

Defining the Meaning of Independent Living among Persons with Intellectual Disabilities: A Systematic Literature Review

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Abstract

Independent living is one movement that enables people with disabilities to exercise choice and control over their lives and make all decisions regarding their own lives. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) clearly stated that any person with disabilities deserves the same opportunity to make choices and control their life. Persons with disabilities may choose where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement. Even though many studies discuss the concept of independent living among persons with disabilities in general, the research focusing on intellectual disability is still limited. Thus, this research aims to define the meaning of independent living among persons with intellectual disabilities. This systematic literature review adapts the publication standard of ROSES. It analysed 30 relevant articles from Scopus and Web of Science databases. The study identified three themes regarding the meaning of independent living among persons with intellectual disability, namely (a) responsibility, (b) decision making, and (c) new skills. Therefore, this paper discusses how the three themes emerged and the three central meanings of independent living for intellectual disabilities.

Keywords: Independent Living, Choice and Control, Decision Making, Social Skills, Disability.

Introduction

Disability is part of the human condition where almost everyone is expected to go through a temporary or permanent impairment at some point in their life (World Health Organization, 2011). According to the World Bank (2021) statistic, 15% of the world's population or equal to one billion people, may experience some form of disability at one point in their life. Persons

with disabilities (PWD) are more likely to experience poorer health, fewer education opportunities, lower employment rates, and, as a result, may bring higher rates of poverty among PWD. Term disability in most people minds is synonym with dependence (Ratzka, 2007). Intellectual disability is a part of a learning disability that refers to a particular state of functioning that begins before age 18, characterised by significant limitations in intellectual functioning and adaptive behaviour (Shree & Shukla, 2016).

Independent living is a philosophy developed by persons with disabilities to control their own lives and take responsibility for their actions (Ratzka, 2007). There are three main essential elements in defining the concept of independent living: first, the same opportunities for choice and control, second a challenge to the usual interpretation of independent living, and lastly, the aspiration that any assistance required should be controlled by the person with disabilities themselves (Morris, 2004).

Little is known about independent living among persons with intellectual disabilities. Most of our society nowadays tends to assume that those diagnosed with intellectual disability have no chance to live as a part of our society members (Mendis, 2015). As intellectual disability always being associated with social functioning where it could affect the person itself, as well as the family and society as a group (Shree & Shukla, 2016), it is hard for people to define and adapt the concept of independent living into the lives of a person with an intellectual disability. Although there are many studies, focus on the concept of independent living among person with disabilities in general (Baart & Taaka, 2017; Barrera et al., 2009; Brisenden, 1986; DiGennaro Reed et al., 2014; Morris, 2004) but there were still limited scholars discussing on independent living among person with intellectual disability. Lack of studies discussing the concept and meaning of independent living among persons with intellectual disability may cause the lack of literature review to help the reader understand the concept of independent living.

Methodology

This paper is one kind of systematic literature review that will discuss the concept of independent living among persons with intellectual disabilities. A systematic literature review is a method of making sense of large bodies of information and contributing answers to what works and what does not (Petticrew & Roberts, 2008). The systematic literature review examines formulated questions that use systematic protocol and guidelines with several advantages over traditional reviews, such as its numerous and rigorous procedures (Samsuddin, et al., 2020). Writing a systematic literature review had to go through a rigorous reviewing process that included developing research questions, keywords used, and the articles selection process (Shaffril et al., 2020).

This systematic literature review is guided by the research question: what is the meaning of independent living among persons with intellectual disabilities? The main focus of this study was on the definition and concept of independent living from the perspective of the person with intellectual disability, their families and professionals. The next part will discuss more on the research method, including the type of review protocol used, the formulation of the research question, the systematic searching strategies, data abstraction, and analysis.

The Review Protocol- ROSES

This systematic literature review was guided by establishing a publication standard called ROSES. ROSES stand for Reporting Standard for Systematic Evidence Synthesis. ROSES

protocol is an established guideline that develops as a reference and framework for guidance to any author who wants to develop a systematic literature review paper (Ahmad et al., 2020). ROSES review protocol aims to guide the authors in drafting and writing the systematic literature review by offering them information and steps to follow with the correct level of detail based on the guided protocol.

The process of the review protocol starts with the authors developing research questions guided by PICO (Problem, Interest, Context). The authors then proceed with the systematic searching strategy, which comprises three processes: identification, screening, and eligibility. After going through this process, the next step is to go through quality appraisal. In this step, the experts will examine the selected articles to ensure that the selected expert in the field reviews the quality of the articles. Two databases used as this systematic literature review sources: Scopus and Web of Sciences. The choosing of these two databases is based on the justification that both Scopus and Web of Sciences are today's leading sources for citation data (Mongeon & Paul-Hus, 2016) and covers multidisciplinary fields of research worldwide. Moreover, Scopus is an abstract and indexing database with full-text links produced by Elsevier Co. (Burnham, 2006) and covers over 35,000 titles. While on the other hand, Web of Science is a database of a selective citation index of scientific and scholarly publishing covering journals, proceedings, books, and data compilations (Birkle et al., 2020). Until 2020 it covers around 34,000 journals.

Formulation of Research Question

The first step in a systematic literature review is formulating research questions. In this stage, the authors will develop a set of research questions. For this paper, developing the research question will adapt the process called PICO. PICO is based on three main concepts: population or problem, interest, and context. The population and the problem that has been identified is the meaning. At the same time, the interest for this research is independent living, and lastly, the research context is intellectual disability. Based on these keywords, the authors have come up with one research question: What is the meaning of independent living among persons with intellectual disabilities?

Systematic Searching Strategies

There are three main processes in the systematic search strategies: identification, screening, and eligibility (refer to Figure 1).

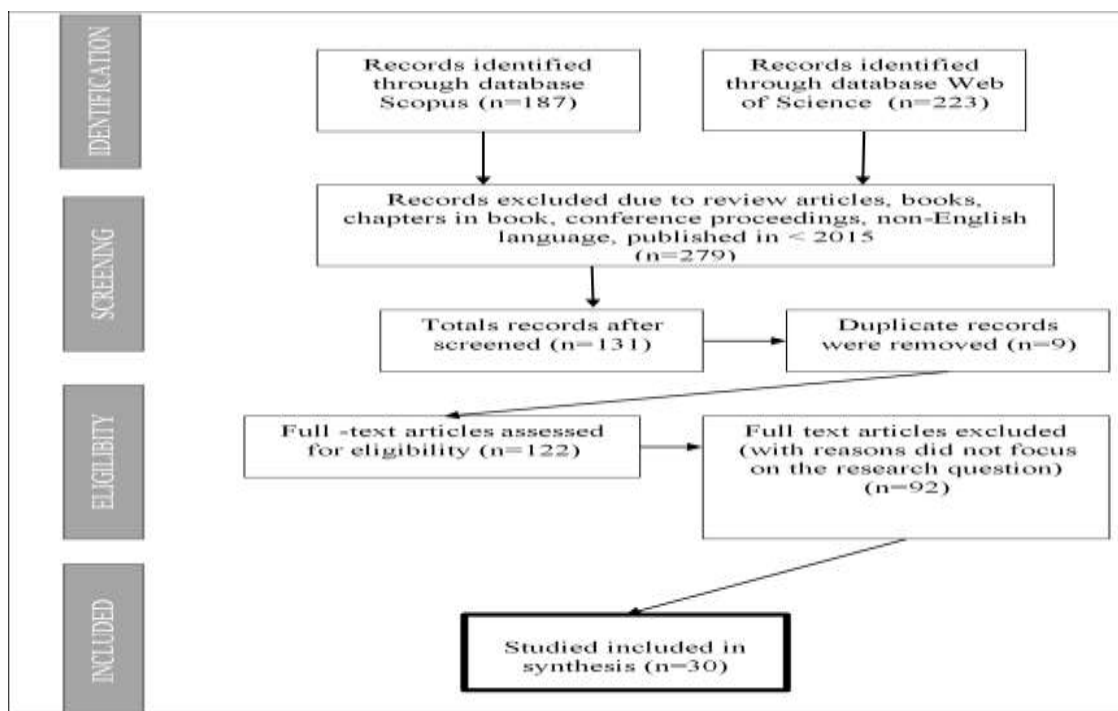


Figure 1: Systematic Searching Strategies (Adapted from Shaffril et al. 2019)

Identification

Identification is a part of the systematic searching strategies that involve a process to search synonym, related terms and variation for the main keywords identified in the research question formulation (Ahmad et al., 2020). The identification of synonym keywords relied on thesaurus online. For the keyword of the meaning, the author had identified two keywords: understanding and explanation, the keyword of independent living: autonomous, self-supporting, and lastly, for intellectual disability: mental disability, learning disability, and learning disorder. Based on the keywords that had been identified in this process, these keywords next are being used as a part of a search string for database Scopus and Web of Sciences (refer to Table 1)

Table 1

Search String

Databases	Keywords used
Scopus	TITLE-ABS-KEY ((meaning OR understanding OR definition OR explanation OR view* OR perspective*) AND ("independent living" OR "autonomous" OR "self-supporting" OR "community living") AND ("intellectual disability" OR "mental disability" OR "mental retardation" OR "learning disability" OR "intellectual disabilities" OR "mental disabilities" OR "learning disabilities"))
Web of Science	TS= ((meaning OR understanding OR definition OR explanation OR view* OR perspective*) AND ("independent living" OR "autonomous" OR "self-supporting" OR "community living") AND ("intellectual disability" OR "mental disability" OR "mental retardation" OR "learning disability" OR "intellectual disabilities" OR "mental disabilities" OR "learning disabilities"))

Screening

Screening involves including and excluding relevant articles based on the criteria determined by the authors (Samsuddin et al., 2020). This study screen the 410 selected articles by choosing the criteria for selecting the articles that are done automatically based on the sorting function available in the database. Three eligibility criteria have been sorted out for this research: literature type, language, and timeline (refer to Table 2). The first criteria are literature type which only article journals are included in the list of potential review articles. At the same time, the chapter in the book, proceeding and conference paper are excluded. The second criteria are the language where only English articles are included, while non-English articles are excluded from this research. The third criteria are the timeline of the selected articles. The timeline for the selected articles is set to seven years. Only articles between the years 2015 until 2021 are included in this review. After going through this process, the number of articles left behind is 131, and then ten articles were removed due to duplicate among each other.

Eligibility

Eligibility is when the authors manually monitor all the remaining articles after the screening process to ensure all the articles are in line with the criteria and aims of this paper. In this process, authors have to go through the face reading of the title and abstract of all potential articles. During this process, the authors excluded 91 articles because some focus on other types of disability rather than intellectual disability. Some of these articles focus more on independent living skills than the meaning of independent living. After going through this eligibility and screening process, only 30 articles were selected to review in this research.

Table 2

The inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Literature type	Article journal	Chapter in book, proceeding, conference paper
Language	English	Non- English
Timeline	2015-2020	<2015

Data Abstraction Analysis

After going through the quality appraisal process, the remaining articles were evaluated, reviewed, and analysed by the authors to develop results that parallel this paper's objective. Subsequently, the authors perform thematic analysis to identify any relevant themes and sub-themes based on the patterns rising from the data that has been assessed and abstract. In order to systematically analyse the data from these relevant articles, thematic analysis was done by the authors. Thematic analysis is a method for identifying, analysing, and reporting patterns within data by minimally organising and describing any data set in detail (Braun & Clarke, 2006). Thematic analysis guides the authors in identifying findings regarding the research question and the implication of the findings (Burke et al., 2019). The first process of thematic analysis is to identify patterns that emerge among the abstract data of all reviewed articles. After reviewing and analysing data, three themes and seven subthemes had been identified regarding the topic of independent living among persons with intellectual disabilities. These themes are responsibilities, decision making and new skills. The following process reviews the accuracy of these themes. The authors had to reexamine all the main

themes and sub-themes during this process to ensure their reliability and accurate data representation.

Results

A total of 30 articles were analysed, along with the data abstractions and analysis process. Among the 30 articles, 18 articles involve persons with disabilities (intellectual disability, learning disability, or autism) as a research sample. Seven articles analyse data from the family of the person with intellectual disability, and four articles have professionals working for persons with intellectual disability as research participants. Most of the articles in this review are from England and Spain, five articles respectively, Ireland four articles, USA three articles. They are followed by Iceland, Sweden, Canada and Norway, two articles respectively and each article from New Zealand, Australia, Israel, Belgium and Netherland.

This review resulted in three main themes and seven subthemes defining the meaning and concept of independent living among persons with intellectual disabilities. Three main themes identified are responsibility, decision making and new skills. Two sub-themes for the theme of responsibility are financial responsibility and security responsibility. Three sub-themes emerge under the theme of decision-making: self decision-making, decision-making by family members, and decision-making by professionals. While for the last theme, which is new skills, there are two subthemes: daily living skills and social skills (refer to table 3).

Table 3

Themes and sub-themes

Authors	Year s	Region	Sample	Responsibili ty		Decision making			New skills	
				FR	SR	SD M	FD M	PD M	DL S	SC S
Agarwal, Heron & Burke	2020	USA	Parents of Person with Intellectual Disability				/		/	/
Björnsdóttir, Stefánsdóttir & Stefánsdóttir	2017	Iceland	Person with severe/profound disability			/				
Burke et al.	2019	USA	Sibling of the person with intellectual and developmental disabilities				/			
Conder & Mirfin-Veitch	2020	New Zealand	Adult with learning disability independent dependently	/		/			/	

Engwall	2017	Sweden	Parents of children with intellectual disabilities			/
Fullana et al.	2019	Spain	Professionals working with disabled	/	/	
Fullana, Pallisera & Díaz-Garolera	2019	Spain	People with learning disabilities	/	/	
Höglund & Larsson	2019	Sweden	Women with intellectual disabilities	/		
Iriarte, McConkey & Vilda	2020	Ireland	Family members of people with intellectual disabilities	/		/
King et al.	2017	Ireland	Adults with intellectual disabilities			/
Longtin, Dufour & Morin	2020	Canada	Educators working in rehabilitation centres	/		
McConkey & Craig	2017	Ireland	Adults with intellectual disabilities	/		
Miller et al.	2018	USA	Parents individuals with intellectual and development al disabilities			/
Miskimmin et al.	2019	Canada	Older person with intellectual disabilities			/
Mooney, Rafique & Tilly	2019	England	People with a learning disability live independentl y	/		
Neuman	2020	Israel	Parents of adults with	/	/	

			intellectual disabilities			
Pallisera et al.	2016	Spain	Young people with intellectual disabilities and their family		/	/
Pallisera et al.	2018	Spain	Front-line managers	/		/
Power & Bartlett	2018	England	People with learning disabilities	/		
Puyaltó & Pallisera	2018	Spain	People with intellectual disability	/	/	
Richardson et al.	2016	England	People with learning disabilities or autism's	/		
Roberts et al.	2018	England	Young people with learning disabilities	/	/	
Salmon et al.	2019	Ireland	People with intellectual disabilities			/
Swerts et al.	2017	Belgium	Individuals with mild or moderate intellectual disabilities		/	
Voss et al.	2019	Netherlands	People with intellectual disabilities		/	
Williams & Porter	2017	England	People with intellectual disabilities	/		
Witsø & Hauger	2020	Norway	Person with intellectual disability			/
Witsø & Kittelsaa	2018	Norway	Professional working for person with intellectual disabilities		/	

Björnsdóttir, Stefánsdóttir & Stefánsdóttir	2015	Iceland	Person with intellectual disability	/		
Bigby, Bould & Beadle-Brown	2017	Australia	People with intellectual disability	/	/	
THEME: RESPONSIBILITY			THEME: DECISION MAKING		THEME: NEW SKILLS	
FR- Financial Responsibilities			SDM- Self-decision making		DLS- Daily living skills	
SR- Security Responsibilities			FDM- Decision making by family		SCS- Social Skills	
			PDM- Decision making by professionals			

Responsibilities

The first theme that arises in this review is responsibilities. Independent living has been associated with responsibilities that had to bear by the person with intellectual disability that chooses to live independently. Two sub-themes have been identified in this theme, namely financial and security. For financial responsibilities, persons with intellectual disabilities must ensure that they are aware of their financial and economic resources to help them live independently (Puyaltó & Pallisera, 2018). Financial is the most crucial aspect in ensuring that those who choose to live independently can manage their living expenditure, whether in paying rent, buying household needs or daily spending (Puyaltó & Pallisera, 2018; Williams & Porter, 2017). This idea is supported by professionals stating that people with intellectual disabilities who choose to live independently should be provided with the skills to manage their financial and personal economy budgeting (Pallisera et al., 2018). Opposite to that, some researchers stated that those who choose to live independently could face barriers in adapting to independent living when they cannot manage their finances and economy well, which could bring frustration and cause them to give up on living independently. As a result, this situation could drive them back to their homes, staying with their family. The failure to manage financial responsibility well may cause the person with a disability who choose to live independently to give up and get back to their family (Conder & Mirfin-Veitch, 2020; Richardson et al., 2016).

Financial responsibilities mean that people with intellectual disabilities must be aware of their current economic situation in managing their financial expenditures. In order to live independently effectively, the person with disabilities should be well trained on how to manage their own money. Mendis (2015) suggested that children should be provided with practical and financial support as a preparation to face a wider community. The second subtheme is securities responsibilities. In this concept, a person with an intellectual disability admits that to live independently, they should be responsible for their security aspect, such as ensuring their living community's safety (Iriarte et al., 2020; Power & Bartlett, 2018). While on the other hand, the person with an intellectual disability thinks that the experience they gained from living independently as a part of society encourages them to become more

responsible and alert toward the security aspect from time to time (Puyaltó & Pallisera, 2018). Some of the people with intellectual disabilities shared the experience of harsh treatment from the neighbour, being bullied at school (Roberts et al., 2018), and being abuse victims (Höglund & Larsson, 2019), causing them to feel insecure when living on their own. This experience took a toll on their securities responsibilities aspect and may cause them to feel unsafe to live independently in society (Richardson et al., 2016). Parents of a child with an intellectual disability thought that to live independently, persons with intellectual disabilities should cooperate with others in the community or society to protect the security aspect. This aspect is essential and could help them adapt to the independent living phase efficiently (Mooney et al., 2019; Power & Bartlett, 2018).

Decision Making

The second theme that arises from this systematic literature review is decision making. In this theme, the authors identified three subthemes: self decision-making, family decision-making, and professionals' decision-making. Independent living was associated with the right of a person with disabilities towards decision-making, especially in deciding how they want to live their own lives (Iriarte et al., 2020). Self-decision making is the first theme that arises from the theme of decision making. Self decision-making refers to situations where the person with an intellectual disability is directly involved in the decision-making process regarding the right of their life. The person with an intellectual disability thinks that independent living is associated with the right of choosing and making own control regarding their own life (Björnsdóttir et al., 2017; Conder & Mirfin-Veitch, 2020).

Höglund & Larsson (2019) stated that any man and woman deserve the same right to decide on every situation and ability. It is undeniable that a person with an intellectual disability may need assistance from family or staff in a specific phase. However, it does not mean they cannot decide on their behalf (Björnsdóttir et al., 2015). In discussing this matter, front-lines share the same thought that those diagnosed with intellectual disability should be trained to make decisions. The training could help them gain experience and encourage them to live independently (Pallisera et al., 2018). The person with an intellectual disability is constantly reminded that every individual is responsible for choosing and creating their path in life. Institutions are not supposed to decide on their behalf as it may cause them to feel that they have little control over their own lives (Bigby et al., 2017). Persons with disabilities are aware that the concept of independent living always promoted human rights in making choices about how and with whom they want to live their lives (Fullana, Pallisera, & Díaz-Garolera, 2019). Bigby et al (2017) discuss how deinstitutionalisation has been the most powerful strategies to promote social inclusions. It gives a sense of freedom for a person with intellectual disability to do their own thing and make up their minds. The person with intellectual disabilities keeps on talking about how independent living is always associated with a more excellent choice and control over their whole life than others living in the institutions (Bigby et al., 2017). Some people with learning disabilities stated that even though they were living in supported accommodation, they knew how to live independently and make decisions regarding their lives (Roberts et al., 2018).

The second subtheme is decision-making by family. It is a situation where the family will choose and control the person's life with an intellectual disability. Research by Voss et al (2019) stated that even though the person with intellectual and developmental disabilities

are willing to live independently yet, they still feel that their family members still have significant influence in making any decision regarding their life. There are some situations where the family plays a significant role in deciding the way of life on behalf of other family members with intellectual disabilities (Neuman, 2020). This condition may bring a result where later on, the child chooses not to discuss this matter with their family (Burke et al., 2019). Although there are some cases where family plays a significant role in any decision-making, some parents encourage their children to be more responsible in managing their daily schedules (Agarwal et al., 2020). While the last subtheme is decision-making by professional means that those living independently have to cooperate with the decision-making made by the professional in the institution or community, there were living (Vilà, et al., 2019). In this aspect, professionals could be made up of clinicians, social workers or community managers at the centre of independent living directly involved in decision making on behalf of the person with intellectual disability (Swerts et al., 2017). Even though some professionals have been involved directly in decision-making, at the same time, they are still encouraging people with intellectual disabilities to make their own decision, especially in the activity regarding their daily activity (Bigby et al., 2017; Witsø & Kittelsaa, 2018). Some persons with intellectual disabilities are told "yes or no" in every situation, which shows that the professionals have the last word in the decision-making process (Fullana et al., 2019). In discussing this matter, Pallisera et al (2016) stated that there should be a clear line in deciding how far the professionals could decide on behalf of persons with intellectual disabilities. Fullana, Pallisera & Díaz-Garolera (2019) suggested that there should be a set of guidelines in deciding the limitation and boundaries of decisions that professionals could make.

New Skills

The last theme that has been identified from this systematic literature review is new skills. Independent living is always seen as an opportunity for people with disabilities to gain new skills through their experience to go to independent living (Conder & Mirfin-Veitch, 2020). Two subthemes will be discussed: daily living skills and social skills. Living independently in society gives chances for persons with intellectual disabilities to get new experiences and learn new skills by cooking and doing laundry on their own (Salmon et al., 2019). It is opposite with various situations when they live with their family, where their family members are in charge of doing all this stuff, thus leaving the persons with intellectual disabilities no changes in learning these new daily living skills (King et al., 2017). To the surprise, family members are amazed by the increasement in their relative's daily skills who start living independently (Iriarte et al., 2020). Engaging in independent living is associated with increasing the skills related to cooking, cleaning, personal care, time management, and using public transportation (Agarwal et al., 2020).

The last theme identified in this systematic literature review is that social skills. It means that independent living could be utilised as a chance for persons with intellectual disabilities to enhance their social skills. Being independent is described by some of the parents as a part of social advantage toward their child with intellectual disability (Engwall, 2017). Some of the parents think that letting their son or daughter live independently in society is the best mechanism in order to encourage their child to learn new social skills and, at the same time to encourage their social involvement (Miller et al., 2018; Neuman, 2020). Living independently generally requires persons with intellectual disabilities to spend more of their time engaging in their social activity (Miskimmin et al., 2019). It is unavoidable for a person

with an intellectual disability who choose to live independently to get involved in leisure activity with the society in the community that they are living (Witsø & Hauger, 2020) and improve their socialisation skill (Agarwal et al., 2020).

Discussion

Up till now, the meaning of independent living for persons with intellectual disabilities remains unclear. Even though the concept of independent living among persons with a disability has been discussed in general yet, it is still hard to adopt those definitions and concepts to independent living in the life of persons with intellectual disabilities. Thus, this paper systematically reviewed the definition and concept of independent living for persons with intellectual disabilities. As a result, this paper has come out with three themes regarding the concept of independent living. There are three essential concepts in defining the meaning of independent living toward the person with intellectual disability: responsibilities, decision-making, and new skills. To live independently, people with intellectual disabilities must bear two kinds of responsibilities: financial responsibilities and security responsibilities. Responsibilities were identified as essential aspects in defining the meaning of independent living for persons with intellectual disability responsibilities. Hudnall (2014), in his research, stated that some of the parents assumed that their PWD children are responsible for ensuring the aspect of security is a guaranty for them to live independently as a part of society members. Some parents share the same thoughts that independent living makes their children more responsible than they would have when living at home with their parents. On the contrary, when responsibilities are being defined as a part of the concept in independent living, there are some PWD who think that they are not fit enough to live independently become a victim of particular adverse treatment such as harassment or being bullied (Richardson et al., 2016).

In addition, in defining the concept of independent living among persons with intellectual disabilities, decision-making is one of the concepts that cannot be neglected. To live independently means that people with disabilities are given the same choice and control in their own daily lives (CRPD, 2015). This concept is in line with Ratzka (1992) idea, highlighting that independent living has the same range of options and the same degree of self-determination that people without a disability take for granted. In addition, Budde and Bachelder (1986) stated that independent living seems to be one of the concepts enhancing the decision-making skills among PWD. Finally, gaining a new skill is the third concept in defining independent living among persons with intellectual disabilities. Independent living gives a chance for persons with disabilities to learn and adopt a new skill that they cannot get when living with family or in institutions. Runo (2014) highlighted that independent living is an efficient method of training persons with disabilities to acquire many new skills.

Conclusion

In conclusion, this paper discussed the definition of independent living among persons with intellectual disabilities from three perspectives: persons with intellectual disabilities, their families, and professionals. This same paper highlighted three main concepts in defining the concept of independent living: responsibility, decision-making, and new skills. In understanding the meaning of independent living, the view from the persons with disabilities

is essential as independent living might differ from different perspectives of persons with different abilities.

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