A Whole of Life Approach to Disability Reform

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About the Author

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.

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Introduction

In this paper 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
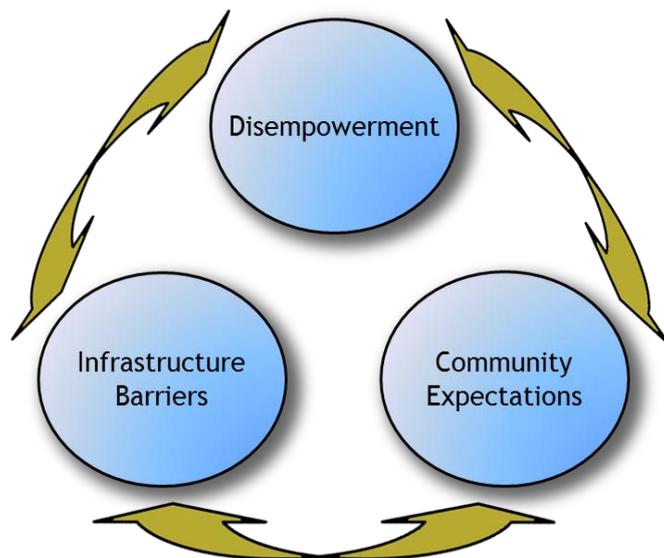

Figure 1: Barriers to Participation for People with disability

infrastructure, and partly 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. The 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 unsustained) 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 marketeers 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.
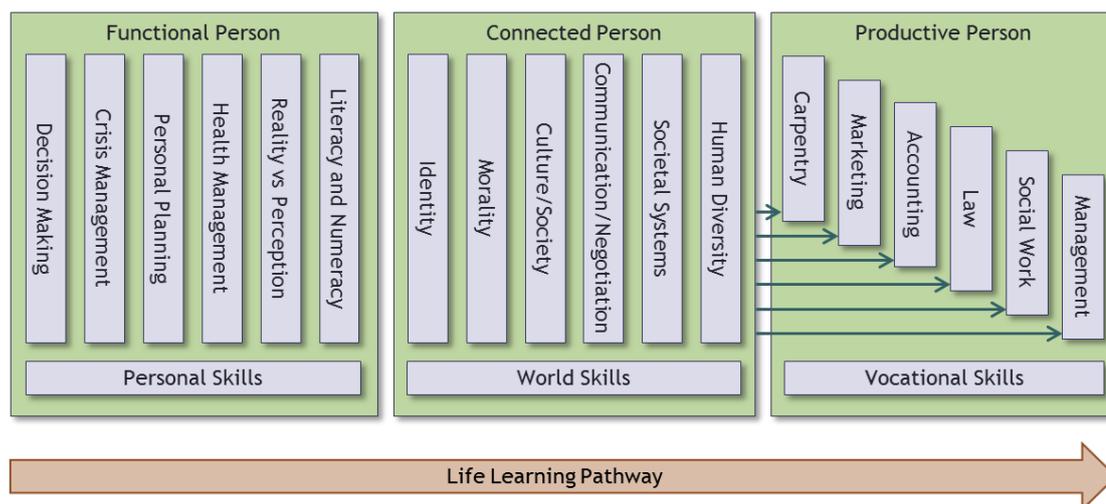

Figure 2: The three components of lifelong learning that make up the Life Learning Pathway

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

Figure 3: Maslow's Hierarchy of Needs and the Life Learning Pathway

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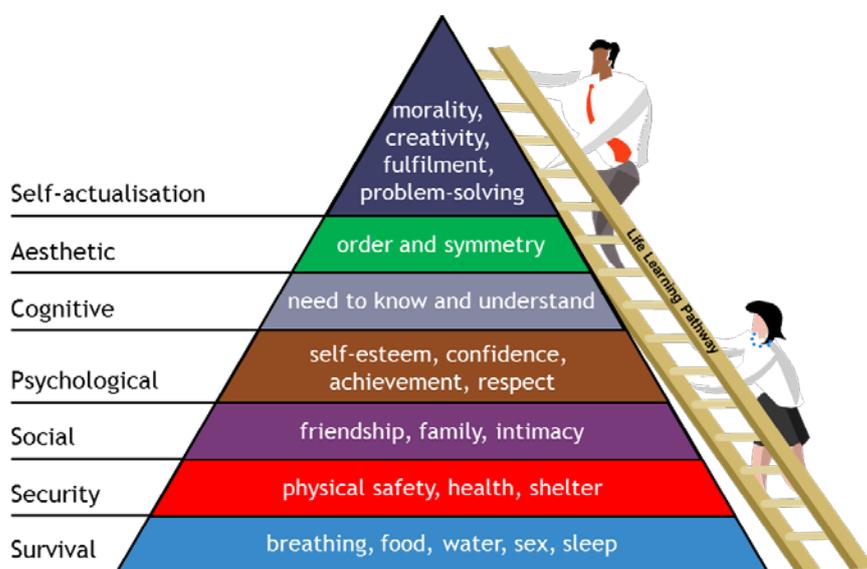
often thinks that "successful" people with disability are somehow superhuman or have an "X factor" that explains their "success".

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.