

# Down but not out: Exploring the barriers of employment for Persons with Down syndrome from the Malaysian perspectives

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## ABSTRACT

Globally, individuals with disabilities have a notably higher unemployment rate. The socioeconomic research on individuals with Down syndrome in Malaysia is scant, as no current data on their employment exist, and the reasons for these low employment rates are not understood. With the utmost need to uphold their employment rights, this study aims to explore the employment barriers of individuals with Down syndrome in Malaysia from multiple perspectives. A series of online semi-structured interviews were conducted. In total, 45 participants, including six individuals with Down syndrome, ten family members, six employers and co-workers, 22 community members, and one policymaker were interviewed. A reflexive thematic analysis was employed to generate a thematic concept on the barriers of employment. Five themes were generated to explain the employment barriers for individuals with Down syndrome: (1) “in the end, it’s they themselves”: individual circumstances; (2) “would their family support them?”: family concerns; (3) “employers are hesitant to change”: organisational practice; (4) “some people shy away from them”: social norm; and (5) “there’s not enough room to grow”: restrictive environment. Barriers to employment for individuals with Down syndrome are complex issues interwoven within every aspect of our social and environmental context. Therefore, securing employment is not only individualistic but demands the willingness of society and the workforce to accommodate them. Relevant authorities, non-governmental organisations, and private sectors can utilise the findings to develop employment policies.

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Today, people with Down syndrome lead longer and healthier lives than at any other time in the past [1]. With the advancement of medical care and improved quality of life, their life expectancy had increased drastically, from 12 years in the 1950s to 60 years in 2000 [2]. Therefore, our emphasis on the issues of employment concerning individuals with Down syndrome is important to ensure that their socio-economic well-being is upheld.

The clinical presentation of the syndrome varies across individuals [3]. It is often associated with congenital anomalies, dysmorphic and characteristic of facial and physical appearance, along with a higher incidence of other clinical disorders [3], [4]. People with Down syndrome may also experience emotional and behavioural difficulties associated with limitations in social interactions and integration [5- 7]. In terms of cognition, there exist wide individual variations, and individuals with Down syndrome may experience mild (IQ of 50 – 75) to severe intellectual impairment (IQ of 20 – 35) [8- 10]. Research has also recorded that individuals with Down syndrome may significantly impair adaptive behaviour and executive functions [11], [12].

These characteristics of lower-than-average IQ and reduced adaptive functioning are associated with intellectual disability in general [13]. However, Down syndrome also results in phenotype-specific characteristics, such as relative difficulties in expressive language and relative strengths in social functioning [11] that distinguish it from other neurogenetic disorders associated with intellectual disability [14]. In addition, research has also documented that there is a wide range of functional abilities and asynchrony of skills in individuals with Down syndrome, which could impact the types of jobs for which they would qualify [15].

Employment is vital to individuals with disability as it allows for meaningful social relationships, social status, and political standing [16]. Employment could enhance life quality by providing a sense of identity, contribution, and belonging [17]. Consequently, individuals with disability are often able and willing to become financially independent and contribute to the community and societal development [18]. However, like many individuals with disabilities globally, disabled community in Malaysia have significantly higher unemployment rates than their peers without disabilities [19]. Their lower income and job insecurity expose them to living and working conditions which are more difficult [17], [20]. Unemployment would also keep them dependent on parents, family, or the government, jeopardising their transition goals towards independence [21]. In Malaysia, employment for individuals with disability can be generalised into open employment (i.e., working in mainstream market, often with training and financial support from the government or NGO's) or sheltered employment (i.e., segregated work settings for individuals with disability, with training and financial support fully provided). Therefore, the focus of this research was to explore barriers pertaining to both the employment course for individuals with Down syndrome.

In Malaysia, no data exist on the employment rate specific for individuals with Down syndrome, though the overall trend of employment for people with disability shows grim reality of their exclusion from the labour market. In the private sector, cumulative data from 1990 to 2018 showed that only 14,252 (0.001%) individuals with disabilities had been employed from the 13.74 million total workforces [22]. On the other hand, recent statistics showed that only 3,685 (0.3%) out of the 1,262,736 total posts in civil services were filled by individuals with disability [23]. Therefore, the widening gap between the labour force participation of individuals with disability and those without disabilities has been an enduring concern for many governments worldwide [24]. This concern has led to policy initiatives such as labour market activation programs, welfare reforms, and equality laws. Among those implemented in Malaysia include the affirmative action policy to employ 1% of the civil service workforce with people with disability, and the