Employment and Disability: A Population Left Behind
Trevor R. Parmenter
Where have we come from?

Normalization: Bengt Nirje & Wolf Wolfensberger
Where have we come from?

Deinstitutionalization
Commitment to a strong value base

• Normalisation Principle- Swedish initiatives in the 1960s and the impact of Wolfensberger’s Social Role Valorization (SRV) principles

• UN Resolution 2856 (XXVI). Declaration on the Rights of Mentally Retarded Persons (1971)

    The mentally retarded person (sic) has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
Persons with disabilities have equal rights to work and gain a living. Countries are to prohibit discrimination in job-related matters, promote self-employment, entrepreneurship and starting one’s own business, employ persons with disabilities in the public sector, promote their employment in the private sector, and ensure that they are provided with reasonable accommodation at work (Article 27).
A Paradigm Shift

• The Convention marks a ‘paradigm shift’ in attitudes and approaches to persons with disabilities.

• Persons with disabilities are not viewed as "objects" of charity, medical treatment and social protection; rather as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

• The Convention gives universal recognition to the dignity of persons with disabilities.
Each Member for which this Convention is in force undertakes to declare and pursue a national policy designed to promote, by methods appropriate to national conditions and practice, equality of opportunity and treatment in respect of employment and occupation, with a view to eliminating any discrimination in respect thereof. (Article 2)
Each Member shall, in accordance with national conditions, practice and possibilities, formulate, implement and periodically review a national policy on vocational rehabilitation and employment of disabled persons. (Article 2)

The said policy shall aim at ensuring that appropriate vocational rehabilitation measures are made available to all categories of disabled persons, and at promoting employment opportunities for disabled persons in the open labour market. (Article 3)
Enactment of a Legislative Base

United States: *The Developmental Disabilities Assistance and Bill of Rights Act* - 1984

Australia: *Disability Services Act* - 1986

United Kingdom: *Valuing People* - 2001
People with intellectual disability can learn

• **Principles of good teaching**
  - start where the learner is at
  - proceed in easy steps
  - provide positive reinforcement
  - teach to mastery before proceeding to next stage

• **Work of Marc Gold in 1970s**
During the late sixties, Marc Gold, then a special education teacher in East Los Angeles, began to formulate a conceptual framework of instruction based on a few fundamental beliefs:

• His students with severe disabilities had much more potential than anyone realized;
• All people with disabilities should have the opportunity to live their lives much like everyone else; and
• Everyone can learn if we can figure out how to teach them.
Achievements of people with intellectual disabilities

- Have real jobs
- Live in the community with support
- Make choices
- Can have relationships and marry
Work
A Home of His Own
Friends
Intimate relationships

Paul and Andrea on their wedding day
Wedding Announcement:
Sujeet Desai & Carrie Bergeron

- We were very proud of both Suj & Carrie for their gracious presentation as bride & groom with no reason to doubt by anyone why these two special adults should not have been married.

- Suj amazed us as always with his unexpected first air travel on his own. Just two days before the wedding to NY city where he played in fundraising event for "Best Buddies" on Yacht "Highlander" with a special request from Anthony Kennedy Shriver! He will continue to do his solo instrumental entertainment along with power point workshops. Only now he will be joined by his wife Mrs. Carrie Bergeron Desai! (Carrie herself is an excellent motivational speaker). They will present their first workshop as a husband wife team next week in Atlanta at the 2006 National Down Syndrome Congress convention.
CHALLENGES: stigma

- Community attitudes
- Family attitudes
- Employer attitudes
How do we combat ignorance?

- Demonstrate competencies obtained from good education and training

- Publicise success stories

- Emphasize that disability is a natural part of human diversity
Changes in the way we assess people for special assistance

- We assess their support needs and **NOT** their level of intelligence/impairment
- The support needs assessments show us where the person needs help:
  - health
  - everyday living
  - job
  - social
  - leisure and recreation
  - spiritual
What is the I-CAN?

The Instrument for the Classification and Assessment of Support Needs (I-CAN):
“a support needs assessment designed to assess and guide support delivery for people with a disability including mental illness. It provides a support services and family friendly holistic assessment, conceptually based upon the internationally recognized WHO ICF framework.”

http:// cds.med.usyd.edu.au
I-CAN v4.2
Domains

Health & Well Being
- Physical Health
- Mental & Emotional Health
- Behaviour of Concern
- Health & Support Services

Activities & Participation
- Applying Knowledge, General Tasks & Demands
- Communication
- Self-care & Domestic Life
- Mobility
- Interpersonal Interactions & Relationships
- Life Long Learning
- Community, Social & Civic Life

My Goals

About Me, My Dreams & Aspirations, Current Life Situation, Support Network
Person-Centered Planning

Individual

Adulthood

Individually oriented
Personalized
Individual quality of life
Tom’s Life vision

- Social Inclusion
- Self-Determination
- Personal Development
- Rights
- Interpersonal Relations
- Emotional Well-Being
- Physical Well-Being
- Material Well-Being
Mary’s Life: Visions

- Disability-Related Support
- Family Interaction
- Physical/Material Well-Being
- Emotional Well-Being
- Parenting
WHAT WORKS IN EMPLOYMENT?

- Transition Planning
- Work Experience
- Role of Job Coach
- Job Matching
- Accommodations: Job Carving
- Importance of Peer/Mentor Support
- Importance of Work-Related Social Skills
Transition Planning

- Needs to start in early secondary schooling
- Driven by an individual transition plan
- Needs to involve families
- Needs to involve potential employers
Work Experience

• Having work experience as a part of the curriculum is a good predictor of later employment success

• It gives the student a taste of the “world of work”

• It helps the student to make choices about what s/he would like to do
Transition to work - Community Work Options

FOUR CHARACTERISTICS OF THE COMMUNITY WORK OPTIONS PROGRAM:
1. Training towards agreed transition goals rather than a curriculum
2. Real work settings are used rather than classrooms
3. The use of skilled and experienced staff
4. A strong link with an effective open employment service (Jobsupport Inc) that provides on-going support and training
Role of the Job Coach

• Assessing the person’s strengths

• Assessing the person’s interests

• Matching these factors with possible jobs

• Assisting with the job application

• Helping to initiate the client into the job

• Provide intermittent support as needed
Job Matching & Job Carving

• Job Matching is a procedure involving matching a person’s interests and skills, following a detailed job analysis, to ensure both the employee and the employer get the best outcomes.

• Job Carving is a similar principle which may involve finding a job or a part of a job which can be modified to suit the employee’s needs and interests—sometimes referred to as accommodation.

• Instead of the employees’ adapting to the job demands; job carving adapts the job to the employee.
Importance of Peer/Mentor Support

• Evidence strongly suggests fading out the support role of the job coach to a fellow employee promotes sustainability of the job

• The Job Coach may maintain contact with the employer and/or the employee as a back-up in case of crises
Importance of Work-Related Social Skills

• Case Study

Bill who has a moderate level of support needs, got a job in a factory where his liberal use of bad language would not be noticed, as the work culture made this acceptable. What no-one had told Bill was that his liberalism didn’t extend to the Boss, who was told to ‘**** off’ by Bill when asked to move some boxes out of the gangway. Luckily the Boss saw the funny side of this. When the difference was explained to Bill he understood and never made the same mistake (Leach, 2002).
Successful Supported Employment Models

• Definition

In Supported Employment, the job must be in the community, real wages must be paid and the person with the disability must receive ingoing support. (Wehman et al. 2003)

• Supported job model

The essential characteristic is its ‘place, train & support’ feature with the jobs being in integrated settings in the community
More SE Models

**Enclave Model**

- Consists of a group of people with disabilities who are trained and supervised among workers who do not have a disability.

- To be a true SE model these workers need to be paid a productivity-based wage, rather than the income being channeled through another agency.

- There is moderate support in the literature for this model.
SE Models

Mobile Crew

- This model is a combination of service and business. It may consist of a crew of people with and without a disability who perform service jobs in the community. Examples include gardening, rubbish collecting and disposal, car washing and window cleaning.

- To meet the criteria of SE, employees need to be paid according to their productivity and not have their pay channeled through another agency which may retain an amount.

- There is evidence that this model may provide greater opportunities for community participation than the Enclave model.
**SE Models**

*Benchwork Model*

- Initially developed for persons requiring very high support as an employment alternative to day activity programs.
- It is similar to a factory where people with and without disabilities can work together on assembly-type jobs.
- The work is not dissimilar to that used in sheltered employment, but keeping true to the principles of SE, it is a small business located within a normal community business setting.
- Workers are able to access neighbouring community facilities during lunch and other breaks.
Other Models

• Self-Directed Employment

• Social Firms

• Community Economic Development
Other Models

**Self-Directed Employment**

- This model is also called a Micro Enterprise- a small business created around one or more persons.

- There is evidence that there were more successful experiences with this model in low to middle income countries than high income countries.

- A possible reason is that low to middle income countries are more resourceful. They also tend not to have a highly developed welfare system.
Other Models

Social Firms

- Social Firms are one type of social enterprise.
- Social Enterprises are businesses which trade for a social or environmental purpose.
- Profits are re-invested back into the company to help them achieve this purpose.
- The Social Enterprise movement has a higher profile in European countries.
Other Models

**Community Economic Development (CED)**

- CED is a community-based and community-directed process that combines social and economic development on a ‘bottom-up’ fashion.
- CED projects may provide an alternative approach to providing support for people with disabilities.
- It may be an option for regional area of a country to consider.
WHAT DOESN’T WORK?

- Not all persons with a disability require a rehabilitation model (train and place), where pre-training occurs before job placement.
- As a person’s support needs increase, the ‘place, train and support’ model becomes increasingly appropriate.
- Likewise, placement in a sheltered workshop to enable someone to be “ready” for integrated employment is not supported by research. In fact, the more capable workers are usually not encouraged to leave.
- Programs which do not provide ongoing support, usually fail.
Characteristics of Successful Implementation of SE

- A commitment to a strong value base
- Enactment of a legislative base
- Allocation of start-up funds to sponsor pilot projects
- Evaluation of pilots-collaborate with local and international research centres
- Publicise results – develop strategic plan to expand successful models
- Initiate effective quality controls to ensure outcomes and sustainability
- Establish national and regional SE support organisations- link with similar international bodies
A reputable US study suggested the following points as “good practices” in SE:

- Individuals should be able to choose the kind of job they want,
- Work should allow individuals to obtain independence from paid support,
- Supports 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.