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# POLICY PAPER

## Fostering inclusion and protection of rights of people with disabilities in Albania

May 2019

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## Fostering inclusion and protection of rights of people with disabilities in Albania

Based on the results of discussions of Stakeholder Working Group meetings held in the context of SOCIETIES project

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**DISCLAIMER:**

The SOCIETIES project is funded within the European Union's Civil Society Facility and Media Programme 2014-2015 - Support to regional thematic networks of Civil Society Organisations.

The opinions expressed in the document herewith are based on the discussions and the references provided by the participants of the stakeholder working group meetings held during the project, and thus do not necessary represent the opinions of the supporting institutions, including European Union, SOCIETIES project, Caritas Albania, or other partner organizations in the project.

## Acronyms

ADRF	Albanian Disability Rights Foundation
AEC	Albanian Electoral Code
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
ECHR	European Court of Human Rights
EU	European Union
EURALIUS	EU Project for Consolidation of the Justice System in Albania
ICT	Information and Communication Technologies
INSTAT	Albanian Institute of Statistics
NAIS	National Agency for Information Society
NAPPD	National Action Plan on Persons with Disabilities
NGO	Non-governmental Organization
PA	People's Advocate
PWD	Person(s) with Disabilities
SEE	South East Europe
UN	United Nations
UNDP	United Nations Development Program
UNICEF	United Nations Children's Fund
VET	Vocational Education and Training
WHO	World Health Organisation

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## 1. EXECUTIVE SUMMARY

This report summarises the key findings and policy recommendations coming from a series of working groups meetings held (during 2018-2019) by the project with a large number of stakeholders, including representatives of organizations of persons with disabilities, different civil society organizations, central and local government institutions, as well as various international organizations and development projects working with PWD in Albania. While the number of recommendations made by participants in the working group sessions have been very large and covering a wide range of topics, the following ones have been selected as the most important one that would need to be tackled with priority:

- Ensuring the full harmonisation of Albanian laws with the Convention on the Rights of Persons with Disabilities (CRPD).
- Improvement of accessibility for the persons with disabilities, on an equal basis with others, to the physical environment, transportation, information and communication, including ICT and other facilities and services.
- Development of "supported decision-making" for persons with disabilities throughout the country, thus replacing the current "guardianship system".
- Introduction of the concept and roles of "personal assistance" to persons with disabilities, thus replacing the current concept of "carer".
- Development of community based services and reforming the health and social care system for persons with disabilities, including allocation of adequate resources for the development of community-based alternatives.
- Development and increased effectiveness of free legal aid services and raise awareness among the broader public and institutions about the availability of free legal aid.
- Design and implementation of wide and effective public information and awareness campaigns about PWD's capacity to act as well as training sessions with public servants (including legal, health, social, counselling, etc.) to accept, respect and enforce such rights.
- Fostering economic and social inclusion of PWD and strengthen the capacities of PWD community and their organizations to raise their voice and advocate more widely and effectively for their rights.
- Improvement of access to and the quality of education services for PWD, including improvement or redesign of curricula, provision of special resources and equipment for PWD learning processes and improvement of the teachers' qualification about how to work with and better meet the needs of the children with disabilities.

## 2. INTRODUCTION

Disability is not something individuals have, what they have are impairments. These impairments may be of various nature, including physical, sensory, neurological, psychiatric, intellectual or of other nature. Disability is the process which happens when one group of people create barriers by designing a world only for themselves, not taking into account the impairments other people have. Disability relates to the interaction between the person with the impairment and the social and physical environment and has a lot to do with discrimination. According to the INSTAT assessment<sup>1</sup> about 6.2 % of the Albanian population over 15 years of age have at least one of the following forms of disabilities: sight, hearing, mobility, sensory impairment, self-care, and communication. According to the information quoted in the 2016 National Action Plan on Persons with Disabilities (NAPPD), 162,350 persons in 2014 and 157,434 in 2015 respectively, received disability-related social benefits, and 74,373 of them were persons with labour-related disabilities. It has been reported that about 79% of the households who have members with a disability are dependent on some form of social care benefits.<sup>2</sup> Despite the range of legislation and policies in place and improvements in the recent years, PWD continue to face multiple barriers in social, economic and political inclusion.

Caritas Albania, based on its vision for dignity of every member of society as an inherent element of the human being, supports and provides services for persons with disabilities as well as advocates and serves as spokesperson for their rights and interests. It accompanies and listens to them, as well as advocates on their behalf, so the topics presented in this document are also the expression of their interests. Caritas Albania, along with other partners from various countries, is implementing the SOCIETIES<sup>3</sup> project. The project is financed by EU and is implemented in several Western Balkan countries during January 2016 do December 2019. Its overall objective is to improve the capacities of CSOs in South East Europe (SEE) in managing social inclusion processes and in promoting social inclusion policies, through an efficient dialogue with public authorities during the decision-making processes. The project has two main specific objectives: (i) to strengthen the CSOs' skills in promoting the social inclusion of people with disabilities and mental disorders (including capacity building, exchange of knowledge, regional networking, managing of social inclusion initiatives and services, monitoring and evaluating of the social impact); and (ii) to foster the CSOs' capacities to carry out an efficient and impactful dialogue with the pubic authorities responsible for

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<sup>1</sup> Ferré C., Galanxhi E., and Dhono O. 2015. Profile of the Disabled Population in Albania. INSTAT, UNDP

<sup>2</sup> National Action Plan on Persons with Disabilities 2016-2020.

<sup>3</sup> Support of CSOs in empowering technical skills, inclusion of people with disabilities and EU standards in South East Europe (SOCIETIES)

social inclusion (including strategic and communication planning, advocacy, local networking and participation to decision making processes).

This report summarises the key findings and policy recommendations coming from a series of working groups meetings held by the project with a large number of stakeholders including, representatives of organizations of persons with disabilities, other relevant civil society organizations, central and local government institutions as well as various international organizations and development projects working with PWD in Albania. These meetings covered a wide range of topics, including: (1) PWD legislation in Albania and EU; (2) disabled children in school, and in family; (3) disabled adults in family/community and at work (labour insertion); (4) minors, adults, elders and mental health; (5) disabled elders in asylum/ home cares and abandoned elderly persons; (6) legislation on mental health, psychiatric hospital, and legislation on welfare in favour of disadvantaged categories; (7) architectural barriers and alternative treatments for disabled and mental health patients; and (8) fundraising for improving financial sustainability of CSO-s dealing with PWD in Albania.

### 3. PROFILE OF THE PWD IN ALBANIA

According to the INSTAT assessment<sup>4</sup>, about 6.2 % of the adult population<sup>5</sup> in Albania identify themselves as having severe or extreme difficulty in at least one of the following: seeing, hearing, mobility, cognition, self-care, communication, or disability. The most commonly encountered type of disability is movement restrictions (3.7%), and the least common ones are hearing and communication (1.7% and 1.5% respectively), while vision, learning and self-care fall somewhere in between. When “some difficulty” is included, the numbers of PWD in Albania rise to 22 % of the population who report having some difficulty, strong difficulty or inability to perform daily tasks. The gradient between “some limitation” in carrying out tasks and the Washington Group (WG) measure of disability is steepest for the oldest working-age group: individuals with strong disability usually constitute one third of the population with at least some disability, but among people aged 50-64 that share drops to one fifth. (INSTAT, 2015)

While statistics about adult population with disabilities in Albania have somewhat improved in recent years, the available statistical information about children with disabilities remains very limited. It is provided mainly through administrative records of children with disabilities who receive cash benefits and social care services, and those who are registered in at the

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<sup>4</sup> Ferré C., Galanxhi E., and Dhono O. 2015. Profile of the Disabled Population in Albania (INSTAT, 2015).

<sup>5</sup> Population aged 15 years and above. Statistics are presented on a restricted sample of the population due to the large number of erroneous responses for children: mothers often qualified their children as experiencing difficulties in walking for instance, when they were not yet in age of walking, or self-care, when they were still being taken care of by their mother

education system. However, these records leave out children that are unable to access these services and therefore provide an incomplete picture. According to Save the Children estimates,<sup>6</sup> in 2014, about 17,786 children with disabilities (0-18 years) in Albania received disability allowances. Based on the global prevalence rate estimate<sup>7</sup>, the number of children with any form of disability in Albania could be up to about 93,038. The extrapolation (*the process of assessing the conditions outside available data, but based on plausible trends*) suggests that only around 20% of children with disabilities may have been identified by the social protection system. Furthermore, according to Save the Children's study, in 2015, only about 2.5% of total registered children received social care services. This situation was related to the limited provision of residential and day care centres, offering a limited range of services and located only in a few cities.

According to INSTAT study (2015), the physical limitations (such as seeing, hearing and mobility) are not very much correlated with one another or with cognitive, communication and self-care limitations. On the other hand, indicators of various functioning limitations seem to be highly correlated if the incidences of these limitations are driven by common factors such as aging, poverty, poor health care infrastructure, or unfavourable environmental conditions. Disability prevalence is very much linked to age, with older age cohort being more affected by difficulties in performing daily tasks. Youth and prime age population record low levels of disability, below 3% for both sexes. On the other hand, older working-age cohorts (50 to 64 years old) already start displaying larger incidence of disability: 6 and 8% respectively for men and women. These figures increase as individuals become older: respectively 20% of men and 25% of women above 65 report experiencing at least one severe difficulty in carrying out daily tasks. Looking more closely at the type of disability experienced and age and gender groups, one notices a sharp increase of physical difficulties with age, especially among women: 17% of women over 65 have limited mobility (15% for men), and about 10% of men and women have either vision or hearing limitations. Mobility restrictions can already be observed among the 50-64 years-old group, where about 5% of men and women report such a limitation. Cognitive, communication and self-care restrictions are less common and only rise among those 65 years and above, again with a strong gender gradient: 5% of men are affected while about 8% of women over 65 are. Individuals with disabilities are concentrated mostly in larger households. Only 13% of households with no disabled member have 6 or more members, while 27% of households with at least one disabled member have 6 or more members.

The results of the INSTAT study don't vary much across regions, with the capital city, Tirana, displaying the lowest incidence of disability, with less than 5%, and Gjirokastra the highest with about 8% of adults self-reporting disabilities. There are no drastic differences between prefectures in the prevalence of each of the daily limitations that people face. Households

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<sup>6</sup> Save the Children. Albania Country Spotlight (accessed on 5 May 2019):

[https://resourcecentre.savethechildren.net/sites/default/files/documents/albania\\_proof\\_fonal.pdf](https://resourcecentre.savethechildren.net/sites/default/files/documents/albania_proof_fonal.pdf)

<sup>7</sup> Ibid.

with disabled members are quite dependent on social assistance transfers. Households with at least one disabled household member are about twice as likely to receive any social assistance transfer: respectively 42 and 79 % of the households with and without disabled member are covered by at least one social assistance transfer. Households with a disabled household member are also more likely to be covered by the disability assistance benefit or the work invalidity transfer: 38 % of households with one disabled member receive the work invalidity transfer and 12.5 % receive the disability assistance benefit.

Disability and vulnerability are dynamic and intricately linked phenomena. Many empirical studies show that persons with disabilities experience inter-alia comparatively lower educational attainment, lower employment, higher unemployment rates, worse living conditions, and higher poverty rates. The Albanian constitution and a large body of laws prohibit discrimination against persons with physical, sensory, intellectual, and mental disabilities. Nevertheless, employers, schools, health-care providers, and providers of other public services at times are (directly or indirectly) engaged in discrimination. The law mandates that new public buildings must be accessible to persons with disabilities, but the government only sporadically enforced the law. During the last years, the government adapted the premises of about 80 health care facilities and 32 schools, and built eight new schools, to accommodate persons with disabilities.<sup>8</sup> The has government sponsored social services agencies to protect the rights of persons with disabilities, but these agencies traditionally and continuously lack funding to adequately implement their programs. Resource constraints and lack of infrastructure made it difficult for persons with disabilities to participate fully in civic affairs.<sup>9</sup> Very often both the public and private service centres, are located in facilities lacking accessibility and with questionable quality of services for persons with disabilities.

## **4. OVERVIEW OF THE PWD SITUATION IN ALBANIA**

### **4.1 Main legislation about PWD rights**

Albania has ratified, in 2012, the UN Convention on the Rights of Persons with Disabilities (CRPD). The social inclusion of persons with disabilities is supported by various laws, 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). In 2016 the government adopted a policy document on social inclusion 2016-2020, which provides for a framework for

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<sup>8</sup> Dunja Mijatović, 2018. Report of the Commissioner for human rights of the Council of Europe. Following her visit to Albania from 21 to 25 May 2018

<sup>9</sup> Ibid.

monitoring and measuring social inclusion in a number of areas relating to civil, political, social and economic rights. The National Action Plan on Persons with Disabilities (2016-2020), which was adopted in 2016, sets objectives and activities to be implemented in a set of priority areas which attempt to be aligned with the Council of Europe Disability Strategy 2017-2023, namely accessibility, participation, equality, education, health, social protection, and international co-operation.

**Box 1. The Basic Concepts of the CRPD<sup>10</sup>.**

**(a). A social model:** Persons with disabilities were for a long time framed as objects rather than subjects and therewith as rights-holders. The objecting of disabilities resulted in a narrowing of exclusion and inaccessibility to a sole emphasis of the impairment, also referred to as the medical model. Towed into that approach, persons with disabilities were looked on as objects of pity who required “help” through charity efforts. This aspect of poetization is also referred to as the welfare based approach to disabilities. Based on the premise that all human beings have inherent dignity, which entails the enjoyment of all human rights, persons with disabilities are unconditional (human) rights-holders. Subsequently the focus is not on the possible impairment(s) but rather on the constraints that the social fabric builds in hindering access to the enjoyment of rights. In addition to the more obvious physical barriers, this approach focuses on the manifold social, behavioral, stereotype-based barriers that lead to and potentially sustain the exclusion of persons with disabilities.

**(b). Non-definition of “impairment” or “disability”:** The CRPD does not define impairment or disability. Rather, the Convention provides an open description of what constitutes an impairment. In addition to an open-ended list of medical and/or physical manifestations of impairments – such as long-term physical, mental, intellectual or sensory – but places the emphasis on the barriers, which in interaction between persons with impairments and attitudinal and environmental barriers cause disability.

**(c). Anti-discrimination:** The Convention includes a definition of discrimination - “Discrimination on the basis of disability’ means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.”

**(d). Inclusion:** The principle of inclusion also connotes the process towards a society, which provides equal opportunities for all. The Convention aims at ensuring that persons with disabilities are no longer separated or segregated from mainstream but rather are brought into the mainstream on equal terms with others, with assistance – by personal assistance or other means – where necessary.

**(e). Accessibility:** The capacity to act is also directly linked with accessibility. Accessibility should be understood in four dimensions. The support for overcoming social barriers such as stereotypes and prejudices, which exclude persons with disabilities from the mainstream. The communications dimension of accessibility, which covers issues such as accessible formats for persons with visual impairments and who are blind, the accessibility for people who have a hearing impairment or a deaf through sign languages and assistance for persons who are non-verbal. Then there is the intellectual dimension of accessibility: to ensure that documents and information generally are provided in easy to read and easy to understand formats. Finally, there is the physical dimension of accessibility, namely the signage of floors, the width of doorways and the provision of ramps and related adaptations to the physical environment as well as access to goods and services. Note that accessibility is both a principle and a right, covered in Articles 3 and 9 of the Convention respectively. Furthermore, universal design, which is also defined in the Convention, provides guidance on how to ensure that newly designed goods – and services – can be made accessible also for persons with disabilities.

<sup>10</sup> Based on: Schulze M., 2011. Assessment Report on conformity of national legislation with Convention on the Rights of Persons with Disabilities. UNDP.

The Constitution of Albania prohibits discrimination against persons with disabilities with regard to, inter alia, access to justice, employment, education and health care. Anti-discrimination safeguards pertaining to persons with disabilities are also embedded in the 2010 Anti-Discrimination Law, the 2012 Law on Pre-University Education System in Albania, and the 2014 Law on Inclusion of and Accessibility for Persons with Disabilities which incorporates the CRPD's main principles and provisions.

A number of by-laws have been adopted in the recent years, with a view to improving accessibility for persons with disabilities, formalising the sign language for persons with hearing impairments, and improving the collection of aggregated data relating to persons with disabilities. In addition, a National Disability Council was established in 2015, as an advisory body to the government composed of 17 members, the majority of them persons with disabilities and their associations. Since the ratification by Albania of the CRPD the authorities have organised a series of trainings for public officials and awareness raising campaigns concerning the rights of persons with disabilities with the support of donors and civil society organisations.

Notwithstanding these positive developments, there still remains a significant gap between legal improvements and local realities. Persons with disabilities in Albania continue to be confronted with significant difficulties owing, in particular, to shortcomings in the implementation of the existing legislation, structural problems in the social care system, and poor access to quality education and employment opportunities.

There are also issues with various pieces of legislation no being well harmonised with the CRPD, EU and other international best practices. The People's Advocate (PA) declares<sup>11</sup> that there are several issues with miss-translation of the Convention on the Rights of Persons with Disabilities from English into Albanian. In Article 16 of the above Law, the PA was given the role of a monitoring institution for the implementation of this law in accordance with the Convention on the Rights of persons with disabilities. Convention "On the rights of persons with disabilities", is a fundamental international instrument in the field of rights of disabled people. The People's Advocate institution noted that there are problems in the accuracy of the translated terminology, of the translated version of the Convention into Albanian, of the preposition "of". According to paragraph (b) of Article 29 of the Convention, it is stated that: "forming or joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels". Whereas in Article 32 of the Convention it is stated that: "States Parties recognize the importance of international cooperation and its promotion, in support of national and effective efforts in this regard, between and among States and, as appropriate, in partnership with relevant international

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<sup>11</sup> People's Advocate. 2015. Information concerning Albania and the convention on the rights of persons with disabilities. Albania.

and regional organizations and civil society, in particular organizations of persons with disabilities...". PA emphasises that, according to the explanations made by an official translator, regarding the phrase "Organization of Persons with Disabilities", used in Articles 29 and 32 of the Convention "On the rights of persons with disabilities", it turns out that Article 29 and 32 of the Convention, make use of the phrase "Organizations of persons with disabilities", to refer to organizations that are composed of people with disabilities. So, after the Convention refers to non-governmental organizations and associations operating in the public and political life of the country (subparagraph i) in subparagraph (ii) of paragraph (b) of this article, it points out "...the establishment and membership of those organizations of persons with disabilities to represent persons with disabilities at the international, national, regional and local levels." In these conditions, People's Advocate believes that the term "*organizata për personat me aftësi të kufizuara*" should be changed and replaced with the term "*organizata e (të) personave me aftësi të kufizuara*". Given that miss-translation into Albanian as a results leads into an incorrect understanding of the Convention, an incorrect conception of the acts arising after its ratification, wrong perception of liabilities. Further into his reporting to the Albanian state on the implementation of CRPD, on 12.05.2015, the PA recommended to the Minister of Justice, to take the legal initiative for the accuracy of translation of Articles 29 and 32 of law no.108/2012 "On Ratification of the UN Convention on the rights of persons with disabilities". In response to the PA's recommendation in February 2016, a revised version was submitted to the PA office, which had no changes. So the problem remains the same.

## 4.2 Accessibility of PWD to spaces and institutions

The Article 9 of the CRPD enshrines a positive obligation of member states to take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas in order to enable persons with disabilities to live independently and participate fully in all aspects of life. Although the CRPD is not directly legally binding on private actors, it obliges states to require that private entities that are open to the general public comply with Article 9. This article remains large unimplemented and widely overlooked by public institutions in Albania.

In Albania, the movement of persons with disabilities in public spaces and their physical access to institutions (such as healthcare institutions, schools, administrative and other institutions) remains considerably limited. The National Action Plan on Persons with Disabilities quotes that access to streets and pavements is virtually impossible for people with physical disabilities, in particular those using wheelchairs, and that public transport also remains inaccessible. There are no sound signalling devices at street or road crossings, or on public transport services and bus stops are not marked, making orientation difficult for

persons with disabilities. In addition, specific by-laws on spatial planning provide that all public buildings should be made accessible to persons with disabilities and that new buildings must be constructed to ensure accessibility. However, reportedly the implementation of the by-laws has been very slow and with limited impact on increased accessibility.

The Ministry of Health and Social Care and the Ministry responsible for urban planning have worked together to improve accessibility in public institutions and some government buildings have been rendered physically accessible for persons with disabilities, while other public buildings are being renovated to this end. However, in some of the public buildings, including schools, where renovation or adjustments have been made to render them accessible for persons with disabilities, some facilities within those buildings, such as restrooms, remained inaccessible.<sup>12</sup>

As concerns the accessibility of information, in her 2018 report<sup>13</sup> for Albania, the Council of Europe Commissioner for Human Rights notes that the 2014 Law on Inclusion of and Accessibility for Persons with Disabilities provides for the right to independent living for persons with disabilities by introduction of communication and information policies and accessible formats, such as prints in Braille or large font, use of simplified language and reader-accessible electronic formats. However, textbooks for mainstream schools, for instance, do not exist in Braille or audio format. Moreover, government websites and portals are not easily accessible for persons who need large font or higher contrast, or are hearing-impaired. It is noted in the 2016 National Action Plan for Persons with Disabilities that the standards for government websites developed by the National Agency for Information Society (NAIS) must take into account accessibility aspects.

### 4.3 The right of PWD to legal capacity to act

The majority of the Albanian legislation provides for a major distinction between the capacity to hold rights and legal capacity to act.<sup>14</sup> Albanian civil law includes as one of the conditions for engagement in legal and civil relationships the legal capacity to act. According to Article 1 of the Civil Code, every physical person enjoys full and equal capacity to have civil rights and obligations, and this capacity begins with a person's birth and ends upon his death. Article 9 of the Civil Code refers to treatment of "psychiatric diseases" vis-a-vis capacity to act. Thus, during a lifespan of a person from 14-18 years old, if he/she is suffering from "psychiatric disorders" or has "mental development problems", he/she may be restricted in or deprived of capacity to act by a court verdict/ruling. This also holds true for adults (over 18 years old) who due to a psychiatric disorder or due to intellectual disability are entirely or partially

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<sup>12</sup> Dunja Mijatović, 2018. Report of the Commissioner for human rights of the Council of Europe. Following her visit to Albania from 21 to 25 May 2018

<sup>13</sup> Ibid.

<sup>14</sup> ADRF, 2016. Country Report - Deprivation of capacity to act in Albania. PERSON

unable to take care of their affairs, whose capacity to engage in legal acts may be reduced or removed through court verdict.

The Civil Code includes definitions of mental health status that entail mental disorders, as they are now referred to in the Law on Mental Health. The main procedure for deprivation or restriction of the legal capacity to act of adult persons with disabilities is provided for in the Family Code, Articles 307-313. With reference to Article 10 of the Civil Code, deprivation or restriction of the capacity to act may be determined only through court verdict, and is always accompanied with placing a person under guardianship. The rules and procedures for commencing and processing cases related to deprivation or restriction of capacity to act are provided for as part of special deliberations. Article 382 of the Civil Procedure Code provides for certain persons who enjoy the legitimate right to address the court during guardianship proceedings. These include the spouse of the person who is the subject of proceedings, next of kin, prosecutor, or persons with a legitimate interest in the case. This also includes persons with a legal interest in the case.

Furthermore, the court can hear from third parties, drawn from the section of assistance and social services in the respective communes or municipalities, in line with Article 267 of the Family Code. The Social Service submits an evaluation of the person, which includes the examination of the development of the personality of the person whose capacity to act is sought to be restricted or removed, in the family, education and social background/context, and makes an assessment of the conditions and suitability of the future guardian or care institution. In addition, the court must submit the person whose capacity to act is sought to be removed or restricted, to examination by a team of expert doctors, specialised in the field.

With the full deprivation of one's capacity to act, a person becomes equal to a minor under 14 years of age, whereas with a partial restriction of the capacity to act, a person is equal to a minor of 14-18 years of age. However, it is worth pointing out that in practice there is no difference between full and partial deprivation of legal capacity. The practical legal implications are the same for all legal procedures that take place on behalf of the person placed under legal guardianship. This is due to the lack of clear definition of partial restriction of legal capacity, and its scope.

Another piece of legislation that continues to permit to deprivation of the legal capacity to act is the Law on Mental Health<sup>15</sup>. This law provides for treatment of a person without his consent. This is referred to as "involuntary treatment" and is authorized through a court decision. It results in the person's placement in a psychiatric facility and allows for other medical procedures to be conducted, without his/her consent, while placed in the facility. Article 9 of the law describes the circumstances under which deprivation of the capacity to

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<sup>15</sup> Law on Mental Health, no. 44/2012 [http://www.shendetesia.gov.al/files/userfiles/shendeti\\_mendor/Ligji\\_Nr.44,\\_2012\\_per\\_shendetin\\_mendor.pdf](http://www.shendetesia.gov.al/files/userfiles/shendeti_mendor/Ligji_Nr.44,_2012_per_shendetin_mendor.pdf)

act may occur for the purpose of involuntary treatment, with direct reference to the procedures of the Civil Procedure Code.

The law on Mental Health also provides for the (so-called) "voluntary" treatment, for persons with partial capacity to act, when the decision for the treatment is approved by the legal guardian. It is obvious that this provision is contrary to the CRPD, giving total power to the legal guardian to determine the medical treatment. There is no provision regarding the will and preferences of the concerned person. On the other hand, even though the law encompasses the concept of "informed consent", it does not have any provisions about the delivery of information in accessible formats for the concerned individual.

The use of guardianship remains prevalent also in the National Action Plan on Persons with Disabilities (2016-2020), due to the lack of a functioning system of supported decision-making.<sup>16</sup> It also constitutes an dominant way of community thinking and an almost standard ruling result in the domestic court deliberations. In an expert report,<sup>17</sup> analysing a certain number of court incapacitation cases in Albania, it was noted that domestic court judges had a tendency to resort to full deprivation of legal capacity even in cases in which a decision on partial deprivation of legal capacity should be rendered. The report also noted that in the majority of those cases the incapacitation proceedings were initiated by a family member (33% by one of the siblings, 18% by one or both parents, 12 % by a spouse and 14% by children, while for 22% of cases there was no data available). It was also noted in the report that despite the aforementioned safeguards domestic court decisions in incapacitation proceedings are often based solely on medical expertise and the participation of the concerned person in the court proceedings tends to be limited.

The situation becomes more complicated in the instances of involuntary treatment. This procedure does not formally require deprivation/restriction of the capacity to act (even though in practice, the procedure entails exactly the same restriction of the rights of a person), but is solely focused on involuntary treatment. The law refers to the principle of the "best interests" of the concerned person. In addition, the law provides that consent of the legal guardian, where one exists, bypasses the need for the person with "mental health disorders" to provide personal consent or refusal of the treatment.

People deprived of capacity to act by the court are also excluded from most administrative procedures by the public institutions. On this basis they are excluded from register of voters by the Albanian Electoral Code (AEC), although the AEC is unclear as to whether this exclusion applies only to those persons who have been fully deprived of legal capacity or also those who are partially deprived of legal capacity. By virtue of not being registered as voters, people deprived of capacity to act (and often also several of those whose capacity has been restricted) cannot vote in any kind of national or local elections, which is not compliant with

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<sup>16</sup> National Action Plan on Persons with Disabilities 2016-2020.

<sup>17</sup> Albanian Disability Rights Foundation, Country Report: Deprivation of the Capacity to Act in Albania, 2016.

Article 12. This provision also contradicts Article 29 of CRPD that guarantees participation in political and public life to people with disabilities. This is also contrary to other instructive international documents, like the Code of Good Electoral Practice provided by the Venice Commission and it also contravenes the ECHR<sup>18</sup>.

The "Law on Inclusion and Accessibility of Persons with Disabilities" adopted in 2014, reflects some of the principles of the CRPD and it is more advanced than the rest of the existing legislation, in particular the basic Codes. Articles 5 and 6 of the law address aspects of independent living in particular, providing for concrete services that may be delivered by the government, in line with this law. In support of the implementation of the CRPD, the Article 7 of the Law establishes the obligation to provide decision-making support to enable the will of a person with disabilities to be exercised through a specific added competence, supports its best intention and interest, enabling it to carry out actions to gain rights and to assume obligations. It further stipulates that any disabled person, who needs help in decision-making, may receive proper supportive decision-making from an individual or group of trusted individuals. Support can be provided in a variety of ways, including support through interpretation and plain language, as well as assistance with third-party relationships that cannot understand its communication ways. Support is given gradually, giving enough time to those who ask for it, to learn how to use the support for their best. In line with this law, "supportive decision-making" is the exercise of the will of a person with disabilities through an added specific requirement that this service supports his "best goal and interest," enabling the person to exercise rights and obligations. However, it still uses the "best interest" test on supported decision-making, which is contrary to the CRPD<sup>19</sup>.

Article 12 of the General Comments of the Committee on the Rights of Persons with Disabilities guarantees the right to equal recognition before the law for persons with disabilities and, in particular, the right to enjoy legal capacity on an equal basis with others in all aspects of life. The CRPD Committee has reaffirmed "that a person's status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in article 12."<sup>20</sup> It has called on states' parties to "review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences."<sup>21</sup> Article 12 of the CRPD necessitates that guardianship systems to be replaced by systems of alternatives, including, in particular, methods of supported decision-making. This concept entails that everyone has the right to make their own decisions and to

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<sup>18</sup> [http://www.venice.coe.int/webforms/documents/default.aspx?pdffile=CDL-AD\(2002\)023rev-e](http://www.venice.coe.int/webforms/documents/default.aspx?pdffile=CDL-AD(2002)023rev-e)

<sup>19</sup> Para. 27 General Comment on Article 12. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

<sup>20</sup> Committee on the Rights of Persons with Disabilities, General Comment on Article 12 on Equal recognition before the law, paragraph 9.

<sup>21</sup> Ibid. paragraph 22.

receive adequate support to do so. The Committee stresses that, when setting up safeguards for systems of supported decision-making, the authorities should consider Articles 12, 13 and 16 of the CRPD.

As reiterated in the General Comments of the Committee on CRPD, all approaches and legislation that allow for decisions to be taken on behalf of adults with disabilities, based on “best interest” should be abolished. The Committee noted that the “best interests” test is used for children, and this is considered inappropriate for adult persons with disabilities. For adults, the support should be granted only based on the will and preferences of the concerned person. In absence of the expression of will, the supporters in decision-making engage in the best possible interpretation of will, based on all available information about the will and preferences of the person, with reference to knowledge, experience, background and relations with others, etc. Also the case-law of the European Court of Human Rights establishes that the non-recognition of a person’s legal capacity, severely limits their human rights and that full deprivation of legal capacity is a very serious interference with the right to private life protected by Article 8 of the Convention. The existence of a mental disorder, even a serious one, cannot by itself justify incapacitation.

#### 4.4 Access of PWD to legal aid

Until 2016, despite the existence of the State Legal Aid Commissioner, most legal aid to vulnerable groups, including persons with disabilities, continued to be provided by NGOs. Although there have been improvements since then, obstacles to access to justice for vulnerable groups persist. The results of a 2017 UNDP survey<sup>22</sup> on access to justice demonstrated a high level of legal illiteracy, dubious attitudes on justice, and a general lack of trust in the justice system among Albanians. According to this survey, persons with disabilities face various obstacles that make access to justice even harder than for the average Albanian citizen. Many of them, are victims of discrimination and economically deprived, which leaves them unable to access better quality services. As a result of these obstacles, and the wide spread lack of trust, many of them do not even attempt to reach out to institutions, leaving their legal issues unaddressed.

In order to address this, a new Law on Legal Aid was approved in 2017. The preparation of necessary by-laws is underway and is being carried out in close co-operation with relevant international partners, including EURALIUS and UNDP. The law provides for the establishment of a directorate within the Ministry of Justice as a responsible body for free legal aid, as well as legal aid offices in each of the country’s four districts.

While the law on Legal Aid is yet new and not fully implemented, persons with disabilities continue to rely mainly in support from various national NGOs which are involved in the

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<sup>22</sup> UNDP, Survey on Access to Justice in Albania, 2018.

protection and promotion of the human rights of these persons. The authorities should make better use of their valuable expertise to bring their practice fully into line with international and European standards. This is even more important in cases of Down syndrome for which public institutions do not have neither the means nor expertise to properly do the required screening or assessment of cases. NGOs dealing with Down syndrome in Albania have continuously raised the concern that in order for the families with a child with Down syndrome to be entitled to social care benefits they need to present the authorities with the results of a special screening for Down syndrome, which can only be done abroad and involves expenses that most of these families cannot afford.

#### 4.5 The right to live independently, in family and in society

The right of PWD to live independently and being included in the community is closely linked to other human rights such as equality and non-discrimination, physical and mental integrity, liberty, freedom from inhuman and degrading treatment or punishment, autonomy, legal capacity, privacy, family rights and freedom of movement. Despite some positive developments in the recent years, persons with disabilities continue to be confronted with significant difficulties, owing in particular to shortcomings in the implementation of the existing legislation, structural problems in the social care system, and poor access to quality education and to employment. Independent living for people with intellectual disabilities is considered to be impossible for the time being and that it is coupled with a variety of barriers. Despite the readiness that persons with disabilities have to live an independent life, their decisions are mostly made from the family or other guardians. Fear and disbelief about the skills from the part of their family and others; economic difficulties, little employment opportunities, alternatives that they have available for habitation, abandonment by family, gender, are among the main factors influencing the opportunities for them to live an independent life, enjoy a healthy emotional state, not be discriminated against and not isolated.<sup>23</sup>

One of the aims of the 2014 Law on Inclusion of and Accessibility for Persons with Disabilities is to ensure independent living for persons with disabilities and improve their autonomy and supported decision-making. This law, for the first time, provides for measures to ensure support and assistance for persons with disabilities who would like to live independently, such as “personal assistance, supportive technical equipment and devices, accessibility services, reasonable accommodation, and, where necessary, supported decision-making”. However, the respective bylaws have yet to be enacted for independent living services to become possible.

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<sup>23</sup> The Network of Disability Organizations. 2019. Alternative report to the UN Committee on the Rights of Persons with Disabilities (on Albanian Government's Initial Report on the Convention on the Rights of Persons with Disabilities).

The law 121/2016 “On services of social care in the Republic of Albania” provides for the homecare service for persons with disabilities, which is a typical medical model type of service and that provides no choice and control for persons with disabilities. It remains to be seen how it will work in practice but people with disabilities are concerned that funds and attention will be drawn away from the personal assistant and that they are going to be put into the home caring service instead. According to the Network of Disability Organizations, the law and its bylaws were not properly consulted with disability organizations. Article 9 of the law 93/2014 “On the social inclusion and accessibility of persons with disabilities” provides for assistive devices, but so far, nothing has been done to even remotely go down that path. The state doesn’t provide even the most basic assistive device, the wheelchair.<sup>24</sup>

Despite the existing legal framework there are not yet services in place for persons with disabilities who would like to lead an independent life in their communities. Most of the community-based services were provided by civil society organisations and volunteers in shelters or day-care centres, while the authorities are responsible for ensuring the monitoring of the provision of those services. According to the Network of Disability Organizations, in 2018, in Albania there were 28 social service facilities for persons with disabilities, including 12 residential institutions, 14 day-care centres and two non-public community centres. According to the authorities, in 2018 there were about 182 persons with disabilities in residential facilities, 38 of whom were children. The persons with disabilities are placed in public institutions when independent living is not possible, where family members are unwilling or unable care for the persons and in cases of abandonment or inadequate living conditions. A request for placement of a disabled person in a residential centre can be made by a parent or court-appointed carer, the Medical Commission for Assessment of Working Capacity, the police, and social care administrators at the local level. The admission decision rests with the Managing Council of the State Social Service, chaired by the General Director of the State Social Service.<sup>25</sup>

In the recent years, the government has initiated a deinstitutionalisation process. However, civil society representatives have expressed concerns that recently, under the pretext of deinstitutionalisation, some persons with disabilities who have been released from institutions ended up on the street without any support or assistance. In this context, the Council of Europe Commissioner on Rights of PWD emphasises<sup>26</sup> that the process of deinstitutionalisation needs to be carefully planned and implemented, and no hasty measures should be taken which may result in persons with disabilities being left behind without the necessary support and protection. Despite the commitment of the authorities to moving

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<sup>24</sup> The Network of Disability Organizations. 2019. Alternative report to the UN Committee on the Rights of Persons with Disabilities (on Albanian Government's Initial Report on the Convention on the Rights of Persons with Disabilities)

<sup>25</sup> Dunja Mijatović, 2018. Report of the Commissioner for human rights of the Council of Europe. Following her visit to Albania from 21 to 25 May 2018

<sup>26</sup> Ibid.

towards deinstitutionalisation, there remain persons with intellectual and psycho-social disabilities, including children, in institutions for social care in Albania. The Commissioner calls the authorities to draw up and implement, with the active involvement of persons with disabilities, a comprehensive plan for deinstitutionalisation and the replacement of institutions with community-based services, while ensuring that no deinstitutionalised person with a disability is left without the necessary protection and support. Abstaining from any new placement of persons with disabilities in institutional settings and ensuring that such persons are provided with community-based services would be an important step in the right direction.

## 4.6 Adults with disabilities at work

Many studies have shown that the onset of disability may lead to lower living standards and poverty through adverse impact on education, employment, earnings, and increased expenditures related to disability. Stigma associated with a health condition may lead to activity limitations and participation restrictions given a particular social and cultural context and it might be worsened by the stigma associated with poverty. Environmental factors due to limited resources in the community, leading for instance to an inaccessible physical environment, make it difficult for an individual with a disability to have activities and participate in the community, further reinforcing poverty and social exclusion. Conversely, poverty may also increase the likelihood that a health condition may result in disability or impairment, activity limitation, or participation restriction. This could be the case if there is a lack of health care and rehabilitation services or a lack of resources to access those that are available. In poor communities where such services are not provided or are of low quality, health conditions may be more likely to lead to disability and even when such services are available, they may not be affordable.

People with disabilities are much less likely to participate in the labour market than their nondisabled peers. According to various studies, half of the non-disabled adult population is engaged in the labour market, while 8 in 10 disabled working-age adults are out of the labour force, i.e. neither working nor looking for work.<sup>27</sup> Consequently, disabled adults are about 5 times less likely to be working than the non-disabled population.<sup>28</sup> There are no stark gender disparities, as both non-disabled men and women are both about 5 times more likely to be engaged in employment as respectively disabled men and women. This tendency seems to be the same also in other transition countries, where evidences shows that disabled working-age adults are systematically less likely to work than non-disabled adults: this ranges from a high of 60 percentage points less likely to work in Moldova, to a low of 20 percentage points in Bosnia and Herzegovina. In addition, workers with disability are much more likely to be

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<sup>27</sup> UN Project Document “Leave No One Behind”

<sup>28</sup> INSTAT. 2015. Profiles of Disabled Population in Albania

working as family workers or self-employed without employees than their valid counterparts. The barriers that these disadvantaged groups face, are mainly linked to their low level of education to meet the requirements of market economy and discriminatory attitudes of employers.

According to INSTAT study (2015), there is a higher prevalence of holders of low quality jobs in the disabled working population. Disabled workers are twice as likely to be engaged in activities with the lowest skill level, i.e. people engaged in elementary occupations. They are also more likely to be engaged in the second lowest skill level, i.e. clerical support, services and sales, skilled agricultural, forestry and fishery, crafts, and plant and machine operations. The correlation between low quality jobs and disability may highlight two factors: (i) low quality jobs may pose higher health hazard, resulting in higher share of low skilled workers experiencing disability, and (ii) low productivity jobs and the resulting lack of resources may lead to the lack of or limited access to health and rehabilitation leading to onset of disability.

In addition, it is useful to recognize the heterogeneity among the disabled population in this context, because some of the disabled may be more disadvantaged in terms of employment compared to the rest. Those with cognitive, self-care and communication restrictions emerge as the most disadvantaged in terms of employment prospects. Individuals with physical restrictions are more likely to work, and also more likely to want to work: people with vision, hearing and mobility impairments are 2 to 3 times more likely to be employed than people with severe difficulties in concentration, self-care and communication. Furthermore, people with vision limitations, especially the youth, record very high probabilities of being unemployed: 1 in 5 visually-impaired youth is not working but looking for a job and ready to take one, suggesting strong barriers to employment for people who would prefer to work.

The National Employment and Skills Strategy 2014-2020, aiming to increase social assistance beneficiaries through mobilization in community works and increasing employment access of people with disabilities through tailor-made vocational training courses. The Strategy notes that barriers to PWD's benefiting from VET (including: physical accessibility to VET courses, lack of adequately trained educators, lack of adequate materials, limited information, reluctance by companies as well as public institutions to hire PWDs, missing accompanying support services to PWDs and their care-givers, and transportation issues) will be have to be addressed by adequate measures.<sup>29</sup> However, the most of the CSOs have emphasised the slow pace of implementation of both the 2016 National Action Plan on Persons with Disabilities as well as the National Employment and Skills Strategy. The employment quota introduced by the authorities, which mandates the employment of one person with disability per 25 employed persons, has not yielded the expected results. Accordingly, one of the important areas in which the public authorities need to make more progress relates to the access of persons with disabilities to the labour market.

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<sup>29</sup> Albanian National Employment and Skills Strategy 2014-2020

## 4.7 Children with disabilities in education system

As in other sectors, education has undergone several reforms in the last five years, complemented recently with a new strategy for pre-university education. Regardless of targets defined for children with disabilities, clear inclusion approaches are generally overlooked in the strategy. The revision of curricula and improvement of pre- and in-service teacher training are highlighted actions in the government policies for the near future. Considering the ambitious targets presented, and the limited financial resources allocated, it is to be seen how these priorities will compete against others. The 2012 Law on Pre-University Education provides for free and mandatory education without discrimination on any ground, including ethnicity or disability. Albania has significantly increased access to all levels of education, reaching the level in which primary and lower secondary enrolment is nearly universal. Nonetheless, some children remain excluded from mainstream education due to a number of factors, in particular disability, extreme poverty and migration.<sup>30</sup> The children with disabilities are among most at risk of being out of school in Albania.

The 2012 Law on Pre-University Education stipulates that “the education of children with disabilities in special schools is temporary and that their integration in mainstream education shall be a priority”. The law also provides that every child with disabilities shall be provided with an assistant teacher and rehabilitative services according to their needs. Additionally, one of the strategic objectives of the 2016 National Action Plan on the Rights of Persons with Disabilities is to ensure access to quality and inclusive education for children with disabilities.

There is no reliable updated data on the number of children with disabilities living in Albania and often different sources of data are contradictory. Disabled children were not required to complete compulsory schooling in Albania, therefore data on them remain uncertain and record keeping is unreliable. The main barriers for children with disabilities are the inaccessibility of education facilities, the lack of support teachers in basic education, textbooks for mainstream education are not available in accessible formats (Braille, or digital for children with hearing problems), the lack of multidisciplinary teams to establish child’s needs for assistance and support, lack of physical access to schools and school facilities, as well as discrimination and prejudice against them.<sup>31</sup>

While various studies show different figures, they show almost the same tendency about education of children with disabilities. An recent child disability assessment,<sup>32</sup> the majority of the children with disabilities pursuing education (94.3%) attend nurseries, kindergartens or mainstream schools, 4.4% attend special educational institutions and 1.3% attend vocational

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<sup>30</sup> Dunja Mijatović, 2018. Report of the Commissioner for human rights of the Council of Europe. Following her visit to Albania from 21 to 25 May 2018

<sup>31</sup> UNICEF, 2017. Albania The cost of Underinvestment in Education: And ways to reduce it.

<sup>32</sup> Voko K. Kulla F., 2018. Child disability in Albania: Disability prevalence, access to services and quality of services. Save the Children

schools. There is a high risk for children with disabilities who, due to the limited provision of special education, are likely to never enrol or to drop out early.<sup>33</sup> According to INSTAT, while 96 % of children aged 6 to 14 in the non-disabled population are attending school, only 75 % of children with some disabilities are enrolled. The numbers are slightly higher for girls compared to boys – respectively 7 and 4 %.<sup>34</sup> The picture varies greatly by type of disability faced by children: more than two thirds of the children with eyesight, communication, cognition and self-care impairments are enrolled in school. On the other hand, only half of children with hearing difficulties or mobility difficulties are attending schools. In addition, children living in households led by a disabled household head are less likely to attend school. The difference is not so stark for primary-school-aged children, who are 1.8 % points less likely to go to school when their father or mother has a disability. but it is quite significant when looking at youth aged 15 to 24: if the household head is valid, the probability of their children being enrolled in school is 49 %, but if your household head is disabled, that probability drops to 38 %, or 20 % less.

Consequently, disabled persons display lower educational attainment than their valid peers. While less than 3 % of non-disabled adults never attended school, one in four disabled adults was not able to attend school, the vast majority of which remained illiterate. This is particularly true for youth (15-24 years-old) who experienced physical and cognitive restrictions early on in their lives, as educational facilities adapted to their needs may not be available, accessible and/or affordable. In addition, according to INSTAT, one adult with a disability in four was not able to attend school, the vast majority of which remains illiterate. The education gap between non-disabled and disabled individuals is thus huge: individuals with disabilities are much more likely to stay out of the school system, and when they do attend, they are more likely to drop out of the education system after primary school. 2011 Census data show that only 55.6% of persons with disabilities over 15 years of age have completed basic education. Only 3.3% of persons with disabilities have completed (post)university studies and almost a quarter (24.3 %) never attended education. The education gap between non-disabled and disabled individuals is thus huge: individuals with disabilities are much more likely to stay out of the school system, and when they do attend, they are more likely to stop after primary school.<sup>35</sup>

Although the law provides for the right of children with disabilities to receive assistance in schools, including by assistant teachers, in most cases the funding for such assistance is lacking. The scarcity of funding and of available specialised staff is in fact conducive to the concentration of children with disabilities in special schools, in segregated settings. There are currently ten special schools in Albania attended by about 700 children with disabilities, including the special school “3 qershor” in Shkodra. In this school children with different

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<sup>33</sup> Cuninghame C. & Hallkaj E., 2015. Child Rights Situation Analysis 2012-2015. Tirana. Save the Children in Albania

<sup>34</sup> INSTAT. 2015. Profiles of Disabled Population in Albania

<sup>35</sup> Ibid.

types and levels of disabilities and of different ages are educated together. In the recent years, the government opened two new development centres for persons with disabilities in Pogradec and Bulqiza, supported by the UNDP, and three day-care centres for children with disabilities in Pogradec, Saranda, and Permet.<sup>36</sup> In addition, the number of assistant teachers has increased (to about 620), to ensure that every child with disabilities who needs such assistance is provided with it in mainstream schools. However, despite the increased number of assistant teachers, their qualification to deal with children with disabilities and children in difficulties remain generally very low.

For children with disabilities already in the education system, the curricula are inappropriate and/or are not designed for them. No additional or special resources and equipment are provided to support appropriate teaching and learning processes. Teachers are unqualified in how to meet the needs of the children and are unmotivated to make significant changes to their normal teaching style. They continue to use "tried and tested" authoritarian approaches, failing to use inclusive teaching methods.<sup>37</sup> Children with disabilities are not only denied equal access to education, but become more vulnerable to stigmatization by their peers. Furthermore, this exclusion is magnified by the complete lack of participation mechanisms for children with disabilities.<sup>38</sup> Sustained opportunities for these children to representation themselves have not been established, apart from in selective instances of consultation among a limited number of individuals in public activities or events.

Environmental barriers hamper access to school and services among children with disabilities. Generally, the physical infrastructure of buildings in Albania is not adapted to their needs. A lack of suitable transport is a further trigger for their access difficulties.<sup>39</sup> Following the administrative reform in Albania, there is not yet clear how national and local government share responsibilities for physical infrastructure investments to improve accessibility for both children and adults is only vaguely defined.

About 96% of families of children with disabilities earn low or meagre incomes. The majority of these families (78.8%) consist of a large number of members (4-6) and the parents' unemployment rate is quite high. High correlation between poverty and disability implicates the need to find innovative, cost effective schemes to support to these families. About 36% of mothers and 32% of fathers of children with disabilities have basic or lower compulsory education. Also, approximately 58% of mothers and 33% of fathers are unemployed or have part-time or seasonal jobs.<sup>40</sup>

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<sup>36</sup> Country Report on Human Rights Practices 2018 - Albania

<sup>37</sup> Cuninghame C. & Hallkaj E., 2015. Child Rights Situation Analysis 2012-2015. Tirana. Save the Children in Albania

<sup>38</sup> Partners for Children & Peoples Advocate. 2015. Monitoring of People with Disability access to Services - Draft report of findings and recommendations. Tirana

<sup>39</sup> Ibid.

<sup>40</sup> Voko K. Kulla F., 2018. Child disability in Albania: Disability prevalence, access to services and quality of services. Save the Children

While Albania has made significant strides towards advancing the education agenda (especially in including the principle of inclusive education and the prohibition of discrimination in education are enshrined in Albanian legislation), there are still gaps to be bridged with regard to sustaining universal rates in primary education, improving quality of education, increase access and quality of preschool education and reduce disparities with a focus on ethnic minority children and children with disability.<sup>41</sup> Considerable time will be required before the new policy measures can be translated into inclusive practice in schools. Meanwhile, children with disabilities in kindergartens and in schools will continue to face daily challenges. The authorities are called upon to pursue vigorously their efforts to ensure that all children with disabilities are included in and benefit from the necessary individual support and reasonable accommodation in mainstream education settings.<sup>42</sup>

The Commissioner for Human Rights of the Council of Europe<sup>43</sup> underlines that the exclusion of children with disabilities from mainstream education further reinforces and legitimises their marginalisation in the later stages of their lives. The Commissioner emphasise that the placement of students with disabilities in mainstream classes can only be successful if accompanied by structural changes. She urges the authorities to take measures to ensure that children with special education needs effectively benefit from individual support and reasonable accommodation in mainstream settings, in accordance with Article 24 UN CRPD. Such measures should be accompanied by a clear and ambitious timetable and an adequate budget. The transfer of children from special to mainstream education should be based on accurate statistical data concerning children with disabilities enrolled in special education or home schooling. The Commissioner calls upon authorities to pursue vigorously their efforts to ensure that all children with disabilities are included in and benefit from the necessary individual support and reasonable accommodation in mainstream education settings.

## 4.8 Mental health in minors, adults and elders

Factors that contribute in the occurrence of mental health problems are different. According to the WHO data, the higher levels of psychiatric morbidity are associated with poor living conditions in large urban conglomerates, as social groups living in adverse situations under chronic stress would be more likely to present mental disorders. Also social exclusion, amplified by poor access to education, was reported to be an important risk factor for mental disorders.

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<sup>41</sup> UNICEF, 2017. Albania The cost of Underinvestment in Education: And ways to reduce it.

<sup>42</sup> Dunja Mijatović, 2018. Report of the Commissioner for human rights of the Council of Europe. Following her visit to Albania from 21 to 25 May 2018

<sup>43</sup> Ibid.

While there are not reliable data at national level, in a recent independent study<sup>44</sup> conducted in Shkoder region, the incidence (per 100.000 residents) of mental disorder resulted to be 3,786.2 persons (out of a total the 6,287 patients' records). Stratified by sex, men were more predominant in our study compared to women: 3,766 (59.9%) and 2,521 (40.1%), respectively. The minimum age was 5 years old and the maximum 85 years old; the average age was 43±4 years. About 3,544 (56.37%) patients were residing in rural areas and 2,743 (43.63%) were from urban areas. The most prevalent mental disorder in this study was Schizophrenia with 2,884 (45.87%) patients. More than 765 (12.16%) patients reported a lifetime history of depressive disorders, 739 (9.17%) affective disorders and 477 (7.6%) mental retardation. Personality disorders and any alcohol or drugs disorders were 3.56% and 2.67% respectively. The other patients reported a life time history of any delusional disorders; anxiety disorder 1.14%; any mood disorder 3.56%; bipolar disorder 1.81%; and epilepsy, dementia and Alzheimer 0.63%, 0.68% and 0.17% respectively. Major depression and specific phobia were the most common single mental disorders. Women were more likely to suffer from mood, anxiety and depressive disorders compared to men, while men were more likely to suffer alcohol and drugs abuse disorders. In conclusion, mental disorders were quite frequent in the region, with predominance of Schizophrenia. The mental health problems were more common in men, in patients residing in rural area and among the unemployed individuals. Young people and the active age-group were also more likely to experience mental disorders indicating an early age of onset for mood, anxiety and alcohol disorders.

The Civil Code includes definitions of mental health status that entail mental disorders, as they are now referred to in the Law on Mental Health (2012). This law clearly states the rights of the children with disabilities to integrated and inclusive services. The law in its definitions allows treatment of a person without his consent. This is referred to as "involuntary treatment" and is authorized through a court decision. It results in the person's placement in a psychiatric facility and allows for other medical procedures to be conducted while placed in the facility. The law also provides for voluntary treatment, for persons with partial capacity to act, when the decision for the treatment is approved by the legal guardian. As previously discussed above, it is obvious that this provision is contrary to the CRPD, giving total power to the legal guardian to determine the medical treatment.

The situation becomes more complicated in the instances of involuntary treatment. The law provides that involuntary treatment takes place only under special circumstances, and must be undertaken only by a specialized doctor, where three concomitant conditions are met: a) where there is a severe mental disorder that impairs the person's ability to understand or control his/her behaviour; and b) without receiving involuntary treatment a person's life or security and those of others is at stake; and c) all existing possibilities have been exhausted

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<sup>44</sup> Gusha K., et al. 2018. Epidemiological profile of mental disorders in Shkoder, Albania. <http://web.keminet.al/amj2/?p=2946> (checked on 5 May 2019)

for treatment in the community, and the necessary medication can only be provided through hospitalization, in keeping with the principles of the less restrictive alternative.<sup>45</sup>

The Criminal Code of Republic of Albania focuses on the criminal responsibility of either people (a) lacking legal capacity or those people (b) deemed to be “insane” tempore criminis. The Code has an exclusion from criminal responsibility if a person tempore criminis “suffered from psychiatric and neuropsychiatric disorders ruining his mental balance entirely and, consequently, was unable either to control his actions or omissions, or to understand that he/she is committing a criminal act.” Partial culpability is imposed if the person had only a partial “mental imbalance” when commencing the criminal act. However, this is significantly different from the situation of exclusion from criminal responsibility based on “mental imbalance”

There is also an existing gap between laws, when combined with Mental Health Law and it remains unclear whether the involuntary hospitalization may continue after the court takes a decision. When connected to Mental Health Law, this is not impossible in practice since the person can be involuntarily treated if posing a required type and degree of danger, but it seems that after criminal proceedings finish and only the civil courts would deal with the person(s) concerned. What raises a significant problem in that sense is that there is no an expiration date; a person may be indefinitely placed in a psychiatric hospital under the Albanian law, if considered to be posing a danger to others due to mental disorder, which, when taken within the light of a criminal sanction, results in life-long sentences.

Despite this, the complete harmonisation of legislation with Article 26 of CRPD, which obliges the Albanian state to guarantee developmental and rehabilitation services in the sectors of health, employment and education towards autonomy, complete mental, physical, social, vocational training, inclusion and participation in all aspects of life, will require more time. In addition, the National Action Plan for Persons with Disabilities (2016-2020), regardless of the innovations with respect to implementation of persons with disabilities rights, does not contain sufficient specific objectives for children with disabilities. Its main objectives are treatment and rehabilitation, notwithstanding the great gap to provision of community-based services that do not prioritise prevention and early identification of children with disabilities.<sup>46</sup>

Persons with disabilities are entitled to free health care services, but they face difficulties to access the healthcare centres and hospitals. Rehabilitation and treatment services for persons with disabilities are limited in number, range and quality, inaccessible to the majority of people with a disability and/or not functional, particularly those intended for children with disabilities. The Office of the Ombudsman inspected only a few mental health institutions. Both the admission and release of patients at mental health institutions were problematic

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<sup>45</sup> ADRF, 2016. Country Report: Deprivation of the Capacity to Act in Albania.

<sup>46</sup> Ibid.

due to inadequate psychiatric evaluations. There was societal discrimination and stigmatization of persons with mental and other disabilities.<sup>47</sup>

Mental health services in Albania have a traditional profile, focusing on psychiatric, neurologic or shamanic treatments. Mental health patients are usually treated in psychiatric ambulatory settings, psychiatric hospitals or psychiatric cabinets. The process of services decentralization and psychiatric hospital patients' deinstitutionalization has been associated with the services typology change and the expanding range of professionals involved in mental health services. The number of mental health professionals in Albania is very low in comparison to the European countries number. Proper identification of human resources remains difficult, due to the confusion that existed with the health authorities on the differences between neurologists and psychiatrists. Mental health professionals for children and adolescents are mainly concentrated in Tirana, making it difficult to obtain such services in other regions of the country. Meanwhile there are other data that confirm the lack of mental health professionals' retrieved from "Mental Health Atlas 2011". Comparing the rate of WHO serves to highlight the great difference that exists between the Albanian reality and what is recommended by the WHO.<sup>48</sup>

In addition, mental health services in Albania suffer a total lack of alternative and multidisciplinary treatment, enormous problems with assessment of patients' problems and treatment outcome. Despite the increasing number of psychologists, social workers or occupational therapists in recent years, the country continues to suffer from a substantial variation in coverage of human resources by geographical area, creating obstacle in the population's access to mental health services and to a more specialized referral system. While some progress has been made in development of private services, the main pathway to get psychiatric treatment in Albania still remains through hospital doctors. Establishment of new services based on previously unknown community was followed by the drafting of job descriptions, as well as role details, responsibilities and competencies of each professional within the integrated network of mental health services.<sup>49</sup>

In addition, unlike the situation associated with the use of the general health services, the use of specialised health services by children are very few, thus showing great differences between children with and without disabilities. According to an independent study,<sup>50</sup> about 41.8% of children with disabilities and only 9.8% of children without disabilities have been evaluated by at least one specialised professional, such as: logopedist, child psychologist, social worker, child psychiatrist, physiotherapist, ENT doctor, ophthalmologist, neurologist, etc. The main reasons provided by parents of children with or without disabilities are: not

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<sup>47</sup> Country Report on Human Rights Practices 2018 - Albania

<sup>48</sup> Frasheri E. 2016. Problems and challenges of mental health professional in Albania during the process of decentralization of mental health services. *European Journal of Research in Social Sciences* Vol. 4 No. 6

<sup>49</sup> Ibid.

<sup>50</sup> Voko K. Kulla F., 2018. Child disability in Albania: Disability prevalence, access to services and quality of services. Save the Children

being able to afford the financial costs for receiving the service, lack of transport and lack of the service provision in the community, and poor quality of services.

According to Voko et al., (2018), a considerable number of children demonstrate difficulties especially in the emotional aspect. This important data suggests the need for more focus on awareness regarding mental health, preventive and treatment services on mental health in community and schools; training of parents; education, social and health professionals. This focus also needs to expand at the community level in order to identify, acknowledge, and treat difficulties related to mental health; the promotion of safe spaces in schools, family and community; awareness of the value of respect and dignity for the children; positive parenting etc., which are all factors which might lead to the decrease of prevalence and treatment of this number of children having difficulties in this aspect.

## 4.9 Multiple stigma and discrimination

Despite some progress made in the recent years in Albania, social norms that stigmatise persons with disabilities and their families continue to create barriers to inclusion and further worsen their discrimination. This stigma and discrimination can come from both the family and the community and often occurs due to lack of knowledge of what disability is. Stigma associated with a health condition may lead to activity limitations and participation restrictions given a particular social and cultural context. In addition, families of persons with disabilities are also likely to be economically disadvantaged and this can compound the stigma they experience in the community, limit access to general social services, as well as access to social and economic opportunities.

Several studies affirm that children with disabilities in Albania and their families experience multiple stigma, discrimination and social exclusion in four main different settings: in the community, educational institutions, while playing with peers, in their communities and at other public services the child received. According to Voko et al., (2018)<sup>51</sup> one in two children in this group experience some level of discrimination in the community (52.9%), in educational institutions (52.4%) and while playing with peers (54.9%), whilst 1 in 3 experience discrimination in other public institutions, as well as health or social institutions. Children and parents perceive stigma as the root cause of the challenges they face, limiting their opportunities and increasing their vulnerability to neglect and violence.

As the children become adolescents and begin to think about their independence the dissonance between the ambitions of children and those of their families may exacerbate existing tensions arising from stigma, discrimination and lack of opportunity.

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<sup>51</sup> Voko K. Kulla F., 2018. Child disability in Albania: Disability prevalence, access to services and quality of services. Save the Children

## 5. MAIN RECOMMENDATIONS

This section summarises the main recommendations made by participants in the working group sessions, held by the project with a large number of stakeholders including, representatives of organizations of persons with disabilities, other relevant civil society organizations, central government institutions as well as various international organizations and development projects working with PWD in Albania. While some of these recommendations made by participants may not be new to the readers, they are based both on various documentary reviews (previous reports and assessment made by different actors) as well based on their expended personal and professional experience in working with PWD in Albania. While the number of recommendations made have been very large and covering a wide range of topics, the following ones have been selected as the most important one that would need to be tackled with priority:

**1. Ensure full harmonisation of Albanian laws with CRPD:** The legislation is not consistent and not yet in full compliance with the Convention on the Rights of Persons with Disabilities (CRPD) and various pieces of legislation run contrary to the standards and rulings of ECHR. The public authorities should:

- 2. repeal of the existing legislation, starting with the Family Code, Civil Code, and Civil Procedure Code, the Law on Inclusion and Accessibility** regarding elimination of the deprivation of legal capacity to act for persons with disabilities;
- 3. review, clarify and harmonize** (ensuring its proper translation into Albanian language) **on the legal capacity** to act throughout the various legal acts in Albania.

**4. Improving accessibility:** Recalling Article 9 of the CRPD, it was emphasised that accessibility is a precondition for the full realisation of the rights and inclusion of persons with disabilities in society. The public authorities should step up their actions to ensure that persons with disabilities have access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

**5. Development of supported decision-making:** The public authorities should develop laws and policies to replace the regime of substituted decision-making with supported decision-making. In the meantime, while the guardianship system remains in place, the Albanian authorities should ensure that this does not amount to a full deprivation of legal capacity, and that persons placed under guardianship have effective access to judicial review proceedings to challenge the guardianship or the way in which it is administered. They should always be recognised as persons with equal standing in courts and tribunals and empowered to effectively challenge any interference with their right to legal capacity. In addition, until the supported decision-making is fully implemented, there is need to

clarify/redefine and put in place the legal and procedural mechanisms necessary for monitoring the exercise of duties by the legal guardian and support persons, in order to ensure that all their decisions and actions are made on the basis of expressed will of persons with disabilities that they represent or support, or on the best interpretation possible of such will/intention.

**6. Introduce the concept and roles of "personal assistance":** The public authorities should substitute in all the legislation and the policy measures the concept of "carer" (usually referring to assistance with physical needs such as washing, bathing, dressing, feeding and related chores) with the concept of "personal assistant" (a broader concept encompassing both aspects of enabling a person with disabilities to overcome barriers, by providing a hand or completing tasks that the person with disabilities physically cannot do, as well as providing support in decision making or communication assistance).

**7. Development of community based services:** Isolating persons with disabilities in institutions perpetuates their stigmatisation and social marginalisation, in violation of their right to live independently in the community, guaranteed by Article 19 of CRPD. The public authorities should adopt a clear deinstitutionalisation plan, replacing institutions with community-based services. Abstaining from any new placement of persons with disabilities in the institutional settings would be an important step in this direction. The authorities should prove their commitment to reforming the health and social care system for persons with disabilities by closing down residential institutions and allocating adequate resources for the development of community-based alternatives. Given that Albania is at the very beginning of this process it is very important that there is no unambiguous understanding of what the right to live in the community means. It needs to be ensured that big residential institutions are not replaced with small ones which resemble the previous model and that an individual's ability to choose or interact with others or be included in the community is not compromised.

**8. Development and increased effectiveness of free legal aid services:** The public authorities should increase their efforts to further develop and ensure an effective implementation of the 2017 Law on Legal Aid, with a view to facilitating effective access to justice for vulnerable persons and persons with economic difficulties, and to raise awareness among the broader public about the availability of free legal aid. The public authorities should also further increase their engagement with and make better use of civil society organisations which provide legal aid and draw on their extensive experience in this field.

**9. Information and awareness about capacity to act of PWD:** The level of information and awareness about capacity to act of people with disabilities remains still very low among the society and all stakeholders involved, including public institutions and service providers. There is need to:

**10. define and implement wide and effective information, awareness and capacity building campaigns,** targeting the community of persons with disabilities,

their parents, law professionals, and social science professionals, civil society organizations, and (very importantly) public institutions and public service providers, in order to uproot the prejudice against the abilities of people with disabilities to be decision-makers in their own right, and fight the existing harmful stereotypes and mind-sets;

**11. define and implement effective training sessions with psychiatrists and others working in hospitals, centres or social workers**, offering legal expertise/opinions as well as public officials, police, prosecutors and judges requesting and/or accepting such expertise/opinions.

**12. Fostering economic and social inclusion of PWD**: the participants urge the public authorities to:

**13. develop and implement more effective inter-institutional and inter-stakeholder cooperation mechanisms**, and foster engagement of public and private sector for increased social inclusion of persons with disabilities;

**14. define and implement project/interventions to support persons with disabilities of more than 18 years old** to develop their social autonomy potential their intellect and self-decision-making skills through therapies and other services;

**15. strengthen the capacities of community of persons with disabilities and their organizations** to raise the voice and advocate more widely and effectively for their rights.

**16. Improve access to and quality of education services for PWD**: It is very important to speed up improvement of access to school for children with disabilities, by providing assistance and transport, as well as safer and accessible schools. For the children with disabilities already in the education system, there is need to improve the curricula and/or redesign the appropriate one for them. There is need more special resources and equipment to be provided to support appropriate teaching and learning processes. Very important also, the is significant need to foster the efforts in improving the qualification of the teachers in how to meet the needs of the children with disabilities and find effective ways to motivate them to make changes to their normal teaching style.