BUILDING CAPACITIES FOR INCLUSION: IDENTIFYING THE PRIORITIES OF INCLUSION AND MAINSTREAM CAPACITY BUILDING FOR PEOPLE WITH A SPINAL CORD INJURY (SCI) AND POST-POLIO SYNDROME

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CITATION

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ABBREVIATIONS
AT  Assistive Technology
DDA  Disability Discrimination Act
GP  General Practitioner/Practice
LGA  Local Government Authorities
ILC  Information, Linkages and Capacity Building
NDIS  National Disability Insurance Scheme
PP  Post Polio syndrome
SCI  Spinal Cord Injury / damage
TM  Transverse myelitis
UD  Universal Design

BUILDING CAPACITIES FOR INCLUSION
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PROJECT PURPOSE

The National Disability Insurance Scheme (NDIS), through its Information, Linkages and Capacity Building (ILC) Strategy, includes a significant focus on capacity building of mainstream and community ‘to be inclusive and responsive to people’s needs’.

However, while building the capacity for inclusion is a critical activity, there is a lack of evidence about which capacities need to be built in order to meet the needs of people with disability, including those with spinal cord injury / damage (SCI), and people with post polio syndrome (PP).

WHAT WAS THE PROJECT ABOUT?

In 2017, Spinal Life Australia received an ILC National Readiness grant from the National Disability Insurance Agency. Spinal Life Australia (in QLD), and their partner AQA (in Victoria), represent people with SCI. Spinal Life Australia also supports people with PP, in conjunction with Polio Australia and the Polio Network Victoria. The agencies reported feedback from their members about barriers to inclusion within community and mainstream services.

Spinal Life Australia contracted Deakin University (stage 1) and Swinburne University (stage 2) to undertake a research study to investigate these barriers.

WHAT IS CAPACITY?

‘Capacity building’ means ‘Increasing people’s knowledge, skills and abilities. This might apply to an individual ... or community as a whole, for example, building the capacity of organizations to be more inclusive’.

The literature on capacity building suggests that capacities can include:

- Knowledge
- Skills
- Attitudes
- Behaviours / Actions
- Networks
- Infrastructure / Resources
- Policies / Legislation
- Culture.
WHOSE CAPACITIES ARE WE FOCUSING ON?

In order to identify ways to increase inclusion, the project aimed to identify priorities for capacity building of mainstream services to better meet the needs of people with SCI or PP.

It was anticipated that many of the findings from this study would be applicable to others with diverse experiences of disability.

The focus was on what specifically needs to change in mainstream services for people with SCI and PP:

— Which services / businesses needed to change?
— Whose capacities needed to change?
— What capacities needed to change?
— What are the strategies for bringing about this change?

We included a focus on the service areas of:

— Health (physical and mental)
— Transport
— Employment
— Recreation and Leisure
— Housing
— Environment
— Relationships/ social support
— Finances
— Education
— Ageing.

People also made comment about disability services (and the NDIS).

‘Mainstream services’ means services that are non-disability specific including:

Government funded services (for example, education, health care, public housing, transport and employment services)

Services / supports provided by the community or private sector (for example, a swimming pool, neighbourhood houses and men’s sheds, gym or theatre).
WHO PROVIDED INFORMATION?

Information was collected from 153 people with SCI and PP (in multiple States, both rural and urban).

While the projected targeted QLD and Victoria, some responses also came from Tasmania.

There was almost even representation of men and women.

In all, 153 individual responses were returned (this includes a small number of people who made more than one response, for example participating in a discussion group as well as an interview or online survey). Data collection targeted people in QLD and Victoria, but a small number of people in Tasmania also chose to complete surveys. Responses include: 88 from QLD, 55 from Victoria, 5 from Tasmania, totalling 148 useable responses. A further 5 participants provided only demographic data and were therefore excluded.
The respondents represented a wide variety of ages, though a significant proportion (45%) were aged 65 years or over, with 37% aged 40-65 years.

HOW WAS THE INFORMATION COLLECTED?

The research utilized a range of methods for data collection dependent on participant preferences including discussion groups utilizing existing regional member networks (12 across QLD and Victoria), individual interviews (20 participants) and online survey (25).

Participants were asked to rate their priorities in regard to service areas where capacity was most needed to be built, then explain issues and suggest solutions.
WHAT DID WE FIND?

The mainstream service area of physical health was consistently rated as the top priority for capacity building. This was closely followed by the wider and built environment (including buildings, public spaces, retail environments, community infrastructure such as footpaths and parking, as well as public attitudes), and transport services.

In the main, the dominant capacity areas showing deficits were those of knowledge, policy, attitudes, and infrastructure/resources. The data in this report is organised around these capacity areas.

The following short summaries are provided of the main capacity-building priorities. Priorities are those most frequently identified. Discussion of these has been significantly synthesised with only a small number of qualitative comments presented to reflect the major concerns. The Appendices contain detailed priority mapping of capacity needs, also identifying key stakeholders (i.e. whose capacities are to be built). Detailed participant commentary is provided in regional qualitative reports (10 reports for QLD, 4 for Victoria and 1 for Tasmania) which include a wider discussion of all priorities and strategies to address issues.
Just going to those specialist type of appointments - there’s a lot of them because of the disability. I would have probably 10 to 15 a year … even things down to levels of podiatry and stocking, lymphedema clinic, and then the normal sort of health things like dental and urology - and all of those I have to first make sure I can access and get into the building. And then I’ve got to check on the attitudes of the staff, their mainstream health staff, allied health staff. Are they around things - disability and my particular condition other than their speciality? And what physically do I need to do if I’ve got to transfer [onto a table or machine] for a test or for a scan or for some other thing? (MELBOURNE PARTICIPANT).

Receiving adequate, informed, timely and accessible health treatments and supports greatly affects health maintenance as well as engagement in life activities. Denied or inadequate health care can lead to significant health complications resulting in lost social and economic participation as well as increased health system costs.

I have recently gotten into the pain clinic because with a spinal injury I’ve got neuropathic nerve pain, which is hard to manage - especially when you’re allergic to all the medication. It took three and a half years for my referral to get through to the pain clinic, for me to be able to see them (MACKAY PARTICIPANT).

It’s hard enough for us without having the stress of fighting to get the right service and then having to wait all this time. And if you’ve got chronic things wrong with you like pressure sores … they’re going to get worse because the waiting time is so long (MACKAY PARTICIPANT).

Health services were frequently inaccessible to people with SCI and PP, particularly noting a lack of hoists and transfer equipment (and staff knowledge of how to use them), as well as lack of height adjustable treatment beds and scanning machines. In some cases, this results in denial of health treatment.

With the masseurs and even with the GPs, they don’t all have height-adjustable tables. I know it is recommended for GPs but they certainly don’t have them (MORETON BAY PARTICIPANT).

Two of the things I’ve found most difficult to do is get x-rays and other scans because I can’t stand transfer anymore. So I need to have a hoist and I’ve looked around long and hard and only found one space in Brisbane … In other situations, people bring their own hoist and their own carers with them … but then you still need to be able to find a service that has sufficient space to be able to use those things in. … Even things like going to the GP and needing to go onto the examination table is very difficult … once you need to be hoisted onto the table that’s a whole different scenario. And you need to bring your hoist.
with you. The same with breast examinations, that’s very difficult because of the position you have to be in and so on for them to do the mammography properly. ... So I’m in a situation currently where I haven’t been able to find a way to do that for the last six years. So that puts me in a vulnerable position (BRISBANE PARTICIPANT).

In general, health practitioners have little knowledge of SCI and related conditions such as pressure sore treatment, or of PP. Lack of knowledge of wound care, for people with SCI, and of anaesthesia, for people with PP, were particularly common gaps in knowledge among health practitioners.

And the understanding of polio specifically in the medical [profession] - it’s eradicated. It’s gone. It doesn’t exist. No-one’s got it. And they don’t care - or they just put it [i.e. diagnose post polio] as old age (GOLD COAST PARTICIPANT).

There’s ... not enough specialty in spinal. You could go to a doctor somewhere that just wouldn’t know spinal. So, it’s tracking that field to find people who deal with spinal - so that you can get to your results quicker ... There’s not many GPs who understand spinal (GEELONG PARTICIPANT).

Negative attitudes held by health practitioners are a significant barrier to receiving suitable health care. A major problem is the unwillingness to value or listen to the expertise of the patient in regard to their own condition. Further, practitioners can lack willingness to learn new information or make the reasonable accommodations necessary to ensure their venue and equipment are accessible.

“My doctor says ‘I don’t know anything about it [post-polio] and I don’t want to know anything about it, so buzz off’. And that was a specialist from the hospital (MORNINGTON PARTICIPANT).

“We can’t walk. It’s not we can’t think – we can’t walk. They [hospital staff] talk to you as though you’re deaf and you’re stupid (SHEPPARTON PARTICIPANT).

“I have a very good understanding and I’ve been managing myself living alone for a long time. I’m quite qualified, I think, to know what works with me ... [But] I’ve been spoken down to and patronised unbelievably. I’ve had a nurse call me a junkie when I’ve just got out of emergency because I insisted on an intramuscular pethidine. It doesn’t constipate me (CAIRNS PARTICIPANT).

If only the [health] professional would listen to the patient ... Sometimes they don’t like to be told (GOLD COAST PARTICIPANT).

A range of policy and program settings also function as barriers to effective health service access (see Appendix 1).
### Priority actions / capacities to be built:

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<tr>
<th>CAPACITY AREA</th>
<th>TARGET</th>
<th>PRIORITY CAPACITIES</th>
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<tbody>
<tr>
<td><strong>Resources and Infrastructure</strong></td>
<td>All health services</td>
<td>Equipment provision: height adjustable treatment tables and scanning equipment; hoists and transfer equipment; shower and wheelchair; accessible call buzzers</td>
</tr>
<tr>
<td></td>
<td>All, especially regions</td>
<td>Service expansion: GPs, specialists, allied health services with SCI and PP knowledge; specialist pain and podiatry clinics</td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
<td>Health professionals, esp. GPs, doctors, wound care nurses</td>
<td>Increased knowledge: SCI and related conditions</td>
</tr>
<tr>
<td></td>
<td>Health professionals, esp. GPs, doctors, anaesthetists</td>
<td>Increased knowledge: Post polio and effects</td>
</tr>
<tr>
<td><strong>Attitudes</strong></td>
<td>All health professionals</td>
<td>Attitude change: Value and listen to expertise of patient Respect for personhood of patient</td>
</tr>
<tr>
<td></td>
<td>Scanning services, pharmacies, admin/ reception staff</td>
<td>Willingness to make reasonable accommodations</td>
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See Appendix 1: Health sector – capacities to be built
SOLUTIONS

Participants proposed a range of solutions in each of the target areas, summarised below.

**Resources & infrastructure:**
— Mandated accessibility standards for health services with compliance checks and fines.
— Subsidies to health services for equipment purchase and venue modifications.
— Disability liaison personnel in hospitals to mediate inaccessibility, organize necessary equipment and personnel.

**Knowledge:**
— Training for health professionals including self-education resources, professional development, publications in medical journals, development and dissemination of guidelines e.g. anaesthesia for people with PP.
— Professional networks and formalized knowledge exchange for health professionals in relation to specific disabilities, treatments and supports. This could be via activities such as mentoring, regional visits of ‘expert’ personnel, identified teams of staff in hospitals with SCI knowledge, register of GPs/health professionals with specialist interest/ expertise.
— Consumer networks, resources and advisory groups: resources to support consumer education of health professionals, consumer networks to share information, consumers on health service advisory and other groups.

**Attitudes:**
— Practice change: health practitioners need to build in more time to enable engagement with patient expertise and requirements.
Accessing services and life activities is fundamentally blocked by inaccessible streetscapes, buildings and car parks. Navigating this inaccessible environment takes considerable time and support, not always available to people with SCI and PP, often leaving them isolated and denied services and activities.

Basic footpaths are non-existent in many places, or kerb cuts not provided.

"You look at modern suburbs developed in the last twenty years and they don’t have a concrete footpath. And so power wheelchairs don’t go so easily over ordinary grass undulating footpaths. ... should that be a mandatory part of development?" (BRISBANE PARTICIPANT)

Buildings remain inaccessible. Design of buildings, as well as car parks, has not catered for the diverse mobility devices in use. This places significant workload on people with disability to pre-plan trips so as to avoid disabling barriers in the built environment.

"When you’re going somewhere that you haven’t been before … I get all this anxiety thinking ‘am I going to be able to park, am I going to be able to access this building? … So quite often I’ll do a dummy run before my day of attending there to see if I can get in. And quite often I have to go home and say, ‘no I’m sorry I can’t come and I can’t get in your place’. (BRISBANE PARTICIPANT)

Even though there is a law that says ramps need to be put in, a lot of times you can turn up and there is no ramp. Or the ramp that’s provided is just so steep you can’t push up it, so it just means access is pretty much impossible (BRISBANE PARTICIPANT).

A lot of ramps too these days are not taking into account people in larger chairs or scooters - you just can’t get around ... And these ramps - and even the toilets and doorways - are just not catering (to this diversity) (CAIRNS PARTICIPANT).

Access to appropriately sized and sited disability parking is a major obstacle. Disability car parks are poorly designed and often mis-used by people without disability.

"Everywhere you go, there’s just no way you can go in and get out [of the disability car park] ... it never used to be like this. I’ve been in a wheelchair for 45 years. But now, they’re [the car parks] just so tiny. Even an average size car - you just can’t get them [a person and wheelchair] out (SHEPPARTON PARTICIPANT).

Accessible toilets in public facilities are inadequate, poorly maintained, locked or mis-used for other purposes such as storage.

"I went to Corio shops and I asked where the toilet was and they said it was broken … They’ve only got one disabled toilet in the whole of the complex at Corio Shopping Centre (GEELONG PARTICIPANT).
The environment is made inaccessible not only by physical barriers but also by attitudinal ones. Even where accessible facilities have been provided, such as disability parking or disability toilets, these are mis-used by the general public.

We were at Harbour town ... and this BMW pulled up alongside us in a disabled spot. And this young woman got out and [my husband with SCI] said, 'excuse me dear. You've parked in a disabled spot'. And she said, 'yes, I know. I'm picking up my mother'. So we were going shopping ... [but my husband with SCI] said, 'I'll just wait here. You go and do the shopping. I'll just sit here for a minute'. So when I come back, the BMW had gone. And I said, 'well, what happened?' He said, 'well she came back, quickly got into her car and I wheeled away and knocked on the [car] window and said 'you've forgotten your mother'. And she said, 'get a life!' (GOLD COAST PARTICIPANT).

People with disability experience negative attitudes across society, including in shops (with shop assistants being unwilling to communicate directly with a person with disability), from local government officials (being unwilling to make reasonable accommodations in all aspects of their work, including building approvals), and businesses (being unwilling to modify premises to enable access).

And I actually took a pamphlet with me to show them [the store owner] how they could buy or make a ramp because I knew that a step was there. But she said to me, 'no, we don't [want it]. I'm not sure I'm even going to look at it' (BUNDABERG PARTICIPANT).

Lack of knowledge of disability or accessibility solutions contributes to many of the difficulties in the built environment. The design of facilities such as disability parking and toilets is outdated, based on inaccurate assumptions about the types of people with disability accessing community, and the equipment they utilise. Similarly, lacking is knowledge of design requirements and solutions to built environment issues such as retrofitting old or heritage buildings, or ways to support businesses to become more accessible.

Unfortunately, I find that even with local governments, state government ... As soon as they hear the word ‘disability’ they throw their arms up in the air, ‘I don't know about that. I've got to go get someone else.’ Whereas if they thought ‘hang on ... it's actually quite simple. There's a standard, there's a person that has to approve that standard’. It's not that hard (GEELONG PARTICIPANT).
Priority actions / capacities to be built:

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<th>PRIORITY CAPACITIES</th>
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<tr>
<td><strong>Infrastructure</strong></td>
<td>LGA</td>
<td>Neighbourhood infrastructure: accessible and connected footpaths, roads and kerb cuts.</td>
</tr>
<tr>
<td></td>
<td>LGA, developers</td>
<td>Accessible car parks and drop off zones: width/ length to suit diverse mobility equipment, well situated.</td>
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<tr>
<td></td>
<td></td>
<td>Accessible toilets: increased number, automatic doors, appropriate width, specified (not shared) purpose.</td>
</tr>
<tr>
<td><strong>Attitudes</strong></td>
<td>General public</td>
<td>Attitude change: respect for people with disability, compliance with disability parking and toilets.</td>
</tr>
<tr>
<td></td>
<td>Businesses and retail</td>
<td>Attitude change: willingness to make reasonable accommodation, treat person with disability as equally entitled to service.</td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
<td>LGA, developers</td>
<td>Increased knowledge: design of disability parking and toilets to suit needs; ‘solutions’ to built environment issues (e.g. retrofitting, heritage buildings).</td>
</tr>
<tr>
<td></td>
<td>Retailers, businesses, service providers</td>
<td>Increased knowledge: accessible shops/ businesses/ services</td>
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See Appendix 2: Environment sector – capacities to be built
Participants proposed a range of solutions in each of the target areas.

**Resources and infrastructure:**

— Increase disability toilets via Changing Places initiative, and implement strategies such as pin numbers or keys to exclude general public usage.

— Link disability parking quantity and design to reliable data on population and need (including type/size of mobility device), and implement stronger deterrents for parking offenders.

— Involvement of people with disability as advisers for locality and building design and upgrade, testers, and review panel for developments.

— Consumer advocacy: active advocacy by people with disability to make complaints, lobby for improvement, share information about accessibility levels of venues etc.

**Attitudes:**

— Increase contact between people with and without disability through disability awareness in schools, events, through the media and simulated disability experiences for those in authority.

— General education about disability, reasonable accommodations, and benefits of universal design (UD).

**Knowledge:**

— Knowledge sharing, particularly by LGAs, on disability design (good practice solutions and examples), disability parking, requirements and examples for DDA compliance in building applications – informed by people with disability.

— Training for businesses in accessibility requirements and solutions; best practice examples (e.g. of disability toilets in businesses), UD, customer service.

The need to upgrade disability legislation and standards related to the built environment, including parking (for example through Building Codes), as well as enforcement of these was seen as a fundamental underpinning to the above solutions.
PRIORITY AREAS OF INADEQUATE CAPACITY

Participants identified key capacity gaps across all areas of transport including buses, trains, planes, taxis and private car modification. A particular priority is bus transport that is a critical local link to services and life activities. Buses are affordable but not accessible nor safe for people using wheelchairs and mobility aids. Bus infrastructure is lacking including: wheelchair tie downs/anchor points, accessible ramps/boarding, and accessible bus stops.

“You hop on a bus there’s no tie downs, so you can easily tip out, end up in hospital, … have an accident … so there’s no safety (BRISBANE PARTICIPANT).

“The other thing is the ramp angles. This one occasion they’ve [the driver] missed the bus stop and he says, ‘You have to get out here’. It’s on the road. Went down the ramp and there’s a cut off - and the wheelchair … just took off. But he wasn’t even really holding me and I thought god that could’ve been so bad because 180 kilos of wheelchair - smashing your head into the bitumen (CAIRNS PARTICIPANT).

Some [bus drivers] were really good and some helped me on and off the bus and everything like that, and others would just basically refuse to help and drive like absolute maniacs (MACKAY PARTICIPANT).

Airplane travel is a vital link particularly for people living in regional areas of QLD to enable them to access necessary health services, among other life activities. While Qantas was praised for having policies fostering inclusion and informed staff practices for supporting passengers with wheelchairs, other airlines had exclusionary policies and practices (particularly around manual transfers and transporting wheelchairs) as well as lack of equipment such as hoists and on-board wheelchairs.

“You’ve got to disassemble your chair on the tarmac, … the maximum weight you can have in any one item is like 20 kilograms … so you’ve got to pull your chair apart on the tarmac after you’ve just got out of it … And there’s no actual portable hoist there to hoist you … you need five people to do it for me. And you’ve got to get a sling under you and move it all - do all that on the tarmac. And then when you get at the airport, say it’s Tullamarine, there’s no hoist to transfer you again. When you’re on the plane you’ve got to transfer manually into the seat (GEELONG PARTICIPANT).

Inadequate and inconsistent policies to mandate accessibility standards, particularly for air travel, are barriers to transport access.
It needs uniform standards – they need to be a lot broader and a lot more enforced. You should be able to go get on a plane here and get off a plane there and have the [boarding transfer] equipment there (SHEPPARTON PARTICIPANT).

The budget airlines haven’t got those [lifting machines] and they haven’t been made to bring them in. And then they bring in their own guidelines saying unless you can transfer yourself you can’t fly on the plane. But they’re discriminatory in a way if they’re not willing to provide ... any alternative (MELBOURNE PARTICIPANT).

Inadequate taxi subsidies were also identified as a problem, particularly in QLD, where taxis may be the only means of accessible transport to connect with regional public transport options. Taxi drivers were sometimes unwilling to take passengers with different subsidy arrangements.

Lack of knowledge of disability and how to make reasonable adjustments to support travel was commonly identified across transport modes.

They’re [taxi drivers] supposed to have training, how to handle a person with a disability in a chair... I’m not quite sure if regional areas have it as much (BUNDABERG PARTICIPANT).

I watched the staff on the plane try to work the hoist and that was a bit of a circus (CAIRNS PARTICIPANT).

They [taxi drivers] all get training and they all know that they need to slow down when they’ve got people in wheelchairs in their car and, like, I had a go at one of them ... he just didn’t slow down for a speed bump and I was just like, ‘Hey dude, I’ve got enough injuries’ (MACKAY PARTICIPANT).

Negative attitudes of staff were encountered across all forms of transport. A lack of willingness to assist, along with disrespectful to passengers with disability, acted as barriers to travel.

I guess the attitude of the [airline] booking staff ... needs to improve. They often just view it as it’s too difficult, complex, ‘I’m not sure your wheelchair will fit on the plane’ and ... they put up a lot of barriers at the front to try and even stop you from getting on there (MELBOURNE PARTICIPANT).

I have been subject to a tendency of airport staff to behave as if they know everything, having done a brief disability training seminar, and to minimise the knowledge/ experience/ concerns of passengers with a disability or their carers (MELBOURNE PARTICIPANT).

I’ve given up on Melbourne [taxis]. It’s just disgusting. If you’re on the street, they won’t even stop (SHEPPARTON PARTICIPANT).

The taxi driver told me to get out because I wasn’t going far enough (SHEPPARTON PARTICIPANT).
### Priority actions / capacities to be built:

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<th>CAPACITY AREA</th>
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<th>PRIORITY CAPACITIES</th>
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<tr>
<td>Resources and</td>
<td>Buses</td>
<td>Accessible buses: Tie downs, anchor points, folding seats, ramps, bus stops, more</td>
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<tr>
<td>Infrastructure</td>
<td></td>
<td>frequent accessible buses</td>
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<td></td>
<td>Airlines</td>
<td>Accessible planes: Hoists/ lifting equipment, onboard wheelchair, accessible toilets,</td>
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<tr>
<td></td>
<td></td>
<td>cargo storage for larger wheelchairs, larger planes in regional areas that can carry</td>
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<td></td>
<td>wheelchairs, support at airport, transport between terminals</td>
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<tr>
<td>Policy</td>
<td>Airlines</td>
<td>Standardised policy for all airports and airlines including: mandated assistance for</td>
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<td></td>
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<td>travellers with disability and lifting equipment, procedure for wheelchair transfers,</td>
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<td>carriage of wheelchairs and higher weight limits, priority seating, cost subsidies.</td>
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<td></td>
<td>Taxis</td>
<td>Subsidy: Subsidy to connect to regional public transport, requirement to accept all</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Bus drivers</td>
<td>Supporting passengers with disability: Safe driving, boarding support, use of ramps.</td>
</tr>
<tr>
<td>Attitudes</td>
<td>All transport staff</td>
<td>Positive and helpful attitudes: willingness to assist, respect for passengers with</td>
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<td></td>
<td></td>
<td>disability and their expertise, understanding of obligations against discrimination.</td>
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See Appendix 3: Transport sector – capacities to be built
Participants proposed a range of solutions in each of the target areas.

**Resources and infrastructure:**
- Equipment upgrades and provision in trains, buses and airplanes to deliver on the capacity gaps identified.
- Service development and expansion to include increased accessible regional plane and train services, along with designated disability assistance in airports.
- Information resources such as readily available information on accessibility of transport locations and modes (e.g. every airport), along with a passenger database to store requirements and preferences.

**Policy:**
- Overarching accessible public and air transport policy to set standards for all modes, including disability impact assessment on all public transport procurement.
- Consistent accessible airline policy and regulations across airline/airports mandating accessibility standards and supports (including lifting equipment, use of own chair/AT for as long as possible, wheelchair required to travel on same flight as person).
- Extended taxi subsidies for longer travel to access regional public transport connections.

**Knowledge:**
- Training for transport staff (e.g. bus drivers re safe driving; taxi drivers re supporting wheelchair users, airline staff re safe transfers from wheelchairs).

**Attitudes:**
- Policies and training of staff to utilise preference of passenger.
- Passenger complaints systems linked to fines.
INTERDEPENDENT AND UNDERPINNING CAPACITIES

While required capacities have been identified across the capacity domains of knowledge, attitude, policy, and infrastructure / resources, it is clear that capacities are strongly interdependent. For example, an overly heavy entrance door to a building that may house a dentist, shop or politician, is the result of a web of interdependent capacity gaps at a range of levels and stakeholders. While the door is the barrier to inclusion, the capacity gap is evident in relation to knowledge, attitudes and policy/legislation, which combine to create the immediate barrier. This is mapped below as an example:

Capacity gaps:

— Building tenant and building owner: response to needs of clients requires **knowledge** of these needs, **knowledge** of solution, **knowledge** of human rights or **legislative** requirement to respond, and positive **attitude** (willingness to make change);

— Builder / architect: adequate design of door requires **knowledge** of diversity of user needs and practical solutions to these (e.g. option of automatically opening door), as well as knowledge of building codes interpreted within Disability Discrimination Act (**policy/legislation**) and willingness to apply these (**attitude**) to ensure standards are met;

— Policy makers / legislators of building codes: need **knowledge** of how to strengthen application of DDA (**policy/legislation**) to increase requirement for design solutions rather than ‘exemptions’, as well as willingness to make these changes (**attitude**).

In this context, stakeholders at all levels can be compelled by informed policy and legislation, and can act to enable an inclusive environment if they also have the knowledge of the diverse needs of users (including those with diverse disabilities) along with design solutions and a willingness to apply these (positive attitudes to disability inclusion).

Positive attitudes about, and informed knowledge of, disability have been repeatedly highlighted in this data as underpinning capacity gaps for all community members (general public, service providers, and professionals).

I think a lot of the problem in this day and age is simply that able-bodied people do not understand how difficult it is for people with a disability. A lot of them don’t understand, and a lot of them don’t care (BUNDABERG PARTICIPANT).

CASCADING CAPACITY ISSUES

Just as capacity gaps are interdependent, lack of capacity in one sector (for example, the health sector) adds to pressure on other sectors, highlighting capacity gaps along the chain. For example, lack of local health service knowledge of conditions related to SCI or of PP, and lack of local specialised services, require people to seek knowledgeable services in other localities. This in turn raises the importance of the transport sector in meeting the transport needs of people with disability to reach appropriate health services. Capacity gaps in the transport sector then contribute to capacity gaps in the health sector, both resulting in the exclusion of people with disability from necessary health services.
CONCLUSION

People with SCI and PP experience a range of barriers from mainstream services. These can be understood as capacity gaps in the areas of knowledge, attitude, policy and, most frequently, infrastructure and resources. This report highlights the priorities for action, as well as the inter-relationship between inadequate capacity areas.

However, participants in this study also identified many areas where individuals or organisations were already acting with strengthened capacity by demonstrating positive and inclusive attitudes, in-situ problem solving, and drawing on the considerable expertise of people with disability in developing solutions to issues. Additionally, people with disability, and their associations, evidenced significant capacity to both provide peer support and information, as well as work with mainstream service providers (where invited) to identify capacity improvements.

Public investment and broader activity to build capacity to offer relevant and inclusive mainstream services needs to focus attention on not only knowledge, but also policy and infrastructure/ resource capacities. Perhaps most importantly is attention to building the attitudinal capacities of inclusion as negative attitudes and unwillingness to make reasonable accommodations remain significant capacity gaps in services and community.

Addressing the issues identified in this study would enable people with diverse disabilities, including people with SCI and PP, to equally participate in services and communities.
APPENDIX 1

HEALTH – capacities to be built

Knowledge of spinal cord injury and associated conditions
Knowledge of post polio and effects

Consideration of empathy for impact of SCI
Willingness to believe in PP, effects and implications for other procedures
Respect for personhood of patient

Understand importance of carer knowledge of person’s needs
Understand importance of listening to/being informed by expertise of the patient/person with disability

Willingness to offer support and make reasonable accommodations
Willingness to take holistic/wider view of patient and care needs; wider view of “problem” considering multiple conditions and interactions
Willingness to explore alternative treatments e.g. acupuncture, medical cannabis

Review and minimise requirement for health professionals to sign off on multiple forms (taxi, govt services etc)

Require adjustable treatment tables/beds and accessibility features
Expand to enable carer views to inform response to needs not just person with disability
Seek local suppliers to reduce wait times
Require speedier delivery from suppliers
Include funding for high cost specialist wheelchairs
Inclusions made clear and consistent
Include funding for high cost specialist wheelchairs

Ensure people with SCI have access to funded home nursing (catheter and wound care)
Enable patient’s carers to stay in rooms to provide level of care required
Nurse allocation to patients on basis of expertise/knowledge e.g. of SCI care
Allow patient to bring in private physio to provide treatment where hospital cannot meet required treatment level

Raise status of fall by person with SCI to higher emergency level to reduce wait times
Need increased support for patient travel
Clarity and longevity of interface between multiple funding types
Stronger requirements/enforcement of reasonable accommodation

Access to specialists with SCI knowledge
Increased availability (especially in regions) of specialists (all disciplines)
with SCI knowledge; specialist podiatry, spinal clinics, pain clinics
Increased availability (especially in regions) of GPs with SCI knowledge
Increased availability of physio in hospitals and rural areas
Increased allied health: OT with SCI knowledge, physios, home visit

Availability of support staff of both genders to suit client preference
Support to travel to Melbourne to access health specialists
Rehabilitation – increased time frame of support
Increased ambulance services

Register of specialists with SCI knowledge
Patient information resource on discharge
Shared/available medical records
Increased information on patient travel supports, options etc
APPENDIX 2
BUILT AND WIDER ENVIRONMENT SECTOR – capacities to be built

**Infrastructure**
- Roads, footpaths and kerb cuts: accessible, connected, reduced obstructions, gradients
- Disability toilets: increased number, auto doors, width, specified purpose
- Shops, businesses: increased accessibility, ramps, doors, lifts, layouts
- Public buildings: increased accessibility and detail of information about this
- Motels: increased accessibility and detail of information about this
- Parking: increased accessible parks, suitable location, width, connectivity and wheelchair drop off zones
- Information: clear information on responsible party for roads, footpath, range of information formats for public information

**Policy/Legislation**
- Disability access requirements and design solutions (new building, retrofitting older and heritage buildings and areas)
- Public: Understanding of and compliance with designated use of disability toilets
- Public: Understanding and compliance with designated disability parking
- Public: Respect for people with disability
- Businesses: Willingness to make changes to improve accessibility
- Public: Pedestrian awareness of people using wheelchairs
- Customer service staff: Willingness to make reasonable adjustments for people with disability (e.g. provide services as equal customers when without carers present, communicate directly with customer with disability)
- Local laws, traffic and parking officers: Willingness to make reasonable adjustments
- Built environment practitioners: Willingness to apply UD principles and make reasonable adjustments in building/locality designs

**Knowledge**
- Design of kerb cuts
- Design of disability toilets
- Design of disability parking
- Disability access requirements and design solutions (new building, retrofitting older and heritage buildings and areas)
- Accessible shops, services, businesses
- Knowledge of disability to inform business adaptation
- Design of disability access options during road/footpath closures

**Attitudes**
- Business: Requirements for accessible modifications
- Customer service staff: Willingness to make adjustments
- Local laws, traffic and parking officers: Willingness to make reasonable adjustments
- Built environment practitioners: Willingness to apply UD principles and make reasonable adjustments in building/locality designs
- Citizen participation: changes to policies in local government and Electoral Commission to support increased participation of people with disability

**KEY**
- Highest priority
- 2nd highest priority
- 3rd highest priority
APPENDIX 3
TRANSPORT SECTOR –
capacities to be built

Drivers: Willingness to assist
Staff: Willingness to assist; positive attitudes; respect for passengers with disability expertise
Public and staff: Positive attitudes, respect
Drivers: understanding of obligation not to discriminate

Remove restrictions on number of wheelchairs buses can take; mandate non-refusal of wheelchairs
Mandate assistance and lifting equipment; priority seating near entry; procedure for wheelchair transfers; carriage of wheelchairs and higher weight limits; cost subsidy; standardised policy all airports and airlines
Taxi subsidies to access regional travel; requirement to accept all subsidy types
Broaden policy NDIA-funded vehicle modification and purchase

Drivers: Use of ramps; safe speed, stopping and take offs
Staff: Use of hoists; appropriate transfers; seat allocation; folding and storage of wheelchairs
Staff: appropriate position and support of people using wheelchairs; assist with boarding and deploy ramps
Drivers: appropriate support of people with disability (esp. rural areas); safe driving speeds and handling

Bus transport
Airplane transport
Train transport
Taxi transport
Private car transport

ACCESSIBLE PLANE
Hoists/lifting equipment; onboard wheelchair; accessible toilets; cargo storage for larger wheelchairs; larger planes in regional areas that can carry wheelchairs; support at airport; transport between terminals
Accessible platforms (lifts to access; standard height); toilets available; increased frequency and reliability of accessible trains; visibility and signage of disability boarding area
Kerb cuts and ramps to taxi ranks; increased accessible fleet
Increased vehicle modifiers
ENDNOTES


4 This includes a small number of people who made more than one response, for example participating in a discussion group as well as an interview or online survey.

5 Regional reports are available at: https://www.swinburne.edu.au/research/our-research/access-our-research/find-a-researcher-or-supervisor/researcher-profile/?id=ewilson