

National Conference 2019 – Who is the Target Market for SDA?

DR GEORGE TALEPOROS: Hello, Melbourne. How are we? Are we happy?

Yeah, feel the energy, we've just had morning tea, feeling good, you're at a conference, it's exciting.

Awesome. It's so good to see everyone here today.

I want to let you know that you have a lanyard that is more than just a lanyard.

On that lanyard, there is information and you access that information by plugging it in to your computer and all this amazing knowledge will be available to you, so please access that and make the most of it.

Don't give it to your animals or anything like that.

All right, this is the first of two plenaries.

This one is about who is SDA for?

Our presenters, in order, are Cathy Bucolo.

Yeah, Cath.

(Applause):

Juliana Svaganovic:

(Applause):

And Deborah Rouget.

(Applause):

I want to introduce Cath now.

Cath is one of my favourite people.

She is actually someone who knows more than I do about SDA, which is really saying something.

Cath is our Clinical Practice Lead at the Summer Foundation.

Cath works to ensure that people with disability have the right supports in place so they can live in the community and she specialises in ABI, rehabilitation, disability advocacy and capacity building.

Please welcome Cathy Bucolo.

(Applause):

CATHY BUCOLO:

Thank you, George.

So for Summer Foundation, SDA means a real opportunity for people living in aged care to have the choice to leave if that's what they want, and for people at risk of entering aged care, an alternative pathway.

We have the tenancy matching service at Summer Foundation.

They are a very focused group and a little bit obsessed with the target market for SDA.

Put simply, TMS finds tenants for SDA providers and TMS finds housing for people with disability.

Up until this point, the people who are likely to be determined for new build SDA high physical support has been TMS's focus.

We really know that the need is for different design categories and we know that the needs in an SDA are for people without only physical impairments.

In the near future, we hope that TMS work will progress and include different design categories and different building types.

For today, I'll give you an update from TMS's view about who is the target market for SDA.

To help us frame this information, I'm going to resurrect an old acronym that I invented in a workshop years ago.

I haven't used it since because to be honest, it's terrible.

It doesn't have any clever double meaning, it just sounded like something you'd yell out across a footy field.

I think the universe is telling us it's time to resurrect CUDA.

CUDA stands for consider the person first, understand the disability, do two things at once, ask smart questions.

If we talk about CUDA in the next seven to eight minutes, we'll begin to know the target market for SDA.

I can guarantee you that people with SDA who get funding like to have their nails painted.

They have a committed, loving girlfriend.

They fell in love and got engaged.

They prefer cognac, but a vodka sunrise will do.

They are a professional writing, they have been subject to trauma.

They cook spag boll, they love taking photos, they got divorced, they argue with their mother because she brought in a picture of some flowers and he thinks that's too girly for his new digs.

They've got kids, they're single, they have purple hair, they love Netflix, they want to go to the beach and they have an amazing mother in law who breaks all the stereotypes of the annoying mother in law and she's here today.

GT: Where is she?

CB: People, George, let me speak.

People are people.

When we present a TMS summary report about a potential tenant to a new build SDA property, SDA provider that I'm working with at the moment, he often asks an initial question that sounds something like this:

Cath, will her sister really be able to visit easily? Can you check that?

To me, that's an SDA provider who knows that the target market for SDA is people first.

Understand the disability: the people who live in SDA will have a disability.

We need to understand that as more than a label.

TMS have matched 45 people with new build SDA high physical support properties and they have been determined with that SDA type, single occupancy in New South Wales and Victoria.

14 people have cerebral palsy, and what does that tell us about the target market?

The Cerebral Palsy Association Research Foundation says 1 in 3 people with cerebral palsy is unable to walk.

That starts to tell us about design category.

1 in 4 people is unable to talk, emergency coms and assistive tech.

1 in 10 has a severe vision impairment design category.

1 in 2 has an intellectual disability, supports and design category.

On our site, 7 people have acquired brain injury. What does this tell us?

People who have sustained their injury as an adult are not likely to have an intellectual disability, so this tells us the target market have the decision-making capacity, they enact their choice and control and direct their supports and it's a participant-led transition.

People with ABI may have weakness on one side, this tells you design category.

People with ABI have difficulty with executive skills, planning, organising, problem solving, initiation, judgment, abstract thinking.

Not all people have those, but they may have some, this tells us design category, supports and how are they going to cope with transition and then we can see there are 45 people who have lived where they have before they moved in to SDA and RAC, stands for residential aged care.

We also know in TMS that people living in SDA need to include people who have specialised support needs to keep them safe, minimise risk and ensure they have opportunities to participate in meaningful activities.

They have high care levels of nursing.

They need support due to severe mental illness.

They have multiple disabilities, complex presentations and very high support needs. I got the rush.

They need to do two things at once and what this means is people who live in SDA will have significant limitations, but they will also have great capacity for future development. So we always need to do and acknowledge those two things.

The SDA rule pushes us in to looking at someone's limitations, which we need to do so that they can meet eligibility, but we should always also look at their capacity. And the last letter of the acronym is ask smart questions.

We all need to keep doing this. The Housing Hub is a great place to find housing options for people with disability, but it will soon also be a place where people will create their own profile and tell us the answers to these smart questions.

Where do you want to live, who do you want to live with and what type of people do you want to live with?

Come to the Summer Foundation booth if you want to keep talking, but for now, remember Marvel Stadium and CUDA.

(Applause):

GT: Thanks Cath, great advice there, a great acronym as well.

Our next presenter is Julia Svaganovic.

Julia is a self-confessed geek girl, bibliophile and power chair sports athlete.

Julia transitioned to the NDIS in April 2018 and this is now supporting her independently in a purpose built unit, which is awesome.

Please welcome Julia.

(Applause):

JULIA Svaganovic

JT: Thanks, George-.

GT: Julia, do you mind if I indulge for a minute?

JT: Sure, you're going to embarrass me now, aren't you?

GT: Julia and I went to school together and Julia was a lot smarter than me and we haven't seen each other in over thirty years, so the conference that brings people together.

JT: Yeah, I don't know why you're saying I'm smarter than you, you're the one with the doctorate.

GT: Over to you, Julia.

JT: I'm going to give you a really short and simple answer as to who is a target market for SDA.

It's people like me.

It is disabled adults who want to live an ordinary life who can't access housing because of accessibility requirements and unaffordability, because let's be honest, wheelchair users can't even get in to 99% of residential houses, no matter what year they were built.

It is disabled adults whose primary support comes from ageing parents and who will end up in inappropriate housing such as aged care or group homes, when that parent is unable to support them any longer.

It is disabled adults who want freedom and space to be themselves and it is the disabled adults who want to choose where and how they live.

I feel like I am living the dream because I have been fortunate enough to be living independently in a purpose built duplex since October last year.

This has come as a great relief.

My parents, who are in their late sixties and early seventies were my primary physical support until then, were simply worn out.

The reality of my future before this, was I would end up in aged care because of my high support needs and lack of alternatives or funding.

It was really scary because these settings dramatically increase people's risks of being abused and severely compromises physical and mental health.

It would also end my independent and active life as I knew it.

When I did find the best solution for my needs, my fight to live independently hit nothing but brick walls, like the 12 months it took to get an early NDIS transition after I was offered tenancy, and the 2, 3 month NDIS plans after that, when I was told to go explore my housing options. All the while, my brand new accommodation sat empty.

Having finally moved and settled in, things suddenly felt precarious, against last month when I received an official letter from my landlord stating my tenancy was conditional on receiving SDA physical support funding.

Not once has this been mentioned before, not in the interview, not in being the successful applicant and not when I signed my lease.

I had provided my planner with my current plan with the landlord's SDA registration details and my plan had actually been delayed when the planner waited for my eligibility for SDA funding to be approved.

There is also mention in my current plan of SDA home maintenance.

Even though I've been living in SDA for 6 months now, it really still is a memory to me.

We all know what the acronyms stand for, but in funding terms, there is no clear information for participants.

We need to know how SDA works in our plans and what level of funding we can expect landlords to request and be entitled to.

Without that knowledge, we can't hope to navigate it successfully.

The most important thing we need from SDA is security.

It's no use moving in to a place if you are constantly anxious that your funding levels will be cut, whether it's regarding SDA or support workers because without sufficiently funded support hours, I can't live independently.

SDA also needs to be a lasting change that provides stability for disabled tenants.

We cannot live in fear of future, we cannot live in fear of funding being cut and no longer being able to live in a place we make our home.

It cannot give us a taste of independence, only to take it away.

As someone who's been and is once more faceted at the target market and has been living in SDA for 6 months, I thought I would share some of my insights.

SDA needs to be in as many places as possible. I live in the outer south-eastern suburbs and my accommodation is the first one I knew of in the area.

Most before then had been north of the city, but we live everywhere and a lot of people don't want to move far from where they currently are because we build a very reliable support network and starting from scratch again is hard.

Don't assume one size fits all, we all have different requirements and desires, the more options, the better.

We want to have the range of choice that able-bodied people have.

Within buildings, we need accessibility to be flexible.

I actually nearly declined my tenancy because I was very unhappy of where the fixed ceiling close tracking was.

The bedroom is so small, my chair needs to be parked in the bathroom and I have to fly across the hallway to transfer in and out of bed.

Anyone who uses a hoist regularly knows that the further you travel, the more risk and the more uncomfortable it is.

You need to consult and listen to disabled people in design processes, for example, my pantry is the worst pantry in the history of pantries.

It is a corner pantry that is wide and deep, but with a narrow door, so I can't even see all of the pantry and able-bodied people literally have to walk in to the pantry to retrieve anything.

One thing I do love about my house is the smart technology, which has given me back independence and empowered me. Through a gate where I can open and close my front door, which means that for the first time ever, I can exit and enter my house alone.

But if you are putting smart technology, please make sure it's through the entire house.

The blind in the second bedroom, which is my home office, is manual and it's so frustrating having to ask somebody to open and close them.

I'm getting a bit of a hurry up, so unfortunately, I'm going to have to miss a few things, but I would like to leave you today with 2 visions I have for the future.

Firstly, every disabled person should have the opportunity to live independently with full choice and control over their lives, wherever and whatever setup is best suited for them.

This is especially urgent for the over 6000 younger disabled people currently living in a nursing home because even one a year, young disabled person living in a nursing home, is one too many. And it is my hope that sooner rather than later, we will not need SDA because whether voluntarily or through legislation, designers and the building industry embrace universal accessible design and all residential housing is accessible. Thank you.

(Applause):

GT: Thank you, Julia and there are some important people here who I hope have been listening who will be able to sort out that unfortunate situation that you're having, and we know that there are a lot of stories like Julia's.

Julia is not the only person who's had difficulties with the NDIS, but we hope to fix this at some stage soon.

Our next presenter is Deb Rouget.

Deb is the CEO of Belonging Matters, and she started Belonging Matters in 2003.

Deb has spent over 30 years supporting adults who have a disability, and families, in various ways to help them to belong and to be in the community, to have direct family experience, a lot of flack to support people with mental health needs and disability.

Deb has a Bachelor of Applied Science and presents at various seminars and conferences like this one today.

Please welcome Deb Rouget.

(Applause):

DEB ROUGET

Hi, thanks, George, it's great to be here.

Good morning, everybody. It's such an important topic that we meet on today and SDA has been a struggle for many people with disabilities over a long period of time. And particularly our work focuses on people with intellectual disability who have often found themselves in group homes.

I think no matter who is deemed eligible for SDA, we must uphold the sanctity of home.

What does it mean to have a real home?

As Dr Michael Kendrick said, a real home is not solely one's dwelling place, but rather a key cubicle in life that helps to stay and uphold much of what is personally private and intimate about ourselves and reflects our deep identity, values and preferences for a good life.

Although market and commercialised factors are important, we can't be driven by those factors alone because we lose sight of the person and the typical principles and practices of home.

Over the years, I have seen home being distorted even with good, well-intended systems like in the picture here, which can further marginalise people with disabilities and foster notions of difference.

For example, finding a home could be limited to finding a vacancy or an option to fit in to congregations of people with disabilities, a service setting, a facility and residential service and so on. Even the term 'accommodation' sets people apart.

I don't know about you, but the only time I look for accommodation is when I go on holidays, usually short term, transient and perhaps somewhere very exotic.

But I can't wait to get back home. So to prevent us drifting too far away from the concept of home, it's important and although it's different for all of us, it's important for each and every one of us when we're helping someone to create home, to reflect on what home means to us so we can hold on to the principles of home.

Our efforts at Belonging Matters stem from the extreme satisfaction for people with disabilities, predominantly with developmental disabilities and families, who have very few choices other than congregate group homes.

With capacity building investments now, close to 40 people with developmental disabilities now live in a home of their own, that's personally directed with personally tailored support.

Our efforts really were inspired by a worldwide movement and recently backed up by a study referred to as the Individualised Supported Living (ISL) project that was led by Curtin University, University of Melbourne and the University of Sydney.

I think this study, if you have not read it, you need to get hold of it. It examined 130 individualised supported living arrangements in 3 states in Australia.

Some of the people who we've journeyed with over the years took part in this study and it provides a framework for our efforts.

There is a number of themes in relation to the ISL project and that is that home starts with the vision of an ideal home for a person, a willingness to uphold that sanctity of home and work out the practicalities around each person. And home is not a once off thing.

It's an ongoing process and I think we've heard that today. And it requires the leadership of at least 1 person.

Home is different for every person, it's private and personal, it's not a service setting and home needs to reflect people's personal taste and routines.

Home needs to be designed around each and every person and their unique identity. And people should not be compelled or coerced to live together based only on their diagnosis or planning needs, to focus on the person and assist the person to develop their own sense of home.

Control needs to be in the hands of people, we should not be pre-designing home arrangements and people should have real and typical choices.

People need flexible, creative support that includes a mix of formal and natural supports and not be locked in to predetermined support arrangements.

Like everybody, people need to thrive, not just survive. And they need a range of valued roles in the community, which includes paid employment. And we know how low those rates are and most of us need paid employment to afford to live in our own home.

Most importantly, people need to connect with other people and know as many different people as possible. So it's not just enough to live in your home, you've got to be connected, you've got to have things to do, and relationships.

As Brene Brown states, a deep sense of love and belonging is a deep need of all people, we are biologically, cognitively, physically and spiritually wired to belong.

When those needs are not met, we don't function as we're meant to. We break, we fall apart, we numb, we ache, we hurt others and we get sick.

The picture in this slide here shows Dee living in her own apartment with a range of supports. And some thinking about how she would meet her neighbours, through a 'get to know your neighbours' night. So she got to know her neighbours.

It would be remiss of us not to think about home in the terms of community and what it is to be a neighbour and be part of a neighbourhood.

I'm hoping that's going to stay. Here's a picture of Cameron who now lives in his own home, but he's a much-loved neighbour.

He's an employee of a local business and a volunteer at a local community market.

I'd like to finish with a quote from social researcher Hugh McKay.

He says, how we contribute to the minutiae of life in our family, in our street, in our suburb and in our town will ultimately develop the big picture. Thank you.

(Applause):

GT: Thank you, Deb for your wise words. We don't have a lot of time, but what I've done is I've gone through the questions on Slido and I'm going to ask a question that summarises what a lot of those questions are saying. And there are a lot of families and parents here were who are concerned about their children who have cognitive disabilities, and who are concerned that they won't have access to SDA. Can I ask the panel what are your thoughts on how we can support these families and make sure that people with disabilities who have cognitive impairments get what they need when it comes to housing and I'll start with you, Cath.

CB: sure, I think the best thing I could do is just give you information, so based on our work at TMS, where we look at the SDA rule all the time. What I'd say is a person is eligible for SDA if they have an extreme functional impairment in one of these areas, so mobility, most people are familiar with or self care and the last one is self-management. So if somebody has a cognitive impairment, it's likely that they could qualify under that self-management. So

self-management means organising my medical appointments, organising my supports, making decisions. So if you have a cognitive impairment and as well as that, it's extreme enough that you need one-to-one support to be able to self-manage and you can't live, or I should say other mainstream housing doesn't meet your housing needs and an SDA response means you would be able to live more independently, then if you look at it that way, you would be eligible for SDA.

GT: Thank you, Cath. And Deb, with your work with families, what do you say to them?

DEB: This is a huge concern for the families we've travelled alongside for over 10 years. What's going to happen to my son or daughter when I'm no longer here? My advice would be to get going on that question sooner than later. Never too late and it's never too early. Have a vision for home, what home is. It's got to be the starting point. And there are many people and families who I can put you in contact with, so please email us at Belonging Matters, who have done this work and have crafted individual arrangements which are being funded through their NDIS package at the moment. As well, with a range of supports, we've still got some work to do on more creative options such as trying to get home sharers, that type of model supported, but I think there needs to be space in SDA for people with intellectual and developmental disabilities. I think we've heard that this morning, it needs to expand, but I think there are lots of creative ways of trying to do that work.

GT: Julia?

JG: Cath and Deb have really summed it up, but just be persistent, nothing comes easy. Especially in funding, as we all know. You just keep knocking down those doors and I know we all get tired, and trust me, I did. But you just keep going and you keep knocking on doors and you keep speaking to people and you find the right people to push for you.

I was really lucky when we were having no success in trying to get an early NDIS transition, I just happened to team up with someone who became a great advocate for me and within 2 to 3 weeks, we had a planning meeting. So it's finding people, when you can't go any further to push for you.

GT: That's fantastic advice, let's remember that we fought very hard for the NDIS to work for everyone and we all have rights and we have rights to a life and I think that our presenters really showed that in what you had to say.

Please thank your presenters.

(Applause):

END OF TRANSCRIPT