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# ENCOURAGING THE POLITICAL PARTICIPATION OF PERSONS WITH DISABILITIES THROUGH CREATION OF SOCIAL CAPITAL

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## ABSTRACT

Persons with disabilities and their families do still belong to the most marginalized part of the Albanian society. They are poor and feel isolated in a society which still has to destroy several architectural and social barriers. Studies on the opinion of the public with disabilities highlight a lot of aspects of the social behavior and attitudes that make persons with disabilities invisible. The purpose of this paper is to analyze the social capital and social inclusion as two factors that influence the participation of persons with disabilities in the political and social life. The methodology used to explore this multiple relationship between the social capital, social inclusion, self-determination and political participation of persons with disabilities, is deep investigation in literature. Empirical research demonstrate that social capital and social inclusion have been considered recently as two meaningful concepts for the personal and social well-being of persons with disabilities. Their relationship has not been explored sufficiently, although it has been accepted in the academic literature. From our findings it results that extending social relationships of persons with disabilities and connecting them to important social structures increase their chances to make choices and decisions that influence their quality of life. Social capital gives them the support to have a more self-determined life. Women with disabilities in Albania are less involved in policy-making process regarding disabilities, but they have more information about the laws and political initiatives of the government because they spend more time inside the house and follow media channels. Study results show a lower participation in policy-making of the persons with disabilities that live in rural areas . Persons with disabilities and the family members who represent them and are actors in the process, may have a static and expecting position, or may take the leading role and take initiatives for a certain policy based on the ecology of the social environment where they live and based on the characteristics of their community's social status. Research shows also the low level of Albanian citizens' involvement as volunteers or members of organizations, which also shows their indifference of involvement in general, and also of the civil society in particular. Individuals and organizations should become aware of the importance of being heard when policies that affect your life are made, but should also educate and enforce the capacities towards working with participation.

**General Terms:** Persons with disabilities

**Keywords:** Persons with Disabilities, Social Capital, Political Participation, Albania



## 1. INTRODUCTION

People with disabilities and their families do still belong to the most marginalized part of the Albanian society. They are poor and feel isolated in a society which still has to destroy several architectural and social barriers. ILO (2002), argues that persons with disabilities have been excluded from the National Strategies of Alleviating Poverty. There are poor quality social, educational and health services. The evaluation system is oriented towards the medical model of disability and despite some improvement in the last five years, the legal framework does not protect equally all persons with disabilities. Studies on the opinion of the public with disabilities highlight a lot of aspects of the social behavior and attitudes that make persons with disabilities invisible. The purpose of this paper is to analyze the social capital and social inclusion as two factors that influence the participation of persons with disabilities in the political and social life.

## 2. METHODOLOGY

The methodology used to explore this multiple relationship between the social capital, social inclusion, self-determination and political participation of persons with disabilities, is deep investigation in literature. The empirical experience of the author as a person with disability and her professional experience in the disability field, once as a civil society activist and actually as a policy maker, bring a relatively full picture of the issue seen from different points of view as well.

## 3. THE IMPORTANCE OF SOCIAL CAPITAL

Empirical research demonstrates that social capital and social inclusion have been considered recently as two meaningful concepts for the personal and social well-being of persons with disabilities. Their relationship has not been explored sufficiently, although it has been accepted in the academic literature.

Despite being similar for their vision of a healthy society, they use different perspectives to motivate and challenge each other. The starting study of the Social Action research project (Health Development Agency, 1999) used six concepts as key components of the social capital: participation in the area community (Do they feel like part of the area), mutuality, feeling confident and safe (at home and outside), social relations, citizen power, community perception, Social capital refers to a number of social relations and relationships that expand somebody's possibilities to choose, to increase the chances of having a better quality life. This can be illustrated through the social services dedicated to persons with disabilities. If carefully interpreted, social capital gives a helpful perspective in providing services that can promote inclusion of this category. Traditional services are characterized by vertical relationships, in which the staff has power over the users of the service, while social capitalists and advocates of the services users watch horizontal relationships (Riddell et al., 1999). Service providers must find a balance between trying to create new social capital or inclusion projects, and saving existing services. Customers with disabilities might not have the ability or experience to be active in a process where decisions are taken, consequently their abilities should be developed before participating. Clients that get services in daily or residential centers, feel unrepresented and are not asked of informed about important events (ADRF2008a, pp.37;ADRF2006a, pp.31). The results of the studies match the previous research, according to whom there's a degree of dissatisfaction about the way civil employees treat persons with disabilities or clients of the services centers (World Bank 2001).

Self-determination is a clear indicator of the quality of the inclusion of these people in decision-making and community life. It's an important aspect for persons with disabilities, that helps orientation and creation of democratic communities, where all citizens have equal rights, which aren't just expressed in the legal framework that leads these communities, but are also monitored and respected in every aspect of life (Higgins 1997). Citizens' ability to live with dignity by having self-determination is put in question in case they don't have sufficient social capital because these two things are connected. This paper defines social capital as: the personal and social power of persons with disabilities and their organizations to promote full inclusion in the community, to reach social support networks, and to increase their quality of life (Walker, et al., in press). Social capital is not only discussed in disability studies, but also plays a key role in these individuals lives who are in danger of being neglected and having less self-determination chances (Trainor, 2008; Field et al., 1998). Self-determination is also connected to the social capital on an individual level which in exchange can make collective capital grow and can improve the perception of persons with disabilities as an effective part of society. The way persons with disabilities are seen by others might be more important for their capabilities to contribute in the social capital and for their inclusion than their own disabilities. There are two cases in these people's lives in which social capital acts clearly. These are formal and informal support networks. Social networks are not given as a product of social capital, but must be constructed through



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systematic trying and building suitable strategies of investment to achieve possible benefits from this kind of capital. Information through informal networks can improve the chances to find a job and this is one of the most widespread and one of the most effective ways of employing persons with disabilities in Albania today. Mutuality is another feature of social capital that makes mutual relationships create a culture where learning and contributing between community members and between different communities flourish. Other values of social capital are having friends and supporters, developing relations with others that might help, and also helping others (Gardner, Ward, & Weintraub, 2010). Supportive friendships can handle stress and diseases. Having the support of family and friends is vital to people who have just begun creating their social capital. The more support they get from their friends and community, the more are the resources and mechanisms in action that make things happen in their lives. Social capital might bring a more emotionally satisfactory lifestyle, might create a variety of choices and bring higher autonomy in decision-making, essential elements of realizing self-determination in somebody's life.

Extending social relationships of persons with disabilities and connecting them to important social structures increase their chances to make choices and decisions that influence their quality of life. Social capital gives them the support to have a more self-determined life. Individuals that own a considerable quantity of social capital, have as result resources, mechanisms, capacity and natural support from the community, which are necessary to achieve a greater inclusion, a better quality of life and to have the ability to advocate for others who might not have the ability to do this for themselves. Disability advocacy groups offer the example of organizations that have social capital.

Researches show that social capital is given from parents to children, just like other forms of capital (Bourdieu, 1986). Trainor (2008) notices that participation of the family influences the student's ability to gain social capital through education. Putnam (2000) discovered that social capital and economical equality often go together. Trainor (2008) shows that students with disabilities often have a low social capital which comes from their racial status, their social-economical past, as much as from their status of disabled. Being a student does not guarantee them social capital if the chances of relationship and networking are low. Relating to adults that have resources, helps youngsters with disabilities to socialize with mutual norms and take significant social roles which prepares them for taking leading roles in their community areas and wider society (Jarrett, et al., 2005, p. 42). On an individual level, the staff that works to create social capital, should be able to notice other factors such as clients' access to experienced social inclusion advocates, empowering clients to decide independently, to keep a house, a job, and make social life. Incapable career advisers might exclude persons with disabilities from the natural environment involuntarily, by trying to offer them more intensive individual sessions. Potts confirms that persons with disabilities usually face extraordinary obstacles when looking for a job, such as lack of social capital or development of professional training programs (Potts, 2005). (Lin, 1990) says that social capital is exchanged for another form of capital such as social capital (in the form of information that comes from informal networks) or economical capital (a job placement). We should understand how to support persons with disabilities to work in an open market instead of frequenting supporting workshops, how to live in their houses instead of living in community houses, how to participate in the community life instead of separating them in special neighborhoods for persons with disabilities. Although it might be difficult to identify the unique contributions that a person with disabilities has give, without giving them the chance to express themselves, it might be never discovered and they may never have the chance to be appreciated for their real work.

The social capital theory should be of interest and should be developed further for health care and community safety programs and for various initiatives that improve directly or indirectly persons' with disabilities lives. There's a growing consensus that the social capital includes a number of relationships and social structures which are based on mutual norms and trust. Social capital exists on individual level, as well as on social/community level and other forms. Putnam (2000) refers to the social capital as the glue that keeps the community together. Inside these groups, the bonding type of social capital (between group members) is found in their identity or common history. This shows that for some reason persons with disabilities and their advocates have to deal with social capital. There's also the bridging type of social capital (connections to other organizations that have nothing to do with disability) as well as the linking type of social capital (connections to policy-making state agencies, service providers or corporations). Including persons with disabilities into programs where they can learn to help developing community inclusion and social capital, is a way to build such relationships. Individuals gain social capital through this process and also benefit from the wider community resources. Inclusion affects positively on so many plans, First of all, it empowers clients and actors, increases solidarity and influences the creation of social networks, which are the base of social capital. Secondly, it influences the creation of stronger and more stable communities, by stimulating the culture of cooperation between policy-makers and excluded groups (Mizrahi, Humphreys, Torres 2009; Geddes 1998). Social inclusion means persons with disabilities have full and equal access to activities, roles and social relationships along with people who have no disability. Furthermore, persons with disabilities need to create relations with these social structures to secure supportive services. They need to be taught how to actively look for services from agencies. Despite the commitment of the staff that works with persons with disabilities in the community, their personal attitude really influences the life of persons with disabilities who



use social services. There's a kind of risk that the staff that offers the service might determine the services users lives according to their preferences or personal choices. Inclusion is a process of learning, transformation and self-development for the participants. Research made to evaluate participation and control of persons with disabilities in service centers, showed that despite the staff efforts, the participation of the services users in the decision-making process was low and that the authority of the staff was indisputable (Barnes 1993; Scarbrough 2000 cited in Potting 2009). On the same line, Beresford & Campbell (2006) in a survey about the services users inclusion in planning, implementation and monitoring the whole work of development institutions, found out that the field organizations were engaged. This is important because persons' with disabilities organizations, which have been a major force in policy changes in the developed countries, stand on the top of initiatives to eliminate exclusion and alleviate poverty. Practically, there is inclusion in cases when individuals with a disability leave their cause's advocacy groups to join other groups which interest them the most as citizens in order to improve the community. In a research of FSHDPAK (2008b, pp.13), participants with disabilities and their families evaluated with a failing grade their participation in the decision-making on local or central level (4.88). The same series of research (Flagler 2009, pp.172-173), showed that participants with disabilities perceived themselves as marginalized and that they felt like no serious working had been done to protect their rights in the framework of human rights. One over three respondents (35,3%) thought they were not considered as partners in decision-making in the daily residential centers, as well as in their municipalities, civic centers, ministries, consequently their vote was an average vote of 5.26. According to Caritas (2008, pp.45), in a research that intended to evaluate the status of persons with disabilities needs, 89.3% of the participants felt excluded from the policy making process and only 7.3% of them believed they were represented in a dignified way by the disability representation organizations. When social positions are unfavorable, barriers can be created and can obstacle the community's participation in decision-making; while when they're open, they produce resources and motivation (Chapin 2007). It's the right and the duty of every citizen to take part in drafting, implementing and evaluating the policies of his country, not only as a customer and beneficial, but also as a citizen. The above perception of inclusion makes the difference between "consumerism" and "democratic" theories. In order to guarantee a successful participation, citizens should be informed in advance about political issues being discussed and participation mechanisms.

Harknett (2006), cites the barriers that obstruct their participation in the development process as: "Persons with disabilities are the poorest and the less educated in society, marginalized because of poverty and discrimination. This exclusion and physical barriers make them invisible. Law education level, lack of working in the community and lose of faith are the three elements that affect the degree of their participation". The need for training and information, lack of access and the paternalistic attitude of professionals, are some of the obstacles to persons' with disabilities participation. Their disadvantageous education level, is another addition to the list of obstacles (Carmichael 2002, fq.21; Barnes 2007b). Barriers in attitude and structures, have an international character, because they are the same for all persons with disabilities in the world (Ballard 2005).

Not every individual in a society has the chances, information, education, the will and resources to take part and give contribution to policy making spheres. Research shows an unequal representation of different interests groups, which is affected by the material level of the interests group, membership level, connections and cognitive skills (De Bievre2007, cited in Finke (2007) Drenovci (2011). Women with disabilities in Albania are less involved in policy-making process regarding disabilities, but they have more information about the laws and political initiatives of the government because they spend more time inside the house and follow media channels. They're more invisible and isolated, and they assign the leading role to the male members of the family. Study results show a lower participation in policy-making of the persons with disabilities that live in rural areas Ibid (2011). Although urban areas have more buildings to use for events and activities, small rural areas have more networks and informal chances to make every day life practices easier for persons with disabilities. People with intellectual disabilities or mental health problems, and their families, are the ones who feel the most excluded and the most insignificant.

#### 4. CONCLUSION

Persons with disabilities and the family members who represent them and are actors in the process, may have a static and expecting position, or may take the leading role and take initiative for a certain policy (Jansson 2008), based on the ecology of the social environment where they live and based on the characteristics of their community's social status. Self-determination and involving citizens in the policy-making process on national or local level can be realized through their direct participation or through their representation by advocacy civil society organizations. Literature highlights that is more difficult to include in policy-making marginalized groups, and persons with disabilities belong to this category. Individuals and organizations should become aware of the importance of being heard when policies that affect your life are made, but should also educate and enforce the capacities towards working with participation. Recently, talks about 'citizens' active participation' are being held in Albania too. Albanian citizens are



slightly involved directly in the policy-making processes that might affect their lives. Research shows also the low level of Albanian citizens' involvement as volunteers or members of organizations, which also shows their indifference of involvement in general, and also of the civil society in particular (IDM&CIVICUS 2010). Political elites perceive this participation trend as an evidence of the deepening of the gap between citizens and the State, and public opinion studies prove the increasing trend of losing citizens' trust, which deepens the gap further. The connections between organizations and persons with disabilities are weak, and they confirm they feel unrepresented and not part of these organizations (Caritas 2008). As for the commitment of interests groups, involvement of the actors in policy drafting requires time investment, resources and growing capacities (Kelley 2006; Conell 1997). Despite the fact that there are no formal mechanisms for policy-making inclusion, the civil society in Albania has taken part in consulting for several important laws and has been able to include the section's interests in them. The legal framework, while stimulating the inclusion of interest groups and civil society's organizations in the policy-making, does not obstruct, but the lack of formal tools (European Commission 2009) makes the participation remain only a desire of policy-makers, who often do not understand its importance and consequently neglect it. The creation of the social position for the involvement of persons with disabilities and their organizations in the central and local policy-making processes, is based on the context created by the Albanian legal framework of the post-communist period (FSHDK2008c; FSHDK2009b). There are also advocacy organizations that collaborate with interest groups to promote the inclusion of disability in the policy agenda and to reach positive results regarding the legal framework of the disability field.

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