Financing and Delivering Services for Adults with Acquired Disability and High Care Needs in Queensland

Results from an on-line survey

Paul Henman, Michele Foster, Jennifer Fleming, Cheryl Tilse, Ros Harrington & Stephen Thornton

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Social Policy Unit

The School of Social Work and Human Services has a long history in teaching and research in social policy. It is one of the School's recognised core teaching, research and service strengths. Given the current environment in which we work, the School recognises the need for leadership in critically informed and practical engagement with social policy issues at a state, national and international level. The Unit has three main aims:

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2. To develop the social policy discipline and its visibility at UQ and in Australia;
3. To develop partnerships with external bodies to promote public debate and advocacy on key contemporary social policy issues.


Biographies

Dr Paul Henman is a senior lecturer in social policy and Director of the Social Policy Unit at the University of Queensland. His main research interest is in the nexus between social policy, public administration and information technology.

Dr Michele Foster is a Senior Lecturer in the Social Policy Unit, School of Social Work and Human Services, University of Queensland. Her primary research interest is in the area of applied health policy and health services research, with an emphasis on policy implementation, professional decision-making and patient experience.

Associate Professor Jennifer Fleming is an occupational therapist and researcher in the field of brain injury rehabilitation. She employed in a conjoint research appointment between The University of Queensland School of Health and Rehabilitation Sciences and the Occupational Therapy Department, Princess Alexandra Hospital, Brisbane.

Cheryl Tilse is an Associate Professor in the School of Social Work and Human Services, University of Queensland. Her primary research interest is in the intersection of policy, practice and consumer experiences in the field of ageing.

Ros Harrington is an occupational therapist and APAI PhD candidate in the School of Social Work and Human Services, University of Queensland. She is studying the association between motor accident insurance scheme design, traumatic brain injury service system capacity and quality of life after brain trauma.
Financing and Delivering Services for Adults with Acquired Disability and High Care Needs in Queensland – Results from an on-line survey

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The report authors are:

- Dr Paul Henman - School of Social Work & Human Services
- Dr Michele Foster - School of Social Work & Human Services
- A/Professor Jennifer Fleming - School of Health & Rehabilitation Sciences
- A/Professor Cheryl Tilse - School of Social Work & Human Services
- Ms Ros Harrington - PhD Candidate School of Social Work & Human Services
- Dr Stephen Thornton - School of Social Work & Human Services

Correspondence may be addressed to:

Dr Michele Foster
Chief Investigator
ARC Lifetime Care project
Chamberlain Building (35)
School of Social Work & Human Services
The University of Queensland
St Lucia Qld 4072

Email: m.foster@social.uq.edu.au

Project website: www.swahs.uq.edu.au/lifetimecare
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- Dr Tim Geraghty - Spinal Injuries Unit, Princess Alexandra Hospital
- Mr Brendan Horne - Carers Queensland
- Ms Michelle Howard and Mr Lindsay Irons - Office of the Public Advocate
- Mr Paul Larcombe - Disability Council of Queensland
- Mr John Pini - Lifeline Community Care Queensland
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## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>ALSP</td>
<td>Adult Lifestyle Support Program</td>
</tr>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>ARC</td>
<td>Australian Research Council</td>
</tr>
<tr>
<td>CSDA</td>
<td>Commonwealth/State Disability Agreement</td>
</tr>
<tr>
<td>CSTDA</td>
<td>Commonwealth State/Territory Disability Agreement</td>
</tr>
<tr>
<td>EACH</td>
<td>Extended Aged Care at Home</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care Program</td>
</tr>
<tr>
<td>HAS</td>
<td>Home Assist Secure Program</td>
</tr>
<tr>
<td>HwSS</td>
<td>Housing with Shared Support Program</td>
</tr>
<tr>
<td>MASS</td>
<td>Medical Aids Subsidy Scheme</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
</tr>
<tr>
<td>SCIR</td>
<td>Spinal Cord Injury Response Program</td>
</tr>
<tr>
<td>STEPS</td>
<td>Skills to Enable People and Communities Program</td>
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<tr>
<td>YPIRAC</td>
<td>Younger People in Residential Aged Care Initiative</td>
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Executive Summary

There is a growing population of adults aged 18 - 65 years with acquired severe and profound disability and high care needs in Australia who requires lifetime care and support (Senate Standing Committee on Community Affairs 2007). In August 2009, 59 not-for-profit, for-profit/private, and government organisations delivering disability care and support services in Queensland were surveyed as part of a three-year Australian Research Council (ARC) Linkage project. This report provides a descriptive snapshot of the organisational provision of disability care and support services in Queensland, sources of funding, and linkages, focusing on six targeted disability types: acquired brain injury; acquired spinal cord injury; Huntington’s disease; motor neurone disease; multiple sclerosis; and Parkinson’s disease.

Key findings

- Respondent organisations have significant experience in provision of disability care and support services to the targeted population, with the majority of respondent organisations (79%) providing services for more than ten years.
- Not-for-profit organisations, located primarily in the disability sector were the most common respondent organisation (69% of respondents).
- The majority of organisations indicate a generic rather than specialist service focus, providing services to a range of disability types, predominantly in South-East Queensland. Provision of services state-wide was more likely among for-profit/private and government organisations than not-for-profit respondents.
- While there is considerable variation in the services provided across organisations and to different disability types, respondent organisations provided on average four service types, the most common being, personal care (46%), information and advocacy (44%), and respite (42%). Personal care and domestic help were the most common pairing. Provision of health/nursing (25%), counselling (22%), and accommodation (20%) services was less common.
- For people with acquired brain injury and spinal cord injury, personal care and information and advocacy were the two most common services offered by organisations. For other disability types domestic help and information and advocacy (Huntington’s disease); equipment and information and advocacy (Motor Neurone Disease); personal care and respite (Multiple Sclerosis); and personal care and domestic help (Huntington’s disease) were most common.
- Supporting carers represents a significant part of the work of respondent organisations, with the majority (78%) indicating they provide services to carers. In the main, information is the most common service provided to carers, followed by advocacy and respite.
- A small number of surveyed organisations (13) provided services to adults with a specific disability type. These organisations tended to offer a greater number of services and had a wider range of funding sources than generic organisations.
Demand management was an ongoing challenge for the majority of organisations. Of organisations using demand strategies, waiting lists (66% respondents) and prioritising (60% respondents) were the most common strategies. Referral to other organisations is also a common demand management mechanism (30% respondents), particularly among not-for-profit organisations.

For those organisations using waiting lists to manage demand, the wait times for services ranged from less than one month (30% respondents) up to three years (4% respondents).

State government funding constitutes the primary source of funding for the majority of organisations, with 54% of respondents indicating 61-100% of their funding derives from this source.

Not-for-profit organisations rely heavily on state government funding with approximately two-thirds (66%) of respondents indicating nearly half to all of their funding comes from this source. However, this is more likely a combination of recurrent and individualised funding given that almost half of the not-for-profit organisations deliver services as part of the Adult Lifestyle Support Program.

The Adult Lifestyle Support Program and the Home and Community Care program were the most common government programs delivered by respondent organisations (59% and 55% respondents respectively). Delivery of services as part of special government initiatives such as the Younger People in Residential Aged Care Initiative (33%) and Spinal Cord Injury Response program (22%) was also indicated by respondents.

Inter-organisational collaboration is widespread amongst the respondent organisations. The majority of organisations (81%) indicate they collaborate often or very often in service provision, with assessment of clients (73%), care planning (72%), case management (71%), and case review (68%) being the main areas of collaboration.

Lack of appropriate accommodation; fragmented and bureaucratic service delivery; crisis-driven funding; equipment shortages; and non-individualised support were the main problems identified by respondent organisations in relation to disability care and support services.

Areas that require further research include the organisational scope and capacity to provide services to adults with acquired disability; individualised support and funding; and coordination and collaboration between organisations. These issues are especially important in light of the current debate about systemic reform of the disability sector at the national level which will necessarily require consideration of the different service delivery and funding environments in each state and territory, including Queensland.
1. **Background**

There is a growing population of adults aged 18 - 65 years with acquired severe and profound disability and high care needs in Australia who requires lifetime care and support (Senate Standing Committee on Community Affairs 2007). Better survival rates following severe traumatic or acquired brain injury and other injuries or illnesses means demand for lifetime care and support will continue to grow (Senate Community Affairs References Committee, 2005). These individuals are identified as needing:

> help or assistance in one or more of the three core activity areas of self-care, mobility and communication because of a disability, long term health condition (lasting six months or more), or old age (ABS 2007).

According to the 2003 *Survey of Disability, Ageing and Carers* (AIHW 2009), six per cent (1,244,500) of the Australian population has a severe or profound disability (ABS 2004). Despite the large number of people with disability in Australia, the Disability Support Services 2007-2008 report noted that there were only 245,746 users of support services under the former Commonwealth State/Territory Disability Agreement (CSTDA), now National Disability Agreement.

A significant number of individuals with severe and profound disability reside in Queensland. Of the 279,100 Queenslanders who have a severe or profound core activity limitation, 210,600 have a physical disability including diseases of the nervous system, diseases of the musculo-skeletal system and connective tissue, injury and other external causes. Of these, 124,200 are younger adults aged between 15 and 64 years. (ABS 2004).

Disability care and support for individuals with disability is largely provided by a mix of government and non-government programs and services. While Australia’s social security system provides a modest level of safety net support by way of Centrelink pensions and allowances, the nature of individuals’ severe and profound disabilities often means they require substantial support packages, funded largely by state governments.

The CSTDA sought to overcome a lack of clarity and coordination concerning the provision of services for people with a disability. Yet this area continues to be plagued by significant and substantial levels of unmet need. Further, the level of unmet need is also likely to be underestimated given the difficulties and variability in data collection across jurisdictions. It is also of note that individuals fall outside the CSTDA structure if they have access to funding for long-term care through insurance or compensation schemes covering road, or work related injuries or disabilities; or if they receive compensation under public liability (The Senate Standing Committee on Community Affairs 2007; Foster M., Fleming J., & Tilse C. 2007).

In order to adequately meet the needs of individuals with acquired severe or profound disability and high care needs, an intricate mix of services and funding sources is required (AIHW 2007a). Input is needed from a range of organisations across a number of sectors, primarily the
disability, health, community services, and housing sectors. The types of services demanded by these high care individuals include personal care, accommodation, information, financial management, aids and equipment, transport, domestic help, counselling, and respite services (Foster et al. 2007; McCluskey A., Johnson M., & Tate R. 2007). These services are provided through government, for profit/private and not-for-profit organisations, as well as through the informal care of family and friends (Foster et al. 2007).

A number of issues have been identified in regard to the complexity of existing service systems in countries such as Australia. For example, relationships between service providers are often characterised by poor communication and overlapping, ill-defined responsibilities and accountabilities. Failures in collaboration can put the focus population at risk of inadequate care and support, as service delivery is fragmented (Lloyd 2000; Wistow, Knapp, Garding & Allen 1994). Relationships between service provider organisations and government departments can also be problematic as can be levels and types of funding arrangements. This suggests that before lifetime care models can operate effectively, the way in which lifetime care and support services are currently provided, funded and coordinated must be critically examined.

It is from within this policy and service delivery context that there have been recent calls for the introduction of an Australian National Disability Insurance Scheme (NDIS) to finance and coordinate more equitable and adequate services to children and adults (under 65 years of age) with disabilities and high care needs. These calls by disability advocates, disability organisations, and people with disability recognise the necessity to “change the way services for people with disabilities are funded and structured in Australia” (NDIS 2009). The Australian Government has responded to these discussions by asking the Productivity Commission to undertake an inquiry into a National Disability Long-term Care and Support Scheme.

The Terms of Reference for the Inquiry require the Productivity Commission to assess the costs, cost effectiveness, benefits, and feasibility of such a scheme that provides long-term essential care and support for eligible people with a severe or profound disability. This includes making provision for coordinated packages of care services, including individualised approaches, and assisting individuals to make decisions about their care and support needs. The Commission has also been asked to investigate replacing the existing funding system for the eligible disability population (Productivity Commission 2010). As part of the public consultation process, an Issues Paper was released in May 2010 with public hearings conducted in each state and territory capital city in June/July 2010. Two rounds of public submissions are scheduled for August 2010 and April 2011. The Productivity Commission’s final report is due to government in July 2011 (Productivity Commission 2010). Inherent in the Terms of Reference for the inquiry are issues around the role of State and Territory governments in delivering care and support services as part of a new scheme, how these will be coordinated and managed, and the capacity and service reach of the various State and Territory organisational networks to deliver such services to high care needs individuals.
In order to inform these significant policy debates and devise appropriate transition mechanisms from the current to a potentially new scheme, greater understanding of current arrangements, their operation, financing and effects on users is necessary. The current ARC Linkage project examines the financing and management of lifetime care by adults with acquired disability, with a view to identifying effective mechanisms for funding and providing sustainable lifetime care and support for this population.

The project involves two components. The first component involves a mapping exercise to identify the distinguishing features of current systems of financing and management of lifetime care for adults with acquired disability and high care needs. This component is particularly focused on identifying the key features relating to funding, and benefits and services, the mechanisms for negotiating and accessing lifetime care, and for the ongoing management of lifetime care. This component incorporates interviews with key policy, service delivery and financing agencies, followed by an online survey of Queensland organisations who provide services to adults with severe acquired disabilities. The findings of this online survey are the focus of this report.

The second component of the project involves a series of individual case studies incorporating qualitative interviews with individuals with acquired disability, their families, care coordinators and financial managers. This component is designed to understand how systems of financing and management of lifetime care operate and interact, and to critically assess the effectiveness of different mechanisms to address current and changing need, and their capacity to ensure sustainability of future care.

The report is structured in the following way. Sections 2 and 3 outline the aims and method of the survey. In Section 4, a profile of respondent organisations as well as a profile of these organisations’ clients is discussed. Section 5 reports the services provided to organisations’ clients such as personal care, domestic help and respite and also to the carers of these clients. Included in this section is a breakdown of service provision across six disability types as well as how services are clustered together, that is, how common it is for certain services to be provided together by organisations. In Section 6 (Funding), we report the sources of organisational funding and the proportions of such funding including State and Federal government funding, client fees, donations, fundraising, and membership fees. This section also shows the proportion of government-specific programs that are delivered to the target disability population. Section 7 examines the arrangements for organisations which provide services largely to a single disability type to assess what the differences might be compared with the wider sample. Section 8 reports the organisational processes employed by respondent organisations, specifically the eligibility criteria they use for individuals wanting to access their services, demand management mechanisms, collaborative functions, strategic initiatives being undertaken as well as the perspectives of organisations as to how well the ‘system’ or network of disability services in Queensland works. Finally, Section 9 provides a discussion and
conclusion of the three major themes of the survey being disability service provision; organisational funding; and the organisational network.

2. **Aim of the Survey**

This report provides a snapshot of the organisational service delivery and funding environment in Queensland for adults aged 18 – 65 with acquired disability and high care needs. The focus is on organisations providing services to adults aged less than 65 years of age with a severe or profound acquired disability including acquired brain injury, acquired spinal cord injury, multiple sclerosis, motor neurone disease, Huntington’s disease and Parkinson’s disease. The aim of the survey is to better understand the current organisational disability care and support service environment in Queensland by examining the range, distribution and characteristics of government, not-for-profit and for-profit organisations providing services to the target population, how they are funded and activities of inter-agency coordination and strategic service development.

While the survey of organisational services, funding, and partnerships, linkages and networks in Queensland on which this report is based forms part of a larger research project, it is expected that the contents of this report will be a useful resource for policymakers, industry, professionals, and others by providing an enhanced understanding of the complexity of the organisational environment in one of Australia’s larger states, both in terms of population and geography. Ultimately, it is hoped such data will help inform deliberations and policy making in moving towards a proposed National Disability Insurance Scheme (NDIS).

3. **Method**

A four-section, on-line survey instrument was developed using *SurveyMonkey* an online survey tool that enables collection and preliminary analysis of findings (www.surveymonkey.com). Two screening questions were incorporated into the survey to ensure only organisations that provided services to the target disability population completed the survey and that organisations provided these services within Queensland. Organisations self-selected to participate in the survey.

Section One of the survey comprised seven questions relating to organisational type and sector, organisational focus, service sector, and geographical service reach. Section Two of the survey comprised eight questions relating to service delivery including questions relating to the disability type to which organisations provide services, the types of services delivered, eligibility criteria, and demand management. Section Three examined organisational funding sources. The final section of the survey contained five questions, including open-ended questions, relating to organisational partnerships, linkages and networks.

The survey sample was purposively obtained using two methods. First, organisations were identified by the project Reference Group and research team using their collective knowledge
of disability organisations in Queensland. Forty-six organisations were identified using this method. Second, the Queensland Health directory of health and community services, QFinder, was utilised (www.qfinder.qld.gov.au). Organisations were identified through this tool using a combination of the keyword search “disability services” and a major city or town within each of the Queensland government’s Office of Economic and Statistical Research 13 statistical divisions (see Appendix 1). In total, 323 organisations were identified using QFinder. Invitations to participate in the survey were sent by email. To this end, email addresses were identified directly through their QFinder profile or through their own organisational website. Limited project resources did not permit follow-up telephone contact where email addresses were not readily available through these means.

To complement these two methods, a snowballing sampling approach was additionally used whereby organisations were invited to forward their email invitation to other organisations that might fit the eligibility criteria. Organisations that completed the survey were also asked to identify other organisations that may be eligible to complete the survey and to provide their email address if known. Fifteen organisations identified other organisations and provided email addresses, although these organisations were previously identified and contacted in the main sampling methods.

Overall, 369 disability service organisations were invited to complete the survey by email in August 2009. Organisations were informed that their participation was voluntary, that the information they provided would be confidential, and that their computer IP address would not be recorded. A Participant Information Sheet and Consent Form were provided in an electronic format at the beginning of the survey. A two week reminder email was sent to organisations, and a final reminder sent at the end of September.

Of the 369 email invitations sent to disability organisations in Queensland, 38 emails were not delivered because of an invalid email address. Of the 331 organisations that received an invitation to participate in the survey, 98 initially responded. However, the two screening questions decreased the response rate to 59 organisations. The final response rate was 59 out of 331 organisations (18%).

There are a number of explanations for this modest response rate. In a similar mapping survey administered by the United Kingdom Acquired Brain Injury Forum, consultation with participants enabled the researchers to identify reasons for the poor initial response rate (12%) to their online survey, prior to a systematic telephone reminder (UKABIF 2004). First, it was considered that as emails were sent to general administration addresses, the most appropriate person to complete the survey may not necessarily have received the email or may have been difficult to identify. Second, some participants reported that they found it difficult or did not have the knowledge necessary to answer some of the questions. A third possible explanation relates to staff shortages and demand for services within the organisation which could lead to this task being given low priority.
While the modest response rate for this survey limits the analysis in terms of being representative of all relevant organisations in Queensland, it is considered large enough to provide a broad mapping of the diversity of care and support services provided to adults with severe or profound acquired disability and high care needs in Queensland. It is notable that most of the large organisations operating in this sector did respond to the survey. A limitation of the survey, however, is that many of the smaller, local organisations that did not have websites or contact email addresses and were subsequently not included in the sample. Thus the findings reported here are potentially biased in reflecting the experience of larger organisations and are less representative of smaller, localised organisations.

4. Organisational and Client Profiles

4.1 Profile of Respondents

Organisational type

Organisations were asked to identify whether they were a government, for-profit/private or not-for-profit organisation. By far the largest sector represented among the respondents was the not-for-profit sector, with forty-one organisations (69%) identified as such (Figure 1). Eleven (19%) organisations were government. The smallest group was the for-profit/private organisational type, comprising seven (12%) of respondent organisations.

Figure 1: Respondent Organisations by Organisational Type (n=59)

Sector of best fit

Organisations were asked to specify which sector(s) best fitted their organisation: health; disability; community services; housing; transport; or other. Figure 2 indicates over half of respondents (60%) located themselves within the disability sector; 23 per cent in the health sector, and 14 per cent in the community services sector. Only two respondents (4%) identified their organisation as primarily belonging to the housing sector. No organisation identified in the transport sector. There was a large crossover between the health, disability and community sectors with 34 per cent of respondent organisations indicating that they operate across all
three sectors, to varying degrees. Two organisations responding to the previous question did not nominate a specific service sector.

Figure 2: Service Sectors of Respondent Organisations (n=57)
Note: Percentages add to 101% due to rounding

Examiner the distribution of organisations by sector and type, the survey also revealed that certain organisation types are more likely to be located in specific sectors. As Table 1 shows, government organisations are largely located in the health sector, with seven of the ten respondents (70%) identifying as primarily belonging to this sector. Many of these government organisations provide services to individuals with acquired brain injury and/or acquired spinal cord injury which, by the nature of these conditions, have distinct post-acute medical and allied health teams that provide follow-up support services.

Table 1: Organisational Type by Service Sector (n=57)

<table>
<thead>
<tr>
<th></th>
<th>Health Sector</th>
<th>Disability Sector</th>
<th>Community Services Sector</th>
<th>Housing Sector</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>10 (18%)</td>
</tr>
<tr>
<td>Not-for-Profit</td>
<td>2</td>
<td>30</td>
<td>6</td>
<td>2</td>
<td>40 (70%)</td>
</tr>
<tr>
<td>For-Profit/Private</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>7 (12%)</td>
</tr>
<tr>
<td>Total</td>
<td>(23%)</td>
<td>(60%)</td>
<td>(14%)</td>
<td>(4%)</td>
<td>57</td>
</tr>
</tbody>
</table>

For-profit/private organisations, as with government organisations, also identified themselves as predominantly in the health sector. Of the seven respondent organisations, four (57%) located themselves in the health sector (largely providing/selling medical aids and equipment), two in the disability sector (29%), and one in the community services sector (14%). Unlike government and for-profit/private organisations, not-for-profit organisations were largely located in the disability sector. Three-quarters (75%) of not-for-profit organisations identify in the disability sector, with six (15%) identifying themselves in the community services sector and two in both the health (5%) and housing (5%) sectors. This finding is arguably reflective of the funding models operating within the health and disability sectors in Queensland. In particular, Queensland Health operates under a service provider model while Disability Services operates under a service funder and regulator model, subcontracting service delivery out to non-governmental organisations (NGOs) and private sector organisations.
Geographical service reach

Organisations were asked to nominate the regions within Queensland in which their services are provided. The survey provided respondent organisations with a list of 13 regions within Queensland as identified by the Queensland government’s Office of Economic and Statistical Research (see Appendix 1) as well as National; Statewide; and Other/Unsure.

Figure 3: Service Reach of Respondent Organisations in Queensland (n=59)

Figure 3 shows that a considerable proportion of organisations reported that they deliver services statewide (41%), with a small proportion delivering services at the national level (7%). Three organisations also stated they were not limited by the state boundary and that they serviced Northern New South Wales. As expected, organisations were predominantly clustered in South East Queensland consistent with the higher population in this area of the state, with the bulk of services being concentrated in the major metropolitan areas of Brisbane (31%), the Sunshine Coast (21%), and the Gold Coast (19%).

There was a spread of organisations servicing regional areas defined in the survey instrument, with the combined Northern Queensland area (Townsville and Cairns) being serviced by 18 per cent of organisations and the Darling Downs region, West of Brisbane, by 14 per cent. By comparison areas in the South West (5%); North West (5%); and Central West (3%) regions of the state were less likely to be serviced by respondent organisations.

When disaggregating these data according to organisational type (government, not-for-profit, for-profit/private), the geographical service reach pattern varied greatly. For-profit/private organisations largely operated services statewide (four of the six, 67%), as did government organisations (six of the 11, 55%). This contrasts to only one-third (34%) of not-for-profit organisations delivering services on a statewide basis. Figure 4 shows the geographical service reach of not-for-profit organisations.

As Figure 4 shows, the service reach distribution of not-for-profit organisations is similar to the service reach distribution of the aggregate respondent organisations as shown in Figure 3. However, not-for-profit organisations are much less represented on the Gold Coast (10%) compared to the Sunshine Coast (17%). Interestingly, the service reach of respondent not-for-profit organisations in the Far North region (10%) is similar to their service reach in regions
more highly populated and closer to the South-East corner such as Wide Bay-Burnett (10%) and the Darling Downs (10%) which includes the city of Toowoomba.

Figure 4: Service Reach of Not-for-Profit Organisations in Queensland (n=41)

**Years of operation**

Respondent organisations were asked to indicate the length of time they had been involved in service provision to individuals to the target disability population. Of the 52 respondent organisations, over three-quarters (79%) of organisations have been providing services for more than ten years, with 19 per cent providing such services between four and ten years. Only one organisation (2%) was relatively new to service provision, operating for less than three years.

**4.2 Disability Types Serviced by Organisations**

Organisations were asked to nominate which disability types they provided services to from a list incorporating six types: acquired brain injury; acquired spinal injury; Huntington’s disease; motor neurone disease; multiple sclerosis; Parkinson’s disease. An ‘other’ category was also available for organisations to indicate other disability types.

Most respondent organisations offered services across a range of disability or diagnostic types (Table 2). Of the 45 respondent organisations who serviced adults with acquired brain injury, 31 (or 69%) reported that only made up 1-20% of their client bases. Of the 36 organisations that indicated they provided for adults with acquired spinal cord injury, they made up an identical proportion (69% or 25) of their overall client base. There was a similar pattern across the remaining disability types (Huntington’s disease 86%; motor neurone disease 90%; multiple sclerosis 85%; Parkinson’s disease 88%) indicating that many organisations work across a broad spectrum of disabilities and are more often generalist in service provision.
Despite the broad focus of the majority of organisations, some organisations did indicate that they provide care and support services largely to individuals with particular disability types, primarily acquired spinal cord injury (7 organisations), acquired brain injury (5 organisations) and Huntington’s disease (1 organisation). The characteristics of these services are discussed in greater detail in Section 7.

Adults with acquired brain injury (n=45) and acquired spinal cord injury (n=36) were the two largest disability types to which respondent organisations provided services. Few organisations provided services to adults with Parkinson’s disease (n=16, or 31%).

Although not shown in Table 2, 43 per cent of organisations reported that they also provide services to other disability types not specified in the survey instrument. These included: autism; spina bifida; cerebral palsy; spastic quadriplegia; orthopaedic trauma, and other non-specified physical, intellectual and psychiatric conditions.

5. Services

5.1 Services Provided to Clients

Individuals with severe or profound disability and high care needs require a range of care and support services to meet their needs. Organisations were asked to nominate from a list which of eleven service types they provided to clients: accommodation; personal care; domestic help; aids and equipment; rehabilitation and therapy; information and advocacy; respite; health and nursing; counselling; carer support; and transport.

\[\text{Table 2: Average Proportions of Organisational Clients by Disability Type}\]

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>1-20%</th>
<th>21-40%</th>
<th>41-60%</th>
<th>61-80%</th>
<th>81-100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired brain injury (n=45)</td>
<td>69%</td>
<td>18%</td>
<td>2%</td>
<td>7%</td>
<td>4%</td>
</tr>
<tr>
<td>Acquired spinal cord injury (n=36)</td>
<td>69%</td>
<td>3%</td>
<td>8%</td>
<td>3%</td>
<td>17%</td>
</tr>
<tr>
<td>Huntington’s disease (n=21)</td>
<td>86%</td>
<td>10%</td>
<td>0%</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>Motor neurone disease (n=21)</td>
<td>90%</td>
<td>10%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Multiple sclerosis (n=26)</td>
<td>85%</td>
<td>12%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Parkinson’s disease (n=16)</td>
<td>88%</td>
<td>6%</td>
<td>6%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Note: Some rows add to 101% due to rounding
Figure 5 indicates a wide range of services are offered across organisations. The most common services provided to adults in the targeted disability groups are personal care (46%), information and advocacy (44%), and respite (42%). Approximately one-third of organisations provide domestic help (36%), rehabilitation and therapy (36%), carer support (34%), transport (32%) and equipment (29%). One-quarter of organisations provide health and nursing (25%) and just under one-quarter of organisations provide counselling services (22%). Accommodation services were the least frequently provided, with 20 per cent of organisations providing such services.

In addition to the 11 care and support services specified in the survey instrument, 15 per cent of organisations reported that they also provide other services to adults with acquired disability and high care needs in the six targeted disability groups. These services included case management, psychosocial and behavioural intervention and social support, home modifications and maintenance, security and networking. There was a considerable variation in organisational focus among respondents. Different respondent organisations described their service focus as disability support; community services; information, advocacy and awareness; home maintenance, modifications and repairs; provision of equipment; accommodation; respite; rehabilitation; in-home support; transport; counselling; health and nursing; and administration.

The maximum number of services types provided by any one organisation was 11. Nearly one-quarter (22%) of organisations only provided one service type. The average number of service types provided by respondent organisations was four, thereby demonstrating that organisations typically provided a small number of complementary services to adults with acquired disabilities.

When examining how services were clustered together, correlation coefficients suggest that personal care and domestic help are often provided together within an organisation (cc=0.738). A second larger clustering of services involves carer support, counselling, health/nursing, rehabilitation and therapy, and information and advocacy. Other services tended to be provided alone, including accommodation, equipment, transport and respite.
Figure 6 shows the 11 care and support service types disaggregated across the six disability types: acquired brain injury; acquired spinal cord injury; Huntington’s disease, motor neurone disease, multiple sclerosis and Parkinson’s disease. For individuals with acquired brain injury and acquired spinal cord injury, personal care was the most common service (49% and 62% respectively) and information and advocacy the second most provided service (47% and 53%). While accommodation services for all disability types was low, individuals with acquired brain injury were provided the most accommodation services of all disability types with 11 of 43 organisations (26%) providing such services to that group. However, for individuals with acquired spinal cord injury accommodation services were by far the least provided service (12%) of all services provided to these individuals with the next least common service provided being counselling (24%) and transport (24%). Counselling was also the least provided service to individuals with acquired brain injury (23%).

These results may represent a variance in models of service delivery for people with high care needs attributable to acquired brain injury and those for people with spinal cord injury in Queensland. The SCIR provides prioritised access to social housing, or funding for home modifications to existing housing for people with a SCI acquired after 2005, as well as funding for the attendant care and support required to live in this housing. This, combined with the relatively low prevalence of SCI in comparison to acquired brain injury would indicate less of a need for access to supported accommodation services. In comparison, in Queensland, there is no targeted whole-of-government initiative to respond to the accommodation and lifetime care and support needs of adults with acquired brain injury which links individualised housing options to funding for care and support services, resulting in a higher representation of this
group in residential care facilities. Indeed increased pressures on the acute care system, a lack of rehabilitation programs for slow recovery patients, and limited accommodation options provided the adequate mix of medical, rehabilitation and long-term support services are common factors leading to transfer to residential aged care facilities (Foster M. et al 2007; O'Reilly K. & Pryor J. 2002).

Organisations providing care and support services to adults with Huntington's disease most commonly provided domestic help (46%) and information and advocacy (46%). Of the 22 organisations providing services to these individuals, 36 per cent provide carer support and approximately one-quarter provide personal care (27%), equipment (27%) and respite (27%). Only two organisations (9%) indicated that they provide accommodation services to individuals with Huntington's disease.

From feedback from the 17 organisations that identified as providing services to people with motor neurone disease, the services commonly provided were: equipment (41%), information and advocacy (41%) and respite (41%). Transport was the least provided service, with only one organisation (6%) indicating that they provided such services. Accommodation services were provided by 18 per cent of organisations providing services to individuals with motor neurone disease.

Of the 22 respondent organisations providing services to individuals with multiple sclerosis, the most common services provided were personal care (50%) and respite (50%), followed by domestic help (46%), equipment (41%) and information and advocacy (41%). Health and nursing and transport were both offered by 23 per cent of organisations providing services to individuals with multiple sclerosis.

Individuals with Parkinson's disease had the lowest number of organisations providing services to them, with only 16 organisations providing such services. Of these, seven organisations (44%) reported that they provide personal care and domestic help services. Six organisations (38%) provide equipment, respite and information and advocacy services. Accommodation services were provided by only one organisation (6%), with no organisation providing transportation services to individuals with Parkinson's disease.

This variation in service delivery may be explained by population statistics for the conditions covered by the survey. Acquired Brain Injury is relatively common in Australia with 1 in 45 Australians (432,700) reporting an Acquired Brain Injury with activity limitations or participation restrictions due to disability in the Australian Bureau of Statistics’ 2003 Survey of Disability, Ageing and Carers (ABS 2004). Almost 157,500 (0.8% of the Australian population) of these people reported having a severe or profound core activity limitation, with the majority (99,900) being aged under 65 years (AIHW 2007b).

In comparison, the estimated prevalence of Spinal Cord Injury in Australia is between 10,000 (O’Connor P. J. 2005) and 9,000 (Cripps R.A., & Harrison J.E. 2008) individuals. MS Australia estimates that approximately 18,000 Australians have multiple sclerosis (MS Australia 2005).
with over 50% of people living with MS in the community being fully ambulatory (AIHW 2009b). Huntington’s Disease affects approximately 6-7 people per 100,000 (Hunttingsons Australia 2010) and Motor Neurone Disease affects approximately 1400 people in Australia (MND Australia retrieved 2010) Parkinson’s disease is more prevalent with 290 per 100,000 aged 55 to 64 years affected by this condition (Access Economics June 2007).

On the basis of these statistics it is not surprising that there were more organisations providing care and support to people with Acquired Brain Injury. The high proportion of organisations providing support to people with Spinal Cord Injury living in the community is of note, given the relative prevalence of this condition. Also significant is the high proportion of organisations providing dedicated services to individuals with SCI, in comparison to the other groups. The development of a ‘whole-of-government’ program, the Spinal Cord Injuries Response (SCIR), which commenced in 2005 and provides targeted funding for the lifetime care and support needs (modified housing, home modifications, equipment, attendant care and lifestyle support services) for people with spinal cord injuries leaving hospital may explain these statistics.

5.2 Services Provided to Carers

Informal care constitutes a significant proportion of the care received by the target disability population (Senate Standing Community on Community Affairs 2007). Accordingly, supporting informal carers is a critical aspect of providing care and support for adults with high care needs. The survey asked organisations whether they provided services to carers and the types of services they provided. A considerable proportion (78%) of organisations reported that they do provide services to carers. Figure 7 shows the range and frequency of services offered to carers by respondent organisations both aggregated and disaggregated by organisational type (government, not-for-profit, for-profit).

![Figure 7: Services Provided to Carers by Respondent Organisations (n=51)](image)

As shown in Figure 7, information services are the most common service provided to carers with 63 per cent of respondent organisations providing these. A significant proportion of organisations also indicated that they provide advocacy (41%), respite (37%), and education services (22%). By comparison, only six per cent of organisations reported providing cash
payments to carers. Other services not specifically listed in the survey are provided by 24 per cent of respondents. These were primarily support services such as counselling and support groups. Some organisations reported that they provide consultations, community access, case management, funding for household items, transport and recreational activities.

While it is not unexpected that not-for-profit organisations provided the majority of services to carers given their larger representation in the sample, it is of interest that they provide nearly all of the respite services (33%) and all of the cash payments (6%) to carers, whereas government organisations were over-represented in education to carers.

6. Funding

6.1 Organisational Funding Sources

Organisations were asked to identify the sources of their funding that they received. Respondents were asked to identify both government sources of funding and whether this was recurrent funding or ad hoc funding, such as grants, and other additional sources of funding, and what proportion each of these funding sources constituted of the overall organisation’s income. Fifty organisations provided a response to this question, with all not-for-profit organisations (n=41) identifying the source of their funding (Table 3).

Queensland state government recurrent funding constitutes the primary source of financing for all organisations, with 54 per cent of all organisations receiving the majority of their funding (defined as 61-100%) from this source. Forty nine percent of not-for-profit organisations received recurrent funding from the State Government. No for-profit/private organisations received the majority of their funding from this source. Approximately one-third of all organisations (34%) and not-for-profit organisations (34%) receive ad hoc funding from the Queensland government, although this comprises less than 20 per cent of their total funding.

Federal government recurrent funding is a significant source for only five organisations (10%) and 12 per cent of not-for-profit organisations receiving the majority of their funding from this source. Ninety per cent of all organisations reported receiving no federal government ad hoc funding such as grants. No organisation reported receiving recurrent funding from any local government, with only four not-for-profit organisations (10%) receiving less than 20 percent of their total funding from ad-hoc local government funding.
In terms of funding received from non-government sources, Table 3 shows that almost half of not-for-profit organisations (46%) receive funding from client fees; 37 per cent receive funding and 32 per cent receive funding from membership fees and 24 per cent receive funding from fundraising activities. Five (12%) not-for-profit organisations also received a small percentage of their overall funding from other sources such as grants from community organisations, research project funding, insurance, and archdiocese funding.

The funding source for government organisations is almost exclusively derived from Queensland state government recurrent funding. Of the eight government organisations that indicated their source/s of funding, seven (88%) receive 80-100% of their funding from the State government, while one government organisation reported receiving a mix of Federal and State government recurrent and ad-hoc funding. Of the four for-profit/private organisations that responded to this question, there was a mix of funding sources and no clear pattern can be established, both due to this mix and the low number of responses from this organisational type. Generally, however, for-profit/private organisations receive at least 41-60% of their funding from state or federal governments and less than 40 per cent of their funding from client fees.
6.2 Specific State and Federal Government Funding Programs

Looking in more detail at the specific funding sources, the survey asked organisations about specific state and federal government funding programs from which they obtained funding (Figure 8). This included six specific programs: the Queensland government’s Adult Lifestyle Support Program (ALSP); the Queensland government’s Spinal Cord Injury Response (SCIR); the joint State and Federal Younger People in Residential Aged Care Initiative (YPIRAC); the joint State and Federal Home and Community Care (HACC) program; the Queensland government’s Housing with Shared Support (HwSS) program, and the Queensland government’s Home Assist Secure (HAS) program.

Figure 8: State and Federal Government Programs Delivered by Organisations (n=49)

Over half of the respondents indicated that their organisation received funding from the Adult Lifestyle Support Program (ALSP) (59%) and Home and Community Care (HACC) program (55%). A considerable proportion of organisations were also involved in delivering the Younger People in Residential Aged Care Initiative (YPIRAC) (33%), Home Assist Secure (HAS) program (27%), and the Spinal Cord Injury Response (SCIR) program (22%). Fewer organisations delivered the Housing with Shared Support (HwSS) program (12%). Thirty-three per cent of organisations also reported delivering other government-funded programs such as: disability support programs; aged care programs; mental health programs; family support and emergency or crisis funding; post-school programs; job and housing support; subsidies for medical aids or equipment; and insurance or compensation.

Of all respondent organisations receiving funding from at least one of the six listed funding programs, typically organisations received funding from one of the programs (41%), yet almost a third received funding from two of the programs listed (30%), and 10 per cent benefited from three listed funding programs. There was no clear clustering of funding sources.

In disaggregating this data by organisational type, government organisations delivering these specific programs were largely acquired brain injury and acquired spinal cord injury rehabilitation and outreach teams within Queensland Health. All 11 government respondent organisations answered this question in the survey. Five organisations delivered services in relation to the ALSP (45%); four for the SCIR program (36%); four for the YPIRAC program (36%); six for the HACC program (55%); four for HwSS program (36%); and six for the HAS program (55%).
Of the six for-profit/private organisations that responded to this question, there was a similar proportion delivering the ALSP (50%); SCIR program (33%); and HACC program (50%). Two for-profit/private organisations delivered the HAS program (33%), while only one such organisation delivered the YPIRAC program (17%). No for-profit/private organisation reported delivering services as part of the Housing with Shared Support program while five for-profit organisations reported delivering other programs including the state government’s Medical Aids Subsidy Scheme (MASS) and the federal government’s Extended Aged Care at Home (EACH) program.

Figure 9 demonstrates that the most commonly delivered program by not-for-profit organisations is the ALSP (49%), with almost half of such organisations delivering this state government program. Also commonly delivered is the HACC program (41%), followed by the YPIRAC program (27%) and HAS and SCIR programs (12%). Only two organisations (5%) are involved in delivering the HwSS program.

7. Disability Specific Organisations

As noted above, few organisations operated with a specialist focus on a specific disability or diagnosis type. The exceptions included seven organisations (20%) with a specialist acquired spinal cord injury focus, providing largely dedicated services (61-100%) to individuals with acquired spinal cord injury. Government organisations represented four of these specialist organisations, while three were non-government organisations receiving funding from a variety of sources including the ALSP, SCIR and HACC programs.

Acquired brain injury was the second disability type in which organisations were found to specialise. This disability type constituted 61-100 per cent of their client base for five (11%) organisations. Two of the five organisations were government, funded by a mix of funding programs, while the remaining three were not-for-profit organisations. In the latter group, two receive funding solely by the HACC program, while the other receives a mix of ALSP, YPIRAC and HwSS program funding.

Huntington’s disease was the only disability type with a single organisation (not-for-profit) dedicated specifically to service provision for people diagnosed with this condition.
These disability-specific organisations offer, on average, 5.75 types of disability services which is two services more than the entire sample (3.88) (see Section 6.1). Information and advocacy (11 of 12 organisations), carer support (10), rehabilitation and therapy (9) and counselling (8) are the most common services provided by this sub-group of organisations. Three of the 12 disability-specific organisations provide accommodation which is a much greater proportion of the organisations than for the entire sample. These findings are perhaps not surprising as it could be expected that those who offer services to a clients with a specific disability might seek to provide a whole-of-person service, integrating different aspects of their care and support needs.

The funding of these organisations also seems to differ from the entire sample, with organisations obtaining, on average, funding from three of the five listed programs in Section 7.2 (compared with 1.73 for the entire sample), and 9 of the 12 organisations stating that 81 to 100 per cent of their funding derives from the State government.

8. Organisational Processes

8.1 Eligibility Criteria

Eligibility criteria are an important device to determine allocation of resources and to manage demand. Often eligibility is dictated by government policy and funding requirements, whereas at other times it reflects an organisation’s specific aim (for example to service a particular population or geographical space). In times of high demand, it can also be an important factor in determining prioritisation.

Organisations were asked to indicate from a specified list what criteria they used to assess and determine an individual’s eligibility to access services: diagnosis/client condition; geography; individual income; individual assets; household income; household assets; compensation payment; and fee-for-services, and the proportion of respondents that used each criterion to determine client eligibility.

Figure 10 shows that the most used eligibility criterion for determining access are diagnosis/client condition (38 organisations, 76%); and geographical location (36, 72%) Fee for services is much less used (18, 36%) and 11 organisations use compensation payments (22%), while only two organisations (4%) use individual income to determine client eligibility. No organisation used individual assets, household assets, or household income as eligibility criterion. Fourteen organisations (28%) reported using eligibility criteria other than that specified in the survey instrument. These included self-identification as a person with a disability, submission to external bodies for assessment and approval, and residency and citizenship status.
Of the 50 respondent organisations to this question, 36 were not-for-profit organisations, eight were government organisations and six were for-profit/private organisations. Figure 11 disaggregates the eligibility criterion used by these three organisational types.

While the small sample size of the for-profit/private and government organisations limits the comparative analysis in terms of statistical significance, Figure 11 shows a clear difference in the eligibility criteria used by the three organisational types. Not-for-profit organisations (66%) and government organisations (73%) give similar consideration to diagnosis/client condition, while this is less used in for-profit/private organisations, which not surprisingly tend to focus more on fee for services (71%). Not-for-profit organisations give much more consideration to the location of clients (71%) than either for-profit/private organisations (43%) or government organisations (36%).

8.2 Organisational Demand Management Mechanisms

There are a range of organisational techniques for managing demand within a resource-constrained environment. Organisations were asked to indicate how they manage demand for their services. The survey instrument listed four demand management strategies: waiting lists; prioritising clients; client payments, and referring the client elsewhere. Organisations were also provided the opportunity to nominate other demand management strategies that they used.
Figure 12: Demand Management Mechanisms for all Organisations (n=47)

Figure 12 shows waiting lists and prioritisation were the most common demand management strategies. Two-thirds of respondent organisations (31 or 66%) use waiting lists, while over half (28 or 60%) prioritise their clients to manage demand. For the majority, prioritisation was determined by conducting a needs or risk assessment. Some (14 or 30%) respondents refer to other organisations and two respondents (4%) use payments to manage demand. Ten organisations (21%) reported using other mechanisms such as not accepting any further clients, applying a co-payment (i.e. requiring the client to pay deficits in government funding for services), and a monitoring list. Of the 47 organisations who report using a demand management mechanism, most used either one or two mechanisms (47% and 36% respectively). There were evidence of some clustering of the use of waiting lists and prioritising (0.359), and also between client payments and referring elsewhere (0.336).

Figure 13: Demand Management Mechanisms by Organisational Type

Figure 13 shows the demand management mechanisms used as disaggregated by different organisational sectors. Not-for-profit organisations use waiting lists less often (19 or 58%) compared to for-profit/private organisations (100%) and government organisations (6 or 75%). However, not-for-profit organisations are more likely than other organisations to refer clients elsewhere (39% of NGOs) as opposed to government organisations (13%) and for-profit organisation (0%). Prioritising was popular with not-for-profit organisations (20 or 61%) and government organisations (6 or 75%), though less popular with for-profit/private organisations with only one-third (2 or 33%) using this mechanism. Only two organisations used payments to manage demand, both being not-for-profit organisations.

Also included in this section of the survey was a question asking organisations to report the average length of time that their clients have to wait for services, whether of not they used
waiting lists. Responses to this question varied greatly. Figure 14 shows the average wait times of clients for services.

![Figure 14: Client Wait Time for Services (n=50)](image)

Of the 50 organisations that provided a response to this question, 15 organisations (30%) report clients wait less than one month. Of the six (12%) organisations that reported their clients wait between one and three months, four were not-for-profit organisations, one a government organisation and one a for-profit/private organisation. Four organisations (8%) indicated their clients wait up to 12 months, all but one being not-for-profit organisations. Two organisations (4%) reported clients wait up to three years to access their services. One organisation (2%) reported waiting time ‘varies’, while another (2%) reported client waiting times are not available. Twenty-one organisations (42%) indicated waiting time was ‘not applicable’ to their organisations. Interestingly, 11 of these organisations also reported using waiting lists or prioritising as demand management mechanisms. Although the reason for these organisations reporting this is not clear, it may be that these organisations accept clients on a referral basis from government departments and agencies when a vacancy exists in their service.

8.3 Collaboration with Other Organisations

Given the diversity of services and funding arrangements for care and support to adults with high care and support needs, collaboration is an important exercise to enhance service delivery and effectiveness. The survey sought to better understand how respondent organisations currently collaborate with other organisations involved in service provision to the six target disability groups. In other words, how joined-up these organisations are. Figure 15 shows that between 35 and 42 organisations provided a response to each of the five activities specified in the survey instrument: assessment; care planning; case review; case management; and service provision. The number of respondents for each of the five collaborative functions excludes those organisations that reported ‘not applicable’ or that did not answer the question.
As Figure 15 shows, respondent organisations collaborate to a high degree and regularly. Of the five activities listed in the survey, organisations that collaborate at all, do so most often for service provision. Of the 42 respondent organisations, 43 per cent reported that they collaborate often and 38 per cent very often, a total of 81 per cent. Less than one-fifth of organisations (19%) reported collaborating on service provision rarely or very rarely. Thirty-eight organisations reported that they collaborate with other organisations in the assessment of clients. Of these organisations, 73 per cent collaborate often or very often, while approximately 26% of respondent organisations do this very rarely. A similar proportion of organisations collaborate often or very often in care planning (72%), while 28 per cent collaborate in care planning rarely or very rarely. A slightly smaller proportion of organisations collaborate often or very often in case management (71%) with 28 per cent collaborating rarely or very rarely.

About 68 per cent of organisations collaborated often or very often in case review. Survey participants were also asked to specify if there were any other ways they collaborate with organisation in Queensland. Respondent organisations further identified functions such as education, consultation, advocacy and professional development workshops.

8.4  Strategic Development

It was of interest to assess the level of innovation and development occurring in the organisations surveyed. Overall, there was evidence of a significant level of strategic development. Of the 59 survey respondents, a total of 27 organisations (46%) identified that they were undertaking development strategies within their organisations. Of the three organisational types, 18 of the 41 not-for-profit organisations (44%) stated that they were involved in some type of strategic development, while six organisations indicated that they were not considering development strategies.

Not-for-profit organisations reported developing educational resources and support services as well as constructing new accommodation and rehabilitation facilities. Organisations also reported developing partnerships with other service providers by way of forums, working groups and sharing information regarding service provision. Strategic development in service delivery
is also taking place at the state and federal government level, with organisations identifying different initiatives they are working on in conjunction with government and other service providers, such as the Spinal Cord Injury Response (SCIR). A number of organisations also stated they are working on developing policy, alongside government departments. Specifically, a community-centred approach to addressing disability and the National Disability Insurance Scheme was identified. For some, strategic development was not possible due to a shortage of funding.

With regard to the other two organisational types, two of the seven for-profit/private organisations (29%) reported they were pursuing strategic development, largely around building additional facilities and support services. Of the 11 government organisations that initially responded to the survey, seven (64%) reported undertaking strategic development activities largely focused on improving communications between government departments and agencies and also with non-government organisations.

8.5 Organisational Perspectives

Respondents were also given opportunity to provide qualitative information about what works well and what does not work well with regard to disability care and support services in Queensland for the six target disability groups. Thirty three responses were received and a thematic analysis was conducted to identify the main themes. Table 4 shows the five main themes evident in respondent comments: lack of appropriate accommodation arrangements; fragmented and bureaucratic service delivery; crisis-driven funding; equipment shortages; and non-individualised support.

Almost all of the 33 responses indicated aspects of the current service delivery and funding environment in Queensland that were important for the system to work well, rather than what currently works well in the system. Respondent organisations clearly and sometimes vehemently expressed what could and should be improved in the current system for care and support services to individuals in this disability population.
Table 4: Organisational Perspectives of Service Delivery/ Funding in Queensland (n=33)

<table>
<thead>
<tr>
<th>Category</th>
<th>Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accommodation arrangements</strong></td>
<td>Current accommodation arrangements are considered problematic. There is a lack of suitable accommodation options, including supported and affordable accommodation which can result in clients remaining in inpatient environments for extended periods of time. It is inappropriate to place adults with acquired disability, aged 18 – 65, in aged care facilities. Co-tenancy/collective agreements can be problematic, especially when clients are placed in situations where positive interaction is low and community access is limited.</td>
</tr>
<tr>
<td><strong>Fragmented and bureaucratic service delivery</strong></td>
<td>The current model of service delivery is fragmented and bureaucratic. The artificial division between health, disability and community services make the appropriate services difficult to locate, navigate and coordinate. The process is confusing as providers have to liaise with multiple organisations and departments. This results in some clients 'falling through the cracks'. Organisations and carers and families are placed under pressure by the high volume of paper work required for service delivery. The process for applying for funding is 'lengthy and complicated'.</td>
</tr>
<tr>
<td><strong>Crisis-driven funding</strong></td>
<td>Funding is crisis-driven instead of planned ('crisis-driven mindset'). Clients must experience a series of crises, resulting in high levels of stress for the individual, in order to receive more resources. Some organisations argued that the imperative for early intervention has been ignored and has resulted in a more resource intensive service.</td>
</tr>
<tr>
<td><strong>Equipment shortages</strong></td>
<td>A shortage of available and affordable equipment impacts on service delivery. The cost of equipment is a burden to clients, with the Queensland government's Medical Aids Subsidy Scheme (MASS) lagging behind the real costs of certain pieces of equipment (e.g. electric wheelchairs) and not providing subsidies for other essential items, such as electric beds. The availability of specialised equipment is limited, especially in regard to ventilators. The time to process applications for equipment is too long.</td>
</tr>
<tr>
<td><strong>Non-individualised support</strong></td>
<td>Non-individualised support is problematic. It is common for clients to be expected to fit into existing service requirements instead of organisations adapting to the individual needs of the client. Organisational inflexibility causes informal supports (i.e. family and friends) to bear the financial and care burden.</td>
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</table>

9. Discussion and Conclusion

This report has provided a descriptive snapshot of the organisational provision of disability care and support services, sources of funding, and linkages, focusing on six targeted disability types: acquired brain injury; acquired spinal cord injury; Huntington’s disease; motor neurone disease; multiple sclerosis; and Parkinson’s disease. Some caution is warranted in the interpretation of the findings due to limitations of the data; in particular, the low response rate and the unknown representativeness of the organisations. However, respondents included most of the large organisations that occupy a central role in provision of disability care and support in Queensland. A further limitation is that the size of organisations in terms of client numbers is unknown and to that end, all organisations were treated equally in the analysis regardless of their client population. Nevertheless, taking the findings as a whole, three central
themes are indicated: service system and organisational complexity. Each of these issues is discussed further below.

9.1 Service System and Organisational Complexity

The provision of disability care and support in Queensland clearly constitutes a mixed economy of care as indicated by the diverse funding arrangements and involvement of government and non-government and public and private sectors. Moreover, as is consistent with a mixed economy of care, the findings indicate financing of services derives largely from government while a range of agencies have responsibility for service provision, including in this case a major role for not-for-profit organisations. The survey found that government organisations comprise approximately one-fifth (19%) and non-government organisations four-fifths (81%) of respondent organisations delivering disability care and support services to adults with high care needs in Queensland. Of the non-government organisations, for-profit/private organisations comprise only a small proportion of non-government organisations (15%) compared to not-for-profit organisations (85%).

Government organisations are largely located in the health sector and mainly provide services to individuals with acquired brain injury and/or acquired spinal cord injury which, due to the catastrophic nature of these conditions, have dedicated post-acute medical and allied health teams. However, not-for-profit organisations providing services to individuals in this disability population are primarily located in the disability sector and are well established. They are also typically generalist in their service provision to a range of disability types, with only seven not-for-profit organisations providing dedicated care and support services to any one disability type. The emphasis on generic models is potentially problematic for populations with diverse and fluctuating patterns of need and creates unnecessary competition for resources (Foster, Fleming & Tilse, 2007). Moreover, it raises questions about mechanisms to ensure good collaboration across organisations and sectors and the competency of service providers to provide integrated and quality care (Foster, Fleming & Tilse, 2007). For-profit/private organisations, like government organisations, largely operate in the health sector, providing/selling medical aids and equipment to a range of disability types including those in other disability populations.

Although these results demonstrate that a “mixed economy of care” exists in regard to the provision of care and support services for younger adults with disability in Queensland, it is mostly the case for individuals experiencing an acquired brain injury or an acquired spinal cord injury. All government organisations in this survey reported providing either no services or twenty per cent or less of their services to individuals with chronic progressive conditions such as multiple sclerosis, Huntington’s disease, motor neurone disease and Parkinson’s disease. Therefore, individuals with acquired brain injury and acquired spinal cord injury, their service providers, informal carers and coordinators are a group that may experience more difficulties associated with the artificial division between the two largest sectors reported in the survey, the health sector (23%) and the disability (60%) sector.
The machinery-of-government change in Queensland in 2009 resulted in the formation of two agencies, Disability and Community Care Services and Housing and Homelessness Services, under the umbrella of a new Department of Communities. This department now cuts across three sectors identified earlier in the report: the disability sector, community services sector; and housing sector. However, for individuals needing to access health sector services, this artificial division remains between the newly formed Department of Communities and Queensland Health. This suggests that there is an inherent complexity in the current service environment which could be overwhelming for those requiring services across separate departments, notwithstanding likely divisional issues between agencies within the same department. Individuals with chronic progressive conditions also require access to services within Queensland Health, particularly relating to the Medical Aids Subsidy Scheme, and, therefore, they too are likely to experience divisional issues between the sectors.

The systemic governance of disability care and support needs and their financing is of significant importance to ensure that the system addresses the needs of the relevant population. It is well known that the system is fragmented and dispersed with no real overall governance. Within this context, however, systemic collaboration between organisations can be an important mechanism to enhance systemic governance. In regard to collaboration at the inter-organisational level, while the results show that collaboration is widespread amongst the respondent organisations, further analysis shows that some organisations report collaborating ‘very rarely’ in one collaborative function and ‘very often’ in another. This was most often the case with organisations reporting that they only collaborated ‘often’ or ‘very often’ in service provision. Many of these organisations also reported collaborating rarely or very rarely in other collaborative functions. Of more interest, however, are those organisations that reported collaborating ‘rarely’ or ‘very rarely’ consistently across all five collaborative functions. Of all respondent organisations, six not-for-profit organisations reported this. Four of the six organisations provide services in the South-East corner of the state, one in the North of the state, and one in the Darling Downs region.

9.2 Disability Service Provision

While the quality and choice of services are important factors in determining optimal lifetime care for adults with acquired disability and high care needs, it is access to services which ultimately determines the quality and appropriateness of lifetime care and support. Taking the findings as a whole, access to services can be considered in terms of organisational presence; organisational capacity; and eligibility for services.

The issue of access, either through geography or eligibility or even waiting lists, is particularly pertinent to the domain of disability services. An individual’s needs do not necessarily translate to the receipt of service at the level and timing that is regarded as appropriate. Michael Lipsky (1984) usefully coined the term ‘bureaucratic disentitlement’ to highlight the administrative realities, rather than formal policies and principles, that denied access to government funded services. Thus, it is important to look beyond formal policies to the playing out of those policies.
in practice to understand the way those policies are experienced by citizens. This will be studied in further depth in the project’s Component 2 interviews with adults with disability, their family, formal carer and financial manager (where appropriate).

Organisational Presence

There were two main aspects of organisational presence explored in the survey; geographical service reach and the range of services provided to clients. It is important to understand these two aspects simultaneously when considering access to services and organisational presence. While a number of organisations might service a particular region of Queensland (geographical service reach), their scope of disability care and support services may be limited (for example, offering personal care and not accommodation). Similarly, while few organisations may provide services to a particular region, these organisations may have a greater scope of services.

While 41 per cent of organisations reported providing services statewide, it is not clear how many of these organisations provide services to specific regions and areas within these regions. However, as has been previously reported, the lack of infrastructure in rural and remote areas is of particular concern for people who are reliant on disability services (Spall P., McDonald C, & Zetlin D. 2005). As such, the service reach of organisations providing disability services in Queensland is an area that requires further research.

In regard to the scope of services provided by respondent organisations, there are five service types that are limited across all six disability types: accommodation; health/nursing; rehabilitation/therapy; counselling; and transport. While the low number of services provided by respondent organisations for health/nursing services may be attributed to the small number of large not-for-profit organisations providing this type of service across the state (for example Blue Care), the reasons for organisations providing fewer or some of the other service types is less clear.

First, there is a distinct lack of accommodation services provided by respondent organisations to all disability types, with the exception of individuals with acquired brain injury which were provided by approximately one-quarter (24%) of all respondent not-for-profit organisations. The implications of lack of appropriate accommodation for adults with acquired disability and high care needs is well documented, including being at risk of remaining in inpatient environments for extended periods of time and also at risk of being transferred to residential aged care facilities (Winkler D., Farnsworth L. & Sloane S., 2006a). The accommodation pathways and choices for adults with acquired disability and high care needs is an area that requires further research.

One of the major policy responses from the Council of Australian Governments (COAG) to this recognised need has been the development of the Younger People in Residential Aged Care Initiative. First introduced in 2006, this program involves funding and disability support services to move young adults out of residential aged care facilities and to identify appropriate
accommodation for those at risk of entering residential aged care. The results show that one-third of respondent organisations (33%) are involved in delivering this program despite accommodation being provided by only 12 (or 20%) of the organisations' services. Fewer organisations (12%) are involved in delivering the Housing with Shared Support program, which is intended to assist people with disability to live successfully in the community with ongoing support, including the opportunity for a group of people to live together in close proximity to facilitate the sharing of resources (www.housing.qld.gov.au). Nevertheless, over the past decade there has been a gradual increase in the range of accommodation and support models supported under government initiatives (Winkler D., Farnworth L., Sloane S. & Brown T., 2006b).

**Organisational Capacity**

Organisational capacity may be determined by analysing the wait times for services that clients experience and the demand management mechanisms that organisations use to manage the demand for their services. Of the organisations that responded to the question about demand management strategies, 30% reported clients wait less than one month to access their services. However, approximately 24 per cent indicated clients wait between one month and three years to access services. These findings must be treated with caution since 40% of organisations surveyed did not respond to this question. However, clearly among some organisations, timely provision of services is an ongoing concern. It is possible that organisations that did not respond were not using any specific demand management strategies or alternatively, could not report accurately about waiting lists. Yet, the likelihood of high levels of unmet need within the sector is well recognised. Data on the use of specialist disability services across all Australian states indicate the population of users is increasing, with the number up by 31% between 2003-04 and 2007-08, or approximately 7.5% per annum (AIHW 2009a). Moreover, there are similar growth rates in the level of unmet need and an over-reliance on informal care (Senate Standing Committee on Community Affairs 2007).

The capacity for organisations in Queensland to provide services in a timely way, and to be able to refer to other appropriate organisations in a non-competitive environment, is fundamental to managing the demand at a network level and not just at the intra-organisational level. The waiting times reported by respondents suggest that while some individuals are able to access certain services in a timely way, it is not the case for others. This raises questions not only about how well the needs of the current population of adults with disability are being met, but about the ability of the current system to cope with the predicted increased demand for services in the future.

**Eligibility for Services**

The third aspect of access to services in Queensland for this disability population is an individual's eligibility for services. Of the eight criterion specified in the survey, no organisation reported using individual assets, household assets, or household income to determine eligibility
for their services, with only two organisations using individual income as a criterion. While this indicates that means testing is not used at the organisational level, it does not mean that individuals are not means tested by government departments for particular programs when initial application for services is made. While there is no means testing for the Adult Lifestyle Support Program, which is the disability program delivered by the highest proportion of respondent organisations (59%), means testing is used to determine applications for other programs at the department level, for example, social housing.

While approximately three-quarters (76%) of organisations use diagnosis/client condition as an eligibility criterion and 36 organisations (72%) use geographical location, of note is the 18 organisations (36%) that use ability to pay a fee for services to determine an individual’s eligibility for services. While the small sample size of the for-profit/private and government organisations limits the comparative analysis in terms of statistical significance, the results unsurprisingly show that it is largely for-profit/private organisations that tend to focus more on fee for services (71%).

9.3 Organisational Funding

Respondent organisations are highly reliant on state government funding. It is particularly important to focus on non-government organisations and in particular the 85 per cent of these that are not-for-profit organisations. In regard to not-for-profit organisations, approximately two-thirds (66%) of respondents reported that nearly half to all of their funding comes from state government funding. This funding is generally channelled through state government administered programs such as the Adult Lifestyle Support Program and the Home and Community Care program. The findings suggest funding is characterised by a combination of recurrent and individualised funding which is consistent with other empirical findings. Although the adoption of individualized funding approaches is increasing, it is more the case that funding is paid directly to organizations who provide care and support to people with disability, rather than directly to individuals (Chenoweth 2009; Fisher et al. 2010). Funding from other sources such as the federal government, client and membership fees, donations, and fundraising activities comprise only a small proportion of their funding.

This reliance on government funding indicates a structured funding arrangement between the state government and well established non-government organisations. While some organisations reported that funding is crisis-driven instead of planned, these perspectives might largely be attributed to the amount of funding received for clients and a focus on short-term planning for individuals rather than ‘lifetime planning’. Funding would seem to be planned in terms of budgetary planning by (especially) the state government, rather than ‘planning’ for the individual’s care and support needs and focusing on individualised support. While programs such as the Adult Lifestyle Support Program are ‘individualised’ to some extent in that they provide a set amount to individuals, it is not clear that they consider the full extent of the needs of individuals in this disability population and fund these appropriately.
The perspectives of some organisations are that the imperative for early intervention has been ignored and that this has resulted in later demand for more resource intensive services. This demand appears especially evident in areas such as counselling, rehabilitation/therapy and other services that may not be considered essential services, such personal care and domestic help, but nevertheless can have a significant effect on quality of life (Kortte et al. 2010; Martin Ginis et al. 2010).

9.4 Conclusion

This report has provided a snapshot of the organisational service delivery and funding environment in Queensland for adults with acquired disability and high care needs. The aim of the report has been to provide policymakers, industry professionals, and others with a better understanding of the characteristics of this environment and some of the issues that exist within it. Despite the modest sample size, the results of the survey highlight areas that need to be more closely examined in terms of deficient service provision, consideration of existing funding arrangements, and how this environment, or network, might be more effectively and efficiently coordinated and linked to improve the lifetime care and support for individuals in this disability population.

The areas that require further investigation relate to the organisational scope and capacity to provide disability support services to adults with acquired disability and high care needs; individualised support and funding; and coordination and collaboration between organisations. These identified areas of further research are especially important in light of the current debate about systemic reform of the disability sector at the national level which will necessarily require consideration of the different service delivery and funding environments across the states and territories, including Queensland.
References


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Appendix 1 – Survey Regions in Queensland

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<tr>
<th>Statistical Divisions</th>
<th>City/Town</th>
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