

## Independent Advisory Council to the NDIS

# Enhancing outcomes from *Social and Community Participation*

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## Purpose

The purpose of this paper is to provide advice as how to improve outcomes for participants using *Assistance with Social and Community Participation* and its capacity building sister *Increased Social and Community Participation*. The paper is particularly focused on participants not engaged in work or education in order to contribute to increased participant independence and inclusion and hence to Scheme sustainability.

## Executive Summary and Recommendations

Participants who are not engaged in work or education use *Assistance with Social and Community Participation* and *Increased Social and Community Participation* to support their engagement in the community. There is conflicting data<sup>1</sup> on the extent to which the NDIS has helped participants improve their social and community participation. This includes a lack of clarity as to which participants have achieved what outcomes and who has been left behind.

Whilst the NDIS has a clear responsibility to support participants to achieve outcomes, participants, providers and NDIA staff have little expectation of achieving outcomes from social and community participation. There is little or no data about the way in which participants use social and community participation support but anecdotal information suggests that a significant but unknown proportion use day programs (many in order to be 'out of the house' for SIL providers or as a form of respite for families) that create low expectations, foster a charity model, add stigma, limit choice and increase reliance on paid support.<sup>2</sup> UK research<sup>3</sup> indicates that exposure to alternatives to traditional day services impacts on satisfaction with services received and opens opportunities for change.

The NDIA lacks insights into participants using social and community participation support, including the impact of disability type, complexity and gender on its use and outcomes and the pathways to positive outcomes including the role of family, peer networks, engagement with mainstream and community services, disability providers and other influences. This lack of data is a significant barrier to improving practice.

The paper canvasses more contemporary approaches. The evidence base about good practice however is anecdotal and needs additional work to develop in a way that can

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<sup>1</sup> The Quarterly Report, 30 September 2018 at p19 indicates that 70% of participants 25 years and over indicated that after 2 years, the NDIS had helped them with social, community and civic participation. However, this is inconsistent with data in the NDIS Quarterly Report, 31 March 2018 at p36 that indicates that 46% of the participants report the NDIS has not helped them meet more people and 39% report that the NDIS has not helped them to be more involved.

<sup>2</sup> National Disability Services, (2016) *Community Participation in Action: A Resource Guide for Disability Service Providers*. Accessed at [https://www.nds.org.au/images/resources/resource-files/CII\\_Community\\_Participation\\_in\\_Action\\_Guide\\_2016.pdf](https://www.nds.org.au/images/resources/resource-files/CII_Community_Participation_in_Action_Guide_2016.pdf) 22 June 2019

<sup>3</sup> Simons, K.& Watson, D., (1999) *New directions: day services for people with learning disabilities in the 1990s: A review of research*, Bristol: Norah Fry Research Centre, Univ of Bristol, Reported in SCIE (2007) *Adult services knowledge review* 14 p6.  
Mencap (2002) *Doing, showing and going: Mencap's art strategy*, London, Mencap, Reported in SCIE (2007) *Adult services knowledge review* 14 p8

be showcased and built to scale. There is some evidence about how to assist participants to identify outcomes including outcomes that may lead to work options in the future. There are documented processes such as increasing expectations, setting goals and outcomes, selecting, planning and monitoring support, enhancing provider capacity and securing competent workforce that have a record in contributing to positive outcomes but these processes are not always used. Some services are outcomes oriented but many are not.

Hence the IAC recommends the following immediate and medium term strategies.

## **Immediate**

The IAC recommends that the NDIA:

1. Facilitates a deeper understanding of participants and practice via a deep dive into quantitative and qualitative data to understand:
  - a. the impact of disability type, complexity and gender on how participants use social and community participation
  - b. barriers and enablers of pathways to outcomes including the role of family, peer networks, engagement with mainstream and community services, disability providers and other influences
  - c. what success would look like and steps toward success especially for participants with complex needs
  - d. workforce issues related to attracting, training and supporting staff with the 'right' attitudes who are skilled at facilitating outcomes.
  
2. Strengthens demand via:
  - a. peer networks through the Disabled Persons and Family Organisations (DPOFO) initiative including the use of the Technical Support Stream to stimulate peer discussion and to promote peer advocacy directed at building inclusive communities.
  - b. the development and distribution of resources to showcase examples of people participating in a broad range of activities including people with complex support needs.
  - c. planner and LAC conversations with participants about the meaning and implications of conflict of interest when a Support Coordinator also provides core supports.
  
3. Strengthens supply by increasing longer term community capacity building grants in the ILC, requiring demonstration that actions of community capacity building reflect priorities of participants. Examples of community capacity building activities already funded in the ILC can be found at Appendix A.

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## Medium term

In the light of deeper understanding, the IAC anticipates strategies of the following nature will be required.

1. Enhance planner and LAC practice to begin conversations that increase expectations of outcomes and ensure that all participants not engaged in work or education have opportunities to build capacity and work toward outcomes.
2. Further strengthen demand by:
  - a. identifying and showcasing approaches to support participants to achieve outcomes including participants with complex disability.
  - b. moving to ensure that the Support Coordinator is independent of provider of core supports at the participant level, starting with participants in centre-based day programs in metropolitan areas.
3. Further strengthen supply by:
  - a. developing practice guidance informed by literature review and research recommendations
  - b. signposting contemporary options in the Price Guide such as how a provider will support a participant to develop a circle of support, be an intern, develop a micro enterprise or develop and sustain a volunteer relationship.
  - c. showcasing examples of good practice including:
    - how providers have transitioned from traditional to contemporary options
    - program logic and behind the scene strategies that facilitate outcomes with direct support
    - challenges/ solutions
    - providers partnering with mainstream agencies.
  - d. identifying strategies to incentivize providers of day centre services to transition to more outcomes focused support.
4. Partner with appropriate organisations to develop and deliver training in skills required to deliver evidence-based disability support worker practice.
5. Strengthen research and evaluation to grow the evidence that underpins good practice.
6. Make representation to the Quality and Safeguards Commission to:
  - a. ensure market and workforce issues are continually addressed in a coherent way
  - b. work with participants and providers to enhance registration requirements related to capacity building outcomes focused requirements.

## Context

Participants who are not engaged in work or education use *Assistance with Social and Community Participation* and *Increased Social and Community Participation* to support their engagement in the community. There is conflicting data<sup>4</sup> on the extent to which the NDIS has helped participants improve their social and community participation. This includes a lack of clarity as to which participants have achieved what outcomes and who has been left behind.

The 2018-22 NDIS Corporate Plan goal of increasing the number of participants in paid employment is critical for the significant group of participants who can be assisted into open and supported employment. Effort must also be directed at achieving outcomes in this domain, especially for participants who are unlikely to seek or achieve open or supported employment. Anecdotal evidence from State and Territory systems suggests that without goal directed effort, participants become more dependent rather than more independent. Given that social and community participation represents the main support for the achievement of outcomes in participants not engaged in work or education, the goal of Scheme sustainability requires that the NDIA take action.

The paper aims to improve outcomes from social and community participation and will:

- review research on health and wellbeing
- identify proposed outcomes
- describes the available information about the range of activities undertaken with reasonable and necessary support in the domain of social and community participation
- review challenges presented by day programs and identify approaches to facilitate increased opportunities for current day program participants
- discuss drivers of improved outcomes as well as services and supports to achieve those outcomes; and
- make recommendations as to actions the NDIA can take to improve participant outcomes from social and community participation.

## Health and wellbeing research

For participants not working or in education, outcomes from social and community participation matter to both the participant and the Scheme. There is a growing body of evidence that suggests that the health and wellbeing of people with disability is enhanced by access to social resources (such as those derived from social relationships, networks and interactions).<sup>5 6</sup> In addition, there is some evidence that

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<sup>4</sup> See footnote 1.

<sup>5</sup> Berry, H., and Welsh, J. (2010) Social capital and health in Australia: an overview of the household, income and labour dynamics survey. *Social Science and Medicine*, v70, p588-596, Reported in Mithen (2015) op cit p27

<sup>6</sup> Kawachi, I., Berkman, LFFF, (2001) Social ties and mental health, *Journal of Urban health Bull N Y, Acad. Med.* V78, p 458-467; Lakey, B., Orehek, E., (2011) Relational regulation theory: a new approach to explain the link between perceived social support and mental health, *Psychology Rev*, v118 p482-495; Cohen, S., Wills TA., (1985) Stress, social support and the buffering hypothesis, *Psychology Review*, v98, p310-357 reported in Aitkin, Z.,

social support can act as a buffer that protects the individual from experiencing poor mental health during times of life stress.<sup>7</sup> It is therefore plausible that social support may protect people with disability against poor mental health.

## Comparison with people without disability

World Health Organisation (WHO) data reports that disabled people have poorer physical and mental health than those without disability and many of the conditions they experience are not directly related to their impairment (e.g. high rates of diabetes and depression among people with intellectual impairments).<sup>8</sup> Australian data, including that reported in the NDIS Participant Outcomes Report<sup>9</sup> confirms WHO findings with Australians with disability faring poorly compared to Australians without disability on indicators related to education, participation in paid work and income.<sup>10</sup> Australian research also suggests that the poorer health of people with disability is at least partly explained by their disadvantaged living circumstances.<sup>11</sup>

People with disability also have lower levels of community participation<sup>12</sup> and social support than people without disability.<sup>13</sup> Cohen defines social support as people's perceptions of available social resources that are provided to them by other people in their primary group (small, enduring, intimate, informal, commonly family/close friends) and secondary group (groups associated with work, voluntary and religious organisations).<sup>14</sup>

These differences between people with and without disability are confirmed in Australian studies in relation to people in regional areas who were found to have a lower level of contact with family and friends;<sup>15</sup> in young Australians who had less

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Krnjacki, L., Kavanagh, A., LaMontagne, A., Milner, A., (2017) "Does social support modify the effect of disability acquisition on mental health? A longitudinal study of Australian adults, v52, p1247-1255 p1248

<sup>7</sup> Lakey, B., Orehek, E., (2011) Relational regulation theory: a new approach to explain the link between perceived social support and mental health, *Psychology Review*, 118: 482-495

Milner, A., Krnjacki, L., Butterworth, P., La Montague, A., (2016) The role of social support in protecting mental health when employed and unemployed: a longitudinal fixed effects analysis using 12 annual waves of HILDA cohort. *Soc.Sci. Med* 153:20-26

Olstad, R., Sexton, H., Sogaard, A., (2001) The Finalnd study. A prospective population study of the buffer hypothesis, specific stressors and mental distress, *Social Psychiatry Epidemiology*, 36: 582-589

<sup>8</sup> World Health Organisation and World Bank (2011), *World Report on a Disability*. WHO Geneva

<sup>9</sup> NDIS (2018) Participant Outcome Report

<sup>10</sup> Mithin, J, Aitken, Z., Ziersch, A., Kavanagh, A., (2015) "Inequalities in social capital and health between people with and without disabilities, *Social Science and Medicine*, v126, p27

<sup>11</sup> Emerson, E., Llewellyn, G., Honey, A., & Kariuai, M., (2012) Lower wellbeing of young Australian adults with self-reported disability reflects their poorer living conditions rather than health issues, *Australian and New Zealand Journal of Public Health*, v36, p176-182;

Honey, A., Emerson, E., Llewellyn, G., (201) The mental health of of young Australians with disabilities: impact of social conditions, *Soc Psychiatry Epidemiology* v46, p1-10 reported in Aitkin, Z., Krnjacki, L., Kavanagh, A., LaMontagne, A., Milner, A., (2017) "Does social support modify the effect of disability acquisition on mental health? A longitudinal study of Australian adults, v52, p1247-1255

<sup>12</sup> Verdonschot, M., de Witte, L., Reichrath, E., Buntinx, W., Curfs, L (2009) Community participation of people with intellectual disability: A review of empirical findings, *Journal of Intellectual Disability Review*, v53, p303-318, Reported in Mithen (2015) op cit p28

<sup>13</sup> Mithen, J et al (2015) op cit p28

<sup>14</sup> Cohen, S., Gottlieb, BH., Underwood, LG., "Social relationships and health: challenges for measurement and intervention, *Adv Mind Body Med*, v17, p129-141 reported in Aitkins, op cit p1248

<sup>15</sup> McPhedran, S., (2010) Regional living and social participation: are people with disability at a disadvantage? *Australian Social Policy*, v9, p111-135 Reported in Mith (2015) op cit p28



social contact with friends and fewer had someone to turn to in times of crisis;<sup>16</sup> and in people with intellectual disability who were less likely to be able to get help from family and friends or neighbours.<sup>17</sup> The study of young Australians also found that differences in access to social support between people with and without disability had worsened between 2001 and 2011.<sup>18</sup>

NDIS Outcomes data<sup>19</sup> for the cohort 25+ reflects studies reported above. 28% of participants said they did not have any friends apart from family or paid staff. 24% of participants said they had no-one outside their home to call on for practical assistance, 24% had no-one to call on for emotional assistance, and 21% had no-one to call on in a crisis. By comparison, the ABS General Social Survey (2014) (GSS)<sup>20</sup> found that only 5% of people 25-64 were unable to get support in times of crisis from persons living outside the household.

Research by Mithin et al<sup>21</sup> found that Australians with disability have less informal and formal networks, social support and lower self-rated health status than Australians without disability and that Australians with intellectual disability and psychological impairments were the most disadvantaged. Once again, the NDIS Outcomes data reflects that observed in other studies with 48% of the adult cohort rating their health as good, very good or excellent, compared to 87% of Australians aged 25 to 64 overall.<sup>22</sup>

## Social support and mental health

A few studies have examined whether social support influences the mental health of people with disability.

A study of Australian adolescents that examined whether mental health inequalities between people with and without disability were modified by social support (having a good neighbour) found larger mental health inequalities for those with low compared to those with higher social support.<sup>23</sup> A Finnish study found that increased social support and access to instrumental support buffered the effects of receiving a DSP on mental distress.<sup>24</sup>

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<sup>16</sup> Llewellyn, G., Emerson E., & Honey, A., "Left behind 2013: Monitoring the social inclusion of young Australians with self-reported long term health conditions, impairments or disabilities 2001-2011, *Centre for Disability research and Policy*, University of Sydney, Sydney. (2013) reported in Mithen (2015) op cit p28

<sup>17</sup> Dept of Health (2011), Victorian Population Health Survey of people with an intellectual disability 2009, State Government of Victoria, Melbourne reported in Mithin (2015) op cit p28

<sup>18</sup> Llewellyn, G., Emerson E., & Honey, A., "Left behind 2013: Monitoring the social inclusion of young Australians with self-reported long term health conditions, impairments or disabilities 2001-2011, *Centre for Disability research and Policy*, University of Sydney, Sydney. (2013) reported in Mithen (2015) op cit p28

<sup>19</sup> NDIS (2018) Participant Outcome Report p102

<sup>20</sup> ABS General Social Survey (GSS) 2014.

<sup>21</sup> Mithin, J, Aitken, Z., Ziersch, A., Kavanagh, A., (2015) "Inequalities in social capital and health between people with and without disabilities, *Social Science and Medicine*, v126, p26-53

<sup>22</sup> ABS National Health Survey (NHS) 2014-15.

<sup>23</sup> Honey, A., Emerson, E., Llewellyn, G., (201) The mental health of young Australians with disabilities: impact of social conditions, *Soc Psychiatry Epidemiology* v46, p1-10. Reported in Aitkins (2017) op cit, p1248

<sup>24</sup> Oldstad, R., Sexton, H., Sogaard, J, (2001) The Finnmark Study, A prospective population study of the social support buffer hypothesis, specific stresses and mental distress, *Social Psychiatry Epidemiology*, v36, p582-589. reported in Aitkins (2017) op cit, p1241249

These findings were confirmed by an Australian study<sup>25</sup> that found that in general, social support buffered the effect of having a disability on poor mental health. The study found that:

- people with low social support subsequent to the acquisition of disability experienced the poorest mental health;
- people who changed from high to low social support experienced the largest decline in mental health<sup>26</sup> demonstrating that (contrary to the research hypothesis), high levels of social support prior to disability acquisition did not protect against mental health deterioration; and
- people who experienced an improvement in social support subsequent to the acquisition of disability experienced the smallest negative effect of disability on mental health;
- the effects of disability acquisition on mental health were about two-fold higher in women than in men, across all categories of social support.<sup>27</sup>

Other Australian research<sup>28</sup> highlights significant variability in access to social support across different types of impairment. People with physical impairments were found to have low level of ties to organisations. People with intellectual disability and psychosocial impairments were found to have particularly low levels of direct and indirect contact with informal networks (family and friends) and to have the poorest self-rated health. This confirms other Australian studies examining socioeconomic disadvantage that show people with intellectual disability and psychosocial impairment were particularly vulnerable to disadvantage.<sup>29</sup> The considerable literature documenting high levels of discrimination and associated stigma that people with intellectual disability and psychological disability experience are likely to contribute to their weaker informal networks and lower levels of informal social support.<sup>30</sup>

Research by Lippold and Burns<sup>31</sup> provides insights into the limited social support experienced by adults with intellectual disability. They found that adults with intellectual disability had more restricted social networks than people with physical disability despite being involved in more activities. The research highlighted that there are additional processes attached to having an intellectual disability which lead to

<sup>25</sup> Aitkin, Z., et al (2017) op cit

<sup>26</sup> When social support was lost at the onset on disability, the person experienced the double loss of ability and social support leading to a significant decline in mental health. High levels of social support appear to buffer the acquisition of disability only if that level of social support is maintained after the onset of disability.

<sup>27</sup> Aitkin, Z., et al (2017) op cit p1253

<sup>28</sup> Mithen, J et al (2015) op cit

<sup>29</sup> Beer, A., Faulkner, D., (2008), The housing careers of people with disability and carers of people with disability, AHURI, Hogan, A., Kyaw-Myint, S., Harris, D., Denronden, H., (2012) Workforce participation barriers for people with disability, *Intellectual Disability Journal of Management*, v7, p109 Reported in Mithen, (2015) op cit p33

<sup>30</sup> Schomerus, G., Schwahn, C., Holzinger, A., Corrigan, P., Grabe, H., Carta, M., (2012) Evolution of public attitudes about mental illness: a systematic review and meta-analysis, *Acta Psychiatrica Scandinavica*, v125, p440-452, Scior, K (2011), Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Res Developmental Disability*, v32, p2164-2182,

Yazbeck, M., McVilly, K., Parmenter, T., (2004) Attitudes toward people with intellectual disabilities: An Australian perspective, *Journal of Disability Policy Studies*, v15, p97-111 Reported in Mithin (2015) op cit p33

<sup>31</sup> Lippold, T. & Burns, J., (2009) Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability, *Journal of Intellectual Disability res.* V53, p463-473

continued impoverished lifestyles and that being physically integrated and engaged in a wide range of activities does not guarantee good social and emotional support.

Drawing on research from the fields of ageing, adolescence, health and mental health deepens our insights into factors that contribute to health and wellbeing.

Relationships stand out as a significant contributor to health and wellbeing from multiple disciplines. Studies of older people may be particularly relevant, with the finding that social engagement and relationships are associated with health and wellbeing despite the presence of chronic health conditions, declining health and lower rates of being partnered.<sup>32</sup> Relationships also represent a protective factor in wellbeing frameworks for young people within education and care settings<sup>33</sup> with the absence of a sense of belonging identified as a risk factor.

In a meta-analysis of 148 studies that investigated the correlation between social relationships and risk mortality, Holt-Lunstad<sup>34</sup> found that individuals with adequate social relationships have a 50% greater likelihood of survival compared to those with poor or insufficient social relationships, a finding comparable in scale with quitting smoking.

There is growing evidence that participation in groups is associated with less psychological distress<sup>35</sup> and good mental health<sup>36</sup> while volunteering is associated with reduced mortality risk,<sup>37</sup> good mental health,<sup>38</sup> higher levels of self-reported personal wellbeing<sup>39</sup> and neighbourhood wellbeing.<sup>40</sup> In addition, data from the Wisconsin Longitudinal Study<sup>41</sup> showed continuous volunteering and volunteering for more organisations resulted in increased wellbeing.

There is also compelling evidence about the relationship between social isolation and health. Older people who are socially isolated or excluded are more likely to have poorer health<sup>42</sup> while adolescents who are isolated are more likely to experience depressive symptoms and have lower self-esteem.<sup>43</sup>

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<sup>32</sup> Australian Government, Department of Health and Ageing, (2013) *Staying Connected*

<sup>33</sup> Dept. of Education and Children's Services, South Australia (2007) *South Australian Learner Wellbeing Framework*

<sup>34</sup> Holt-Lunstad, J, Smith, TB & Layton, JB 2010, Social relationships and mortality risk: a meta-analytic review, *PLoS Medicine*, v7 No 7 pp14

<sup>35</sup> Ellaway A & Macintyre S 2007, "Is social participation associated with cardiovascular risk factors? *Social Science and Medicine* v64, pp1384-91

<sup>36</sup> Priest N, Waters, E, McLean, P & Webster K 2008, *Evidence of the link between social participation and mental health and wellbeing outcomes*, Victorian Health Promotion Foundation & McCaughey Centre, University of Melbourne

<sup>37</sup> Ayalon L 2008, "Volunteering as a predictor of all causes mortality: what aspects of volunteering really matter?" *International Psychogeriatrics* v20, no 5 p1000

<sup>38</sup> Piliavin JA & Siegel E 2007, "Health benefits of volunteering in the Wisconsin Longitudinal Study", *Journal of Health and Social Behaviour*, v48, no 4 pp450; Priest et al 2008 (2008) op cit

<sup>39</sup> Morrow-Howell n et al 2003 'Effects of volunteering on the wellbeing of older adults' *The Journal of Gerontology Series B, Psychological Sciences and Social Sciences* v58, no 3, p137; Mellor D et al 2009, 'Volunteering and its relationship with personal and neighbourhood wellbeing', *Non profit and voluntary sector quarterly*, v38, no1 pp144

<sup>40</sup> Mellor et al 2009, op cit

<sup>41</sup> Piliavin & Siegel 2007

<sup>42</sup> Cornwell EY & Waite, LJ 2009, "Social disconnectedness, perceived isolation and health among older adults", *Journal of Health and Social Behaviour*, v50, no 1, pp31

<sup>43</sup> Hall-Lande JE et al 2007, 'Social isolation, psychological health and protective factors in adolescents' *Adolescence*, v42, no 166, pp265

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## Research in relation to young people with disability

Research in relation to young people with disability has direct relevance. Research on promoting independence reveals the critical importance of relationships for their role in the formation of identity.<sup>44</sup> The stories young people tell reveal how they shape their identity and are made possible via the networks to which they belong. Whilst young people with disability have the same hopes and aspirations as their peers without disability, they have less opportunity to develop social networks (especially where relationships are mediated by a carer or family member) and less opportunity to develop stories or narratives of themselves that draw on a wide range of resources and social interactions.<sup>45</sup> Their reduced social networks inhibit the development of identity and inhibit their aspiration for independence.

A Northern Ireland study<sup>46</sup> that aimed to understand how young people with disability manage the stresses they encounter provides useful insights as to factors that enhance wellbeing for people with disability.

The study found that the subjective well-being of study participants was enhanced when they:

- experienced pride in themselves, commonly engendered by sporting or school achievements and by personal development;
- were engaged in self-development activities that developed personal strengths and skills;
- participated in activities that influenced others and in which there was a belief that their voice was being heard. Examples included presentations in front of an audience and having a say in service planning.

The study confirmed evidence that participation in physical activities is an important source of social contact and contributes to mental health benefits,<sup>47</sup> linking young people and their families with schools, community facilities and networks<sup>48</sup> and partially mediating risks for depressive symptoms in both boys and girls when the team sport is a positive experience.<sup>49</sup>

The importance of engaging in self development activities and experiencing a challenge is highlighted in research in brain theory that recognizes that deeper learning occurs when young people are provided with experiences and environments that

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<sup>44</sup> Stokes, H., (2012) *Imagining Futures: Identity narratives and the role of work, education, community and family*, Melbourne University Press, Melbourne

<sup>45</sup> Stokes, H., Turnball, M. & Wyn, J., *Young people with a disability: independence and opportunity: A literature review* at [http://web.education.unimelb.edu.au/yrclinked\\_documents/research\\_report39.pdf](http://web.education.unimelb.edu.au/yrclinked_documents/research_report39.pdf)

<sup>46</sup> Kelly, G., Kelly, B., & MacDonald, G., (2016) *Improving wellbeing of disabled young people*, Queens University Belfast

<sup>47</sup> Dowd SM et al 2004 'Exercise for depression: it really does help – here's how to get patients moving' *Current Psychiatry*, v3 no 6, pp10 ;Sports Matters Group & Public Policy Forum 2004, Investing in Canada: fostering an agenda for citizen and community participation,

<sup>48</sup> Vic health 2002, *Promoting physical activity: VicHealth's investment plan 2002-2005*, Victorian Health Promotion Foundation, Melbourne

<sup>49</sup> Boone EM& Leadbeater BJ 2006, "Game on- diminishing risks for depressive symptoms in early adolescence through positive involvement in team sports", *Journal of research on Adolescence* v16, no1 p79

encourage active involvement with their learning. Students are more likely to be involved in learning activities which are challenging, relevant and meaningful and which are tailored to their interest, strengths and aspirations.<sup>50</sup> Optimal learning occurs when people take on a task that offers a challenge but sits beyond their existing range of skills, creating a learning opportunity.<sup>51</sup>

The study confirmed that good relationships with peers helps adolescents to develop social skills, enhance their self-esteem and establish autonomy<sup>52</sup> and has a protective effect on adolescent health, including their psychological well-being.<sup>53</sup>

Participants who were most satisfied with their lives and exhibited good mental health were those who: believed that opportunities existed for them to make their own decisions, realise their potential and continue to develop as a person; that what they did in life reflected helping others as well as themselves; and those who had positive social relations with others.

The young people identified as having lower well-being did not display signs of autonomy in the way their life was going, perceived themselves as having little choice over major aspects of their life, and had low self-acceptance.

This study confirmed that self-determination<sup>54</sup> strongly predicted higher levels of perceived satisfaction with personal development and fulfilment.<sup>55</sup> Of significance was the differing expectations of whether or not their plans and/or goals would be achieved. Those participants who displayed higher expectations of achieving goals tended to be younger and all were still in post primary education. There was also a strong sense of determination and self-belief, often in spite of the complex nature of some of the young people's circumstances and the daily challenges these conditions presented.

Finally, the study found that having a 'purpose in life' had a positive effect on a young person's self-esteem. A number of participants discussed how drawing attention to issues that they saw as discriminatory, not just towards themselves but to others in similar situations, and putting forward proposals for improvement, increased their individual feelings of self-worth.

## Implications of research

The research provides clear signals that health and wellbeing is enhanced through:

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<sup>50</sup> Koen, S & Duigan (2008) "Forging Brighter Futures, paper presented a History and Future of Social Innovation Conference, Adelaide, 19-21 June

<sup>51</sup> <sup>51</sup> Stokes, H., Turnbull, M. & Wyn, J. op cit

<sup>52</sup> Currie, C., Zannotti, C., Morgan, A. et al (2012) Social Determinants of Health and Well-being among Young People, Health Behaviour in School Aged Children (HBSC) study, International report from the 2009/10 survey. Copenhagen: World Health Organisation reported in Kelly, Kelly and Macdonald

<sup>53</sup> Zambon A et al. (2010) 'The contribution of club participation to adolescent health: evidence from six countries', Journal of Epidemiology & Community Health, 64(1) pp 89–95. Reported in Kelly, Kelly and Macdonald

<sup>54</sup> The concept of self-determination was interpreted as relating to a young person's perception of the choices available to them in life, their aspirations, future planning and goal setting.

<sup>55</sup> McDougall, J., Evans, J. and Baldwin, P. (2010) 'The Importance of Self-Determination to Perceived Quality of Life for Youth and Young Adults with Chronic Conditions and Disabilities', Remedial and Special Education, Vol 31, (4), pp 252-260. Reported in Kelly, Kelly and Macdonald op cit.

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- increased social support: relationships of an informal nature and relationships formed through membership of groups
  - having purpose
  - experiencing achievement and pride in self
  - having voice and participating in activities that influence others
  - strategies that recognise the variability between different disability groups.

The research reviewed leads to guidance similar to that underpinning UK policy and practice guidance from the Social Care Institute for Excellence (SCIE).<sup>56</sup> SCIE proposed that 'successful provision' of community-based day activities for people with disability implies people would be 'having a good day', seen in:

- undertaking activities that have a purpose
- being in ordinary places, doing things that most members of the community would be doing
- doing things that are right for them personally
- receiving support that meets their individual and specific requirements and overcomes inequalities
- meeting local people, developing friendships, connections and a sense of belonging.

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<sup>56</sup> SCIE Report 14, pix

## Identifying appropriate outcomes

UK research into residential and day services<sup>57</sup> commented on the lack of attention to the aim, role or function of day supports for people with disability. Another study concluded that day services are all too often 'aimless' and 'ill-defined', offering little more than an alternative to being at home.<sup>58</sup> The lack of consensus about what day services are intended to achieve has, according to some, contributed to a dearth of evaluative research on the impact of day services.<sup>59</sup>

Simons and Watson<sup>60</sup> grouped evidence from the very small amount of material that pertains to outcomes in day services into four categories of broad domains that outcome measures might attempt to illuminate:

- engagement in meaningful activities
- time spent in a non-segregated setting
- extending people's social networks
- generating income for people (including wages, benefits, charges).

In research designed to develop conceptual clarity and a typology of different types of community participation, Bigby<sup>61</sup> reported that outcomes of community participation were commonly framed as:

- personal development such as skills, self-esteem or confidence
- increased social networks or
- subjective experiences such as enjoyment or happiness.

An Australian research tool developed by Koritsas et al<sup>62</sup> is reported<sup>63</sup> to be beginning to show some promise for simple self-reported outcome measurements, using a 5-point Likert scale to rate the extent to which a service or support has had an impact on nine life domains of personal wellbeing, social life, political life cultural life, recreational and leisure life, economic life, educational life, spiritual/religious life and your environment.

In proposing outcomes, this paper takes into consideration the implications from research outlined above and the 2014 IAC paper *Reasonable and necessary support across the lifespan, an ordinary life for people with disability*. The paper proposes that outcomes from reasonable and necessary support for adult participants not engaged in work or education social and community participation could be used to enable participants to move toward two main goals:

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<sup>57</sup> Felce, D., Lowe, K., Perry, J., Jones, E., Baxter, H. & Bowley, C., (1999) The quality of residential and day services for adults with intellectual disabilities in eight authorities in England: objective data gained in support off social inspectorate inspection', *Journal of Applied Research in Intellectual Disabilities*, v12, No 4, p273-293

<sup>58</sup> Mencap (2002) op cit.

<sup>59</sup> Ward, L. (2000) op cit.

<sup>60</sup> Simon, K & Watson, D. (1999) op cit.

<sup>61</sup> Bigby, C., Anderson, S., Cameron, N, Duff, G., (2018), op cit p3

<sup>62</sup> Koritsas, S., Hagiliassis N.& Cuzzillo, C., (2017) The outcome and impact scale revised. *Journal of intellectual disability research*, 61(5) 450-460

<sup>63</sup> Bigby, C., Anderson, S., Cameron, N, Duff, G., (2018) op cit p16

- to increase relationships and belonging and
- to create a challenge and to contribute to others and the community.

In this context:

- *relationships* refers to informal connections with others of a secure and enduring nature
- *belonging* refers to a sense of membership at a level that facilitates inclusion in the specific 'community'
- *challenge* refers to active involvement with learning and engagement in a task that sits beyond existing range of skills, creating a learning opportunity
- *contribution* refers to doing something to benefit beyond oneself.

There are already measures in the NDIS Outcomes Framework that may provide a proxy for the outcomes proposed.

## Outcome 1: Increased number of relationships at the partnership level<sup>64</sup>

### Outcome measures

Desired measure	Actual measures from NDIS Outcomes Framework
Increased number of relationships at a social or partnership level	Domain: Relationships <ul style="list-style-type: none"> <li>• Do you have someone outside your home to call on for practical assistance, emotional assistance or in a crisis? (Qs1,2 &amp; 3)</li> <li>• Do you have friends other than family and paid staff? (Q9)</li> </ul>
Increased sense of belonging	Domain: Social, community and civic participation <ul style="list-style-type: none"> <li>• Have you been actively involved in a community, cultural or religious group in the past 12 months?</li> <li>• How do you feel about your membership of the group? (Q8&amp;9)</li> </ul>

<sup>64</sup> Secure relationship that the person can count on including to identify threats and provide new opportunities: In mapping a person's relationships, one can consider: scope: the number of relationships; spread: the diversity of relationships; strength: whether the relationships are ad hoc (seen from time to time); one dimensional (e.g. the barista at McDonalds), social (connected regularly) or partnerships (secure relationship that the person can count on including to identify threats and provide new opportunities).

<http://www.relatedvision.com/Relationship-Measurement/measuring-relationships.html>



## Outcome 2: New opportunities, experiences, skills and avenues for contribution

### Outcome measures

Desired measure	Actual from NDIS Outcomes Framework
Increased experience, participation, skill or capacity	<p>Domain: Social, community and civic participation</p> <ul style="list-style-type: none"> <li>• Do you have the opportunity to try new things and have new experiences? (Q3)</li> <li>• How often do you feel you have an opportunity to have a say within the general community on issues that are important to you? (Q15)</li> <li>• How often do you feel you have an opportunity to have a say within an organisation that provides support for you (Q16)</li> </ul>
Increased opportunities to contribute	<p>Domain: Social, community and civic participation</p> <ul style="list-style-type: none"> <li>• Are you a volunteer? (Q5)</li> <li>• Has anyone ever asked you to volunteer? (Q6)</li> </ul>

## Current use of social and community participation

As already noted, the NDIA does not yet know which participants are achieving which outcomes with social and community participation support.

What is known is that in the 2017/18 financial year, 24.5% of core support for the cohort 15-24 was committed to *Social and Community Participation*, with 20.4% committed for the cohort 25+. This core item was the second highest committed support (2<sup>nd</sup> to core for daily activities) for all adult cohorts. It would however be useful to understand the impact of disability type, complexity of disability and gender on use of and outcomes achieved in this domain as well as the pathways to positive outcomes including the role of family, peer networks, engagement with mainstream and community services, disability providers and other influences.

Capacity building in *Increased Social and Community Participation* involves supports for participation in skills-based learning in order to develop independence in accessing the community. 2.0% of capacity building support for the cohort 15-24 was committed to *Increased Social and Community Participation* with 0.8% committed for the cohort 25+. Overall, 5.5% of all capacity building resources were committed to social and community participation but only 32% were actually used. Participants who committed highest level of capacity building resources to this domain included those with psychosocial disability (13.9%) visual impairment (13.2%), intellectual disability and Down Syndrome (both 6.8%) and ABI (5.8%).

### Findings of the NDIS Outcomes Report for the cohort 25+

Data reported in the Outcomes Report aggregates data from all participants of that cohort. The report does not provide an analysis for participants not engaged in work or education for whom social and community participation represents their support for engagement.

#### Relationships

28% of participants said they did not have any friends apart from family or paid staff. 24% of participants said they had no-one outside their home to call on for practical assistance, 24% had no-one to call on for emotional assistance, and 21% had no-one to call on in a crisis.

Participants from major cities were less likely to want to see their family more but slightly more likely to have no friends other than family or paid staff. Participants from major cities were more likely to often feel lonely (23% compared to 16% for those in inner regional areas and 10% for those in more remote areas).

Overall 27% of this cohort indicated they have no friends other than family or paid staff, with participants with autism (41%), a psychosocial disability (40%), ABI (35%) and from a CALD background (34%) more likely to say they have no friends other than family or paid staff and those with sensory disability and multiple sclerosis less likely.

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## Belonging

36% of participants had been involved in a community, cultural or religious group in the last 12 months, with 90% of respondents feeling a sense of belonging to the group.

Participants with hearing loss or other sensory/speech disability are most likely to have been involved in a community group in the last 12 months with those with a psychosocial disability least likely.

### Increased experience, participation, skill or capacity

Opportunity to learn new things, and involvement in hobbies/ interests declined with age.

NDIS participants were less likely to feel able to have a say within the community on important issues: 23% of participants felt able to have a say all of the time or most of the time, 12% some of the time, and 66% a little of the time or none of the time. From the 2014 GSS, the corresponding figures for 25 to 64 year olds were 25%, 30% and 45%.

47% of participants felt able to have a say with their support providers either all of the time or most of the time, however 26% were only able to have a say a little of the time or not at all. Participants with a sensory disability or multiple sclerosis are more likely to feel able to have a say with support services whereas those with autism or an intellectual disability are least likely.

### Increased opportunities to contribute

13% of participants said they currently volunteered, and a further 23% expressed an interest in volunteering.

The percentage volunteering increased with remoteness.

## Observations

Discussions with National Disability Services (NDS) and advocacy organisations provide insights into current usage for participants not engaged in work or education.

A significant group of participants combine individualised support with some small group and centre-based support. The main users of centre-based day programs tend to be older participants and those with high support needs although some participants enter centre-based day programs from SLES. The majority of the SLES population however seek something different from that which is offered by centre-based options.

The vast majority of centre-based day providers also offer more individualised options. Many of the participants who spend most days in a centre-based service do so because the centre is trusted compared to the community that is perceived as 'risky', and their family or SIL provider require them to 'be out of the house' for core hours; their family as part of having the person 'busy' so that they can work and the SIL

provider in order to juggle shifts and budgets. In this context, activities in groups are 'preferred' to individualised support to manage within the constraints of the participant budget. The widespread use of centre-based services is also compounded by the lack of sophistication of participants and families in understanding the complexity of funding. Many are guided by their provider to read their plan 'as requiring' specified time in specific support ratios and are not aware that it is possible to use the total core social and community participation budget in different ways.

Key informants identified a number of factors that contribute to the continued use of centre-based day programs by many participants. These include:

- the lack of community infrastructure (e.g. toilets with hoists and change tables) for participants with high physical support needs
- the challenge of 'hanging out' in the community for 6 hours
- the low disposable income of participants on the DSP, especially those in shared supported accommodation, limiting their ability to afford costs associated with community participation
- the lack of community capacity building to enhance the welcoming nature of organisations and communities
- the NDIA pricing structure that:
  - incentivises the use of larger groups
  - is generally agreed <sup>65</sup> to make insufficient provision for skill development for workers
  - makes processing claims very onerous, hence drawing organisational resources away from internal planning, supervising and supporting workers in ways that would enhance the quality of provision
- the lack of independence of Support Coordinators, often working with participants who attend a day programs auspiced by their employer. Such conflict of interest at least has the perception that less effort will be directed at exposing participants to other options
- the requirement to be 'out of the house' a specified number of hours for both participants in group homes and those living with family.

Processes reported to inhibit genuine community engagement and inclusion include:

- the way in which people are grouped, especially strategies that place people with high support needs together
- the lack of partnerships with mainstream community organisations that could help foster participation and belonging
- the lack of a community development approach
- the lack of behind the scenes planning to facilitate goal directed direct support
- the limited skill set of support workers
- the lack of research findings of what works and
- the lack of avenues to disseminate good practice to participants and providers.

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<sup>65</sup> By providers and participants

## Day Programs

### Challenges

National Disability Services (NDS) developed a set of resources<sup>66</sup> to support providers of day and community participation programs to question the impact of buildings and sites used exclusively by people with disability and staff. The resource suggested that services still rely on old fashioned 'bricks and mortar' because:

- “Seen as financially economical to operate
- Offers respite and sense of security to families
- Meet some family expectations of ‘a place to attend’ (like school)
- A ‘safe place’ where people with disability can mix with their peers
- Lack of essential community infrastructure (bathrooms, hoists) to go elsewhere
- Allows for planned activities 5 days per week
- Logistically easier for transport arrangements
- Often co-located with other organisational buildings
- Tradition (a sense of ‘this is how it has always been done’)
- Funding contracts which require number count of people attending centres
- Suits shifts of supported accommodation staff
- History – hours fundraising of past members who ‘built’ the centre
- Boards who may be risk averse about support being provided in the community
- Asset on the balance sheet – security for loans
- Too hard to change – too expensive to change.”<sup>67</sup>

The resource went on to document impacts of segregated services including creating low expectations, fostering a charity model, adding to stigma, limiting choice, reducing opportunities to socialise with other members of the community and increasing reliance on paid support. The resource notes that the *Shut Out Report*<sup>68</sup> described segregated services as the least desirable and that the significant resources required for maintaining buildings and providing transport diverted resources from other things.

The views expressed in the NDS resource reflect research and commentary as to the quality of services and the deleterious effects of segregated support from the UK<sup>69</sup> and US.<sup>70</sup> The research is from the first decade of the 21<sup>st</sup> century, prompting consideration

<sup>66</sup> National Disability Services, (2016) Community Participation in Action: A Resource Guide for Disability Service Providers. Accessed at [https://www.nds.org.au/images/resources/resource-files/CII\\_Community\\_Participation\\_in\\_Action\\_Guide\\_2016.pdf](https://www.nds.org.au/images/resources/resource-files/CII_Community_Participation_in_Action_Guide_2016.pdf) 22 June 2019

<sup>67</sup> National Disability Services, (2016), *ibid*

<sup>68</sup> National People with Disability and Carer Council, (2009) Shut Out Report. Accessed at [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/nds\\_report.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf) 22 June 2019

<sup>69</sup> SCIE (2007) Adult services knowledge review 14, *Having a good day*, p6 Accessed at <https://www.scie.org.uk/publications/knowledgereviews/kr14.pdf> 22 June 2019

<sup>70</sup> Cimera RE. (2011) Does being in sheltered workshops improve the employment outcomes of supported employees with intellectual disabilities? *Journal of Vocational Rehabilitation*. v35:21–27; reported in Towrey, D., Parsons, M. & Reid, D., Increasing independence within adult services: a program for reducing staff completion of daily routines for consumers with developmental disabilities, *Behav Anal Pract*. 2014 Oct; 7(2): 61–69.

Dague B. (2012) Sheltered employment, sheltered lives: family perspectives of conversion to community-based employment. *Journal of Vocational Rehabilitation*. v37:1–11. reported in Towrey et al  
Parsons MB, Rollyson JH, Reid DH. (2004) Improving day-treatment services for adults with severe disabilities: a norm-referenced application of outcome management. *Journal of Applied Behavior Analysis*. v37:365–377. doi: 10.1901/jaba.2004.37-365. reported in Towrey et al

as to whether the lack of discussion about segregated day programs in the last decade reflects the debate having ‘moved on’ in the context of a broader range of options available.

The UK and US research noted above found that participant and family attitudes to day services were mixed and somewhat contradictory. A large-scale study by Emerson et al<sup>71</sup> reported that nearly everyone (96 per cent) who went to a day centre said they liked going and only a quarter said they would like to change what they did in the daytime. Similarly, Simons and Watson<sup>72</sup> found that those using day centres tended to be positive about them, while those who had moved onto other day activities, such as employment or further education, tended to be negative about day centres. These findings were echoed by Ward<sup>73</sup> who reported many people were bored attending a day centre and expressed greater interest in activities run outside a day centre setting, and Jahoda and Markova<sup>74</sup> who found that people moving from home and from long-stay hospitals (institutions) to living arrangements in the community believed attendance at a day centre to be stigmatising. Questionnaire returns from more than 1,000 people with intellectual disability canvassed for their views about the arts showed that almost 90 per cent preferred integrated or inclusive activities to those arranged within traditional day service settings.<sup>75</sup>

The research suggests that exposure to alternatives to traditional day services and the location of daytime support is a factor in people’s satisfaction with the day service they receive.

The Emerson study found that whilst people had attended a day program, they were also likely to have participated in some types of community-based activities, such as going to the cinema, attending a concert and watching sport. Asked what they would like to do more of during the daytime, their priorities were to go out, get a job (or a different job), sports, visit people and generally have more things to do. Others mentioned having money for things, moving on from college/day centre, going shopping, using a computer, going out to pub/meals, going to a day centre more often, listening to music and doing arts and crafts.

The largest longitudinal study of the resettlement of people with intellectual disability from institutions also contained powerful messages about people’s priorities in daytime activities. Structured interviews with almost two hundred people revealed that they preferred activities that are not associated with day centres: outings, education and

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Felce D, Jones E, Lowe K. (2002) Active support: planning daily activities and support for people with severe mental retardation. In: Holburn S, Vietze PM, editors. *Person-centred planning: research, practice, and future directions*. Baltimore: Paul H. Brookes Publishing; 2002. pp. 247–269 Reported in Towrey et al

<sup>71</sup> Emerson, E., Malam, S., Davies, I. & Spencer, K., (2005) *Adults with learning difficulties in England 2003-4* London: Health and Social Care Information Centre, Reported in SCIE (2007) Adult services knowledge review 14 p6

<sup>72</sup> Simons, K. & Watson, D., (1999) *New directions: day services for people with learning disabilities in the 1990s: A review of research*, Bristol: Norah Fry Research Centre, University of Bristol, Reported in SCIE (2007) Adult services knowledge review 14 p6

<sup>73</sup> Ward, L. (2000), *Learning difficulties, Research matters*, No 8, Oct 1999-April 2000, p62-64, Reported in SCIE (2007) Adult services knowledge review 14 p6

<sup>74</sup> Jahoda, A., & Markova, I., (2004), *Coping with social stigma: people with intellectual disabilities moving from institutions and family home*, *Journal of Intellectual Disability Research*, v48, no 8, p719-729 Reported in SCIE (2007) Adult services knowledge review 14 p8

<sup>75</sup> Mencap (2002) *Doing, showing and going: Mencap’s art strategy*, London, Mencap, Reported in SCIE (2007) Adult services knowledge review 14 p8

work, relaxation and leisure.<sup>76</sup> This confirmed earlier findings suggesting that a proportion of those using day centres would prefer an alternative – such as paid work, voluntary work, college – although some wanted to take up these options and ‘keep a foot in the door’ of the day centre.<sup>77</sup>

This sense of ‘keeping a foot in the door’ is important since most activities outside centres do not equate to full-time provision.<sup>78 79</sup>

## Moving beyond day centres

Any discussion of alternatives to day programs must wrestle with the issue of hours of support and the lack of community infrastructure, especially to support the inclusion of participants with complex needs. Centre-based day programs provide respite for families and carers. For participants with severe disability who live with families and carers, this is a very live issue since their informal supporters need secure hours of paid support so they can work, meet their responsibilities and perhaps pursue interests. When NDIS planning decisions limit reasonable and necessary support, centre-based day programs are often used to extend the hours available.

Significant resources in the UK have been directed at assisting providers of centre-based day services to ‘open the door’ to enable participants to ‘have a good day’. The framework of the Social Care Institute for Excellence (SCIE)<sup>80</sup> featured below included a 2-part, Day Service Modernisation Tool Kit<sup>81</sup> to assist providers of centre-based day services to transition to more contemporary supports.

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<sup>76</sup> Reported in SCIE (2007) Adult services knowledge review 14 p6

<sup>77</sup> Simons K., & Watson, D., op cit

<sup>78</sup> Dowson, S. (1998) *Certainties without centres: A discussion document on day services for people who have learning difficulties*, London, Values into action, Reported in SCIE (2007) Adult services knowledge review 14 p6

<sup>79</sup> Mencap (2002) op cit.

<sup>80</sup> SCIE (2007) Adult services knowledge review 14, *Having a good day*,

SCIE, (2007) Community based activities and supports for people with learning disabilities. Accessed at <https://www.scie.org.uk/publications/guides/guide16/> 22 June 2019

<sup>81</sup> [http://peterbates.org.uk/wp-content/uploads/2017/04/vpst\\_day\\_service\\_toolkit\\_-\\_part\\_1.pdf](http://peterbates.org.uk/wp-content/uploads/2017/04/vpst_day_service_toolkit_-_part_1.pdf)  
<http://peterbates.org.uk/wp-content/uploads/2017/04/vpstdayservicetoolkitpart2.pdf>

**Figure 1: Keys that open the door**

Key ingredients		Key tasks		Results: people are:
Partnerships with people and families		Empowering people		earning money
Leadership		Changing the model to community life		contributing to society and being respected
Cultural change in services		Organising resources		controlling their own lives and the support they get
Personalised planning with people				using ordinary community places and facilities
Individualised funding		Building support around people		being as independent as possible
'Smart commissioning		Creating barrier free community		having ordinary patterns of life
Workforce development				making choices and decisions
Community capacity building		Achieving inclusion in community life		making and keeping friends
Good information		Supporting people into paid work		doing the things they want to do
Good transition planning				achieving their ambitions
Political will and support		Creating opportunities for all		doing things that are personally meaningful and purposeful
Skilled team management		Ensuring quality		connecting with local people
Wider partnerships working				getting the level and type of quality support they need

Resources developed by NDS<sup>82</sup> to support centre-based providers to open the doors focus on similar issues.

<sup>82</sup> National Disability Services (2016) op cit.



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## Drivers of improved outcomes

There are a number of drivers the NDIA needs to address to improve outcomes. These include a lack of understanding of good practice, low expectations; lack of participant experience in setting goals and outcomes and planning and monitoring support; provider knowledge of how to deliver good practice support within the Price Catalogue; the lack of community capacity building; the lack of focus on partnerships and the low requirements of Quality and Safeguards Commission.

### Understanding practice

A recent literature review<sup>83</sup> about effective support in community participation programs found very little research about effective programs or interventions and argued that the lack of conceptual clarity about community participation was an obstacle to the achievement of better policy and practice (especially innovation) and ultimately of better outcomes. In addition, it was noted that the absence of reliable national data on outcomes of funding to support community participation is hampering the spread and sustainability of good practice that could inform participants and their families and carers about effective support.<sup>84</sup>

Bigby<sup>85</sup> has developed a typology of community participation programs aimed at building relationships that provides a start for the identification of practice insights. More work is required to ensure evidence-based guidance leads practice.

### Increased participant expectations

Most participants entering the Scheme who are not engaged in work or education have low expectations of themselves and their lives. These low expectations are shared and sometimes reinforced by well-meaning family and support networks. The NDIS provides the opportunity to dream beyond their current circumstances. The real challenge is that they must have the opportunity to hear about and try alternatives, preferably from trusted sources. It will take time for many to lift their eyes toward high expectations.

### Clear goals and outcomes

Goals are big picture visions that can set the path to the life a person wants to live. Maslow argued that without satisfaction of one's basic needs for physiological security, safety and belonging, one could not achieve high level goals of self-esteem, an essential prerequisite to self-actualization.

State disability service systems provided maintenance support for most service recipients who on Maslow's hierarchy were struggling with lower order needs related

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<sup>83</sup> Bigby, C., Anderson, S., Cameron, N, Duff, G., (2018) Executive summary and policy commentary: Designing effective support for community participation for people with intellectual disabilities. Report for the Disability Research and Data Working Group. Melbourne, La Trobe University, Living with Disability research Centre, p13

<sup>84</sup> Duff, G., 'Commentary on policy implications in Bigby, C., Anderson, S., Cameron, N, Duff, G., (2018),ibid, p13

<sup>85</sup> Bigby, C., 'Understanding types of community participation and designing effective support for people with intellectual disabilities', Presentation available from C. Bigby

to physical survival, safety, social belonging and self-esteem. The NDIS opportunity to set goals and a vision for their future is new to many.

Three key questions can guide planning for goals that enhance outcomes from social and community participation. Participants must be supported to ask: Does the endeavour increase:

- my skill and capacity?
- my motivation, confidence and empowerment to act?
- my participation and contribution to the community?

Goal setting emphasises a direction for the long-term. An outcome on the other hand is the end point of the journey, one of probably many specific, observable and measurable achievements that bring the vision and goal to life.

For a participant to move from goals to outcomes, he/she may require assistance to identify, plan, support and implement the multiple steps or outputs on the way. For example:

Vision: An ordinary life

Goal: Living in my own home

Outcomes

- Personal care (timed need to go to the toilet)
- Daily living (ability to prepare and eat a light meal independently)
- Relationships (2 new people who provide emotional and practical support)
- Travel (able to use public transport)

Each outcome requires an effective process to identify, plan, support, implement and monitor progress on the multiple steps that are required to move toward the outcome.

## Supports

### Selecting services

A very significant proportion of participants would gain value from active assistance in selecting services that have an orientation and skill set matched to their goals and outcomes.

NDIA processes for plan implementation include assistance from an LAC or Support Coordinator and service agreements. Whilst it is understandable that an LAC cannot recommend a service, in the absence of an E-market with service ratings of a Trip Advisor nature, most participants with a cognitive impairment and many others, require

active assistance to differentiate between the promotional material of providers in relation to their capacity to assist in moving toward their goals.

Where the Support Coordinator is employed by their day program provider, questions must be raised about the independence of advice and whether the participant is actively assisted to consider alternate options.

The vast majority of capacity building should take place in the ordinary community settings in which the skill will be used and a capacity building plan should include a plan for practice and repeat exposure to maximise impact.

## Planning Support

Recent research<sup>86</sup> demonstrated that individualised support can and does occur in the context of a program. The programs showcased delivered person-centred support, underpinned by planning processes that required staff to know each participant well. Families were included in the planning and for many participants were partners in negotiating the type of activities they preferred and the support they needed.

A goal without a plan is only a wish. Hence a well-chosen goal should be backed up by a plan that specifies:

- the goal and the timeframe in which it might be accomplished
- the desired outcome in connection to the goal, important for motivation to keep focused
- how the participant will know when the desired outcome is achieved including changes in self
- milestones to mark progress on the way to the outcome
- any negatives associated with achieving this outcome so that the participant can either accept these negatives or redefine the goal
- any unanticipated positives that will be lost by achieving the outcome so that the participant can let go of these positive and accept how they will impact on their goal or redefine the goal
- the practical strategy for carrying out the required actions including:
  - small, regular, measurable steps that enable practice of the emerging skills or opportunities required to achieve the desired outcome
  - ways to track daily, weekly and monthly progress.

The practical strategy is crucial for the achievement of outcomes. Any new skill or opportunity to form a relationship requires exposure and practice. Capacity building without identified support to take the small, regular measurable steps is almost a waste of time for most participants. For this reason, capacity building must include discussion with collaborating providers and any others who can assist in practicing emerging skills to promote maximum opportunity for success.

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<sup>86</sup> Bigby, C., Anderson, S., Cameron, N, Duff, G., (2018) op cit p10

The Quality and Safeguards Commission NDIS Practice Standards (at Standard 3) set out clear expectations in relation to support planning including the requirement to demonstrate that *“Progress in meeting desired outcomes and goals is assessed, at a frequency relevant and proportionate to risks, the participant’s functionality and the participant’s wishes. Where progress is different from expected outcomes and goals, work is done with the participant to change and update the support plan.”*

The active review of achievements should be reflected in adjustments to the plan and in support over time to reflect move toward an outcome.

### Developing service agreements

Service agreements are a crucial but not mandatory NDIA tool to assist participants to negotiate with providers. The IAC is concerned that even though the NDIA recognises the uneven power differential between participants and providers, unrealistic confidence is placed in service agreements as representing participant interests.

The Quality and Safeguards Practice Standards in relation to service agreements (p14) seem to place the participant as an object of the agreement rather than as an active designer of an agreement that documents support requirements to address their unique needs and circumstances.

More is required to ensure that service agreements are the potent tool they could be in a partnership between the participant and provider.

### Monitoring support

Monitoring support can be undertaken by the participant, by the provider, by the NDIA and by the regulator.

It is critical that participants have confidence and either competence or support to speak up when the provider is not assisting them in ways that move toward goal achievement. In addition, participants need to know that where a provider is unresponsive, they can change providers and/or make a complaint to the Quality and Safeguards Commission.

Participant progress should be monitored by the support provider on a regular basis to ensure support is effectively targeted to achieve milestones and by the NDIA planner or LAC partner at plan review. Where a participant does not meet milestones on the pathway to outcomes, the support plan needs to be changed to reflect revised effort. Participant progress and provider processes can also be monitored through the Quality and Safeguards Commission registration and complaints processes.

Overtime, it is hoped that an E-market, rating scales and provider reports, perhaps developed jointly between the NDIS and the Quality and Safeguards Commission, that outline the extent to which participants using their supports have achieved their goals, would provide helpful data helpful for participants in selecting supports.

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## **Workforce oriented to contemporary practice**

Building capacity of participants requires support staff who are oriented, supported and supervised to work in a developmental way to facilitate opportunities and support their clients to increase their skills and engagement.

NDS<sup>87</sup> foreshadowed the different balance of workforce skills required to support community inclusion. Traditional practice in which activities were often based on staff skills enabled providers to hire staff based on technical or ‘hard’ skills such as instructing, teaching, qualifications, and hobbies. Contemporary supports require ‘soft’ skills that are person centred, support participation and inclusion, innovative, good customer relations, personal accountability and awareness and capacity to engage and educate the community on behalf of the participant.

In addition, the provision of direct one to one support ‘in the moment’ is only a small fraction of the overall work associated with supporting each individual’s community participation”.<sup>88</sup> A significant proportion of total staff time is spent behind the scenes, establishing the infrastructure to create opportunities. Bigby outlines staff behaviours that enable or hinder convivial encounters between people with disability and ordinary citizens in the community including skills necessary to support community participation as spanning community mapping and development, evidence-based disability support worker practice such as Active Support, Active Mentoring, Risk Enablement and Support for decision-making. This must be recognised and embedded in funding rates, together with the centrality of staff knowledge about individual participants and the importance of individual planning processes.

Recruiting staff with preferred attitudes and ensuring they have training and ongoing supervision to be competent facilitators of community inclusion is a major challenge.

## **Community capacity building**

Focusing at the individual level on the motivation, skill and support for participants to lead ordinary lives without concurrent community capacity building can place participants in a difficult position. The lack of community infrastructure for participants with significant support needs has been noted above. Equally important is the can-do attitude of community organisations that feel supported to welcome and include a participant.

Local place-based investment, resourced by peer networks, can drive community development projects and tap into community creativity. Core elements of planning, community development, specialist support and advocacy can assist communities to become more welcoming, enabling participants to move away from total dependence on paid support.

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<sup>87</sup> National Disability Services (2016) op cit. p47

<sup>88</sup> Ibid, p9

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## Partnerships

Many mainstream community organisations are clearly interested to welcome members with disability but feel more able to do so when in partnership with a skilled specialist support provider. Case studies<sup>89</sup> document the way in which the success of strategies to support community participation depends on partnerships and collaboration between specialist disability services and the broader community. Potential strategies and roles of local government require further exploration.

### Providers that build capacity and focus on outcomes

The NDIS Quality and Safeguards Commission has an important role in improving quality of disability support. Providers registered for *Assistance with Social and Community Participation* and its capacity building sister *Increased Social and Community Participation* must meet core requirements related to rights and responsibilities for participants, governance and operational management, provision of supports and the support provision environment.

Practice Standards in the Early Childhood Supports Module however include requirements related to capacity building and outcomes that would improve practice if set as requirements for all providers. These standards are attached in Appendix A.

Building on the Early Childhood Supports Module while recognising the significant differences between participants who are adults and those who are children, it would be beneficial to see the capacity building and outcomes focus extended to the area of social and community participation.

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<sup>89</sup> Bigby, C., Anderson, S., Cameron, N, Duff, G., (2018) op cit p12

## Services and supports designed to achieve outcomes

Emerging and established evidence about services and supports designed to achieve outcomes are discussed below. Much of the evidence is however anecdotal and will be enhanced through a program of research and evaluation. Further work will also be required to translate evidence into practice that can be showcased and built to scale.

### Activities that build relationships and belonging

Research<sup>90</sup> draws attention to the fact that deliberate, purposeful strategies are required over an extended period of time to develop relationships of trust, reciprocity and emotional support that genuinely increase informal support and decrease the likelihood of crisis. This is more so in developing relationships with adults with severe intellectual disability where research by Johnson<sup>91</sup> provides a framework for teaching others how to have a positive relationship with people with severe intellectual disability. The first step is to ensure people with disability have the opportunity to engage with others in ways that provide an opportunity for engagement.

Meaningful valued social roles<sup>92</sup> provides one framework that supports the development of relationships. Valued social roles move activities to interests that are meaningful for the person and provide a pathway to strengthen relationships and belonging and to enable people to make a contribution.

Analysis<sup>93</sup> of 'promising' community participation programs that aim to build relationships and belonging described a typology of programs and notes the constant undervaluing of staff skills in the values skill equation. Some of the programs analysed promote social relationships between adults with and without disability on the logic that relationships equal engagement in activities. Relationships were facilitated by matching volunteers to seek friendship, creating connections to places of common interest and teaching social relationship skills to people with disability. Circles of support and leisure buddy programs are examples but the research noted the lack of data on durability or quality of new relationships.

Other programs focus on belonging and identity with the creation of community between people of similar identities. These programs focus on people with disability building an identity based on their skills, talents and interests as a catalyst for relationships with others with similar identities in the mainstream. Many of these programs use segregated groups or activities such as drama, sports and self-advocacy

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<sup>90</sup> Lippold, T., & Burns, J., (2009), op cit

<sup>91</sup> Johnson H, Douglas J, Bigby C, Iacono T. (2012) A model of processes that underpin positive relationships for adults with severe intellectual disability, *Journal Intellectual and Developmental Disability*;37(4):324-36

<sup>92</sup> Sherwin, J., (2011) The desire for friendship comes quickly, friendship does not: an exploration of valued roles and relationships, *The SRV Journal* 1(1), 58-62. Accessed at [https://socialrolevalorization.com/wpcontent/uploads/2019/04/The\\_Desire\\_for\\_Friendship.pdf](https://socialrolevalorization.com/wpcontent/uploads/2019/04/The_Desire_for_Friendship.pdf) 23 June 2019

<sup>93</sup> Bigby, C., Anderson, S., & Cameron, N., (2017) "Effective programs to support community participation, Presentation at Roundtable 2017. Accessed at [https://www.latrobe.edu.au/\\_data/assets/pdf\\_file/0004/843736/Round-Table-2017-Bigby-draft-participation.pdf](https://www.latrobe.edu.au/_data/assets/pdf_file/0004/843736/Round-Table-2017-Bigby-draft-participation.pdf) 23 June 2019

with the positive outcome of increased skill, confidence and peer relationships but little evidence about the flow on effects on social interaction or status.

The third type of program focuses on the idea of facilitating ‘convivial encounters’ of moments of shared identification, of everyday recognition and processes that help the person ‘to be known’. Convivial encounters are reported to fill the void between passive presence and fully-fledged relationships.<sup>94</sup> Bigby reports that approaches to facilitate convivial encounters have the most rigorous evidence base and support for scaling up and provide an approach to enable day program participants to enjoy more meaningful engagement in the community.

The analysis identified a range of activities used to build relationships and belonging. These include:

- create opportunities for interaction
- create new activities
- ensure the regularity of attendance that turns fleeting encounters into convivial ones
- provide support to natural supports
- undertakes task analysis to ensure engagement
- provide ingredients of enabling that can be mixed and matched to an individual.
- activities and places.

The research concluded that without the activities noted above *people with intellectual disability remain visitors or have paid companions and [are] dangerously required to depend on the broad community ‘inviting’ people into shared spaces and activities.*<sup>95</sup>

### Support by providers

The programs analysed in the Bigby research created an individually tailored mix of activities of engagement in specific tasks and social interaction with community members with an element of reciprocity or skill development in collaboration with others in the locality. All were run by providers that assisted participants to achieve outcomes through individualised support within the framework of a program.

In addition, providers assist participants to build relationships and belonging when, for example, they assist a participant to go out with a friend of their choosing, to build, maintain or strengthen relationships with family, friends or neighbours or to participate in ways that build informal support in a local group (as noted below). Providers also build relationships via buddy / mentoring type programs that link a participant with another person and provide support to enable a relationship to grow and develop.

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<sup>94</sup> Bigby, C., & Wiesel, I., (2015) Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability, *Journal of Applied Research in Intellectual Disabilities*, 28(4), 307-318

<sup>95</sup> Bigby, C., Anderson, S., & Cameron, N., (2017) *ibid*



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## Participating in a local group with a shared interest or purpose

The common interest of a local group is often able to be leveraged into friendship.

Many activities that build relationships in a mainstream community group require the provider to lay the ground work with the mainstream activity to ensure an understanding of expectations, to identify possible informal supports and to establish safeguards. This behind the scenes work is especially essential if the aim is to decrease reliance on paid support and may extend ad hoc assistance for the informal supporters when the person participates without paid support. Stancliffe's work on supporting older people with disability who had spent their lives in closed systems, transition into retirement in mainstream activities for seniors provides an example of what may be required.<sup>96</sup>

Most providers are not aware that with the agreement of the participant, the provider can claim payment for these behind the scenes activities that are pivotal to achieve outcomes.

Participating in a local group focuses on increasing the number of relationships, some of which will be one dimensional and some of which may be social. It will also increase the diversity of relationships, providing a bridge to further opportunities.

Each linkage to a mainstream social group may need a different set of supports to facilitate the relationship.

### Circles of support

A circle of support develops relationships around one individual.

A circle of support is a group of people who are invited to come together in friendship to support a person with disability. They meet on a regular basis to promote and support the person's interest, goals, relationships, wellbeing and needs in building a meaningful life. A circle of support is an intentional strategy and many circles have a facilitator who helps to organise and run meetings, providing a framework for people to be involved and for planning in a practical and structured way.

A circle of support focuses on increasing the number of partnership type relationships and may also increase the diversity of relationships.

The NDIS could provide vital assistance to initiate and maintain a circle of support. Most families do not develop a circle of support because they find it extremely difficult to ask other people to come into the life of their family member in an unpaid capacity. They are afraid of rejection and exhausted with day to day life. Some providers have successfully used NDIS resources to support the development and facilitation of circles of support. An exploration and publication of ways in which reasonable and necessary

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<sup>96</sup> Stancliffe, R., et al (2013) Transition to Retirement, Policy Bulletin No 2, <https://sydney.edu.au/health-sciences/cdrp/pdfs/policy-bulletin-2-retirement-2013.pdf> Accessed 10 July 2018

support can enable circles of support could showcase an effective capacity building outcomes focused strategy.

## Peer networks

Peer networks with an empowerment focus provide an important strategy for strengthening relationships. The recent Social Policy Research Centre (SPRC) review of the DSO peer network project <sup>97</sup> found benefits of participation in a peer network included increased confidence and capacity, increased social and emotional support, access to a safe space to share experiences and problem solve and access to positive role modelling and leadership from peers.

The SPRC review also found that participants in peer networks reported access to increased information and knowledge and increased participation in community life.

Peer networks focus on increasing the number of social relationships but do not increase the diversity of relationships.

The new DPFO initiative in the ILC will provide positive new opportunities to enable people with disability to connect to peer networks.

## Activities that foster skill development and contribution

Most participants not engaged in education or work are unlikely to engage in growth facilitating activities that stretch their abilities, enable them to learn new skills, take on challenges or push themselves to be better. They are unlikely to have opportunities to contribute to others or to the community. These participants are unlikely to have networks that can assist them to access new opportunities.

It is possible to assess the level of participant engagement in activities by the extent to which the participant experiences:

- meaning and purpose in what they are doing
- autonomy: the freedom and ability to make choices
- growth: from current activities and whether there are new opportunities for growth and development
- impact: feeling successful in what they are doing and seeing their effort making a difference to others
- connection with the people with whom they spend time.

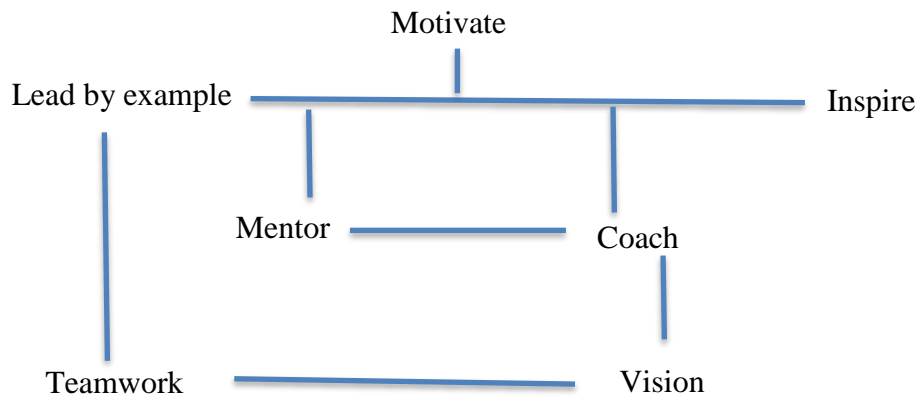
## Building a culture for personal growth

Support for social and community participation activities should occur in a culture that facilitates personal growth. Elements that build this culture are identified below.

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<sup>97</sup> Davy, L., Fisher, K. R., Wehbe, A. (2018). Peer support practice review: Final report of Stage 1A findings (SPRC Report #/#). Sydney: Social Policy Research Centre, UNSW Sydney

Figure 2: Building a culture for personal growth <sup>98</sup>



### Support by providers

A support provider assists a participant to develop skills and contribute by assisting the participant to plan and implement a project that is outside their current repertoire. For example, a participant who enjoys food and wants to learn photography can be assisted to produce a cook book. Skills learnt and practiced would include planning meals, shopping for ingredients, making the food, photographing and writing a summary of each step as well as steps related to self-publishing.

A support provider who assists a participant to contribute may assist them to identify, negotiate and support a volunteer role, membership of a committee or to learn skills such as gardening, washing cars and cooking dinner that will assist family or neighbours.

### Volunteering

Volunteering Australia defines volunteering as ‘time willingly given for the common good and without financial gain’. In a manual targeted at supporting community groups to enhance volunteer programs to be inclusive of people with disability, Inclusion Melbourne promotes volunteering as a way to support social empowerment, confidence, skill development and engagement for people in all stages of life. Volunteering provides a way in which community members can participate in activities within their areas of interest, build on their talents and obtain valuable work experience, sometimes as a stepping stone to successful careers.<sup>99</sup>

<sup>98</sup> Johnson, E., (2011) How to develop a culture for personal growth, Accessed at <http://www.success.com/article/how-to-develop-a-culture-of-personal-growth> How to develop a culture for personal growth, 5 July 2018

<sup>99</sup> Inclusion Designlab *Taking that extra step*, Accessed at <https://www.bgkllen.org.au/wp-content/uploads/2017/12/taking-that-extra-step-web-version.pdf> 12 December 2018

## Micro-enterprises

Some people with disability who have difficulty finding a job, have created their own jobs by developing a micro enterprise, a very small business that is simple to start, requires minimal capital and provides the vehicle for the person to work and be valued in their community. Micro-enterprises are highly individual tailored to the scale, stamina and schedule that suits a person. Micro-enterprises provide a positive opportunity for social participation even where they do not enable economic participation or increased independence

Micro-enterprises have grown and developed in the UK, US, Canada and Singapore.<sup>100</sup>

Australian examples include *Errands with heart*<sup>101</sup> in which Emily works 10-12 hours per week assisting 5 business customers by watering plants, getting the mail and shopping for small items. *Moopster's Munchies*<sup>102</sup> is a micro enterprise in which Alexandra makes and delivers home-made morning teas to workplaces and homes. *Ground Control by Major Tom*<sup>103</sup> is a micro business in which Tom sells his gardening services. All examples build the skills, confidence and social and economic participation of the participant.

## Mentoring

Mentoring builds opportunities by connecting a participant with an experienced and trusting advisor "to support and encourage the person to manage their own learning in order that they may maximise their potential, develop their skills, improve their performance and become the person they want to be." <sup>104</sup>

Mentoring is a strategy most often offered to people with disability at points of transition: secondary school students as mentors for their primary school peers, young adults for secondary students thinking about their adult life and people working in a specific field as mentors for young people who wish to enter the field.

There are few well-designed studies to determine the effectiveness of mentoring although positive changes related to a mentoring relationship include improved self-esteem, social skills and behavioural competence.

There is however consensus that the way in which mentoring is implemented has a significant impact on its effectiveness. Evidence<sup>105</sup> suggests that for a mentoring program to have the greatest chance of assisting protégés achieve positive outcomes, it needs to be well structured, use theory-based and empirically based best practices and focus on the quality of relationships (through the matching process, guidance in

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<sup>100</sup> McQuillan, H., *Let's Get Started, Self-employment options for people with disabilities*, Brothers of Charity Clare Accessed at <http://www.brothersofcharityclare.ie/assets/Uploads/pdfs/Good-Practice-Reviewfinal-Lets-Get-Started.pdf> 5 June 2019

<sup>101</sup> <https://www.vbs.net.au/all-abilities/>

<sup>102</sup> <https://micro-enterprise.valuedlives.org.au/listing/moopsters-munchies/>

<sup>103</sup> <https://www.facebook.com/MajorTomsGroundControl/>

<sup>104</sup> Eric Parsloe, The Oxford School of Coaching & Mentoring

<sup>105</sup> IAC (2015) *Capacity building for people with disability, their families and carers*

relation to goals, expectations, duration and continuity of relationships, training, ongoing support and supervision of mentors and monitoring the quality of relationships). Critically, research demonstrates that mentoring is more effective when combined with other services and supports.

Mentoring focuses on increasing the diversity of relationships at a partnership level.

The NDIS Price Catalogue item Life Transition Planning makes provision for mentoring. With a volunteer mentor, the support could be used to identify, match and support a volunteer mentor.

### Facilitating experiential learning to enable initiative

Experiential learning is the process of learning through experience. It focuses on the learning process for the individual and encourages the learner to make discoveries and experiment with knowledge firsthand, instead of hearing or learning from a teacher. It is an approach used successfully by NSW Council for Intellectual Disability in *Run Projects* of My Choice Matters, that enabled people with disability apply for grants of up to \$5,000 and be support to run a project of their choice.<sup>106</sup>

People with disability often lack the opportunity and support to show initiative in the lives. This is a significant barrier to their development of self-efficacy because it confirms their generalised negative self-perceptions and simultaneously deprives them of accomplishments that are critical to challenge that self-perception. These factors compound to strengthen learned dependence and deflate self-efficacy.

Building on evidence that people learn best and more willingly apply what they have learned when they do it themselves, experiential learning uses an action research approach to support people who are traditionally clients, to apply for a small grant to complete a project of choice.

Strategies that employ an experiential learning approach ask people with disability to set a goal or solve a problem that is pressing for them individually. Each person has a key worker to nurture the participant to the point where he/she can take responsibility for the process.

Evidence from *Run Projects* of My Choice Matters demonstrates the power of this approach in enhancing the self-efficacy of individuals. Components that enhance effectiveness include:

- high expectations that everyone can use money wisely to meet a goal for the benefit of themselves or their family member with disability
- a simple framework to assist people to plan

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<sup>106</sup>My Choice Matters, *Run Projects*, Accessed [http://www.mychoicematters.org.au/index.php?option=com\\_content&view=category&layout=blog&id=14&Itemid=115](http://www.mychoicematters.org.au/index.php?option=com_content&view=category&layout=blog&id=14&Itemid=115)  
5 June 2019

- relationship with a trusted key worker to support growth in confidence and competence. As well as providing crucial support, this relationship provides a safeguard for the management of risk.
- the provision of a budget for which the individual has responsibility. Having their own budget provides a critical training tool that leads people to seek value for money and use money wisely and frugally.

Experiential learning such as adopted by *Run Projects* focuses on increasing the diversity of relationships at a partnership level and supports an individual to be stretched and challenged in ways that promote personal growth. Projects of this nature could be developed by providers in the ILC or could be showcased as capacity building outcomes focused ways to use social and community participation support.

## Internships

Internships connect a participant with a company or organisation that will assist them to take on a challenge. Whilst internships are usually used to secure employment, internships can be crafted to enable a participant to learn new skills and behaviours and see themselves as valued contributors.

Internships focuses on increasing the diversity of relationships at a partnership level if well planned and supported.

## Appendix A: NDIS Practice Standards, Early Childhood Supports

### Capacity building p34

Outcome: each participant receives supports that build the knowledge, skills and abilities of the family and other collaborating providers in order to support the child's learning and development

To achieve this outcome, the following indicators should be demonstrated

- Work is undertaken with the support network in each child's life to build their capacity to achieve the functional outcomes identified in the support plan
- Each family's confidence is built to understand how their family routines and everyday activities can support their child's development
- The capacity of the child, family and collaborating providers involved with the child is built through coaching, capacity building supports and collaborative team work
- Collaboration is undertaken to affirm, challenge and support the child, family and collaborating providers to further develop their skills and to improve practice and relationships
- Feedback and learnings from the child, family and professionals is used to improve service delivery

## **Outcomes based approach – p35**

Outcome: Each participant receives supports that are outcomes based and goal-focused

To achieve this outcome, the following indicators should be demonstrated

- The functional outcomes for the child and their family are based on their needs and priorities, and the skills needed to achieve those outcomes are identified through collaboration with the child and family
- Each child has a documented support plan that describes the interventions and their functional outcomes
- The family is actively involved in the assessment of the child and the development and review of the support plan
- A copy of the support plan is provided to the family in the language, mode of communication and terms that they are most likely to understand
- The functional outcomes support the child's meaningful participation in family and community life
- The assessment, intervention planning and outcomes for the child and family are measured, evaluated and reported in ways that are meaningful to and understood by the family.

## Appendix A Examples of Community Capacity Building

The material below is sourced from plans of Community Capacity Building projects funded in the ILC Jurisdictional Round 2017-2018 in NSW.

**Building Inclusive and Accessible Youth Services in NSW** auspiced by People with Disability Australia in partnership with Youth Action & Policy Association (NSW)

This program will develop resources to build the capacity for 221 youth service providers in NSW, responsible for approximately 375 programs and services for young people that reach over 60,000 young people with disability. The project will consult young people with disability to understand barriers and common experiences in accessing youth services and use feedback to develop a Disability Inclusion Tool Kit which will include policy, resources, tools and training. Complementing this will be the establishment of an on-line self-advocacy platform which will include resources for youth services co-developed by young people with disability.

**Our Voice**, auspiced by Settlement Services International Limited

This project builds capacity of mainstream services to respond to the accessibility needs of people with disability from Culturally and Linguistically Diverse (CALD) backgrounds. The project will recruit 20 Lived Experience Educators (i.e. people with disability from CALD backgrounds) to deliver capacity building activities. Funding is directed towards training the Educators in facilitation, presentation and story-telling with impact, with the goal of creating pathways for future employment as adult educators. Each Lived Experience Educator will deliver a minimum of 10 learning activities, with the project aiming to deliver 200 learning activities overall, benefiting hundreds of mainstream services. The targeted locations will be in Metropolitan Sydney and regional centres with high populations of people from CALD backgrounds.

**Mainstream Transition Project**, auspiced by Blind Sports NSW Incorporated

This two year awareness campaign includes a range of initiatives to build the capacity of mainstream sport organisations to provide sporting, active recreation and social group activities for people who are blind or have low vision. Project activities include working within sports and active recreation state organisations to adapt equipment and rules. The program will also mentor people with disabilities to conduct public speaking, leading to greater media and social awareness of inclusive sport and recreation. Further supporting this project is the expansion of the current website to include more content around how to get involved and how sports and recreation organisations can make appropriate adaption.



**Lost Business**, auspiced by Dare Disability Support Limited in partnership with Blue Mountains Economic Enterprise

The Lost Business initiative will focus on businesses in the Nepean Blue Mountains region of New South Wales, raising disability awareness and demonstrating the economic and social value in meeting the needs of people with a disability. Building greater business understanding and experience is anticipated to lead towards greater confidence of people with disability to use local services. The multifaceted program, initially focusing on the needs of adults with an intellectual disability or Autism, includes: training and creation of resources to assist owners and employees; the creation of a Business Ambassadors scheme; distribution of inclusion awards; published audit self-assessed checklists; and development of a mystery shopper program. The project aims to benefit the 5,000 people in the Blue Mountains region that self-report disability\

**Inclusion for all**, auspiced by NSW Business Chamber Limited

Organisations and community groups will be provided with information, practical advice, solutions, and factual evidence on why being inclusive and accessible is not only good for business, but is also good for the community. Though a comprehensive stakeholder engagement program, the project will tap into the NSW Business Chamber's extensive influence in business, government and community, taking a key focus on supporting regional and remote areas of NSW. Forums, presentations and online resources will be developed and delivered through existing relationships with other peak organisations and people with disability.

**Knowledge Exchange Inclusion Program**, auspiced by NSW Sports Federation Inc.

This program engages people with disability to design and deliver an education and capacity building program for local community organisations. Local clubs, schools, councils, community organisations, universities, local business, health service providers and leisure providers will be targeted to attend education workshops delivered in 10 major regions of NSW: Hunter / Central Coast, Illawarra Riverina / Murray Northern Rivers, South Eastern NSW, Far Western NSW, Blue Mountains, Sydney Southwest, Inner Sydney, Sydney North and Northern Beaches. Workshop participants will be supported with resources including adaptive equipment kits, adaption 'how-to' videos on the Sport NSW YouTube channel, phone service support and a real-time chat portal through the [www.sportnsw.com.au](http://www.sportnsw.com.au) website.

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