

Can You Hear My Voice?

Nothing about Us without Us - from Slogan to Reality for People with Intellectual Developmental Disabilities

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According to the United Nations Convention on the Rights of Persons with Disabilities (CRPD 2006), and the innovative agenda of various movements of people with disabilities around the world, the perception is gaining ground that people with disabilities, including intellectual developmental disabilities (IDD), can represent themselves and be partners and leaders in planning policy relating to all fields of their lives (Caldwell, Hauss & Stark 2009).

"Nothing about us without us" was one of the slogans of the African-American struggle for equal rights in the United States. In the wake of the change that was led by Dr. Martin Luther King, who redefined the perception of human rights, a number of groups facing social exclusion raised their heads and demanded a place in human society, and full participation in all areas of life, from planning the policy that affects their lives through to its everyday expression. People with disabilities were among these groups, and in the mid-1970s they embarked upon a struggle in which this statement was adopted as a central rallying cry. However, people with intellectual development disabilities were left without a voice. In this article, we will trace the reasons, and demonstrate how it is possible to enable this group to make its voice heard in an egalitarian, dignified, and educated manner.

Social advocacy is a strategy for action through which people with a common interest organize and act together in order to generate change and improve their quality of life (Sadan, 2009). Joint organization for action enables people to do what they cannot do as individuals, promoting the achievement of results and a solution to the social problems that they face, and also creating opportunities for social participation that is meaningful and respectful.

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Community participation can produce a national social leadership, acting on behalf of the public, and ensuring collective quality of life. This participation has an impact on two different levels: on the personal level, the participant develops a high sense of efficacy, and enjoys opportunities for self-fulfillment and filling roles of social value, control of new skills, power, and influence. At the community level, the group benefits from recognition of its joint strength, and the power of acting collectively, and develops social skills relating to this work, such as holding negotiations, and an understanding of the social context of the difficulties they have previously faced only in the personal sphere.

Effective advocacy and leadership actions take place as a result of a process of empowerment, representing a very important principle for personal development and the development of community leadership, in which people escape from a state of helplessness to one of a great sense of efficacy, control over their lives, and the ability to make decisions relating to their fate (Sadan, 1997).

The process of forming individuals into an organized community group involves a number of different stages and components, such as: choice of the appropriate strategy, the right timing, persistence, passion, the ability to learn from mistakes, courage, and the development of leadership capabilities. The group frequently provides individuals who are experiencing isolation and social marginalization with a sense of belonging, friendship, mutual concern, and a purpose to life (Brown, 2006). The leadership group of people with a common cause serves as a source of learning, support, and reciprocal assistance. Participation in a group enables each of the participants to understand the connection between his or her personal situation and the social situation, and as a result the change that takes place in people's awareness and ability, expands beyond the personal to include social and political awareness (Sadan, 2009).

Leadership groups of people with disabilities, demanding to move from the edges of society to center stage, and be partners in making decisions, have had to redefine the concept of "disability" and its implications. The social model of disability, which began to develop at the beginning of the 1980s, separates impairment from disability, and makes the distinction that while impairment is the objective medical situation, disability is, in fact, social exclusion (Shakespeare, 2016). In other words, disability is the social product of relations between people with impairments and the society that limits them. The UPIAS (Union of the Physically Impaired Against Segregation) defines "disability" in its 1975 document of principles as "restriction of activity caused by a social structure that does not take into account people with impairments, and thus excludes them from participation in important social activities." This model sees disability as being structural and public, related to culture and history, and demands that society take moral and practical responsibility for removal of the obstacles that produce repression and social exclusion, removal of physical and social obstacles (such as negative opinions), legislation prohibiting discrimination, and enabling

independent lives by providing accessibility and adaptations, with the aim of achieving a full and satisfying independent life.

As noted, the call for "nothing about us without us" is the most important statement of the social model, putting across a message that demands the full inclusion of people with disabilities in decisions relating to their lives, and sharpening the idea that people with disabilities should be allowed to decide, determine, and influence everything that relates to them - from decisions relating to their personal lives, through policy decisions, to the organization of research, and so on. Those who believe in this principle support the right of people with disabilities to make themselves heard, and to influence a correction of society, since they are the experts in their lives and have the relevant knowledge and experience to promote a change in their situation.

Development of leadership among people with intellectual developmental disabilities

The population of people with disabilities is comprised of sub-groups. One of these is people with IDD, who are seen as "voiceless" even among their peers who are coping with various other disabilities. The power mechanisms operating on them are seen not only as natural, but also moral, intended to protect the helpless from possible exploitation by society. In this way, people with IDD have found themselves sent to the back, while other sub-groups have begun to realize their rights in practice, and participate in processes of determining local and national policy.

Social self-advocacy is a significant tool in social processes for weak and excluded populations, but is missing from the repertoire of tools of those dealing with developing services for people with intellectual developmental disability, due to a perception that this disability, by its nature, is inconsistent with leadership capabilities. Later in this article we will present the tools for developing self-advocacy and leadership, and demonstrate their suitability for developing advocacy and leadership among people with IDD.

Over the past 30 years, one step at a time, programs for self-advocacy of people with IDD have been developing around the world, challenging the view that they are not able to handle leadership tasks.

The exclusion of people with IDD out of society's normative routines leads to a lack of opportunities for gaining experience with leadership roles, such as participation in school activities, participation in training experiences in the informal education systems, or participation in employment (Pederson, 1997). Despite the developments taking place in this field, as mentioned, there are still considerable gaps between the influence of people with IDD, and the achievements of leadership groups representing other excluded populations.

In a literature review looking at the way in which people with IDD are involved in the development of leadership, public activities, and community activities, large gaps were identified in the degree of influence of these leadership groups on decisions

relating to their lives (Beckwith, Friedman, & Conroy, 2016). The review identified various barriers, among them: literacy, language, concepts and communication barriers; lack of appropriate supports and provision of accessibility; shortage of opportunities to try leadership roles; people's limited, partial and inaccurate knowledge of the issues they want to influence; time and duration of the meetings; fear of the unknown; and lack of knowledge of the rules of behavior in different formal and informal situations.

As mentioned, in recent decades there has been greater participation of leaders with IDD in community activities and in policy-making processes. However, the roles given to them are frequently symbolic gestures, leading to presence without inclusion and true influence.

In our experience, the development of leadership capabilities among people with IDD will only occur if three main conditions are fulfilled:

First, participation in a training program to develop leadership, specially adapted for people with IDD - programs for developing leadership focus on the development of capabilities, and creating access to resources in order to reinforce the activists as strong public speakers with an understanding of the processes of power in society (Sadan, 2009). In such programs, the activists learn to make their voice heard and represent people, to act as social influencers, and to use the tools and skills that they acquire effectively, in order to generate change and achieve aims.

Second, participation and experience in community advocacy groups - good quality leadership development programs combine learning and action, enabling people to act and experience implementation of the knowledge, skills and other new resources acquired in the process (Sadan, 1997).

Third, making a skilled facilitator available to the group at all stages of their development as leaders (or to implement leadership roles) - organizing into an active leadership group aimed at change at the local level, development of a service, or influencing national policy, is usually based, in particular in weak and socially excluded groups, on an external facilitator who represents a source of knowledge, encourages experience, provides support and appropriate training, makes information available, and supports action in practice. Each facilitator has three main roles: a) developing leaders and the leadership skills of each member of the group and of the group as a whole; b) helping the group structure its work model in the sense of determining objectives, and deriving targets and tasks for realization; c) knowledge and expertise in providing cognitive accessibility and making different environmental contexts accessible.

Development of a national leadership group of people with intellectual developmental disabilities - description of the working model

Beit Issie Shapiro and Israel Elwyn have developed a network of local leadership groups for community self-advocacy. As part of the program, a national leadership group was established for influencing policy. The national group members are members of the local groups, and were chosen to represent their groups in order to influence policy-making at the national level. The slogan of the self-advocacy movement - "nothing about us without us" - was adopted in the leadership development program, shaping the essence of the program and its characteristics, as well as the training content and methods of action.

We chose to use the PIP (Partners in Policymaking) approach, developed in Minnesota in 1987, in order to bring people with IDD to the stage of being involved and active partners in public discussions on principles and policies impacting their lives and their role in the community (Rosenberg, Zuver, Kermon, Fernandez, & Margolis, 2017). As part of this approach, the participants get to know the structure of policy-making systems, the processes of policy-making and legislation, and learn in an accessible and adapted way about laws, regulations, and procedures at different stages of the legislative process, according to their relevance and impact on their lives. This provides them with the knowledge to formulate their wishes, positions, and demands in these matters.

The participants practice new skills in order to define, discuss, and present subjects and challenges that are relevant to the community of people with disabilities, efficiently and effectively. Afterwards they meet with public figures, legislators, and the general public, and are involved in determining policy.

In order to realize this, a number of guiding principles for developing leadership have been formulated:

- Adapting the time and duration of the meetings to the participants
- Ensuring full participation of all members of the group in discussions
- Cognitive accessibility - linguistic simplification of knowledge and information in different formats
- Communicating information in a direct, simple, and clear way
- Increasing opportunities for acquiring the knowledge, skills, and tools required for their development as influential leaders, by means of structured training, discussions, and exercises at regular meetings of the group
- Repeated experience in implementation, in order to reduce fear of the unknown, learning from success, and reinforcing different skills
- Increasing the effectiveness of the work of the facilitators as mentors, making information, knowledge and environments accessible so as to provide support to each of the individuals, and to the group as a whole, according to their needs and the situation for which accessibility is required

- Increasing the ability of the group members to manage themselves and to make decisions as a democratic and inclusive group.

Training the national leadership group

The program is based on two main content areas: one is the development of leadership - an ever-expanding body of knowledge; and the second is access and the removal of barriers for people with IDD - a field that is still insufficiently developed. The working model relates to the research findings of Caldwell (2010), who identified four main issues contributing to the development of leadership:

- **Repression and resistance** - personal and collective experiences of repression and resistance have led to the shaping of the social approach to disability, and contributed to the development of leadership. Anger, frustration, and resistance to oppression, against the background of disability experienced by people with IDD, have been found to be a formative component on which to develop a positive approach to disability as identity.
- **Environmental support and relations** - broader environmental forces play a significant role in the process of developing leadership, and these are: (1) family influence; (2) reciprocal relations, in particular with key support people; (3) community support and services.
- **Leadership skills** - creating opportunities for participation in different activities, such as volunteering in the community, training and workshops for developing leadership skills, and practical experience of the skills learned.
- **Leadership opportunities at the macro level (advanced)** - creating opportunities for breaking the glass ceiling preventing leaders with IDD from joining multi-disability or universal groups, or participating in management committees and decision-making committees and forums.

Stages of development of the leadership group for influencing policy

We have chosen to present the stages of development of the national leadership group through a description of the activities of the group to influence the law of legal competency and guardianship. The process of growth of the group as a community advocacy group is described in this article in sequential stages; in practice, the process is spiral, and different components appear at each stage, intertwined with each other. Special emphasis is given in the process to making information and tools available to the participants, as well as the central nature of knowledge based on the experience they have gained in their lives, and the learning process prior to conceptual structuration.

Stage 1 - Shaping identity and self-definition, both as a person with an intellectual disability and as a leader

The experience of negative labelling and bullying towards people with IDD is a frequent one, shared by many of them. Experiences of oppression related to disability play a considerable part in shaping people's development as leaders, and affect the

formation of their identity. Forming a positive approach to disability is essentially tied to the question of who we are. Self-definition is a starting point for the development of self-awareness, and an essential basis for the ability of people with disabilities in general, and IDD in particular, to refine and improve their personal and group capabilities. It requires that the participant recognize his or her strengths and difficulties. It is important to note that self-definition is an ongoing and changing process to which members of the group relate to all the time.

This issue came up compellingly when the leadership group drew up a position paper in which it had to present itself. The question of how we define who we are confronted the group members with the formal external definition of "people with IDD," and exposed the complexity of the implications of this definition on their lives. This definition is experienced as a labelling and oppressive mechanism. Statements such as "To say that I am intellectually disabled is like saying that I'm stupid..." were accompanied by tears and emotional outbursts to the point of leaving the room - these were some of the stormy and emotional reactions of the participants. Some of the participants reacted by withdrawing, and returning to the old terms of the medical model such as slight retardation (the word slight is very important), while others brought up the need to create their own, new definitions. In the end, after a number of emotionally charged meetings, the members of the group decided on the phrase "people with difficulties." It is important to note that they understood the implications that could arise from the use of an unfamiliar term in meetings with external entities, and chose to keep their own definition even though it might not be clear to those who are not part of the group.

Self-definition and autonomy are a practical expression of the perception of human rights that is the backbone of advocacy and leadership processes. Self-definition enables the group to present ideological alternatives to the labelling approach, and expand the boundaries of the mainstream, as was done by the movements of people with disabilities when they defined the social model, and demanded that society take responsibility for removing the barriers that create oppression and social exclusion (Shakespeare, 2016).

Studying the history of the social struggles of groups coping with disability, alongside an in-depth study of the perception of rights, enables advocates to create appropriate models for imitation and identification. Looking at these fields produces the hope that it is possible to achieve results in such struggles, and therefore it is worth paying the personal price that they may demand.

It is worth noting that the ideological infrastructure and historic course of movements of people with disabilities take on greater significance when one studies the processes that have led to the writing of the CRPD, the involvement of leaders with disabilities in writing it, and in the processes of signing and ratifying it in different countries.

Stage 2 - Studying the Legal Competency and Guardianship Law

In 2012, the State of Israel ratified the CRPD, and as a result was required to amend the Legal Competency and Guardianship Law accordingly.

After the facilitators brought the issue to the knowledge of the advocates from the local advocacy groups, the groups chose representatives to study the issue and deal with it on their behalf at the national level. These representatives, in time, became the national leadership group.

Studying issues of human rights, and the rights of people with disabilities, had already begun in the local groups and was reinforced in the process of studying the Legal Competency and Guardianship Law.

Study of the subject of guardianship was divided into three stages:

Learning about the right to make independent decisions - together with the right to receive, as necessary, adapted support in order to do so, as required by Article 12 of the Convention which deals with legal competency and guardianship.

Studying the Legal Competency and Guardianship Law - in its previous version, alongside the amended law and in an accessible manner.

Collecting the accumulated knowledge of the advocates themselves - this stage is the most central and essential part of the process, making a connection between the personal experiences brought up by the participants and the concepts studied. In this way, both the facilitators and the advocates became aware of the scope and depth of knowledge of the advocates, based on their life experience and expertise regarding their lives.

Meetings of the study group taught us that the advocates know very well what they want. They understand the significance of someone else making decisions instead of them, and have clear opinions on the subject (both positive and negative). In addition, the advocates showed considerable interest in the field of guardianship in general, and the new draft bill in particular. Since this is a complex issue, studying and discussing it required extended periods of concentration by the participants (three-hour meetings), as well as cognitive capabilities such as abstraction, generalization, and so on. One of the important results of this learning was that the advocates understood that their voice was of enormous importance in shaping the new law, and wanted to express their opinion and influence it (Barak et al., 2014).

Stage 3 - Shaping the position of the group on the subject, as representing people with intellectual developmental disabilities

This stage also included sub-stages:

Moving from personal experience and familiarity with the concepts to generalization - and defining the action required to correct or retain the existing

situation, according to the article under discussion. It is important to note that the advocates did not have a uniform opinion during the discussion, and needed powers of persuasion, the ability to hold an internal negotiation, and willingness to reach agreement and compromise. They also had to recognize the importance of a democratic decision even when some of them were in the minority, in order to reach a position reflecting the opinion of the entire group, and to trust the representatives to express this position in the relevant discussions.

Holding a national conference of all the groups - the conference focused on questions for discussion formulated by the national group, including: Are you interested in having a guardian, or decision support person, or do you want to decide for yourself about everything relating to your life? What are the subjects on which you want to decide for yourself?

At the conference, the advocates heard a lecture on the subject of guardianship and the proposed amendments to the legislation, and were divided into discussion groups in which members of the local groups from around the country discussed questions formulated by the national group, with representatives of the national group moderating the discussion groups. The participants in the discussion groups expressed different opinions: there were those who wanted to continue the accompaniment of a guardian in its current form, while others expressed a desire for the assistance of a decision support person on some issues, and a guardian on other matters, or to make independent decisions. Later in the day, all of the discussion groups presented their conclusions to the plenum, and left the product to the national group.

Summarizing the results of the groups - following the discussions, a position paper was written expressing the positions of all the advocates on the subject, and was turned into a document that the group representatives undertook to promote at the policy level.

Stage 4 - In depth familiarization with the processes of legislation in Israel, and the possibilities for citizens to influence it

After formulating the position paper, the group studied the structure of the Knesset (Israeli Parliament) and processes of legislation, with the focus on the ability of citizens to participate in the process and affect its outcome.

In order to make the environment accessible to the representatives, there was a guided and cognitively accessible tour of the Knesset, and meetings were held with Knesset Member (MK) Nissan Slomiansky, chair of the Constitution, Law and Justice Committee dealing with the subject, and other members of Knesset. In order to make the arena of the discussion a more familiar and safe environment, it was important for the members of the group to visit the committee room, and hear an explanation of how discussions take place in practice, and who are the relevant officeholders, such as the committee chair, the legal adviser, and so on.

Stage 5 - Participation by representatives of the national leadership group in Knesset discussions on the legislative process

With the start of discussions in the Knesset, three advocates were chosen to participate regularly in the discussions of the relevant committee, and express the views of the public they represent. Seated alongside them were facilitators, whose role was to make the complex legal and philosophical debate accessible in simple language, and sometimes to illustrate it by linking what had been said to life experiences familiar to the advocates, in the discussion taking place on life under guardianship.

When the advocates felt that their voice was not being heard in a sufficiently equal manner in the discussions themselves, they asked the facilitators to help them think of a solution. After the discussions they formulated the following solution themselves - a meeting of the entire group with the committee chair, in order for him to understand that the representatives were acting on behalf of a broader public, and not only on their own behalf. At the meeting with MK Slomiansky, each of the advocates told of his or her own personal experiences, and demonstrated the basis for the generalizations and demands they were making in the committee discussions. The direct connection formed between the advocates and the committee chair led to their voice being heard, and becoming central in the committee discussions. It is important to note that during the committee discussions, all of the participants were forced to adjust to the fact that the facilitators were whispering what was being said to the advocates in simple language, and sometimes advocates asked the speaker to repeat what had been said. The need for accessibility affected the entire discussion, also taking into consideration the presence of people with other disabilities, for which different means of making the discussions accessible were required (for example, people with impaired hearing).

Stage 6 - towards implementation of the law: Involvement in enacting the regulations

On completion of the legislative work, the focus of the discussions moved from the legislative authority to the implementing body, and the government ministries began writing pilot programs and drafts of procedures and regulations.

When an inter-ministerial team was established to examine the issue of guardianship, the committee coordinator contacted the program directors and asked to meet with the advocates, in light of her familiarity with their work in the Knesset. Ahead of the meeting, a preparatory meeting was held with the advocates on the processes of the government's work and the significance of the inter-ministerial team. After the group decided that it was willing to work with the team, the members invited the committee coordinator in order to hear further details on what had already happened in the

committee discussions. At the end of the discussion with her, permanent representatives were chosen to serve as observers in the inter-ministerial team, and to be part of all the committee discussions.

Following the good work carried out by the advocates in the inter-ministerial committee discussions, the committee members asked to meet with the entire group, and in this way the voice of people with IDD was taken into account as an equal and meaningful voice in guiding the actions of the committee, which are still in the formative stages. It is hard to assess the degree of influence on the final product at the time of writing this article.

Conclusion

Developing a new, independent identity as a person who is involved and capable, able to make his or her voice heard and influence the reality of life, and understanding the strength of the advocacy group, are the foundation on which the task of social change is based. The involvement and active participation in forums and committees that affect policy, such as Knesset committees and public councils, offer people with IDD the opportunity to make use of their knowledge and skills, and are the basis for the growth of leaders.

From a description of the work processes with the group, and with an understanding of its achievements, it can be seen that given appropriate accessibility, accompaniment, and training for people with disabilities, including people with IDD, they are willing and able to make their voice heard in a clear manner and thus be part of shaping policy. The description presented in this article reinforces the approach of the social model and the insight that the lack of efficacy that has been perceived until now as a fundamental characteristic of the impairment itself, is nothing more than a result of the exclusion and discrimination faced by people with IDD.

Expressing the voice of people with disabilities is important not only in order to affect their lives, but also because they are part of the diversity of voices in human society. As agents of change, we must take responsibility for the creation of suitable conditions for the development of leaders with disabilities so as to empower them to exercise their rights and make their voices heard.

‘Nothing about them without them’ must become the compass that guides us, both when we design services for individuals, and when we, as policy-makers, work on formulating policy that relates to the lives of people with IDD. As expressed well by one of the members of the advocacy group: "The person with special needs is the one who knows what he wants and what his rights are, and if he does not stand up for his rights he will continue to be miserable [...] We are disabled, but we also have something to say."

List of sources

- Barak D., Kaminsky S., Kraim Y., Sadovnik S., and Schwartz G. (2014). The participation of independent advocates in shaping policy - the case of the draft bill for changes in the guardianship law. In: *Guardianship and Self-Representation, Rehabilitation, the Journal of the Homesh Association, Issue 26*.
- Sadan A. (1997). *Empowerment and Community Planning*. Hakibbutz Hameuchad Press.
- Sadan A. (2009). *Community Work: Methods of Social Change*. Hakibbutz Hameuchad Press.
- Shakespeare T. (2016). The Social Model of Disability. S. Mor, N. Ziv, A. Kanter, A. Eichengrun, V. Mizrahi (eds.). *Disability Studies: A Reader*. (pp. 91 - 113). Jerusalem: Van Leer Press and Hakibbutz Hameuchad Press.
- Beckwith, R., Friedman, M. G., Conroy, J. W. (2016). Beyond Tokenism: People With Complex Needs in Leadership Roles: A Review of the Literature. In: *Inclusion, Sep 2016, Vol. 4, Issue 3*
- Brown M. J. (2006). *Building Powerful Community Organizations*. Long Haul Press.
- Caldwell J., Hauss S. Bethany Stark B. (2009). Participation of Individuals With Developmental Disabilities and Families on Advisory Boards and Committees. *Journal of Disability Policy Studies* 20: 101
- Caldwell J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, 54 , 11 pp. 1004–1014.
- Pederson E. (1997). Including self-advocates in community leadership. *Disability Solutions* 2, 1–9.
- Rosenberg A., Zuber D., Kermon M., Fernandez c., Margolis L. H. (2017). Reflections on the contributions of self-advocates to an interdisciplinary leadership development program for graduate students in health affairs. *Disability and Health Journal* , 1-5.
- UPIAS - *Union of the Physically Impaired Against Segregation and the Disability Alliance discuss Fundamental Principles of Disability* (1975). Retrieved September 2017, from <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf>