Pattern of Engagement of People with Disabilities

and Their Family Members in the Policy Making Process in Albania

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Abstract

Post-communist Albanian legislation (1995-2010) provides the preliminary context for the creation of enabling social niches for the engagement of people with disabilities and the family members representing them in the policy-making processes both at the national and local levels. The goal of this study was to determine the pattern of engagement of people with disabilities and their family members in the policy making process at the national and local level and identify the barriers as perceived by them. Participants were 874 persons with disabilities and their family members. The results indicated a strong interest but a poor engagement pattern of people with disabilities and their family members in the policy making process and various structural and attitudinal barriers. Conscious work needs to be done by the government agencies as well as advocacy organizations to create enabling social niches for people with disabilities that encourage their participation in the policy making process as valuable stakeholders in shared governance.

Key words: disability, participation, policy-making

Self-determination is an important aspect of building democratic communities where all citizens have equal rights, which are not only expressed in the legislation that governs those communities, but are observed and respected in all aspects of life. Literature indicates that an expression of self-determination for people with disabilities is their engagement in the process of policy making at the national, local or service agency level (Battams & Johnson, 2009; Day, 2007; Linhorst, Eckert & Hamilton, 2005; O'Donell, 1993; Pearlmutter, 2002) be it through direct participation or representation by advocacy organizations (Mladenov, 2009; Potting, 2009). Policy making includes agenda setting, policy formulation, policy legitimating or enactment, policy implementation, and policy evaluation (Dye, 2008) and in this process, the people with disabilities and the people representing them, although stakeholders in the process, may take on the roles of bystanders, or policy initiators (Jansson, 2008) based on the ecology of the social environment where they live and the characteristics

as social niches of their communities. While entrapping social niches crate barriers for community participation and engagement in the policy-making process, the enabling social niches provide both resources and incentives (Chapin, 2007).

Post-communist Albanian legislation (1995-2010) provides the preliminary context for the creation of enabling social niches for the engagement of people with disabilities and the organizations representing them in the policy-making processes both at the national and local levels. Such laws as "The Status of Blind People" (Law nr. 8098 of 3/28/1996), "The Status of Labor Invalids" (Law Nr. 7889 of 12/14/1994), "The Law on Mental Health" (Law Nr. 8092 of 3/21/1996), "On Economic Assistance and Social Welfare" (Law Nr. 9935 of 3/10/2005) and "On the Organization and Functioning of the Local Government" (Law Nr. 8652 of 7/31/2000) as well as Decisions of the Council of Ministers (DCM) such as "The National Strategy for People with Disabilities" (DCM Nr. 8 of 01/07/2005), "On the Status of State Social Services" (DCM Nr. 542 of 7/27/2005) and " On the Approval of Standards of Social Welfare Services for People with Disabilities in Day and Residential Care Services"(DCM Nr. 822 of 12/06/2006) provide specific articles on the required participation of people with disabilities and their representing organizations at every stage of policy making.

However, "Albania 2009 Progress Report" prepared by the European Commission indicated that the role of coordinating mechanisms for the engagement of civil society in the policy making process has been ineffective. Additionally a study conducted in 2009 with 1041 people with disabilities and their family members showed that about one in three participants (35.3%) felt that they were not considered as partners in the policy making process at the national or local government level (Flagler, 2009).

The goal of this study was to determine the pattern of engagement of people with disabilities in the policy making process at the national and local level, identify the perceived barriers as well as effective ways for increased participation.

Methodology

The study was designed as a cross-sectional survey with people with disabilities and family members (guardians) of people with disabilities from six regions in Albania: Durres, Tirane, Shkoder, Elbasan, Korce, and Fier. The participants were recruited through non-governmental organizations that represent people with disabilities, service agencies, and local government agencies. A total of 874 people volunteered to complete the survey, 477 people with disabilities and 397 parents, family members or guardians of people with disabilities. The parents or family members were guardians of minors with disabilities or people with severe intellectual disabilities. Although a convenience sample, participants represented all categories of disabilities (18.3% intellectual disabilities; 18.1 % labor invalids; 18% wheelchair users; 12.9 %, severe

visual impairments mental health; 11, 2%, severe hearing and speech impairments; and 7.7%, chronic diseases 6.9%); both genders (with a slight overrepresentation of males, i.e., 57.1%); and both rural and urban areas (with an overrepresentation of the latter, 82.4%).

The instrument was a written questionnaire that consisted of 14 questions organized in three sections: demographic questions, closed–ended questions and open-ended questions. The closed-ended questions focused on two areas: (a) knowledge of main disability related social policy provisions, and (b) engagement in the disability-related policy making process at the local and central government. Most of the questions had several alternatives that could be checked. Some of the questions asked for ratings based on the Albanian school grade system: from four to ten. The third section asked the opinion of the participants on effective ways that would encourage a more active participation. The instrument was piloted with a group of people with disabilities whose recommendations for changes were reflected in the final version.

Data were entered and processed with SPSS as part of a larger study. For the purpose of this article, only descriptive statistics were calculated and will be reported in the results.

Results

The findings of the survey will be presented in three sections. First, the reader will be informed on the results of the mini-quiz on the level of knowledge on disability related provisions of Albanian social policies. Then, quantitative data will be presented on the participation of people with disabilities and their family members in the policy making process through (a) the information they receive on policy-making events and (b) participation in the policy-making events, followed by (c) the attitude for engagement and (d) the perceived barriers. In the end, the qualitative data will be summarized to represent the participants' opinions on increasing the opportunities for involvement.

Knowledge of Significant Disability Related Provisions

The participants were asked to rate as True or False ten statements that described disability- related provisions such as, "a person with disabilities may use public transportation without a ticket, " or " a child with disabilities can only attend special education schools." The statements covered ten areas of life. The data were processed in two ways. First, a grade was calculated for every respondent, with 100% correct receiving 10 and 40% receiving 4 (fail). The mean grade for all respondents (N=874) was 4.6, and the standard deviation was 2.1. The mean grade of 4.6 would be considered Fail in the grade system used to evaluate the accuracy of responses. Second, the percentage of correct responses was calculated for each statement. This revealed that

the range of the percentage of respondents who did not have the correct response per question was from 71.2% (that was the percentage of people who did not know that people with disabilities benefited from state subsidized mortgage) to 35.1% (that was the percentage of people who did not know that they could sue if their rights for education, employment and services were denied). On an average, only 52.8% of the responses were correct.

Participation in the Policy-Making Process

Information on policy-making events. About half of the participants (n=496, 56.7%) responded that they had received information on the work conducted to change public policies for people with disabilities at the national or local level. The following table summarizes the data for each field in a descending order:

Table 1

Fields of Information

Field	Percentage
Social assistance for people with disabilities	51.7%
Vocational training and employment for people with disabilities	31.0%
Education of people with disabilities	27.9%
Social services for people with disabilities	26.7%
Health services for people with disabilities	24.4%
Accessibility	11.9%

The main source of information were the national disability organizations (n=227, 26.1%) and media (n=223, 25.6%) followed or other organizations (n=170, 19.5%). A smaller number have received information from the local government, the municipalities or communes (n=135, 15.5%) and only 2.7% (n=24) checked the box for the central government.

Participation in the policy-making events/process. About a quarter of the respondents (n= 236, 27.1%) had participated in meetings where new policies relevant to people with disabilities were discussed. The participation in various fields has been summarized in the following table in a descending order:

Table 2

Fields of Participation

Field	Percentage
Social assistance for people with disabilities	23.7%

Social services for people with disabilities	10.5%
Health services for people with disabilities	10.4%
Education of people with disabilities	8.2%
Accessibility	8.2%
Vocational training and employment for people with disabilities	7.9%

More people participated in meetings initiated by the local government (n=81, 36.3%) than the central government (n=10, 4.5%). Only a small percentage (4%) checked the box of participating at a meeting initiated by the disability organizations. The primary sources of information about the meetings were different service and advocacy organizations (55.5%), followed by the local government agencies (29.2%).

The people who participated in meetings rated their participation level and their involvement after the meeting as low average. The mean for "I talked several times at the meeting" was 6.11/10 (standard deviation= 1.5) and the mean for "I was kept informed and received a copy of the final draft" as 5.9/10 (standard deviation=1.7). On the other hand, 45.3 % of the participants in the meetings felt that their opinion was not valued at all and 39.5 % felt that their opinion was somewhat valued, which leaves only 15.2% of the meeting participants satisfied with their treatment.

Attitude for engagement. Asked whether they would like to be actively engaged in the formulation of local and central disability related public policies an overwhelming majority of the participants of 86.1 % (n=722) responded positively. The reasons cited are summarized in descending order in Table Three.

Table 3

Reasons for Engagement in the Policy Making Process

Reason	Percentage
I feel appreciated.	64.7%
Engagement increases equal opportunities for all citizens.	53.6%
Engagement strengthens the collaboration of citizens and their representatives at all levels of governance.	44%
My involvement helps provide new information through the examples I provide.	33%
My involvement in the policy formulation increases the chances that I will support it after approval.	30.5%

Perceived barriers. The information on the perceived barriers in presented in Table Four according to four categories: (a) central government, (b) local government, (c) accessibility, and (d) attitudes.

As the data indicate, more view the central government as a barrier than the local government, accessibility is an acute issue for many participants, and among attitudes, the feeling that their abilities and opinions are not valued are powerful barriers for almost half of the respondents.

Table 4

Perceived Barriers

Barrier Category	Barrier	Percentage
Central government	I am not informed by the central government	58.1%
	I am not invited by the central government	54.9%
	There is no funding to facilitate our participation at the central government.	44.7%
Local government	I am not informed by the local government	40.2%
	I am not invited by the local government	43.6%
	There is no funding to facilitate our participation at the local government.	36%
Accessibility	I do not have a wheelchair to get out of the home.	15.9%
	There are no accessible buses or vans for my transportation	25.3%
	I live far way and do not have transportation.	15.9%
	Meetings are organized in places that have no accessibility (no ramps or elevators).	21.4%
	No sign language interpreters are provided.	7.1%
	The materials are not printed in Braille and I cannot read them.	10.1%
	I do not have an assistant to accompany me to the meetings.	16.6%

Attitudes	People with disabilities lack the needed training to participate in task forces.	22.2%
	We do not believe that our situation will change.	39.6%
	People with disabilities do not understand how important their participation is.	28.1%
	Many of us are not interested; we only wait for others to do for us.	22.5%
	They do not believe in our abilities.	50.8%
	Our opinions are not valued	41.5
	We are ignored.	47.8%

Recommended Improvements

The interest of the respondent in their engagement in shared governance was also expressed in the high number of open–ended responses to the question "What would make sure that people with disabilities are included in the social policy process for disability related public policies at the national and local level?" A total of 1044 comments were provided by the respondents. The responses were coded into main themes whose frequency was calculated to determine their level of significance. The themes and subthemes have been summarized in Table Five. The most recurrent subthemes are those related to the necessity of the involvement and representation of people with disabilities in all decision–making bodies of disability related public policies.

Table 5

Recommendations.

Themes	Sub-Themes	Percentage of Recommendations
Representation and involvement	Make sure that people with disabilities are part of every task force that covers issues of people with disabilities	30%
	No disability related decisions should be taken without the involvement of people with disabilities.	15.3%

	Improve existing legislation to encourage engagement of people with disabilities in the policy-making process.	15.3%
	People with disabilities need to be represented in the Parliament as well as in the municipal and communal councils.	11.7%
	Awareness needs to be promoted among people with disabilities, their advocacy organizations, and government agencies on the significance of the involvement of people with disabilities in the policy-making process.	5.4%
	Special funds need to be provided to ensure access to the process by the people with disabilities	3.6%
	People with disabilities need to be included in the monitoring process of the implementation of disability related policies.	2.4%
Information	Better organization by the disability advocacy organizations to draw the opinions of their members and provide information on new developments	8.0%
	More information needs to be provided on existing policies and the proposed changes.	8.04

Discussion and Implications for Practice

The results of this study indicate without any doubt that people with disabilities in Albania are not indifferent to the process of policy advocacy and they have a strong interest in being involved in it. Both the high percentage of respondents who indicated direct interest (86.1%) and the high number of open ended responses on recommendations that could improve this engagement (a total of 1044 statements) are a testimony to it. The interest may be due to a new political climate in the country created by several factors. Among the most important are the creation of a powerful

disability advocacy movement and the democratic changes in the political climate of Albanian society. Additional significant factors are the efforts for the approximation of Albanian legislation with the standards of developed European countries, the start of the process for the ratification of the Convention of the Rights of Persons with Disabilities, and the pressure on government agencies to treat the inclusion of people with disabilities as a human right issue.

The pattern of engagement observed through the data of this study indicates four tendencies. First, *there is some effort for the involvement of people with disabilities and their family representatives in the policy making process* by providing information and inviting them to meetings. People with disabilities and their representatives are involved more at the local government level than at the national level. This is expressed in several instances. More people had received information from the local government than the central government (respectively 15.5% and 2.7%). More people participated in meetings initiated by the local government (n=81, 36.3%) than the central government (n=10, 4.5%). And finally, more people indicated that they had never invited at a meeting at the central government (54.9%) than at a local government meeting (43.6%). Second, *there is some effort to consider people with disabilities* as partners, by giving them a chance to be heard: 15.2% of the meeting participants were satisfied with their treatment and they felt their opinion was respected. However, much more needs to be done in this regard, since 47.8 % of participants believe that people with disabilities are ignored, and 41.5 % believe that their opinions are not valued and 50.8% of the participants feel that other people do not believe in their capabilities. Third, *the most notable barriers for participation are structural*: they are related to (a) the attitude and lack of effort on the part of the local and central government and (b) general accessibility issues. However, attention needs to be paid to the barriers within: 39.6% state that people with disabilities do not participate since they do not believe that they can have an impact, 28.1% are of the opinion that there are people with disabilities that do not understand the significance of their participation, 22.5% of respondents think that many people with disabilities wait for the others to bring about change for them and 22.5% suppose that people with disabilities do not have the training to participate in task force groups. Fourth, *people with disabilities and their family members express more interest in policies related to social assistance and invalidity pension* (which is a cash benefit) than the other fields. This is noticed in several instances. First, more respondents reported information on and participation in meetings on related policies. Then, the results of the quiz that covered several areas, but did not include social assistance/pension questions, indicated poor knowledge of the main benefits for people with disabilities provided by the Albanian legislation (the mean grade for all respondents was 4.6, e., Fail, and the standard deviation was 2.1). Elwan (1999) explains that the vicious cycle of chronic poverty and disability is to blame for this focus on cash benefits rather than the rights to services, education, vocational

training and employment. Fifth, *the disability advocacy organizations play an important role by providing information but they are not seen as leaders* of the process of the engagement of people with disabilities in shared governance. While a high number of respondents reported receiving information from the disability organizations, only a small percentage of respondents who participated in a meeting (4%) checked the box of participating at a meeting initiated by the disability organizations.

The results of the study reveal that although there is significant interest for direct involvement by people with disabilities and family caregivers, their pattern of participation in the policy making process in Albania is rather inconsistent and more exclusionary than inclusionary. Conscious work needs to be done by the government agencies at the central, regional and local level as well as advocacy organizations to create enabling social niches for people with disabilities that encourage their participation in the policy making process as valuable stakeholders in community building.

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