

## EXPERIENCE IN EMPLOYMENT AND MEANING OF INDEPENDENT LIVING AMONG ADULTS WITH LEARNING DIFFICULTIES

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### ABSTRACT

*Participation in open employment is deemed as a means to independent living for the majority of persons with disabilities. However, the experience of being independent could have resulted differently for persons with learning difficulties who joined the labour market. Thus, it is substantial to understand the real meaning of 'independence' for persons with learning difficulties by exploring their life experiences after joining open employment. This study examined the knowledge and perspectives of persons with learning difficulties who joined integrated employment and linked the resulting changes brought about to their personal and social lives. Twenty-three persons with learning difficulties aged between 20 to 35 years old working in the retail sector in Malaysia participated in focused group interviews. A thematic analysis was conducted, and the themes connected to the markers of adulthood -biological, cognitive, emotional, role transitions, and responsibilities- to relate to the meaning of independent living. Findings suggest that the most explicit description of their personal and social lives is their dependency on parental support. Besides, their limitation to deal with everyday tasks also contributes to the ambiguity of independence. Despite having secure employment and are biologically adequate to be viewed as an adult, most of them are still far from stepping forward and leading their lives independently. Besides, the beliefs and cultural values also do shape the social construction of independence among persons with learning difficulties. Hence, it is essential to develop healthier surroundings to empower them to achieve meaningful lives.*

Key words: Disabled people, Persons with Learning Difficulties, Employment, Independent Living

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### INTRODUCTION

In Malaysia, the debates of disability rights are booming and becoming an increasing concern commitment from the government as being pushed on the policies, influenced by the conventions of the International Labour Organisation and the United Nations as well as disability movements. Undeniably, various forms of disability policies and legislation have been formulated by the Malaysian government to advocate for the rights of people with disabilities (PWDs) (Khoo, Ta, & Lee, 2012). Hence, PWDs are encouragingly contesting their rights towards equal employment opportunities and gaining the government's attention to establish the right to employment on the national agenda. Similarly, persons with learning difficulties (PLDs) are also fighting for their rights for supported employment with the assistance of a job coach system.

The past decades have seen the changes in the employment trend for PLDs from sheltered to open employment after many studies have emphasised the significant impact of integrated work with the inclusion of PWDs into the mainstream community. This transition reflects a healthy, growing movement towards integrating job seekers with disabilities into competitive employment, to work together with other non-disabled people rather than providing them with work in specialised centres and placing them in separate working stations from others. Much of the literature on employment has highlighted three inter-related benefits of employment: it offers an opportunity for economic independence, encourages social participation in the community and increases the self-image of an individual in terms of self-confidence and self-esteem (Baker et al., 2003; Brief & Nord, 1990; Saunders et al., 2014; Saunders et al., 2017). These benefits reflected in the illustration of adulthood lives, which are frequently associated with independence.

While extensive research has been carried out on employment among PWDs, little research has been done to explore supported employment practices for PLDs and offering empirical findings from real employment experiences. Considering supported employment for PLDs is still a new and unfamiliar approach initiated in Malaysia, this study aims to fill the gap through providing some substantial evidence and new insights about the experience of PLDs in integrated employment. It attempts to understand their perceptions of their involvement in this integrated work and its contribution to their adulthood and independent lives. This understanding is deemed significant to contribute to the knowledge of the scenario of adulthood and independence among PLDs. It would suggest the interventions to fulfil their independent living as an adult. The critical research question raised for this study is: *"Have these young adults with learning difficulties experienced independent adult lives when they joined the labour market?"*

This paper reviews the previous literature on persons with learning difficulties, employment and independent living. Then, it describes the methodology of the research involving study design, data collection and data analysis. Further, it reports the findings and discusses the implications of the study.

## **LITERATURE REVIEW**

### ***PERSONS WITH LEARNING DIFFICULTIES IN MALAYSIA***

Malaysia Persons with Disability Act (PWDA) (2008) defines the term of people with disabilities as persons with physical, sensory, learning, and psychosocial disabilities and impairments. This study is limited to persons with learning disabilities and intellectual disabilities. Learning disabilities refers to several disorders which may affect the acquisition, organization, retention, understanding or use of verbal or nonverbal information. These disorders may interfere with one or more processes related to oral language (e.g. listening, speaking, understanding); reading (e.g. decoding, phonetic knowledge, word recognition, comprehension); written language (e.g. spelling and written expression); mathematics (e.g. computation, problem solving); organization and social skills. In Malaysia, there is no generally used definition of 'learning difficulties' per se other than categories of learning difficulties within the purview of the Ministry of Education Malaysia, which are Education Act 1996 (Act 550) & Selected Regulations 2008 (2008) and Education (Special Education) Regulations (1997) as well as Persons with Disabilities Act (2008) under Department of Social Welfare. In 2019, Malaysia Social Welfare Department has identified PLDs into six sub-categories i.e. Global Developmental Delay (GDD), Intellectual Disabilities, Down Syndrome, Autism Syndrome Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD and specific learning difficulties (i.e., dyslexia (difficulties in reading), dyscalculia (difficulties in mathematics), dysgraphia (difficulties in writing) and dyspraxia (difficulties in motor skills)). Persons with learning difficulties are recorded as the largest population among registered PWDs with 169,853 people (38 per cent) registered with the Social Welfare Department (Social Welfare Department Malaysia, 2018). Despite being the largest group, PLDs are recognised to drop behind other groups in terms of education, training, employment, and social development (Yeo, 2007).

### ***PERSONS WITH LEARNING DIFFICULTIES AND EMPLOYMENT***

Labour market participation is often seen as having a crucial contribution to empowering persons with disabilities to achieve both greater independence and inclusion in society (Ernst & Berg, 2009; Saunders et al., 2014; Saunders et al., 2017). However, they are often confronted with the multitude of barriers to participate in open employment actively, become economically self-reliant, and contribute towards national economic development (Barnes et al., 1999; Migliore et al., 2008; Grant et al., 2019). Inaccessible employment infrastructure, inadequate skills, and qualifications, as well as the undesirable perception of the capacities of persons with disabilities to cope with paid work, are widely believed to be significant obstacles which have restricted their employment opportunities (Jayasooria et al., 1997; Jones, 2008).

The evidence from a range of countries suggests that there is a crisis of unemployment among persons with disabilities. In comparison with non-disabled people, the case is worst for those with learning difficulties, most of whom are confined to forms of sheltered employment or other activity or staying at home (Brown et al., 2006; Wehman, 2006). There is a lack of opportunity for them to be in mainstream employment due to a combination of their mental characteristics, the assumptions of others and the lack of education and training provided for them (Burge et al., 2007; Migliore et al., 2008; Yeo, 2007). Given that PLDs have a higher level of restrictions at work, it is assumed that they face extraordinary challenges for making successful transitions into significant areas of adulthood, such as employment, higher education, marriage, and parenthood. It is expected that they would be hampered as well as discouraged by their limited abilities or skills and tasks of transitioning to adulthood, such as achieving financial and residential independence.

Even when joining integrated employment, the jobs offered are mostly limited to unskilled or non-professional jobs through individual placement support (McLaren et al., 2017) such as production operators, handicrafts, general workers, shop assistants, gardeners, and sweepers. These works do not require more than necessary communication or interpersonal skills (Norani Mohd Salleh et al., 2001). Moreover, they are often being paid on piece-rates as they are presumed to be less productive than other non-disabled workers. As a result, they are frequently assigned to low-wage employment and, thus, may earn less than other workers, including those with different categories of disabilities (Norani Mohd Salleh et al., 2001).

### ***ADULTHOOD AND INDEPENDENT LIVING***

The markers of adulthood have four main rules, i.e., biological through physiological growth or age; cognitive in terms of appropriate reasoning and self-choice; emotional criteria in terms of relationship and emotion control, as well as the role transition as an individual or part of the community to relate with the meaning of independence. Biologically, the change in physiological growth could be observed as an adult. Correspondingly, independence from a social model perspective is a complex phenomenon, much more than the usual images of active and physically independent individuals. This perspective is inconsistent with Vasey's description of independence; the personal feeling in control of their lives rather than being controlled by others (Vasey, 1996). Therefore, it could be understood that independence is about the amount of power we have in life.

## **METHODOLOGY**

### ***STUDY DESIGN AND APPROACH***

This study engaged qualitative research methods with an exploratory approach that upholds the phenomenological methodology concerned with understanding social and psychological phenomena from the perspectives of people involved (Wehman, Krueger, & Mitchell, 2005; Moriña, 2018). Besides, an emancipatory research paradigm was suggested to be espoused for disability-

related research (Barton, 2006). It aims to eliminate the marginalisation of PWDs as well as to have a significant effect on their empowerment and the practical policies which benefit their lives (Barnes, 2003). Emancipatory research also supports the slogan of disability movements "Nothing about us without us" (Walmsley, 2005), which seeks the participation of PWDs in any investigation concerning the subject of disability.

Concerning this, a purposive sampling method was applied to identify and select the key informants in a limited setting with detailed knowledge and experience regarding the unknown phenomenon (Creswell & Plano, 2018; Junaidah & Saodah, 2014). The study was conducted in one of the largest retail companies and the first company which introduced the integrated employment in Malaysia. Accordingly, the researcher focuses on the pioneer employees who joined the scheme. Five focus group interviews were undertaken with 23 employees with learning difficulties aged between 20 to 35 years old. Respondents were asked to review and sign the Participant's Consent Form before the interview. They were informed about the aim of the group interview and the role they act as 'experts' on their own experiences. Anonymity and confidentiality of the participants were assured. Formal access to BZ Corporation was applied to conduct the survey and interviews among their employees with learning difficulties.

### Data Collection

Data were collected through semi-structured group interviews to create more insightful expression and discussion as a result of listening to others and thinking further (Puchta & Porter, 2004). There was also a sense of spontaneity and naturalness in their interaction as if talking among friends as they work together in a natural social context (Krueger & Casey, 2000). A semi-structured interview schedule with pure Malay or English language, suitable in enabling better understanding among PLDs (Flynn, 1986), were developed revolving around a few central questions of their experience in integrated employment. This preferred choice allows the researcher to enjoy some level of flexibility during interviews to maintain some structure over their parameters (Bailey, 2008). The interviews lasted from 60 to 90 minutes and were digitally recorded with the permission of all respondents. The researcher also continually checked the accuracy of respondents' meanings, engaged them in ongoing feedback, and confirmed any data interpretations throughout the interview.

### Data Analysis

The standard process of data analysis began with the exploration and reduction of data, which includes step by step analysis to uncover significant issues, concepts, categories, and relationships. A thematic analysis approach (Devenish, 2002) was used, firstly, to gather connected ideas, words, or thoughts; and followed by searching for abstract principles. Additionally, the NVivo10, a qualitative analysis software package, was used to organise and code data more efficiently and securely. However, due to changes to the coding process and the small number of interviews, analysing the data by colour coding on a large chart sheet was found easier compared to using the NVivo10. The meaning of their independent lives is examined by referring to the four criteria of the markers of adulthood- biological, cognitive, emotional, and role transition.

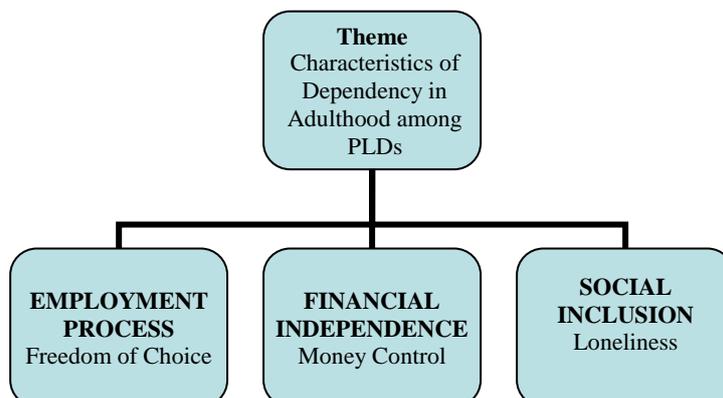
### PARTICIPANTS

A total of 23 respondents, of whom 18 were male and five females, participated in the study. They are from a range of ethnic backgrounds -11 are Malays, eight are Chinese, three are Indians, and one has mixed heritage. All respondents are single and aged between 20 to 37 years old.

### FINDINGS

From the interviews' script, the barriers to adulthood were identified. The markers of adulthood were also referred to build the sub-themes. Figure 1 illustrates the emerged theme and sub-themes.

Figure 1 Theme and Sub-Theme Emerged



### Theme: Characteristics of Dependency in adulthood among PLDs

The theme that emerged in the study was recognised as the characteristics of dependency in adulthood among PLDs. It is noteworthy that PLDs still faced barriers in their experience of integrated employment though they have reached adulthood stages and have a secure job. The analysis of the sub-themes concentrates on three areas of work, i.e., recruitment processes, financial independence, and social inclusion. Accordingly, three sub-themes were categorised as freedom of choice, money control, and loneliness, which are related to the markers of adulthood: cognitive, emotional, and role transition.

#### Recruitment Process: Freedom of Choice

In terms of the recruitment processes, the respondents described that the decision made to participate in employment is not indeed their decision. Their teachers or trainers mainly evaluated their readiness to work. For example, Chia clarified on the selection made by his teacher:

*"..My teacher chose him and me. Only two of us. Others can't talk. They can't do work properly. Only the good one can work here...I think my other friends also can do this job. But they have to ask the teacher first. If the teacher finds that they are capable enough, she will bring them here too."(Chia)*

In a small number of cases, respondents described the decision to work as being made by their parents. Michael said:

*"My father contacted Malaysian Care and then registered me.. I got the interview, and my father brought me to the interview"(Michael)*

Besides, some view that the managers ignore their wishes to the first task they were given. They also mentioned about having no choice whether they could stay at the preferred place. Therefore, as they have no qualifications, they must accept whatever task assigned to them. Jo mentioned stating his preference, but because of his limitation, it was not granted:

*"I want to be an artist, but Mr N said I couldn't. He placed me as Sales Assistant."(Jo)*

Even some respondents revealed that they have no choice to remain in the job. Although they feel like quitting, they are disallowed to do so. Salim declared:

*"My mum asked me to take this job. Whenever I told her I want to quit, she said not to. She said what I am going to eat if I don't work."(Salim)*

There were, conversely, four respondents who described how they had made the decision to work and had searched for the job themselves through the employment services or friends. Iskandar and Alif reported that they contacted the Labour Department when they saw the vacancy advertised on television. At the same time, Salleh and Choo informed that their friends who have already joined the scheme introduced and encouraged them to apply for the job.

#### Financial independence: Money Control

In terms of economic freedom, even though they have a secure job with a pleasant amount of monthly salary, a quarter of the respondents portrayed that they did not know the number of their wages. Chua said:

*"I never check the payslips"(Chua)*

About three-quarters of the respondents did not have experience withdrawing money from the bank. They just depended on their families. Farid described in his case:

*"My mother withdraws money. She writes a note every time I take the money. Sometimes I finish my salary. So, I have to pay her back"(Farid)*

Around the same proportion of respondents reported that their parents generally had considerable control over their wages. They described that they were given pocket money on a daily or weekly basis. Salim, for example, stressed:

*"My mum gives me RM5 a day for me to buy food. If I want to buy something else, new jeans or t-shirts, I asked her more. I don't know the balance."*

Choo similarly affirmed that she had to ask for permission to spend money:

*"My father gave me the money. Sometimes RM20. Sometimes RM50. When finished, I asked him (money)"(Choo)*

Nevertheless, not everyone was entirely dependent on their parents or family in terms of money management. Alif, for instance, is given total freedom in handling his salary. Ismail, Laila, and Azreen, who lived in the hostel, also manage their own money. Despite others mostly controlling the way they should spend their money, all respondents talked about understanding that their parents are doing the best for them, including saving money for their future security. Though living with their parents, all of them believed that their family would not use their money for family expenditure. Mary, for instance, trusts her parents:

*"My mum takes my salary. I don't know how to withdraw. But not all. She gives me a small amount only. When it finishes, she gives again. She doesn't write how much she has given me. I trust her. She won't take my money."(Mary)*

However, other respondents illustrated the situation contrarily. Although he appreciated the purpose of his parents wishing to control his money, Jo expressed his wish to have freedom of choice in spending his salary:

*"Sometimes, I feel I want to save my own money. It's my salary. But my mum afraid that I won't save it and be spendthrift. She said that my salary is for my future savings"(Jo).*

### **Social Inclusion: Loneliness**

The third theme of loneliness could be seen when they described their daily working lives as having occasional interaction with other employees or supervisors. Most of the time, they concentrate on doing their tasks and have their break or lunch alone. Data from the interviews showed that most employees were delighted to have an opportunity to join the company. Nevertheless, only some were generally pleased with their co-workers and supervisors who were portrayed as being helpful and as treating them well. Aiman expressed that:

*I like my supervisor. He is so kind. He always advises me..."(Aiman)*

and Mary also said:

*I can get along with my other colleagues... they are all kind-hearted"(Mary)*

More importantly, not all were confident enough to have social contact with non-disabled colleagues, even those in the same department. Only three employees described interacting comfortably with other employees, having lunch together, and sometimes meeting outside of work. For some, however, socialising with some groups of non-disabled employees was described as complicated. Jo informed about his difficulty in mingling with some groups and of feeling left out:

*I have many friends. In the morning, I will have my breakfast with the cashiers. Ladies. They asked me to follow them as they know what the best food for me is. In the afternoon, I go with groceries [sales assistants]. But always be friends with ladies only. If the guys don't want to go with me, I don't care. I am not a child anymore. I am an adult."(Jo)*

Most employees were cautious about taking the first step to start a social interaction, afraid of being rejected. Some said that initiating social communication is not spontaneous for them as they felt challenging to converse with their colleagues. Mei said:

*..during the working hours, I seldom speak or chat with other employees at my department... I don't know what to talk about"(Mei)*

Accordingly, their social interactions with either supervisors or co-workers were described as limited mainly to conversations about their work tasks. The accounts of the majority indicated that they continue to accomplish their job without having much social contact at all. Chee stated that:

*I rarely talk with my supervisor. Only if I am confused about doing something, I'll ask him"(Chee)*

Moreover, their description of their working lives discovered a considerable amount of isolation. One indicator of this is that nearly all of them have their lunch alone as Faiz said:

*I eat at the food court but alone... other employees have their own group"(Faiz)*

Some said that they preferred to be alone and to avoid having social contact. Liew stated his preference for being alone mainly because of his discomfort at being asked about life:

*I eat alone. I don't like to be with others. I don't like to commit ...asking about my father...my mother... no need... why they want to know?"(Liew)*

Additionally, Michael gave a different reason for wanting to eat alone. For him, being a good timekeeper was essential, and he was aware that for most of them, having lunch in a group took more time. Michael asserted that he does not want to be behind schedule, as this portrays a lousy attitude. Hence, he prefers to eat alone, as he said:

*I eat at the restaurant. I don't like to eat with others. It will take so long. Chatting and talking. I am afraid I will be late to go back to work"(Michael)*

Furthermore, since most claimed to have no non-disabled friends before joining supported employment, they reported their difficulties in having social contact with non-disabled employees. Most said to be friends with other colleagues with the same challenges. Mei, Choo, and Chee who work in the same workplace usually have their lunch together as the following quotes suggest:

*During my working hours, I seldom speak or chat with other employees at my department. I have my lunch usually either alone or with Choo or Chee. After the break, I'll continue folding the clothes" (Mei)*

*I have my breakfast at home and usually have my lunch at the food court with Mei and Chee. I don't mix with others except these two"(Choo)*

*My other colleagues have their lunch at the customer service counter. They have their own group already. I eat at the food court. Three of us (Mei and Choo)"(Chee)*

From those experiences revealed, it is apparent that some employees with learning difficulties demonstrated to have limited social contact with other non-disabled. Since most of them have limitations in social interactions, the lack of community participation could be seen clearly from their experience sharing. The message of "we are the same!" implies the need for a better understanding and treatment from the community.

## DISCUSSION AND IMPLICATIONS

According to Hendeby and Pascall (2001) in their study of young disabled adults in the United Kingdom, employment has made the transition from childhood to adulthood, by which giving them daily activity, self-confidence, independence, control over day to day life, a place in society, an escape from the stigma of claiming benefits and the concomitant sense of identity as an equal citizen (Hendeby & Pascall, 2001:30). Nevertheless, contradict to this, the situation described by respondents provides a diversity of views and experiences, which correspond with the literature indicating the limitation of control PLDs have of their own lives. The three areas of work concentrated in the study revealed the restriction of freedom, self-control and social inclusion.

Most respondents demonstrated limited choice in their decision to work and limited freedom in participating in their selection and recruitment process. The majority reported that their teachers or trainers determined their readiness to work and only suggested them to work once found ready. It could be understood that the interest of the employees was disregarded when placing them in a job. This practice is seen as contradictory to the importance of matching clients with tasks that they want to do and are interested in, which is stressed in the literature on supported employment (Siegel & Gaylord-Ross, 1991; Wilson, 2003). This lack of choice shows the restriction in the definition of empowerment, which concentrates on the employability as claimed by Galster and colleagues (Galster et al., 2009) in their Swiss study. Besides, most positions allocated to them are specified to sales assistants relying on the general assumption that repetitive job is the most suitable for most persons with learning difficulties (Bond et al., 1997; Brown et al., 2006). Some also reported that they remained working because of their parents. Thus, this scenario of supported employment could be understood as not a universal remedy for enhancing all recipients' abilities as they have no freedom in the decision-making process.

There is evidence from the literature that supported employment possess a positive impact on the lives of PLDs in terms of integration within the community (Bass et al., 1996; Drake et al., 1994) and a better chance to live more independently with their income (Jenaro et al., 2002). Despite this, the situation described by PLDs in this study indicates the limited control they have over their lives. Their dependency on family support could be seen in their limitations to deal with everyday tasks of daily living, such as managing their money. Their monthly salary is still under the control of the family, and they do not taste the enjoyment of spending their income. Consequently, they seem to have no precise control over their future lives.

Moreover, while supported employment seems to meet the needs of the participants for work in an open organisational setting, it does not meet the needs of PLDs to become fully socialised into the labour market. Despite enjoying the opportunities to have social contact and friendship with other non-disabled employees, painful experience in social inclusion was proven. Only a small number of employees with learning difficulties described having comfortable interactions with other non-disabled employees. While most described having limited interactions and having a better friendship with other employees who have similar disabilities.

However, few described freedoms of choice by which they applied for the job by their initiatives either through the related agencies or recommendations from close friends. Four of them got the job by their effort either through employment agencies or through friends' recommendations. This group also is not entirely dependent on their family in their daily lives as compared to others.

The findings of this study have important implications for the employment of PLDs and the other stakeholders. The voices and views of PLDs can provide information about their feelings, reflecting on their experiences. PLDs are lagging in terms of engaging with the government to offer opinions and perspectives to benefit their group. Therefore, their attitudes about their employment experience in the study should be taken seriously and considered by the policymakers in reviewing the employment support services provided. This vulnerability implies the need to enhance the involvement of all stakeholders, including PLDs and their organisations in setting priorities for disability-related reform and taking an active part in its implementation. Voices and views of PLDs can provide information about their feelings, reflecting on their experiences with education and training reform if employment chances are to be increased.

Equally important is the availability of support from all the parties in the community to interact with one another, learn from each other and collaborate in accomplishing mutually desired outcomes as there is no limit to what can be learned and accomplished. The effort to promote the ability and potential of PLDs requires active and positive public awareness, ongoing monitoring, and evaluation, especially in the current practice and policy implementation. Promoting disability awareness such as Disability Equality Training at the national level and providing Job Coach Training as an initiative by the Ministry of Women, Family and Community Development would be impactful in ensuring PWDs' right to work in accordance to the Persons with Disabilities Act 2008.

It is hoped that there is a commitment to use this research as a basis for subsequent policy discussions and practice development as well as a medium for promoting the challenges faced by PLDs to further deliberate appropriate methods and approaches for better functioning as adults among PLDs.

## CONCLUSION

The study contributes to understanding the experiences of employees with learning difficulties in integrated employment. Despite its exploratory nature, this study offers some insights into the influence of work towards persons with disabilities' independent living. To answer the research question of "Have these young adults with learning difficulties experienced independent adult lives when they joined the labour market?", the researcher concluded that they are still far from stepping

forward and leading their own lives independently. The situation portrayed by these employees with learning difficulties indicates the lack of control they have over their own lives. Moreover, their dependency on parental support describes their personal and social lives as being eternal children by their parents. The beliefs and cultural values also shape the construction of independence among adults with learning difficulties. Likewise, their limitation to deal with everyday tasks of daily living, such as managing money and making decisions contributes to the ambiguity of the concept of independence.

In conclusion, it could be summarised that the integrated employment scheme has allowed them to work in an open environment and receive a better salary. However, their experiences in employment could not be regarded as a turning point for them to start an independent life. Also, others still doubt these individuals' capabilities to have better control over their lives. Given that the labour market is not entirely inspired by the PLDs to lead their independent lives, it is crucial to develop healthier surroundings and atmosphere to empower them to achieve meaningful experiences.

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