

REVIEW

Independent living of individuals with intellectual disability: a combined study of the opinions of parents, educational staff, and individuals with intellectual disability in Greece

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Abstract: The study of independent living (IL) of individuals with disabilities during the last decades has been in the focus of scientific field of educational and social sciences. The conceptual framework formed around the concept of IL led to practices that have been supporting the idea that IL may be a significant option for individuals with disabilities. Specifically, for individuals with intellectual disability (ID), the goal focuses on the development and implementation of integrated programs of IL in the community. The purpose of this study is to explore the opinions of parents, educators, and individuals with ID about IL. The sample consists of 124 individuals with mild and moderate ID, aged 13 years and plus, 124 parents of individuals with ID and 193 educators. The research tool was exploring five elements: (1) meaning/characteristics of IL, (2) factors affecting IL, (3) limitations of IL, (4) IL skills, and (5) IL settings. An analysis of the results indicates that the concept of IL revolves around housing. Furthermore, the support systems, family and community, were proved as main influence to IL of individuals with ID. Knowledge of safety rules and self-care appears as primary skills. Finally, independent apartments in the city are the ones preferred by individuals themselves, whereas parents and educators prefer a more controlled environment under the supervision of an official body.

Keywords: Intellectual disability; independent living; independent living skills; transition

Introduction

For centuries, individuals with intellectual disabilities lived in isolated environments and they could not develop any characteristic of adaptive and socially acceptable behavior. Today, a new support model has been developed internationally. This model supports and demands the presence and inclusion of individuals in the community and in structures, leaving behind the model of institutionalization of the 19th century (Wehmeyer and Bolding 1999). The main move for the social integration of individuals with intellectual disability (ID) is the transition from a single service program to a personalized design and functional support. The term ‘support’ is defined as a service area, where individuals and structures are facing individual’s needs (Wehmeyer and Bolding 1999). Support systems are psychological structures, which state that the pattern of supporting an individual’s needs requires him to engage

in activities related to typical human functionality (Schalock *et al.* 2007, 2010). Most of the time, family members informally provide socio-emotional and financial support to the individual, which goes beyond the official support that may be provided by the organized social policy of a state. This unofficial form of support is of greater value to the individuals themselves, as it relates to enhance their morale, reduces loneliness and anxiety, feeling incapacitated, mortality, offers longer life expectancy, and reduces institutionalization (Heller and Schindler 2009).

Independent living (IL) refers to the right of every individual to make his/her own decisions about his/her life and to control his/her daily life itself. What we need to understand is that as independence is defined the will of the individual and his final decision to conduct a behavior, no matter who, ultimately, performs the desired behavior. Conversely, performing the desired behavior-will is what characterizes autonomy. Autonomous living indicates that the individual acts entirely on his own while self-determination (a

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component of an individual's independence) means that the individual is the determining factor for the final action, even if that means that the person who starts the action is the trainer or another adult (Wehmeyer and Palmer 2003).

'Supported living' is defined as an organized support system that focuses on the individual with disability and is designed to make it easier for the individual to choose how to live, work, learn, and participate actively in the community along with individuals without disabilities. Supported living is based on the philosophy that individuals with disabilities have the right to make responsible decisions, just like individuals without disabilities. The system includes training in life skills and professional skills, supervised care, environmental adaptations, and physical assistance. The aim is to integrate the individual with disabilities into society, bringing services to the individual rather than placing him in a structure that will provide such services (e.g. an institution) (Accardo and Whitman 2011). Support should be seen as a system of resources which enables individuals with ID to achieve (better) independence, community participation, and personal satisfaction.

Individuals with intellectual disabilities may lack the skills required to respond in IL and adult life challenges (Takamine 1998).

However, to support the adult-centered approach, the individual should be able (a) to recognize, evaluate, and prioritize his/her interests, capabilities, and primary needs; (b) to know his abilities; and (c) to recognize and communicate his preferences, values, and 'beliefs'. When an individual sets his goals, he/she tends to be more effective, as he/she receives immediate feedback. That makes him/her more responsible and assists decision-making and self-assessment skills to be developed (Dimitriadou et al. 2016). Some specific areas of skills, such as communication, self-care and lifelong skills, social skills, basic academic skills (language, mathematics), self-regulation and self-guidance, independent community functioning and work skills, should be a priority for the curriculum, regardless the type of school attended by the child (special school, integration class, individual support, etc.) (Westwood 2004). From these areas, self-care, social skills, empowerment of self-guidance, self-determination, self-regulation, and work skills are the main teaching areas in an adult-centered approach that sees the individual with disability as a potential active citizen of society and community, and not as an eternal child, fully dependent on his parents or other adults (Wehmeyer and Bolding 1999).

There are over 20 skills, which are called life skills or IL skills. The IL skills of individuals with intellectual disabilities are divided into four categories: (a) daily living skills, (b) community-related skills, (c) social skills, and (d) professional skills (Network of

Services and Information for Individuals with Disabilities, www.liferight.gr).

While the IL movement is improving worldwide, in Greece there are few IL structures and few IL programs available. These few structures are the result of a private initiative and, specific, parents' associations of disabled individuals. These initiatives are minimally supported by the Greek state.

Purpose of research: research questions

The purpose of this research was to find the components needed for the creation of successful IL programs. The survey focused on the views of parents, educators, and individuals with ID about the characteristics and concept of IL, the factors that reinforce it and the limitations that prevent it from becoming reality, the necessary IL skills to accomplish this, and the settings in which IL can occur.

Also, the goal of research was to study the views of the three partners and to find agreements and disagreements. The exploratory questions are as follows:

1. How do the three groups (parents, educational staff, individuals with ID) perceive the meaning and characteristics of Independence and IL of individuals with ID?
2. Which are the main factors (according to the direct stakeholders) for the realization of the IL of individuals with ID?
3. What IL skills are recognized as important and necessary for the realization of the IL of individuals with ID?
4. What is the most appropriate setting for teaching IL skills and for IL to occur?

Methods

Research plan: procedure

All three groups that participated were involved in the three stages of research undertaken. Stage 1: the views of parents, teachers, and individuals with ID about the independence and IL of the latter were explored, to construct a questionnaire on issues of independence or IL for individuals with ID. This first stage created the basis on which the second stage of the main research was initiated. The purpose of the first stage was, through interviews, to explore the views of the three teams who participated on the general issues of independence and IL. This stage lasted from April to June 2011.

Stage 2: construction and provision of a questionnaire addressing the issues of IL for individuals with ID. The most popular but also the most controversial answers of the first stage were the main questions of the questionnaire. The purpose of the pilot study (second stage of research) was both to explore the views of parents, educators, and individuals with ID on issues of IL and to consider whether the questionnaire

Table 1. Demographic of participants in all three stages of study.

Gender	Parents			Educational staff			Individuals with ID		
	1 st	2 nd	3 rd	1 st	2 nd	3 rd	1 st	2 nd	3 rd
% male	80	67.7	75	60	64	76.7	62.9	60	50
% Female	20	32,3	25	40	36	23,3	37,1	40	50
Age	50 (51–60 y)	27.7 (31–40 y and 51–60 y)	42.7 (46–55 y)	60 (19–30 y)	34 (31–40 y)	47.7 (23–30 y)	51.4 (21–30 y)	35 (18–20 y)	36.5 (21–30 y)

used for this purpose is valid and reliable. The second stage lasted from March to May 2012.

Stage 3: construction and delivery of the final questionnaire, which was based on the analysis of the results of the pilot questionnaire. The purpose of the basic research (3rd Stage of Research) was to investigate the views of parents, educational staff, and individuals with ID on the concept, characteristics, factors, limitations, and skills of IL. The questionnaire was launched in November 2013 and completed questionnaires were collected by the end of February 2014.

At all stages, there was the consent of the individuals and stakeholders who participated in the survey.

Participants

The participants who took part in all the three stages of the research, presented in Table 1 (only the basic demographics have been included).

Research tool

Stage 1: Semi-structured interview, which consisted of two parts and each of them had open-ended questions. Each part consisted of 8–9 questions about the daily routine of young individuals, their needs, their abilities and the obstacles they encounter in their attempt to express independence.

The interview was conducted on two main areas: independence and IL of individuals with ID. The first issue raised questions concerning the definition of independence and its differentiation from the definition of autonomy. In the second part, the questions revolved around the concept of IL, the ability of individuals to live on their own, and the potential for development of such initiatives in Greece.

Stage 2: A questionnaire designed by the researcher which was based on international research data and on IL programs applied abroad. An important role in the choice of questions was also played by the results of the interviews of Stage I of the survey. The questionnaire consists of questions relating to the demographics of each respondent.

The main questions of the questionnaire were formed in tables by groups, which are the subscales. All subscales contain statements that respondents are asked to score on a five-step Likert scale, with the following gradations: none, little, enough, much, and too much. Respondents were asked to answer to what extent they

agree with each statement. The first subscale concerns the characteristics of IL and consists of seven statements. The second concerns the factors and consists of 11 statements, the third concerns the restrictions and also has 11 statements, the fourth concerns IL skills and has 12 statements, the fifth concerns those directly involved in the education process with 6 statements, the sixth concerns the teaching settings with 6 statements, and finally the seventh subscale refers to the teaching strategies and contains 9 statements.

Stage 3: A questionnaire designed by the researcher and based on international research data and IL programs applied abroad (Table 2). An important role in the choice of questions was played by the results obtained from the answers given in the second stage of the survey. The most popular answers that emerged during the pilot survey were included in the basic survey questionnaires. The questionnaire consists of 10 demographic questions. The main questions of the questionnaire were formed in tables by groups, which are the subscales. All subscales contain items that respondents are asked to score on a five-point Likert scale, with the following gradations: none, a little, enough, much, and too much.

Factor analysis

To summarize the answers given during the interviews, appropriate statistical measures were calculated and frequency allocation tables were constructed by group of respondents, question, and demographics. Statistical comparisons were made between the different categories of respondents' demographic data per question and group.

In the next phase, exploratory factor analysis (EFA) was conducted. Accordingly, statistical comparisons were made between the different categories of respondents' demographics by factor and group. Finally, statistical comparisons were made between the groups per question and per factor.

The statistical comparisons were made by applying Kruskal–Wallis non-parametric controls (with Mann–Whitney post-hoc controls and Bonferroni adaptation) and Mann–Whitney. EFA was conducted on a sample of 441 individuals, including parents, teachers, and children. During the preliminary examination, the suitability of the sample for EFA implementation was examined through Bartlett's test of sphericity and the

Table 2. Subscales and indicative options.

Statement	Indicative options
Characteristics/concept IL – the independent living of my child means:	<ul style="list-style-type: none"> • Be functional (self-care and self-sufficient). • Do what he wants, within the limits set by the community. • To live without being dependent on someone else • The acquired skills of the individual (e.g. social skills).
IL factors – the independent living of my child depends on:	<ul style="list-style-type: none"> • The IQ level • The opportunities given by parents
IL restrictions – the limitations my child is facing to acquire independent living skills are due to:	<ul style="list-style-type: none"> • The individual himself • Individual's family • The social context which the individual lives in
IL Skills – the skills that my child must have to live independently are:	<ul style="list-style-type: none"> • Chores • Money management • Purchases and payments • Choice and care of clothing • Self-care
Setting for realization of IL – the training on independent living must:	<ul style="list-style-type: none"> • Occur in the classroom • Occur in a specially arranged setting within school • Occur to independent apartments in the city center

sampling capacity based on the Kaiser–Meyer–Olkin measure (KMO Measure of Sampling Adequacy). The EFA was conducted using the principal component analysis method.

The proportion of participants with the questions is 15:1, which exceeds the proposed minimum (10:1) proposed in bibliography.

Bartlett's test of sphericity provides a particularly significant result ($\chi^2 = 5947,775$, d.f.=351, $p < .001$) while the KMO measurement of sampling adequacy is considered very high and equal to 0.895.

Internal cohesion was tested for each factor (question scale) using the Cronbach's alpha index. In particular, the reliability analysis showed that factors 1, 2, 3, and 4 were reliable since the corresponding Cronbach's alpha measurements were above 0.70. Factors 5 and 6 are considered to be marginal as unreliable ($0.6 < \text{Cronbach's alpha} < 0.7$). Finally, the correlations between each question and the overall score of each factor vary from 0.381 to 0.760, that is, above 0.3. The above results show good reliability of the scale (Table 3).

Results

Stage 1: Regarding the characteristics and the concept of IL, the statements focused on the fact if an individual with ID wants to be considered independent, he should be able to live alone, without supervision. Individuals have strongly expressed their desire to live alone or with a roommate, in an apartment, independently of their parent. Support systems have also emerged as an important factor in the development of IL skills by individuals. On the other hand, individuals focus more on the economic agent (material support) for the development of IL skills. What was observed was the fact that the factors that were reported to assist IL were directly related to the limitations that prevent it.

Stage 2: The limitations of support systems are those that restrict the possibility of IL. In particular, the inappropriate training of people working in such structures is the primary factor and should be the core of

such educational support systems. Still, the inadequacy of support systems is also supported by the fact that educational staff have to work in an inadequate state infrastructure. Staff think that daily life skills are the primary skills individuals with ID need to know to live on their own, and in particular they need to know self-care skills with the knowledge of security rules to follow. Also, the interdisciplinary team is preferred in the questionnaires as being suitable for teaching the relevant skills. A specially formulated setting is the answer with the highest frequency to the questionnaires and is considered as the right place for IL to take place. Parents strengthen the views of teachers and also consider that daily living skills, the knowledge of security rules and then knowledge of self-care, should be the goal of the educational process for the IL. Parents stress that inadequate teacher training and inadequate state infrastructure are responsible for the failure to implement IL programs. The specially designed setting within the school environment and the support from a multidisciplinary team are considered essential for the design and implementation of IL programs.

Individuals with ID focus on the economic factor, which is related to the fact that IL structures are expensive. The state does not finance such initiatives and pays a minimum allowance to individuals themselves. The professional skills of individuals are not developed sufficiently to provide them with a paid job. They also need self-care skills but also money management to be able to live independently. Curriculum that exists and applies to schools attended by individuals with ID does not allow the development of professional skills, as they fall short in the existence of appropriate learning facilities that are an important part of the education of individuals with ID, as they allow learning in real conditions. Finally, individuals think that special education teachers and parents are the ones who can effectively teach them the necessary skills for an independent life.

Stage 3: The core element of IL of individuals with ID is he/she to be functional, self-sufficient, and to live

TABLE 3. Cronbach's alpha.

Factor	Subscale	Number of questions	Cronbach's alpha	Question – total correlation
1	IL characteristics	4	0.804	0.584–0.696
2	Factors	5	0.765	0.480–0.615
3	Limitation	4	0.706	0.455–0.659
4	IL skills	12	0.903	0.381–0.760
5	Setting 1 and 2	2	0.605	0.434
6	Setting 3 and 4	2	0.642	0.473

without dependences. IL is affected by the poor infrastructure and is restricted by inadequate educational system and inadequate government funding. The main IL skills seem to be the knowledge of safety rules and IL training should happen either in an adequate setting inside school or in an independent apartment (Tables 4–7).

Discussion

This research is a first attempt at Greek research data and a rare international effort to capture the views and thoughts of those who are actively involved in the educational process of IL individuals with ID. In Greece, research data on adulthood issues for individuals with ID are few and very specific. Thus, for example, some data on the quality of life of individuals with ID or their self-determination are identified (Kartasidou 2007, Fetsi 2008, Kartasidou *et al.* 2009). In the international arena, there are a number of research papers (Thoma *et al.* 2002, 2008, Agran *et al.* 1999, Thoma and Getzel 2005) of parents and teachers about the adult life, independence and IL of individuals with ID. In addition, there are studies (Stodden and Whelley 2004, Wehmeyer and Bolding 1999) of individuals themselves. Nevertheless, there has never been a combined study of the views of parents, educators, and individuals with ID on issues related to independence. Such a combined study is considered important, as it takes into consideration the views of all three groups who are actively involved in the lives of individuals with ID. Parents and educator staff do not speak instead of individuals, but in addition to them. They express their own opinions and views. In this way, a comprehensive picture is created by all the partners involved and supporting such an educational process, by parents and educational staff who are the main support systems. This research gap was the main consideration of this work. After a thorough study of the existing literature and articles and its correlation with existing IL programs, the existing IL structures and the conditions for its realization, it is concluded that the application of the concept of independence and IL of individuals with ID can become reality (Conroy 1996, Stancliffe 2001, Heller *et al.* 1999, Stancliffe *et al.* 2000, Wehmeyer and Bolding 2001). The conclusions of the study will focus on linking quantitative and qualitative data. The quantitative conclusions that emerged during the stage of basic research are supported and enhanced by the

qualitative results of the interview stage, as well as by the qualitative results of other similar research conducted at the international level.

As found in this study, there may be degrees of independence, but the dividing lines between them are inconspicuous. In addition, the choices of people directly involved (parents and educational staff) in education and support for individuals with ID indicate ways to understand the social process of IL and the methods to be adopted for its realization. The important contribution of this research primarily lies in the development of a new research tool (Questionnaire for the Investigation of Perspectives on the Independent Living Individuals with ID) which emerged through a thorough and complete research process. This questionnaire is now at the disposal of any researcher who wants to deal with this issue.

It also highlighted the skills to be taught in the educational process of individuals with ID. These skills are also confirmed by the international literature (Dimitriadou *et al.* 2016). Although they should be able to be evaluated and measured to introduce an individual with ID into an IL training program, they are not being included at all. Assessment should be based on objective and meritocratic criteria. Evaluation of the skill itself, its adequacy (whether it is generalized or aided and what kind of help is needed), and the opportunity from the family and school to implement it should be able to be counted. So, there is a need for the existence of a list or a protocol which will evaluate the above matters. This list will aim at assessing the readiness of an individual with ID to be admitted to or not in an IL training program.

As has emerged from this research, parents, educational staff, and individuals with ID are the groups, which should be involved in the process of assessing IL skills.

Therefore, the diametrically opposed views posed by parents and educational staff on one hand, and the individuals themselves on the other hand, should be a point of concern. Individuals revolve around economic factor, financial management, and incomplete financial support when they talk about IL. Parents and education staff refer more to philosophy and the theory of IL without touching practical, everyday problems. We would say, therefore, that individuals with ID are much more aware of what they want to achieve, as well as more oriented to everyday practice and to solving everyday issues.

Table 4. Average of the most preferable answers.

Statement	Parents	Staff	Individuals
The core element of independence is that individual becomes:	Functional, self-caring and self-sufficient (average = 4.0726, Std = 1.0757)	Functional, self-caring and self-sufficient (average = 4.4952, Std = 0.77136)	Capable to live alone, with no dependences (average = 3.4919, Std = 1.17214)
IL is affected by the poor infrastructure IL settings have	Average = 4.0323, Std = 1.19576	Average = 4.4145, Std = 0.79897	Average = 3.8629, Std = 1.02279
IL is restricted by:	Inadequate educational system (average = 3.9919, Std = 1.17214)	Inadequate educational system (average = 4.2994, Std = 0.86599)	Inadequate government funding (average = 3.9597, Std = 1.05460)
IL skills: knowledge of safety rules	Average = 4.1371, Std = 1.09199	Average = 4.6010, Std = 0.72270	Average = 4.4113, Std = 3.71333
IL training should happen in:	An equipped setting in school (average = 3.5968, Std = 1.20243)	An equipped setting in school (average = 3.8756, Std = 1.12966)	An independent apartment (average = 3.6371, Std = 1.18483)

Table 5. Factor analysis between parents and individuals.

Subscale	Parents	ID individuals	Z, p
"IL characteristics" ($\chi^2=44.123, p<.001$)	3.3125 ± 0.97145	3.7883 ± 1.01004	Z=-3.771, p<.001
"Factors that affect IL" ($\chi^2=24.805, p<.001$)	3.6484 ± 0.78123	3.8968 ± 0.86240	Z=-2.691, p=.007
"IL limitations" ($\chi^2=108.916, p<.001$)	2.9543 ± 0.92768	3.4489 ± 0.96370	Z=-3.766, p<.001
"IL skills" ($\chi^2=8.187, p=.017$)	3.9054 ± 0.87921	3.5777 ± 0.95143	Z=-2.646, p=.008

Table 6. Factor analysis between staff and individuals.

Subscale	Educational staff	ID individuals	Z, p
"IL characteristics" ($\chi^2=44.123, p<.001$)	4.0350 ± 0.67537	3.7883 ± 1.01004	Z=-6.9000, p<.001
"Factors that affect IL" ($\chi^2=24.805, p<.001$)	4.0777 ± 0.52596	3.8968 ± 0.86240	Z=-5.327, p<.001
"IL limitations" ($\chi^2=108.916, p<.001$)	4.0777 ± 0.64841	3.4489 ± 0.96370	Z=-10.228, p<.001
"IL skills" ($\chi^2=8.187, p=.017$)	3.7541 ± 0.62428	3.5777 ± 0.95143	Z=-1.956, p=.050

Table 7. Factor analysis between parents and staff.

Subscale	Parents	Educational staff	Z, p
"IL limitations" ($\chi^2=108.916, p<.001$)	3.4489 ± 0.96370	4.0777 ± 0.64841	Z=-6.020, p<.001

This should be taken into serious account in any process of building IL programs.

Future research should focus on a comparison between individuals and their families who have tried IL and those who have not done, so will most likely reveal aspects of the subject that have not been investigated in this research. Direct experience in IL and its structures will certainly bring different results from the theoretical engagement.

Furthermore, the majority of the institutions that provide IL programs for individuals with ID did not participate in the research, by filling out a relevant questionnaire. This is a barrier to any attempt to change the current situation in Greece.

In Greece, unfortunately, the structures are minimal and often inappropriate. Most of them are a result of private initiative and especially care for parents and guardians of individuals with ID. If the state wants to support individuals with ID to complete themselves as self-regulated and self-determined personalities and to live the life they choose, independently, but not separated from reality, it has to make a practical

contribution to all the issues discussed and analyzed above. The basic thinking pattern of all those involved in educating young individuals with ID should be a statement by Maria Montessori (1870–1952): ‘The child who lives in an environment created by the “adult” with their own way of life, cannot satisfy his/her own physical and mental needs. Repressed by a powerful adult who bends his will and forces him to adapt to a hostile environment, he cannot grow intellectually and morally’.

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