Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF PROFESSOR BRUCE BONYHADY AM

I, Professor Bruce Bonyhady AM, Executive Chair of the Melbourne Disability Institute, of the University of Melbourne, say as follows:

1   I make this statement on the basis of my own knowledge, except where otherwise stated. Where I make statements based on information provided by others, I believe that information to be true.

2   I am giving evidence to the Royal Commission in my personal capacity and not on behalf of my employers or organisations of which I am a member.

Background

Qualifications and experience

3   I am the father of three adult sons, two of whom have disabilities, and I have been involved in the disability sector since the late-1980s, so soon after my eldest son was born with cerebral palsy. Therefore for most of my life I have been deeply committed to improving the lives of people with disability.

4   My formal qualifications are in economics. In 1976, I received a Bachelor of Applied Economics (Honours Class 1) from the University of New England. In 1978, I received a Master of Economics from the Australian National University.

5   In the 2010 Queen's Birthday Honours, I was awarded the honour of Member of the Order of Australia for services to people with disabilities, their families and carers, and to the community as a contributor to a range of charitable organisations.

6   In 2014, I received a Doctor of Letters (Honoris causa) for distinguished service to people with disabilities from the University of Western Sydney, and a Doctor of Laws (Honoris causa) for distinguished eminence in public service from the University of Melbourne.

7   I began my career in the Australian Treasury and have also worked in economic consulting, funds management, property and insurance in both Australia and the UK. I have held senior positions at ANZ Investments, BT Funds Management and the National Mutual Life Association.

8   I have held a number of non-executive director and advisory roles in the disability sector. Key roles I have held include:

Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.

(a)   Chairman of the Advisory Panel to Solve@RCH (Centre for Development Disability Research, Royal Children's Hospital, 2004 to present);

(b)   Deputy Chair of the Council of Australian Governments (**COAG**) National Disability Insurance Scheme Advisory Group (2011 to 2013);

(c)   Chairman of the Expert Group on NDIS Quality and Safeguards (2012 to 2013);

(d)   Chairman of the Independent Panel advising the Productivity Commission Inquiry into Disability Care and Support (2010 and 2011);

(e)   Member of the Disability Investment Group (2008 and 2009);

(f)   Chairman and Director of Yooralla (2001 to 2013);

(g)   Patron of the National Disability and Carer Alliance (2009 to 2013), which auspiced the Every Australian Counts Campaign for the establishment of the NDIS;

(h)   President of Philanthropy Australia (2006 to 2013); and

(i)   Treasurer and Member of the Committee of Management, Noah's Ark Toy Library (1987 to 1991).

9   Attached to this statement and marked 'Attachment BB-1' is a copy of my CV.

10   Attached to this statement and marked 'Attachment BB-2' is a discussion paper which I co-authored and which was prepared for the Safeguards and Quality Assurance Expert Group titled 'A Personalised Approach to Safeguards in the NDIS'.

11   Attached to this statement and marked 'Attachment BB-3' is the University of Melbourne's submission in response to the Australian Human Rights Commission's Human Rights and Technology Discussion Paper.

12   Attached to this statement and marked 'Attachment BB-4' is the 2019 Annual Report of the Melbourne Disability Institute.

My previous role as Chairman of the National Disability Insurance Agency

13   I served as Chairman of the National Disability Insurance Agency (**NDIA**) from its inauguration on 1 July 2013 to the end of 2016, which comprised the initial 3 year trial phase of the National Disability Insurance Scheme (**NDIS**) and the first 6 months of the roll out of the scheme.

14   I have been involved with the NDIS from its initial conceptualisation and design, its progress through various government committees, through to its establishment in 2013.[1] I first coined the name 'NDIS' in a submission I made in collaboration with Helen Sykes, who was the Chair of the James Macready-Bryan Foundation, to the Rudd Government's Australia 2020 Summit in April 2008. While neither Helen nor I were invited to the Summit, it identified the NDIS as one of its 'Big Ideas' and so this was also the first time that the NDIS received any public recognition. The fact that the NDIS came to the fore at the Summit, amongst the thousands of ideas which were discussed, was an early sign of the potential of the NDIS to capture people's attention and support.

Applying an insurance-based approach to disability services

15   My involvement with the NDIS dates back to around 2004-2005, when I first became interested in the idea of adopting an insurance-based approach to supporting people with disabilities. I had become acquainted with Hon Brian Howe through a board role I held at the time. I was becoming interested in the question why disability services were underfunded, and I asked Mr Howe what could be done about this. He told me that disability services should not be thought of as a welfare issue; instead, they should be framed as an insurance and investment issue. With my background in insurance and funds management, I instantly saw this as a powerful way of reframing the issue, from one which poses the question of how society can support poor and disadvantaged people, to one which considers the question of how the entire population can insure and therefore protect itself against a common risk, being the risk of having a disability.

16   This idea of an insurance-based approach to disability comprises several core concepts. The first is that everyone pays so that everyone is covered: all members of society pay a small amount through their taxes, which provides funding (as and when a need arises) for those who have a disability. This idea appealed to my own sense of fairness and equity, since the costs of disability services are unaffordable for most individuals, unless they are extraordinarily rich.

17   The second core concept is that lifetime costs should be minimised, while lifetime benefits should be maximised. Insurance companies are typically operated in a manner that is designed to minimise lifetime costs. In contrast, government budgets are typically set in way that is designed to minimise costs in a particular year. If one is able to minimise costs over a person's lifetime, there is a greater willingness to make an upfront investment if that investment leads to a better quality of life and lower costs over the person's lifetime. In that sense, I consider that insurance schemes are inherently more closely aligned to

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[1] The NDIA has provided a submission (dated 20 August 2019) to the Commission in which it gives an overview and history of the development of the NDIS.

the needs and wants of citizens in comparison to year to year budgets and the usual annual fiscal processes.

My current role as Executive Chair and Director of the Melbourne Disability Institute

18   The Melbourne Disability Institute (**MDI**) is one of five interdisciplinary research institutes at the University of Melbourne. Established in 2018, its role is to catalyse research across the academy, with a focus on disability. The stated vision of the MDI is to transform the social and economic wellbeing and health of people with disability using high quality research, teaching and training, and knowledge translation. Areas of particular interest to the MDI include opportunity and equity, inclusive communities, health and wellbeing, markets and sustainability, and policy and practice.

19   For me, the big factor which motivated my direct involvement in the formation of the NDIS for more than a decade was a desire to see a much fairer and equitable society for people with disabilities; for people with disabilities and their families to have equal opportunities. However, overcoming deeply entrenched disadvantage and prejudice takes enormous effort and ongoing vigilance and, through my role as Chair and Executive Director of the MDI, I am able to continue this lifetime work. Our focus is therefore broader than the NDIS and includes all people with disabilities and the National Disability Strategy. Further details are available in the MDI's 2019 Annual Report.[2]

State and Commonwealth engagement and national reform

Ways in which state and Commonwealth governments could better work together to effect systemic and enduring reforms to service systems

20   There are many policy areas that are the joint responsibility of Commonwealth and state governments, including mental health, disability, domestic violence, housing and homelessness. In the absence of the Commonwealth and state governments working hand in glove, progress will be almost impossible to achieve. A highly cooperative relationship between Commonwealth and state governments is therefore essential to securing reform in these policy areas.

Factors that assist Commonwealth-state cooperation

21   Strong political leadership can greatly assist in the achievement of enduring reform. The National Cabinet is a recent example of this, where the Prime Minister has successfully brought the states together to address the COVID-19 pandemic. The Gillard government also showed strong leadership in relation to the delivery of the NDIS; Prime Minister

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[2] The MDI's 2019 Annual Report is Attachment BB-4 to this statement.

Gillard, along with the then Minister for Disability Reform, Hon Jenny Macklin, and the then Assistant Treasurer, Hon Bill Shorten, showed a willingness to lead and collaborate with the states and territories to ensure that the scheme was delivered. This is reflected in the funding arrangements, which are close to 50 per cent Commonwealth: 50 per cent states and territories.

22   Strong political leadership at the State level can also facilitate effective cooperation. For example, in 2004, the Bracks Government, concerned about falling productivity, started work on a range of policy changes, and in August 2005, released a major policy document, 'A Third Wave of National Reform', which became the foundation of the National Reform Agenda endorsed by COAG under both the Howard and Rudd Governments.

<u>Factors that hinder Commonwealth-state cooperation</u>

23   A key source of tension in Commonwealth-state relations is vertical fiscal imbalance that characterises those relations. States are responsible for far more policy areas than those for which they have sufficient funding. The states' own sources of funding are also primarily a tax on employment (payroll tax) and frequently regressive (excise duties) or very volatile (such as stamp duty or resource taxes), whereas the Commonwealth has access to progressive taxes and taxes that grow proportionately to economic growth.

24   The cultural aspect of Commonwealth-state relations is often characterised by a lack of respect for the strengths that each side can bring to discussions. For example, the Commonwealth government generally brings a deeper understanding of economic issues, while states bring a deeper understanding of policy implementation issues.

25   In addition, Commonwealth-state negotiations generally progress through an established hierarchy. This starts with the issue of whether or how much the Commonwealth or States will pay, followed by identification of the policy that is to be funded, and finally the issue of how that policy is to be implemented. Nowadays, this process is further complicated by the increased outsourcing of services by governments to non-government agencies, including not-for-profit organisations. Further, because the Commonwealth is contributing funding to State-managed services, it is also very common for the Commonwealth to set performance indicators and these can also be changed with little or no warning. It is therefore a very top-down rather than bottom-up process and the loop is not closed on this process with respect to funding. As a result, the allocation of funding and performance indicators are often not reviewed and recalibrated on an ongoing basis in response to performance monitoring or feedback received in relation to policy implementation.

Ways in which state and Commonwealth governments could cooperate to achieve good mental health outcomes

A shared vision

26   One key element required for effective intergovernmental cooperation is a shared vision for what it means to be a citizen with disability (or with mental health issues). This is closely related to questions of what is fair, affordable and sustainable.

The economic case for reform

27   Another key element is a clear understanding of what the benefits of the reform(s) sought are. In Australian politics, economic consequences are always central to the public policy agenda. In the case of the NDIS, we sought to transform what was previously only a social policy and rights issue into an economic one. When the Productivity Commission found in its 2011 report that the economic benefits of the NDIS would outweigh the costs, this provided a strong basis for overcoming potential opposition to the scheme from Commonwealth and state treasury and finance departments worried about its costs.

28   It is essential that the economic case for reform be made. In the case of mental health, this issue (probably more than any other) lies at the heart of the future productivity growth of Australia. For the past decade, productivity growth in the country has more or less stagnated. In the same period, there has been a rise in the number of mental illness cases, and there is arguably a significant degree of causality linking these trends. Further, given the importance of services to the economy, investing in their efficiency is likely to be more effective than capital allowances or accelerated depreciation for businesses. Therefore, in framing how to optimise how the nation emerges from the present circumstances brought about by the COVID-19 pandemic, mental health, and particularly the economic benefits of mental health reform, need to be front and centre.

Funding arrangements

29   Once the economic case has been made for reform, funding is the next key issue to be addressed. In the case of the NDIS, we realised that if disability policy and costs continued on the same trajectory, spending on disability services would eventually overwhelm state government budgets. At the time, the states and territories were responsible for about 80 per cent of disability funding. This led to the view that the Commonwealth government had to be persuaded to become the main funder of the NDIS. Part of this reasoning was that, as noted above, the Commonwealth government had access to stable and progressive taxes that would grow in line with the economy. The Commonwealth was also the only government which could underwrite the costs of the

NDIS and this is also reflected in the funding arrangements with the Commonwealth responsible for any cost over-runs.

30   In respect of the Commission and the implementation of its recommendations, I note that one of the recommendations in the Interim Report was an increase in taxes to fund increased spending on mental health services in Victoria. The challenge with implementing this recommendation is that there are very few areas in which the State would be able to raise taxes in a manner that is progressive (as opposed to regressive). As noted above, this was a challenge we encountered with the NDIS, when we recognised that the states were not able to be the primary source of funding for the scheme. It follows that giving further thought to how the Commonwealth government could be engaged in responding to the need for additional spending on mental health services will be important to the success of the implementation of the Commission's recommendations.

31   One option which I believe would be worthy of consideration is to carefully consider new forums for Commonwealth – State collaboration now that COAG has been abolished and replaced by the National Cabinet. As a result of the abolition of COAG, all of its subcommittees have also been effectively abolished. One option would be for Victoria to propose a new National Mental Health Cabinet, comprising the Commonwealth and state and territory Ministers responsible for mental health. This should be supported by a committee of mental health experts (including consumers), in a manner analogous to the way that the Australian Health Protection Principal Committee has been permitted to give expert advice directly into the National Cabinet in recent times. Further, the findings from this Royal Commission, while principally directed at Victoria, have national implications and so its recommendations could become the blueprint for national reform, as did 'A Third Wave of National Reform' proposed by the Bracks Government in 2005. The current Federal Health Minister, Hon Greg Hunt, is deeply engaged in mental health issues and so may welcome such a way forward.

Circumstances required for social policy issues such as disability and mental health to be consistently and fairly prioritised

32   Sector-wide unity is a critical ingredient in the prioritisation and implementation of reform in areas like disability and mental health. Before the introduction of the NDIS, the disability sector was deeply fragmented and disorganised. Particular groups within the sector (i.e. people with a particular disability) would advocate for solutions or supports that were specific to their disability. For example, people with cerebral palsy wanted more wheelchairs and people with autism wanted more autism services. What changed with the introduction of the NDIS was that we proposed a system that was designed to meet need, and that need was not characterised as being confined to any particular kind of

disability (such as intellectual or physical disabilities). Advocacy within the sector shifted as a result, from targeting needs that were very specific to each sub-group within the sector, to promoting a national scheme in the form of the NDIS. The language of insurance played an important role here; the concepts comprised by the idea of insurance (explained above) made the NDIS relevant to every Australian because no one knows if or when they themselves (or a relative) might have a disability. We were therefore able to broaden support for the NDIS beyond the disability sector. In that way, we were able to shift the debate from what was essentially a social policy debate to an economic one and ultimately, due to the unity of the disability sector and beyond, a political one that no government or political party could afford to ignore.

33   Based on my own observation, the mental health sector has been deeply divided along clinical mental health and community mental health lines. There has been conflict and envy between these groups regarding who should receive funding – and at times this has led them to undermine each other's claims and this has made it easy for governments to ignore both. Sector unity is an essential requirement for large-scale reform.

34   Sector unity must be promoted by champions, individuals who can represent and advocate for the interests of the sector as a whole and help to make the economic case for reform (as described above). Ideally, these champions should also come from outside the sector and so bring strong, independent voices to the public debate for reform.

System governance

Benefits and risks of distributing system management functions such as oversight and commissioning across multiple entities

35   System management in relation to difficult areas such as disability or mental health is hugely complex. There was not enough thought put into system management during the development phase of the NDIS.

36   In this context, system management is perhaps better understood as market stewardship. Market stewardship may entail consideration of how to build sector capacity to provide the services required, how to monitor and manage performance of existing service providers and how to attract and retain a quality workforce. In effect, when we introduce control and choice for consumers, we are creating a type of market, but it is a market created by governments and these markets require careful stewardship to avoid exploitation of disadvantaged people, avoid market failure and ensure that there are appropriate services for the most complex and vulnerable people. If we rely totally on the market, supports will not be equitable or fair so some minimum level of market intervention is essential.

37   One of the great benefits of referring the examination of the proposed NDIS to the Productivity Commission was that it spoke with great authority about the economic benefits of the scheme, which helped to build momentum for its introduction.

38   However, the Productivity Commission did not focus as much on system management and market stewardship. I think there may have been an implicit assumption in the Productivity Commission's work that if people with disabilities (and their families and carers) were given funding, the market would develop and grow organically to meet their needs. In hindsight, much more thought and direction should have been put into how the market stewardship role would be undertaken.

Benefits and risks of co-locating system management functions with the functions related to the implementation of significant reforms

39   I think that the skills that you need to manage a system require an eye for detail and a focus on continuous improvement, whereas significant reforms require a big picture of how systems should undergo major change, their interfaces and ensuring that, in making those changes, the key strengths of the old system are not lost. It is striking that, with the NDIS, the impetus for reform and the reframing of disability as an insurance and investment issue came from outside governments, not from those within governments with the responsibility for managing disability services prior to the introduction of the NDIS.

Capabilities and functions required of system managers to oversee significant reform

40   The key capabilities and functions required of system managers to oversee reform are a focus on the whole person (not just their disability or mental health needs), cultural competence, an understanding of the diverse needs of citizens, a deep understanding of interactions with other systems, an ability to combine the theoretical with the practical, and a strong knowledge of human behaviour. System managers must also listen, learn and recalibrate existing funding, policies and services based on that feedback to create and maintain truly person-centred human service systems.

<u>Person-centred culture must include families and carers</u>

41   It is very important to recognise that many people with disabilities and mental health issues exist within families and family relationships. One needs to include the family and carers in the group of citizens that need to be supported. If one only focuses on the individual who has a disability or mental health issue to the exclusion of their family and carer(s), many of the informal supports that are provided by families and carers are at risk of being worn away or exhausted. Nurturing and sustaining families and carers is a

critical part of designing disability or mental health support systems. It is also essential for system sustainability.

42   In the case of the NDIS, there was initially an almost singular focus on the person who has a disability; the balance was probably not quite right, but I think this is being corrected over time.

Understanding interactions with other systems

43   Many people who have a disability or mental illness access a range of services; in addition to disability or mental health services, they may also need access to housing and other services. It is essential to understand the intricacies of the various interactions between these support structures when considering systemic reform.

A culture of listening and learning

44   It is essential that a constructive culture be nurtured in which a cycle of listening, learning, recalibrating and then delivering is facilitated. This also relates to the challenges concerning funding identified above, where performance monitoring or feedback received may result in the need for adjustments to funding. At present, our systems are poorly attuned to this need.

Performance monitoring

Ways in which performance monitoring arrangements can capture outcomes and experiences that are meaningful to consumers, families and carers

The shift towards person-centred data

45   Insurance systems are, by their very nature, data-rich systems. The NDIS has facilitated arguably the best data collection concerning people with disabilities anywhere in the world. Data has been collected not only on a person's primary disabilities, but also on a range of other topics: their functional impairments, goals and aspirations, where they spend their money and outcomes across eight domains.

46   Data agencies like the Australian Digital and Data Council,[3] and the Victorian Centre for Data Linkage,[4] have a critical role to play as repositories of information that can be used to improve outcomes for Australian citizens.

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[3] The Australian Digital Council was established in September 2018 to facilitate and drive better cross-government collaboration on data and digital transformation.
[4] The primary function of the Centre for Victorian Data Linkage is to create and maintain linkages within and between Victorian government, health and non-health administrative data collections, and extend the capability for building a nationwide data linkage infrastructure.

47   Prior to the introduction of the NDIS, data collection in relation to people with disabilities was primarily organised around service providers. Data was collected on where a given service provider provided a service and how many people it provided that service to. However, there was no data that tracked the full range of services accessed by a given individual across multiple service providers or from a particular service provider.

48   The current shift is towards collecting person-centred data on people with disabilities. The big opportunity here is to link existing data collected on people's disabilities and the disability services they are accessing with additional data on the health, education, tax, housing, justice and employment outcomes. Clearly, it is essential to be able to link and analyse such data in a way that is secure and does not compromise the privacy of individuals.

Levers and structures needed to ensure approaches to performance monitoring continuously evolve

49   A key aspect of performance monitoring is ensuring that the metrics that are tracked are those that matter to citizens, rather than those that are considered to be most important to governments or bureaucrats. In order to identify what matters most to people, you need to ask them.

50   Transparency is another essential element of performance monitoring. Performance metrics not only need to be based on what matters most to people, they also need to be couched in language that is accessible and meaningful to people.

51   Accountability is also important; if the stated objectives are not met, there must be a clear allocation of accountability for addressing why they have not been met and fixing the problem.

Lived experience in governance

How the contributions of people with lived experience to the development of policy, practice and research make services more reflective of peoples' needs and aspirations

52   I think processes which engage with people affected by government policy, programs or service changes is essential. In successful businesses, consumer feedback is an essential touchstone driving change and continuous improvement, but in government the processes for co-production or co-design are often poorly developed or a box to be ticked, rather than being integral to the process. This needs to change, because without the contribution of people with lived experience to the development of government policy,

practice and research, services will not be reflective of the needs and aspirations of citizens, and governments will fail in their duty to serve.

Factors that have constrained the participation of people with lived experience in decision-making across systems, such as the mental health system or the NDIS

53   Cultural factors have historically been very influential. Disability (and mental health) services were, until quite recently, seen as a form of charity. That is, they were often seen as services that were provided to the 'deserving poor'. Until recently, there was no established culture of giving those in need a voice in the design or implementation of such services. However, there has slowly and steadily been a recognition that people with a disability or mental illness are all citizens, and the rights and privileges of citizenship include the right to have a voice. This cultural shift has been reinforced on a global scale by bodies like the United Nations and the Convention on the Rights of People with Disabilities. However, I also think we still need more of a cultural shift in governments to a position where they truly recognise that they are there to serve current and future generations and that, to achieve this objective, they must not just consult citizens, but also see them as equal partners. This needs to become the default position, part of 'business as usual', rather than an afterthought or tokenism.

My assessment of the success of the NDIS in giving a greater voice to people with lived experience in relation to service design and delivery

54   In the design phase of the scheme, we were fairly successful in including the voice of people with disabilities and their families in the design process. Much of this is owed to the structures put in place by the Commonwealth government and particularly by Hon Jenny Macklin, the then Minister for Disability Reform. Minister Macklin set up the COAG NDIS Advisory Committee, which was comprised of a majority of people with lived experience. Bringing people with lived experience into the existing power and decision-making structures is critical. To the best of my knowledge, this power sharing has not been done so effectively before or since.

55   In the trial and early roll out phase of scheme, we were less successful in involving people with disabilities. When people are under pressure to get things done quickly, they tend to take shortcuts – co-design will often be neglected in those circumstances. This is not to downplay the difficulties involved with co-design; it generally always leads to better outcomes.

56   However, while I was Chair of the NDIA, it quickly became a leading employer in relation to the inclusion of people with lived experience (i.e. disability). By the end of 2016, approximately 15% of NDIA staff had a disability, and there were many more who had other lived experiences of disability. As a result, internal NDIA processes were generally

inclusive and diverse. This is not the same as bringing external lived experience to reform, but it is an important change which we managed to achieve. In contrast, before the introduction of the NDIS, I estimate that government disability departments around the country employed less than one-half the proportion of people with lived experience of disability than the NDIA achieved in three and a half years.

<u>Characteristics that could be replicated in a mental health context</u>

57   It is important to recognise the value of lived experience, and particularly the role people with lived experience can play at a board or management level. Lived experience should be recognised, along with any other kinds of qualification or skill-sets (such as legal or accounting), as an essential component or skill-set in the composition of the boards of mental health organisations. On the initial NDIA Board of nine people there were two people with disabilities and an additional four people with lived experience of disability. The Independent Advisory Council comprised a majority of people with disabilities.

Determining the role of people with lived experience in governance and service delivery

58   The end goal should always remain the focus of any design or reform process. The end goal, in a mental health context, would be to ensure that people with mental illness have access to the services that best meet their needs. If one focuses too much on the organisations that deliver the service, there is a risk of prioritising an interim goal over the ultimate objective.

59   Based on my experience, I would think that lived experience needs to be an integral part of the governance of any mental health organisation. However, it is also important to get the balance right; whether a mental health organisation that is run entirely by people with lived experience would lead to the best outcomes for people with mental illness is another question. In my view, effective governance depends on having the right combination and balance of skills and experience.

Streaming and care pathways

Key considerations that should determine who needs a separate 'stream' of care

60   The priority of any system should be that it is trusted, fair and equitable. Whether separate or streamed pathways are the best way of achieving that is essentially an operational issue.

61   There are several guiding principles which may inform whether streamed pathways are likely to be optimal in a given case. One is that streaming is likely to be beneficial where the degree of specialist knowledge required for the delivery of services is particularly high.

The size of the relevant population may also determine whether streaming will be optimal, i.e. whether the group is sufficiently large such that it would be best supported through a separate stream.

62   There may also be cultural factors that will determine whether streaming is appropriate. For example, staff who are dealing with Aboriginal and Torres Strait Islander people would need to be culturally competent and may also need local language skills. Streaming may be appropriate where people from culturally and linguistically diverse backgrounds are not comfortable (or able) to converse in English.

63   One risk that may arise when using streaming is that different people may receive different treatment, not because their needs are in fact different, but simply because they were allocated to different streams. To mitigate this risk, it is important to focus on maintaining "inter-rater reliability", which means that two people assessing the needs of two similar people assign broadly the same quantum of support to those people. This requires not only a deep knowledge of the subject matter of the specialised area in question, but also effective knowledge sharing and training among staff within each sub-stream or pathway.

64   In addition, it is important to ensure that people receive the support and treatment that meets their needs, regardless of the particular stream to which they have been allocated. For example, if an Aboriginal or Torres Strait Islander person who has a psychosocial disability were streamed based on their cultural background (rather than their disability), they would clearly need access to someone who has specialised knowledge in psychosocial disabilities (or someone who is part of the psychosocial disability stream), otherwise the streaming of that person (based on their cultural background) could result in unfairness. That is when people can lose faith and trust in the system.

Psychosocial supports

The tension between the NDIS framing of permanent disability and best practice recovery-oriented mental health care

65   In relation to the NDIS, the language of "permanent disability" served to distinguish between disabilities intended to be covered under the scheme (that is, disabilities that are likely to be lifelong) and other more temporary disabilities, such as those arising from an injury. In relation to mental health services, the notion of a recovery-oriented approach to service provision signifies the aim of gradually improving the mental health of patients over time.

66   In my view, the focus by some in the mental health sector on the language of "permanent disability" is overdrawn and missed an opportunity. Putting that language aside, the insurance-based approach to disability services (outlined above), and particularly the

investment aspect of that approach, is totally aligned with the concept of recovery. Tailored investments through NDIS capacity building should lead to improved outcomes over time or, to use the language of mental health, 'recovery'. That is why I believe the focus on language, as opposed to the practices of the NDIS, has been unfortunate.

Ensuring equity of access to services for people with episodic conditions

67   In the case of the NDIS, a more problematic issue is ensuring equity of access, particularly for people who have episodic needs. There is a risk that such people will only present to the NDIA on a "good day". It is essential that such people have access to reports and other resources that can convey the full extent of what I would term their "permanent need". Such needs may fluctuate from day to day, but their ongoing nature makes them permanent and they may also be multi-dimensional. For example, many people who have physical disabilities may also have mental health issues. While some people with disabilities have good family and carer supports, and may have access to psychiatric or psychological reports detailing their needs, others may not. This is a weakness of the NDIS in its current form: there are not sufficient measures in place to ensure equity of access to medical reports and other resources to gain access to the NDIS and then be allocated 'reasonable and necessary' supports.

Disability

Barriers to accessing mental health services for people living with disability

68   Both mental health services and advocacy services that facilitate access to mental health services are underfunded. This means that some people may not be able to access the mental health services they need unless they are able to strongly advocate for their own interests or they have access to someone who can strongly advocate on their behalf.

69   People with disabilities may be particularly disadvantaged when seeking mental health services, because they may have a disability (such as a speech impairment or intellectual disability) that inhibits their ability to advocate for themselves and they may or may not have family members who can advocate on their behalf.

70   In my view, any system in which access to services is determined by whether a given individual has access to someone who can advocate for their interests on their behalf is deeply unfair and must be changed urgently.

Key features of inclusive health service systems

71   Accessibility is an essential feature of an inclusive health service system. Inclusive systems will provide accessible means of communication for people with disabilities, whether that be physical (in person) or remote forms of communication. People with

disabilities need to feel like they are heard and believed; to do that, they often need to be supported to communicate their needs clearly. Therefore, a key element of accessibility is providing some kind of service navigation support. Many people with disabilities will struggle to navigate service systems on their own, or even when they have reasonably service-savvy relatives or carers. This is especially the case when they need to interact with a number of service systems: disability, mental health, housing, etc.

72   Looking at the health system as a whole, my sense is that the paediatric side of the system functions very well in terms of accessibility for people with disabilities; it is when people leave that system at age 18 and enter either the adult primary or tertiary health care systems that challenges tend to arise. These systems are not properly set up to cope well with people with disabilities. It is also notable that this is a time when people leave school and this can also be a difficult transition and so I think this stage is very complex and challenging for young adults and their families and more support is needed to help determine the best path as adults.

Workforce

Preparing and supporting workforces to take part in significant and sustainable reform

73   It is important to keep in mind that many workforce issues transcend disability, just as they transcend mental health. Although mental health workforce needs may be growing, so too are the workforce needs of the health system as a whole and aged care. Therefore, the mental health workforce cannot be considered in isolation. This means that sustainable workforce reform requires a systemic approach (rather than a narrower, sector-based approach).

Learnings from the NDIS

74   In the case of the NDIS, the workforce has been one of the weakest aspects of its implementation, partly due to the lack of clear accountability. For example, when the scheme was introduced, we knew that we would need the equivalent of about 90,000 new full-time workers. Further, the existing disability workforce is older than the workforce as a whole, and a number of workers have disabilities themselves and so we knew this would lead to additional demands for new workers. It is also a sector in which there are high rates of casualisation and most workers work part-time. On average, disability workers work about 50 per cent of a normal week – so in effect, that meant we needed around 180,000 additional workers.

75   It was clear that, while the NDIA could contribute to workforce planning, it needed to be managed at a whole of government level and to be integrated with vocational and other training initiatives. However, because there was a lack of clear accountability, there was

a lot of talk about the importance of workforce issues, but few initiatives. There was also a view expressed by some people with disabilities that the primary attribute they were looking for in support workers was the right attitude and they could train them themselves in their individual needs. However, this clearly was not an option for those with very complex needs and limited communication. Nevertheless, this contributed to a lack of government action.

76   One challenge we faced with the implementation of the scheme, which I think we underestimated, was that the Vocational Education and Training (**VET**) sector had been greatly weakened by the competitive forces introduced about a decade ago when the sector was first exposed to competition from the private sector.[5] The VET sector simply has not been able to respond to the growing workforce needs of the NDIS. While it is clear that there needs to be a shift in the approach to workforce training, from face-to-face learning to online learning, and a greater focus on micro-credentialing, this transition is only occurring very slowly, as the VET sector continues to primarily offer Certificate courses.

77   In terms of the mental health workforce, consideration should be given to how the right people can be recruited and retained to work in the sector. This involves more than simply arranging job-specific training; it should also include proper planning around career pathways and various forms of qualification, from micro-credentials through to certificates, diplomas and degrees.

78   Consideration also needs to be given to how the training of a new workforce is to be funded. In the case of the NDIS, the funding of the scheme did not make any allowance for workforce training, which meant that individuals had to bear that cost if government subsidies were not available – and to date governments have been slow to respond to this need.

Timing and sequencing considerations for workforce reform

79   There needs to be an understanding of the time it takes to implement workforce reform. There is often a lag between when workers commence their training and when they are ready to work. Proper management of workforce training and recruitment requires careful planning.

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[5] The VET sector is a partnership between the Australian government and industry. VET qualifications are provided by government institutions, called Technical and Further Education (TAFE) institutions, as well as private institutions. Australian governments (both federal and state) provide funding, develop policies, and contribute to regulation and quality assurance of the sector.

Quality, safety and oversight

Principles, characteristics and components of best practice regulatory approaches to safety and quality in social service delivery

80   I was heavily involved from the beginning in the design of quality and safeguards for the NDIS. A huge amount of effort was put into the optimal design of these measures.

81   As noted above, the COAG NDIS Advisory Committee formed a sub-committee named the Safeguards and Quality Assurance Expert Group, of which I was a co-chairperson. The work of this group led to the publication of a discussion paper titled 'A Personalised Approach to Safeguards in the NDIS', in which we developed a number of person-centred approaches to quality and safeguards.[6]

Importance of a person-centred approach

82   When designing a person-centred system, one needs a person-centred approach to quality and safeguards that is framed around the individual's capacity to protect and safeguard themselves. In our discussion paper, we took a holistic approach to examining the human capital of an individual, which comprises their personal capital, knowledge capital, material capital and social capital. We then developed safeguards based on the following three levels:

(a)   developmental safeguards – these concern how an individual can build or be supported to build their own capacity to protect themselves;

(b)   preventative safeguards – these include protections built in at the service provider level; and

(c)   corrective safeguards – these include measures put in place in the event that something goes wrong; to ensure there is justice and to learn to reduce risks in future.

Key regulatory and oversight components

83   There are several key components and characteristics of a strong regulatory and oversight system. First, it is essential to have an independent regulator that has an oversight role in relation to quality and safeguards and has strong and freestanding ('own-motion') investigative powers. A good example of this is the National Quality and Safeguards Commission.

84   An effective regulator also needs to have the necessary resources to analyse and interrogate the data it receives, so that it can identify and address changes or trends in

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[6] The discussion paper is Attachment BB-2 to this statement.

service provision as they emerge. It must also be able to 'join the dots' and so identify service providers with any emerging widespread unsafe practices or workers and supervisors who are frequently involved in critical incidents and then have the resources to investigate these situations thoroughly.

85   Second, there should be regulatory oversight of service providers, and particularly those that conduct high risk activities, such as intimate care, restrictive practices and support for complex clients.

86   Third, there should be mandatory reporting of serious critical incidents.

87   Fourth, effective and rigorous screening of the workforce is essential. There should be a capacity to exclude workers on the basis of what I would term the "balance of probabilities", rather than being limited to only being able to exclude workers who have a court conviction (which must be established beyond reasonable doubt) or an unsatisfactory police check. It should be possible to exclude workers who have a history of reported serious incidents involving them, which may not have led to court convictions, but which are sufficient to indicate they should no longer be permitted to work with a person who is mentally ill or has a disability.

88   Such screening measures should also be extended to prohibit people with a history of reported serious incidents from working with vulnerable people (for example children and elderly people). One of the major weaknesses of the existing quality and safety system in human services is that there is no integration of worker screening and protection across the various sectors (such as child care, aged care, disability and mental health).

89   Finally, it is important to make available a public advocate (such as the Office of the Public Advocate) that is able to represent those people who do not have strong family supports and are unable to make decisions for themselves.

The Community Visitors program

90   This program, which is run by the Office of the Public Advocate, consists of unpaid volunteers who are authorised to pay unannounced visits to disability accommodation services, supported residential services and mental health services. The purpose of these visits is to ensure that residents are receiving the care they need and are being treated with dignity and respect. Community Visitors will typically visit a residence several times a year.

91   It is now well understood that violence and abuse is more prevalent in closed systems that are not subject to regular and independent scrutiny. It is important to find innovative ways of exposing such systems to greater independent scrutiny, and I think the

Community Visitors program and their powers to make unannounced visits play an important part in this process.

Recent developments and innovation in best practice approaches to regulating quality and safety in social service delivery

Innovation driven by new technologies

92   In the case of the disability sector, there is currently more innovation occurring on the service delivery side than the regulatory side. One area that has seen a considerable amount of innovation is monitoring. For example, services have greatly expanded the ways in which people with disabilities (or elderly people) can be monitored in their own home for their own safety. There are now all sorts of smart devices which can check, for example, whether the electric jug has been turned on in the morning and, if this does not occur, send a text message to a family member or close friend.

93   An organisation called Enabler Interactive is now offering some interesting forms of training to disability workers that utilise gaming technology to create scenarios in which workers can practise making decisions (i.e. there might be a right action and a wrong action in a given scenario).

Broader evolution of regulatory frameworks

94   The broader picture of the regulatory frameworks governing quality and safety in service delivery has also been shaped by international developments, notably the United Nations Convention on the Rights of People with Disabilities. The Convention, which has seen widespread adoption by states, has been influential in shaping how signatory states address these issues, which has in turn led to a general lifting of standards in relation to quality and safety issues.

Digital services

Benefits and risks of using digital technologies to support people with disabilities in receiving mental health treatment, support and care and to self-manage their own needs

Benefits

95   Technology has been a huge enabler for people with disabilities. Many modern technological devices (such as smart phones and iPads) have been designed with accessibility features at their core (because people without disabilities want to use these personal devices when they cannot see them, touch them or hear them because of noisy environments). Personalisation has simultaneously generated significant benefits for

people with disabilities (even if those features were not specifically intended to meet the particular needs of people with disabilities). In addition, technology companies have been at the cutting-edge of introducing accessibility features designed specifically for people with disabilities, including touch accommodations and features designed for the vision and hearing impaired. These devices can also be used to monitor the health of people with disabilities (as noted above) and for many other purposes. For example, the "Find My Friends" iPhone application can be used to monitor the location of vulnerable people (subject to their agreement and therefore without intruding on their privacy).

96   Several new technology platforms have also been developed to match support workers with NDIS participants. This has enabled many NDIS participants to find support workers with whom they share common interests. In some of these cases, when the formal arrangement ends (for example, when a student graduates and gets a permanent job) they become friends, thereby expanding the circle of the person with a disability.

97   Another major area that has seen advancement through technology is the provision of telehealth and "tele-disability" services, which can offer vital protection to people who might ordinarily struggle to reach a hospital or other service provider. These people are increasingly able to access services remotely from their home, which provides a terrific opportunity for service providers to reach people who previously may not have been able to access their services. An example is highly specialised speech pathology or augmentative communication to assist those with severe speech or communication impairments, which will always only be available in major centres.

98   The development of artificial intelligence also offers great benefits. A simple example is the prevalence of predictive text messaging, which enables people with an intellectual disability to communicate much more effectively. This is another example of a technological innovation that was not originally intended to specifically benefit people with disabilities, but rather was designed to save people time when typing text messages. It shows that universal design innovations that are designed to make life easier for those people without disabilities can be of great benefit to people with disabilities. I think that the reverse is true as well: if you design for people with disabilities, there are significant benefits for all. In fact, the phrase 'Design for Disability = Design for All' is a motto we have championed at the MDI.

Risks

99   The increasing prevalence of digital technologies does risk creating a deep divide between those people who can access digital services and those who cannot, either because they cannot afford to or they are not digitally literate. This is especially the case as more and more services go online.

100   There is also a risk that the spread of digital services will lead to an invasion of the privacy of individuals.

101   A further risk relates to the loss of normal legal protections. Many digital applications and programs require users to agree to a set of standard terms, yet most people do not read through those terms as a matter of course. The Office of the Public Advocate in Victoria has highlighted some of the onerous obligations included in NDIS service contracts.[7] The Australian Human Rights Commission has investigated the challenges posed by new technologies to legal and regulatory frameworks in a discussion paper titled 'Human Rights and Technology Discussion Paper'.[8]

102   On balance, I consider that the above risks can be managed and should be managed proactively and are far outweighed by the opportunities presented by advances in technology and the proliferation of digital services.

sign here ►

print name   Bruce Bonyhady

date   16 June 2020

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[7] Office of the Public Advocate (June 2019) 'NDIS service agreements: making choice and control more real'. The report is available at <https://www.publicadvocate.vic.gov.au/resources/research-reports/ndis/625-ndis-service-agreements-making-choice-and-control-more-real> [accessed 12 June 2020].

[8] The discussion paper is Attachment BB-3 to this statement.

Royal Commission into
Victoria's Mental Health System

ATTACHMENT BB-1

This is the attachment marked 'BB-1' referred to in the witness statement of Professor Bruce Bonyhady dated 16 June 2020.

PROFESSOR BRUCE PHILLIP BONYHADY AM

E-mail: bruce.bonyhady@unimelb.edu.com.au

Executive Chair and Director of the Melbourne Disability Institute with a strong track record as a disability reformer and leader, including as one of the key architects of the NDIS, inaugural Chair of the National Disability Insurance Agency and President of Philanthropy Australia, with deep experience in disability, insurance, economics, funds management, philanthropy, government and partnerships.

UNIVERSITY CAREER   JAN 2018 - present

University of Melbourne

Executive Chair and Director, Melbourne Disability Institute
Enterprise Professor, Disability Economics
The Melbourne Disability Institute is an interdisciplinary research institute established by the University of Melbourne in 2018, which seeks to transform the social and economic wellbeing and health of people with disability through high-quality research, teaching, training and knowledge translation. Professor Bonyhady's particular interests and expertise include: a deep understanding of social insurance scheme design with particular interests in lifetime approaches to maximising opportunities and minimising costs of supporting people with disability; nurturing and sustaining informal supports; data and behavioural economics; harnessing markets to serve people with disability; building a quality workforce; housing for people with disabilities; education and employment of people with disabilities; quality and safeguards; inclusive and accessible communities; and building partnerships across universities, philanthropy, the disability sector and business.

NON-EXECUTIVE DIRECTOR AND ADVISORY CAREER   AUG 2002 – present

National Disability Insurance Scheme (NDIS) and Disability

Chairman (Inaugural), Advisory Panel to Solve@RCH (Centre for Development Disability Research, Royal Children's Hospital, Melbourne), 2004 to present. Formed in 2004, Solve auspices research into causes and improved treatments of children with disabilities. It has led to the establishment of two professorships in developmental medicine at the University of Melbourne, the creation of Australia's first Centre for Research Excellence in Cerebral Palsy, funded by the NH&MRC and raised in excess of $15 million over the past decade.

Member, Victorian Department of Education, Inclusive Education Advisory Board, May 2018 to present. Chaired by the Secretary of the Department the Advisory Board gives expert advice on education of students with disability so they can achieve their potential.

Member, NSW Department of Education and Training Disability Strategy Reference Group, August 2018 to present. Provides advice on inclusive education to senior Department officials.

Member, Victorian COVID-19 Disability Advisory Group, May 2020 to present. Provides advice to the Minister.

Member, National Disability Data Asset Advisory Group, May 2020 to present. Provides advice to the Australian Data and Digital Council of COAG

Chairman (Inaugural), National Disability Insurance Agency (NDIA), 1 July 2013 to 31 December 2016. The NDIA has been established under the National Disability Insurance Scheme Act (2013) to manage the NDIS and commenced its operations on 1 July 2013. During

my time as Chairman the NDIS was delivered on time, on budget and with participant satisfaction of more than 90 per cent. At full Scheme it is expected that there will be 460,000 participants and a total annual cost of $22 billion.

Deputy Chair, COAG National Disability Insurance Scheme Advisory Group, 2011 to 2013. The Advisory Group reviewed all aspects of the design of the National Disability Insurance Scheme and made recommendations to the Select Council of COAG on Disability Reform.

Chairman, Independent Panel advising the Productivity Commission Inquiry into Disability Care and Support, 2010 and 2011. The Independent Panel met regularly with the Productivity Commission during its Inquiry and had a significant influence on its recommendation to establish a NDIS.

Member, Disability Investment Group (DIG), 2008 and 2009. The DIG made a number of recommendations to Government on disability reform in its report *The Way Forward: A New Disability Policy Framework for Australia.* The major recommendation was a NDIS and led directly to the Productivity Commission Inquiry.

Chair, Expert Group on NDIS Quality and Safeguards, 2012 to 2013. This group provided expert advice on the quality and safeguarding issues in the introduction of a NDIS.

Chairman and Director, Yooralla Society of Victoria (2001 to 2013): Yooralla was the largest provider of disability services in Victoria, had 1,750 staff and annual revenues of $100 million and the Board provided oversight and strategic direction of all activities.

Treasurer and Member of Committee of Management, Noah's Ark Toy Library (1987 to 1991): Noah's Ark was in its formative years and was already a leader in early intervention services and family centred practice.

President, 6th Camberwell North Scout Group (now Tende beck Scout Group) (2003 to 2011): Tende beck Scout Group is a scout group which provides opportunities for children and young people with disabilities to enjoy scouting. It "knocks the 'dis' out of disability".

Funds management, Insurance and Property

Director, Dexus Wholesale Property Limited (2005 to 2017): DWPL is the Responsible Entity for the Dexus Wholesale Property Fund (DWPF). DWPF is a top quartile-performing $7.5 billion unlisted property trust investing in commercial, retail and industrial properties, which has grown from $1.7 billion over a decade.

Chairman, Acadian Asset Management Australia (2005 to 2015): Independent Chairman of this very successful boutique manager which raised $4.9 billion in funds under management from superannuation funds, other institutions and retail investors of which $1.4 billion was invested in Australian equities.

Director and Member of the Investment Committee, Unisuper Limited and UniSuper Management Pty Ltd (2008 to June 2012). Unisuper manages more than $28 billion on behalf of its defined benefit, accumulation and pension members. I was a member of the Investment Committee from 2008 and then also became a Director in 2011.

Chairman, ANZ Trustees Limited (2002 to September 2009): ANZ Trustees managed $2.4 billion, 320 philanthropic trusts and distributed $50 million annually. It was the largest

manager of foundations, had a specialist investment process designed for perpetual foundations, a creative grant-making philosophy and best-practice corporate governance.

Membership and Peak Organisations

President, Philanthropy Australia (2006 to 2013). Philanthropy Australia is a member organisation and the national peak body for philanthropy. Its mission is to lead an innovative, growing, influential and high performing philanthropic sector in Australia. I personally led Philanthropy Australia's application for specific listing as a DGR.

Patron, National Disability and Carer Alliance (2009 to 2013) The Alliance, which I co-founded with Dr Rhonda Galbally AO in 2009, brings together the three key segments within the disability sector. The Alliance is a world first and auspiced the *Every Australian Counts* Campaign for the establishment of the National Disability Insurance Scheme.

Other previous directorships/positions include:

Trustee, Sylvia and Charles Viertel Foundation
Member, Felton Bequests' Committee
Director, Disability Housing Limited
Director, Singleton Equity Ltd
Chairman, ANZ Life Insurance Ltd
Director, Japan Bankers Trust
Director, Bankers Trust Investment Management (Japan)
Director, BT Funds Management (Hong Kong)
Director, BT-Commerce Unit Trust Managers (Malaysia)

Trustee, William Buckland Foundation
Member, Pension Review Reference Group
Director, Supported Housing Ltd
Chairman, ANZ Managed Investments Ltd
Director, ANZ Lenders Mortgage Insurance Ltd
Director, BT Funds Management (Singapore)
Director, BT Funds Management (NZ) Ltd
Director, Thai Capital Management
Director, NM Funds Management (Europe)
Director, NM-Korea Fund (Ireland) Ltd

EXECUTIVE CAREER   1974 – AUGUST 2002

ANZ INVESTMENTS	APRIL 2000-AUG 2002
BT FUNDS MANAGEMENT	MAY 1996-OCT 1999
NATIONAL MUTUAL LIFE ASSOCIATION OF AUSTRALASIA	FEB 1988-APR 1999
SYNTEC ECONOMIC SERVICES	NOV 1982-DEC 1987
AUSTRALIAN TREASURY	FEB 1974-NOV 1982

TERTIARY QUALIFICATIONS AND ACADEMIC AWARDS:

- Doctor of Laws (Honoris causa) for distinguished eminence in public service, University of Melbourne (2014)
- Doctor of Letters, (Honoris causa) for distinguished service to people with disabilities, University of Western Sydney (2014)
- UNE Distinguished Alumnus Award (2013)
- ANU College of Business and Economics, Distinguished Alumnus (2006)
- Master of Economics, Australian National University (1978)
- Bachelor of Applied Economics, Honours Class 1, University Medal, University of New England (1976)
- Edgar H Booth Memorial Medal and Prize, for the Most Distinguished Undergraduate Career, University of New England (1976)

ORDER OF AUSTRALIA

Member of the Order of Australia (Queen's Birthday Honour's List 2010) "for service to people with disabilities, their families and carers, particularly as Chairman of Yooralla, and to the community as a contributor to a range of charitable organisations".

OTHER AWARDS AND COMMUNITY ROLES

- Finalist, Victorian of the Year, 2011
- Life Member, Association for Children with a Disability
- Australia Day Ambassador (2010 to present)

Royal Commission into
Victoria's Mental Health System

ATTACHMENT BB-2

This is the attachment marked 'BB-2' referred to in the witness statement of Professor Bruce Bonyhady dated 16 June 2020.

A Personalised Approach to Safeguards in the NDIS

Executive Summary

This discussion paper is the result of work led by the Safeguards and Quality Assurance Expert Group as part of the NDIS implementation groups.

It draws together current thinking around capital building for all citizens and empowering safeguarding in the context of the emerging NDIS.

The paper offers an outline of a Safeguarding Framework that enables citizens to be safe, well and included. The Framework is person centred and starts from the premise of building citizens capital through developmental investments. The approach is fundamentally steeped in the notion of citizens having an active role in safeguarding themselves.

Key Findings

Citizen Capital is the foundation of understanding people, their resources and their context and is a valuable way to develop a good plan that incorporates effective safeguards.

The assessment process and determining reasonable and necessary supports should have a focus on and preference for developmental investments. Investing in citizens and families to further develop the notion of capital and developmental investments, will also lead to people having higher expectations of the planning and supports they receive.

Further exploration is needed to develop ways in which the broad range of potential providers can be encouraged and incentivised to offer high quality, inclusive products and services.

The proposed framework seeks to acknowledge the individuals assessment of their own vulnerability and build on their capital and encourage expectations for high quality supports.

This paper provides a new conceptual framework and opportunity to develop new thinking and behaviours from the start of the NDIS.

Marita Walker, Kate Fulton and Bruce Bonyhady

March 2013

Context

As the development of the NDIS progresses, resources, decision making and accountability will sit closer to people and their families, more so than ever before. The need for a balanced, proportionate safeguarding process is being explored to offer clarity, protection and safety to people, families and workers. The current Safeguarding mechanisms and regulatory frameworks in place across Australia, are largely focused on the relationship between the Government and the Support Organisations. As part of this, governments in the past have set quality standards and other requirements as part of their service funding agreements with Support Organisations and which have been applied at the service provider and service levels.

This primary relationship between the Government and the Support Organisations is currently supported by a developed regulatory framework and has recently been extended through the National Quality Framework. However as the NDIS develops, the primary relationship will change focus to that between the Government and the Person and their families.

Current Relationship – Government and Support Organisation
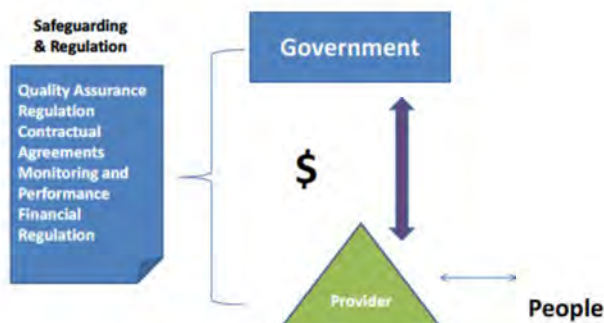
New Relationship – Government and People / Families
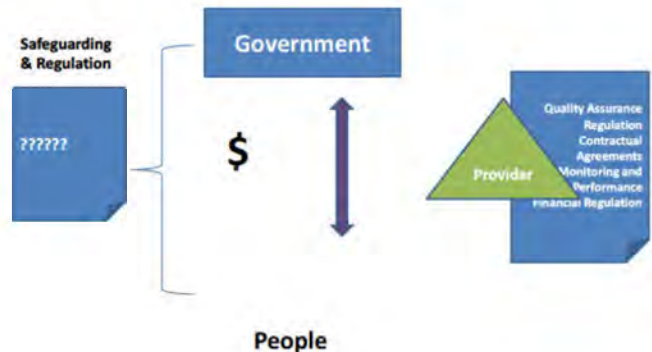
The changing nature of this relationship requires a radical re think in the way that all mechanisms designed to support people's safety and wellbeing will operate. Whatever is designed needs to be mindful and helpful to both relationships with people and Support Organisations– which may require different elements.

Safeguarding is more than child and adult protection, its primary function is concerned with the promotion of the welfare of the person - supporting them to have a good quality of life, to be an active and equal citizen, to reach their potential AND to promote their safety.

Questions

Is it possible to design a framework whose primary aim is to promote people's **wellbeing** and safety and maximise their opportunity to have a good life? Is it possible to capture the learning to date from people, families and workers and give some indication of what helps to keep all citizens safe, including a mixture of local informal supports such as family, friends, neighbours, community connections and formal Statutory Supports such as regulation, police checks and registers? What other processes are in place in today's society that promote wellbeing balancing informal and formal supports? Is it possible to develop a Framework that benefits all citizens not just those identified as vulnerable? What should be the potential national role of mechanisms that exist in some jurisdictions but not others, (e.g. Care Concerns Units and Community Visitor Programs), under a NDIS?

Potential Framework

This paper explores the potential design of a safeguarding framework that starts with the person, their capacity, their circumstances and crucially the elements that all citizens need to have in place to build good and safe lives. If we began from this position, could we work alongside people and families to explore their personal resources, identifying strengths and gaps and then best use public resources and safeguarding supports to fill and develop the gaps for each person within their own local communities and resources? We would like to use a frame of reference that refers to all citizens.

Potential Starting point for Understanding

The Fact Sheet on Safeguards for the NDIS outlines initial thinking. The inter-governmental agreements which govern launch sites, specify that the quality and safeguarding framework should be based on current regulations and requirements in each jurisdiction. This reflects the

practical reality that there is not time before 1 July to develop a new framework and ensure that service providers are ready for it.

This underlies that there is still a lot of thinking and work to be done. There is also the potential to influence outcomes during launch through the emerging values and behaviours of the National Disability Insurance Agency and amongst service providers.

The challenge is to focus on the individual, first, starting with the fact that they are citizens and understanding the range of factors that may increase their vulnerability.

An early question is, 'vulnerable to what?' In this context, it is the entire spectrum from death or serious personal harm to sub optimum or ineffective formal supports that reduce achievement of desired outcomes.

Participants in the NDIS will also potentially be vulnerable to not receiving the package of supports they need. Those who are most vulnerable to this are also likely to be vulnerable to other risks too. However, the vulnerability to not receiving "reasonable and necessary" benefits is not the subject of this paper, as it is better addressed as part of eligibility and assessment.

One of the principles in the NDIS Fact Sheet states that safeguards should be "risk based and person centred". The parameters on which risk may vary are much more complex than those listed i.e." functional capacity, natural support and services available". There are a whole host of potential factors that are likely to impact on increased vulnerability which we have begun to explore. For each of the factors there is a spectrum of risk from low to high. An example of the extremes of the possible combinations is described below.

Risk Low	Risk High
Eg: Adult Good communication & self advocacy skills. Not requiring intimate personal care. High socio-economic standing. Multiple relationships – family, friends, community who are close by and possess system advocacy skills. Living in a supportive and involved neighbourhood and community	Eg: Adult Reduced cognitive capacity. Use behaviours to communicate. Poor communication and social skills, vulnerable to suggestion and exploitation. Family not involved. No close friends. Homeless or living in housing with potential exposure to people who are likely to exploit.

The presence of formal services cannot of itself be seen as a safeguard because as we can see above, the presence of a service does not simply eradicate the range of risks.

Quality assurance of government funded disability services has been a main focus of our current system. The capacity to maintain an effective quality assurance system in an environment where there is no direct relationship between government and the providers, has been a focus of discussion to date. However this should not be seen as the only, or main way to ensure adequate safeguards for individuals.

A better starting point would be to begin with the individual and explore how it might be possible to reduce their vulnerabilities in one or more of the areas where they are vulnerable. Then explore what could be put in place within the context of an NDIS and current safeguarding mechanisms.

Michael Kendrick's[1] approach of developmental, preventative and corrective approaches would be a useful starting point in this regard.

A framework that builds and invest in citizen's capital

Working from a strength and asset based approach a helpful and universal economic term and analogy to understand resources is that of citizen's capital as explored by Roland & Landua 2011[2] and Duffy & Murray 2010[3]. We understand that all citizens have capital in all aspects of their lives. How much capital and what investment is needed is different for everyone, depending upon their social and economic lifestyle and circumstances. Our starting point to explore capital in this context is the categories of the four areas of capital developed by Robbi Williams 2013[4]. As the authors of this paper we expand upon this initial work to describe the four categories of capital and examine the implications for safeguarding vulnerable citizens.

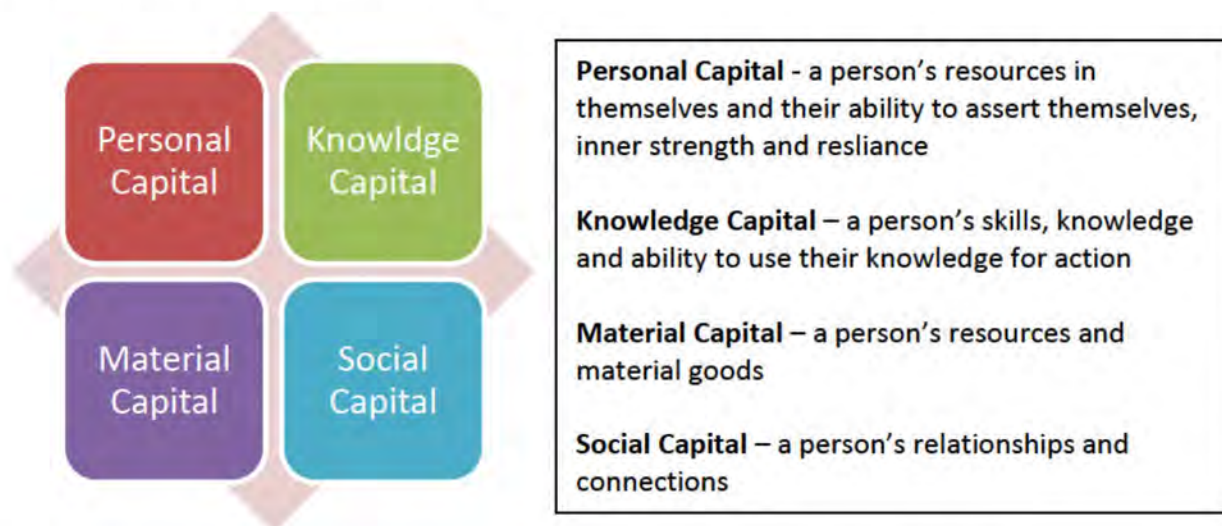[1] Kendrick 2005 Self Direction in Services and The Emerging Safeguarding and Advocacy Challenges that may Arise.
[2] Roland and Landua, 2011, http://appleseedpermaculture.com/8-forms-of-capital/
[3] Duffy & Murray, The Centre for Welfare Reform, 2010.
[4] Williams, Purple Orange, Personal Communication 7.2.13

The aspects of Capital for all Citizens are:

Personal Capital	**Knowldge Capital**	**Personal Capital** - a person's resources in themselves and their ability to assert themselves, inner strength and resliance
Material Capital	**Social Capital**	**Knowledge Capital** – a person's skills, knowledge and ability to use their knowledge for action
		Material Capital – a person's resources and material goods
		Social Capital – a person's relationships and connections

These various aspects of capital are one way of seeing and understanding the range of resources that all citizens need in their lives to enable them to live safely and well, in their local communities. It helps to think about resources in a way that best reflects real lives for all citizens – resources that are way beyond purely monetary and material resources.

Although not exhaustive they may include:

Personal Capital including self-esteem, confidence, cognitive and intuitive capacity, ability to self-advocate and be present and their inner strength and resilience

Knowledge Capital including skills, and general / specialist knowledge and the ability to access information from people, the internet and the community and to act on this information

Social Capital including relationships, family support, friends and community connections.

Material Capital including income, material goods, own home and community resources e.g. library, beaches, parks, which vary depending on location.

This perspective of capacity makes it possible to learn what it takes for all citizens to live well and have safe lives. Viewing resources and wealth in this way enables people and families themselves to measure their own wealth and resources, for example a person can be materially poor and relationship wealthy.

Citizens Capital

Who I am
Personal Capital

What I know
Knowledge Capital

Citizen

Who I know
Social Capital

What I have
Material Capital

Kate Fulton
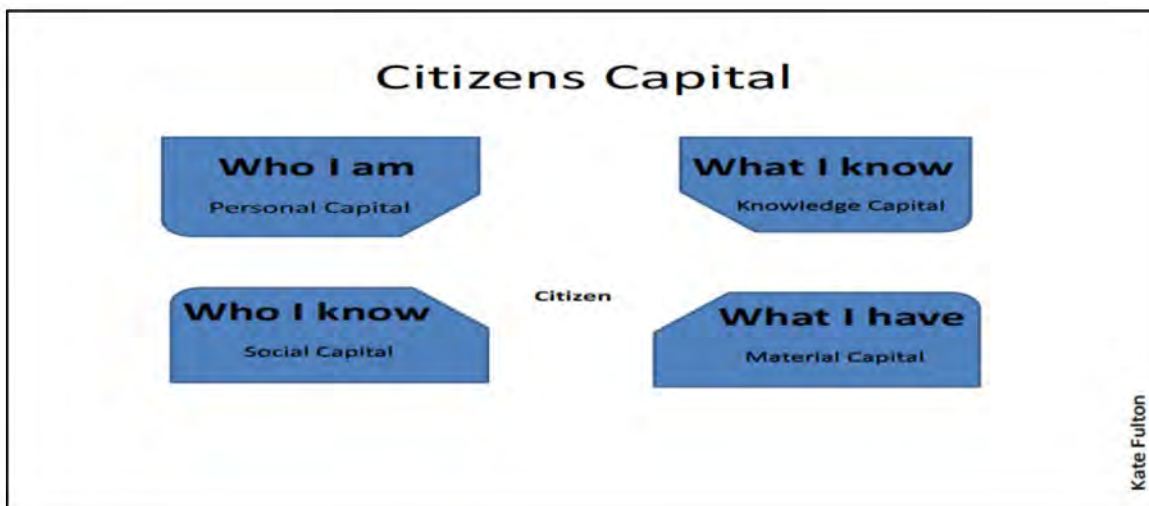
The measurement of capital across all domains is challenging, but we are keen to explore the possibilities of determining a base line of capital that all citizens require to be well and safe. The majority of citizens will have a range of resources in each area of their capital.

This base line measure would enable **all citizens** to determine themselves via a self or shared assessment / wellbeing check where there may be gaps in their own capital resources and to consider what risks this may present to the person and their life. The level of risk associated with gaps in their own capital, will then enable them to consider the right investment to build and boost their capital in the immediate and long term. The aim with any investment is to increase areas of capital to ensure any investment is an activity that promotes growth of capital and prevents erosion of capital and that supports the person to be included and protected.

| Understanding Capital | Idenitfying the gaps | Measuring the risk given the gaps - high / low | Focused investment to build capacity | Reduce risk and increase capcity and outcomes |

Empowering Safeguarding
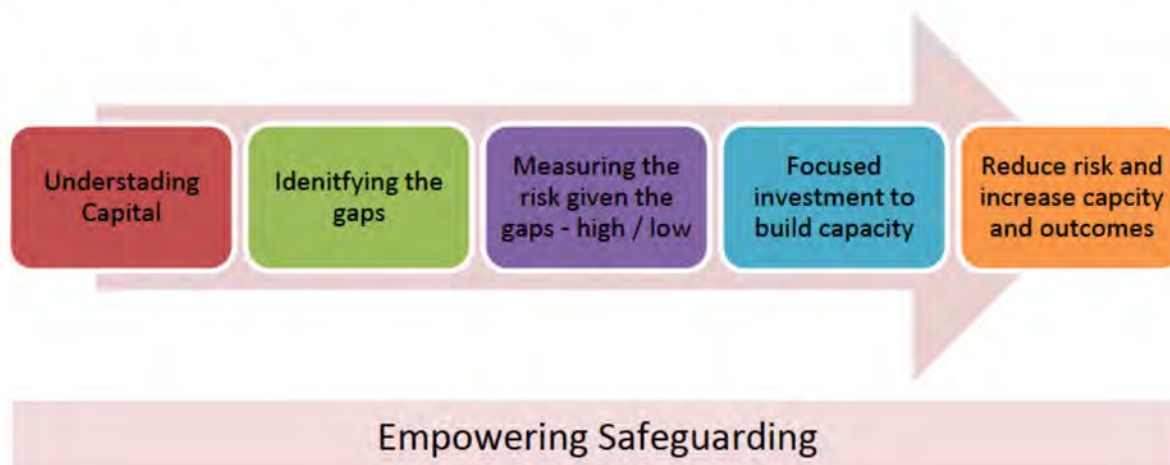
What could a measure look like?

One way of exploring capital is to provide an easy to use and robust measure in each area of capital - making it relatively simple for people, families and workers to explore.

The following provides a simple measure of capital in each area of people's lives – providing simple statements that the person and their family can relate to and determine which statement best represents their own life and circumstances.

The following is an example for Personal Capital

Level of capital	Levels of Personal Capital
Significant capital	Ability to be assertive, strong identity, ability to make decisions, confident in self-determination , control over physical environment
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction including wishes and needs
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction

In using this simple measure we can explore all areas of capital across each of the four domains. The colours provide and easy and accessible measurement using a traffic light rating.

Understanding those most at risk

Level of capital	Level of Personal Capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination , autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person including family, friends, strong community presence and participation	Financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person's lifestyle. Limited access to info and can act on this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt

This potential measure needs to capture all four domains of capital helping to easily identify and understand those people most at risk. This requires all four areas being considered in a person's life.
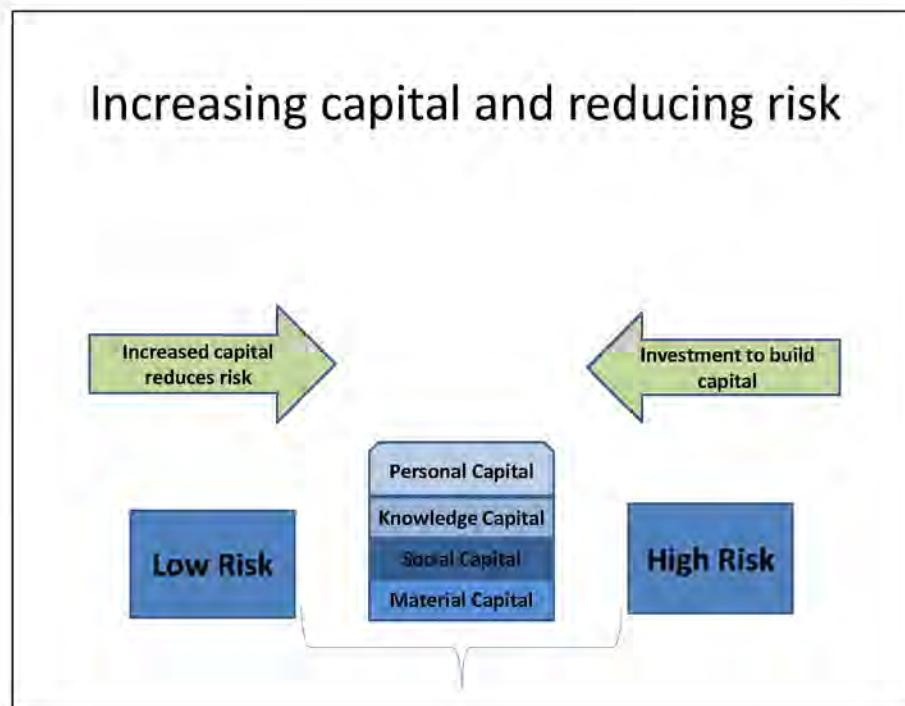
Across all areas there is some level of risk for all citizens; however measures enable us to consider given the persons capital, whether the risk low or high. Therefore we can add alongside the measure of capital an easy to use measure of risk;

- the more capital a person has, the lower the risk
- the less capital a person has, the higher the risk

Level of capital	Level of Personal capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital	Risk
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination, autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person inc family, friends, strong community presence and participation	I am financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.	Low risk
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person's lifestyle. Limited access to info and can act of this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.	
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.	
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt, living in a community with limited resources	

High Risk

Minimising risk with developmental investments

This potential framework acknowledges the fact that for all citizens reduced capital increases risk and the sensible role for a safeguarding framework is to provide investment that builds capital in the short term as well as importantly, building capital for long term benefit. The framework would be based on current thinking in building all citizens capital for a good and safe life.

Increasing capital and reducing risk

Increased capital reduces risk → ← Investment to build capital

Low Risk

Personal Capital
Knowledge Capital
Social Capital
Material Capital

High Risk

Developmental investments are investments that aim to grow areas of a person's capital, not simply adding a short term immediate solution, but developing and growing the person's capital and are proportionate to the risk posed.

Kendrick (2005)[5] describes Developmental Safeguards as safeguards which aim to produce socially desirable conditions for the inclusion and protection of people with a disability, supporting their valued status in community and developing supports through family and intentional relationship building.

Examples of Developmental Investments may include things such as a peer supporter; someone who can provide an immediate connection but who can also connect the person to other locals based on shared interest and support the person to increase their social capital over time. Another example of a Developmental Investment is education, investing in a person's low knowledge capital enables the person to secure employment leading to the potential increase in both knowledge capital, social capital and material capital.

Developmental Investments are critical in any safeguarding framework and in any service delivery, to ensure the framework provides longevity and is investing in people to grow.

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[5] Ibid

The following provides an overview of how the kind of Developmental Investments may be used to support people in each domain whose capital is low and who are at potential high risk. The list is not exhaustive but provides an insight into typical developmental investments.

The right hand column shows some of the kinds of Developmental Investments that are likely to support a developmental approach and areas in italics depict areas that the NDIA are likely to influence and promote.

Level of capital	Level of Personal capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital	Risk	Developmental Investments to increase Capital and have a Safeguarding effect
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination, autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person inc family, friends, strong community presence and participation	I am financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.	Low risk	*Self-directed support* *Individualised funding* *Service models and approaches that support individualised supports* *Individual & Family capacity building* *Organisational Capacity building to promote and encourage strategies that increase investment in capital* *Outcome Based Monitoring – that increases capital via Review - Reflection and refinement of the plan / outcomes*
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person's lifestyle. Limited access to info and can act of this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.		
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.		
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt		
High Risk						
Development Investments That develop each domain of capital	Investment to speak up for yourself, Lifelong learning and development Communication, Environmental controls, Assistance to control environment, Nominee for Supported Decision Making, Advocacy, Family Leadership, Family Investment	Initiating social contact, opportunities for leadership, the opportunity to speak for others, Family Advocacy Education, Access to info and IT	Lifelong learning and development, carer development Assistance to build circles of support, build community relationships support to develop friendships,, , Peer Support, assistance to achieve diverse experiences	Investment support, Disability Trust, Shared Housing Employment Support,		

* (inconsistent across jurisdictions / Italics – NDIA Role

Preventative and Corrective Safeguards

Alongside developmental investments we need to acknowledge the preventative and corrective safeguards that are currently in place that protect all citizens including those deemed as vulnerable and will be an integral part of any safeguarding framework that aims to enable the NDIS. Preventative and corrective safeguards work alongside developmental investments. Kendrick 2005[6] describes them as follows:

- Preventative safeguard: which is focused on service design and cultures to prevent abuse and neglect and actively address risks for individuals
- Corrective safeguards: which offer redress and trauma support after incidents occur

The graph demonstrates the kind of preventive and corrective safeguards that are typically used as a response to low capital in each area. The right hand column depicts the typical safeguards open to all citizens.

However it is important to note and further explore that for many people who are low in capital across all or many of the areas, their ability to fully access and utilise the preventative and corrective safeguards can be very reliant upon their current support strategy. An example may include a person with an intellectual disability who has been a victim of abuse who requires support and assistance to report the crime, to be understood, to benefit from criminal legal advice and to fully utilise the court system. We know that many people do not always gain access to these safeguards in the same way the majority of citizens do.

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[6] Ibid.

Level of capital	Level of Personal capital	Level of Knowledge Capital	Level of Social Capital	Level of Material Capital	Risk	Developmental Investments to increase Capital and have a Safeguarding effect	Preventative Safeguards	Corrective Safeguards
Significant capital	Ability to self-advocate, strong identity, ability to make decisions, confident in self-determination , autonomous physical capacity	Have recognised qualifications, skills and expertise. The capacity to access knowledge and information and to act on this knowledge	Lots of people connected to the person inc family, friends, strong community presence and participation	I am financially secure, with sufficient resources to meet my needs. I have a job and security of tenure.	Low risk	*Self-directed support*	Restrictive Practice Legislation & Guidelines *	Ombudsman *
Reasonable capital	Can make significant decisions known, limited understanding of their identity, reasonable sense of confidence, reasonable control over physical autonomy	Have knowledge and expertise that enables the person's lifestyle. Limited access to info and can act of this info	Family, friends, some community presence	I have sufficient funds to meet my needs and lifestyle, with security of tenure.		*Individualised funding* *Service models and approaches that support individualised supports*	Community Visitor Schemes * Care Concerns Units	Consumer Law Complaints Procedure* Police Courts – Legal
Fair Capital	Require support with decision making, limited self advocacy, limited understanding of own determination / direction inc wishes and needs	Require support to acknowledge / promote skills and contributions. Require support to access info	One or two family, paid support team, no community connections	I have limited funds and mostly manage to meet my needs and lifestyle, with limited security of tenure.		*Individual & Family capacity building* *Organisational Capacity building to promote and encourage strategies that increase investment in capital*	Police Checks *Acquittal Procedures* *Registration of Specialist Disability Providers - Developmental not compliance Based on National*	Litigation Child Protection HADSCO / Disability Commissioners *
Low capital	Little personal capacity in making major decisions, limited communication, limited autonym over physical space and limited ability to create direction	Limited education, lack of access to info and knowledge. Limited and disconnect to cultural knowledge and communities	No unpaid people in life, limited paid people	Reliant on Income Support, no employment, no inheritance, no secure housing, debt		*Outcome Based Monitoring – that increases capital via Review - Reflection and refinement of the plan / outcomes* *Independent Individual Advocacy / Systemic*	*Disability Standards AND Accountability for individual outcomes that increase capital Outcome Based Monitoring* Disability	Antidiscrimination Laws
High Risk								

Dev Investments That develop each domain of capital	Investment to speak up for yourself, Lifelong learning and development Communication Technology, Environmental controls, Nominee for Supported Decision Making, Advocacy, Family Leadership, Family Investment	Initiating social contact, opportunities for leadership, the opportunity to speak for others, Family Advocacy Assistance to build circles of support, build community relationships, support to develop friendships,	Lifelong learning and development, carer development Education, Access to info and IT, Peer Support, assistance to achieve diverse experiences	Investment support, Disability Trust, Shared Housing Employment Support,	*Advocacy Agencies*	Access and Inclusion Plans	
Preventative Safeguards	Minimal Personal Care Support	Relationships with paid staff	Information, Advice and Guidance – Buyers guide	Income Support Housing Assistance, Medicare,			
Corrective Safeguards	Guardianship* Involuntary treatment orders *	False and misleading Advertising – Corrective action	Guardianship	Legal Aid Consumer redress processes			

* (inconsistent across jurisdictions)

Italics – NDIA Role

Developmental Investments and Service Delivery

In exploring a Safeguarding Framework it inevitably raises the issue of how any investment provided by Government either directly or indirectly works to either increase the person's capital or erode it. The NDIA will undoubtedly be concerned with this element of the NDIS in exploring the kind of approaches and models that the NDIS may promote as development investments to citizens directing their own supports.

Developmental approaches are more likely to build capital while congregated and segregated services responses cannot promote or sustain individualised and flexible responses.   Within institutional settings developmental approaches are even more compromised and individuals , particularly those with labels of challenging behaviour can be housed in settings that are isolated, restrictive and punitive. Some people end up in the corrective services system as a result of inadequate support. Examples of developmental approaches and models that should be actively promoted by NDIA are shown below.

Individualised Funding
Individualised Supports
Emotional support and decision making
Individual Planning and Review
Mentoring / Coaching
Shared Management
Shared Living
Social networking/ social connecting/Circle of support
Drop-in volunteer support/ natural support
Independent living development and support
Peer support
Family Leadership\
Positive Practice Support
Preparation for leaving home
Community Engagement / Connection
Recreational Support
Educational Options / Support
Occupational Options
Employment preparation
Transport Training

Developmental Investments and Assessment

The focus of assessment could made be citizen centric by starting with the four areas of capital, relative to the person and their circumstance, rather than a more traditional focus on diagnosis and function. Often this approach leads the assessment into identifying 'needs', but doesn't help identify what will make the most difference to the person, in their life and context. Assessment should acknowledge and assist people to explore the nature of the support required, whilst recognising the depth and hugely individualised solutions, that what will actually move people towards social and economic participation. By building citizen capital into the heart of assessment it can focus on enabling people to think differently and explore more diverse solutions based upon their own resources and community capacity.

Whilst acknowledging that the development of an insurance system has a need for data for actuarial purposes, there are alternatives to collect this data. The need to gather data should not drive the assessment and planning processes, but could be addressed though a formal research approach, that initially used the standardised measures. However it would be logical in the future to look at measures of increases in capital and the correlation to social and economic participation.

Recognising and starting with the person, their contribution and their capital means that assessment is really about one person at a time.

Citizens Safeguarding Themselves

A new system should be intentional in how it actually builds awareness, ability, confidence and assertiveness for all citizens to actively safeguard themselves. Initiatives to consider are:

- Explore and better understand the current approaches that exist across Australia e.g. self advocacy, leadership training for disabled people
- Identify what could be shared and replicated across states and from international experience e.g. user lead organisations,
- Identify what would benefit from being harmonised across States e.g. Community Visitors
- Intentionally develop, resource and support peer support
- Further develop, resource and support family to family mechanisms of peer support

The new system needs to start from the premise that people and families can and should be able to navigate it with ease and for some with little or no assistance. However where people require assistance, there should be a range of options that are easily accessible to all.

Quality Assurance of All Suppliers

It is highly likely there will be a quality assurance mechanism based on the National Disability Service Standards for specialist disability service providers. What shape and form a national system will take is still to be negotiated by the jurisdictions. However as we develop the NDIS there will be an expanded and more diverse range of suppliers when people choose to use their resources in different ways. This will include suppliers beyond the traditional specialist services. We need to consider an approach that recognises and acknowledges all provision that citizen may use or purchase.

The possibilities might include;

- A feedback mechanism that is based on citizens experiences and suggestions for change e.g. Shop for Support
- Intentional awareness building of government and commercial enterprises e.g. Count Me In strategy in Western Australia
- Opportunities for businesses to commit to inclusive practices that create a point of difference with some objective measure e.g. Heart Tick.
- Structured assistance by people with lived experience to be more consumer focused e.g. Quality Checkers with lived experience in the UK Health service
- A legislative framework for Disability Access Improvement Plans e.g. Western Australia

This is an area of enormous potential and can affect the success of outcomes gained by those participating in the NDIS. It is important that we consider how we shape and influence suppliers now and in the future.

Conclusion

This paper attempts to

a) pull together current thinking around both capital building for all citizens and empowering safeguarding in the context of the emerging NDIS.

b) outline the possibilities of developing a Safeguarding Framework that enables citizens to be safe, well and included. It is person centred and starts with participants to build their personal, knowledge, social and material capital through developmental investments.

The proposed framework therefore contrasts with the current Quality and Safeguards framework, which starts with the primacy of the government/provider relationship and through funding agreements, seeks to set provider and service standards, without necessarily taking account of the people's or families own capacities to assess quality or risk.

The challenge and the opportunity is to develop new thinking and behaviours from the start of the NDIS, whilst also recognising the practical reality that the inter-governmental agreements for launch specify using existing quality and safeguard frameworks.

This paper provides an alternative conceptual framework for taking up this challenge and has the potential to be developed further, within the launch of the Scheme, in at least three key areas.

First, Developmental Investments should be made part of the assessment process and determining reasonable and necessary supports.

Second, investment in citizens and families to both understand and further develop the notion of capital and to explore how the NDIS can best support people in this, ensuring the messages are consistent in raising expectations, person centred supports and in a quality assurance mechanism. To ensure we begin from the premise of citizens having an active role in safeguarding themselves.

Thirdly, further thought is worthwhile to develop ways in which the broad range of potential providers can be encouraged and incentivised to offer high quality, inclusive products and services.

The initial draft of this paper was presented to the Safeguards and Quality Assurance Expert Group and further development and refinement has been undertaken as a result of their feedback and discussion at the meeting.

Marita Walker, Kate Fulton and Bruce Bonyhady

March 2013

Royal Commission into
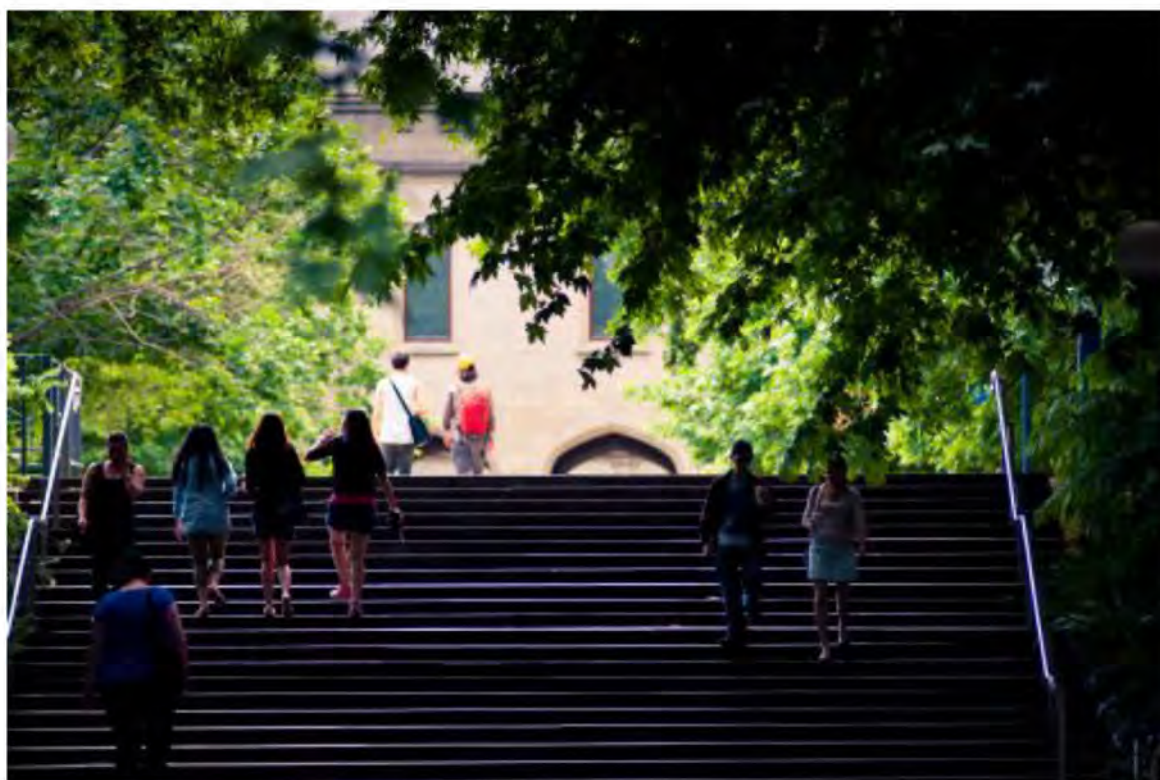Victoria's Mental Health System

ATTACHMENT BB-3

This is the attachment marked 'BB-3' referred to in the witness statement of Professor Bruce Bonyhady dated 16 June 2020.

Human Rights and Technology Discussion Paper
Australian Human Rights Commission

The University of Melbourne response

April 2020

Executive summary

The University of Melbourne welcomes the opportunity to respond to the Australian Human Rights Commission's *Human Rights and Technology Discussion Paper*. The development of new technologies poses considerable challenges to legal and regulatory frameworks intended to support the rights and interests of Australians. The Human Rights Commission (AHRC) is to be commended for its contributions in this area.

The contents of the Discussion Paper reflect the key point that the development of new technologies and digital applications entails opportunities as well as risks. There are clear dangers of human rights being compromised where, for example, new technology fails to protect individual privacy or where algorithms discriminate against certain groups. It is also true that the new technology can serve to enhance the wellbeing of individuals and communities, for example by enabling social connection for those with a disability or those who reside in remote locations. It is important to manage the legitimate risks that come with new technology, without allowing this to prevent the considerable benefits from being realised. We also note that new technologies can either enable or impede political participation and therefore impact rights of citizenship. While these issues are understandably out of this consultation's scope, this broader context is relevant to the framework for reform proposed in the Discussion Paper.

The impact of new technology on already marginalised groups is appropriately a point of focus in a discussion of the human rights implications of that technology. We welcome the attention the Commission has given to accessibility for people with disability throughout the consultation process; the comments below add to those the University offered on the issue of accessible technology in our earlier contributions to the consultation process. We note that accessibility and inclusion are matters of particular concern not only for people with disability but for other marginalised groups. The human rights framework should be sensitive to the ways in which these groups may be further disadvantaged by poorly designed technology or inadequate laws and regulations. In addition we reinforce the observation that universal design benefits all, not just special groups.

We also note that the issues addressed in this consultation have also been addressed in other public inquiries, most notably the ACCC Digital Platforms Inquiry and Data61's AI Ethics Framework. Given this overlap, the outcomes of the Commission's work would be bolstered by ensuring that they are integrated with the outcomes of those other inquiries, where appropriate, or seek to engage with those agencies where there is divergence.

Submission overview

This submission draws upon the expertise of leading researchers from the University of Melbourne across a range of fields, and was assisted by an internal roundtable held in February to discuss the Commission's Discussion Paper. Many of these researchers also contributed to the University's response to the Issues Paper and White Paper released in earlier stages of this consultation. A list of contributors has been included at the end of this submission.

The following comments are not an exhaustive response to each of the Discussion Paper's proposals or questions. Rather, the submission addresses specific elements of the framework set out in the Discussion Paper, building upon points made in the University's earlier submissions to this consultation process. The comments are limited to Parts B, C and D; where appropriate, we note specific proposals to which these comments are addressed.

Key points:

Part B – Artificial Intelligence

The University of Melbourne:

- recommends that the Commission should avoid attempting to distinguish between AI and non-AI technology for the sake of the human rights framework, given the problems associated with this distinction.
- recommends that the Commission consider amending the proposed definition of "AI-informed decision making", in view of problems associated with the phrase "legal or significant effect".
- recommends that the Commission should proceed in proposing "statutory cause of action for serious invasion of privacy", but should go further in proposing broader reform of the *Privacy Act* along the lines of reforms enacted in the EU.
- supports the proposed reforms that mandate both explainability and reasonableness.
- supports the proposal to establish a taskforce, but notes that the success of this measure will depend upon a range of groups and interests being represented.
- supports the proposal to use 'regulatory sandboxes' to test compliances, but suggest that this should involve a number of sandboxes (rather than just one) given the range of applications to be tested.

Part C – National Leadership on AI

- The University of Melbourne suggests that the proposal to establish an AI Safety Commissioner needs to integrate with other elements of the framework set out in the Discussion Paper. In particular, the Commissioner role must be integrated with any independent body established to inquire into ethical frameworks recommended in Part A.

Part D – Accessible Technology

- The University of Melbourne supports the proposal for COAG to lead a national process for promoting 'human rights by design', but encourages that this be taken further to include service development and delivery.

For further information, or to discuss the submission, Professor Liz Sonenberg, Pro Vice-Chancellor (Research Infrastructure and Systems), can be contacted at l.sonenberg@unimelb.edu.au or on (03) 9035 8619.

Part B: Artificial Intelligence

Distinction between AI and non-AI technology

Part B of the Discussion Paper is dedicated to Artificial Intelligence and AI-informed decision making, by implication excluding technology that does not involve AI. As per the University's responses to the Issues Paper and White Paper[1], we argue that it is best to avoid attempting to distinguish between AI and non-AI technology within the human rights framework. There are three reasons for this. First, there is no clear or agreed distinction that separates "AI" from other algorithmic technologies. Second, the distinction is not relevant: there is no reason for laws and regulations to apply to an AI algorithm but not to other algorithms tasked with similar types of decisions. Third, limiting human rights-related provisions to AI technology will likely result in organisations seeking to avoid these provisions by arguing that what the relevant technology accomplishes does not count as AI.

Definition of 'AI-informed decision making'

Question A invites feedback on the Discussion Paper's proposed definition of AI-informed decision making as containing the following two elements: (i) "there must be a decision that has legal, or similarly significant, effect for an individual; and (ii) "AI must have materially assisted in the process of making the decision".

Notwithstanding the preceding point about avoiding provisions that are specific to AI-technology, the University of Melbourne proposes that the proposed definition should be re-worded. The phrase "decision that has legal, or similarly significant, effect" could be replaced with "decision that has human rights implications". This would reflect the broad intent of the current definition – to ensure that the basic entitlements of individuals are safeguarded in the face of the risks posed by new technologies – while avoiding potential confusion associated with determining whether a "legal effect" can be ascribed to the application. The recently released *Guidance on the AI auditing framework* from the U.K. Information Commissioner's Office may be helpful in informing thinking around the interaction between individual rights and the development of AI systems.[2]

Privacy

Proposal 4 suggests introducing "a statutory cause of action for serious invasion of privacy". The University of Melbourne supports this proposal. It is in keeping with recommendations of the Australian Law Reform Commission's *Serious Invasions of Privacy in the Digital Era* (ALRC Report 123, June 2014); Department of Prime Minister and Cabinet's Issues Paper, *A Commonwealth Statutory Cause of Action for Serious Invasion of Privacy* (September 2011); and the Australian Competition and Consumer Commission's, *Digital Platforms Inquiry – Final Report* (July 2019). We note also that the Government in its Response to the ACCC Report has undertaken to review the question as part of a broader review of the *Privacy Act*. Further, we note a potential link between the need for more elaborated provisions about consent in the context of privacy, and the need for meaningful explainability in decision making scenarios.

However, Proposal 4 arguably does not go far enough. An additional sentence should be added along the lines of the Australian Government "reforming to the Privacy Act to give better account to the right to privacy". Such reforms should include, at a minimum, a more up-to-date definition of 'personal information' and a right for individuals to bring a claim in court for damages for breach of the Act. The EU has enacted reforms that reflect the need to ensure that increases in data sharing

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[1] Submission 50 at https://tech.humanrights.gov.au/submissions-white-paper and Submission 79 at https://tech.humanrights.gov.au/submissions

[2] https://ico.org.uk/media/about-the-ico/consultations/2617219/guidance-on-the-ai-auditing-framework-draft-for-consultation.pdf, see pp.86-93.

are accompanied by stronger privacy protections. The General Data Protection Regulation (GDPR) – which provides a right to deletion and a more accurate definition of re-identification[3] – serves as a useful model for Australia to follow.

Other jurisdictions, including the UK and California, have made progress in developing broad yet flexible, principles-based regulation, coupled with an ability of those whose data has been misused to individually or collectively bring a claim in court for breach of a data privacy/data protection statute and recover damages. These changes would embody a recognition that privacy is a right, rather than a mere privilege, whose enforcement is left to the discretion of the regulator. The ACCC has recommended these and other reforms to the Act in its Digital Platforms inquiry, arguing that such changes are needed for the empowerment of consumers. The Australian Government's Response indicated that these issues will be addressed in the planned review of the *Privacy Act*. It would help to build the case for the changes if the AHRC's position aligned with that of the ACCC.

Explainability and the right to review

Proposals 7 and 8 suggest legislative reforms to mandate that AI applications are both explainable and reasonable. The University of Melbourne supports these proposals. As articulated in Proposal 7, individuals that are impacted by algorithmic decisions are entitled to an explanation of those decisions, including both a non-technical explanation that identifies the reasons for the decisions as well as an account of the technical details of the algorithm. Important legislative reform in this area should establish a 'right to review'. This is an essential accountability mechanism to ensure that the relevant decision making does not involve unfair discrimination.

Taskforce

Proposal 13 suggests that a taskforce be established to "develop the concept of 'human rights by design' in the context of AI-informed decision making and examine how best to implement this in Australia". The University of Melbourne supports the proposed taskforce. We note, however, that the success of the taskforce will depend upon it being composed of members representing a broad range of knowledge and interest groups. Broad representation should include researchers from a range of fields, industry, technical experts, user groups, and representatives of disadvantaged groups, all the while ensuring that the taskforce is not dominated by any particular interest.

Regulatory sandboxes

Proposal 15 suggests that the "Australian Government should consider establishing a regulatory sandbox to test AI-informed decision-making systems for compliance with human rights." While supporting this proposal, we argue that it would be better couched in terms of regulatory sandboxes rather than a single sandbox. Given the diversity in technological applications to be tested in this way, and the rapid evolution of technology, a variety of forums appropriate to different types of application would be more effective in ensuring compliance with human rights.

Relatedly, the University encourages the Commission to adopt a broad view of what should be tested in the sandboxes. As well as assessing new technologies, sandboxes could also aid the development of evaluation and review mechanisms. For example, sandboxes could aid in the development and testing of tools aimed at harnessing AI to empower financial wellbeing, as identified by University of Melbourne researchers in a 2019 FinFuture White Paper[4]. A regulatory sandbox for the testing of AI-based decision-making tools to support financial decision-making would enable the testing of these tools in a safe environment to against the requirements of human rights compliance.

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[3] e.g. https://gdpr-info.eu/chapter-3/
[4] https://www.unimelb.edu.au/finfuture/whitepaper

Part C: National Leadership on AI

AI Safety Commissioner

The Discussion Paper proposes that the Australian Government "establish an AI Safety Commissioner as an independent statutory office to take a national leadership role in the development and use of AI in Australia. The proposed AI Safety Commissioner should focus on preventing individual and community harm and protecting and promoting human rights." (Proposal 19).

While there is some merit in the proposal, consideration should be given to how the proposed Safety Commissioner relates to other elements of the framework outlined in the Discussion Paper. Proposals 1 and 2 suggest the development of a National Strategy and the establishment of an independent body to inquire into ethical frameworks for new and emerging technologies. It is important that these elements are properly integrated. Specifically, it would be helpful if it were made clear whether the Safety Commissioner is envisaged as belonging to the proposed independent body or being separate from it.

We also note that the effectiveness of this measure in protecting and promoting human rights will depend upon the remit it is given and on how it interacts with existing bodies. Along these lines, the University suggests that three key features should guide the establishment of the Safety Commissioner:

1. Its remit should not be limited to AI (as per our earlier comments)

2. It should be designed to work in a co-ordinated manner across existing bodies with oversight responsibilities relating to the development and use of technology and data (e.g. the Privacy Commissioner)

3. Its responsibilities should include monitoring international developments in the regulation of new technology to facilitate Australia's alignment with international developments.

Part D: Accessible Technology

Part D of the Discussion Paper focuses on issues of disability and accessible technology.

It is essential that all people can enjoy the benefits of new technological advancements. The University of Melbourne welcomes the Commission's discussion of accessibility and human rights, particularly the suggested measures to enhance and prioritise disability accessibility in the field of digital technology.

Proposal 25 suggests that the Council of Australian Governments (COAG) lead a process for "federal, state and territory governments to commit to adopting and promoting 'human rights by design' in the development and delivery of government services using Digital Technologies", and suggests COAG "include policy action to improve access to digital and other technologies for people with disability as a priority in the next National Disability Strategy".

The University of Melbourne supports this proposal. However, we recommend that this proposal be taken further to include a focus on human rights by design from the start of the service development and delivery, ensuring that all technologies are friendly to disabled users. It is essential that a new National Disability Strategy be implemented this year alongside a new National Disability Agreement (as recommended by the Productivity Commission's *Review of the National Disability Agreement*[5]) and that both the Agreement and Strategy place an emphasis on technology as a key enabler of full citizenship and inclusion for people with disabilities.

The Productivity Commission's Review offers a guide as to what a new National Disability Agreement may look like, identifying seven key person-centred objectives for the new Agreement: Learning and skills; Health and well-being; Inclusive and accessible communities ; Family and carer wellbeing; Rights protection, justice and legislation; Personal and community support; Economic security.

Appropriate technological support will facilitate each of these objectives; it is crucial that people with disability are not excluded through any digital divide. The organisation commissioned under Proposal 28 may provide an important mechanism to assist in the delivery of digital inclusion.

Question G raises the issue of private sector measures to eliminate barriers to accessibility, specifically relating to the affordability of digital technologies for people with disability. We direct the AHRC to a program of research led by the Melbourne Social Equity Institute and developed in collaboration with industry, people with cognitive disabilities, and representative organisations of people with disabilities and mental health consumers. The 'Better support for consumers with cognitive disabilities' project[6], funded via the Australian Communications Consumer Action Network (ACCAN) Grants Program, involved the development of practical resources to increase support and access to online telecommunications products for consumers with cognitive disabilities. That resource included a set of recommendations to guide service providers to improve and clarify their web content and a toolkit of Easy English templates to support providers to develop accessible information.

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[5] https://www.pc.gov.au/inquiries/completed/disability-agreement#report
[6] https://socialequity.unimelb.edu.au/projects/support-for-consumer-transactions/

List of Contributors

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*Note that while the researchers listed provided expert comment that informed the content of this submission, the submission ultimately represents the views of the University and not necessarily the views of each of these contributors.

Royal Commission into
Victoria's Mental Health System

ATTACHMENT BB-4

This is the attachment marked 'BB-4' referred to in the witness statement of Professor Bruce Bonyhady dated 16 June 2020.

2019

MELBOURNE DISABILITY INSTITUTE

2019 ANNUAL REPORT

THE MELBOURNE DISABILITY INSTITUTE
WOULD LIKE TO ACKNOWLEDGE THE
PEOPLE OF THE KULIN NATION WHO ARE
THE TRADITIONAL CUSTODIANS OF THIS
LAND.

WE ALSO PAY RESPECT TO THE ELDERS
BOTH PAST AND PRESENT AND EXTEND
THAT RESPECT TO OTHER INDIGENOUS
AUSTRALIANS PRESENT.

LETTER
FROM THE

DIRECTOR

In the nearly two years since the Melbourne Disability Institute was founded, it has grown into both a fixture and a resource for many in the University of Melbourne community and beyond.

PROFESSOR BRUCE BONYHADY, AM
EXECUTIVE CHAIR AND DIRECTOR

In the nearly two years since the Melbourne Disability Institute (MDI) was founded, it has grown into both a fixture and a resource for many in the University of Melbourne community and beyond. Our growing internal cadre of faculty, researchers and staff and external partners are working together to drive our mission to build a truly collaborative research program to improve the lives of people with disability, their families and carers.

It has been a year of very significant progress. We committed more than $595,000 for capacity building through our seed funding program, helped shape and explore new disability research through collaborative partnerships and our community of practice; and, helped to translate this knowledge by facilitating connections with governments and the disability sector.

We have also built significant external partnerships. Foremost amongst these is the National Disability Research Partnership (NDRP), which is being led by MDI. The NDRP has received $2.5 million from the Commonwealth Department of Social Services and will facilitate a collaborative, translational research program through deep engagement between academics, governments, service providers and advocacy groups to guide Australia's actions in ensuring all people with disability have the opportunity to become full citizens and live in an inclusive and accessible society.

In 2018, MDI convened a coalition of Australian researchers and stakeholders in the disability sector committed to ensuring that data related to disability would be linked to health, education, employment and other data and be made available to researchers to undertake world-leading research. We were therefore delighted when the Australian Data and Digital Council announced in September 2019 that an enduring National Disability Data Asset will be established to underpin policy-related research and evaluation.

The under-utilisation of NDIS plans was noted by the Productivity Commission's Inquiry into NDIS Costs in 2019 as a major issue of concern. MDI is therefore very pleased to be working closely with both the Victorian Department of Health and Human Services and the Commonwealth Department of Social Services to provide a detailed description of the predictors of plan utilisation using sophisticated quantitative and qualitative research techniques.

MDI has also been busy building international links. In close collaboration with the Nossal Institute of Global Health, we are working with the Department of Empowerment of Persons with Disabilities in the Government of India to advance a number of collaborations, including a co-designed community-based disability course and an economic analysis for increased investment in disability.

Building on these foundations and achievements, we are now aiming higher to address new research and knowledge translation gaps that will positively impact more Australians with disability, their families and carers and lead to improvements in other countries as well. Our goal is to build a leading global and university-wide centre of excellence for disability research, education and capacity building.

I would also like to take this opportunity to thank the members of the MDI Executive Committee, all MDI staff and our partners. Without your dedication, hard work, resourcefulness and creativity, we could not have achieved any of our results since MDI was established.

Now with the COVID-19 pandemic upon us and with the additional significant risks it is creating for people with disabilities, their families and carers we will need your support, advice and counsel even more in the very challenging times which lie ahead.

LETTER
FROM THE

ACADEMIC DIRECTOR

PROFESSOR ANNE KAVANAGH

When we started the Melbourne Disability Institute just over two years ago, we established a vision to help transform the social and economic wellbeing and the health of people with disability through high-quality research, teaching and training, and knowledge translation.

It is our mission to create an evidence-base that informs policy and service development across all aspects of the lives of people with disability including employment, housing, education, participation in the community and freedom from discrimination. Our program is centered on providing much needed evidence for the disability sector and to do so by uplifting and supporting the research capability that exists on campus.

This includes driving collaboration and innovation across the research pipeline, strengthening transdisciplinary research collaboration, providing better access to research infrastructure, maximizing opportunities for research translation and positioning the University to tackle future challenges.

In line with our remit as a portal for disability research, MDI hosted a range of events and activities throughout 2019 that brought together University of Melbourne researchers, and the external communities we serve, in innovative discourses around the future state of things. Among our highlights, we hosted the Hon Jenny Macklin, former member of Parliament at our Disability Research Community of Practice, launched a new podcast to explore some of the most complex issues facing people with disability today and provided seed funding to 24 new projects across the University.

We look forward to the year ahead and appreciate your support in our ongoing efforts to support collaborative research.

ABOUT US

As one of the University of Melbourne's five Interdisciplinary Research Institutes, the Melbourne Disability Institute's mission is twofold – to build vision and greater activity across the University's faculties and disciplines in disability-focused research, and to be a portal to the outside world for translating and disseminating disability knowledge that builds a platform for addressing the critical issues of our time.

OUR STRATEGIC OBJECTIVES:

- Build research capacity at the University of Melbourne by catalysing new research, facilitating research translation, promoting all aspects of research, and creating new partnerships

- Provide a point of contact into the relevant fields of research expertise at the University of Melbourne

- Grow the University's reputation as a leader in accessible, important and relevant disability research

- Actively generate external funding and other resources for disability research at the University of Melbourne

OUR VISION:

To transform the social and economic wellbeing and the health of people with disability through high-quality research, teaching and training, and knowledge translation.

Harnessing interdisciplinary research to provide innovative solutions

OUR EXECUTIVE COMMITTEE

MDI enjoys the support of a diverse and vibrant Executive Committee made up of experts, thought leaders and champions of disability research within the University of Melbourne. The Executive Committee provides assistance with strategic planning for MDI and provides advice on areas in which MDI can create linkages with external stakeholders in order to grow the research program and attract funding.

Professor Mark Hargreaves
Pro Vice-Chancellor
(Research Collaboration &
Partnerships)

Professor Lou Harms
Department of Social Work

Professor Anne Kavanagh
Melbourne School of
Population and Global
Health

Dr Anna Arstein-Kerslake
Melbourne Law School

Professor Bruce Bonyhady
Melbourne Disability
Institute

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Professor Brendan Gleeson
Melbourne Sustainable
Society Institute

Professor Keith McVilly
School of Social & Political
Sciences

Professor Abigail Payne
Melbourne Institute of
Applied Economic and
Social Research

Dr Simon Wilkins
Translating Research at
Melbourne (TRAM)

OUR
TEAM

MDI'S EXCELLENCE IS BUILT ON THE FOUNDATION OF HIGHLY DEDICATED AND TALENTED STAFF, COMMITTED TO THE SHARED VISION TO HELP TRANSFORM THE SOCIAL AND ECONOMIC WELLBEING AND THE HEALTH OF PEOPLE WITH DISABILITY THROUGH HIGH-QUALITY RESEARCH, TEACHING AND TRAINING, AND KNOWLEDGE TRANSLATION.

Professor Bruce Bonyhady
Executive Chair and Director

Professor Anne Kavanagh
Academic Director

Tessa de Vries
Institute Manager

Dr. Sue Olney
Senior Research Fellow

Campbell Message
Program Manager

Lishia Singh
Program Manager

Sara Donaldson
Communications Manager

Georgia Katsikis
Co-research Coordinator

Alicia Yon
Project Coordinator Housing

OUR RESEARCH

PROGRAM

SUPPORTING RESEARCHERS AND BUILDING CAPACITY

Our research funding portfolio is designed to support and develop collaborative research that atively influences policy and practice to improve the lives of people with disability, their families and carers.

RESEARCH PRINCIPLES

The MDI research program is underpinned by four foundation principles: data; interdisciplinarity; experience-based co-production with people with lived experience of disability; and active partnerships.

In 2019 we were proud to facilitate a wide range of interdisciplinary research at the University of Melbourne through our three funding schemes; seed funding for small-medium projects at the discovery or pilot end of research, event funding to support disability-related public

events, and our community-based research scheme through which we encourage and support the evaluation and research of innovative ideas in the broader disability community, by linking community organisations to researchers.

PARTNERSHIPS AND ENGAGEMENT

The MDI could not achieve its goals without strong partnerships with academics, the disability sector, governments, business and philanthropy. Some of the partnerships and key relationships that underpin the MDI program of work include:

- The Commonwealth of Australia and the State Government of Victoria

- Disability service providers and not-for-profits such as the Brotherhood of St Laurence and Baptcare

- Peak bodies, disability people organisations, disability advocacy organisations, and family advocacy and support groups

- Other universities and research institutes in Australia and internationally.

01

OPPORTUNITY AND EQUITY

Ensuring equitable access for people with disability to justice, inclusive education, meaningful employment, intervention and support, and mainstream services

02

INCLUSIVE COMMUNITIES

Research that focuses on the structures and practices that increase the participation and inclusion of people with disability into everyday activities

03

HEALTH AND WELLBEING

Improving all other aspects that contribute to a person's health and well-being, focusing on the intersection between disability and health

04

MARKETS AND SUSTAINABILITY

The introduction of the NDIS is creating opportunities for research into smart and ethical technology, effective market design, new models of service delivery, best practice approaches to consumer-directed models of technological and service development, and niche industries

05

POLICY AND PRACTICE

This theme focuses on the best approaches to incorporating evidence into policy and practice so that we can transform the lives of people with disability, families and carers for the better
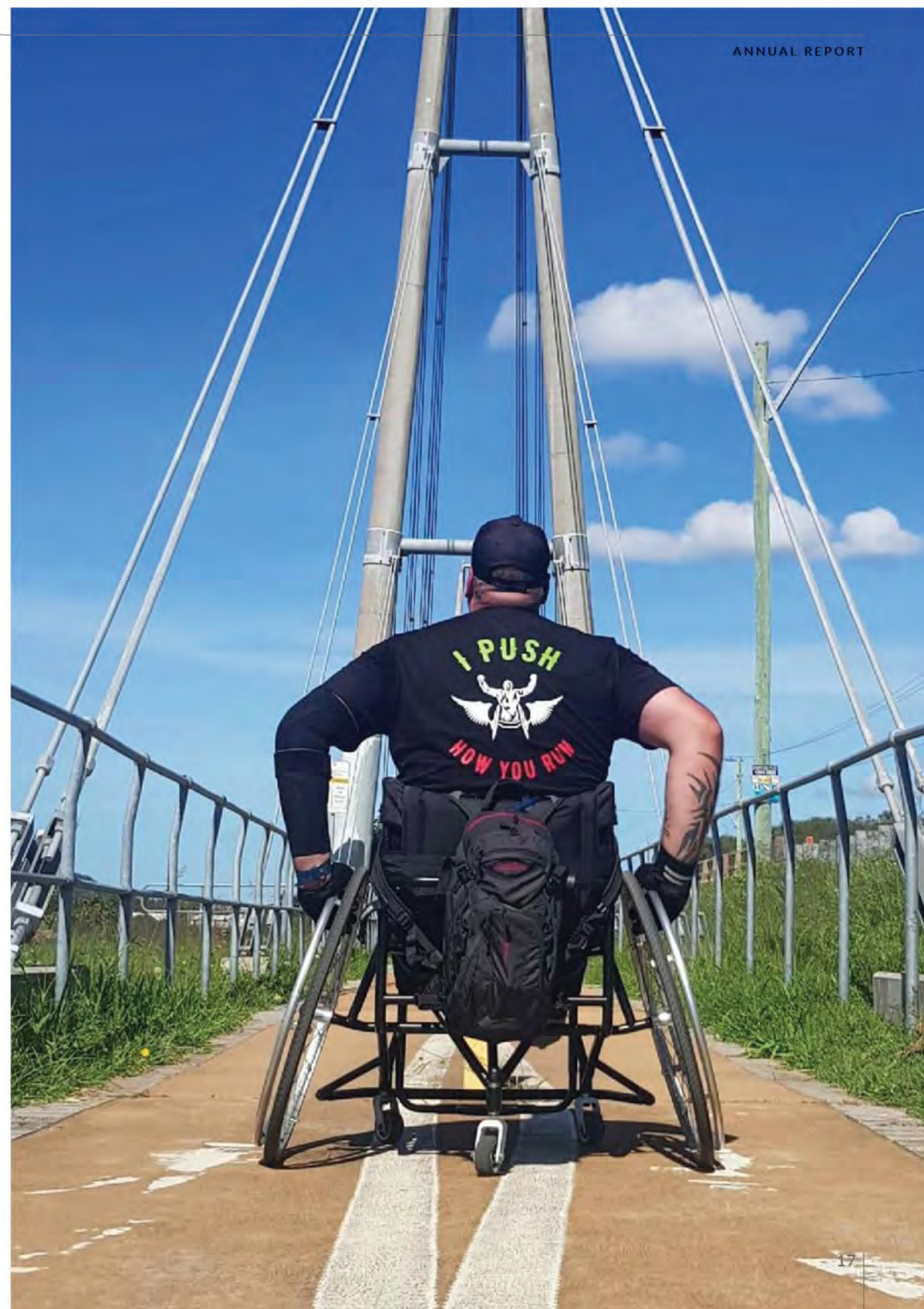
SUPPORTING NEW RESEARCH

Seed Funding

The MDI Seed Funding scheme is intended to support pilot or discovery research that falls within five strategic research themes. Funding supports innovate, interdisciplinary research that is likely to improve the lives of people with disability, their families and carers, and shows significant potential for impact or further funding.

In 2019 we were pleased to support 24 projects to a total value of $ 595,201.55.

MYTH BUSTING AND NUMBER CRUNCHING: THE DISABILITY PAY GAP

Faculty of Medicine, Dentistry and Health Sciences
Centre for Health Equity, Melbourne School of Population and Global Health
Lead researcher: Dr George Disney

People with disability often experience poor employment outcomes. However, the size and nature of employment disadvantage faced by people with disability is not understood and remains unaddressed. To bridge the gap between evidence and understanding of disability-related inequalities, this project will pilot t a data-driven, Q&A style on-line interactive tool where the general public, policy makers and users of disability statistics can learn about the disparities that people with disability experience in the job market. The pilot study will use an analysis of the "disability pay gap", a simple comparison of average earnings for people with disability in comparison to those without. The tool will use creative visualisations and accessible user-engagement to maximise knowledge translation.

EVERYONE'S MOOMBA

Faculty of Arts
Work Integrated Learning, Academic Support Office
Lead researcher: Dr Lea Campbell

The Committee for Melbourne, a non-for profit NGO, is collaborating with the City of Melbourne to deliver a benchmarking audit and community survey of Moomba, Australia's largest and free community festival. A report will inform the City of Melbourne on how to strengthen and future proof the festival for people with a disability. Other organisation will potentially be able to use Everyone's Moomba as a best practice example for holistic and authentic inclusive events hosting.

ACCESS TO SERVICES FOR ABORIGINAL CHILDREN WITH INTELLECTUAL DISABILITY (WA)

Faculty of Medicine, Dentistry and Health Sciences
Indigenous Epidemiology and Health, Melbourne School of Population and Global Health
Lead researcher: Dr Alison Gibberd

Intellectual disability and/or autism spectrum disorder ('developmental disability') affect 4% of Aboriginal children in Western Australia, more than twice the percentage of non-Aboriginal children. Overall, they are less likely to access disability services prior to school entry. However, it is not known whether this reduced access is uniform across the state and families or whether there is important variation within the population. This project will use total population data from Western Australia to understand why Aboriginal children with developmental disability are less likely to receive disability services prior to school than non-Aboriginal children. The project also aims to understand the current relationship between Aboriginal families affected by developmental disability and the child protection system.

VIOLENCE AGAINST PEOPLE WITH DISABILITIES: MAXIMISING THE USE OF DATA TO INFORM THE ROYAL COMMISSION

Faculty of Medicine, Dentistry and Health Sciences
Centre for Health Equity, Melbourne School of Population and Global Health
Lead researcher: Professor Anne Kavanagh

In light of the Royal Commission on Violence and Abuse against People with Disabilities, there is an urgent need for contemporary estimates of the prevalence of violence and abuse against people with disability for the public, policy makers and Commissioners to consider. This is particularly important as misinformation on the prevalence of violence is promulgated such as that 90% of women with intellectual disabilities have been sexually assaulted. This project will inform a submission to the Royal Commission into Violence and Abuse against people with disability by providing the most up-to-date population-based estimates on the prevalence of violence among people with disability in Australia. In addition, the project will identify existing Australian data sources and make recommendations for improvements including the potential for data linkages. Co-researchers with disability will work with key stakeholders to design dissemination strategies to maximise the impact of the research.

TRIAL AND VALIDATION OF THE ASQ-TRAK – A DEVELOPMENTAL OUTCOME MEASURE FOR AUSTRALIAN ABORIGINAL CHILDREN

Faculty of Medicine, Dentistry and Health Sciences
Indigenous Child Health, Department of Paediatrics
Melbourne Medical School
Lead researcher: Dr Anita D'Aprano

The ASQ-TRAK Extended has been developed in collaboration with communities in the Northern Territory and South Australia. Comprised of culturally and linguistically modified items from the Ages and Stages Questionnaires, 3rd edition (ASQ-3), the ASQ-TRAK Extended is a developmental outcome measure for Australian Aboriginal children that can assess individual children's developmental progress and evaluate the impact of early childhood programs and intervention. The ASQ TRAK Extended is a prototype that still needs to be trialled and validated in the contexts where it will be implemented. A three-tiered research program has been conceived to achieve this. First, to develop the ASQ-TRAK Extended; second, to validate the ASQ-TRAK Extended; and third, to examine the feasibility and the cost of implementing the ASQ-TRAK Extended.

PATHWAYS FOR RESPONDING TO CONFLICT AND HIGH-RISK BEHAVIOURS IN FAMILIES: A FEASIBILITY STUDY BASED ON FAMILIES LIVING WITH A CHILD/YOUNG PERSON WITH AUTISM

Faculty of Medicine, Dentistry and Health Sciences
Department of Social Work, Melbourne School of Health Sciences
Lead researcher: Professor Cathy Humphreys

This research aims to investigate the difficulties of familial conflict, high risk behaviours, and sources of support for families living with a child/young person with Autism Spectrum Disorder (ASD). This research will include the lived experiences communicated by family members as well as input from practitioners and managers within disability, family violence and autism services about their perspectives on responding to needs of families

with ASD. It also seeks to better understand when support may be most important, across pre-diagnoses, diagnosis and beyond. The outcomes of this small-scale study may identify pathways for service development in this area, and further inform sensitive and appropriate service provision and interventions for families where there is a child/young person with ASD.

DENTAL HEALTH FOR PEOPLE WITH INTELLECTUAL DISABILITY

Faculty of Arts School of Social and Political Sciences
Lead researcher: Professor Keith McVilly

This activity is part of a larger project titled 'Communities of Practice - Dental Health for People with Disabilities' which aims to improve the oral health of people with intellectual disability and increase the volume of people with intellectual disability being treated in community and private dental practice settings. In the short-term, this current project will identify best practice solutions for Australian dental professionals to include people with intellectual disability in their everyday practice. In the long-term, this interdisciplinary project will establish an evidence-base model derived by dentists, people with intellectual disability, disability support professionals, and allied health practitioners for use across both dentistry and disability sectors.

NATIONAL DISABILITY INSURANCE SCHEME (NDIS) LEGAL CLINIC

Melbourne Law School
Disability Human Rights Clinic
Lead researcher: Associate Professor Dr Anna Arstein-Kerslake

This project will establish the NDIS Legal Clinic at Melbourne Law School, which is the first of its kind in Australia. People with disability, their families and carers are struggling to find appropriate, independent assistance in dealing with the NDIS. This clinic will fill this significant gap. Students will be trained and supervised to deliver information and assistance in accessing, navigating, and successfully utilising the NDIS. More specifically, the clinic will assist with the provision of advice to NDIS participants, their

families and carers, who would be otherwise unable to access it; a database of practical experiences of issues in the NDIS system will inform current research and policy advice. Additionally, this clinic provides an opportunity for students to gain practical experience and develop associated skills, while providing assistance to people with disability, their families and carers in exercising informed consumer choice and demanding appropriate products and services under the NDIS.

AFRICAN AUSTRALIANS WITH DISABILITY AND THE NDIS: EXPLORING THE SUPPORT AND SERVICE NEEDS OF AFRICAN AUSTRALIANS WITH DISABILITY

Faculty of Arts School of Social and Political Sciences
Dr Claire Spivakovsky

This project will explore the experiences of African Australians with disability seeking access to the NDIS. Particular focus is on the gaps that form between the available support, this group's service needs, and the coverage of the NDIS. The exploration will include consideration of this group's awareness of NDIS coverage; the pathways African Australians with disability take to access the NDIS; the funding experiences and outcomes, including the transition period; and intersecting factors, including migration and settlement experiences that shape each of the above.

EVALUATION OF SAFE PLACE PILOT PROGRAM

Faculty of Medicine, Dentistry and Health Sciences
Centre for Health Equity, Gender and Women's Health team, School of Population and Global Health
Lead researcher: Erik Martino (PhD Candidate)

MDI was pleased to provide top-up funding to this project as part of the Housing Hallmark Seed Fund Scheme. Safe Steps and its partners will deliver a pilot program that uses vacant homes in Melbourne's private real estate market to fill the emergency housing gap for intimate partner violence survivors, to provide quality, affordable and safe emergency housing to women. This research project is to evaluate the economic and social impacts of this housing

pilot program and examine possibilities for upscaling the model. Specifically, the project will initiate and refine the pilot program and evaluation criteria; plan the pilot and its evaluation; conduct the pilot and its evaluation; communicate findings; and use findings to inform improvements.

A MIXED METHODS EVALUATION OF A WELLBEING SERVICE FOR PARENTS OF CHILDREN WITH COMPLEX NEURODEVELOPMENTAL CONDITIONS

Faculty of Medicine, Dentistry and Health Sciences
Department of Paediatrics
Lead researcher: Professor David Amor

This project is to evaluate a Parent Wellbeing Service, a pilot program currently being run within the Department of Neurodevelopment and Disability, Royal Children's Hospital. Parents/caregivers of children with a neurodevelopmental disability have consistently been identified as a group at higher risk of experiencing mental health problems compared to parents of typically developing children. There are currently limited options for parents to access free or low cost services in the community. This pilot supports parents of children with a neurodevelopmental disability who receive ongoing outpatient medical care within the department. Pilot data suggests that parents are willing to come to appointments about their own wellbeing when the service is embedded in the broader care system for their child and has no cost to parents. Given that this is the first service model for supporting the mental health of parents of a child with a neurodevelopmental condition in a paediatric tertiary institution, we believe it is critical to evaluate the model, considering potential benefits to parents as well as to the hospital system. This research will identify the barriers and facilities of the program, and inform the improved modifications of the service. It will provide key data on whether taking an innovative, novel approach to focus on parents within a paediatric tertiary hospital has the potential to improve medical treatment for the child and save money in terms of reduced inpatient stays from complex psychosocial contexts and lengthy paediatrician consult times.

THE IMPACT OF LOW VISION ASSISTIVE TECHNOLOGY ON MOBILITY IN PEOPLE WITH VISION IMPAIRMENT

Faculty of Medicine, Dentistry and Health Sciences
Optometry and Vision Sciences
Lead researcher: Dr Lauren Ayton

Impaired mobility is one of the most significant challenges that affects people with vision loss and blindness. Low-tech mobility aids such as long canes and guide dogs are still the mainstay of support, but newer technologies such as visual-to-audio substitution, tactile wearables and 'augmented-reality' smart glasses are gaining wide-spread interest in the community. At the same time, the National Disability Insurance Scheme (NDIS) requires evidence to fund assistive devices such as these, which unfortunately is lacking in the low vision space. As new technologies emerge that support people with vison impairment to engage and participate more independently in the community, evaluations will be needed to influence funding and policy decisions. This pilot study will investigate the effect of smart glass technology on mobility and gait, using advanced biomotion laboratories within the Department of Physiotherapy at the University of Melbourne.

EXPLORING THE INTERFACE OF THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS) AND DISABILITY EMPLOYMENT SERVICES (DES) AND THE INFLUENCE ON EMPLOYMENT OUTCOMES FOR AUSTRALIANS WITH DISABILITIES

Faculty of Medicine, Dentistry and Health Sciences
Nossal Institute for Global Health, Melbourne School of Population and Global Health
Lead researcher: Alexandra Devine (PhD Candidate)

There is limited evidence on whether and how the NDIS/DES interface is functioning effectively to improve employment outcomes for Australian's with disability. Understanding in this area is further complicated as the NDIS/DES interface intersects (and sometimes competes) with multiple Federal, State and Territory education and training, and,

employment programs. This exploratory project will seek to understand stakeholder perspectives and concerns on the functioning and positioning of NDIS/DES interface within the broader education, training and employment sector. This project also aims to foster collaborative partnerships and research opportunities towards the improvement of employment outcomes for Australians with disability.

IMPROVING PAEDIATRIC ADVANCE PLANNING FOR CHILDREN WITH SEVERE NEURODISABILITY

Faculty of Medicine, Dentistry and Health Sciences
Melbourne School of Population and Global Health
Lead researcher: Professor Lynn Gillam

When a child is nearing the end of their life, their parents and clinicians are faced with difficult decisions. Paediatric advance care planning is a recommended process that facilitates shared decision-making at these times. Importantly, advance care planning can commence early in the life for a child with severe neurodisability and involves communication between their parents and clinicians. It may reduce conflict between the child's parents and clinicians, and facilitate the provision of optimal care for the child and family. To improve advance care planning we need information about effective communication elements. This research, using state-of-the-art simulation methods, aims to create knowledge about the most effective and helpful ways to communicate with parents when faced with uncertainty.

DIGITISING SOCIAL CARE: AN ALTERNATIVE VISION FOR AUSTRALIA'S DIGITAL FUTURE OF CARE

Faculty of Arts, Faculty of Business and Economics, Melbourne Law School
Melbourne School of Government
Lead researcher: Timothy Kariotis (PhD Candidate)

The current Australian digital health strategy excludes social care services such as disability and community support services, which risks creating a two-tiered system where innovations, efficiencies and experiences are developed in the health system,

while other services are left behind. Adoption of information technology could improve the siloed and fragmented nature of care, and could support the collection of quality data to assist in planning, policy and evaluation. This is especially pertinent with the huge amounts of data collected in the NDIS, and the recent announcement of a National Disability Data Asset. This project aims to describe the current information technology readiness of the social care sector and will explore the adoption and use of information systems, data collection and quality, and workforce readiness. Further, working with the social care sector, an alternative vision for digital health that is inclusive of these sectors will be designed to support policy, advocacy and planning.

UPSKILLING HEALTH PROFESSIONALS ON EARLY DETECTION AND INTERVENTION FOR INFANTS AND YOUNG CHILDREN WITH DEVELOPMENTAL DISABILITIES IN LOW TO MIDDLE INCOME COUNTRIES

Faculty of Medicine, Dentistry and Health Sciences
Department of Physiotherapy, Melbourne School of Health Sciences
Lead researcher: Professor Alicia Spittle

Early detection and intervention for infants and young children with neurodevelopmental disabilities is essential to maximise outcomes for the child, family and community. World-wide, the allied health workforce are directly involved in delivery of early intervention for infants and young children with developmental disabilities. Educational standards in many low to middle income countries are varied and have not been able to keep up with the rapidly expanding evidence in this field over the past decade. With plans for schemes similar to the National Disability Insurance Scheme to be implemented in developing countries, it is essential that health professionals are trained in current evidence-based practice to ensure families receive appropriate and timely intervention. This project will develop and pilot a training program on early detection and intervention for infants and young children with neurodevelopmental disability targeting health

professionals in low to middle income countries (including Kazakhstan and Nepal), with a focus on capacity building of allied health professionals. The aim is to provide evidence for training programs, towards creating a skilled provider market if schemes such as the NDIS are to be implemented in other regions.

CULTIVATING WELLBEING BY EMPOWERING FAMILIES: ESTABLISHING EVIDENCE FOR AND IMPACT OF THE NOW AND NEXT PROGRAM

Melbourne Graduate School of Education, Centre for Positive Psychology
Lead researcher: Associate Professor Peggy Kern

Current policies and programs for disability care often rely on reactive, treatment-based, expert provided services. Additional benefit may arise from proactive approaches that place parents at the centre of care. 'Now and Next' is an evidenced-informed program that fosters empowerment, agency, and wellbeing for the family as a whole. Results to date suggest that parent capacity building can successfully be delivered early in a family's experience, with high levels of engagement by both mothers and fathers. The program helps parents successfully return to work, and has positive impacts on the health, wellbeing, and trajectory of the child and family. However, to impact upon disability policy, further evaluation of the immediate impact of the program, consideration of mechanisms, comparison with standard approaches to care, testing of longer-term effects, and examination of sustainability and scalability of the program are needed. This project will launch an inter-disciplinary, collaborative longitudinal impact study, with the intention of informing proactive policies and approaches to early childhood disability care.

TOWARDS A BETTER UNDERSTANDING OF HOW TO REDUCE SOCIAL STIGMA AMONG MEDICAL STUDENTS: A QUALITATIVE STUDY

Faculty of Medicine, Dentistry and Health Sciences
Disability and Health Unit, School of Population and Global Health

Lead researcher: Dr Ashley McAllister

While not everyone who experiences a mental illness will experience disability, those that do can experience significant disadvantage leading to social and economic exclusion. Physicians are formal gatekeepers to medical care, but also informal gatekeepers to essential government support such as housing benefits, welfare benefits, or more recently, the National Disability Insurance Scheme, as many of these supports rely on a physician's medical assessment to determine eligibility. Evidence suggests that physicians are not neutral in their medical assessment. A contributing factor could be psychosocial disability-related stigma. In general, the evidence shows that physicians' negative attitudes towards people with mental illness can contribute to inequalities in care provided. Health professionals, including physicians, have been identified as a major source of social stigma and discrimination, including by the Australian Government. Reducing stigma among the healthcare workforce is therefore critical to improving the outcomes for people with psychosocial disability. This project aims to address the prejudicial and stigmatising views of healthcare professionals regarding persons with mental health conditions. This research focuses on medical students' perceptions, current educational training targeting stigma, as well as an exploration of evidence-based approaches to reduce stigma.

DIGITECH4ALL: OPTIMISING INCLUSIVE PEDAGOGIES FOR TEACHING THE DIGITAL TECHNOLOGIES CURRICULUM

International Centre for Classroom Research , Melbourne Graduate School of Education
Lead researcher: Dr Carmel Mesiti

There is a recognition in local, national and global contexts that inclusive education is crucial for providing a high quality of life for people with disability. Research has consistently shown important academic, social and economic benefits for all learners in school systems where adjustments are made to support students with disability. The central problem is that a significant number of educators do not have the expertise to provide the reasonable adjustments required for students with disability to be successfully included within their classrooms. This

project will investigate effective teaching strategies so that students with disability and additional needs are included in Digital Technologies lessons alongside their same age peers in a mainstream middle school classroom. DigiTech4All is a pilot research project designed to bring together the professional knowledge and experiences of mainstream and specialist educators. In addition to significant policy implications, this project will develop a set of principles for planning and designing inclusive Digital Technologies Lessons for students with disability. A video library of effective teaching strategies will also provide a useful resource available to relevant stakeholders.

EXTENDING PARENTAL LEAVE AND PAY FOR PARENTS OF BABIES BORN PRETERM OR SICK

Faculty of Medicine, Dentistry and Health Sciences
School of Health Sciences
Lead researcher: Professor Alicia Spittle

In Australia, of the 300,000 babies born each year, approximately 48,000 are born preterm or sick. A baby who is born preterm or sick may spend weeks or months in hospital, which means parents use a large amount, if not all of their leave entitlements before their baby goes home. Time for babies and parents to spend together in the early developmental period is fundamental to optimal child development and bonding. Some babies go on to have significant medical needs and disabilities after they have gone home from hospital and are more vulnerable to common colds and viruses, which mean they may not be ready to enter childcare by the time parents have to start work, or may require hospital readmission. Yet, mothers and fathers who have a baby born preterm or sick are not currently entitled to any extra parental leave or pay. Extended leave for parents of preterm or sick babies has existed in some European and Scandinavian countries for many years. In New Zealand, policy was recently introduced for extended parental leave for parents of preterm babies, and the UK Government is currently conducting a neonatal leave and pay consultation. However, no current policies exist in Australia since the introduction of paid parental leave. This project

will conduct a scoping review and survey of parents of preterm and sick babies in Australia to understand the impact of current and future leave policy, specific to parents of babies born preterm or sick. This will used as a foundation to lobby the Australia Government for policy change in parental leave and pay for parents of preterm and sick babies.

THIS IS ME: EXPLORING HOW INCLUSIVE MUSIC WORKSHOPS CAN SUPPORT MENTAL HEALTH & QUALITY OF LIFE IN AUTISTIC CHILDREN AND YOUNG ADULTS

Faculty of Fine Arts and Music
Music Therapy Unit
Lead researcher: Dr Grace Thompson

While research shows that participating in community music making can foster a sense of belonging and connection between group members, this potential has not been researched in the Australian autistic community. This pilot project will examine and evaluate the benefits of group music making on the mental health and quality of life of participants from three different age groups of upper primary school aged children (year 4 and 5), secondary school aged children, and young adults between the ages of 18-25 years. Participants will have the opportunity to build peer networks by engaging in expressive music creation that does not rely on verbal communication. This participatory project will co-design and deliver an innovative creative arts music program aimed at improving wellbeing outcomes in autistic children and young adults; build and share knowledge, while engaging the community by sharing the results through a symposium to facilitate further dialogue with the stakeholders.

LINKING THERAPY AND COMMUNITY PARTICIPATION THROUGH CYCLING (CYCLINK) FOR CHILDREN WITH DISABILITIES: A FEASIBILITY STUDY

Faculty of Medicine, Dentistry and Health Sciences
Department of Physiotherapy, Melbourne School of Health Sciences
Lead Researcher: Dr Rachel Toovey

Cycling is a popular activity and a common goal for children with disability yet few inclusive community cycling initiatives exist in Australia. Until recently there was limited high quality evidence regarding best practice in achieving goals related to cycling in people with disability. A recent study found that a task-specific, bike skills program was more effective for attaining cycling goals than a parent-led home program in children with cerebral palsy. Recent research suggests that building relationships and capacity between therapists and community-based sport and recreational organisations are key ingredients of participation interventions for children with disabilities. As such, our study aims to work towards addressing the gap by testing the feasibility of "CycLink," an intervention that builds on the task-specific bike skills program by linking therapy to community participation. CycLink will be a co-designed and delivered program that draws on the knowledge of local programs and facilities from community sport and recreation organisations and families, while utilising the expertise of the physiotherapists in disability and skill development. A positive outcome of this study would inform a model for cycling through a partnership between rehabilitation and/or therapy services and community organisations. The knowledge gained may also be applied to other sports and activities, towards more inclusive community sporting programs.

THE PREVALENCE AND CAUSES OF HEARING LOSS IN THE KANDAL PROVINCE OF CAMBODIA USING THE RAPID ASSESSMENT OF HEARING LOSS

Faculty of Medicine, Dentistry and Health Sciences
Melbourne Audiology and Speech Pathology Clinic, Melbourne School of Health Sciences
Lead researcher: Chris Waterworth (Research Audiologist & PhD Candidate)

The Rapid Assessment of Hearing Loss (RAHL) is a new survey methodology recently developed by the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine. The RAHL is a population-based survey of the prevalence and causes of hearing loss in people aged

50 and over. This project aims to provide evidence on the prevalence and causes of hearing loss in one province of Cambodia for people aged 50 and over; to identify the main barriers to the uptake of ear care services in urban and rural areas; and to improve the baseline data for planning of ear care services and awareness of the need to improve health policy, programming, and delivery.

INCLUSIVE CITY OF MELBOURNE

Faculty of Medicine, Dentistry and Health Sciences
Melbourne School of Population and Global Health
Lead researcher: Dr. Jerome Rachele

This study brought together people with disability, City of Melbourne staff, disability advocates, and academics, with the aim of generating ideas on how to make the City of Melbourne more inclusive for people with disability. It further aimed to see which of these ideas were the most important and feasible to implement. The City of Melbourne Disability Advisory Committee and the Inclusive Melbourne Steering Committee with representatives of Melbourne University, the Melbourne Disability Institute, City of Melbourne and people with disability worked in partnership assisting the project team throughout the project. Findings from this study will inform the development of the City of Melbourne's Disability Action Plan and other relevant strategies.

RESEARCH TRANSLATION

FUNDING TO SUPPORT THE TRANSLATION OF RESEARCH INTO POLICY OR PRACTICE

CLARIFYING FACTORS TO TARGET IN UNDERTAKING MODULAR PSYCHOLOGICAL INTERVENTION FOR POORLY RECOVERING INDIVIDUALS WITH MILD TRAUMATIC BRAIN INJURY

Faculty of Medicine, Dentistry and Health Sciences
Melbourne School of Psychological Sciences

Chief investigator: Dr. Jacqueline Anderson

Individuals recovering from mild traumatic brain injury are recognised as having significant cognitive, psychological and physical disability, which prevent them from returning to work or undertaking their normal activities during the recovery process. Following mild traumatic brain injury, individuals are expected to make a complete recovery within 3 months of injury but 20% of individuals (approx. 12,000/ year in Australia) have delayed or incomplete recovery. Most of these 'poorly recovering' individuals continue to report debilitating changes in cognition, mood and physical factors for many years afterwards. There is clear evidence that early

psychological intervention can improve recovery for many of these individuals, but we do not have a clear understanding of how cognitive, psychological, psychiatric and physical factors interact to result in poor recovery for a particular individual. Consequently, we are unable to design appropriate individualised interventions for this group. This study will follow up an existing cohort of individuals with mild traumatic brain injury to provide detailed characterisation of factors that are amenable to psychological intervention and are contributory factors to poor recovery. This will enable us to develop, deliver and measure the first-ever evidence-based modular mild traumatic brain injury specific psychological intervention package.

MARKETING FOR NDIS MARKET STEWARDSHIP

Melbourne Social Equity Institute

Chief Investigator: Aviva Beecher Kelk (PhD Candidate)

Market stewardship literature is primarily top-down, and does not include consumer views; it has not examined the information consumers need to ensure the market is functional; and it has not examined what kind of

capacity-building work is required to ensure than the information is accessible, relevant and useful. While there is some evidence in healthcare literature about how patients make decisions, and behavioural economics literature provides another body of evidence around consumership and decision-making, very little has entered the market stewardship literature or been applied to the NDIS. The PhD project sought to contribute to filling these gaps as an exploratory study. Results showed show that NDIS participants place an extremely high value on trusted interpersonal sources of information. They also showed that trust was being used in place of information in order to reduce uncertainty in the NDIS environment. This Research Translation project will build an online tool that service providers can use to see what information they should use to assist consumer decision-making, and a second online tool that consumers can use to think about where to look for information and what to ask potential providers.

PRODUCTIVITY COMMISSION INQUIRY INTO MENTAL HEALTH

SUBMISSION TO THE INQUIRY TO IMPROVE THE NDIS EXPERIENCE

NATIONAL DISABILITY INSURANCE SCHEME AMENDMENT (STREAMLINED GOVERNANCE) BILL 2019

EMBEDDING ACCESS AND INCLUSION INTO THE DNA OF THE CITY OF MELBOURNE

POLICY SUBMISSIONS

SUPPORTING
THE COMMUNITY

COMMUNITY BASED RESEARCH SCHEME

The Community Based Research scheme provides support for projects run by community-based organisations that build social capital. The Scheme connects community-based organisations with researchers to support close working partnerships focusing on research or evaluation of innovative practice or ideas that improve lives of people with disability, their families or carers. The Scheme launched in 2019 to help build evidence in the disability sector and replicate and share ideas, and supported 11 projects in the first two rounds. We look forward to supporting more community-based research in 2020.

**IMAGE COURTESY
OF YELLOWBRIDGE QLD**

PATHWAY FOR CARERS: NO-ONE CAN DO IT ALONE

Maroondah City Council

This project is an evaluation of the Pathways for Carers program which began in 2015 in response to a need for carers to learn more about news, services and supports available in their community. The Pathways for Carers is an evolving community development initiative that aims to improve the health and wellbeing of carers within the City of Maroondah and four additional local government areas. Pathways for Carers combines the physical and mental health benefits of social group walking, with the direct delivery of targeted messages from providers on an informal platform.

THE BENEFITS OF THERAPEUTIC HORTICULTURE FOR PEOPLE WITH AUTISM

Kevin Heinze Grow

The aim of this project is to evaluate Kevin Heinze Grow's 'Grow Model' and its impact on participants with autism. The Kevin Heinze Grow Model is a therapeutic horticultural program. The organisation works with NDIS participants; Children and teenagers who have experienced significant trauma; People with an acquired brain injury; People with mental health challenges or dementia; Refugees and asylum seekers; Schools, aged-care services, and disability providers. The model uses the peaceful stress-free environment of a garden to support social, emotional, educational and vocational goals, enabling Kevin Heinze Grow to work holistically with people to meet their needs.

This evaluation will look at the benefits of the program for people on the autism spectrum, and possibly for participants with intellectual disabilities. It will also look at the strengths and weaknesses of the program and what changes could be made to improve the program.

EVALUATION OF THE COMMUNITY ABUNDANCE WORKSHOPS

Community Abundance

This project aims to evaluate the processes and outcomes of the capacity building workshops

offered by Community Abundance. The aim is to help Community Abundance improve the ongoing workshops, and to understand the impact of workshops on understanding of disability and the NDIS, on understanding of advocacy, confidence in speaking up, and access to the NDIS.

ASSISTIVE TECHNOLOGY FOR ALL

Council on the Ageing (COTA) Victoria

Assistive technology plays a powerful role in the lives of people with disability by facilitating independence, social inclusion and economic participation. This study will review literature to demonstrate the economic and social benefits associated with providing people with timely access to affordable assistive technology. The areas explored will include an examination of the economic modelling to demonstrate the cost-benefits of providing timely access to assistive technology; the positive impact on families and carers of people with disability; potentially decreasing the risk of people with disability experiencing violence, abuse, neglect and/or exploitation. Additionally, the role of assistive technology in supporting in-home care will be explored in relation to reducing social isolation and loneliness, with positive impact on mental health and well-being. The research will result in a business case that will be presented to the Government outlining the social and economic benefits of increasing access to assistive technology for people with disability outside the NDIS.

SUPPORT WORKERS AS MEDIATORS BETWEEN LEARNERS, CARERS AND PROVIDERS IN LEARN LOCAL DISABILITY PROGRAMS.

Laverton Community Education Centre

This is a local small-scale case study research project to investigate the dynamic relationships between education and training providers, NDIS-funded support workers, learners and carers. The case study would be conducted across two to three learning groups in Laverton Community Education Centre and Yarraville Community Centre. The key components include desktop research to identify

support models for people with a cognitive disability in community-based education and training providers; interviews with experts with experience in this context including people with a disability, carers, support workers, teachers; and observation of classroom dynamics where these participants are all present. A set of guidelines will be produced to assist with consistent engagement of support workers and build and communicate a clearer message to people with a disability and their carers about how government funded education and training can be effectively coordinated with NDIS funded supports, such as Support Workers.

AMPUTEES AND SPORT. A QUALITATIVE STUDY MEASURING THE IMPACT OF PARTICIPATION IN SPORT FOR AMPUTEES REQUIRING SPORTS PROSTHESIS OR ADAPTIVE SPORTS EQUIPMENT

START Foundation

This project aims to understand the following three concerns: the impact of participation in sport and recreation on the lives of amputees, from a range of perspectives including physical, psychological, social and emotional; the role of sports prosthesis or adaptive sporting equipment in increasing the ability to participate in sport and recreation; and the quality of the experience of participating in sport and recreation with a sports specific prosthesis or adaptive sporting equipment. The data gathered from this project will inform policy and the scope to which the NDIS supports the funding of sports prosthesis for amputees.

YELLOWBRIDGE COLLECTABLES IMPACT STUDY

YellowBridge Queensland

This evaluation project measures the community and social impact of the support delivered by the Collectables Boutique Opportunity Shop which is a community service provided by YellowBridge Queensland, a not-for-profit and registered charity. The analysis will be used to improve outcomes for both the clients who are supported, and the community organisations supported by the program.

The evaluation can also potentially provide guidance for replicating the model used at the Collectables Boutique Opportunity Shop elsewhere.

EVALUATION OF A PILOT PROJECT ASSESSING WHETHER HOLOLENS MIXED REALITY HEADSETS, IMPROVE THE WORKPLACE SKILLS AND INDEPENDENCE OF PEOPLE WITH COGNITIVE DISABILITIES

Ability Works Australia Ltd

Ability Works is seeking to empower employees with cognitive disabilities in the workplace by improving their skills, independence and sense of achievement. To realise this, a Microsoft HoloLens headset using Mixed Reality as a medium is being programmed to pilot test whether this is achievable in a real-world manufacturing workplace, on one wire bending machine. The evaluation of the pilot will monitor and assess the product design, implementation and initial user experience, understand the early results and areas for change or improvement, and identify ingredients and costs of the model for further scaling. The project will only be scaled if based on the evidence collected it is a viable solution, to many of the issues faced in the workplace by people with cognitive disabilities.

ACTIVE FOR EVERYONE

Disability Sport & Recreation Limited (DSR)

This project aims to review the Inclusive Leisure Initiative (ILI), a tool which audits disability accessibility at leisure centres, developed in 2010, within the context of NDIS. This project aims to build capacity in the leisure industry, increase understanding of enablers and barriers, develop appropriate resources, establish benchmarks and inclusive standards, provide training and advocate for people with a disability. The partnership between DSR and the University of Melbourne led to the scoping and design of 'Active for Everyone', which aims to develop and evaluate a best practice step-by-step resource (pathway) for organisations so they can support participation and inclusion of people with disability in sport, leisure and outdoor recreation.

EXTERNALLY FUNDED RESEARCH PROJECTS

FLAGSHIP PROJECTS AND COMMISSIONED RESEARCH

We are strongly committed to working collaboratively both across our own institution and through research partnerships with government and other universities and organisations.

We regularly work in partnership with external organisations to provide evidence to inform policy or practice.

NDIS HOUSING PATHWAYS PROJECT

BROTHERHOOD OF ST LAURENCE

Academics at the University of Melbourne in collaboration with the Brotherhood of St Laurence and people with disability are co-designing a guide to housing for NDIS Participants who are not eligible for SDA. This guide aims to help people with disability understand what their housing options are, which might be most suited to their situation and how to access funding, in order to help find the right home. The guide will be distributed alongside a training program to support Local Area Coordinators and Support Coordinators in helping their clients find suitable housing.

NDIS HOUSING PROJECT

BAPTCARE

This project produced and presented an overview of the strategic opportunities that may be available to Baptcare (and Baptcare Affordable Housing) in responding to the housing needs of NDIS Participants and suggests a series of criteria to frame further investigations. Due to the scale and complexity of the potential opportunities, this project is proposed as the first part of a multi-stage process.

INFORMING THE TAC'S CHILD AND YOUTH FRAMEWORK

TRANSPORT ACCIDENT COMMISSION

The Transport Accident Commission (TAC) developed an enterprise-wide Child and Youth Framework for supporting young clients and their families using a family-centred approach informed by contemporary disability practice. The University of Melbourne (Melbourne Disability Institute in collaboration with the Murdoch Children's Research Institute) undertook a project that delivered a comprehensive evidence base of current effective approaches to health and disability assessment, planning and management for young people (aged 0-18 years) who have sustained major traumatic injuries including acquired brain injury and spinal cord injury.

BUILDING THE EVIDENCE-BASE FOR LOCAL AREA COORDINATION

BAPTCARE

Local Area Coordinators play a key role in the delivery and navigation of the NDIS. Many aspects of local area coordination have limited or no evidence base, making it difficult for organisations to identify and model best practice.

This project, commissioned by Baptcare and closely aligned with the Brotherhood of St Laurence, builds on existing work to synthesise available academic and non-academic literature on key selected areas to help build an evidence-base to support best practice local area coordination. This project is intended to make a contribution to the literature and provide guidance to inform Baptcare's practice.

NDIS PLAN UTILISATION

DEPARTMENT OF HEALTH AND HUMAN SERVICES AND DEPARTMENT OF SOCIAL SERVICES

The under-utilisation of NDIS plans was noted by the Productivity Commission's Inquiry into NDIS Costs in 2019 as a major issue of concern. Some analyses of utilisation rates have been reported by the Productivity Commission and in the COAG Disability Reform Council Quarterly reports, however more in-depth analyses are needed to fully understand the drivers of plan utilisation. There is also anecdotal evidence which suggests that participants and families who are strong and effective advocates are benefitting most from the NDIS and so there

NDIS PLAN UTILISATION

(CONTINUED)

is a need to ensure that the NDIS is fair.

While the Productivity Commission acknowledged that utilisation rates will never reach 100%, they contended that with the maturing of the market, utilisation rates should increase to between 75-85% by the end of the transition period. In accident compensation schemes, utilisation rates are typically around 95%.

Now, there is a need for a much more nuanced analyses of the groups and support types that are most affected, the reasons for under-utilisation and recommendations for policy interventions to address the problem. MDI is therefore very pleased to be working closely with both the Victorian Department of Health and Human Services and the Commonwealth Department of Social Services to provide a detailed description of the predictors of plan utilisation through sophisticated quantitative analysis of longitudinal NDIS data across Australia, investigate the reasons for the patterns of low utilisation through qualitative participant interviews in Victoria, investigate utilisation rates from comparable programs with individualised funding models in Australia and internationally, and develop recommendations for improving utilisation in Victoria and how policy interventions could be evaluated.

EVERY OPPORTUNITY: INCREASING EMPLOYMENT OF PEOPLE WITH DISABILITY

DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS)

This report, commissioned by the Office for Disability in the Victorian Department of Health and Human Services (DHHS), explores opportunities to improve the prospects of Victorians with disability finding and keeping a job.

Every Opportunity 2018-2020 was the first iteration of a whole-of-government plan to boost the economic participation of people with disability in Victoria. Nested within the Victorian Government's state disability plan, it set out twenty-one actions to encourage and support people with disability to contribute to and participate more fully in economic life through improved education and learning pathways, employment opportunities and business ownership. The report produced by MDI builds on that foundation and draws in new evidence to inform the plan's next iteration.

NDIS MARKET ANALYSIS

THE GORDON INSTITUTE / TAFE NETWORK

MDI supported ACIL Allen in this project which aimed to understand NDIS associated workforce trends, facilitate workshops and deliver a report outlining recommendations to the TAFE Network for responding to the core and emerging markets with a key aim of supporting TAFEs in building a high-performing NDIS workforce and being a provider of choice in the training market.

INTERNATIONAL PROJECTS

COLLABORATION WITH THE DEPARTMENT OF PERSONS WITH DISABILITIES, MINISTRY OF SOCIAL JUSTICE & EMPOWERMENT FACILITATES

GOVERNMENT OF INDIA

Last year MDI was involved in two senior visits from the Department of Empowerment of Persons with Disabilities (DEPWD) within the Indian Government which resulted in the signing of a bilateral Memorandum of Understanding to advance a number of collaborations, including a co-designed community-based disability course.

Developed in partnership with DEPWD and the University's Nossal Institute for Global Health and Melbourne Disability Institute, the unique course is designed to train and equip locals to help them respond to the rehabilitation and inclusion needs of community members living with disability. It is currently being rolled out in India.

Other key initiatives with the DEPWD include the development and delivery of a joint leadership training course for the heads of national disability in Australia and India, where leaders will share their expertise and discuss challenges and opportunities.

CAMBODIA NATIONAL SOCIAL PROTECTION COUNCIL

CAMBODIA

In 2019 MDI was approached by the Cambodian National Social Protection Council for guidance and advice on social protection for people with disabilities in Cambodia. Following several initial conversations, MDI has been invited to participate in a workshop in Cambodia to drive further exploration into the Social Protection Policy Framework, as well as share learnings from the Australian experience and the National Disability Insurance Scheme.

NATIONAL DISABILITY RESEARCH PARTNERSHIP

We are pleased to be coordinating and leading the establishment of a new National Disability Research Partnership (NDRP). The NDRP will bring together experts in disability policy and research to facilitate a collaborative, translational research program through deep engagement between academics, people with disability, peak advocacy and consumer groups, governments and service providers to guide Australia's commitments to enable people with disability to be full citizens.

The Partnership will be inclusive and will ensure that top researchers, who are committed to the rights and purposes of people with disability, work collaboratively with the disability community, government, advocacy bodies, the disability service sector, philanthropy and industry. The NDRP aims to build capacity and conduct high quality research to provide evidence that can be applied to solve pressing and emerging disability policy and practice challenges informed by human rights approaches and other relevant frameworks.

Over the next two years, the NDRP will build a case for sustained disability research and identify potential long-term funding streams to ensure that policy and practice reform delivers the optimal outcomes for people with disability and their families and carers into the future. It will work with stakeholders across a range of different activities to achieve this including:

- Producing a research agenda that focuses on research for evidence-informed policy and practice to ensure people with disability have equal opportunities and are acknowledged as full citizens

- Mapping relevant research capability in Australia and proposing strategies and activities for building research capacity and partnerships

- Producing a practical guide to research approaches including principles for disability-inclusive research

- Demonstrating the capacity of the NDRP to work together to deliver solutions on priority issues as identified in the research agenda and inform long-term governance arrangements, and

- Developing a governance model designed to engage a range of stakeholders across the disability community, advocacy bodies, governments, philanthropy, service providers and industry which will attract future on-going, significant funding for disability research.

NDRP WORKING PARTY

Professor Anne Kavanagh
Chair, Disability and Health
Head, Disability and Health
Unit, Centre for Health Equity
Melbourne School of Population
Health
Academic Director, Melbourne
Disability Institute

Professor Bruce Bonyhady, AM
Executive Chair and Director
Melbourne Disability Institute

Professor Elizabeth Kendall
Program Director
Menzies Health Institute -
Disability and Rehabilitation
Griffith University

Mr Gordon Duff
General Manager
National Disability Services

Professor Gwynnyth Llewellyn
Professor of Family and Disability
Studies
Co-Director Centre for Research
Excellence in Disability and
Health
Head, WHO Collaborating
Centre for Strengthening
Rehabilitation in Health Systems

Professor Helen Dickinson
Professor of Public Service
Research
Director, Public Service Research
Group
University of New South Wales,
Canberra

Professor Jackie Leach Scully
Director, Disability Innovation
Institute
University of New South Wales

Ms Keran Howe
Former Executive Director
Women with Disabilities Victoria

**Emeritus Professor Lesley
Chenoweth**
Former Pro Vice Chancellor Griffith University

Ms Tessa de Vries
Institute Manager
Melbourne Disability Institute

TBC: advocacy representative(s)

ENGAGEMENT

MDI REGARDS ENGAGEMENT AS CENTRAL TO OUR VALUE IN SHARING KNOWLEDGE. FURTHER, EXTENDING OUR ENGAGEMENT WITH COMMUNITIES BEYOND THE UNIVERSITY IS FUNDAMENTAL TO INCREASING OUR IMPACT AND INFLUENCE. WE HOST, CO-HOST AND SUPPORT A SIGNIFICANT NUMBER OF EVENTS, AS WE SEE THESE AS A PRIORITY VEHICLE FOR RESEARCH TRANSLATION, ENGAGEMENT AND IMPACT.

GET BUILDING SDA: NATIONAL CONFERENCE 2019

DISABILITY ROUNDTABLE SERIES: GOVERNMENT OF INDIA

DISABILITY RESEARCH COMMUNITY OF PRACTICE

BROTHERHOOD TALKS: NDIS: WHAT'S WORKING AND WHAT IS NOT?

7TH ANNUAL NATIONAL BRAIN INJURY CONFERENCE

Brain Injury Australia's 7th National Brain Injury Conference was held, in partnership with the Melbourne Disability Institute, at The University of Melbourne, on Monday 28th and Tuesday 29th October, 2019. The Conference has become one of the premier learning and development events on the disability calendar – driving improvements in services and supports for the over 700,000 Australians living with a brain injury.

DISABILITY ROUNDTABLE SERIES: GOVERMENT OF INDIA

Throughout 2019 the Melbourne Disability Institute in partnership with the Australia India Institute and the Nossal Institute for Global Health, led several engagements with the Department of Empowerment for Persons with Disabilities (DEPWD), including two roundtables and an evening reception with senior officials from the DEPWD; as well as an internal University-driven disability engagement strategy for India roundtable to review and discuss disability project work in India and consider an overarching framework for our work going forward.

BROTHERHOOD TALKS: NDIS: WHAT'S WORKING AND WHAT IS NOT?

The Melbourne Disability Institute and the Brotherhood of St Laurence have continued to strengthen their partnership over 2019, collaborating on several projects and events, including the Brotherhood Talks series of lunchtime seminars.

During this session, Melbourne Disability Institute's Executive Chair and Director, Bruce Bonyhady joined Karen Dimmock, CEO of the Association for Children with Disability, Samantha Connor, Disability and Human Rights Activist and John McKenna, Disability Advocate, NDIS Recruiter, Podcaster & Commentator to discuss the progress and future for the NDIS.

GET BUILDING SDA: NATIONAL CONFERENCE 2019

The Get Building SDA conference, auspiced by the Summer Foundation and Youngcare showcased what the Specialist Disability Accommodation (SDA) market has achieved to date and provided a forum for SDA developers, tenants, investors, academics and policy makers to discuss what it takes to achieve sustainable housing outcomes for all Australians with disabilities. MDI's Senior Housing Consultant, Joseph Connellan joined our Executive Chair and Director, Bruce Bonyhady to outline research and analysis by MDI on meeting the housing needs of NDIS participants who will be not be eligible for SDA. It is estimated that only 6 per cent of NDIS participants will receive SDA and so housing the "other 94 per cent" is essential for the equity and sustainability of the NDIS.

DISABILITY RESEARCH COMMUNITY OF PRACTICE GUEST SPEAKER: THE HONORABLE JENNY MACKLIN

The Honorable Jenny Macklin joined our Disability Research Community of Practice to kick-off a 3 part series focusing on the interaction between research and policy. She spoke about research as one of key pillars in the foundation of public policy, and how research impacts can be far-reaching; informing decisions being made right now.

The Disability Research Community of Practice gathers regularly over lunch and the occasional breakfast or evening session to find out what colleagues are working on, discuss current disability policy, hear from experts in the field and connect with like-minded researchers from across the university.

Our conceptualisation of what is wrong in people's lives is actually flawed. There is no one size fits all, and yet we're acting as if there is.

CATH ROPER

ONE IN FIVE
A Podcast about disability research

I'm originally from Albury but everything I want to do is in Melbourne. Finding accessible accommodation is proving - I don't want to say improbable - but if it was more possible I'd already be living there.

OLIVER HUNTER

ONE IN FIVE
A Podcast about disability research

The challenge is erasing preconceived ideas about what cognitive disability, means for participating in decision making and the law, and how the law is implemented.

ANNA ARSTEIN-KERSLAKE

ONE IN FIVE
A Podcast about disability research

With mental illness, every day can be different. A job doesn't wait for you, you have to go and do it and you have to be good. You're not always stable like a job so with mental health conditions, work can be hard.

NATALIE

ONE IN FIVE
A Podcast about disability research

ONEINFIVE

PRESENTED BY THE MELBOURNE
DISABILITY INSTITUTE

PODCAST

At the start of 2019, we set out to create a podcast which would explore some of the most complex issues facing people with disability today.

Our mission was to give voice to people with disability and ask about their experiences with employment, housing, the law, supporting families and early intervention as well as highlight ongoing research from the University.

Through this process, we spoke with a range of experts including people with disability, researchers and people working in the sector to talk about what we can do to improve the lives of people with disability.

In Australia, one in five people live with disability. This powerful statistic is the foundation of our podcast and the driving force behind the need for continued focus on the complex problems facing people with disability, their families and carers.

The podcast was launched on 3 December (International Day of People with Disability). For the launch we released the first three episodes, with the final four episodes released over the next two weeks leading into the holidays.

Since launching the podcast there have been 1,935 unique listens and they are growing everyday. The first employment episode, "When the rubber hits the road: Employment and Disability in Australia" continues to be the most popular.

All seven episodes are available for download through iTunes, Spotify, Stitcher, Pocketcasts or RSS.

EPISODE 1: EMPLOYMENT AND DISABILITY
When the rubber hits the road, part 1

EPISODE 2: EMPLOYMENT AND DISABILITY
When the rubber hits the road, part 2

EPISODE 3: HOUSING AND DISABILITY
Stuck in the middle

EPISODE 4: DISABILITY AND THE LAW
No one size fits all, part 1

EPISODE 5: DISABILITY AND THE LAW
No one size fits all, part 2

EPISODE 6: EARLY INTERVENTION
A whole new language

EPISODE 7: ONE IN FIVE
A podcast from the Melbourne Disability Institute

ONEINFIVE

people in Australia report living with a disability

1,935

total podcasts listens (March 2020)

435

individual downloads of the employment episode (part 1)

One in Five

A podcast about disability research

IMAGE
COMPETITION

At the start of the year, we launched a Diversity in Disability Image Competition to support photographers and images that depict the full spectrum of disability. After careful consideration, one grand prize winner and 13 finalists were selected from over 100 submissions by photographers across Australia. With so many well-crafted, impactful and diverse images to choose from; our job was not easy. We are pleased to showcase these images throughout this report.

COMMUNITY BUILDING

MDI STRIVES TO FACILITATE HIGH LEVEL CHANGE-MAKING DISCUSSIONS, AND CONNECTIONS WITH A DIVERSE RANGE OF EXPERTS AROUND DISABILITY RESEARCH AND POLICY

CO-RESEARCHER TRAINING PROGRAM

Research done in partnership with people who have lived experience of disability is core to MDI's program of work. To help facilitate co-production and co-research, we are designing a training course that will equip people with disability with the skills and knowledge needed to be effective co-researchers. We have drawn together researchers from across the University to scope and design this short-course and hope to pilot it in 2020.

DISABILITY RESEARCH COMMUNITY OF PRACTICE

As part of the Melbourne Disability Institute's ongoing effort to support University of Melbourne researchers working in the field of disability, in 2019 we introduced a community of practice to:

- Provide a forum to enable showcase research, share information (e.g., research findings, experiences, lessons learned, best practices) and problem-solve relevant to disability research

- Spark dialogue about disability, research and translation of research into practice

- Encourage collaboration within and outside of the University of Melbourne

- Develop, facilitate and mobilise resources for disability research

- Cultivate champions and facilitate connections between experts who might not otherwise interact

In the start of the year we sent out a survey to UoM researchers working in the field of disability to gather feedback on how MDI could best support this community.

Next, we convened a group of researchers, representing 8 of 9 faculties to serve on the planning committee, where they help inform activities and spread awareness about the community.

Mid year we held a launch event to welcome UoM researchers into the practice, gather more feedback on how to best shape the community and introduce MDI.

In October, we held the first meet-up which featured the Hon. Jenny Macklin as the guest speaker. Jenny spoke about her experience and the importance of evidence-based policy. This event marked the first of a larger series on policy translation to be launched in 2020.

At the end of the year we held our second meet-up, which provided a forum for 4 university researchers to briefly present on their projects, answer questions from peers and colleagues and find out more about projects taking place across campus.

Building on the success of this program, we will continue to drive the Community of Practice into 2020, creating a platform for University of Melbourne researchers to become informally bound together by shared expertise and passion to improve the wellbeing of people living with disability through research, by gathering insights, building understanding and sharing knowledge.

DEMOCRATISING DISABILITY DATA

In 2018, MDI convened a coalition of Australian researchers and stakeholders in the disability sector committed to capitalising on data related to disability, so we can learn from practice and continually refine services and policy to achieve better outcomes. The coalition included academics and universities; disability advocacy organisations; disability services and non-government organisations.

In September 2019, the Australian Data and Digital Council announced the establishment of a National Disability Data Asset, which will help bring together data from multiple sources and inform service choices by people with disabilities and their carers.

The Commonwealth will provide up to $15m to fund the pilot of the National Disability Data Asset, which will commence with data from the Commonwealth, New South Wales, Victoria, Queensland and South Australia.

This decision paves the way for a national view of the disability sector with significant potential, for example to inform the National Disability Strategy. We are pleased to see this significant step towards improved access to disability data and statistics, and are grateful to the coalition of researchers, advocates, service providers and other stakeholders who have been working with us to help shape this progress.
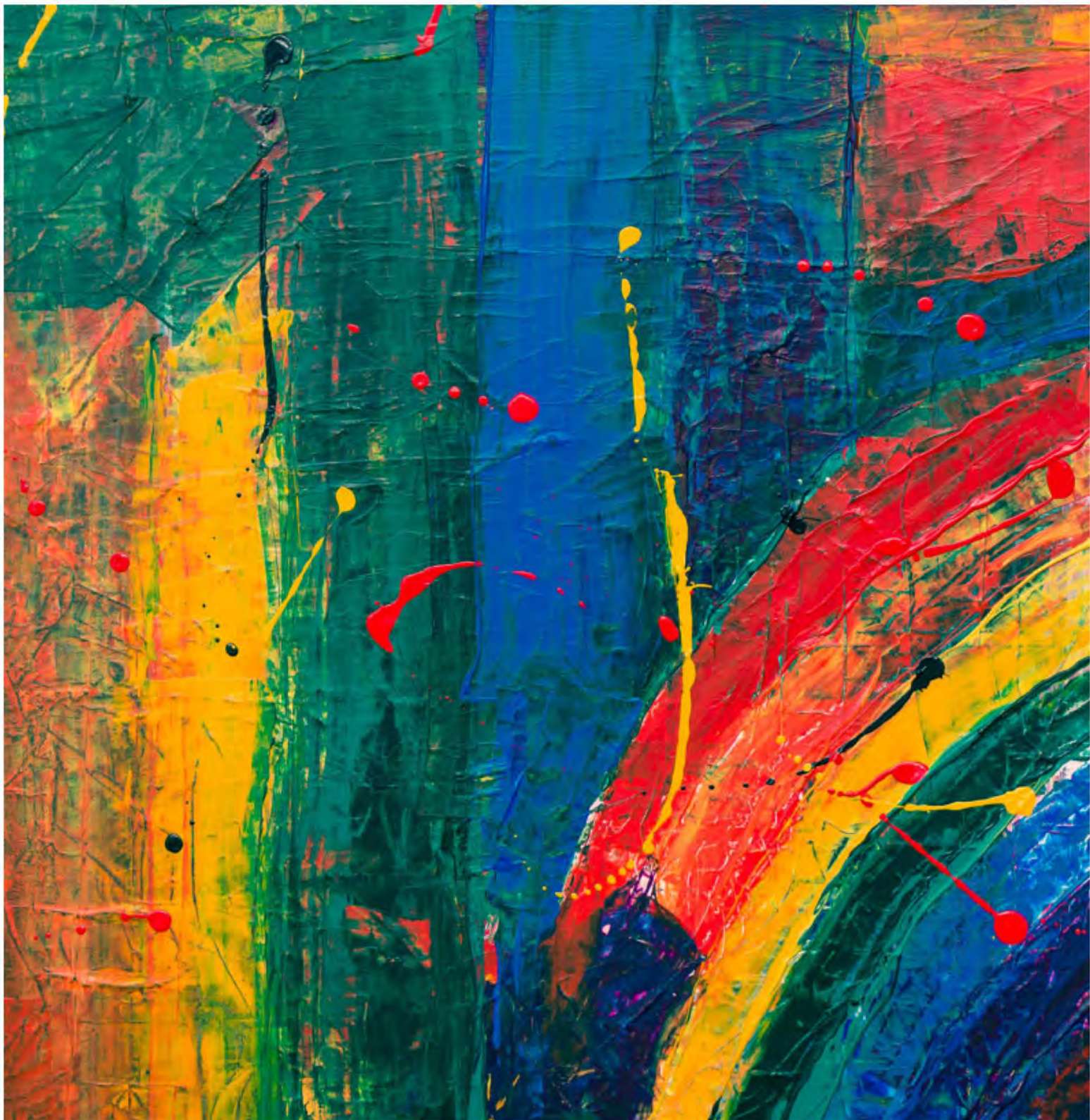
FINANCIAL STATEMENT

INTERNAL INCOME

University of Melbourne Chancellery

• Melbourne Disability Institute core funding	1,127,000.00
• Vice-Chancellor's Strategic Initiatives and Allocations Fund contribution	100,000.00
• Chancellery Research & Enterprise strategic allocation	200,000.00
• Space contribution	30,000.00
Total	**$1,457,000.00**

EXPENDITURE

Core staff salary	590,253.83
Research project salary	80,368.93
Seed funding	595,201.55
Community-based research scheme	29,144.44
Research translation	44,000.00
Events & communication	26,673.01
Operating & administrative	28,710.98
Partnership development	25,919.90
Space charge	30,000.00
Total	**$1,450,272.64**
Surplus	**$6,727.36**

EXTERNAL INCOME

Industry	511,880.00
Government	470,000.00
Total	**$981,880.00**