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Research article

Social Sciences

CONCEPTUAL SKILLS OF PEOPLE WITH INTELLECTUAL DISABILITIES FOR INDEPENDENT LIVING

智力障碍人士独立生活的概念技能

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Abstract

In the effort to improve the quality of life of people with intellectual disabilities, the concept of independent living is still a novelty. As most previous research has focused on the concept of independent living among people with disabilities generally, this study will focus on people with intellectual disability (PWID) in particular. Therefore, this study aims to discuss the conceptual skills required by PWID to empower them to live independently. This qualitative study was based on a case study aimed at exploring the conceptual skills needed by people with intellectual disabilities to live independently. A total of 30 informants, including PWID, their mothers, and teachers, were involved in this study. The study results have identified six conceptual skills of PWID toward independent living in terms of financial management, choosing a profession of interest, using public transportation, recognizing one's abilities and weaknesses, understanding the concept of time, and reading and writing. This study could be used as a new source of reference for PWID, families, and communities in understanding the concept of independent living to improve the quality of life of PWID.

Keywords: intellectual disability, independent living, conceptual skills, quality of life



摘要 在努力提高智障人士生活质量的过程中，独立生活的概念仍然是一个新鲜事物。由于之前的大多数研究普遍关注残疾人独立生活的概念，因此本研究将特别关注智力障碍人士（注射吸毒者）。因此，本研究旨在讨论注射吸毒者所需的技能概念，以帮助他们独立生活。这项定性研究基于一个案例研究，旨在探索智障人士独立生活所需的技能概念。共有 30 名知情人参与了这项研究，其中包括注射吸毒者、其母亲和老师。研究结果确定了注射吸毒者独立生活的六项技能概念，包括财务管理、选择感兴趣的职业、使用公共交通、认识自己的能力和弱点、理解时间概念以及阅读和写作。本研究可为注射吸毒者、家庭和社区了解独立生活的概念以提高注射吸毒者的生活质量提供新的参考来源。

关键词：智力残疾，独立生活，技能概念，生活质量

I. INTRODUCTION

Disability is a part of the human being as 1.3 billion people or equal to 16% of the global population nowadays comprise of people with disabilities (PWD) [1]. United Nations (UN) defines a person with disabilities as any individual who has a physical, mental, intellectual, or sensory deficiency that can cause obstacles to the individual and prevent their full involvement in society [2]. According to the World Health Organization (WHO), disability is the result of the interaction between people with a health condition, such as cerebral palsy, Down syndrome, or depression, and personal and environmental factors, such as negative attitudes, inaccessible transportation and public buildings, and limited social support. Some common types of disabilities include physical disability, vision impairment, hearing loss, mental health conditions, acquired brain injury, autism spectrum disorder, and intellectual disability [3].

Intellectual disability is one of the subcategories of disabilities where this term is used to describe anyone who has problems with cognitive functioning and skills, such as their ability to communicate, get along with others, or take care of themselves [4]. According to the DSM-V issued by the American Psychiatric Association, intellectual disability refers to neurodevelopmental disorders that start in childhood [5]. In Malaysia, intellectual disability refers to children five years or older who experience deficiencies in intellectual functioning or cognitive impairment [6].

In discussing the issues faced by persons with disabilities around the world, attention is often emphasized on how they are said to face injustice and oppression [7]. Until now, persons with disabilities still face oppression in various aspects, whether in education, work, or health, which negatively impacts their daily lives [7]. The oppression often faced by persons with disabilities has caused them to become isolated

from engaging and socializing with other community members and has subsequently contributed to their isolation [8]. Persons with disabilities still have to deal with negative stereotypes, discrimination, poverty, and dropping out of school because of unfair situations, all of which have a negative effect on their daily lives [8]–[10]. This dilemma has been going on for a long time, but because they are often thought of as a minority group, they are getting less and less attention in our society [11].

A series of issues that are often faced by persons with disabilities has caused the United Nations (UN) to come out with the Convention on the Rights of Persons with Disabilities (UNCRPD) as part of an intervention to deal with issues related to the oppression of people with disabilities [12]. The UNCRPD, first developed in 2006, aims to promote, protect, and ensure equal rights for all people with disabilities [13]. The right of persons with disabilities to live independently has been clearly outlined in the UNCRPD, where Article 19 states that they have the right to decide where and with whom they want to live [14]. This right has given space to persons with disabilities to determine their own lives and make their own choices, while the surrounding community only acts as a support system for them in achieving their life goals [15]. The idea of independent living still causes public debate because there are opinions that persons with disabilities still need help from others in determining their fate and life [16], [17]. However, without us realizing it, the inability to achieve self-determination may also impact the quality of life of PWID [18].

Quality of life focuses on an individual's physical, mental, emotional, and spiritual wellness [19]. Social isolation and lack of access to self-determination can negatively impact PWID's quality of life. Therefore, increasing social activities and exercising independence should be recognized as fundamental components

required to improve the quality of life of PWID [20]. Therefore, independent living is seen as a relevant approach to improve the quality of life for PWID. Independent living is a part of normal life where PWID should be granted the same possibilities and freedom to make decisions that could impact their lives [21].

II. RESEARCH OBJECTIVES

The main objective of this research is to identify the conceptual skills required by PWID to live independently. Being able to live independently and have their own family is a hope and dream for most people with disabilities [22] and the same goes for people with intellectual disabilities. However, some family members of people with intellectual disabilities often doubt the ability of their children to live independently [23]. This doubt becomes more worrisome when parents see their child's cognitive skills and behavior seem unsuitable for living independently as part of society [15]. To live independently, an individual must possess specific skills to avoid encountering unfavorable circumstances daily. However, previous studies have shown that people with intellectual disabilities who usually live isolated from society face limitations in mastering the adaptive skills needed to live independently [24].

Regardless of the opposing views on independent living among persons with disabilities, PWID still keeps hoping they will be given the opportunity to enjoy an independent life just like their peers. Given that being able to live independently is one of the main goals of persons with disabilities; thus there is a need to identify the skills that PWIDs require to ensure that they are given the right to live independently. However, to our knowledge, there is still scarce information on the independent living skills for PWID. Therefore, the main objective of this article is to discuss what are the essential conceptual skills for PWID to empower them for independent living.

III. METHODS

This study was conducted in 2021 and employed a qualitative design to identify the skills that PWID need to live independently. The choice of this methodology was based on the justification that a qualitative study is suitable to obtain an overview of a phenomenon, pattern, and meaning of human behavior in their social environment [25].

This study was conducted based on a case study approach, which is a study that provides an in-depth description and analysis of the system

being studied [26]. The researcher chooses a case study approach because it allows the researcher to understand the meaning behind independent life among PWID more profoundly. Simultaneously, this approach also provides space for researchers to explore and gain a deeper understanding of the skills needed by PWID to live independently. This point aligns with the idea that case studies play a role in researching any behavior or contemporary phenomenon identified as a case [27].

A. Data Collection

Data collection involved two methods for this research: semi-structured interviews and focus group discussions. The first data collection process began with a semi-structured interview among 16 PWID from the selected vocational school in Malaysia, known as Sekolah Menengah Pendidikan Khas Vokasional (SMPKV). The second data collection process involved another focus group discussion session between the 11 teachers of the PWID. At the same time, the third process involved focus group discussions between three mothers of intellectual PWID students and the researcher.

The data collection process for this study was carried out by relying on the study protocol developed by the researcher along with other research experts. This interview protocol is fundamental to the researcher in conducting a qualitative study because it acts as a guide and supplies the researchers with information to run the data collection session smoothly. Next, this interview protocol has been sent to the Ministry of Education for further review and approval. Once approval to use the study protocol was obtained, the researcher conducted the data collection process involving the study informants as listed.

B. Participants

Given that the objective of this study was to gain insights into the skills needed to live independently, the researchers chose to use a purposeful sampling technique in which all the informants had to meet the inclusion criteria of this study. Purposive sampling is a technique in which researchers base their judgment on selecting a respondent and sample from a population according to the purpose of this research [28]. The informants for this study were selected on the basis of the inclusion and exclusion criteria established in the preliminary stages of this study. As for PWID informants, the selection criteria are as follows: being 17 years old and above and living in the SMPKV

dormitory for at least a year. This means that persons with disabilities under other categories (physical, various, auditory, visual and speech) and those under 17 years old will not be involved as informants in the semi-structured interview sessions.

As for the focus group discussion, the first session of the focus group discussion for this study involved teachers from the four SMPKV involved as the location of this study. The selection of informants for this focus group discussion was based on the criterion that the teacher must be directly involved in managing students with intellectual disabilities at SMPKV. Any teacher who was not involved in handling students with intellectual disabilities were not be involved in the focus group discussions among these SMPKV teachers. At the same time, the second focus group discussion session involves focus group discussions carried out among mothers of PWID who have been involved in semi-structured conversations. This means that mothers of students who are not involved in semi-structured conversations are not involved in this focus group discussion session.

C. Data Analysis

The data analysis process for this study was carried out following the simultaneous data analysis procedure. The researcher used thematic analysis to analyze the data. Given that this study used a qualitative research approach, part of the data analysis process was run along with the data collection process. While the interviews were ongoing, the researcher conducted preliminary analysis by writing memos and field notes, which were eventually included in the final report of this study. After the entire data collection session was conducted, this study entered the next stage, data analysis. The data obtained through the interview sessions and focus group discussions were then transcribed before being entered into the Nvivo version 12.0 software. The use of the Nvivo version 12.0 software is seen to assist researchers in organizing the study data before analyzing it into specific sections according to relevant themes.

D. Ethical Considerations

This study was approved by the Secretariat of Ethics Research, Universiti Kebangsaan Malaysia. The ethics approval code for this study is JEP-2021-444. Moreover, before conducting the interview and focus group discussions with the informants, researchers provided an informed consent form that needed to be signed by each informant. This informed consent acts as a formal agreement from the research participants to be involved in this study. This form also states that any information obtained by the researcher throughout this study is subject to ethics of confidentiality and is only used for academic purposes.

IV. RESULTS AND DISCUSSION

A. Demographics of the Participants

This study involved 30 participants. These 30 informants included 16 PWID who participated in semi-structured interviews and 11 teachers and three mothers of PWID who participated in focus group discussions.

For informants under the PWID category, eight 17-year-old PWIDs, three 18-year-old PWIDs, four 19-year-old PWIDs, and one 20-year-old-PWID were interviewed for this study. Each PWID involved in this study was asked to sign a letter of informed consent before the interview began. For PWIDs under 18, their guardians signed the informed consent letter indicating that they allowed their dependents to participate in the study. Table 1 shows the information of the PWID involved as informants for this study.

This study involved 11 teachers from SMPKV across Peninsular Malaysia with different teaching experiences. Four teachers were reported to have teaching experience in SMPKV between one and five years, two teachers with teaching experience between six and ten years, three teachers with teaching experience between 16 and 20 years, and one teacher with teaching experience exceeding 20 years.

Table 1.
Information on PWID

PWID (P)	Gender	Years in dormitories	Specialization
P1	Female	2	Food Preparation
P2	Female	3	Food Preparation
P3	Male	5	Desktop Publishing
P4	Male	4	Desktop Publishing
P5	Male	3	Food Management

Continuation of Table 1			
P6	Male	2	Reflexology
P7	Female	2	Esthetic Beauty
P8	Male	2	Hair Dressing
P9	Female	3	Pastry Making
P10	Female	2	Food Preparation
P11	Male	2	Aquaculture
P12	Male	4	Aquaculture
P13	Female	4	Food Preparation
P14	Female	3	Culinary
P15	Male	2	Culinary
P16	Female	2	Pastry Making

At the same time, the teachers who are the informants of this study come from different role backgrounds. In summary, the 11 teachers involved in this study consisted of a chairperson, a science teacher, a counseling teacher, four classroom teachers, and four teachers who acted as dormitory wardens.

At the same time, this study also involved three mothers as study informants. The selection of these three mothers as representatives of family members who are stakeholders of PWID. The three mothers of PWID had been involved in the semi-structured interview sessions conducted in the previous stage.

The results of this study identified six main themes in discussing the conceptual skills required by PWID to live independently. Conceptual skills focus on an individual's ability to control certain aspects of their lives. These skills include understanding abstract ideas, solving problems, and understanding how systems are organized [29]. For this study, six themes are identified under the conceptual skills theme that relates to conceptual skills for PWID to live independently: financial management, choosing a profession of interest, using public transportation, recognizing one's abilities and weaknesses, understanding the concept of time, and reading and writing.

B. Financial Management

The first subtheme under the theme of conceptual skills is financial management, which focuses on how the PWID manages the money that has been accounted. The analysis showed that people with intellectual disabilities who want to live independently also need to know how to use money. Informants of this study argue that to live independently, PWID need to be able to manage and use their finances effectively. For example, some of these study informants who also PWID stated the following:

"If I want to live independently, financial

management is essential. Indeed, because being independent means I must use money..."

In discussing this financial management skill, some teachers believe that financial management skills are important for any PWID who wants to live independently. For example, there is an informant that is also a teacher who shares his opinion:

"In my opinion, in terms of independent life, it is important for this PWID to have the skills of financial management and self-management as well. They must organize in terms of money which they will spend in such a way..."

In sharing the skills that PWID needs to be independent, the participants in this study believed that using money is among the skills they need to master if they want to live independently. Most informants shared the same opinion, stating that to live independently, they must be proficient in managing their financial aspects. The skill to manage money is seen as essential to be mastered by PWID, considering that when they live independently, they need to manage their finances on their own. PWID who want to live independently need to be exposed to training that can help them manage their financial aspects [30].

C. Choosing a Profession

The second subtheme concerning conceptual skills is the ability to choose a field of work or profession in which the individual is interested. The informants of this study identified this skill as one of the essential skills possessed by PWIDs who want to live independently. For example, there is a study informant that is also a PWID student who shared the following:

"...Next step to living independently, after I finish my training here, I hope I can pass the course, then I will continue to study in the field that I like..."

"After this, if I want to live independently, I want to look for a job, but for the time being I

will work with people first looking for experience, soma capital. Later, if I have enough, I want to open my own business as I will, I want to open a shop”

At the same time, in discussing the ability of PWID to choose a profession of interest, it can also be seen that teachers share the following opinion:

“In my opinion, PWID should look for job opportunities. Not necessarily working in the field, for example, working near the market, anywhere as long as there are opportunities to work. PWID rarely choose a job that is important to them to gain experience, which means they can earn their own income and their interest...”

The ability to choose a profession is closely related to the ability to use money to ensure the survival of the PWID in living independently. The ability to choose a profession of interest is vital, considering that they should get a job if they want to live independently in the future. At the same time, being independent means that PWID need to have a profession or job that conforms to their interests. In addition, the failure of PWID to choose a field of profession, in which they are interested in, can cause them to take a long time to adjust to the new field in which they participate. This situation may also lead to poor productivity in the PWID [31]. Similarly, the inability to select a profession of interest can also impact the mental health of the PWID, as past research has found that failure to choose an appropriate field of work has led to the perpetuation of social isolation among PWID [32]. In connection with it, the ability to choose an occupational field of interest is also seen as essential to be possessed by PWID to ensure they can adjust to an independent life as best as possible.

D. Using Public Transport

The third skill that has been identified as a conceptual skill that PWID who want to live independently need is the ability to use public transportation. The respondents in this study argue that PWID need to be proficient in using public transportation if they want to live independently. For example:

“If I want to live independently, I need to know how to use public transport. Public transport is important, I can use something like grab a bus...”

“Public transport knowledge is necessary. I think if I want to be independent, I need to know how to use public transport...”

PWID who live independently cannot avoid using the public transportation system because

they need to move by themselves from one place to another even though they have a driver's license. The respondents share several forms of public transportation that PWID always use, such as busses, trains, and e-hailing. Considering that, the ability to use public transportation was identified as one of the basic skills that need to be mastered by PWID who want to live independently. Even though the ability to use public transportation is among the skills that are easy for PWID to master, a handful of PWDs are still afraid to use public transportation, especially at night [33], [34].

E. Acknowledge Strengths and Weaknesses

The fourth subtheme has been identified as among the conceptual skills that need to be mastered by PWID who want to live independently: the ability to recognize their strengths and weaknesses. The participants of this study argue that PWID must always be sensitive to their strengths and weaknesses if they want to live independently. For example, there are informants of this study who have stated the following:

“If I want to live independently, I must make what I am good at, for example, what I am interested in. I want to open a shop to sell bread and become a successful online business too”

In discussing the skills to identify their strengths and weaknesses, most of this study's informants, consisting of students, stated that they can identify their strengths and weaknesses. However, at the same time, informants consisting of teachers also shared their worries and doubts about PWID students who were unable to determine their own strengths and weaknesses. For example, one teacher shared how her students were still unable to determine their interests:

“Some of these students are unable to identify their own strengths. For example, when I teach an aquaculture operator, there is a student who doesn't have much interest in the field, but when we get into the topic of maintenance, we will use a lawn mower. Even if it is broken, he can fix that machine because he is capable of doing so”

To live independently, the PWID also should be able to recognize their strengths and weaknesses. In relation to that, it can be seen here that it is necessary to ensure that these PWIDs can recognize their strengths and weaknesses to empower them toward independent living when they grow up. Given that recognizing strengths and weaknesses is vital for PWID who want to live an independent life, parents and teachers need to play a role in helping them identify their

strengths and weaknesses. At the same time, recognizing one's strengths and weaknesses is found to help the individual build stronger resilience [35]. Identifying strengths and weaknesses is also seen to influence the PWID's decision-making process and is required because it is indispensable as a foundation in striving for an independent life.

F. Understanding the Concept of Time

The next skill that has been identified as required by PWID to live independently is the ability to understand the concept of time. In discussing this matter, study informants shared that PWID need to understand this concept and make good use of their free time live independently. For example, there are student informants who share the following:

"...I will play with friends in the evening, for example, playing futsal. Sometimes when I have free time, I play skipping rope with them to..."

In talking about how PWID spend their days living independently, some informants shared how they use their free time by doing things they are interested in. For example, one informant stated:

"I always have medical and health books, full books that are complete with the medical ones because I can help treat all the people. Afterwards, I will study a book that explains various body images of bone anatomy, including which part is the muscle, which part is the vein, and which part is the blood. So indeed, I like to read..."

At the same time, in talking about how PWID spend their time doing things they are interested in, an informant who is also a teacher to PWID students stated that most male students are more interested in mechanical activities and hobbies. For example:

"...Some boys here have certain skills normally if male students are more into mechanical things or repairing motorcycles or things like that..."

The informants of this study have outlined that to live independently, PWID also need to be proficient in understanding the concepts of time. Thus, in discussing the ability to understand the concepts of time, most of the informants of this study are more likely to share how they need to spend their time doing activities of interest. In addition, when talking about the ability to understand the concept of time, some informants said they prefer to spend time with their friends at school. For example, an informant that is also a student stated that he prefers to spend his time doing fitness activities with his friends at school.

Through this, it can be seen that some PWID prefer to spend time doing activities with their friends. The time an individual spends doing activities of interest is seen to positively impact the cognitive development of the individual [36]. However, a previous study found that PWID living in independent living centers felt they were not given enough space to spend time with their friends [37].

G. Reading and Writing

The sixth subtheme recognized as a conceptual skill required by PWID to live independently is the skill of reading and writing. The informants of this study believed that to enable PWID to live independently, reading and writing skills are among the essential skills that they need to possess. For example, one informant stated:

"...Okay, reading skills are important if you want to live independently. Yes, it's critical..."

At the same time, in discussing this reading and writing skill, a study informant who was also a mother stated that teachers play a role in equipping PWID with reading and writing skills. For example, a mother informant stated:

"...We make a kind of in terms of ordinary social management. But in terms of education, how to educate him so that he is good at reading, that is the teacher's job, right..."

Through this discussion, it can be seen that the informants also believed that to live independently, PWID need to be proficient in reading and writing because these skills are acknowledged as essential skills required when living independently in the future.

The results of this study have identified six conceptual skills required by PWID to live independently. Conceptual skills are recognized as necessary for PWID to live independently, as these skills ensure that individuals can control and achieve some aspects of their daily lives [29]. Even though the findings of this study have outlined six conceptual skills, the financial management skill is acknowledged as one of the most required conceptual skills to be possessed by PWID who want to live independently. This opinion agrees with a past study that stated that money management [30], [38] is among the skills that need to be mastered by PWID, given that this skill is a fundamental skill required by any individual to enable them toward an independent life [30]. A set of conceptual skills that have been identified as skills required by the PWID to live independently are interrelated with the quality of life, as discussed in [39]. As the quality of life emphasizes the elements such as physical, social,

and psychological dimensions of one's well-being, the skills that had been outlined seem to be very significant in improving PWID's quality of life. In connection with this, to live independently, PWID must master the most independent living skills. In relation to that, it can be concluded that the skills possessed by PWID are among the factors that could directly affect their quality of life.

While most previous studies have acknowledged the importance of independent living skills for people with intellectual disabilities, there is a lack of comprehensive research specifically delineating the specific conceptual skills required by PWID to live independently. By explicitly outlining these skills, this research offers a holistic framework that addresses crucial aspects of daily life and social participation for PWID. First, in terms of financial management, this research has identified that this skill is fundamental for PWID in managing personal finances, budgeting, understanding transactions, and making informed financial decisions, all of which are vital for independent living and economic self-sufficiency. The second is regarding the profession selection skill. As most previous research has often focused on vocational training people with disabilities, this study specifically emphasizes the process of career exploration, decision-making, and pursuing a profession of interest, considering the unique challenges and opportunities faced by PWID in the job market. Choosing an appropriate profession is crucially important for PWID as employment is identified as a significant component of community living [40].

Next, by identifying reading and writing skills as an essential skill needed by PWID, this research provides a detailed analysis of reading and writing skills. These skills are essential considering factors such as comprehension, communication [41], [42], and functional literacy have their own impact on educational attainment, social participation, and quality of life for PWID. By systematically examining and categorizing these key independent living skills, this research not only contributes to a deeper understanding of the challenges faced by PWID but also provides actionable insights for the development of targeted interventions, educational programs, and support services aimed at promoting their independence, well-being, and social integration.

The findings of this study may be limited by the sample size and demographics of the participants. Because people with intellectual disabilities comprise a heterogeneous population with varying levels of cognitive functioning [43],

researchers face challenges in accurately capturing the full spectrum of independent living skills, and the findings may not be fully generalizable to all PWID within their population.

V. CONCLUSION

Thus, for future research, it is suggested to conduct comparative studies to examine differences in independent living skills across different subgroups of PWID that consist of varying levels of cognitive functioning, age groups, or cultural backgrounds. This future research could offer insights into the factors contributing to skill variability and inform personalized intervention strategies among PWID.

In conclusion, this study has provided new knowledge for persons with disabilities by discussing the essential skills needed by PWID to live independently. In relation to that, just like other individuals, PWID should be given the freedom to enjoy independent living regardless of the limitations and restrictions they face. However, to empower PWID toward independent living, they need to be provided with appropriate training to be prepared with the necessary skills to live independently. It is vital to ensure that PWID can live independently to the best of their ability and subsequently improve their quality of life.

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