



# **“Raising the Bar”:** Achieving the Best Outcomes for People with Disability from the National Disability Insurance Scheme

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Discussion Paper

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## About the Authors

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The authors of this document have been involved in the disability reform process—and a broad range of social development initiatives on a global level—for decades. We share an aspirational view of the potential for the National Disability Insurance Scheme (NDIS) to transform the lives of people with disability.

We bring a range of expertise and experience to the challenging task of deconstructing the old system of disability support and constructing a new one that delivers on the promise and expectations of the NDIS.

**Mark Bagshaw** has extensive management experience at senior levels in the business sector, primarily in the IT industry, much of which he gained over 28 years with IBM. He has also undertaken a wide range of leadership roles in the social development area, particularly related to disability reform. Mark has chaired or been a member of many government and non-government boards and advisory bodies in Australia and overseas, many of which have focused on disability reform across the spectrum, especially education and employment. As a result of a spinal injury at age 16, Mark has successfully met the challenges of living with a disability for all of his adult life.

**David Clarke** was a 2007 John Monash Scholarship winner, completing a Master's of Public Administration at Harvard University's Kennedy School of Government. David has acted as a strategic change consultant with CARE International, a leading international humanitarian NGO, and as an economic development consultant with the Cape York Institute for Policy and Leadership. He is currently a Principal at The Boston Consulting Group (BCG), where he is a core member of the public sector practice.

**Craig Harrison** is recognised as a leader in the disability sector and for the past 15 years has managed one of Australia's most highly respected disability open employment services. He has been instrumental in developing some of the most significant changes to Australia's disability support system and his advice and counsel is frequently sought by governments and other bodies. Craig was appointed Deputy Chair of the Australian National Training Authority Disability Forum in 1994 and has since remained an executive member of each of Australia's disability advisory bodies in the training system. In 2010, Craig was inducted into the Association for Competitive Employment Hall of Fame.

**Karen Marshman** is currently the Director of Let's Talk Australia, which focuses on organisational training, leadership development and coaching, with a particular focus on supporting and transitioning individuals with workplace injuries. Karen first came to prominence as a leader in social and human development when she ran an innovative and highly successful youth leadership organisation in South Australia. The organisation focuses on building fundamental life skills for disadvantaged young people, transforming their lives and substantially reducing youth unemployment and disengagement in some of Australia's most economically disadvantaged regions.

A collaboration between Karen and Craig resulted in the leadership programs being successfully integrated into Craig’s disability employment service, which led to better employment outcomes for clients.

**Martin Stewart-Weeks** has over 20 years’ experience in the public sector and in organisational management and consulting in the corporate, public and not-for-profit sectors. In his current work with the global public sector practice in Cisco’s Internet Business Solutions Group (IBSG), Martin works at the senior executive and political level to help shape Internet business solutions and online strategies at both an agency and whole-of-government level. Martin was a member of the Australian Government’s “Government 2.0” task force and is on the Advisory Committee for the Victorian’s Government’s ICT Strategy. He set up the Australian Social Innovation Exchange and is a director of the Australian Centre for Social Innovation.

## "Raising the Bar"

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The NDIS represents the best opportunity Australia has had in decades to address the appalling lack of participation in society by people with disability, who make up 18.5% of Australia's population (ABS, 2009), and in particular the 410,000 people who will receive direct funding for disability support under the NDIS.

The NDIS will not achieve its potential by doing more of what we are currently doing and doing it a bit better. Instead, the situation calls for a new approach to disability support based first and foremost on a fundamental shift in thinking about the very nature of disability.

That shift in thinking needs to challenge all of the current perceptions of people with disability and their capacity. It needs to set the bar high. It needs to create a shared vision that sees every person with disability offered the same opportunities currently only offered to a few. And it needs to be bold, and open to ideas, approaches, and solutions that stretch our current thinking about the potential for reform.

We need to take a strategic approach based on one simple but fundamental objective: to create a smooth pathway for every individual with disability from the beginning to the end of every day, throughout their life.

The greatest challenge for the NDIS is not that we can't get this right, but that we don't.

The potential is enormous, the risks are great, and the challenges are significant.

The authors of this report believe we *can* design a system that will result in vastly increased numbers of people with disability participating in society. The many people with disability (even of the most profound type) who are participating today and contributing to Australia's economic and social capital prove one critical thing: disability is not an inherent barrier to being an active part of society.

## Introduction

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*We believe that the NDIS represents the best chance people with disability in Australia have ever had to get prepared to contribute to our society—and for society to welcome their active participation.*

*We believe passionately that people with disability are far more capable of participating at all levels of our society than most people believe— including many people with disability themselves.*

*We don't accept that a 40% difference in workforce and education participation is OK. We don't accept that a person with disability can't choose where she or he lives. And we don't accept that it's OK for the community to expect so little of people with disability.*

*In our view, genuine change will only occur if we embark on this journey with a truly aspirational vision.*

*We must raise the bar around expectations and accept nothing less than people with disability achieving all that they can and want to achieve. When they do that, our entire nation will benefit.*

The introduction of the NDIS offers Australia a once-in-a-lifetime opportunity to fundamentally change the lives of people with disability. It is a chance to create a new environment in which people with disability can contribute their passion, drive, skills and capacity to help build an even better nation for all of us.

Today, despite decades of effort, far too few people with disability are participating in society at the level to which they aspire and are able. Yet those people who do make an enormous contribution to our society and economy—regardless of their type and severity of disability—prove the merit and value of an aspirational view.

The authors of this document share a passionate belief in the often untapped potential of people with disability. We have come together with a single aim: to contribute our decades-long involvement in disability, social development and strategic change management to help shape an NDIS that achieves outcomes far beyond the expectations of most people. We believe that the time has come to take a fundamentally different approach to disability reform.

The Australian people have embraced the need for a different approach. Thanks to the hard work of disability advocates across the community, the NDIS has become a national priority. The level of bipartisan political support for the NDIS is almost unprecedented, and there are high expectations across the community that the NDIS will create a significant breakthrough that leads to greater participation of people with disability in all aspects of our society.

For people with disability and those close to them, the anticipation that the NDIS will transform their lives—and the anxiety that it may not live up to their expectations—is palpable.

The NDIS carries some significant risks, and managing them will be critical to its success. The greatest risk is that it does not lead to increased participation of people with disability. This would mean the lives of people with disability would not improve, public support would likely wane, and perceptions about people with disability being less capable than everyone else would remain unchanged. It would also put severe pressure on NDIS funding, which relies on greater participation to increase GDP, generate greater tax receipts for government and reduce long-time disability support costs.

This document sets out our vision for creating a truly great NDIS, drawing on our collective experience. We identify the key issues that we believe need to be addressed and propose a set of strategic interventions to support and encourage people with disability to achieve inclusive, rewarding and productive lives.

Specifically, we focus on four areas that we believe will be critical to get right in order to make the NDIS a success and to deliver on expectations. For each, we note the challenges associated with it and strategies for overcoming those challenges.

We define the four elements of success as:

- **Charting a course** that is truly aspirational;
- **Empowering the consumer** to take control of the support they need and therefore their lives;
- **Transforming the market** to respond to consumer demand with timely and quality solutions;
- **Integrating the support system** to create a smooth pathway for every person with disability, from the beginning to the end of every day.

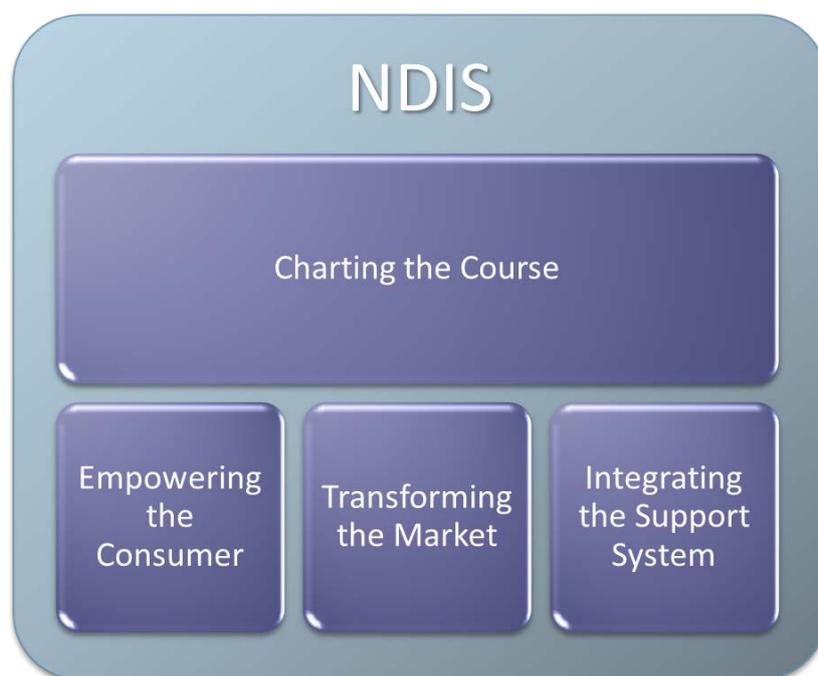


Figure 1: Critical Success Elements for the NDIS

## Key Challenges and a Way Forward

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### Charting the Course

**The Challenge:** People with disability are missing out. Workforce participation rates for people with disability are currently half that of the general population (OECD, 2010), and even when people do work it is often in roles significantly below their capacity. Only 30% of students with disability completed Year 12 in 2009 versus 55% of students without disability, and only 15% of students with disability completed a bachelor’s degree or higher compared to 24% for the general population (ABS, 2010a). 45% of people with disability in Australia live in poverty; more than double the OECD average of 22% (OECD, 2009).

These statistics are concerning on a number of fronts.

First, this level of disparity is clearly not good enough. In a country like Australia, it is unacceptable that citizens with disability are subject to additional disadvantage.

Second, these gaps don’t need to exist at all, at least for the vast majority of people with disability. We have to close the gaps, and quickly. Reducing disparity is good for people with disability and their families, as well as the economy, and the social fabric of our country.

Third, these statistics are emblematic of a range of persistent negative impacts, such as lost opportunity, anxiety and fear, shattered hopes and dreams, and wasted human resources. The unhappy truth is that we have yet to see the kind of improvements we’ve been hoping for, and working hard to achieve, over the last 30 years. That, too, has to change.

The NDIS is a chance to make things dramatically and permanently different.

Obviously, achieving strategic change on the scale of the NDIS will not be quick or easy. The NDIS represents a very different way of delivering support to people with disability. It will bring about a shift in power by putting people with disability at the centre so they control the products and services they need to participate in society.

The focus at present is on changing the mechanics of the system. However the NDIS must also deliver a significant cultural change. That means promoting a much more aspirational mindset of what people with disability can achieve which we call “raising the bar”—see *Annex A: Our Vision for the NDIS*.

Investing deeply in communication is critical to counteract the inevitable obstacles, frustrations and potential detours that will arise. The leaders of the change must maintain a strong vision and purpose, and clearly communicate it to all stakeholders throughout the transformation.

**Meeting the Challenge:** Raising the bar is undeniably challenging. For many, it remains a daunting prospect. But is it impossible? Absolutely not.

For the NDIS to create the breakthrough sought by so many people, we first need to build a picture of what is possible.

So how do we find out what is possible? What would participation rates look like if we removed the obstacles that so many people face?

Let’s start by challenging every basic assumption about the capacity of people with disability. We want to open people’s minds to the range of possibilities, continually asking not why something can’t be done, but how we can make it happen. How many people with all types and all severities of disability simply cannot participate in society? We believe the real number is far lower than society thinks. To prove it, let’s gather the experiences of people for whom their disability is anything but a barrier and show that to the Australian people. If they can do it, what is stopping so many others? Let’s build on the momentum already generated by the NDIS and get people excited about the possibilities.

At the same time, let’s affirm or reaffirm our commitment to an aspirational vision and transformational mindset. Let’s establish benchmarks, goals and targets based on a new shared vision that sees everyone in Australia with disability achieving what some but far too few are currently able to achieve.

Finally, let’s make sure that everything we do in building the NDIS aligns with that shared vision. Every plan, every program, every initiative, every system, every process. That’s how we’ll build a great NDIS.

#### **Recommendations:**

1. Define a shared vision for the NDIS that challenges preconceived notions about the capacity of people with disability and builds on the momentum for real change.
2. Establish benchmarks, goals and targets based on the vision, to "raise the bar" and measure our progress at translating an aspirational mindset into a reality for people with disability.
3. Align the systems, processes and structures of the new NDIS disability support model to that shared vision.

## **Empowering the Consumer**

**The Challenge:** People with disability will be at the centre of the NDIS for good reason. The most disempowering aspect of disability for most people is not the disability itself, but the lack of control they have over their lives. That lack of control creates an environment of dependence and erodes the confidence that everyone needs to face life's challenges.

One of the key objectives of the NDIS is to give back that control, and create a system in which people with disability—who know their needs better than anyone else—can choose the products and services they use to help them overcome their disability.

An increasing number of people with disability are already doing that today. For them, the NDIS simply has to ensure the solutions they need are available and they have the financial resources to purchase them. While they accept the need to ensure public funds are being used effectively, they don’t want a system looking

over their shoulders, telling them what to do. For this group of people, we need to question, for example, the assumed requirement for a Participant Plan, and whether this reinforces traditional “systems thinking”, rather than adding value to their lives. After all, most of these people have been getting on with their lives without a “plan”, often for decades, just like other people in the community.

We recognise that many people with disability are unprepared to take on the level of control that the NDIS will offer, primarily because they have never had the opportunity to develop the skills to do so. That is not the same as believing these people are incapable of assuming control and that “the system” must do so on their behalf.

**Meeting the Challenge:** Many people with disability will need support to become empowered consumers in the new market. While some are very savvy consumers in other markets, it would be naive to assume that those skills translate directly into becoming informed consumers of a market that has traditionally made purchasing decisions on their behalf.

Our starting point is that everyone involved in the NDIS must be driven by an aspirational mindset. This includes people with disability, those close to them, people providing direct support for people with disability, and those administering and managing the system, and making strategic decisions about it.

To illustrate with just one example: frontline NDIS agency staff will often be the first point of contact for many people with disability. These staff members will therefore play a key role in shaping the on-the-ground experience of people with disability. They need to take an aspirational view of what the individual with disability is capable of in order to encourage them on their journey towards full participation, rather than acting as gatekeepers to a range of supports and services. These frontline roles should therefore adopt a "coaching" orientation (rather than one of "case management") that is applied to all aspects of the NDIS human resource management, such as recruiting, training and development, and professional support.

The next step is to support people with disability to develop networks and life skills so they can engage in the system and community on their own terms. Examples of new skills include personal planning, decision making, negotiation, and financial management. The design of the NDIS should focus on ways to develop these skills, rather than introducing bureaucratic controls and red tape to protect the interests of vulnerable participants (see [\*Annex B: The Lifelong Learning Pathway\*](#) for a detailed discussion of our approach).

Finally, system administrators must take care to ensure the scheme, when implemented, stays true to the fundamental principle of individual choice and control. For example, under the funding arrangements for the launch sites, the choice of supports will be limited to varying degrees toward existing programs and

service models<sup>1</sup>. This is despite the fact that dissatisfaction with current arrangements is a fundamental driver for the new scheme.

#### Recommendations:

4. Determine the profile of an empowered consumer, in a functional disability support market. Do this by understanding how, and in what ways, the profile of a disability consumer differs from a generic consumer, and how effectively people with disability today operate in generic and disability support markets.
5. Build a lifelong learning pathway for individuals with disability that identifies the life skills they need to be an empowered member of the community. The “life learning curriculum” must contribute to creating empowered consumers.
6. Identify opportunities to integrate aspirational thinking and new ideas into the five NDIS launch sites, for example:
  - Embed a "coaching" mindset and approach for all frontline staff (via recruiting, training and development, professional support, and so forth);
  - Ensure one or more cohorts of participants have full flexibility to design their own package of supports (rather than purchasing existing programs and services).

## Transforming the Market

**The Challenge:** The current “disability market” is a market in name only. At present, providers of disability support products and services are equipped and skilled to operate in a “market” in which the “customer” (who pays the bills—currently predominantly governments) and the “consumer” (who uses the product or service—people with disability) are different entities. Providers run businesses that have been designed to operate in this environment.

Under the NDIS, the fundamental dynamics of the disability market will change. This will present challenges for many existing businesses and no doubt many new entrants.

The government will also need to adapt to a new role, shifting from being a “customer” of the market, to being the market maker and regulator (see [Annex C: Building a New Market for Disability Supports](#) for a more detailed discussion). It will also be rightly concerned about developing a competitive market in rural and regional locations.

**Meeting the Challenge:** We need to create an efficient and effective market for disability support services. Characteristics of this market will include:

- Transparent price and quality signals, and the ability to innovate and evolve over time.
- Informed consumers who know what they want and who are intellectually and financially able to make “value for money” decisions.

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<sup>1</sup> Under the intergovernmental agreements signed for the launch sites, funding from the States and Commonwealth will be provided as a combination of cash and ‘in kind’ contributions of existing programs and services. The latter comprises between 35 and 55 % of total funding, depending on the terms of each agreement.

- Sufficient and timely information flow between people with disability and providers. This will ensure people with disability are able to make an informed choice about which provider(s) they contract with, and will also ensure that providers listen to their needs, offer tailored solutions, and understand how those solutions integrate into an overall “support package”.

The government must create the right environment to transform the existing service provider market via a combination of market signals such as minimally sufficient rules and regulations, pricing and incentive models, initiatives to promote information transparency, and transition arrangements. There is a significant role for experienced business minds in this process given governments are traditionally not strong at business and market development. See [\*Annex D: Design Principles for Better Public Services\*](#) for further discussion.

#### **Recommendations:**

7. Build a new market model for disability support that takes what is good about the existing disability services market forward, embraces the best things about other mainstream markets, and adds the critical unique elements of the new disability support market. Involve experts in market dynamics in this process.
8. Conduct a forensic examination of the existing disability services market to identify existing best and worst practices and providers here and in other markets. Use the resulting insights to encourage the best providers to transform into the new market, encourage the worst to leave, and attract new entrants. This process should be led by consumers with disability who are already empowered, and draw heavily on experienced business thinking.

## **Integrating the Support System**

**The Challenge:** We believe this is the greatest challenge, because the magnitude of the task overwhelms many people, who subsequently relegate it to the “too hard” basket.

In reality, as important as the NDIS is, it is only half the story. The NDIS is primarily about *preparing* people with disability to participate in society. But society, for its part, needs to be ready and willing to include people with disability in all aspects of life, including in education and in the workforce.

Unless the NDIS is designed as part of a broader integrated approach to disability, it runs the risk that more people with disability will become “participation ready”, and try to enter a society that is not “inclusion ready”. In effect, this will set them up for failure.

A broader, “Whole of Life Approach” to disability reform is based on a simple premise: every aspect of the disability reform process is ultimately about creating a smooth pathway for every individual with disability from the beginning to the end of every day throughout their life. We explore this approach in more detail in [\*Annex E: A Whole of Life Approach to Disability Reform\*](#).

An integrated approach recognises that many of the obstacles facing people with disability can't be fixed by the NDIS alone. While in theory, the need for an integrated approach is supported by the UN Convention on the Rights of People with Disability and the National Disability Strategy, in practice, the mechanisms to deliver it don't currently exist.

**Meeting the Challenge:** Despite the challenges associated with designing an integrated approach to the NDIS, we have no choice but to embrace it. The current “siloed” approach to disability, which focuses on specific interventions and programs rather than on the total needs of an individual, is the key reason we have made so little progress in reform to date.

The NDIS is our best opportunity yet to implement an integrated, Whole of Life Approach. For the first time, we will have an entity with both the will and the capacity to bring it together. While its primary focus is to prepare people with disability to participate in society (for example, it is not responsible for making our infrastructure more accessible), it has a strong vested interest in ensuring that all its hard work doesn't result in more people with disability being ready to participate in society but having nowhere to go.

Much has been said about the need for a “whole of government” approach, but that rarely happens without a mechanism to drive it. An obvious and potentially early step forward would be for the NDIS to foster improved coordination among government departments, agencies and programs, which will be critical to maximising the community and economic participation of people with disability.

There are many examples where inter-and intra-government cooperation could support a more integrated approach. For example, government should consider reforms to the Disability Support Pension to support greater employment participation (in line with the Productivity Commission's recommendations). In other portfolios (e.g., health, education) eligibility criteria and processes for disability supports should be aligned with the NDIS to minimise red tape and bureaucracy.

More broadly, the government could undertake a review to determine other mechanisms to drive disability reform, assessing industry policies, workplace regulations, disability rights legislation, leveraging reforms such as the Gonski Review into school funding, and engaging with industry bodies and employer groups. This could uncover some early wins for the NDIS and establish a precedent for ensuring that people with disability are considered in all aspects of government.

### **Recommendations:**

9. Form a Disability Integration Task Force, possibly under the auspices of the proposed NDIS Ministerial Council and operating as part of the NDIS Launch Transition Agency. Its roles would be to foster existing and create new linkages at an intra- and inter-government level, and with non-government disability bodies and currently disconnected parts of the community.
10. Create a road map from the perspective of individuals with disability that identifies all the elements of total community support that need to come

together to create a smooth pathway through each and every day, and how they are linked. Existing initiatives and interventions—generic and disability specific—can then be analysed against the road map to identify missing elements and links.

## Conclusion: Three Opportunities to Act Now

In this paper, we have identified four main challenges that we believe need to be addressed to ensure the NDIS meets the community's high expectations. We have also offered our view on how to respond to those challenges. The 10 recommendations in our paper are intended to foster an open and robust discussion about the actions required to deliver an NDIS that is genuinely aspirational, and empowers people with disability to actively participate in society and achieve the things they want in life.

As a starting point, we think there are three things that could be done now to ensure the NDIS helps to "Raise the Bar":

1. Set aspirational targets and benchmarks around active participation by people with disability in the community and economy, and establish a rigorous evaluation framework to assess how each element of the NDIS system helps to achieve them.
2. Carefully consider the role design, recruiting methods, learning and development model and professional support for frontline staff at launch sites.
3. In one launch site, align the scheme design and implementation with the aspirational principles and recommendations outlined in this paper, to test how well such a system can deliver improved outcomes for people with disability, compared to the standard design.

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## Summary of Recommendations

1. Define a shared vision for the NDIS that challenges preconceived notions about the capacity of people with disability and builds on the momentum for real change.
  2. Establish benchmarks, goals and targets based on the vision, to "raise the bar " and measure our progress at translating an aspirational mindset into a reality for people with disability.
  3. Align the systems, processes and structures of the new NDIS disability support model to that shared vision.
  4. Define the profile of an empowered consumer, in a functional disability services market. Do this by understanding how, and in what ways, the profile of a disability consumer differs from a generic consumer, and how effectively people with disability today operate in generic and disability support markets.
  5. Build a lifelong learning pathway for individuals with disability that identifies the life skills they need to be an empowered member of the community. The “life learning curriculum” must contribute to creating empowered consumers.
  6. Identify opportunities to integrate aspirational thinking and new ideas into the five NDIS launch sites, for example:
    - Embed a "coaching" mindset and approach for all frontline staff (via recruiting, training and development, professional support and so forth);
    - Ensure one or more cohorts of participants, have full flexibility to design their own package of supports (rather than purchasing existing programs and services).
  7. Build a new market model for disability support that takes what is good about the existing disability services market forward, embraces the best things about other mainstream markets, and adds the critical unique elements of the new disability support market. Involve experts in market dynamics in this process.
  8. Conduct a forensic examination of the existing disability services market to identify existing best and worst practices and providers here and in other markets. Use the resulting insights to encourage the best providers to transform into the new market, encourage the worst to leave, and attract new entrants. This process should be led by consumers with disability who are already empowered, and draw heavily on experienced business thinking.
  9. Form a Disability Integration Task Force, possibly under the auspices of the proposed NDIS Ministerial Council and operating as part of the NDIS Launch Transition Agency. Its roles would be to foster existing and create new linkages at an intra- and inter-government level, and with non-government disability bodies and currently disconnected parts of the community.
  10. Create a road map from the perspective of individuals with disability that identifies all the elements of total community support that need to come together to create a smooth pathway through each and every day, and how they are linked. Existing initiatives and interventions—generic and disability specific—can then be analysed against the road map to identify missing elements and links.
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## Annex A: Our Vision for the NDIS

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### How High the Bar?

The most fundamental starting point for the NDIS must be to develop a shared belief in what it is possible for people with disability to achieve in their lives. It is our view that this shared belief needs to establish a new and higher level of expectation within the Australian community about the participation and contribution of people with disability.

Our first question in designing and building the NDIS should be: “how high should we set the bar?”

If we set the bar too low we will design a system that will undoubtedly improve the lives of people with disability, but will fall short of what is actually achievable. That will not only put the NDIS itself under unnecessary long-term pressure, but also represent a failure of our society to understand the enormous but often untapped potential of our fellow citizens, particularly those with disability.

If we raise the bar too quickly and without ensuring that the individual is equipped to participate, and that our community is ready to welcome them, we will be setting up an already significantly disadvantaged group of people for failure, further undermining their confidence and the community’s belief in their capacity. For some people, this will result in poorer outcomes than today.

Some people believe the bar is already as high as it ever could be. Others, like ourselves, believe the bar for each individual should be set as high as it would be if they didn't have a disability. Understandably, many people find this a very confronting statement. While statistics show that other countries are doing better than Australia—in some cases by a substantial margin—no country is producing participation rates even close to that of the general population.

We acknowledge that there are a very small proportion of people who have disabilities so profound that it would be unfair and unreasonable to expect them to participate in society as they would have done without their disability. We also recognise it would be unfair and unreasonable to expect many others to participate fully under our current inadequate approach to supporting their needs and removing the obstacles they face.

However, we believe the current level of participation of people with disability in all aspects of our society is far below what it should be. We believe that workforce participation rates for people with disability, currently half that of the general population (OECD, 2010), should be almost equal, with only people with profound intellectual and psychiatric disabilities considered less likely or incapable of participating in our workforce. Only 30% of students with disability completed Year 12 in 2009 versus 55% of students without disability, and only 15% of students with disability completed a bachelor’s degree or higher compared to 24% for the general population (ABS, 2010a). We believe these gaps should be close to zero.

Our view is driven by a passionate belief in the resilience of human nature, and backed by decades of involvement in disability and social reform and personal experience living with disability. Members of our team have seen first-hand, and led, initiatives that demonstrate beyond any doubt that when a person with disability has the support he or she needs, has learnt the life skills he or she needs to manage the challenges of disability, and is welcomed into his or her community, disability is not a barrier to participation in society.

We believe that the NDIS must be driven by an aspirational mindset and guided by our most experienced and informed thinking about the fundamental nature of disability and people's capacity. It should also be informed by real examples of innovative approaches to disability support around the world that have proven beyond any doubt that people with all types and all levels of severity of disability are far more capable than most people imagine. Members of our team have been directly involved in leading some of the most inspiring examples.

Too often those successes are only celebrated within the narrow bounds of the initiatives themselves. Even worse, they rarely connect with other inspiring initiatives that could potentially form part of the “smooth pathway” that we believe is the fundamental objective of disability reform.

#### ***Our Vision for the NDIS***

- *A system of support for people with disability that challenges preconceived notions of their potential to contribute to society, continually raising the bar of what is possible at a pace that is demanding but realistic.*
- *People with disability are confident they can face the world and have the knowledge, the tools, the resources and the support they need to succeed despite life's inevitable challenges.*
- *A culture in which those who have previously felt that they need to protect people with disability—and that the best way to do that is to control aspects of their lives and to make decisions on their behalf—understand that they need to let go. A culture that understands that the most disabling thing of all for every human being is a feeling that their own lives are not within their control, and they are in effect “second class citizens”.*
- *A future where the world has responded to the need to design and build all of our society in a way that includes every one of our citizens. In this world, the specific needs of people with disability are an integral part of the design criteria for every part of our infrastructure and every product or service developed and sold in our economy.*
- *People with disability are in every workplace, on every level of every organisation chart, at every sporting event, on every form of transport, in every streetscape, in numbers that reflect their existence in society.*

## Annex B: The Lifelong Learning Pathway

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*Karen Marshman and Craig Harrison reflect on two elements of the Lifelong Learning Pathway—empowerment of the individual and meaningful employment pathways, and also on the collaborative effort across systems and stakeholders to meet individual needs.*

The development of life skills happens for most people in a combination of formal and informal ways. Life experiences and the lessons we extract from them provide us with the tools we need to navigate our way through life and enable us to lead successful lives.

For many people who experience significant disadvantage (and people with disability are clearly a major cohort of disadvantaged citizens), the opportunities to develop many of the life skills needed to lead successful lives are less available. Along their pathway of life, these losses of opportunities and skills can have a cumulative effect on an individual’s aspirations, and subsequently their fulfilment and participation in life. There are some common opportunities and experiences across all societies that are positively related to an individual’s wellbeing, skill development and societal participation, such as positive family engagement or role models or acquisition of meaningful employment.

Intensive interventions that redress these reduced opportunities are a key to building real and achievable pathways to participation for people with disabilities.

### Harnessing Empowerment and Self Belief to Live Life to Our Full Potential

*Karen Marshman explores the importance of encouraging people to think differently about their futures and giving them the skills to do so, drawing on principles of motivational and positive psychology. Karen's perspective combines her experience running one of Australia's most highly respected personal leadership and development programs for disadvantaged young people, and more recently successfully applying these principles in services for people with injury, disability or facing significant life challenges.*

An individual’s ability to “dare to hope” is the act of imagining they can create a future for themselves with aspirations that inspire them, and hope and belief in reaching these aspirations. For the NDIS, this ability will significantly affect how participants’ get the most out of the scheme and what impact it will have on their community participation, including employment.

An individual’s dare to hope and personal expectations for themselves will be influenced by many factors. These include the infrastructural barriers that the NDIS seeks to address. They also include an individual's *self-efficacy*. Self-efficacy is essentially how we measure our ability to do something and reach goals, and is often drawn from our past experience with that challenge or something similar e.g., “I’m confident to go and meet people, because I’ve always been fun at parties” or

similar experience e.g., “I’ve never played squash, but I’m good at tennis, so I should be ok at squash”.

In life situations that are either new and/or life-changing, or that potentially affect our perceived inclusion with others; we often struggle to find personal resources. We may have few personal reference points to immediately draw on, and we may need assistance to tap into our resources, identify aspects of our life experience, or to create hope and challenge ourselves to positively resource ourselves. Often in these circumstances, we draw our information from the experience of those around us or who know our, or similar, circumstances.

Thus, where our circumstances involve a personal disability, we may re-evaluate our identity, our concept of ourselves and our expectations. To do this, we will likely draw on some key inputs, such as:

- Our own internal personal resources (for example, our capacity for resilience. Some key factors can contribute to resilience, such as giving meaning and purpose to life events, which we may need assistance to identify) which can be influenced by those around us;
- The influence of those who are perceived to be “like us” (e.g., have a similar disability, likeness, background or circumstance);
- The expectations of those around us, that know us (e.g., our family or friends); and
- The expectations of those who have experienced the circumstances of the extra many others “like us” (e.g., carers, support services).

For the NDIS, the achievements of a number of individuals, when visible or available to others, will influence each of the key input factors above. The critical aspect is to ensure that participants of the NDIS dare to hope even in circumstances where there is an unconscious bias toward low expectations. To achieve this, people with less access to opportunities to develop the skills to participate, will likely require resources and support (e.g, coaching and championing them) to overcome the internal and external barriers they face and bring their aspirations to life.

### Intensive Intervention

A truly person-centred model has the individual and their aspirations at the centre of their life journey, empowered to activate the resources needed to fulfil those aspirations. Thus, the model or landscape ensures that flexible and time appropriate services: a) facilitate and reinforce their aspirations, with tools to navigate life-long goal planning, problem-solving and personal development and leadership; and b) support participants with their specific challenges and needs at a particular stage of their journey. For example, there may be potential variation in initial service delivery for those experiencing traumatic or acute onset of a disability (who require immediate assistance with grief, loss and adjustment) compared to those with a non-acquired disability who require ongoing and developmental support.

The model will provide services that:

- Assist the individual to identify their aspirations, goals and needs;
- Cater to the emotional, developmental and motivation needs of the individual through the challenges of navigating various systems related to their disability; and
- Offer support to challenge and overcome the infrastructure barriers and expectations of their immediate and wider communities.

Key to this model will be:

- Recruiting key “coaches” to facilitate and support championing achievement of aspirations, and overcoming barriers;
- Facilitating positive connectivity with others through appropriate personal development/adjustment and leadership training, i.e., connecting those in similar journey phases;
- Appropriate design to ensure that personal aspiration thinking can be carved out of the process-related aspects of the NDIS;
- Facilitating the inspiration from similar-circumstance success stories in the right way to leverage hope in others.

### Real Life Examples: Individuals

#### *Melissa*

Melissa is 26 year old residential care worker who sustained an injury to her lower back rendering her permanently impaired. As this was a workplace injury, she was entitled to worker insurance. The processes involved in managing her claim, her return to work and subsequently determined inability to work, left her feeling despondent. From Melissa’s perspective, much of the communication with her over the cycle of her claim had related to her current disabilities within this context, her treatment and prognosis. She had become quite focused on her injury and was not feeling hopeful about a new job. Through her workplace she was offered the support of an external service to review her aspirations and what she wanted for her life. She was relieved at a refocus from her disability.

With some guidance, she realised that she could view her future not through the eyes of disability but instead in terms of her aspirations, and then how to achieve those while managing her injury. She realised that she could actually apply for a more senior position in team leading in the sector, and not risk her back being further injured in her life. She needed to engage her current employer positively and requested some administration and finance duties in her last weeks of her alternative duties workplace plan. This gave her the experience to take a leap and apply for a more senior role. She won a more senior role in a new organisation and had a significantly higher income!

### *John*

John acquired a shoulder injury in direct care in the health sector. The injury acquired was quite serious and rendered him unlikely to have a strong shoulder in the future and it was something he would always have to consider in his future work. John grappled with the idea of doing a lesser role with his current employer, though he was uninspired. In talking with a support service offered by his organisation and his family, he realised that he had a long-time hankering to go back and do his masters in dietetics and health. He realised that this may mean he had to sacrifice some potential employment related benefits, but he could also sacrifice the focus on his injury and the adjustments that had been made to his workplace for him to do lighter duties. John worked through some choices for his next two years, and realised that he could stay at home for some further rental support and could complete assignments using voice activated technology, rather than the repetitive strain of typing. He embarked on his study with enthusiasm, with view to becoming a clinician – a more senior clinical role with no duties that could not be managed for his shoulder.

### *Mark*

Mark was 16 years old, living with his parents and sister and attending a private school with aspirations to go to university when he had a diving accident. Within a week, Mark was receiving direct care in the rehabilitation centre of a major hospital after a spinal cord injury had caused quadriplegia. After various assessments, the occupational therapists spent some time with Mark showing him a device that those with quadriplegia often used to be able to put their socks on. Mark recalls the OTs saying to him in time he would be able to complete the task within a couple of hours. Mark reflected on his aspirations for the future and determined in that moment that his future aspirations would best be fulfilled by him paying a carer to fulfil this duty for him, as he wished to spend his time in business. He had little desire to master the task and wished to have it done as quickly as possible. For over 35 years, Mark has managed the services of personal carers to assist with some of his required basic functions and activities, both at home and whilst travelling. He has gone on to fulfil his ambitions including an extremely successful career with over 25 years in an International Management role within a global company. Mark has never learnt to put his socks on.

### *Jess*

Jess acquired a spinal cord injury in a car accident at the age of 25. Her described her first 3 weeks in hospital as “horrendous”. She said that despite very loving and caring nurses, she had a sense that “this was it”. As she transitioned to the inpatient rehabilitation service, she met a nurse that she said was “putting up with none of your moaning”. Jess told the nurse she was worried about losing her friends, not being able to go to pubs, and losing her sport and sense of competition. She was struggling to see what she had to live for. The nurse told Jess, “you can have a leave pass for an afternoon at the pub if you can make it up that hill”. Jess said in that moment, she took on the challenge, threw her arms into gear and

propelled her chair up the hill. That afternoon, she went to the pub with friends and realised “I’m still here; I’m still competitive and still me”. Jess now plays basketball competitively, and describes that nurse’s attitude to as a key turning point in her recovery.

### *Libby*

Libby was born with a spinal injury from birth and has been using a wheelchair all of her life. Libby is now 70 years old and has competed in 11 Paralympic games for Australia winning many medals, and was once Paralympics Secretary to Australian Paralympics Team. She is also a mother, wife, grandmother and active worker in community service. When asked about her success in life and the challenges of her disability, she described her success as being a result of never seeing that she had a “disability”. She said she developed this attitude from her mother, who never allowed her to see herself as any different or less capable and ensured that Libby had equal chores as her siblings, with no real allowances because of her disability. Libby said she developed ways of doing and achieving things, and developed confidence and self-belief as anyone does in overcoming any of their challenges.

## Better Pathways and School to Work— An Early Intervention Approach

*Craig Harrison, one of Australia’s most respected disability leaders and thinkers, discusses the importance of creating smooth pathways for people with disability through the formal part of their life learning experience and on to participation in the workforce. Craig has been demonstrating the power of this approach for over 20 years as a leader in Australia’s disability employment service.*

For individuals with a disability, as with any prospective employees, an initial step to acquiring meaningful employment is to understand the skills they have already developed on their life journey and their readiness and requirements for employment. One transition point to employment services is commonly from the education sector.

Within the school sectors across Australia, over 85 % of school students with identified disability are defined as having a Developmental Disability. Traditional approaches channel these students to congregate care models of community inclusion or Supported Employment (e.g. Australian Disability Enterprises). The majority of these students will likely be eligible for the NDIS.

For over 25 years in Australia, Open Employment has been demonstrated to be a real option for these individuals. Earning wages and enjoying conditions of employment the same as their co-workers without disability, many workers with disability have proven their value as productive and loyal employees over many years. The author knows of individuals who have worked with their current employer for over 20 years.

Over the past 10 years in Adelaide, a partnership has formed between the 3 school sectors, the VET sector, the South Australian Government and the Australian Government contracted Disability Employment Services (DES). The State Transition Program was developed and coordinated by a DES provider with specialist expertise working with people with intellectual and learning disability.

Building a strong partnership between schools and employment services promotes the opportunities and vision of Open Employment within school communities. As more students, teachers and parents see the pathways taken by peers, aspirations rise about what is both possible and desirable.

Engaging students and parents early in thinking about employment goals is important. Students with disability are at greater risk of leaving school early and subsequently experience lower employment rates than other students.

Allied with the South Australian Government *Better Pathways* initiative, the aim of this early intervention approach is to support a smooth transition from school to real work for students with disability by:

- Mentoring students with disability who are at risk of early disengagement from learning. Commencing in year 9 of secondary school, mentors work with students, families, schools and other relevant services to support goal planning and decision making for the student. A “vision” of employment and further learning is encouraged and supported among all stakeholders.
- Establishing a clear plan for the transition year. This also assists students, who struggle with change due to their disability to prepare for this significant step in life. It also ensures resources from the student's own networks, school based resources and those of the specialist disability employment system are collectively focussed upon this learning pathway to employment and active participation.
- Facilitating/brokering accredited training and workplace experience (via Structured Workplace Place Learning) that assist students in the job market. Labour market competitiveness is improved by enabling students with disability to achieve vocational qualifications as part of their secondary schooling. Practical experiences in real work settings further support the student to make choices about career directions.
- Establishing ongoing relationships between the student, their parents/carers, teachers and post school services early in the transition year. Involvement of a Specialist Disability Employment Support Worker is a key factor in this approach to transition. Planning is driven by student aspiration, not service/program design. A key element is the investment in the student through interventions that support personal leadership skills and life goal setting.
- Providing on-going employment support from the service post-school. Long term partnerships with the disability employment support staff ensures that the young person has support with career advancement and other

challenges encountered by most young people as they transition to the world of work.

### Real Life Example: Individual

#### *Ben*

In year 10, Ben was referred to a school to work transition program provided by a disability employment service.

He has Dyslexia and, at the time of referral, had Severe Conversion Disorder, was using a wheel chair, and had school-based support to assist with Dyslexia and learning difficulties.

His ambition was to become a chef, an occupation for which his physical disabilities were considered a barrier.

Deterioration in his health was of such concern that fears were held for Ben. However, his mother remained absolutely committed to Ben having the opportunity to participate in work experience in real workplaces like his school peers.

Transition workers arranged participation in a TAFE commercial cookery program and, after significant searching and negotiation, identified a commercial kitchen where he could complete his Structured Workplace Learning (SWL), a key component of the VET Certificate training. He was supported in his SWL by the disability employment service staff. Given health concerns, a gradual introduction to the workforce of 1 day per week work experience was arranged, with opportunities for further development available.

Most importantly, he “dared to dream”.

Ben, in partnership with his disability employment service, then secured an apprenticeship as a chef with an International hotel group. He subsequently successfully completed his apprenticeship and aims to further his career with his employer in overseas locations.

Ben’s journey to a valued role in a career of his choice required the application of a number of life skills: Literacy and numeracy; health management; decision making; commercial cooking; communication. Ben acquired some of these skills from his family, some through schooling and some through targeted interventions designed to build Ben's capacities.

As Ben stated, “dreams do come true”.

### Real Life Example: Effective Service Partnerships

There are various opportunities along the life journey that may have eluded some individuals with a disability. This becomes an important factor for collaboration of services to meet the individuals’ needs and fulfil aspirations, according to where they are at on their journey. One example of this collaboration was the partnership between a disability employment provider and a specialist organisation in personal

leadership training. This partnership recognised that vocational education and employment pathways required confidence, self-belief and aspirations of the participants to pre-empt or assist in initiating a training and employment pathway.

This partnership introduced a training and coaching program for individuals with a disability, for one day per week, providing them with frameworks for goal setting, and communication. Participants became aware of their interests, aspirations and plans for how to achieve them. Further, they developed the skills to enrol others in their aspirations, including family members, generating their own positive support networks. Through coaching support on their graduated goal plans, they were supported in taking steps through the employment pathway of their interest, and in the process built self-efficacy, confidence and personal skills. This intervention positively impacted on the individual's ability to achieve goals and their overall employment outcomes.

## Annex C: Building a New Market for Disability Supports

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*David Clarke sets out a number of emerging issues that will need to be addressed to ensure a successful and smooth transition from the current market for disability supports that relies on block-funded grants, to one that is driven by citizen choice, and is more efficient, effective and empowers consumers.*

### The Shift from Today's Environment to the NDIS Market

If the establishment of the NDIS was viewed through the lens of a typical new business build, it would need to start by developing a winning strategy and having a clear customer value proposition. The various business and operating model choices relating to branding, structure, staffing, performance incentives and rewards, governance and so forth would need to align with that value proposition to ensure it could be delivered.

Businesses can only effectively deliver on their customer value propositions when the key elements of the business model are aligned. For example, while the products of a cruise travel company may be holidays, what they ultimately deliver is a fantastic customer experience. This influences their staff selection, training and development, performance management and business processes, which are all explicitly designed to deliver the desired customer experience.

The same sorts of questions should be asked about the establishment of the NDIS. For example: What type of customer experience are we trying to deliver for people with disabilities? How do we make sure that the business and operating models are aligned? How do we ensure that the staff selection, development and other frameworks support the desired experience?

Answering such questions requires an explicit conversation around the strategy for success and a clear articulation of the desired customer experience, followed by the development of a clear business and operating model blueprint. This can be done at a system level not just at the enterprise and firm level to ensure the NDIS meets the expectations of people with disability.

Today, the disability supports industry is characterised mainly by a government-funded sector drawing on block funding under the National Disability Agreement. Under the agreement, providers primarily access four 'pools' of funding for different kinds of supports that are in scope for the NDIS—namely accommodation, community support, community access, and respite.

The sector has been growing at approximately 6% p.a. on average nationally, but there are some significant variations by state. Most providers are state-based (i.e. focus on one state only) and there tend to be three main types:

- 40% are delivered by the public sector or state/local government agencies;
- Larger non-government providers (typically community sector organisations) deliver around 50% of the services;

- A very 'long tail' of small community sector organisations deliver the remaining 10%. These are diverse and many specialise in a particular type of service or disability.

The NDIS will fundamentally change the roles and relationships of all the major players in disability support and use market forces to drive efficiency and effectiveness. Government's role will shift from being the primary 'customer' who buys services on behalf of people with disabilities, to facilitating and regulating a new market where people with disabilities purchase supports directly from providers. Instead of block funding to providers for supports, funding will be assigned to individuals. Providers will no longer just deliver services agreed with government, but will need to compete and tailor supports to meet the individual needs of people with disability. Over time, people with disability will become more empowered consumers who can exercise individual choice over the supports they receive.

## The Role of Government as Market Maker

To build and manage the market for disability supports under the NDIS, the government has a number of levers at its disposal. For example, it can establish standards and regulations, mandate activities and other requirements, and create pricing models. In designing the use of these levers, government must seek to meet two objectives.

The first is to ensure the products and services delivered in the NDIS market help it to achieve its social policy objectives. The second is to build a market that is efficient, effective and competitive. The key characteristics of such a market include:

- The presence of multiple consumers and providers
- Low entry/exit barriers
- Low transaction costs
- Information symmetry (e.g. clear price and quality signals)
- A reasonable rate of return for providers
- Rights and responsibilities that are clearly defined and fairly enforced.

The challenge for policymakers is to reconcile these often competing objectives. For example, regulations that restrict the scope of products and services in the market can be expected to increase transaction costs and create barriers to entry for new market players. Providing grants and subsidies to support the transition to the new market may lead to market distortions and potentially prop up inefficient providers.

Getting the balance right in other social services markets has been a very challenging task. For example, the Victorian Government has been experimenting with flexible, individualised funding since the 1990s, including introducing Individual Support packages (ISPs) in 2008. Significant effort has gone into the design of ISPs, which according to a Victorian Auditor-General's report of 2011

comprise approximately 20% of total Victorian disability funding. While that report points out many positive benefits of ISPs, it also highlights the lack of change that ISPs have brought to the provider market, with a high proportion of people spending ISP funds through traditional DHS service agreements, and few providers entering or exiting the market.

Critically, the government must also be mindful of potential unintended consequences in the design of intervention levers. For example, in the Job Network market, the government has introduced standard reimbursement payments based on the achievement on outcome measures (i.e. placing participants in a job), but in doing so created a potential perverse incentive for providers to avoid clients with more complex needs who may require significantly more effort to place in employment.

What does a framework for a competitive market that meets the government's social objectives look like? The following characteristics appear critical:

- A system that respects the rights of the individual, assumes full decision-making capability as the default for all participants, and does not unduly restrict choice and control. For example, rather than being overly prescriptive in defining permissible products and services, government should design for maximum choice and flexibility, and instead ensure compliance via a robust audit and review process. It would also be desirable if, as in the case of Victorian ISPs, people have early guidance in the planning process on the amount of funding they are eligible to receive;
- Mechanisms to assist consumers overcome information asymmetries and navigate complex purchase decisions. For example, many disability supports are 'experience goods', whose quality cannot be assessed before purchase (e.g. personal care and support in the home). Mechanisms for consumers to assess provider quality and evaluate service offerings may include accreditation frameworks and product comparison services such as the *MySchool* website or social network-based services along the lines of *TripAdvisor* and similar websites;
- Pricing models that do not unduly restrict the operation of the market. In an ideal world, pricing controls should be kept to a minimum, since the government is not well positioned to determine the true cost of service provision, and controls are likely to stifle innovation and quality. On first principles, if a sufficient number of providers are available for an NDIS participant to choose from, competitive forces should dictate the optimum market price rather than require the government to set unit prices centrally. There may, however, be an argument for unit pricing in certain situations, for example in the case of care provided by relatives, or in markets where the supply of providers is thin (e.g. in regional or remote locations, or highly specialised services); and
- A robust monitoring and evaluation framework. Such a framework would assess whether the desired social policy objectives are being achieved, and

how the various elements of the system help or hinder them. In doing so, it would provide the necessary fact base for the government to alter its use of intervention levers over time.

## Challenges in the Transition to the NDIS

Making the transition to the new NDIS market will present challenges for all involved. There will be a significant expansion of the sector, with the Productivity Commission proposing a doubling of funding. In states that have already been experiencing expansion in recent years (e.g. NSW, Queensland), managing an additional level of growth may be difficult. In more stable states, like Victoria, the sector's ability to adapt to rapid expansion is unclear. Challenges are expected to include capacity constraints, price inflation and workforce shortages that may also impact adjacent sectors such as aged care. Service quality may also be affected as organisations transform their culture, workforce capability, business models and core processes to adjust to the new environment.

In managing this transition, the NDIS will need to account for the specific challenges facing different segments of the current provider market:

- *Public sector providers:* as responsibility for disability services gradually transfers to the Commonwealth from the States, it will be important to manage this transition to minimise any disruption to people with disability. It is also unclear what involvement the states will continue to have in service provision in the future. Can States compete in the new market, and if so on what basis (e.g. as government agency or trading enterprise)? Is there a role for States as provider of last resort? Should States exit direct service provision altogether, and if so how?
- *Large non-government providers:* although well positioned given their scale, many of the existing large providers will need a very different business model to succeed in the new market. Specifically, they will need new capabilities as they move from managing a guaranteed block funding stream to managing unit pricing and individually tailored services. For traditional NGOs, this will involve a significant degree of business capability development.
- *The 'long tail' of small community sector organisations:* given their small size and for many their reliance on disability funding (rather than providing a broad spectrum of social services), small organisations may struggle to adapt to the new market. For example, it is reasonable to expect there will be a shift towards larger providers (including via sector consolidation) that are able to generate and leverage economies of scale. While this may bring tangible benefits to people with disability, driven by the ability of larger players to invest in innovation, systems, quality support processes, training and so forth, it will invariably bring disruptions to long-established smaller players. Such organisations are likely to need support to understand their strategic options, including merger and acquisition opportunities.

## Annex D: Design Principles for Better Public Services

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*Martin Stewart-Weeks summarises design principles from a growing body of public service design and social innovation research and experience which is driving new models of co-designed and collaboratively delivered public services.*

These simple, but powerful principles should inform all aspects of the design and delivery of the NDIS, right from the start.

### Don't ask questions about the service, ask questions about the aspirations and expectations of those who you are trying to enable

We need to think again about how to infuse innovation, a focus on productivity and an obsession with impact and results into the way we conceive and develop our public services, especially for people with disability.

Understandably, for many people who are working hard to provide a service, often the instinctive place to start a discussion about innovation and improvement is with the service itself rather than with the people who use or benefit from the service.

Despite the rhetoric of citizen-centricity and customer focus, the lived reality of people on the receiving end of services is often very different. It turns out to be much harder than it sounds to start the discussion about quality, innovation and impact not from the perspective of the service but from the perspective of the people it is supposed to be serving.

So the first question should not be "what can we do to improve the service" or "how should we design the service better". The first question should be directed squarely at the existing or potential users and should work hard to understand not only their expectations of the service but, even more importantly, their aspirations for their lives and the lives of those who are closest to them. "What are you trying to achieve for your life?". "What do you aspire to for you and your family?" These are the places to start the design process together with a counter-intuitive assumption that the answer may not necessarily translate neatly into a service response, or at least not within the constraints of existing service models. In some situations, the service may not be the point at all. Instead, the most important thing might be to recognise and give effect to a set of aspirations by a response as basic as repairing bonds of association and engagement within and between family, friends and communities.

## The NDIS is building a movement and giving life to a philosophy as much as it is delivering a set of programs and creating a new delivery structure

For reforms like the NDIS, it is natural to think of the initiative in program terms. People involved in their design and development are like architects and builders and it's hard to avoid conceiving of their work in structural terms. In that sense, for many on the inside of the NDIS process, there is an understandable temptation to see their work as being to almost literally “construct” a thing or a product.

The problem is not that this structural or programmatic approach is either wrong or avoidable. In some fundamental respects, something as large and complex as the NDIS does need a robust architecture and strong program management structures. It needs to be built with clean and simple lines.

But that can't be all it is. In fact, we think the real power of the NDIS is the extent to which it is emblematic of a much larger set of ideas or philosophies of disability services. In that sense, it is not fanciful to see the NDIS as a movement as much as it is, and has to be, a program and a structure.

Critical aspects of the design and build for the NDIS should therefore reflect the fact that it is as much a philosophy as it is public program.

## Formal institutions and organisations have to find better ways to see and nurture the work and aspirations of looser networks and communities of people close to the ground who are actively engaged in the lives of people with disability

Another challenge for the NDIS will be to forge a different relationship between the institutions and organisations of the formal public sector—agencies, regulatory authorities, government departments—and the proliferating networks and communities that are increasingly active in the places and spaces where it needs to make a difference.

Who is in these networks? Well, they would include the mix of non-government, not-for-profit organisations, self-support groups, think tanks and so on actively involved in different dimensions of disability policy, services and research.

More likely now, building on pervasive and cheap access to communication and collaboration technology, these looser and more fluid (but still organised) networks will include a more varied mix of people. This could include people with disability themselves, innovators and social entrepreneurs, and people investing in and helping to form start-up ventures. It is also likely to include highly localised but loosely connected networks of people with service needs and those able to find cheap and flexible ways to help them.

In that sense, the game has changed from the time when it was a relatively simple prospect for those inside the "cathedrals" of large public institutions and

organisations to find a few more or less representative voices from outside the cathedral to talk to or from whom to elicit feedback.

Now, the mix and variety of voices and skills and needs has grown into a more unruly "bazaar" of players where connections and coherence are harder to discern. What these people want most of all is conversation, not consultation. What they are seeking is engagement and a chance to genuinely co-create the solutions that end up in their lives. What they expect is an interaction that is authentic, sustained, respectful and productive.

This translates into new demands on the public sector to find better ways to interact with, and nurture, these looser but increasingly powerful networks and communities. Part of the role is also to help these people and organisations work more effectively with each other.

## Need to manage the economies of flow, not just scale

The work of English management researcher and consultant John Seddon has drawn attention to some very basic system design principles. One that is especially relevant to the NDIS is the risk of missing the benefits of the “economies of flow” by focusing only on the supposed “economies of scale”. The focus should be on dealing with variance, an especially critical part of the service challenge. This is how one description puts it:

*In service, John Seddon discovered that variety was even greater. He realized that the ability to handle variety was key to improving service and reducing costs. Further, what he discovered was that “people are good at handling variety and computers are not.” This meant that in service the need for fewer computer applications and systems (in a management paradox) leads to more control and ability to absorb variety with people—reducing costs AND improving service. Seddon also talks about pursuing efficiency and cost reduction targets to the point where poor service ends up creating “failure demand”, the demand generated by failing to deal with the problems in the first place. <sup>2</sup>*

A number of challenges flow from these persistent, but increasingly uncomfortable demands for scale and flexibility at the same time. For example:

- How does the NDIS ensure equity and consistency of access and quality but also allow—and positively encourage—difference of approach and action for different people in different places? How does the NDIS make sure it is the same for everyone and completely different for everyone too?
- How does the NDIS avoid the risk of over-reliance on targets and traditional methods of performance measurement and accountability and, in the process, carve out the necessary space for requisite variability and adaptability? In other words, and like many other public service programs, how does the NDIS avoid the risk of hitting the target but missing the point?

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<sup>2</sup><http://blog.newsystemstinking.com/economies-of-flow-defined-for-service/>

- How does the NDIS reflect the difference between economies of scale and economies of flow and, just as importantly, the creation of "failure demand" that emerges as a drive for cost efficiency and process ends up creating more expense and higher costs?

## Enable some measure of co-production to flourish at the core of the NDIS

A final challenge for the NDIS, and for public services more generally, is how to combine the need for predictability and accountability with an ability to embrace the "co-production" and "perpetual beta" ethic.

"Co-production" is something of a buzzword in contemporary discussions of innovation and reform in the public sector. But in the context of the NDIS, especially at this early stage of its development, it has some very practical implications.

For example, if the launch sites are going to offer maximum value to the larger NDIS rollout process, they should be treated as opportunities for co-production and design innovation. That means that the different locations should have the capacity to take different approaches to some of the NDIS elements so that we build up a stock of practical examples of good practice that can inform the larger rollout of the program.

It also means that, in each location, people with disability and their communities of care and support are invited not to roll out a program that has already been designed and locked down in every detail, but rather to take part in a process of invention and experimentation, at least to some extent, so that they can put back into the design process knowledge, experience and insights to benefit the larger program.

The term "perpetual beta" also derives from innovation. It is the idea that, in a fast-moving and unpredictable world, it isn't sensible to assume that the innovation process is something akin to a factory production line where inputs are turned into "widgets" at the end of the line signalling the conclusion of the process.

Instead, the reality is that program design and delivery decisions are seen as a series of temporary solutions to the complexity they face. These solutions will reflect the best judgement at any given time about the right mix of investment,

- *Don't ask questions about the service, ask questions about the aspirations and expectations of those who you are trying to enable.*
- *The NDIS is building a movement and giving life to a philosophy as much as it is delivering a set of programs and creating a new delivery structure.*
- *Formal institutions and organisations have to find better ways to see and nurture the work and aspirations of looser networks and communities of people close to the ground who are actively engaged in the lives of people with disability.*
- *Need to manage economies of flow not just scale.*
- *Enable some measure of co-production to flourish at the core of the NDIS.*

infrastructure and management to achieve the objectives as they have been designed.

The idea of the "perpetual beta" recognises that the prospects of playing pretty much indefinitely with all of the settings, up to and including program objectives and outcomes themselves, is not only necessary but normal.

But turning the language of "perpetual beta" into the reality of public sector management is obviously not easy.

The truth is that the public sector, for very good reasons, is wedded to relatively inflexible notions of predictability, linked to equally inflexible notions of accountability. Politicians, the media, public servants themselves and of course many in the community instinctively want public programs to operate on the "no nasty surprises" principle.

Indeed, in the public sector, mistakes and "surprises" are rarely welcomed as the learning opportunities expounded in management theory.

But, notions of co-production and “perpetual beta” are inescapable ingredients of innovation.

And while the NDIS can't avoid the demands of predictability and surety for the outcomes it wants to secure for people with disability, neither can it overlook the instincts of "beta" and co-production on which a measure of its success will rest.

## Concluding Thoughts

Each of these principles can be reflected in practical tasks from the NDIS process.

Let's finish with one example—recruiting Local Area Coordinators in the launch sites and then more broadly across the country. It makes no sense to construct the formal job descriptions for those roles, and the less formal but arguably more important view of the aptitudes and values we want in these pivotal positions, without first reflecting deeply on the design principles. That might mean recruiting people who can offer some evidence that they "get" the distinction between the NDIS as a program and NDIS as a philosophy. If they do indeed understand that distinction, and the need to integrate both frameworks, they are more likely to work in a way not only consistent with each but capable of delivering the best of both.

None of these design principles is simple or easy to implement in a public sector context, let alone one as complex as the NDIS. Yet our sense is that embracing them will be critical in order for the NDIS to do what we want: to lift the bar once and for all in Australia's treatment of, and support for, people with disability.

## Annex E: A Whole of Life Approach to Disability Reform

*Mark Bagshaw shares his thoughts about the fundamental reasons why so many people with disability are not participating in our community to the level they are capable of and to which they aspire. Combining his extensive strategic business management experience with his decades long involvement in the disability reform process and his personal experience living with spinal cord injury from age 16, Mark begins by “deconstructing” disability and identifying three key obstacles he believes are preventing many people from participating. He then replaces his “disability hat” with his “business hat” to propose an integrated, strategic approach to remove those obstacles.*

### The Problem

A common question I am asked is: "Why are so many people with disability staying at home on disability support pensions when they can and want to work?" I have concluded that three fundamental and interrelated factors are pulling people with disability down in an almost endless downward spiral:

- They face massive **infrastructure barriers** that make every day hard work;
- Our community still doesn't believe people with disability can participate fully in society and therefore has significantly **lower expectations** of them than the average person;
- Many people with disability feel overwhelmed and **disempowered** because they have never built the life skills to give them the knowledge, strength and confidence they need to deal with all of this.

Just as importantly, each of these factors is linked.

- We're not removing the **infrastructure barriers** quickly enough because the community and those responsible for the infrastructure barriers are observing people with disability staying at home and they conclude there is little point spending money making the world accessible;
- **Community expectations** are low, partly because people observe people with disability struggling with the infrastructure, and partly

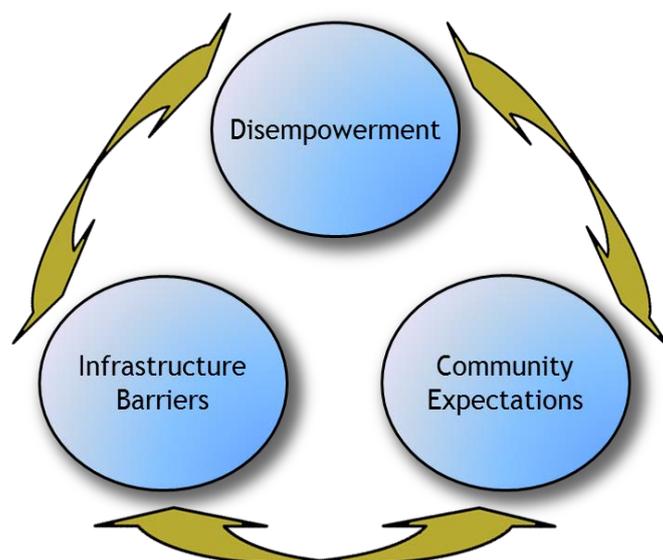


Figure 2: Barriers to Participation for People with disability

because, in their interactions with people with disability, they notice how disempowered many people with disability feel;

- People with disability feel **disempowered** in large part because of the challenges they face with the infrastructure, and because of their reaction to the sense of discomfort and sometimes pity they feel from the general community. They feel like second-class citizens.

It's a continual downward spiral.

## A Solvable Problem

Our challenge as a community is to break the downward cycle for everyone with a disability.

Although these problems exist, we know they don't stop everyone. Indeed, significant numbers of people with all types of disability are participating fully in our community, including in the workforce. For those people, something has happened to break down the downward spiral. In most cases, that "something" has reduced the effect of each of the three factors outlined above. This has resulted in them having better access to resources and tools to help them overcome the infrastructure barriers, ensured the people closest to them have maintained high expectations, and given them an inner strength and confidence that counteracts the potential for disempowerment.

To break the downward spiral for all people with disabilities, we need to do three things. We need a much greater focus and urgency on removing infrastructure barriers. We need a more concerted effort and strong leadership to shift the community's perception of people with disability from one based on "welfare thinking" to one that is truly aspirational. And we need to build the internal capacity of people with disability to empower them to manage the challenges of their daily lives.

Collectively, this requires a "Whole of Life" approach to disability reform.

## The Solution

The greatest failures in history—whether in business or government—arise not from a lack of investment or effort, but because the investment and effort has been applied in the wrong way.

A fragmented, "silo" approach to disability reform based on individual programs and interventions rather than a total "package" of solutions tailored to each individual's needs, does not reflect the reality faced by the majority of people with disability. It fails to create a smooth pathway for each individual from the beginning to the end of each day, throughout their life.

At a conceptual level, the solution is relatively simple. We need to create a "Whole of Life Approach" business model that addresses all three factors: infrastructure barriers, community expectations, and disempowerment. While many individual

changes are needed across all aspects of society to do this comprehensively (which will involve significant costs), a small set of "strategic interventions" could initially guide our approach to reform.

### Infrastructure Barriers

Four strategic interventions offer the potential to remove the infrastructure barriers faced by people with disability.

- The first recognises the need for **substantial financial and intellectual investment** to define, develop and implement solutions that remove infrastructure barriers. Many solutions already exist but are not rolled out universally, and where solutions don't exist they could be rapidly developed with a combination of smart thinking, money and process, particularly from the private sector. The first strategic intervention therefore involves demonstrating to businesses that a market opportunity exists (both as customers and valuable employees) as a result of the ~20 % of the population who have a disability, and at least as many others directly affected by disability.
- The second revolves around **universal design**. Making our global infrastructure fully accessible to all people with disability can be very costly where it involves retrofitting solutions to existing infrastructure (although with "smart thinking" we can find ways to do this without exorbitant cost—for example, a *wheelchair that climbs stairs* would be a much more cost-effective way of making every building in the world accessible for people who use wheelchairs). With this in mind, there will be profound benefits from including the needs of people with disability into the original design of everything society creates.

An example of universal design is the design of buses. Several years ago, all bus chassis manufacturers around the world decided to change the design of buses to a "low floor" design. While the decision was not directly in response to a need for accessibility, it has meant that every bus in the world will ultimately become wheelchair accessible as old buses are replaced. In most cases this will happen within 10 years.

- The third relates to **integrating the needs of people with disability** into every structure, system and process in our society—every planning process, every human resource process, every legal process, every education process, and every approval process. We are currently in (and have been for decades) a "laboratory" stage of disability reform in which solutions, programs and services for people with disability are developed by "disability specialists" under a system and structure that is mostly "added on" to mainstream systems and structures.

Just as importantly, the ownership of the disability reform process currently resides, for the most part, in that laboratory. Until everyone (every manager, for example) understands that they are just as responsible for

people with disability as they are for anyone else in whatever they do, people with disability will remain disconnected from mainstream society and thinking.

It’s time to move to the “integration” stage of disability reform.

- The fourth relates to the concept of having a “**licence to operate**”. Every one of us is subject to a range of obligations that we must meet to be part of society. Businesses face a range of obligations, many of which are enshrined in legislation (occupational health and safety, legal and tax, quality and safety standards), as well as cultural expectations from the community. Together these represent a business’ “licence to operate”. That licence already includes a responsibility to people with disability, articulated in our Disability Discrimination Act. The mechanisms are there, but we need to give them teeth.

### Community Expectations

Many people believe that changing community perceptions of people with disability is impossible, or at least highly problematic. While it is undeniably a significant task (given that existing perceptions are deeply ingrained in the community's psyche), experts in social change marketing would argue it is possible.

Anyone who was in Sydney during the Sydney Paralympics in 2000 will recall how, for a short (and ultimately unsustainable) period during and immediately following that event, people with disability and their achievements were celebrated. People with disability themselves felt welcome in the city, partly because many of the infrastructure barriers they normally face in Sydney were removed for the period of the Paralympics and perhaps even more so because they were treated as "normal". People on the streets were talking to people with disability like they'd known them forever, when only weeks before they would have avoided those same people.

This example demonstrates that it is possible to change community attitudes towards people with disability, including in our own backyard. But as experienced social marketers will attest, achieving sustained change about ingrained social attitudes requires a long-term effort (at least three years) during which positive images are presented to the population on a daily basis.

The techniques we are talking about to market a positive image of people with disability are the same as those used to market anything, including products. The only difference is the magnitude of the task. No country has ever undertaken a coordinated, consistent and long-term approach to changing community attitudes about people with disability and their capability. Let's be the first.

We need a properly funded **National marketing strategy** to change community attitudes about disability. In terms of cost, the ability to leverage existing community networks and modern technologies could dramatically reduce this.

## Empowering People with Disability

All of us spend a great deal of our lives learning new things. Many people believe that not a day goes by when each of us does not learn something new, sometimes through formal and structured learning experiences offered by our education system, and at other times through the conversations and experiences of everyday life. The combination of the attributes with which we were born and our life learning experiences makes us what and who we are.

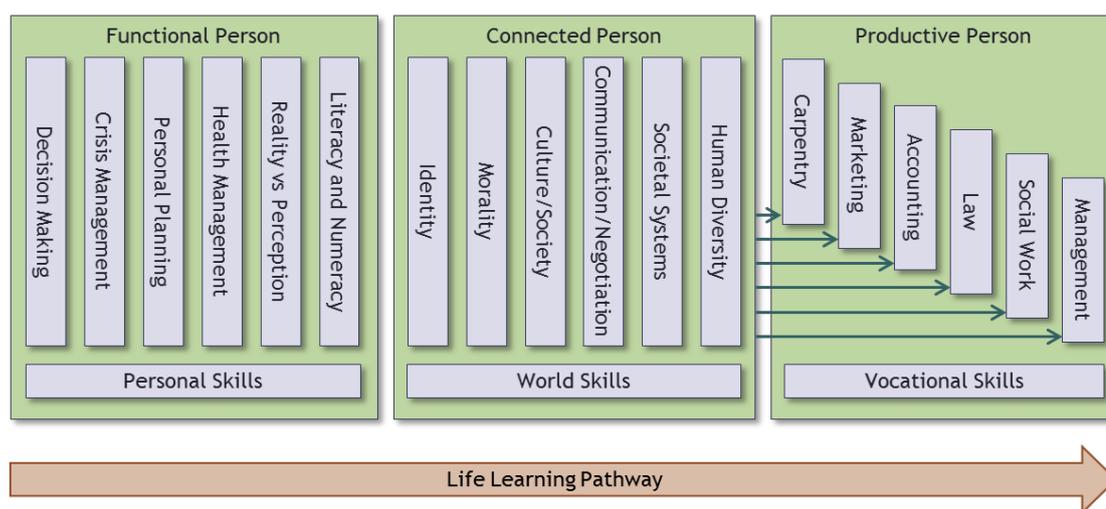


Figure 3: The three components of lifelong learning that make up the Life Learning Pathway

For a number of people, lifelong learning experiences come together well, and the lifelong learning pathway is a smooth one. Those who are born into emotionally and economically stable families generally acquire basic “personal skills” through the experiences afforded them primarily by their supportive families and their interactions with others in their local communities. Together these skills create a functional person—a person ready to connect with the world. As a person acquires “world skills”, through a combination of life experiences and early formal education (often in primary and secondary school), he/she becomes a connected person—one who understands what participating in the world means. It is only when the person has developed significant levels of personal and world skills that he/she is ready to acquire the formal “vocational skills” that will lead to them becoming a productive person, capable of contributing economically to our society as a member of the (paid and unpaid) workforce.

For many people, however, the lifelong learning pathway is nowhere near as smooth. They may have far fewer opportunities to acquire life skills and may struggle to acquire even the most fundamental personal skills. This means their potential to develop world skills and vocational skills is significantly reduced. Given that individuals become stronger, more confident and more capable as they build their life skills, it is apparent that many people who, as a direct consequence of

disadvantage lack the opportunities to develop life skills, will struggle to achieve their full potential.

Abraham Maslow’s oft-quoted theory of human motivation, referred to as “*Maslow’s Hierarchy of Needs*”, provides a very simple but powerful model for understanding how human beings develop and grow, and it maps directly to the lifelong learning pathway concept. His theory describes human needs in layers or categories that build on each other as people develop. Just as importantly, the theory suggests that individuals must meet the majority of their needs at each layer before they can move up to the next layer, ultimately reaching the state that Maslow refers to as “self-actualisation”.

While widely acknowledged for its contribution to our understanding of human nature, Maslow’s analysis only describes what our human needs are—it doesn’t attempt to describe how those needs are met. It is clear, though, that the majority—if not all—of the individual needs within each of Maslow’s categories are met through our

experiences, all of which are, in one way or another, life learning experiences. In this sense the Life Learning Pathway is like a ladder that we use to climb Maslow’s pyramid. As we meet our needs at one level through our life learning experiences, we are able to step up to the next, ultimately reaching the point where we become fully included, productive and fulfilled members of society.

In combination, Maslow’s Hierarchy of Needs and the Life Learning Pathway help us understand why some people do very well in life, while others struggle. Those who develop effective life skills throughout their lives are more likely to feel fulfilment in their lives, while those with poor and/or fragmented life skills often don’t. When we add to that a system of education that focuses on delivering individual vocationally-oriented “skill modules” designed around the “average” individual, it becomes clearer why people who have not had the opportunity to develop strong personal and world skills are less likely to participate fully in society, including in employment.

This one explains why some people with disability participate fully in all aspects of life even with the most severe disabilities of all types. Our community, however,

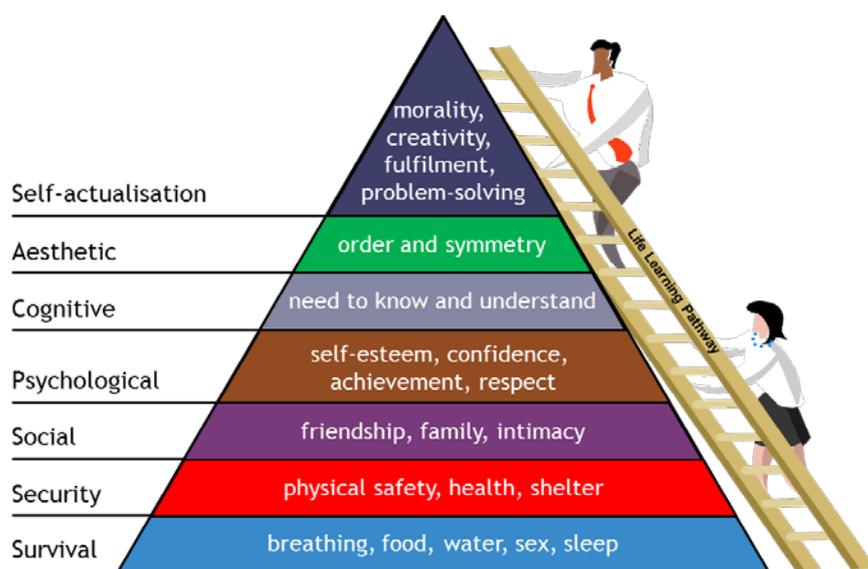


Figure 4: Maslow's Hierarchy of Needs and the Life Learning Pathway

often thinks that “successful” people with disability are somehow superhuman or have an “X factor” that explains their “success”.

The reality is that on its own our “X factor” is never enough for any of us to lead successful lives.

We need to learn how to maximise all of the attributes we were born with by developing our life skills on our lifelong learning pathway. Everything we learn every day of our lives becomes our “life toolkit”. I call that life toolkit our “Y Factor” And all the resources provided by society, in order to achieve life outcomes that match our potential.

Together our X factor and our Y factor prepare us to enter the world. But as poet John Donne so eloquently stated, “No Man Is An Island”. For each of us to achieve our maximum potential we must live in a world that welcomes us. A world in which the vast infrastructure of society is designed to enable our participation. And a world in which the people around us believe in us and have high expectations of us. The world in which we live is our “Z factor”.

For every one of us it is the combination of our X, Y and Z factors that determines our ability to participate and to contribute to our society, and ultimately our quality of life.

Disability does not affect one’s X factor. Some people with disability have a lot, others not so much, just like the general population. But unlike the “average” person in our society, people with disability are often offered fewer opportunities to develop their Y factor, and the Z factor is way below the general population.

To build the Y factor of people with disability we need to develop a lifelong learning pathway that identifies all of the life learning experiences an individual needs to build their Y factor, and offers a “life learning curriculum” of formal and informal life learning experiences tailored to each individual’s needs.

We explore the development of a person-centred lifelong learning approach to empowerment, and present practical and proven methodologies in [Annex B: The Lifelong Learning Pathway](#).