

Valued, good and ordinary lives

Some stories enhance life, others degrade it so we must be careful about the stories we tell and about the ways we define ourselves and other people – Burton Blatt (1987).¹

Our ways of seeing, being with and talking about people with intellectual disability, their families/whānau and communities can open up or close down opportunities and create hope or despair. Different ways of viewing and behaving can impact to build capacity, competence and confidence or give rise to marginalization, helplessness and fear. These are reflected in the expectations we have and the messages we give about how people can and should be able to live their lives; how welcoming and inclusive communities are; ethical, policy and funding decisions that are made; the quality of services and supports provided; and what safeguards are in place.

Our starting point is to see the person first and not the label. When we recognise others of equal value to ourselves we enter into relationships of respect. Thirty years ago John O’Brien wrote about the five basic tasks of good support – discover a person’s gifts and interests, create opportunity, make connections, assist and teach, and safeguard. These are as valid today as when they were first written.

Table 1 – Enablers for and barriers to valued, good and ordinary lives²

	Enablers	Barriers
Starting Points	<p>Person’s life is valued for their unique gifts and contributions</p> <p>Know and understand the person, their family/whānau, culture and communities</p> <p>People, their families/whānau and relationships in communities are seen as having the solutions</p> <p>Funding models triggered by opportunities for learning, independence, participation and contribution</p>	<p>Person is stigmatised, seen as a burden and has to demonstrate need and deficit</p> <p>Person is seen as the ‘other’, is defined by a label and is known in silos separate from their family/whānau, culture and communities</p> <p>Programmes, services and rules are seen as solutions</p> <p>Funding models triggered by deficits and needs</p>

¹ Burton Blatt (1987) cited in John O’Brien and Beth Mount (1991), Telling new stories: The search for capacity among people with severe handicaps. In L.H. Meyer, C.A. Peck and L. Brown (Eds.) *Critical Issues in the Lives of People with Severe Disabilities*.p.89

² Adapted from the work of Bob Rhodes

	Enablers	Barriers
Pathways	<p>Paths that create and discover opportunities, join up and are connected in communities</p> <p>Paths that go in the right direction for active learning, participation and contribution</p>	<p>Paths are hard to find, have lots of hurdles, lead nowhere and are disconnected from good and ordinary lives with family/whānau and in communities</p> <p>Paths that force people as passive recipients into cul-de-sacs of what is available irrespective of what direction they want to go</p>
Ways of Working	<p>People coming together and working with care, compassion and consensus</p> <p>Positioning the person and their family/whānau as active decision makers</p> <p>Based in trusted relationships, community assets and shared authority</p>	<p>Lives driven and controlled by government institutions, agencies and professionals</p> <p>Positioning the person and family/whānau passively as consumers/service users or recipients only</p> <p>Based in contracts and gate keeping assessments</p>
Good Supports	<p>Treat people with dignity and recognise interdependence - all of us need help and support at times</p> <p>Are individually tailored, flexible and responsive to a person's preferences and culture</p>	<p>Needing help is seen as an individual problem and the response seen as a gift granted by government and professionals for which people should be grateful</p> <p>One size fits all approach that is dominated by the agendas and schedules of others – particularly funders and service providers</p>

Citizenship³ (see Figure 1) brings together our rights and duties by offering starting points, pathways and practical ways of working for good support:

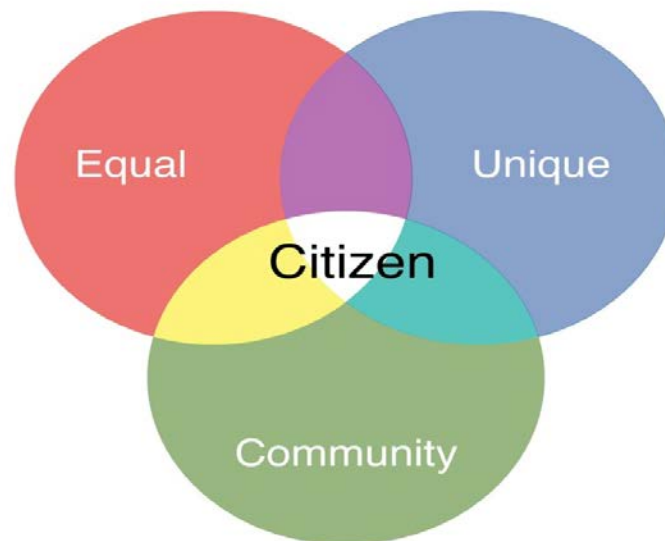
- in which people can live together with fairness and justice;
- where we all belong and know we belong;
- where everybody's contribution is valued;
- where we can be different but equal; and
- where rights and entitlements are respected, responded to and safeguarded.

Te Tiriti o Waitangi is central to New Zealand society. The Treaty gives recognition to the rights of Māori as Tangata whenua and the responsibilities of the Crown by enshrining the principles of partnership, participation and protection. The Treaty encompasses the need to acknowledge and respect the dignity and rights of people (mana tangata), customary rights and connections between

³ Simon Duffy (2003) *Keys to citizenship*

people, generations and land (mana whenua) and how they are intertwined and are central to culture and practice (tikanga).

Figure 1: Citizenship - Simon Duffy and Wendy Perez (2014)⁴.



The ‘right’ frameworks are grounded in human rights with freedom and well-being as the core values to be promoted, fulfilled and protected⁵. These are reflected in the international conventions and treaties to which New Zealand is a signatory such as the United Nations *Declaration of Human Rights*, the *Convention on the Rights of Children*, the *Covenant of Social and Economic Rights* and most recently the *Convention on the Rights of Persons with Disabilities*. They are echoed in New Zealand law, strategies and policies such as the Bill of Rights Act, the Human Rights Act, Children and Young Persons and Families Act, Education Act, and the New Zealand Disability Strategy.

The *UN Convention on the Rights of Persons with Disabilities* has given us a new lens through which to consider the lives and citizenship of people with intellectual disability and their families/whānau and against which we can monitor our laws, policies and practices as a civil society.

The CRPD speaks to all of society and the nature of the social contract between individuals, families, communities and government. In order to fully understand the implications of the CRPD and to sustainably redress the historic and systematic exclusion of people with disabilities communities, governments and societies need to think and act differently. A shift is required from seeing disability as a programme or issue area in which people with disabilities are the recipients or subjects of policy to a transformative process which helps build stronger communities. It means not

⁴ Simon Duffy and Wendy Perez (2014) *Citizenship for All: An accessible guide*, p.4

⁵ Tony Ward and Claire Stewart (2008) Putting human rights into practice with people with an intellectual disability. *Journal of Developmental and Physical Disabilities*, 20, 297-311

*only looking at the person with a disability but also at their families and support circles and the communities that they live in and understanding how to strengthen the social fabric of our societies.*⁶ Inclusion International (2012)

The foundation and starting point for inclusive communities that reduce inequities is a strong base in universal services in which we are all entitled to enough good support to achieve citizenship and participate in the community while also having timely access to needed additional supports and specialist services.

Simon Duffy⁷ has identified seven keys that work together to promote citizenship and to keep people safe. People are at greater risk when some or all aspects are missing from their lives (Table 2). Some people need greater support or a different approach but citizenship is possible for all. If we think and work hard enough and innovate, we can make citizenship real for everyone.⁸

Table 2 – Citizenship keys, safety and risk

Citizenship keys	Safer when	Riskier when
Purpose - citizens have lives of their own, reflecting their own unique character and their own particular gifts	You can set your own direction and find a path that is right for you – this also helps other people see you with respect	Your life doesn't fit your passions, interests and abilities and you cannot develop and share these
Freedom - citizens are free and able to make their own way and choices, take their own risks and learn from their experiences	You are able and are seen to be able to take charge of your own life	You cannot communicate or express personal authority
Money – citizens have enough money in order to pursue their goals and direct their own life	You have money and the means to direct your own support	You live in poverty or have an insufficient income that leaves you dependent on the good will of others and cuts you out of a life of citizenship
Home – citizens have homes of their own, places where they have privacy, where they belong and where they are able to be with those they love	You can control who lives with you and who you let in and you have a place that establishes you as a real member of the community	You lack privacy, security and real housing rights and when you appear rootless and disconnected

⁶ Inclusion International (2012) Global Report on Article 19: *Inclusive Communities = Stronger Communities: The Right to Live and be Included in the Community*, p.9

⁷ Simon Duffy (2003) *Keys to Citizenship*

⁸ Simon Duffy (2013), *Travelling Hopefully*, p.17

Help – citizens need other people and can get the help they need	You get help from the people you want, in the way you want, when you want it and in the right amount - not too little or too much	You cannot get help from people you choose or value and the help you get is not controlled by yourself and the people you trust and who care about you
Life – citizens get involved, contribute and make a difference	You are part of your community with a valued role	You are cut off from ordinary life and the chance to meet people and try new things
Love – citizens make friends, fall in love, have families, and create all the relationships that we value as the very stuff of life	You have people who love and care about you	You are without friends, family, partners or peers

Adapted from Self Direct (2013) *Self-direction: The key to a better life*, Don Derrett and Simon Duffy Table 1.1 – Citizenship is safer, p. 26

Bibliography

- Duffy, S. (2013). *Freedom – a guide to good support*. The Centre for Welfare Reform
<http://www.centreforwelfarereform.org/uploads/attachment/374/freedom.pdf>
- Duffy, S. (2003). *Keys to Citizenship*. Birkenhead: Paradigm
- Duffy, S. (2013). *Travelling Hopefully: Best practice in self-directed support*. The Centre for Welfare Reform.
<http://www.centreforwelfarereform.org/uploads/attachment/359/travelling-hopefully.pdf>
- Duffy, S. and Perez, W. (2014). *Citizenship for All: An accessible guide*.
<http://www.keystocitizenship.com/>
- Inclusion International (2012) *Inclusive Communities = Stronger Communities: Global report on Article 19: The Right to Live and be Included in the Community*. Author.
<http://inclusion-international.org/living-in-community/>
- O'Brien, J. and Mount, B. (1991). Telling new stories: The search for capacity among people with severe handicaps, pp.89-92. In L.H. Meyer, C.A. Peck and L.Brown (Eds.) *Critical Issues in the Lives of People with Severe Disabilities*. Baltimore: Paul. H. Brookes.
- Rhodes, B. (2012). *Imagining and pursuing our good lives – making sense of self-direction*. Seminar – Wellington, New Zealand, 12 November, 2012.
- Rhodes, B. (2010). *Much more to life than services: Unleashing the potential of personalisation in social care*. Peterborough, England: Fastprint Publishing
- Self Direct (2013). *Self-direction: The key to a better life*. Hove Pavilion Publishing.
- Ward, T. & Stewart, C. (2008). Putting human rights into practice with people with an intellectual disability. *Journal of Developmental and Physical Disabilities*, 20, 297-311.