



ARC LINKAGE LIFETIME CARE RESEARCH REPORT

A STUDY OF FINANCING AND MANAGEMENT OF LIFETIME CARE AND SUPPORT FOR ADULTS WITH ACQUIRED DISABILITIES AND HIGH CARE NEEDS IN QUEENSLAND

Foster M, Henman P, Fleming J, Tilse C, Allen S, Harrington R

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Mr Andrew De Ambrosis – Department of Families, Housing, Community Services and Indigenous Affairs

Ms Helen Ferguson - Disability and Community Care Services, Department of Communities

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

Ms Marina Vit - Youngcare

Mr Tim Feely and Mr Steve Forster (ex-officio) - The Public Trustee of Queensland

Ms Cathy Pilecki (ex-officio) - Motor Accident Insurance Commission

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GLOSSARY

ABI	Acquired Brain Injury
ABIOS	Acquired Brain Injury Outreach Service
ACFE	Adult, Community and Further Education
ALSP	Adult Lifestyle Support Program
ARC	Australian Research Council
BIRU	Brain Injuries Rehabilitation Unit
CACP	Community Aged Care Packages
CASS	Continence Aids Subsidy Scheme
CBRT	Community Based Rehabilitation Team
COAG	Council of Australian Governments
CSTDA	Commonwealth, State, Territory Disability Agreements
CTP	Compulsory third party
D&CCS	Disability and Community Care Services
DEEWR	Department of Education, Employment and Workplace Relations
DHS	Department of Human Services
DoHA	Department of Health and Ageing
DSP	Disability Support Pension
DSQ	Disability Services Queensland
EACH	Extended Aged Care at Home
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
FSP	Family Support Program
HACC	Home and Community Care
HD	Huntington's Disease
HHS	Housing and Homelessness Services
HwSS	Housing with Shared Support
LTCSS	Long-term care and support scheme
MAIC	Motor Accident Insurance Commission
MASS	Medical Aids Subsidy Scheme
MND	Motor Neurone Disease
MOUs	Memorandums of Understanding
MS	Multiple Sclerosis
MVA	Motor Vehicle Accident
NDA	National Disability Agreement
NGOs	Non-Government Organisations (and is used interchangeably with not-for-profit organisations)
NQSS	North Queensland Spinal Service
NRCPP	National Respite for Carers Program

QDoC	Queensland Department of Communities
QHealth	Queensland Health
QSCIS	Queensland Spinal Cord Injuries Service
SCI	Spinal cord injury
SCIR	Spinal Cord Injuries Response
TBI	Traumatic brain injury
YPIRAC	Younger People in Residential Aged Care Initiative

PUBLICATIONS AND DISSEMINATION ARISING FROM THE PROJECT

PUBLICATIONS

- Foster, M., Henman, P., Fleming, J., Tilse, C., & Harrington, R. (2012). The politics of entitlement and personalisation: Perspectives on a proposed National Disability Long-term Care and Support Scheme in Australia. *Social Policy and Society*, 11(3), 331-342.
- Henman, P., & Foster, M. (2011). Models of Governance in Long-Term Disability Care and Support: A framework for assessing and reforming social policy. *Social Policy Research Paper No. 2, September 2011*. Brisbane: Social Policy Unit, University of Queensland. <http://www.uq.edu.au/swahs/lifetimecare/SPUresearchpaper2-governancemodels.pdf>
This paper is based on the ASPA 2011 conference presentation.
- Henman, P., Foster, M., Fleming, J., Tilse, C., Harrington, R., & Thornton, S. (2010). Financing and delivering services for adults with acquired disability and high care needs in Queensland: Results from an On-line Survey Report. *Social Policy Research Paper No. 1, July 2010*. Brisbane: Social Policy Unit, University of Queensland. <http://www.uq.edu.au/swahs/lifetimecare/SPUresearchpaper1-onlinesurvey.pdf>
- Harrington, R. (2009, November 26). Meeting Lifetime Care Costs. *Australian Policy Online*. <http://apo.org.au/commentary/meeting-lifetime-care-costs>
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CONFERENCE PRESENTATIONS & SEMINARS

International

- Foster, M. (2010). Invited Address: *Investing in Personalised Lifetime Care and Support: Disability Reform in Australia*. University of York Social Policy Research Unit, UK, June 1.

National

- Foster, M., & Henman, P. (2011). Oral Presentation: *The politics of entitlement and personalisation: A perspective on the proposed National Disability Long-term Care and Support Scheme*. Australian Social Policy Association Conference, 6-8 July, Sydney.
- Henman, P., Foster, M., & Harrington, R. (2011). Oral Presentation: *Assessing the relative merits of disability service governance models*. Australian Social Policy Association Conference, 6-8 July, Sydney.
- Harrington, R. (2011). Oral Presentation: *'No Fault' National Injury Insurance: Can we afford it?* Australian Social Policy Association Conference, 6-8 July, Sydney.

- Harrington, R. (2011). Oral Presentation: *Motor Accident Insurance Scheme Design, Service System Capacity and Quality of Life after Severe Traumatic Brain Injury*. Occupation Therapy Australia 24th National Conference & Exhibition, 29 June – 1 July, Gold Coast.
- Henman, P., Foster, M., Fleming, J., Tilse, C., Harrington, R., & Thornton, S. (2011). Oral Presentation: *An overview of the finance and governance of Queensland organisations providing disability care and support services: findings from an on-line survey*. School of Social Work and Human Services, Research Symposium, July 12, The University of Queensland, Brisbane.

ROUNDTABLES AND WORKSHOPS

- Foster, M., & Henman, P. (2011). *Lifetime Care for Adults with Acquired Disability and High care Needs: Presentation of findings. Disability and Community Care Services*. Department of Communities, 9 September, Brisbane.
- Henman, P. (2011). Chair, Roundtable Discussion: *Critical questions of design and operationalisation of the proposed National Disability Insurance Scheme Australian Social Policy Association Conference*, 6-8 July, Sydney.

INTERNATIONAL LINKAGES

- Gillian Parker, Professor of Social Policy and Director of the Social Policy Research Unit, The University of York. Professor Parker spent four weeks at The University of Queensland at the invitation of CI Foster. This visit was supported by a UQ Travel Award for International Collaborative Research. Professor Parker's core research expertise is in service delivery and organisation and boundaries in health and social care. Her recent work includes national evaluation of integrated care for people with long-term neurological conditions (LTNCs) in the UK, and review of outputs from a national programme of research on continuity of care.

EXECUTIVE SUMMARY

In Australia currently, lifetime care for adults with acquired disability and high care needs is characterised by complex funding arrangements between the Federal and State governments, involvement of government and non-government agencies, and multiple sectors and services with varying roles and responsibilities.

The Australian Government has proposed the development of a nationally coordinated approach to lifetime care for people with disability and in 2010, initiated a Productivity Commission Inquiry to examine the feasibility of a long-term care and support scheme for people who acquire a disability before the age of 65 years. The report of the Productivity Commission Inquiry (2011) recommends a National Disability Insurance Scheme (NDIS) to provide all Australians with insurance for the costs of support if they or a family member acquire a disability. As part of the Budget 2012-13 commitments, the NDIS will be implemented in a restricted number of selected sites in Australia in 2012 with an expanded implementation of the scheme in additional sites expected in 2014 (<http://www.ndis.gov.au/>). Importantly, this is a critical phase in national disability reform in Australia.

From 2008-12, a team of researchers at the University of Queensland, in partnership with the Motor Accident Insurance Commission (MAIC) and the Public Trustee Queensland undertook a project to examine lifetime care for adults with acquired disability and high care needs in Queensland. The purpose was to obtain a better understanding of the features of financing and governance arrangements for lifetime care and how these intersected and operated at the delivery level for individuals, their families and care service providers. The project used multiple methods, including macro-level policy and service analysis and 25 in-depth case studies of recipients of lifetime care, and incorporated multiple perspectives. Participants in the study included senior policy makers, financial and insurance representatives, service organisation representatives, individuals from one of five targeted disability groups [Acquired Brain Injury (ABI), Spinal Cord Injury (SCI), Multiple Sclerosis (MS), Motor Neurone Disease (MND), Huntington's Disease (HD)], and their nominated family members and care service providers (CSPs). The project governance included a Reference Group with representatives from state and federal government departments responsible for funding and policy development, government and non-government service provider organisations, and peak advocacy and consumer organisations. Industry Partners were also represented on this group. The Reference Group had a significant role in knowledge translation and exchange throughout the research process and moreover in provision of strategic advice in relation to research findings, policy and service development and dissemination of the research.

At the policy level, the distinguishing features of financing and management of lifetime care in Australia include: separate but also shared responsibilities between Federal and State governments negotiated under the National Disability Agreement; complex jurisdictional responsibility and unclear boundaries for financing and management of services for adults with acquired disability and high care needs; complexity of intergovernmental arrangements and processes at State and Federal levels surrounding policy development, regulatory oversight and funding allocation; multiple and uncoordinated funding streams; and service

delivery organised and provided through government and non-government, for-profit and not-for-profit organisations.

At the service organisational level, there is considerable reliance on State government recurrent funding among service provider organisations and variation in services provided across organisations and to disability types. Eligibility and demand management strategies also vary across organisations. Most service organisations are long-established, with most servicing all disability groups, while others are more targeted and tend to provide a more holistic service.

From the individual level perspective, lifetime care resembles an intricate web of finances and services drawn from across public, private, formal and informal domains. There is a marked reliance on informal care to supplement inadequate levels of funding and capacity to pay personally is often important in addressing personal care preferences and/or unmet needs, resulting in diverse and unequal outcomes. Funding for lifetime care is also not routinely quarantined for an individual's use and packages are more commonly paid to and managed by the CSP. Four broad approaches to financing, provision and management of lifetime care were evident at the individual level: uncoordinated; case worker coordinated; dwelling based coordinated; and user-coordinated. All types comprise advantages and limitations experienced by individuals, families and CSPs, and in some cases, clearly illustrate the precarious nature of lifetime care arrangements.

Choice in lifetime care was highly valued by individuals and families, both in relation to daily routines and lifestyle preferences and how care is managed and funded. Choice in determining care arrangements, carers and care agencies was highly valued, as was choice in use of funding. However, this was largely restricted due to the way funding was governed, inflexibility of agency-based care provision and the lack of transparency around level and use of funding.

Lifetime care was perceived by most individuals and families to be adequate and sustainable, although in the majority of cases this depended on other factors being met. Such perceptions were often tempered by realistic expectations. While the majority of individuals were satisfied with their lifetime care, all reported some areas of unmet need, with the majority reporting two or more unmet needs. Health and rehabilitation was the most commonly reported area of unmet need. Additionally, participants identified the level and flexibility of care as problematic, and this was also related to crisis and emergency situations.

Overall, the findings indicate there are a number of issues that need to be addressed in order to optimise lifetime care for all adults with acquired disability and high care needs, and particularly in the context of national disability reform. If these issues can be addressed through positive and evidence based policy reform, which also supports appropriate financing and governance strategies, the benefits are likely to include more equitable and effective lifetime care for all people with disability.

Recommendations

1. National policy reform must address the level and model of funding and resourcing
2. Governance models should avoid complexity in service coordination and provision and optimise service user choice
3. There must be clarity about needs-based entitlement and 'reasonable and necessary supports' and commitment to an accountable and quality care planning process
4. There is need for stronger government investment in information systems with capacity to capture accurate longitudinal information about lifetime care, system performance, and individual outcomes
5. A lifetime care system must include appropriate organisational resources and procedures and supportive decision-making practices to safeguard choice
6. Policy and service delivery systems must enable 'care in place' where this is the preference of the individual
7. There must be appropriate recognition of informal care networks as a critical resource in lifetime care both in policy and service delivery systems

1. FINANCING AND MANAGEMENT OF LIFETIME CARE AND SUPPORT FOR ADULTS WITH ACQUIRED DISABILITIES AND HIGH CARE NEEDS

BACKGROUND AND POLICY CONTEXT

The topic of financing and provision of lifetime care and support (henceforth lifetime care) for adults with acquired disabilities and complex care needs resulting from injury or serious illness is generating substantial policy debate in Australia. The debates centre around how best to finance and manage the individualised and intricate mix of health, rehabilitation and disability services and supports required to meet their needs for life; and how to ensure lifetime care is personalised, equitable and sustainable. Use of specialist disability services across all Australian states is increasing, with the number of all service users up by approximately 7.5% per annum¹ with similar growth rates in the level of unmet need². In 2007-08, the largest proportion of users of specialist disability services was people aged 25-64 years with intellectual, physical or psychiatric disability as their primary disability¹. Notably, service users increasingly have complex and diverse needs with many people experiencing multiple disabilities³. This demand for care and the financial cost of lifetime care are both projected to increase as survival rates following traumatic injuries or illnesses improve⁴. The most common groups likely to generate this increased demand are adults with traumatic or acquired brain injury and spinal cord injury and physical conditions arising from other injurious events. Many will have a normal life expectancy and require 20 to 50 years of care⁴.

In Australia currently, lifetime care for adults with acquired disabilities and high care needs is characterised by multiple funding arrangements between the federal and state governments, and between governments and non-government agencies, and involvement of multiple sectors and services, with varying roles and responsibilities. Notably, there is no overarching mechanism to coordinate or integrate unshared resources and multi-sector and service input. There are marked variations in financial commitment and levels of expenditure by Federal, State and Territory Governments in discrete areas such as community access and respite, and in the programs and services available, as well as inconsistencies in eligibility and access⁵. Many adults with acquired disabilities and high care needs live in the community, supported by government and community funded health and support services, and family⁴. However, pressures at the health-disability interface, including pressures on acute care beds and the lack of infrastructure in the community to address the needs of people with acquired disabilities has also meant some reliance on residential aged care for lifetime care^{4, 6, 7}. Some 6,500 people under the age of 65 years reside in residential aged care facilities in Australia⁸; adults with acquired brain injury represent the single largest category of this population (30%)⁴.

In 2006, the Council of Australian Governments (COAG) acknowledged the need to develop alternative models of lifetime care for younger people with disabilities resident in, or at risk of transfer to residential aged care facilities⁹. A five-year joint government initiative with matched funding of up to \$244 million from Australian and State and Territory Governments was endorsed with the aim of reducing the number of younger people with disability in residential aged care and providing more age-appropriate care for younger people remaining in aged care facilities.

More recently, the Australian Government has proposed the development of a nationally coordinated approach to lifetime care for people with disability. In 2010, the government initiated a Productivity Commission Inquiry to examine the feasibility of a long-term care and support scheme (LTCSS) for people who acquire a disability before the age of 65 years. The Inquiry's Draft Report of February 2011 included a recommendation for the assessment of an 'individualised support package' that 'concentrate[s] on the reasonable and necessary supports people require'¹⁰. Notably, the recommendations also included two schemes: a national disability insurance scheme to cover people born with or who acquire a disability and require lifetime care; and a national injury insurance scheme to cover the financing and care for people who sustain a catastrophic injury from an accident.

The three-year ARC Linkage project, *Financing and Management of Lifetime Care and Support for Adults with Acquired Disabilities and High Care Needs* (henceforth the *Lifetime Care* study), was a collaboration between researchers based at the University of Queensland and industry partners, the Motor Accident Insurance Commission (MAIC) and The Public Trustee of Queensland. The broad aim of the study was to map the financing and management of lifetime care and support for adults (18-65 years) with acquired disabilities and high care needs and to examine the operation of the financing and delivery systems, including the intersections and relationships between different sectors and service systems in the provision of care, from multiple perspectives. To that end, the purpose was to provide an empirical basis for developing effective mechanisms for coordinating and integrating the financing and management of appropriate and sustainable lifetime care for adults with acquired disabilities.

Aims of the Lifetime Care study

- To identify and map the current systems of financing and management of lifetime care for adults (18-65 years) with acquired disabilities and high care needs
- To critically assess the adequacy and sustainability of current systems of financing and management of lifetime care for adults with acquired disabilities from the perspective of funding bodies, providers, financial managers, individuals, and families
- To develop a conceptual understanding of lifetime care for adults with acquired disabilities and high care needs within the contemporary care environment.
- To identify effective mechanisms for financing and management of integrated and sustainable lifetime care for adults with acquired disabilities and to contribute to policy development in this field

LIFETIME CARE FOR ADULTS WITH DISABILITY

Responsibility for lifetime care for adults with complex and high care needs sits at the intersection of government, private sector, not-for-profit organisations, and informal and voluntary relationships¹¹. This is often described as a mixed economy of care¹². In Australia, specialist disability support is commonly provided by the voluntary and private sectors alongside the public sector^{13, 14}. Publicly funded lifetime care is often identified with the benefits and services such as accommodation support, community support, community access and respite provided under the National Disability Agreement (NDA, formerly the Commonwealth State/Territory and Disability Agreements). However, this addresses only

part of lifetime care for adults with acquired disabilities resulting from catastrophic injury or serious illness. Due to the sudden or traumatic onset of many acquired conditions, resulting in multiple and fluctuating needs, these adults often require substantial and ongoing input from health and rehabilitation service systems, alongside disability support. Unsurprisingly, organisational and funding complexity and multi-agency input are distinguishing features of this broader concept of lifetime care, yielding potentially inequitable and unsustainable impacts¹⁰.

A perceived advantage of the mixed economy of care is that it provides diversity of supply, a capacity within the service system to appropriately and adequately meet the lifetime care needs of people, and a systemic way of ensuring the appropriate mix of services¹⁵. Yet, in Australia there are significant and substantial levels of unmet need⁵. Moreover, there is a high reliance on the non-government and informal (i.e., personal, family, voluntary) sectors to address demand¹⁴, more so if families want to avoid placement in residential aged care. There are also troubled relationships between different service sectors involved in provision of lifetime care; lack of clarity on funding responsibilities; and poorly coordinated crisis responses, rather than properly planned care^{5, 16}. The unpredictability of need and the high and often fluctuating demands on service systems mean that funding arrangements and care management for adults requiring lifetime care are often grossly inadequate and unsustainable for the lifetime¹⁷. Research in the UK has highlighted similar problems in financing and management of health and social care for people with disabilities and complex care needs¹⁸. Coordinating multi-agency input has been identified as a particular challenge¹⁹ often due to inflexible service boundaries which mean agencies have discrete areas of responsibility and taken for granted ways of operating that do not necessarily support collaborative or coordinated approaches^{20, 21}. In many areas of health and social care, models of joint working have been developed to address these challenges²².

Lifetime care in Australia is in some cases financed through compensation schemes which cover road, or work-related injuries or disabilities; or under public liability⁵. Compensation schemes are state-based and therefore differ in terms of scheme design and operation across jurisdictions. For example, motor accident insurance schemes in Australia comprise both no-fault and fault-based schemes, which operate through different funding and administration models and vary in terms of how payments and service delivery are arranged. In some cases, a financial or trust manager is often involved in managing compensation funds and overseeing how these are used in the provision of lifetime care. However, compensation does not necessarily guarantee a lifetime of reasonable care and medical management as sufficient amounts of compensation are often not awarded^{16, 23}. Effective mechanisms for managing lifetime care is important in this event, particularly given that there are limits on eligibility for other publicly funded benefits and services for recipients of compensation. In recent years, some state-based motor accident insurance systems have undergone major structural reforms, including in some cases a shift to a no-fault system, to improve the approach to lifetime care for people with high care needs²⁴. Although at present Queensland retains a fault based motor accident insurance scheme, a high priority for government is the identification of effective mechanisms for managing lifetime care to ensure appropriate, adequate and sustainable care, particularly given that compensation funds may be poorly invested and managed to meet future care needs¹⁶.

The starting point for achieving a more coordinated and integrated model of lifetime care for adults with acquired disabilities is to develop a better conceptual understanding of lifetime care currently, which incorporates the distinguishing features of the mixed economy of care, as well as the health, rehabilitation and disability support aspects of lifetime care for adults with acquired disabilities. A further critical aspect is to understand how lifetime care actually operates at the service delivery level and to apply this understanding to developing effective mechanisms for the coordination and management of lifetime care. This includes understanding how diverse financing and multiple sector and service inputs, and areas of responsibility, are negotiated and coordinated; and the mechanisms and capacity within current approaches to lifetime care to address appropriateness and adequacy, as well as sustainability of future care, particularly given the multiple and changing nature of needs. The *Lifetime Care* study addressed these gaps in knowledge, yielding a conceptual and empirical basis for policy and service delivery-driven responses.

RESEARCH DESIGN

Research Questions

- RQ1. What are the distinguishing features of financing and management of lifetime care for adults with acquired disabilities and high care needs?
- RQ2. How do the various systems of financing and management of lifetime care operate and interact at the service delivery level?
- RQ3. What are the strengths and limitations of the current systems of financing and management of lifetime care from the perspectives of funding bodies, providers, financial or trust managers, individuals and families?

The Queensland based *Lifetime Care* study involved two sequential components and multiple methods. The first component involved a policy and service mapping exercise with the aim being to identify the distinguishing features of current systems of financing and management of lifetime care for adults with acquired disabilities and high care needs. The second component involved a series of individual case studies incorporating qualitative interviews with individuals with acquired disabilities, their families, care providers and financial managers. The second component was 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. This approach was significant in uncovering not simply the formal policy aspects of lifetime care but how these actually performed and were experienced on the ground. Five selected disability groups were targeted in this project: Acquired Brain Injury (ABI), Spinal Cord Injury (SCI), Multiple Sclerosis (MS), Motor Neurone Disease (MND) and Huntington's Disease (HD). The focus on these specific groups was purposeful for several reasons: a) it ensured a diverse sample both in terms of the nature of disability and needs, including need for specialised services; b) it provided an opportunity to examine the lifetime care arrangements and experiences of those people with sudden onset disability (e.g. ABI and SCI) and those with progressive conditions (e.g. MS, MND, HD); and c) it included those groups with high care needs (e.g. ABI and MS) who have traditionally been at high risk of transfer to residential aged care facilities. An overview of the research design is shown in Table 1.

Table 1: Overview of Research Design

Component	Aim	Method	Participants
Policy mapping	Describe key characteristics of policy, financing and management (RQ1 and RQ3)	Key stakeholder interviews and desktop research	18 representatives <ul style="list-style-type: none"> • 7 policy • 6 financial/insurers • 5 service provider
		On-line survey of service providers in Queensland	59 QLD organisations providing services to people with disability
Individual case studies	Examine operation of policy, financing and management incorporating multiple perspectives (RQ2 and RQ3)	<ul style="list-style-type: none"> • Semi-structured interviews with individuals, families, service providers and financial managers • Service Obstacles Scale 	25 individual case studies comprising 65 interviews: <ul style="list-style-type: none"> • 25 individuals • 22 family members 18 care providers (of 22 individuals)

PhD Project

The Lifetime Care study also incorporated a PhD project supported by the industry partners. This study is being undertaken by Rosamund Harrington, a PhD candidate at the University of Queensland, supervised by two of the Lifetime Care study investigators (CI Foster and CI Fleming). This project on: *Motor Accident Insurance Scheme Design and Life after Severe Traumatic Brain Injury*, was supported by an ARC Australian Postgraduate Industry Award (APAI). The aim of this project was to examine the pathways, choices and outcome of adults with severe acquired traumatic brain injury (TBI) and their families, within two different Motor Accident Insurance schemes, and to understand how these might vary according to key features of the schemes. The results of this study will be reported elsewhere.

2. GOVERNANCE AND FINANCING LIFETIME CARE FOR QUEENSLANDERS

This chapter describes the key features of financing and management of lifetime care for adults with acquired disabilities in Queensland (RQ1). This description was derived from analysis of face-to-face interviews with 18 senior policy and service managers in government and the non-government sectors conducted between 2008 and 2009; and desktop analysis of online, publicly available policy information. Results are presented on two broad topics: 1) governance and funding frameworks which considers the governance of publicly financed and insurance financed services; and 2) provision of services.

GOVERNANCE AND FUNDING FRAMEWORKS

The provision and funding of services for people with acquired disability and high care needs are governed by various legislative and funding frameworks within both public and private domains. There is no overarching governance to coordinate care and support services, with many fragmented, parallel, overlapping and sometimes contradictory elements. This has the potential for inequality and unfairness in outcomes.

Nevertheless, some key components can be discerned. At the heart of the provision of care is a key distinction between individuals whose care is largely financed through some form of compensation scheme as a result of an acquired injury (typically workplace or transport accident) and those whose care is primarily financed by the state (a mix of Federal and State governments)¹. This divide denotes two distinct modes of governance – one based on insurance principles and one on public financing – which are operationalised through different policies, institutions and partly separated through eligibility criteria and priority ranking, such as Disability Support Pension (DSP) and state-managed disability services. However, these two domains do overlap at times. For example, people receiving compensation for lost income are typically ineligible for DSP through a preclusion period; however a part-rate Pension may be paid in certain circumstances. Compensation may also reduce, not exclude, access to State-based disability services funding. Care is also financed by both groups privately through household income, savings, superannuation and private insurance, and by informal care provided by family and friends.

The contours of care and support for adults with disability and high care needs are also complicated by unclear boundaries between services provided to older Australians (i.e. over 65 years of age) and health services. The former are largely organised and governed under different arrangements as part of the 'aged care' system. The latter are also separately organised under the medical system. While the boundaries may be difficult to discern, this project does not include consideration of these two systems.

Governance of publicly financed services

Due to the multi-faceted nature of services for adults with acquired disabilities, the public financing and provision of care sits constitutionally with both Federal and State/Territory

¹ This distinction is also at the heart of the Productivity Commission's (2011) proposal for financing lifetime care and support in Australia.

governments, with both separate and shared service responsibilities (see Table 2). Given these complex jurisdictional responsibilities for financing and management of services for adults with acquired disability and high care needs, policy development, regulatory oversight and funding allocation is managed through various intergovernmental arrangements at both State and Federal levels, as well as State-Federal processes.

The major policy framework is the National Disability Agreement (NDA), which replaced the former Commonwealth, State, Territory Disability Agreements (CSTDA) on 1 January 2009. The NDA outlines a 6 and a half year agreement between the two tiers of government. Financing is shared with Federal financing at \$5.3 billion over 5 years. The NDA outlines funding arrangements and provides a strategic framework for the multi-lateral planning and provision of specialist disability services. It outlines shared strategic priority areas, and details the principal areas of individual and shared roles and responsibilities for each level of government. While the NDA aims to clarify relationships and activities between the two tiers of government, the reality of these arrangements are complex and fragmented.

Table 2: Current jurisdictional policy responsibility and relevant governance agencies

Federal responsibility	Shared responsibility	State/Territory responsibility
Income support [Centrelink/DHS; DEEWR; FaHCSIA]	Care and domestic support [DoHA; QDoC; FaHCSIA]	Accommodation support [QDoC]
Employment services [DEEWR]	Aids & Equipment [DoHA; QDoC; QHealth] Disability advocacy [QDoC; FaHCSIA]	Rehab & Therapy [QHealth; QDoC] Compensation schemes [MAIC; WorkCover] Respite [QDoC] Community access [QDoC] Financial Management [Public Trustee]

The NDA stipulates that the Federal Government assumes responsibility for the provision of employment services and income support for people with a disability, and the allocation of funds to States and Territories. The provision of all other specialist disability services in the areas of accommodation support, community support, community access, rehabilitation and respite is the responsibility of the State and Territory Governments. Responsibility for support for advocacy and print disability is shared between Federal, State and Territory governments (see Table 2).

Detailed policy responses within the NDA framework are generally developed in siloed environments which can result in fragmentation. In an attempt to reduce the tendency to fragmentation, a range of inter-governmental and inter-agency relationships and strategies are utilised. A more multi-lateral and collegial environment (or ‘cooperative Federalism’) emerged with the Rudd-Gillard governments from 2007. As part of this, National Partnership Agreements have been established to further formalise multi-lateral relationships. Other multi-lateral agreements include the Home and Community Care Agreement between the Federal and State governments and Memorandums of Understanding (MOUs) between

different State government departments. Some government departments have also established specialist disability policy/program units to enhance a whole of government, or joined-up approach to the provision of services for people with a disability. For example, Queensland Health developed an intra-intergovernmental policy unit with its own Disability Services Plan (July 2007-June 2010).

A range of legislative instruments further regulate and clarify the responsibilities and services provided. The most relevant legislation operating at a Federal level includes the *Disability Services Act 1986*, and *Home and Community Care Act 1985*. Key Queensland legislation includes the *Disability Services Act 2006*, *Health Services Act 1991*, *Carers (Recognition) Act 2008*, and *Housing Act 2003*.

Governance of insurance financed services

Compensation insurance arrangements are primarily monitored and regulated through State-based statutory legislation. In Queensland these are the *Motor Accident Insurance Act 1994*, and *Workers Compensation and Rehabilitation Act 2003*, for compensation coverage for individuals injured through motor vehicle accidents or at their workplaces respectively. The corresponding agencies are the Motor Accident Insurance Commission (MAIC) and WorkCover Queensland. Both schemes are privately financed through compulsory insurance premiums. Funding for a full range of services, including personal income, is provided to people with acquired injuries covered under these insurance schemes. However the depth and breadth of services funded is an outcome of legal processes, with evidence that compensation payouts are often inadequate to cover care across the lifetime¹⁰.

In transport injuries, MAIC is a policy body regulating the requirements of compulsory third party (CTP) insurance for transport-related injuries. The owners of all vehicles registered in Queensland must pay a CTP insurance premium set in price bands by MAIC. The Queensland CTP scheme is underwritten by six licensed private insurance companies which manage claims arising on behalf of their insured policy holders. Suncorp is Queensland's largest CTP insurer. People are compensable under common law. Queensland operates on a 'fault based' system, which is different to many of the other state systems, and thus requires proof of liability, i.e. the injured party must be able to establish negligence against an owner or driver of a motor vehicle. Assessment of claims is also based, in part, on expert reports from medical and allied health practitioners. Compensation for injury is awarded in the form of a lump sum settlement with the majority of claims settling out of court. Funds awarded in settlement are reflective of an individual's established or agreed degree of contributory negligence in causation of their injury. An injured individual may access a range of CTP insurer funded supports on a 'without prejudice' basis prior to claims settlement, dependent on an insurer's estimation of funding liability. Persons determined by CTP insurers not to qualify for compensation can make application to the courts.

All employers in Queensland are required to be part of WorkCover, with the exception of some very large organisations that have their own insurance systems. Compensation for workplace injury covers lost wages, medical expenses and necessary services for ongoing disability. Application can be made by the individual or by their medical doctor. Individuals typically receive fortnightly payments until their condition is stable, and they are eligible for

lump sum payments, which are based on medical reports and the degree to which they are permanently impaired. An individual's compensation drops at 26 weeks (to around 75%) and at 2 years to encourage a return to work where deemed appropriate. Although proving 'fault' is not required in a workplace injury, an injured employee is eligible if their employment is a 'significant contributing factor' to the injury.

PROVISION OF SERVICES

The above complex governance and funding arrangements give rise to an equally complex array of providing services. The wide array of services are actually delivered on the ground by a mix of government, non-government not-for-profit and for-profit organisations, as well as self and family provision.

Table 3 documents the types of care and support services that different State and Federal government agencies cover through their various programs. As evident in the table, some organisations support a wide range of services, especially Queensland's Department of Communities which covers both disability services and housing services. Queensland Health also has wide service coverage, including accommodation, aids and equipment, rehabilitation and therapy, information and advocacy, respite, health and nursing, and counselling. However, some such services may be limited to highly specific groups, such as people with ABI. In comparison, other government agencies have a very specific focus, such as financial assistance (Centrelink, WorkCover) and financial administration (Public Trustee).

The majority of personal and domestic care and respite services managed by the Queensland government under the NDA are largely delivered by non-government agencies through contractual arrangements with the Queensland government. Financing for such services can occur through a mix of block funding and individualised packages which an organisation manages and delivers on an individual's behalf. Third-party organisations do at times reallocate funds between 'individuals' to meet their combined needs of their clients. The delivery of services under Extended Aged Care at Home (EACH) packages operates similarly.

Alongside these services is a range of services purchased by individuals through the market. People covered under compensation payments largely operate through this mechanism, as do people who use their personal finances to access or increase the level of services they might not otherwise obtain through publicly financed services. Therapy services and aids and equipment are examples where the private sector provision is significant.

Summary: The distinguishing features of financing and management of lifetime care in Australia include: separate but also shared responsibilities between Federal and State governments negotiated under the National Disability Agreement; complex jurisdictional responsibility and unclear boundaries for financing and management of services for adults with acquired disability and high care needs; complexity of intergovernmental arrangements and processes at State and Federal levels surrounding policy development, regulatory oversight and funding allocation; and service delivery organised and provided through government and non-government, for-profit and not-for-profit organisations.

Table 3: Types services provided by responsible government agency

Agency	Accom.	Personal care	Dom. help	Aids & Equip.	Rehab. & Therapy	Inform. & Advocacy	Respite	Health/ Nurse	Couns.	Carer support	T'port	Financial Assist.	Financial Admin.	Other
QDoC - D&CCS	SCIR	ALSP HACC	ALSP HACC	ALSP SCIR	SCIR	FSP	HACC	SCIR HACC			HACC	SCIR HACC		
QDoC - HHS	Long Term Social Housing; HwSS					Home Assist Secure								Home Assist Secure
Queensland Health	Jacana			MASS	Rehab. Units CBRT QSCIS NQSS Jacana	CBRT	Jacana	BIRU QSCIS NQSS Jacana	NQSS					ABIOS Rehab. units
WorkCover Qld.												Workers Comp. Scheme		
MAIC												CTP Insurance Scheme		
Public Trustee of Qld													Public Trusts	
DoHA		EACH CACP	EACH CACP				NRCP	EACH		NRCP	EACH CACP			
FaHCSIA						National Disability Advocacy Program	Respite Support			Respite Support			Special Disability Trusts	
DoHA - Centrelink												DSP; Mobility Allowance; Pensioner Concession Card; Carer Payment; Carer Allowance		

ABIOS - Acquired Brain Injury Outreach Service, ALSP - Adult Lifestyle Support Program, BIRU - Brain Injuries Rehabilitation Unit, CACP - Community Aged Care Packages, CBRT - Community Based Rehabilitation Team, DSP - Disability Support Pension, EACH - Extended Aged Care at Home, FSP - Family Support Program, HACC - Home and Community Care, HwSS - Housing with Shared Support, MASS - Medical Aids Subsidy Scheme, NQSS - North Queensland Spinal Service, NRCP - National Respite for Carers Program, QSCIS - Queensland Spinal Cord Injuries Service, SCIR - Spinal Cord Injuries Response

3. MAPPING THE SERVICE SECTOR IN QUEENSLAND: RESULTS FROM AN ON-LINE SURVEY

This chapter presents the results of an on-line survey conducted as part of the policy mapping component. The aim of the on-line survey was to better understand the current organisational disability care and support service environment in Queensland. This was achieved 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 their activities of inter-agency coordination and strategic service development. In this section, a snapshot of the organisational service delivery and funding environment in Queensland for adults aged 18 – 65 with acquired disability and high care needs is provided. 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 (ABI), Spinal Cord Injury (SCI), Multiple Sclerosis (MS), Motor Neurone Disease (MND) and Huntington’s Disease (HD).

THE ONLINE SURVEY

Full details of the design and implementation of the on-line survey are provided at <http://www.uq.edu.au/swahs/index.html?page=118361&pid=28788>. The survey was designed to elicit information about service type and focus; service delivery; funding sources and partnerships. 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 were identified through the Reference Group and the Queensland Health directory of health and community services, *QFinder* (www.qfinder.qld.gov.au) and contacted by email. Of 331 organisations contacted by email, 98 organisations responded, of which only 59 were relevant to the study’s focus.

OVERVIEW OF RESULTS

Respondents

Sample: Majority were not-for-profit, largely from the disability sector and generalist in focus

Not-for-profit organisations represent the majority of respondents (41 organisations, 69% of respondents). Eleven (19%) organisations were government. For-profit/private organisations comprised seven (12%) respondent organisations. Over half of the respondents (60%) were within the disability sector; 23 per cent in the health sector, and 14 per cent in the community services sector. For-profit and government organisations are largely located in the health sector. Many of the government organisations provide services to individuals with ABI and/or acquired SCI which, by the nature of these conditions, have distinct post-acute medical and allied health teams that provide follow-up support services. Unlike government and for-profit/private organisations, not-for-profit organisations are largely located in the disability sector. Organisations are predominately located within south east

Queensland; however, a considerable proportion provide services statewide (41%), with a small proportion providing services nationally (7%).

The majority of organisations had 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. Respondents had significant experience in providing disability care and support services to the targeted population, with the majority of respondent organisations (79%) providing services for more than ten years.

Results:

Key finding: Considerable variation in services provided across organisations and to disability types

A summary of the main results are provided in Table 4. 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 ABI and SCI, 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 (HD); equipment and information and advocacy (MND); personal care and respite (MS); and personal care and domestic help (HD) were most common. A small number of organisations reported they also provide services such as case management, psychosocial and behavioural intervention and social support, home modifications and maintenance, security and networking.

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 more generic organisations.

Key finding: Support for carers is a significant component of service provision of most organisations

Support for carers represented a significant part of the work of the majority of respondent organisations (78%). In the main, information was the most common service provided to carers, followed by advocacy and respite. However, a significant proportion of organisations also indicated that they provide advocacy (41%), respite (37%), and education services (22%). 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.

Key finding: High reliance on state government recurrent funding

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. 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.

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. Other sources of funding for five (12%) not-for-profit organisations included 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.

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.

Key finding: Eligibility criteria and other demand management strategies differ across organisations

Most organisations use diagnosis/client condition (38 organisations, 76%); and geographical location (36, 72%) to determine eligibility for access. Fee for services is much less used (18, 36%), as is compensation payments (11, 22%) and individual income (2, 4%).

Demand management is an ongoing challenge for the majority of organisations. Of organisations using demand strategies, waiting lists (66% respondents) and prioritising (60% respondents), on the basis of needs and/or risk assessments, are the most common strategies. Referral to other organisations is also common (30% respondents), particularly among not-for-profit organisations. For those organisations using waiting lists to manage demand, the wait times for services range from less than one month (30% respondents) up to three years (4% respondents).

Key finding: Evidence that organisations collaborate to a high degree and regularly

Inter-organisational collaboration was reported to be 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. However, it is unclear as to the extent to which inter-organisational collaboration is formalised or occurs on a more adhoc basis.

Key finding: Significant impediments to optimal service provision across sectors

Respondent organisations also identified a number of challenges in providing services to adults with acquired disability, including: a lack of appropriate accommodation; fragmented and bureaucratic service delivery; crisis-driven funding; equipment shortages; and non-individualised support. Areas requiring further research include: 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.

The full report on the on-line survey is available on request and a fuller discussion of the key results can be found at <http://www.uq.edu.au/swahs/arc-lifetime>

Table 4: Summary of main results

Organisation type	Not-for-profit 71%; Government 19%; For-profit 10%
Sectors	Disability 59%; Health 22%; Community Service 16%; Housing 3%
Disability focus	Largely generalist across a range of disability types
Years established	More than 10 years 79%; 4 – 10 years 19%; less than 4 years 2%
Service reach	National 7%; Statewide 41%; Queensland area specific 52%
Funding source	Majority reliant on Queensland government funding
Programs provided	Most common: ALSP 59%; HACC 55%
Services provided	Most common: personal care 46%; information and advocacy 44%; respite 42%. Least common: accommodation 20%
Services for carers	79% provide services to carers. Most common: Information 63%; Advocacy 41%; Respite 37%
Client wait time	Generally 0 – 12 weeks. Some organisations 1 – 3 years
Eligibility criteria	Diagnosis 76%; Geography 72%; Fee-for-service 36%; Compensation 22%; Income 4%; Other 28%
Demand management	Waiting lists 66%; Prioritise 60%; Refer 30%; Payments 4%; Other 21%
Collaboration	Collaboration is widespread. Most common in: service provision 81%; assessment 73%; care planning 72%
Strategic initiatives	13 organisations developing internal initiatives

4. OPERATION AND INTERACTION OF LIFETIME CARE: EXPERIENCES OF INDIVIDUALS, THEIR FAMILIES AND CARE SERVICE PROVIDERS

INTRODUCTION

This section presents the findings of the 25 individual case studies. These case studies aimed to understand how the financing and management of lifetime care and support for adults with acquired disability operated on the ground. It describes the financing and management arrangements for lifetime care and elicits the key themes that capture the experiences of individuals in the five disability groups examined, their families and care service providers. The main findings presented here derive from the analysis of interviews with 65 participants - 25 individuals, 22 nominated relatives or friends, and 18 care service providers. The 18 care service providers were care providers for 22 individuals with lifetime care needs.

Textual data from the transcripts of interviews were coded and analysed for their experiences of obtaining, receiving, managing and/or providing lifetime care. In this report, the main findings from the analyses of individual case study data are grouped under five main topics: 1) financing of lifetime care services; 2) intersection of financing, provision and coordination of lifetime care; 3) choice in lifetime care; 4) adequacy and sustainability of lifetime care; and 5) unmet need. Personal information about each person with lifetime care has not been included in this report. One or more quotes from each case study are included in the report¹¹.

PARTICIPANTS

Details about gender, age, marital status and residential situation for each of the 25 individuals receiving lifetime care are provided in Table 5. The final column, 'Relationship', lists the relationship of the nominated family member or friend who was interviewed. The sample included six participants with Acquired Brain Injury (ABI), three with Huntington's Disease (HD), three with Motor Neurone Disease (MND), eight with Multiple Sclerosis (MS), and five with Spinal Cord Injury (SCI). Of the 25 individuals, 14 were male and 11 female. Their ages ranged from 20 to 66 with a median age of 52 years. Ten in the sample were divorced or separated, nine married, five were single and one widowed. Sixteen lived at home (including social housing), nine of whom lived with family members who provided some lifetime care. Nine lived in a facility, including three in an aged care facility.

Of the 22 family and friends who were interviewed, all were actively involved in the care or support of the individual with acquired disability. This group comprised nine spouses (five wives and four husbands), four daughters, three mothers, two male friends, one sister, one neighbour and one carer. Six males (i.e., more than a quarter of the family and friends) were actively involved in this role. Among the nominated care service providers were

¹¹ To protect the identity of participants while ensuring that the disability-specific experiences are readily identified, participants have been coded as ABI for those with Acquired Brain Injury, SCI for Spinal Cord Injury, MS for Multiple Sclerosis, HD for Huntington's Disease, MND for Motor Neurone Disease, F for family or friend, and CSP for care service provider. In each case, individual participants are identified e.g: ABI_01, ABI_02, SCI_01, SCI_02 etc

several people with health care qualifications (e.g., in clinical nursing or social work), while others had a background as carers. Job titles for care service providers (CSPs) included care service provider manager, service coordinator, residential support coordinator, senior support worker, community care manager and case manager.

Table 5: Demographic details of 25 individual lifetime care case studies

Case	Gender	Age	Status	Residential situation	Relationship
ABI_01	Male	48	Divorced	Share unit in facility	Friend
ABI_02	Female	52	Divorced	Own room in facility	Mother
ABI_03	Female	38	Married	Share house in facility	Husband
ABI_04	Male	37	Divorced	Home with carer support	Carer
ABI_05	Male	20	Single	Home with family, carers	Mother
ABI_06	Male	47	Married	Home with family	Wife
HD_01	Male	61	Divorced	Aged care facility	Daughter
HD_02	Female	66	Married	Aged care facility	Husband
HD_03	Female	47	Single	Home with daughter	-
MND_01	Male	57	Divorced	Home with carer support	Friend
MND_02	Male	63	Married	Home with wife, children	Wife
MND_03	Male	44	Married	Home with wife, children	Wife
MS_01	Male	52	Divorced	Home, daughter nearby	Daughter
MS_02	Female	55	Married	Home with husband, son	Husband
MS_03	Female	51	Single	Home, with carer support	Neighbour
MS_04	Female	59	Divorced	Aged care facility	Sister
MS_05	Male	56	Married	Home with wife	Wife
MS_06	Female	44	Divorced	Share unit in facility	-
MS_07	Female	58	Married	Share unit in facility	Husband
MS_08	Male	48	Divorced	Share unit in facility	-
SCI_01	Male	57	Married	Home with wife, children	Wife
SCI_02	Male	20	Single	Home with mother, brother	Mother
SCI_03	Female	47	Single	Home, with carer support	Aunt
SCI_04	Female	60	Separated	Home with carer support	Daughter
SCI_05	Male	54	Widowed	Home with carer support	Daughter

RESULTS

1. Financing of Lifetime Care

Key finding: Lifetime care resembles an intricate web of finances and services drawn from across public, private, formal and informal domains. However, there is a marked reliance on informal care to supplement inadequate levels of funding and capacity to pay personally is often important in addressing personal care preferences and/or unmet needs. Funding for lifetime care is also not routinely quarantined for an individual’s use and packages are more commonly paid to and managed by the CSP.

The more typical approach to lifetime care under the public sector model is for funding to be paid to the CSP organisation under specific programs (e.g. Adult Lifestyle Support Program or Home and Community Care) with the expectation that the organisation will manage and arrange lifetime care packages for individuals assessed as eligible based on need. There are exceptions evident with the insurance based approach and the Spinal Cord Injuries Response (SCIR) initiative, both of which allow scope for more individualised and flexible planning of lifetime care. The funding approach impacts on the extent to which services are able to be personalised to the needs of the individual and the extent and level of choice available to individuals and families.

Consistent with the observations in Section 2, the predominant funders of lifetime care services for participants, specifically accommodation, personal care and income support, are the Federal and State governments. Government funding covers a wide array of services and supports, including individual income support; accommodation and facility infrastructure; service coordination; carers or support workers; domestic support; medical, allied health and welfare services; equipment; respite; and transport. For a summary of the funding sources and service providers see Appendix 1, Table A.1.

For income, 18 of the 25 individuals received the means-tested Disability Support Pension (DSP), with 13 receiving full DSP and five part DSP. Two were under 21 years of age and lived at home with parents. Seven individuals did not receive any DSP (ABI_06, HD_02, MND_01, MND_03, MS_06, MS_08 and SCI_05), with three (MND_01, MND_03, MS_06) funded by an income protection policy, and the others through private sources or injury compensation. Typically participants did not have income protection insurance, workers' compensation or other compensation entitlements. Of the three who received injury compensation, two were funded by third party insurance claims for a motor vehicle accident, and one for a work-related accident. Income for family members providing care included three receiving means tested Carer's Payment (MS_02F, MS_05F, SCI_01F) and in another three cases a small non-means tested Carer's Allowance was paid (SCI_02F, MS_05F and MND_03F).

Individual's accommodation is significantly shaped by how it was financed. Five participants lived in subsidised public housing, while nine lived in a facility. Three of the nine in a facility lived in an aged care facility.

Several CSPs offered differing combinations of lifetime care services for each participant. In only one instance, personal care was provided solely by a family member. Personal care and domestic assistance were commonly provided by the same organisation. Some participants received both Federal and State government funding for lifetime care such as those living in purpose built dwellings. For others, funding for lifetime care was provided from the State government, while some or all of their care support was from the Federal government. Four were unable to access DSQ funding for lifetime care at the time of their interview.

The provision of equipment is inconsistently sourced and funded, and cannot be separately accessed by those in receipt of an Extended Aged Care at Home (EACH) package. Financial sources for equipment include the Queensland government's Medical Aids Subsidy Scheme (MASS), Federal Government funded Continence Aids Subsidy Scheme (CASS), insurers, and disability organisations. Some participants had limited equipment expenses while others had

considerable expenses. Several participants had personally paid large amounts for modified cars, home modifications, furniture, equipment and other items to manage their disability. In the 20 cases in which equipment expenditure was discussed, 16 identified MASS and 14 identified self or family funding as financing their equipment. There is overlap between these two groups as some individuals received some MASS funding and contributed some private funding to equipment purchases.

There were no instances of direct funding for lifetime care at an individual level from the private sector. However, there was often a range of expenses that were self-funded or funded by family, including some health needs (e.g., private GP and specialists, medication, allied health, dental bills), and some had substantial ongoing expenses (e.g., MND_01, MND_02, MND_03, MS_05, SCI_01, SCI_03, SCI_05). Those with the capacity to pay personally were more able to access more appropriate services and equipment. For example, one individual (MND_01) purchased his own equipment when he had difficulty obtaining what he needed through other means: *“I probably have about five thousand dollars’ worth of equipment I purchased myself, only for the ease of picking something that was just right”* (MND_01).

The financing of lifetime care cannot be fully understood without acknowledgement of the informal contribution of family, friends and community. This includes essential practical, social-emotional and financial support that contributes to the person’s care and wellbeing. This gratuitous care and support of family and friends is difficult to quantify, but is an essential component of lifetime care for adults with acquired disability and high care needs. For some family members, their informal care may mean being available 20-24 hours a day compared to ½ hour to 8½ hours of care offered by a paid carer. Without this contribution, the person in receipt of lifetime care would need to obtain this care elsewhere and pay for it, or go without which would make his or her situation more precarious and even untenable. In some situations, more costly publicly-funded lifetime care would instead be required. While some family members offered what they could within their capacity, others were clearly stretched by the emotional and physical demands of lifetime care. Of particular concern is the potential for negative flow on effects in terms of the health and well-being of carers. In some cases, family income decreased as family members reduced or ceased their former work in order to provide informal care (e.g., ABI_05F, MND_03). This is concerning given the implications for family members in terms of provision for their retirement, or in some instances lifetime care (e.g. superannuation). Long term disability has a high financial cost for the individual and their families. This lesser known aspect of lifetime care deserves recognition and support by the community and benefactors within it.

2. Intersection of Financing, Provision and Management of Lifetime Care

Key findings: Financing, provision and management of lifetime care is consistent with four broad types: uncoordinated; case worker coordinated; dwelling based coordinated; and user-coordinated. All types comprise advantages and limitations experienced by individuals, families and CSPs, and in some cases, clearly illustrate the precarious nature of lifetime care arrangements.

Taken as a whole, the analyses illustrate the complexities of financing and management of lifetime care and the dynamic way that individuals, families and CSPs obtain, use, interact with and attempt to adapt around lifetime care provision, which is on the whole, not systematic, automatic or neatly packaged. When describing aspects of service provider management and coordination, participants focussed on: the aspects of lifetime care coordinated by the CSP and other key stakeholders such as medical specialists; the nature of relationships between individuals and CSP organisations; the overlapping role of families, medical services and CSPs in the coordination of lifetime care; and how the parties communicate about routine matters as well as problems. While there is typically regular communication between the person receiving lifetime care and a CSP, there may be limited or no contact between CSP and other key stakeholders, particularly family and medical and allied health services.

Over half (16) of the individuals receiving lifetime care lived in their own accommodation (privately rented, mortgaged or owned). Nine lived in fully supported accommodation. Management and coordination of lifetime care typically involved two or more people and organisations, each with an interest in or responsibility for an aspect of lifetime care. In some cases there was a case coordinator with whom the individuals had regular contact (MND_01, MS_02), but who may not coordinate all relevant parties, or manage lifetime care. In at least one case the absence of effective case management was a source of concern to a participant and in another there were differing perceptions of who was principally responsible for overall management of care. In some instances, participants with lifetime care appeared unaware of the extent of the case management or coordination role of their CSPs. Conversely, a number of CSPs did not acknowledge or did not appear to be fully aware of the extent of coordination of services by some family members. Across the 25 individual case studies, the management and coordination of lifetime care for individuals could four broad types could be discerned:

- **Uncoordinated:** characterised by an individual receiving services that they are deemed to need and have eligibility to receive. Different organisations provide different types of services funded by different funding streams. This is common in disability services, particularly given the lack of a nationally coordinated approach. As a result, there are multiple CSPs who coordinate their own service delivery, with no overarching coordination and limited input from the individual. An example is provided in Box 1.
- **Caseworker coordinated:** a case worker initiates and/or coordinates lifetime care on behalf of the individual who receives them (see Box 2). Services may be funded through the diverse range of funding streams (as with the uncoordinated model), or in some cases, funding can be directly provided to the caseworker with which to 'purchase' services on behalf of the individual, as is often the case with injury compensation.
- **Dwelling based:** services are coordinated for the individual from within the facility and is defined by the dwelling. Although lifetime care can be financed by various avenues, funding is pooled into the dwelling either for each individual or collectively for all residents in the facility (Box 3).
- **User-coordinated:** the individual has control and autonomy over their care and support needs and shapes the package and timing of services according to their personal needs and preferences (see Box 4). In this approach, funding is generally provided directly to the individual, or the individual is self-funding, and the person has the resources and/or capacity to organise, direct and finance their service needs.

These four types describe key features in the provision of lifetime care. A specific case study may not precisely fit one of these types and could have features from several. A fuller discussion of the different governance approaches to lifetime care can be found at <http://www.uq.edu.au/swahs/lifetimecare/SPUresearchpaper2-governancemodels.pdf>.

Box 1: Uncoordinated model of governance

'Anna' is a 47 year old single woman with HD who has four children. Anna lives at home in a public housing dwelling with her youngest child of 17 years who assists her mother constantly. Anna has four carers, two coordinated from a non-government organisation (NGO) which provides both personal care and domestic help. These services are funded by the organisation and the state disability organisation. A second organisation comes three times per week to assist with showering and one morning a week to provide domestic assistance. Anna's daughter is her fourth carer, and a third NGO provides respite for her daughter. Anna's income is from the means-tested Australian government Disability Support Pension (DSP), and her aids and equipment have been initiated by herself and variously funded by herself, the Queensland Department of Housing and the government program, MASS. Anna reported satisfaction with her NGO provider. However, Anna's experience of care was that there were "lots of different people" coming to her home and it "gets confusing". Moreover, her perception was that insufficient funds were "a big problem". In this example, Anna is not getting help on weekends, but relies on her daughter. Anna also lacks the financial resources to pay personally for medical rehabilitation and disability-related services, despite the perceived need for physiotherapy for balance and back pain issues. Anna's responses on the Services Obstacles Scale reinforced these observations. She agreed with the following statements: 'I am dissatisfied with the amount of professional help and services being provided'; 'Lack of money to pay for medical, rehabilitation, and injury related services is a major problem'; and 'For my problems, there are very few resources in the community'. Anna did, however, express confidence in the quality of care she received and her knowledge of care and support services in the community.

While some common types of financing and management of lifetime care can be derived from the analyses, at the same time, individual examples illustrate the limitations and problems experienced by individuals, families and CSPs, and the precarious nature of some arrangements. Some involve constant negotiation between the individual, family and CSPs about the level of lifetime care or the different needs of those involved. In one case (MND_02) this involved how best to balance the high care needs of the individual, the safety and respite needs of the family member, the safety needs of carers, and the funding limitation of the care package.

In many examples, the integral role of the family or informal support systems was evident. In one example (MS_05), the CSP and family shared management and coordination. However, according to the CSP, the family did "a huge job. It's like having - well she's a PA. Most of her day is involved around [MS_05]. But things like his incontinence products, that's a nightmare to organise and she deals with all of that" (MS_05CSP). Without such support, even short-term, the individual was at risk of going to hospital to have his needs met. In another example, a family member (SCI_05F) described the difficult role she had as her father's main carer, a role she had reluctantly undertaken since her mother's death.

If I wasn't here Dad's life would be so much more of a mess than it is now because there is nobody in a family role to say that this is working well for us or it's not. And we were ready to move [overseas] when Dad had his accident and so we've continued to

put that off for seven years because we just think if we leave now, honestly I feel the man will be dead in a year or two just due to the quality of the care and, you know, younger brothers wanting money and things like that. I just think that [financially] there'd be nothing left if I wasn't here. So it's a big weight to carry. (SCI_05F)

Box 2: Case worker coordinated governance

'Beth', aged 47, has a SCI. Beth lives in public housing, with care and support coordinated by a dedicated spinal cord injury NGO. The services coordinated by this organisation are funded under a special Queensland government program, SCIR. The NGO coordinates four rotating carers who come three times per day, for up to eight and a half hours at a time, and personal carers are arranged for holidays. Psychological counselling is also accessed; however, Beth was unable to access psychological services on an ongoing basis, suggesting funding was capped. Although Beth perceived a need for more therapeutic services, including psychology, she was not able to afford private physiotherapy, psychology and psychiatry services. By contrast, Beth's air-conditioner was funded from unused carer hours for one year, and an emergency grant of \$2000 towards her fully adjustable bed was funded by the same organisation. The government program, MASS contributed to a power-assist wheelchair, to which Beth personally contributed from her own funds. Personal income comes from a partial government Disability Support Pension (DSP) as well as private superannuation. The caseworker plays an important role in providing Beth's services. While satisfied with the level of personal care and domestic support, Beth found the intrusion of carers "*drives me insane*" and created a lack of control. While Beth has an assessed package of care, managed by her case worker, the NGO has discretion over the expenditure of unused care hours at the end of the year. Unused funds are not automatically rolled over to her. Rather, the organisation decides in consultation with their government funding agency. This is perceived as unfair by Beth, "*If they are your hours, you should be allowed to have access to them for equipment and things that you may need*". In her responses to the Services Obstacles Scale, Beth strongly agreed that "*lack of money*" for services was a major problem, and agreed that there were "*very few [support] resources in [her] community*". She did, however express satisfaction with transportation to access help.

In some situations, CSPs, individuals and families had very different perceptions of what level of lifetime care was required, and for those with progressive conditions these perceptions could also change readily with changes in health status. This is illustrated by one example of a woman with HD (HD_03) whose primary carer was her daughter who was under 18 years of age. In this case, the CSP wanted to apply for more funding to increase the care hours due to a marked deterioration in the woman's health status, but this decision had implications for the daughter's financial support.

Yeah and it is a hard call because if we were to put 24-hour support in there [the family member] is going to lose that income you know what I mean, so it's really hard. (HD_03CSP)

As an example of a user-coordinated approach, one individual (MND_01) decided to fully self-fund his care by re-mortgaging his home. He deemed this necessary to continue to meet his needs according to his preferences. Aside from being self-funded, this is also a unique situation in which funding is used to employ carers from overseas at less expense (see also Box 4).

... well to be very honest to get an Australian carer the cost factor is just astronomical because [he] needs almost 24/7 care. You know he can sit there and amuse himself

during the day but someone that, you know, if he needs a sandwich made or he needs something and there's the issues of workers' compensation and insurances and all that sort of stuff. We have had had to go with overseas, especially the ones at the moment, it's a lot of Thai people. ... We advertised on Gumtree ... (MND_01F)

Regular contact with health professionals, particularly hospital and medical practitioners, as part of lifetime care is evident in 20 of the 25 individual case studies. Those with physically stable conditions especially those with ABI may not have regular contact with health professionals while those with more rapid deterioration in health (e.g., MND) may see health professionals every 2-3 weeks. This raises further questions about coordination across health and disability sectors, how individuals and families negotiate the interfaces between acute or specialist care and disability services, and what mechanisms are available to facilitate coordination.

Box 3: Dwelling model of governance

'Cath', is a 38 year old mother who sustained an ABI. Cath has limited independence in activities of daily living and currently lives in a share house during the week with two other women and support workers where she receives 24 hour care. She receives a disability pension. Following her ABI, Cath spent 14 months *"bedridden"* in a hospital, and then endured multiple changes of living arrangements which included two years in an aged care facility which she found *"depressing"*, five months in a slow-stream rehabilitation unit, and a share home with male occupants. Prior to her current share house arrangement, her husband also looked after her unsupported for 2½ years, living on savings from his previous work. At the time, he was also caring for their 13 year old daughter who has a disability. He also spent 2 years waiting for a wheelchair for Cath. Cath currently has several agencies involved in her care, including the facility-based support workers. Cath was able to access some physiotherapy which she saw as having contributed to her improved function, an achievement she regarded as *"very important"*. Cath goes homes most week-ends to spend time with her children and as part of community-access. This is very important to Cath since it *"makes me feel like I'm doing something for my children as well and being part of their lives"*. After many difficult transitions, Cath exercised the choice of being near her family as this was very important to her and she did not feel so *"helpless"*. However, the family continue to experience financial stress due to expenses involved with caring for four children and additional expenses to meet Cath's needs.

3. Choice in Lifetime Care

Key findings: Having choice about daily routines and lifestyle preferences was identified by individual participants as equally important as having options about how their care is managed and funded. Choice in determining care arrangements, carers and care agencies was highly valued, as was choice in use of funding. However, this was largely restricted due to the way funding was governed, inflexibility of agency-based care provision and the lack of transparency around level and use of funding. Accommodation was an area perceived to offer the least choice opportunities.

Those aspects of lifetime care where choice was most valued by individuals and families included care hours, care providers, care agencies and funding model. Being able to express lifestyle preferences about daily routines (e.g., meals, rising and showering times), and social and community access activities (such as decisions regarding relationships and leisure activities) were also highly valued by participants. For individuals and families, choice over

these dimensions of lifetime care was equated with more flexible and personalised care. However, in all cases there were problems identified such as a lack of choice, lack of flexibility, lack of access to experienced carers, and high turnover of carers. Choice over lifestyle issues generated a sense of normality and contributed to psychological health as indicated by this example from a family member of a woman with MS living in a residential facility.

As soon as she wakes up she wants to get in that wheelchair and go down to the garden, which I think is fantastic because it's an interest for her...If she didn't have that garden she would be very depressed... (MS_04F)

The way funding was structured and governed had a bearing on whether individuals had choice and the extent to which they could make choice. Funding approaches that were flexible and allowed the individual and families some control over the lifetime care were a highly valued choice dimension. By contrast, the nature of block funding not only inhibited choice of care agency, but as this extract from a mother of a young man with SCI shows, dependency on this type of funding also sometimes cultivated an acceptance of lack of choice and suppression of personal preferences.

...the block funding model is a problem in that the client doesn't have the right or opportunity...to say I would like to go to this agency because they offer me something that is more tailored to my needs...They feel uncomfortable making any complaints...They just grin and bear it... (SCI_02F)

Individualised approaches to funding could provide for more individual choice around determining the nature and components of lifetime care. Some individuals regarded their package of care as their entitlement or "right" and resented it when they had no control over allocating unused care hours or finances (see also Box 2). Also, there was still a general perception among some participants that the lack of transparency around their level of funding and how it operated was a barrier to real choice, as illustrated by this extract from a woman with SCI who was receiving an individualised care package coordinated by a specialist non-government agency.

They're quite happy to keep you like a mushroom in the dark. (SCI_03)

Accommodation was an area where most participants valued choice but perceived a lack of *real* choice. As there are limited accommodation options, moving and living in close proximity to family or home is highly problematic. Quality respite close to family or home was another area of limited choice. These were linked to a perception by many that it was choice in theory, but not in practice. This is vividly illustrated in one example where a family member commented, "Yeah it's not a lock-up. It's not that she's got no choice because she's signed on the dotted line. She can discharge herself out of here any time she likes" (ABI_03F). However, in this situation, there had been several changes in accommodation and therefore, regarding the individual's actual choice, the family member said "if she wanted to move, then yes she's got the choice, but to find a place that is small and happy – [they] are very limited" (ABI_03F).

It is important to note that there are different dimensions of choice and participant reports indicated that autonomy in day to day lifestyle decisions, including decisions about meals or personal care, was as highly valued as more significant decisions concerning where to live or what care agency or carers should provide their lifetime care. This was similar for individuals living at home and in facility-based arrangements. The extract below is from a CSP of people with MS living in a specific purpose facility.

And also they have got a choice here of the meal. They would sit with a staff member and make their meal plan, two of them in each house and then we go with them and do shopping. (MS_08CSP)

Box 4: User coordinated model of governance

'Dave' is a 57 year old male, diagnosed with MND. Dave is divorced and has a daughter who contributes to his personal and domestic care. He lives in his own home with a live-in 24/7 carer who provides the majority of his personal care and support needs and receives personal care for showering three days a week from a NGO financed by a government personal care package. He personally employs a carer directly from Thailand after finding the options available to him inappropriate to his needs. He pays for the carer's return flight to Australia, wages, board and lodging for three-months and then employs a new Thai carer. His previous experience of carers provided by a NGO was that care was not provided at a time he desired: *"I like to have a shower before about ten every day. ... I don't really want to sit, especially in summer until three o'clock for someone to come and shower me that day and then, seven o'clock one morning and then half past four the next day"*. Dave then decided that he wanted a live-in carer, but found that Australian options were too expensive, involved having three rotating carers a day who may not be needed for most of the time, and ultimately there was *"just the lack of available services and the willingness of people to come in"*. Self-funding care provides Dave with flexibility to meet his own care needs, as well as calmness and companionship. This is also reflected in his decision to purchase an electric wheelchair rather than borrow from a NGO: *"we chose for convenience to buy...I probably have about five thousand dollars worth of equipment I purchased myself, only for the ease of picking something that was just right"*. However, this would not be possible without significant financial resources. Dave purchases his services from a disability pension from private insurance, savings obtained by selling his business, and remortgaging his house, which he described as *"eat[ing] my house"*.

The exercise of choice will ultimately depend on being well informed. Lack of access to good information about their entitlements and how funding operated, particularly in relation to choice of CSP, meant some participants were unaware of the choices open to them. For example, in the case of one family participant (MND_02F) a lack of awareness about how funding operated when the individual was in respite meant that they did not know they could ask for payment to cease when using respite to avoid being overcharged. In other examples, there was dissatisfaction with the poor communication and feedback in response to requests, which in one example (SCI_04) was perceived to be related to staff turnover.

You know you ask for things and nobody gets back to you or you ring and leave a message and still nobody gets back to you...But I really think myself [the CSP] need a good shake-up. I really do. It needs a real good shake-up because they're going through staff like you know. (SCI_04)

Other participants were fortunate to be informed. In one example, a family member (ABI_05F) had “luckily” discovered that there was a choice of case manager and care agency for her son who had individualised funding through injury compensation after previously being led to believe that these decisions were not negotiable.

[The new case manager] said, ‘Well it is entirely your choice. If you want to change, you can do that, whether it is me or with somebody else or you want to change your support agency you can do that.’ She said, ‘You’re well within your rights to do that.’ And yeah, that was something that I had no idea [about]. So then we just went through the solicitor to the insurer to say we would like to change case managers for various reasons and they didn’t seem to have any qualms about that. (ABI_05F)

In the minority of cases where individual or self-funding was possible, it was evident that these approaches enhanced choice opportunities and were also significant in optimising flexibility in lifetime care. This is illustrated in the user-coordinated model of governance (Box 4) and also the extract below which is from a man with MND (MND_01), living in his own home, who had disability insurance but who was also willing to use his assets to enhance his choices.

I can access [care from non-government agency] to go morning and afternoon and I can self-fund five days a week...I can still make choices. To get a live-in carer, it’s difficult but it’s still possible...My choices are limited, but I still have choices for my care at the moment. (MND_01)

4. Adequacy and Sustainability

Key findings: Lifetime care was on the whole perceived to be adequate and sustainable by most individuals and families, although in the majority of cases the precarious nature of lifetime care was also evident with the majority reporting adequacy and sustainability was dependent on meeting several conditions.

Table 6 summarises findings relating to experiences of individuals and families about adequacy and sustainability of lifetime care. The majority of participants perceived their lifetime care to be generally adequate. This included a satisfactory level of personal care now and in the past, or as one family participant stated “everything she needs done seems to get done” (SCI_03F). The majority of individuals (18 of 25 individuals) also perceived their lifetime care as sustainable, though this was dependent on meeting particular conditions. It was also clear that the unique disability trajectories and personal circumstances present challenges for timeliness, adequacy and sustainability of lifetime care.

Despite a widespread perception that lifetime care was generally adequate, with six exceptions (two ABI, one HD and three MS), individuals perceived their lifetime care to be lacking in one or more of the following areas: carer hours; rehabilitation; information and assistance with aids and equipment; appropriate respite; and community access. Those with MND, SCI and MS generally perceived lifetime care as less adequate. The lower perceived adequacy of lifetime care by these groups contrasts with the group of participants with ABI, all of whom considered their care adequate or mostly adequate apart from their personal

finances (n=3), access to rehabilitation (n=3), psychological counselling (n=2) or sufficient community access (n=1). However, the responses of those with ABI must be understood in context, rather than being reflective of the ABI population in Queensland. Two of the participants with ABI had moved from residential aged care facilities to accommodation purposely designed for younger people. Further, three were receiving, or had received, compensation for their injuries thereby presenting greater opportunities for services.

Table 6: Adequacy and sustainability of lifetime care

Case	Adequacy	Qualifiers	Sustainability	Qualifiers
ABI (n=6)	Yes/Mostly	<ul style="list-style-type: none"> Financial concerns Limited or specific rehabilitation Limited community access 	Yes Somewhat/unsure	<ul style="list-style-type: none"> until 65 years subject to place of living Subject to funding/personal finances Subject to settlement claim
HD (n=3)	Yes/Mostly Somewhat	<ul style="list-style-type: none"> Information for family More care hours week-end 	Yes	<ul style="list-style-type: none"> Subject to financial situation
MND (n=3)	Somewhat	<ul style="list-style-type: none"> Subject to mortgaging home and using lower paid overseas carers Lack community based professional and transport services Subject to disease progression Lack of respite Personal finances 	Yes Somewhat	<ul style="list-style-type: none"> Subject to reorganising finances Spouse's willingness to care; health Availability of respite
MS (8)	Somewhat/yes/ mostly	<ul style="list-style-type: none"> Additional care at certain times High quality respite Financial support for lifestyle choices Some health & rehabilitation 	Yes	<ul style="list-style-type: none"> Pension and finances Spouse's health Until 65 Disease progression
SCI (n=5)	Mostly/ Somewhat/ Limited/ Inadequate	<ul style="list-style-type: none"> Inadequately trained carers - routine and emergencies Inadequate funding of catheter supplies Adjust personal situation Lack psychological support Quality and timeliness 	Yes/Mostly	<ul style="list-style-type: none"> Concerns about personal finances Subject to political change At current level Better manage investment from payout

Among participants as a whole, a number of qualifiers were noted (Table 6). Nineteen participants perceived that their lifetime care was lacking in a range of dimensions including: carer hours; domestic hours; rehabilitation; financial assistance with aids or equipment; appropriate respite care; and sufficient community access. Some individuals listed four such insufficient domains (e.g., all three with MND). No participant with SCI indicated that their lifetime care was adequate without qualifying it (i.e., it was inadequate in some way).

Across the 25 individual case studies there were also discrepancies among individuals, families and CSPs about the perceived adequacy of lifetime care. For example, for four participants with SCI, perceptions of adequacy varied with the higher rating of adequacy being made in each case by the CSP. In one example (SCI_05), the CSP and individual rated lifetime care as *“mostly”* adequate, while the family member rated it as *“limited”*. Further detail about differences in perceptions among CSPs, individuals and families is provided in Appendix 1, Table A.2.

Although some of the inadequacies noted by participants may be inconvenient or unpleasant (e.g., more consistency in carers, more cleaning) others would appear to compromise the safety, health or wellbeing of the participants. In particular, the analysis indicated the perceived precariousness of daily living for those who cannot obtain emergency assistance when it is required (e.g., if they fall on the floor or lie in faeces for extended periods until assistance arrives).

Change in health status or sudden emergencies were obvious threats to adequacy of lifetime care. For example, one participant (MND_03) said that he felt that he had adequate care and support arrangements at present, but would need more as the disease progresses. He regarded that the care would become burdensome if the approved EACH package does not eventuate, and that the current care was adequate because they privately pay for additional care. His family member said, *“And we rely on one person being home so we, yeah. We pay for extra and we rely on there being one carer at home all of the time”* (MND_03F). They considered they need an extra 6 hours of assistance per week (which would come with the EACH package). Another participant (SCI_01), while agreeing lifetime care was generally adequate, highlighted emergency situations as particularly challenging since *“... it’s a bit of a juggling act really”* and, *“We would struggle with less.”*

In the 23 cases in which sustainability was discussed, the vast majority (n=18) perceived that lifetime care was sustainable (Table 6). In another four cases it was considered to be mostly or somewhat sustainable. The CSP of a 44 year old woman with MS living in a facility (MS_06CSP) said that residents’ care will be *“automatically accommodated”* as their conditions change. In contrast, the CSP of one man with SCI living at home (SCI_05CSP) stated, *“It will run out and he can’t - the level of support he gets, equipment he needs, consumables he needs, I don’t believe that can be sustained until the end of his life with his [injury] payout, no”*. In this case, the CSP indicated that if the man’s money runs out then his only other option was a nursing home. The man’s daughter (SCI_05F) was also concerned about this eventuality and was taking action to improve management and investment of his funds.

Yet even those who considered their lifetime care was sustainable stated that it was conditional upon other factors such as the management and adequacy of their personal finances, suitable respite, their own health, or their spouse's health. One participant who appeared to capture the nature of sustainability of lifetime care (MS_04) said it was *"predictable, but not guaranteed"*. Another participant (MS_05) captured a different perspective, which was that sustainability was dependent upon a range of factors including government policy, his wife's continued health, and the availability of in-house respite. Six participants referred to broader concerns about the global economic situation impacting on their finances or national political change impacting on lifetime care policies. As with the example above (SCI_05), the key policy concern is how best to ensure and protect the longevity of self-managed funds and lump sum settlements awarded to cover lifetime care.

5. Satisfaction and Unmet Needs

Key findings: While the majority of individuals were satisfied with their lifetime care, all reported some areas of unmet need, with the majority reporting two or more unmet needs. Health and rehabilitation was the most commonly reported area of unmet need. Participants also identified the level and flexibility of care as problematic, and this was also related to crisis and emergency situations.

Participants spoke of unmet needs in six areas: physical health and rehabilitation; care; lifestyle activities; other health and rehabilitation; transport; and information and advocacy. The majority of participants reported two or more unmet needs (see Table 7).

Twenty of the 25 individuals reported regular contact with health professionals, primarily hospital based and medical specialists, but also nursing and allied health professionals. Nevertheless, in 17 of 25 cases, health and rehabilitation concerns were raised as unmet needs, making it one of the main areas of perceived unmet needs.

Physiotherapy (or other physical therapy including hydrotherapy, fitness sessions, exercise designed or monitored by a physiotherapist or a personal trainer, and massage to manage pain) was singly the largest area of perceived unmet need in health care (n =13), reflecting that the people with lifetime care needs keenly experience the loss of physical ability or aim to maintain or improve their decreased abilities. Several participants had concerns about the physical deterioration of the person with lifetime care needs and wanted them to be able to improve or maintain their physical abilities especially their walking. In one example (SCI_02), the need for physiotherapy once or preferably twice weekly was regarded as *"vital"* to *"maintain"* physical health. The perception being, *"as a young man I think that is important"* (SCI_02).

Other health and rehabilitation including occupational therapy, speech therapy, dental care, nursing care, podiatry, specialist medical care, or psychology was also identified as a further area of unmet need by 10 participants. Participants often had more than one area of unmet health needs (e.g., physiotherapy and occupational therapy). Psychological support was perceived by one CSP (ABI_01CSP) as a *"gaping hole"* for individuals living in a purpose built facility.

Lifestyle enhancement and increased hours, flexibility or quality of care were two other large areas of perceived unmet need (n = 10). Lifestyle enhancement included social activities, mental activities, and community access. In one example, the family wanted more outings and more contact with their family member who had an ABI (ABI_04), but perceived this to be restricted by the care hours.

I think it would be nice if he had an outing once a month and he had care for the whole day so he could go places...And I think he stops doing a lot of things because he goes by the time we get there, and he's thinking constantly about his funding and his hours. (ABI_04F)

In another example, a single woman with MS who lived alone at home (MS_03) wanted to take a brief coastal holiday but did not have sufficient hours allocated for a carer to go with her. In this case the woman was willing to personally fund the holiday.

But see I'm willing to pay for the unit, I'm willing to pay for a hire car. I'm willing to pay for petrol. I'm willing to buy food and everything, but it's just the support that I need to go away with. (MS_03)

Regarding care, participants identified a need for one or more of the following: increased carer hours, more flexible or more responsive carer hours, better back-up or emergency carers (e.g., SCI_04), and better trained carers (e.g., SCI_04). For example, one male participant with MND (MND_03) had been approved for an EACH package, but there was not one available. His wife (MND_03F) described her conversation with a potential EACH package provider.

'Well you know, I'm sorry there are still no EACHs available. You're about sixth on the list and I am just letting you know that the last one we gave was in February' and I said, and it probably sounds terrible, I said, 'So the likelihood is [MND_03] will be dead before we ever get an EACH package' and she was kind of a bit shocked and said, 'Oh no, no. I hope not' and I said, 'I hope not too, but if you are telling me that you have got six in front of us and the last one you gave was six months ago, that's the likelihood isn't it' [Laugh]. (MND_03F)

Others commonly perceived clusters of need for participants included respite, counselling, transport and getting around in the community. The main carer of one man with MS (MS_01) was unable to take him out in his own van because he needed a stronger ramp.

I have just got a ply-wood ramp that I run up into the back of the van, but it is a little bit awkward and I'm just a bit over the weight. (MS_01)

Nine participants perceived that they needed or had needed better information about aspects of lifetime care and, at times, better ways of negotiating lifetime care. Improved information and negotiation would lead to feeling more empowered to make choices about lifetime care in a more timely way. In the case of an individual with ABI (ABI_05), a family member (ABI_05F) wanted more information and advice about Centrelink services and eligibility instead of finding out "by complete chance".

Table 7: Unmet needs

Area of need	Number of Participants
Physiotherapy, hydro, exercise, fitness	13 (MS, ABI, SCI)
Increased hours, flexibility or quality care	11 (MND, MS, SCI)
Lifestyle enhancement*	10 (ABI, MS, SCI)
Other health and rehabilitation**	9 (ABI, MS, SCI)
Transport	9 (All groups)
Information, advice, negotiation, advocacy	9 (ABI, MND, MS, SCI)

*Lifestyle enhancement includes one/more social activities, mental health activities, community access

**Other health includes occupational therapy, speech therapy, nursing, dental and other specialist care

Occasionally participants or their families identified that they had no unmet needs. One woman (MS_04) who reported that she had no unmet needs, said that if given the opportunity, *“Well, I don’t think I would make any [changes]”*. Similarly, her sister (MS_04F) stated, *“I mean the family is very happy with [aged care facility] and [MS_04’s] very happy. It’s the happiest I’ve seen her in years and years and years”*. In this case, the woman had experienced a number of stressful events prior to moving to her current accommodation, including the breakdown of her marriage and loss of independent living. In another case of a woman with HD (HD_02) who lived in an aged care facility the husband (HD_02F) reported that there was nothing in particular that his wife needed now that her medication for agitation had been adjusted and her symptoms better managed. In this case, the husband lived independently in the community, visited regularly and was a strong advocate for his wife. In contrast to these examples, in one case the individual, family and CSP each had a different perception; the man who had HD (HD_01) reported that he had no unmet needs, his daughter perceived that he needed dental care and his CSP said he needed more social activity.

6. Services Obstacles Scale

In addition to descriptive interview data, each individual receiving care and their family member were invited to complete the internationally recognised Services Obstacles Scale (SOS).ⁱⁱⁱ Although the SOS is designed in relation to services for adults with ABIs, the scale was modified slightly to include all study participants. The scale asks respondents to assess their experience against a range of typical service problems according to a seven point scale (1 = strongly disagree to 7 = strongly agree); the higher the score, the larger the problem.

Table 8 summarises the results from respondents (positive responses in green, negative in pink, strongly response shown in darker colour).^{iv} The level of professional help and services provided, and the confidence in the quality of care provided were the two services overall with the most positive responses. The most negative response involved the amount of

ⁱⁱⁱ See <http://tbims.org/combi/sos/>.

^{iv} Unfortunately, not all study participants completed the Scale. Useable responses were obtained from 16 of 25 individuals receiving care, and 20 of 25 family members/friends.

available resources in the respondents' community. Within these questions there was some variation, so that lack of money was highly problematic for the SCI group, but not for the MS group.

Table 8: Service Obstacles Scale

	1	2	3	4	5	6	
Ave all	2.92	3.83	3.97	4.31	4.83	2.53	3.73
Ave SCI all	4.33	4.67	6.11	4.89	5.56	4.22	4.96
Ave ABI all	2.55	2.91	3.36	5.55	5.91	2.09	3.73
Ave MS all	1.22	3.22	2.33	3.00	2.89	1.56	2.37
Ave MND all	4.50	5.75	5.00	4.25	5.50	2.50	4.58
Ave HD all	3.00	4.00	3.33	2.00	3.67	2.00	3.00
Ave all pairs	2.79	3.79	4.50	4.92	5.29	2.67	3.99
Ave ind pairs	2.58	4.08	4.92	5.33	5.92	2.75	4.26
Ave fam pairs	3.00	3.50	4.08	4.50	4.67	2.58	3.72

Scale 1-7, disagree strongly to strongly agree, on items 1-6

1. I am dissatisfied with the amount of professional help and services provided
2. Transportation is a major obstacle toward getting enough help
3. Lack of money to pay for medical, rehabilitation and injury related services is a major problem
4. I don't know if there are good treatment resources in my community
5. For my problems, there are very few resources in my community
6. I have little confidence in the quality of care now being provided

Over the six questions asked, people with SCI and their family respondents were the most negative, closely followed by those respondents associated with MND. This finding was somewhat surprising given the higher level of services provided in the community to those with SCI than others. The most positive respondents were respondents with MS and their families, and then the HD group.

5. KEY MESSAGES AND RECOMMENDATIONS

The purpose of this study was to examine lifetime care and support for adults with acquired disabilities and high care needs in order to describe and distil the key features of financing and management of lifetime care; and to examine individual case studies to understand the operation and complexities of current systems of financing and management of lifetime care through the experiences of individuals, families and formal care providers. The case studies focused on five specified groups: Acquired Brain Injury (ABI); Spinal Cord Injury (SCI); Multiple Sclerosis (MS); Motor Neurone Disease (MND); and Huntington's Disease (HD). As a whole, the analyses allowed the development of a conceptual understanding of lifetime care and a critical assessment of current approaches, including the adequacy and sustainability of lifetime care, for our populations of interest. In this section, the key messages and recommendations for policy and service delivery are outlined.

KEY MESSAGE #1

National policy reform must address the level and model of funding and resourcing

The financing of lifetime care occurs through two main mechanisms, although there are areas of overlap: a publicly financed and governed approach; and a compulsory insurance-based model covering accidental and catastrophic injury. There is also a small market of private insurance products for individuals to self-insure in the case of injury. However, regardless of the mechanism of financing, lifetime care is commonly supplemented by private sources of funding from household income, savings, superannuation or private insurance, and informal care, in order to adequately meet the breadth and complexity of needs of individuals, as well as the changing nature of needs. Further, the current delivery system which resembles a mixed economy of care is ill-equipped to adequately respond to the multiple and changing nature of needs of individuals with acquired disability, and particularly those with progressive conditions. Most individuals and families experience limited capacity within the system to address the level and complexity of need and limited responsiveness and flexibility to address crisis and emergency situations. Organisations are highly reliant on State government recurrent funding, although multiple sources of funding are common. Moreover, service organisations are largely generic focused rather than specialising in a specific disability group, which coincides with some individual and family perceptions that providers are inadequately trained, and are dealing with increasing demand management issues.

A key consideration around funding of lifetime care is the *level of funding* and *how best to fund*. First, sufficient funding is critical for more personalised lifetime care that adequately meets the needs of the individual and family. Although on the whole, lifetime care was perceived as adequate and sustainable by the participants in this study, this was not the case for crises and emergencies or health and rehabilitation, and in many cases it was dependent on the status of personal finances, and the availability, willingness and health of family or other informal networks to make up for the shortfall in formal provision. The policy issues relate to the level of funding that is equitable, appropriate and cost effective, and the appropriateness of public/private contributions. Indeed, the question of resourcing relates

to what minimum benchmark of care and support the policy regime is aiming to achieve, for example, supporting simple existence or full social participation.

Second, in determining how best to fund, a more integrated model of funding, which pools funding from across a number of sources and programs, will derive benefits for individuals and families by overcoming reported fragmentation and other potential problems with respect to inequities in funding, obstacles to access, poor coordination and diffuse accountability. Equally, individualised funding approaches which provide ‘cash for care’ coupled with appropriate flexibility offer particular advantages²⁵.

Queensland’s approach contrasts with those of other jurisdictions in Australia where a range of programs offering individual funding have been streamlined into one integrated Individualised Support Package (ISP), with clear guidelines to assist assessment and clarify use of such funds²⁶. Similarly, the New South Wales Lifetime Care and Support Scheme (LTCSS), which provides treatment, rehabilitation and attendant care for people who sustain catastrophic injuries such as SCI and ABI through motor vehicle accidents, includes a legislated schedule of benefits detailing what is funded. For example, the guidelines for attendant care services for someone affected by SCI specifies the level of personal, domestic and community care activities funded, dependent on level of SCI. In Queensland, the Spinal Cord Injuries Response (SCIR) program is a unique illustration of integrated funding and resources. This whole-of-government initiative quarantines funding from different government departments for people with newly acquired SCI.

The proposed National Disability Insurance Scheme (NDIS) promotes the idea of a more universal, individualised approach to lifetime care for people with acquired disability. The concept of *individualised lifetime care* can be operationalised in different ways: direct payment whereby individuals are paid the cost of the services they need which they then purchase (perhaps with the support of professionals); pooled funding in which the funding for the various types of care and support needs are pooled to form an overall ‘individual budget’ where services users have some scope to decide what services and providers they utilise; and ‘self-directed services’, where service users (and service providers or brokers jointly) determine a package of care and support that best meets their needs and preferences.

Integrating funding from different resource streams would appear to have a number of efficiency/cost-effectiveness-related advantages. These include streamlining assessment and accounting mechanisms; reducing the risk of duplicate spending; and with inbuilt flexibility, increasing not only the potential to spend on the highest priorities that maximise individual benefits and welfare at appropriate times, but also to shift from acute/crisis responses to invest in prevention, which is often a low priority when it comes to difficult funding decisions²⁶.

KEY MESSAGE #2

Governance models should avoid complexity in service coordination and provision and optimise service user choice

The findings in this study emphasise the need for governance models that address both the need for improved coordination of lifetime care and more choice opportunities. Importantly, in this study choice opportunities concern autonomy and decision-making about care processes and lifestyle preferences, as well as more control over use of funding and the organisation and provision of lifetime care. Choice over service providers and the types of services received are essential elements of a care market. However, the research also demonstrates that choice is often exercised within the service agency, such as timing of showering, participating in the community, the capacity to have friends visit, and contributing to meal preparation. These everyday choices are also critical to the feeling of wellbeing and the quality of care that respondents reported.

However, capacity to confront and/or overcome personal, structural and economic barriers is integral to choice in practice²⁷. Individual choice is also reliant on knowledge and understanding of service options and affected by the emphasis on public/private responsibilities, and more broadly, the stability of the care market. Moreover, people with disability have different capacities, different circumstances (illness, cognitive impairment, exposure to risk, geographical location) and above all, varying social and economic capacity to exercise choice.

Some of the options for governance models include a case manager/service broker model that is located either within a funding agency but restrained by budgetary constraints, or within a supplying agency. It may be that locating both roles in one 'agent' would optimise planning and delivery of personalised services; however, this approach also raises a number of concerns related to conflict of interest and likely risk of provider capture. Some care coordinators in England have reported a subtle pressure by management to encourage individual budget holders to use in-house services rather than contract out to private agencies²⁸. The key benefit is the ability to control quality in the market by maintaining a preferred list of providers and removing services where there is concern over quality²⁶. On the other hand, this in essence creates restricted choice for individuals. A further effective option, supported by empirical evidence, is a model of case manager/service broker which is independent of both funder and service, but involves a strong regulatory role by government to monitor quality.

Providing a dedicated case manager is one way to reduce the complexity of service provision. However, it can result in multiple people from multiple organisations being involved in care provision. Another alternative is the operation of organisations providing integrated, 'whole-of-person' services. The online survey findings reinforced the finding that many organisations typically provide three or four different types of services, thereby requiring clients to seek assistance for other services from different organisations. Organisations that offered services for a specific disability population, however, typically provided six different service types. Such 'one-stop-shops' for services would greatly reduce

service complexity. A downside may be organisational lock-in, or people falling through the gaps in cases where organisations only provide for a specified group.

Direct cash payments to individuals based on self-assessment of need is another option, although as the English experience shows, this model also generates confusion among users about what they can legitimately spend the funding on²⁹. In Australia, there is strong support for individualised funding to be paid directly to a 'consumer intermediary', or agent of choice, for example, a community agency. The benefit of the 'consumer intermediary' model being proposed as part of the NDIS is that it in itself is a mechanism for feedback to the market and advocacy for service capability development. In that sense, it would enhance accountability to the individual rather than to the funder/purchaser as is the case with the current system.

There are broader considerations in determining appropriate governance models which optimise choice through direct cash payments. These relate to equity and quality care. In the case of direct cash payments there is potential for this to act as a market-alternative to directly funded public services. Where adequate resourcing is provided, a competitive market model could drive innovations and respond to unmet need such as providing more flexible, responsive, and personalised services. Moreover, this could occur in locations that are not well serviced. There are also likely potential opportunities for care recipients and families to establish their own businesses to formalise previously informal care. However, a key lesson from England's experience is the importance of balancing the level of cash benefits with service eligibility so as to maintain sufficient incentive to use public services and thereby encouraging continuous investment in public infrastructure and quality²⁸.

It is also a well understood characteristic of markets that they fail to develop in domains that are (perceived to be) not cost-effective. This can include geographical locations with inadequate numbers of service users as well as populations with highly complex and difficult needs. In England, there has been a high degree of market instability in community care services with many service providers exiting the market within a twelve month cycle and increasing reliance on immigrant workers. Glendinning³⁰ has reported the increased privatisation of community care services, with multiple small providers, a high degree of turnover, and increased use of migrant workers. In 1992, only 2% of home care hours were delivered by private providers, whereas in 2005, 73% of home care hours were delivered by private providers³⁰. Within competitive markets, the challenges to integration of services are readily apparent with likelihood of decreased collaboration between providers and moreover, restricted choice in the range of services offered by a specific organisation, service quality and staff turnover.

If the aim of governance is to reduce complexity and optimise choice this will mean creating the right conditions for personalised service responses. This would include finding the appropriate incentives and resources to encourage organisations to not only diversify in their service provision to be more holistic, but to be responsive to individual needs and preferences by providing a wide range of services to meet those needs.

KEY MESSAGE #3

There must be clarity about needs-based entitlement and 'reasonable and necessary supports' and commitment to an accountable and quality care planning process

The findings indicate that in the main, entitlement and eligibility for lifetime care in Queensland is a negotiated process regardless of the mechanism of financing; moreover, the gateway for determining eligibility and level of care often lacks transparency, varies across programs, is disjointed, and in some cases, unsystematic. This suggests the need for more clarity about needs-based entitlement and 'reasonable and necessary supports' as proposed under the NDIS. Whilst traditionally it is usually left to social policy to determine what might be deemed reasonable and necessary services and supports, and for service providers to implement policy, this 'top-down' approach is both ambiguous and at odds with a more individualised approach also recommended under the NDIS proposal. This could mean either taking the idea of user choice and control to its fullest, allowing the individual to determine the means by which his or her needs will be met, or conversely, using a more circumscribed process whereby the individual user is provided with a range of options to choose from to meet their needs³¹.

From an individualised approach, what counts as *reasonable and necessary* will differ considerably depending on whether the objective is to support people to live independently in the community, with their preferred options of care and support, or whether it is to support people to realise a broader conception of social inclusion and participation. It will also differ according to personal contexts as indicated by the case studies. For example, Beth and Dave's situations (see boxes 2 and 4 in section 4) showed both the highly personal nature, but also uncertainty of need and how these differed in the context of a sudden onset disability such as acquired SCI compared to a progressive condition such as MND. In Beth's case, reasonable and necessary services from her perspective included longer-term rehabilitation and therapy. Evidence on the substantial health and quality of life benefits gained from physical activity suggests rehabilitation is reasonable and necessary for people with SCI³². Despite Beth's lack of ongoing access to psychological services there is also evidence to suggest that such intervention is important in facilitating positive behaviour and recovery³³. By contrast, Dave's situation involves a marked degree of uncertainty regarding his care needs over his lifetime, as is consistent with the degenerative nature of MND. From Dave's perspective, his needs included a 24/7 live-in carer to allow him to remain in his own home.

Under an NDIS, an actuarial model is likely to be applied to calculate the risks and costs of disability and lifetime care, and to set the insurance premium. However, needs-based entitlement that also delivers individualised care will potentially generate some challenges for decisions about resource allocation and cost containment. This is in part because of the complexity of translating actuarial based assessments into entitlement at the individual level, particularly when uncertainty and subjectivity of assessment often impact²⁷. Service providers often display immense variability in their decision-making about the allocation of assistance, willingness to advocate for service users and for enhanced service responsiveness^{34, 35}. Therefore, it will be important to ensure the integrity and quality of all care planning processes³⁶. One strategy advocated by the Australian Government is the

appointment of 'consumer intermediaries' to enable people with disability to activity plan and control their lifetime care³⁷.

In Australia, there are complicating factors such as geography and service capacity within different jurisdictions that limit availability and accessibility and are not easily overcome without significant investment in infrastructure and workforce planning. Hence, there is a real danger due to such constraints that the opportunity for choice is grossly overstated for some populations³⁸. Moreover, it cannot be assumed that all people will have the same degree of and capability for choice. Indeed, an insurance model whereby service packages are not means-tested will unavoidably result in inequities of outcome due to inequalities in the levels of personal and family finances to increase service provision level and quality. The examples of Beth and Dave also suggest that some people will have access to more social and economic resources, including compensation, household income or private insurance, which will enhance their opportunities for choice. Private funding, for example, can allow people to supplement their publicly funded provision³⁰, or alternatively, to 'opt out' of the public system. In terms of the NDIS, these are potentially contentious issues with implications for equity of access and relate specifically to the social objective of the proposed scheme and how public-private relationships are likely to operate and evolve.

KEY MESSAGE #4

There is need for stronger government investment in information systems with capacity to capture accurate longitudinal information about lifetime care, system performance, and individual outcomes

An individualised needs-based approach assumes that the care planning process will determine what is 'reasonable and necessary' according to the individual's perspective of need, and more so, that there will be some mechanism for monitoring services and supports to improve social policy and decisions about resource distribution³⁶. To that end, any national scheme will require significant investment in sophisticated information systems with capacity to capture accurate longitudinal information about lifetime care, system performance, and individual outcomes. This will assist in identifying the range of formal and informal services and supports that individuals access; areas of poor accessibility and unmet need; and more importantly, how these individual and system issues relate to outcome.

KEY MESSAGE #5

A lifetime care system must include appropriate organisational resources and procedures and supportive decision-making practices to safeguard choice

Adherence to the principle of choice may run the risk of increasing inequalities by primarily benefitting those with greater access to good information about services available, cost and quality, and therefore be of less benefit for those disadvantaged in these respects. Moreover, as the England example has shown, public concern about risk led to care coordinators and managers being mandated to scrutinise and potentially reject individual choice on the grounds of risk to the person, to others, and to the public purse, in the sense of wasting public money²⁸. The need for independent support agencies has been advocated

to support parents of children with disability who are in receipt of direct payments^{25, 28}. The role of these agencies is to monitor and regulate the market to ensure complaints and allegations of poor services can be reported, investigated and dealt with, and the systemic performance is achieved vis-à-vis equity, access and quality.

There are several ways in which government agencies can support choice and inclusive decision-making including through information and guidelines, facilitators and co-ordinators, case managers, and use of peak bodies and advocacy organisations to work directly with people with disabilities receiving individualised funding²⁶. The awareness amongst clients that they have choice is critical, and is critical in contributing to organisational and systemic governance, performance and accountability. Some research participants had experienced occasions when they were not aware of their capacity to change providers. Differential opportunities for choice are more likely where there are extensive personal resources to draw on, including income and assets, and capacity to negotiate and/or challenge the system, either personally, or with assistance from formal care providers or advocates.

Clarity around entitlement is also a key element in developing the accountability of the system. Research participants with individual care packages sometimes referred to the funding as “theirs” and their “right”, and there was a sense of injustice if unused funds were not able to be personally redirected to areas of need, or were recouped and used by the organisation in other ways. This sense of entitlement for and ownership of the care package by recipients can underpin a strong sense of accountability that the individually-allocated resources are used appropriately, effectively and efficiently.

KEY MESSAGE #6

Policy and service delivery systems must enable ‘care in place’ where this is the preference of the individual

Policy programs that promote and enable care to be provided in the individual’s preferred place of living, despite changes in or increasing need for support, are required to prevent inappropriate and/or involuntary transitions, to minimise dependence on families and to overcome the lack of responsiveness and flexibility in current delivery systems. Recent Australian research details that flexibility in providing care in people’s preferred accommodation has greater wellbeing outcomes at no greater cost than group homes³⁹. Similarly, policies and programs that support community-based care arrangements for older populations have been pursued in the area of ageing policy and service delivery^{40, 41}.

In order to achieve ‘care in place’ several issues will need to be considered, including: the mechanisms for comprehensive and systematic assessment to accurately identify both the differing and changing care needs of individuals; a range of programs that have capacity for flexible and responsive delivery; and support for informal care networks.

KEY MESSAGE #7

There must be appropriate recognition of informal care networks as a critical resource in lifetime care both in policy and service delivery systems

Informal care is a critical and valued component of many people's care. Informal care by family and friends is part of the interdependency of social relationships. Use of informal care can be preferred because it makes use of personal relationships one is comfortable with and there is likely to be more opportunity for negotiation of these care arrangements⁴². It is also part of the gift exchange in which people are embedded. Ensuring that formal care does not crowd out valued informal care is important. A way forward can be to enable the conversion of informal care givers to paid formal care givers⁴³.

However, there are also risks in using informal care. The boundaries of voluntary informal care and informal care which is given without a choice and under a sense of obligation can be quite difficult to discern, and can be quite corrosive to personal relationships^{43, 44}. The provision of appropriate levels of formal care and a healthy respite care service sector is thus critical in reducing the development of unsustainable reliance on informal care.

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APPENDIX 1

Table A.1: Provision and Funding for Service Types by Individual Case Study

Case Study	Accommodation	Personal Care	Domestic Help	Respite	Aids & Equipment	Funding & Income
ABI_01	Facility Purpose built for young people with disability	NGO at facility	NGO at facility	-	Not applicable	YPIRAC & DSP
ABI_02	Facility Purpose built for young people with disability	NGO at facility	NGO at facility	NGO	MASS	YPIRAC & DSP
ABI_03	Facility	Facility	Facility	Facility & NGO	MASS	DSQ & DSP
ABI_04	Public housing	NGO	NGO	NGO	NGO & MASS	DSQ (ALSP) & DSP
ABI_05	Owner occupied (parents' home)	Business	Business	-	CTP Insurer	CTP compensation & part DSP to be refunded on settlement
ABI_06	Owner occupied	WorkCover & self	Self	Wife's holiday – Work-Cover	No equipment required	WorkCover, wife & Work-Cover settlement
HD_01	Facility (aged care)	NGO	NGO	-	-	Dept. Health & Ageing's ACFE, DSP
HD_02	Facility (aged care)	Facility	Facility	-	-	ACFE, Independent & Aged Pension
HD_03	Public housing	NGO1 (carers) & NGO2 (showering)	NGO1 & NGO2	-	MASS, privately funded & Department of Housing	DSQ (ALSP) & DSP

Case Study	Accommodation	Personal care	Domestic help	Respite	Aids & equipment	Funding & Income
MND_01	Owner occupied	Live-in carer, Privately -> DSQ	NGO - HAAC funded	-	Privately funded & specialised NGO --> DSQ	Independent --> DSQ individual funding, independent
MND_02	Owner occupied	NGO1 - EACH package	NGO1 - EACH package	NGO1 - EACH package, QHealth	NGO1, NGO2, MASS, specialised NGO & Privately funded	Dept. of Health & Ageing, DSP
MND_03	Owner occupied	CACP, business1, 40% privately funded	Business1 & privately funded	Business2 & private – short holiday	Specialised NGO & privately funded	Dept. Health & Ageing, independent & MND_03F carer's allowance
MS_01	Public housing	NGO1 & NGO2	NGO2	-	MASS & privately funded	DSQ block funding & DSP
MS_02	Owner occupied	Husband	Home Care (DSQ funded)	Specialised NGO & C'wealth Carers Respite	MASS, specialised NGO & privately funded	DSQ, DSP & MS_02F carer's pension
MS_03	Public housing	NGO	NGO, Home Care	No source	MASS, QHealth & privately funded	DSQ funded ALSP, DSP
MS_04	Facility (aged care)	Facility	Facility	-	MASS, & privately funded	Dept. Health & Ageing's ACFE, DSP

Case Study	Accommodation	Personal care	Domestic help	Respite	Aids & equipment	Funding & Income
MS_05	Owner-occupied	NGO1	NGO1 & MS_05F	NGO1 - weekly respite & longer respite at NGO2 (50% C'wealth funded)	CASS, MASS, specialised NGO, Community-Health, Home Assist, & privately funded	Dept. Health & Ageing's CACP, DSQ, HAAC, DSP (part), wife has carer's pension (part) & carer's allowance
MS_06	Facility	NGO at facility	NGO at facility	Privately funded short holidays & weekend home visits	Wheelchair & other equipment funding not identified	DSQ funded facility & independent
MS_07	Facility	NGO at facility	NGO at facility	-	MASS, CASS, & privately funded	DSQ block funding, DSP (part) & husband
MS_08	Facility	NGO at facility	NGO at facility	-	MASS, CASS & privately funded	DSQ block funding, Blind Pension & independent
SCI_01	Owner occupied	NGO	NGO & wife	NGO - weekly respite	MASS, SCIR, & privately funded	SCIR-DSQ, DSP & SCI_01F carer's pension
SCI_02	Private rental (mother rents)	NGO	NGO	Not taken	SCIR, MASS, & privately funded	SCIR-DSQ; DSP (part), mobility allowance & carer's pension
SCI_03	Public housing	NGO	NGO	NGO & family	Privately funded & MASS	SCIR-DSQ; DSP (part) & independent

Case Study	Accommodation	Personal care	Domestic help	Respite	Aids & equipment	Funding & Income
SCI_04	Public housing	NGO & self	NGO	-	MASS	SCIR-DSQ; DSP
SCI_05	Owner occupied	NGO	NGO & privately contracted cleaner	Family provided a holiday with two privately funded carers	MVA compensation payout	MVA compensation payout

Table A.2: Extent of Adequacy and Sustainability of Lifetime Care by Individual Case Study

Case	Adequacy	Qualifiers	Sustainability	Qualifiers
ABI_01	Mostly	Financial concerns (P & F). Limited rehabilitation (P). No "in house" psychological counselling available (CSP).	Yes	Till 65 years.
ABI_02	Mostly	Specific rehabilitation (F). No "in house" psychological counselling available (CSP).	Yes	Till 65 years.
ABI_03	Mostly	Financial concerns (P & F). Limited rehabilitation (P). Limited community access (P).	Somewhat	If she chooses to move, limited options remain (F). Subject to Centrelink funding (P).
ABI_04	Mostly	Financial concerns (P). "Very good" lifetime care (CSP).	Yes	Concern re funding (P). Concern re personal finances (F). "Very sustainable" (CSP).
ABI_05	Yes	-	Yes	Subject to settlement of third-party injury case, cessation of current intensive levels of therapies, & delay in transfer of payout to financial administrator (CSP).
ABI_06	Yes	-	Yes	-
HD_01	Mostly	Family not informed of hospitalisation for suicide attempt (F).	Yes	-
HD_02	Yes	Nil	Yes	Subject to global financial situation (F).
HD_03	Limited	Needs more carer hours on weekends (P). Needs her carer hours to almost double as her condition deteriorates (CSP).	Not discussed directly	Subject to decisions about funding increased care at home or admission to a facility (CSP).

Case	Adequacy	Qualifiers	Sustainability	Qualifiers
MND_01	Somewhat	Subject to him mortgaging his home (P) & using lower paid overseas carers (P & F). Specialised NGO has inadequate equipment supplies (P). He has insufficient suitable community based professional & transport services (P). He has applied to DSQ to fund a permanent live-in carer (CSP).	Yes	Subject to him reorganising his financial matters (P).
MND_02	Somewhat	Needs more consistent carers (F). Needs help with equipment costs (P). Needs affordable reliable taxis (F). Needs in-house respite or (medication) safe respite (F). Needs increased carer hours to further relieve MND_02F (CSP).	Somewhat	Subject to spouse's health & availability of respite (F). Subject to his declining health & wife's health (CSP).
MND_03	Somewhat	Subject to: disease progression (P), obtaining approved EACH package with 6 extra hours/week (P & F, & continuing private payment for extra care (P & F). Financial assistance is needed (e.g., health care card) (P).	Yes	Subject to his declining health, he may need to have a palliative care team replace his CSP carer (CSP).
MS_01	Somewhat	Additional combined personal & domestic care needed (CSP), especially in summer (F), & when ill (P).	Mostly	Subject to global financial situation (P), increased care as needs change (F), access to more funding (CSP).
MS_02	Somewhat	Additional cleaning needed (P & F). Lack of local high-quality respite care beds (F). Additional care needed (CSP).	Yes	Subject to pension meeting ongoing cost of living (F), spouse able to provide care (P), & respite breaks for spouse (CSP).

Case	Adequacy	Qualifiers	Sustainability	Qualifiers
MS_03	Somewhat	More good quality cleaning (P), on-call carer hours & carer support for outings needed (F). More carer hours when she is experiencing difficulties (CSP). Financial support for carer on short holiday (P, CSP).	Yes	-
MS_04	Yes	-	Yes	Personal financial concerns (P).
MS_05	Mostly	Suitable respite so MS_05F can take family holiday (F, CSP). Inadequate funding for catheters (P).	Mostly	Subject to political change (P), wife's health & access to in-house respite (P & F). Subject to decreased funding, his decline, wife's health (CSP).
MS_06	Yes	-	Yes	Till 65 years (CSP).-
MS_07	Mostly	Some health & rehabilitation services & social/mental activity not available in new facility (P), outings (CSP).	Yes	Till 65 years (P, F, CSP)
MS_08	Yes	-	Yes	Till 65 years (P, CSP).
SCI_01	Somewhat (P,F) to mostly adequate (CSP)	Adequately trained extra carer for roster & extra carer hours for emergencies (P). Inadequate funding of catheter supplies (P).	Yes	Subject to political change (P).
SCI_02	Mostly	Subject to adjusting to his situation (P).	Not discussed	-
SCI_03	Mostly (P) to Yes (CSP)	Apart from early psychological support, & limited security of her unit (P). Funding is adequate (CSP).	Yes	Apart from concerns about her personal finances (P).
SCI_04	Limited (P,F) to mostly (CSP)	Inadequate trained & available routine carers (P), & emergency carers (F), expectations of carers (CSP).	Yes	At current level.

SCI_05	Inadequate (F) to mostly (P, CSP).	Although adequately funded, quality and timeliness of care & support services are not adequate (F).	Limited (CSP) to mostly (F).	Better control & management of investment of his payout (F). Money could run out leaving option of a nursing home (CSP).
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Note: In Table A.2, (P), (F), and (CSP) mean that the person with lifetime care, the nominated family member or friend, or the Care Service Provider respectively has made the qualifying statement.

Table A.3: Summary of Unmet Care and Support Needs

Unmet care and Support Needs	Participant
Physiotherapy, hydro, exercise, fitness, massage	ABI_01, ABI_02, ABI_03, ABI_04, HD_01, HD_03, MS_01, MS_02, MS_03, MS_06, MS_07, SCI_02, SCI_03, SCI_04 (n= 14)
Increased hours, flexibility or quality care	HD_03, MND_01, MND_02, MND_03, MS_01, MS_02, MS_03, MS_05, MS_08, SCI_02, SCI_03, SCI_04, SCI_05 (n = 13)
Lifestyle enhancement*	ABI_01, ABI_02, ABI_03, ABI_04, ABI_06, HD_01, HD_02, MS_03, MS_05, MS_07, MS_08, SCI_04, SCI_05 (n = 13)
Other health & rehabilitation	ABI_02, ABI_03, ABI_04, HD_01, MND_01, MS_07, SCI_01, SCI_02, SCI_03, SCI_05 (n = 10)
Transport & getting around	ABI_01, HD_03, MND_01, MND_03, MS_01, MS_02, MS_03, MS_07, SCI_02, SCI_05 (n = 10)
Information, advice, negotiation, advocacy	ABI_03, ABI_05, ABI_06, HD_03, MND_02, MS_02, MS_04, SCI_03, SCI_04 (n = 9)
Counselling/stress management/support	ABI_01, ABI_02, ABI_04, MS_06, MND_01, MND_02, SCI_03, SCI_04 (n = 8)
High quality respite/holiday support	MND_02, MND_03, MS_02, MS_03, MS_05, SCI_03 (n = 6)
Additional (family) financial assistance	MND_01, MS_02, SCI_01, SCI_02, SCI_03, SCI_04 (n = 6)
Increased domestic assistance	HD_03, MND_02, MS_01, MS_02, MS_03, SCI_01 (n = 6)
Transparency of funding/use of lifetime care	MND_02, MS_02, SCI_02, SCI_04 (n = 4)
Case manager/coordinator	ABI_01, ABI_06, SCI_05 (n = 3)
More secure/safer housing	HD_03, MS_05 (n = 2)
Improved wheelchair accessibility	MS_05, SCI_02 (n = 2)
More independent living/own space	ABI_01, ABI_05 (n = 2)
Legal advice about compensation	ABI_01 (n = 1)
More choice of care & therapy	ABI_05 (n = 2)

Note: * Lifestyle enhancement includes two or three of the following activities: social activities, mental activities, and community access.

