This is the published version


Available from Deakin Research Online

http://hdl.handle.net/10536/DRO/DU:30066555

Reproduced with the kind permission of the copyright owner

Copyright: 2014, University of British Columbia
The 30th International Seating Symposium, 4-7th March, p. 178-181, Vancouver, Canada.

(Schmidt 2014)
A social justice scrutiny of the seating service experiences: What can we learn?

Rachael Schmidt (OT)

PhD Supervisors:
Prof Karen Stagnitti (OT)
Dr Genevieve Pepin (OT)

Content Mentor: Yvonne Duncan (PT)
‘Investigation of the stakeholders’ experiences of Australian specialized seating service participation’

The participant’s perceptive

(2010-2014)
Research method

Qualitative In-depth case study (Yin, 2009; Simon, 2009)

60 participants: in-depth interview process (solo interviewer) taped/full transcription (member checked)

Recruitment: ARATA (peek body) listserve & network snowballing

Multi-phase data analysis process
Phase 1: Thematically (peer reviewed)

Phase 2: Social Justice lens
Research Questions

How does participating in a specialised seating service benefit (or compromise) customised wheelchair procurement?

What type of seating service delivers quality wheelchair outcomes?

How does the type of seating service employed affect the decision making process?
Why is social justice theory relevant?

Who’s controlling the wheelchair-seating procurement? Vickery (2001): control is govt centric


Social justice: equality of power and resources
(Buchanan, 1980)

What type of seating service assists MPT?
Is sophisticated technology the only option?

(Schmidt 2014)
Rawls’ 3 principles of Social Justice

(Buchanan, 1980)

1. Principle of Greatest Equal Liberty

2. Principle of Difference

3. Principle of Fair Equality of Opportunities

1. Access to specialized wheelchair seating prescription services

2. Greater need: optimal access to sophisticated technology

3. Appropriate WC facilitates same degree of opportunity

(Schmidt 2014)
The data speaks!

**Access:** Systems control of service access
Funding protocols control WC-seating selection

**Equity:** equal service provision for complex needs
Equitable $$$ for appropriate WC-seating provision

**Equality of appropriate WC provision:**
Optimises occupational performance

(Schmidt 2014)
System control $$ & service eligibility

Systems control of $$$ to seating services

✔✔ Recurrent funding; ↑ service experience: “ongoing funds”
(Clinician Tammy)

😊 Intermittent funding; ↓ service experience “funding dumps”
(Clinician Rocko)

State-funded WC procurement: unique protocols not transferrable $$$ packages

✔✔ Needs-based: longer waiting times =↑ “person-centred [occ.] outcome” (Clinician Catrina)

❌ ❌ Inventory-based (listed WC items): ↓ WC choice “one size fits all mentality” (Consumers Mac & Hallie)

😊 😞 Subsidy-scheme (60-80% full purchase): Top-up “funding stress” (Consumer Vince)

(Schmidt 2014)
Australian seating service delivery types

Specialist Seating service

Centre of Seating Excellence (19 x CoSE)

Secondary consultative team (vendor)

1. Expert therapy team
   Seating clinician: consultant

2. Expert technical team
   Metro-based venue: clinic
   Tight eligibility criteria
   Variable outreach service

≥ Custom-made seating approach

Informal Seating Team

Local Collaboration (accessible)

1. Primary therapist:
   Principal Prescriber

2. Consumer + Principal Care provider

3. Local Wheelchair supplier
   Workshop/technology

   ✓ ✓ Trusted network
   ✓ ✓ mobile/locally-based
   Consumer’s home

≥ Modular seating approach

(Schmidt 2014)
Specialist service access to

✓ specialist service → Centre of Seating Excellence
✓ WC selection → Collaboration with all stakeholders
Access: collaboration with experts

‘I suppose he is but I think [rehab engineer] says it the way he sees it and if he says, you know, I’ve reached the limit of what I can do, you need to have tilt-in-space to be able to get the pressure off, then that’s probably good advice. Not much point saying that’s not what I wanted to hear, if you know what I mean.’ (Consumer Max)

sad

Metro-based specialist services limits access to all postcodes

(Schmidt 2014)
Adequate time allocation

And I have to say I’ve been burnt a couple of times, by things that maybe were over looked or were incorrectly processed because it really hasn’t been adequate time...’ (Clinician Nadia)

Sad face

Primary therapists struggle with caseload demands

(Schmidt 2014)
Competency Vs system control

Equity: Prescribing clinician = WC-Seating prescription

‘The difference of opinion between the therapist and the client as to what they needed and what would be right for them but even when the therapist would prescribe a chair that was going to enable the person to do what they wanted to do, it would be changed by the approving committee to something less.

So there were at least two points of battle …’ (Consumer Max)

✔ ✔ Consistency in WC prescription ....

(Schmidt 2014)
Equity

Consumer lead control
Quality W/C prescription
Seating competency & expertise
Support locally-based service providers
'...so I had to purchase my own wheelchair and, at that time, they said well they're sort of $3,000. I haven't got $3,000, and so I bought one through the then- Trading Post for, I think it was $1,000. It was a second-hand folding one.

Inappropriate WC prescription
one size doesn’t fit complex needs

... but folding ones are really not designed for permanent use, day in, day out, and within six months it started distorting, and within a year it ... needed to be upgraded severely.'

(Consumer Hallie)
Access: $$$ control

😊 No control

‘All our funding comes from there... but you can’t just access it yourself, you have to have specialists tell you that you need the stuff.’
(Care Provider Donna)

‘I suspect that they didn’t recommend it because there wasn’t enough funding. I mean really there is no other reason.’
(Care Provider Donna)
‘Yes, because what it allows us to do is to work together on the problems and, believe me, I’ve got heaps, with my seating I mean. He classes me as a significant challenge. Well, I’d be less of a challenge if I could buy a different wheelchair and didn’t need to drive the car from it.’ (Consumer Max)

✓ Equity & collaborate for quality outcomes!
‘In an ideal world...’ (Care Provider Cara)

✓ Choice & Control

‘Price is an important thing, but I would much rather pay for something more expensive that lasts, than something that's cheaper that's crap.’ (Consumer Hallie)

✓ Flexibility in controlling one’s $$$ package provides greater control than the $$$

(Schmidt 2014)
‘There was a perception at one stage that I wasn’t capable of driving a wheelchair so no therapist ever prescribed one for me. It was given to me by the Quota Ladies [charity].’ (Consumer Christine)

✓ Person-centred: Listening to the personal needs of the wheelchair occupant

(Perunit 2014)
Equity: Quality specialisation

✓ Access to specialisation
✓ ‘I’ve got there at half past eight on a morning and still been there at six o’clock with him working on cushions and whatever nonstop. He didn’t even stop for lunch, which is not bad from a public servant.’ (Consumer Max)

✓ Person-centred occupation approach BUT at what cost?

😊 Protecting our workforce asset?
‘That [service provider] takes a very structured, unhurried, orderly approach to solving the problem, to identifying the problem first and then looking for solutions.

He’s prepared to explain what he’s doing and what he’s thinking and what the issues might be and involve, he involves me in the discussion.

So it’s a two-way conversation, rather than a, you know, bit of didacticism.’ (Consumer Max)

Looking after our service resources
The individual can make a service difference

(Schmidt 2014)
Who’s controlling quality WC outcomes?

Person-centred occupational approach works if...
- Time allocation = caseload demand = listening
- Optimizes WC choices based on consumer needs & wants

Appropriate WC procurement enables occupational performance to enhance community participation, if...
- Consumer control of $$$ package: flexibility
- Consumer lead appropriate WC procurement
- Support primary services: locally-based

Workforce capacity and sustainable sector is assured if...
- Specialist service eligibility based on consumer need (not protocol)
- Recurrent service funding enables quality service capacity
- Centres of Seating Excellence nurture ↑competency and expertise

(Schmidt 2014)


A social justice scrutiny of the seating service experiences: What can we learn?

Author: Rachael Schmidt (OT/PhD candidate), Prof Karen Stagnitti (OT), Dr Genèveve Pépin (OT) and *Yvonne Duncan (PT)

Deakin University; *Yooralla Society Victoria

I, Rachael Schmidt, do not have an affiliation (financial or otherwise) with an equipment, medical device or communications organization. Speakers who have no involvement with industry should inform the audience that they cannot identify any conflict of interest.

Aim: The paper presents the social justice findings from a study into the Australian (wheelchair) seating service experience. As this study explored the insider's perspective, three participants' examples are shared (in the presentation) to demonstrate the benefits accorded to equality, equity and equal opportunity and the injustices experienced when denied;

- Brian* (pseudonym) a young Australian whose two accessories for his power chair changed his life.
- Donna* whose adult son was provided a heavy standard manual wheelchair instead of the power chair requested.
- Vince* a young self-employed businessman whose newly provided robust power chair is crimping his productivity.

Introduction: The John Rawls Theory of Justice Theory (1971) addressed the equitable distribution of society's resources. Rawls theory of social justice proposed equal distribution of basic resources (work, education, money, power). Rawls championed greater distribution of essential resources to those who have the least and in doing so enabled individuals with the same motivations and abilities to same opportunities as others in their society.

In the study, Rawls principles of social justice are contextualised to wheelchair-seating procurement as: Access to appropriate wheelchair-seating technology is a basic human right. For those with specialised postural and mobility needs, their access to essential specialised seating services, adequate funding and appropriate technology should be prioritised. Finally, by providing appropriate wheelchair-seating technology (and services) based on person-centred goals enhances an individual's opportunity to engage across all life domains as desired.

The Australian specialised seating service sector and appropriate wheelchair-seating provision are controlled by an overarching healthcare system. Reliant on healthcare funding, the current Australian disability support system was described by the Productivity Commission as being "underfunded, unfair, fragmented, and inefficient" (Australian Government, 2011:1). Access to specialised seating services, adequate funding resources and appropriate wheel-seating procurement are governed by a complex labyrinth of Australian healthcare policies and disability programs.
Research design: The qualitative study was informed by an in-depth case study approach (Yin, 2009) exploring the insiders' experiences of Australian seating service participation. Sixty participants were interviewed in-depth (between 1-2 hours by first author), audio-recorded and the full transcriptions were member checked. The interviewees included 11 consumers, five care providers, 28 prescribing clinicians (8 physiotherapists, 20 occupational therapists) and 16 vendors (10 wheelchair suppliers, 2 seating technicians and 6 rehabilitation engineers). The in-depth interview, informed by guiding questions, encouraged the interviewees to explore their seating experiences. A multi-phased analysis process scrutinised the data; initially thematically (peer reviewed) and again using analytical lenses of decision making and social justice. John Rawls Principles of Equality, Equity and Opportunity Equality (Buchanan, 1980) was employed as an analytical lens to scrutinise the data from a social justice perspective.

Findings: The study findings reveal many consumers living with complex mobility conditions do not have equal or equitable access to essential specialised seating resources. Access to appropriate wheelchair-seating procurement is systematically stymied by insufficient funding and inadequate essential seating resources. Furthermore, the seating service experience is variable and access to specialised seating service is not universally accessible or available for those consumers who need optimal wheelchair technology. Denied access to essential specialised seating resources is shown to reduce consumer's occupational performance, diminish their community participation and increase their carer support service needs.

The Australian seating service sector is small and polarised; with 19 identified dedicated specialist seating services operating in eleven Australian cities. Service access is controlled by eligibility criteria and some, but not all provide outreach services. A small vendor cohort (high-end wheelchair suppliers) with the seating expertise are also based within densely populated centres (metro-based) and some but not all provide mobile services.

Access to specialised seating resources is unequal: The study exposes two seating service delivery types: specialist seating service and the informal seating team. As noted, access to the specialist seating service is governed by the consumer's postcode (geographical access) and by meeting the required service eligibility criteria. Therefore, if the consumer resides close to a specialist seating service and is service eligible, they are fortunate.

Inequitable service provision based on eligibility: The study shows a comprehensive spinal seating service system operating throughout Australia. Consumers living with spinal cord injury receive life-long access to health funded spinal seating services as metro-based spinal unit service and mobile spinal seating services. The spinal seating service model offers a viable service model operating within an Australian context.

Consumers living with other disabilities are not so fortunate. A fragmented non-government disability sector provides seating services according to specific demographics (age or disability type) and/or by location (postcode). As a result many consumers seeking specialist seating service are ineligible or exclude due to excessive travel. As such they do not receive the seating services or the wheelchair-seating systems that appropriately match their mobility and postural needs.
Consumers with the same mobility goals may not have equal access to an appropriate seating service within acceptable travelling distance. For those who cannot access specialised seating services, the only alternative a service from an informal seating team. Informal teams form upon referrals (as needed) and as the providers' seating experience varies, this is reflected in the quality of service they can provide.

Some informal seating teams also seek support from with accessible specialist seating services and high-end suppliers, although the primary therapist remains the prescribing clinician. While access to competent service providers is relevant, optimal wheelchair-seating procurement is directly related to available funding.

_Inequity in funding distribution:_ Systemic inequality of funding distribution is evident within the Australian healthcare system. Two broad funding environment exist in Australia: the privately funded (compensable) and government funded (non-compensable) systems. Compensable consumers enjoy un-incumbent access to specialist services, better technology choices and optimal wheelchair-seating provision. Non-compensable consumers, bound by healthcare systems, protocols and policies enjoy less control of their choices (of providers and technology) this can crimp their wheelchair-seating provision.

Further inequity to wheelchair-seating provision is associated to fragmented state-run funding programs. There are eight Australian states operating independent and non-transferable disability funding programs. Although all state programs adhere to an authorised wheelchair-seating prescription (by a prescribing clinician), each runs their own unique program. Each funded program decides what, when and how wheelchair technology is provided, as based on needs or technology provided from a restricted inventory list. Some state-run subsidy-schemes attempt at funding equality by subsidising (≥50-70%) of the purchase cost, however many consumer suffer from having inadequate funding to enact the wheelchair purchase. Subsidy-schemes require extra effort to acquire top-up funding from consumers, (their care providers) and busy prescribing clinicians. Well supported consumers are better positioned to attract top-up funding and acquire an appropriate wheelchair system, while those without are prone to receive a standard wheelchair, despite personal needs.

_Conclusion:_ The study findings expose a fragmented, under resourced and inequitable Australian seating service sector. As the consumer need is unlikely to abate, the Australian seating sector needs to develop a robust competent workforce adequately resourced to provide accessible, equitable and affordable seating services into the future. More than ever, a robust seating service sector is needed to meet the rapidly evolving Australian disability-related service sector (National Disability Insurance Scheme). The study's findings help to illuminate the injustices as experienced by the stakeholders and to inform current service stakeholders and policy makers towards building a relevant seating service sector for future needs.

_References_


Address of contact person: Rachael Schmidt @ Occupational Science & Therapy Faculty of Health Waterfront Campus, Deakin University 1 Gheringhap Street Geelong Victoria 3220 Australia Email: rachaels@deakin.edu.au