

# The Physical Disability Council of NSW

## 'Leading The Life You Want to Live' Youth Consultations and Survey

April – June 2007

### Final Report

Prepared by



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## **Background**

The Physical Disability Council of NSW engaged handykapp to facilitate a series of youth consultations in Sydney and various parts of regional NSW including Bathurst, Wagga Wagga and Armidale. (The regional towns were chosen because they each have large tertiary student populations.)

The consultations were run in tandem with a paper and web-based survey called, 'Leading the Life You Really Want to Live'. As the survey title suggests, the aim of the consultations and the survey was to find out, from young people with physical and other disabilities aged between 18 and 35, what was stopping them from leading the life they really wanted to lead.

The survey and the consultations were promoted through PDCN's ebulletin and email network, websites and mailing lists such as InfoXchange and YouthGas; various service providers, local councils and the HACC network.

PDCN's plan is to use the information collected during the consultations and in the survey to inform its future policy directions on young people with physical disabilities and to continue its advocacy work on behalf of young people with disabilities in NSW, particularly to various government agencies and disability service providers.

Both the survey and the consultations focused on four main areas: living and personal care arrangements, transport, equipment and experience of PADP and physical access to the community. Participants were also invited to raise any general issues that they felt affected their quality of life.

Other issues such as employment and education were deliberately omitted, particularly to keep the survey length manageable for both the respondents and PDCN. It is anticipated that PDCN will conduct future youth consultations and surveys specifically focusing on these issues and others.

PDCN ran a total of four consultations and collected 45 survey responses from the online survey. The consultation events were only attended by a handful of participants but raised some interesting issues and debates, many of which were not anticipated by PDCN. The surveys also reflect the broad range of needs of, and frustrations experienced by, young people with disabilities.

The following report details the major findings of the consultations and the survey and makes recommendations about how services can better meet the needs of young people with disabilities.

## Consultations and Individual Service User Visits

### *Sydney*

The top 5 issues indicated by participants at the Sydney consultation were:

1. Need for more regular informal social networking amongst young people with disabilities. Additionally, information to make socialising easier e.g. website about accessible pub and club venues.
2. Better accessibility to address feelings of social isolation e.g. sitting down the front of lecture rooms because of no space for wheelchairs at the back.
3. Public transport. Taxis were a particular concern. Could taxis be made to give more accurate ETAs when booked? Could information about people's transport needs be kept on file so that information doesn't have to be constantly repeated?
4. Attendant Care. Need a 24 hour mobile service like the Night Life service in Victoria.
5. Employment. When asked about their experience of PADP participants agreed it was a case of 'be prepared to pay or wait'. One participant spent six months on a waiting list and then decided to go elsewhere and pay for the equipment instead.

Overall, the Sydney consultation highlighted the need for more opportunities for young people with disabilities to socialise with their peers and it also raised the issue of the role that technology (like SMS and mobiles) might play in facilitating better communication and networking.

### *Armidale and Wagga Wagga*

No one attended the Armidale or Wagga Wagga consultation event so visits were made to individual service providers to distribute surveys and meet with young people in person.

Interestingly, while no one from these regions attended a face-to-face consultation, the majority of the completed surveys (40%) completed came from 'Regional/Country NSW'.

Some of the issues raised during visits to individual service providers included lack of adequate wheelchair taxi services (with many towns reporting only 1 or 2 wheelchair taxis) and limited access to personal care, attendant care and/or respite care services.

### *Bathurst*

The three issues identified as being of most concern to *service providers or advocates* at this consultation (no young people attended) were:

1. Lack of adequate respite care services in the region.
2. Lack of adequate accommodation services in the region.
3. The length of time needed to access equipment and mobility aids.

Participants particularly expressed concern at the uncertainty faced by many smaller service providers who now fear being “gobbled up” by large service providers who have recently established a presence in major towns (but who they felt don’t often have extensive experience working in regional areas.)

There was also a consensus that many service providers develop programs based on what they *think* young people need as opposed to what young people are really asking for. (This may happen for a range of reasons such as lack of basic funding and the limited participation of young people in more isolated parts of the region.) It was agreed that the lack of adequate services in the region affects young peoples’ ability to choose their peer group, engage in “risk-taking” behaviour and more successfully access education.

Some of the suggestions that came from this consultation were creating a more central point for information for carers and young people with disabilities, establishing a 24-hour mobile care service for young people to access and improving transport services such as making Countrylink coaches and private buses more accessible and offering a larger number of wheelchair taxis (there are currently two servicing the Lithgow-Orange-Bathurst region.)

### *Key Themes and Analysis*

The key themes to emerge both from the consultations and the visits to individual service providers in Sydney, Armidale, Wagga Wagga and Bathurst were:

- need for more sophisticated and flexible personal, respite and attendant care services, particularly in rural and regional NSW;
- need for more accessible public transport (taxis were a particular concern at all consultations and individual service provider visits);
- the experience of PADP in all regions is similar i.e. either be prepared to pay or wait;
- the impact that the lack of access to services or technology can have on young peoples’ development of social networks and life skills.

## Survey

### *At a Glance*

There were a total of 45 responses to the survey. Below is a summary of selected survey statistics. The unabridged results can be found in Appendix 1 of this report.

### *Location*

40% of respondents were from 'Rural/Country NSW'.  
37.8% of respondents were from Metropolitan Sydney.

### *Age*

48.9% of respondents were aged between 18 and 26.  
24.4% of respondents were aged between 27 and 29.  
26.7% of respondents were aged between 30 and 35.

### *Country of Birth, Language and Cultural Background*

88.9% of respondents were born in Australia.  
95.6% of respondents spoke English as their first language.  
No respondents were of Aboriginal or Torres Strait Islander background.

### *Major Impact of Disability*

28.9% of respondents said their disability had a major impact on personal care.  
37.8% of respondents said their disability had a major impact on mobility.  
8.9% of respondents said their disability had a major impact on communication.

### *Activities*

11.1% of respondents were involved in secondary education.  
37.8% of respondents were involved in tertiary education.  
33.3% of respondents were involved in OTEN, Community College, volunteer work, part-time or full-time employment. (The remainder considered the question 'Not applicable'.)

### *Mobility Aids*

40.0% of respondents did not use any kind of mobility aids.

### *Income*

58.5% of 41 respondents identified their main source of income as a Centrelink payment.

### *Living Arrangements*

43.9% of 41 respondents were living with parents or other family members.

### *Accommodation*

82.9% of 41 respondents were living in a home or apartment and no responses were received from people living in SEPP 5, DADHC group home or nursing home accommodation.

### *Personal Care*

51.2% of 41 respondents are receiving a total of between 0 and 5 hours of personal care or help at home each week.

22.0% of 41 people receiving assistance with personal care believed they were receiving enough services and 24.4% believed they did not receive adequate services.

60% of 25 people receiving assistance with personal care said that if services weren't enough they would have to go without physiotherapy or fitness activities.

### *Public Transport*

37.1% of 35 people, who said they used public transport, used it everyday.

74.3% of these people use the Internet to find out information about timetables or services.

48.6% of 35 respondents described transport customer service as 'friendly and helpful', another 48.6% described it as variable and 17.1% described it as 'competent'.

61.3% of 31 respondents said the cost of taxi travel was the most difficult transport issue to deal with.

### *Key Themes and Analysis*

While the statistical data reflected the key themes set by PDCN - living and personal care arrangements, transport, equipment and experience of PADP and physical access to the community, the survey's open-ended questions elicited responses that reflected a combination of material and social concerns. Examples of each are given below.

#### *Greater support to live in the community*

"[I would like to be] living alone, but with support in household chores and grocery shopping. Location close to relatives and a supermarket. Being able to see a GP without having to walk more than 200m, walk up any inclines or walk up any stairs would be an improvement."

"Help at home."

"A house that come with carers."

"Satisfied mostly. More respite care."

"Access to physio and massage."

"Support for family to let me stay at home."

"An emergency back up care service that could be called upon 24/7."

*Shorter waiting times for aids and equipment through PADP*

"No problems after an initial wait."

"Very slow. Received a very old manual chair from equip pool, waited since for funding, since then condition deteriorated to point need a power chair."

"Fairly good with repairs, but long wait for new products eg. new chair."

*An improved aids and equipment system*

"Information about what aids would be appropriate, and availability of such aids."

"Each application to be considered on its merits."

"Easier access to TIEMAN tip catheters."

"Scrap means testing."

"More funding available so no family has to wait inappropriate periods."

"Greater emphasis on the need for communication devices."

"Greater job opportunities without losing Centrelink benefits."

*Need for independence and freedom*

"To live on my own or with friends, and have someone take care of general home care."

"Living in a fully accessible house with my partner with enough service and carers so I can live independently without putting stress and strain on my partner."

"Housing with personal care attendant who could visit regularly."

*Access to more recreation and leisure opportunities*

"Funding for a carer to accompany me for holidays. I can't afford to pay their way."

"Disability friendly hotels/motels."

"Access to social contacts."



### *Ownership and control*

"I don't have to rely on my mother for physical support and I had many houses, no disability, a wife/girlfriend and lots of money."

"My own car."

"Would prefer my own car so that I could drive myself."

"One billion dollars so that I might have some control over my life."

"Not to be treated as though every disabled person is 'ripping off the system'."

### *Flexibility*

"Flexible hours, no rigid routine, ability to access community more often and independently."

"Funds to have unlimited access to community at times convenient to me and not restricted to day periods."

### *Reduced costs*

"Free physio."

"A free grocery delivery service."

"To cut the cost of TIEMAN catheters, they are much more expensive than straight tipped catheters. CAAS does not provide enough money to be a year of straight tipped catheters let alone a year's worth of TIEMAN tip catheters."

"Reducing the overall cost associated with medicines, specialists (out of hospital visits), equipment, etc, especially for people with partners (who face much higher safety net thresholds and have partner's income in all assistance assessments) without consideration of financial burden of disease/disability."

"More money for transport to medical appointments and for education/rehabilitation, especially in rural areas."

### *More access to transport*

"The public bus fleet needs to be 100% accessible. All Cityrail stations need to be accessible."

"Existing transport with more thought into wheelchair accessibility."

"Private transport with a driver."

"More wheelchair accessible taxis in the country."

"To differentiate between disabled parking and wheelchair parking – they are not the same."

## **Future Directions and Recommendations**

Both the survey and the face-to-face consultations and meetings have provided PDCN with a much better understanding of what young people with disabilities need from, and expect of service providers and the community in general.

In addition to raising the issues identified by the survey and consultations (which have been summarised in this report) with government agencies and service providers, the following should also be considered:

- Further research into young people's views of education and employment for people with disabilities.
- Further exploration of the social impact of disability for young people and consideration of these issues in the design of the physical environment.
- Development of informal social networks and identification of potential leaders for those networks.
- Further exploration of how the effective use of technology, such as email, Internet and SMS, could improve the lives of young people with disabilities and particularly their ability to connect with each other.
- Development of initiatives to reduce the cost of living for young people with disabilities.
- Establish more flexible services, such as a 24 hour mobile personal care service to increase young peoples' sense of independence and freedom.

## Appendices

*Appendix 1 – Survey Data Summary (Survey Monkey)*

*Appendix 2 - Open-ended survey responses (Survey Monkey)*

*Appendix 3 – Copy of 'Leading the Life You Want to Live' survey*