THE MCKELL INSTITUTE

Disability & Rare Disease:

TOWARDS PERSON CENTRED CARE *for* AUSTRALIANS *with* RARE DISEASES

OCTOBER 2019

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ABOUT RARE VOICES AUSTRALIA

Rare Voices Australia (RVA) is the national non-profit peak organisation advocating for all Australians who live with a rare disease — a strong common voice to advocate for policy and systems that work for those with rare diseases. RVA has been funded by the Australian Government to collaborate with stakeholders to develop and deliver a National Strategic Action Plan for Rare Diseases. RVA acknowledges and thanks the RVA Partner organisations and Australians living with rare disease who contributed to the development of this Report.

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Disability & Rare Disease:

TOWARDS PERSON CENTRED CARE for AUSTRALIANS with RARE DISEASES

ANGELA JACKSON
(EQUITY ECONOMICS)

OCTOBER 2019

EQUITY ECONOMICS

ABOUT THIS REPORT

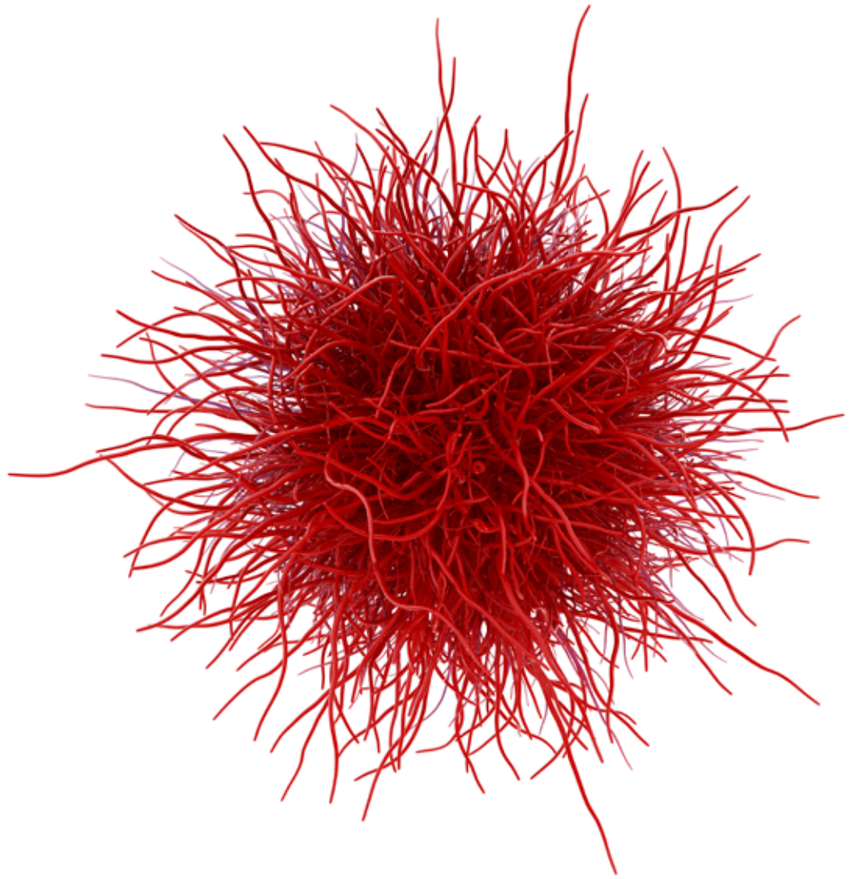
This White Paper was commissioned by Rare Voices Australia on behalf of partner organisations and people living with rare disease to inform their ongoing advocacy efforts for equitable access to high quality services for all people living with a rare disease. The White Paper was also timed to be able to inform the development of the National Strategic Plan for Rare Diseases.

In developing the White Paper, we held consultations with stakeholders, conducted a nationwide survey of people with a rare disease and their carers and reviewed the international literature on the provision of health and disability care services.

In undertaking the first national survey of people with rare diseases on access to health and disability services, we aim to give people that are often not heard or understood a voice. They have told us the current system is not meeting their complex health and disability care needs.

The evidence collected highlights very high levels of unmet need for health and disability care services and significant gaps in the policy framework in providing integrated care across the health and disability care services.

Our recommendations are focused on reforms which would deliver integrated care for those with health and disability care needs, improve the understanding of rare diseases by health and disability care workers and ensure that the systems can respond to the changing needs of people with rare diseases that are complex and sometimes difficult to predict.



ABOUT THE AUTHOR ANGELA JACKSON

Angela Jackson is an experienced public sector economist with almost 20 years' experience working as an economist on public policy issues.

Angela was Senior Advisor and Deputy Chief of Staff to the Australian Minister for Finance and Deregulation from November 2007 to September 2010.

Currently completing a PhD in health economics, Angela has specialised knowledge of the health sector alongside an intimate understanding of government.

Angela also serves as a non-Executive Board Member of Melbourne Health, which runs Royal Melbourne Hospital, and is a member of the Victorian Advisory Board for the National Heart Foundation.

This report and independent economic modeling was prepared by Equity Economics, a unique economic consultancy providing original analysis and new approaches to addressing complex economic policy challenges.

www.equityeconomics.com.au

The report was commissioned by Rare Voices Australia (RVA) with independent funding assistance from Sanofi Genzyme.

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CONTENTS

FOREWORD

As Australians, we are fortunate: we all have the right to quality care and support when we need it. Many of Australia's most successful public policy achievements have been in the field of health, creating a universal system that is the envy of much of the world. But, despite the successes of Australia's health system, not every Australian receives the quality of care and support they require.

This report explores an issue that rarely makes front page news: the care and support of people living with rare disease and whose conditions lead to disability.

Diseases are considered 'rare' when they affect less than five in 10,000 Australians. But while the individual diseases may be rare, the overall number of Australians living with rare disease is not uncommon.

Between 5-8 per cent of the population, or almost two million Australians live with a rare disease — as this report highlights, this is more than the number of people living with diabetes, a key Government health priority.

These people regularly experience forms of disability as a result of their condition. Unfortunately, the existing disability support system has proven unable to consistently meet the needs of these people. Overcoming this major deficit in the health and disability systems is this report's focus.

The formation of the National Disability Insurance Scheme (NDIS) has been one of the most significant reforms in Australia's history. While it has led to major improvements in support for many Australians living with disability, it is still a nascent institution with obvious deficits. One such deficit has been the NDIS' inability to offer the support required by many Australians experiencing disability as a result of rare disease.

This report tables alarming findings based on extensive survey data made possible by the participation of people living with rare disease.

It finds that a third of people have experienced a deterioration in the support they receive under the NDIS, that NDIS planners and coordinators often lack vital expertise to offer the support required, and that many people living with rare disease incur significant out-of-pocket costs just to receive some of their most basic needs.

This report also shares powerful anecdotes by research participants. In sharing their experiences, these participants allow us to look beyond the data and understand the human story of a system that too often fails to meet its objectives.

Despite the challenges, there are pathways to a better system. This report offers seven key recommendations aimed at improving the delivery of care to people living with rare disease across Australia, and ensuring that the NDIS continues to improve its ability to meet its vital mandate to guarantee support and dignity to all Australians living with a disability.

EXECUTIVE SUMMARY

Health and disability care systems increasingly focus on providing person centred care, which responds to the needs of the individual. Person centred care is higher quality and more cost effective care,[1] and is particularly important for people with rare diseases who frequently have complex and multi-system needs.[2]

While a rare disease is defined in Australia as affecting less than five in 10,000 Australians,[3] around 5-8% of Australians live with a rare disease.[4] This compares to the five in 100 Australians with diabetes.[5] Therefore, while the occurrence of individual rare diseases is uncommon, having a rare disease is in itself relatively common.

Having a rare disease creates specific challenges as the health and disability care system is traditionally focused on detecting, treating and managing diseases and conditions that affect a large number of patients and is not geared towards meeting the unique, complex and multi-system needs of people with rare diseases.

We present results from a Rare Disease survey of 771 people with a rare disease and their carers and find that over **seven in 10 people with a rare disease report not having their health and disability care needs met**.

While not every person with a rare disease will have an associated disability, those who do will often require assistance in activities of daily living.[6] However, unlike many other conditions that cause disability such as intellectual disability or paraplegia, rare diseases often progress over time and change the nature of an individual's needs. Any system providing support to people with rare diseases therefore needs to be flexible and responsive.

The National Disability Insurance Scheme (NDIS) commenced in a number of trial sites in July 2013 and currently covers over 200,000 Australians. The NDIS is scheduled to be fully rolled out by June 2020 and will cover over approximately 275,000 people.

The NDIS has revolutionised the way in which disability support is delivered in Australia, aiming to meet individual needs and aspirations. However, the NDIS has also broken down many of the existing linkages between the health and social care sectors relied on by people with rare diseases.

The NDIS is explicitly not designed to replace mainstream health services for people with a disability and consequently, only covers supports for activities of daily living and not medical expenses. For individuals who have a disability with an underlying and ongoing medical cause, such as people with rare diseases, there can often be grey areas in coverage creating delays and confusion. In addition, this delineation between health and disability services does not promote care integration that can best support the complex needs of people with rare diseases.

The Accessing Support for People with Rare Disease survey (Rare Disease survey) finds that despite the NDIS increasing the funding for disability services threefold, **almost one in three people have experienced deterioration in the supports they receive under the NDIS**. Respondents to the Rare Disease survey reported that NDIS planners and support coordinators lack necessary clinical expertise leading to failure to incorporate key support recommendations in plans.

In order to address the high level of unmet needs and the lack of knowledge and expertise around rare diseases we review international approaches to delivering person centered care. The majority of countries studied have developed and are implementing rare disease plans and strategies covering access to services, early diagnosis and research.[7]

A key pillar in these strategies is the establishment of specialist centres for rare disease to provide disability and health care providers with up to date information on individual rare diseases and inform best care pathways.

In some countries the delivery of services is supported by specific policies to better integrate care for people that require both health and disability care services, including the use of a single individualised planning process.[8]

RECOMMENDATIONS

Drawing on this international evidence and the findings from the Rare Disease survey we make a number of key recommendations:

RECOMMENDATION 1

Australia develops, endorses and implements a Rare Disease Strategy.

RECOMMENDATION 2

Australia establish a model of rare disease centres of excellence to address knowledge gaps and ensure all Australians with a rare disease have access to the best evidence-based care.

RECOMMENDATION 3:

Australia introduce personal care plans to cover an individual's health, education and disability care needs. These over-arching integrated care plans would allocate responsibility for the delivery of services to specific levels of government.

RECOMMENDATION 4

The Government centralise existing information on rare disease with a searchable data base of information on rare diseases which health and disability professionals, patients and families, can access and inform.

RECOMMENDATION 5

Introduce mandatory training of relevant health and disability care professionals on the nature of rare diseases, effective management strategies, how to locate information and referral pathways to support and advocacy groups.

RECOMMENDATION 6

Urgent review of delays in access to equipment to ensure that NDIS participants receive approved equipment in a timely manner.

RECOMMENDATION 7

NDIA to incorporate a 'fast tracking review' category for people with rare diseases who have been identified as having permanent and significant disability. This would allow quicker access to additional supports when required through consultation with clinicians.

PERSON CENTRED CARE

Person centred care is a way of structuring services with people as partners in the planning, developing and monitoring of care to make sure their needs are met . It is now considered a key component of delivering high quality health and social services.[10]

Person centred care can be seen as valuable in itself, but it also aims to deliver:[11]

- Improved quality of services;
- Care that is needed when it is needed;
- Enable people to be more involved in caring for themselves; and
- Reduce pressure on health and disability services.

Person centred care has many different components, and how it is implemented will depend on the specific circumstances of the services being delivered and the individuals receiving care. As such there is no single definition of what defines person centred care and it must be developed for each situation.[12]

There is extensive research on what matters to people receiving care and how to make sure people have a good experience. This research has identified a number of components to person centred care including:[13]

- Respecting people's values and putting people at the centre of care;
- Taking into account people's preferences and expressed needs;
- Looking at people's whole experience of care to promote coordination and continuity;
- Making sure that staff are supportive, well trained in communication and striving to put people at the centre of their care;
- Making sure there is continuity between and within services; and
- And making sure people have access to appropriate care when they need it.

A growing body of research shows that person centered care can improve people's health and also reduce the burden on services.[14] However, the evidence can be mixed because person centred care often means different things to different people.[15] This makes it critical that we answer the question: **"how can we place people with rare diseases at the centre of their care, and make this care appear seamless because it is organised around the individual?"**

PART ONE: BACKGROUND

People with rare diseases often require health and medical services, and assistance with meeting their daily living needs. While not covered in detail in this report, children and adults with rare diseases also often require supports to access education.

Successfully navigating separate systems that are supported by a mix of commonwealth, state and private funding with services delivered by government, for-profit and non-profit providers requires detailed knowledge of each system. Below we provide background information on Australia's disability support, health and education systems.

About the NDIS

The NDIS was launched in 2013 and will cover approximately 450,000 participants at a cost of $22 billion per year when fully rolled out.[16] The NDIS represents a fundamental transformation of disability service provision in Australia, with a move to choice and competition in the sector for the first time.

The NDIS provides funding for individuals with a disability to live their lives how they want to live. Through in-person planning meetings with an NDIS planner or local area coordinator, people with a disability are able to identify what it will take for them to meet their goals.

In order to qualify for funding people with rare diseases must provide evidence from medical providers and allied health professionals of their needs in daily living. These reports often require payment for specific assessments and reports.

Importantly, the NDIS explicitly does not cover medical services or education services delivered in schools.

Funding can cover the cost of supports for education, employment, independent living, health and wellbeing, but must meet the criteria for being "reasonable and necessary".[17] This means that the supports must:

- Be directly related to an individual's disability;
- Represent value for money;
- Be effective and benefit the participant; and
- Factor in the informal supports provided by family, carers, and communities.

Options are available for people with a disability to decide who they get support from and how it is delivered, coordinate the support and receive funding. This coordination and funding management can be undertaken by a third party if they choose — and can be included in their NDIS plan under "support coordination".

The NDIS also covers supports delivered or supervised by health professionals where the person's functional capacity has reached stability.

This may include:[18]

- Funding for a support coordinator to help organise service providers;
- Allied health and other therapy where this is required as a result of the participant's impairment, including physiotherapy, speech therapy or occupational therapy. However, the health system is responsible for these supports if they are required as part of rehabilitation from an accident or injury or as part of treatment for medical conditions;
- Home and vehicle modification (e.g. installation of ramps, rails, hoists);
- Community activities (e.g. support to access social groups, sports clubs or study); and
- Nursing or delegated care associated with feeding, catheter care, tracheostomy care, skin integrity checks.

The health system responsibilities

Australia's health system is famously fragmented with public and private provision, combined with state government, Commonwealth government and private funding.[19]

The state governments operate public hospitals, which provide around two thirds of all hospital admissions. The Commonwealth has responsibility for Medicare (for out of hospital medical care and in-hospital private medical services) and for Pharmaceutical Benefits Scheme (which covers prescription medicines).

In addition, there is a large role for private health insurance and private health care, which is heavily subsidised by the Commonwealth Government.

The health system is responsible for providing people with rare diseases with clinical and medical care, including:

- Diagnosis of medical conditions (including chronic conditions);
- Clinical treatment of medical conditions, including services such as general practitioners, hospital care, surgery, dental care and medical specialists; and
- Pharmaceuticals such as medicines, vaccines, topical preparations.

Previous research indicates that people with rare diseases face significant issues, including delays in diagnosis, lack of available treatment and difficulty finding the right health service.[20]

Education system

Australia's education system is also characterised by government and private provision.

Children with rare disease that attend school may receive additional supports where necessary. These supports can be funded under the NDIS if they are general, such as for feeding. The schools must provide any educational specific supports directly.[21]

In order to access additional school supports, parents must apply to relevant state or private providers. This process is separate from supports provided by the NDIS.

> "LOGAN AND JORDAN HAVE FALLEN ON THE WRONG SIDE OF THE ARTIFICIAL LINE BETWEEN DISABILITY AND MEDICAL NEEDS."

LOGAN & JORDAN'S STORY

Logan and Jordan are 7 and 10 year old brothers growing up on the Central Coast of NSW, they were both born with a rare genetic condition.

Our family has had a lot of luck over the years and with hard work we have made contributions to Australia in the fields of sport, the arts and many other ways. But we have also had some bad luck, and thanks to modern medicine we now know that that bad luck was caused by a genetic disorder.

The condition which has affected our family means that Logan and Jordan are unable to absorb nutrients from food or fluid and must receive all their nutrients required to sustain life through a tube straight into their bloodstream. They have a form of Intestinal Failure, which requires intestinal drainage tubes and incontinence requiring changing up to 20 times a day. The boys cannot go swimming or do a lot of things kids their age enjoy. But with the right support they could be doing more things other kids take for granted — like go for a sleepover.

Both Logan and Jordan struggle with managing their condition, and have associated behavioural problems. They require speech pathology for oral aversion and physio for muscle strength. These services are not provided by the health system and without access under the NDIS they are not getting the interventions they need to lead their best lives.

In days gone by my grandsons Logan, 7, and Jordan, 10, may not have made it out of infancy. With the right treatment the boys have an expected life expectancy of early adolescence. We feel lucky, that there is now a way to treat the condition that has impacted our family for generations. When it was announced we hoped that the NDIS would finally be able to provide much needed help in caring for Logan and Jordan, including speech pathology, physiotherapy, occupational therapy and behavioural psychological supports.

However, we got unlucky again. Logan and Jordan have fallen on the wrong side of the artificial line between disability and medical needs, despite their condition being life long and requiring assistance in daily living such as feeding, toileting, dressing and bathing. They both also have developmental delays, and Jordan is receiving assistance under the NDIS for an intellectual handicap but not for his genetic condition. Logan has been denied access to NDIS.

Jordan and Logan need assistance across the health, disability and educational sectors — but the support is not coordinated and requires us to advocate continuously for support. Why the system can not work as one around the people and families needing help doesn't make sense to me — instead we are left trying to piece it all together and unfortunately for us Logan and Jordan have fallen through the cracks.

The whole extended family pitches in to help care for Logan and Jordan, from helping get them ready for school in the morning, to staying with them during regular hospital stays — it is a huge task and I am very proud of how my family has come together.

Logan and Jordan are going to have shorter lives because of their condition. All I want as their "Pop" is that those lives are their best lives. To do that we need to be able to access the supports they need — and artificial lines are no help.

PART TWO: THE SURVEY RESULTS

In order to better understand the issues facing people with rare disease in accessing health and disability services, and the impact of the NDIS, we conducted an online Rare Disease survey (see Appendix for details of survey methodology).

398 people with a rare disease and 373 carers of people with a rare disease completed the survey (see the Appendix for full survey methodology).

> "THE RARE DISEASE I HAVE IS EXTREMELY MISUNDERSTOOD AND EXTREMELY ISOLATING. COMPLETELY APART FROM THE PHYSICAL EFFECTS IT HAS HAD ON ME ARE THE EMOTIONAL AFFECTS."
>
> PARTICIPANT, NSW

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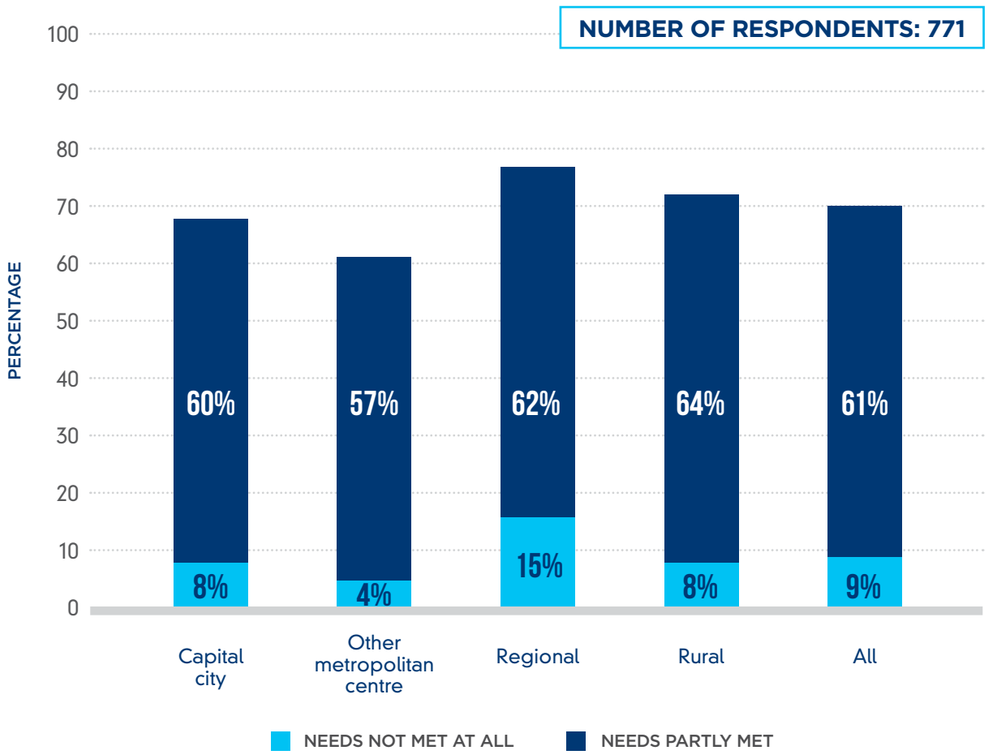
Health care needs

The survey asked whether people with a rare disease had their health care needs met. Seven out of 10 respondents reported having their health care needs either partly met or not met at all. The problem is worse in regional Australia where over 77 per cent of respondents have unmet needs for health care services, including 15 per cent who do not have their health care needs met at all.

> "What care? I can't even find decent basic services in a rural town I need to travel four to five hours for anything regarding treatment or basic diagnostics." **PARTICIPANT, NSW**
>
> "I just sometimes wish doctors and medical professionals had more compassion and understanding." **PARTICIPANT, WA**

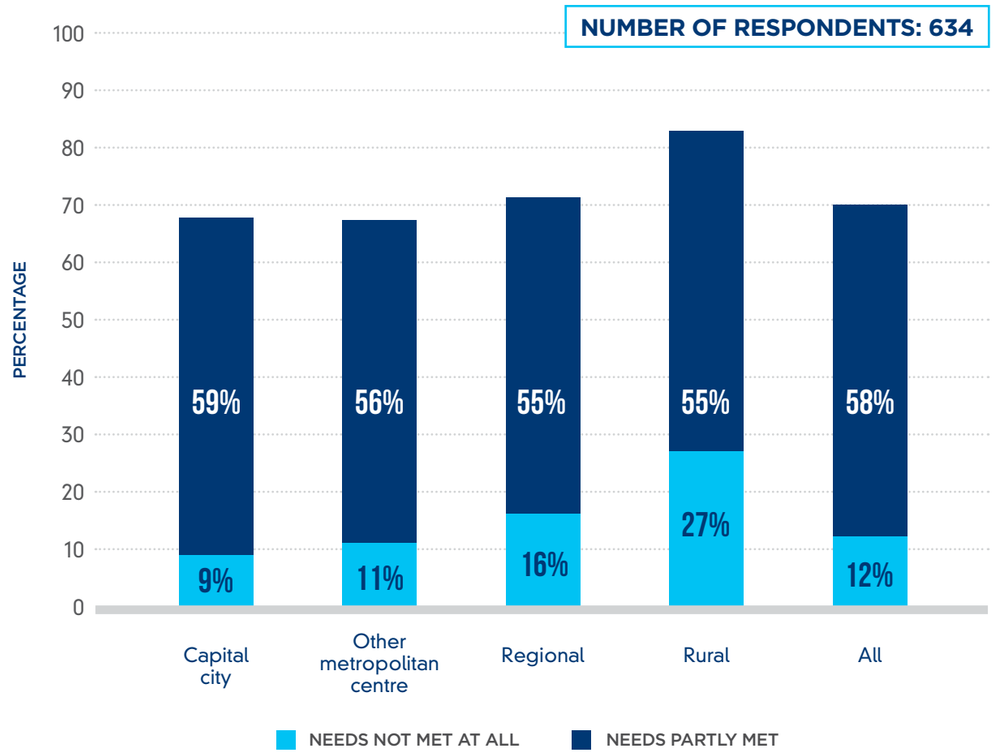
FIGURE 2.1
UNMET NEED FOR HEALTH CARE BY AREA OF RESIDENCE



Assistance care needs

Seven out of 10 respondents with disability care needs reported these were either not met at all or only partly met. Again the problem is worse in rural Australia, where over eight in 10 report not having their needs fully met, including over one in four people reporting that their needs for assistance were not met at all.

FIGURE 2.2
UNMET NEED FOR DISABILITY ASSISTANCE BY AREA OF RESIDENCE

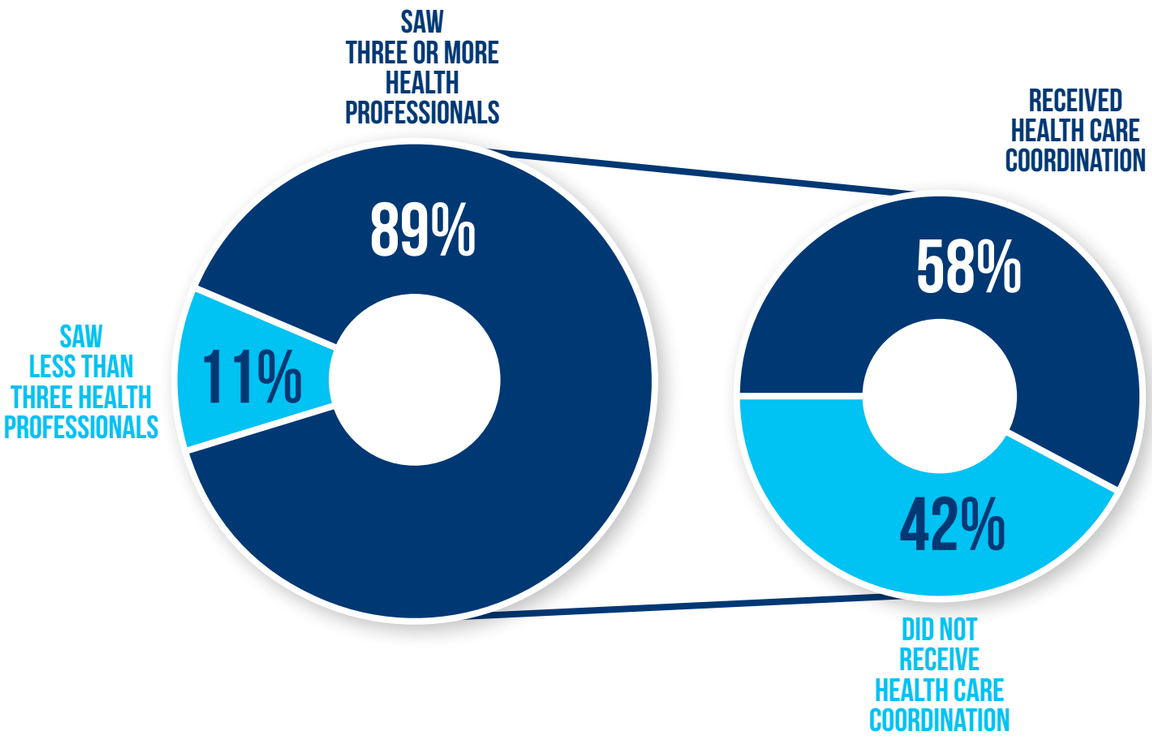


Rare diseases are complex

Almost 90 per cent of the survey responders reported seeing three or more health professionals in the last year for their condition. This is significantly higher than the 37 per cent of people who responded to the 2015 Survey of Disability and Carers and reported seeing three or more different health professionals for the same condition.

Thirty five per cent of those reporting seeing three or more health professionals did not have any help with health care coordination.

FIGURE 2.3 COMPLEX NEEDS

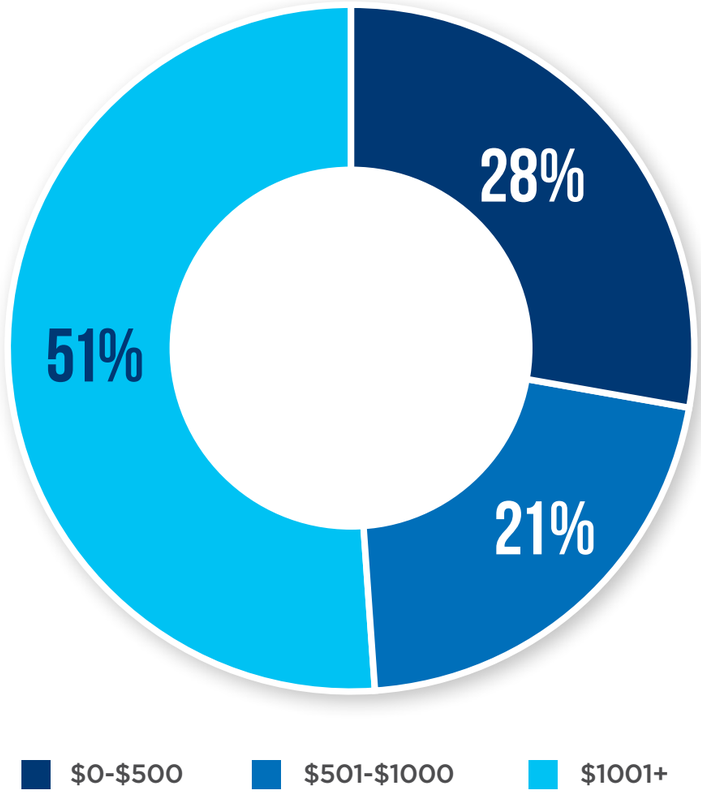


NUMBER OF RESPONDENTS: 771

Rare diseases are costly

The survey included questions about the size of out of pocket costs associated with an individual's rare disease. Almost half of the respondents reported spending more than $1000 a year on treating their rare disease.

FIGURE 2.4 HIGH OUT OF POCKET COSTS



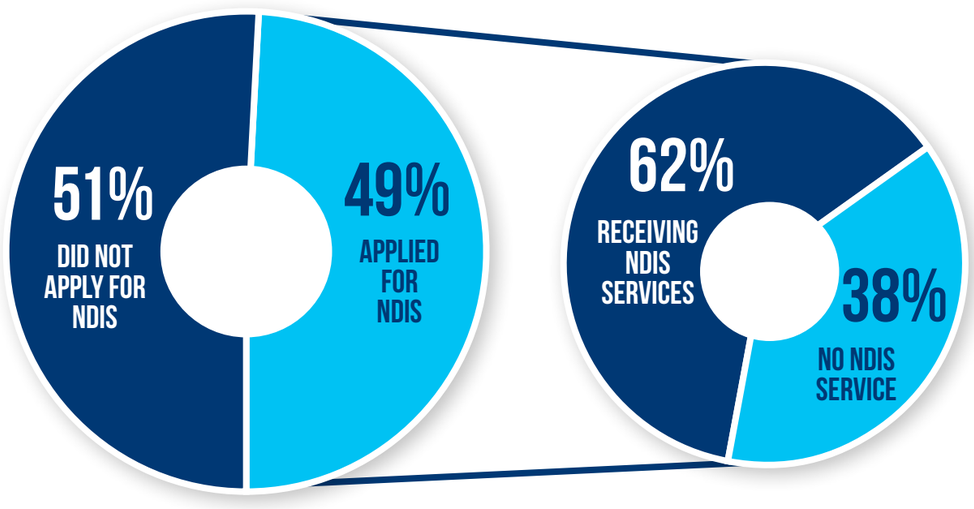
NUMBER OF RESPONDENTS: 771

The National Disability Insurance Scheme

Almost half of the survey responders had applied for funding under the NDIS, with over three quarters that had applied receiving assistance under the scheme.

> "The NDIS does not cater to those that have a medical condition and they have made that very clear … and that's not fair."
> **PARTICIPANT, VIC**

FIGURE 2.5 ACCESSING THE NDIS



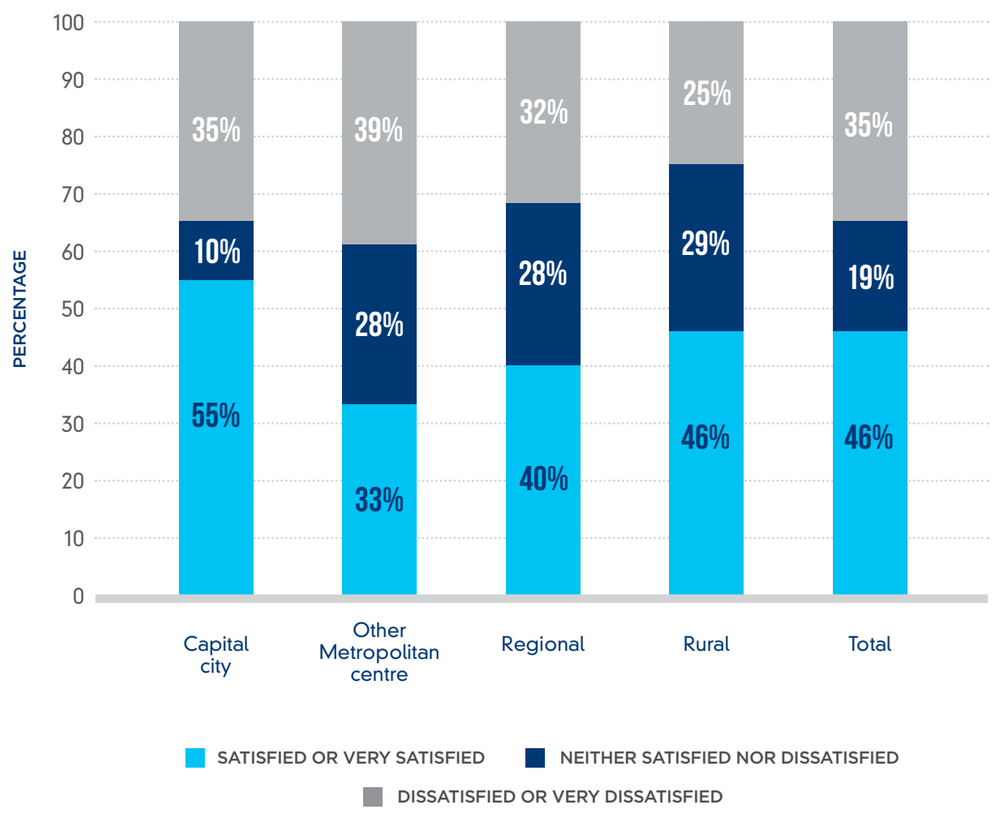
NUMBER OF RESPONDENTS: 771

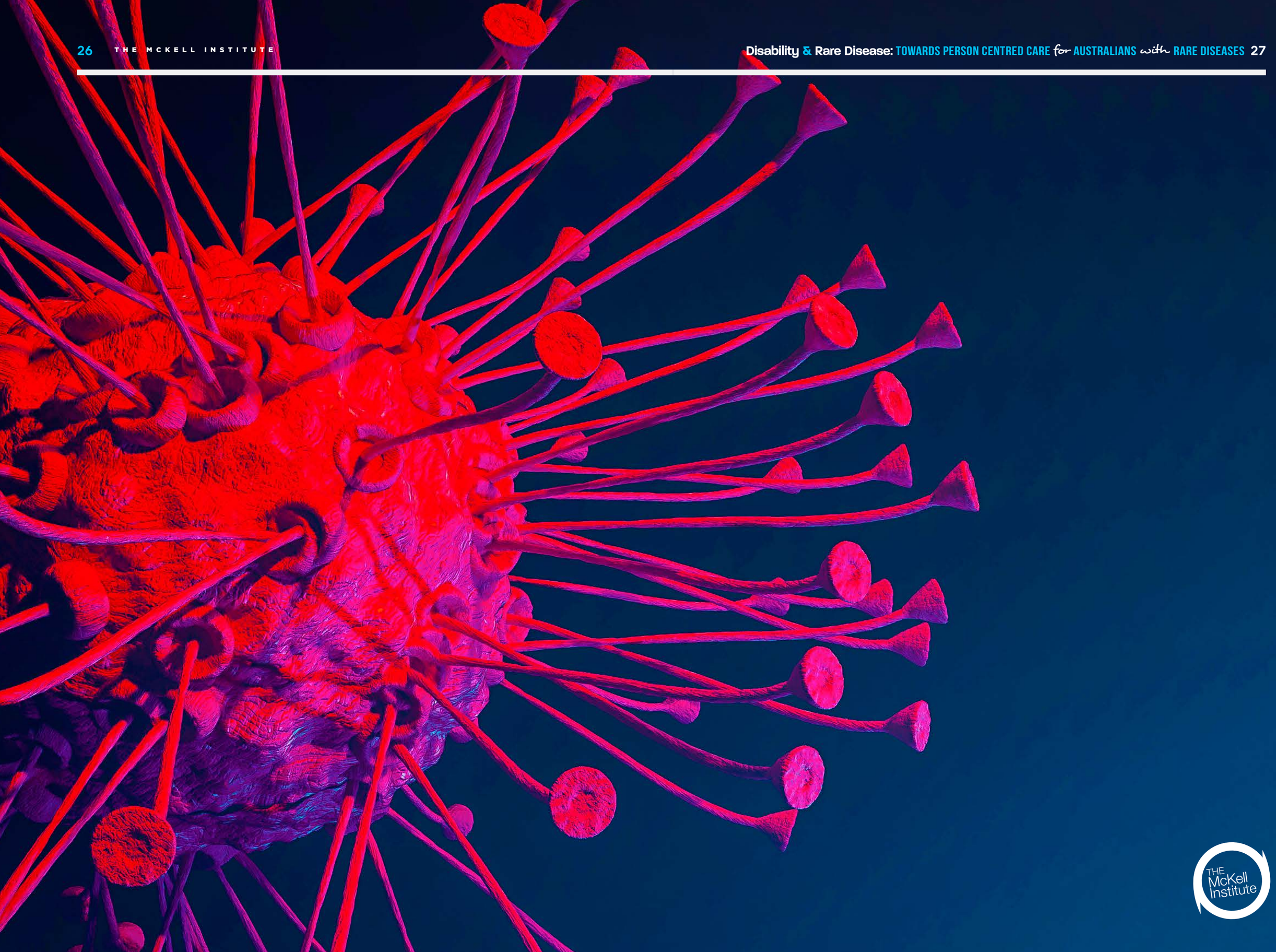
NDIS satisfaction

Asked about their satisfaction with services received under the NDIS, one in three people report being dissatisfied or very dissatisfied with the NDIS. Of those receiving services under the NDIS nine per cent report being very satisfied, and 35 per cent report being satisfied. The highest level of dissatisfaction is in outer metro regions, where 40 per cent of people are either dissatisfied or very dissatisfied.

FIGURE 2.6 NDIS FUNDING SATISFACTION BY AREA OF RESIDENCE

NUMBER OF RESPONDENTS: 277





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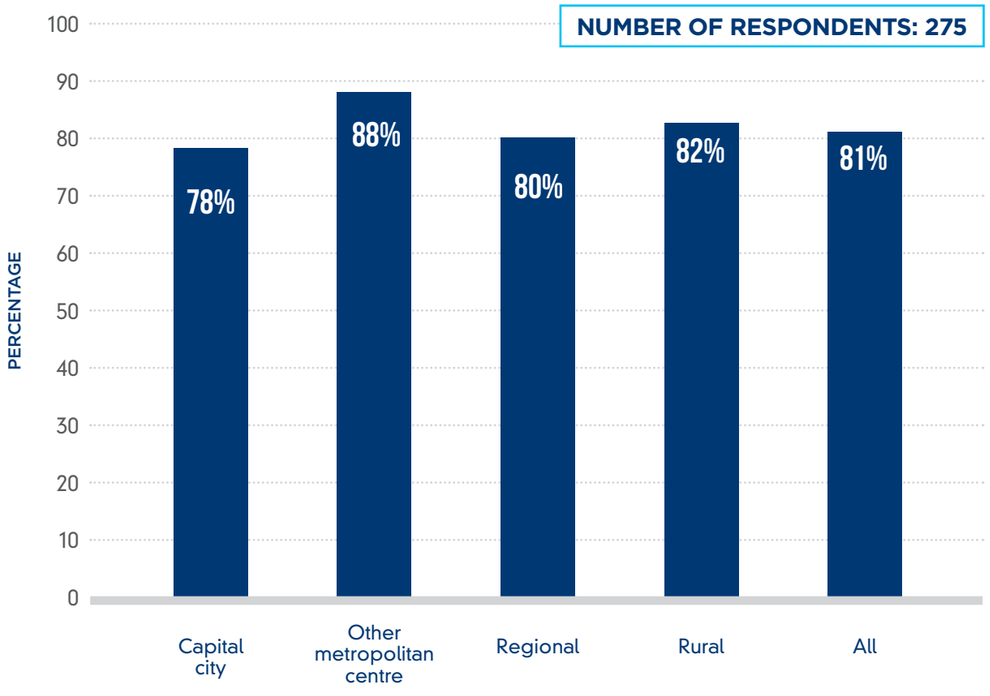
NDIS delays

While a high proportion of respondents were satisfied with the services they were receiving under the NDIS, four out of five respondents indicated they had experienced delays in receiving supports.

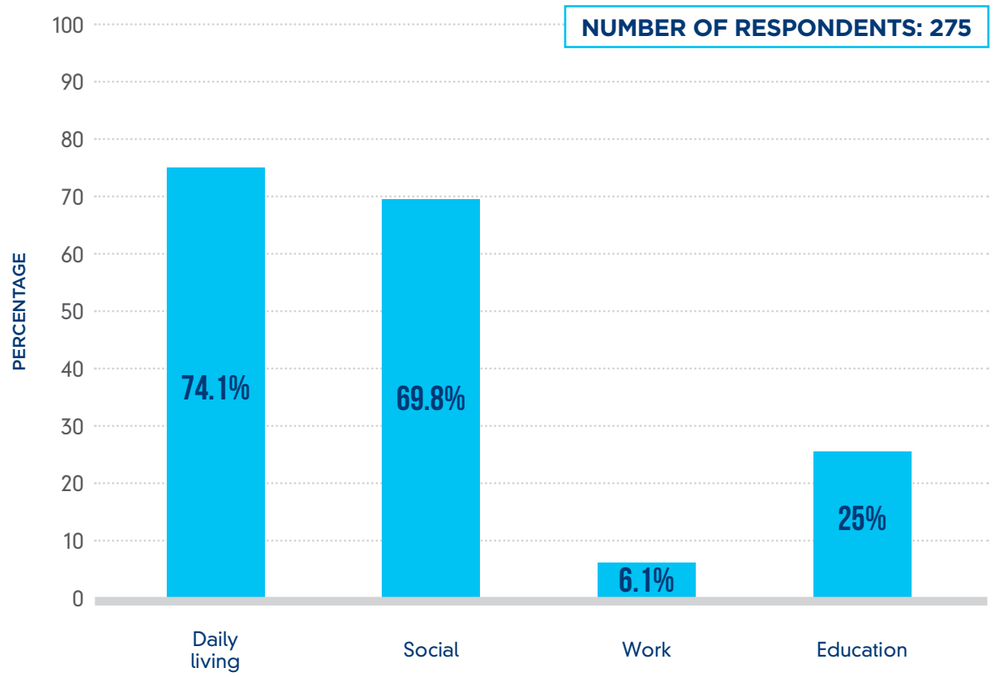
"Now that I have the NDIS it is great, but getting approved for the scheme was very difficult. It took 18 months in total, three appeals and lawyers and advocates getting involved. If it were not for the work of my advocate and her determination I would have given up long before the end of the process. The NDIA eventually settled the case two weeks before we were due for a hearing at the AAT. It was a soul destroying, horrible process that made me feel like a useless burden. They continually argued that my condition was medical, and not a disability. But the people I dealt with had no understanding of my condition, and also could not explain to me what the difference between a debilitating medical condition and a disability was. I feel that much of the problem stemmed from the fact my condition is so little known... it doesn't have the same recognition as something like MS or muscular dystrophy." **PARTICIPANT, VIC**

FIGURE 2.7 NDIS DELAYS BY AREA OF RESIDENCE



Of those experiencing delays we asked how this had impacted their ability to undertake day to day activities, and the results indicated that the delays impacted the ability to undertake daily living activities for almost three out of four respondents, and the ability to undertake education activities for one out of four respondents.

FIGURE 2.8 IMPACT OF DELAYS IN NDIS FUNDING

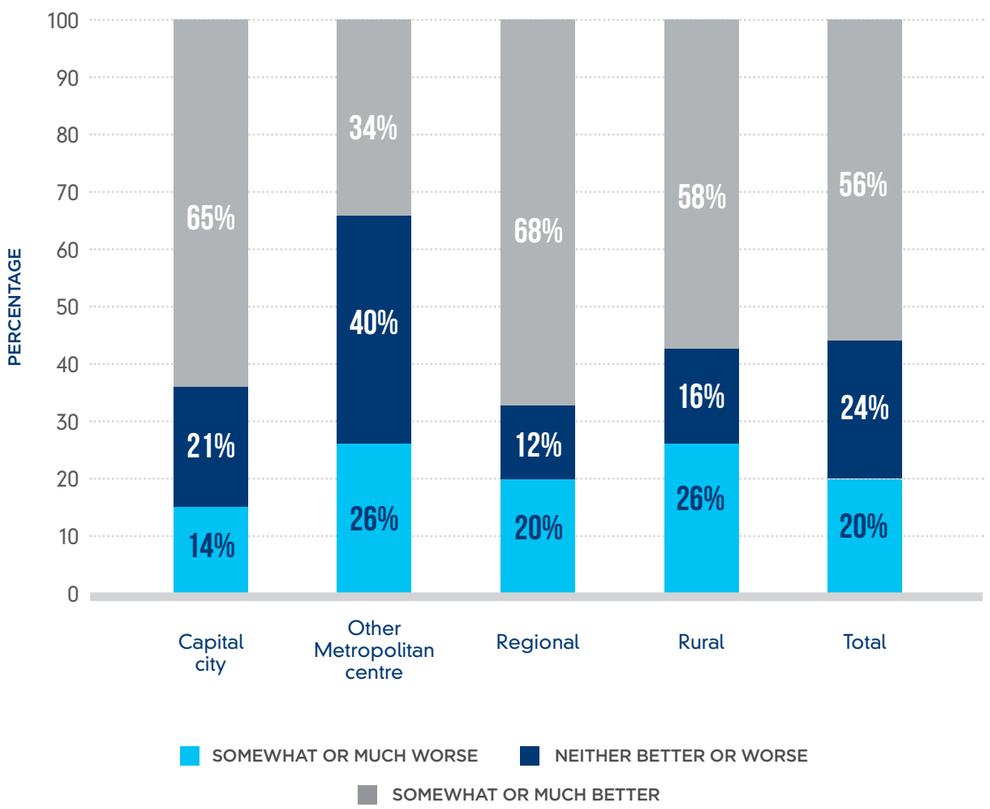


The impact of the NDIS

We asked respondents whether the NDIS had improved or worsened their situation. One in five respondents indicated that the NDIS had made their situation worse. One in four respondents in rural and non-metro centres reported that the NDIS had made their situation worse.

FIGURE 2.9 NDIS SERVICE CHANGE BY AREA OF RESIDENCE

NUMBER OF RESPONDENTS: 275

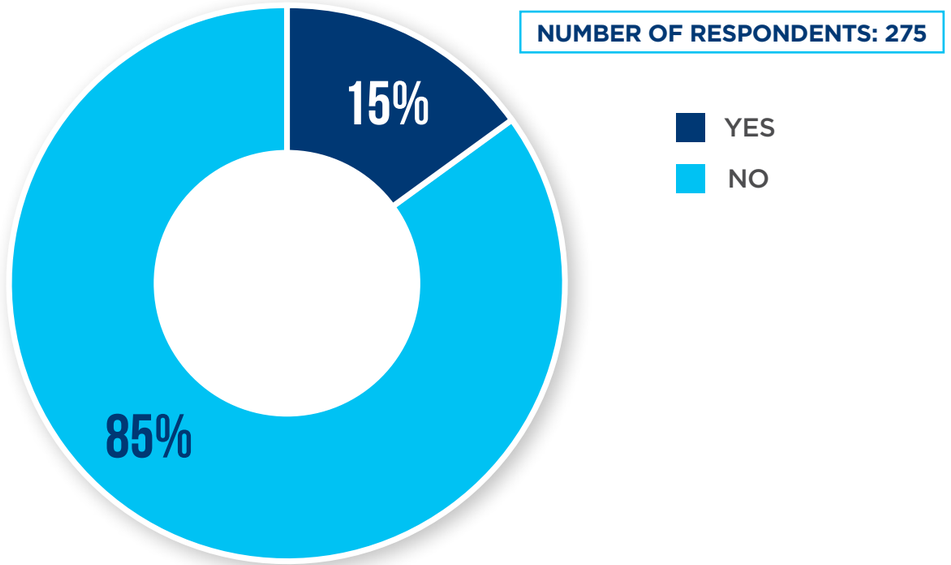


Ability to meet changing needs

Respondents who received services under the NDIS were asked whether they thought the NDIS would be able to meet their changing needs. Eighty five per cent of respondents indicated that the NDIS would not be able to meet their changing needs in a timely manner.

> "Many of us do not qualify for help because our conditions go in and out of remission. Sometimes I can work other times I can't for months but there is nothing to consider this. The majority of time we cannot afford medications or specialist appointments either." **PARTICIPANT, VIC**

FIGURE 2.10 WILL THE NDIS MEET YOUR CHANGING NEEDS



The Rare Disease survey provides a snap shot of the experience of people with rare disease attempting to access health and disability care services. It provides strong evidence of significant gaps in services, which are negatively impacting on the ability of people with a rare disease to live their best lives.

Drawing on the survey results in the next section we explore the key issues with the current systems.

PART THREE:
KEY ISSUES

People with rare diseases face a number of issues as they seek to have their health and disability care needs met, so that they can have their diseases properly treated and live their best lives.

Drawing on the findings from the Rare Disease survey, detailed case studies and consultations with representative bodies, we outline below the key issues for people with a rare disease trying to live their best life.

Unmet needs for health and disability services

Individuals with rare diseases rely on an array of services from both the disability care and health sectors to meet their needs. The high levels of reported unmet needs in the Rare Disease survey indicates that the current system has significant gaps in the necessary disability and health supports for individuals with rare diseases.

The problems are worse in rural and regional Australia, where there are often no specialists or treatment options available. As a result, people with rare diseases have to travel significant distances to receive treatment and may have no access to supports to meet their daily living needs. The lack of coordination can often lead to people making multiple trips into larger centres, adding to these issues.

The separation of funders which has occurred under the NDIS between the disability and health sectors has created gaps in service provision, which in contested spaces, can impact individuals with rare disease that have an underlying medical cause of their disability. This is evidenced by the high number of people reporting in the Rare Disease survey that the NDIS worsened their situation. In addition, there were a number of reports of people being denied access to the NDIS or having access delayed as it was argued that they had a medical condition and not a disability.

There are also concerns that such gaps may open up in other areas as well including accommodation services and school transportation services, as responsibilities transfer from state government to the NDIS.

CHARLIE'S STORY

A Mum shares her experiences with accessing the NDIS for her three-year-old son Charlie, who has an undiagnosed genetic condition.

Our little boy Charlie is a typical three year old in many ways — always smiling and with an infectious laugh; he adores his big sister Chloe. But Charlie has complex disability and medical needs due to a rare and undiagnosed genetic condition.

Despite extensive genetic testing we still do not have a diagnosis. This has made it hard to come to terms with Charlie's condition, as we had no explanation for why this happened.

We hoped the NDIS would offer us inclusive and coordinated care, but a lack of diagnosis has been a road block to obtaining the level of funding Charlie needs.

I recognise that without a diagnosis there is no clear path for the NDIS to follow however this is not Charlie's fault. More education of the NDIA workforce around the unique challenges of raising a child with a complex rare or undiagnosed condition is essential.

It feels to us that Charlie's NDIS funding is very much tied to his future potential or lack thereof to contribute to society. What NDIA fails to recognise is that Charlie's potential does not exist in isolation, as funding Charlie properly also accesses the potential of his sister, parents' and extended family.

Charlie brings immense joy to our family, but he also brings personal stress and financial challenges.

As a parent, it is heartbreaking to see the impact Charlie's condition has on his five-year-old sister. There are no provisions in Charlie's NDIS plan for the unique challenges facing Chloe, such as her mental health and social wellbeing.

I've returned to part-time work, however, this is an immense challenge with Charlie's needs. He is unable to be adequately cared for in traditional childcare and the NDIA funds only half a day of care a week. This is completely insufficient and doesn't recognise the societal and tax potential of our family.

When I made a request to NDIA to increase the number of care hours I was informed that we could lose rather than gain carer hours. All I want is to have my son properly cared for while I work.

A failure of NDIS to fund much needed equipment in a timely manner is another issue. It took two years of advocacy to obtain a standing frame for Charlie to enable his bones and hips to develop properly. Sadly, this might be too late for Charlie.

Such equipment apart from providing Charlie with basic dignity will also avoid extensive orthopedic surgeries at great cost to the healthcare system down the track. These funding decisions to save a few dollars now will have immense funding ramifications in the future.

We need a system that treats the whole child and supports the whole family, not just a very narrow view of needs.

A lack of diagnosis does not negate the need for coordinated care in the form of adequate funding, timely access to services, and social supports for Charlie and our family.

There are insufficient resources invested by health and the NDIS to support collaboration across multiple systems, and to coordinate individual planning processes for people with complex support needs.

Issues also arise when individuals with rare diseases do not have a diagnosis, or very little is known about disease progression. Without a diagnosis, accessing supports under the NDIS can be difficult, and where state governments used to provide fill in options, these are often no longer funded.

"COORDINATED CARE FROM DOCTORS AND ALLIED HEALTH PROFESSIONALS IN A CENTRAL LOCATION NEEDS TO OCCUR TO REDUCE COSTS AND TIME DEVOTED TO HEALTH CARE. A BETTER OUTCOME WILL OCCUR IF DIFFERENT PARTIES ARE WORKING TOGETHER. CURRENT APPROACH VERY INEFFECTIVE."

55-64 YEAR OLD FEMALE
FROM WESTERN AUSTRALIA

THE McKell Institute

"It would be great if the planners were educated or knowledgeable on your condition especially when going for third or fourth plan. It is very frustrating that planners after third or fourth plan still are unaware of client's needs and requirements especially when the disease is a deteriorating one, one would expect the planners to provide for this." **55-64 YEAR OLD FEMALE FROM WESTERN AUSTRALIA**

Lack of knowledge and understanding

Having a rare disease means that most health and disability workers will never have encountered another individual with your condition or specific needs, and this is true of NDIS planners.

Comments provided in the Rare Disease survey highlight the difficulties faced by people with rare diseases in having their condition understood by their health care providers and NDIS planners. Without this knowledge and understanding, meeting the needs of people with rare diseases is difficult if not impossible.

A number of people reported that even if they could provide detailed evidence on the impact of their condition from a medical professional, NDIS planners lacked detailed knowledge of the health system to adequately provide for all their needs.

There is also a lack of understanding of participants with rare diseases and associated complex health and disability support needs. With inadequate training in the use of clinical expertise, planners cannot incorporate key support recommendations from clinicians that support people to live in their community.

DELAYS IN RECEIVING CARE AND EQUIPMENT

Eight out of 10 respondents to the rare disease survey receiving supports under the NDIS reported delays in receiving supports. Two main themes emerged in the survey.

First, a number of participants in the survey and consultations reported unacceptably long delays in receiving equipment necessary for daily living activities. One woman from NSW reported waiting 18 months for a wheelchair.

In the case of children long waits can have long lasting impacts. For example, one mother explained how if they had waited to receive a standing frame from the NDIS it would have been six month too late and she would have lost the ability to stand and bear weight all together.

Second, there were reports that the NDIS is not prioritising the needs of individuals with rare diseases waiting for a rapid plan review.

Rare diseases are often progressive in nature, and depending on the disease progress may be uncertain due to how little is known about the particular rare disease. Where changes occur rapidly, individuals with a rare disease may need resources to be approved quickly to meet their needs. Participants with high complex needs can experience unanticipated events, for example, for urgent equipment upgrades or repairs.

"The waiting times with NDIS is ridiculous when waiting five months for a piece of equipment that is vital for the person suffering a rare disease is just unacceptable especially when the equipment helps them with everyday activities." **PARTICIPANT, SA**

Financial strain

Having a rare disease reduces the ability of an individual to work and for parents of children with rare diseases can often result in them needing to take on full time caring roles. The inability to participate in the labour market is a significant financial strain on people with a rare disease and their families.

While out of pocket costs are an issue across Australia's health care system, they are having a significant impact on many people with a rare disease. Almost 50 per cent of responders reported having out of pocket costs of over $1000 per year associated with their disease, and many people reported that this was their biggest concern.

"NDIS needs to be much more flexible with allowances for treatment and equipment as goals and development is forever changing for children with rare diseases. It has been a nightmare for us and we have used so much of our own money to support our child as the process cause much more stress than it gives aid." **PARTICIPANT, QLD**

While no system can meet everyone's needs, it is clear it could be improved to better address the health and social care needs of people with a rare disease. In the next section we review approaches taken in other countries and draw lessons for the Australian system.

LYN'S STORY

Lyn is 45 years old and moved to Wodonga 18 months ago from Wagga to be closer to her mother.

I am the youngest of seven children, there are four girls and three boys. I lost my brother to cancer 20 years ago and my father to cancer 13 years ago. At first they thought I had cancer too, but then in 1982 just before my ninth birthday I was diagnosed with Fibrodysplasia Ossificans Progressiva.

The disease causes muscles and soft tissue to calcify and turn hard like bone, this locks all your joints so you cannot move them. I have been confined to a wheelchair since I was 28 years old and now only have the use of one arm. This allows me to use a laptop and ipad and drive my wheelchair, giving me some independence.

But I still need help to do normal everyday things like wash myself and go to the toilet, and I live in a group home. I also need help to get meals but with the use of one arm I can feed myself.

I have received supports throughout my life, from my family and from government funded services. I simply couldn't live without this help.

My mother has always provided me with love and support. Around 18 months ago I moved from Wagga to Wodonga to be closer to her and my two remaining brothers who live in nearby Wangaratta.

When I was in Wagga, I had a services package from the government which met all my daily needs, and provided extra support if I wanted to go on an outing or come to Wodonga to visit my mother. If I ever needed repairs to my wheelchair or my showerchair I would call the provider and they would arrange for it to be fixed and pay for it.

Since I moved to Wodonga, I've also moved onto the NDIS and life has changed. And not for the better as was promised.

After my first planning meeting, it took 10 months for the funding to start. Because the planner didn't put a quote for a new wheelchair into my plan as I had asked, I still have to use my old wheelchair. While I was waiting for my NDIS plan to be approved the wheelchair needed new tyres which I had to pay for and now I have the plan it doesn't include any funding for repairs so these are no longer possible.

The planner only included the funding for the staff in my group home, and as such if I want to go out or visit one of my brothers in Wangaratta, this is no longer possible as there is no funding for the staff to assist me. If I need to get transport to appointments I also need to pay for this myself, whereas previously this was all included in my package of supports.

Five months ago I put in for a review of plan, so that I could get the support I need to continue to live the fullest life possible. I am still waiting to hear back from the NDIS.

PART FOUR: INTERNATIONAL EVIDENCE

In this section we present research on the international experience of dealing with rare diseases, and draw lessons for the Australian policy environment. We focus on how systems that rely on choice and competition and the heavy involvement of private provision of services manage to encourage and support integrated and coordinated care.

Germany

Germany's health and social care systems follow choice and competition organisational models, funded by mandatory health and long term care (LTC) insurances.[23, 24]

There are a number of policies to encourage integrated care:[25]

- Treatment pathways from hospitals to long term care, avoiding multiple hospitalisations and improving transfers from the health to the social care system. This involves the coordination of health and long term care insurers, residential and in-home care providers, social welfare groups, health care providers, and housing companies.
- Care support centres established within local branches of health and LTC insurance providers, coordinating providers, and providing support and information on an individual level.
- Creation of decentralised networks linking health and social care providers as 'stakeholders' within the network, and gathering these stakeholders to discuss issues of coordination of care, and individual case management. This approach has been employed in Dortmund Germany to better integrate health and social care services for the elderly.

Germany launched a National Action Plan for People with Rare Diseases (NAMSE) in 2013, which included the establishment of a three-tiered system of rare-disease centres.[26]

Specialised centres provide targeted outpatient services to patients with confirmed diagnoses of a single disease; other, different specialised centres also cover multi professional and inpatient care; a third tier receives unconfirmed or uncertain diagnoses.[27]

Sweden

Long term care and health care in Sweden follows a choice and competition model, funded through taxation revenue from multiple levels of government.[28]

The national government is responsible for health policy, however funding and provision of health care services is entirely the responsibility of county governments. Social care services, such as long term care services, including both in-home and residential care, are provided and funded by municipal councils.

In order to achieve a more coordinated health and long term care system, the 'chain of care' approach to delivering services has been adopted in Sweden. Since 2010, it is mandatory that an individual patient care plan is drawn up upon the commencement of treatment, detailing all required steps to treatment, and which providers or authorities are responsible for each service or care provision.[29] This was in effort to reduce the fragmentation of the Swedish health and long term care systems after the market was opened to private and for-profit providers in 2008. This additional case management improves the integration of care on an individual level despite a health and social care system operating with a choice and competition model.[30]

South Korea

In South Korea, almost the entire population is covered by a single health insurance provider, the National Health Insurance Corporation. Social insurance is also administered through the same organisation.[31]

There is little integration between healthcare and social care sectors, as both are largely privately owned, without much interference from the government.

Long Term Care Insurance covers both residential and in-home care for those aged over 65, with co-payments ranging between 15 per cent and 20 per cent.[32] The insurance was introduced in order to reduce the hospitalisations of South Korea's increasingly elderly population. However, there is no specific policy to improve access to services for those with disabilities or rare diseases.

Disability Pensions are available for those with severe disabilities, and Disability Benefits accessible for individuals with moderate disabilities living in poverty. These are paid in the form of cash payments, aiming to supplement or replace income, rather than pay for care.[33]

United Kingdom (England)

In England, the National Health System (NHS) is funded through general taxation, National Insurance, and relatively small user copayments. The majority of NHS services are free of charge, with the aim of making them accessible to all.

The health market operates on a choice and competition model, with relatively unrestricted entry into most areas of the healthcare market, and free user choice from among the available services.

The social care system is administered through local councils, with funding allocated directly from the central government.[34] Despite the health and social care systems being administered by different levels of government, the UK, and England in particular, have taken large steps in recent years to overhaul both systems, and deliver an integrated, locally focused network of care providers.

England has introduced a Strategy for Rare Diseases, which calls for improved care coordination to reduce complexity in diagnosis, treatment, and care for patients with rare diseases.

The strategy recognises that care coordinators overseeing individual patient cases greatly reduce unplanned hospitalisations and the length of hospital stays. Furthermore, they were observed to improve transition processes between levels of care, with patients and families alike feeling more connected to the transition process, aware of relevant information relating to the transition, and having access to more physical and emotional support services during transitions.

To achieve these outcomes, the Strategy for Rare Diseases aims to develop and implement a rare diseases scorecard that presents criteria holding health and social care providers to account for the treatment of patients with rare diseases. It would be mandated that there is a responsible coordinator of care for each patient, that each patient is given an 'alert card' with a record of all relevant and essential treatments recorded, and that, following treatment, each patient is actively moved into appropriate long term or social care services.[35]

Canada

Like Australia, the Canadian healthcare and social care systems are considered to be highly fragmented, both in funding and in service provision.

Both sectors operate as choice and competition models, in which users are free to choose between service providers. Unlike many other western countries, Canada does not have a national health insurance or national coverage of health services. Provincial and Territorial governments provide health coverage in various forms, complying with the general 1985 Canada Health Act, which mandates that each provincial health insurance plan must be publicly administered, comprehensive in coverage, universal, portable across provinces, and accessible to all.[36]

Social care funding in Canada varies across provinces and territories. Generally, it is at least partially subsidised by local governments, with the remainder either paid by user co-payments, or means-tested government subsidies as outlined in the Canada Assistance Plan.

Canada has taken some steps towards integrating all levels of health and social care. Most Canadian provinces have implemented regional health authorities in order to transfer responsibility for the allocation of resources from provincial to municipal or regional level.[37] Ontario is the most notable example of attempts to integrate health and social care. The Government of Ontario established Local Health Integration Networks, which connect and fund health and social institutions at a local level, including hospitals, community health centres, long term care, mental health agencies, and community support. The general aim of these networks is to make health and social care patient-centred and efficient through improved collaboration and coordination between relevant organisations.[38]

Canada published a Rare Diseases Strategy in 2015, aiming to better coordinate care for patients with rare diseases, enhance community support, and improve access to services. The Strategy calls for provincial governments to establish patient registries, improve professional training, provide patient and public education, and create supportive services for patients outside of residential or inpatient care.

TABLE 4.1 SUMMARY OF INTERNATIONAL APPROACHES

COUNTRY	SINGLE FUNDER	CHOICE AND COMPETITION	PORTABLE BUDGETS	POLICIES FOR INTEGRATED CARE	POLICIES FOR RARE DISEASES
AUSTRALIA	**NO**	**YES**	**NO** Separate budgets for health and social care.	**NO** No overarching policy for integrated care between health and social care sector.	**NO** In development. An Action Plan for rare diseases is currently being formulated.
GERMANY	**NO** Separate social insurance models for health and social care.	**YES**	**NO** Separate contributions from employees/ employers/ pensioners fund health care and social care individually, without a crossover of budgets.	**YES** Creation of local administrative bodies that aim to facilitate links between health care providers and social care providers within an area.	**YES** German policy allows for insurance to be claimed in cash, rather than as services, allowing for greater flexibility in families providing informal care.
SWEDEN	**NO** Tax-based funding model. Healthcare is provided by county governments, whilst municipal councils are responsible for the provision of social care.	**YES**	**YES** The health care budget is the responsibility of the county government, whilst social care budgets remain held by municipalities. However, collaboration between the two levels of government can allow for budgets to be joined.	**YES** Mandatory Individual Care Plans for each patient, describing from the beginning of treatment what care the patient receives, and which authority or provider is responsible for each stage. A focus on a 'chain of care'.	**YES**
SOUTH KOREA	**NO** Mix of social insurance, private payments and revenue from taxation.	**NO**	**NO** Revenues are pooled and redistributed, but health and social care budgets remain separated.	Very little integration between levels of care, either connecting primary and secondary health care, or inpatient care to social care.	**NO**
UNITED KINGDOM	**YES**	**YES** Choice and competition within health care sector. Some choice but through managed competition in the social care sector.	**NO** Budgets are allocated to each separately. However, some local areas, such as Greater Manchester, have signed devolution agreements, allowing them total control of health and social care budgets.	**YES** Integrated Care Systems Better Care Fund: a reallocation of funds from the NHS towards local social services, aiming to interconnect the two, and create smoother transition pathways between health care and social care.	**YES** Policy focuses on screening and testing, diagnosis and early intervention, coordination of care (through specialist centres) and research.
CANADA	**NO** Mix of provincial and federal funding.	**NO**	Varied based on region.	Varied based on region. Regional Health Authorities. Local Health Integration Networks in Ontario.	**NO**

Key lessons

The international review provides a number of key lessons for the Australian system.

Like Australia, a number of countries have responsibilities for funding and provision of services split across different levels of government and have choice and competition for health and social care. These systems have successfully implemented policies that support care integration for people with complex needs including people with rare diseases.

A RARE DISEASE STRATEGY

Countries that have a comprehensive approach to rare disease management have developed and implemented rare disease strategies that address the need for access to specialised and integrated care for people with rare diseases. These strategies cover care coordination, research, diagnosis and patient engagement.

SPECIALIST CENTRES AND CARE COORDINATION

The term “coordination of care” is used to describe resources designed to improve the provision of timely, equitable, and evidence-informed care.

Specialist centres are used in the UK, Germany and Sweden to both inform best practice care for people with rare diseases and facilitate faster diagnosis, but also to support the coordination of care.

CARE INTEGRATION MODELS

The Swedish have developed a sophisticated approach to address fragmentation of health and disability care across levels of government.

Using individual care plans which cover an individual’s health and disability care needs. These plans allocate responsibility for aspects of care to the responsible level of government or agency, provides an example of how Australia could move away from its current siloed approach to a more integrated approach to care — even when funding is split across levels of government.

PART FIVE: KEY REFORMS

Addressing the issues facing people with rare diseases in accessing health and disability services and moving towards a person centred approach of care require a number of key reforms.

Underpinning these reforms is the need for a Rare Disease Strategy, which covers access to services, prevention, early diagnosis and research.

RECOMMENDATION 1

Australia develops, endorses and implements a Rare Disease Strategy.

Unmet needs for health and disability services

Centres of Excellence are a feature of rare disease policy in the United Kingdom, and support a system that can better respond to the health and disability care needs of people with a rare disease.

They provide the capacity to acquire and maintain knowledge and expertise through both research and patient interaction. Through facilitating the coordination of multi-disciplinary teams of health and disability care professionals they can manage patient care and local resources effectively.

Through providing a central point of contact for people with rare diseases, their families, and health and disability professionals, everyone can have access to the same information on a rare disease.

RECOMMENDATION 2

Australia establish a model of rare disease centres of excellence to address knowledge gaps and ensure all Australians with a rare disease have access to the best evidence based care.

No system will meet all an individual's health and disability care needs, however through improving the level of coordination and integration we can ensure that the services we provide are person centred rather than organised around a level of government or particular provider.

Introducing personal care plans that bring together an individual's health, education and disability care needs would ensure an integrated approach to care planning. As part of this process, funding responsibilities would be allocated to levels of government so as to avoid cost shifting and ensure that all the agreed needs of an individual were met.

Administrative savings could be achieved through replacing the current planning that occurs across difference levels of government. For example, rather than requiring a separate health, education and disability plan, individuals would have one plan to cover all their needs.

RECOMMENDATION 3

Australia introduce personal care plans to cover an individual's health, education and disability care needs. These over-arching integrated care plans would allocate responsibility for the delivery of services to specific levels of government.

Lack of knowledge and understanding

Until the government is able to establish rare disease centres for excellence there remains a need for relevant health and disability professionals to access reliable information on specific rare diseases in one place. While a number of useful websites and resources exist currently in Australia, there is not one central depositary of information.

The government is in a position to coordinate the collation of such information, and provide professionals with the information they require to improve their knowledge and understanding and better address the needs of people with rare diseases.

RECOMMENDATION 4

The Government centralise existing information on rare disease with a searchable data base of information on rare diseases which health and disability professionals, patients and families, can access and inform.

It is not feasible to train every health and disability professional in every rare disease. However, through linkages with rare disease centres of excellence and specific training on the nature of rare diseases and how they can be managed, we can better equip relevant professionals to better respond to people with rare diseases.

RECOMMENDATION 5

Introduce mandatory training of relevant health and disability care professionals on the nature of rare diseases, effective management strategies, how to locate information and referral pathways to support and advocacy groups.

Delays in care and equipment

Reports of individuals waiting 18 months for approved wheelchairs are not acceptable for any system, and there is a need for an urgent review into the supply of equipment under the NDIS. These delays can have lasting impact, especially for children that require equipment to meet specific developmental requirements such as the ability to stand or walk.

RECOMMENDATION 6

Urgent review of delays in access to equipment to ensure that NDIS participants receive approved equipment in a timely manner.

The current design of the NDIS is based on a static concept of disability, which doesn't fit the nature of many rare diseases that maybe episodic or degenerative. Without a more flexible system of funding it will continue to not meet the needs of people with rare diseases and others with episodic disabilities. Many conditions are life limiting — people need support to live the fullest life possible for the time they have available.

RECOMMENDATION 7

NDIA to incorporate a 'fast tracking' category for people with rare diseases who have been identified as having permanent and significant disability. This would allow quicker access to additional supports when required through consultation with clinicians.

CONCLUSION

Reforms are needed to deliver person centred care for people with rare diseases that meets their needs. This report was motivated by ensuring that our health and disability care systems deliver the necessary care and supports so that people with rare diseases can live their best lives.

Fundamentally the system must shift from treating individual diseases towards treating individuals. While primarily aimed at supporting people with rare diseases, these reforms will also improve the care received by other users of the health and disability care system with complex needs.

Reforms that focus on enhancing collaboration between the health and disability sectors, through establishing specialist centres and implementing single care plans will improve access to services for people with rare diseases.

Providing health and disability care professionals access to information on specific rare diseases and training on the nature of rare diseases will increase understanding across the system, and give people with a rare disease a stronger voice.

Finally, increasing the flexibility of the NDIS to recognise that not all disabilities are static and that needs can change quickly and unpredictability will reduce delays in necessary supports.

In order for the objectives of the NDIS to be met for people with rare diseases, both the disability and health systems must commit to work alongside each other so that an individual's health and disability needs are met. Fragmented funding does not need to mean fragmented care with the right systems in place.

By placing the person with a rare disease at the centre of care, we can make care more seamless for people with rare diseases and deliver on the promise of the NDIS.

APPENDIX

Survey methodology

The purpose of the survey was to collect primary data on how well the needs of people with rare diseases and conditions are being met. The survey used to collect this information drew heavily on the Survey of Disability, Ageing and Carers developed by the Australian Bureau of Statistics. This approach ensured that the survey questions had been previously validated in an Australian context.

Distribution

Online survey tool Survey Monkey was used to format the survey questions then Rare Voices Australia forwarded the link to the survey to not-for-profit organisations that represent people with rare diseases or conditions. These organisations were asked to forward the link on to their members and urge them to respond. Rare Voices Australia contacted the following organisations:

- AAAF - Australia Alopecia Areata Foundation Inc
- Acute Necrotizing Encephalopathy (ANE)
- Angelman Syndrome Association Australia Incorporated
- ausEE Inc.
- Australian Cystinosis Support Group
- Australian Mitochondrial Disease Foundation (AMDF)
- Australian Pompe Association
- Batten Disease Support and Research Organisation
- CDH Australia
- Charles Bonnet Syndrome
- Fabry Australia Inc
- FOP Australia
- Foundation for Angelman Syndrome
- Fragile X Association of Australia
- Friedreich Ataxia Research Association
- HAE Australasia
- Haemochromatosis Australia
- HCU Network Australia
- Gaucher Association of Australia & New Zealand
- Genetic Alliance Australia (GA)
- Genetic and Rare Disease Network (GaRDN)
- Genetic Support Network Victoria (GSNV)
- Immune Deficiencies Foundation Australia (IDFA)
- ISMRD
- Jack's Butterflies
- Leukodystrophy Australia
- Leukodystrophy Resource & Research Organisation Inc.
- MdDS Australia
- Metabolic Dietary Disorders Association (MDDA)
- Myasthenia Gravis Association of Queensland Inc. (MGAQ)
- MPN Alliance Australia
- MPS Society
- MS Australia
- Muscular Dystrophy Association, SA
- Muscular Dystrophy Association, WA
- Muscular Dystrophy Association, Queensland
- Muscular Dystrophy Foundation
- Myositis Association Australia
- Narcolepsy Australia
- National Myasthenia Alliance
- Parenteral Nutrition Down Under Inc. (PNDU)
- PCD Australia
- PNH Support Association of Australia
- Porphyria Australia Inc
- PSC Support Australia Inc
- Pseudomyxoma Survivor
- Rett Syndrome Association of Australia
- Sanfilippo Children's Foundation
- Save Our Sons Duchenne Foundation
- SCN2A
- SMA Australia
- Syndromes Without a Name (SWAN) Australia
- The Australian Addison's Disease Association
- The Australian Dercums Disease Support Group
- Tuberous Sclerosis Australia (TSA)

The survey was opened on 21/03/2019 and closed on 10/05/2019. During that time, Rare Voices Australia sent out two reminders to the organisations prompting them to get their members to respond to the survey.

In addition a link to the survey was posted on the Rare Voices Australia Facebook page, Twitter Account and Linkedin profile, and information included in the March Rare Voices Newsletter.

Responses

771 survey responses were collected. The table below summarises responses by category of respondent and access to the NDIS.

RESPONDENT	NOT RECEIVING SUPPORT THROUGH THE NDIS	RECEIVING SUPPORT THROUGH THE NDIS	TOTAL
Carer of someone with a rare disease	134	239	373
Someone with a rare disease	358	40	398
TOTAL	**492**	**279**	**771**

Limitations

There were several limitations of the survey design and implementation:

1. The method used to distribute the survey meant the survey population is unknown. It is not known how many members each of these organisations has and it is highly unlikely that all the organisations that Rare Voices Australia approached forwarded on the survey link to their members. Therefore, there are likely to be unidentified biases in the survey population.
2. The response rate is unknown for the same reasons as have been cited above, it is therefore not possible to determine if bias was introduced into the results because of differing response rates for different groups.
3. Changes were made to the introductory blurb and final survey question after the survey was launched following feedback that individuals not eligible for the NDIS due to their age were excluded and a substantial number of survey responses had been collected.

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FOOTNOTES

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38. Survey responses were counted if respondents answered at least the first three questions.

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