

EXECUTIVE SUMMARY

Exploring the Issues of PwIDs in Adulthood

1. Background

1.1 World wide concern regarding Persons with Disabilities (PWDs)¹ began in the 1970s with the UN Declaration on the Rights of Mentally Retarded Persons (1971) and the UN Declaration on the Rights of Disabled Persons (1975). One of the outcomes of the UN-ESCAP's Decade of Disabled Persons (1993-2002) was the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which specify major areas for action to ensure PWDs can participate fully and equally in all aspects of social life. Commitment to issues facing PWDs continues with the declaration of 2003-2012 as the Second Asia and Pacific Decade of Disabled Persons and the ratification of the Biwako Millennium Framework by many governments including Malaysia.

1.2 As a signatory to these universal declarations, Malaysia is committed to working towards an inclusive, barrier-free and rights-based society for all PWDs. We are also committed to the principles of the World Declaration on Education for All (1990) and the Salamanca Statement (1994) which calls for inclusive education for children with special needs. However, there is as yet no specific legislation in Malaysia to protect the rights of PWDs or prohibit discrimination against them in education or employment, although there is a *Code of Practice for the Employment of Persons with Disabilities in the Private Sector* (1991) and a 1% quota reservation of jobs for PWDs in the civil service since 1989. Matters concerning PWDs sometimes fall between the cracks of four separate Ministries - the Welfare Department of the Ministry of Women, Family and Social Development; the Ministry of Education; the Ministry of Human Resources; and, the Ministry of Health – each of which takes care of different issues that may affect PWDs.

1.3 There is increasing awareness in Malaysia of issues affecting PWDs. Nevertheless, there is a dire lack of statistics and systematic studies on the issues facing PWDs, in particular People with Intellectual Disabilities (PwIDs)² and the problems they encounter as they become adults. "*Exploring the Issues of PwIDs in Adulthood – A Report on the Situation of People with Intellectual Disabilities in Penang*" which is based on two surveys undertaken by Asia Community Service is an attempt to fill this gap. The main objectives of the two surveys were:-

- To understand and more accurately assess the situation of PwIDs
- To identify the services they require
- To identify the types of support needed by families with PwIDs
- To know the employment situation of PWDs and PwIDs
- To know the demands and attitude of employers

¹ PWD – People with Disabilities, includes all types of disabilities, Eg. blind and visual impairment; deaf and hearing impairment, physical impairment and intellectual disabilities.

² PwIDs – People with Intellectual Disabilities. Eg. down syndrome, mentally retarded, slow learners etc..

2. Survey Findings

2.1 The overwhelming majority (94%) of 218 PwIDs had attended some kind of education program with NGO service providers and/or early intervention centres catering for the highest proportion (68.3%). 16.1% have attended Special Classes, 17.4% normal classes and 4.6% have been to Community Based Rehabilitation Centres.

2.2 More than half (54.6%) of 218 PwIDs had no work experience at all while 24.8% (or 54 persons) have worked in sheltered workshops, 5% in family businesses and 8.7% have worked in the wider community. Of 32 persons who had resigned or been terminated from previous jobs, 14 were still unemployed.

2.3 29.4% are capable of fairly independent living in the community, 52.8% are fairly independent within a home environment while 18.3% need help to cope with daily living needs.

2.4 48.1% (105 persons) were staying at home with no access to suitable training or work opportunities. There is a significant gender difference in that 61.7% of female PwIDs were staying at home compared to 38.1% of males.

2.5 The aspiration of PwIDs and their families to improve their situation through more training and skills is expressed clearly in the fact that the three most sought after services were for vocational training (48%), sheltered workshops (44.4%) and living skills training (38.4%). Equally significant is the fact that more than half of the 105 persons currently staying at home would be interested in work opportunities either in a sheltered workshop or out in the wider community.

2.6 An overwhelming majority of respondents (90.8%) think that more services and programs are needed to improve the life of young adult PwIDs – in training, preparation for work, day or respite care as well as opportunities for leisure activities. Families of PwIDs indicated that they needed support for their family's members in terms of training and workshops (70.2%), counseling and emotional support (67.7%), as well as information and resources (51.6%).

2.7 The fact that the majority (87.2%) of the respondents were registered with the Penang State Welfare Department but only 11.5% were registered with the Penang State Labour Department reflects a perspective that there is a greater need for PwIDs to rely on welfare.

2.8 Only 4.8% (or 69) of 1,431 companies responded to the survey, indicating a low level of interest or concern. Of these 69, only 19 (27.5%) were currently employing PwIDs and the total number of PwIDs employed was 58.

2.9 The reasons for this may be found in the fact that 73.9% of the companies that responded expressed apprehension about employing PwIDs. The three most common reasons given for not employing PwIDs were - the companies are unable to take responsibility if anything happens, budgetary constraint and a preference for foreign labourers.

2.10 Some reason for optimism may be found in the fact that 58% of the companies were willing to consider employing PwIDs if they are able to adapt to the job environment and work satisfactorily and 39.1% are willing to accept external support to reduce their concerns about employing PwIDs. No less important is the fact that companies that did employ PwIDs expressed more positive opinions and less hesitancy towards employing PwIDs.

2.11 Significantly, there is a low level of awareness of policies and even benefits related to employment of PwIDs. Only 18 companies (26.1%) of the companies were aware that the government had introduced a 1% quota reservation of jobs for PwIDs in the civil service since 1989. A larger number (46.4%) were aware of the double tax deduction benefit available for the private sector but even then 7 of the companies that did employ PwIDs were unaware of this benefit!

3. Main Recommendations

The survey findings on the current living and employment situation of PwIDs in Penang, indicate that concerted efforts by several parties (indicated in parenthesis), working in collaborative partnerships, is still very much needed for PwIDs to achieve the objectives of living independent and dignified lives, as well as enjoying full and equal participation in all aspects of social life.

3.1 Better Education & Training - foundations for independent and dignified living in adulthood (Ministry of Education, Service Providers, Families).

- Access to appropriate basic education for *all* children with disabilities based on an inclusive philosophy, with Individual Education Plans adjusted within the framework of a flexible curriculum, to meet the special needs of *each* child.
- Training in basic self-care and self-help skills at the earliest possible age, moving on to adaptive skills and exposure to real-life experiences as the transition towards inclusive living within family, social and community environments.
- Transitional support, through collaborative inter-agency partnerships, to assist PwIDs through critical changes, e.g. from pre-school to primary, to secondary, to post-secondary, to pre-employment training, to employment.
- Pre-vocational, vocational and employability training in functional and practical skills, adjusted to individual needs and abilities, to equip PwIDs with the essential social and behavioural skills for work environments
- Training opportunities for families to equip and empower them in supporting PwIDs

3.2 Improve Work Training and Employment Opportunities – pathways to financial independence and becoming productive members of the community (Ministry of Human Resources, Potential Employers, Service Providers)

- Supportive Sheltered or Community Work Places that provide effective on the job training, good working conditions, creative work tasks, job

- opportunities for the severe PwIDs, and delineate transitions for able PwIDs to move into open employment
- Skills enhancement and training centres dedicated to assisting capable PwIDs to adjust to open employment – that can serve as one-stop job guidance and emplacement centres, as the link with employer to understand job requirements and determine realistic goals, provide job coaches who prepare PwIDs and provide support in initial adjustment to job situation.
- Ensure full implementation of *Code of Practice for the Employment of Persons with Disabilities in the Private Sector* and the 1% quota of jobs for PwIDs in the civil service with a Special Unit for Employment of Disabled Persons staffed by well-trained personnel, sensitive to and competent in handling disability work place issues.
- Promote positive awareness amongst employers of their social responsibility of supporting PwIDs as human resource; institute and widely publicize benefits (e.g. tax deduction) of employing PwIDs among all corporations and companies.

3.3 Conditions for Better Quality of Life – essential support systems for an inclusive, barrier-free and rights based society (Welfare Department in Ministry of Women, Family and Social Development, Ministry of Finance, Ministry of Transport, Service Providers, NGOs)

- Provide a disability allowance and increase government funding to service providers to increase and improve range of services needed by PwIDs and their families, in particular Day care service and/or Long-term care service programs for severely disabled, Respite Care to relieve families, Counseling Services for PwIDs and their families.
- Institute Residential Options for PwIDs in all housing schemes and promote planning of necessary disabled friendly and/or support facilities for inclusive living within the community.
- Improve public transportation for disabled and require provision of disabled friendly amenities.
- Provide more and better disabled friendly Leisure and Recreational opportunities and/or facilities.
- Promote public awareness of disability issues, provide more information and resources to families of PwIDs, encourage formation of support groups and networks, empower families and PwIDs to engage in self-advocacy.
- Begin a registration of PwIDs campaign and collect relevant statistics as basis for better understanding of PwIDs, their numbers and the issues they face

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