share a home.
3. Do not have to live “independently or on their own. (Actually, very few of us live independently).

There are eight ISL themes - to which I have added some of our leanings!

### **1. [Vision] and leadership**

Home starts with a clear vision and ideal of home for the person, a willingness to uphold the sanctity of home and work out the practicalities around each person. Making a home is an ongoing process and it requires the leadership of at least one person.

### **2. My home**

Home is different for each person. It's a private and personal place rather than a public, staff or service setting! The person requires secure tenure and sovereignty in regards to their home. Home reflects the person's tastes, preference & routines.

### **3. One person at a time**

Home is designed around the unique identity of each person who remains at the centre of all efforts. People are not compelled nor coerced to live together and there is intentional avoidance of grouping people based on disability e.g. in a group home, cluster arrangements, on one level of a building etc

### **4. Planning**

All planning is focused on the person. The person and those close to them actively work together to plan and assist the person to develop their home. This means not starting with a predesigned/standard model. They look towards the future and not just the current situation.

### **5. Control – Person designed and directed**

Agencies and systems should not own and control people's homes. The person should have real, relevant and typical choice which includes where, with whom they live and all design features - not just incidental choices over what to eat or how to decorate their bedroom.

## 6. Support

The person has choice over a range of flexible, creative and responsive informal and formal supports to meet their needs that are inclusive of family, friends, neighbours, non-disabled homesharers etc. This means not locking people into predetermined providers and support arrangements.

## 7. Thriving

Most of use rely on our income to purchase a home but many people with a disability remain locked out of the work force due to attitudes. For example, only 5% of people with an intellectual disability state that paid employment is their main source of income (AIHW, 2009). If people are to thrive, not just survive, they need a range of valued social roles at home and in the community, which includes paid employment.

## 8. Social inclusion

This means the person is connected with others, knows many different people and actively participates in their local community. Having a home is very important but it's not enough if you're lonely, isolated and disconnected.

"A deep sense of love and belonging is a need of all people. We are biologically, cognitively, physically, and spiritually wired to love, to be loved, and to belong. When those needs are not met, we don't function as we were meant to. We break. We fall apart. We numb. We ache. We hurt others. We get sick."

Brene Brown (2016)

The picture on this slide shows Dee hosting a "Meet the Neighbours" night at her apartment building.

It would be remiss not to think about home in terms of community. A lot can be learnt from the worldwide cohousing movement, not designed specifically for people with a disability but around people coming together because they want to be good neighbours. It's an example of how we can enact neighbourhood and community, as well as financial and environmental sustainability. People who live in cohousing have genuine control, there is a mix of people from all sorts of backgrounds and shared space is factored into the design to offer connection and exchange.

Here's some pictures of Cameron who not only lives in his own home but is a well-loved neighbour, employee of a local business and volunteer at his community market. I'd like to finish with a quote from social researcher Hugh MacKay (2017) states:

"How we contribute to the miniatures of life – in our family, street, suburb and town – will ultimately help to determine the big picture."

Hugh Mackay (2017)

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