

# Leadership of people with intellectual disability promoting policy and legislation

## Introduction

Israel's national Self-advocacy group of people with ID has been active since 2015 in policy and legislation procedures. The groups' model of action is based on the principles of “partners in policymaking” (PIP) which requires 3 conditions:

1. To participate in leadership development training which is adapted to the needs of the group.
2. To participate and be involved in community advocacy groups.
3. To have a Facilitating/supporting mentor aside them along their leadership steps.

## Aim

**To evaluate Self - advocates:**

1. Understanding and perceptions of the goals of the national group.
2. Personal development and group gains.
3. The outcomes achieved on the policy legislative level.

**To evaluate Facilitators/supporters view of** changes and developments with respect to each of the Self - advocates on the personal and group status.

## Participants

**Self – advocates** with ID (N=10); **Facilitators/supporters** without ID (N=7) of national and/or local Self-advocacy groups

**Sociodemographic characteristics of Self-advocates**

Gender	Age	Family Status	Living Arrangement
Male = 40%	Mean = 39	Married = 30%	Independent / Community = 90%
Female = 60%	Range = 30-50	In Relationship = 10%	With Parent = 10%
		Single = 60%	

## Data collection

- 1) Semi structured interview with the **Self-advocates**.
- 2) Self-administered questionnaire (open) for **Facilitators/supporters**.
- 3) Additional data and information:
  - Review of group protocols transcripts from meetings (2015-2018).
  - Group meetings observations.
  - Review of documentations related to project.

## Main Results: Qualitative - Content/thematic analyses:

### 1. Perceived goals as viewed by the national Israeli Self-advocates Vs. Project initiators

Self-advocates	Project Initiators
Promoting relevant issues in their lives	Developing leadership skills and autonomy that will enable control
Voicing themselves	Developing learning abilities, discourse and debate
Raising awareness to their rights	Developing of social responsibility
Self-advocacy tools	Recognition of their role as representatives
Emotional support to each other	Development of a sense of personal capability

### 2. Growth and development – Personal & group changes: Self-advocates vs. Facilitators

	Self-advocates	Facilitators / supporters
<b>Personal Change</b>	Improvement in self-expression	Improvement in self-expression
	Improvement in self-confidence	Improvement in self-confidence
	Better emotional coping with social environment	Ability to accept criticism
	Increased independence	Awareness to rights Increased self-awareness
<b>Change in the groupe</b>	Identity definition: <i>who are we?</i>	Role in the group ('leader', 'peace maker', 'mediator', 'authority' etc.)
	Create opportunities to influence and promote social change.	Developing moderation skills
	To hear and be-heard	Accepting and respecting other points of view

### 3. Perceived leadership capabilities of Self-advocates

Self-advocates	Facilitators / supporters
<ul style="list-style-type: none"> <li>• Leadership skills</li> <li>• Self-expression</li> <li>• Desire to bring change</li> <li>• Communications skills</li> </ul>	<ul style="list-style-type: none"> <li>• Desire to lead &amp; promote meaningful social change</li> <li>• Increased leadership skills</li> <li>• Increased ability to express themselves, and their communication skills etc.</li> </ul>

## Discussion

Social advocacy is means of action that people with common goals organize and act to create a change in their Quality of life. People with ID can represent themselves and be partners as leaders in planning issues, which are related to their lives. The Israeli Self-advocates succeeded in achieving change on the **Personal** dimension by significant increase in personal confidence, self-perception, capability and leadership skills; on the **Social** dimension by forming a united and active representative group and on the **National** dimension by influencing legislation: Supported decision making became an alternative to guardianship.

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