Strengthening primary Medical care in IsoLated and deprived cross-border arEas

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Constraints' analysis to access PHC

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Description:	The current document is the Deliverable 4.2.1 Deliverable 4.2.1 identifies constraints that disabled persons encounter in PHC access, based on both literature research and interviews carries out with disabled persons and PHC practitioners.
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Project Partners

Role	Partner name	Country
Lead Beneficiary	4th Health District of Macedonia Thrace	Greece
Partner Beneficiary 2	Aristotle University of Thessaloniki - Special Account for Research Fund (Department of Medicine)	Greece
Partner Beneficiary 3	Multi-profile Hospital for Active Treatment of Ardino	Bulgaria
Partner Beneficiary 4	Municipality of Harmanli	Bulgaria
Partner Beneficiary 5	National Emergency Aid Center	Greece

Short presentation of the programme

The Cooperation Programme "Greece-Bulgaria 2014-2020" was approved by the European Commission on 09/09/2015 by Decision C(2015) 6283. The total budget (ERDF and national contribution) for the European Territorial Programme "Greece-Bulgaria 2007-2013" is €129,695,572.00. The total financing consists of €110.241.234,00 (85%) ERDF funding and €19.434.338,00 (15%) national contribution. The eligible area of the Programme consists of the Region of Eastern Macedonia-Thrace (Regional Units of Evros, Kavala, Xanthi, Rodopi and Drama) and the Region of Central Macedonia (Regional Units of Thessaloniki and Serres) in Greece and the South-Central Planning Region and South-West Planning Region (Districts of Blagoevgrad, Smolyan, Kardjali and Haskovo) in Bulgaria. The Priority Axes are PA 1: A competitive and Innovative Cross-Border area, PA 2: A Sustainable and climate adaptable Cross-Border area PA, 3: A better interconnected Cross-Border area, PA 4: A socially inclusive Cross-Border area.

Abbreviations

AMA: American Medical Association

EKAV: Greek National First Aid Center

PEDY: National Primary Health Network

UN: United Nations

UPIAS: Union of the Physically Impaired Against Segregation

WHO: World Health Organization

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1 Introduction

World Health Organization and the World Bank estimate that, in the end of the last decade, more than one billion people were living with some form of disability (WHO & World Bank, 2011, p. xi). The improvement of standards of living, often seen as "ageing", and the estimated increase of life expectancy contribute to the increase of the part of the population that will be living with disabilities in the near future. Experts depict this increase as "dramatic", both in developed and in developing countries, and as an evolution with significant political and financial implications (IDF, 1998; Barnes, Oliver and Barton, 2002, p. 2).

This condition represents a major challenge for policy making, starting from the answer to the question "what is disability", which constitutes a demanding academic and political experiment (Aday & Andersen, 1974, p. 208). World Health Organization' s International Classification of Functioning, Disability and Health (WHO, 2001) has pointed a shift for health policy on disabilities, as, instead of continuing on the path of previous conceptual models of disability, it focused in a wide spectrum of environmental factors, both natural and social, which constitute either barriers or facilitators to access to health for persons with disabilities: structured environment, social support and relations, services and policies (WHO & World Bank, 2011, p. 5).

The widening of perspective on disabilities permitted to relate disability politics and facilitators for persons with disabilities with other groups facing difficulties in their everyday activities because of environmental barriers: pregnant women, pre-school children, elderly. In Greece, the amount of population with usual disabilities is estimated at 9,3%, while the amount of the population facing limitations in their everyday activities reach up to 48% (Naniopoulos & Tsalis, 2016 ·YPECHODE, 1997).

Starting from the community level, where primary healthcare services are involved, studies show that people with disabilities often do feel healthy and can be successful in managing their own health needs if they receive the appropriate support and information (Watson, 2002; Nazli, 2012). Yet, these needs are not adequately met, due to several access and attitudinal barriers (Shakespeare T. and Kleine I., 2013). Some of these barriers reflect the strength of disability medicalization (Conrad, 1992), that is to say of the explanation and the treatment of socio-economic and environmental burdens as medical ones, related exclusively to impairment.

The austerity measures undertaken since 2010 have increased socio-economic burdens, leading to a reduction in health care coverage (which has left out 2.5 million Greeks, since health care coverage is linked to employment until 2015), and in the health benefits they are entitled to by the coverage (Smith, 2017; World Health Organisation, 2016). In studies conducted after 2015, people with disabilities in Greece were reporting higher unmet health care needs compared to non-disabled people, with transportation, cost and long waiting lists being the main barriers (Rotarou and Sakellariou, 2017). Once more, the identification of

social and environmental barriers proved to be a significant orientation for social and medical research.
In the framework of the interregional program "Strengthening primary Medical care in Isolated and deprived cross-border Areas [(SMILE)-INTEREGG V-A cooperation program: Greece-Bulgaria]", we conducted a qualitative study on barriers to access to primary healthcare, based on semi-structured interviews with 15 health professionals (phsysicians, nurses, administrative staff) and 10 persons with disabilities (4 of whom with visual impairment and 6 with hearing impairment).

Our study is articulated in five parts. In Chpater 2, we analyze the main approaches (models) to disability, exposing the basic assumptions of each one and relating them to the diverse orientations for health policy that they imply. In Chapter 3 we examine the concepts of access and accessibility, summarizing environmental, socio-economic and professional competence related barriers, as identified in disability studies literature. In Chapter 4 we outline our study design and the methods followed and in Chapter 5 we present our findings. Finally, in Chapter 6 we discuss our main results, taking into consideration the suggestions proposed by the professionals and the persons with disabilities interviewed.

2 What is disability? Concepts and models

In non-academic discourse, the terms "disability" and "impairment" are commonly used interchangeably without distinction: disability is considered to be a synonym of impairment, and a person's physical impairment is sufficient to qualify (and label) that person as disabled. However, the evolution of the theoretical discussion of disability from the mid-1960s to the present shows that the choice of terminology has different connotations.

In 1992, the American Medical Association (AMA) distinguished between impairment and disability, explaining that impairment "is a medical concept involving a change in one's health status" and that "impairment results from illness or disease". On the other hand, disability "is a non-medical phenomenon, essentially the difference between an impaired individual's capacities and the social or occupational demands of a particular situation"(AMA, 1992).

Therefore, the terms "impairment" and "disability" take on different meanings within the different theoretical-methodological models of health and disability. The theoretical model is a set of guiding assumptions, thoughts, and suggestions about the nature of phenomena or human experience, which is often appointed as an understanding tool and an action guide (Smart, 2001: p. 33). In what concerns disability in particular, the adoption of each of these models is also linked to different orientations in health policy (Smart, 2004). In the case of disability, the main distinction supported by a wide range of scientists (doctors, epidemiologists, social scientists, philosophers), is the one between the *biomedical-individual* and the *social model of disability* (Engel, 1977; Smart, 2004; Giddens, 2009).

As shown in Table 1, the individual model approaches disability from the standpoint of personal tragedy, as an individual problem that requires individual treatment and individual adjustment, and therefore falls solely within the competence of specialized health professionals and targeted policies.

In contrast, the social model places disability within the context of social relations in which it manifests itself. It emphasizes social action and radical policy change, and, instead of medicalizing disability, it proposes social change: elimination of discrimination against people with disabilities, de-professionalization of healthcare towards self-help, distinction of disability experiences, guarantee of rights through politics.

Table 1: Individual and social model of disability (Oliver, 1996 [adapted by Giddens, 2009])

Individual model	Social model
Personal tragedy model	Social oppression theory
Personal problem	Social problem
Individual treatment	Social action
Medicalization	Self-help
Professional dominance	Individual and collective responsibility
Expertise	Experience

Individual identity	Collective identity
Prejudice	Discrimination
Care	Rights
Control	Choice
Policy	Politics
Individual adjustment	Social change

Despite the challenges, the individual-biomedical model remains strong, along with the charity model that sees caring for people with disabilities as a case of charity (UN, 2014). One explanation suggested for its strength is the fact that it was linked to a long tradition in the health sciences, in which it was adopted as the most objective model (Smart, 2004). This scientific tradition was founded on the mechanistic paradigm of health in the 17th and 18th centuries, and on the positivism of 19th-century physiologists.

The basic assumption of the mechanistic model was that every living being was subject to the laws of simple machines: the body was a machine, disease was the result of that machine's collapse, and the task of the physician-engineer was to repair it. (Engel, 1977; Canguilhem, 2015). As early as in the 1940s, however, physician and philosopher Georges Canguilhem had disputed these views, together with the positivist position of Auguste Comte, who had proposed that health meant normality (the "normal") and the only norm, "real order" (Geroulanos & Meyers, 2012, p. 2-3; Marietti, 2000/1994).

For Canguilhem, illness (and therefore disability) is not a visible abnormality. As long as we fail even to think of an organism that never gets sick as 'normal', then the pathological is also a kind of normal (Canguilhem, 2012): a version of biological norm, albeit pathological, that departs from normality only in relation to a determined situation (Canguilhem, 2007, p. 243). For Canguilhem, the norm is a convention, established on the basis of values that prevail in the social environment - and is always relationally instituted. Positivism and the mechanistic paradigm, on the other hand, ignore these relationships.

Another explanation for the strength of the biomedical model emphasizes the dimension of moral bias that, as we have seen in Table 1, links illness (disability) to tragedy. This explanation traces the roots of the biomedical model to the system of religious beliefs that, for centuries, has attributed disability to lack of virtue and moral punishment. The biomedical model has remained popular even after its significant contestation, which we would follow later, because it provided the "scientific" explanation of such a deeply rooted moral and religious prejudice (Bickenbach, 1993).

The biomedical model was seriously challenged hit with the bio-psychosocial definition of health adopted by the World Health Organization in its first statute. According to WHO, "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). This direction gave rise to the formation of the social model of disability, which has been called the 'big idea' of the British disability movement (Hasler, 1993; Shakespeare and Watson, 2002).

The intervention of the Union of the Physically Impaired Against Segregation (UPIAS) has been a landmark moment in the 1970s. For UPIAS,"disability is something we have to deal with. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing, etc. "(UPIAS, 1976, p. 4).

At a similar wavelength, British epidemiologist Geoffrey Rose argued that the causes of disease were primarily economic and political (Rose, 2017). Based on studies of coronary heart disease and depression, he stressed that nature does not provide evidence for a strict distinction between health and illness - normality and pathology. And while, at the level of clinical practice, the difference between the two must somehow be clarified (the clinical treatment of individual illness always presupposes a clear 'yes' or 'no' to the question of whether one gets sick), at the level of population (and thus, of public health policy), we must conversely familiarize with uncertainty: from the beginning of life to the manifestation of illness, any definition of a normal state is a "matter of convention" (Rose, 2017, p. 45). Disease is not a distinct entity: it is not an autonomous existence "somewhere inside" man, supposedly waiting to be brought under control. Health is a state and disease is a spectrum, moving as a whole.

Based on the above, modern approaches tend to regard disability as a spectrum as well, starting from complete autonomy and ending in complete dependence of a person - hence the term "disability situations" (Sherlaw et al., 2014, p. 446). In this spectrum, She and Stapleton distinguish sensory disabilities, functional limitations, mental disabilities, limitations in daily activities (ADLs), limitations in instrumental activities of daily living (IADLs), and work disabilities (She and Stapleton 2006).

In an attempt to reconcile the two conflicting models (WHO, 2001, p. 20), the International Classification of Functioning, Disability and Health proposed by the World Health Organization in 2001 distinguishes disability from impairment by considering disability "an umbrella term for impairments, activity limitations or participation restrictions" (WHO, 2001, p. 3) and explaining that "a person's functioning and disability is a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors "(WHO, 2001, p. 8). On the other hand, "[i]mpairments represent a deviation from certain generally accepted population standards in the biomedical status of the body and its functions, and the definition of their constituents is primarily undertaken by those qualified to judge the physical and mental functioning according to these standards "(WHO, 2001, p. 12). Understood as deviations or losses, impairments can be either permanent or temporary (WHO, 2001).

Even though the United Nations Convention does not fully adopt the social model, it recognizes that disability "is an evolving concept and that disability results from interactions with persons with disabilities and environmental barriers that impede their full and effective participation in society on on an equal basis with others" (UN, 2014). The evolution of the theoretical models of disability is summarized in Table 2:

Table 2: Models of disability, key components and conceptualization (Bickenbach, 2012)

Model	Key components	Conceptualization of 'disability'
Nagi (1965, 1969, 1977, 1991)	• Pathology • Impairment • Functional limitation • Disability	Pattern of behavior that evolves in situations of long-term or continued impairments that are associated with functional limitations
Social (UPIAS, 1976; Oliver 1990, 1992, 1996)	• Impairment • Disability	Limit or loss of opportunities to take part in community life because of physical and social barriers
Verbrugge and Jette (1993)	• Pathology/disease • Impairment • Functioning limitation • Disability	Disability is experiencing difficulty doing activities in any domain of life due to a health or physical problem
Institute of Medicine (Pope and Tarlov, 1991; Brandt and Pope, 1997; Field and Jette 2009)	• Pathology • Impairment • Functional limitation • Disability	The expression of a physical or mental limitation in a social context – the gap between a person's capabilities and the demands of the environment
ICIDH (WHO 1993)	• Impairment • Disability • Handicap	In the context of health experience, any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being
ICIDH-2 (WHO 1997)	Body function and structure (impairment) • Activity (Activity limitation) • Participation (Participation restriction) • Contextual factors: environment and	Disability is an umbrella term comprising impairments as problems in body function or structure as a significant deviation or loss, activity limitations as difficulties an individual may have in the performance of activities, and participation restrictions as problems an individual may have in the manner or extent of involvement in life situations

	personal	
Quebec (DCP) (Fougeyrollas 1989, 1995; Fougeyrollas et al. 1998)	• Risk factors • Personal factors: – organic systems: integrity/impairment – capabilities: ability/ disability • Environmental factors: – facilitator/obstacle – life habits • Social participation/ Handicap	No conceptualization of disability as such, rather a model of the 'disability creation process: 'an explanatory model of the causes and consequences of disease, trauma and other disruptions to a person's integrity and development'
ICF (WHO, 2001)	• Body function and structure (impairment) • Activity (Activity limitation) • Participation (Participation restriction) • Contextual factors: environment and personal	As in ICIDH-2. cf.: 'Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' (Leonardi et al. 2006)

3 Access, accessibility and barriers for persons with disabilities in primary health care

3.1 Access and accessibility

The social model of disability emphasizes the potential exclusion of people with disabilities originating from social relations, economy and the environment. One category of social and environmental barriers are barriers to access to health care and the healthcare services. Even when such services are available to people with disabilities, access is not guaranteed.

The World Health Organization distinguishes three dimensions of access (Evans, Hsu and Boerma, 2016):

- Physical accessibility, that is to say "the availability of good health services within reasonable reach of those who need them and of opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services when they need them".
- Financial affordability, which is considered to be "influenced by the wider health financing system and by household income".
- Acceptability, which refers to "people's willingness to seek services" (and which is low "when patients perceive services to be ineffective or when social and cultural factors such as language or the age, sex, ethnicity or religion of the health provider discourage them from seeking services".

In the context of disability studies, Eichorn and Buchalis distinguish between the concepts of "access" and "accessibility", which are commonly used interchangeably as equivalent. While access refers to *individuals*, accessibility refers to the *relationship* between the individual and the environment as well as to the removal of related environmental barriers. Accessibility can therefore only be defined *relationally* (Eichorn & Buchalis, 2011).

Focusing on the interaction between individual and environment, the concept of accessibility raises the issue of planning of the built environment and, in particular, of health services' infrastructures. This planning implicitly implements a pattern of normality that refers to the "Vitruvian Man". This is the well-known drawing by Leonardo da Vinci (1490), depicting a naked man in overlapping positions, in a circle and a square, with his upper and lower limbs extended. "Vitruvian" construction standards correspond to a particular concept of "normality"and the "normal" body, the implementation of which creates barriers to access: those who do not correspond to them are tacitly considered "abnormal" and do not affect the planning of infrastructures, even in health services which are addressed to them.

3.2 Environmental barriers

In attempting to group the barriers to access generally presented to people with disabilities, the two authors distinguish three categories:

- barriers to physical access,
- attitudinal barriers and

- barriers related to lack of information.

The first category of barriers includes inaccessibility to transport and infrastructure. The second category refers to individual and collective attitudes that contribute to perpetuating barriers to access. The third and final category is related to information (Eichorn and Buchalis, 2011).

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According to Naniopoulos, Tsalis and Nalbandis, accessibility requires buildings, premises and services to be planned and managed in a safe, healthy, comfortable and enjoyable way so that all members of society can use them. Accessibility must therefore be ensured globally, combining all policy areas, such as construction, information and communication technologies, education and transport (Naniopoulos and Tsalis, 2016).

Focusing on different access needs, Vlavianou-Arvaniti (Βλαβιανού-Αρβανίτη, 2004) summarized the environmental barriers set up by the built environment per type of disability.

Table 3: Environmental barriers for different types of disability (Βλαβιανού-Αρβανίτη [Vlavianou-Arvaniti], 2014 [adapted])

Wheel-chair users	Persons with walking disabilities	Persons with limb disabilities	Persons with walking disabilities	Persons with limited vision	Persons with limited hearing
Accessing the height difference between the street and sidewalk	Accessing height differences	Opening heavy doors	Orientation	Spotting obstacles on the sidewalk	Crossings
Accessing big height differences where there are stairs	Moving in conditions where speed is required	Opening door handle	Spotting obstacles on the sidewalk	Orientation	Managing situations associated with speech, speech transmission and language communication

Passing through narrow spaces	Going up stairs or ramps	Using public drinking fountains	Crossings	Crossings	Inability to perceive doorbell, elevator floor alarm system and alarm
Passing through narrow door openings and high thresholds	Moving inside toilets		Moving in elevators	Moving in elevators and in emergency situations	
Access to controls and other objects placed at height	Passing through narrow door openings and high thresholds		Recognition of emergency situations	Detection of facilities	
Moving inside toilets			Spotting exit or stairs		

Regarding access, Darcy distinguishes three dimensions: physical, sensory and communicative. In these three categories, he argues, access should not be treated as problematic, but as an inclusion process (Darcy, 1998).

In their model, Aday and Andersen distinguish two main conceptualizations of access to health care:

- The first one emphasizes population characteristics (family income, insurance coverage, attitudes towards medical care) or the distribution system (resources - capital and labor- and organization of human resources and facilities).
- The second approach, conversely, focuses on outcomes that have to do with a person's passage through the health system; in this reasoning, service utilization rates or satisfaction levels are considered to allow for the "external validation" of the system's significance and/or of individual characteristics (Aday and Andersen, 1974, p. 209).

The same authors cite two quantitative indicators for assessing access. The first one derives from the weighted sum of the waiting time for an appointment, the time required to patient's transport, the time in the waiting room, and the time needed for the treatment process in a given medical care facility. The second indicator is the weighted sum of the difference between the ideal and actual number of services, the ideal and actual number of staff, and the ideal and actual availability of equipment in a given community (Aday and Andersen 1974, p. 209).

Finally, in what concerns accessibility, the same authors distinguish two main aspects in which access can be facilitated or hindered:

- *socio-organizational* (such as the provider's sex, fee scale and specialization), and
- *geographic*, referring to the time and physical distance that must be traversed to obtain care (op.cit.).

3.3 Social and economic barriers

According to what is mentioned above, the *availability* of health services does not necessarily means *access* to those services. The "Behavioral Model of Healthcare Services Utilization", developed by Andersen (Aday and Andersen, 1974), emphasizes on service utilization, synthesizing five parameters: health policy, the characteristics of a health delivery system, the characteristics of the population in risk, the use of health services and the satisfaction of consumer (Ricketts and Goldsmith, 2005, p. 274).

Against Andersen's model, and the emphasis it placed on the use of services, Penchansky contrasted the "fit" between the patient's needs and the system's ability to respond to them. For Penchansky, there were five parameters that determined this match:

- availability of doctors and other health services;
- accessibility, namely the spatial relationship between the provider and the users of health care;
- accommodation, ease of use that has to do with clinic hours, waiting times and wait for an appointment;
- affordability, meaning the population's economic ability to use the care provided by the system; and
- acceptability, namely the attitudes of users towards providers and vice versa (Penchansky, 1981; Ricketts and Goldsmith, 2005, p. 275).

Extending this model, Julio Frenk introduced the concept of *resistance* in order to clarify the difference between availability and accessibility. Resistance was defined as "the set of barriers that arise from health resources and hinder the search for and access to care" (Frenk, 1992; Ricketts and Goldsmith, 2005).

As for Andersen's model, the emphasis it placed on high-risk population failed to recognize that disability is a spectrum, not a distinct entity. Following Rose (Rose, 2017), Sherlaw et al. note that, while it is crucial for persons with disabilities to receive appropriate interventions (medical, psychological and social), these interventions should take into account the different contexts and environments (situations) in which these persons live or move. Individual treatment, they note, does little to change the conditions that create barriers (Sherlaw et al, 2013, p. 448).

In contrast to Penchansky's model, which explicitly sees patients as service consumers, Sherlaw et al. promote a "social determinants of health" approach (Marmot 2000 and 2010). Drawing on the case of France, where children of lower socio-economic backgrounds are seven times more likely to enter institutions than children from upper socio-economic backgrounds (Sherlaw et al., 2013, 445), they argue, following Rose, that health of a certain population can be modified on the condition that the societal factors that determine it are modified.

Updating the social determinants model, Solar and Irwin distinguish between *structural determinants* (governance, macroeconomic and social policies, a part of which are health and housing policies), and *intermediary social determinants*, which are "over-determined" by the aforementioned structural ones, and include material living conditions (Solar & Irwin 2010).

How can these observations be specified? Karagianni notes that exclusion from access to health is linked to factors that are mainly economic and social -from low levels of literacy to communication problems due to different languages, and from limited mobility to poor income and long distances from services (Καραγιάννη [Karagianni], 2017, p. 37).

These trends are confirmed at international level. In 2005, with Resolution 58.23 ("Disability, including prevention, management and rehabilitation"), the World Health Assembly authorized the Director-General to prepare a report on disability on an international scale, using the available scientific evidence. Table 3 shows beyond doubt that: (a) barriers to access are economically and socially determined, affecting the whole population, both disabled and non-disabled. Low-income countries are thus "ahead" on all barrier indicators, and in particular those of financial inability to pay a visit or secure the cost of moving to a healthcare provider.

(b) People with disabilities are at the "extremity" of each indicator, albeit following the general trends in the population.

Table 4: Reasons for lack of care (WHO and World Bank, 2011)

	Low income countries		Middle income countries		All countries	
	Non Disabled	Disabled	Non Disabled	Disabled	Non Disabled	Disabled
Male						
Could not afford the visit	40.2	58.8*	11.6	29.8*	33.5	53.0*
No transport	18.4	16.6	6.9	28.3*	15.2	18.1
Could not afford transport	20.1	30.6	2.1	16.9*	15.5	27.8*
Health-care provider's equipment inadequate	8.5	18.7*	5.0	27.8*	7.7	22.4*
Health-care provider's skills inadequate	5.8	14.6*	9.9	13.5	6.7	15.7*

Were previously treated badly	4.6	17.6*	7.2	39.6*	5.1	23.7*
Could not take time off	9.5	11.9	6.2	7.9	8.8	11.8
Did not know where to go	5.1	12.4	1.5	23.1*	4.3	15.1*
The person did not think he/she/his/her child was sick enough	42.6	32.2	44.1	18.0*	43.7	28.4*
Tried but was denied care	5.2	14.3*	18.7	44.3*	8.5	23.4*
Other	12.8	18.6	12.5	20.5	12.4	18.1
Female						
Could not afford the visit	35.6	61.3*	25.8	25.0	32.2	51.5*
No transport	14.0	18.1	7.9	20.4*	13.8	17.4
Could not afford transport	15.3	29.4*	4.4	15.2*	13.3	24.6*
Health-care provider's equipment inadequate	10.2	17.0	8.4	25.7*	9.8	17.0*
Health-care provider's skills inadequate	5.3	13.6*	8.9	20.6*	6.3	15.7*
Were previously treated badly	3.7	8.5*	9.3	20.1*	5.3	10.2*
Could not take time off	6.1	8.3	8.3	17.8	6.6	10.6
Did not know where to go	7.7	13.2	9.3	16.2	9.0	12.2
The person did not think he/she/his/her child was sick enough	30.7	28.2	21.3	22.6	29.3	29.3
Tried but was denied care	3.8	9.0*	19.6	54.6*	7.3	21.7*
Other	30.2	17.0*	23.0	24.0	28.5	16.4*
18–49						

Could not afford the visit	38.7	65.4*	14.1	27.7*	33.6	58.7*
No transport	12.7	13.7	6.6	25.1	11.3	16.0
Could not afford transport	15.0	29.5*	4.6	11.2*	12.8	25.8*
Health-care provider's equipment inadequate	9.7	17.4*	9.2	29.3	9.5	20.3*
Health-care provider's skills inadequate	6.2	15.4*	10.9	18.4	7.4	16.3*
Were previously treated badly	5.1	15.1*	6.8	17.9*	5.5	15.5*
Could not take time off	9.0	13.4	8.8	23.9	8.8	15.8
Did not know where to go	7.0	11.9	2.0	9.0*	5.9	11.8*
The person did not think he/she/his/her child was sick enough	40.2	30.6*	26.8	26.9	37.0	29.4
Tried but was denied care	5.3	12.9*	27.5	49.5*	10.5	21.4*
Other	16.0	13.5	17.5	14.4	16.2	13.3
50–59						
Could not afford the visit	49.6	67.4*	17.9	26.7	42.8	58.0
No transport	19.8	16.0	2.9	2.3	16.3	13.0
Could not afford transport	23.1	33.0	0.7	4.0	18.5	26.3
Health-care provider's equipment inadequate	8.6	14.5	4.2	29.1	7.7	15.1
Health-care provider's skills inadequate	6.5	13.3	10.0	40.9*	7.2	17.6
Were previously treated badly	6.7	12.4	7.2	31.1	6.8	14.0
Could not take	8.8	9.7	14.9	10.8	10.2	9.7

time off						
Did not know where to go	11.6	18.5	6.5	4.5	10.5	15.6
The person did not think he/she/his/her child was sick enough	35.4	14.5*	38.2	5.3*	36.0	13.0*
Tried but was denied care	6.4	17.9	18.0	55.3*	9.0	24.5*
Other	18.6	12.8	34.8	44.5	22.1	19.9
60+						
Could not afford the visit	36.8	47.7	14.4	21.1	30.6	38.7
No transport	25.1	24.3	9.5	30.3*	20.6	22.0
Could not afford transport	23.6	27.5	1.9	28.5*	18.0	24.7
Health-care provider's equipment inadequate	9.1	17.1	3.2	20.6	7.7	16.5
Health-care provider's skills inadequate	4.1	11.8	6.6	18.5	4.8	14.8
Were previously treated badly	1.7	6.7*	8.7	36.7*	3.7	14.1
Could not take time off	5.4	4.1	2.7	1.2	5.1	3.2
Did not know where to go	4.5	13.8	9.0	37.6*	6.1	16.5
The person did not think he/she/his/her child was sick enough	31.8	32.7	56.2	21.6*	38.9	31.2
Tried but was denied care	2.6	7.8	4.5	62.1*	3.2	25.8*
Other	27.7	25.2	12.2	35.5*	23.7	22.6

3.4 Austerity policies as socio-economic barrier for persons with disabilities: the Greek experience of re-medicalising disability

In the case of Greece, the experience of adopting radical fiscal adjustment measures in times of crisis seems to confirm the above findings. Stuckler and Basu point out that, in times of crisis, the real danger to public health is "not the recession itself, but austerity" (Stuckler and Basu, 2013). People with disabilities are subject to the same barriers that the entire population faces because of austerity: a combination of unemployment, loss of insurance coverage, reduced wages, reduced public spending and increased health care needs, which make health professionals feel like being in a 'war zone' (Kesidou et al., 2016).

In this respect, Rotarou and Sakellariou note that "unemployment can cause economic barriers but also barriers in access due to waiting lists, since unemployed people cannot access alternative health care services, such as private health care". In their study, only 12.7% of people with disabilities reported being in paid employment. Their findings also showed that people with a disability were "2.6 times more likely to have an unmet need for mental health care due to cost", in a context of increasing incidence of mental health problems and suicide attempts, and funding cuts for mental health care services (Rotarou and Sakellariou, 2017; Kentikelenis, Karanikolos, Reeves, McKee, & Stuckler, 2014).

But while austerity as a crisis management strategy concerns the population as a whole, in the case of people with disabilities in particular, it takes on particular characteristics. Co-payment for medications, for example, applies to all but "may disproportionately affect people with disabilities who may not be entitled to any discounts for medication they require regularly" (EOPPY, 2017; Rotarou and Sakellariou, 2017).

Already before the crisis, Greece had the lowest spending globally as a percentage of GDP on disability benefits; in a period of increased demand for social care, due to the effects of the crisis, both financial spending and services contracted (Καραγιάννη, 2017, p. 34). In the case of people with disabilities, the cost of care was given in cash (€ 2.6 billion), excluding medicine (physiotherapy, speech therapy). These services, however, were provided for a limited number of people and were related to accessibility, not access (Καραγιάννη, 2017, p. 34-9).

In this context, crisis management in the case of people with disabilities has led to a significant setback: the shift from the social model of disability to the biomedical model. "The group of the disabled," notes Karagiannis, "was designated at the same time both as a group in need of social protection and as a factor of social and moral disorder" (Καραγιάννη, 2017, p. 129): as abusers of benefit protection that had to be identified, classified, controlled and disciplined, and as bodies that cost. This re-medicalization meant blaming people for disability, rather than blaming the economic policy that created barriers to their access to health services.

3.5 Professional attitudes as barriers and facilitators

As shown above, the recognized barriers to receiving health care are not only physical (e.g., inaccessibility of facilities), but they are also related to the knowledge and attitudes of health care professionals (Field and Jette, 2007; Symons, McGuigan and Akl, 2007; White and Olson, 1998). Whereas among people with disabilities the primary complaint about the care provided is usually the lack of physical access, in many studies primary care providers are mentioned to have lack of necessary time, clinical training, equipment, and resources to provide adequate care for their complex medical needs (Shakespeare and Kleine, 2013). McGuigan and Akl note that possible "lack of knowledge and skills, and negative attitudes towards patients with disabilities, may adversely affect the services available to this group and negatively affect their health outcomes"(2007).

In a literature review conducted in 2013, Brown and Kalaitzidis grouped the main barriers related to healthcare providers into three main categories (themes) and their relevant sub-themes, as below:

Table 5: Barriers related to healthcare providers (themes) (Brown and Kalaitzidis, 2013 [adapted])

Themes	Sub-themes
Professional competence	Knowledge deficit Skill deficit Communication deficit Identifying specialized needs deficit Client-centred deficit
Attitudes	Positive/negative attitudes of nursing staff Experience Gender
Organisational management	Time deficit Staff deficit

Kritsotakis et al. summarized the five major problems detected in disability studies: "lack of specific knowledge to conduct health assessments specific to disability, insufficient skills to address the complex needs associated with disability, discomfort with working with disabled people, challenges with communication and negative attitudes-misconceptions about disability (Kritsotakis et al., 2017).

In their qualitative study, Matziou et al. were noting that, among 441 nursing students and professional paediatric nurses, many did not exhibit "the essential sensitivity and appropriate attitudes towards them, resulting in a poor quality of nursing care". One of their findings showed that females were holding significantly more positive stances than males (Matziou et al., 2009).

In a more recent study, Kritsotakis et al. found that nursing students "held less favorable attitudes regarding physical disability when compared to medical students". Their findings agreed with previous studies showing that "although nursing undergraduates have more positive attitudes than the general population and age-matched non-nursing peers, they also have more negative attitudes compared to medical and other healthcare students"(Kritsotakis et al. 2017).

4 Study design – Methodology

We designed a qualitative study based on semi-structured interviews. It is one of the most common types of interviewing in the context of qualitative research in health sciences, commonly used to investigate the beliefs and opinions of health providers (Green and Thorogood, 2004; Green and Browne, 2005). In a semi-structured interview, the interviewer determines the topics to be covered, but the type of information to be extracted on these topics and their significance are determined by the interviewee's responses (Green and Thorogood, 2004).

This type of interview included a semi-structured thematic guide (see Index), which allowed to explore how respondents experience, conceptualize, and formulate their views (Green and Thorogood, 2004; Green and Browne, 2005) on disability, the needs of people with disabilities, the barriers and facilitators to access primary health care.

The guides were given to 25 persons in total, 15 health professionals (physicians, nurses, administrative staff) and 10 persons with disabilities (4 of whom with visual impairment and 6 with hearing impairment). The guide was issued to health professionals working in two health centers of the 4th Health Region of Northern Greece, in June 2018 and March 2019, and to persons with disabilities, during meetings at the premises of the Department of Medicine of the Aristotle University of Thessaloniki in November 2018 and January 2010. In both phases, participants were asked for their approval to use the material for the purpose of the study, and the researchers guaranteed anonymity. Conversations were recorded and transcribed verbatim.

The results were synthesized using thematic analysis, a method of identifying, analyzing, organizing, describing and reporting themes in a dataset (Nowell L., Norris JM et al., 2017). By recognizing patterns in the data, emerging themes became categories of analysis (Fereday J. and Muir-Cochrane E., 2006). The process involved a careful and focused review of the data, its coding, and the creation of categories based on the characteristics of the data, in order to reveal themes related to disability.

5 Results

We analyzed our findings combining the themes that Brown and Kalaitzidis (2013) and WHO and World Bank (2011) used in their studies. We used these themes and sub-themes for both health professionals and people with disabilities. These themes were: *professional* competence (including the sub-themes: *knowledge deficit, skill deficit* and *communication deficit, identifying special needs deficit, client-centered deficit*), *attitudes* (including the sub-themes:*, positive/negative attitudes of nursing staff, experience* and *gender*), *organizational management* (including the sub-themes: *time deficit* and *staffing deficit*) (Brown and Kalaitzidis, 2013).

We also grouped the themes used in WHO and World Banks' study (2011) into two categories: *socio-economic barriers* (including the sub-themes: *inadequate equipment, no transport* and *inability to pay for medicines*) and *environmental barriers*, focusing here in inaccessible structures.

We used these themes despite knowing that some of them overlap and also that some sub-themes could be categorized in more than one main categories. Four examples:

1. time and staffing deficits are also socio-economic barriers, related to health policy and the socio-economic priorities that dictate it.
2. negative attitudes are usually related to communication and knowledge deficits.
3. lack of professional knowledge is due, among other factors, to lack of experience.
4. lack of transport is both a socio-economic and an environmental barrier, as it makes healthcare services structure inaccessible.

Despite these limitations, we kept the distinctions as mentioned. Regarding particularly the sub-themes of communication, knowledge and skill deficits, we have to do with "structural"barriers, and not only individual/professional incompetence; on the contrary, the attitudinal barriers mentioned correspond to more"subjective" stances.

5.1 Healthcare professionals (PR)

As shown in Table 6, most of the professionals interviewed (12 out of 15) mentioned professional competence barriers, mainly knowledge and communication deficits, as the most significant limitations to access to healthcare for persons with disabilities. Many among them stated that they search information on their own, either asking specialized societies, or searching the literature and ,"on the internet" (PR2). PR1 stated, for example:

> I contacted Panagia Faneromeni (Society of Parents of Disabled Persons) because I wanted to be able to cater for disabled children and adults. [...] I hadn't been informed from anyone previously, I did it voluntarily, all on my own.

PR3 confirmed:

> "As health professionals we should take some specialized training. We do what we can on our own".

PR2 explained that

> there is no coordination. If you want to look it up then you can do it, if you want to read about it there is enormous literature.

For PR10, the personal motivation is a significant factor: "Apart from those who are more sensitized to disability issues, most of the people have no idea".

– *Where do we health professionals draw information related to disability issues?*
– At seminars or else on the internet. But normally we should train at seminars on how to manage different cases.
– *Have you ever attended such a seminar?*
– No, until now I haven't.

Socio-economic barriers, such as inadequate equipment, lack of means of transport and the inability of persons with disability to pay for their medicines, were the second most significant category of barriers (7 out of 15 referred to it).

PR1 openly admitted:

> I don't have all the necessary equipment, gags for example.

PR15 added:

> We have a lot of desire to help, but we don't have the means [...] If three disabled persons come at the same time, I only have two wheelchairs [...] I also need crutches. I only have a pair [...] They don't have the means [to come here]. They don't have the money needed for transport. [...] Some of the medicine the doctors prescribe for them, they can't afford to buy them.

PW10 confirmed the previous findings:

> The crisis has taken its toll on these people [...]. We took in women from all the nearby villages for free. Now the municipality no longer gives us the possibility. [...] We're talking more than 10-12 villages. [...] Those of us who want to work can no longer work.

PR5 mentioned one case of person with disability who "has no insurance and cannot take his medicines". This was not an unusual case. As PR6 explained, most patients "come either because a colleague cures them here at the Health center or as uninsured who have no possibility to address to a private doctor".

PR1 summarized the barriers related to the socio-economic context:

> It's not always easy for a disabled person to come to my practice... Maybe the parents don't have the proper car, or the money needed. There are many barriers that may seem negligible to some people, but for a disabled person they are very serious. Even their transport is difficult. There are no special buses or anything.

Organizational barriers, such as time and staffing deficits, were revealed to be equally crucial barriers, as 7 out of 15 professionals questioned reported such an experience. PR15 mentioned, for example:

> "Is there any doctor next door, at "Home Care"? [...] I don't see any! [...] You can't follow the patient's course [...] We used to have a social worker. Do you see any social worker here now? [...] She left in 2005 or 2004 [...] I work alone in the evenings, alone at nights [...] Yesterday someone asked for a dermatologist. Where am I supposed to find one? Once we had a dentist here. Where is he now? [...] We don't have a urologist either".

PR2 admitted: "We can't take up all of them, maybe because our working hours are strange or maybe because we don't have a lot of free time".

PR10 explained how lack of knowledge and lack of time interacted:

> Maybe it's our fault too, maybe we don't do our best administratively but we also don't have the time, because we have to look for the relevant legislation ourselves, we have to inform the staff ourselves on what it is we have to do... So we act more or less spontaneously.

Working at EKAV (Greek National First Aid Center / National Center for Emergency Care), PR9 reported that had to perform duties other than those assign to him/her, explaining thus how staffing and knowledge deficits interact:

> I work at EKAV and I sometimes have to perform duties other than my own, so I ask what happens in these situations. And it comes down to what each person happens to know. No one has informed me on whether I need to take any special training, other than the basic stuff I learned at the school of EKAV, so I go on this way. I believe that, for handling these situations, it's up to each person's character and how sensitized they are.

Apart from staffing deficit, staff instability is another barrier, with effects to the continuity of the care provided ("The staff, ok, is not stable", PR5).

Inaccessibility due to environmental barriers revealed to be the third most important category (6 out of 15 professionals mentioned one relevant barrier at least). PR4 explained:

> We don't allow them in, we leave them outside, we do the checks and we hand it over afterwards

PR3 and PR9 admitted that there were no specialized toilets, while PR1 stated that the space was"not wide enough for a wheelchair to come through". One professional (PR11) stated that there were particular categories of people with disabilities excluded:

> ...for people with sensory disabilities, blindness and the like, I don't think it's accessible. [...] There is no special signage or anything".

PR10 referred, among all, to the lack of "parking spaces".

Finally, our study revealed notable attitudinal barriers. Some of them had obviously to do with lack of knowledge. One of them was reflected in the terms used to describe disabilities such as Down syndrome:

> A little mongoloid came over [...] (PR7)

In one case (PR2), it was difficult to distinguish whether the professional was describing a situation or expressing a prejudice:

> Psychiatric cases raise issues and create problems [...]

The latter would add that

> The social level of people who come to Health Centers is rather low, maybe because they don't have the financial means to go to a private doctor. So the Health Center is... how should I put it... a convenient solution for them? They think all their problems will be solved there.{PR3} expressed another kind of prejudice, stating that "[...] they try to use their disability to skip the line and get in faster. I'm not sure these people should be allowed to come in without an appointment".

On the other hand, such negative attitudes do not necessarily mean identifying special needs deficit:

> These individuals [people with disability] need a special approach, how to approach them, how to cure them, [to learn] a bit their psychology, to learn how they react (PR2).

PR3's attitude reflected another kind of prejudice:

> There are some people who may miss an arm or may have a prosthetic limb or something, and they try to use their disability to skip the line and get in faster. I'm not sure these people should be allowed to come in without an appointment.

Commenting certain professionals' negative attitudes, PR1 would admit:

> There are of course many health professionals who are not willing to engage with these people, or, if these people ask for their help but don't immediately cooperate, they get upset and tell them to leave and come back some other time. They don't want to spend any time, because approaching such a person takes time and willingness to put yourself at their disposal.

Table 6 summarizes our main findings:

Table 6 Barriers to access to healthcare for persons with disabilities according to health professionals (PR)

Professional competence knowledge deficit, skill deficit, communication deficit, identifying special needs deficit, client-centered deficit	Attitudes positive/negative attitudes of nursing staff, experience, gender	Organisational management time deficit, staffing deficit	Socio-economic barriers inadequate equipment, no transport, inability to pay for medicines	Environmental barriers inaccessible structures
{PR1} "I hadn't been informed from anyone previously, I did it voluntarily, all on my own"	{PR1} "There are of course many health professionals who [...] get upset and tell them to leave and come back some other time"		{PR1} "I don't have all the necessary equipment, gags for example [...] Even their transport is difficult. There are no special buses or anything"	{PR1} "The door at my practice is not wide enough for a wheelchair to come through"
{PR2}"All the knowledge I've got comes from looking things up on my own on the internet"	{PR2}: "Psychiatric cases raise issues and create problems [...]"	{PR2} "We can't take up all of them, maybe because our working hours are strange or maybe because we don't have a lot of free time"		
{PR3} "As health professionals we should take some specialized training. We do what we can on our own"	{PR3} "[...] they try to use their disability to skip the line and get in faster. I'm not sure these people should be allowed to come in without an appointment"			{PR3}"If someone needs to use the toilet we have no appropriate infrastructure, until now at least"
{PR4} "We do what we can voluntarily to learn a few things in				{PR4} "We don't allow them in, we leave them

order to help them"				outside, we do the checks and we hand it over afterwards"
{PR5} "Systematic training, no, there is not any"		{PR5 } "The staff, ok, is not stable"	{PR5} "this person [with disability] has no insurance and cannot take his medicines"	
{PR6} "- *Are we properly trained to cater to the needs of these people?* - I don't think so"			{PR6} "they come either because a colleague cures them here at the Health center or as uninsured who have no possibility to address to a private doctor"	
{PR7} "[...] normally we should train at seminars on how to manage different cases"	{PR7}"A little mongoloid came over (ed.: he means a kid with Down's syndrome)"			{PR7} "Maybe it is difficult for a person [with disability] to come here alone"
{PR8} "I do whatever I can to help, but I can only help so much"				
{PR9} "It is very difficult to be properly informed, it usually comes down to each person's sensibilities"		{PR9} "I sometimes have to perform duties other than my own, so I ask what happens in these situations"		{PR9} "There are no toilets for people with disabilities"
{PR10} "I haven't really dealt with the issue [...] It makes it hard for us not having the appropriate information"		{PR10}"Unfortunately, we have a problem there" (time deficit) "The local Health Center does not offer home care"		{PR10} "We don't have designated parking spaces for disabled people"

		{PR11} “The local Health Center does not offer home care”		{PR11} “…for people with sensory disabilities, blindness and the like, I don't think it's accessible. […] There is no special signage or anything”
{PR12} “There was no training or seminar or anything that I was invited to follow. […] I make do with what I have studied as a midwife. […] Of course I would be interested in such a seminar”		{PR12] “We are short on certain specialties and we try to stand in for these people”	{PR12} “The crisis has taken its toll on these people […]. We took in women from all the nearby villages for free. Now the municipality no longer gives us the possibility. […] We’re talking more than 10-12 villages. […] Those of us who want to work can no longer work”	
{PR13}“Communication is really hard for us”[…] “- *Have you received any specific training on disability issues?* – No”.			{PR13}“There is a lot of medical equipment that needs maintenance or replacement”	
{PR14} “We can’t communicate well. He’s a little Muslim, doesn’t speak our language”[…] “– *Have you*			{PR14} “Their transport to the hospital is difficult. […] It would be easier with a small bus […]”	

received any training? – No"				
		{PR15} "Is there any doctor next door, at "Home Care"? […] I don't see any! […] You can't follow the patient's course. […] We used to have a social worker. Do you see any social worker here now? […] She left in 2005 or 2004 […] I work alone in the evenings, alone at nights. […] Yesterday someone asked for a dermatologist. Where am I supposed to find one? Once we had a dentist here. Where is he now? […] We don't have a urologist either"	{PR15} "We have a lot of desire to help, but we don't have the means. […] If three disabled persons come at the same time, I only have two wheelchairs. […] I also need crutches. I only have a pair" They don't have the money needed for transport. […] Some of the medicine the doctors prescribe for them, they can't afford to buy them"	

5.2 Persons with disabilities (PWD)

Barriers related to professional competence were revealed to be the most significant for persons with disabilities, as it has been earlier for professionals. 8 out of 10 person with disabilities questioned referred to communication and knowledge deficits, mentioning in some cases that these deficits had effect on their self-confidence. This was the case of PWD1:

> When the Pap test was over, he started telling me words I didn't know. In order to not waste time he wrote the words down for me, but they were medical terms I could not understand. At that point I realized that I made a mistake and that I had to use an interpreter […] I knew the doctor and so I thought I would be able to communicate. But I am not particularly good at lip reading and if the other person's diction is not very good it is hard for me, so I learnt my lesson. That I shouldn't trust myself so much and that I should have an interpreter. It's impossible without an interpreter."

PWD2 explained how frustrating and insulting a communication deficit experience could be:

> I went to a pathologist and he talked too fast. I had told him that I am deaf and still he talked too fast, he couldn't understand [...] He told me that they will inform me, that they inform all the people who get CAT scans. But when I lied down I didn't know that I had to keep my breath, because no one is allowed to be there with you, neither interpreter nor anyone. There was no window or anything either, and I had to lie completely still, but that is a big problem for deaf people because there have no other way to communicate. It was very hard [...] Then came a woman, I didn't see her, she was standing still and, without poking me or anything, she told me that I had to get my pants down and then immediately she got my pants down herself. I was just lying there and she got my pants down without warning. Was I supposed to be insulted, laugh, or what?

Communication deficits were connected to negative attitudes, with PWD3 reporting:

> The same guy then came forward, put his stethoscope on my back without saying anything, didn't examine my mouth or nose as I had asked before, and said "there's nothing wrong with you". I said "excuse me, but I feel weird, I would like you to examine me thoroughly and see what's going on". "No", he replied, "there is no need; I'll just grant you one day of sick leave and you'll feel better after you rest". I was sure that was not going to happen, I could feel that things would only get worse. I told him that I didn't agree and the doctor started talking to himself –of course I couldn't understand a word [...] I realized that he was not interested in communicating with me.

In some cases, lack of communication reflected lack of skills and experience. This was the case of PWD4, reporting:

> He went on with the examination but he seemed to be unsure whether my problem was with my legs or with my hearing. [...] It was then I realized that the real problem was our lack of communication.

In our study, organisational barriers were the second most important category, as 7 out of 10 persons with disabilities questioned had an experience of time and/or staffing deficit to mention. For PWD8, the main problem was the "lack of staff". Moreover, the barriers of this kind were connected to their shift towards private sector. PWD1 admitted:

> I [visit] private [doctors] because I can get an appointment with them quickly and I waste no time. If I go to a doctor of the public [sector] I will have to wait 1-2 months to make an appointment [...] When I see that a doctor is in the PEDY, I know it will take a long time so I have to go to a private one. With a private doctor you go online and they serve you faster, the difficulty is in the money but there is no other solution...

PWD10 confirmed that the previous case was not a unique one, mentioning the lack of companions as a siginificant barrier:

> We avoid going to hospitals because you can't always find a companion, so we go to private doctors [...] If a blind person goes by himself, for example, there is no staff to attend to him. [...] I've had such experiences and made my everyday life very hard.

Time deficit was also mentioned to be an important problem, with PWD4 stating that "some [doctors] say: 'I don't have that much time to give you'"and PWD2 confirming:"They want to do their job as fast as possible [...]".

Time deficit seemed to reflect on professionals negative attitudes: "Doctors want to get rid of us as quickly as possible, [they tell us] "go on, you're okay", PWD6 reported.

The attitudinal barriers mentioned (5 out of 10 persons) revealed the dimension of gender. Female professionals were reported to be more patient and skillful in terms of communication:

> I have noticed that male doctors find it more difficult to communicate, they have no patience, and they want to get it over with. On the other hand, women are more patient [...] female doctors always tell me everything in detail.

PWD2 would confirm this difference:

> My dentist is a woman, she talks to me about her life and we get along very well. She is very sociable and patient. My other pathologist is also very good but his character is different. He wants to make faster because he has a lot of patients, he works all day so he has to be faster.

Another attitudinal issue had to do with gender prejudices on behalf of professionals. PWD3 reported such an attitude against homosexuality:

> "I have something to tell you. You being a teacher and everything, it's not right that you are with a woman". I replied, "What does being a teacher have to do with my personal life? These are two separate identities that you're confusing here".

Socio-economic and environmental barriers were mentioned by 3 persons for each category. For PWD10,

> When we go to a hospital things aren't easy with all the problems hospitals have due to the crisis, which also plays an important role.

In what concerns environmental barriers, the persons with disabilities questioned mentioned them as causes not to visit healthcare services or to prefer the private sector:

> I would prefer the private sector due to its accessibility"[...] Elevators and doors don't have appropriate signage or audio signals (PWD7).

PWD10 summarized the problems for people with visual impairments:

> When blind people are by themselves and they can't follow a queue, that's one practical problem for us. Another practical problem is, mainly, the lack of easy access.

In Table 7 we summarize the main barriers as mentioned by persons with disabilities interviewed:

Table 7 Barriers to access in healthcare for persons with disabilities according to persons with disabilities (PWD)

Professional competence knowledge deficit, skill deficit, communication deficit, identifying special needs deficit, client-centered deficit	Attitudes positive/negative attitudes of nursing staff, experience, gender	Organisational management time deficit, staffing deficit	Socio-economic barriers inadequate equipment, no transport, inability to pay for medicines	Environmental barriers inaccessible structures
{PWD1}"When the Pap test was over, he started telling me words I didn't know. In order to not waste time he wrote the words down for me, but they were medical terms I could not understand"		{PWD1} " If I go to a doctor of the public (health system) I will have to wait 1-2 months to make an appointment"	{PWD1} "At the time I was in a very difficult financial situation. I went to Aghios Pavlos hospital, they helped me, I was very happy"	
{PWD2} "I went to a pathologist and he talked too fast. I had told him that I am deaf and still he talked too fast, he couldn't understand"	{PWD2} "I have noticed that male doctors find it more difficult to communicate, they have no patience, and they want to get it over with. On the other hand, women are more patient [...] female doctors always tell me everything in detail"[...] When they realize that we are deaf, they start looking at us differently –not all of the doctors, but some of them. Especially the older ones think of us as patients, as a problem. As if there is something wrong with us mentally".	{PWD2} "They want to do their job as fast as possible [...]"		
{PWD3} "I realized that he was not interested in communicating with	{PWD3} "But she said, 'I have something to tell you. You being a teacher and			

me"	everything, it's not right that you are with a woman'"			
{PWD4} "He went on with the examination but he seemed to be unsure whether my problem was with my legs or with my hearing. [...] It was then I realized that the real problem was our lack of communication."	{PWD4} "Then I happened to go to this doctor and he talked about me saying "this deaf-and-dumb boy". Being deaf, I can lip read very well and I got him. I explained to him that using the term "deaf-and-dumb" is not nice, and that I was deaf only. He should know the difference and speak more politely"	{PWD4} "Some [doctors] say: "I don't have that much time to give you".		
{PWD5} "Doctors in the public sector start to change – "Some of them seem very eager to communicate. [...] They give you the time you need; they try to be more articulate [...] but some of them feel embarrassed or turn cold [...] Once I was asked if I can read, just because I'm deaf. [...] They think that all the problems we have are somehow connected to being deaf"	{PWD5} [In Disability Certification Centers] communication is difficult. They talk too fast for example. Basically, they do it on purpose. They try to check if my hearing loss percentage is true or not. [...] They want to see if I get what they say. But this has nothing to do with my hearing: I might be reading their lips, or I might have adjusted to my hearing loss.	{PWD5} "There were no interpreters in Corfu. [...] In order to find one, I need to ask for someone far in advance. [...] When the need arises at the last minute, I can't find one"		
{PWD6} " There is no knowledge in the National Health System that she is deaf, she has this, or she is allergic to that"	{PWD6} "Doctors want to get rid of us as quickly as possible, [they tell us] "go on, you're okay""	{PWD6} "It would be very good if there were interpreters at the hospitals on, say, a 24-hour rotation"	{PWD6} "Aerolin' is very expensive"	
				{PWD7}"I would prefer the private sector due to its accessibility"[...] Elevators and doors don't have appropriate signage or audio signals"

{PWD8} "Doctors are a little impersonal for some reason. I don't know why"		{PWD8} "[The main problem is] lack of staff"		
{PWD9}"He didn't diagnose my condition with precision and he didn't tell me that I had to go to someone higher up. He just gave me glasses and showed me out"				{PWD9} "I don't go by myself [to the nearby medical practice], because I will end up casting about. [...] When there's no audio signal in the elevator, I have a big problem".
		{PWD10}"We avoid going to hospitals because you can't always find a companion, so we go to private doctors [...] "If a blind person goes by himself, for example, there is no staff to attend to him. [...] I've had such experiences and made my everyday life very hard"	{PWD10} "When we go to a hospital things aren't easy with all the problems hospitals have due to the crisis, which also plays an important role"	{PWD10}"When blind people are by themselves and they can't follow a queue, that's one practical problem for us. Another practical problem is, mainly, the lack of easy access"

6. Discussion

Trying to differentiate impairment and disability, Karagianni notes that, while impairments *exist*, disabilities are (socially) *performed* and *constructed*, establishing thus limitations in education, work and the economic relations of people with impairments (Καραγιάννη, 2017, p. 15).

In our study, many of the persons with disabilities reported a better health status than one would expect due to their impairment. PWD10 stated, for example:"Sometimes I get out of bed forgetting that I have a visual impairment". But the interaction of these persons with the health services, the limitations performed and constructed in health under the form of professional, organizational, attitudinal, socio-economic and environmental barriers, can harm this self-confidence, making a person's impairment a reason for it to feel guilty and unfit.

In terms of barriers prioritization, our study revealed a common place between healthcare professionals and persons with disabilities: both categories reported professional competence issues, mainly communication and knowledge deficits, as the most frequent barriers.

For persons with hearing impairment, communication was mentioned to be the most important, as the barrier for them is posed before a person reaches the services, that is to say before the phone appointment. What should be done?

> The greatest problem in my opinion is the phone appointment. There should be another program available to deaf people so that we can make appointments faster. [...] That's our biggest problem [...] when I want to make a doctor's appointment I always ask for help, I send message to a friend of mine who is deaf but his mother isn't and they make the appointment for me (PWD4).

PWD1 emphasized the use of internet:

> I would like hospitals all over Greece to be able to accommodate via the internet, to make appointments online so that deaf people too have accessibility. Since we can't make phone calls, do we have to look for someone to help us all the time? [...] For a deaf person it's impossible without the internet.

In the same path, PWD6 suggested that people with hearing impairments "could have an interpreter on teleconference to translate for me what you say".

For both professionals and persons with disabilities, a siginificant part of suggestions had to do with training professionals:"We need to train staff, both doctors and nurses", PR1 reported. "I think there should be seminars for all staff working in health care facilities on the proper ways to treat a deaf person coming for a visit", PWD3 would add. For PWD5,"since it's difficult to hire interpreters, the doctors and nurses should at least be trained".

The suggestions of persons with disabilities concerning training, in order to eliminate communication deficit, were realistic. An "ideal" doctor has"to be direct and helpful to the patient, he has to know his case very well and not abuse them in any way" (PWD8). As PWD2 posed it,

> The most basic thing is to maintain contact. The doctor must remain calm; his face must be calm because otherwise deaf people tend to be affected. If the doctor looks troubled, a deaf person will get very upset thinking that there is a problem. The doctor must remain calm.
>
> PWD3 would add:

> First of all, the deaf patient will probably know sign language, in which case they should get him an interpreter. If he doesn't, they should communicate in writing or speak slowly to allow lip reading. Technology could help as well. In many hospitals there are
>
> screens that can be used for written announcements, and led boards as well. Also, printed billboards could be clearer [...]

In areas of Greece with a significant national and lingual diversity, professionals underlined the need to provide patients healthcare services "in their language [...] These people lived in villages, they've never been around Greeks (PR14).

While for people with disabilities organizational barriers proved to be the second most important category of access limitation, for persons with visual impairments staffing deficit weighed more. For PWD9, "there should be a phone number for the transport of disabled people to health care facilities or airports and stations". An "audio signal in the elevator"was also mentioned as a crucial facilitator (PWD9).

In the context of organizational barriers, staffing deficits seemed to interact with time ones, as the lack of staff obliges professionals to perform duties for whom they have little or no knowledge and little or no time. In the same time, staffing deficits guide persons with disabilities out of the public healthcare services. As PWD10 posed it, "We avoid going to hospitals because you can't always find a companion, so we go to private doctors".

Professionals seemed to recognize this reality. PR1 suggested that

> To get an appointment, waiting times are... It's crazy. A disabled person cannot wait in the waiting room, it's impossible. So there should be a medical center, if I can call it that, where they would have instant access to doctors of different specialties... where there would be psychological support for the parents, because those parents really need psychological support.

For PR15, the work of professionals in the community shouldn't start when a person with disability asks for services, but before, and by the professionals: "the families that include disabled persons have to be identified."

The aforementioned suggestions make obvious that the interventions to lift barriers to access to healthcare services needed cover a lot of fields: social policy, education, structure design. But these interventions are realistic, at least if someone does not see persons with disabilities as "allowance hunters", victims of a "tragedy" or "cursed due to a lack of virtue", but on the contrary, as persons who should enjoy social rights, instead of being excluded and stigmatised.

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7 Index

7.1 Information Sheet

Persons with Disabilities

☐ ♀ ☐ ♂ ☐

1. Age

2. Number of individuals in the household...

3. Type of relationship with these individuals..

4. Marital Status :

Married ☐ Divorced ☐

Unmarried ☐ Widowed ☐

5. Children, if any :

☐ Number Age of children ☐

6. Profession / Employment

....

7. Level of education

....

8. Profession / Employment of parents

....

9. Level of education of Parents

....

In case of adult children

10. Place of residence.. Level of education..

11. Profession/ Employment............................

……………………………………………………………………………

10. In case the person has monthly income or receives disability allowance – estimate of amount ☐

11. Total monthly income of all individuals living with the interviewee. Up to :

500 €	
32501 - 1000 €	
1001- 1500€	
1501-2000 €	
2001-3000 €	
3001-5000 €	
More than 5000 €	

12. Incase of mortgage / other debts, estimate of total amount

13. Home ownership

Yes ☐ No ☐

14. Type of residence / Description

Rooms

Internet access

Heating

Access to means of transport

Adaptation of living environment to the needs of the PWD

15. Area of residence: urban, semi-urban, rural

7.2 A guide to conducting semi-structured interviews with persons with disabilities

The location of the interviews will be determined according to the convenience and availability of the two parties.

The content of the interview will be recorded only with the agreement of the interviewee and will be complemented by the preparation of an information sheet.

Information Sheet / Individual Record

(Information collected systematically)

1. Age
2. Sex
3. Number of individuals in the household
4. Type of relationship with these individuals
5. Marital Status:
   Married–Unmarried–Divorced – Widowed
6. Number and age of children, if any
7. Profession / Employment
8. Level of education
9. Profession / Employment of parents
10. Level of education of parents
11. In case of adult children:place of residence, profession / employment, level of education
12. In case the person has monthly income or receives disability allowance –estimate of amount
13. Total monthly income of all individuals living with the interviewee. Up to :
    500€.........................
    501 - 1000 €...........
    1001- 1500 €...........
    1501-2000€.............
    2001-3000€ ....
    3001-5000€............
    More than 5000 €.....
14. In case of mortgage / otherdebts, estimate of total amount
15. Home ownership (yes/no)
16. Type of residence / Description(rooms, heating, internet access, access to means of transport, adaptation of living environment to the needs of the PWD)
17. Area of residence: urban, semi-urban, rural

7.3 Interview Guide

Objective	Topics to be explored
Highlighting the personal experience of the person with disabilities regarding health issues.	- Identification of important events that, according to the interviewee, have affected his or her health; - Identification of health problems (in chronological order);
Self-estimated health.	- General health assessment.
Identification of information sources of the person with disabilities regarding health issues.	- Sources of information/orientation on health issues.
Demand and use of healthcare services – especially of PHC services.	-Description of the latest use of health services. Clarification on the use of primary health care services; - Description of the health services and the reasons they were sought in the last year. What are the most usual reasons health services are used?
Identification of problems faced by the person with disabilities regarding their access to health care.	- Description of a particularly negative and / or positive experience with the use of health services; - Description of the most common problems faced by the person with disabilities in their access to health.
Identification of unmet needs regarding access to health care.	-Description of the strategies the interviewee uses to address them, and assessment of their effectiveness;
Submitting suggestions for improving access of the person with disabilities to health care.	- Proposals that would improve the interviewee's access to health care.
Identification of every day activities and their changes over time.	-Description of the activities of the interviewee during the previous day/week.
Identification of individuals among relatives /friends and health workers/professionals, aswellas the type of interaction-relationship they develop with the interviewee, with emphasis on health issues.	-Description of the kind of help and identification of the people who offer it. Clarification of activities more specifically related to health issues;
Identification of the most important problems (unmet needs) faced by the person with	-Description of the most important problems

disabilities in their everyday activities(reduced autonomy, communication, accessibility, safety, etc.) and could have an impact on their health. Involvement of relatives/friends and health-care professionals in creating or addressing the problem. Addressing problems and submitting suggestions for improving the health of the person with disabilities.	faced by the person with disabilities in their everyday routine; -Description of the strategies the interviewee uses to address them, and assessment of the results. - Proposals to improve the overall health of the person with disabilities.

7.4 Information Sheet

Nr.

PHC Staff

Age:	♀ :	♂ :

1. Profession (and professional experience)

....

....

....

2. Short professional resume

....

....

....

....

....

....

....

....

....

3. City / area of HC unit

....

4. Type of HC unit:

-Number of employees:..

-Collaborations with other structures/professionals: YesNo

-If yes, specify which structures/professionals...

5. Number of persons with disabilities received / watched daily:..................................

6. Degree, place and year of attainment:

....

7. Other education (lifelong learning)

....

8. Reasons for choosing to work in specific structure

....

9. Any other comments?

7.5 INTERVIEW GUIDE

HEALTH CENTER STAFF

-Types of disability and estimation of the number of people with disabilities coming to the health center. - Type and reason of services sought. -Frequency of demand by category of persons with disabilities (categories will be defined by the interviewee).
Description of the cases of persons with disabilities met by the interviewee on the day of the interview / on the previous day. Alternatively, description of the last case met by the interviewee. For this case(s): -Description of the case(s). -Identification of needs – health status assessment of the person(s) with disabilities -Ways to facilitate the expression of needs by the person(s) with disabilities -Practices used to meet the needs of the person(s) with disabilities - Obstacles encountered and practices used to overcome them - Identification of unmet needs - Practices that could improve the person's health Description of a specific case that constitutes an important (positive or negative) experience for the health professional. For this case:

-Reasons that make this case special for the interviewee. -Assessment of needs - health status assessment of the person with disabilities. -Practices used to meet the needs of the person with disabilities - Obstacles encountered and practices used to overcome them -Identification of unmet needs -Practices that could improve the person's health - Proposals to improve professional practices
-Relationship of health-care professional with the caregivers: who they contact and for what reason(s). - Possible cooperation with other public or private bodies: example of cooperation/common actions. -Sources of information on health issues for health professionals and persons with disabilities. -Relationship of health-care professional with persons with disabilities and caregivers regarding their information on health issues. - Problems encountered by the health-care professional in accessing information or coordinating actions with other actors. -Training received or planned by the health-care professional on disability issues. -Proposals related to the training of health professionals. - Proposals to facilitate the access of persons with disabilities and their caregivers to health-related information sources.