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UN Support to Social Inclusion in Albania Programme

THE SOCIAL EXCLUSION PROFILE OF PERSONS WITH DISABILITIES

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ABSTRACT

This study focuses on the social exclusion profile of persons with disabilities in Albania. Drawing on 37 individual and group interviews with persons with disabilities, disability-rights activists, service providers, and government officials in Tirana, Lushnja, and Korça, the study sheds light on numerous barriers that facilitate social exclusion. The study shows that the lack of physical access and adaptability, poor access to information and knowledge, poor access to rehabilitation services, unaffordable treatment costs, and discriminatory attitudes and practices undermine the potential of persons with disabilities. The disability community views social exclusion as an outcome of institutional exclusion. Institutions perpetuate social exclusion through the lack of responsiveness, corruption, clientelistic accountability, preferential treatment, and poor law enforcement. Several exclusionary practices were reported, such as avoidance, rejection, bullying, and harassment. These findings suggest that promoting the social inclusion of persons with disabilities in Albania requires multilevel interventions that should focus on creating a barrier-free environment and instilling a culture of accessibility; reshaping social protection; enforcing disability rights laws; fighting discrimination against persons with disabilities; organizing informative sessions at the grassroots level; improving interinstitutional collaboration; establishing collaborative ties with professionals working in the disability field; and implementing interventions that cut across different sectors.

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INTRODUCTION

Living with a disability in Albania means having the courage and strength to overcome endless barriers. In the words of persons with disabilities, it means feeling ashamed to get out of the house; being unable to express thoughts and opinions; lacking opportunities to interact with others; being physically excluded; facing exorbitant health expenses; being unable to cross streets; lacking access to rehabilitation services; experiencing bullying in kindergartens and schools; being unable to voice concerns; lacking access to public transportation; being mocked and discriminated in public spaces. Living with disability means struggling on the brink.

Around 10 percent of the world's population (or around 650 million people) live with a disability (Disabled World, n.d., para. 1). Eighty percent of persons with disabilities live in developing countries (Disabled World, n.d., para. 2). Disability and poverty go hand in hand. Lacking access to public goods and services, such as health care, nutrition, employment, and education, the poor are at risk of acquiring a disability. At the same time, living with a disability increases the likelihood of experiencing job loss, living in material hardship, and having poor access to public goods and services. Twenty percent of the world's poorest people have a disability (Disabled World, n.d., para. 2).

Disability rates are higher among individuals with lower levels of education. Ninety percent of children with disabilities in developing countries do not attend school (Disabled World, n.d., para. 6). Persons with disabilities are more likely to be victims of violence or rape and less likely to obtain police intervention and legal protection. Violence against children with disabilities occurs at greater rates than for children without disabilities (Disabled World, n.d., para. 8). Women and girls with disabilities are more likely to experience gender-based violence than women and girls without disabilities (UN Enable, n.d., para. 7). Persons with disabilities, compared to persons without disabilities, experience higher unemployment rate and lower earnings. Even when persons with disabilities participate in the labor market, they are relegated to low-level jobs. Unemployment rates are the highest among individuals with mental health problems. Employers believe that persons with disabilities can't complete the required tasks. In addition, they hesitate spending on facilities that would support the physical inclusion of persons with disabilities (Disabled World, n.d., para. 12).

Contrary to popular belief, persons with disabilities constitute a very diverse group. Their health conditions vary considerably: they "can be visible or invisible; temporary or long term; static, episodic, or degenerating; painful or inconsequential" (WHO, 2011, p. 8). Persons with disabilities are not equally disadvantaged. The World Report on Disability (2011) highlights that "people who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments" (p. 8). A study conducted by the Office of Policy Development and Research (2005) shows that "Individuals who appear most severely disabled may experience more discrimination" (p. 52).

Disability interacts with individual characteristics, such as gender, age, income, assets, and ethnicity. For instance, women with disabilities, compared to men with disabilities, are more likely to live in poverty. Furthermore, they are more likely to experience family violence, abuse, and exploitation (WWDA, n.d., para. 4). Evidence shows that women with disabilities are denied access to reproductive healthcare and health providers do not know how to accommodate them (WHO, 2009).

Depending on how disability is defined and measured, the percentage of persons with disabilities in Albania ranges from 6.2 to 22.¹ A recent study shows that persons with disabilities in poor Albanian households, compared to persons with disabilities in wealthy households, are more likely to have more than one disability (UNDP, 2015). Furthermore, they have worse access to water and sanitation. Persons with disabilities are 5 times less likely to be in the labor market than persons who do not have any disabilities. Households with at least one member with disabilities spend, on average, 5.2 percent of their income on medical care; meanwhile, this percentage for households that do not have any member with disabilities is 2.9 (UNDP, 2015). A study conducted by the National Center for the Rehabilitation of the Blind (2014) in the 12 regions of Albania (n=1,031) shows that only 5 percent of blind persons work. The majority reported facing discrimination – by colleagues and employers – in the workplace.

The government of Albania has ratified the Convention on the Rights of Persons with Disabilities in 2012 (Albanian Disability Rights Foundation, 2014a). The social inclusion of persons with disabilities is supported by the legislation, strategies, and programs, such as the Law 7995 on Employment Promotion (1995), the Law 10039 on Legal Aid (2008), the Law 10221 on Protection from Discrimination (2010), the National Strategy for Employment and Skills (2014-2020), and the Strategy for Persons with Disabilities (n.d.).² However, there is a significant gap between legal improvements and local realities (Albanian Disability Rights Foundation, 2014b).

This study focuses on the social exclusion profile of persons with disabilities.³ There are many competing definitions of social exclusion. For instance, social exclusion is defined as “a process through which individuals or groups are wholly or partially excluded from fully participating in all aspects of life of the society, in which they live, on the grounds of their social identities, such as age, gender, race, ethnicity, culture or language, and/or physical, economic, social disadvantages” (DESA, 2009, p. 3). In this study, social exclusion refers to “the systematic denial of entitlements to resources and services, and the denial of the right to participate on equal terms in social relationships in economic, social, cultural or political arenas” (GSDRC, n.d., para. 1). The emphasis is on social relationships within and between families, neighborhoods, communities, and state actors.

The goal of social inclusion is to ensure equal opportunities for all individuals, so they can realize their full potential. Inclusive societies are characterized by equal access to public

information; equity in the distribution of resources; effective leadership; strong civil society; universal access to public infrastructure and facilities; respect for human rights, freedoms, and the rule of law; and people’s participation in social, economic and political life (DESA, 2009, pp. 9-10).

Social exclusion does not affect the lives of the poor and marginalized alone. It affects everyone. Social exclusion is associated with “increase in insecurity, high crime rates, brain drain, emigration, social conflict, expansion of slums, instability, urban violence, divided societies, and violent conflict” (DESA, 2009, p. 37). A society that celebrates diversity is more creative and innovative. The efforts of promoting the social inclusion of persons with disabilities should be viewed as “a long-term investment for sustainable development” (DESA, 2009, p. 38).

The analysis presented in this report is based on the person-in-environment framework. This framework emphasizes that the individual is the agent of change and the environment shapes his or her experiences (Lesser & Pope, 2011). The person and the environment are in a dynamic, interactive relationship; they influence, shape, and change one another. The environment can refer to natural and built environment, social networks, political and economic systems, services, and policies. Environmental factors can act either as facilitators or barriers. For instance, a built environment that is not accessible to persons with disabilities, e.g. lacks wheelchair ramps or elevators, facilitates social exclusion. The person-in-environment framework suggests that key to promoting social inclusion is removing environmental barriers and unlocking the potential of persons with disabilities. One of the outcomes of a disempowering environment is self-discrimination: persons with disabilities do not believe that they can make a change and have low self-esteem. The obstacles that they face inhibit their personal and professional growth, and talent.

The purpose of the analysis is to identify the mechanisms that facilitate social exclusion and shed light on the attitudes and behavior of actors – family members, neighbors, government officials, service providers – who interact with persons with disabilities. The evidence will be used to inform interventions seeking to promote social inclusion and enhance the well-being of persons with disabilities in Albania. Social exclusion will be examined in relation to the following services: employment and vocational training, education, health, social housing, justice, and social protection.

The rest of the report is divided into 3 sections. Section 2 focuses on the methodology. Section 3 introduces findings and section 4 provides conclusions and recommendations.

¹ See UNDP (2015) for a discussion of these estimates.

² See Fondacioni Shqiptar për të Drejtat e Personave me Aftësi të Kufizuara (2014) for a description of legal changes in the disability field.

³ Referring to the World Health Organization (2013), disability “is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (p. 5).

METHODOLOGY

The study draws on in-depth interviews that were conducted with persons with disabilities, disability-rights activists, service providers, and government officials in Tirana, Lushnja, and Korça. Overall, 37 in-depth interviews were conducted, out of which 4 were group interviews (number of study participants = 45; 71 percent were women). Interviews lasted from 30 minutes to 2 hours.

Interviews with persons with disabilities focused on their experiences of social exclusion; interactions with state officials, service providers, and professionals; and ways of addressing social exclusion. Questions with representatives of civil society organizations focused on the work of organizations in the field of disability; type of interventions implemented in Albanian communities; ways of addressing social exclusion; interventions that have worked (or not); and suggestions for addressing social exclusion. Questions with service providers and officials focused on their work in the field of disability; ways of addressing social exclusion; and suggestions for addressing social exclusion. Questions with disability-rights activists focused on their efforts of advocating for policy change and promoting the rights of persons with disabilities.

Interviews were conducted with representatives of the following organizations: People's Advocate; the Commissioner for Protection from Discrimination; Albanian Disability Rights Foundation; Tirana Legal Aid Society; the Association of the Blind (Tirana); Down Syndrome Albania; the Association of Persons with Paraplegia and Tetraplegia (Tirana); Albanian Association of Deaf People (Tirana); The Institute of Students Who Can't See (Tirana); the Association of Persons with Disabilities (Lushnja); the Center of Children with Autism (Lushnja); the Association of Persons with Paraplegia and Tetraplegia (Lushnja); the Association of the Blind (Lushnja); Protecting the Rights of Persons with Disabilities Association (Korça); the Association of the Blind (Korça); and the Center of Physical Rehabilitation (Korça).

Two types of purposive sampling strategies were used: range sampling and comparable case sampling. The purpose of range sampling was to capture the variation within the population, specifically capture the experiences of women, men, young adults, older adults, people living in urban and rural communities. This strategy served the purpose of capturing variations within the disability community. In addition, comparisons were drawn between different groups within the disability community, e.g. children with autism vs. children with Down syndrome.

Range sampling was also used to identify service providers in the areas of employment and vocational training, education, health, social housing and urban integration, justice, and social protection.

The selection of persons with disabilities was based on individual characteristics, such as type of disability (sensory, physical, intellectual, cognitive, or a combination of different types of disability), degree of severity (mild, moderate, severe), age, gender, location, level of education, employment status, civil status, ethnicity, recipient (or not) of personal assistance,

and disability cause.

The recruitment of persons with disabilities in Lushnja was assisted by a social administrator who was very familiar with the community. The researcher, together with the social administrator, visited the neighborhoods of Lushnja to identify study participants. Another approach was followed in Korça. To recruit study participants, the researcher was assisted by the Center for Physical Rehabilitation. The center offers numerous services for persons with disabilities from rural and urban Korça. Some of the members of the center were approached and asked to participate in the study. Disability-rights activists and state officials were contacted on the phone or via e-mail and were asked to participate in the study. Interviews were audiotaped and transcribed verbatim. Thematic analysis was used to analyze the data (Bernard, 2011). Four theme-identification techniques were used during the data analysis process: repetition, similarities and differences, metaphors and analogies, and indigenous typologies (Ryan & Bernard, 2003).

FINDINGS

The following themes emerged from the qualitative analysis: changing realities; lack of physical access and adaptability; poor access to information and knowledge; poor access to rehabilitation services; exorbitant and unpredictable treatment costs; family vulnerabilities; neighborhood effects; ‘tilting at windmills’; poor law enforcement; lack of political voice; preferential treatment; and collective action and change.

Changing realities

Study participants⁴ drew comparisons between communism and post-communism. They emphasized that during communism there was greater presence of persons with disabilities on the labor market and therefore they had more opportunities to interact with others. While attending schools, they relied on peer support. Furthermore, the disability community was characterized by greater solidarity. However, the communist system did very little to elevate the social and economic status of persons with disabilities. A disability activist mentioned that “the worst legacy of the [communist] system is the medical model. The individual was treated as someone needing only medicine, a crutch, or a wheelchair.” The presence of persons with disabilities on the labor market might have provided opportunities for friendship and support; however, persons with disabilities were treated as different and often pitied.

After the fall of communism, explained one of the interviewees, persons with disabilities “disappeared” from the labor market. Compared to the past, they are more isolated. In addition, group solidarity has weakened. However, some positive changes were reported as well. Disability-rights activist argued that gradually people’s attitudes have changed: they are more open and therefore more likely to accept persons with disabilities. The parents of children with disabilities are more vocal and they demand service improvement. In addition, policymakers are more knowledgeable about the rights of persons with disabilities. However, such changes have mostly been observed in urban, developed areas.

Lack of physical access and adaptability

Study participants reported lacking access to assistive devices, such as reading, writing, hearing, and mobility aids, that would allow them to perform daily tasks and promote independence. They also reported that schools lack specialized equipments, for instance speech-generating devices, magnifiers, and walkers that could facilitate students’ learning. Schools do not have wide ramps, and accessible toilets and sanitation facilities. They lack sign language interpreters and supportive teachers. Hospitals and health centers have narrow doorways and inaccessible medical equipments. In the absence of ramps, platform lifts, and other facilities, roads, pathways, schools, health centers, hospitals, state departments, shops, and recreational areas are not accessible.

⁴ The names of study participants have been changed to preserve confidentiality.

Interviewees shared numerous stories of isolation. Dritan suffered from a severe mental illness. He left the house after 15 years of isolation. The social worker shared that Dritan was scared to take public transportation. Ana lived on the 6th floor of a multi-story building. The building did not have an elevator and she rarely left the apartment. The ramp close to Rina’s apartment was so steep that she needed two people to assist her. A school social worker shared her recent experience in a newly reconstructed school in Korça:

I am very sensitive to this issue [physical access]. I went to the school and asked the constructors: “Where is the ramp?” Well, the ramp was there but the restroom was not accessible. The door was too narrow; making it impossible for a student in a wheelchair to go to the restroom. Can you stay in a school where the restroom is not accessible?

Improving access and adaptability is not just about building wheelchair ramps. A physical therapist in Korça explained that even when ramps exist, physical access for persons with disabilities has not improved:

The majority of these people are imprisoned in their homes. The road infrastructure [in Korça] has improved considerably. They [roads] have ramps as well. But how many persons with disabilities walk on these streets? Have you seen any person in a wheelchair today? Probably not. They don’t use the road because they don’t feel safe.

Then, he continued his discussion about the poor road safety across the country.

Zana, a young member of the Blind community, characterized roads and pathways as dangerous: “How do I know if the green light is on or off? Would it be so difficult to install audible street signals?” Another member of the Blind community asked: “How am I supposed to walk on a street where some people sell shoes, some cigarettes, and some bananas?” She worked in an institution specialized for persons with disabilities. Even her institution was not barrier-free and adapted to fulfill the needs of persons with disabilities.

Poor access to information and knowledge

Access to information and knowledge is critical for persons with disabilities. Referring to UNESCO (2005), information and knowledge “offers individuals the ability to compensate for physical and functional limitations, thus allowing them to enhance their social and economic integration in communities by enlarging the scope of activities available to them” (para. 7). Interviewees shared that they have limited access to information. Disability-rights activists reported instances of persons with disabilities, especially in rural areas, who did not have

information on disability entitlements. Therefore, they did not apply and benefit from such entitlements. Irena, a member of the disability community, raised the following concern:

I spent 1,000 euros for an MRI [Magnetic Resonance Imaging] in a private clinic. I am sure that there is state support for persons with disabilities. The government has signed many international conventions. Who knows them? Who knows the convention of children's rights? Nobody. Do villagers know anything about it? Has anyone explained it to them?

A disability-rights activist shared her experience with the parents of children with Down syndrome:

If he [the parent] is informed and prepared, he will defend the rights of his child. A year ago, we organized a meeting with parents and what we realized is that they had no idea that by law their child can go to school. They used to take the child to school, face the rejection of school principals and teachers and give up.

Often, persons with disabilities lacked knowledge of medical procedures and medications. Deaf women, explained one of the leaders of the Deaf community, can't communicate their concerns to health providers. Gradually, their problems aggravate and they end up in emergency. Their healthcare concerns could have been prevented if they had information and a sign language interpreter would facilitate their access to healthcare. The lack of information, coupled with the insensitive behavior of healthcare specialists, leads to the exclusion of Deaf women from healthcare services.

Kindergartens and schools do not provide quality information that would allow children with disabilities to excel in education. In the absence of supportive equipments, facilities, and supportive teachers, educational settings become places of physical rather than social integration. As a result, children with disabilities lag behind other children and do not realize their full potential.

Similar to kindergartens and schools, libraries are not accessible. They do not have specialized staff, such as sign language interpreters. Braille books, e-books, easy-to-read books, tactile picture books or other materials are not available. Entrances, restrooms, stairs, elevators are not accessible.

The lack of access to information and knowledge undermines people's ability to defend their rights. A representative of the legal aid community argued that the low level of legal literacy among the poor is one of the main barriers to social inclusion. She asked: "How can they [the poor] protect their interests if they don't know their rights?" Disability-rights activists argued that the poor are less likely to have access to information and knowledge. A social worker and a member of the disability community shared his experience of working with the disability community:

I believe that the lack of access to information is one of the main things that we need to be concerned about. Poverty and backwardness go hand in hand. I don't know how a person in Thumana can obtain information. His child is stigmatized day after day. The teacher tells him that his child will not be enrolled in kindergarten. What can he do? How should he react?

Poor access to rehabilitation services

Cash assistance does not promote the independence of persons with disability. Indeed, it does quite the opposite: it locks them into a continuous state of deprivation and dependency. The complex needs of persons with disabilities cannot be addressed through cash assistance alone. Interviewees emphasized that access to services, such as vocational rehabilitation and physical therapy, are more important than cash assistance. Below are some examples of comments:

The program of cash assistance helps you get a slice of bread. It doesn't do anything about social inclusion.

I need physical therapy. I need aquatic therapy. Where can I find a swimming pool in Lushnja?

What can I do with 80,000 [old] lekë per month? I need to take my child to a logo therapist, a physical therapist ... Keep the money for yourself and offer me services!

Health and mental health services are fundamental for children with autism ... They need physical therapy, ergotherapy, logotherapy. Otherwise, they will never be independent.

Their right to treatment is denied. When I say treatment, I do not mean just medication. Key to the treatment of persons with disabilities is rehabilitation.

Nothing has been planned for the rehabilitation of persons with disabilities. For instance, they get reimbursement of medical expenses. What about physical rehabilitation? Nothing has been planned for this. They should be reimbursed for this [rehabilitation] as well. In my opinion, each city should have a rehabilitation center.

Rehabilitation services have a significant impact on the well-being of persons with disabilities. This is how a few members of the Center for Physical Rehabilitation in the municipality of Korça described the impact of physical therapy:

Going to the gym makes me feel alive ... We don't just need to use the bicycle; we need friendship. We need to be with people who share pretty much the same problems. We want to feel equal. There is one thing to be a member of the gym and there is another thing to interact with others. Here, you observe how people's lives have improved and you get hopeful.

Rehabilitation is a must! Here, we support one another by saying: Do you remember how I used to be? Worse than you can imagine! I could not walk; I could not straighten up my body. They used to comfort me by saying: You will get better. We are getting better; you will get better as well. This is as important as exercising. Socialization is critical.

We are talking about long-term rehabilitation. At least, they will not be a burden to their family anymore. At the same time, they will not be a burden to the state because they can do some kind of work.

Some of the reported benefits of rehabilitation include: improved physical and mental health, decreased levels of stress, and increased opportunities for socialization. The head of the Center for Physical Rehabilitation shared the case of a woman from Voskop:

She was paralyzed; she never left her room in four years. Her family members insisted that she comes to the center; family support is critical. Gradually, she changed from a woman who could not walk to a woman who could take the bus to Korça and do household chores.

The problems faced by persons with disabilities differ and their treatment should differ as well. There are significant differences within and between disability groups. Some emphasized the importance of improving communication and others improving road infrastructure. The elderly for instance emphasized the importance of recreational activities; meanwhile, young adults the importance of vocational rehabilitation. Parents highlighted the importance of taking their children to school and having access to supportive teachers.

All interviewees, despite their gender, age, ethnicity, or other characteristics were dissatisfied with their access to rehabilitation services. They believed that their chances of living independently were greatly diminished because of their lack of access to services. Those who had better access were dissatisfied as well. They mentioned that they could afford only short-term treatments.

Exorbitant and unpredictable treatment costs

Persons with disabilities and their families have to afford the high cost of surgeries, check-ups, therapies, and other treatments. To afford treatment costs, they mobilized outside resources, relied on their relatives – in Albania and abroad – or took loans. The poor could not afford treatment costs and their health conditions, gradually, worsen. It was typical for persons with disabilities to have other chronic health conditions. Often, they used traditional medicine for healing.

Study participants counted the number of times they have visited hospitals and health centers. Wheelchair users for instance reported post-surgery injuries and health complications. Others had multiple disabilities. Family members did not only find treatment costs unaffordable, but also felt exploited by doctors and healthcare professionals. In other words, they felt that service providers took advantage of their vulnerability. Mezan's wife had a spinal cord surgery. Overwhelmed by his experience in several public and private hospitals, Mezan said: "If you end up in hospitals' doors, they [doctors and health professionals] will rip you off."

All interviewees, despite their age, gender, income, ethnicity or other characteristics shared that they couldn't afford treatment costs. When I asked Liri if she does physical therapy, she said:

A session with the physical therapist costs 10 thousand lekë. I receive 250,000 [old] lekë per month. I pay 100,000 to the caregiver, 150,000 for personal care, and 50,000 for the car that takes me to the hospital in Tirana. My husband paid 3,500 euros for the prosthesis. Where can I find the money for the physical therapist? His fee is 10,000 lekë per hour, multiplied by 30 days equals 300,000 lekë per month.

I met Ana, the mother of a 14-year old girl with cerebral palsy, in one of the neighborhoods of Lushnja. Ana could not afford taking her daughter to a physical therapist, even though she was aware of the importance of physical therapy. When I met Ana, her daughter was crying because of a toothache. Ana explained that dental care for children with disabilities was not available in Lushnja; hence, she had to take her daughter to Tirana. Ana said: "Going to Tirana will cost me 100,000 lekë; almost half my husband's salary." While waiting for the salary, Ana was in distress and her daughter in pain.

'Tilting at windmills'

'Tilting at windmills' captures the experiences of persons with disabilities with state officials, service provider, and professionals. Study participants characterized institutions as bureaucratic, inefficient, and corrupt. Specifically, they argued that state officials, service providers and professionals are characterized by low levels of responsiveness and accountability. Furthermore, they lack ethics and professional expertise on persons with disabilities. Several exclusionary practices were reported, such as avoidance, rejection, bullying, and harassment.

Low levels of responsiveness. Interviewees characterized institutions as bureaucratic and inefficient. They shared that applications for cash assistance take a long time; officials do not provide explanations for application procedures or status; reimbursements for medical treatments and public transportation are delayed and sometimes not delivered at all. Many shared their experiences:

It took four months for KEMP^a to be approved. We were waiting for four months.

Sometimes I am in [the cash assistance program] and sometimes out. How does it come? My disability does not change.

Why do I have to go to Tirana to check the status of my application?

Disability-rights activists shared similar concerns:

How can you ask a person with intellectual disabilities to visit the regional office of Fier to check the status of his application? He does not have any idea where Fier is.

A woman with disabilities has been receiving cash assistance for 24 years. They [state officials] decided that she will not get cash assistance any more. We complained to the municipality and they responded by saying “We have no idea why. Go to Tirana.” We took her file to Tirana. The people in Tirana don’t have any idea about this woman. They have never met her. Do they know where she lives?

No one cares about this group. Do they [state officials] receive their salary on time? Why should cash assistance for this group be delayed 3 or 4 months?

You visit office after office and barriers follow one another. Then, you realize that there is a chain of problems that you can’t break. We are tilting at windmills.

Clientelistic accountability.⁵ Study participants explained that those individuals who have personal or political affiliations with officials and service providers are more likely to obtain services on time. The same for individuals who offer bribes. Below are some examples of explanations:

He doesn’t have food to eat; how can you delay his cash assistance? ... They lie. They do all this to get bribes. Those who have paid have received it.

I get very angry when I see non-poor families that receive cash assistance and poor families that do not receive cash assistance. The poorest families are totally excluded.



^a KEMP refers to the Medical-Labor Examination Commission (Komisioni i Ekspertimit Mjeko-Punëtor); however, here the respondent is referring to the disability entitlement.

⁵ Clientelistic accountability captures the idea that non-accountable officials have more incentives to meet private than public interests (Keefer, Narayan, & Vishwanath, 2006).



I work with persons with disabilities who go to bed hungry and do not get cash assistance; they are happy with a sack of flour. Others live in a world of plenty and receive cash assistance.

There was a general perception that the only way to get cash assistance is by offering bribes to healthcare providers. Specifically, healthcare providers demand bribes to issue official documents that will allow persons with disabilities to obtain cash assistance, and they approve benefits to individuals who are physically and mentally healthy. Respondents reported that bribes were demanded by the members of KMCAP.⁶ Bribes were offered to teachers and doctors as well. Sonila did not hesitate sharing her experience with a kindergarten teacher:

I have faced many difficulties with my brother. I could not enroll him in kindergarten. I offered a bribe to the teacher even though it was a public kindergarten. I was forced to do so; I thought that an incentive would help but still ... How will she treat my brother if she doesn’t want to accept him in the first place?

Ana also shared her experience with an official in a municipality. After sending tens of requests for information on children at risk of trafficking, the service provider responded by saying: “What do I earn [if I provide you the information]?” Another interviewee mentioned that he had “to give a coffee” to the doctor to obtain medical treatment in the hospital. “They do all this [they do not respond] because they want money from you,” he said. Then, he added: “This is all it is.”

When I asked Luljeta, a young disabled woman, if she had applied for social housing in the municipality, she responded by saying: “I have applied but I don’t think I will get housing.” “Why?” I asked. “You should have connections in the municipality; otherwise, they [local government officials] won’t care,” she responded.

The politically-motivated appointment of teachers is another example of clientelistic accountability. While sharing my enthusiasm about a supportive teacher appointed in one of the schools, the school social worker said: “The teacher was not a good fit for the position; she was not qualified. However, they kept her.” “Why did they keep her?” I asked. She responded by saying: “What I know is that they [the Department of Education] did not make such a decision because they were concerned about children’s well-being but rather they wanted to keep the teacher in school.” Then, she concluded by saying: “This is the reality. Our institutions are still not aware of why supportive teachers are important.”

Lack of ethics and professional expertise. Interviewees highlighted that officials, service providers, and professionals lack ethics and expertise to serve persons with disabilities. They do not have information about the complexities that characterize the lives of persons with

⁶ KMCAP refers to the Medical Commission of Work Capability (Komisioni Mjekësor i Caktimit të Aftësisë për Punë).

disabilities, and they don't know how to communicate with them. Disability-rights activists shared their thoughts:

They [officials] lack the willingness to understand and serve persons with disabilities.

Service providers in state departments lack professionalism; do not respond to the requests of civil society organizations and do not collaborate. They do not want to grow professionally and invest in their career.

They [officials] get discouraged very easily. They say: I can't do it. It is impossible.

Ticket collectors make fun of them [persons with disabilities].

It is very common for persons with disabilities to hear offensive terms; they are called 'handicapped', 'stupid', 'insane', 'crippled', 'retarded', and 'slow'. A young blind woman shared her experience:

I had a very interesting experience. It is quite bitter in fact; I don't know why I am laughing. I wanted to get a document, a registration card. They asked me a few questions that they usually ask. The lady [who was filling out the form] turned to me and said: *profesioni yt eshte invalid* [lit: your profession is invalid]. I told her: wait a second, don't write it like that. Why? She asked ... I had an interesting fight; I can't believe that they think in such a way.

Another common discriminatory attitude and practice is interacting with the caretaker, as Luljeta explained:

They [state officials] offend you. You go for your own problem and they respond to the person you are with, not you ... You can imagine the outcome.

Other problems that plague the health sector include: doctors and health professionals do not have information about the screening tests that pregnant women should take (e.g. screening tests for Down syndrome); disabilities are not identified on time; and parents are not referred to resources. Often, parents learn about the disability of their child months after the child is born.

Often, doctors and health professionals provide advice based on myths, not scientific evidence. For instance, they tell mothers that it is ok for children with Down syndrome to have high temperature 24/7. Or, doctors believe that the mother should learn that the child has Down syndrome after she stops breastfeeding the child. Often, rather than referring parents to resources, doctors advise them to take the child to an orphanage.

Myths are present in other settings as well. Some of the commonly held beliefs are: persons with disabilities deserve to be pitied, always need help, and cannot live a productive life. Myths are reinforced by the media, explained a blind teacher:

The news that you always hear is that even though he is blind, he has achieved a lot! Another person might have a heart problem. So what? You should give a positive and inspiring example, but please do not exaggerate it. The media either forgets about you or exaggerates the situation.

For her, positive discrimination is more hurtful than negative discrimination. "I want to be treated equally. I don't want to be the exception," said a college student. Then, she added: "I want to show that I can do the work. I don't want to have a job where I just get the salary because I am blind."

Exclusionary practices. The most frequent exclusionary practices include avoidance, rejection, bullying, and harassment.

Avoidance and rejection. Often, children are not accepted in kindergartens and schools. Interviewees provided three explanations for why this is the case: school principals, teachers and other education professionals hold discriminatory attitudes; they don't know how to work with children with disabilities; and schools lack facilities and equipments that could assist children with disabilities. The mother of a child with autism shared her experience:

My child is not accepted in school. My daughter is 9 years old and is still in kindergarten. I went to school and they told me that they are not capable to work with her. They can keep her but they don't know how to work with her. They are right; they haven't worked with children with special needs before. This is why supportive teachers are needed. The law has been approved but is not implemented yet ... It is a completely different experience to take my child to the supportive teacher. She will take care of my child because this will be her task, not because she will sorry for her. I will hold her [the teacher] accountable.

There were also instances of teachers who tried to avoid children with disabilities. Specifically, they encouraged parents to complain to the school principal about their children sharing the class with a child with disability. "Why would they want to do that?" I asked the sister of a boy with Down syndrome. "They do so because they don't want to get out of their comfort zone," she responded. Then, she added: "They don't want to be bothered." However, there was a difference on the ability of families to interact with state departments and demand service improvement. Those who had information about disability programs and were knowledgeable about state laws were more likely to be proactive. Zana, who was working with children with autism, shared her experience:

I enrolled my brother [with Down syndrome] in the first grade; the school principal was very supportive. Then, he was replaced with another person who told me that I had to remove my brother from the school. I went to the Education Department where I received a document indicating that children with disabilities must be enrolled in school.

Besides having access to information, Zana had personal connections in the Education Department.

Often, schools perpetuate inequality and exclusion. The school is a place where children receive consistent messages, which remind them that they are too different from others. A school social worker explained: "Even when teachers enroll them [children with disabilities] in the kindergarten, they don't do much. They [children with disabilities] are simply numbers." Children's presence in schools does not result in physical or social inclusion.

Avoidance and rejection were common among health professionals as well. A community social worker discussed access to dental care in Tirana:

One of the people we are helping has a severe mental illness. She wanted to go to the dentist. There was no way that state hospitals would treat her. She went to a hospital and received a shameful response: We don't work with stupid people!

Similar stories were shared in Korça and Lushnja. There were instances of parents in Korça who took their children to Greece for a tooth filling or root canal.

Bullying and harassment. Interviewees shared that children with disabilities in kindergartens and schools experience bullying and harassment from their peers. Liza, a school social worker, shared an example from her work:

There is a teenager with disability in one of my schools. His classmates avoid him. They slap him, spit on him, hit him. He shares his experiences with me. He tells me that his classmates harass him, bother him. He feels pretty bad and there are instances when he doesn't want to go to school ... It is even worse for those children who can't speak. They can't express their feelings in words.

Similar stories were shared by the parents of children with disabilities. There were cases of children dropping out of school because of threats, physical assault, and name-calling. A school social worker raised the concern that school principals and teachers tolerate physical abuse:

Schools should focus on bullying prevention, especially for children with disabilities. I studied bullying years ago. My boss [i.e. the school principal] would make fun of me and say: What kind of topic is this? What are these American terms? They did not understand that bullying is overly present in Albanian schools. You see children bullying one another everywhere: in schools, neighborhoods, streets. It is socially accepted.

Furthermore, teachers use derogatory terms – calling students 'retards', 'idiots', and 'morons'. Often, teachers do not know how to welcome a child with disability in class, let alone protect him or her. Social and psychological services in schools are inadequate. Given the heavy workload, explained one of the school social workers, psychologists and social workers focus on cases of emergency rather than prevention. "I visit schools once a week. I can't follow-up cases systematically," said a school social worker.

Family vulnerabilities

The disability has a profound effect on the family as a whole. The health and mental health of the person with disability affects parents, siblings, and close relatives. But family characteristics also affect children's health and well-being. "The family can lift you up but also bring you down," said a disability specialist and also a member of the disability community.

The disability consumes resources, energy, and savings. Family members have to adapt to the changing circumstances. If both parents are employed, one of them, usually the mother, gives up the job and takes on caregiving responsibilities. But there are exceptions. Sonila, the sister of a boy with Down syndrome, shared the experience of her family. Her mother worked in Greece and the other family members were in Albania. The father took the son to school and helped him in the classroom. "We have divided the work in the family. We don't keep him [the brother] isolated. We take him to school, parks, coffee shops, wherever we go," said Sonila.

Mothers shared that they were not prepared to deal with the disability. They didn't know what to expect; how to read their children's reactions; how to support their children; or how to communicate with them. Many blamed themselves for the circumstances. However, there were differences among mothers based on their level of education. Mothers with higher levels of education were more knowledgeable about the disability. They mentioned reading online sources and books, and participating in conferences or workshops. Furthermore, they relied on networks and accessed resources outside of their community. Despite these differences, both groups were dissatisfied with their access to services and the extent to which their efforts have improved the well-being of their children.

Mothers reported worry, guilt, anxiety, anger, resentment and uncertainty. They felt guilty for their children; worried about the future; could not manage the difficult behavior of their children; could not find professional services; disagreed with their partners; and were concerned about the increased financial burden. They also faced the resentment of other

children for the attention given the child with disability. Often, mothers were blamed for the disability of their child. They had to educate their neighbors, friends, relatives, and teachers about the disability. Below are some examples of parents' experiences:

Children with autism surprise you. Today, you think my daughter does not have any problems; why should these things happen to me. Tomorrow, she tells you that she really needs you. What I mean is that every day is different. It is exhausting.

They need a teacher who can support them, look after them. We are killing the other children as well. I have heard a mother from Kosova, in a village of Kosova, telling her oldest daughter not to play with her friends. The oldest daughter was 8 years old and the youngest one was 6 years old. The oldest daughter had to take care of the youngest daughter. What's her fault? We are losing the other children as well.

In Albania, it is not clear yet that children with autism are not sick. Here, and everywhere across the country, they are called disabled and they are excluded. But they are not disabled. I will fight for this until everyone understands it!

There were instances when parents' beliefs and attitudes facilitated social exclusion. One of the ways through which parents undermined the potential of their children was by isolating them. Different forms of isolation were reported, for instance parents taking the child out only during the night (so others could not realize that the child had a disability) or refusing to accept that their child needs special treatment. Also, there were instances of parents who did not apply for cash assistance, even though they were aware that such a program existed. "I thought that if I apply for cash assistance everyone in the city will know that my child has a problem. I would feel ashamed," shared one of the mothers. Then, she added: "Now, I regret it but it is too late. At least, I get it now."

Parents believed that by isolating their children, they would protect them from discrimination. For a disability activist and a parent of a child with autism, isolation is a response to institutional exclusion:

You have no idea how hard I have worked to raise the awareness of parents. Parents are aware but they are discriminated. They are afraid to accept it not because they don't know that their child has a problem. We accept our children but we are afraid to accept them. We are afraid because our children will not be accepted in kindergartens and schools.

This is a message of thousands of mothers: We accept our children. The institutions do not accept them. They [teachers] realize that something is not going right and they do not accept them. They want to live a comfortable life and not deal with difficulties. They say your daughter has a problem and does not fit in here. She really has a problem and she needs a teacher to support her. I have been around the world and I have seen how well they [children with autism] are treated. They need love! Give them love and you will see the difference that it will make!

Others argued that isolation is a mechanism that they have developed to avoid the burden of dealing with people who judge, stigmatize, and reject persons with disabilities. They shared instances of disparaging remarks and looks.

The disability isolates the family as a whole, especially mothers who have the responsibility of taking care of the child. Young mothers felt that others – friends, relatives, and neighbors – could not understand them. They spent most of the time working and taking care of the child; they were overwhelmed. Mothers who participated in associations that worked for the disability cause were more likely to reach out, voice their concerns, and understand the needs of their children.

Gender, disability, and social exclusion interact with one another. A representative of the Association of the Blind mentioned that blind women are more likely to be isolated than men. In addition, they are less likely to marry than men. There were instances of Blind women maltreated by family members. The head of the Association of the Blind shared the example of a blind woman who had the property inherited from her parents stolen by her brothers. There were also instances of persons with disabilities who "don't know how much money [cash assistance] they receive."

Neighborhood effects

Neighborhoods are not friendly to persons with disabilities. Often, they do not offer any kind of facility, such as public parks and libraries. In the absence of public goods, as Arta explained, children's entertainment is very expensive.

Parents want to take their children out but where? If you go to a children's park, you have to pay two thousand lekë. But the child wants to drink something as well, so you end up paying five thousand lekë. Where can parents find the money? Everything – children's parks, recreational areas – are privately owned.

The lack of physical access and adaptability is compounded by other problems, such as the negative attitudes and discriminatory practices of neighbors. Redi – a boy with Down syndrome – was strongly supported by his family. His parent and siblings gave him the best they could. Part of this was taking him to a park in the afternoon. This is how Redi's sister described her experience in the park: "When I take my brother to the park, others remove their children from the playground."

Poor law enforcement

Interviewees raised many questions: Why isn't the law on inclusive education being implemented? Why aren't business owners being penalized for not respecting the employment quota? The mother of a child with autism said:

Education laws have been approved by the Parliament. Why aren't they being implemented? My daughter is 9 years old and still in the kindergarten. Why should I take her to school? For physical integration, so others can make fun of her? Why isn't the law on supportive teachers being implemented? This is what concerns me and other parents.

Other interviewees raised similar concerns:

Business owners should pay the minimum wage; implement the law – one in 25 employees must be a person with a disability. I am sure that no one cares about this law.

What about parking spots? Even when they are assigned to us, they are used by other drivers. Police officers should fine them and teach them a lesson but they don't.

Study participants provided two explanations for the poor enforcement of disability laws: laws are not budgeted and local institutions that should be responsible for implementing the laws are not established. Both problems were attributed to the lack of political will. The majority of interviewees said that persons with disabilities do not constitute a priority for the government. For them, social exclusion is closely associated with the attitudes of government officials and their lack of commitment to the disability cause. "How does it come that ramps are available in kindergartens, schools and health centers during elections?" asked a disability-rights activist. Then, he added: "They care about our votes, not about our rights."

The institutions of People's Advocate and the Commissioner for Protection from Discrimination were characterized as ineffective. One of the interviewees mentioned that "they have been established to satisfy EU requirements; they don't have any impact at the grassroots level." In part, the lack of confidence in the justice system explains the small number of discrimination cases reported to the Commissioner for Protection from Discrimination. In 2014, the number of cases was 19 (Komisioneri për Mbrojtjen nga Diskriminimi, 2014). People don't believe that their cases will be taken into consideration and justice will be served.

Lack of political voice

Local government officials were characterized as too distanced from the disability community. Study participants emphasized that local government officials do not provide any kind of support and do not respond to the calls of organizations for collaboration. One of the leaders of the disability community said:

Now, goddamnit, the local government should be a bit responsible for this group. We have approached them and asked for collaboration but they have turned a deaf ear and a blind eye.

Then, he continued:

The main thing is that the state should be more supportive. This is not about providing cash assistance. This is not the most important thing. The most important thing is that state stays closer or communicates with them. Those in power should stay closer to organizations that are working in the disability field. We invite them on December 3rd – the Day of Persons with Disabilities – but they don't show up.

Furthermore, interviewees argued that local government officials are more likely to respond to the people they share political connections with. Another leader of the disability community said:

Everything is politicized. It is only when you have political connections in the municipality that you can benefit, otherwise you won't benefit anything. There are many ways that the municipality can help. There are children with disabilities from rural areas who live in misery. Their parents are unemployed and do not have any financial means. Can the municipality help them access rehabilitation services? There are many others who live too far and never get out of their houses ... What about transportation services? Can the municipality provide any kind of help?

The majority of interviewees reported that they do not have influence over decision making. This finding did not differ by their individual characteristics, such as age, gender, and ethnicity. They emphasized that their political participation was restricted to voting. The few respondents who had participated in public or political meetings, said that their presence did not have any effect on meeting outcomes. Furthermore, they mentioned that meetings are used by officials to discuss their political agenda rather than discuss the concerns of the disability community.

Preferential treatment

For study participants, one of the ways through which the government facilitates social exclusion is by treating the different groups within the disability community differently. Interviewees shared the concern that the status of some disability groups is recognized by the government and they receive more generous support than others. Meanwhile, others receive less support and have less voice in decision making. This difference is not based on objective criteria.

To explain the different treatment, one of the respondents referred to the ability of different disability groups to advocate for their needs and affect policy making. Some groups have been more successful than others. He said: "It is more challenging for the Deaf community and individuals with mental health problems to advocate for themselves." One of the unintended consequences of preferential treatment is the fragmentation of the disability community; the different groups are alienated from one another and it is very unlikely that they will organize and advocate for change.

Collective action and change

The extent to which the disability community will affect policy change and promote social inclusion depends on the strength of the community itself – how each group within the disability community is organized and how the different groups collaborate with one another. Collaboration is one of the preconditions of collective action. The analysis revealed low levels of collaboration within and between disability groups. Even when collaboration exists, it is based on personal rather than collective interests. Below are a few descriptions of collaboration:

The association has been too closed, not just with other organizations but inside the association itself.

The relationship between the association and our institute has not been institutional. It has been a personal relationship meaning that if the head of the institute is a friend of the association, then let's collaborate and only a small number of people benefit.

If the head [of the institute] does not have a close connection with the association, then everyone does his or her own thing. I feel really bad that most of our students do not have any information about the association... We look after our own interests. It is unfortunate; if we do not support one another, then we can't expect anything from others.

Different individuals had different perceptions of collaboration. For one of the leaders of a disability group, collaboration meant that people at the grassroots implemented his directives. Meanwhile, those at the grassroots wanted to have their voice heard and their opinions taken into consideration.

Activists characterized the impact of their lobbying and advocacy efforts as limited. "Change," said a member of the Deaf community, "does not happen because of our efforts alone. Other forces should be at play: state leaders who are committed to the disability cause, strong international pressure, and proactive civil society organizations." It takes a long time for lobbying and advocacy to affect policy change; it takes even longer to bring about change at the grassroots.

Conclusions and Recommendations

This study sheds light on how persons with disabilities experience social exclusion in Albania. Findings show that social exclusion interacts with other types of exclusion, such as physical and institutional exclusion. Persons with disabilities face numerous barriers, including lack of physical access and adaptability, poor access to information and knowledge, poor access to rehabilitation services, unaffordable treatment costs, and discriminatory attitudes and practices. Institutions perpetuate social exclusion through the lack of responsiveness, corruption, clientelistic accountability, preferential treatment, and poor law enforcement. While interacting with institutions, persons with disabilities experience avoidance, rejection, bullying, and harassment. The study also shows that the disability community is fragmented, which undermines the efforts of acting collectively and affecting policy change. These findings suggest that promoting the social inclusion of persons with disabilities requires implementing multilevel interventions. Below are several recommendations that draw on study findings.

Creating a barrier-free environment and instilling a culture of accessibility

It is imperative that the central government and local governments embrace the idea of universal design for persons with disabilities. One of the disability-rights activists suggested that each municipality should allocate a separate fund with the purpose of improving physical access and adaptability. Improved accessibility does not benefit persons with disabilities alone. For instance, wheelchair ramps can be used by the elderly or parents pushing baby strollers (WHO, 2011, p. 169).

Reshaping social protection for persons with disabilities

The extent to which persons with disabilities realize their potential depends on their access to rehabilitation services. Such services are fundamental to their well-being and independent living. Social protection should also focus on early-age interventions, preventive services, and family support. Otherwise, persons with disabilities will continue to be isolated and marginalized.

Addressing group bias

The government must establish objective and multidimensional criteria for measuring and assessing disability and make the information transparent to disability groups.

Enforcing disability rights laws and promoting inclusive justice

For disability-rights activists, three measures are imperative: budgeting disability-rights laws; creating local structures that will be responsible for enforcing laws and monitoring their

implementation; and punishing lawbreakers, e.g. penalizing professionals who demand or accept bribes, or drivers who park in spaces reserved for persons with disabilities.

Fighting discrimination against persons with disabilities

One of the disability-rights activists said: “you can’t fight discrimination with words but with the punishment of those who discriminate.” Besides enforcing the rule of law, study participants suggested strengthening the role of the Commissioner for Protection from Discrimination, working with families and communities at the grassroots level, and encouraging people to denounce cases of discrimination. If the role of the Commissioners for Protection from Discrimination increases, gradually, people’s confidence in the justice system will improve.

Organizing informative sessions at the grassroots level

State officials characterized open days and media campaigns as effective; meanwhile, community activists characterized them as ineffective. For community activists, awareness raising campaigns and educational programs should focus at the grassroots level, e.g. assisting families to defend the rights of children, or facilitating parents’ interaction with teachers and school principals. One of the community activists and also a member of the disability community gave the following suggestion:

We should organize small community meetings ... If you want to raise the awareness of people, you have to go where people live! You tell them that you don’t deserve to live this reality; your child deserves to go to school and I will assist you to get your child to school. You can knock on my door if you need help.

Improving interinstitutional collaboration

One of the misconceptions is that social inclusion should be the focus of the Ministry of Social Welfare and Youth alone. To promote the engagement of other institutions, discussions can focus on topics such as: What is social inclusion? Why does social inclusion matter? How does social inclusion interact with economic, political, and institutional inclusion? Why should everyone care about social inclusion?

Establishing collaborative ties with professionals working in the disability field

Professionals working in the disability field were willing to share their knowledge and expertise with state officials and service providers. One of the disability-rights activists said: “We should collaborate with teachers and school principals. We don’t expect them to know everything. But if we interact, things can change.”

Decreasing regional disparities through mobile services

Disability-rights activists argued that mobile services are an effective way of reaching rural, remote areas. For instance, legal aid and informative sessions on children with Down Syndrome can be offered through mobile services.

Implementing interventions that cut across sectors

The analysis shows that the sectors of education, health, employment, social protection and justice share some common challenges. This suggests that some of the interventions should cut across sectors. Specifically, the following interventions should be implemented in all sectors: first, improving physical access and adaptability; second, enforcing disability-rights laws and fighting discrimination; third, improving professional expertise and ethics, especially on how to interact and communicate with persons with disabilities; fourth, offering supportive services; and fifth, making families part of the social inclusion process. Specific suggestions are provided below:

Inclusive education

- Proving information on the right to education for children with disabilities. This can be accomplished through a nation-wide campaign that targets both urban and rural areas.
- Expanding social and psychological services in schools.
- Providing facilities and teaching tools for children with disabilities.
- Improving teachers' knowledge of disability and communication with children with disabilities.
- Improving teacher-parent communication and collaboration. One of the disability-rights activists suggested organizing meetings where teachers learn how to communicate with parents and view parents as partners.
- Increasing parents' involvement in schools. One of the school social workers described parents' involvement in the following way: "Mainly, they attend grades meetings. These meetings are formal. They are not really involved." She provided several suggestions, such as inviting parents to talk about their work, asking parents' opinion on how things should change in schools, and discussing classroom activities with parents.
- Promoting collaboration between institutions that provide specialized and non-specialized education; organizing disability open days in schools.
- Revising educational programs and school textbooks.
 - Increasing the visibility of persons with disabilities in school textbooks. Study participants mentioned that even when the topic of disability is mentioned, the information is very general.

- Emphasizing the importance of socialization in educational programs. A school social worker provided the following insights:

As social workers, we have realized that socialization should be part of the curriculum. Children do not learn that they should support one another, not just this group [children with disabilities] but others as well. In other words, they are concerned only about academic achievements. But the child should learn about emotions, feelings, support, and altruism. Socialization should be part of the curriculum and children's assessment.

- Including the topic of disability in professional training, e.g. in the fields of construction, information science, architecture, design, and marketing.
- One of the greatest barriers to inclusive education is the political appointment of teachers. For as long as this barrier will not be removed, the education of children with disabilities will suffer.

Inclusive health

- Improving patients' access and knowledge of developmental screening tests.
- Developing guidelines on what parents should do after they learn that the child has a disability.
- Providing sign language interpreters in healthcare settings.
- Providing information to healthcare providers about ways of accommodating persons with disabilities.
- Training healthcare providers on patient-clinician communication.
- Providing health information that is accessible for persons with disabilities. For instance, the information can be provided in large print, Braille, as well as other accessible forms.
- Providing basic preventative health education for persons with disabilities.
- Providing caregiving tips for families of persons with disabilities, e.g. how to obtain information, how to get support, and how to take care of themselves.
- Providing social and psychological services in healthcare settings.

Inclusive employment

- Providing supportive services for persons with disabilities before and after finding a job. Even when persons with disabilities find a job, they face discriminatory attitudes. Interventions should focus on the workplace, not just persons with disabilities.

- Integrating persons with disabilities into the labor market requires numerous interventions: providing assistive devices, access to vocational rehabilitation programs, on-the-job coaching, peer support, referrals to employers. One of the lessons shared by the Foundation on the Rights of Persons with Disabilities is that each person needs an individualized program.
- Evaluating the impact of the Economic Empowerment of Persons with Disabilities Program implemented by the Foundation on the Rights of Persons with Disabilities. It is important to understand what work and what does not work, and use the evidence to inform the expansion of the economic empowerment program. One of the shortcomings of the program is that job placement is based on personal connections. The challenge is to shift the emphasis from personal to impersonal relationships. In other words, business owners should be legally not just morally obliged to enforce the employment quota.
- Providing supportive services to fight discrimination in the workplace. The economic empowerment of persons with disabilities is not just about finding a job. What happens after persons with disabilities find a job? How accessible is the physical environment? Do they face discrimination? Do they denounce discrimination?
- Challenging employers' negative perceptions of disabilities. For disability-rights activists, besides enforcing the employment quota, other steps should be undertaken, such as increasing employers' awareness of disability and accommodation issues, and exposing employers to the contribution of persons with disabilities in the workplace. One of the disability-rights activists said:

Business owners should be more open and have confidence in persons with disabilities. I absolutely agree that persons with disabilities should not be employed just because they should fill a quota. They should be employed because they have the required skills to do the job.

- Providing sign language interpreters in employment departments.

Inclusive social housing

- Providing accessible information about social housing programs and the application process.
- Increasing transparency on the allocation of social housing funds.
- Providing supportive services for persons with disabilities who benefit from social housing programs.
- Ensuring that buildings and facilities are accessible and usable by persons with disabilities.

- Informing housing providers about the rights of persons with disabilities and the legal consequences when such rights are infringed.
- Reviewing the legislation on social housing and examining the extent to which it addresses the needs of persons with disabilities and promotes inclusive housing.
- Providing sign language interpreters in housing departments.

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