Equipped for life – a very private public issue – policy and equipment in the lives of children and families.

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My study examines life with equipment for a small number of families who care for a child with severe physical disabilities. Equipment policy has a major impact on the lives of these young people and their families. The study provides a timely opportunity to review their lived experience of equipment policy in order to assess whether enabling policy directions recently articulated at the State level are being enacted in practice. The study reveals that despite welcome policy reforms, children and families continue to be denied access to appropriate equipment. They are left without basic and essential items for long periods, and denied equipment that could facilitate access to and participation in the community. Ironically, although their lives are very much dominated by a public policy, equipment tends to remain a very private issue. Examining equipment provision in relation to children reveals systemic barriers that affect children and adults with disabilities alike. It suggests practical strategies to address these, and is therefore relevant beyond the small group study.

People who live with severe physical disabilities frequently require multiple and costly items of equipment. In NSW at the state level, policy acknowledges the role of equipment in meeting social as well as clinical needs (NSW Health Department, 2000). Stated policy objectives for the provision of equipment include: the promotion of improved access, improved quality of life, and improved capacity to participate in family and community activities. (NSW Health Department, 2000)

There have been significant policy reforms in relation to eligibility. For children, eligibility for equipment is no longer means tested at all (NSW Health Department, 2000).

In NSW equipment is distributed locally through the NSW Health Department via the Program of Appliances for Disabled People. This program and its local distribution centres are commonly referred to as ‘PADP’. A number of charities provide some further equipment support, but there is no coordinated system as a whole, and individuals are limited in their ability to access support.

Clearly all individuals should be able to access appropriate equipment in a timely manner. It is equally important to recognise that an individual’s body may change over time or as a result of illness, and that if this occurs, additional items of equipment may be required, and existing items may need to be replaced.

Children and young people have particular developmental, maturational and sudden growth patterns that, combined with changing, often critical, medical conditions, can result in families urgently requiring a number of expensive items in rapid succession. For families desperately trying to keep up with their child’s changing requirements, [often while still adjusting to the previous influx of prescribed equipment items], the sudden requirement for additional items can be surprising, extremely disturbing and quite frightening.
The system, as a whole, responds with equipment support in a random and piecemeal manner. Families lurch from one equipment crisis to another. It may be difficult to predict the particular equipment formula for any individual child or their carer. However, my study [which has collected current and retrospective, quantitative and qualitative data] suggests that, as a group, these children will need clusters of expensive, individually prescribed items at particular stages of their development. Rather than continuing to mirror families’ crisis driven and reactive responses to changing need, the study indicates that with appropriate data, the system should be able to plan for and equip children and young people with a holistic package that meets their individual requirements.

There tend to be three stages when holistic clusters of items will be required. These stages are: early intervention, beginning school and adolescence. Adolescence demands our particular attention. At this stage sudden growth often interacts with changing medical conditions, creating multiple physical changes to the body. A costly cluster of inter-related items for the young person and their carer tend to be required. Because this pattern of staged need eases off from mid to late adolescence, the provision of appropriate equipment during adolescence can be seen as a long-term strategy that sets young people and families up for life. It can be seen as an investment in the future that can result in cost savings to equipment services over time, as well as to other health services and across other areas of government spending.

We are only considering the support requirements of a relatively small group of people. Only 3% of children aged between 0-14 years will experience profound or severe restrictions due to disability (Australian Bureau of Statistics, 2000). Numerically they do not represent a powerful lobby group, and because their numbers are small, our community awareness of the importance of equipment in their lives tends to remain minimal. Perhaps it’s not just because of numbers. In relation to disability Christopher Newell describes an ‘apartheid that knows no name’ (Newell, 2001). Children with physical disabilities are often physically hidden away. They continue to remain isolated from the community via special schools and inaccessible environments (People with Disabilities (NSW) Inc, 2001 p. 11), and, as this study indicates, by our shared failure to equip young people for life.

Just as most parents care for children without disabilities, the parents in this study care for and make personal sacrifices for the benefit of their child with a disability. Caring includes embarking on a lifetime of dealing with equipment. Large and cumbersome equipment takes up space in the home. Parents make significant financial and other sacrifices to acquire it. They modify their homes to accommodate it, and they purchase expensive, specifically adapted vehicles to transport it. For families, equipment is expensive and the need is constant.

Becky is a bright eleven-year old who lives with cerebral palsy. Her mother explains:

She needs the equipment to help her through her day. Because she has fine and gross motor movement difficulties, she needs equipment for lots of
different things; to help her eat, to seat her properly, for mobility, in the
shower so she’s safe. In virtually every aspect of our life we have to have
pieces of equipment, of cost, that are generally suited just for her.

Young people wait with anxiety for long periods for prescribed equipment. Hannah,
aged fifteen, handed me a protest letter about her wait of more than twelve months for
her prescribed wheelchair. Her current chair was no longer safe, and she was
restricted and constrained while she waited for a new one.

For parents equipment can be a painful reminder of their child’s deteriorating
condition, or of their exclusion from the expected developmental activities of
childhood. The prescription of one piece of equipment has a snowball effect. Families
form a captive market. Fourteen-year old Amy lives with cerebral palsy. Her mother
explains:

It’s a rude shock. I mean no way would I have ever thought that we would
need a hoist. And I mean you don’t even know what they are. You know. And
some people are talking about a special kind of bed, and electric wheelchairs,
and a hoist – where did that come from!? And you think, ‘God!’

[the wheelchair] was quite easy to accept. But it’s what goes with it!! Like the
changing the vehicle, and what you’ve got to do to your house to make it fit
into your bathroom….

Fourteen-year old Laura has a degenerative condition. Her mother describes their
family’s relationship with equipment.

Laura is [now] completely dependent. So she has high equipment needs. She
needs an electric wheelchair, and she needs a hoist. And we need a shower
chair. We wouldn’t be able to shower her without the chair. She has a special
bed that she needs for comfort. She has an electric bed. Well, we still need to
manually roll her through the night.  Mmmm. *Note: Parents work in
partnership with equipment.*

Sam’s mother lists just some of the expenses incurred as Sam has matured.

It [the wheelchair] comes with other expenses. We’ve just acquired a vehicle,
a total of forty-five thousand dollars. Twelve thousand of that was conversion
to take the wheelchair. Other costs have included altering and adapting the
house to accommodate equipment needs…Currently we are spending ninety
thousand dollars on these [latest] renovations *[in particular to alter the
bathroom to fit the wheelchair and the hoist.]*

The most costly equipment-related expenses fall outside PADP parameters of support,
and are born by the families. Even so, many of the equipment items that have had to
be purchased for Sam to meet his rapidly changing needs, and which theoretically
could have been supplied by PADP, have in fact also been acquired without any
PADP support. While there is a new PADP Information system, it does not pick up
this sort of data.
With inadequate data the real level of need and real cost of equipment, as well as the significant contributions made by families and others, tends to be camouflaged from policy and planning.

The next overhead [see Chart page 10] also indicates the limits of PADP involvement. However it also highlights the rising cost of equipment. This is the frightening context within which families and equipment services, both with limited budgets, try to manage. Yet paradoxically in equipping families we tend to see children and families, rather than the market, as ‘the problem’. We tend to accept the marketplace as a given, and expect children and families to accommodate their needs to it.

Sam’s story is unique only in that his family has, so far, had the financial resources to acquire essential items. For families without such material resources, the children frequently do without. Occupational therapists and physiotherapists are clear about the clinical repercussions for the bodies of the children and/or their carers when they are forced to do without appropriate equipment. [see Interim Report]

Sam’s mother explains her sense of urgency and crisis:

I mean, well I would say in the last few years with the onset of adolescence, and the growth spurt, and Sam deteriorating hugely… We were able to somehow struggle on, and kept pretending that we could easily lift him into the bath. And then suddenly – overnight you go from not wanting to do it, not liking to do it, but doing it. And then suddenly you think, ‘I can’t actually lift this kid.’

I’ve actually slipped trying to get him out of the bath, and I’ve just not had the energy, or my back’s hurting so much, that I’ve dropped him back in the bath.

Limited support from PADP means that many families struggle for assistance through a complex and uncertain web of charitable support. A complex ominous, invasive equipment system becomes a constant ‘in our lives, on our minds and in our space’. And in the end a holistic package of support is rarely achieved.

Sam’s mother describes both the government and charitable support as those:

… tedious invasive processes that we currently have.

It’s not pleasant, she explains,

… being a charity case, where you have to basically um sell your soul, or look grateful, because you know that it’s a means to an end, that you must have this equipment for the child to function, or for you to function….

Rapid advances in technology have resulted in the development of sophisticated and enabling equipment. While parents never lose sight of equipment as a health item, they also view equipment through a lens of ability. They, and their children, do want
enabling equipment. We have the technology to produce wheelchairs that move efficiently and safely at speed. In them children can demonstrate great dexterity and skill. They whirr along, and they can get to where they want to go incredibly quickly. They can keep up with, and even overtake, the other kids in the playground. They can ‘run away’ from their teacher’s aide. They can occasionally be naughty!

Children with severe physical disabilities often experience a lack of personal space. Equipment can be liberating, releasing children from the constant gaze of an adult. It allows them to be children, to play, to be free, to experiment, to take risks, to have fun, to experience joy and to explore the world. In their wheelchairs the children are extremely skilled, and graceful. They race and whirl and wheel and glide. They can spin and twirl around and around in circles, or fly along and chase the wind, and then stop on a sixpence. For an adult watching, it can be quite heart stopping. But for the children their world becomes ‘a free and fearless space’.\(^1\)

A teacher explains:

> The kids love their wheelchairs. They decorate them. They put streamers on them, and they hang their treasures from them. In terms of physical disability their tyres are more important than their feet. When she [Amy] is with her friends in wheelchairs, she feels safe. They all get in a line and go swoosh down the flat cement path that the Lions Club put in. From here to the shopping centre, they fly along full bore. It’s great.

For children a wheelchair can be a way of entering, engaging with and exploring the world. It is something they can be proud of, and importantly it is a tool that actually facilitates making connections with other people.

Sam’s mother explains:

> You see that equipment’s the thing that facilitates their entry into the community. It was what got Sam down to football yesterday, to watch the next door neighbour’s team play, and he led them onto the field.

Becky’s mother watches her eleven-year old out in the community in her beautiful, new, and very much loved, purple wheelchair:

> It was good to see how much she was sitting up watching. She was all of a sudden part of the world. And the enjoyment that she got on her face as being part of the world. See when she was [down low] in a pushchair she sat back, and the world met her. Now all of a sudden she’s in everybody’s face. She’s up the front in the wheelchair in the middle of everywhere, and she obviously feels a part of it, and [she] commands a space in her own right now. So that was good to see that. That it stands out that she’s special, and she’s different, and she’s proud to be that.

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\(^1\) This phrase taken from Welcome song by Fay White, Exclusion & Embrace Conversations about disability and spirituality, Melbourne October 18-21, 2001
Children living with illness can get very tired. The right equipment assists children in preserving valuable energy that is needed to embrace childhood. Sam’s mother comments:

When you think that children are sitting there trying to support their body, trying to support their trunk, trying to support their head, trying to control saliva when they speak, trying to control spasm in their arms while they simply try to use their computer, that it is no wonder that kids don’t have the energy without appropriate equipment.

Amy’s mother says:

For Amy the [electric] chair was freedom, movement and something she dreamed of for years… [Before] she was so dependent on other people and that was really, really scary for her at times.

The literature (Chenoweth, 2002; Sobsey, Wells, Lucardie, Mansell, & Waxman, 1995) indicates that children with disabilities are ‘more likely to be maltreated than children without disabilities’ p.? Promoting independence through the provision of enabling equipment might then be viewed as an important strategy to reduce risk for young people. Ironically, a failure to provide essential items of equipment to children not only reduces their independence, but such a policy failure is experienced at a personal level as no less violent, constraining or emotionally damaging than other more recognised forms of emotional and physical abuse and/or neglect.

Amy’s much-needed electric wheelchair took 18 months to arrive. During that time she was immobile in an inappropriate manual. Her father states:

She had the ability to push herself, but because of the chair [design] she couldn’t actually go anywhere!!!…It was physically too hard for her to move around.

Consider for a moment Laura’s plight. Her mother explains:

Laura is having a lot of back pain. And she’s falling to the side again. We thought it was maybe a spinal thing happening. But the doctor had a good look at it, and he said, ‘No it’s postural’. And he said, ‘It’s the wheelchair’ [causing the pain]. Because of her change of needs, she needs those supports. She needs a headrest. She needs something that is going to support her more.

And there’s been times when her electric wheelchair has broken down and she’s been in her manual chair. And it’s been quite disastrous actually. She’s been, she’s had to be tied in with tape. [pause] [soft voice] which was pretty awful.

Reflect too on the eighteen months that fourteen-year old Amy was constrained in a wheelchair that wouldn’t move. Amy’s statement that the “best” thing about the new electric wheelchair is that she can now “finally” get to the fridge by herself indicates her lived experience for those eighteen months was one of extreme and unnatural physical restraint even within her own home.
What sort of framework do we need for developing enabling policy?

Goggin and Newell suggest that to be inclusive and enabling, ‘universal’ policies and services must be developed and evaluated using ‘a lens of disability’. (Goggin & Newell, 2000) We can see that such a lens has been used to assess and to reform some non-inclusive ‘universal’ services. Public transport, public buildings, public housing and public streets are becoming more disability friendly. In education the move has been towards integration. The ‘lens of disability’ described by Goggin and Newell can also be used to interrogate equipment policy. Certainly PADP policy is ‘universal’ in that all children are now eligible to apply for equipment. But we may still ponder why equipment is not delivered to families through a ‘universal’ service such as Medicare.

Sam’s mother states:

You should be able to go to the accredited therapist for individualised assessment and prescription, and then the required item could be ordered, and your Medicare card swiped. And that’s all it should take.

It may be naive in the short-term to try to return responsibility for the provision of equipment to the Commonwealth, but we should not lose complete track of Goggin and Newell’s challenge.

The ‘lens of disability’ used by Goggin and Newell suggests a corollary that can be used when policy and services are delivered through specialist or separate services. In such a case the reverse “lens of ability” should be utilised. Parents use this lens when they modify their homes so that their child can fully engage in family life. They use this a lens of ability when they build links to the external world with expensive ramps, or when they purchase vans to accommodate wheelchairs to take children out to participate in the world.

As Sam’s mother tells us:

Parents do have the vision of what our children’s lives can be. You can take this stand, even though for you it [equipment] is hideously ugly and big, and it brings on all sorts of other costs and expenses. It is the lived experience. Because you start by seeing the horror of it all, its size, its ugliness, and all of the expenses. And then you see the enabling point of it for the children. You see that it’s the thing that facilitates their entry into the community.
The families’ stories reveal that in reality ‘medical’ and ‘social’ needs are inter-linked and intertwine – imagine a double helix. [See diagram 1] In practice however we tend to separate the medical from the social, seeing them dualistically. [see Diagram 2 below.]

Even so, using the *lens of ability* we are still able to view these two areas as a continuum [See Diagram 3] \(^2\) where ‘*I can*’ extends outwards with *possibilities*. Indeed we saw this is the language of possibility previously in PADP policy.

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\(^2\) This concept is borrowed from the Seasons for Growth mental health and wellbeing program.
However, despite the *lens of ability* appearing in PADP policy language, this study identifies that a *lens of disability* tends to be applied in practice. This lens uses a narrow ‘medical’ interpretation to define or validate need. PADP and charities do assist families, but they are also sites of oppression, where administrative decisions are made to prioritise the ‘medical’ or ‘clinical’ over the social. [See Diagram 4. Note the boundary between them is now solid a fence]. In times of budgetary restraint, we see the medical accepted as ‘essential’ and the social dismissed as ‘optional’.

Diagram 4.
But even more importantly, because it is more hidden, it is at these sites that the definition of medical or clinical is re-framed and constricted with the flick of an administrative pen. [Again borrowing an image from Seasons for Growth], the ‘I can’ shrinks and ‘the world’ become simply an ‘if only.’ When we no longer provide equipment to meet “social” need, and at the same time we reduce the ‘parameters’ of what is accepted as a ‘medical’ or ‘clinical’ requirement, we constrain ability and crush potential.

Diagram 5.

However, the study also reveals that we have an opportunity to radically, cooperatively and cost-effectively re-think the ways in which we can equip adolescents and families for life. The families’ stories demand we act. In my longer report to the Ageing and Disability Department (Dowling, 2002) practical achievable strategies are identified.

The summary of systemic barriers AND suggested strategies are attached, and are discussed in more detail in the Interim Report to the Department of Ageing and Disability (Dowling, 2002).
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**Summary of key factors that contribute to prolonged periods without appropriate equipment:**

- A complex and fragmented system of government and non-government support
- Small and geographically dispersed population of children with high needs
- Increasing levels of complex need requiring specialized and technically sophisticated equipment
- Reactive rather than proactive systemic responsiveness
- The rising market price of equipment
- Fragmented funding processes that leave local equipment services, individual organisations and individual families in a weak purchasing position in the equipment market place
- Funding for children and young people that becomes merged with funding for other disparate groups
- Inadequate funding to meet an increasing population of children with increased needs who are living longer
- Failure to predict the staged time-limited equipment requirements of young people
- Failure to provide a holistic package of complementary equipment items
- Failure to equip adolescents, young people and their families for the long term
- Short-term cost saving decisions at the expense of long term savings
- Cost inefficiencies in the area of repairs
- Cost inefficiencies in the area of maintenance
- Cost inefficiencies in the area of re-cycling
- Piecemeal purchasing
- Lack of cooperation, coordination and information sharing between government and non-government support systems
- Lack of adequate qualitative and quantitative data to address the above issues effectively
Summary of recommendations

• That the questionnaire developed in this study is refined and extended to form a state wide census to profile high need families.

• That data from the proposed state wide census and a proposed pilot project (discussed below) are used to complement data being gathered in the PADP Information System to establish an accurate demand framework that takes into account the flow of particular and staged needs of children and young people who need equipment. Particular attention should be paid to adolescence.

• That coordinated strategies are developed to provide holistic packages of items that meet the long-term needs of young people and their families in a timely manner. Coordination between government and non-government agencies should be aimed at streamlining the prolonged periods of doing without equipment while applications are reviewed and processed in a number of agencies.

• That coordinated strategies are also developed with the aim of creating a stronger purchasing position in the equipment market place, while at the same time retaining local individualised clinical assessment and prescription.

• That the use of a more centralised purchasing system and/or the formation state wide purchasing coalitions are explored as strategies to strengthen the purchaser position in the market place and to combat some of the problems associated with the need to import quality items. Active collaboration between government and non-government groups is proposed.

• That any market place strategies are also directed to reducing the cost of repairs through proactive maintenance arrangements.

• That a pilot study with a small group of families in the Hunter is funded to examine in more detail the particular clinical needs of adolescents, to provide a holistic package of complementary items, and to monitor the long-term cost benefits of providing such a holistic package. The pilot project could be used to trial a joint-funded cooperative single assessment – single application - joint provision model for the acquisition of a holistic package for high need adolescents.

• That where possible the proposed pilot study is also used to trial innovative strategies that address market factors. These should also focus on addressing current systemic barriers to importing equipment.

• That private enterprise is encouraged to support such a project. A joint sponsorship scheme similar to that being undertaken by the Department of Education and Training, the Catholic Schools Office and the Port Waratah Coal Loader in the Hunter could be modelled.
• That a separation of funding lines for high-cost low-volume items is considered

• That further possibilities for directing joint support from government, non-government and businesses to fund one-stop access points across the state should be explored in more detail.

• That the proposed state census gathers data to develop a database of equipment that has been purchased outside the PADP system and that is no longer used by families and which can be recycled throughout the state.

• That PADP and Equipment Loans Centres accept donated second-hand equipment. That any legal obstacles in relation to warranties for second hand equipment that may prevent equipment services accepting donations of used equipment are examined and addressed.

• That all strategies incorporate appropriate ongoing independent feedback mechanisms that give voice to the expertise and experience of families.

That these feedback mechanisms incorporate the voices of key advocacy groups such as Physical Disability Council of NSW.

Summary of Recommendations Continued
Key factors that contribute to prolonged periods without appropriate equipment:

- A complex and fragmented system of government and non-government support
- Small and geographically dispersed population of children with high needs
- Increasing levels of complex need requiring specialized and technically sophisticated equipment
- Reactive rather than proactive systemic responsiveness
- Rising market price of equipment
- Weak purchasing position in the equipment market of local equipment services, individual organizations and individual families due to fragmented funding processes
- Funding for children and young people that becomes merged with funding for other disparate groups
- Inadequate funding to meet an increasing population of children with increased needs who are living longer
- Failure to predict the staged time-limited equipment requirements of young people
- Failure to provide a holistic package of complementary equipment items
- Failure to equip adolescents, young people and their families for the long term
- Short-term cost saving decisions at the expense of long term savings
- Piecemeal purchasing
Further factors that contribute to prolonged periods without appropriate equipment:

- Cost inefficiencies in the area of repairs
- Cost inefficiencies in the area of maintenance
- Cost inefficiencies in the area of re-cycling
- Lack of cooperation, coordination and information sharing between government and non-government support systems
- Lack of adequate qualitative and quantitative [current and retrospective] data to address the above issues effectively

Overhead Two Systemic Issues Continued.
People with Disabilities (NSW) Inc. (2001). UN Special Session on Children. LinkUp, 126(September), 11.