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SMALL BUSINESS ENTERPRISE MODELS OF EMPLOYMENT

For persons with intellectual disabilities and high support needs

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Executive summary

Adults with disabilities are substantially disadvantaged, economically and socially. Ample national and international comparative data indicate low labour force participation rates (just over 50%) and double the unemployment rates for persons without disabilities. Australian performance in this area is poor with Organisation for Economic Co-operation and Development (OECD) data indicating Australia ranks 21/29 countries on disability employment rates. Further evidence indicates the strong connection between disability, and social exclusion and poverty, with the OECD estimating that 45 per cent of persons with disabilities live in poverty in Australia.

The focus of this project is specifically on adults with intellectual disabilities who have high support needs and experience almost complete exclusion from employment, much more than other disability groups. This group is typically excluded even from sheltered employment and more likely to attend adult day centres that have no focus on employment.

Recently, an employment option has emerged that we have named Small Business Enterprise (SBE) to clearly distinguish it from self-employment approaches, which are well developed and primarily focused on persons with physical rather than intellectual disabilities. This is particularly pertinent with regards to support needs as intellectual disabilities contribute to high support needs.

A structured literature review showed virtually no research publications or evidence for SBE. This qualitative case study of four examples of SBE (three in WA and one from the ACT) provides possibly the first account of SBE development, outcomes, and potential to address the employment needs of persons with intellectual disabilities who have high support needs.

The four SBEs illustrated how parents have developed employment options for their sons that provided meaningful and rewarding economic and social participation for adults with intellectual disabilities and high support needs. These were tailored to individual strengths, interests, and circumstances. Two of the case studies provide examples of arrangements that have existed for a decade or longer, illustrating some of the successful strategies deployed and the rewards gained. The other two case studies are of recently established arrangements (less than two years) and illustrate some of the challenges in establishing SBEs.

There is a dearth of information on SBEs in research literature, with further work required to build an evidence base, and develop quality frameworks for SBE to assist in planning new, and reviewing existing, arrangements.

Key findings

Background

- The definition and prevalence of disability is a contested area, which considers medical, psychological, social, cultural, environmental, political, and economic influences.

- Disability and poverty are closely related.

- It is estimated that 18.3% of Australians have disabilities.

- Persons with intellectual disabilities have a reduced capacity to function independently, and have a prevalence rate of 10.37 per 1,000 Australians.

- Australia ranks 21st out of 29 OECD countries in disability employment participation rates.

- Labour force participation rates decrease substantially as the degree of disability increases.

Methods

- A reference group consisting of researchers and practitioners with disability employment experience was consulted during the research project.

- The study focused on persons with intellectual disabilities who had high support needs and were engaged in Small Business Enterprises (SBEs).

- SBEs were defined as being individualised, with ownership vested in the person or those in close relationships, as generating some income, and facilitating community engagement and relationships.

- A structured search of research literature revealed only two examples of SBEs, though uncovered a large number of self-employment projects, indicating SBEs are a largely unexplored area of disability employment.

- Four case studies of SBEs were carried out, three in WA and one in the ACT.

Case Studies

- Two case study SBEs were established over 10 years ago and two within the past 2 years, providing some contrasts.

- The case studies used interviews to identify issues related to establishment, development, and maintenance of the businesses, benefits for the persons with intellectual disabilities in the SBEs, the range of supports accessed for the SBEs, and implications for growth of SBEs.

Discussion and Conclusion

- The four SBEs had clearly been developed around the five focal persons, specifically around their unique identity, skills, interests, and strengths.

- Parents played a key role in establishing, maintaining, and continuing the arrangements. In the two established arrangements, there was clear evidence of safeguarding progress made, including drawing in a range of support and specialist skills.

- There was a range of financial supports across the SBEs, including from the business and the Disability Support Pension (DSP). These case studies illustrate that financial independence is important, but other benefits may be even more important for some persons with intellectual disabilities, and high or very high support needs.

- Work plays a crucial role in facilitating community inclusion, and these SBEs illustrated the range of benefits.

- Further research to expand the evidence base of SBEs, as well as developing a quality framework which can assist in planning new arrangements and reviewing existing arrangements may be warranted.

Introduction

The purpose of this report is to describe a relatively recent development of an employment strategy for persons with intellectual disabilities who have high support needs. Our structured literature review found virtually no address of this strategy in the research literature. We have identified the approach as Small Business Enterprise (SBE), particularly to distinguish it from self-employment which is well described in the literature. Using a qualitative methodology, the project carried out four case studies (two set up over 10 years ago, and two established more recently) with the purposes of describing SBEs, and beginning an analysis of their benefits and challenges.

Persons with disabilities are significantly disadvantaged socially and economically. International data indicates they have a much lower labour force participation rate of just over 50 per cent, compared to more than 80 per cent for persons without disabilities, and an unemployment rate almost double. This is directly related to very high levels of poverty (Organisation for Economic Co-operation and Development (OECD), 2010). The OECD estimated that within its membership countries, 45 per cent of persons with disabilities in Australia lived in poverty, only exceeded by the US. Australia ranked 21 out of 29 countries on disability unemployment rates (ibid, 2010).

For adults with intellectual disabilities and high support needs the situation is even more challenging. Commonly, they are denied access to employment. At best, they may work in Australian Disability Enterprises (previously known as sheltered workshops), or adult day centres that typically have little or no work-related activity. These options involve limited developmental opportunities for full inclusion and participation in the community.

In this research a new and emerging model was investigated. Persons with intellectual disabilities and high support needs commenced an SBE with the help of their families and a range of community volunteers, and advocates. They also gained the assistance of principled, flexible disability support agencies (NGOs). These SBEs were distinguished by their focus on the needs and interests of each individual, the importance of building community connections and relationships, and flexible and innovative approaches to addressing the economic challenges of the SBEs. To the best of our knowledge, this may be the first systematic study of SBEs and the Report's conclusions are particularly important for future evolution and development of this approach.

This report:

- examines literature related to SBE and distinguishes it from self-employment;

- describes the case study methodology illustrating the SBEs, including two SBEs that had been in existence for 10 years or more, and two for less than 2 years; and

- provides an analysis of the findings of the research, including some of the innovative and creative aspects of the development of SBEs.

Background

How is Disability Defined?

The World Health Organization (WHO) and the World Bank (2011, p3) described disability as "complex, dynamic, multidimensional, and contested".

> Disability … poses several challenges for measurement. Approaches to measuring disability vary across countries and influence the results. Operational measures of disability vary according to the purpose and application of the data, the conception of disability, the aspect of disability examined – impairments, activity limitations, participation restrictions, related health conditions, environmental factors – the definitions, question design, reporting sources, data collection methods, and expectations of functioning (WHO and The World Bank, 2011, p21).

Recent approaches to definitions of disability have shifted from diagnostic emphases on aetiology, medical conditions, and syndromes, to functional definitions based on the International Classification of Functioning, Disability, and Health (ICF). The ICF was ratified by all 191 WHO member countries in May 2001 (WHO, 2001). The adoption of the ICF is a major move away from the medical model of disability towards an acknowledgement of the social model, and social determinants of disability (Shakespeare and Watson, 2001; WHO and The World Bank, 2011).

The social model of disability was first described by Oliver (1983) in his proposed "new paradigm" of understanding and responding to physical disabilities. The model rejects the notion of individual inadequacies or faults, and focuses broadly on environmental influences. This new paradigm involved a fundamental switch away from the physical limitations of particular individuals, to the way the physical and social environments impose limitations upon certain groups or categories of people. For example, a physical disability under the medical model might be defined as limitation in the person's ability to use one or more limbs, whereas under the social model the limitations are described within the environmental adaptations and supports required to address individual differences. While the social model of disability foremost addressed the inadequacies of conceptualising and redressing physical disability, it has been applied to all disabilities and was instrumental in the development of the ICF.

It is not surprising that there is no single definition of disability in Australia (Committee on the Rights of Persons with Disabilities, 2012). Operational definitions of disability in Australia vary between the Federal, State, and Territory anti-discrimination legislations, and qualification for social security such as the Disability Support Pension (DSP) and provision of special assistance. The National Disability Strategy 2010-2020 highlighted that different levels of government are "working together to develop a nationally consistent definition of disability" (Council of Australian Governments, 2011, p57) that has not yet emerged.

The challenges of different disability definitions are reflected in the data collected by the Australian Bureau of Statistics (ABS). It is commonly accepted that the ABS, in its periodical Survey of Disability Ageing and Carers (SDAC), provided an accurate snapshot of disability prevalence rates. In 2015, the latest survey by the ABS suggested that 4.3 million Australians, 18.3 per cent of the population, have a disability (ABS, 2016). For the purposes of the SDAC "a person has disability if they

report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities" (ibid, 2015).

The challenge of different operational definitions is illustrated when reviewing the disability prevalence rate. The 2009 SDAC stipulated that one-quarter of Australians with disabilities were aged 15-64 years of age – a prevalence rate of 14.8 per cent among the working-age population (ABS, 2011). The ABS Survey of Education and Training Experience (SET) indicated that in 2009, 4.7 million working-age people in Australia had a disability - 32.5 per cent of the working age population (ABS, 2010). The SET disability prevalence rate is more than double the prevalence rate noted in the SDAC. Both the SDAC and SET identified persons with disabilities using the ICF framework, although the SDAC used the full ICF while the SET used a short form. Although the short form "explains 81 per cent of the variance" of the full instrument (Ustün et al., 2010), this methodological difference only partially explains the major discrepancy in disability prevalence rates. The differences in disability prevalence ascertained in these two surveys do, however, provide a good example of the complexities involved in measuring disability.

The ICF was developed, in part, as an international response to questioning the medical model of disability. The ICF complements the International Classification of Diseases and Related Health Conditions (ICD) (WHO, 2011). The ICD specifically accounts for aetiology, medical conditions, and syndromes, and is closely related to the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013). While the DSM is commonly used by clinicians and researchers it is also used by regulatory bodies and health insurance companies to determine health coverage. The advantage of the ICF is that it captures level of support need, which may be viewed as a proxy measure for severity of disability, without "medicalising" disability. However, it is important to note that support need may not be limited to disability, and is compounded by, for example, poverty, cultural background, and ethnicity.

These different approaches, including the ICF, do not take into account the issue of the reliability of self-report or self-identification of a disability. Self-report is the most common way of determining disability status in administrative datasets, and often in disability research. As a final comment on the uncertainties of disability definitions, the Australian Government placed major importance on the functional capacity of a person with a disability to engage in work in recent times. This included the "new participation requirements for DSP recipients under the age of 35 with some capacity to work" in the 2011-2012 budget and new impairment tables in the 2009-2010 budget (Macklin et al., 2011). There has been a substantial drop in the grant rate of DSP applications. While the grant rate increased slightly from 63.0 per cent to 64.5 per cent from 2006-07 to 2008-09, there was a slight drop to 63.6 per cent in 2009-2010 and more substantial drop to 44.4 per cent from 2010-11 to 2012-13. This led to the first drop in overall numbers of DSP recipients for decades (Department of Social Services, 2014).

Intellectual disability

The definitions for persons with intellectual disabilities can also be very confusing. Intellectual disability is often grouped with acquired brain injury, dementia, stroke, and other psychosocial issues, normally considered quite separate for the group under consideration here (ABS, 2014). Within the SDAC, intellectual disability is defined as "difficulty learning or understanding" (ABS, 2016). The WHO defined intellectual disability as:

> Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

> Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society" (WHO, 2017).

The key point of differentiation from other forms of impairment is acquisition before the age of 18. Using this definition, the prevalence of intellectual disability has been calculated as 10.37 per 1,000, although this is highly dependent on the income level of the country. Higher prevalence rates are found in lower income countries due to less standardised testing methods (Maulik et al., 2011). A figure of 1 per cent of the population is commonly used which means that intellectual disability comprises the largest of all groups of young persons with disabilities.

Employment of persons with disabilities

Article 27 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) declared that:

> States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities...

> [Which includes a responsibility to] [p]romote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business (United Nations, 2006).

As a signatory to the UNCRPD, Australia is required to progress the attainment of these rights by persons with disabilities. However, there is a considerable way to go in Australia before this goal is reached. In light of the second point above, the approach we have called SBE is a particularly apt response to poor employment outcomes for persons with disabilities.

Persons with disabilities experience significant social and economic disadvantage (National People with Disabilities and Carer Council, 2009; Australian Council of Social Services [ACOSS], 2013). Disability is significantly associated with poverty. The WHO and the World Bank (2011, p10) stated that "disability may increase the risk of poverty, and poverty may increase the risk of disability". A major contributing factor for the interrelationship of poverty and disability is the low labour force participation rate and high unemployment rate among persons with disabilities. The 2015 SDAC (ABS, 2016) found that while 83.2 per cent of persons without disabilities were in the labour force, the participation rate of persons with disabilities was 53.4 per cent and their unemployment rate of 10.0 per cent was almost double the 5.3 per cent unemployment rate for persons without disabilities. The participation rate includes a significant number of persons with intellectual disabilities who attend sheltered employment and receive relatively low wages. The labour force participation rate decreases substantially according to support need. Persons with mild core activity limitation (defined by the SDAC as it relates to a set of major human functions) have a participation rate of 58.9 per cent, which decreases to 47.4 per cent for persons with moderate and 25.0 per cent for persons with severe or profound core activity limitations. There is less variation in the unemployment rate, which fluctuates from 11.4 per cent, 9.4 per cent, and 13.7 per cent respectively for persons with each level of core activity limitation. Employment outcomes for persons with intellectual disabilities are even poorer, also reflecting the higher support needs of this group, as illustrated in Table 1. Their labour force participation rate is less than half of that of persons without disabilities, their unemployment rate is five times that of persons without disabilities and two and half times that of persons with other disabilities. Their fulltime employment rate is one-fifth of persons without disabilities and one-third of persons with other disabilities (ABS, 2014).

Table 1   Labour force characteristics 2012 (persons aged 15-64)

	Labour force participation rate (%)	Unemployment rate (%)	Full-time employment rate (%)
Persons with intellectual disabilities	39.1	20.0	11.7
Persons with other disabilities	55.2	8.3	31.7
Persons without disabilities	82.5	4.9	55.2

Source: ABS (2014).

The high risk of poverty for Australians with disabilities can be viewed as the combined result of low labour force participation and high unemployment (OECD, 2010; Deloitte Access Economics, 2011; ABS, 2016). Poverty is also the result of low or inadequate social security benefits (ACOSS, 2013). The OECD (2014) utilised two measures of relative poverty: 50 per cent of median income and 60 per cent of median income. ACOSS (2013) has identified that the average gap between the DSP and the 50 per cent median income poverty gap was $129 between 2005-06 and 2009-10, or $168 for the 60 per cent income per week. Australians with disabilities have the highest relative poverty risk among all OECD countries and the poverty rate is the second highest in the OECD (after the USA) (OECD, 2010). The OECD estimated that 45 per cent of all persons with disabilities in Australia were living in poverty (ibid, 2010). Persons with disabilities face complex challenges to obtain and maintain employment. There are low vocational expectations, including among family members, (Grigal, Hart, and Migliore, 2011) contributing to the lack of access to vocational pathways from school for persons with disabilities (Cocks and Thoresen, 2013). Persons with disabilities also face discrimination in the labour market (Deloitte Access Economics, 2011; Lewis, Thoresen, and Cocks, 2011; Lysaght, Ouellette-Kuntz, and Lin, 2012; Draper et al., 2012). This is despite Australian and international research consistently confirming that employment enhances wellbeing and quality of life (Jahoda et al., 2008; Kober, 2010). Low labour force participation and high unemployment rates among persons with disabilities are indicators of social and economic disadvantage - issues which Australian policymakers seek to address, but with very limited success thus far.

Australia's achievements in disability participation in employment compare poorly with OECD countries as we rank 21st out of the 29 countries on disability employment rates (Productivity Commission, 2011). This is despite the fact that Australia was a relatively early adopter of evidence-based employment policies and practices (Parmenter, 1999; Tuckerman et al., 2012). For example, internationally Australia was one of the earliest adopters of supported employment, an approach developed in the US in the early 1980s that first asserted the capacity and right of persons with disabilities to open employment (Symonds and Luecking, 2013). It is by no means clear why persons with disabilities continue to experience relatively low participation rates and high use of the DSP. Detailed analysis of the complex policy context for disability employment is beyond the scope of this report. The authors assert that this analysis, including a focus on the historical development of disability policy and practice in Australia, is of major importance.

Methods

Methodology

This research was conducted as a set of case studies of four SBEs. The research study was approved by Curtin University Research Ethics Committee (approval number HR57/2016). All participants provided informed consent for interviews, and the use of business and personal names, along with photographs provided to the researchers, in reports and publications.

Reference group

A reference group was established to guide the research. The membership of this group included people with direct experience of establishing and maintaining SBEs for persons with intellectual disabilities and high support needs, as well as people with small business expertise. Not all members of the Reference Group were able to attend all meetings, but were kept informed of developments.

Literature review

The focus of the research was on persons with intellectual disabilities who had high support needs and were engaged in SBEs. In the view of the researchers, this group had traditionally been the most likely to be overlooked for new service initiatives and were typically associated with low expectations and levels of participation. They did not figure prominently in research studies on disability employment. In keeping with the ICF discussed earlier, the definition of persons with high support needs commonly refers in part to their assumed inability to work or engage in employment.

For the purposes of this report, and the literature review, our operational definition of high support needs refers to persons with intellectual disabilities who are not required to seek open or supported employment to remain eligible for the DSP. Two of the participants in SBEs in the research project had very high support needs, described as persons with disabilities who are not required to seek sheltered employment to remain eligible for the DSP.

An extensive review of the literature was undertaken by the authors to determine the extent of SBE development and initiatives. From the researchers' experience with SBEs, four criteria were agreed for the search of the research literature.

1. SBEs were highly individualised and focused.

2. Ownership and control of the SBE were vested in the person with disabilities and those whose relationship to the person was very close. In the event, this consisted of a parent/s.

3. The SBE generated some income, but it was not essential that it was totally self-supporting or profitable.

4. The SBE encouraged and facilitated the development of community engagement and relationships with people in the community.

A structured search was conducted in PsychINFO, Current Contents Connect, and Scopus in early February 2016. The following search string was used: "Disability AND ((micro-business) OR (small business) OR (self-employment) OR (micro-enterprise) OR (social enterprise) OR (entrepreneur*))", with * representing the wildcard function within the databases.

The literature search revealed scant formal literature, with the initial search returning 262 publications. This reduced to 97 publications after inspection of article titles, further reducing to 60 articles after a reading of abstracts, with 39 meeting only some of the criteria. From this group, 26 were found to contribute to the broader area of interest, with three meeting all of the criteria. Further, only two were identified as focusing on intellectual disabilities and high support needs.

Conroy et al. (2010) studied 27 persons with intellectual or developmental disabilities who were engaged in "microenterprises". Some also had secondary conditions such as cerebral palsy or attention deficit hyperactivity disorder, Tourette syndrome, and other disorders. The microenterprises were supported by a vocational service in Michigan USA where the support of microenterprises was one of the employment options available. Overall, the income of participants in the study did not change significantly, but there was a major improvement in their quality of work life, (27 points on a 100-point scale measuring quality of work life). Support staff did not rate the improvement so highly, but the improvement was still rated as significant. They concluded that microenterprises were a viable alternative to adult day programs and sheltered workshops.

Hagner and Davies (2002) described supported self-employment arrangements that were very similar to SBEs. They interviewed eight owners of SBEs and those most directly involved in supporting them. The business owners all had intellectual disabilities. They found that the businesses grew out of, and were connected to, genuine interests and talents of each business owner. The owners saw themselves as business people, took risks and made plans in typical ways. In most cases they were in charge, and support persons actively supported this. This was difficult, partly due to the tradition of support workers being in a powerful position and the level of support required by the individual. The businesses were not economically viable by traditional criteria and the income generated was supplemented by other income sources. Multiple sources of support were seen as being necessary, coming from family, friends and agency workers. This was seen as essential so that the requirements on any individuals were not unrealistic. In most situations a support worker from a disability service provider played a key role, but this individual normally did not have any business expertise. If they recognised this fact, they saw their job as facilitating contacts and relationships between the business owner, and business and community support groups that did have this expertise. Overall they saw personal choice as a hallmark of self-employment and important to their success. Individuals may have wished to limit sales to a manageable level or take a break occasionally and this needed to be supported. The individual business owner was able to reject advice.

Selection of case studies

Together with members of the research team, the reference group discussed and reaffirmed the four criteria on which the literature search was based. Four SBEs were identified. One high profile example from Canberra was well established with good documentation available on the internet. A second established example was located in Perth. These two SBEs had been in existence for over 10 years. Subsequently, two SBEs in Perth that were in an earlier stage of evolution were recruited. The major focus was on the two businesses that had been operating for an extended period as they had shown the capacity to survive and grow as well as overcome bureaucratic obstacles and the inevitable lack of early experience. The other two examples were more recently established with developing structure and principles.

Data collection

In each of the four SBEs selected, key individuals were contacted to determine their interest in being involved in the research. In all cases the individuals and their support staff were enthusiastic about being involved as they saw their model having the potential to improve the lives of many persons with intellectual disabilities and high support needs. After initial permission was gained, participants were assured of the voluntary nature of their involvement in the research with the option to withdraw at any time, and the intention to respect the confidentiality of the businesses. In fact all participants were very interested in gaining exposure for their business and were very willing to have the business name and details publicised. An application to the Curtin University Human Research Ethics Committee allowed for this to be followed. Prior to the publication of the final draft of research papers and this report, the four SBEs were provided with copies of their individual case studies to ensure that the information was accurate and acceptable to them on privacy grounds.

For the development of the case studies, one member of the research team carried out a recorded interview with a key person involved in the development and establishment of the SBE. The individuals were asked detailed questions covering a range of areas including the process of establishing the SBE, the stages that it went through, the barriers encountered, the lessons learned, and the benefits of the arrangement. The interview sought economic information, the social benefits of relationships formed, changes in attitude and behaviour of the business owner, and the impact on support staff and others. The person interviewed was then asked for names of other people who might be contacted to discuss any of the issues raised, as well as whether the research team could gain access to written information such as governing principles and procedures. The websites of the SBEs were also considered for additional historic information.

For the Canberra example, the interviews were conducted by a research colleague from Sydney University. In all cases, the additional information collected had already been published on the business websites or in press reports.

Analysis

Recorded interviews from a number of people involved with each business, and field notes from each investigator were used to construct the four case studies. The recordings and notes were examined for themes common to two or more of the cases and/or individuals. These themes helped to shape the discussion and conclusion section of the report.

Case studies

Case studies

The case studies are organised with the two longest established SBEs discussed first, followed by the two more recent SBEs. The case studies clearly exemplify the developmental stages of the long-established, compared with the relatively newly established examples.

The websites for each case study are provided at the end of each description below, including a link to a video developed around JACKmail.

Cam Can Services

Cameron is a young man with a significant intellectual disability and very high support needs. He had a very difficult time in mainstream schooling so his parents started planning towards the end of his education for his life beyond school. They strongly believed in Cameron's capacity and had a vision of him running a proper business as a real alternative to the sheltered workshop or community participation programs, which were the only options potentially available from the service system.

The first point of reflection was consideration of what Cameron could do. He had limited skills but during time involved with the service system he had become accustomed to waiting: waiting for staff to arrive, waiting for an activity to commence, and waiting for transport. This idea was turned into a business for Cameron. We are all sometimes faced with the situation where a service, such as a plumber or electrician, is required and we have to stay home to wait for the person to come so that we can let them in. Cameron's business is to do the waiting. Cameron will come to the person's house with a support worker and wait for the service person to arrive, and while waiting he can do a series of tasks negotiated with the homeowner. These might be raking or sweeping or cleaning a car.

A group of six people worked on the original plan to develop the details of the concept. The people were Cameron's parents, friends who had experience with human services and management, and one person who had knowledge of small business. All had a direct knowledge of, and commitment to Cameron. The particular spread of skills was found to be very advantageous as there are considerable complexities in negotiating the bureaucracy of setting up a small business, as well as designing one that has a high likelihood of success. For example, as Cameron has a very significant disability he did not have access to many of the normal documents to prove identity or credit history. He did not have a credit card or any business background. Negotiating the registration of a business name, gaining insurance cover and many other requirements took much longer than they would for others who had easy access to documentation.

A key aspect was that right from the start Cameron's parents had high expectations for him and a belief in the vision of him having a good life that encompassed living in the community, having work and a range of community connections and friendships. They viewed the available alternatives of some limited sheltered work or a community access program as unsuitable and unable to meet his needs for a positive image in the community, valued roles, and full participation as a citizen. They drew up a set of "Guiding Principles" to provide the basis for decisions into the future to ensure that the needs of the business or staff did not come to supplant the core aims of the arrangement. The principles focused on ensuring that Cameron's needs are paramount, the business is individualised and there is always a focus on building community connections for Cameron. The original group, Cameron's "Circle of Friends", also meets regularly to review the changes in Cameron's life and ensure that the development of the good life for Cameron, within and outside the business, is an ongoing process.

Initially the business was very small as it was felt that Cameron had to progress at a rate that was comfortable for him and the business was completely reliable from the customers' perspective. The group also had to work through the issues of

safety, insurance, transportation, business image, and presentation, marketing, and ensuring the presence of well-trained support staff. They also had to build in safeguards to cater for potential problems such as illness in Cameron or staff, vehicle breakdowns, or too much work to complete reliably. The centering of the business on Cameron, the need for a high quality and reliable service, and the necessity for constant and regular communication between all involved became the core issues in the day to day operation of the business.

The ambition was for the "waiting service" to expand over time to include an arrangement with a department store for the delivery of items. When a person purchased an item they were offered the service to have someone available at the house to collect the parcel if they were not going to be there. Over time the business both expanded and diversified. As relationships developed with customers, they would suggest other tasks that Cameron could do apart from waiting. In particular the service around car cleaning developed considerably, and he is also involved in doing shopping for people or work around their house. Most recently the business tendered for and won a contract to clean cars for a business. While the waiting service continues to be the core business, Cameron is now fully employed and is at the point of losing his pension as his income grows. The business pays for itself apart from the support workers who are separately funded to provide support for him at home and in the community. If it is required to employ additional help to complete a job due to Cameron being sick, this is paid for through the business.

Figure 1 *Cameron cleaning a car*

As the business grew, the support structure was developed. Cameron lives in his own public housing unit in the community with a community member who shares his house and provides companionship in the evenings. He also has visiting support staff who assist with cooking and other household tasks, and these staff also provide support to Cameron in the SBE. This means there is continuity across the day with all support staff knowing Cameron extremely well, many having worked with him for several years. The service also has a coordinator, who is responsible for ensuring that staff are always available to meet Cameron's needs and to coordinate jobs, invoicing, preparing needed materials, and ensuring that everyone knows what is happening, and are made aware of any changes. This is done electronically through the WhatsApp application, which allows for multiple people to be provided with the same information simultaneously on their phones.

Developing the business

There was a considerable amount of learning over time. For example, restricting the geographical range of the business made it more manageable as well as reducing costs from transport. An image of the business was developed, with both Cameron and the support staff wearing uniforms and the business vehicle having signage of the business on the side. They now employ a coordinator for the business whose role is to negotiate the jobs, ensure the required equipment is available for the support worker involved, communicate with all members of the team, invoice for work done, and report progress to the board of the business. This person is a key safeguard to ensure that easily forgotten issues are not overlooked. For example, in car cleaning it is essential that all of the needed equipment is available and replenished when necessary. A specific person is given this task to ensure that when the staff arrive to take Cameron to his work washing cars, the needed material is always correct. Clearly, the arrangement and support is seen as positive by the staff and supporters as several of them have been involved for five years or longer.

Figure 2 Cameron shopping

Cameron started working at a local yacht club refilling the vending machines and through that process has built relationships with a wide range of staff and club members who are very supportive of him and his business. Several people at the yacht club have noted Cameron has become much calmer and relaxed over time, with very few instances of showing any discomfort. This is a dramatic improvement from his time at school where he was clearly not feeling comfortable. Cameron does his own shopping, using photographs of items needed. He is assisting with cooking his meals, loading the washing machine, helping to hang the clothes on the line, and with other household tasks. All of these skills were unimaginable in the past. He is also engaged in a wide range of community activities.

There were initial costs in setting up the business, such as providing the initial vehicle, purchasing of uniforms, fuel, and many day-to-day expenses. These were borne primarily by the family, but over time the profits from the business were large enough to cover these so that now all business-costs are covered by the business.

When key personnel were asked what they thought were the key aspects of the business the following points were made:

- Cameron and his needs were central to the development of the business.

- A focus on quality of service provided and ensuring reliability.

- A great deal of planning to ensure that quality and reliability could be assured.

- A commitment to the venture being a real business.

- All staff and those involved not only had to have a good relationship with Cameron, but also have a great belief in his competence, have high expectations, and be confident both with Cameron and with the customers.

- Decisions needed to be team decisions so that all involved knew what was going on.

Challenges

To establish and maintain the business a large amount of work, by a group of dedicated people has been essential. A key issue that this arrangement demonstrates is that the service system is not structured in such a way to make such a development easily achievable. In effect, the whole arrangement has been developed by his parents and a group of highly dedicated individuals who gave their own time. Another family, without the level of enthusiasm and commitment, or indeed the financial resources to sustain the initial losses and start-up costs, would find the establishment of a similar arrangement very difficult with the current service system. Even if families are able to obtain an appropriate level of paid support to establish such an arrangement, access to the necessary advice around establishing and maintaining a business, developing a business plan, marketing, and similar business requirements is not readily available for most families.

Carrying out the basic bureaucratic establishment of a business was found to be incredibly difficult. To get an Australian Business Number or a business name, one has to have a range of personal identification documents and normally some links to financial institutions. Many persons with intellectual disabilities do not have easy access to much of these resources. It is also extremely difficult to get access to finance without any credit history, so essentially a person with an intellectual disability establishing such a business needs a family member, or some other means of gaining access to start-up capital.

When the business does start to become successful, the person starts to run into "welfare traps". The loss of pension is the most obvious cost, and the proportion of pension lost for every dollar gained makes this group one of the most highly taxed people in the country. For persons with very high support needs, the loss of a home could have devastating consequences.

Benefits

There are major benefits for Cameron. His community image improved dramatically and he started to be seen as a capable person with his own business. His confidence increased markedly and many of the issues that were prominent through his schooling effectively disappeared. A range of behaviours that were problematic receded and became very unusual. He has achieved a state of financial independence where he is about to lose his pension due to the level of income he receives from the business. He has a range of community relationships, particularly at the yacht club where he is well known and liked.

Figure 3 **Cameron out in his community**

For his family, the change has been profound. He is now an independent person with his own business and, in conjunction with the development of the business, he has also moved into his own home. Both of these changes would almost certainly not have been possible for those in the service system or schools. His parents are very proud of him, and have found that he is a much easier person to live with and interact with. He has also shown his parents and others that he is so much smarter than anyone had previously thought.

The major ongoing benefit is that Cameron has a full life with many relationships, days that are full of meaningful contribution, and an income that allows him to gain financial independence. His image has been transformed from a range of negative roles associated with the service system, to those of a business owner, house mate, and contributor to the community.

Figure 4 *Cameron watering his garden*

For more information, visit http://camcanandservices.org/index.html

JACKmail

JACKmail is a courier service that offers mail pickup and delivery. The business provides collection of mail from a business's Post Office box and delivery to the business location, as well as collection of out-going mail from the business to the post office to be posted. JACKmail operates in the inner southern area of Canberra, five days a week between 8:30am and 12:00pm, and services a total of 15 clients. The service is carried out by Jackson West, with his support worker Philippe who drives the work vehicle, facilitates interaction between Jackson and JACKmail clients, and supports Jackson in all aspects of the work tasks. Operational and administrative tasks such as invoicing, reconciliation, preparing tax statements, creating run sheets, and arranging for vehicle maintenance are carried out by Sally Richards, Jackson's mother and JACKmail owner. Any matters relating to the employment of support staff is coordinated by Hartley Lifecare, a Canberra disability service provider. The business has been in operation for ten years, and Philippe has been supporting Jackson for about nine years.

Figure 5 *Jackson delivering mail to one of his clients*

The genesis of the idea occurred through a discussion between Sally and a small business owner in the area who stated that a mail delivery and pick up service would definitely be something that she would pay for. What followed was in-depth investigation of further details and possibilities through talking with solicitors, accountants, and other social enterprises. Sally's vision was to create meaningful employment and a valued role for Jackson, which was not built on a charity model, but rather on a reputation for a reliable and cost effective service that met a genuine business need. Sally approached a local service provider, Hartley Lifecare, to see if they would be willing to participate and provide staff for the venture. The Chief Executive Officer of Hartley Lifecare strongly supported the proposal and saw it as fitting in well with the aims and objectives of the agency. Hartley Lifecare is a

Canberra-based organisation that has provided accommodation support and respite care for children and adults with physical and complex disabilities and their families in the ACT and region for 50 years. Sally commended Harley Lifecare for their flexibility. Although they had never been involved in a similar arrangement before, they were willing to work with the family to see JACKmail come to fruition.

Jackson West is a 30 year old man who lives in Canberra, Australia. He is the sole employee of JACKmail. Jackson also volunteers at the library and loves music. He has a profound intellectual disability which affects all aspects of his life. He has also been diagnosed with autism. His support worker, Philippe, was a former youth worker who was looking for a sea change. He found out through his wife that Sally was looking for a driver for JACKmail and applied for the job. To him, commencing this role "was an eye opener", as the whole idea of JACKmail was for Jackson to be part of the community. Philippe felt that this had been missing in his previous roles, where he experienced many boundaries to community inclusion. To him, working with Jackson was refreshing, where he could be led by the motto: "Let's not work this way, but work in a different way". To Philippe it is important that both clients, as well as members of the wider community, see Jackson as Philippe's boss, highlighting his capabilities and the contribution that Jackson makes to his community: "There [is] much more to Jackson than their eyes can see."

Philippe has worked with Jackson for almost ten years, although initially, he would never have imagined working in a job for more than two to three years. At the time of the interview he felt it was unlikely he would ever go back to the old way of working. He works 25 hours a week.

Sally is the mother of Jackson and his three brothers. She is a prominent disability advocate, known for her work in setting up an intentional community where Jackson lives, as well as a family governance group.

The continued success of JACKmail can be attributed to a number of factors:

- The business is designed around Jackson and his likes, strengths, and support needs. It is underpinned by a clear vision for his life that includes having a meaningful job and a valued and contributing role in the community. The vision is shared by the family, the support organisation, and Jackson's support workers.

- The business is genuine – offering a real service that is reliable and fulfils a specific need for the clients. About half of the businesses have been a customer of JACKmail since it first started. When customers have opted out, it had been because of relocation out of JACKmail's area, never due to dissatisfaction with the service.

- The business has grown a customer base in a specific geographical area, focusing on southern Canberra. This means that the deliveries remain manageable, whilst maximising revenue through a strategic route. New customers have to be in the exact geographical area. In the past, when the business was growing, other customers were accepted, but JACKmail can now be selective to suit the schedule and Jackson's mobility requirements.

Developing the business

Setting up JACKmail was similar to setting up any other sole trader business, however some aspects of the business were specifically developed to suit Jackson's skills and preferences. JACKmail was listed as Sally's business so that she could employ Jackson under the supported wages system. This is an open employment scheme which provides eligible businesses with an annual subsidy to offset some of the costs associated with employing a person with a disability, including equipment or support. In the case of JACKmail, the subsidy is utilised to cover part of the costs associated with "one on one" support for Jackson.

The revenue generated through the business covers business-related costs, such as purchasing, running, and maintaining the delivery vehicle, worker's compensation, uniforms, and a small wage for Jackson. An important factor contributing to the success and sustainability of the business is maximising income through providing multiple services. JACKmail offers both delivery and pick-up services, which incur separate charges, but can be performed in the same trip.

There are a range of supports in place for JACKmail. These are both formal and informal. Supports are flexible and creative in the way they function – family or alternate staff will fill in if Jackson or his support worker are unavailable for any reason. High levels of flexibility are required to make the business a success. Jackson is a complex young man with complex needs, hence it is important that the job works around his capabilities on any given day.

The people involved in the business know each other well and share a commitment to both Jackson and the business. If Jackson is supported by someone he doesn't know well, he gets very frustrated. For the family, a commitment to the business is prioritised, meaning the family step in if Phillipe, the support person, it is unavailable, putting their own employment second.

The National Disability Insurance Agency that manages the National Disability Insurance Scheme (NDIS) was helpful and supportive transitioning from ACT-based funding to the NDIS. People involved commented that the high profile of JACKmail may have contributed to the agency being very cooperative and flexible, as the positive outcomes for Jackson and the community are widely acknowledged.

Before the roll out of the NDIS, the support person's wage was covered through the supported wage system payment and a small funding package through Disability ACT. Any additional staff costs were covered through the business. The introduction of the NDIS was beneficial for JACKmail. The scheme covered the full over-expenditure of wages for the support person that exceeded the supported wage system payment, which has freed up funds for a new work vehicle in the near future.

Careful and consistent planning is required to build and sustain a business such as JACKmail. This required a strategic, step-by-step approach, taking advice, brainstorming, and researching information. A successful enterprise needs safeguards and systems in place. From the conversation with all stakeholders it became obvious that planning for such an enterprise required resilience, dedication, creativity, and a willingness to do things differently. When Jackson's mother first set up the business,

she provided six weeks of support for Jackson herself, so that she could establish what would be involved before employing support staff.

Figure 6   *Jackson and Philippe at work*

Challenges

Stakeholders have commented that the business runs very smoothly, without a need for further development or improvement. However, they acknowledge the onus on the family to keep the business running smoothly. Sally, Jackson's mother has invested much time and effort in the business and Jackson.

There have been challenges in accessing the sorts of services and supports Jackson needed or wanted, especially in the early stages. Sally described her many years of experiences with services and the limited choice and control awarded to her and her family:

> The default position is 'no' – whatever you're asking for, the answer is 'no you can't have it'. There is always a reason – I mean not a very good reason as far as families are concerned. But it is always about the structure, the philosophy, and the policy, and the parameters of the service provider… it's that old thing of they have a menu and you can choose from the menu. So if it's not on the menu, you can't have it. And if it is on the menu, it might not be being served that day, or they've run out… the typical answers that we get are 'we've run out of money', 'there's a waiting list', 'your son is too young', 'too old', 'out of area', 'has the wrong kind of disability', 'too disabled', 'not disabled' [enough], or 'we don't provide this service'.

Benefits

JACKmail provides a range of benefits. His work gives Jackson a purpose and a valued role in the community, and provides a regular everyday activity. In conjunction with his living arrangement, JACKmail provides opportunities for Jackson to interact with a number of people from the wider community. Involvement in JACKmail and Jackson's life has given Phillipe, his support worker, steady and fulfilling employment. He knows Jackson well and considers him to be a friend. In setting up JACKmail, Jackson's mother has been able to show that an individualised approach to creating meaningful community participation through employment is possible, but it took strong advocacy, dedication, and time to make it happen. Families and services need to work alongside each other to achieve these results – doing "with", as opposed to doing "for".

> "There is a real difference between somebody giving you a job and having a job. Nobody was ever going to give Jackson a job. It didn't mean that he couldn't have a job, but it had to be a job that was his job. And I think that's possible, for everybody…. The potential for other people to create person-centred employment is limitless, it's absolutely limitless. It just has to be looking at who the person is, what they can do, what they want and what they like?"

For more information, visit http://jacksonwest.org/jackmail

Belonging Matters has developed a number of videos in a series titled "Talks That Matter", including one around JACKmail, available at https://www.youtube.com/watch?v=90PQjH7pD1U&feature=youtu.be

The Really Useful Recyclers

The Really Useful Recyclers was established in 2015 around two young men, Joshua and Courtney. They collect papers, boxes, and bubble wrap each week from a roster of shops and businesses and turn them into firelighters, decorative artworks, bowls and platters, jewellery, and a Christmas tree particularly popular at the time of interview (towards the end of 2016).

Figure 7   Courtney showing his skills

The Really Useful Recyclers sell their products primarily online, at markets, and by word of mouth. They also exhibit and sell artwork at several art shows. When they go to markets, Courtney likes to demonstrate his paper recycling skills while Joshua prefers to engage from a "safe" distance behind the stall.

The Really Useful Recyclers is a way to provide meaningful work for two young men who have autism spectrum disorder. Joshua, 18 years old, and Courtney, 19 years old, live in their family homes. As they live at a distance from each other, they tend to work separately on the products for the Really Useful Recyclers. Joshua's mother, in conjunction with Courtney's mother, coordinate the process of production. Joshua's verbal ability is quite structured and Courtney has some verbal ability, however both communicate in other ways as well.

Courtney attends a range of community venues, including a community garden, the library, and the youth centre. He plays all-abilities football and enjoys music, computer games, and trampolines. Courtney prefers to prepare the initial "donuts", made of compressed, shredded paper, and "biscuits", made by rolling and winding sheets of paper.

Joshua's mother said his transition from school had been going really well, partly because of the planning and getting the Really Useful Recyclers set up to provide

work that Joshua liked. He is very good at using the biscuits and donuts to compose artworks and decorations from templates prepared by his mother. Working from home for the Really Useful Recyclers means that Joshua is not expected to fit into an environment where not everyone "gets" him. His support workers can adjust things to his needs when he works in the home.

Figure 8 *Joshua at work for The Really Useful Recyclers*

Joshua's mother had the original idea for the business. She connected two of his favourite characters, Thomas the Tank Engine and Wall-E, as inspirations to find ways to make usable products from waste newspaper. Joshua's and Courtney's mothers met when the young men attended an early intervention program together as young children. Their continued friendship resulted in Joshua's mother approaching Courtney's mother to join them in the business. The families live some distance from each other, but there is regular personal and electronic communication between the families The families work well together and respect each other.

Both families were clear that the main reason for setting up the Really Useful Recyclers was to provide meaningful work for the young men. Joshua's mother stresses that it is important to be proactive and have a positive attitude to enable Joshua and Courtney to be engaged and productive. She wants Joshua to have positive and valued social roles so he will be appreciated by others.

> "Jump into their minds to tap into what they think they would like to do, embrace what they are about, what they are interested in."

Developing the business

Joshua's mother continues to be the driving force behind the Really Useful Recyclers. She provides inspiration for various new products, and then prepares prototypes for Joshua, Courtney, and their support workers to use as templates. The young men both receive considerable support from their families. Both mothers identify family support as vital for the Really Useful Recyclers. They said the business takes hard work, inspiration, and financial support from the limited finances of the immediate families.

Both Joshua and Courtney work from home most of the time. The importance of support workers to the Really Useful Recyclers is highlighted by families and staff alike. The selection and training of support workers is directed by the mothers. New staff work buddy-shifts so that they all know each other's roles, and can change shifts to suit any developments in the young men's lives. Support workers need to be committed to focussing on the business and the lifestyles of Joshua and Courtney. They also need to be flexible, consistent, and patient, and to have a positive and strengths-based attitude.

Joshua's mother wants his support workers to enjoy their roles, to try new things, and to feel empowered in their job. She gives staff a degree of autonomy to get things done. One support worker, who had known Joshua in school, said that the best thing about the Really Useful Recyclers was seeing Joshua focussed and concentrating, and enjoying his work.

Courtney's mother does not use a service organisation to source support workers. Instead she advertised for a person of the same gender and similar age to Courtney. A second support worker is female, and provides more creative support to Courtney.

Another important source of support for the Really Useful Recyclers has been the Men's Shed. Much of the equipment used by Joshua and Courtney to produce the donuts and biscuits has been constructed by volunteers at the Men's Shed. Men's Shed also provided special items, such as the wooden stand for the 600mm high Christmas tree made from biscuits, which was auctioned at the Men's Shed Fair in 2016.

Challenges

The Really Useful Recyclers business structure had not been determined at the time of the case study. The families are considering options and consulting with various expert parties. It is hoped this will increase both the sustainability and the profitability of the business.

The Really Useful Recyclers is a relatively new business, and Joshua and Courtney are young men. There is currently little provision within either the business or their lives for major changes such as illness, or loss of their parents. Planning tends to be more or less ad hoc occurring when the two families meet every few months.

"Burnout" is a possible risk for the business. Joshua's mother in particular spends enormous amounts of time and effort on the business. She transports Joshua and the products to fairs and markets, travels to meet with Courtney's mother and people from the Men's Shed, buys supplies for the business, and helps with the collection of the recyclable materials from a range of regular suppliers. Joshua's mother also designs the new products, makes prototypes, and prepares step-by-step training guides for the production of each item. She is largely responsible for the social media and print media coverage for the business.

There appears to be a problem with limited outlets for selling the paper art products. A reliance on word of mouth and markets reduces the income-generating capacity of the business, which is not yet covering costs or generating a surplus. In addition, the imminent roll-out of NDIS WA may have a detrimental effect on the funding of the support staff for the men, which can have a further impact on the economic sustainability of the Really Useful Recyclers, hence affecting the valued, productive, and meaningful roles Joshua and Courtney have through the business.

Benefits

For community participation and inclusion, Courtney does some of his work at the local community centre where he also attends some recreational sessions. Joshua goes to the Men's Shed each week, and people from there have been most helpful in constructing some of the equipment used by Joshua and Courtney.

The young men have improved their manual, social, and communication skills while working in their business. Families and support staff agree that both young men have more community involvement and recognition than they have had previously, with this particularly provided through the businesses they service as they collect materials for recycling. Courtney's support worker describes him as having a sense of purpose, believing that Courtney is both known and respected in the local community. Joshua and Courtney show more confidence in dealing with change, for example when tackling new product lines such as the highly popular Christmas trees, a line of jewellery, and key rings.

Figure 9 *Joshua and Courtney with some "donuts"*

Joshua and Courtney are not yet 20 years old. As they mature and develop more skills, particularly around communication, self-determination, and decision-making, one or both may decide that this is not the work they want to do. However, the discipline and learning experiences entailed in the Really Useful Recyclers is likely to stand them in good stead whatever they decide for their future.

For more information, visit https://www.facebook.com/thereallyusefulrecyclersWA/

Chirpy Bird Seed

Chirpy Bird Seed supplies quality seed mixes for "backyard birds". The business is based in the family home of the proprietor, Josef, who has a disability. His mother and a support worker employed through a disability service provider specialising in individualised services, are assistants in the business. The seed is sold by delivery, through markets, or by third parties as the product cannot be sold from the home.

Figure 10 Some of Chirpy Bird Seed products

The family began thinking about different options for Josef to have a meaningful vocation when he was still in school. During an annual planning meeting Josef's Local Area Coordinator (LAC) suggested that Josef starting his own business could be an option, and this "planted the seed". Josef's mother emphasised that they were always committed and passionate for him to have "a meaningful and contributing life". However, this was very restricted by the need for support and limited funding available. This was why they initially explored the sheltered workshop option. Josef did start work at a sheltered workshop as part of work experience through school for one semester, and then for a couple of months after he left school. The needs of others at the sheltered workshop often interfered with his needs and his work. This realisation strengthened their commitment to pursue his aspiration of running his own business.

Developing the business

The business had been in existence for about 6 months at the time of the case study, with investigation of different options having taken place for about 3 months prior to establishment of the business. Much planning and research went into the start-up. Bird seed was not the original business idea. Initially, preparation of cakes and other food items was considered before deciding that it was not really a viable business for Josef. After a few other business ideas, bird seed just "popped up" as an idea one day, and led to a lot of research around different types of bird seed, of which there are many!

There were numerous challenges around the start-up, including obtaining the right permits and approvals. The business was not growing as fast as they wished and they hoped for an increase in business and orders. As Josef said: "It would be nice if more people wanted my product." Many people supported the development of Chirpy Bird Seed. When they started researching their options they would trawl through the internet to identify people or companies from whom they could seek advice. Many people obliged, some as far afield as the USA who provided advice around edible glue. Other times they would be referred to others through people they contacted to obtain the advice they sought. This had been a productive learning curve and they met many wonderful people Josef may not otherwise have met.

An important supporter for Chirpy Bird Seed was a large company that had shown Josef around their factory and production facilities. They also donated substantial merchandise, including seeds, which enabled Josef to initially set himself up. The sister company also donated moulds and provided advice on seed mixes that were popular. They committed to continue supplying Chirpy Bird Seed with produce at a reduced wholesale price. In addition, an avian veterinarian, considered an authority in his field, as well as other bird retailors, provided substantial advice around seeds and mixes that are appropriate for different native birds. They were also advised that they may want to market the products for "backyard birds" rather than "wildlife birds" to avoid environmental protection concerns.

Additional advice was obtained from their local Small Business Development Centre. They developed an initial business plan based on a template available from the website and sought advice in person. The Centre focused on the business side, which was its role, and the need for making a profit and increasing volumes. The support and suggestions the Centre provided were not always suitable or realistic strategies for Chirpy Bird Seed. Its main goal is for Josef to have a meaningful and productive vocation, and making some money is almost an added bonus. Josef has met a lot of people through Chirpy Bird Seed. He enjoys being his own boss and is proud of owning his own business. He loves talking to people, talking about his business, and seeking advice from others. His family also shares his pride.

Challenges

An initial hurdle related to the regulations of the business permit they obtained, which restricted retailing from their home. Instead, they rely on deliveries or sales through markets or third parties. The mileage cost of delivery can be prohibitive, as well as the stall fee at markets. They have looked into a range of different grants to support the business, but had not identified anything suitable at the time of the interview. Josef does not meet the eligibility criteria for the start-up grant to support persons with disabilities to start their own business. That scheme requires registration with Centrelink as well as a Disability Employment Service. However, Josef's support needs have been assessed as being too high to qualify for support from a Disability Employment Service.

The main future challenges for Chirpy Bird Seed, apart from having to organise the appropriate permits, insurances, and other regulatory requirements, is to increase the volume of sales. They are achieving only a third of the volume they would like. One challenge is the difficulty of generating repeat business. Some produce are sold through a third party, but their mark-up makes Chirpy Bird Seed less competitive compared to the other brands they stock.

With limited funding available, including the hours of support Josef can access in a week, his mother and grandparents have provided much support in setting up, as well as the running of the business. His mother contributes at least 10 hours a week. His grandparents assist with deliveries as well as cleaning the buckets they re-use for the bird seed. There are also others who are supporting Chirpy Bird Seed, including friends of the family who have created jigs for Josef to use, and businesses in the local area that are supplying their empty buckets from cheeses and other products for Josef to collect and re-use for the birdseed mixes.

Benefits

Figure 11 Josef and some Chirpy Bird Seed products

Having his own business gives Josef a lot of flexibility and control, and reflects his concern for the environment, health, and safety. For example, as a result of researching products, they use pharmacy grade charcoal as they know that some of the products on the market include carcinogens. While it is cheaper and simpler to use some products, Josef is not in favour of using any product perceived as dangerous. Running his own business has also opened up a lot of other opportunities for Josef to do what he loves. For example, he has been invited to present at different events, including as a keynote speaker at a youth conference for school-aged persons with disabilities. Such additional opportunities are invaluable. It is also evident that since setting up the business, Josef has undergone considerable personal growth and become much more independent.

Contemplating the future, Josef would like Chirpy Bird Seed to provide employment opportunities for some of his friends who may not have meaningful vocational opportunities elsewhere. However, that will need to be organised appropriately, including obtaining sufficient support, so it does not detract from his support. There are also regulatory issues which need to be overcome. They had looked into these concerns at the time of the interview, but decided there were more pressing issues with which they were dealing at that time.

For more information, visit https://www.facebook.com/Chirpy-Bird-Seed-1721940888083039/

Discussion

and conclusion

Discussion and conclusion

There is strong evidence that persons with disabilities in Australia experience low rates of participation in employment and high levels of unemployment and associated poverty. There is a close association between more severe levels of impairment and lack of participation in the labour market. This situation is not ameliorated by provision of the DSP alone, since the DSP rate is below the poverty line. In these areas, Australia compares unfavourably with almost all OECD members that constitute, arguably, countries that share important political and economic characteristics and advantages with Australia. It must be acknowledged that data relating to employment of people with disabilities across all OECD member countries is of uneven quality. Nevertheless, these outcomes are surprising because in the 1980s Australian Government disability policy and NGO employment services were early adopters of international initiatives promoting open and supported employment. There is much evidence of innovation and achievement in disability employment policy and practice in early literature. It is beyond the scope of this project to look more closely at the impact of more recent disability employment policy and practice, however important this is.

Australian disability data incorporate a wide range of types of disability and levels of functioning that vary from mild to severe impairment. Our specific focus in this research was adults with intellectual disabilities, with high or very high support needs. In Australia, high support need commonly reflects involvement in some form of sheltered employment or day activity service, which are usually non-vocational and don't lead to full time engagement. Very high support needs means attending an adult day centre, or possibly having very little structured activity.

Through personal contact, we became aware of a small number of family-inspired efforts to enable their sons (in these cases) to engage in work based on small businesses which provided some income and, most importantly from the families' perspectives, enabled their sons to participate in the community and develop relationships with people they encountered in their work. A case study approach of a small number of these initiatives seemed to us to be a productive way to learn more.

In developing a research project, we decided to give these approaches a "name". The term "Small Business Enterprise" (SBE) model was coined which captured both the small business focus and the obvious enterprise we encountered in the study. It would have been accurate to also incorporate something of the remarkable initiative shown by parents in the SBEs they developed. We selected four SBEs for the case studies. Two of these had been in existence for around a decade and were well developed. Two had been in existence for a couple of years and clearly were in earlier stages of development.

The researchers were interested in examining relevant academic literature, to see the extent to which these approaches were being adopted and were the subject of research and investigation. Four criteria were identified to provide guidance. These criteria remained central throughout the study and we believe provide the key characteristics of SBE.

A systematic search of the international formal literature identified only one article that focused on the approach. On the other hand, there was an extensive

literature over many years that explored self-employment developments for adults with disabilities. This was very different from the SBE that we were investigating. Commonly, self-employment was adopted by persons with sensory and physical impairments rather that intellectual, and often embedded in substantial enterprises. Nevertheless, this literature was inspiring in its own right, clearly indicating the benefits of work and career for persons with disabilities.

A starting point for addressing findings from the study is discussing how each of the four SBE criteria became operationalized and the emergence of related issues.

1. SBEs were highly individualised and focused.

All four SBEs were clearly built around the five participants. This was clearest in the two more developed SBEs that were "shaped" to fit their capacities, which was also a feature of the two more recent SBEs. All five were willingly engaged in the business activities. There was a high consciousness amongst the various support people, including parents in particular, to keep the focus of the SBEs on the individual young men.

2. Ownership and control of the SBE was vested in the person with disabilities, and those whose relationship to the person was very close. In the event, this consisted of a parent/s.

In the four SBEs, parents established, maintained, and supported each SBE. In one SBE, parents were working on broadening the involvement of others in the arrangement although their continuing involvement remained crucial. In the medium to long term, the style and nature of parental leadership will necessarily change, requiring the development of a strategy to ensure the ongoing influence of support from people who have personal involvement who are not necessarily remunerated. This is a fundamental safeguard for individualised arrangements and there was a clear awareness of its importance. At the same time, one of the SBEs illustrated how an NGO provided important support to the arrangement, indicating how more flexible NGOs can provide strong support to SBEs without having to "own" them. In the disability sector, parents have devised ways to set up arrangements to provide personal connections between their sons and daughters with disabilities and other people. Examples include "Microboards" and "Circles of Friends" that enable the development of personal supports that may supplement the crucial involvement of family members. This is an important challenge to ensure sustainability. The NDIS may become a crucial partner through flexible funding that is supportive of continuing family involvement in contrast to the tendencies of some NGOs to assume control and inadvertently reduce family influence.

In the case of the two SBEs that had been operating for around a decade, the involvement of families had also established homes for their sons that reflected a high degree of individualisation and focus. These are excellent examples of the application of such principles in the closely connected address of individual supported living and SBE. The interconnected manner in which these two fundamental needs were being addressed was very impressive and provides an inspirational approach for adults with disabilities and, in their cases, very high support needs.

3. The SBE generated some income, but it was not essential that it was totally self-supporting or profitable.

Financial support for the continuation of the SBEs is an important issue. Income came from more than one source including from the SBE, the DSP, and income in kind, for example from NGO support. Time will tell whether the SBEs can become completely self-supporting, and whether this should be a primary objective. In fact it has become apparent that there are challenges associated with generating greater amounts of income. One potential problem is a substantial reduction in the DSP once income crosses a threshold. Similarly, increased income may eventually lead to loss of access to subsidised public housing. Either of these events could have serious negative effects on the quality of life of the person with disability and increase financial burden on their family.

The emerging "culture" of SBE for persons with disabilities who have high or very high support needs would suggest that financial independence is important but other benefits may be seen as equally, or even more important. As such, it may be warranted to investigate further the interrelationship between SBEs and social enterprises, noting that a social enterprise in itself is not necessarily an SBE. However, SBEs can be set-up as a social enterprise, as, for example, JACKmail was. This does not only relate to the importance of "values" to both SBEs and social enterprises, but also to the importance of accessing a range of supports, including grants.

4. The SBE encouraged and facilitated the development of community engagement and relationships with people in the community.

Reading the accounts of the four SBEs makes it very clear that the benefits that come from community inclusion and participation are major objectives. Work is one of the most important "connectors" for us all and serves to break down barriers as the case studies indicated.

A key consideration for the development of similar initiatives is developing ways to assist families to establish SBE's. These initiatives all shared a major investment of time, energy and resources from the family and this will not be possible for all persons with disabilities and high support needs. Similarly, when the initiatives were supported by NGO's these NGO's demonstrated a high degree of flexibility to incorporate the support within their funding guidelines. Direct support for such initiatives within funding guidelines could open up possibilities for new and creative ways to establish and support such initiatives.

Future research on SBEs would benefit from engagement with female participants with disabilities. We have recently become aware of other SBE arrangements developed around young women with intellectual disabilities. Given the very limited research base of SBEs identified in this study, it is clear that it will be important to build the evidence base of this emerging employment pathway for persons with disabilities and high or very high support needs.

It would also be beneficial to expand the research into SBEs to develop a quality framework which may include themes and attributes illustrating the core components of strong arrangements. Such a framework will assist in both planning new arrangements, by identifying what would be required to develop a quality SBE, as well as constitute an evaluation or review framework for assessing the quality of existing SBEs and identifying areas for improvement. As illustrated by contrasts between

the two well-established and two more recent arrangements, there are substantial differences between the establishment and continuation of a business, and a future framework will need to take into account these differences.

Finally, we are very grateful for the wholehearted cooperation of the participants from the four SBEs. We found their aspirations, efforts, and stories inspirational and believe more work is needed to extend the SBE model, especially for persons with high support needs. One of the SBEs has been documented in a video that is referenced in the case study and we encourage readers to view it to learn more about this approach.

SBEs are a valuable option for persons with disabilities and high support needs by enhancing community inclusion and participation, and the development of valued social roles associated with work.

Glossary
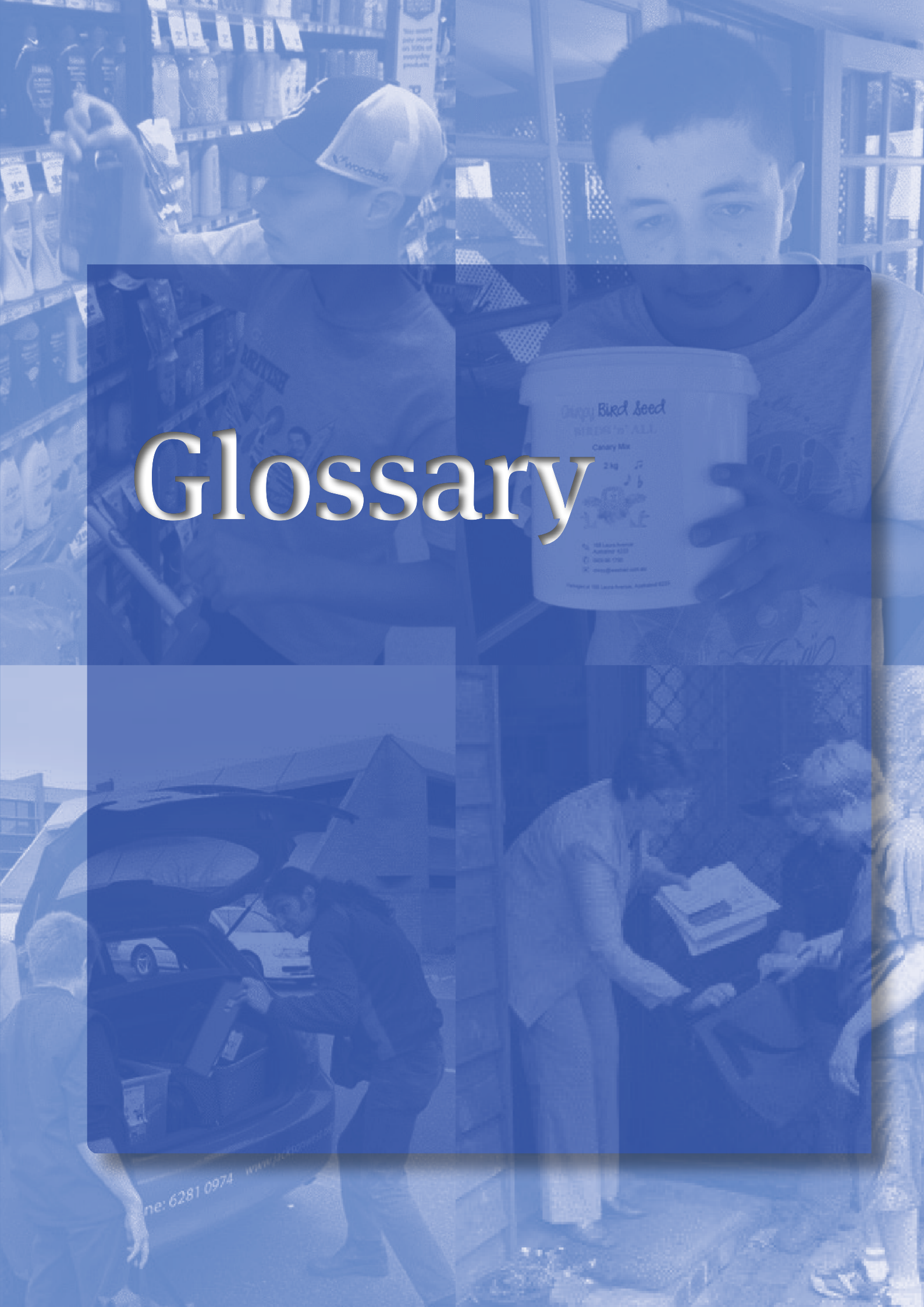
Glossary

Adult day centres/programs

Adult day programs are centre-based and/or community-based. They are disability support programs or services for adults who are unable to engage in regular employment activities. These may be funded through different government programs or schemes, such as Alternatives to Employment or Community Access.

Australian Disability Enterprise (ADE)

Not for profit organisations providing supported employment opportunities to persons with disabilities. ADEs provide a wide range of employment opportunities and they operate within a commercial context. They are most closely related to what were known as sheltered workshops and/or social enterprises.

Circle of Friends/Circle of Support

Any group of people who meet regularly to help an individual accomplish life-objectives, acting as a "community" for that person who, for whatever reasons, cannot achieve those objectives on his/her own or may not be able to ask others for help.

Disability Employment Services (DES)

Disability Employment Services (DES) are specialist service providers to support persons with disabilities to find and maintain a job in open employment in Australia. They may be for-profit or not-for-profit organisations.

Disability Support Pension (DSP)

The DSP is the social security payment in Australia for adults with disabilities assessed as having severe activity limitations that affect their capacity to maintain paid employment. Part-pension is also available for people who are able to do some work, but unable to earn a full-wage.

Intentional Community

Within the context of this report, an intentional community refers to residential communities developed to enhance the social and community inclusion of a relatively small number persons with disabilities who may be supported by a larger group of persons without disability who may reside in the same co-operative.

Local Area Coordinator/Local Coordinator

Government officers employed through state disability services and now largely incorporated into the National Disability Insurance Scheme in Australia. They support people with disabilities and their families to identify, plan, and address needs for specialist and mainstream services.

Men's Shed

A Men's Shed is a community-based, non-profit, non-commercial organisation that is accessible to all men, and provides a safe, friendly, and welcoming environment where men can work on meaningful projects at their own pace, in their own time, in the company of other men. A major objective is to advance the health and wellbeing of their male members and to encourage social inclusion.

Microenterprise

"[A] very small enterprise owned and operated by poor people, usually in the informal sector....10 or fewer workers, including the microentrepreneur and any unpaid family workers" (Conroy et al., 2010, p269). These ventures tend to focus more heavily on economic benefits rather than increased community participation, engagement, and the development of relationships.

Microboards

A formal not-for-profit organisation of family, friends, and advocates established and maintained to provide support for a person with disabilities and high support needs. It may be a more formalised 'Circle of Friends'.

National Disability Insurance Scheme (NDIS)

A national scheme to support the access of people with disabilities to reasonable and necessary supports. It is being phased in across Australia, with the first trial sites launched on 1 July 2013 and full implementation anticipated by 2020. It is the most significant change in Australian disability services for decades and is managed by the National Disability Insurance Agency (for more information, visit https://www.ndis.gov.au/index.html). Western Australia has opted to manage its own NDIS-based scheme, unlike all other Australian jurisdictions.

Open employment

Variously referred to as competitive, open, mainstream, integrated community, or supported (in the USA) employment. Employment in a mainstream enterprise, with or without initial and/or ongoing assistance from a Disability Employment Service provider.

Sheltered employment

See Australian Disability Enterprise (ADE).

Small Business Development Centre

Free service to assist start-up, growth, and development of small and medium sized businesses within a specific jurisdiction.

Small business enterprise (SBE)

These are defined in this Report as businesses that meet the following criteria:

1. Highly individualised and focused.

2. Ownership and control are vested in the person with disabilities and those whose relationship to the person is very close. In this Report, this consisted of a parent/s.

3. Generates some income, but not necessarily totally self-supporting or profitable.

4. Encourages and facilitates the development of community engagement and relationships with a range of people in the community.

Supported employment (in Australia)

This is employment provided by an Australian Disability Enterprise (ADE), formerly known as sheltered workshops, funded under the Disability Services Act 1986. ADEs are commercial enterprises which provide employment opportunities for persons with disabilities, for whom competitive employment at, or above, the relevant award wage is unlikely, and who need substantial ongoing support to obtain or retain paid employment because of their disabilities.

Supported self-employment

Self-employment is a form of open employment where individuals work for themselves, sometimes as a sub-contractor or franchise holder. In many cases, the main object is to earn a living from the business. Hagner and Davies (2002) used the term "supported self-employment" to describe businesses very like SBE that included individually-tailored approaches, owner control, and income generation that resulted in increased community connections.

Supported Wage System

Productivity-based wage for persons with disabilities where their salary is matched to their independently-assessed productivity. For example, if a person has been assessed as working at 50 per cent productivity of a typical worker, his or her wage would be 50 per cent of the award. The system also allows employers to access specific support and grants to facilitate the employment of persons with disabilities.

WhatsApp

"WhatsApp" is a messenger application that enables easy communication between a group of people, such as persons with disabilities, their families, and their support staff, via smart phone, computer, or tablet.

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