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Promoting Training and Employment Opportunities for People with Intellectual Disabilities: International Experience

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Promoting Training and Employment Opportunities for People with Intellectual Disabilities: International Experience

Abstract
The rights of people with disabilities have been given new attention with the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in May 2008. The provisions of the CRPD contribute to other international standards concerning persons with disabilities, signalling a dramatic shift in international policy terms. In relation to training and employment, for example, states are called on to provide opportunities for disabled people alongside non-disabled people.

Many countries have already declared their commitment to the goal of inclusion of persons with disabilities through ratification of the CRPD, while others have signed it with a view to ratification. Many have also ratified ILO conventions, committing themselves to the goals of equal opportunity and non-discrimination.

People with intellectual disabilities are entitled to benefit from the provisions of the CRPD and ILO Convention concerning the Vocational Rehabilitation and Employment (Disabled Persons), 1983 (No. 159), as well as people with other kinds of disabilities. Yet, they are frequently not well placed to gain from this changed emphasis on inclusion. In many developing countries, in particular, they are often excluded from school and deprived of opportunities to acquire relevant vocational skills at all, presenting further disadvantages when it comes to seeking jobs. Yet, experience in many countries shows that, with the right training, support in the workplace as required, and the right opportunities, they can make valued contributions in the workplace and to a country's economy.

Measures to open employment opportunities for this group of persons with disabilities in line with the CRPD and ILO Convention No. 159 can build on extensive experience in recent decades in developing new approaches to training and employment. The review of international experience carried out for this working paper highlights good practice in supporting people with intellectual disabilities in integrated employment settings. Evidence clearly points to better outcomes for employees with intellectual disabilities, when they work in integrated settings, with appropriate supports.

The aims of this paper are to: examine changes over time in the understanding of intellectual disability and the capacity of persons with disabilities to learn; provide an international overview of employment options for people with intellectual disabilities, with special emphasis on Supported Employment (SE) models; examine and critically analyse from a research perspective examples of SE across a range of low- and high-income countries; and make recommendations for the expansion and future development of inclusive employment options for this population. Section 1 provides a brief overview of the shift from classifying people with intellectual disabilities on the basis of IQ bands to a support needs 2 framework. It then explores the impact of research initiatives that demonstrated the learning capacity of people with intellectual disabilities in a work environment. Section 2 discusses the range of employment models currently accessed by people with intellectual disabilities in countries around the world. It highlights that, despite the emergence of a number of more inclusive practices, the predominant model continues to be sheltered employment in segregated settings, and that a high proportion of people with disabilities are unemployed. Section 3 reviews recent and emerging developments in promoting training and employment opportunities for people with intellectual disabilities, drawing from examples in both high- and low-income countries, with reference to factors facilitating and posing challenges to the spread of supported employment. The findings of research on these developments are summarized. Section 4 examines the policy implications of research findings and draws

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some conclusions about the way forward. The Working Paper has been informed by the report of the ILO/ Irish Aid sub-regional conference People with Intellectual Disabilities – Opening Pathways to Training and Employment, held in Lusaka, Zambia 9-11 March 2010 (ILO, 2010a), and the accompanying Lusaka Declaration People with Intellectual Disabilities: Achieving Full Participation in Training and Employment (ILO, 2010b).

The views of several individuals with intellectual disabilities on what work means to them are presented in different parts of the report, so that their voices are reflected, in line with the self-advocacy movement which is gaining momentum.

Keywords
people with disabilities, United Nations, UNCRPD, intellectual disabilities, employment, ILO, training, international, inclusion

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Promoting training and employment opportunities for people with intellectual disabilities: International experience

Trevor R. Parmenter

Skills and
Employability
Department

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Preface

The primary goal of the ILO is to contribute, with member States, to the achievement of full and productive employment and decent work for all, including women and young people, a goal embedded in the ILO Declaration 2008 on *Social Justice for a Fair Globalization*,[1] and which has now been widely adopted by the international community.

In order to support member States and the social partners to reach this goal, the ILO pursues a Decent Work Agenda which comprises four interrelated areas: respect for fundamental worker's rights and international labour standards, employment promotion, social protection and social dialogue. Explanations of this integrated approach and related challenges are contained in a number of key documents: in those explaining and elaborating the concept of decent work,[2] in the Employment Policy Convention, 1964 (No. 122), and in the Global Employment Agenda.

The Global Employment Agenda was developed by the ILO through tripartite consensus of its Governing Body's Employment and Social Policy Committee. Since its adoption in 2003 it has been further articulated and made more operational and today it constitutes the basic framework through which the ILO pursues the objective of placing employment at the centre of economic and social policies.[3]

The Employment Sector is fully engaged in the implementation of the Global Employment Agenda, and is doing so through a large range of technical support and capacity building activities, advisory services and policy research. As part of its research and publications programme, the Employment Sector promotes knowledge-generation around key policy issues and topics conforming to the core elements of the Global Employment Agenda and the Decent Work Agenda. The Sector's publications consist of books, monographs, working papers, employment reports and policy briefs.[4]

The *Employment Working Papers* series is designed to disseminate the main findings of research initiatives undertaken by the various departments and programmes of the Sector. The working papers are intended to encourage exchange of ideas and to stimulate debate. The views expressed are the responsibility of the author(s) and do not necessarily represent those of the ILO.

José Manuel Salazar-Xirinachs
Executive Director
Employment Sector

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[1] See http://www.ilo.org/public/english/bureau/dgo/download/dg_announce_en.pdf

[2] See the successive Reports of the Director-General to the International Labour Conference: *Decent work* (1999); *Reducing the decent work deficit: A global challenge* (2001); *Working out of poverty* (2003).

[3] See http://www.ilo.org/gea. And in particular: Implementing the Global Employment Agenda: Employment strategies in support of decent work, "Vision" document, ILO, 2006.

[4] See http://www.ilo.org/employment.

Foreword

People with disabilities include persons with physical, sensory, intellectual and mental impairments. While this understanding is reflected in ILO international standards relating to persons with disabilities since 1955, the ILO has only recently focused specifically on training and employment opportunities for persons with intellectual disabilities, reflecting the emerging understanding/awareness of their status and rights as citizens.

With the entry into force in 2008 of the UN Convention on the Rights of Persons with Disabilities (CRPD), whole societies are changing the way in which the rights and requirements of people with disabilities are catered to in laws, policies, programmes and services. Moving from an approach that segregated disabled people from the rest of society, including in education, vocational training and employment, steps are now underway to open access to the mainstream, to general services and to the general labour market. Everyone stands to gain from this new approach, as people with disabilities are enabled to take their place as citizens on an equal basis with others and make their contribution to their communities and the wider society in which they live.

People with intellectual disabilities as well as people with other kinds of disabilities are entitled to benefit from the provisions of the CRPD and from other international labour standards, such as ILO Convention concerning Vocational Rehabilitation and Employment (Disabled Persons), 1983 (No. 159). Yet, they are frequently not well placed to gain from this changed emphasis on inclusion. A major hurdle they have to tackle comprises the inaccurate stereotypes and mistaken assumptions of their capacities and protective, at times negative, attitudes towards them. As a consequence, people with intellectual disabilities miss out on opportunities of education, training and full participation in the labour market and in society more generally.

This international review of research and experience around the world shows that, with the right training, support in the workplace and targeted opportunities, people with intellectual disabilities make valued contributions in the workplace. It is hoped that this working paper will encourage further joint-action by governments, employers, trade unions and civil society so as to open the doors of opportunity that will bring people with intellectual disabilities in from the margins of society.

Professor Emeritus Trevor R. Parmenter, University of Sydney, was the author of this working paper, which was edited by Barbara Murray, ILO Senior Specialist on Disability. Comments and feedback provided by Debra Perry, ILO Senior Specialist in Disability Inclusion are much appreciated. Anna Kealy, Jo-Ann Bakker, Jane Auvre and Elodie Dessors made valuable contributions in copy editing, formatting and finalizing the document.

Christine Evans-Klock
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Contents

Page

PREFACE ..... **I**

FOREWORD ..... **III**

ABBREVIATIONS AND ACRONYMS ..... **VII**

INTRODUCTION **1**

1. PEOPLE WITH INTELLECTUAL DISABILITIES **3**

1.1 IDENTIFYING PEOPLE WITH INTELLECTUAL DISABILITIES 6
1.1.1 IQ testing *6*
1.1.2 Support needs framework *7*
1.1.3 Relevance to training and employment programmes *7*
1.1.4 Cultural considerations *8*
1.2 LEARNING AND WORKING CAPACITY 9
1.2.1 Normalization, deinstitutionalization, community living and working *9*
1.2.2 Groundbreaking work of Marc Gold in the US *10*

2. EMPLOYMENT OPTIONS **11**

2.1 DAY PROGRAMMES/CENTRES 12
2.2 SHELTERED WORKSHOPS 13
2.3 SUPPORTED EMPLOYMENT 15
2.3.1 Supported jobs model *16*
2.3.2 Enclave model *18*
2.3.3 Mobile crew model *18*
2.3.4 Benchwork Model *19*
2.3.5 Summary of SE models *20*
2.4 CUSTOMIZED EMPLOYMENT (CE) 20
2.5 SELF-EMPLOYMENT, SELF-DIRECTED EMPLOYMENT, MICRO-ENTERPRISES 22
2.6 SOCIAL FIRMS 23
2.7 COMMUNITY ECONOMIC DEVELOPMENT (CED) 24
2.8 EMPLOYMENT OPTIONS - SUMMARY 25

3. DEVELOPMENT OF SUPPORTED EMPLOYMENT INITIATIVES **26**

3.1 HIGH-INCOME COUNTRIES 26
3.1.1 United States *26*
3.1.2 Australia *27*
3.1.3 Canada *28*
3.1.4 Finland *29*
3.1.5 Ireland *30*
3.1.6 The Netherlands *31*
3.1.7 New Zealand *33*
3.1.8 United Kingdom *34*
3.1.9 Other European Countries *37*
3.1.10 Examples from Asia *38*
3.2 MIDDLE-INCOME COUNTRIES 40
3.2.1 Example from Asia *40*
3.2.2 Example from South America *41*
3.3 LOW-INCOME COUNTRIES – EXAMPLES FROM AFRICA 42
3.3.1 Examples from South Africa *42*

3.3.2 Example from Zambia *44*
3.4 WHAT MAKES FOR SUCCESSFUL INCLUSIVE EMPLOYMENT? 45
3.4.1 Barriers to participation *45*
3.4.2 Preparedness of individuals with disabilities *45*
3.4.3 Individualized financial support *46*
3.4.4 School to work transition initiatives *46*
3.4.5 Characteristics of successful programmes *47*
3.4.6 Workplace characteristics *52*
3.4.7 Outcomes *54*
3.4.8 Concluding remarks *57*

4. MOVING FORWARD 58

4.1 POINTERS FOR POLICY DEVELOPMENT 59
4.1.1 National level *60*
4.1.2 Regional level *62*
4.2 IN CONCLUSION 62

BIBLIOGRAPHY AND USEFUL LINKS 64

Boxes

BOX 1.1 WHO WE ARE, WHAT WE WANT. 3
BOX 1.2 VOICES OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES: MR QUINCY MWIWA. 4
BOX 1.3 DEVELOPMENT OF SELF-ADVOCACY GROUPS: AFRICA 5
BOX 2.1. MOVING TO SUPPORTED EMPLOYMENT - WITH EXTERNAL SUPPORTS 17
BOX 2.2. SUPPORTED EMPLOYMENT WITH 'NATURAL' SUPPORTS 18
BOX 2.3. MOBILE CREWS 19
BOX 2.4. CNS PRECISION ASSEMBLY 20
BOX 2.5. CUSTOMIZED EMPLOYMENT SUCCESS STORY 21
BOX 2.6 CORE VALUES OF SOCIAL ENTERPRISES 23
BOX 3.1. WENDY PATTON'S STORY 34
BOX 3.2. PATHWAY TO A FULFILLING JOB: MS JACQUELINE MINCHIN 36
BOX 3.3. UPGRADING THE JOB COACH POSITION – CHALLENGES 40
BOX 3.4 VOICES OF PEOPLE WITH INTELLECTUAL DISABILITIES: MR BENYAM FIKRU 42
BOX 3.5. MR JACK MNISI – A WORKING MAN 44
BOX 3.6. PROVEN TRANSITION PRACTICES 47
BOX 3.7. QUALITY INDICATORS 50
BOX 3.8. EMPLOYEE AND EMPLOYER PERSPECTIVES 53

Abbreviations and acronyms

AAIDD	American Association on Intellectual and Developmental Disabilities
ADA	Americans with Disabilities Act
ADE	Australian Disability Enterprises
ANDD	Africa Network for Developmental Disabilities
APSN	Association for Persons with Special Needs
ASENZ	Association for Supported Employment New Zealand
CACL	Canadian Association for Community Living
CASP	Centuro Ann Sullivan del Peru
CBR	Community Based Rehabilitation
CE	Customized Employment
CED	Community Economic Development
CRPD	Convention on the Rights of Persons with Disabilities
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders-IV
ENAID	Ethiopian National Association on Intellectual Disability
ESF	European Social Fund
EU	European Union
EUSE	European Union of Supported Employment
FAIDD	Finnish Association on Intellectual and Developmental Disabilities
IASE	Irish Association of Supported Employment
IASSID	International Association for the Scientific Study of Intellectual Disabilities
ICD-10	International Classification of Diseases-10
ICF	International Classification of Functioning, Disability and Health
IHC	Intellectually Handicapped Children
ILO	International Labour Organization
ITP	Individual Transition Plan
IQ	Intelligence Quotient
JEED	Japan Association for Employment of the Elderly and Persons with Disabilities
JICA	Japan International Cooperation Agency
MINDS	Movement for the Intellectually Disabled of Singapore
MINSA	Ministerio de Salud del Perú
NFU	Norwegian Association for People with Intellectual Disabilities
NGO	Non-governmental organization
NICHD	National Institute on Child Health and Human Development

NSW	New South Wales
OSI	Open Society Institute
SE	Supported Employment
UKDDA	United Kingdom Disability Discrimination Act
UN	United Nations
UNESCO	United Nations Education, Scientific, and Cultural Organization
WASE	World Association for Supported Employment
WHO	World Health Organization
ZAEPD	Zambia Association on Employment for Persons with Disabilities

Introduction

The rights of people with disabilities have been given new attention with the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in May 2008. The provisions of the CRPD contribute to other international standards concerning persons with disabilities, signalling a dramatic shift in international policy terms. In relation to training and employment, for example, states are called on to provide opportunities for disabled people alongside non-disabled people.

Many countries have already declared their commitment to the goal of inclusion of persons with disabilities through ratification of the CRPD, while others have signed it with a view to ratification. Many have also ratified ILO conventions, committing themselves to the goals of equal opportunity and non-discrimination.

People with intellectual disabilities are entitled to benefit from the provisions of the CRPD and ILO Convention concerning the Vocational Rehabilitation and Employment (Disabled Persons), 1983 (No. 159), as well as people with other kinds of disabilities. Yet, they are frequently not well placed to gain from this changed emphasis on inclusion. In many developing countries, in particular, they are often excluded from school and deprived of opportunities to acquire relevant vocational skills at all, presenting further disadvantages when it comes to seeking jobs. Yet, experience in many countries shows that, with the right training, support in the workplace as required, and the right opportunities, they can make valued contributions in the workplace and to a country's economy.

Measures to open employment opportunities for this group of persons with disabilities in line with the CRPD and ILO Convention No. 159 can build on extensive experience in recent decades in developing new approaches to training and employment. The review of international experience carried out for this working paper highlights good practice in supporting people with intellectual disabilities in integrated employment settings. Evidence clearly points to better outcomes for employees with intellectual disabilities, when they work in integrated settings, with appropriate supports.

The aims of this paper are to:

- examine changes over time in the understanding of intellectual disability and the capacity of persons with disabilities to learn;
- provide an international overview of employment options for people with intellectual disabilities, with special emphasis on Supported Employment (SE) models;
- examine and critically analyse from a research perspective examples of SE across a range of low- and high-income countries; and
- make recommendations for the expansion and future development of inclusive employment options for this population.

Section 1 provides a brief overview of the shift from classifying people with intellectual disabilities on the basis of IQ bands to a support needs

framework. It then explores the impact of research initiatives that demonstrated the learning capacity of people with intellectual disabilities in a work environment.

Section 2 discusses the range of employment models currently accessed by people with intellectual disabilities in countries around the world. It highlights that, despite the emergence of a number of more inclusive practices, the predominant model continues to be sheltered employment in segregated settings, and that a high proportion of people with disabilities are unemployed.

Section 3 reviews recent and emerging developments in promoting training and employment opportunities for people with intellectual disabilities, drawing from examples in both high- and low-income countries, with reference to factors facilitating and posing challenges to the spread of supported employment. The findings of research on these developments are summarized.

Section 4 examines the policy implications of research findings and draws some conclusions about the way forward.

The Working Paper has been informed by the report of the ILO/Irish Aid sub-regional conference *People with Intellectual Disabilities – Opening Pathways to Training and Employment*, held in Lusaka, Zambia 9-11 March 2010 (ILO, 2010a), and the accompanying Lusaka Declaration *People with Intellectual Disabilities: Achieving Full Participation in Training and Employment* (ILO, 2010b).

The views of several individuals with intellectual disabilities on what work means to them are presented in different parts of the report, so that their voices are reflected, in line with the self-advocacy movement which is gaining momentum.

1. People with intellectual disabilities

People with intellectual disabilities have existed throughout the world across human history, making up a part of all cultures. They represent a small part of the extremely wide variety of people in the human population at any one time. They are reported to make up one per cent of the population globally, although this may be an underestimate of the true prevalence, even in terms of the criteria of impairment and activity limitations and there is no clear indication of the level of uniformity of the definition or the comprehensiveness of national data. Different cultural environments may also affect the definition and a decision on whom to include and whom to exclude (Solarsh and Hofman, 2006). Cultural factors may present difficulties in the identification of people with disabilities, as families often persist in hiding their child with a disability because of negative community prejudices (Mung'omba, 2008).

People with intellectual disabilities would like to take part in a range of life experiences, like any non-disabled person or people with other types of disability. Yet they face difficulties in doing so, in one or more of the following areas:

- learning;
- communication (receptive and expressive language; verbal and non-verbal);
- social skills;
- academic skills;
- vocational skills;
- independent living.

Box 1.1 Who we are, what we want.

We are self-motivated and have ambition to learn, achieve and belong. (We) Need jobs to feel good and contribute, (we) want proper jobs, pay and will work hard. Accept us as people first, don't see the disability first. We can cope with things, we are doing well. Don't call us names it causes pain. We have skills even if we can't read and write. We are all different and unique and want to be treated like that. Respect is a two way street, we show it, so must others. We want to be financially independent. (We) want jobs outside. (We) want people to be as honest with us as we are with them. We need to be understood and not judged and labelled.

From *Proceedings of 2nd African Down Syndrome Conference held in Johannesburg, 2005. http://www.downsyndrome.org.za/main.aspx?artid=55.*

Research has shown that people with intellectual disabilities often have multiple secondary impairments, including complex physical and mental health problems (Beange et al., 1999; Einfeld et al., 2006; Hofer et al., 2009). These co-existing disabilities are particularly likely to be problems of agility, mobility, speech and language; and emotional problems including anger control, anxiety and depression. They are also more likely to experience loneliness and lack of friends (McVilly et al., 2004).

It is acknowledged that people with all categories of disabilities have experienced discrimination and stigmatization throughout the millennia. Yet, an intact intellect has historically been highly valued and often seen as the essential characteristic of being fully human (Parmenter, 2001), and people with intellectual disabilities are often the last within the community of disabled persons to receive attention. In the not-too-distant past a person with an intellectual disability "was viewed not as a second-class citizen, but rather as one who possessed *no citizenship*" (Stevens, 1967).

An important example of how this discrimination affects the lives of people with intellectual disabilities on a daily basis is found in the field of education. In the past, and to this day in some countries, children with intellectual disabilities lack access to basic education, which seriously limits their chances to obtain meaningful employment as adults (UNESCO, 2010). In Canada, for example, 70 per cent of people with intellectual disabilities had attained less than high school graduation in 2001, compared to 46 per cent of people with other disabilities and 25 per cent of adults in the general population; about 63 per cent of working-age people with intellectual disabilities had attended special education, compared to 13 per cent of other people with disabilities; while an estimated 35 per cent of people with intellectual disabilities had undertaken training to improve existing employment-related skills, with programme accessibility and costs as key deterrents (CACL, 2006).

Children with disabilities are often isolated within their societies and communities because of a mixture of shame, fear and ignorance about the causes and consequences of their impairment. Pointing the way forward, the UNESCO report acknowledges that governments across the world have recognized that inclusive education for people with disabilities is a human rights imperative and that practical examples of a move from special schools to inclusive education in mainstream schools are beginning to emerge, with significant gains being reported in some cases.

Box 1.2 Voices of individuals with intellectual disabilities: Mr Quincy Mwiwa.

At an ILO regional conference in Lusaka, Zambia, in March 2010, Mr Quincy Mwiwa, self-advocate, emphasized the difference education and training makes to the lives of people with intellectual disabilities.

'I am 34 years old. I live in Livingstone, a Tourist Capital town of Zambia. When I enrolled in grade one, it became obvious to both my parents and the teachers that I was a person with an intellectual disability. Since my parents wanted me to be in school, it was recommended I be taken to a special school. Later, I was lucky to have attended a skills training at Livingstone Trades where I graduated with a certificate in catering. I have worked for Sun Hotel in Livingstone and ZAEPD Restaurant as a manager…. Work means everything to me and my fellows with intellectual disabilities. Without work we are marginalized; we remain perpetual beggars for almost everything we need.'

ILO, 2010a.

Changes in approach

There have been many changes in recent decades in the way people with intellectual disabilities have been named and categorized. Terms formerly used such as *idiot, imbecile, feebleminded, mentally subnormal, moron, mentally deficient* and *retard*, are now seen as highly pejorative and stigmatizing, although at the time of their use they were acceptable terms in the scientific literature. For instance, the term 'mental retardation' has come to be seen as a derogatory term and has been gradually replaced by the term 'intellectual disability' in many parts of the English-speaking world. In the United Kingdom, the terms 'learning disability' or 'learning difficulty', which have both social and definitional qualities, are used. In Canada, 'intellectual disability' and 'developmental disability' are used synonymously, whereas in the US the latter term also encompasses conditions such as cerebral palsy and Asperger's syndrome, which do not necessarily involve an intellectual disability, and 'learning disability' is understood to include people with dyslexia. Representative organizations have responded, changing their names to reflect more contemporary acceptable language. Examples are: the American Association on Intellectual and Developmental Disabilities (AAIDD) (formerly the American Association on Mental Retardation, and earlier, the American Association on Mental Deficiency); the International Association for the Scientific Study of Intellectual Disabilities (IASSID) (also, formerly 'of Mental Deficiency'); and Inclusion International (formerly the International League of Societies for Persons with a Mental Handicap).

Eminent researchers from a psychology background, such as Ellis (1963, p. xi) in the US, commented that "mental retardation was a social problem" and Clarke and Clarke (1958, p. xiv) in the UK suggested that, "mental deficiency is a social-administrative, rather than a scientific, concept, varying between different countries and within a given country at different times."

Self-advocacy groups, representing people with intellectual disabilities, have become very instrumental in changing the way language is used to refer to the condition, arguing that terms used demean them because of the implicit negative connotations. Even the term 'disability' implies a condition less than 'normal'. These groups have also been instrumental in highlighting the aspirations of men and women with intellectual disabilities in recent years.

Box 1.3 Development of Self-Advocacy groups: Africa

The voices of persons with intellectual disabilities are beginning to be raised and heard, through the recent development of training programmes in self-advocacy and the establishment of self-advocacy groups.

In Africa, for example, 85 persons with intellectual disabilities were trained as self-advocates in 2008 through workshops arranged by Inclusion International, a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide, in partnership with the Norwegian Association for People with Intellectual Disabilities (NFU) and in collaboration with the Africa Network for Developmental Disabilities (ANDD). The rationale of the workshops was to empower people with intellectual disabilities with knowledge that shall enable them to speak for themselves on issues that affect their lives; to inform self-advocates about the UN Convention on the Rights of Persons with Disabilities (UNCRPD); and to contribute to the development of training material for Self-Advocacy. Arising from these workshops, self-advocacy groups were formed in Uganda, Namibia, Swaziland, South Africa, Kenya, Zanzibar, Tanzania and Malawi.

1.1 Identifying people with intellectual disabilities

1.1.1 IQ testing

In the nineteenth and early twentieth centuries, approaches to the education and training of people with intellectual disabilities were influenced by the rising discipline of psychology. It was Alfred Binet (1857-1911), the director of the psychology laboratory at the Sorbonne in Paris, who is credited with the development of the first scale to measure 'intelligence'. Developed in 1905, this scale involved ranking individuals on a number of everyday problems of life requiring processes of reasoning. The tasks were arranged in an ascending order of difficulty, with an age-level assigned to each task, giving rise to the concept of mental age and subsequently, the intelligence quotient (IQ). Binet's motives for the development of a scale were prompted by the need to identify those children whose lack of success in general classrooms may have given rise to the need for a special education programme.

The combined impact of Charles Darwin's Origin of the Species, published in 1859, and the genetic discoveries of Gregor Mendel (1822-1884) reinforced the view that intellectual disability was a single inheritable condition, and not one that can be attributed to a variety of genetic and other causes. Eugenics societies sprang up over much of the Western world, emphasising the possibility of improving the qualities of the human population, especially by such means as discouraging reproduction by persons having genetic defects or presumed to have inheritable undesirable traits. This led to pressure being placed on parents of people with intellectual disabilities to discourage their marriage and procreation. Arbitrary sterilization laws were enacted in many countries, including Canada, the United States, Sweden and France. Most of these laws were repealed by the late 1970s.

The classification of intellectual disability, or mental deficiency, as it was then described, became a topic of popular debate in the early twentieth century. Three categories emerged: 'idiots', who did not develop speech and had mental ages below 3; 'imbeciles', who did not become literate and had mental ages between 3 and 7; and 'high grade defectives' or 'morons', who could be trained to function in society. The net effect of the eugenics movement was a rapid increase in the numbers of people who were institutionalized across the Western world. It was in these institutions that the first recorded vocational training for people with intellectual disabilities was conducted (Sandys, 2007).

From the mid-twentieth century onwards, several significant advances were made in the definition and classification of intellectual disabilities (Parmenter, 2004). These were influenced by at least three factors. First, the results of research demonstrated the learning potential of people with intellectual disabilities. Second, the proclamation by the United Nations in 1971 of the *Declaration of the Rights of Mentally Retarded Persons* provided an impetus for countries to re-examine their laws to ensure that the rights of people with intellectual disabilities were being safeguarded. Third, the growing de-institutionalization movement in several western countries provided a spirit of optimism which challenged commonly held beliefs about

the moral status of people with intellectual disabilities (see Section 1.2.1 below).

Since 1921, AAIDD has published definitions and classification systems of intellectual disability. In essence, intellectual disability has been defined and classified, up to recently, according to the results achieved on intelligence tests, and to some extent measures of adaptive behaviour. The most recent definition, in the eleventh edition of the AAIDD *Definition Manual*, states:

> Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18 (Schalock et al., 2010 p. 5).

1.1.2 Support needs framework

A significant development occurred with the publication of the ninth edition of the AAIDD manual where the traditional classification system linked to IQ levels (mild, moderate, severe and profound) was replaced by the concept of levels of support required (Luckasson et al., 1992). This development represented a significant shift in the way intellectual disability was conceptualized. The reformulated definition and the accompanying classification of supports acknowledged that the disability resulted from the interaction of the person with his/her environment, rather than being an absolute trait of an individual.

This development was also consistent with the emerging strength of the social, as opposed to the medical, model of disability (Mercer, 1992). While the medical model focuses on the person's impairment and steps to reduce or remove this, the social model recognizes that barriers to a person's participation in general community activities are not solely determined by a person's impairment, but arise in combination with elements of the environment. For instance, in the case of a person with an intellectual disability, community attitudes are generally the greatest barrier to participation, involving low expectations of the person's capacity to participate and contribute.

Subsequent revisions of the AAIDD position (Luckasson et al., 2002; Schalock et al., 2010) have further developed the conceptualization and planning of individualized supports and the measurement of adaptive behaviour (Schalock, 1999; 2004a). Throughout these recent revisions there has been a deeper appreciation of the relationship between the AAIDD approach to definition and classification of intellectual disability and that of other relevant international classification systems such as the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, the WHO *International Classification of Diseases (ICD-10)* and the WHO *International Classification of Functioning, Disability and Health (ICF)*.

1.1.3 Relevance to training and employment programmes

In the planning and delivery of educational and vocational programmes for people with intellectual disabilities, a support needs approach to classification has significant benefits in contrast to the earlier practice of classification based on IQ levels (mild, moderate, severe and profound). First, it calls for a personal and individualized approach to service delivery that

meets the individual support needs of that person. This is important since rigid stereotypes concerning the behaviours of people within a specific IQ band fail to predict the actual support needs of an individual in a work context. Nor does the IQ approach fit comfortably with the social and rights models of disability where environmental factors must be taken into consideration.

Rather than addressing a person's particular cognitive impairment, it may be more effective to make an accommodation to the person's environment by the provision of support that lessens the impact of the impairment. Support needs assessment instruments, which assess a person's needs across a range of everyday life domains, are now available (Arnold et al., 2009; Riches et al., 2009a, 2009b; Thompson et al., 2004).

Areas of functioning important to employment, where people with intellectual disabilities may need specific supports, include:

- literacy and numeracy;
- comprehension of instructions and information;
- interpreting non-verbal language;
- short-term and long-term memory;
- attention span and concentration;
- motivation;
- problem-solving and decision-making skills;
- making choices;
- following instructions;
- time telling/management and organization;
- ability to travel and/or live independently;
- appropriate behaviours and social skills;
- grooming and self-care.

The degree of difficulty and the extent of support required will vary from person to person.

1.1.4 Cultural considerations

The growth of the IQ testing movement throughout the twentieth century within western industrialized countries has been heavily influenced by social, political and economic forces linked to the perceived needs of an industrialized economy. Using a more anthropological approach, Cianciolo and Sternberg (2004, p. 22), commented that "…people in different cultures may develop somewhat different intellectual abilities, depending on what types of intellectual competence are valued in their particular culture".

Competence and one's ability to navigate effectively within a culture depends very much on the environmental contexts of that culture. Emerson, Fujiura and Hatton (2007, p.607) suggested that:

> …most societies seem to construct competence in more socially and culturally situated terms, rather than (as) an abstract conception of intelligence, with substantial diversity in these constructions according to the specific needs and cultural mores of different cultural groups… from a global context the provision of classification systems and services based on conceptions of intellectual disability may be misguided; classification systems and services starting from local conceptions of competence and the proper social role of a competent person may be more productive.

In summary, there is strong evidence that socio-cultural factors largely determine what is seen as competent behaviour. Within western high-income countries, driven by the values of utilitarian individualism, the construct of intellectual disability has been largely determined to meet the needs of urban, industrialized societies. In contrast, competence in non-industrialized societies may be better reflected in collaborative, interpersonal problem-solving skills, such as those found among Nigerian students labelled as intellectually disabled (Edeh and Hickson, 2002). However, as Emerson, Fujiura and Hatton (2007) pointed out, people who are judged to be incompetent or 'obtrusive' in countries deficient in support services are often neglected and consigned to a life in poorly managed segregated institutions.

1.2 Learning and working capacity

The first reported formal employment programmes for people with intellectual disabilities were those conducted within the large institutions established in the Western world in the first half of the twentieth century. The residents, often referred to as 'inmates', a custodial term generally applied to prisoners, were employed in both indoor and outdoor occupations, many of which contributed to the economic operation of the facility. For instance, many residents were employed in the facility's laundry or in small farming activities that contributed to the facility's food supply.

For people with intellectual disabilities living at home in rural non-urbanized communities, daily activities would not be dissimilar to those of other people living in the community. The phenomenon of the '6-hour retarded child', described by Edgerton (1967, 2001) emerged once children with intellectual disabilities were enrolled at school, where the demands of literacy and numeracy skills challenged their cognitive limitations during the six hours they spent in the classroom. Outside of school activities, however, except for those with high-intensity support needs, most people with intellectual disabilities blended into the general community, being able to perform basic everyday living skills. This pattern underscores the problem of using IQ tests as predictors of the capacity of people to participate in community living activities such as open employment, since many of these tests were designed specifically to predict school performance rather than anything else.

For those children who were denied access to public schools because of their intellectual limitations, family and charitable groups established special schools. Not surprisingly, once the children reached late adolescence, these same groups established sheltered workshops and day activity centres, often with governmental financial support in countries such as Australia, Canada, France, Germany, New Zealand, Sweden, the UK, the Netherlands, the US, and later in middle- to low-income countries. The conventional view was that these people would never enter the open labour market because of their perceived learning limitations.

1.2.1 Normalization, deinstitutionalization, community living and working

Developments in the early 1970s, particularly in the US, led to the development of alternatives to sheltered workshops and day activity centres as the major employment facility for people with intellectual disabilities. A number of underlying factors can be identified which are still relevant to the

present-day international context. First, the widespread acceptance of the principle of normalization led to the deinstitutionalization movement, which called for people with disabilities to live in normal community settings (Nirje, 1969, 1985; Wolfensberger, 1972). Second, a number of projects across the US during the 1970s demonstrated the employment potential of people with intellectual disabilities (Kiernan and Schalock, 1997; Kiernan and Stark, 1986). A third factor was the increasing dissatisfaction with the major model of adult services prevalent at the time, namely sheltered workshops.

A large US study of sheltered workshops found that only 200,000 people were being served, whilst an additional two million people with intellectual disabilities were in need of work (Whitehead, 1979). People with high support needs, in particular, were denied access to sheltered workshops as they were deemed to be insufficiently productive. Studies conducted by Greenleigh Associates (1975) indicated that workshops were seriously limited by: (a) the absence of adequate varieties and quantities of work; (b) prevalence of low-challenge assembly work; (c) the absence of modern tools and machines on which to train workers; (d) a limited number of skilled and competent staff; and (e) funding mechanisms which encouraged continued service to employees in a segregated environment.

1.2.2 Groundbreaking work of Marc Gold in the US

In the late 1960s and early 1970s, the conviction that people with intellectual disabilities do not have the capacity to work in regular employment settings was challenged by researchers such as Marc Gold, a former special education teacher who developed a conceptual framework of instruction entitled “Try Another Way”. Through his ground-breaking applied research, he demonstrated that people with very high cognitive support needs could learn to complete quite complex employment tasks (Gold, 1972, 1975). Gold’s work, together with that of other research and training initiatives on the learning capacity of people with intellectual disabilities clearly demonstrated that with appropriate training and supports people with intellectual disabilities could work in real jobs up to high levels of complexity (see for example the early work of UK researchers such as Clarke and Clarke, 1965; Gunzberg, 1965; and Tizard and Loos, 1954).

Undoubtedly the early work of Gold and Tizard was a catalyst for change in promoting a deeper understanding of the learning potential of people with even the highest level of cognitive impairment. Later research focussed on a more systems-based approach where emphasis has been placed on adaptations and accommodations in a person’s environment, in addition to effective skills training (see http://www.marcgold.com).

Research helped to lead the development of the “place and train” model of employment support services, in contrast to the more traditional rehabilitation approach of “train and then place”. Experience has shown that, to be effective, teaching and training of people with intellectual disabilities should take place using real work in practical situations to the extent possible. Support staff should also be aware that making modifications to the person’s environment may be an alternative way to assist individuals in handling the requirements of a job. Therefore, support staff should be encouraged to target both their learning needs and adjustments to the workplace. In addition to a good knowledge of work practices, support staff require training in the basic teaching procedures and principles used by special educators.

2. Employment options

Despite a more enlightened approach to the needs of people with disabilities generally fostered by human rights initiatives and the application of research and technological findings which have led to increases in their overall quality of life, their participation in the open labour market falls considerably lower than that of the general population. In industrialized countries, the unemployment rate among people with disabilities of working age is 50 to 70 per cent, which is at least twice the rate of those without a disability (International Disability Rights Monitor, 2004. In developing countries, the situation is somewhat worse: it is estimated that 80 to 90 per cent of people with disabilities of working age are unemployed (Zarocostas, 2005).

> The UN Convention on the Rights of Persons with Disabilities emphasizes "the right…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"
> *(CRPD, 2006, Article 27(1).*

Evidence indicates that, irrespective of the culture or the economic circumstances of a country, the employment circumstances for persons with intellectual disabilities are equally alarming, if not worse (Dempsey and Ford, 2009; Department of Health, 2009). Just as they have been denied education, they have been denied access to jobs. This dismal state of affairs has come about largely through ignorance and superstition (Parmenter, 2001).

In Canada, for example, a survey reported in 2006 found that people with disabilities continue to experience some of the lowest rates of employment in the country, a situation common across the world (Canadian Association for Community Living, 2006). The survey found that: people with disabilities who *are* working work only half as many weeks per year as people who do not have a disability; are unemployed longer; and spend three times as long outside the labour force. People with intellectual disabilities were found to experience even lower rates of employment, with only 27 per cent being employed at the time of the survey, while 40 per cent had never worked. In terms of income, nearly 50 per cent of people with intellectual disabilities had incomes below the Statistics Canada low-income cut-off, a widely used measure of poverty.

In Australia, people with intellectual disabilities made up 41 per cent of those served in government funded employment services in 2010, with more males than females benefitting (64 per cent vs. 36 per cent). They represented 27 per cent of all participants with disabilities in open employment, but 73 per cent of those in segregated business enterprises, formerly called sheltered workshops. There has been a gradual decline in the proportion of people with intellectual disabilities accessing inclusive employment services. And finally, there is evidence of 'creaming' - that is, providing services to people who have relatively low support needs and are easier to place in employment - by providers of both employment options, leading to increasing numbers of people with high support needs being referred to state/territory day option programmes.

In European Union countries, the unemployment rate for people with intellectual disabilities was found to approach almost 100 per cent (Greve,

2009). The vast majority who do work are found in sheltered workshops and those with high support needs are generally directed to day activity centres. A similar picture was reported by Verdonschot et al. (2009), who found from a systematic review of the literature that people with intellectual disabilities were three to four times less likely to be employed than people without intellectual disabilities. In Northern Finland a follow-up of those born with intellectual disability in 1966 revealed a similar position (Taanila et al., 2005).

Employment options for people with disabilities, and those with intellectual disabilities in particular, can be broadly distinguished as those in which people with disabilities work in a segregated environment of only workers with disabilities; and those in which they work in an integrated or inclusive environment of workers largely without disabilities (Kregel and Dean, 2002). Employment models under these headings, currently accessed by people with intellectual disabilities in countries around the world, are described below. The section starts with a brief overview of day centres, which are an option for people judged not suited to sheltered or open employment.

2.1 Day programmes/centres

Under a medical model of service delivery, people with intellectual disabilities who were assessed or deemed to be unsuitable for employment were catered for in "activity therapy centre" programmes, where one of the goals was to prepare them for employment options. Typically, only a very small number "graduate" to sheltered employment. In practice, these centres in the past became the life-long option for people assessed as not being suitable for employment[5].

A combination of personal and programme influences are likely to underlie this pattern. Some of the constraints to moving to other employment options may arise from the reluctance of persons with intellectual disabilities themselves to move from a day centre where they have built up friendships over many years. This reluctance acts as a barrier to change, unless opportunities are open to maintain friendships outside of work. This pattern has been highlighted in the UK context by Beyer et al. (2004), who also found that people with intellectual disabilities in day centres were considered to have had restricted lives, leading to a poor attitude to employment, low desire to work, and little self-confidence, in combination with the lack of the experience to make a judgement about what work they might want to do.

Traditional day centres were initially based on the principles of occupational therapy and were created as respite for family members caring for their adult children or siblings with disabilities. This is slowly changing, however, as programmes offered become more skills-based and focused on increasing independence. For instance, in New South Wales, Australia, one of the post school options initiatives for school leavers classified as not being ready for open employment, is the "transition to work" programme. Since the programme's inception in 2004, Jobsupport, the most successful agency delivering the programme, placed 60 per cent of the 179 school leavers it supported into paid open employment. This agency specifically targets young

[5] See, for example, http://www.guardian.co.uk/education/2008/aug/19/specialeducationneeds

people with intellectual disabilities who have been classified as having moderate support needs, referred to under the older classification system as "moderately intellectually disabled"[6].

Other contemporary non-vocational day programmes provide on-going daytime activities and supports for people with intellectual disabilities who have moderate to very high support needs. These include:

- opportunities to participate in the community;
- meaningful leisure and recreation activities;
- respite for families and carers;
- development of social skills.

These day centres are traditionally segregated and centre-based, offering training in life skills (such as meal preparation and basic literacy), activities (such as crafts, games and music classes) and external activities (such as day trips). Some more progressive day centres also support people to access vocational training opportunities (such as college courses), and offer individualized outreach services (planning and undertaking activities with the individual, with support offered one-to-one or in small groups). Some centres, in the spirit of inclusion, are supporting their clients to access regular community cultural, recreational and continuing education facilities.

2.2 Sheltered workshops

Sheltered workshops, initially established by parent groups, were essentially segregated facilities established for people considered unable or unlikely to obtain or retain a job in the open labour market. The majority of those employed have tended to have intellectual disabilities. The workshops engage in remunerative work to cover some of their costs. Workers are often paid a training allowance in addition to any welfare payments they might be entitled to, and very minimal or no wages - sometimes in the form of a bonus if production targets are met. Up until recently, contracts of employment were not issued and the provisions of general employment legislation did not apply. In many countries, these facilities are described as rehabilitation and training facilities, but very few workers ever graduate to the general employment market, even when financial incentives are offered. In fact, there was a major disincentive to progress the more skilled workers to real jobs in the open labour market, as their productivity was crucial for the financial viability of the organization (Murphy and Rogan, 1995; Parmenter, 1980).

ILO Vocational Rehabilitation (Disabled) Recommendation (No. 99), adopted in 1955, was the first international instrument regarding national legislation and practice concerning vocational guidance, vocational training and placement of disabled persons, guiding practice for almost 30 years. While recommending mainstreaming of vocational training, equality of opportunity and no discrimination in pay for equal work, the Recommendation saw the establishment of sheltered workshops as one method of widening employment opportunities for workers with disabilities. This option was also cited by the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities; the Council of Europe Social

[6]http://www.jobsupport.org.au/main/images/documents/transition%20outcomes%20update%20august%202011.pdf

Charter (1961); the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society in the period 2006 to 2015; as well as the ILO Recommendation concerning Vocational Rehabilitation and Employment of Disabled Persons, 1983 (No. 168) that provides guidance on the implementation of ILO Convention No. 159. It is not envisaged, however, in the UN CRPD.

Given the results of research studies, in combination with the realization that a real job in the community gives people a strong sense of identity, it came to be recognized that segregated settings send a message to people with disabilities, and to the population at large, that they are different from the rest of society, and that alternatives were needed to allow them to have the same conditions of life as everyone else (Nirje, 1985). This gave rise to a debate about sheltered workshops that continues to the present.

Arguments have been put forward in favour of sheltered employment. These include the avoidance of perceived physical risks in the outside world (Dudley and Schatz 1985; Migliore et al. 2008); the high complexity of jobs in outside employment being beyond the skills range and psychological capacity of people with intellectual disabilities (McConkey and Mezza 2001; Visier, 1998); that sheltered workshops provide greater opportunities for the development of friendships than outside jobs (Dudley and Schatz 1985; Weikle 2008); and that sheltered employment tends to provide surety of employment across the person's life span without affecting disability benefits. Sheltered workshops are also seen to provide an option for people who fail to secure or maintain employment in the open labour market.

Yet it is widely recognized that change was and continues to be required. In recent years, for example, high-income countries, such as Australia, have re-badged sheltered workshops as "Australian Disability Enterprises" where a much greater emphasis has been placed on good business practices and productivity. Wages and working conditions for the disabled employees have improved, in some cases as a result of Trade Union support. In New Zealand, legislation has ensured workers receive the minimum wage unless an exemption is granted in individual cases, based on assessed productivity rates. In Australia, wages are linked to assessed productivity of the individual employee, compared to the normal industrial award.

Despite these advances, there is evidence that workers in sheltered workshops do not enjoy the same standards of protection available to workers in the open labour market. A survey of 5,000 workers in sheltered workshops in 24 states in the US revealed that people with disabilities in sheltered workshops earned US$101 per month based on an average of 74 work hours (NCI, 2008). In contrast, Kregel and Dean (2002) showed that annual earnings for persons in integrated employment settings was at least twice of that earned by people in sheltered workshops.

The rate of successful transition of people with disabilities from sheltered workshops to the open labour market is minimal, ranging from under one per cent to about five per cent (Beyer et al., 2002; US Government Accountability Office, 2001). However, Cimera (2011) found that two matched cohorts of employees - one in which employees had previously worked in sheltered workshops and the other in which they had not had prior sheltered workshop placement - were equally likely to be employed in the open labour market. There was a difference in the rates of pay with the non-sheltered workshop

cohort earning significantly more than those from the sheltered workshops. The former group also worked more hours per week and cost less to support.

Studies conducted in Northern Ireland, Spain and the US have shown that people working in sheltered workshops would like the opportunity to work in outside employment (McConkey and Mezza, 2001; Migliore et al., 2007; Verdugo et al., 2009).

In the US, a network of 23 state developmental disabilities agencies have developed policies under the umbrella of Employment First which has led states and providers to adopt service delivery strategies for persons with disabilities, including those with the most significant disabilities, that embrace the principle of integrated competitive employment (Kiernan et al., 2011). This initiative is strongly supported by self-advocates (Walker, 2011).

There are increasing signs that many sheltered workshops are transitioning to community employment options. In Australia, Greenacres, a large employment agency for people with intellectual and other disabilities, conducts an open employment programme in parallel with its sheltered workshop. It has a policy of actively seeking to move its employees into the competitive employment labour market[7]. In the US, Rogan and Rinne (2011) have described the processes followed by ten organizations that have shifted their service delivery from sheltered to community employment.

In summary, sheltered workshops continue to provide an employment option in many countries around the world, although the need for improved conditions and opening of other opportunities is widely recognized. It will be interesting to see how those countries that have ratified the CRPD reconcile their on-going support of sheltered employment with its underlying principles.

2.3 Supported employment

Alternatives to sheltered employment and day activity centres emerged in the early 1970s (see 1.2.1 above). In the US, in addition to the factors described above, the establishment of the President's Panel on Mental Retardation (now 'The President's Committee for Intellectual Disabilities') in 1961, and the subsequent research agenda under the auspices of the newly created National Institute on Child Health and Human Development (NICHD), saw the development of energetic research teams which targeted the post-school options for this population.

These influences led to the establishment of an *Employment Initiative for Persons with Developmental Disabilities*, which promoted the concept of supported employment (SE) to business leaders, community groups, and journals, and to the enactment of two public laws that provided a mandate for the national development of SE: *The Developmental Disabilities Assistance and Bill of Rights Act* of 1984 (P.L. 98-527), and the *Rehabilitation Amendments* of 1986 (P.L. 99-506). These developments emerged from experience with 'competitive employment' that generally focused on people being employed in regular jobs after a period of rehabilitation training, where on-going support was not required or provided.

[7] See http://www.greenac.com.au/employment.html

Supported Employment was defined in US legislation as:

> … competitive work in integrated settings for individuals:
>
> > (a) with severe handicaps for whom competitive employment has not traditionally occurred, or
> >
> > (b) for individuals for whom competitive employment has been interrupted as a result of severe disability; and who, because of their handicap, need on-going support services to perform such work (*The Rehabilitation Amendments* of 1986, P.L. 99-506*)*.
>
> …. involving paid work, integrated work environments, and on-going supports. (*Developmental Disabilities Assistance and Bill of Rights Act* of 1984, P.L. 98-527*)*.

While this definition has wide acceptance, it may be interpreted differently in other countries. The essential elements of Supported Employment as defined by the Association for Supported Employment New Zealand (ASENZ) reflect a generally accepted understanding of this form of employment. To be classified as SE, jobs should involve the following characteristics.

- **Open employment:** The employment and inclusion of people with disability in the mainstream workforce.
- **Wages and benefits:** The provision of the same wages and related conditions of employment that are the expected norm in any mainstream workplace.
- **Placement first:** Direct access to the labour market through a precise job/person match and without prolonged 'getting ready' activities or training.
- **Inclusiveness**: No exclusions or screening from supported employment programmes on the basis of perceived 'severity' of disability.
- **Individualized and on-going support:** Support services and strategies that are not time-limited, are tailored to the individual's needs, and maximize job retention.
- **Choices and career development:** Services and outcomes based on the preferences and aspirations of the individual and a commitment to on-going pursuit of careers.

Researchers working with people with very high support needs developed four alternative pathways, all of which were characterized as 'supported employment' (Mank et al., 1986). The first was called the 'supported jobs' model, which later became the SE model described above. Other alternatives were the 'enclave' model, the 'mobile crew' model and the 'benchwork' model. Each of these models specifically targeted people with intellectual disabilities who had high support needs.

2.3.1 Supported jobs model

The 'supported jobs' employment model involves a 'place and train' approach, rather than the practice in rehabilitation facilities where the model is 'train and then place'. Therefore, to provide employment, a job is required at the outset of the service, and not just at its completion.

The ‘place, train and support’ model for SE usually involves job coaches working with the potential employee to identify interests and skills. This is followed by job seeking, matching and placement. The employer might also be encouraged to make adaptations (i.e. *accommodations*) to a specific job in order to match it with the abilities and skills of the employee with an intellectual disability. In many cases the job coach might learn to do the job first, in order to subsequently teach the employee with the disability. In other circumstances, the employer might prefer for a regular staff member to teach the skill. This person may subsequently become a ‘mentor’ to the person with the disability, thus becoming part of the natural support for the person within the workplace.

> *Reasonable accommodation* means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. *CRPD Art 2.*

Irrespective of who does the initial training, research consistently shows that on-going natural supports (through a staff member) are leading to greater sustainability of job placements than external supports (through a job coach employed by pubic authorities or an NGO). However, while natural supports are proving to be a promising method of increasing the integration and support of people with intellectual disabilities in the workplace, a combination of job coaching and natural supports may be needed, tailored to individual circumstances and needs. Box 2.1 outlines an example of the steps followed by a sheltered workshop in securing a job and supporting a person in **integrated employment.**

Box 2.1. Moving to Supported Employment - with external supports

Once a suitable job match is established, the person with intellectual disabilities and their parents are notified and an interview is arranged. The job sourcing personnel endeavours to procure a job trial in order to allow both the prospective employer and the person with a disability an opportunity to assess the suitability.

The duration of the job trial is three days with no cost implications to the potential employer. Nevertheless, the job trial may be prolonged if this is deemed necessary. At this juncture, issues of job redesign and workplace accommodations are discussed with the prospective employers, as the hands-on job trial would offer insights of how variables in the environment or processes could impede the work of the prospective employee. When the offer of employment is made and accepted, intensive coaching continues, the occupational health and safety issues at the job site are carefully analysed, and any concerns are addressed with the employers.

The first week of job placement is a critical period for the employee as much as it is for all the stakeholders. The quantum leap from sheltered environment to mainstream work can be overwhelming. The family may be unsettled as the liaison between the job coach/service agencies is more intensive. The learning curve for the person with intellectual disabilities is steep. His or her community mobility now extends to travelling between home and the job site; job site rules need to be comprehended and respected, and new friendships need to be established.

While vocational skills are tailored to meet the demands of the job site, generalization of life skills are critical to ensure the person maintains his or her employment.

Parent, Hill and Wehman, 1989.

Another way in which supported employment is organized involves training and supports provided through 'natural supports' - in other words by supervisors and staff within the company (see Box 2.2 below).

Box 2.2. Supported Employment with 'natural' supports

Jenny works as a dining room attendant in a local fast-food restaurant. She greets customers, removes trays, and keeps the dining room clean and neat. Jenny has a job coach, but the restaurant's assistant manager taught her to do her job. The restaurant's regular customers speak to her every day and ask her about her when she misses work. The district manager knows her by name and has featured her in the local advertising campaigns. When asked about this, the district manager says, "Jenny represents the message our company wants to send to the customers in this area – friendly, courteous, hardworking employees".

See: http://www.worksupport.com

2.3.2 Enclave model

The enclave model consists of a group of people with disabilities who are trained and supervised among workers who do not have a disability, usually in an industrial or commercial environment. In its original design, the workers were to be paid at a level commensurate to the non-disabled workers, often adjusted according to their relative productivity. As the model was taken up by sheltered workshops, more often than not the contract for the enclave was between the company and the sheltered workshop management. This meant that wages for the person with a disability continued to be paid by the sheltered workshop, at the sheltered workshop rates.

On-going support is provided to the enclave workers of much of the same nature as given by the job coach in SE. The literature does indicate that in some cases companies were willing to take on the job coach role along the principle of 'natural' supports described above. There is a danger that there may be little opportunity for work and social interactions. For instance, in some cases the enclave group may not share the common facilities of the company, such as lunchrooms.

There is a commonly held view that enclaves have the potential to become 'sheltered workshops' within a normal business. Nevertheless, limited research has found some positive gains for people in the programme. In a robust study comparing social interactions between people with intellectual disabilities and high-support needs and non-disabled workers in three work settings (individual job placements, enclaves and work crews), Storey and Horner (1991) found that individual and enclave job sites were more likely to involve interactions between disabled and non-disabled workers. However, the authors suggested that it could possibly be the features of specific job sites rather than the employment model in itself that result in positive interactions.

Kregel, Wehman and Banks (1989) reported that group settings such as enclaves and mobile work crews provided significantly fewer opportunities for both physical and social interactions. They also found that people with very high-support needs were more likely to be placed in enclaves than any other supported work placements.

2.3.3 Mobile crew model

This model is a combination of service and business. It may consist of a crew of five people with disabilities working from a van, rather than a

building, performing service jobs in community settings. Examples of work carried out may include lawn cutting, window cleaning, and general ground maintenance. In its original conception, a mobile crew is set up as a small, single-purpose business, rather than as an extension of a large organization. As with the enclave model, sheltered workshops have expanded to include this as another option of their services. Again, it is more common in these circumstances for the workers to remain dependent on the sheltered workshop for their wages and conditions.

Box 2.3. Mobile Crews

Mobile crew models are set up as small, single-purpose service businesses whose employees move from site to site in the community. A general manager is responsible for small crews and there is one supervisor/job coach per crew. Companies using the mobile crew model are often organized as not-for-profit corporations, performing such services as cleaning or landscaping. The full-time presence of the crew supervisor is generally required to monitor the crew's performance. There is strong evidence suggesting that mobile work crews provide fewer options for social interactions and fewer opportunities for choice than other models of supported employment.

Boeltzig et al., 2006.

2.3.4 Benchwork Model

This model was developed in the early 1970s by the Specialized Training Programme at the University of Oregon, US, as an alternative to day-activity programmes to provide long-term employment to people previously denied access to any vocational services. This model operates as a small, single-purpose, not-for-profit commercial operation providing a range of goods or services. The model requires a number of highly qualified staff skilled in instructional technology with no more than a 1:5 staff-to-worker ratio.

The size of the business was limited to 20 workers and they were located in close proximity to stores, restaurants, and other community venues that can provide opportunities for integration and participation into the regular community activities during lunch breaks as well as before and after work. At first the model was faithfully replicated in five states of the US and in Australia. The costs of operating the facilities were no more than those incurred in the day-activity centres, but employees received wages based on their productivity for the first time in their lives. Follow-up studies showed that some opportunities for community participation were realized, especially during meal breaks when employees could access local shopping centres. CNS Precision Assembly is an Australian example of a benchwork model (Box 2.4).

Although designed for people with very high support needs, who would not normally be employed in a sheltered workshop because of their supposed low productivity, the benchwork model shares many characteristics and constraints with traditional sheltered workshops. It initially also depended heavily on contracts from the electronics industry, many of which have disappeared as this industry has become more automated. However, in its early phases this model provided opportunities for its workers to have opportunities for greater community participation.

Box 2.4. CNS Precision Assembly

CNS Precision Assembly, an Australian Disability Enterprise (ADE), was founded in 1984, employing people with intellectual disabilities. It is a contract electronic manufacturing company offering a range of services to industry.

The goal of CNS is to help individuals to participate in the economic mainstream of local communities by offering supported work opportunities and employment-related services. CNS serves as an important component of a community system fostering individual productivity, independence and integration.

http://www.cns.org.au

2.3.5 Summary of SE models

The four models described above have undergone some transformations since their original conception. Supported Employment has expanded and has become the preferred option internationally, particularly as it embraces the core values of the UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, and the more recent UN CRPD, which advocates employment options in inclusive work settings for all people with disabilities, irrespective of their level of support needs. Even in high-income countries, however, the penetration of SE has not been sufficient to encompass all people with intellectual disabilities wishing to work. In recent years efforts have been made by both researchers and field workers to refine the strategies of SE to enable much higher success rates. This has resulted in an increased emphasis on job matching and making adjustments to jobs, so that all or part of a job can be performed by people with a range of disabilities, including intellectual disabilities. This has led to a modified version of SE called customized employment.

2.4 Customized employment (CE)

In the US, another model of employment has recently been developed which aims to place people with disabilities in jobs earning competitive wages. It is known as ‘customized employment’, a term first defined by the Office of Disability Employment Policy in 2001.

This model embraces a ‘person-centred’ approach, beginning with the person’s needs, aspirations, talents and skills. This profile serves as a basis for contacting potential employers (Inge, 2006; 2008). It also emphasizes the person’s choices, strengths and abilities. It is employed in One-Stop Service Delivery Systems (Blanck et al., 2009; Inge, 2008) where workforce investment, education, and other human service programmes work together to optimize access to services and long-term employment outcomes (see Box 2.5). Similar principles are used by Jobsupport Inc., one of Australia’s most successful SE programmes, in its transition from school to work initiative (Tuckerman, 2008a).

Box 2.5. Customized employment success story

A large commercial real estate business decreased the time it took to complete transactions by restructuring administrative support to manage a central filing room. Specific administrative support tasks were identified and assigned to José, a jobseeker with a disability. The job was customized to align with his skills and his interest in an office job. His job duties included delivering packages and faxes, creating files for property submissions, routing submissions to the appropriate account manager, collating packets and selected filing. This allowed other, more detailed administrative tasks to be performed by co-workers. As a result, real estate transactions were accomplished much more quickly, the volume of transactions increased, and the business began making more money on each of its real estate transactions.

Office of Disability Employment Policy, 2001.

While the process of job carving, as illustrated in Box 2.5, is unique for each individual and each employee, the process generally involves these steps:

- determine the contributions, potential and dreams of the individual;
- seek out employment opportunities that utilize, exploit, or highlight these contributions;
- perform a formal (written) job analysis in order to determine task sequencing, natural supports, operations that may require additional instruction, modification, alternative production methods, or those that may need to be performed in partnership with, or entirely by, another worker;
- engage in interest-based negotiation with the employer highlighting the individual's contribution to the workplace and offering a reasonable and understandable re-arrangement of work tasks in order to employ the individual[8];
- provide quality consultation to the employer and co-workers so that they can teach the individual the job;
- provide on-going support to the employer and the worker. (Griffin and Hammis, 2002, p. 1; Griffin, Hammis and Geary, 2007).

Beyer and Robinson (2009) reported on a 2005 study conducted for the US Department of Labor, which found that CE had been used successfully with people with high support needs. In the first round of the study 345 people had been placed in competitive employment. The majority had found high-quality jobs, with 95 per cent earning the minimum wage or above, and over 50 per cent placed in jobs with the potential for career advancement. A second round of data collection on 536 randomly selected individuals yielded similar results. Approximately 42 per cent of the sample disclosed a psychiatric or emotional disability, with 20 per cent reporting an intellectual disability.

In essence, the major contribution of the CE model to the SE model has been the recognition that a person's job choices play a crucial role in achieving a successful job match. It is another example of the application of

[8] Interest-based negotiation, in this instance, assumes that the applicant and the employer both have common desires; one person wants to work and the other needs someone to work.

the social model of disability, in that environmental adjustments may be more important than trying to change the person.

2.5 Self-employment, self-directed employment, micro-enterprises

Neufeldt and Albright (1998, p. 6) defined self-directed employment as:

> Income-generating work where disabled people, to a significant degree, have a prime decision-making role in the kind of work that is done, how time is allocated, what kinds of investment in time and money should be made, and how to allocate revenue generated.

Duce and Biersdorff (2002) suggested that business considerations for people with intellectual disabilities are little different from those for people who do not have a disability. In the case of the former, it is usual for someone to perform duties not dissimilar to the role of a job coach. Sometimes this is a family member. They proposed five major steps in the process of establishing a business: i) developing a business plan; ii) obtaining the required skills; iii) securing start-up capital; iv) implementing the business plan; and v) expanding the business. Again, the skills necessary to support self-employment will be very similar to those for SE, and may include job analysis, skills training and on-going provision of support. It is also possible for the support worker to initiate contacts with natural supports such as unpaid volunteers and mentors who have experience as entrepreneurs who can act as an on-going resource.

This model has also been described as a micro-enterprise: a small business created around one person. Beyer and Robinson (2009, p. 65-66) reported that the main strengths of the model for people with intellectual disabilities are that:

- it respects the capacity and the assets of people with intellectual disabilities, by focusing on people's interests and strengths, and can be more flexible than mainstream employment and working conditions;
- it pursues equality by opening up the self-employment sector of the labour market, where people with intellectual disabilities are not represented;
- it reflects aspects of governmental thinking on increasing employment for disadvantaged groups, and on developing services to meet individual needs;
- it is for some people a way of gaining income from a hobby or an interest, with support and funding through person-centred planning, direct payments and individualized budgets; and
- it provides another way for a person with intellectual disability to move from being a client to being a citizen.

A review by Neufeldt and Albright (1998) of over 120 self-employment projects across low-, middle- and high-income countries found that there was considerably more experience in low- to middle-income countries in supporting entrepreneurship for people with disabilities than in high-income countries. In the context of people with intellectual disabilities, the small

amount of research conducted on this model has addressed the best practice processes involved, rather than outcomes (Okahashi, 2001a, 2001b).

Despite it being a popular option for people with other disabilities, self-employment was not considered a viable option for people with intellectual disabilities during a recent technical cooperation project in Zambia, on the grounds that they lacked business skills (Koistenen, 2008). While family-based businesses were seen as an option suited to those with higher support needs, involving support to the well-being of the family as a whole, they provided only limited opportunities for social integration and, in some cases, the people with intellectual disabilities were not receiving wages for their work efforts.

2.6 Social firms

Social firms are a type of social enterprise initially developed in the European context for people with psychosocial disabilities following the closure of the large 'mental asylums'. Social enterprises are businesses which trade for a social or environmental purpose, with the profits being reinvested into the company to help them achieve this purpose. The specific social purpose of social firms is to create jobs for people who find it hardest to get them.

In the UK the criteria used to assess whether a business is a social firm can be found in the Values-Based Checklist (http://socialfirmsuk.co.uk/about-social-firms/what-social-firm). These criteria are based around three core values to which social firms will subscribe within their businesses: enterprise, employment and empowerment (Box 2.6).

Box 2.6 Core values of social enterprises

Enterprise - social firms are businesses that combine a market orientation and a social mission ('businesses that support', rather than 'projects that trade'). The business activities of social firms vary widely. At least 50 per cent of the firm's turnover will be earned through sales of goods and/or services, The firm will have an appropriate legal status. It must not be governed or driven by individual profit (except for worker co-operatives).

Employment - more than 25 per cent of employees will be disadvantaged people. Reasonable adjustments will be made for employees relevant to their needs.

Empowerment - social firms are committed to the social and economic integration of disadvantaged people through employment. A key means to this end is economic empowerment through all employees having a contract of employment and a market wage at or above national minimum wage.

http://socialfirmsuk.co.uk/about-social-firms/what-social-firm

Sheltered workshops have sometimes established small businesses which are labelled as 'social enterprises'. In Singapore, for example, MINDS, an organization which provides sheltered employment for people with intellectual disabilities in Singapore, has established a car-wash business in a regular community setting. In this case, all of the workers are people with intellectual disabilities with limited opportunities to engage in regular work-related or social activities within the general community. The organization has had to overcome opposition from some parents who prefer their adult children with intellectual disabilities to work in a more protected environment.

Li and Wong (2007) have provided an outline of the social enterprises policies of the UK, Spain and Hong Kong, including definitions, problems faced by the social enterprise sector, social enterprise strategies and creating an enabling environment for social enterprises. The Enterprise Vegetable & Fruit Processing and Supply Service of the Tung Wah Group of Hospitals in Hong Kong trains and employs 29 disabled persons. The company purchases large volumes of fresh vegetable and fruit in the wholesale market and after processing and preparing, the vegetables and fruit are delivered to their customers. (http://www.avantageventures.com/avcatalogue/sv-enterprise-vegetable-fruit-processing-and-supply-service-es-tung-wah-group-hospitals).

There is limited research information on the outcomes achieved by social firms for workers with intellectual disabilities. In a comparison of 40 people with intellectual disabilities working in a social enterprise and 40 others attending day centres, Forester-Jones et al. (2010) found that people in the social enterprise scored significantly higher on measures of life experience, self-esteem and satisfaction than those in day centres. They concluded, however, that while social enterprises represented better training settings for future employment compared to the day centres, social inclusion was still inadequate.

2.7 Community Economic Development (CED)

CED has emerged as an alternative to conventional approaches to economic development. It is founded on the belief that problems facing communities - unemployment, poverty, job loss, environmental degradation, economic instability, and loss of community control - need to be addressed in a holistic and participatory way.

There are varied definitions of CED, but the following captures the essential characteristics.

> "CED is a community-based and community-directed process that explicitly combines social and economic development and is directed towards fostering the economic, social, ecological and cultural well-being of communities and regions. As such, it recognizes, affirms and supports all the paid and unpaid activity that contributes to the realization of this well-being."
> *(See Simon Fraser University Community Economic Development Centre* http://www.sfu.ca/cscd/gateway/sharing/principles.htm)

CED projects may provide an alternative approach to providing support to people with disabilities. In the highly urbanized communities of high-income countries, policies and services are generally managed in a top-down fashion and controlled by large government bureaucracies, increasingly delivered through large bureaucratized not-for-profit organizations. Stainton et al. (2006) suggested that to overcome barriers to the employment of people with disabilities, connections must be made with existing groups of people in order to overcome prejudice and discrimination

Decision-making must take into account the perspectives of people with disabilities as far as possible in a 'bottom-up' fashion. For instance, Wilson (1996, p. 617) commented that "…community economic development, if it is truly to empower people, must build community from the inside out – i.e. from the individual's realization of self-efficacy and interconnectedness with the larger community".

CED has proven successful in addressing the needs of various marginalized groups in low-income countries. Each community is encouraged to develop viable initiatives based on an appreciation of its strengths and capabilities through a process that Kretzman and McKnight (1997) have described as 'asset mapping'. McCall (2003) suggested that, unlike a needs-based approach, which often looks to external professional input for solutions, asset mapping looks to the community's own assets that may be utilized to solve the local problem.

The process "…is driven by the relationships between community members as individuals and as components of associations and institutions" (McCall, 2003, p. 107). It is imperative, as Hopkins (1995, p. 50) pointed out, to avoid viewing CED "just as job generation for poor people and poor communities… what community businesses must grasp is that wealth and work can be created by them taking action in the local economy to meet social, as well as individual, needs that are widespread and have commercial potential". (See http://rtc.ruralinstitute.umt.edu/RuEcD/Update.htm for an account of a Vocational Rehabilitation Programme within a Rural Community Economic Development Project in the US).

2.8 Employment options - summary

Recent decades have seen growing recognition of the working capacity of persons with intellectual disabilities in many countries around the world and a flourishing of initiatives to provide them with opportunities to perform meaningful, productive work in ordinary workplaces. Supported Employment has been the main approach adopted, in a variety of forms reflecting the different levels of support required by different persons with intellectual disabilities. The experience in implementing these approaches in different countries around the world is summarized in the following section, along with the main findings of research carried out.

It must be recognized, though, that the SE model was developed in high-income countries with well-established formal services. In low-income countries, the informal economy, especially in rural and less developed areas, is the major source of employment. People with intellectual disabilities are often employed in village-based industries, including farm work, similar to the patter in western countries in the pre-industrial era.

3. Development of Supported Employment Initiatives

The implementation of supported employment in several high-income countries and on a smaller scale in some low-income countries is described in this section. It has not been possible to detail developments in all countries, but those with the most significant research activity in this field have been chosen, together with those that have demonstrated some innovative initiatives. The research findings are summarized in Section 3.3 below.

3.1 High-income countries

3.1.1 United States

There was an exciting uptake in Supported Employment across the various states of the US in the 1970s and 1980s, following the development of this model in university-based applied research centres, essentially motivated by groups of researchers and advocates interested in viable day-activity options for people with intellectual disabilities who had very high support needs (see Section 2.3 above). Indeed, many of these people were unable to gain employment in existing segregated sheltered workshops, and many had been residents of very large, segregated residential programmes. Other initiatives supported this initial trend, such as the Youth Transition Programme, which has operated throughout the state of Oregon in the US for almost two decades, providing an excellent, evidence-based example of a model transition programme for students with disabilities (Benz and Lindstrom, 1999).

A feature of the SE programmes in the US, not always present in other countries, is the legislative base supporting inclusive employment options for people with disabilities in general (see Section 2.3 above). This strong legislation supported the initial growth of SE programmes across the country. At the same time, the strong support the US Federal Government gave to research and to research centres specializing in the study of intellectual disability was another significant factor in the growth and support of SE programmes. Legislation and subsequent funding initiatives led to better educational services for this population, including an emphasis on the transition of students with disabilities from school to work and further study.

Despite this enabling environment, there is consistent evidence that there has not been a parallel diminution in the number of people with intellectual disabilities in segregated sheltered employment settings (Braddock et al., 2008). And the latest State of the States in Developmental Disabilities, conducted by David Braddock and associates at the University of Colorado, reported that the proportion of Supported Employment workers among recipients of day/work programmes declined from a high of 24 per cent to 21 per cent in the period 2000 to 2006. The report also indicated that there is approximately a 3:1 ratio of non-competitive to competitive work outcomes for people served in day work, and sheltered employment programmes (Braddock et al., 2008).

In some states, such as Wisconsin, an early leader in the roll-out of supported SE programmes, there has been a negative trend in its growth in recent years, while several states exceed the national average in their

expansion of SE programmes. In order to explore possible explanations for this trend, a study was commissioned by the Wisconsin Department of Health and Family Services (Mills, 2006). The findings and recommendations are particularly relevant to both implementation and sustainability issues (see Section 3.3 below). The inherent difficulties experienced in transporting innovative disability programme models to other jurisdictions and to other countries include the degree to which factors such as cultural values, political and legal systems, economic situation, historical background, level of education and language are comparable

Along with other states, in the mid-1980s Wisconsin received federal systems change grants focused on community-based and Supported Employment. Between 1988 and 1990, Wisconsin made positive strides and exceeded the national mean in terms of the percentage of people with developmental disabilities receiving vocational or day services who were in integrated employment (23 per cent, as against a national mean of 21 per cent). As the federal system change grants were phased out, there was a related drop in the percentage of people accessing the SE programmes. By 2004, Wisconsin reported only 2,800 people in SE, while over 15,000 were reported to be in segregated or non-work services. Its performance had dropped to 15 per cent, while the national average stood at 24 per cent. In contrast, over the same period other states continued to make significant positive strides in increasing integrated employment for people with developmental disabilities.

Early efforts were made to assist the transition from segregated employment services to more inclusive options. In 1985, the US Federal Government introduced initiatives for state systems change which have led to several studies exploring the challenges and opportunities involved in this transition (McGaughey and Mank, 2001; Novak et al., 2003; Parent et al., 1989). For instance, Novak et al. (2003) found that activities perceived to be the most effective in the implementation and expansion of state SE programmes were: technical assistance; capacity building; and policy and funding initiatives. Sustenance of the initiatives once fiscal incentives expired was revealed as a real problem.

Experience in the US indicates that the anti-discrimination provisions in the *Americans with Disabilities Act (ADA)* of 1990 appear not to have stimulated effective employment outcomes for people with intellectual disabilities. Therefore, it is assumed that there is still a strong belief that a person with cognitive limitations is incapable of gaining an integrated employment outcome, despite evidence that even those with high support needs are capable of learning complex tasks with adequate training and support (Bellamy et al., 1988; Gold, 1972, 1975; Horner et al., 1988).

3.1.2 Australia

The development of employment services for people with intellectual disabilities in Australia has followed a similar trajectory to that of the US. In the early 1970s, the Australian Association for the Mentally Retarded (now the National Council on Intellectual Disability, or NCID) expressed concern about the high numbers of people with mild intellectual disabilities entering sheltered workshops rather than open employment (Rigby, 1973). The Australian Federal Government, through the Commonwealth Rehabilitation Service subsequently established seven Work Preparation Centres for school

leavers with mild intellectual disabilities in a number of state capital cities. After 12 to 18 months of intensive job skills and social skills training, trainees obtained permanent employment in the open labour market, generally in manufacturing industries, which were the major employers in those years in Australia (Parmenter et al., 1977; Ward et al., 1978). During their ten years of programme development, the Work Preparation Centres commenced trials of SE models, based on the research work being conducted in the US.

In 1985, following an intensive consultation process with people with disabilities, their advocates, support groups and service organizations, the Australian Government published *New Directions. Report of the Handicapped Programs Review* (Grimes, 1985). This report was instrumental in the enactment of the Australian Disability Services Act (1986) the following year which was accompanied by a set of disability service standards. Disability service agencies receiving government funding were required to meet these standards to ensure on-going financial support.

In order to stimulate the development of paid employment in integrated settings, the Australian Government sponsored several open employment demonstration pilot projects, a number of which concentrated on supporting people with high support needs. One of these, Jobsupport, has continued since its inception in 1986 and has achieved one of the best records in the country for supporting people with intellectual disabilities and high support needs (Tuckerman, 2008a; Tuckerman, et al., 1999).

The overall picture currently for integrated employment in Australia is not dissimilar to that in other countries. There has been no reduction in the numbers of people with disabilities employed in segregated settings. In fact the Commonwealth Government, despite earlier attempts to limit funds to this area of employment, has given way to the strong lobby groups including parents and service organizations by accepting segregated options as a viable employment alternative. This is also in spite of strong anti-discrimination legislation and a formal commitment to the various United Nations Declarations and Conventions.

3.1.3 Canada

Neufeldt et al., (2000) found that the SE model was fairly well established in the four provinces of Nova Scotia, Ontario, Manitoba and Alberta. Canadian SE programmes are funded by the federal government under the Opportunities Fund, some Labour Market Development Agreements and by provincial/territorial governments, or by cost-sharing with the federal government.

In a review of employment policy and programme arrangements concerning the employment of people with disabilities in Canada, Crawford (2006), pointed out that people with intellectual disabilities would not be eligible for ‘mainstream’ employment programmes because they do not qualify for employment insurance. Based on this, it appears that the unfounded assumption that people with a disability are a higher risk in terms of work place safety is still deeply entrenched in the bureaucracy. However, some provinces do make exceptions to this rule. Many people with intellectual disabilities continue to participate in sheltered employment and many others access SE, but there are no data available to indicate relative participation rates.

In Canada, as in other countries, there is a pattern of SE agencies rejecting applicants with complex needs, such as those with intellectual disabilities. Stainton et al. (2006) have suggested that the increasing market competition in service provision and the emergence of for-profit organizations into the disability 'industry' have increased the 'commodification' of disability (in other words people with intellectual disabilities become commodities from which to make a profit), resulting in competition among agencies for clients who are easier to support. Special incentives may have to be built into the funding systems to counter the trend towards 'creaming' practices.

3.1.4 Finland

With Finland's entry into the European Union (EU) in 1995, the country could access the Community Initiative Programmes of the EU Social Fund (ESF) to start several pilot projects on SE for people with intellectual disabilities. Regular surveys of the state of SE in Finland have been conducted since 1998 (Saloviita and Pirttimaa, 2007). The researchers defined SE as paid work in integrated settings with on-going support. In the latest survey (2003) of the 93 responding organizations, 22 had workers in SE. In 1999 there were 21 such organizations and in 2001, there were 19.

Thus, while it appeared the number of organizations providing SE remained stable, there were many changes. Some agencies have ceased providing SE and new ones entered the field but the scale of activity was very small. Of all the organizations, 17 employed only one or two people in SE. The organization with the highest number employed in SE was one which supported people with mental health problems. Most of the organizations were sheltered workshops providing employment for people with intellectual disabilities and other marginal groups.

It was concluded that since the introduction of SE programmes in 1995, no more than 100 people had been supported. Clear changes in the composition of the people being supported changed markedly during the period 2001–2003. There was a major increase in the proportion of people with mental illness and a similar decrease in the proportion of those with intellectual disabilities being supported. The original concept of SE appears to have been distorted to be used to facilitate employment of people from different marginalized groups and, in the process, people with significant intellectual disabilities have found themselves barred, with sheltered employment and day care centres being the main options (Saloviita and Pirttimaa, 2007, p. 233).

The situation of SE in Finland is instructive on the question of the sustainability of efforts to increase the participation of people with intellectual disabilities in the regular labour market. Abiding by the principles of the new paradigm has been a significant challenge in most countries, and the experience so starkly revealed in the Finnish study is not unique. It clearly indicates that there are differing moral, political and economic value systems operating when the question of how best to support people with intellectual disabilities is considered, in contrast to other marginalized groups in a society.

3.1.5 Ireland

Ireland has also been at the forefront in pilot-testing SE, the first programme being introduced in the late 1980s when a not-for-profit organization, St Michael's House, set up the "Open Road" demonstration project designed to provide job coaches for adults with moderate to severe intellectual disabilities to support them finding regular entry-level jobs. Soon after, several other similar programmes were initiated by other not-for-profit organizations, including St John of God's STEP Enterprises, Sunbeam House's Dargle Employment Centre and KARE's Employment Assist Bureau. At a conference *Disability and Employment - What the Research tells Us*, sponsored by the National Disability Authority, McCormick and McRae (2005) cited the 1996 RISE evaluation study by Lynch, McCormack, Pierce and Kelly into the status of SE in Ireland which found that 388 individuals in 30 agencies were in part-time employment, using the individual Supported Employment model, increasing to 449 by 1999. By 2005, McCormick and McRae reported that almost all agencies supporting people with intellectual disabilities offered supported employment to at least some of their service users.

Earlier evaluations of the "Open Road" initiative (Walsh, Rafferty and Lynch, 1992; Walsh, Lynch and deLacey, 1994) showed that the participants not only accessed real jobs for real pay, but also gained significant improvements in their social competence. The pilot project also had a positive impact on families who came to value their son or daughter's new-found status as a wage earner. Similar positive effects were found among co-workers and employers. Walsh, Lynch and deLacey (1994) also highlighted the disincentives welfare payments placed on the amount of money people could earn under the SE programme.

In its Strategic Plan of 2005-2010, the Irish Association of Supported Employment (IASE) cited the EU Horizon Project Consortium Mainstream Supported Employment Project Research Report (2000) which revealed that of the 405 participants surveyed, only occasional support was required. It also found that the social benefits of SE were significantly higher than the social costs. Sustainability of the jobs was also the case for many of the people surveyed.

In their paper to the conference mentioned above, McCormick and McRae (2005) highlighted that many people with intellectual disabilities who were working in Dublin supermarkets did not progress beyond entry-level jobs and did not get opportunities to move onto jobs of their choice. They emphasized the need for job development and career enhancement through additional on-the-job training. They also raised the possibility that low expectations of employers were placing a ceiling on the potential of people with intellectual disabilities.

The National Disability Authority (2011) reported that, in 2004, Ireland's Intellectual Disability Database showed that:

- 36 per cent of adults with intellectual disabilities are in some form of work, 29 per cent in sheltered centres and seven per cent in an open employment setting.
- Only a small minority (one per cent of adults with intellectual disabilities) in sheltered employment services are considered to

> be in employment. The remainder were in what is termed sheltered work, where a normal employment relationship does not apply, there is no entitlement to a minimum wage, and earnings are nominal.

The report noted that the Intellectual Disability Database only included people with mild intellectual disabilities where they are using, or considered in need of, intellectual disability services. A higher proportion of those with mild disabilities who are registered in the database are in open employment. The report also observed that it is likely that the adults with mild intellectual disabilities who are not registered on the database are less likely to hold a job than the population at large.

Kelly, Craig and Kelly (2010) reported that in 2009, 951 persons with intellectual disabilities were in some form of SE, whereas a group four-fold in size attended sheltered workshops.

Following IASE lobbying for the introduction of a national SE programme (see IASE Research Report, 2000), the Irish Government in 2000 restructured training and employment services for people with disabilities in line with its policy of mainstreaming disability-related services. Under this policy the responsibility for vocational training and employment for people with disabilities in the open labour market was transferred from the Department of Health and Children to the Department of Enterprise, Trade and Employment. The Department of Health retained the responsibility for rehabilitative training and for Sheltered Occupational Services. The IASE Strategic Plan (2005, p. 11) noted that:

> Employment and vocational training policies for people with disabilities are now formulated in the Department of Enterprise, Trade and Employment as part of the general labour market policy, underlying the move from a medical attitude to disability to an inclusive economic and social view, recognising that people with disabilities have a contribution to make in the economy.

This is similar to a policy shift that was recently made in Australia, but questions remain as to whether the extension of the SE model to people with other impairments, such as those with mental health disabilities, has led to discrimination against people with intellectual disabilities who have higher support needs; the very population for which it was originally designed.

3.1.6 The Netherlands

In the Netherlands, in addition to special secondary schools, there are two options for students with intellectual disabilities within the mainstream system - the ‘supported learning route’ and the ‘practical education’ route. The former is more appropriate to students who will graduate with a diploma, provided they receive special needs support. The pre-vocational practical education route is for students with higher support needs who would not qualify for a diploma even with additional support.

The evidence suggests that the placement results of the pre-vocational practical schools are more encouraging, reflecting a 60 per cent placement rate to open employment, sheltered employment, or continuing education. There is evidence, however, that insufficient time is devoted to exploring what students are interested in doing. This conclusion is consistent with research, which has

shown the direct relationship between a person's motivation towards work and satisfactory open employment outcomes (Rose, et al., 2005).

The situation for people with intellectual disabilities in the Netherlands is not dissimilar to other countries with a history of welfare provisions for people with disabilities. Likewise, its extensive legal and policy framework establishes an approach that supports active independent living and access to employment for this population.

The Netherlands is attempting, as are other high-income countries, to rein in burgeoning numbers of people who are in receipt of unemployment and disability welfare payments. This policy is having a negative effect on open employment opportunities for people with intellectual disabilities, as government initiatives to increase the employment participation rate of people with disabilities tend to target people with lower support needs. Despite some strong attempts to increase numbers of people with intellectual disabilities accessing SE, sheltered employment appears the preferred option for this population for the majority of parents and government. This position was supported by the OSI/EU Monitoring and Advocacy Programme which monitors human rights and rule of law issues throughout Europe:

> As much as participation may be the aim of Government policy, the reality falls short. Interviews with experts in the field reveal a tendency to view people with intellectual disabilities as more suited to care arrangements than work arrangements….In addition to employer ignorance of the possibilities for financial support (to employ people with disabilities), protective attitudes of schools, parents and of people with intellectual disabilities themselves also limit the possibilities for employment. (Open Society Institute, 2005, p. 84-85)

This 2005 report stated that, of 73,000 people with intellectual disabilities,:

- 41per cent were employed in sheltered employment;
- Four per cent were employed in Supported Employment in the open market;
- 21 per cent were at adult day care facilities doing unpaid employment duties (See also Open Society Institute, 2006).

Schoonheim and Smits (2009) reported that employers' attitudes towards hiring people with disabilities in general have not changed. They pointed out that barriers that prevent people with disabilities entering the labour market, such as bureaucracy and effective support for people with intellectual disabilities, have not been dealt with. They recommended that in order to improve employment opportunities for people with disabilities there is a need to:

- develop an accurate and complete statistical database on the employment position of people with disabilities, disaggregated based on the type and severity of disability, the support needed, the support utilized, gender, age, and ethnicity. Statistics to be updated annually;
- focus on employment opportunities for people with disabilities in institutions and day care centres; and
- impose a five per cent hiring quota for employers and monitor employer progress on this employment quota. While there is

currently no quota system in the Netherlands, the Government has urged employers to adopt a voluntary two per cent hiring target for people with disabilities, but it is unclear if this system is monitored in any way.

The tradition in the Netherlands, until quite recently, has been to support large congregate-care residential centres for people with intellectual disabilities.

3.1.7 New Zealand

New Zealand, a small country with a population of approximately 4.3 million, has been at the forefront of advocating for the rights of people with intellectual disabilities. IHC New Zealand is the country's main parent-initiated, non-governmental organization representing people with intellectual disabilities and their families.[9] Following its formation in 1949 by parents of children with intellectual disabilities, one of its first actions was to advocate for the closure of large institutions housing children and adults with intellectual disabilities. The last large institution closed in 2006.

The repeal of the 1960 Disabled Persons Employment Promotion Act and the adoption of the Minimum Wage Amendment Act in 2007 ensured that people with intellectual disabilities are guaranteed the same employment rights as other workers, including the payment of the minimum wage to people employed in sheltered workshops, unless an individual work has an exemption. Despite the desire to support inclusive employment practices for people with disabilities, the then New Zealand government also protected the continuation of sheltered workshops, as was the case in Australia and most other countries. The procedures for granting exemptions from the minimum wage requirement in sheltered workshops and the resulting employment of disabled persons below this rate continue to be politically contentious (New Zealand Human Rights Commission, 2011). IHC New Zealand continues to promote real employment opportunities while also campaigning on behalf of children with disabilities to have full access to their local schools.

The New Zealand Disability Strategy, adopted in 2001, following widespread consultation with disabled people and their representative organizations, sets out a vision of a fully inclusive society that highly values the lives and continually enhances full participation of persons with disabilities. The strategy sets out what is required, to achieve this vision. People with disabilities will have a meaningful partnership with the Government, communities and support agencies, based on respect and equality. Disabled people will be integrated into community life on their own terms. Their abilities will be valued, their diversity and interdependence recognized, and their human rights protected[10].

Drawing on its Disability Strategy, New Zealand made a valuable contribution to the negotiation of the CRPD, especially through the

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[9] The organization's original name was "Intellectually Handicapped Children"; hence the logo IHC which has been retained.

[10] See http://www.odi.govt.nz/resources/publications/new-zealand-disability-strategy.html

participation of Mr Robert Martin, an internationally respected self-advocate for people with intellectual disabilities.

Development of Gracelands Group of Services

A partnership between IHC New Zealand and Tokanui Psychiatric Hospital led to the development in 1990 of the Te Awamutu Gracelands Trust to support patients moving out into the community. The Graceland Group of Services has expanded its services across New Zealand, supporting people with disabilities (including intellectual disabilities) in inclusive employment opportunities and helping them to live independently or semi-independently.

Box 3.1. Wendy Patton's story

Wendy Paton's story is an example of the contribution Gracelands is making to the lives of people with intellectual disabilities:

"We love having her here, and she's an asset to the company". So says Davies Foods sales administrator Nita Tyson when she's talking about Wendy Patton, a long-term employee of the company and someone who has become very much part of the staff. She began working for the company in 1995 and is still there.

Wendy, who has an intellectual impairment and almost no verbal communication was one of the founding members of Gracelands Trust when it first began.

Paul Davies, the managing director says, "she works very well unsupervised, and she's happy to point out to new staff when things are not going right. Since she joined us she has become very much a changed person".

Field and Macky, 2010, p. 40.

Association for Supported Employment, New Zealand

In the early 1990s a small group of people who had been pioneering SE in New Zealand set up the Association for Supported Employment New Zealand (ASENZ). As noted in Section 2.3 above, ASENZ has developed and refined a set of principles of SE which are universally applicable. These are now accepted as the core principles and are central to all aspects of SE in New Zealand.

The Association has given significant attention to training and development for people who work in SE. To date, New Zealand has not developed a significant research profile in SE. Thus, data on SE outcomes are unavailable. However, ASENZ has a considerable number of association and individual members, indicating that SE is seen by government and service providers as a strongly viable employment option.

3.1.8 United Kingdom

Supported Employment had its early beginnings in the United Kingdom (UK) around 1985, about the same time as pilot programmes were being sponsored in Australia and Ireland (Beyer et al., 1999). The term 'supported employment' in the UK at that time was used by the UK Government's Employment Service, responsible for vocational rehabilitation of people with disabilities, to describe sheltered workshops and a wage subsidy scheme that operates largely without job coach support. This is similar to the way the terminology is currently used in Australia.

Three important UK Government initiatives provide a useful framework in which to examine the penetration of SE in improving the life quality of people with intellectual disabilities. The first is the Disability Discrimination Act (UKDDA), which was passed in 1995. The UKDDA defines a person with a disability as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. The Act seeks to prevent discrimination on the grounds of disability in employment and other areas.

The second important initiative was the release in 2001 of *Valuing people: A New Strategy for Learning Disability for the 21st Century*, which identified significant difficulties in the coordination and delivery of services to people with intellectual disabilities in the UK (Department of Health, 2001). This was a major landmark policy event in the UK, being the first Government White Paper in 30 years dedicated to people with intellectual disabilities. While *Valuing People* has been seen as an important government statement to assist in changing community and government attitudes and supports people with intellectual disabilities, Hatton, Emerson and Lobb (2005) have pointed out that the policy includes no specific objectives that will assist in evaluating its success.

In recognition of the slow progress being made in achieving objectives in employment for people with intellectual disabilities, the UK Government has recently released *Valuing Employment Now – Real Jobs for People with Learning Disabilities* (Department of Health, 2009). This strategy sets out an ambitious goal to radically increase the number of people with intellectual disabilities in employment by 2025. The strategy will focus on people with moderate and severe intellectual disabilities, because they have benefited least from previous initiatives. The strategy specifies that by 'work' it means real jobs in the open labour market that are paid the prevailing wage, or self-employment. The vignette of Ms Jacqueline Minchin's work opportunities is an example of what the mission of *Valuing Employment Now* aims to achieve (Box 3.2).

Box 3.2. Pathway to a fulfilling job: Ms Jacqueline Minchin

The pathway Jacqueline Minchin followed through education led her to the job she holds today. From an early age, she combined attendance at a special school with mainstream education, and soon graduated to full time mainstream primary education, going on to mainstream secondary school and a further education college. Her mainstream educational experience provided her the opportunity to mix with other pupils, learn social skills and gain in confidence and independence.

Jacqueline has worked part-time as a clerical assistant at Penglais secondary school in Aberystwyth (UK) for the past ten years. Her regular daily work includes mail duties, such as opening envelopes, date-stamping letters, putting mail in respective pigeon holes and delivering messages throughout the school, including to the head teacher and sometimes to teachers in their classrooms. Her supervisor tells her about particular things that need to be done each day, in addition to her usual tasks. She often has to address envelopes, looking up addresses on the computer. Her favourite time of the day is when she goes to work in the canteen. She has great fun with her co-workers there, and socializes with them outside of work hours. She is in charge of preparing takeaway orders, takes payment for these and gives change.

She enjoys her work immensely and loves chatting about football and other events with her friends on the staff. She has her own work section and keeps it clean and tidy. One of her colleagues says that the work Jacqueline does is highly valued and helps the school to operate smoothly.

In hindsight, it is easier to identify what it took for Jacqueline to get her job. What made the difference were her parents' expectations, combined with a good careers service and support from REMPLOY which was instrumental in finding an employer with a positive attitude. Her cheerful personality, willingness to learn and accept instructions were central to her keeping her job, supported by mentoring, understanding and a positive attitude on the part of her employer.

Derived from ILO, 2010a.

Given the poor economic climate prevailing at the time it was developed, the strategy suggests there will be little opportunity for new investment. Hence, it aspires to focus on more effective use of existing resources, including education, adult learning and employment support. Local authorities that have a major responsibility for service delivery will be encouraged to refocus their current expenditure on adult day services onto SE.

REMPLOY, the leading UK provider of specialist employment services for people facing complex barriers to employment, offers a combination of supports to placement in mainstream employment along with work opportunities in businesses which it runs in different parts of the country, catering solely to persons with disabilities. Following a review of its future business options in 2006, to enable it to support more disabled people into open employment in a cost effective manner, REMPLOY has taken steps to expand its network of tailored employment support services ('Interwork') and aims to support 20,000 people into mainstream employment annually by 2012/13, including people working at the REMPLOY businesses. While people with intellectual disabilities (called 'learning disabilities' in the UK) are acknowledged to have high support requirements when it comes to mainstream employment, Interwork reports considerable success in its placement rates for job-seekers with this type of disability (see: http://www.remploy.co.uk; Price Waterhouse Coopers, 2006).

3.1.9 Other European Countries

Across the other European countries which have been monitored, only a relatively small number of students with intellectual disabilities are in mainstream schools; the majority are in special schools, and many are totally excluded from education. The quality of education in the special school settings has been found to be variable, with insufficient attention being given to the social skills necessary to live in the community. At the transition level from school to post-school options, there was little evidence of adequate planning and or opportunities for preparation for employment; nor were there opportunities for access to on-going adult education programmes, with the exception of Sweden, which is noted for its lifelong adult education programmes for people with intellectual disabilities.

The unemployment rate for people with intellectual disabilities in Eastern European countries was found to approach almost 100 per cent (Open Society, 2006). The vast majority who do work are found in sheltered workshops, and those with high support needs are generally directed to day activity centres. However, there was evidence of attempts to increase the participation of people with intellectual disabilities in SE. In a comparative study of Supported Employment in ten countries of Europe, undertaken in 2006-2007, it was found that over a third of users of SE services (35.3 per cent) were people with intellectual disabilities (Jordan de Urries, Beyer and Verdugo, 2007).

The European Union of Supported Employment (EUSE), established in 1993 and now with 19 national associations for SE, is a driving force in the endeavour to increase employment opportunities for their clients. EUSE conducts regular conferences and training workshops across Europe. It recently received support from the European Union Leonardo Partnership to develop a European Supported Employment Toolkit which was completed in mid-2010. This toolkit consists of a range of position papers and 'How To' guides, and has been designed to increase the knowledge and skills of professionals responsible for the delivery of Supported Employment services. The toolkit is primarily aimed at service providers for use in their staff development programmes. (See: http://www.euse.org/supported-employment-toolkit-2/EUSE%20Toolkit%202010.pdf/view).

In a comparative study of the situation of SE in Europe, Beyer et al., (2010b) found that organizations offering SE were also involved in vocational training and sheltered work programmes. A significant number had only commenced offering SE in the last five years. The study found that there was a significant variation in the provision of key elements of SE, particularly workplace support, possibly compromising people with intellectual disabilities who require on-going support from either from job coaches or co-workers. The study also found that the funding for SE was fragile and that variations in the way the model was being implemented may have disadvantaged those with higher support needs.

O'Brien and Dempsey (2004) suggested that, while social firms and social enterprises had gained momentum throughout Europe as alternatives to traditional sheltered workshops, there was debate about how social firms differed from sheltered forms of employment. In 2004, the Finnish Government introduced legislation on social firms to distinguish them from other companies. Before the legislation was introduced there were up to 20

companies claiming to be social firms. Subsequent to the legislation being enacted, only one organization had registered as a social firm. O'Brien and Dempsey (2004, p. 130) commented that, "supporters of the model believe it is a viable alternative to more traditional models. However, critics see it as a way to re-badge sheltered workshops without really addressing the concerns of segregation and low wages." While this comment was made in the European context, it is relevant to other countries also.

In order to increase the expansion of those good models that do exist, the reports highlighted the need for governmental and European support, if they are to become the rule rather than the exception. To increase the replication of good models at the national and international levels will require strong government support. A severe impediment to the development of strong policy in this area is the limited availability of data, as noted above by Beyer and Robinson (2009), particularly data disaggregated by individual type of disability. This has posed a barrier in analysing the actual situation for people with intellectual disabilities.

3.1.10 Examples from Asia

Singapore

Singapore is a small island state with a population of about four million. Educational and employment services for the majority of people with intellectual disabilities are provided by two large voluntary agencies: the Association for Persons with Special Needs (APSN), which conducts schools and employment services for those with 'mild' intellectual disabilities; and the Movement for the Intellectually Disabled of Singapore (MINDS), which conducts schools, employment services, day activity programmes and residential living for those in the 'moderate' to 'severe' range. Both organizations conduct traditional sheltered workshops and programmes known as 'social enterprises'.

The Singapore Government encourages all disability organizations providing employment services to conduct community-based programmes. To this end, both APSN and MINDS have made efforts in the last five years to place people in competitive, open employment. In the case of APSN a special programme is being conducted at one of its senior schools to assist students in making the transition from school directly into paid work in the community, a feature of which is extended work experience placements. In the case of MINDS, the open employment programme is an adjunct to the sheltered workshop programme. People are selected to make the transition from the segregated setting to community-based jobs on the basis of their interests and performance in the sheltered environment.

Examples of social enterprises in Singapore are a car wash 'crew' which works in a regular community setting, and a 'thrift shop' that sells recycled clothing. In neither case, though, do employees receive wages generated by the business but are paid instead by the welfare organization. While in some cases, these enterprises are located in regular community settings, they tend to project a welfare impression, rather than a regular commercial image.

Japan

In 1966, Japan adopted a voluntary employment quota policy to benefit workers with disabilities. Since 1976, under amendments to the Law for Employment Promotion for Persons with Disabilities, the quota is now a legal obligation, initially relating to persons with physical disabilities only. In 1998, amendments to the Law extended its provisions to people with intellectual disabilities. Some companies meet their quota obligation through subsidiary companies set up to employ persons with disabilities only. Two hundred and forty two such companies existed, employing 7,700 persons with disabilities. Over 40 per cent of these employees were persons with intellectual disabilities. Subsidiary companies, while increasing the number of people with intellectual disabilities in employment, do not conform to the goal of inclusion in regular company operations, which government policy aims to promote (Matsui, 2008).

The Japan Association for the Employment of the Elderly and Persons with Disabilities (JEED) plays a major role in implementing the nation's policies for people with disabilities. JEED has also taken a leadership role among Asian countries in the field of vocational rehabilitation for people with disabilities. As part of its role, JEED conducts research into employment support methods for various disability groups, including those with intellectual and other developmental disabilities.

Through its network of Local Vocational Centres for Persons with Disabilities, JEED provides support to people with intellectual disabilities in work experience and job coaching in order to facilitate a smooth transition to work opportunities. JEED also provides extensive support services to employers, including general information, counselling services, employment management support and technical advice.

The Japan International Cooperation Agency (JICA) has been active in assisting the development of SE and the training of job coaches in the Asia-Pacific region.

The job coach model in Japan

Job coach positions and their training are supported by the Japanese Government. The processes followed by the job coaches are essentially similar to the model established in the US, involving assessment of the individual with a disability and of the workplace; matching the person to a job; intensive support at the workplace, phased out as the person learns the job; and intermittent follow-up support.

As in other high-income countries, the decline in manufacturing jobs in Japan, once a popular area for job placements, has meant a shift to supporting people with intellectual disabilities in the distribution and service industries.

A recent study by Ishii and Yaeda (2010) explored job development activities for people with intellectual disabilities in Japan. They surveyed 941 companies concerning the type of tasks performed by people with intellectual disabilities and the type of job development activities related to the tasks performed. Almost 60 per cent of the companies who responded did not employ people with intellectual disabilities. Of those who did, the most common task was "cleaning up the office and workplace". Other tasks

included clerical, custodial work, and manufacturing duties. Companies who employed people with intellectual disabilities used job development activities significantly more frequently than those who did not. Job development activities included:

- assisting and enhancing work performance through the use of assistive technology;
- simplifying the work procedure and modifying work equipment for better efficiency; and
- creating new job placement opportunities through job restructuring methods.

The following commentary on the characteristics required when recruiting people to work as job coaches is also relevant to other countries (Box 3.3).

Box 3.3. Upgrading the job coach position – Challenges

At present, in the case of the Nakamachidai Center on Developmental Disabilities, people working as job coaches are mostly those who majored in psychology, welfare or education at university and are interested in social welfare. However, to improve the system of job coaching, the key point is to train people who know more about business and have a good business sense, in addition to the ability to understand the characteristics of people with disabilities… the training program needs to focus on practical know-how in their actual work… in order to get more competent job coaches… make it an attractive job in terms of wages and establish it as a qualified occupation.

See: http://www.disabilityworld.org/06-08_02/employment/coaches.shtml

3.2 Middle-income countries

3.2.1 Example from Asia

Malaysia

In July 2008, the Malaysian Government passed the *Persons with Disabilities Act,* marking a shift from the former charity model to a rights-based approach for people with disabilities in Malaysia. This Act stresses the importance of accessibility, equal opportunities and protection and assistance from the government, private sector and NGOs to ensure the full participation of disabled people in society. The National Council for Persons with Disabilities was subsequently established and a National Action Plan for Disabled Persons 2007-12 was developed.

Employment initiatives

The Ministry of Women, Family and Community Development is taking tentative steps towards implementing inclusive employment for people with intellectual disabilities, with support from JICA. Training programmes on the Job Coaching model have been conducted for NGOs and CBR groups. A Malaysia Job Coaching web site has recently been set up (http://www.jobcoachmalaysia.com/).

The Joy Workshop in Melaka was founded in 1999 to improve the quality of life of persons with learning disabilities through integration into society through employment opportunities and enhanced community living skills. Its INTOWORK programme supports the transition of workers from

the sheltered workshop environment into SE. Inspiration for this initiative was the work of the late Marc Gold and his "Try Another Way" approach to training people with intellectual disabilities. The approach starts from the underlying conviction that everyone can learn. It involves a planning process with the individuals with disabilities, their families and employers; proposed job matches, based on the requirements of jobs and individuals; actual job match based on job analysis; commencement of work, with on-site assistance, fading and transfer; and on-going support where needed (adapted from Warner, 2010).

Supported by the Australia-Malaysia Institute, the Centre for Disability Studies of the University of Sydney and the Universiti Sains Malaysia in Penang collaborated in conducting a pilot training programme in 2010 for support staff working in disability employment and community living facilities in Malaysia. Further trials of this programme are planned for delivery in other sites in Malaysia, using the 'train-the-trainer' model to meet the need for skilled staff to achieve the goals of SE and the wider aims of the country's Action Plan for Disabled Persons.

3.2.2 Example from South America

Centro Ann Sullivan del Peru (CASP)

This organization was inaugurated in 1979 by Dr Liliana Mayo with the help of her parents and colleagues, teaching eight children with different abilities in the garage of her parents' home located in the district of La Punta, Callao, Peru. Since 1985, Dr Judith M. LeBlanc, from the Schiefelbusch Institute for Research in Life Span Studies of the University of Kansas, joined the CASP as principal consultant. With Dr LeBlanc's specialist education input, CASP has turned into an international model centre where a series of unique teaching procedures have been developed into what is known as the Functional-Natural Curriculum.(See: http://en.annsullivanperu.org/student-and-family-programs/supported -employment/index.php).

The CASP SE programme is aimed at youths and adults with different abilities (such as autism, Down syndrome, cerebral palsy or developmental delay) of 16 or more years of age, who have the skills to be included full-time or part-time paid work in a real workplace.

For example, student workers of the SE programme started working at the Ministry of Health (MINSA) in February, 2011. Tasks such as putting codes on documents, filing and other clerical duties have been assigned to them. They have become the first young people with different abilities who work for public institutions in Peru.

An agreement reached between CASP and MINSA in October 2010 made possible this important hiring. It is part of a plan for promoting inclusion for people with different abilities into the Ministry of Health, a policy the present administration strongly supports.

The CASP SE programme follows the principles first established by researchers in the US, including job coaches and on-going support in real jobs in the community. (See: en.annsullivanperu.org/student-and-family-programs/supported-employment/)

3.3 Low-income countries – Examples from Africa

There is a dearth of examples of SE in Africa for people with disabilities in general, and those with intellectual disabilities in particular. This is not surprising, given the degree to which this section of the community has been discriminated against for a variety of complex reasons; a major factor being general community negative attitudes toward this population (Mung'omba, 2008). Even in countries where SE has been an employment option for several decades, the take-up has been difficult. One of the reasons for this is the lack of government initiatives to ensure the long-term sustainability of programmes for people with high support needs, despite the cost benefits that can be achieved. There also remains a tension between the welfare and human rights approaches to support for people with disabilities. Yet examples like that of Mr Benyam Fikru from Ethiopia, reflect the value of taking action (Box 3.4).

Box 3.4 Voices of people with intellectual disabilities: Mr Benyam Fikru

I was born in 1973, the eldest child in my family. I used to have a fever constantly, so mom took me to the hospital and one day the nurse told my mom that I have an intellectual disability. I started going to this school at the age of seven. I learned many things at school and my mom was very happy, because I started to read magazines and newspapers at home. I am known in the compound for dancing and music and also I have good interaction with my family, relatives and neighbours. … I graduated in weaving at the ENAID Vocational Training Centre. At this time, I worked and produced cultural cloth. Work made me independent like other people. I feel so confident myself that I would be able to work and live my life like any other man.

ILO, 2010a.

3.3.1 Examples from South Africa

The following two examples from South Africa and one from Zambia are illustrative of the existing potential for more widespread application of the SE principles.

The Living Link

This non-profit organization, founded in 2000 in Johannesburg, South Africa, supports the inclusion of people with intellectual disabilities in society and facilitates their transition from school to work to independent living. Students at the Living Link complete an Adult Integration Programme aimed at integrating them into society and into the community. The programme is life-skills based and focuses on practical components of daily living that are essential. After students have graduated from the programme, the Living Link assists in placing their members in suitable positions in the open labour market using a SE approach. Adults are placed in ordinary working environments, doing regular work where salaries and benefits are realistic and reflect work performance. Supports are provided to the employers and employers, in a mutually beneficially way. The following services are provided:

- job market screening;
- job site observations;

- job sampling;
- recommendations on job restructuring;
- database of prospective employees with intellectual impairments;
- job matching and placement;
- job coaching/on-site training and support; and
- employer and co-worker sensitization and training.

Traditionally, graduates are placed into entry-level positions that are fairly repetitive and provide a certain degree of structure. Graduates have been placed in a variety of work environments including hospitals, offices, warehouses, factories, schools, gardens/outdoor environments, hotels and kitchens. (See: http://www.thelivinglink.co.za/index.html).

The Ntiro Project for Supported and Inclusive Employment

The Ntiro Project for Supported and Inclusive Employment, founded in 2000 in the Tschwane South District of the Guateng province of South Africa, targets the multiple barriers that people with intellectual disabilities face in the areas of education and work. It seeks to address in a holistic way the many overlapping grounds of exclusion, from poverty and disease to problems of language and curriculum relevance.

Of particular significance is the Ntiro Project's emphasis on changing attitudes and building integrated community-based support. It gives strong focus to providing information and skills to district officials, NGOs and community organizations, and to building partnerships among them. The inclusive model has proved extremely successful, serving to progressively replace older segregationist models throughout the district. The project gives concrete expression to the new vision of inclusive education in South Africa and to the call for more inter-sectoral approaches.

Mr Jack Mnisi's story illustrates the outcomes possible when using the principles of SE (Box 3.5).

Box 3.5. Mr Jack Mnisi – A working man

Jack Mnisi is a 24-year-old man with Down syndrome living in Mamelodi, in Gauteng, South Africa He works in the Assembling Department at IST, an engineering company in the eastern suburbs of the city of Pretoria/Tshwane and is responsible for assembling electrical test connectors.

Jack is fully employed, earning a high salary (even higher than his job coach and certainly higher than the rest of his family members). Added to his salary are benefits such as medical aid, pension, daily meals, and so forth.

When Jack started working there, his job coach travelled with him daily in order to make sure that Jack got to work on time, took the correct public transport, and so on. It wasn't long before a natural support popped up in the form of a co-worker who started assisting Jack in travelling to and from work. Today Jack travels independently or hitches a ride with some of his colleagues.

At work, his job coach initially had to spend a lot of time to settle Jack into the routine of the company. It didn't, however, take long for the co-workers to volunteer when he was in need of assistance. As communication in Jack's mother tongue is vital, the company recently employed a direct supervisor working with Jack. Jack participates in all the activities, meetings and brainstorming sessions of the department. To accommodate him in his work they use colour-coded cards and safe mechanical equipment. When IST decided to comply with Employment Equity and employ a person with a disability, they were unsure of the screening and interviewing process. Using a placement agency such as Ntiro helped to get the right candidate for the specific job. The employer says that it made good business sense to hire Jack and that the company never looked back.

See: http://www.downsyndrome.org.za/main.aspx?artid=81

3.3.2 Example from Zambia

The concept of Supported Employment for people with intellectual disabilities has been introduced in Zambia through a project funded by the Government of Finland. Implemented by the Finnish Association on Intellectual and Developmental Disabilities (FAIDD), in association with the Zambia Association on Employment for Persons with Disabilities (ZAEPD), the project focused on examining the relative benefits of an SE model in formal and informal economies, small business ventures and self-employment (Koistinen, 2008). Building on a previous project that had supported the development of thirteen special vocational training units for people with intellectual disabilities in mainstream vocational training colleges, this project targeted graduates from these special units.

Through this project, which ended in 2005, more than a hundred graduates were placed in employment either in the formal economy (as kitchen assistants, agricultural workers, office orderlies, cleaners, tailors and weavers) and in the informal economy (as housemaids, gardeners and poultry workers) which absorbs up to 70 per cent of the Zambian labour force.

Workers who are working in the formal economy are entitled to pensions, gratuity or social security, or paid leave. These entitlements are not available to workers in the informal sector, however, where there is little protection for working conditions, including wages.

On a number of indices, including social integration and wages, much better outcomes were reported for employees in the formal economy, while there was some evidence of maltreatment of employees in the informal economy, especially females employed as housemaids. The maltreatment

sometimes took the form of withholding wages for minor transgressions of dubious validity.

This project is an excellent example of collaboration between a high-income country with experience in SE policies and practices, and a low-income country. The issue remaining to be addressed, however, is how to ensure the sustainability of such initiatives, especially job retention, when the foreign aid programme concludes. This issue is discussed in Section 4; a major recommendation being that there is a need for the development of a national strategic plan endorsed by government and supported by on-going technical assistance from high income countries. The growth of strong self-advocacy and family-advocacy systems is also crucial as a catalyst for bringing about systems change.

3.4 What makes for successful inclusive employment?

The focus of the research studies from Australia, Canada, the United States and the European Union summarized here has been on factors which have facilitated the growth and sustainability of the Supported Employment model of inclusive employment. As the 'home' of the SE model, it is not surprising that the bulk of research studies has also emanated from research centres in the US.

These research studies have identified a number of factors that influence the impact of SE and characteristics of SE programmes which have led to successful outcomes. These are outlined below.

3.4.1 Barriers to participation

In respect to those people with high support needs, their prospects for employment are hampered by a range of factors that are not directly attributable to their impairments. Stainton et al. (2006) pointed out that factors such as disincentives to employment arising from income and disability support programmes, lack of information about job availability, inadequate training and comparatively low education levels, lack of accessible transportation, and employer discrimination were limitations to being recruited into SE programmes.

In countries which have implemented a quota system for the employment of employees with disabilities, employers will often declare that they have not reached the quota and elect to pay a fine for non-compliance. This money is then used to support sheltered or "special" employment.

3.4.2 Preparedness of individuals with disabilities

Riches and Green (2003) found that people with disabilities were generally well accepted by supervisors and co-workers in integrated employment settings. However, such acceptance was contingent on people with disabilities 'blending in' or 'fitting in' and not drawing attention to themselves – that is, having acceptable social skills.

As people with intellectual disabilities experience additional physical and mental health problems to those of the general population, research has shown that regular health checks prevent more serious problems occurring (Beange et al., 1999). As the prevalence of mental health problems for people with

intellectual disabilities can be as high as 40 per cent, it is imperative that mental health screening be conducted so that those requiring specific support can be identified (Einfeld et al., 2006; Hofer et al., 2009). As indicated above, inappropriate social and emotional behaviours can be a significant barrier to successful employment outcomes.

O'Brien and Dempsey (2004), in their comparative analysis of employment services for people with intellectual disabilities in Australia, Finland and Sweden, emphasized the necessity for education and training as a key factor in improving the participation of people with intellectual disabilities in the general labour force.

Koistinen (2008) in her study of the SE project in Zambia, emphasized the central importance of vocational training in appropriate marketable skills and recommended that a market analysis should be undertaken to identify the precise skills a potential job-seeker needs when vocational training programmes are being designed. Independent living and social skills were also found to be important to successful employment outcomes.

3.4.3 Individualized financial support

Allocating financial support to the individual in conjunction with person-centred planning (see below) provides the person with a disability greater opportunity to exercise self-determination and freedom of choice (O'Brien et al.. 2005; Stainton et al., 2006). Canada has been at the forefront in adopting an individualized funding approach through which government financial support is directed to the individual rather than to an agency.

3.4.4 School to work transition initiatives

The acquisition of job-related skills is a process which should begin long before a student with intellectual disabilities leaves school. Research in the area of transition from school to work and adult living has a long history, reaching back to the early 1970s (Parmenter, 1986; 1990). For instance, Brolin (1972) studied the effects of a school curriculum which facilitated the subsequent employment of people with intellectual disabilities, including programmes such as work study or work experience. A decade later, the emphasis swung to people with much higher cognitive support needs, leading to the first SE initiatives for this population. Rutkowski et al. (2006) provide a description of Project SEARCH, of which a large component is work experience. The *Americans with Disabilities Act* of 1990 (ADA) supported these initiatives in the US by targeting discriminative practices in the workforce.

Box 3.6. Proven transition practices

The following secondary school transition practices are associated with students' greater retention and success while in high school, and better employment and education outcomes after leaving school:

1. direct, individualized tutoring and support to complete homework assignments, attend class, and stay focused on school;
2. participation in vocational education classes during the last two years of high school, especially classes that offer occupationally specific instruction;
3. participation in paid work experience in the community during the last two years of high school;
4. dompetence in functional academic (e.g., reading, math, writing, problem solving) and transition (e.g., money management, personal/social, career awareness, self-advocacy, goal setting) skills;
5. participation in a transition planning process which promotes self-determination;
6. direct assistance to understand and connect with resources related to post-school goals (e.g., four-year colleges or universities, community colleges, vocational rehabilitation); and 7. Graduation from high school.

Benz and Lindstrom, 1999.

One of the keys to a successful transition process is for the secondary school to implement a transition policy, an ingredient of which should be the development of individual transition plans (ITPs) for each student early in the secondary school years. Gradually, inter-agency involvement of agencies such as employment providers and post-school education providers need to be involved in the planning. Towards the end of schooling, part-time work experience has been shown to be a factor predicting later employment success (Parmenter, 1986, 1990; Parmenter and Fraser, 1980; Parmenter and Knox, 1991).

In a pilot programme initiated in the state of New South Wales in 1989, the development of inter-agency and community teams proved to be successful mechanisms in facilitating the smooth transition of students with disabilities to further study and work (Riches, 1996). Similar initiatives have been implemented in many countries, but without a clear legislative and policy mandate many initiatives are left to individuals, with subsequent loss of focus once those people move on to other responsibilities.

Luecking and Wittenburg (2009), in their report of the US Department of Social Security Administration, Youth Transition Demonstration provided an overview of excellent case examples of the intervention components of this initiative. These examples illustrated "…the potential for youth with disabilities to leverage project services and move into employment" (p. 241).

3.4.5 Characteristics of successful programmes

Values base

Programmes in which all the stakeholders, including government, employers, service providers and families, were committed to the principle of

equity for people with intellectual disabilities led to successful and sustainable integrated employment outcomes (Mills, 2006; Wehman et al., 2006).

Programme size

Research in the US has paid particular attention to factors which facilitate the growth of SE programmes, in an effort to correct the imbalance with facility-based models of employment. Programme size appears to play a role in the type and range of day and/or employment services offered. In a national survey of rehabilitation agencies, Kiernan, Gilmore and Butterworth (1997) reported that smaller agencies, providing support to 50 people or fewer, were found to be more likely to provide integrated employment exclusively than larger organizations. In the current globalized climate of business amalgamations, based on the principle of economies of scale, the loss of a personalized service militates against the delivery of effective outcomes for individual beneficiaries.

Support needs assessment

A comprehensive support needs assessment of the person with intellectual disabilities has been shown to be important, not only for the purposes of employment, but also for other life activities, including community living and leisure activities (Riches et al., 2009a, 2009b; Thompson, et al., 2004). It has been shown that work cannot be dealt with in isolation from other life activities (Halpern, et al., 1986). In terms of the sustainability of integrated employment, there is overwhelming evidence that people with intellectual disabilities tend to lose jobs, not because of their inability to perform the job tasks, but because of negative social behaviours (Chadsey et al., 1999; Knox and Parmenter, 1993).

A field-based study which examined the relationships between general community living skills and the degree of community independence in working and living domains of adults with intellectual disabilities found that people who displayed higher levels of basic living skills generally worked and lived more independently. These findings support the inclusion of specific training in basic living skills in school curricula during the transitional school years of a student with intellectual disabilities (Woolf et al., 2010).

On the other hand, Chadsey et al. (1997) warned against too much emphasis being placed on a ‘deficit-remedial model’, rather than emphasizing the congruence or ‘ecological fit’ between the person and his/her environment. It may be more efficacious to find the right environment, rather than changing a particular social behaviour. This principle is especially relevant for people with intellectual disabilities and high support needs.

Person-centred planning

Person-centred planning puts the person with the disability at the centre of the decision-making processes, taking into account the person’s wishes and desires (Coyle and Moloney, 1999; Wiese and Parmenter, 2009). In the employment area, strong motivation on the part of the person seeking a job has been shown to be a significant predictor of a satisfactory outcome. Whilst more work remains to be done on assessing the impact of person-centred planning on client outcomes and satisfaction, research to date has shown promising results (Robertson, et al., 2006). In the pilot SE project in Zambia,

Koistinen (2008) found, that good job matches were made when job-seekers' preferences and needs were recognized, leading to better long-term outcomes.

On-job support

The 'place, train and support' model for SE usually involves job coaches working with the potential employee to identify interests and skills. This is followed by job seeking, matching and placement. The employer might also be encouraged to make adaptations (i.e. accommodations) to a specific job in order to match it with the abilities and skills of the employee with an intellectual disability. In many cases the job coach might learn to do the job first, in order to subsequently teach the employee with the disability. In other circumstances, the employer might prefer for a regular staff member to teach the skill. This person may subsequently become a 'mentor' to the person with the disability.

In Zambia, availability of support programmes for job placements was a crucial element for success not only in obtaining but also keeping jobs. It was not sufficient to rely solely on vocational training programmes to place people in employment.

Irrespective of who does the initial training, research is consistently showing that on-going natural or informal, supports are leading to greater sustainability of the job placements than external/formal supports. In practical terms this means that job coaches need to gradually withdraw their support, but at the same time ensuring there are networks within the workplace that will provide support to the employee when required. For example, they could identify someone in the workplace who is prepared to be a "mentor" to the employee with a disability. However, while natural supports are proving to be a promising method of increasing the integration and support of people with intellectual disabilities in the workplace, Storey (2003) concluded that a combination of job coaching and natural supports may be needed, tailored to individual circumstances and needs.

The frequent presence of a job coach can also be a barrier to the person's opportunities to develop relationships, both formal and informal, with co-workers without a disability (Rogan, et al., 2000). In some circumstances, the job coach may concentrate on assisting with job-related skills, such as social behaviours, in settings outside of the place of work. However, research is equivocal on the practice of social skills training outside the work place, because people may not generalize the skills to the natural environment- they may need the cues that the natural environment offers. McCuller et al. (2002) concluded that a combination of training environments may lead to better outcomes.

In their study of four major SE organizations in the US, Rogan et al. (2002) found several factors that can be put forward as 'best practice' in human supports. These were:

- individuals should be able to choose the kind of job they enter;
- work should allow individuals to obtain independence from paid support, such as reliance on job coaches;
- support should be tailored to each person's needs;
- 'getting to know the person well' is the key to successful workplace support;

- the possibility that a person may not be ready for work should be accepted when appropriate; and
- existing contacts and other natural supports should be used as inroads into the workplace.

Another role for the job coach is as support to families who may initially have negative attitudes to their son/daughter working in a regular work environment, because of fears that they may be victimized. Parents of children with a disability are frequently over-protective. For others, cultural factors may encourage them to persist in hiding their child with a disability because of negative community prejudices (Mung'omba, 2008).

Links to parents

Griffin et al. (2008) and Lindstrom et al. (2007) stressed the importance of families' attitudes toward their adult children's capabilities as being a critical determinant in their support for community-based employment options. Since the first point of contact in the diagnostic process is the medical and allied health professions, limited expectations are often entrenched in the child's early years.

Lack of career choice was highlighted in a study of attitudes of parents and primary caregivers of people with high support needs towards SE (Ford et al., 1995). This study also emphasized the need for greater communication between the service providers and families. Donelly et al. (2010) have shown the importance of family networks to the person with intellectual disabilities achieving satisfactory employment outcomes. Koistinen (2008) concluded that parental support was important, though often lacking in Zambia, especially at the vocational training, job-seeking and placement levels.

Benchmarking quality

In order to abide by the original SE model, commentators are increasingly calling for effective benchmark indicators to be established against which the quality of SE programmes can be measured (Jenaro et al., 2002; Wehman et al., 2003) (See Box 3.7).

Box 3.7. Quality indicators

Wehman et al. (2003) suggested that quality indicators should encompass the following ten areas:

- meaningful competitive employment in integrated work settings;
- informed choice, (wherein the person is allowed to express a preference) control and satisfaction;
- level and nature of supports;
- employment of individuals with significant disabilities;
- amount of hours worked weekly;
- number of people from programme working regularly;
- well-coordinated job retention system;
- employment outcome monitoring and tracking system;
- integration and community participation; and
- employer satisfaction.

One approach is to examine hourly rates of pay. However, Jenaro et al. (2002:18) suggested a broader set of indices:

> … accomplishing the goal of developing a real job requires that employees with disabilities obtain the same salary, duties, benefits, and integration outcomes as anyone else to the greatest extent possible. Quality indicators in employment programmes require a strong commitment to achieving outcomes, not just services. A real job is facilitated when work environments are arranged in such a way that supports and accommodations do not limit either career development or social interactions.

Timmons et al. (2002), who investigated the characteristics of effective state service systems in the US, by examining the experiences of people with disabilities who have used state agencies to find employment, indicated five key components to effective service delivery: i) agency culture; ii) consumer-directedness; iii) access to resources; iv) quality personnel; and v) coordinated services. In a particularly rigorous economic analysis of data in the state of Southern Carolina in the period 1999–2005, geared to determine whether job coaching leads to stable employment in community settings, McInnes et al. (2010) found that:

- 56 per cent of individuals with job coaches were working one year later, compared to nine per cent of those without job coaches;
- those who received job coaching were likely to have favourable job characteristics such as higher IQs and an absence of emotional or behavioural problems; and
- when these endogenous factors were corrected for in subsequent analyses, a sizeable and statistically significant effect remained.

It is possibly not surprising that agencies are tempted to recruit ‘easier to place’ individuals into SE programmes, such as those with higher IQs and good social skills, despite the fact that these programmes were initially meant to target the more disabled population.

Sustainability

Based on the findings and recommendations of a survey of the situation in 25 US states, together with a detailed investigation of over a dozen states which reported integrated employment outcomes well above the national average, Mills (2006, p. 3) suggested that seven factors explained the impressive integrated employment outcomes achieved by these states:

- the existence of strong, clear and unambiguous state developmental disabilities agency policies, rules and programmatic requirements intended to support a clearly articulated agency preference for, and commitment to, integrated employment for people with developmental disabilities;
- the use of funding incentives to encourage the expansion of integrated employment opportunities, and/or funding disincentives to discourage the use of facility-based employment and non-work services;
- a liberal definition of the kinds of employment arrangements which qualify for SE funding;
- adequate state agency staffing dedicated to employment;

- investment in on-going training and technical assistance for agency staff;
- a commitment to supporting organizational change among facility-based (sheltered) providers moving to integrated employment settings; and
- the use of a comprehensive data-tracking system focused on integrated employment outcomes.

3.4.6 Workplace characteristics

Employer attitudes

A US study on employer attitudes (Olson et al., 2001) showed that employers from firms of all sizes have favourable experiences in employing people with intellectual disabilities and value the training done by SE service providers. Accommodations frequently made include extra supervision time, the provision of flexible hours and the use of a job coach. These accommodations were perceived to be of minimal cost to the company. In terms of human resource management, employees with intellectual disabilities were viewed as costing companies the same or less than employees without a disability. However, negative employer attitudes can be one of the most serious threats to the success of a SE programme.

Nevertheless, one variable appears the most reliable in predicting employers' favourable attitudes to people with intellectual disabilities; that is, previous positive job-related experience with a person with a disability (Rimmerman, 1998).

Negative employer attitudes can be one of the most serious threats to the success of a SE programme. Disability may be perceived as taboo. Employing persons with disabilities may be expected to affect the prosperity of businesses. Negative stereotypical views on the concept of intellectual disability are deep-seated and prevail in most countries (Yazbeck et al., 2004).

This suggests the importance of working closely with employers to ensure their satisfaction with the employment outcome. Hence, advertising 'success stories' involving the employment of people with disabilities has been found to be an important strategy. Research has shown that, contrary to the negative stereotypes portrayed throughout history; people with intellectual disabilities can be loyal, trustworthy and diligent workers who seldom fail to turn up for work (Ward et al., 1978).

Tuckerman et al. (1999) found very positive employer attitudes toward workers with intellectual disabilities with high support needs. Smith et al. (2004) reported that the existence of policies on employing people with disabilities, previous contacts with a person with a disability, and the level of the disability were associated with more favourable attitudes.

A survey of 642 Australian employers who had employed a person with a disability, including those with intellectual disabilities, concluded that:

- over 90 per cent of employers who had recently employed a person with a disability said they would be happy to continue employing people with disabilities;

- some 78 per cent of employers described the match between their employee with a disability and the job as 'good';
- in relation to the cost benefit of workplace accommodations for employees with a disability, 65 per cent of employers rated the financial effect to be cost-neutral and 20 per cent identified an overall financial benefit;
- employees with a disability averaged one-sixth of the recorded occupational health and safety incidents of employees without a disability;
- 90 per cent of employees with a disability record productivity rates equal to or greater than other workers;
- 98 per cent have average or superior safety records; and
- 86 per cent have average or superior attendance records. (Graffam et al., 2000; 2002a)

(See Box 3.8 for two perspectives.)

Box 3.8. Employee and Employer perspectives

Peter: I like the work. It's very good – plenty of jobs to do. My favourite is car service – helping customers with their boxes to their car. I've changed – I now live on my own – I'm independent.

Peter's employer: It has worked very well – the customers liked it – he's efficient, he's reliable and he's happy.

Tuckerman,2008b.

Workplace culture

A congenial workplace culture has been found to be critical for the successful placement and maintenance of people with intellectual disabilities in integrated work environments. Butterworth et al. (2000) outlined four salient characteristics of a supportive and interactive work setting: a) multiple-context relationships, for instance opportunities to mix with co-workers after work has finished for the day; b) specific social opportunities, including designated lunch/break rooms where everyone is welcome; c) personal and team-building management style, where managers build a sense of teamwork, take a personal interest in employees, and schedule work around workers' personal strengths and needs; and d) interdependent job designs, which may include 'cross training' employees on several different tasks. This workplace culture also has the opportunity to create career pathways for supported workers, who in many cases, do not progress beyond entry-level jobs.

Such a culture also helps the development of strong relationships between workers with and without disabilities. These relationships are often characterized by the presence of humour and informality, which ultimately assist the processes of job retention (Parmenter, 2002). To assist potential employers to be more accepting of people with intellectual disabilities as genuine workers, and to counter the negative views often rooted in the stereotypical attitudes of the general community, Fabian, Edelman and Leedy (1993, p. 32) have suggested the need for intervention strategies at three levels:

> … the individual co-worker/supervisor, the work group, and the whole organization. Employment consultants found that communication skills

training for co-workers and supervisors, particularly as the training focused on responding to the employee with a disability as an individual rather than focusing on the disability, improved attitudes. In other instances, employment consultants discovered that simply convening a work group to discuss issues of myths and stereotypes about disability in the workplace improved attitudes and morale, as the group became aware of its own sources of power and influence in the work environment.

Storey (2002) and Parmenter et al. (2006) have provided best practice suggestions for increasing the social interaction of supported employees through strategies targeting social skills instruction, communication instruction, problem-solving and co-worker assistance.

A Dutch study found that supported employees were perceived on an equal basis within the workplace by their non-disabled colleagues (Cramm et al., 2008). Most co-workers considered supported employees to be at least 'work acquaintances'. Interestingly, some of them identified supported employees as 'social friends', indicating a higher level of inclusion.

3.4.7 Outcomes

Most of the studies which have addressed outcomes for supported employees have made comparisons between SE and segregated programmes, including sheltered workshops and day centres, on a range of indices.

Performance

An Institute of Employment Studies Survey in the UK in 2005 (Dewson et al., 2005) reported that:

- disabled employees show a high level of commitment and loyalty to an organization, and as a result,
- disabled employees are hardworking, have low sickness absence rates and high retention rates.

Whilst these findings refer to disabled workers generally, they are especially true of workers with intellectual disabilities (Ward et al.,1978).

Consumer satisfaction

Surveys of satisfaction from the perspective of people receiving SE services have found that the majority of consumers like their jobs. Parent, Kregel and Johnson (1996) found, from face-to-face interviews with people with high-support needs receiving SE services in Virginia, that many would like to change some aspect of their job to make it better. More than half indicated that their current job is not the career they would like to have permanently. The study concluded that there was a need to increase consumer involvement in all phases of the SE service delivery.

Lack of career choice was also highlighted in a study of attitudes towards SE of parents and primary caregivers of people with high support needs (Ford et al., 1995). This study also emphasized the need for greater communication between the service providers and families.

Earnings

SE programmes by their very definition give people with intellectual disabilities access to real wages. These are, especially in programmes for

people with high support needs, adjusted according to the person's productivity and pro-rata amounts are paid. There is also a high rate of part-time jobs reported in SE programmes. Overall, however, people in SE programmes earn significantly more than those employed in segregated programmes (see Section 2.2 above).

Quality of life

In terms of quality of life and life satisfaction, studies generally report that those in SE programmes had a higher rating than those unemployed or in alternative disability programmes. In an Australian study, Eggleton et al. (1999) found that those in open employment had a significantly higher quality of life than those in sheltered workshops or who were unemployed. In a Spanish study, Verdugo et al. (2006) found no differences in quality of life between those in SE and those in sheltered workshops. However, there was a direct relationship between the typicality of the employment setting and quality of life for those in SE programmes. There was also a negative relationship between the intensity of external support and quality of life, suggesting that such support should be used when only absolutely necessary.

Kober (2005), in a later Australian study, compared the quality of life and level of empowerment/independence of people in integrated and segregated employment settings. For people with low functional work ability there was no difference in quality of life, while for those with high functional work ability those in integrated work settings were higher on both quality of life and empowerment/independence scales. Interestingly, living in the family home had a relationship to quality of life. For those living at home, irrespective of the type of employment, there were no differences on quality of life. However, in responses of participants living independently or in group homes, quality of life was found to be significantly higher for those in competitive employment settings. This confirms an earlier observation concerning the interdependence of life activities: work outcomes cannot be seen in isolation from other life events.

Knox, Mok and Parmenter (2000) found that people working in an inclusive work setting developed a strong positive self-image, claiming they no longer felt 'disabled'; a finding also reported by Koistinen (2008) in her research in Zambia. This highlights how the label of 'disabled', and especially 'intellectually disabled' and other derogatory terms, influence the self-concept of people with intellectual disabilities.

A comparison on objective and subjective quality of life indices within a sample of people employed in SE, traditional sheltered workshops/day activity centres, and a group of non-disabled co-workers in Wales found that those in SE reported a higher objective quality of life than the groups in both the sheltered workshops and day centres. Non-disabled co-workers reported a higher objective quality of life and autonomy at work than the three groups of people with intellectual disabilities. Interestingly, the SE group reported a higher subjective quality of life than the non-disabled co-workers (Beyer, et al., 2010a). One of the goals for SE was social inclusion in the workplace. In an observational study comparing the levels of interaction and engagement between workers with and without intellectual disabilities (1995), Beyer, Kilsby and Willson. found no significant differences between the two groups.

Economic benefits

While cost-benefit/cost efficiency analyses of SE have produced conflicting results (Schneider, 2003; Beyer and Kilsby, 1998; Beyer and Robinson, 2009), other studies have reported clear gains to both the individual and the taxpayer (Kregel, 1999; Kregel and Dean, 2002; Kregel et al., 2000; McCaughrin et al., 1991). In a comprehensive review of the cost efficiency of SE programmes, Cimera and Rusch (1999) reported that:

- over time, SE is a good investment for taxpayers and society;
- generally, workers earn more in SE than in sheltered employment; and
- cost efficiency of SE programmes varies among regions of countries.

Cimera's comprehensive research of all supported employees funded by vocational rehabilitation throughout the entire US from 2002 to 2007 (2010) returned an average net benefit to taxpayers of US$251 per month per supported employee. Cimera noted that this figure, if extrapolated to the total number of Americans with disabilities served in segregated day services, would amount to over US$1.5 billion in cost benefits for SE. Disappointingly, SE wages still lagged behind those of the general population, and often did not represent a living wage. High rates of part-time employment may have contributed to this finding

Tuckerman, Smith and Borland (1999) also found that the placement of people with high support needs in an Australian context was a cost-effective option for government. As the programme grew in size, the costs per client stabilized, together with a reduction in disability pension costs. The study revealed that the SE programme was significantly less costly than a day activity programme catering for a similar population.

Of special significance to the principle of inclusive communities and the acceptance of diversity was the finding by Graffam et al. (2002b) that employers experience both material and non-material benefits to their organizations from employing a person with a disability, with those benefits being financially cost-neutral or cost-beneficial in a large proportion of cases. In terms of non-material benefits, the presence of people with disabilities in the workforce highlights the need for overall attention to training and supervisory practices, basic work practices, health and safety issues and an improvement of organizational performance. Graffam et al. (2002b) also suggested that their findings provided some evidence of employers acknowledging and accepting diversity in the workplace. Overall, they concluded that, "…an employee with a disability can be seen as a catalyst for positive change, a catalyst for improved organization performance" (p260).

Beyer and colleagues at the Welsh Centre for Learning Disabilities have carried out extensive cost-benefit analyses of SE over the past two decades (Beyer et al., 1996; Beyer and Kilsby, 1998; Beyer et al., 2002; Beyer and Seebohm, 2003; Beyer, 2008; Shearn et al., 2000). Major conclusions were as follows:

- Initial costs of SE can be higher in the start-up period than in the traditional sheltered employment options. Taxpayer cost-

benefits improved over time. It may take up to five years before financial benefits outstrip the costs of SE.

- Welfare benefits regulations and the absence of mainstream funding for SE were seen as significant restrictions on the growth of SE in the UK.
- Higher rates of part-time work, with supported workers working for a few hours and also being on welfare benefits, led to relatively unfavourable levels of cost-benefits, compared to the US.
- Comparison of the costs of SE with those of day activity centres was unfavourable to SE, but SE was found to generate greater outcomes for money spent in terms of social integration.
- Economies of scale in terms of the numbers of workers employed and the hours worked per person were critical factors in determining cost-benefit.
- When factors such as the taxes paid by supported workers and their higher spending capacity are taken into account, community placements represent a net gain for the taxpayer.

In a report commissioned by the UK Department for Work and Pensions, Rangarajan et al. (2008) questioned the findings of cost-benefit studies of SE on the grounds of methodological flaws, including the lack of randomized control trials.

3.4.8 Concluding remarks

It is recognized that almost all existing research in this field has been conducted in high-income countries. Hence, the findings are not necessarily applicable to low-income countries. There is a challenge for existing research centres with an interest in SE to build partnerships with researchers in low-income countries in order to foster indigenous research efforts. Historically in the disability field, there has been a tendency for social policies to move quickly ahead of the research base (Parmenter, 1991).

The involvement of families as strong advocates, witnessed at the ILO Regional Conference *People with Intellectual Disabilities: Opening Pathways to Training and Employment in the African Region* in Lusaka, Zambia, March 2010, and the emergence of self-advocates in low-income countries are promising trends. There is a distinct worldwide movement towards the emancipation of people with intellectual disabilities and their families, leading to greater empowerment and self-determination.

4. Moving forward

Since its inception in the 1970s, SE has provided inclusive employment options for people with intellectual disabilities across several continents. The personal stories of what having a job means to people with intellectual disabilities is testimony to how important this issue is in terms of social justice and human dignity. A key factor in the growth of initiatives has been a clear policy commitment by governments to support such initiatives.

However, experience from both high- and low-income countries indicates that on-going support is required for these initiatives to be sustainable. Low-income countries, given their rural nature and severe fiscal constraints, may be in a better position to test a number of the alternative models described above. For instance, self-employment, small business enterprises, and, at a regional level, CED, may be viable options, but these have not as yet been critically analysed. The evidence from a study conducted in Zambia questioned the viability of the small business enterprise model for people with intellectual disabilities, as it was suggested they lack the necessary business skills (see Koistinen 2008, p. 32). An alternative would be to employ a person with business experience and a strong commitment to assisting people with intellectual disabilities, as the manager. The SE principles, including the important 'place and train' and on-going support features, can be used in each of these approaches.

A positive feature is the growth of national SE organizations which provide advocacy and training support to their constituents. As these organizations gain strength, they may be in a position to mentor initiatives in low-income countries.

Two phenomena are emerging in countries where SE has a longer history. First, there is a natural tendency to extend SE to other disability groups; for instance, to people with mental health disabilities. This has had the effect of lessening the take-up for people with intellectual disabilities. The second, and related, issue is the tendency for agencies supporting SE to select easier-to-place people for SE programmes.

One of the critical features to be recognized when examining the impact of SE on the lives of people with intellectual disabilities in countries such as Canada, Australia, New Zealand, the UK and parts of Europe is the long history of welfare support those countries have provided to people with disabilities. The SE model challenges the very core of the welfare model, and it is not surprising that many of the negative attitudes and in-built disincentives inherent in the welfare system have, to some extent, impeded its growth as a strong alternative to segregated employment options. People with disabilities and their carers who receive income support and health benefits are reluctant to lose these if they exceed an income threshold. The exponential growth of people receiving welfare benefits has led governments in many parts of the world to tighten the criteria and the assessment processes in an attempt to rein in welfare expenditures. However, a contrary position has been taken by Heath (2010), whose analysis suggest that welfare benefits to people with disabilities reduces poverty, but does not necessarily discourage employment.

An important question arises as to why there has not been a sustained growth in SE initiatives worldwide. Why have some programmes flourished whilst others have 'withered on the vine'?

Gottlieb, Myhill and Blanck (2010) have suggested that in order to better understand the obstacles in the way of SE or CE becoming the dominant models, it is useful to make a distinction between those that affect labour supply and those that impact on labour demand. On the supply side, the barriers that are inherent in the life circumstances of people with disabilities must be examined. For instance, inadequate access to transport and the risks associated with losing disability services and health benefits, should income exceed a particular threshold, are potential barriers. On the labour demand side, there are attitudinal barriers still to be confronted and the perceived costs of workplace accommodations, both of which may influence potential employers' reluctance to hire people with disabilities.

Boeltzig, Scott Gilmore and Butterworth (2006) have also addressed this issue. They suggested that we need to take a broader perspective rather than simply looking for obstacles within the community rehabilitation provider network; it is they claim, a wider systemic issue. Their comments are particularly apposite to the current discussion:

> "If the goal is to make integrated employment not only a viable but a desirable employment option for people with disabilities, system and funding structures should be developed that not only encourage more full-time employment and a greater variety of jobs, but also allow for investment in program staff to assist individuals with developmental disabilities with their career plans and provide guidance about the potential impact of work income on benefits." (p. 7).

4.1 Pointers for Policy Development

Various countries have clear policies concerning employment for people with disabilities in general, which affirm the goal of community integration and support for individual choice. Despite this, however, this review has highlighted the reality that the vast majority of people with intellectual disabilities still do not have access to integrated employment; and in many cases, no access to any meaningful day activities.

The following pointers relevant to policy development have been informed by the research outcomes and field initiatives reviewed for this working paper and can act as a guide for the further expansion of SE to facilitate the employment of people with intellectual disabilities in inclusive workplaces. These are relevant to countries presently attempting to revise old policies and/or develop new policies which will go some way in addressing the inequalities experienced by people with intellectual disabilities.

- Programmes need to abide by the principles of Supported Employment and Customized Employment, to achieve good outcomes for people with intellectual disabilities, especially the need for on-going formal and informal supports.
- Long-term success is influenced by sound initial planning, which must start in the transition years at the secondary school level. A well-planned transition process from school is one of

the better indicators of successful employment outcomes, especially if work experience is a feature.

- There is a need for a balance between structure and over-structure in the planning and delivery of employment options. The intensive, clinically-driven rehabilitation model is generally not recommended for people with intellectual disabilities, especially for those with moderate to high support needs.
- Good policies are based on good information. There is a dearth of data on the actual incidence and prevalence of intellectual disability, especially in low-income countries. The use of typical epidemiological methodologies may not be entirely relevant, given that disability is a culturally specific phenomenon. What counts as a disability in an urban context may not be seen as such in a rural community.
- Effective data management systems assist in informing programme needs, programme monitoring and programme development for people with intellectual disabilities, especially those that are embedded in data-gathering systems for the general population.
- Planning which is person-focused and which involves all stakeholders, including families, is also a key factor in its success. Emphasis needs to be placed on the person's strengths, interests and the support system that needs to be provided to achieve personal goals. The importance of matching the person's preferences, wherever possible, to the job placement cannot be stressed too strongly.
- Career planning is recommended, as many people with intellectual disabilities do not progress beyond entry-level jobs.
- Adequate staff training of job coaches, with an emphasis on marketing and on-site training skills, is critical to the success of SE.
- Assessing outcomes on the dimension of quality of life reflects the inter-relationship between work and other life activities, including where the person lives. The reciprocal relationship between levels of independence and feelings of self-determination and empowerment is well established.
- Success stories of positive employment outcomes are one of the best ways to convince potential employers that people with intellectual disabilities can be loyal and productive workers.
- As employment has been shown to impact on the quality of life of people with intellectual disabilities, it may be an important factor in the possible reduction of emotional disorders in this population.

Action is required at both the national and regional levels to give effect to the lessons learned in a way which will lead to improved opportunities for this group of people with disabilities

4.1.1 National level

Governments in consultation and collaboration with civil society and social partners bear responsibility for promoting opportunities for people with intellectual disabilities to take part in their communities and the broader

society. This section outlines the main steps towards meeting this responsibility.

Conduct a systems analysis of current situations

- In collaboration with all relevant stakeholders, including schools, conduct surveys, consultation meetings and individual interviews to determine the current status of employment for people with intellectual disabilities.
- Analyse barriers and facilitators to the achievement of integrated employment for this population across the various geographical areas of the country in order to tap the experiences in urban and rural communities.
- Inform this process through reference to documentation on current models of employment for other disability groups.

Develop goals and objectives for the way forward

- Using the same consultative processes, with the input of all relevant stakeholders, develop a set of goals and objectives to guide the implementation of SE initiatives for people with intellectual disabilities.
- Explore a variety of models to cater to the particular circumstances of local communities. Elements of the Community Economic Development (CED) model are worthy of investigation, as are aspects of the social enterprise approach.
- Agree a statement of the underlying value system which has informed this process.

Develop a national policy on integrated employment for people with intellectual disabilities

- Develop a clear written policy articulating its underlying values, and the corresponding goals and objectives of integrated employment services for people with intellectual disabilities which flow from these values, in consultation with relevant stakeholders, including different government departments, social partners and civil society agencies.
- The recent initiative by the UK government, *Valuing Employment Now,* could be a guide to the process.

Develop a national implementation strategy

- Establish a timeline for the achievement of goals, together with resource allocations.
- Indicate relevant responsibilities of government and non-government agencies, including human resources.
- Set up a small number of pilot programmes, as part of the strategy, together with evaluation processes, in order to initiate a systems change process.
- Identify potential leaders in government and the community to champion the systems change process.

Development of an effective data collection system designed to track progress

- Develop a data collection system to provide information on people supported (inputs); details of the various programme models (processes); details of wages earned, days worked, level of community integration, and skills achieved (outputs); and measures of satisfaction and quality of life of the employees (outcomes).
- Design this data collection system to allow for programme modifications following feedback, and the identification of environmental barriers and facilitators.
- Develop local research capacity to help maintain the on-going sustainability of programmes by developing coalitions with local university research centres, encouraging national universities to collaborate on issues such as programme development and evaluation and staff training, as well as exploring alliances with universities in other countries which have a track record in research into employment of people with intellectual disabilities.

Communicate the results of programmes

- To assist the process of attitudinal change among social partners in the community and widely disseminate positive results of pilot projects through all available media, since success stories can stimulate further successes.
- Involve social partners and community leaders to act as 'champions' who can assist this process.

4.1.2 Regional level

To support initiatives at national level, stakeholders may find it of value to form networks regionally or globally.

Develop a Regional Association of Supported Employment

- To assist in the sharing of information and technical assistance, consideration may be given to the establishment of a regional support organization modelled along the lines of the European Union for Supported Employment (EUSE) or the World Association for Supported Employment (WASE).
- Links with the EUSE and similar national associations for supported employment would give access to training materials and other technical assistance.
- Such an organization could organize workshops and training programmes at regional and/or national levels.

4.2 In conclusion

Despite enormous challenges, including extreme poverty and difficulties faced from attitudinal and policy perspectives in the provision of support to people with disabilities in general, and those with intellectual disabilities in particular, there are some positive trends. Of special significance is that the majority of countries around the world have subscribed to the various contemporary human rights

principles relating to people with disabilities. What remains is the need for a genuine commitment to ensuring these principles are not only incorporated into national disability policies, but are put into practice and monitored to the best level possible in terms of the socio-economic conditions prevailing.

The opportunity to engage in real work in the general community has been denied to the vast majority of people with intellectual disabilities, for reasons explored above. The first step in bringing about change in this situation is a belief that change is desirable and a genuine commitment to effect change. Most countries have signed and ratified the UN *Convention on the Rights of Persons with Disabilities.* Article 27 of the Convention states:

> 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. States parties shall safeguard and promote the realization of the right to work.

This statement provides a compelling reason to explore how a country, even with limited resources, might embark on a programme to assist one of the most disadvantaged groups in its society to become engaged in work ‘ that is open, inclusive and accessible’.

It is crucial that, where ratified, the implementation of the CRPD is closely monitored. The fact that countries around the world have enacted specific disability legislation is a positive feature, but as noted throughout this paper, people with intellectual disabilities are often left until last in the provision of support.

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