Inclusive Research

Strengths and Challenges

A Working Model of Inclusive Research Groups

(IRGs)

Beit Issie Shapiro

Benjamin Hozmi[1], Dana Roth[2]

2024

This guide is a translation of an original article published in "Shikum", October 2020, (Issue 30), the journal of "Homesh"- the union of social workers in rehabilitation in Israel, with permission of the editor.

[1] Dr. Benjamin Hozmi, Academic Director, Director of the Inclusive University, and Director of Knowledge Resources, Beit Issie Shapiro, Israel
bennyh@beitissie.org.il

[2] Dana Roth (PhD.), Director of Research and Evaluation Department, Beit Issie Shapiro, Israel
Danar@beitissie.org.il

Table of Contents

The Development of the Inclusive Research Approach

Various approaches and models for conducting research in the field of disabilities have been developed over the past three decades, involving persons with disabilities as co-researchers at various levels. These approaches began to be documented at the beginning of the 1990s (Oliver, 1992). Inclusive research and various models for active participatory research are the products of changes in the self – perception of persons with disabilities. These new forms of research are also the result of the establishment of worldwide leadership groups and movements promoting the self-advocacy of persons with disabilities. These groups are forged on the guiding principle value of "Nothing about us without us."

Rather than focusing on the medical model which identified people according to their illness, diagnosis and disability, a transition was initiated towards the rehabilitative model, followed by the social model, in turn highlighting the strengths of persons with disabilities, rather than the weaknesses. This transition led to increased participation of persons with disabilities in various social spheres, as well as greater involvement in decisions regarding their own lives. The concept of Emancipatory Research emerged at the beginning of the 1990s. Oliver (1992) described a research model in which the research hierarchy changed from perceiving representatives of population groups merely as research subjects to enabling them to experience emancipation, the right to self-definition, and the opportunity to serve as co-researchers as well as the autonomy to choose the focus of the research. The emancipatory approach that Oliver presented was praised for its significant contribution to the movement for equality and self–advocacy for persons with disabilities. At the same time, his approach encountered extensive criticism regarding its reliability and difficulties in its processes of implementation. Much of the criticism refers to the gap between the research knowledge of skilled researchers and those who are social leaders as researchers (Danieli & Woodhams, 2005).

The Participatory Action Research approach, which involves the participation of persons with disabilities in research, was developed several years after the emergence of "emancipatory active research". This new approach strives to change the current situation and encourages increased social and community involvement. The "co-researchers" - who are persons with disabilities - are participants who are experts of their own lives. The objective is to translate the research findings into practice that promotes quality of life (Keirnan, 1999; Whitney-Thomas, 1997). The research is guided by "enabling researchers" who have extensive experience in research and evaluation methods and combine their knowledge and experience with those of the co-researchers. Bigby et al. (2014) noted that the development of various models of inclusive research in the field of disabilities, was inspired by movements that promoted the rights of excluded population groups and feminist organizations. Krumer-Nevo (2006) views co-researchers from excluded groups as people who contribute "life knowledge" (p. 14).

Alongside the Emancipatory Research Approach, other forms of participatory research also developed. "Inclusive Research" was a concept pioneered by Walmsley (2001). This concept described the framework of research with persons with developmental intellectual disabilities, in which they were more than mere research subjects or respondents. During the past decade, studies have been conducted in various countries, including Israel, in which service recipients reviewed the quality of the services they receive. An example of this is ATEMPO in Austria (https://www.atempo.at/en/) – an organization in which persons with intellectual disabilities determine the index for assessing their satisfaction with the services they receive. They are trained to administer surveys in various frameworks, with the subsequent findings constituting an index for the quality of service. Similar evaluation studies and satisfaction surveys are also being conducted in Israel in the field of mental healthcare.

Persons coping with mental health issues have been interviewing clients regarding housing, employment, and other mental health services within the framework of a program for quality surveys since 2005, with the findings being made accessible to the clients and their families (Hecht, 2011).

Bigby et al. (2014) presented a review of literature that cited various concepts describing inclusive research and reflecting the characteristics of the various active roles played by co-researchers with disabilities. Bigby and her colleagues described the following types of research: Inclusive Research; Participatory Research; Collaborative Research; Co-Research; Partnership Research and Translational Research-all concepts that are common to/in inclusive research. According to Bigby et al. (2014) the use of these various concepts expresses two main common guiding principles: Firstly, persons with disabilities need to be included in studies pertaining to issues that impact their quality of life, and secondly, the practical knowledge and life experiences of persons with disabilities are extremely valuable and improve the quality of the research. However, the large number of concepts create confusion. For example, in some studies the concept "inclusive research" describes a research process that is guided by persons with intellectual disabilities, while in other studies the same concept describes a reality in which academic researchers direct the research process. In addition, no uniform research paradigm has been defined for these research approaches.

Table 1 shows the chronological development of the various approaches to inclusive research.

Table no. 1

Research approach	Researchers with disability status	Characteristics	Source
Traditional research approach	Researched, objects of research	There is no involvement of people with disabilities in the research process	
Emancipatory research	Leaders, research conductors	In the spirit of "nothing about us without us" - there is a reversal of hierarchy and researchers without disabilities will integrate the researchers with disabilities, according to their wishes.	Oliver, 1992
Participatory action research	Participation in certain parts of the research	The enabling researchers guide the research and the participation process, which is aimed at social change	Chappell, 2000
Inclusive research 1	Incorporated as consultants	People with disabilities are integrated into research in "more than just being researched"	Walmsley, 2001
Inclusive research 2	Varies	An umbrella of research approaches defined as participatory, action or emancipating	Walmsley & Johnson, 2003
Collaborative research	Full and equal participants	The enabling researchers and colleagues value the experience and knowledge of each partner and together build a "whole" from the cohesive and full partnership	Bigby et al., 2014

In this article we attempted to adhere to the original concepts used by the authors of the articles that we chose to include. We have, however, chosen to use the term "inclusive research" since the working model that we developed is based on partnership and participation.

Is Inclusive Research a Methodology or Research Approach?

When discussing this issue, we must first and foremost define academic research in the social sciences. Research is a systematic activity for collecting data that aims to create new knowledge about an issue that the researcher has identified as being of interest. Data is collected using various methodologies. The research methodologies that are most commonly used in academic research in the social sciences are the qualitative and quantitative approaches. Beyth-Marom (2013) states that according to the quantitative approach scientific research has fundamental characteristics: objectivity, empirics, quantity, publicity – implying that the research is published in journals so that its reliability can be examined – and curiosity and skepticism on the part of the researcher. The traditional structure of a quantitative study includes a review of literature, presentation of the research questions, description of the methodologies that relate to the research tools and their validity, the manner in which data was collected, structure and size of the sample, presentation of the findings, discussion, and recommendations. The researchers conclude by presenting the limitations of the study.

The objectives of qualitative research are similar, but the methods for collecting and analyzing data differ. Collecting data in qualitative research is based on documented interviews, observations, inclusive observations, focus groups, or open questionnaires. The number of research subjects is relatively small and the study does not deal with statistical comparison between research groups as performed in quantitative methodologies. One of the most common approaches to qualitative methodology is the narrative approach. This approach to data analysis is based on identifying and constructing the main themes in the stories, reports, or responses of the research subjects. Additional qualitative research methods have been developed

alongside the traditional qualitative approach, such as Photo Voice – a visual research tool used in inclusive research. This tool utilizes photography to document and reflect reality, and to provide insight and new perspectives for increasing awareness as a tool for social change (Budig et al., 2018). Another qualitative inclusive research tool makes use of theater and ethno-drama therapy, in which co-researchers present their knowledge and life experiences through expressive drama therapy (Snow et al., 2017) Since inclusive research is research in every sense of the word, it is obligated to encompass both the qualitative and quantitative approaches. The only component that differs is the inclusion of co-researchers with disabilities in the various stages of the research, and their degree of participation.

The degree of participation in the inclusive research process is presented in a tool that includes the series of research activities arranged on a scale (See table 2). The table describes the degree of involvement of co-researchers during each stage of the research (Koren et al., 2018). The degree of involvement of the co-researchers is liable to vary from one research project to another, and it is important that they receive proper acknowledgement for their involvement.

Consequently, all the research conducted using this collaborative approach between the co-researchers is described in detail in the presentation of the research findings. This also assists researchers who are new to this approach to attain a valuable insight to the possibilities for the involvement of co-researchers, therefore enabling them to develop realistic expectations as to the focus of their contribution to the process.

Table 2: The Degree of Participation of Co-researchers in the Research Process

Stage	Research and action	Sequence of actions	Level of participation			Participation characteristics
			Low 1	Partial 2	Full 3	
1.	Research	Advisory Committee	1	2	3	
2.		Choosing the research topic	1	2	3	
3.		Review of the Literature	1	2	3	
4.		Research methodology	1	2	3	
5.		Determination and construction of research tools	1	2	3	
6.		Targeting the study population	1	2	3	
7.		Data Collection	1	2	3	
8.		Data processing	1	2	3	
9.		Learning the findings, analysis and discussion	1	2	3	
10.		Formulation of recommendations and methods for action	1	2	3	
11.	Action	Writing an article based on the research	1	2	3	
12.		Publication of the research	1	2	3	
13.		Presenting the results and their implications	1	2	3	
14.		Strategy for action	1	2	3	

This article will describe the emergence of Inclusive Research Groups (IRGs) at Beit Issie Shapiro, Israel, as a work model, and will build and conceptualize the work processes that have been formed since the establishment of the first IRG in 2006. The enabling researchers (researchers with professional experience in research methods) and the co-researchers (researchers with disabilities), have adhered to research methods that are accepted in qualitative and quantitative academic research. Meticulously adhering to these methods stems from a desire to validate the research findings, and to avoid criticism of the research findings by people in the academia, policy-makers, and service providers. The working model that is presented in this article was constructed and implemented mainly with groups of co-researchers with complex specific learning disorders, as well as groups of persons with moderate to mild intellectual disabilities. However, the guiding principles can also be applied to populations of co-researchers with other abilities and disabilities.

The objective of this article is to increase the number of studies that are conducted using this approach, to expand its use, and to mobilize as many partners as possible. The dissemination of this methodology is most important for increasing evidence-based practices of self-determination and as a result, improving the quality of life of people with disabilities.

This article, which comprises an applicable guide, will present examples of various forms of inclusive research while relating to population groups who require unique adaptations, such as co-researchers with low cognitive abilities and persons with deafness or blindness.

What are the Guiding Ideologies of Incusive Research?

The main working theory behind inclusive research is that it is directed towards adding knowledge in the field of disabilities that in turn that can facilitate practical changes being implemented that will promote a greater quality of life. Accordingly, the main idea that guides this approach is that people with disabilities are included in research by merit, and not by grace. They have the absolute right to be included in the research process and their presence constitutes a vital contribution to the accuracy of the

issues being examined. The IRG works alongside enabling researchers who provide academic guidance. Significant importance is attributed to the applicable-social aspects that are provided by the co-researchers. The connection between these two points of view is important: the co-researchers share their life experiences in the content world that are significant to them; they conceptualize them and offer research questions that are used to design the research tools; the manner in which the research findings are explained is authentic and stems from their existential life experiences rather than being based on theory; the research process empowers the participants because they are a part of its creation; they are not perceived as "research subjects", but as catalysts for the development of ideas and participants in designing and conducting the research, as well as serving as interviewers, data analysts, writers, and distributors of knowledge as well as service recipients (Walmsley & Johnson, 2003).

Robotham et al., (2016) emphasized that there would be no applicable value to the research if persons with disabilities were not involved in determining the research agenda. They claim that inclusive research is not directed towards finding "academic discoveries" that will only be published in academic periodicals, but strives to establish a connection between academic study and practice. Nind (2017) supported this claim by rejecting the idea that the sole purpose of the academia is to create knowledge, in conjunction with that knowledge not being the sole property of distinct exclusive groups.

Persons with disabilities collaborating with enabling researchers, work together to create effective knowledge using the proper recognized tools and work principles. The involvement of people with disabilities in research is an empowering element in the development of leadership among people with disabilities, as differing arguments for equal rights based on research, will cast an evidence-based and rational foundation to drive the action for change. The participatory research connects the wisdom of knowledge with the wisdom of action, based on the idea that "two heads are better than one".

Principles for Ensuring Participation in Inclusive Research

The guiding values of inclusive research are reflected in the working principles that have been outlined by researchers such as Nind and Vinha (2012). They noted that inclusive research has unique characteristics, and enabling researchers must ask themselves honestly whether the study they plan to conduct together with co-researchers with disabilities, is truly an inclusive research. They proposed several questions for focused self-assessment:

1. Is the research topic significant to the lives of persons with disabilities? Will it arouse their interest in the present or perhaps in the future?

2. Does the research actively and significantly involve persons with disabilities?

3. Are the research participants treated with respect?

4. Are persons with low intelligence provided with accessible, comprehensible communication, that enables them to participate in the discussion?

5. Is the role and contribution of each participant in the research process accepted with honesty and transparency?

6. Were the needs of the participants taken into consideration when planning the work processes for conducting the study? Were adaptations made to accommodate those needs?

7. Will the research participants gain long-term benefits in aspects such as new infrastructures, skills, resources, roles, or social participation?

8. Does the research have the power to reach participants, communities and knowledge that other forms of research would not attain?

Nind and Vinha also emphasized that preserving honesty and transparency in inclusive research, also implies devoting attention to ethical issues. The enabling researchers must address issues such as: Who are the owners of the research? Will there be full collaboration between the enabling researchers and the co-researchers? Are the roles of each of the co-researchers clear? Will recognition be given for these parts, and if so, how? Who will decide which of the main parts should be examined further based

on the research findings, as well as other pertinent questions that examine thoroughly the alliance between the co-researchers and the enabling researchers.

Who are the Co-Researchers?

Despite the fact that participatory action research refers to persons with disabilities - whoever and wherever they are – many inclusive research studies that are mentioned in professional literature, refer to research groups comprised of persons with mental or intellectual disabilities. When referring to research with persons with low intelligence, alongside their abilities, numerous questions arise regarding their true involvement in the research process, their ability to conduct an egalitarian research discussion, and to what degree the research product will meet academic standards. Throughout the years that the IRG at Beit Issie Shapiro has been in existence, we have adhered strictly to research tools that meet the high standards accepted by academia. This has resulted in the creation of abilities and skills that are required of members of the group. These will be described in the section about the construction of the research group in Beit Issie Shapiro at a later point.

The Working Model of the Inclusive Research Group

The IRG in Beit Issie Shapiro was developed as part of the "Inclusive University" Program. In 2002, the Trump Institute for Continuing Education in Developmental Disabilities, launched a unique pioneer program for adults with complex specific learning disabilities and difficulties in adaptation and function. The contents of the various learning programs are adapted to the students' needs and are cognitively accessible, with classes taking place in academic institutions. The various study programs were developed over the years, include studies of selected topics in psychology, using language adapted to the students' cognitive abilities, and are designed to empower these students. A course entitled "The Art of Living – Introduction to Practical Psychology" was developed within the framework of the "Inclusive University". The course includes a module entitled "Introduction to Research Methods" and is taught by the research and evaluation department of Beit

Issie Shapiro. During the course we became aware that a large number of students had both the interest and capabilities, as well as the desire to conduct a pioneer research about a significant issue in their lives.

The first such research was conducted with professional guidance of the writers in the form of a participatory action research. The study was entitled: "The Connection Between Social Acceptance and Personal Characteristics of the Individual" (Hozmi & Roth, 2009). The study examined characteristics of social preference among adults with learning, adaptation, and functional disabilities, compared to mainstream university students. This led to the formation of a designated research group using this approach. The group included a selection of adults with complex specific learning disabilities who were graduates of the course "The Art of Living – Introduction to Practical Psychology." The preliminary knowledge of selected issues of psychology and research methods that the students had learned in the course, served as an important foundation for their active participation in research discussions and in conducting research. Research within the framework of IRGs is conducted with guidance from the Department of Research and Evaluation of Beit Issie Shapiro, to ensure that it follows the rigorous academic research protocols. The experience that was acquired in this research approach has led the Research and Evaluation Department to adopt the format of inclusion and collaboration, with representatives of the research population as valued and vital advisors or co-researchers, in its various assessments. This idea stems from the recognition of the importance of the unique added value of their input for improving both the study and the research.

Several studies have been conducted since the initial establishment of the IRGs at Beit Issie Shapiro – some of which will be described in this article. These studies included participants with disabilities from various groups such as persons with intellectual disabilities, persons with specific learning, adaptation and functional disabilities, and persons with sensory disabilities, such as blindness or deafness. During this period, we learned to assess the strong points of the group and the contribution of its members

to the research process. We gained insights and established work methods, but there still remain dilemmas regarding the implementation of this work model. These include

issues pertaining to the roles of the co-researchers and the enabling researchers, whether research conducted using this approach meets full academic standards, the degree of flexibility needed in this type of research, and other issues. In addition to these dilemmas, there are also objective difficulties such as locating resources that will enable us to provide the intensive guidance and support that are necessary in this form of research.

The following sections will describe the working model: the characteristics of the co-researchers in the IRGs: the process of forming the groups, and the research. This will be followed by a structured documentation of several research processes that were conducted with IRGs, and a summary of the advantages, challenges, and dilemmas of the inclusive research approach.

The Characteristics of Members of IRGs

Extensive thought should be devoted to the make-up of the group of co-researchers to ensure that the research meets acceptable research standards:

- **A Proactive Approach** – Participants in the research group must be people with initiative, interest, and motivation to participate in the process.

- **Ability to express their opinion** – This component is important for ensuring a rich academic and practical discussion.

- **Reasonable to good learning ability** – The research process also involves familiarization with structured academic knowledge, the presentation of various research tools and the issues being examined. It is also important to remember that the research process is directed towards an in depth learning of a central topic

- **Reading and writing skills** – These skills are essential for research processes and for performing tasks between research meetings. If members of the group lack these skills, it is important to ensure that they receive mediation and support.

- **Basic background in research methods** – If a member of the group lacks basic knowledge and understanding of the structure of academic research, it is

important to conduct one or two preparatory meetings to enable the co-researchers to have a "road map" of the research process and its guiding principles. Familiarity

with basic concepts in research is extremely important for conducting practical academic discussion, as it increases the involvement of the co-researchers, and ensures the quality of the final product.

The Process of Building the Group

Our experience has shown that conducting inclusive research in a group format, contributes significantly to both the members of the group and to the enabling researchers. IRGs consist primarily of co-researchers with specific learning disabilities, adjustment and function disabilities, that are sometimes accompanied by additional disabilities. One of the main characteristics of people in this group is that there are significant discrepancies between their abilities in different areas. Consequently, inclusive research in a group enables all members to utilize their unique abilities and to contribute their part to the creation of the whole.

The research group, as in any "task group", creates a group identity and closeness. The research discussion exposes different points of view that enrich the discussion. The formation stages involve the following process:

- **Locating and recruitment** – Most members of the group are graduates of the Inclusive University. They are already equipped with previous basic knowledge about many of the research topics, social sciences, and research methods that they can bring to the group discussions. However, in groups being formed only for the purpose of consultation in research processes of various researchers from academia, it is important that the members have a significant connection to the research topic, and are able to express an opinion.

- **Personal Introductory meeting –** This meeting involves an introductory overview of mutual expectations coordination of expectations between the candidates and the enabling instructors. This enables the candidates to become familiar with the research process and assess their level of interest and motivation regarding participation in the research, determine whether or not they can commit

  themselves to the process, as well as assessing what type and amount of support will be required to meet their needs. If the person has a guardian or lives in a supported living facility, they must be notified to ensure that there are no

impediments regarding procedures such as filling out preliminary questionnaires. If such impediments exist, attempts must be made to mediate them.

- **Group Workshop to determine the composition of the group –** During the workshop, members learn about the principles of the research methods. The enabling researchers assess the quality of discussion, as well as the participation and the contribution of each member.

- **Forming the Group –** The optimal number for a group is 6 to 8 participants, preferably from various frameworks, who can provide varied opinions and recruit the research population. Persons who live in community housing frameworks have a full daily routine that is dictated by employers and other figures in authority. It is also important that their participation in the group be supported by significant figures in their lives, such as staff members in housing services, parents, and other figures. Each group should include two professional enabling researchers, or a researcher and assistant.

- **A group workshop**, according to which the composition of the group will be determined - in the workshop the candidates are exposed to the principles of research methods. During the workshop, the enabling researchers learn about the quality of the discourse and the contribution of each participant.

- **Building a Contract and Action Plan** – The frequency and duration of meetings and schedule are determined by the constraints of the group members. Most meetings last for three academic hours, and should take place every two weeks and no less than once each month. If meetings are infrequent it is difficult to retain consistency in performing tasks and maintaining the emerging body of knowledge. The frequency of meetings is derived from the characteristics of the tasks that the co-researchers perform between meetings. The manner and frequency of contact with the enabling researchers must also be determined. Most contact with co-researchers is by email, and the group also sets up a WhatsApp group with which

the members of the group communicate through written or recorded messages, according to their needs. The members of the group agree that the contents of the

discussions will be kept discreet and that the guiding principles for research ethics will be kept.

- **Assigning Tasks** - After the group becomes familiar with the research processes and the enabling researchers become familiar with the various abilities of the group members, tasks are assigned to the co-researchers in a manner that suits their unique skills, such as locating sources of relevant professional literature, reading and summarizing, constructing the system for research and collecting data by group members who have high organization and coordinative skills, documenting the meetings etc.

The Research Process in an IRG

Most stages of the research process are similar to what is accepted in academic research. However, there are unique aspects of conducting research with an IRG using the active participatory research approach, that will be described below.

The involvement of members of IR in the research process is expressed in several ways:

1. **Co-researchers as full participants –** The research topic is initiated by the members of the group.

2. **Co-researchers as partial participants –** The research is initiated by the enabling researchers, who seek the participation of the co-researchers throughout the research process.

3. **Co-researchers as advisors –** The group serves as advisors for researchers who wish to have single or multiple consultations with the group. Most consultations take place during the stage of selecting the methodology or constructing the research tools.

Similarly, Bigby et al. (2014) identified three main patterns of involvement in inclusive research with co-researchers with low intelligence. The first is participation as advisors mainly about issues that deal with designing policies. The second is their participation

in research as self-advocating guides, and the third is integrating them in participatory research that is usually conducted together with enabling researchers from the academia. The research topic in a large majority of IRG studies is determined by coordination and consensus with the members of the group. Each of these working methods validates the members of the group as having an opinion and a unique voice. The following is a description of the working model used in participatory action research with IRGs. It should be noted that documentation of the work processes is extremely important, because it has qualitative patterns and value that can be used in further stages of the research. It is therefore essential for meetings to be documented by recording and/or by writing a protocol.

- **Deciding the research topic –** The first stage consists of an open discussion about issues that members of the group are interested in focusing on. In most cases the topic stems from dissatisfaction with a current situation. Members of the group choose a central issue they would like to examine and provide explanations about the reasons for their choice, and the contribution of the research to their quality of life.

- **Learning about the topic –** The enabling researchers present theoretical research and concepts to deepen the co-researcher's knowledge. Some of the group members begin to gather material for the literature review. The topic is also learned in practice. For example, during an Inclusive Group Study that examined the connection between self-image and relations with partners among adults with complex learning disabilities (Roth & Hozmi, 2011), the co-researchers decided to examine intimate relations and their connection to two bodies of theoretical knowledge they had learned about. The first was Erich Fromm's statement that loving others begins with loving oneself, and the second was the theory about the development of self-value. These served as the basis for the research questions.

- **Focusing on main themes and the main research question -** A discussion is held about the main themes and their derivative variables. These themes will serve as the foundation for implementing existing research tools and for building the research platform.

- **Determining the research tools –** The enabling researchers present existing questionnaires about the issue being examined and a critical discussion develops about these tools. Sometimes the researchers work together to build tools based on these focal points, or decide to adapt existing tools that have been previously examined for validity and reliability. Finally, the co-researchers and enabling researchers select the research tools, and decide upon the internal structure of each tool. The method of quantifying the data is adapted to the cognitive ability of the respondents. For example, if the respondents are persons with significant specific learning disabilities or intellectual disabilities, a Likert Scale of only three values instead of five will be used, or emoticons with happy, neutral, and frowning expressions will be used to signify levels of satisfaction or agreement.

- **Pre-test by members of the group –** Group members conduct a preliminary pilot and fill out the questionnaire to determine its reliability and validity, and to ensure that the wording and quantitative data are comprehensible and cognitively accessible. The co-researchers point out any possible biases that are liable to arise as a result of emotional reactions to items in the questionnaire.

- **Approval by the research Ethics Committee -** Research conducted by the inclusive research group requires approval by the ethics committee of the organization. In 1977 Turnbull cited three components that should be considered among persons with disabilities who consent to participate in research: The capacity to understand and make decisions that influence the self, the provision of information and the necessity for volunteerism. This is especially true when a guardian's agreement is required for participation in the research.

- **Distributing the questionnaires and collecting data –** Members of the research group assess how they can help locate potential respondents, and how many questionnaires they will be able to distribute and collect after they are filled out.

  This implies that in many cases members of the group are responsible for collecting data.

- **Processing Data –** Data Collection is done mainly by the co-researchers who are guided by the enabling researchers. Processing the data is done by the enabling

researchers, since the co-researchers lack the necessary statistical knowledge and skills.

- **Learning the findings and making the main findings accessible –** The main findings are presented in an accessible way to the group so that they can participate as equals in an egalitarian, relevant, -productive and focused discussion.

- **Writing the research report –** Despite the fact that members of the inclusive research group are involved in all stages of the research, the writing of the research report is done by the enabling researchers. This is due to the fact that the co-researchers are persons with complex specific learning disabilities, and lack the necessary skills needed for academic writing. However, the enabling researchers present parts of the entire written research at various stages, to ensure that the members of the group agree with the contents. Members of the group receive the accessible written findings. The discussion is documented during the meeting and -is processed according to an official protocol that is sent to the group members after each meeting. This protocol serves as the basis for the discussion chapter of the research. The enabling researcher drafts and types the contents, which are projected on a screen. Using this technology enables the participants to examine the contents and to offer comments or corrections, if they feel that the findings are not explained correctly. Their comments are extremely important, since they are part of the process and reflect their practical experience. Their interpretations of the findings are authentic, and are testimony to their understanding of reality of their lives and the lives of their peers regarding the research issues.

- **Deriving practical recommendations –** Following the writing of the research and the discussion, the entire research is presented to the group. A discussion takes place in which applicable recommendations are proposed, with the view that they can be translated into a work plan directed towards change. Despite the fact that the research approach is a participatory action research, a large part of these remain recommendations only, mirroring the results of most academic research. Robotham et al. (2016) found that only 13% of research recommendations in the field of mental health are actually implemented. However, it is important to note that the research process itself is a welcome change. The fact that persons with disabilities are deepening their knowledge and understanding of issues that are

relevant to their daily lives, is a positive beginning of possible change. Recommendations of Inclusive researches can contribute to the work of self–advocacy and leadership groups, by supporting their demands on evidence-based claims and practices.

- **Dissemination of new knowledge –** The enabling researchers are responsible for publishing the research in journals, Internet sites, and professional conferences. They also prepare the co-researchers to present the findings in professional conferences and social forums, as well as service providers and policymakers. The experience in Beit Issie's IRG, has shown that most studies arouse significant interest among professionals, parents and persons with disabilities. This is due to the unique characteristics of the final product in which data is translated into a social statement.

The Role of Co-Researchers in the IRG

The roles of the members of the IRG vary according to their abilities. Some serve as consultants, others are involved in carrying out various parts of the research. In most cases they are full, active participants and colleagues in the research process, which constitutes the following:

- Consulting, sharing, and contributing existential knowledge as experienced experts in the contents of their lives.
- Suggesting research topics about issues that are significant and relevant to them.
- Participating in acquiring theoretical knowledge according to his or her ability.
- Taking part in focusing and defining the dimensions of the issue being studied.
- Participating in building the research tools and collecting data.
- Helping to locate ethical issues that are relevant to the research and ways to deal with them, such as receiving approval of guardians, confidentiality, transparency, explanation, and simplification during contact with the research population.
- Participating in understanding the findings and attributing significance to them.

- Participating in echoing the research findings and presenting them in various forums.

The Role of Enabling Researchers

The characteristics and extent of the role of the enabling researchers differ between research, depends on whether members of the group serve only as consultants or whether they participate in all stages. The components are valid for each of the types of inclusive research, but their intensity varies. The role of the enabling researchers is characterized by duality– on the one hand they are research authorities, whilst on the other hand they are attentive learners, who empower the co-researchers.

- Enabling researchers comprise professional leadership in research methods, as enabling leaders and partners.
- Sometimes enabling researchers become learners/the students who are seeking advice, advisors, teachers, or guides during the research accompany processes.
- Skilled in linguistic simplification and making content cognitively accessible.
- Skilled in facilitating group processes.
- Knowledgeable about the characteristics of the co-researcher's disabilities, while relating to them through all of their abilities.
- Guides the co-researchers regarding required ethical rule, and ensures that they are followed throughout the research.
- Oversees the data analysis.
- Ensures that the tasks are carried out according to schedule throughout the research.
- Writes and distributes the research report.
- Trains the group participants to present the research and findings to various forums, in a professional and accessible manner

Inclusive Research with Full Participation

The following table (Table 3) presents several research studies that were conducted at Beit Issie Shapiro according to the working model described above. The table presents the topic of the research or assessment, the background for selecting the

focal point of the study, the role of the co-researchers, and the channels in which the study was published or presented.

Table no. 3

Topic of research/evaluation	Background for choosing the research topic	Characteristics of the researching group	Published in:
Social acceptance among adults with learning, adaptive and functional disabilities	Following a meeting in the cafeteria of the students of the Inclusive University Program at Bar Ilan University, they returned to class with the question: "Do we have a chance to be real friends with the degree students?"	Co-researchers with learning, adaptive and functional disabilities	Issues in Special Education & Inclusion, Hozmi, Roth and KEMACH – The Inclusive Research Group of Beit Issie Shapiro (2009)
Employing people with complex learning disabilities - the profile of the friendly employer	The field of employment comes up a lot in classes at the Inclusive University. Some students praised the attitudes of their employers regarding their needs for adjustments, and some complained of a humiliating attitude. The students asked what could motivate an employer to hire people with disabilities, compared to an employer who would chose to rejects such an option	Co-researchers with learning, adaptive and functional disabilities	Not published. Key findings were disseminated at conferences, curricula for professionals and lectures to employers
The relationship between the self-image of adults	A student announced her engagement and another	Co-researchers with learning,	In the book "From Inclusion towards

with a complex learning disability and their sense of focus of control regarding their ability and desire to be in an intimate relationship	student immediately asked: "Why does she deserve a relationship and I don't? What does she have that I don't?" The group that had formulated the research topic examined that question	adaptive and functional disabilities	Full Participation: challenges and growth over the life span", Roth and KEMACH – The Inclusive Research Group of Beit Issie Shapiro, (2011)
Dependence, independence and self-concept among adults with a learning, adaptation and functioning disability	"Kemach" (Inclusive Research Group) members stated that they moved to supported housing services in the community, in order to develop their independence. This is also how things were presented to them by their family members. At the same time, the experience of the majority is that the degree of autonomy is in reality, limited. Therefore, they chose to focus the research on this topic	Co-researchers with learning, adaptive and functional disabilities	Roth and KEMACH – The Inclusive Research Group of Beit Issie Shapiro, (2020)
Quality of life among people with intellectual disabilities	The CEO of "Agudat Ami" Association contacted the research and evaluation department of Beit Issie Shapiro with a request to check: "How satisfied are the recipients of the service with their lives?" (his words)	Co-researchers with mild to moderate learning disabilities	Issues in Special Education & Inclusion, Roth and Hozmi (2014)

Aging and complex specific learning disabilities	The members of the group produced a play in the community housing system, that dealt with the subject of old age and complex learning disabilities, through the medium of community theater. Dealing with the issue evoked thoughts, feelings and questions which the group members wished to compare the attitudes towards old age of people with and without complex learning disabilities	Co-researchers with complex specific learning, disabilities	Hozmi, Verner and KEMACH – The Inclusive Research Group of Beit Issie Shapiro (2020)

We will now describe two of the research procedures that were presented in the table above: The first is a research procedure entitled "Dependence, Independence, and Self-perception among Adults with Complex Learning Disabilities – Adaptation and Function". The second is entitled "Quality of Life Among Persons with Intellectual Disabilities". The first part of the description will include the series of research activities followed by a presentation of the Roth Scale, which appears at the beginning of this article. The description focuses on the degree of participation of the co-researchers in each study.

1. **IRG Research: "Dependence, Independence, and Self-Perception among Adults with Complex Learning Disabilities"**

Members of a group of adults with learning disabilities were responsible for determining the topic for this research and for the initiative to implement it. The research question was developed after the group members discussed the topic that bothered them as adults – particularly the issue of independence and dependence. The members of the research group discussed what they termed to be "Hypocritical, two-faced" experiences. These "hypocritical experiences" stemmed from the fact that figures in their lives who are supposed to serve as sources of support to empower them and promote their independence, often limit them and infringe upon their right to make decisions and to determine things for themselves.

The Degree of Participation of Group Members in the Research Stages

During the initial meetings the enabling researchers presented a review of literature on the topic of independence/autonomy and dependence, attachment styles, and friendship. They also presented literature that dealt with adults with learning disabilities in various walks of life such as studies, employment, relationships, independence, quality of life, and self-image. It should be noted that not many materials were found on adults, and most of the materials refer to this population being in the education system. The material was presented to the co-researchers in simple, accessible language. This led to an enabling and liberating group discussion.

The group viewed the academic materials as supporting their own perceptions and beliefs about their lives, which in turn helped them realize that these beliefs were shared by others and were not "just in my mind." Some of the co-researchers related to the fact that this information helped them understand, hone, and conceptualize their own thoughts and feelings, as well as those of their environment. The presentation of literature and research provided them with knowledge that enabled them to refine the research question, define the concepts, and assess various measuring tools. After the relevant research tools were selected, the group members asked them to examine whether the items were suitable from the standpoint of language, comprehension, and accuracy. The research tools were then reworded according to the changes that were suggested. The reworded version was then distributed to 20 respondents with complex specific learning disabilities, to examine its reliability and to determine the optimal manner for filling out the questionnaire: in writing, orally, or by means of interviews.

After writing the research proposal, the enabling researcher approached the ethics committee at Beit Issie Shapiro to receive approval for conducting the research. During the next stage, approval was granted by the organizations that provide services (housing, leisure activities, and employment), for the research participants. After these approvals were granted, all the enabling researchers and co-researchers approached social clubs and housing frameworks in which potential participants were active, in order to recruit them to take part in the research. The co-researchers collected all the responses, and the enabling researchers analyzed the data and simplified the findings for the members of the group, who participated fully in their interpretation. Finally, the enabling researcher wrote an article based on the research findings. Several actions were implemented at the completion of the research:

- The research findings were presented to all the participants (with complex learning disabilities) who responded to the questionnaire.
- The co-researchers presented the research findings to professional teams who were involved in their lives. This was done together with the enabling researcher who mediated when necessary.

- Some of the co-researchers reported to parents and family members about the research process and its findings, and in particular about their part in it - an action they described as empowering and awe-inspiring, in their own words
- The research was presented at seminars and conferences.

The following table (Table 4) describes the degree of involvement of members of the IRG during the various stages of this research.

Table No. 4

Stage	Research and action	Sequence of action	Level of participation			Participation characteristics
			Low 1	Medium 2	Full 3	
	Research	Advisory Committee	1	2	③	Not relevant to this study
		Choosing the research topic	1	2	③	The decision of the Co-researchers
		Review of the Literature	1	②	3	The review was adjusted, simplified and summarized by the enabling researchers
		Research methodology	1	2	③	Jointly determined
		Determination and construction of research tools	1	2	③	Joint process
		Targeting the study population	1	2	③	Decision of the Co-researchers

			1	2	3	
		Data Collection	1	2	③	Was carried out in a fashion adapted to the participant's needs
		Data processing	①	2	3	Carried out by the enabling researchers
		Learning the findings, analysis and discussion	1	2	③	Carried out in full cooperation
		Formulation of recommendations and methods for action	1	2	③	Carried out in full cooperation
	Action	Writing an article based on the research	①	2	3	Mainly by the enabling researchers
		Publication of the research	1	②	3	Published in this issue
		Presenting the results and their implications	1	2	③	Co-researchers
		Strategy for action	1	2	③	Co-researchers

1. IRG Group Research: "Quality of Life among Persons with Intellectual Disabilities"

An inclusive evaluation research was conducted by the Ami Organization in the city of Beersheba for the first time in Israel. This pioneer research was conducted from 2009 to 2011 - three years after the establishment of the working model for inclusive research at Beit Issie Shapiro. The research was conducted with co-researchers, who were persons with developmental intellectual disabilities who were residents of the Ami organization housing facilities. The research group required creativity in adaptation, accessibility, and extensive linguistic simplification. The research dealt with components of quality of life among persons with intellectual disabilities, living

in supported housing frameworks. The study was requested by the director of the organization, who wished to learn whether the service recipients were satisfied with their lives. The enabling researchers decided to conduct the study in the form of an IRG, and a group of co-researchers with moderate to low intellectual disabilities was formed. During the group discussions the co-researchers were asked to describe the most important aspects of their lives. They noted several components – the most important of which was **friends**. They were then presented with a questionnaire written by Shalock and Keith (1993), and were asked to relate to it in a critical manner. The respondents noted that the questionnaire lacked items that reflected significant issues in their lives, and asked to include additional questions such as: "Do you have a key to your room or a personal cabinet?" and an additional question about the medical services that were available. After establishing the final version of the questionnaire, a group experiment was conducted in which the participants were able to complete it using a pencil with an eraser. This enabled correctios to be made, thereby vastly reducing any associated anxiety. The questions were projected on to a screen and read by a member of the group. The respondents then rated each item after it was understood. This procedure was also implemented during the actual collection of the data.

Focusing on the quality of life components that were important to the service recipients in the organization, a similar procedure was performed with the staff. They were asked to predict what the service recipients would report to be the most significant components in their lives. The staff predicted that this would be **food**. After the data was collected, a meeting took place with the co-researchers at Beit Issie Shapiro. The co-researchers asked for assurance that the staff was not present or near the room when the meeting took place. When the enabling researchers asked the co-researchers why they felt that the staff imagined that food would be the most important thing in their lives, they stated that it was not. However, the staff encounters with them each evening when they are preparing for dinner, setting the table, and washing the dishes, would explain why the staff felt that food was the most important component in their lives. Another finding in this study revealed that persons with moderate or low intellectual disabilities were more satisfied with the level of autonomy they were granted, while persons with mild intellectual disability were

interested in receiving greater autonomy. One member of the group with a moderate intellectual disability explained: "The staff and the rules watch over us" while a co-researcher with mild intellectual disability responded by saying: "We want more freedom and to meet with young people our age." (He was then in his 30s). "We want an allowance so that we can buy things without asking permission every time". The policies and rules of the framework need to be differentiated (in his words) and should be determined according to each person's level. The higher ones should receive more freedom and the lower ones should be given more supervision."

At the end of the writing of the research by the enabling researchers, its findings were presented to the management of the Ministry of Labor and Welfare and the staff of the organization with the active participation of the co-researchers, who underwent preparation for this task and fulfilled it impressively. This description emphasizes the possible role of the co-researchers in presenting the research topic from their standpoint. This process enabled greater accuracy in constructing the research tools. Their insights were characterized by authentic interpretations based upon the wisdom of practice. The following table (Table 5) describes the involvement of the co-researchers in the various research stages.

Table No. 5

Stage	Research and action	Sequence of action	Level of participation			Participation characteristics
			Low 1	Medium 2	Full 3	
1.	Research	Advisory Committee	①	2	3	Not relevant to this study
2.		Choosing the research topic	①	2	3	By the management of the ordering organization
3.		Review of the Literature	①	2	3	The enabling researchers
4.		Research methodology	1	②	3	The enabling researchers
5.		Determination and construction of research tools	1	②	3	The tools were refined with the group of peer researchers
6.		Targeting the study population	①	2	3	The decision of the organization and the enabling researchers
7.		Data Collection	1	②	3	Enablers and peers together
8.		Data processing	①	2	3	The enabling researchers
9.		Learning the findings, analysis and discussion	1	2	③	A guided process with the Co-researchers

No.	Phase	Task				Who
10.		Formulation of recommendations and methods for action	1	2	③	A guided process with the Co-researchers
11.	Action	Writing an article based on the research	①	2	3	The enabling researchers
12.		Publication of the research	①	2	3	The enabling researchers
13.		Presenting the results and their implications	1	②	3	The enabling researchers and the Co-researchers
14.		Strategy for action	1	②	3	the ordering organization

Co-Researchers as Consultants

In addition to fully collaborative researches that were conducted between co-researchers in IRGs and enabling researchers, other studies are conducted in which this group serve as consultants. In this format, members are selected to represent the research population, and a consultation committee of co-researchers is formed. Members can be recruited effectively from learning groups, leadership groups, activist groups and social clubs, whose clientele consists of members of the research population. The following table (Table 6) describes several researches that were conducted with the help of these consultation groups.

Table No. 6

Topic of the research/evaluation and its products	Background for the initiative	The characteristics of the co-researcher's involvement	The characteristics of the research group
How stigma affects us: The voice of self-advocates (Roth, Peretz & Barak, 2016)	Request from the editors of the book 'Intellectual disability and stigma', to dedicate a chapter on the subject of stigma, based on the research that will be carried out using the Inclusive Research Approach	A consulting committee convened before the research begins	People with intellectual disabilities
Evaluation of a national advocacy group. A report was submitted to the program operators in 2018	A request for a summary evaluation report was received from organizations and the foundation supporting the program	A consulting committee convened before the research begins.	People with intellectual disabilities
Evaluation of a national advocacy group. A report was submitted to the program operators in 2016	A request for a summary evaluation report was received from organizations and the foundation supporting the program	A consulting committee convened before the research begins	People with intellectual disabilities

Evaluation of the program "Visual Supporter" - The Center for the Deaf-Blind. A report was submitted to the Beit David association in 2016	At the end of a year of piloting the program, the association's management requested an evaluation	Focus groups were held with representatives of the research population, to formulate the questionnaire and adapt it to the people being studied. A pre-test was held in order to identify challenges in translating the questionnaire into contact sign language (since in this type of communication it is difficult to translate the questionnaires word for word)	People with both hearing and vision disabilities as well as service providers, who are deaf
Evaluation of the "Academic Friending" program. A report was Handed to JDC-Israel Unlimited in 2018	JDC-Israel Unlimited initiated the evaluation after the end of the pilot period of the program	The co-researchers took part as advisors in three sessions, while constructing the questionnaire, and at the stage of discussing the results of the research, in which they shared their insights and interpretations with the researcher	KEMACH - The Inclusive Research Group of Beit Issie Shapiro

Description of Work Processes with a Consultation Committee

We will now explore in depth several examples of research, in which IRGs served as consultants for researchers who wished to learn from their "life knowledge" (Krumer-Nevo, 2006).

1. **"How Stigma Impacts Our Lives: Voices of Advocates with intellectual Disabilities"**

Before this study was conducted, the researchers had several dilemmas about how the study would -unfold, particularly in light of the fact that the topic is fraught with emotions and is liable to arouse negative feelings among the respondents.

It was decided to form a consultation group that would consist of men and women with intellectual disabilities. The committee consisted of three members with intellectual disabilities from self-representation groups in Beit Issie Shapiro, and two enabling researchers without intellectual disabilities who serve as co-guides in the self – representation program.

The role of the consultation group in this qualitative research was to offer advice about the optimal method of communication with the research participants, the style of questions and their wording, and the manner in which data would be collected. The products of this one-time meeting are described below.

A. Despite the fact that persons with intellectual disabilities in advocacy and representation groups are exposed to basic concepts such as "attitudes" and "stigma", the researchers were made aware of the importance of simple language to describe these concepts.

B. The researchers became aware of the intense degree to which the issue of stigma and attitudes are fraught with powerful emotions among members of the group. This emphasized the need for sensitivity during the research process and discussions with the research participants.

C. The members of the consultation group nevertheless encouraged the researchers to conduct the research. They emphasized that despite the difficulties and pain that this topic arouses among persons with intellectual developmental disabilities, it is extremely important in the process of

facilitating change regarding the attitudes of society, and has a profound impact on their self-perception.

D. The consultation group recommended that the discussions take place in a group rather than in an individual format, to decrease the chances of dealing with painful issues during data collection. They also recommended locating research participants who participated in self-advocacy groups who had previously confronted and discussed these issues. They also suggested that the introduction to the discussions would be given by persons with intellectual disabilities, who would undergo preparation as group guides to serve as catalysts and as role models for holding an open-hearted discussion.

E. The advocacy group is routinely accompanied by enablers. The consultation group proposed that the enablers participate in the meetings for gathering data, and serve as familiar sources of support for the participants.

The recommendations proposed by the consultation group were fully implemented by the researchers and proved extremely effective. The process once again demonstrated how life knowledge of experienced persons is relevant to the research process.

2. **Evaluating Services – "Visual Supporters" in a Center for Persons with Blindness and Deafness**

This evaluation was initiated by service providers at the center for persons with blindness and deafness, that is operated by the Beit David Organization. The service that was evaluated was visual mediation, in which service providers describe the surroundings to persons with blindness and deafness using tactile sign language. The service is provided for several hours once or twice each week. A discussion took place in a focus group consisting of representatives of service providers and service recipients to establish the tools for evaluation. The discussion revolved around central issues to be evaluated and the methodology for collecting data, and yielded the following insights:

A. The main issues raised by the service recipients dealt with gender compatibility. Since tactile sign language involves physical contact, the mediator and client should be of the same gender. Other issues that arose were who should decide

about the content of the activities, and whether or not the mediator should serve as only a mediator. In addition, some people claimed that the hours allotted to them for the activity within the framework of the program were insufficient. These issues were included in a quantitative evaluation tool.

B. The visual mediators played an important role in collecting data as they needed to translate the questionnaire, and make it accessible for the service recipients. (It should be noted that each visual supporter was paired with a service recipient they did not know, in order to avoid bias). The visual mediators explained that not every written word can be expressed by sign language, a fact that is further complicated when working with tactile sign language. The questionnaire was therefore simplified and adapted to tactile sign language.

3. Advising Committee for Research Processes for Academics

In addition to the two research studies described above, some members of the consultation committee gathered previous accessible academic knowledge to support their arguments. For example, a doctoral student conducted a study about autonomy and disability, and asked to meet with a consultation committee about the potential research questions and research tools. The discussion took place among second year students in the Inclusive University program, who were attending the course "The Art of Living – Introduction to Practical Psychology" at Bar Ilan University. This course adapts selected issues in psychology and makes them accessible to students with complex specific learning disabilities. During one of the meetings a student offered the following monologue: "You have to examine trust before autonomy. As Erikson said, if there is no trust, there is no autonomy. People have to believe in themselves, and, as Erich Fromm said, anyone who does not love himself cannot love others. That's what I learned and I am the proof that this is true, because now that I love myself, I am more independent and I have a girlfriend." A member of the group proposed drawing a connection between the variable of autonomy and the variable of trust or self – esteem. This is evidence of the added value of structured knowledge acquired by members of the consultation committee alongside practical knowledge that they have acquired over the course of their lives.

Inclusive Research – Strengths and Challenges

The 20-year journey to establish IRGs at Beit Issie Shapiro has been revelatory. It has shown the outstanding advantages of this approach, as well as highlighting the unique value of that the contribution of its members brings to the research project. However, we have also learned to recognize the challenges presented by this approach. Both the advantages and challenges will be discussed below:

The Advantages of Inclusive Research

The advantages of inclusive research are not limited to the ideological aspects of inclusion, utilizing the right of choice and self-definition. They enable the creation of unique and new bodies of knowledge about practical issues that academic research has seldom explored. We have identified the following major advantages of inclusive research that are connected to the researchers themselves, the research process, or the research product.

- Inclusive research is based on mutual learning that links theory and practice. Members of the inclusive research group are representatives with a voice, knowledge and life experience that are relevant to the research population (Bennett & Roberts, 2004).

- The co-researchers are highly motivated to study the topic.

- The co-researchers replace their subjective angle with a broader objective, focusing on the issues being examined.

- Dialogue with co-researchers enriches the perspectives and insights of the enabling researchers.

- If the co-researchers are graduates of a course in the area of the research topic, learning groups or training such as self-advocacy, they have the advantage of a strong foundation in relevant knowledge in their roles as research partners.

- The research is conducted using processes and tools that are acceptable in academic research.

- The research is conducted in a group format in which each person contributes their valuable perspective to the "whole".

- The research adds a further dimension and practical knowledge, and the interpretation of the findings is authentic and relevant.
- Members of the group experience empowerment and validation of their abilities during the research process.
- They become potential partners/leaders of social change and action concerning the research topic.

Challenges and Dilemmas of Inclusive Research

Most researchers emphasize the rights of persons with disabilities - including persons with intellectual disabilities' – involvement in research processes that pertain to issues in their lives. However, researchers raise questions regarding the essence of their involvement, the quality of the research and its feasibility (Bigby et al., 2014). Nind (2017) noted that a large portion of inclusive research studies are local and assess specific practical issues within a particular audience, location, and time period. This creates a challenging reality when attempting to apply the findings to other audiences and life environments. During the years that IRGs have existed, challenges, shortcomings and dilemmas have been brought into focus.

- Inclusive research requires considerably more time and resources than traditional research methods.
- As the enabling researcher no longer assumes full leadership of the research process, challenges regarding methodological aspects can arise.
- Conducting the research whilst dealing with individuals' demands and the group dynamics - strengthening, bridging, and mediating – as well as, in certain circumstances, expulsion of those who are not committed to the group and its missions.
- The participants have difficulty analyzing the findings, and it is necessary to mediate, adapt, and simplify them as much as possible before and during the group meetings.
- In most studies there is no description or documentation of the degree of involvement of members of the research group, in the process or its character (Heller et al., 1996).

- A discrepancy sometimes exists between the empowering ideological perceptions in the area of disabilities, and the abilities of group members to actively play an equal part in the research process.

- A review of literature reveals that there are instances in which research is documented only as a basic survey, rather than as research utilizing academic standards and tools. Accordingly, significant emphasis has been placed on adhering to all the components of acceptable research processes, when conducting research with IRGs in Beit Issie Shapiro.

- In many cases, data is gathered by members of the group. Consequently, guidance and direction are essential in all matters pertaining to ethics, and to avoid bias or deviation of data.

- It should be noted that gathering data is mainly quantitative. In qualitative studies it is done with the help of enabling researchers.

- Openness is needed on the part of the research community regarding the manner in which findings are presented and discussed. They involve "first-hand" arguments alongside backing from literature – which is uncommon in traditional academic research. We consider this "Achilles' heel" to be an advantage, since the claims raised by the co-researchers provide authentic explanations for the findings, and establish a connection between the research data and life experiences.

- In most cases, participatory action research is not translated into "action" which will lead directly to its recommendations being implemented. Despite this, the involvement of group members in issues that are significant to their lives and their learning, constitute social change. They are transformed into empowered experts who have the power to represent their peers in the research field, and as leaders who possess evidence-based knowledge.

Summary and Vision

This article sought to examine the strengths and challenges in the use of inclusive research with persons with disabilities in general, and persons with low intelligence in particular, while presenting the working model for the inclusive research approach

that was initiated and developed at Beit Issie Shapiro during the past two decades. The professional literature on this topic reveals a lack of a uniform language, and the absence of a uniform defined work doctrine. This article has attempted to organize the existing concepts and to propose a structured and applicable model for various forms of inclusive research. Despite the challenges and the criticism of this approach on the part of academic researchers, it appears that there is unanimous agreement that persons with disabilities have the right to make their voices heard, and to participate in the formative academic discussion that is directed towards changes that will have a positive impact on their quality of life. The studies that were reviewed in this article, teach us about broadening action being taken in the field of inclusive research in academic institutions in several countries. We are witnessing the first emergence of the inclusive research approach in several academic institutions in Israel, as well as the recent establishment of a nationwide forum for inclusive research. This forum includes academic persons, researchers from organizations of service providers, and persons with disabilities. All of whom have formulated an objective of expanding the use of inclusive research approaches in academic institutions, and in research in general.

Our experience has taught us that the involvement of persons with disabilities in academic research pertaining to their own lives, improves the quality of the final product. This enables researchers to reach out and explore existential issues – the importance of which even the most empathetic researchers have failed to grasp. Inclusive research is not a matter of "all or nothing". Consequently, the authors of this article have directed their efforts towards increasing the inclusion of persons with disabilities in this research approach, without recommending any specific level of participation.

First and foremost, it is appropriate to include an introduction to this research approach in the process of academic training in the field of research methods for students in a variety of fields such as: welfare, health, law, education, economics, architecture and design. Students studying research in various degree programs should also be encouraged to conduct research that includes persons with disabilities within the inclusive research group format, as both consultants and as full participants. Dialogue between academic persons and co-researchers should be

encouraged through forums, seminars, and conventions, alongside academic writing in this field. This dialogue will be directed towards creating additional models of this research approach, as well as developing creative answers that will enable us to overcome the shortcomings and challenges of the participatory research approach.

Collecting information and data from research subjects with intellectual disabilities is complex and challenging, and requires adaptation, accessibility, and creativity. Inclusive research should consequently include a variety of research methods together with quantitative and qualitative research, such as Photo-voice and the narrative approach, to create an echo of the inclusive research approach in the field of disabilities. Any convention dealing with various life issues of persons with disabilities, must also involve inclusive group research studies that are presented by the co-researchers, reflecting the idea of "Nothing about us without us." And "No longer researching about us without us."

In order to increase the possibility of implementing the recommendations for actions that promote quality of life, if the research is carried out with a participatory action research approach, it is important that three parties participate in it: academics, policy makers and people with disabilities This will increase the possibility that the recommendations will ultimately be translated into actions that promote quality of life. The involvement of policy makers and service providers in the process, and their understanding of the need inclusive research, will increase the chances of changing priorities in their professional agenda and prioritizing resource allocation. Also, it is appropriate that funds to support programs "for" and "of" people with disabilities, will encourage the need for support by letting the voices of people with disabilities to be heard. This can be done in the form of a needs survey, or through the presentation of data and results of participatory research. Actions in the spirit suggested above are a practical implementation of the "person-oriented service" approach. They have the power to create important bases and foundations for the involvement of people with disabilities in shaping the quality of their lives, and for their contribution as content experts to the creation of bodies of knowledge that promote quality of life.

Bibliography

Bennett, F., & Roberts, M. (2004). *From input to influence: Participatory approaches to research and inquiry into poverty*. The Joseph Rowntree Foundation.

Bigby, C., Frawley, P., & Ramcharn, P. (2014). Conceptualizing Inclusive Research with People with Intellectual Disability, *Journal of Applied Research in Intellectual Disabilities,* 27(1), 3-12. DOI: 10.1111/jar.12083

Budig, K., Diez, J., Conde, P., Sastre, M., Hernán, M., & Franco, M. (2018). Photovoice and empowerment: evaluating the transformative potential of a participatory action research project. *BMC public health*, *18*(1), 432. doi: 10.1186/s12889-018-5335-7

Beyth-Marom, R. (2013). *Research Methods in the Social Science: Guiding Principles and Research styles* (2nd ed.). The Open University of Israel.

Chappell, A. L. (2000). Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities*. *28*(1), 38-43. https://doi.org/10.1046/j.1468-3156.2000.00004.x

Danieli, A., & Woodhams, C. (2005). Emancipatory Research Methodology and Disability: A Critique. *International Journal of Social Research Methodology*, 8(4), 281-296. https://doi.org/10.1080/1364557042000232853

Hecht, Z. (2011). Quality reviewers as a way to my rehabilitation and recovery: a program to check the satisfaction and quality of life of rehabilitators with mental disabilities from their rehabilitation settings in the community. *Medicine Psychiatry*, 18.

Heller, T., Pederson, E.L., & Miller, A.B. (1996). Guidelines from the consumer: Improving consumer involvement in research and training for persons with mental retardation. *Mental retardation,* 34(3), 141-148.

Hozmi, B., Verner, S., Eliezer, S., Dafna, O., Travolski, S., Yinon, M., Cohen, R., Mauda, A., Peleg-Roytman, H., Klein, M., & Roytman, F. (2020). The perception of old age among people with and without learning disabilities, in pre-old age: A participatory action study. *Rehabilitation*, 30, 34-45.

Hozmi, B., & Roth, D. (2009). The Relationship Between Social Acceptance and One's Personal Characteristics. *Issues in Special Education & Inclusion*, 24(1), 45-50.

Keirnan, C. (1999). Participation in research by people with learning disability: Origins and issues. *British Journal of Learning Disabilities*, 27(2), 43-47. https://doi.org/10.1111/j.1468-3156.1999.tb00084.x

Koren, A., Roth, D. & Peretz, H. (2018, January 29-30). *Sense of autonomy, self-image and quality of life among adults with learning disabilities, adjustment and functioning difficulties compared to adults without disabilities: Participatory action research*. [Paper presentation]. Israeli Sociological Association Conference, Ben Gurion University of the Negev, Beer Sheva.

Krumer-Nevo, M., & Baral, A. (2006). Participatory Action Research: The Perspective of Social Service Users Regarding Social Services. *Social Security*, 72, 11-38.

Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research, 17* (3), 278-288. https://doi.org/10.1177/1468794117708123

Nind, M., & Vinha, H. (2012). *Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers*. National center for research methods. https://did.li/kFUNf

Oliver, M. (1992). Changing the social relations of research production?. *Disability & Society,* 7(2), 101-114. https://doi.org/10.1080/02674649266780141

Robotham, D., Wykes T., Rose D., Doughty L., Strange S., Neale, J., & Hotopf, M. (2016). Service user and career priorities in a Biomedical Research Centre for mental health, *Journal of Mental Health,* 25(3), 185–188. doi: 10.3109/09638237.2016.1167862

Roth, D., & Hozmi, B. (2011). Participatory Action Research (PAR) Group of Adults with Complex Learning Disabilities. In M. Hovav & B. Hozmi (Eds.) *From Inclusion towards Full Participation: Challenges and Growth over the Life Span*. (pp. 365-347), Beit Issie Shapiro; Rotem Publishing.

Roth, D., & Hozmi, B. (2014). The Quality of Life of People with Intellectual Developmental Disabilities: Implementation of a Participatory Action Research Approach. *Issues in Special Education & Inclusion*, 27(1), 22-53.

Roth, D., Peretz, H. & Barak, D. (2016). How Stigma affects us: The voice of self-advocates. In K. Scior & S. Werner (Eds.). *Intellectual Disability & Stigma: Stepping out from the Margins* (pp. 49-59). Palgrave Macmillan.

Schalock, R. L., & Keith, K. D. (1993) *Quality of Life Questionnaire Manual*. IDS Publishing Corporation.

Snow, S., D'Amico, M., Mongerson, E., Anthony, E., Rozenberg, M., Opolko, C., & Anandampillai, S. (2017). Ethnodramatherapy applied in a project focusing on relationships in the lives of adults with developmental disabilities, especially romance, intimacy and sexuality. *Drama Therapy Review*, *3*(2), 241–260. DOI: 10.1386/dtr.3.2.241_1

Turnbull, H.R. (ed.) (1977). *Consent handbook.* American Association on Mental Deficiency.

Walmsley, J. (2001). Normalization, Emancipatory Research and Inclusive Research in Learning Disability, *Disability & Society,* 16(2), 187-205. https://doi.org/10.1080/09687590120035807

Walmsley, J., & Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present, and Futures*. Jessica Kingsley.

Whitney-Thomas, J. (1997). Participatory action research as an approach to enhancing Quality of Life for individual with disabilities, in Schalock, R. L. (Ed.), *Quality of Life: Vol II, applications to persons with disabilities* (pp. 181-198)*.* American Association on Mental Retardation.