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**Disability Studies:  
critical analysis to rethink about intellectual disability  
policies in the Italian scenario.**

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*“Let me win.  
But if cannot win,  
let me brave  
in the attempt.”*

*Special Olympics athlete oath*

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## Introduction

The powerful phrase “Nothing About Us Without Us” was the first representative slogan of disability rights movement (Charlton, 2000). It was used to communicate the idea that no policy should be decided by representatives without considering all the social groups affected by the policy. “Nothing About Us Without Us” express the conviction that people with disability have a voice that must be at the table of any planning process. Disability has been around for as long as people can remember, from ancient times to today. However, it was not until the 1960s before the disability rights movement started. In this period, for the first-time people with disability became politically active and began to proclaim their activity in society. Why did it take so long and why do problems still exist today? Which is the meaning of social-model oriented policy?

It has a lot to do with how society deals with disability, the kind of welfare and public policies. Disability is not a medical category but a social one by being socially constructed. In the field of disability, intellectual disability represents the world's largest minority group. ID, historically, culturally and geographically has been the most marginalized and discriminated social group. In a report of Special Olympics on the status and prospects of persons with ID it has been estimated that the number of intellectual disabled around the world is 1/3%, it means approximately 200 million people with intellectual disability in the world (Special Olympics, 2009). Child with ID are hundreds of millions and are daily exposed to risk for cognitive impairment. Intellectual Disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (refers to how effectively individuals cope with everyday life demands, and how well they meet standards of personal independence expected of someone of that age and socioeconomic and cultural background), which covers a range of everyday social and practical skills, ID use to enter in the life of one person before the age of 18 (AAIDD, 2010). Intellectual disability is a category with an extraordinary wide range of different problems associated to different people.

Disability is something that the majorities of people don't want to talk about, sure that is not linked with their lives, as it often happens when something is different. In one sense anyone of us has a disability, if the term disability is referred to limits. The human condition in itself is incomplete (Charlton, 2000). Having a disability surely change the way to live, particularly having an intellectual disability. The world improved a lot by making elevators and ramps, but there are still many conditions that exclude people with disability from “normal” life. There are many awkward situations. Assuming someone isn't able to see, hear, read, walk, speak or understand like everyone else, someone who is different, is immediately considered less smart. Persons with ID are often victims of this wrong reputation. Intellectual disability isn't determined by just an IQ test. On the contrary the evaluation and classification of intellectual disability is a complex issue formed by many elements that should be bringing together. This misunderstanding of considering disabled

and persons with intellectual disability as less smart represents a huge loss in dignity in their everyday lives. Examples are: the lack of access to building, education, employments and social life in general. Person with an intellectual disability often remain unemployed or underemployed. Even if they have capacities, even if they are educated, even if there are solutions in order to work with a disability, even if they are capable of holding a job. The legislation evolved in a way to encourage (force) enterprises to assume persons with disability and with intellectual disability. The development of legislation evolved but the problem remains. In many cases people with intellectual disability aren't in charge of a real working responsibility just because considered, in advance, not able to. This happens because society used to be divided in those considered "able" and those considered "not able".

Charlton (2000) argued that for many years people with disability were victims of disability oppression based on three main dimensions: the kind of political economy and world system, the cultural and belief system, the false consciousness and alienation. The first dimension is relative to how politics and economy distributes opportunities, the second is related to the way of thinking of society that is rooted in cultures, the third is the challenging one in a future prospective: ideology and power that are the main factors to organize how people experience politics, economics and culture.

In order to truly understand and learn about disability, in particular about intellectual disability, it is necessary to think about it differently, changing perspective.

Most of the people grew up knowing which words to use in relation with the meaning, many are still confused about how to describe people with disability.

Is it better to say "disabled" or "handicapped"? What about "differently abled", "crippled" or "retarded"? The definition is important and to talk about disabled as "person with disability" makes many differences in terms of inclusion. Just to give an example, the word handicap came from the vocabulary referred to horses racing. A handicap racing is a race in which slower horses play with better horses, the better horse races with a disadvantage, carrying a higher weight. The disadvantaged is the handicap. Handicap is not the right word to be attributed to disabled and nor for those with an intellectual disability.

WHO, from a healthcare's point of view, made a classification system that allow countries to have a common communication code to share and properly transmit information. The ICIDH-2, the international classification of Impairment, Activities and Participation it is important not only to be a common code but also such a system of classification for epidemiological, research, clinical and educational purposes, since it suggests standardized definitions and terminology which are useful for a better transmission of health and socio-educational data (Buono S., 1999). Historically the quality and quantity of disability's data have been poor. There is a lack of statistical data for national policies and progress for ID. Statistical data could not be considered to have a direct impact on policy change but policy makers might use them as potent tools to inform and galvanize the actions of the agents of change (Special Olympics, 2009). People with disability, especially those with ID, are no longer closed in the insane asylums or mental hospitals. Fortunately, many progresses have been done. Nowadays public policies should be the tool of an inclusive revolution that will get away the idea to make

people with disability fit for society and instead aim to make society fit for person with disability. Collecting data is the first important step in order to design public policies able to respond to the needs of persons with disability. Over the past decade, a great deal of progress has been made in disability data collection. The adoption of the International Classification of Functioning, Disability, and Health (ICF), approved by the WHO World Health Assembly in 2001, provides a common language and standardized framework for the conceptualization of disability (WHO, 2001).

Finkelstein believes that society could become fit for people with disability through the removal of social barriers which restrict the particular lifestyles of people with impairments: 'social barriers' being understood as far more than merely physical, or environmental, barriers (Finkelstein, 2004).

In Finkelstein's words "I am talking about an unfolding awakening in the consciousness of an oppressed group which has faced perhaps the longest and most entrenched of all the prejudices held by 'people with capabilities'. This is a prejudice which enables people with capabilities to see themselves as the quintessence of all that it means to be a 'person', to be 'normal', while at the same time identifying all other people by their possession of some aberration or other. Disabled people can't just be people – we have to be 'people with disabilities', and in adopting this label for ourselves we inevitably accept the 'stigma' imposed on us by people with capabilities".

How to change?

One of the best examples in order to achieve the rights prospective came from the association Special Olympics. Special Olympics, by sport, acts in a way that can be easily considered as a model approach of intellectual disability. Special Olympics athlete Matthew Williams states: "Special Olympics teaches their athletes to be confident and proud of themselves and teach to the world that people with intellectual disability deserve respect and inclusion."

Important note about the data: the gap between the years and sources is justified by a general (national, European and international) lack of statistical data and surveys on intellectual disability that do not allow a linear statistic reconstruction.



## **CHAPTER 1: Disability: history, definition, classification and the specific case of Intellectual Disability (ID)**

### **1.1 Disability Studies and the different models of disability.**

At the end of the previous century in the Anglo-Saxon countries persons with disability became activists. The consequence of this movement was the birth of Disability Studies. The disability's rights movement emerged in the 1970s and 1980s, primarily in US, UK, and Canada giving origin to much of the groundwork for the current development of disability studies. There were people with disabilities themselves who shifted the perspective away from a focus on individual deficiency and pathology, towards a focus on socially constructed barriers (inaccessible architecture, exclusion, prejudice).

In 1993, an official definition of disability studies was adopted by the Society for Disability studies, a professional organization of scholars from around the world. The definition states that Disability Studies, among other things:

"... examines the policies and practices of all societies to understand the social, rather than the physical or psychological determinants of the experience of disability. Disability Studies has been developed to disentangle impairments from the myths, ideology and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social statuses and the assigned roles of people with disabilities are the inevitable outcomes of their condition." (School of Disability Studies, 1999)

The academic group of DS is characterized to be international and interdisciplinary. Being a network, the DS's researchers had a shared goal: to questioning the medical model on disability. The Medical model namely looks at disability as an individual deficit or defect that can be remedied solely through medical intervention or expert's rehabilitation methods. On the contrary DS are more interested to examine social, political, cultural, and economic factors that help to determine personal and collective responses to difference. In DS different ideas of disabilities are placed within broadest possible contest. DS analyze the institutional and social lacks that consequently create exclusion and how the weakness in rights and laws can determine the emancipation of a person with disability (Medeghini, 2013).

DS had a revolutionary idea: there isn't a necessary link between to have a disability and to be disabled. The disability can increase or decrease in relation of the social circumstances.

Many models of disability have been developed inside and outside disability studies, among them more recently, the capability approach model (Mitra, 2006) and the cultural model (Waldschmidt, 2006). The models of disability are important because those are the base due to understand the historical development of the policies and rights of people with disability. Retief M. and Leršosa R (2018) described nine of it:

- Models of disability provide de notions of disability.
- Models of disability provide explanations of causal attribution and responsibility attributions.
- Models of disability are based on (perceived) needs.

- Models guide the formulation and implementation of policy.
- Models of disability are not value neutral.
- Models of disability determine which academic disciplines study and learn about PWDs.
- Models of disability shape the self-identity of PWDs.
- Models of disability can cause prejudice and discrimination.

The oldest model of disability is the moral and/or religious model; according to this theory disability should be considered as a punishment from god or a test of faith (Retief & Leršosa, 2018).

Since the mid-1800 the moral/ religious model was replaced by the medical rehabilitative model

Olkin outlines the basic characteristics of the medical model of disability (1999):

“Disability is seen as a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and to the environment). Persons with disabilities are expected to avail themselves of the variety of services offered to them and to spend time in the role of patient or learner being helped by trained professionals”. (p. 26)

The person with disability is identified by the medical model through its disability. Terms such as ‘invalid’, ‘cripple’, ‘spastic’, ‘handicapped’ and ‘retarded’ are all derived from the medical model (Creamer, 2009). In the medical model the diagnosis assumes a central role and the medical’s professions became fundamental. Social inclusion and the relationships of the person with disability are not considered by Medical model or not considered as effective elements due to evaluate disability. Medical model recognizes only the individual dimension of having a disability: the exclusion is justified by the impairment. Giving an example (Degener, 2014) if a person is blind or deaf can’t participate to the cultural and political life because of its impairment rather than because of social barriers. Michael Oliver (1990) one of the founding fathers of the social model of disability, has called this: the ideological construction of disability through individualism and medicalization, the politics of disablement. The limits of medical prospective of disability stay in the fact that doctors are trained to diagnose, treat and cure illnesses, not to alleviate social conditions or circumstances (Oliver,1990).

Medical model of disability is based on two assumptions that have a dangerous impact on human rights: (1) Disabled persons need to have shelter and welfare and (2) impairment can foreclose legal capacity. The first assumption legitimizes segregated facilities for disabled persons, such as special schools, living institutions or, sheltered workshops. The second assumption has led to the creation of mental health and guardianship laws that take an incapacity approach to disability (Dhanda, 2007).

The social model made a significant difference between the concept of illness and disability proving they have deeply different meanings. Many disabled experienced medical interventions in many, best case, inappropriate and in the worst others with irreversible consequences until the social model clarified the differences between illness and disability. One of the historical examples came from Kennedy's family. Rosemary Kennedy experienced a mental disability. In 1941 at the age 23, Rosemary became increasingly assertive and rebellious, at this moment her father Joseph P. Kennedy decided that his daughter Rosemary should have a lobotomy. Ronald Kessler narrated what happened; the procedure was carried out by Walter Freeman of Wingdale Psychological and Correctional Facility.

"We went through the top of the head, I think she was awake. She had a mild tranquilizer. I made a surgical incision in the brain through the skull. It was near the front. It was on both sides. We just made a small incision, no more than an inch." The instrument Dr. Watts used looked like a butter knife. He swung it up and down to cut brain tissue. "We put an instrument inside", he said. As Dr. Watts cut, Dr. Freeman asked Rosemary some questions. For example, he asked her to recite the Lord's Prayer or sing "God Bless America" or count backwards.... "We made an estimate on how far to cut based on how she responded." ... When she began to become incoherent, they stopped.

After the lobotomy, it quickly became apparent that the procedure was not successful. Kennedy's mental capacity diminished to that of a two-year-old child. She could not walk or speak intelligibly and was incontinent (Henley, 2009).

The story of Rosemary is known because of her family's fame but is full of other stories about persons with intellectual disability victims of a wrong model without dignity and rights.

The reaction to the limits of the medical model was at the base of the British Disability movement during the 1960s and the 1970s. At this moment the perspective on disability changed looking at disability as a social state and not a medical condition. During 1960-1970 the discomfort of people with disability increased because the prevailing culture assigned to disabled person a special kind of social status. Moreover, public utilities, health and welfare services were unresponsive to the particular needs of people with disability (Finkelstein, 2004).

Paul Hunt directly challenged the prejudice on disabled in his pioneering book "Stigma: The Experience of Disability" (1966). Hunt takes also inspiration by the book Stigma of 1963 wrote by Erving Goffman who wrote about the spoiled identities. DS divide Goffman and Hunt in two different model of disability. Hunt is the representing of the Social model while Goffman of the socio-constitutional American model of disability. The father of the social model is considered to be Vic Finkelstein, together with Hunt he has been one of the UPIAS (Union of the Physically Impaired against Segregation's) founders. UPIAS produced one of the most important documents for the interpretation of disability.

Principles of Disability (UPIAS, 1976) drawing an important distinction between the term's "impairment" and "disability". Disability is defined as: "the disadvantage or restriction of activity caused by a contemporary

social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976).

UPIAS defined disability in a radical different way from the medical model:

“Disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.”

According to the social model (sometimes also referred to as the minority model), it is society “which disables people with impairments, and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation” (Barnes , et al., 2010). The social model of disability has impacted on how disability is understood in our time (Goffman, 1963). Disability for social model is considered a social construct and therefore change by time, because how society consider disability change. Disability is proportional to the social barrier.

Michael Oliver (2013), another of the founding fathers of the social model of disability, has recently called for a halt to this criticism, unless someone can come up with an alternative.

It is necessary to clarify that the critics of the social model to the medical one isn't related to the medical treatment of illness, it is perfectly appropriate in most circumstances. What is at issue is whether there is an appropriate role for doctors within the social model of disability (Oliver 1990).

The identity model, is different from both the medical and the social and look at the disability as a positive part of a person identity. Brewer (2012) offers the following illuminating definition, which also explains how the identity model departs from the social model's approach.

“Under the identity model, disability is a marker of membership in a minority identity, much like gender or race . . . Under an identity model, disability is primarily defined by a certain type of experience in the world – a social and political experience of the effects of a social system not designed with disabled people in mind . . . While the identity model owes much to the social model, it is less interested in the ways environments, policies, and institutions disable people, and more interested in forging a positive definition of disability identity based on experiences and circumstances that have created a recognizable minority group called ‘people with disabilities’”.

This model was subject to many critics because it affects the real disparity's conditions, also economical one, and because it seems to compel individuals to identify with a specific group culture (Faster, 2003).

The third model described by Retief M. and Leršosa R (2018) is the Human Rights model, considered by the majority as a synonymous of the social model.

Degener (2014) clarify how the two models differ each's others "Disability studies provide the theoretical background for what we call the shift from the medical to the social model of disability. The social model of disability views disability as a social construct and locates the problem of disability outside the individual in discrimination policies. However, within disability studies the social model of disability has been almost as strongly criticized as the medical model of disability".

Degener considers the HR model as an improvement of the Social model, in Danger's opinion, even if the CRPD doesn't make an explicit separation between the social model and the HR model, there are six's main differences.

Firstly, while social model merely explain disability around a theory, the HR model is able to give the principle and values necessary to found a disability policy. The HR theories by CRPD seek exactly that. chapter 2 of the thesis analyze how. Therefore, HR model is right based approach while social model not.

Secondly Degener (2014) distinguishes the social model as essentially based to support the anti-discrimination model civil right reform, a partial solution to the problem and HR as a model more comprehensive; it encompasses both sets of human rights, civil and political as well as economic, social and cultural rights.

Degener explains the third argument through the word of Jenny Morris (2001), a feminist disabled writer:

"If we clearly separate out disability and impairment, then we campaign against the disabling barriers and attitudes which so influence our lives and the opportunities which we have. This does not justify, however, ignoring the experience of our bodies, even though the pressures to do this are considerable because of the way that our bodies have been considered as abnormal, as pitiful, as the cause of our lives not being worth living. ... In the face of this prejudice it is very important to assert that autonomy is not destiny and that it is instead the disabling barriers 'out there' which determine the quality of lives. However, in doing this, we have sometimes colluded with the idea that the 'typical' disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment."

The HR model look at disability as a part of diversity characteristic of a person the social model of disability neglect the experience of impairment and pain.

Fourthly the social model of disability neglects the identity politics as a vulnerable component of disability policy because the focus is more on the social power relation that on personal emancipation. Some disability's categories have created there's own cultures, in this context the identity plays an important rule for Disability studies. The HR model is characterized to give importance and consideration to different layers of identity. To give an example art. 6 and 7 CRPD are dedicated to disabled children and disabled women. Some impairment related group that have an own identity are recognized. Article 24 (3) a and b CRPD, demands that persons who belong to these impairment groups are provided with the tools to education that are adequate

to their identity, such as Braille and sign language, that they are provided with role models and qualified teachers and the most disputed paragraph reads:

- (1) ... States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to: (...)
- (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development. (...)

Article 30 (4) CRPD on cultural participation demands that states: “recognize and support their specific culture and cultural identity, including sign languages and deaf culture”.

fifth difference: human rights model allows for assessment of prevention policy while social model of disability is critical of prevention policy.

Finally, while social model can give reasons to why most of disabled people in the world live in poverty HR offers a way to change.

It's possible to conclude that the HR right model give guide lines in order to overcome the barriers that disabled people have to cope with, in everyday life, while social model stay theoretical.

The cultural model of disability focused on a range of cultural factors. It is in contrast with the other models. The aim of cultural model is not only to define disability but specifically underline how the cultural filters changed the conceptualization of disability or non-disability status.

The model of charity, still present everywhere and more than expected, looks at disability with the sentiment of compassion and pity: the person with disability is victim of its impairment.

To conclude with the overview of Disability's model there are: the economic model and the limit model.

The first is focused on the economic effect of disability and in particular on labour and employment capabilities' (Amstrong, et al., 2006). The economic model is often utilized by governments as a basic point of reference for formulating disability policy (Jordan, 2008).

According to the limits model all human beings have to experience some level of limitation in their everyday lives (Creamer, 2009). Such limits are experienced to varying degrees during all the phases of our life Rather than being something foreign to human experience, limits are as a matter of fact “a common, indeed quite unsurprising, aspect of being human” (Creamer, 2009: 31). Indeed, Creamer (2009:96,116) prefers to utilize the neologism ‘limit-ness’ – as opposed to the term ‘limitation’ or ‘limitedness’ – in order to emphasis that ‘human limits need not (and perhaps ought not) be seen as negative or as something that is not or that cannot be done’, but rather as ‘an important part of being human’. Furthermore, as people experience ‘various formations’ of embodiment, ‘disabled embodiment’ is one of those formations of embodiment (Creamer 2009:32).

For the American Association on Intellectual and Development Disabilities, Intellectual disability being a particular part of the disabled dimension is based mainly on four approaches. To define the construct referred particularly to ID, AAIDD have been used four assumptions: the clinical assumption, the social assumption, the intellectual assumption and the dual-criterion assumption (American Association on Intellectual and Developmental Disabilities (AAIDD) ad Hoc committee on the Terminology and Classification, 2010). The social and medical approaches have been deeply analyzed yet. Intellectual approach is based on the IQ tests, it increases the idea that having an intellectual disability immediately means being less smart while it can only mean being smart in a different way. The second approach not mentioned yet is the Dual-Criterion approach is the one that use both the intellectual functioning and adaptive behavior to define mental retardation creating classes Heber (1959) used for the first time in 1959 by the American Association on Mental Deficiency. By this approach mental retardation was defined as: “referring to unaverage general intellectual functioning that originates during the developmental period and is associated with impairments in maturation, learning and social adjustment”, in 1961 Maturation, learning and social adjustment were folded under the same term adaptive behavior (AAIDD, 2010). Having an overview on the main disability’s models is the first step to analyze the weakness done by the policy maker in the past on the matter of intellectual disability.

## **1.2 The weakness in the legislative framework.**

Angelo D. Mara (2011) wonders how much the analysis of the disability’s model can influence the legislative framework. In the previous paragraph the medical model emerged as a wrong model to look at disability in an inclusive way. After the previous analysis of disability’s models, it is possible to conclude that a legislative framework should be social oriented or HR model oriented. What does it mean in practice?

First of all, it is important to understand how juridical regulations work and which can be their structural limits. The juridical approach is limitative because of the need to create categories and distinctions. The necessity to make differences in jurisdiction field has strong consequences on the social laws given to disabled person. A Law reflects society’s norms, values, and intolerances, it is an arbiter of power relations, it’s part of the problem by creating social barriers and classifications based on competency or abilities (Kanter & Arlene, 2011).

Minow (1990) through five assumptions describes the law’s weakness for what concern disability’s issues. The first weak point is to look at the differences intrinsically rather than relatively. Giving an example: “Deafness makes a person "different" from hearing people, but does not distinguish him from other deaf people. Moreover, it makes no sense to assert that a person is different from himself. He must be different from somebody else” (Minow, 1990). The second weak point is related with the concept of the norm. Laws need to state what is into the norm and what differs from the norm. If a deaf is different, then hearing must be the norm (McMullen, 1991). The law acts as if the chosen difference and norm were somehow inevitable and dictated by objective facts, rather than by a subjective ordering of priorities and expectations. Thirdly laws

aim to assume just one perspective and this is utopic. Disability should be considered and observed without a particular perspective, because anyone has its own perspective and is impossible to unify all. It is hard to conceive of a person having no starting assumptions, no self-interests, and no past experiences by which to judge the meaning of present experience. The fourth limit identified by Minow regards the lack of disabled perspective in law. Namely the unique important opinion relatively to disabled law should come from their perspectives. The person who is being considered as different in law is entitled to remarks where the differences are. Finally, the law operates on the presumption that the status quo is "natural, uncoerced, and good." Minow in 1990 proposed alternatives criteria. Minow attributes importance to differences looking at those "as a function of relationships". Be focused on the relationships more than differences in itself allow a major flexibility to solve specific problems regarding disability.

Changing approach in legislative framework seems to be fundamental. Powers, society, policies are regulated by laws. Overcoming the law's assumption of differences means to be more creative in the problem solving. For example, Minow suggests that classes should be conducted both in sign language and in spoken language with the result that both would be considered normal and expected, and no one would be "different." In Rome there is a good example of Minow's suggestion with the ISSR, State Institute for the Deaf, where classes are mixed between deaf child and non-deaf child. The result of ISSR classes are excellent. In this case the differences became a resource.

To sum up, a law related to disability, should emphasis the ability of a disabled person rather than diversity. The rights, as for anyone, should guarantee an improvement of life's quality. What jurisdiction should aim at is to promote the empowerment process. It means to make the persons with disability in the condition to be conscious of theirs values, their abilities and theirs rights.

HR and social model can be applied by drafting laws focused on ability's valorization more than be focused on the degree of norm. Legislation delate weakens by encourage the empowerment process.

The weak subject needs to know and discover their capacity to do due to overcome their limits (Charlton , 1998). The Empowerment process allows to have power of themselves. Jurisdiction should become a tool to find ability in themselves. A law is a tool for people with disability and in particular with an intellectual disability to leave the intimidation status to stay in the emancipation one. The empowerment process is structured by law but law needs to act together with an inclusive approach. The final aim is live in societies where the right to be equal came before of arriving in tribunal's room. The DLS disability legal studies combine the aim to overcome the law assumption with the need to apply disability theories

### **1.3 Definition of Disability.**

The word disability gives a bunch of different answers. One word can have few meanings. Defining disability is more complicated than expected. The power of language is particularly relevant relating to words that describe people with disabilities. In the past, disability has undergone many meanings: crippled, lame and



invalid, but those words are not officially used anymore even if it is still common to use the word disability for everyone considered not “normal”. A long philosophical debate can be done regarding what is “normal” and what is not. Without opening the long debate Goffman’s passage ( 1963, p.159) helps to clarify how general the concept of normality is saying that: “ in America, it is possible to affirm that there is only one man who have not to blush; the ones who is young, married, white, who lives in the city, coming from the north states, hetero sexual, protestant, with an university’s background, a good job, a great aspect, right weight and height and interested in many sports”. Terminology referred to disability has been often used to describe what is abnormal, out of “normality”. Examples (Kanter A., 2011) such as “dumb luck,” “lame idea,” “falling on deaf ears,” “blind rage,” and “stand up for yourself” are significant for the images they present and are examples present in many world’s languages, a “crazy” or “retarded” idea is a bad idea; “blind to the fact” means lacking knowledge or having no understanding; and someone who is “crazy” means someone who is out of control and not someone you would want to get to know (p.434). Those expressions are often present in everyday common language; it is time to change trend and to use a different vocabulary. Moreover, using disability as a metaphor not only offends certain individuals, but also creates an environment of unease and exclusion and impedes clear communications, perpetuating false beliefs about disability.

Person with disability is the right respectful name, in this matter the person came before the disability. The usage of the words related to disability is not only about how it is possible to describe it but also related to how disability is seen by society. Indeed, the choice of the terminology, reflect values and speaker’s beliefs.

UNICEF (2007) actively uses “children with disabilities,” arguing that it promotes individuality and positive values. Swain and French (2000), described a right view for looking at disability as:

“(…) non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective ... grounded in the benefits of life style and life experience of being impaired and disabled.” They drew upon the experiences and written expressions of disabled people to formulate a view of disability that could ‘enhance life or provide a lifestyle of equal satisfaction and worth’ (p570).

Looking at Dictionary’s definition (Thesaurus dictionary ): disability imply a lack of power or ability, a disability is some disqualifying deprivation or loss of power, physical or other excused because of a physical disability, a temporary disability. The antonyms of disability are ability, capacity. The antonym of disability is ability. is It true? Is that a right and real definition? Considering these definitions, a person with disability doesn’t have abilities, but how those lack of ability can explain things amazing such as the sports endeavors or people with disabilities who achieve great results. Terminology came from different models of disability, seen before. There are two main models that have been used to describe what disability is. The first one is the Medical Model. Medical model is losing ground nowadays and states that disability is related directly to the impairment. A person is defined by his impairment. Then, if is blind, the fact to be blind came before of his personality. Therefore the disability characterizes the person. Once a person becomes disabled all other

physical, sexual, gender, intellectual, emotional or proper characteristics seem to disappear. The disability itself becomes the person's primary identity. The second approach: the social model, is a bit newer. It argues that disability it's not so much the owned condition, it is more dependent to the social barriers, related with how society is organized. For the social model the disability is something linked with relation between persons. Social model define disability in a personal way, being focusing on the personal experience of disability rather than an impersonal (medical) one. Anyway, for the social model the ability of a disabled person came before its disability as like as its personality. the definition and the idea of disability is then relative because social relations and barrier change with time. Giving an example: many years ago, there were not a solution for people who needed glasses because one thousand years ago there were no glasses. People who were near or far sighted at that time were considered having a disability; society hadn't found a solution yet. The glasses invention doesn't change the medical status of those who held eye's problems but made a better life for people living with eyesight. Today people who wears glasses would not be considered disabled anymore: the medical condition is exactly the same but the social barrier has been removed. If having a disability means to be not able at, then anyone of us is not able in doing something, it depends from the context. In other words, the meaning of disability is always changing as society come up with new solutions. Then what is disability? Basically, it describes how a situation in society can be a barrier to someone's everyday life, simply due to a medical or intellectual condition. Because the thesis is focused on intellectual disability it is important to specifically define the research's subject: intellectual disability.

### **1.3.1 The specific case of intellectual disability**

In the case of Intellectual disability is important to make difference between two terms: mental retardation and intellectual disability. Mental retardation came from the medical model of disability and view the disability as a defect within the person, as a condition internal to the person, whereas the Intellectual disability views the disability as the fit between the person's capacities and the context in which the person is to function, ID is not a condition but it refers to a state of functioning (AAIDD, 2010).

ID has been recently defined by the American Association on Intellectual Developmental Disability. The AAIDD definition, based on three main criteria, is: "intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability origins before age of 18."

The main components provided by AAIDD to have a correct diagnosis of ID are: intellectual functioning, adaptive behavior and age at which disability began are also.

The American Association in Intellectual and Developmental Disabilities (AAIDD,2010) defines ID by using two approaches: an operational definition approach of ID and a constitutive definition approach of ID.

The operational approach indicate how AAIDD definition must be applied through five essential approaches:

Assumption1: “Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.”

Assumption 2: “Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioral factors.”

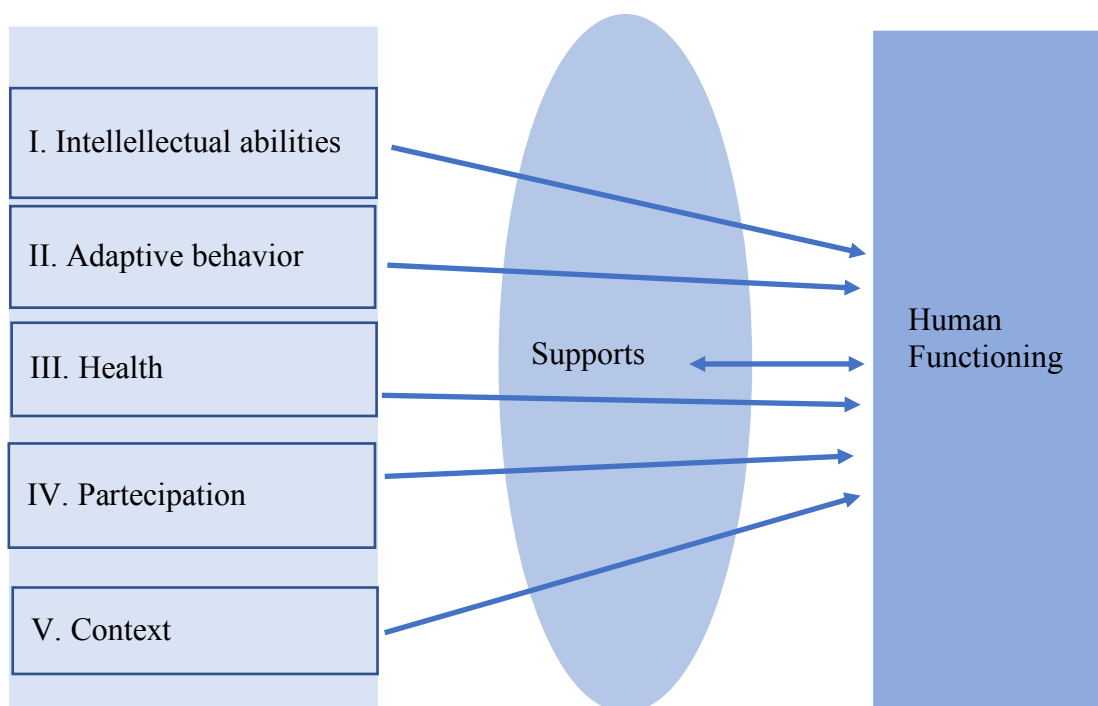
Assumption 3: “Within an individual, limitation often coexist with strengths.”

Assumption 4: “An important purpose of describing limitations is to develop a profile of needed supports.”

Assumption 5: “With appropriate personalized supports over a sustained period, the life functioning of the person with ID generally will improve.”

The second important approach is to define the construct in relation to others construct in terms of limitation of human functioning, conceptualizes disability within an ecological and multidimensional perspective, and emphasize the significant role that individualized supports play in improving human functioning (AAIDD,2010). The conceptual Framework of Human functioning links the five main dimensions and the supports play in human functioning in order to have a correct understanding of the ID. The constitutive approach is able to look at all the features of ID understanding its multidimensional nature. In particular by analyzing the five-dimension associated with the supports to human functioning it’s possible to understanding the vast biological and social complexities associated with ID, captures the essentials characteristics of a person with disability and establishes a logical framework to support provisions.

**Figure 1** Conceptual framework of human functioning (AAIDD,2010)



The intellectual abilities refer in general to mental ability: the capacity to link things and making sense between its, the capacity to program and understand. Intelligence isn't related only with IQ test or academic performance. Intelligence is present in different way in each person. Intelligence includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas learning quickly, and learning from experience (Gottfredson, 1997).

The second dimension, the adaptive behavior is related with personal attitudes and skills learned and performed in everyday lives (AAIDD,2010).

The third dimension, Health, is defined by WHO (1999) as a state of complete physical, mental, and social well-being. Health is very variable in the case of intellectual disability because having an ID do not imply necessary to have significant activity limitations but might be.

The fourth dimension, Participation distinctly related with the social role of the subject with ID. Participation is related with social interaction in every dimension of everyday life: work, school, family, interactions with friends etc.

AAIDD connect all the dimension with the supports: “are resources and strategies that aim to promote the development, education, interests, and well-being of a person and enhance individual functioning”. The interpretation of ID gives by AAIDD agrees with both the International Association for the Scientific Study (AAIDD) and with the recent World Health Organization International Classification of Functioning, Disability and Health.

According to the tenth revision of the WHO (World Health Organization):

“Intellectual disability (ID) is a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development and that contribute to the overall level of intelligence, such as cognitive, language, motor and socialization functions; in this anomaly, adaptation to the environment is always affected. For ID, scores for intellectual development levels must be determined based on all of the available information, including clinical signs, adaptive behavior in the cultural medium of the individual and psychometric findings”.

Words such as “retard”, “crippled”, “lame”, “handicapped” have been replaced with “a person with a cognitive (or intellectual) disability”. This change in the vocabulary linked to intellectual disability represent not merely a “political correctness” it reflect an overdue recognition of the respect owed to people with different impairments. People with ID are no less part of our society, are no longer willing to accept labels of exclusion and stigmatization, even if, still today childrens with “special needs” may face isolation from their peers.

### 1.3.2 The classification of World Health Organization.

In order to share and transmit information about disability communication codes are required.

The most important international classification systems came from two important organizations: The (WHO) World Health Organization that has elaborated the international classification of diseases (ICD) and the American Psychiatric Association that has elaborated the Diagnostic and Statistical Manual of Mental Disorder (DSM).

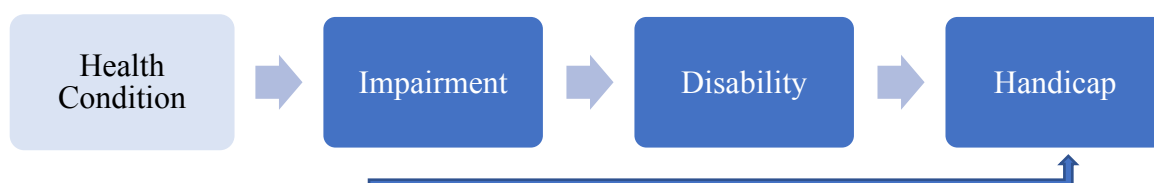
Define and classify disability is a critical dimension. Models of disability have been divided during the classification process of disability. The prevalent influence in the classification process came from the social model.

The classification of WHO had a statistical scope and was done at the end of 1800s. The International Classification of Disease (ICD) in origin was focalized on the illness classification, only since the eight-edition intellectual disability started to be present. The ICD-10 has been completely devoted to mental health problems and behavioral disorders. The ICD-10 classification covers disease, disorders or injuries. The ICD has been based on the medical model of disability with the consequent limits previously analyzed.

In 1973 Dr. Philip Wood (UK) assimilated schemes compatible with ICD; informal circulation of systematized terminology. In 1974 Prof. André Grossiord from Paris discussed separate classification of impairments and handicaps. In 1976 the World Health Assembly with the resolution 29.35 propose supplementary classification of impairments and handicaps. In 1980 in WHO in Geneva, after a team work directed by Dr. Philip Wood, has been published the first International Classification of Impairments, Disabilities and Handicaps (ICIDH). ICIDH promotes a common framework and definition of disability related issues. The 1980's ICIDH distinguished three dimensions that can be studied to monitor the situation of people with disability:

- Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function
- Disability: any restriction or lack of ability to perform an activity in the manner or within the range considered normal for human being.
- Handicap: disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillments of a role that is normal for that individual (ICDIH, 1980).

The ICIDH distinguishes different categories that help to create a common classification system.



**Figure 2** ICIDH (1980).

Should be clear that, a person with disability have not to be qualified or labeled, in fact the categories are connected with the manifestations characterizing of a specific health condition. The ICIDH try to summarize

what can happen as a consequence and in association with an illness using a biopsychosocial approach. ICDH use a codification codes with two or three numbers, the third number is referred to detailed classifications. For disability is possible to add the fourth and fifth number to determine the severity and the prognostic aspects. The linearity of the first ICIDH doesn't allow to represent the complexity of some situations. In fact, an impairment condition can determinate the handicap without disability or disability without handicap. In the case of Down syndrome or trisomy 21 all the three condition are present but in other cases as physical injuries not.

The first ICDH presents limits because the relations between the three components were not clear. The ICIDH has been revised for the first time in 1993, in 1999 has been released the second ICIDH and completed in years 2000. The New ICIDH-2 included innovations in the language and in conceptual terms.

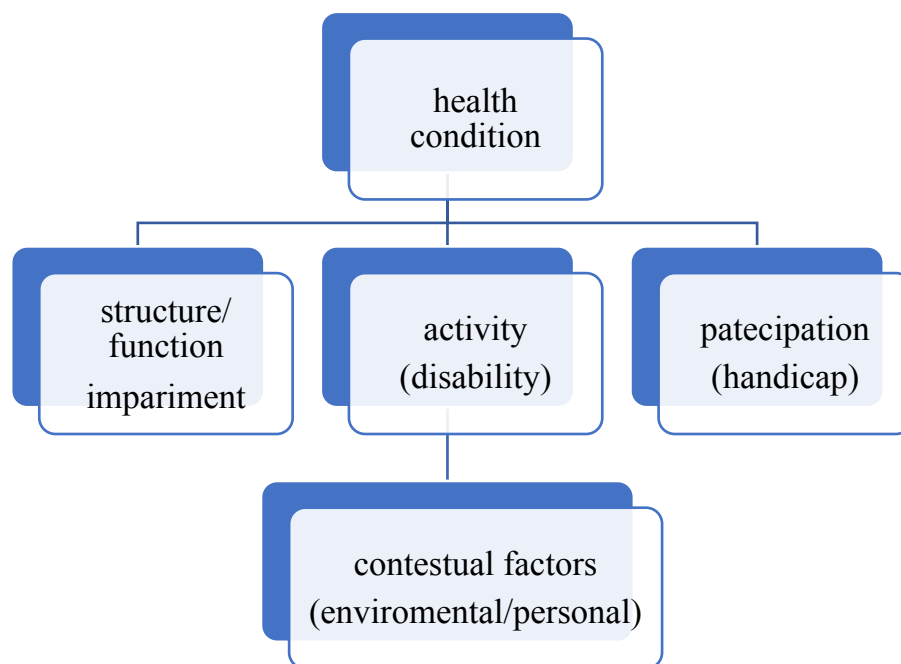
The table below will compare the two ICIDH.

ICIDH	ICIDH 2
International Classification of Impairments, Disabilities and Handicap	International Classification of Impairments, Activities and Participation
Impairment	Impairment
Disability	Activities
Handicap	Participation
	Contextual factors

**Table 1** Classification elements of: ICIDH 1 and ICIDH 2.

ICDH 2 aim to provide a scientific basis for understanding and studying health and health related states, outcomes and determinants to establish the common languages for describing functional states associated with health conditions in order to improve communication between healthcare workers, others sectors and disabled people, to permit comparison of data, to provide systematic coding scheme.

With ICDH-2 the impairment has been divided in structural and functional and the disabilities have been changed with personal abilities. The handicap in ICDH-2 became participation, including all the social lives areas of the person. ICIDH-2 moreover, meet the principle of equal opportunities taken by the United Nation in 1993. Another important innovation in ICIDH-2 is the introduction of the contextual factors allowing the policies intervention on those factors. ICIDH classifications help to achieve a right statistical analysis on subject with intellectual disability, of their social, health and life's condition. ICIDH-2 has been more based on the social model of disability. ICIDH has been used as a statistical tool, as research tool, as clinical tool. It starts to be used by many sectors of society: insurance, social security, labor, education, economics, social policy, general legislation development and environmental modification.



**Figure 3** ICIDH-2.

ICIDH-2 presents some limits. Firstly, it doesn't recognize the presence of social barriers in conceptualization of disability (Bickenbach, et al., 1999). Three are the main areas where ICIDH revealed to be imitated: the approach seems to be based on medical model, the impairments seems to be the main causal element of disability, the representation of impairments as strictly linked to the specialist language (Barnes, 2006).

### **1.3.3 ICF: The International Classification of Functioning Disability and Health.**

In 2001 the 54<sup>th</sup> World Health Assembly presented the final version as International Classification of Functioning Disability and Health (ICF). The ICF provides: conceptual basis for the definition and the measurement of disability, a standard language, a common classifications and codes. The ICF integrates the medical model with the social model in a multidimensional model defined as "bio-psycho-social synthesis". Moreover, Using ICF with ICD, International Classification of Diseases (ICD), makes it possible to provide a full picture of health and functioning. The ICF provides a neutral framework that can serve as a bridge between assessments focusing on health, development, curriculum and social dynamics.

Important in the ICF is the recognized role of the environmental factors, the definitions and categories in the ICF are worded in neutral language and the classification can be used to record both the positive and negative aspects of functioning (World Health Organisation, 2013).

The ICF links the quantitative studies for collecting data with the qualitative studies, descriptive data. The aim of ICF is not to decree who is "normal" and who is disabled, on the contrary is to avoid in any way a form of stigmatization, discrimination or labelling to achieve this result ICF providing clears ethical guidelines

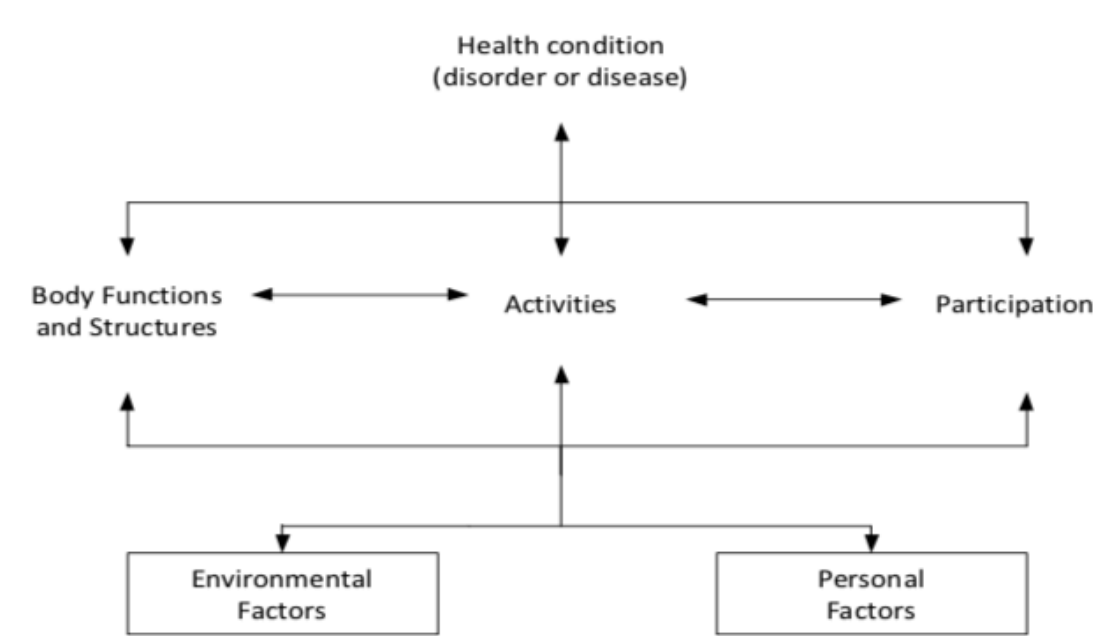
according to the UN Convention. ICF is inclusive because can be applied across the entire life span and is suitable for all age-groups, in different countries and cultures.

ICF considers the functioning and disability of a person as a result of the interaction between the health condition and his environment conditions. ICF represents a unicum in disability classification because puts every person in a context.

**Table 2** ICF How organized information

Functioning and Disability	Contextual Factors
Body functions and body structure	Environmental factors
activities and participation	Personal factors

**Figure 4** The interaction between ICF components (WHO, 2018)





**Figure 5** Definition of ICF components (*World Health Organization, 2001*)

*In the context of health:*

**Functioning** is an umbrella term for body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).

**Disability** is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).

**Body functions** - The physiological functions of body systems (including psychological functions).

**Body structures** - Anatomical parts of the body such as organs, limbs and their components.

**Impairments** - Problems in body function and structure such as significant deviation or loss.

**Activity** - The execution of a task or action by an individual.

**Participation** - Involvement in a life situation.

**Activity limitations** - Difficulties an individual may have in executing activities.

**Participation restrictions** - Problems an individual may experience in involvement in life situations.

**Environmental factors** - The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person’s functioning.

Each ICF component consists of multiple domains, and each domain consists on categories formed by units of classification. The ICF provide textual definitions as well as inclusion and exclusion terms for each class (World Health Organisation, 2013).ICF codes require the use of one or more qualifiers which denote the magnitude or severity of the problem in question. The problem refers to an impairment, limitation, restriction, or barrier when used in combination with b, s, d or e codes, respectively. Qualifiers are coded as one or more numbers after a decimal point (World Health Organization, 2001).

xxx.0	CODE FORMAT		
	NO problem	(none,absent, negligible,...)	5-24%
xxx.1	MILD problem	(slight,low,..)	25-49%
xxx.2	MODERATE problem	(high,extreme,...)	50-95%
xxx.3	SEVERE problem	(total,...)	96-100%
xxx.4	COMPLETE problem		
xxx.8	Not specified		
xxx.9	Not applicable		

generic qualifier of ICF.

**Table 3** The

**Table 4** An example of ICF-code.

b2.1 Sensory functions and pain	first-level item
b210.1 Seeing functions	second-level item
b2102.1 Quality of vision	third-level item
b21022.1 Contrast sensitivity	fourth-level item

The letters b, s, d, and represent the different components and are followed by a numeric code that starts with the chapter number (one digit), followed by the second level (two digits), as well as third and fourth levels (one extra digit each). For example, the following codes indicate a ‘mild’ problem in each case. (World Health Organization, 2001).

By the category, the corresponding code and the numbers or qualifiers, that specify the extent of the functioning or disability in that category, the functioning and disability of an individual may be recorded and it is possible to clarify the extent to which an environmental factor is a facilitator or a barrier. The ICF as a high-level structure of classification offer the possibility, more than ever, to states the building blocks for statistical information. Statistical information, that are analyzed in the next paragraph, in turns are fundamental for policy maker in order to have a right estimation of the needs and of the numbers.

The ICF is a multi-purpose tool which allows for a wide range of use cases, it’s of prime importance in order to supports rights-based policies (Bickenbach, 2009) and provides a framework and model that assist planning and communication across government and other sectors. The ICF provides a common language, terms and for use by people experiencing disability, providing relevant services, or working with disability data and information. This is important because people with functioning difficulties may interact with many professionals and systems, for example health, education and social care. Processes are more efficient if all those involved are basing their approaches and communication on the common language and concepts. ICF provides an organized data structure that can underpin information systems across different areas of policy and services and for policy-relevant population data. If records, research and statistics about functioning and disability are based on the ICF model and framework, they will more efficiently contribute to a coherent national and international understanding of functioning and disability and data comparable across settings and time, clarify the relationship between data, information and knowledge, and to build a shared understanding and interpretation of concepts.

ICF is also relevant for the clinical factors. The ICF used with the ICD – the global standard for classifying diseases presents a full picture of the health status of an individual. The ICF model and classification can support eligibility assessment, service planning, and system-based data generated by administrative processes. In particular, the focus on environmental factors makes it possible to articulate clearly whether the needs of the individual require environmental changes or the provision of personal support. The ICF provides

advantages for population statistics, education, policy and programs and advocacy and empowerment. The ICF took information by primary (person experiencing disabilities) or secondary (e.g. pre-existing documentation or statistics) data sources. The information on intellectual disability are harder to achieve because intellectual functions cannot be observed directly but through standardized testing.

What is new and precious in ICF is the increasing level of details combined with the quality of information. ICF can in future improve a development. For example a 'qualifier for involvement or subjective satisfaction' for the activities and participation component (World Health Organization, 2001). Such a qualifier ('satisfaction with participation') has been developed for use in Australia, to help with delineating Activities and Participation (Australian Institute of Health and Welfare, 2003). Based on findings from ICF-based population surveys done in Japan, a distinction is made in that country between two indicators of performance of activities: 'universal independence' and 'limited independence' (Okawa et al 2008).

Until now, ICF has been explained as a precious tool for policy maker. Previously in the thesis has been analyzed the problems that society has in defining disability and intellectual disability and moreover about how people think about disability. The question is: can the ICF help to clarify how people think about disability? In some situations, the term "disability" may be used without strict understanding or awareness of the potential underlying concepts, beliefs or theories. The term disability is strictly related with the used terms. The use of ICF can lead to a more comprehensive approach to disability because ICF is based on an integration of medical and social models to provide a coherent view of different perspectives of health and disability from a biological, individual and social perspective.

The weakness identifiable in ICF are the personal factors, to record personal factors is relevant to the functioning of the individual. Personal factors are not codified in ICF even if ICF gives important information for a complete description of the functioning profile. Gender, race, ethnicity, age, social and educational background, past and current experiences and life events, character styles, behavior patterns, and psychological assets are all personal factors that may potentially affect functioning. Personal factors are relevant; There are instances when there is a difference between performance and capacity not explained by coded environmental factors. For example, a person may not be working in spite of having the capacity due to a lack of expertise matching job market requirements. In those cases, personal factors may come into play, and their description becomes important and relevant.

ICF has been introduced in this thesis because it is extremely important to support a number of key planning processes in field of intellectual disability public policies. Specifically, Population statistics based on the ICF will identify the need for services and supports. Policies can then be designed specifying which areas of functioning to support. For example, a limited support service program might focus on ICF domains such as mobility and self-care while others might support all areas of activities and participation (World Health Organization, 2013). Setting thresholds for access to support services and income support schemes often

requires a balancing of overall population need against community resources for the program. Population statistics based on ICF enable estimates to be reached of the number of people requiring assistance, and of the numbers to be included in a potential program, using various cut-off points (WHO,2013). Linking different systems to ICF concepts allows for the identification of related services, overlapping responsibilities, or inefficiencies and inequalities in service delivery. Because ICF offers a complete representation of disability and environment, it is possible to underpin assessment about levels of functioning and difficulties encountered, as well as environmental changes or adaptations that could support the individual, such as assistance in the home or work place, assistance with transport, or environmental modifications. ICF is able to bring together information related to: policy and program description and target group specification, determination of needs for program, eligibility assessment, goal setting and case planning, including assessment of the environment and program monitoring and evaluation. In this way ICF gives huge contribute to ensuring and managing integrated, person-centred service provision which addresses needs across policy areas and life situations. Thanks to ICF duplication or contradictory mechanisms in service delivery can be avoided. Comparable recording of disability across different policy areas is important for equitable service delivery and accountability. For example, it is possible to see if people with similar levels of difficulty are receiving similar levels of support services irrespective of age such as when there are separate systems for aged or younger individuals with disabilities. Consistency also enables a specific population sample to be compared to the general population, potentially estimating unmet needs. Clinical data tend to focus on an individual, while population- based survey data identify population characteristics or changes in these characteristics over time. ICF is able to enhance the description of health conditions and impairments with information focusing on learning and development. The ICF provides a neutral framework that can serve as a bridge between assessments focusing on health, development, curriculum and social dynamics. ICF can be used as a framework to develop indicators to measure the overall participation of children in education. ICF can support assessment of the interaction between the functioning of the student and their environment. ICF can support assessments of the interaction between the functional characteristics of the student and their environment.

One of the best practices related to ICF came from Swiss: “since January 2011, the Swiss cantonal education systems have started to implement a multidimensional, context-sensitive procedure to establish eligibility within education systems. The procedure is based on the International Classification of Functioning, Disability and Health (ICF) in accordance with the principles of the UN Convention on the Rights of Persons with Disability. The procedure consists of two parts, (1) organising information on the present situation of the child, and (2) organising information on the future situation of the child as envisaged by the individuals involved. Using ICF as a model and classification, the different factors influencing eligibility-related decisions (e.g. impairments, activity/participation, environment, and personal factors) can provide the basis for a transparent decision-making process to which parents and the child actively contribute” (World Health Organisation, 2013).

Then the ICF can be used as a framework for sharing information at national and international level, to improve functioning to identify environmental barriers which require attention. ICF provides a standard language and framework to facilitate communication across services, organizations and agencies.

Imrie (2004) underlines some imperfections that precludes the possibility of ICF to be a final product: “ICF leaves many questions open and is not able to deeply justify the nature of theories, without clearly define the link between components many interpretations are possible”.

The main critical aspects of ICF are : the regulatory criteria are still influenced by the medical model, the western culture is the referring culture in ICF and the excessive causative burden assigned to the impairment (Barnes, 2012). Moreover, ICF doesn't clarify officially if the proper term is disabled or person with disability. The international process to classify and define disability is still open.

#### **1.4 Overview of Disability's Data.**

The quantity, quality and scope of population statistics on disability is complicated around the world and much more problematic is collecting data on intellectual disability. The majority of nations fail to monitor intellectual disability with any degree of rigor or depth (Special Olympics, 2009).

Art.1 of the United Nation Convention on the Right of Persons with Disabilities UN CRPD of 2006 define the persons with disability as: “(...) Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nation, 2006).

With UN CRPD not only, the definition but also how to measure disability change.

UN CRPD considers inequality a right factor to measure disability. Is no more important the age or the impairment, what take importance is the level of equality. In Italy, for example, the statistical measures on disabled persons are not able to give direct information on the equality's gap described in UNCRPD. As disability is not a singular static state, there is no simple, singular way to collect disability data. Being conform to UNCRPD became a complex challenge. It is necessary to improve not only information about disability but the policy makers consideration based on data. This limit is present in Europe as in other Europeans and world's countries. Is evident the necessity to change and improve the statistical method capacity in a UNCRPD oriented way in particular about intellectual disability. Intellectual disability is one of the most difficult part of disability to statistically analyzed, for more than one reason. Huge investments are necessary to operationalize what UNCRPD theorizes.

Art 31 of UNCRPD is about statistical and data collection:

“1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

- a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
- b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others” (United Nation, 2006).

Paragraph three underlines the responsibility of States, included Italy, in the respect of UN CRPD for what concerns statistical measures.

The establishment of a human rights framework and principles for measurement and monitoring omits the practical aspects of actualizing the *de facto* measurement of disability in populations and the monitoring of compliance with the articles outlined in the UNCRPD. In September 2015, after several years of intergovernmental negotiations, United Nations Member States adopted the 2030 Agenda for Sustainable Development. The 2030 Agenda is comprehensive and has 17 goals for sustainable development, 169 targets and over 230 measurable indicators, and a number of these indicators relate specifically to disability (Eide, 2017).

If the 2030 Agenda of SDGs is going to be successful all of the UN Member States - 193 countries - must include persons with disabilities in their national plans for implementation and monitoring. The required Data from SDGs goals and UNCRPD can become a burden for countries. Data’s collection should address the specific circumstances in each country. The data’s collection includes: the environmental factors, the physical, social, cultural, political and civic environments, the size and characteristics of the population of interest. All those combination of factors vary greatly across geographical regions and even within national boundaries. Similar information from country with similar characteristics can be useful. In an article of January 2017 “Measuring Disability and Inclusion in relation to the 2030 Agenda on Sustainable Development” the researchers Madans Jennifer, Loeb Mitch and Arne H. Eide underline that disability is a permanent characteristic then the indicators should evaluate the evolution of the disability considering the factors around a person with disability. Criteria have to be established to identifies those with and without

disability and to analyzed if there is a condition of equality as UNCRPD. Disability have different levels of impairments and different way to measure the real level inclusion.

The data needed for the implementation of the SDGs and monitoring of the UNCRPD, must encompass both the universal and the place-specific aspects of disability (Arne H. Eide et al, 2017).

This first overview on collecting data shows how more detailed and in- depth data collection can be instituted to provide necessary information also for those with intellectual disability, for program and policy implementation and evaluation. In order to implement the SDGs and the UNCRPD countries have to collected, analyze and report valid data. There isn't a unique way and a unique disability indicator. Indicators nowadays, if carry out powerful approaches looks at outcomes that illustrate the extent to which persons with disabilities are fully participating in society.

The Inter-Agency and Expert Group on Sustainable Development Goal Indicators IAEG-SDG, composed by 27 representative members of UN, in November 2016 in a plenary session together with UN agencies, organizations of persons with disabilities, civil society and independent experts produced a Joint Statement calling on the IAEG-SDGs and the UN Statistical Commission to recommend that national statistical offices move forward with the disaggregation of data by disability. Furthermore, the statement unanimously acknowledged that there are appropriate and broadly tested methodologies already in place to disaggregate data by disability:

“...to ensure international comparability and comparability over time for the purposes of SDG data disaggregation for adults, we recommend the use of the Washington Group short set of questions<sup>1</sup>. For disaggregation by disability among children the recommended tool is the UNICEF/Washington Group module on Child Functioning. Both instruments can be easily and cost effectively inserted in all national data collection efforts.”

At European Level many efforts have been done in order to find way to measure disability and in particular the level of inclusion of people with disability in EU. Even though the efforts of EU and UN the detail and depth information about intellectual disability tend to be severely limited. The reasons why data are referred

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<sup>1</sup> The Washington Group short question set is designed to identify (in a census or survey format) people with a disability and is provided below:

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The scaled responses allow space to capture the full spectrum of functioning from mild to severe, i.e. the continuum of disability.

to disability in general and not specifically on intellectual disability came from the high cost of the specialized surveys in this field.

Intellectual disability is underestimated. Special Olympics (2009) made a survey to check how many national systems divide data collection in general disability and intellectual disability.

**Table 5** Monitoring of ID National Data Systems (n=118 systems) (Special Olympics, 2009).

<b>GROUP</b>	<b>% OF SYSTEMS THAT MONITOR</b>
GENERAL DISABILITY	65.6%
INTELLECTUAL DISABILITY	26.6%

Across the 118 systems (23 census, 72 recurring sample surveys, 23 registries) analyzed by S.O. only a slight minority separately coded persons with ID. Special Olympics survey (2009) demonstrated that even in the most data-rich democracies and developed countries intellectual disability is not typically monitored.

**Table 6** Monitoring of ID by Domain (Special Olympics, 2009).

<b>Domain</b>	<b>% Data Systems That Monitor</b>	
	Intellectual Disability	Other Disabilities
Household Demographics	27.9	70.5
Work	20.0	61.3
Education	29.5	76.9
Health	32.8	75.9
Income	18.9	60.4
Social Participation	33.3	58.3
Services and Supports	45.5	84.1

Data on Intellectual disability use to be largely limited to health status, employment and the administrative tally of individuals who are the recipients of public services or benefit. (Special Olympics, 2009). Around the word seems to be hard to find data on intellectual disability comprehensive and timely. Many steps have been done by the measurement of disability but it is time to develop a broad-based index on intellectual disability within national systems. In order to affect the nature of choices made by governments more quality data on the life circumstances of the world's citizens with intellectual disability are required.

#### **1.4.1 European Data on Disability.**



According to the (EHSIS, 2012) European health and social integration survey in 2012 in EU there were 70.0 million of people with disability, 7,999.5 from Italy. People with disabilities aged 15 in EU-27 represent 17,6% of the population aged 15 and over. Data on disability derived from the EHSIS (2012) are based on the following definition: “people facing barriers to participation in any of 10 life areas, owing to a long-standing health problem and/or a basic activity difficulty.”

**Figure 6** Source Eurostat (online data code: hth\_dsi090)

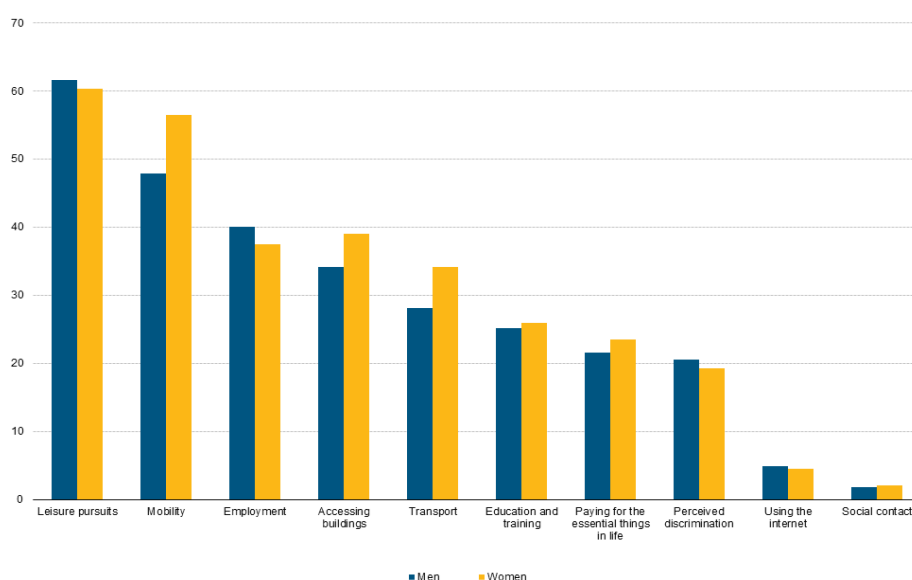
	Life areas									
	Mobility	Transport	Accessing buildings	Education and training	Employment	Using the internet (*)	Social contact (*)	Leisure pursuits	Paying for the essential things in life	Perceived discrimination
EU-27	52.9	31.7	37.0	25.6	38.6	4.6	2.0	60.9	22.7	19.8
Belgium	46.4	24.5	31.2	27.9	44.3	3.3	:	64.1	11.1	23.3
Bulgaria	44.6	34.7	33.2	9.8	26.6	2.0	2.4	35.2	76.4	9.6
Czech Republic	58.1	39.7	40.5	13.9	35.1	2.1	2.4	67.4	34.4	18.5
Denmark	51.0	22.1	33.7	33.6	51.5	7.6	2.8	67.6	11.9	24.3
Germany	50.4	20.8	33.4	31.6	37.9	4.2	1.1	66.0	10.1	20.3
Estonia	56.6	27.1	28.9	14.7	24.7	2.5	:	55.0	44.2	11.4
Ireland	:	:	:	:	:	:	:	:	:	:
Greece	61.2	39.5	40.9	7.7	18.4	:	:	48.1	52.9	9.7
Spain	58.5	34.0	34.9	22.3	40.8	9.1	1.7	69.0	8.7	16.5
France	44.6	29.2	31.5	35.0	35.3	5.6	2.0	66.4	10.5	23.0
Croatia	:	:	:	:	:	:	:	:	:	:
Italy	66.2	51.4	42.7	12.3	20.1	1.7	2.3	54.4	35.2	12.1
Cyprus	49.6	39.2	32.6	19.6	33.3	3.9	:	52.2	35.6	15.1
Latvia	46.7	30.3	24.6	15.1	41.2	2.4	4.1	47.2	51.3	9.8
Lithuania	47.1	32.7	34.3	19.5	42.3	4.2	2.5	48.2	39.4	12.9
Luxembourg	40.7	15.1	26.4	26.9	34.0	5.1	:	63.8	:	23.4
Hungary	60.8	44.6	44.7	16.6	42.4	2.6	:	47.5	54.8	17.5
Malta (*)	48.7	30.4	34.4	16.6	6.7	:	:	43.0	43.5	9.0
Netherlands	36.2	22.3	25.3	25.7	47.1	2.5	2.1	62.7	12.2	21.4
Austria	39.9	20.1	27.7	21.0	36.2	2.0	:	55.4	12.2	14.8
Poland	51.0	35.8	38.5	28.5	43.5	2.6	:	48.9	37.2	17.3
Portugal	47.7	33.5	35.6	13.4	38.0	:	:	42.4	36.3	11.3
Romania	66.1	42.3	51.4	15.3	31.7	1.6	4.3	47.2	65.0	13.4
Slovenia	51.5	33.4	41.0	22.5	23.5	:	4.6	60.9	24.1	13.1
Slovakia	42.5	20.5	27.8	21.0	21.5	2.2	:	55.5	34.5	15.7
Finland	40.3	13.3	25.3	19.5	44.6	4.0	:	64.5	11.0	18.6
Sweden (*)	26.6	15.9	18.5	20.5	46.7	4.3	2.1	67.2	5.1	24.9
United Kingdom	55.7	31.4	45.1	35.7	54.6	9.4	3.6	70.3	10.9	33.3
Iceland	32.1	15.0	14.5	19.6	40.7	:	:	55.1	16.9	27.7
Norway (*)	44.4	15.6	27.0	37.0	66.0	7.2	2.8	65.1	4.9	27.0

(\*) Data with low reliability for most Member States and non-member countries.

(\*) Barriers to employment and barriers of perceived discrimination: low reliability.

(\*) Barriers to paying for the essential things in life: low reliability.

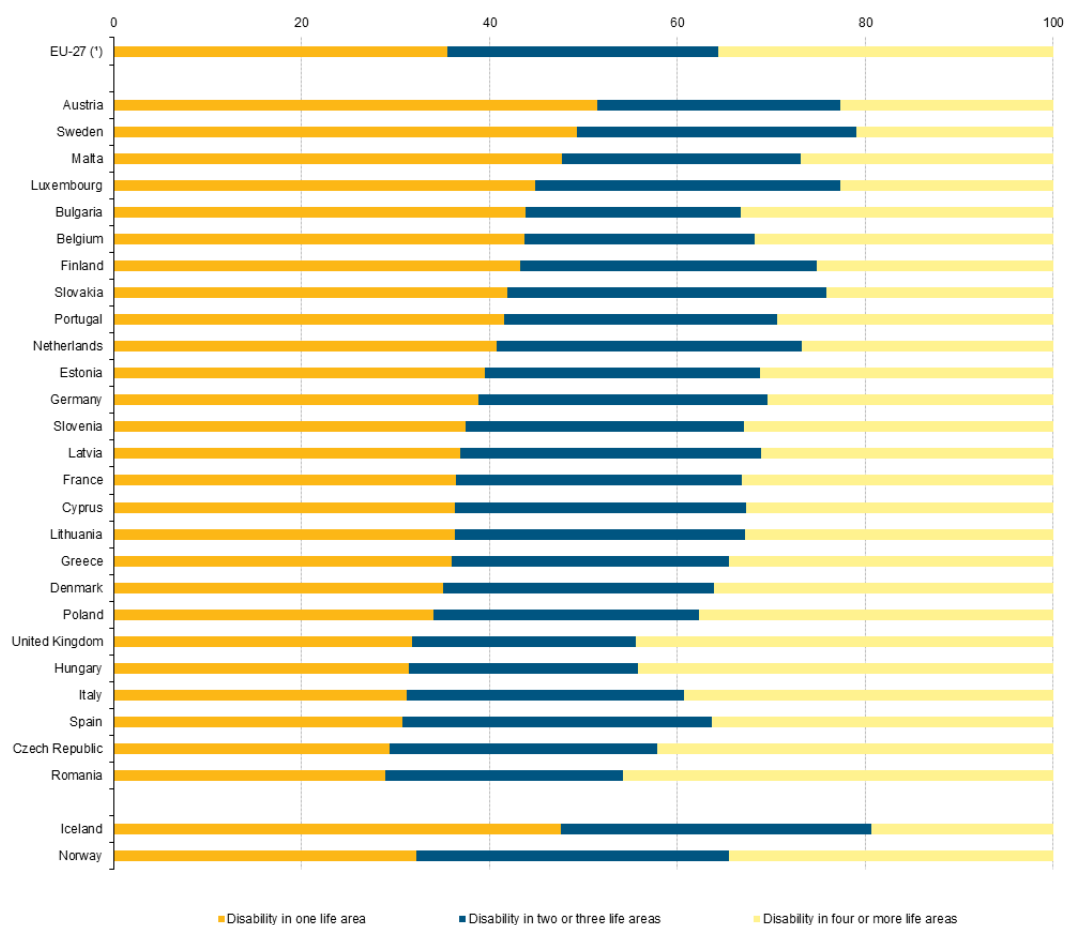
**Figure 7** Source Eurostat (online data code hlth\_dsi090).



Because has seen disability is for the social model proportionate to social barriers EHSIS (2012) associate the disability to the participation in 10 specific life areas. The two main life areas that present social barriers for people with disability are: leisure pursuits with an average of 60.9% of restricted participation and 52,9% for mobility. 16 on 27 EU affirmed that leisure pursuit is where most of disabled reported that they faced disability in 2012 (EHSIS). leisure persist and mobility are followed by Employment 38,6%, assessing building 37,0%

and transport 31,7% life areas. Disability is felt at 25,6% in education and training and 22,7% for paying the essential things in life. Using internet 4,6% and social contact 2.0% represent two areas where people with disability meet less barriers. For what concerns age average younger people with disability (aged 15-44) result to be most likely to report a disability with respect to social contact then older generation (45-65) (EHSIS,2012). EHSIS in a second survey looked at the severity of disability not for every singular life area but by considering the average of life areas in which an individual is restricted. Then the severity will be higher as the number of life areas will increase.

**Figure 8** Eurostat online data code: hlth\_dsi010.

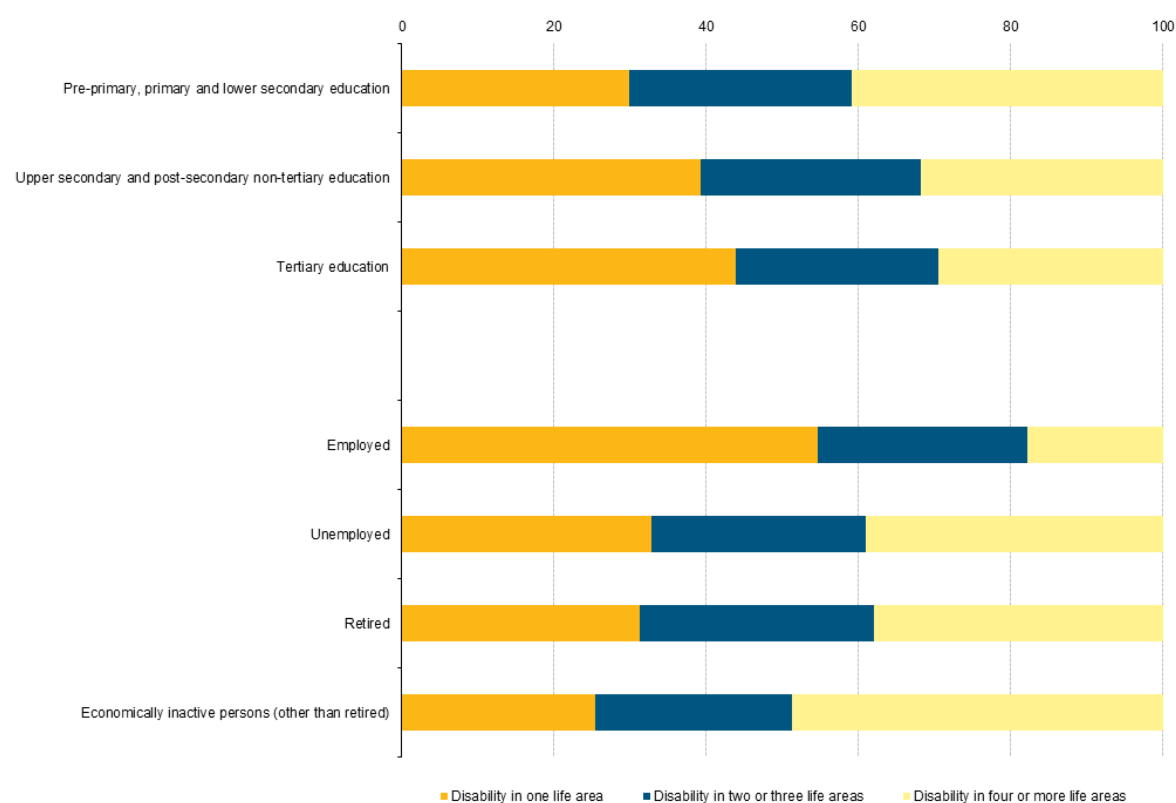


(\*) Estimates.

One life area corresponds to a disability with low severity, while from two to three life areas correspond to medium severity and from four life areas the severity is considered high. Figure show as in many cases such as Italy the people with high severity are more than those with medium and low severity. Is it possible to reduce the severity by remove social barriers? The answer is yes.

In the EHSIS (2012) research project there isn't a part only dedicated to intellectual disability but for many assumptions coming from the concept and definition of Intellectual disability is possible to consider that mostly part of the group of higher severity.

**Figure 9** Eurostat online data code: hlth\_dsi10



(\*) Estimates.

Source: Eurostat (online data codes: hlth\_dsi015 and hlth\_dsi020)

Moreover, looking at the following figure help to analyze the level of severity based on life areas linked with age and sex.

The data prove that in EU 27 disabled men were more likely to report a low severity of disability than were disabled women (EHSIS,2012).

It is possible to observe that the severity of disability increases at the increasing of age. The proportion of people with low severity of disability is higher at age 15-44 and decrease at age 65 will increase the high severity. The fact that at the increase of age increase the disability is something logically understandable that need to find adequate provision services. Because the EU population is going to be older than younger states should offer services to codify need. Becoming older in the case of intellectual disability is a problem higher than for other kind of disability.

Another proportion that is important to underline is between the employment level and the severity level of disability. The higher is the severity the lower is the average of employment while to low severity correspond higher possibility to be employed in EU 27 EHSIS demonstrated (2012) that more than half of the people with disability employed had a disability in just one life area.

Moreover, those who held a disability in four or more life areas represent the higher percentage of economically inactive persons.

Those EU measures represent just a part of the complex dynamics that should be statistically analyzed regarding disability. Moreover the data are referred to the condition of disability without specific focus on the population with intellectual disability.

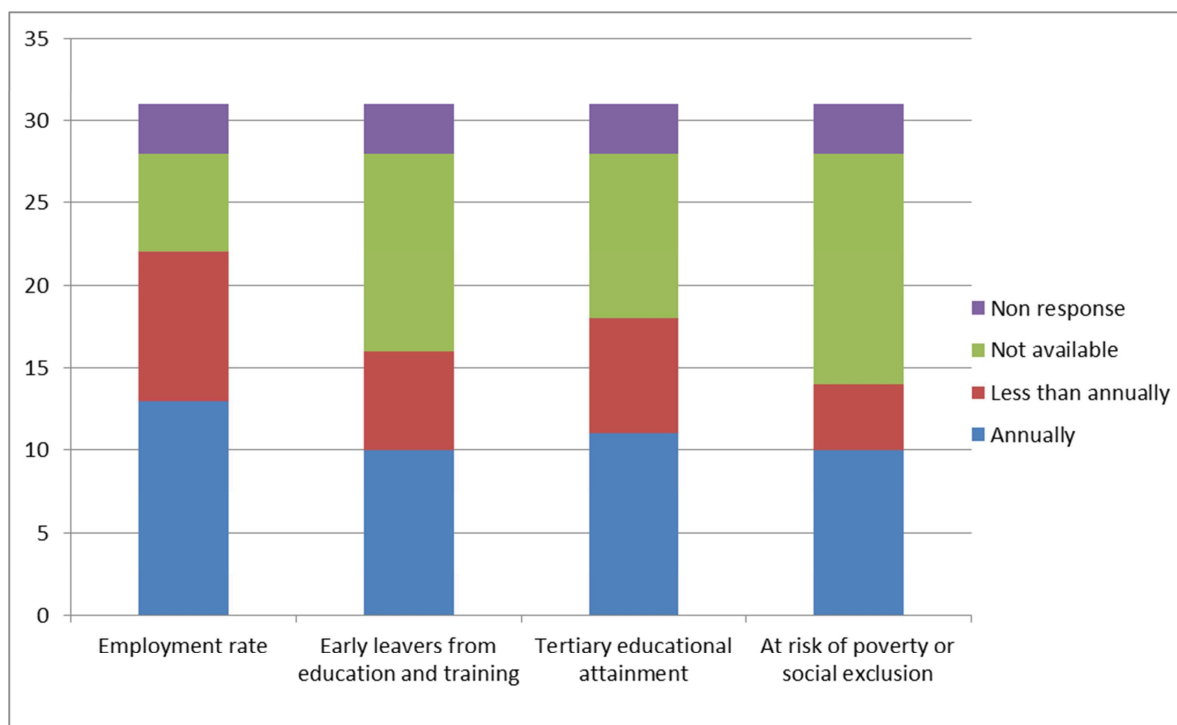
EU need to deal with the necessity of collecting data specifically for intellectual disability.

Currently the data related to disability came from:

- Statistics on Income and Living Conditions (EU-SILC): this annual survey on social inclusion collects data on people with long-standing health problems resulting in limitations on their activity (a proxy for disabilities); however, since the scope of this survey is very broad, and only a limited number of questions relate to disabilities; it therefore covers only some aspects of disabilities;
- European Health Interview Survey (EHIS): this survey, run every five years, gathers data on the level of activity limitations and health status;
- Labour Force Survey (LFS-AHM): LFS ad-hoc module on employment of persons with disabilities, run in 2011; and
- the European Health and Social Integration Survey (EHSIS), conducted in 2012-13, covers a wide range of barriers people with health problems and impairments face.

Disability related data are the precondition for the evidence based policy making and to respect the achievement of equality required by UN CRPD and for the achievement of the European Disability Strategy 2020. How many EU countries effectively produce the social Europe 2020 indicators for disabled people.

**Figure 10** Number of countries able to produce the social Europe 2020 indicators for disabled people



In November 2013, because of the necessity for a more and better EU-harmonized data on health and disability, Eurostat proposed to the Directors of Social Statistics to include a new statistical tool: the Global Activity Limitation Indicator (GALI) together with the Self-Perceived Health Variable (SPH) (European Commission, 2015). Eurostat proposal came from the clear un comprehensive monitoring of the situation of person with disability. GALI might be a new important European tool, it is a single question instrument designed for

measuring long-term activity limitations (European Commission, 2015). GALI has been scientifically developed and tested. GALI have the potential to be considered as a good proxy for measuring disability. European commission analyze the pros and cons of GALI (2015).

**Table 7** Pros and cons of SPH and GALI as core variables.

<b>Pros</b>	<ul style="list-style-type: none"> <li>• Allows for regular monitoring of the situation of disabled people according to UN convention and EU strategy (every two years)</li> <li>• Robustness of GALI</li> <li>• Harmonisation with SILC and EHIS (and possibly in other surveys if approved as core variable)</li> <li>• Lower burden for countries and respondents (compared to introducing a module on employment of disabled people)</li> </ul>
<b>Cons</b>	<ul style="list-style-type: none"> <li>• Less detailed information on different disability measures but sufficient for UN convention and EU strategy (only one variable);</li> <li>• need to test in LFS (apart from FR and CH). BE, DK, HU, NL, UK and NO may also not need to test GALI in LFS.</li> </ul>

### 1.4.2 Collecting Disability's Data in Italy.

Italy has not data on the total number of people with intellectual disability. It is very complex to measure intellectual disability because people with intellectual disability: used to have overlapped disability, data on ID are considered sensible and there are still problems with the definition of Intellectual Disability. Having more than one disability imply a difficulty to measure it. Easier in the field of intellectual disability are those disabilities clearly diagnosed at the birth and universally recognized in the diagnosis. Good examples are the Down syndrome or Autism. In chapter 3 has been analyzed how to cope with diagnosis process and problem to achieve an efficient supports system for people with ID by public policies. Officially the only data on ID with clear distinctions between different disabilities came from the ISTAT survey on the integration of disabled students in public and primary and lower secondary school. The most recent has been in 2016-2017 (ISTAT, 2018).

**Table 8.** Disabled students categorized by problem type, division and scholastic order. School Year 2016-2017 (percentual values).

Type of problem	Primary school				Lower secondary school			
	North	Centre	South and Islands	Italy	North	Centre	South and Islands	Italy
Blindness	0.7	0.7	0.5	0.6	0.9	1.0	0.7	0.8
Partial blindness	3.7	4.7	2.8	3.6	4.6	3.4	2.8	3.7
Acute deafness	1.4	2.4	1.8	1.7	2.1	1.8	1.0	1.6
Partial deafness	2.5	3.4	3.4	3.0	2.1	2.1	3.0	2.4
Problems related to mobility	13.0	11.8	12.1	12.5	10.5	9.0	11.0	10.4
Learning specific disorder	15.0	19.3	20.7	17.9	23.3	24.9	25.2	24.3
Language specific disorder	25.2	22.4	21.0	23.2	15.2	12.0	15.1	14.5
General development disturbance	26.3	25.6	24.8	25.6	20.0	23.7	22.9	21.7
Intellectual disability	43.8	36.5	44.4	42.6	48.9	47.0	50.6	49.2
Attention deficit and behavioural disorders	15.5	20.1	19.5	17.8	15.7	18.2	17.1	16.7
Emotional relational disturbances	17.6	15.7	15.2	16.4	16.0	17.0	17.1	16.6
Other type of problem	24.1	21.8	20.8	22.5	19.4	19.9	18.1	19.0

Note: The sum of each percentage column is greater than 100 because a single disabled student can have more than one type of problem.

The ISTAT survey related to classifications of disability and inclusion at school is one of the major sources of proved information of ID in Italy. The average of intellectual disabled child is high and the majority of ID child have more than one disability at the same time.

A total change of the statistical system in Italy, as in the other country, seems to be an impossible challenge for more than one reason. The Italian Ministry of Labour and the Ministry for the Social Policies together with The OND national observatory for the condition of persons with mental disability aim to achieve during the long period of time a system able to respect the principles of CRPD and SDGs. In particular the OND (Osservatorio nazionale sulla condizione delle persone con disabilità, 2016) institute made an important report

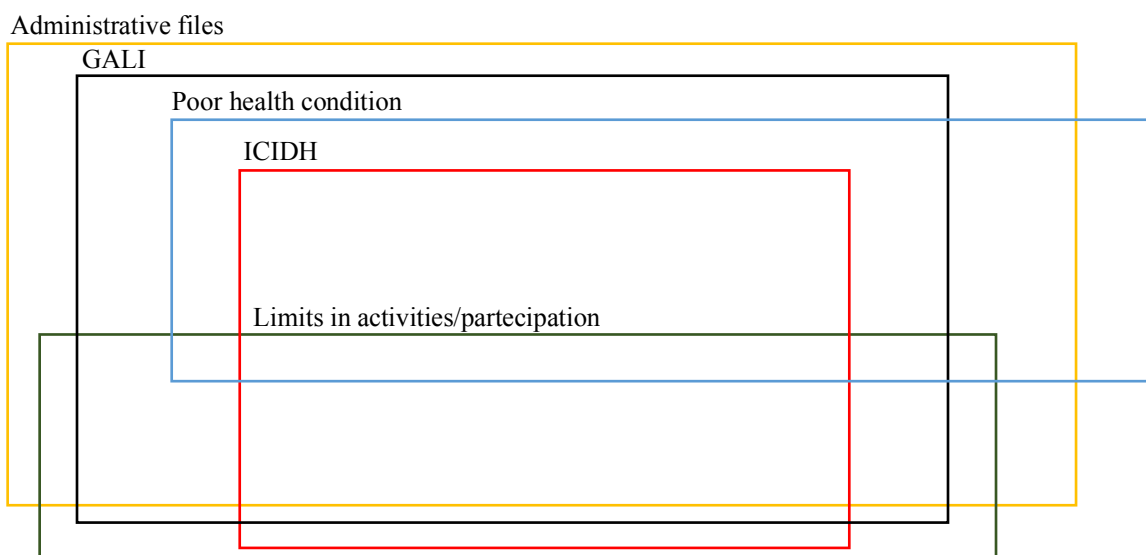
regarding the process for achieving equality for people with disability in Italy. In particular the report is a monitoring of persons of disability conditions.

The report of OND has identified the problems to organize the statistical system to have clear equality's indicator of disability. The mains obstacles are:

1. Confused agreement to link the disability as described in art.2 of CRPD with the statistical information;
2. the statistical data at the base of administrative information's has been generated from different definitions of disability;
3. there isn't enough information to the large vision of rights of CRPD;
4. The concept of equality should be clearly defined in terms of practice to be included in statistical calculations.

There is a complex system of relation between the different criteria due to define the population of persons with disability. The report (2016) of OND shows how all the criteria can be linked together.

**Figure 11** Overlapped systems to define disability (OND, 2016).



Without reliable and adjoined data, divided in the right way between the different categories of intellectual disabilities the works of institutions, organisms and policy maker became more and more difficult. If the date doesn't correspond to reality the result in terms of policies won't be efficient to answer to the needs of people with intellectual disability. The resource management, the organization of services, the preparation of qualify personal etc. Don't cope with the real needs.

It is necessary to find and to rethink about new tools able to notice how to collecting data of ID.

## **CHAPTER 2: Intellectual disability in legislative framework.**

### **2.1 The international protection of people with disability.**

At international level the evolution of rights for person with disability has been firstly cultural and then legislative. International Agreement on Human Right before 70s didn't mentioned persons with disability. The first international Act dedicated to person with disability was the Declaration on the Rights of Disabled Persons adopted by United nations on 9 December 1975. People with disability saw for the first time concretely recognized the same rights as the others persons. The UN CRPD is part of an international process started in 1970.

In 1970 the priority for UN was changing approach to provide social security and welfare services for all persons. The goal was to change welfare system for facilitating the integration of disabled in society. The declaration is very important because it represents the beginning of a new conceptual way to approach disability as human rights issue. Since the declaration was adopted The UN system made inclusion of disabled as priority issue in broader human rights initiatives.

Until 70s and 80s the approach to disability was characterized by having charitable nature, person with disability were considered more "the rest of society" than part of society. On 3 December 1982 the General Assembly implement the World Program of Action Concerning Disabled Persons. The UN goals was to raise awareness of disabled conditions relatives to disability. It was important to pass, from a conception of disability as issue related to disabled, to look at this as a universal social challenge. Decisive was the recognition of the equal opportunities for disabled by the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities by the General Assembly on 20 December 1993. Among the major outcomes of the Decade of Disabled Persons. The most incisive and decisive step at international level, the first binding act, has been The United Nation Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (OP) approved on 13 December 2006.

The United Nation Convention on the Rights of Persons with Disabilities is about dignity, equality and inclusion (United Nations , 2006). The UN CRPD is a profound change in disability policies and laws often neglected by national governments. The UN CRPD was written for people with disability, for people with long term physical, mental, intellectual and sensory impairments, it was signed by 27 EU's member states included Italy and EU itself. As stated in Article 1 of the Convention, "the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

The UN Convention the Right of People with Disabilities by 50s articles states that the persons with disability, included intellectual disability, have: the equality before the law, the full right and freedoms enjoyed by everyone in the community, the recognizing to be capable and contributing member of society, the right to have fiscal access and information access, the right to life, the right to be rescued in time of disaster, the right



to justice, the right to be included in the society, the right to live freely and independently in the community, the right to express opinions, the right to be free of violence, the right to privacy, the right to education jobs and healthcare, the right to participate in cultural and public life and the right to take part and have access to sport.

Some of those are challenging to be realized in practice in particular for intellectual disability such as art. 12 to be recognized as equal person before the law art. 19 the right to independent and community living.

In UN CRPD the equality of rights came before a plea for piety in everyday life of person with disability. UN CRPD include intellectual disability, usually not sufficiently represented. The goals are to take off barriers to include persons with disability in society and to guide persons with disability in the empowerment process. The UN CRPD is based on the social model paradigm and the exclusion of disabled is critically analyzed through the result of barriers and discrimination.

The empowerment process means to acquire consciousness about the own capacity and skills overcoming weaknesses and limits. The empowerment process means to discover the capacity to do something unknown before that moment (Charlton, 1998), the power on itself. Countries should take measures in order to increase the degree of autonomy and self-determination in people. Through the application of UN CRPD society became a more just society, the problem is that as seen previously in the statistical measures there are many hurdles and challenges to overcome in order to completely implement human rights for people with disability. One of the most important steps is organize a control there should be a national monitoring mechanism independent from government and in collaboration with civil society organization.

Empowerment is overcoming a sense of powerlessness as action a process of self-empowerment and to professional support of people to recognize and use their resources. The process of empowerment is necessary to leave the state of subjection to achieve the emancipation. This empowerment process is particularly long and complicated for person with intellectual disability.

Having a full application of people with disability rights and CRPD implementation, means:

1. Leave the caritative approach in favor of an inclusive approach.
2. Person with disability are not a separate part of society they are part of society.
3. Disability is a society challenge that depends on social barriers. For Art. 4 of UN CRPD is a state duty the removal of social barrier in favor of inclusion promotion by positives actions.

The New York convention of 2006 fixed the centrality of the person and the conception of disability as part of the human diversity. The deficit is no more identifiable in the society but in the social barrier. Equality of rights means to remove all the physical, legal and social barrier.

What happened in Turin is interesting (Medeghini, et al., 2013). In Turin some years ago a young student with disability was excluded from part of school activities. In every scholarship she couldn't take the same bus as the other students because the bus wasn't fit to her needs. then the only possibility to enjoy the class trip was to took a "special" bus just for her. The bus wasn't fit for her and she was excluded by her class. The case went to the Italian tribunal that recognized the discrimination by the law 67 of 2006 (indirect discrimination). The society of public transports was constricted to pay the damage and to adapt all the

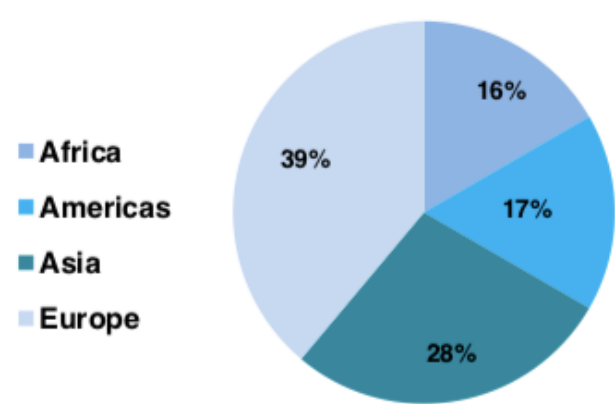
transports to any case of disability. The States who signed the 2006 CRPD have to avoid every case of disability discrimination.

With the 2006 UN CRPD Society should be organized in a more accessible way. It means ensure a community more people-orient. At the end this is an advantage for the whole society not just for people with disability.

Some data about UN CRPD from United Nation (2016).

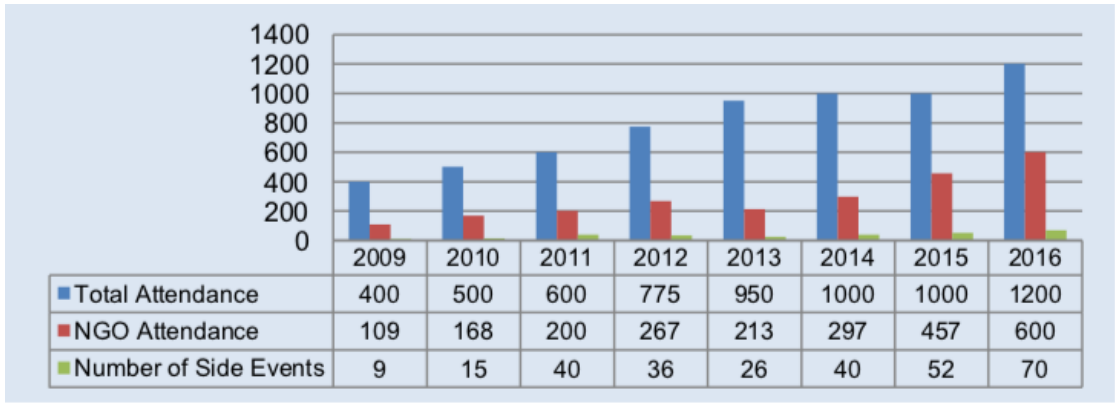
The Committee of the CRPD is the body of independent experts which monitors implementation of the Convention by States Parties. There are 18 members of the Committee. Currently, they represent the following regions (United Nation department of economic and social affairs, 2016)

**Figure 12** members of Un commitee for CRPD (United Nation department of economic and social affairs, 2016)

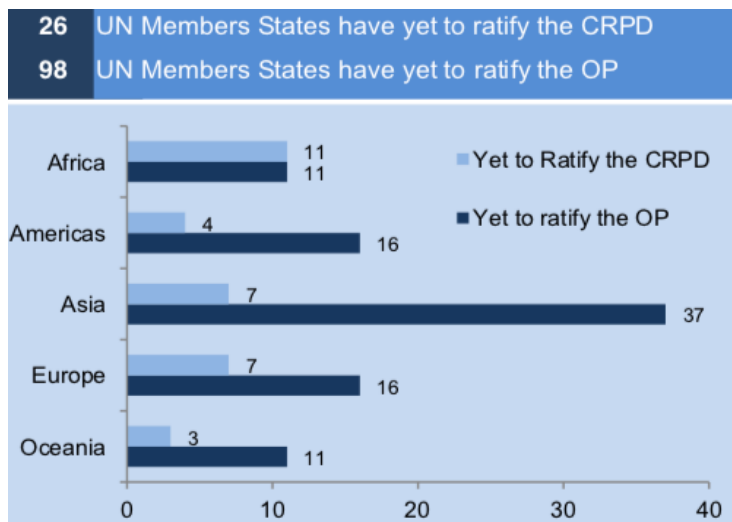


The COSP is the largest and most diverse international disability meeting in the world. It provides a launching pad to advance the human rights and inclusion of persons with disabilities in society and development. The annual Conference sees participatipation from Government delegations, UN Agencies, Civil Society and non- governmental organisations, National Human Rights Institutes, and Disabled Persons Organisations, and has grown in recent years (United Nation department of economic and social affairs, 2016).

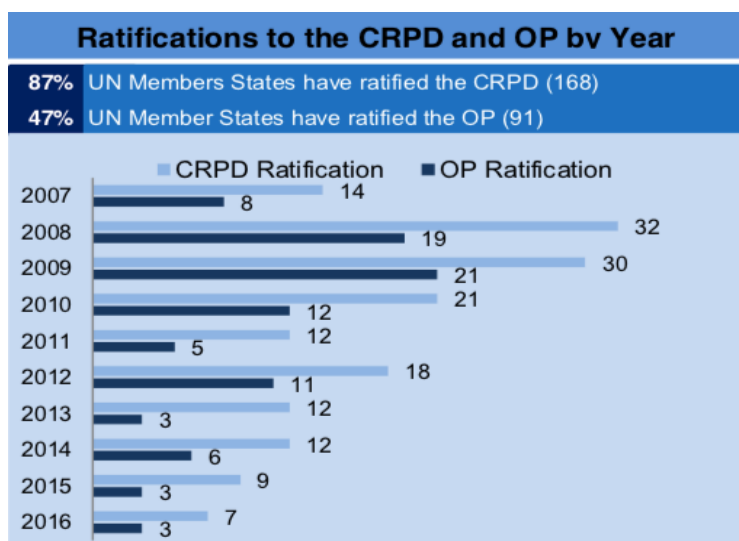
**Figure 13** The COSP attendece (United Nation department of economic and social affairs, 2016).



**Figure 14** Ratifications to the CRPD and OP by Year (United Nation department of economic and social affairs, 2016).



**Figure 15** Member States yet to ratify the CRPD and OP (United Nation department of economic and social affairs, 2016).



## 2.2 The EU strategy for inclusion.

The EU legislation regards rights for people with intellectual disability is most recent. The responsibility of inclusion policies is up to each member state. However, the EU committee collects data due to promote the efficiency of national policies for inclusion of disabled and to achieve a high level of cooperation between member states (Carlo, 2011). It is important for Europe to share best practices and policies regarding inclusion between member states. Europe wants to protect each one of its citizens.

On 9 December 1989 by a declaration of Member states EU adopted the Community Charter of the fundamental Social Rights of Workers. Art.26 was specifically dedicated to disabled persons.

Art.26 (European Council, 8 December 1989)

“All disabled persons, whatever the origin and nature of their disablement, must be entitled to additional concrete measures aimed at improving their social and professional integration.

These measures must concern, in particular, according to the capacities of the beneficiaries, vocational training, ergonomics, accessibility, mobility, means of transport and housing.”

On 25 February 1993 European Council established a third Community action program to assist disabled people (Helios II 1993 to 1996). It was esteemed ( European Council , 25 February 1993) a sum of ECU 37 million to implement this multiannual programme. The first Helios 1988-1991 born from the idea of promoting: vocational training, rehabilitation, economic integration, social integration and an independent way of life for disabled people in EU.

The systematic action of EU in favor of disabled people began after the Treaty of Amsterdam on 2 October 1998. Since this moment the European's institutions tried to develop anti-discriminatory measures and to promote inclusive policies. The Treaty of Nice, Charter of Fundamental Rights of the European Union on 7 December 2000 set up the guidelines for a new European Model of disability; focused on the ability more than the impairment of disabled people. Art. 21 paragraph 1 of Nizza Treaty (European Parliament, 2001) highlight the non-discrimination principle:

“[...] Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited [...]” .

Article 26 of the same Treaty stressed the importance of the integration of person with disability:

“The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”

The European strategy for person with intellectual disability encourage the empowerment process, the participation at social life, recognize the equal right to be considered as a relevant part of European society and community, aiming to be a strategy developed in long term.

Other important tools of EU have been: the European action plan 2004-2010 and the European Social Fund ESF, both have a recent improvement.

“For the next long-term EU budget 2021-2027, the Commission proposes to further strengthen the Union's social dimension with a new and improved European Social Fund, the European Social Fund Plus (ESF+) and a more effective European Globalization Adjustment Fund (EGF)” (European Commission, 2018).

### **2.2.1 European Disability Strategy 2010-2020: a Renewed Commitment to a Barrier Free Europe.**

The communication from the commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions states that in European Union one in six people has a disability and around 80 million are prevented from taking a part in society. Many goods and services, as well as much of buildings, are still not accessible enough (European Commission, 2010). In European countries people with intellectual disability are considered one of the most disadvantaged social group. The EDS refers to disability without giving a precise definition. There isn't EU definition of disability, however the Court of Justice recently interpreted the Framework Directive in light of Article 1<sup>2</sup> CRPD (Court of Justice of the European Union, 2013).

Therefore, EU has strong mandate to improve the situation of people with disabilities, including those who have long-term physical, mental, intellectual or sensory impairments according the UN Convention. The disadvantage of intellectual disability is the creation of a really high level of needs.

Two commission documents, the comprehensive Commission staff Working Document SEC (2010) 1323 and the operational implementation plan SEC (2010)1324, accompanied the EDS 2010-2020.

EU wants to cope with the needs of disabled and by 2020 strategy aim to succeed in creating smart, sustainable and inclusive growth. The problem of making services and products accessible to all, is the high cost this is way in most of the European countries still today, policies and services do not reflect the demand and needs of disabled people adequately. The Eu commission identify in the field of the 2020 Strategy for eliminating barriers, eight main areas of action still not equal in EU's Member State:

- Accessibility: due to a "design for all", EU support national action to allow the access for people with disability on an equal basis with others, to the physical environment, transportation, information and communications technologies and systems (ICT);
- Participation: EU support national action to achieve a full participation of people with disability in society by three main way providing quality community-based services, including access to personal assistance, removing administrative and attitudinal barriers to full equal participation and enabling disabled people to enjoy the benefits of EU citizenship;
- Equality: EU support in national action to eradicate discrimination grounds of disability in EU as required in Art.1,21 and 26 OF EU Charter, Art 10 and 19 of TFEU and by Directive 2000/78/EC for banning discrimination;
- Employment: Eu support national action to open market for person with disability even intellectual disability to enable those to earn by working;

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<sup>2</sup> Art.1 UN CRPD: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

- Education and training: Eu support national action to promote inclusive education for disabled with a particular focus on those with severe disability.
- Social protection: EU Support national action to avoid poorness by social protection system and poverty reduction programs to guarantee decent living condition for people with disability.
- Health: EU support national action to have an equal access to health services including routine medical treatments for people with disability and to promote preventive healthcare;
- External Action

This Areas has been selected considering the UN CRPD of 2006 and considering the results of EU Disability Action Plan 2003-2010. EU Strategy aim to increase between the EU's citizens the awareness on disability issues.

In order to achieve the expected goals in all the eight areas the EDS have four implementation instruments. Firstly, ricing the society's awareness of disability issues and foster better knowledge among people with disabilities of their rights. Secondly, by financial support, using the EU funding for the promotion of action relevant for disabled. Thirdly, by collecting of measures and data to achieve periodic statistics and a possible monitoring of the situation of people with disability. Fourthly by the governance framework required by art 33 CRPD<sup>3</sup>.

A fundamental document in order to look at the effects of European disability strategy 2010-2020 is available since February 2017. It is crucial to find information about the life condition of people with disability. The Commission progress report collect several data on the situation of person with disability, analyzing the main EDS achievement in priorities areas of action.

What took a special importance are the public consultation based on over 1500 replies from civil society 80% from individual citizens and 20% from organizations. In the EDS survey the 61% of individuals and 48% of organizations expressed overall dissatisfaction during the first five years of program (European Parliament, July 2017). It is important to consider that for having a tangible impact to person with disability more time is necessary. Between the areas one has been considered more negative than others: the employment. Just the

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<sup>3</sup> Article 33 UN CRPD – National implementation and monitoring

“1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”

29% of individuals and 36% of organizations suggested a slight improvement, 57% of individual respondents and 48% of organizations saw no improvement at all. (European Parliament, July 2017).

The main challenging areas related to life participation of people with disability, after the 2015-2016 survey are (European Parliament, July 2017):

- Employment: lack of equal opportunity
- Transport: lack of equal access to transport
- Buildings: lack of accessibility of the built environment
- Independent living: difficulties living independently
- Support for children: lack of support for parents of children with disability.

According to the Commission's report, during the first five years since the EDS' adoption, progress in employment and education remained limited.

**Table 9:** European Commission, EDS progress report 2017, p. 4 (ANED estimates for 2014, based on EU-SILC)

Europe 2020 area	% Person with disabilities	% Person without disabilities	EU 2020 target
<b>Employment</b>			
employment rate	48,7%	72,5%	75%
<b>Education</b>			
early school leaving rate	22,5%		Less than 10%
completed tertiary education	30%		At least 40%
<b>Poverty</b>			
Risk of poverty or social exclusion	29,5%	21,5%	Lifting at least 20 million people out poverty.

### 2.3 Italian rights for people with disability.

Italy doesn't have constitutional articles specifically dedicated to person with intellectual disability. In Italian Constitution there aren't *ad hoc* mandatory rules on the protection of persons with disability and even less for those with intellectual disability. Professor Carlo Colapietro made a helpful work by bringing together in the book "Diritti dei Disabili e Costituzione" (2011) all the rights and constitutional provisions referred directly and indirectly to people having disability. The hardest part to overcome is the definition of intellectual disability and disability in itself in the Italian Legislation. Because disability in the last years took different way in being defined, was complicated for the lawyer to find a common juridical definition.

According to the Constitution of the Italian Republic: "all citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal and social

conditions. It is the duty of the Republic to remove those obstacles of an economic or social nature which constrain the freedom and equality of citizens, thereby impeding the full development of the human person” (art. 3)

The Article 2 and 3 of the Italian constitution took fundamentally importance in the development of legislative frameworks for people with intellectual disability. Art 2<sup>4</sup> recognizes the inviolability of person’s right necessary for the equal social dignity expressed in Art.3<sup>5</sup>. These two articles are important for the process of inclusion and equality of those subjects considered vulnerable by society. Art 2 and 3 are referred to the full development of human person and particularly to the concept defined by Franco Modugno as “principio supremo della libertà-dignità” supreme principle of dignity and freedom. Art 3.2 stresses the concept of “euguaglianza sostanziale” effective equality. It means that the Italian state have the duty to guarantee the effectiveness of equality, it means give practical tools to overcome social and physical barriers in everyday life. This is the real challenge to be focused on. The social rights are recognized by the Italian Constitutional Court as perfect rights (Baldassarre , 1989). Then the social rights have to be considered at the same level as the individual fundamental rights. Art. 2 and 3 of Italian constitution are at the base of the process of equality, the process to achieve the full expression of their being the full respect in their dignity and the full equal inclusion in all the part of society. This process is still not concluded.

In 1971 the law n. 118 provided economic benefit for person with biological damage. The efforts at international level to find a right way to classify disability corresponded in Italy to a juridical development. In law 118/71 was not given a clear definition or a distinction, moreover the limits in autonomy were not evaluated at all. in 1992 with law n.104 the limits of law 118/71 were overcome and the law referred to disability as the incapacity to be autonomous in the activities of everyday life.

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<sup>4</sup> “The Republic recognizes and guarantees the inviolable rights of the person, both as an individual and in the social groups where human personality is expressed. The Republic expects that the fundamental duties of political, economic and social solidarity be fulfilled.”

<sup>5</sup> “All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal and social conditions.

It is the duty of the Republic to remove those obstacles of an economic or social nature which constrain the freedom and equality of citizens, thereby impeding the full development of the human person and the effective participation of all workers in the political, economic and social organization of the country.”



An important reform came with Law n. 6 of 9 January 2006 that introduced the *amministratore di sostegno* administrator support. It is an important step because the law is focused not on the person impairment but on the way to overcome the social barriers. This law perfectly matches the UN CRPD.

With the new ICF classification a new important law came into force in Italy: Law 1999 n. 68. The law 68/99 is important in particular for the regulation of work rights for people with disability.

In Italy radical changes in rights and law for people with disability always corresponded to different paradigms. Law 118/71 corresponded to assistive model, it means to give privileges to those that have some disadvantages as in the case of person with disability. The assistive model is coherent with article 38 of Italian constitution about solidarity between citizens. The assistive model does not lead a person with disability to achieve an equal condition and to be included in society is more connected with pity and charitable behavior.

The second theoretical approach present in the Italian legislation is the protective logic the ones adapted in Italy for what concerns the inclusion at work of people with disability. Laws 482/68 and 68/99 oblige public administrations and private enterprises to assume people with disability. The job of person with disability was different from the others. The legislation was strict: for any given numbers of workers without disability there should be proportionally a certain quantity, it depends on the PA or industry capacity, with disability. The proportions were:

- One worker with disability for any 15/35.
- Two workers with disability for 36-50 employees.
- 7% if the workers were more than fifty.

The Legislative Decree n.469 of 1997 gives to the regions the duty for the job-placement organization for people with disability.

Regional laws regulate how to manage the employment for disabled. By Law n.2 of 2001 The region Calabria entrusted to provinces the responsibility to manage the employment and recruitment of person with disability.

The law provided two different kind of sanctions direct by administrative sanctions in terms of money and indirect by the exclusion from public tender for those enterprises without the regular number of employees with disability.

The important difference between law 482/1968 and 68/1999 can be found in the Art two of law 68/1999 that provides the targeted placement “collocamento mirato” for workers with disability.

The idea is to analyze each subject with disability in order to find the job by which he/she can practice the abilities. The idea of the Law 68/1999 is to create a sort of bridge between the protection and the empowerment of person with disability; a training process that must lead to recruitment.

Due to implement the law 1999 the President of Italian Republic the 10 October 2002 has promulgated a Regulation n. 333. The regulation n. 333 contains a specification of people having the right to be enclosed into the special lists for the compulsory assumption, the duty to reserved parts, the exceptions to such duties and

the suspension from them. In the article were mentioned the so-called nominative assumptions, namely the public and private employers have the possibility to choose inside of the lists the Disabled Person who has more ability to effect a certain work and to call this person. (Di Liberto , 2014).

In reality the problem was that most of the employer due to save money, payed persons with disability to stay at home. Why? The costs to build structures without architectural barriers and to include a person with disability in the jobs place with adequate supports is too high.

The paradigm of protection has been the base for the law 104/ 1992 on assistance, social inclusion and rights of people with disability. Law 104 is composed by 44 articles and is considered as the referential Law, addressing disability in all the possible features and aspect of life (Medeghini, 2013).

Law 104 still make a net and remarkable distinction between right for person with disability and without disability and people with disability. It is possible to recognize to Italy a Law process that started during the 70s years and still not concluded that aim to the social inclusion of person with disability particularly those with an intellectual disability.

### **2.3.1 How Italy has incorporated CRPD.**

Italy has been among the first signatory states of The United Nation Convention on the rights of person with disability. Had joined for the first time the convention on 30 March 2007. Italy ratified the UN CRPD and its Optional Protocol OP by the Act. n.18/2009. OND, Nationally Observatory for the condition of people with disability was subsequently established.

The CRPD introduced a new way to look at disability that coincide with the legislative process on disability taken by Italy during the last year.

The new cultural bases focuses the intervention on care and social protection in favor of a social approach, based on human rights which brings all the human differences out (about race, gender, culture, languages, sexual orientation, psycho-physic condition) and underlines how the disability's condition doesn't spring from the subjective condition of person, but from the way of answering by society, discriminating his in all the spheres of life (education, working, services) and breaking his rights (Inter-ministerial Committee for Human Rights., 2011).

The general provision of CRPD (Art.1-4) can be founded in the Italian law 104/92.

Law 104/92 has the purpose to guarantee the full respect and dignity of the person with disability.

Law 104 art. 3<sup>6</sup> aim to promote society integration of people with disability at school, at work, at home and in the whole society as prescribed by art. 1 lett. a), b), c) and d) of CRPD (Unione Italiana Ciechi ).

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<sup>6</sup> Art.3 Law 104/92 Recipients (National Observatory on the Condition of Persons with Disabilities.)

Law 104/92 identifies “in Italy as person with disability who shows a physical, psychic, sensorial, stabilized or progressive handicap, which makes troubles in learning, in relationships, working integration and at the same time such as to determine a social disadvantage process or exclusion.

Persons with disabilities have the right to measures adopted in order to help them, connecting with the kind and seriousness of handicap, with the residual individual ability and with the effectiveness of rehabilitation therapy” (Inter-ministerial Committee for Human Rights., 2011). What the Law 104 didn’t consider is the link between the environment and the impairment. The presence of the environment as an important factor to be evaluated. The law 118/1971 partially modified in 1988 defines the impairment from a civil point of view, this definition is based on ICIDH tables and lead to the idea that people with disability are imitated at work.

The concept of dependence and self-reliance is present, particularly at the regional level, in the law 328/00 for the organization of social assistance. Too often the evaluation of the needs is conditioned by the available resources of the providing institution more than the real conditions of person with disability. The evaluation of the social assistance should guarantee a long-term care as in most of the others Europeans states. In Italy social assistance depend on regional resources. Because Italy is heterogeneous in the management of resources there are consistent difference in level of disability assistance from one region to another and namely between north and south.

Job placement for people with disability and therefore for those with an intellectual disability is regulated by law 68/99 and DPCM 13/1/00 as will be analyzed in chapter 3.

Art 20 of the law 102/09 gives to INPS the national institute of social security the rule to verify disability considering the new ICF and the UN CRPD.

The art 5on equality and non-discrimination of the UN CRPD (2006) states:

“1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

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“A person with disabilities may be defined as any person who has a permanent or progressive physical, mental or sensory impairment that hinders the person's learning ability, social relationships or inclusion in the labour market and that may lead to social disadvantage or exclusion.

Persons with disabilities are entitled to receive benefits in relation to the nature and severity of disability, the individual residual functional capacity and the effectiveness of rehabilitation treatments.

Where the individual’s personal autonomy, in relation to his or her age, is reduced by one or more impairments and therefore permanent, continuous and comprehensive individual and social support is needed, the person is in a condition of gravity. Public services and programs shall give priority to people with disabilities in a condition of gravity.

This Law shall also apply to foreign citizens and stateless persons who permanently live and reside in Italy. The services provided are subject to the limits and conditions laid down by existing legislation and international agreements.”

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.”

The Italian rights of equality and non-discrimination are defined by Art. 3 of the Italian constitution. These rights are then at the based on Act. 104/92 and 68/99. As seen before in the thesis the law 104/92 is the Italian benchmark to achieve the condition and inclusion of the person with disability in society. In fact, Law 104/94 set systematically the safeguards of equality and non-discrimination. The right of non-discrimination has been reinforced by the directive 2000/78/CE implemented in Italy by D.lgs. 216/03. The Directive 2000/78/CE remarked the importance of equality in terms of access to work and condition of work, increasing salary, training etc.

Law 67/06, the judicial protection for the victims of discriminations, direct and indirect discriminations in favor of people with disability is part of the implementation of Art 5 UN CRPD. Law 67/06 has been reinforced by DM 21/6/07 that allow the entities and associations to act in favor of the protection of person with disability.

Article 8 of CRPD (2006) is about awareness-raising:

“1. States Parties undertake to adopt immediate, effective and appropriate measures:

- (a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- (b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- (c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

- (a) Initiating and maintaining effective public awareness campaigns designed:
  - (i) To nurture receptiveness to the rights of persons with disabilities;
  - (ii) To promote positive perceptions and greater social awareness towards persons with disabilities;

- (iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
- (b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
- (c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
- (d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.
- (d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.”

The implementation of art.8 can't be directly implemented it needs the mainstreaming of disability of national governments in order to raise awareness about disability. The law 102/07 represent a good example by setting in 21 February the national Braille day. Moreover, Art 328/00 is in favor of increasing awareness about disability by a range of social systems. Law 104/92 that give to the Italian State the duty to remove all the obstacles and barriers limiting for the autonomy of people with disability.

Art 9 <sup>7</sup> on accessibility has been implemented by D.P.R. 503/96 and DM 236/89 applyng art.2 of Law 118/71 and 13/89. It has been activated (or should be) an assistance service for each public building. The

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<sup>7</sup> Article 9 UN CRPD (2006) Accessibility:

“1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall 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. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures:

(a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;

(b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;

(c) To provide training for stakeholders on accessibility issues facing persons with disabilities;

buildings need to consider the impairments becoming accessible and removing physical barriers. Since 2004 has been in force in Italy the law 4/04 that recognize the protection of each person to have access to information sources. The Italian Administration Code provide guidelines in order to guarantee the access on the web side to people with disability. For what concern school by the DM 30/4/08 were established the rules to guarantee the equal access to education tools for people with disability. Art. 9 has been also implemented in Italy for the accessibility to transports: ferries, trains planes etc.

Art. 117 of the Italian Constitution give to the regions and municipalities the rules to implement art.27 of 104/92 regarding the public transport and the adjustment of the infrastructures.

The rights to life Art10 UN CRPD (2006):

*“States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others”.*

Art.10 of UN CRPD is guarantee by Art. 2, 27 and 32 of the Italian Constitution. Moreover, in1978 thanks to Law 194/78 have been born the Center for life aid. The right to life was also related to Law 40/04. Part of the Law 40/04 was declared by the Italian Constitution unconstitutional. The most important theoretical point made by the Court is that the law does not provide unlimited protection to embryos, since it admits that some of them may not produce a viable fetus (Benagiano & Gianaroli, 2009). Law 104/92 is also related to the regulation of the early diagnosis. The rights to life remain one of the most difficult ethical debate in international and national legislation.

Art. 11<sup>8</sup>of UN CRPD is about situation of risk and humanitarian emergency is automatically implemented in Italy because Italy ratified all the Humanitarian International Conventions. Law 225/92 gives to the

- 
- (d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
  - (e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
  - (f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
  - (g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
  - (h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

<sup>8</sup> Article 11 UN CRPD 2006 Situations of risk and humanitarian emergencies:

regions the responsibility to organize the risk and humanitarian emergency. The DM 10/03/98 and the circular 04/02 require the assistance of people with disability in case of imminent risk such as burning.

Art. 12<sup>9</sup> of UN CRPD on equal recognition before the law is prescribed by the Italian Constitution in art. 3, any Italian citizen is equal before the law. In addition, the Act. 6/04 made available to people with disability the institute of support administrator.

Art 13 access to justice<sup>10</sup> is regulated in Italy by Art 24 of the Italian constitution:

“Anyone may bring cases before a court of law in order to protect their rights under civil and administrative law.

Defense is an inviolable right at every stage and instance of legal proceedings. The poor are entitled by law to proper means for action or defense in all courts. The law shall define the conditions and forms of reparation in case of judicial errors”.

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“States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

<sup>9</sup> Article 12 UN CRPD 2006 Equal recognition before the law:

“1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”

<sup>10</sup> Article 13 of UN CRPD (2006) Access to justice

“1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.”

An emblematic case is the sentence n. 341/99 that declared illegitimate art. 119 of the penal code because it doesn't provide the free assistance of an interpreter for deaf persons in justice's field. The social barrier should be eliminated in order to guarantee an equal access to justice.

Art. 14<sup>11</sup> of UN CRPD on the liberty and security of person is regulated by art. 13 of the Italian constitution and by law 180/78 or Basaglia Law. Basaglia Law is the basis of the mental health legislation; by the approval of Law 180/78 psychiatric hospitals started to be gradually dismantling. The Basaglia Law establishes that any medical treatment should be voluntary, it has been a huge improvement of life condition mostly for people with intellectual disability.

Art. 15 and 16<sup>12</sup> on freedom from torture or cruel, inhuman or degrading treatment or punishment and freedom from exploitation, violence and abuse. For both Italy has ratified many international treaties. Moreover, since 2009 it has been organized a non-violence week to avoid any form of violence.

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<sup>11</sup> Article 14 UN CRPD 2006 Liberty and security of person:

"1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

1. (a) Enjoy the right to liberty and security of person;
2. (b) Are not deprived of their liberty unlawfully or arbitrarily, and that

any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation."

<sup>12</sup> Article 15 of UN CRPD 2006 Freedom from torture or cruel, inhuman or degrading treatment or punishment:

"1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment".

Article 16 UN CRPD 2006 Freedom from exploitation, violence and abuse:

"1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including



Art. 17 of UN CRPD protecting the integrity of the person:

“Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.”

The protection of person integrity can be founded in the Italian Constitution and in Art. 1, 5 and 8 of the Law 104/92.

Art. 18<sup>13</sup> on the liberty of movement and nationality is guaranteed by art 16 of the Italian constitution:

“Every citizen has the right to reside and travel freely in any part of the country, except for such general limitations as may be established by law for reasons of health or security. No restriction may be imposed for political reasons. Every citizen is free to leave the territory of the republic and return to it, notwithstanding any legal obligations.”

Very importance took Art. 19 Living independently and being included in the community of UN CRPD:

“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate

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through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.”

<sup>13</sup> Article 18 UN CRPD Liberty of movement and nationality:

“1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

- (a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
- (b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
- (c) Are free to leave any country, including their own;
- (d) Are not deprived, arbitrarily or on the basis of disability, of the

right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.”

full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

For what concerns living independently and the inclusion there are more than one legislative developments in Italy. First of all, this right is present in law 104/92. Particularly art.10 of 104/92 describes the tools through which inclusion can be achieved: social services, social and sanitary assistance, domestic care, economic aid etc. Art. 9 of 104/92 is related to a specific service delivered to the single person with disability that have a specific need. Art. 20 of Law 328/00 confirmed the National Fund for social policies established for the first time by the Law 449/97. The DPCM 14/2/01 gives the region the duty to assign the social assistance personalize in base of: medical condition, physical condition, mental conditions, the barrier of the subject in relation to the impairment. How much Italy invested on social services in relation of disability is analyzed in chapter three.

Art. 20<sup>14</sup> of UN CRPD on personal mobility regulation in art 16 of the Italian Constitution that guarantee the freedom of movement and residence, by Law 104/92 in order to guarantee the provision of technical subsidies and aids to those people who have specific impairments. Law 224/07 established in Ministry of Transport a specific fund dedicated to the disabled mobility. Then there are many specific regulations to

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<sup>14</sup> Article 20 of UN CRPD on Personal mobility:

“States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- (b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- (c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- (d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.”

guarantee the effectiveness of art. 20 of UN CRPD, such as art. 27 of 104/92 set up the reimbursement of 20% to expenses relatives to make the car proper for the impairments. Furthermore DPR 917/86 and Law 324/74 organized the fiscal deduction in favor of disability person mobility.

Art 21 of UN CRPD is about freedom of expression and opinion, and access to information is recognized in Italy by Art.21 of the Italian Constitution. The same article provide the right to be informed. Italy is one of the last European countries that does not recognize the deaf language as an official one. It means that the Italian deaf do not have the translation in Italian deaf language of public or institutional speech as happen in France. Just to give an example the end of the year speech (2018) of president Macron in France was transmitted on TV with an interpreter for deaf on the side while in Italy the speech of Mattarella not. This is mainly because LIS isn't an official language. At the moment the proposal law to recognize LIS an official language has been ddl n. 302/2017, approved by the Senate but not from the Chamber of Deputies.

Art. 21 UN CRPD states:

“States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

[...]

(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means [...]"

In Italy many facilities have been given in terms of technology access for example in 2008 AGCOM increased the facility for the internet access.

Art. 22<sup>15</sup> respect of privacy and 23<sup>16</sup> respect of home and family are regulated in Italy by constitutional articles. In Particular art 23 by ART. 29-31 of the Italian Constitution. The Italian public policies and aid for

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<sup>15</sup> Article 22 of UN CRPD Respect for privacy:

“1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.”

<sup>16</sup> Article 23 UN CRPD 2006 Respect for home and the family

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1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.”

family are analyzed in chapter 3 together with UN CRPD Art. 24 on Education, 27 work and employment and 30 participation in cultural life, recreation, leisure and sport. Art. 25<sup>17</sup> on Health and 26<sup>18</sup> on habilitation and rehabilitation. The Italian basic principles for the rights of healthcare access are regulated by Art.32<sup>19</sup> of

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<sup>17</sup> Article 25 of UN CRPD 2006 on Health:

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people’s own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.”

<sup>18</sup> Article 26 of UN CRPD 2006 on Habilitation and rehabilitation:

“1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
  - (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.”

<sup>19</sup> Art. 32 of Constitution of the Italian Republic:

“The Republic safeguards health as a fundamental right of the individual and as a collective interest, and guarantees free medical care to the indigent.

Italian constitution. A determinant rule in terms of disability evaluation is given by Law 102/09 to INPS. INPS evaluation of disability is determinant for its consequences defined by law 104/92 and 68/99. Law 833/78 defined the principle of equality at the base of the Italian Healthcare System. Moreover, Law 328/00 in art. 14 give a particular attention to organize a personal assistance by ASL and economic supports of families at local level. Art 3 and 32 of Italian constitution indirectly affirm the non-discrimination principle in the health provision of people with disability. For what concern the right to have rehabilitation Law 104/92 in art. 7 set the duty for the Italian Sanitary system should ensure support to people with disability through its structures or by private structures with conventions. Art. 14 law 328/00 paragraph 2 provides for the possibility to have a personal individual project for the person with disability between sanitary and scholastic structures in order to achieve the full inclusion. Since ICF has been approved by WHO a new rehabilitation plan has been introduced, based on the bio-psyco-social approach.

Art 28<sup>20</sup> of CRPD is on the adequate standard of living. In Italy for article 117 of the Italian constitution is a regional duty how to manage the adequate standard of living for person with disability. Many bonuses can be delivered for electricity, energy and internet services for people with disability. Since 2008 to guarantee the right of an adequate standard of living social card has been introduced is a bonus of 40 euro per month for those who have a level of poverty. Participation on political and public life art. 29 of UN CRPD is ensured in Italy by art. 2, 3, 28, 48, 49, and 51 of the Italian constitution without discrimination for people with disability.

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No one may be obliged to undergo any health treatment except under the provisions of the law. The law may not under any circumstances violate the limits imposed by respect for the human person.”

<sup>20</sup> Article 28 of UN CRPD 2006 on adequate standard of living and social protection

“1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

- (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
- (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
- (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
- (d) To ensure access by persons with disabilities to public housing programmes;
- (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.”

This right became particularly difficult for people with intellectual disability and deaf. The deaf problem is related to the non-recognized sign language as part of Italian official languages becoming a barrier to politically communicate and to receive political and public life share of information. The case of intellectual disability is deeply studied in chapter 3. Those who for impairments cannot physically vote can be assisted as established by law 46/09 by the assistance provided by art 29 of 104/92.

Article 31 of UN CRPD on Statistics and data collection states that:

“1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

(a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

(b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of

States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.”

The Italian National Observatory on the condition of people with intellectual disability has the role established by law 18/09 to collect statistical data and develop survey on disability. Since the law 68/99 Italy paid attention to collect information and data about disability. Art.41-*bis* of Law 104/92 established that the Ministry of social solidarity has to promote statistical survey on disability's related issues. Since 2000 MLPS and INPS collaborate to create a strong Information System of Disability statistics. Nowadays it is possible to find data on disability online at the website [www.disabilita-incifre.it](http://www.disabilita-incifre.it) with open access. Another important Italian source for statistical data on disability is the INAIL. Italy by many efforts is trying to respond to the required necessities of Art.31 UN CRPD and ICF. Law 675/96 that implemented EU directive 94/46/CE responds to a balance necessity between: collecting data and privacy right in the Italian legislation. The Dispositions of law 675/96 and the implementation of the successive Directives 95/46/CE and 2002/58/CE today can be found in the code for the protection of personal data established by D. lgs 322/89. Summing up by art.9 of D.lgs 322/89 statistical information can be delivered only in aggregate form without personal reference. Art. 3 of Law 18/09 provides for a collaboration between the collecting data researchers and the associations that work with disabilities or are representative of disabled.

Art.32<sup>21</sup> is related to international cooperation, this right aim to promote the sharing of know-how, competences and best practice. The DGCS general direction of development and cooperation approved in 2010 is a document to give the guidelines for the introduction of disability issues in public policies and Italian Cooperation. The action plan has been agreed between Minister of Foreign Affairs DGCS and the Italian Network for development and disability AIFO and the final goal is exactly this expected by art 31. Many works in this sense were done by OSCE.

Article 33 of UN CRPD on National implementation and monitoring states:

“1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”

In Italy inside the OND works actively since 2011 a scientific and technical committee CTS. Moreover, in order to achieve the monitoring results specific work group have being organized inside OND. The main goal

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<sup>21</sup> Article 32 of UN CRPD 2006 on International cooperation:

“1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

(c) Facilitating cooperation in research and access to scientific and technical knowledge;

(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.”



is to improve the life of people with disability, to enforce the empowerment process and to achieve into society a full inclusion and a universal design prospective.

## CHAPTER 3: Disabilities Studies and public policies for people with Intellectual Disability in the Italian scenario.

### 3.1 How to build a system of Support: from the diagnosis of Intellectual disability to public policies design.

The American Association on Intellectual and Developmental Disability (2010) provide three assessment function in the field of ID.

**Table 10** Framework for assessment (AAIDD, 2010).

Assessment function	Specific purpose	Examples of measures, tools and assessment methods
Diagnosis	<ul style="list-style-type: none"><li>• establishing presence or absence of intellectual disability;</li><li>• establish eligibility for services;</li><li>• establish eligibility for benefits;</li><li>• establish eligibility for legal protections.</li></ul>	<ul style="list-style-type: none"><li>• Intelligence tests</li><li>• Adaptive behavior</li><li>• Documented age of onset,</li><li>• Developmental measures;</li><li>• Social history and educational records;</li></ul>
Classification	<ul style="list-style-type: none"><li>• classify for intensity of needed support(s);</li><li>• classify for research purposes;</li><li>• classify for special education supports;</li><li>• classify for reimbursement/funding</li></ul>	<ul style="list-style-type: none"><li>• supports needs intensity scales;</li><li>• levels of adaptive behavior;</li><li>• IQ ranges or levels;</li><li>• Environmental assessment;</li><li>• Etiology-risks factor systems;</li><li>• Mental health;</li><li>• Benefit categories;</li></ul>
Planning and developing systems of supports.	<ul style="list-style-type: none"><li>• support the enhance human functioning;</li><li>• support to improve outcomes;</li><li>• support to help implement person's choice;</li><li>• supports to assure human rights</li></ul>	<ul style="list-style-type: none"><li>• Person-centered planning</li><li>• Self-appraisal</li><li>• Ecological inventory</li><li>• Developmental test;</li><li>• Speech/language, motor, sensory assessment;</li><li>• Achievement tests;</li><li>• Support needs intensity scales;</li><li>• Functional behavioral assessment;</li><li>• Behavior support plan;</li><li>• Family centered support plan;</li><li>• IFS, IE, ITP</li><li>• Self-directed plan.</li></ul>

The diagnosis of ID is important to have information and collecting data, to define intellectual disability to make recommendations and to provide supports. Diagnosis is part of ID definition and is the basis for collecting data about it.

As already seen in paragraph 1.3, there are three criteria established by the American Association on Intellectual and Developmental Disability due to diagnosticate ID (2010):

- a) Significant limitation in intellectual functioning;
- b) Significant limitation in adaptive behavior;
- c) Age of onset before 18.

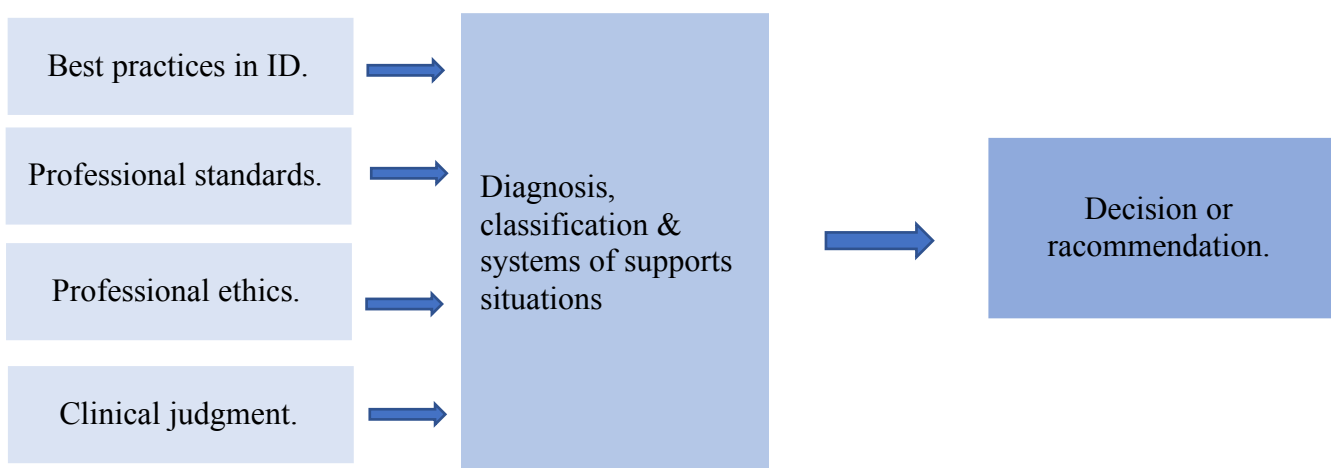
These three criteria distinguish between a disability and an intellectual disability.

In the diagnosis process the key element is the clinical judgement. Clinical judgement is different from the medical model and differs from either ethical or professional judgement. Clinical Judgment as defined by Luckassonet al (2012) and Schalock and Luckasson (2005) (in AAIDD, 2010) is characterize by it being: systematic, formal and transparent.

The diagnosis, classification and provision of individualized supports to persons with intellectual Disability, frequently involved a variety of professions such as psychologists, physicians, diagnosticians, expert educators, special education teachers and social workers (AAIDD, 2010).

Diagnosis is based on the clinician's explicit training, direct experience and specific knowledge of the person with ID and the person's environment. Thanks to the clinical judgement, the diagnosis took validity, quality and precision of the clinician's decision in specific cases. Abbreviated evaluations, stereotypes or prejudices can't be justified by the clinical judgement.

**Figure 16** Clinical judgment as a component of professional responsibility (AAIDD,2010).



The clinical Judgements produce a diagnosis with other three components: professional standards, professional ethics and best practice. Professional standards are referred to the basis of any evaluation used for accreditation or quality control (AAIDD,2010).

Professional ethics indicate the guidelines connected to ethical principles mainly three standards: justice, beneficence and autonomy (AAIDD, 2010).

Best practices fixed by the American Association on Intellectual Developmental Disabilities (2010) are:

- The definition of ID and its bases within an ecological, multidimensional framework;
- The role of assessment diagnosis, classification and developing systems of supports;
- Intellectual functioning and adaptive behavior and their assessment;
- The role of etiological factors in the diagnosis of ID;
- The multidimensional approach to classification.

The clinical Judgement strategies can be summarized in the following table.

**Table 11** Clinical Judgment strategies (AAIDD,2010).

Strategies	Results
Clarify and state precisely the question set before you and determine whether the question relates to diagnosis, classification or systems of supports.	Identifies needed activities and aligns data-collection efforts to the critical question(s) at hand.
Conduct or access a through history.	Understand personal and environmental factors that affect disability, including personal and family history, possible etiology, educational history, and course of disability.
Conduct or access broad-based assessments.	Provides a full picture of an individual 's functioning.
Synthesize the obtained information.	Provides data and information for: <ul style="list-style-type: none"><li>- Generating and testing hypotheses;</li><li>- Considering the relative weight and possible combination of information as a basis for decisions and recommendations;</li><li>- Improving the quality, validity and precision of data-based decision making and recommendations.</li></ul>

In order to produce a valid and credible decision, it is important not only including in the clinical Judgement the four strategies but also avoiding the common thinking errors.

American Association on Intellectual Developmental Disabilities identifies ten categories of mistake to prevent in order to produce efficient recommendations on Intellectual disability.

The common thinking errors are:

1. Affective error: such as incorrect stereotypes;

2. Anchoring error: the first bit of information anchors your mind on an incorrect decision or recommendation;
3. Availability error: what happened recently or most dramatically;
4. Blind obedience: what the authority said;
5. Commission bias: do something, anything;
6. Confirmation bias: you find what you expect to find;
7. Diagnosis momentum: piling on after an initial diagnosis;
8. Framing effects: mistakenly influenced by the context;
9. Premature closure: deciding too soon;
10. Representatives error: what is typically true.

The clinical strategies avoiding the common thinking errors experiment four steps before being active: the analysis, the evaluation, the interpretation and the inference.

During the last twenty years clinical judgements changed a lot because all the required elements, as well as the new kind of standards. As a consequence, during the last twenty years, public policies on Intellectual Disability have experienced the major changes. Legal decisions and service delivery are changed. Clinical judgement strategies need to be followed in order to overcome the challenge of making information and, therefore, decisions and efficient policies

### **3.1.2 Systems of supports.**

Since the mid-1980s support paradigm through public policies aim to promote the development, education, interests, and personal well-being of a person with disability. The support paradigm made three changes in public policies in terms of inclusion and participation of people ID in society (AAIDD, 2010):

1. supports orientation has brought together the related practices of person-centered planning empowerment, self-determination, personal growth and development opportunities and self-determination;
2. the judicious application of individualized supports has resulted in enhanced human functioning and personal outcomes;
3. the pattern and intensity of person support needs is being used as a basis for agency and systems planning and resource allocation.

Which is the meaning of support needs? In the words of Thompson (2009) support needs are “a psychological construct referring to the pattern and intensity of support necessary for a person to participate in activities linked with normative human functioning.”

In order to produce efficient public policies dedicated to people with intellectual disability, is significant to create a system of support needs based on personal needs. People differ and have something in common, and for people with disability is exactly the same. The main difference between a person with and without disability is that the first one needs supports to be an active member of the society. Thanks to supports needs the impairment is reduced and the social and physical barrier removed.

Social supports can be: technologies, physical support, people, referenced to the person or environment. The most important think of supports needs id to be individually adapted.

Supports model have four implications (AAIDD,2010):

1. a mismatch between environmental demands and personal competency results in support needs that necessitate particular types and intensities of individualized supports.
2. To the extent that these individualized supports are based on thoughtful planning and application, it is more likely that they will lead to improved human functioning and personal outcomes.
3. As a bridge between what is and what can be, the focus of educational and habilitation service systems shifts to understanding people by their types and intensity of support needs instead of by their deficit.
4. There is a reciprocal relationship between impairment and support needs in that greater personal limitations will almost always be associated with more intense support needs, a focus on reducing the mismatch between people's competencies.

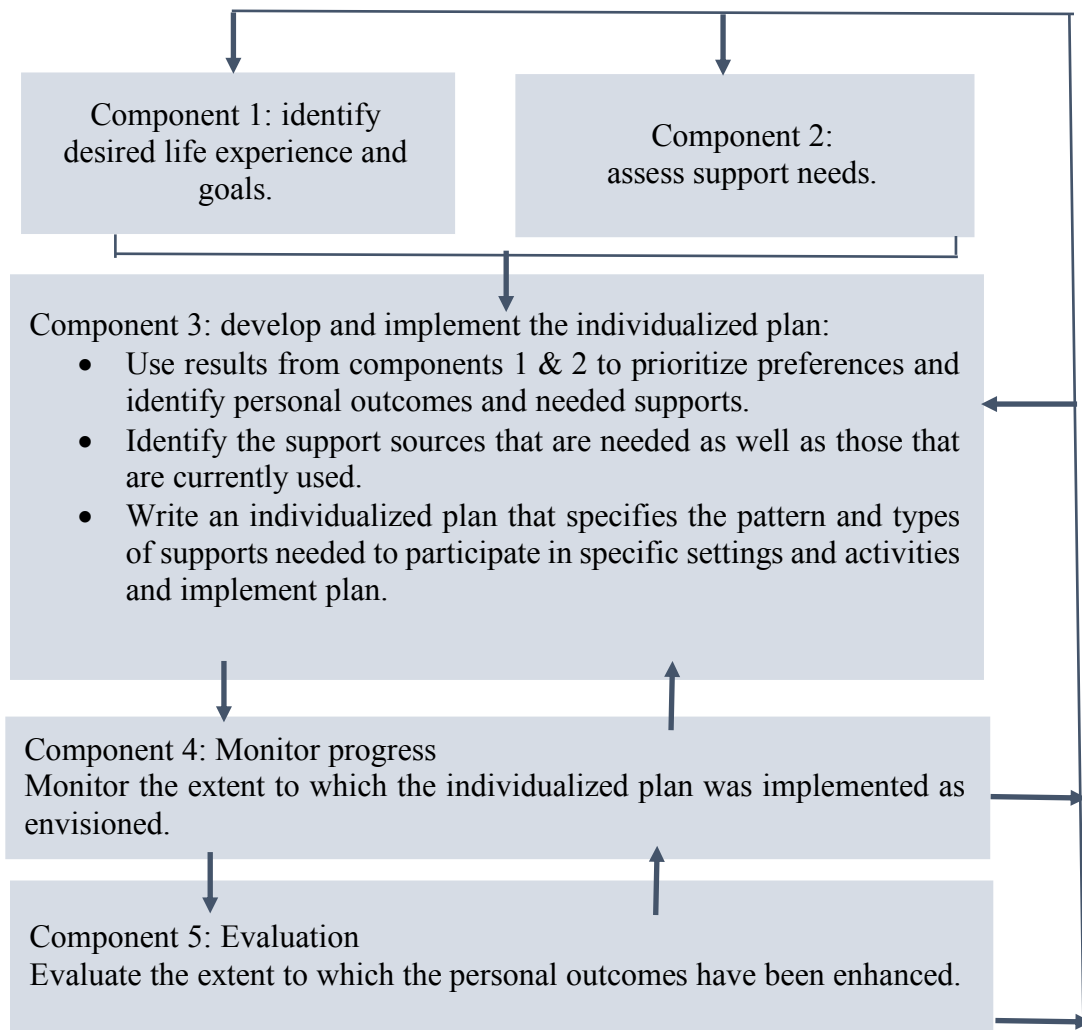
The premise to individuate the right support needs is considering the human functioning and therefore person with intellectual disability influenced by environments and individual capacity.

Analyzing the support needs is fundamental to look at the Wile's HPT Human Performance Technology model (1996). In Wile's thought the performance of the people, of the humans was influenced by seven different elements: Organizational systems, incentives, cognitive supports, tools, physical environment, skills and knowledge, Inherent ability.

American Association on Intellectual Developmental Disabilities connected the HPT model of Wile with the analysis of support needs. To each element individuated by Wile correspond an example of support to provide. The organizational systems can correspond to passing laws and public policies to give incentives to hire persons with disabilities or establishing industry standards for connecting and remodeling home and community setting based on principles of universal design. A support needs examples of the second element, the incentives, might be developing a behavioral contract involving positive reinforcement of behaviors to keep one's house clean and sanitary or increasing opportunities to engage in preferred activities as the result of earning more money because of good performance on a job. To the cognitive support correspond reminders from a coworker to transition to different work activities. the support needs correspondent to tools of using augmentative and alternative communication system device to increase expressive communication or using a calculator to enable accurate money exchanges when shopping. Many time calculations represent a barrier for people with intellectual disability. Physical environment practically can correspond to provide a less-distracting section of the classroom for the test taking or lowering file cabinets for filing by a person who uses a wheelchair. Skills/ knowledge can be teaching a person how to use a local health club or using social stories to prepare a person for a visit to doctor's office. And to conclude Inherent ability by exercising to enhance physical vitality and endurance and using intrinsic motivation to do well in an activity or setting, or matching jobs and other activities to an individual's relative strengths.

The system of support is composed by five main steps that have been synthesized by American Association on Intellectual Developmental Disabilities connected by the following figure.

**Figure 17** Process for assessing, planning, monitoring, and evaluating individualized supports (AAIDD,2010).



### 3.1.2.1 Challenges in society of persons with ID who have higher IQ scores.

Disability includes many different kinds of impairment and also people with intellectual disability differs for their kind of impairment often overlapped. There is a specific part of people with intellectual disability who have higher IQ scores. IT is important to analyze the support needs of those with higer IQ scores because they face the most difficult challenges in society across all areas of adult life. People with disability with high IQ scores is referred to scores comprised about 80% to 90% of all individuals diagnosed with ID. Moreover, there are cases of people that do not receive a formal diagnosis of ID or are just slightly above the upper ceiling for ID's diagnosis that are less protected and very vulnerable. People with disability with high IQ scores is referred to scores comprised about 80% to 90% of all individuals diagnosed with ID. An improvement of clinical judgement can be achieved only through a better understanding of the ongoing strengths and limitation of each person and appropriate support can be identified. By providing

individualized support, the stereotypes on people with intellectual disability can be overcoming. People with ID can have friends, job and can be good citizens.

Because in everyday life people with higher IQ scores do not have access to needed support they face critical obstacle to live a regular life. Those problem tare required to be solved by public policies. The *ad hoc* committee on terminology and classification of AAIDD (2010) individuated the main obstacles that people with ID and in particular those with an IQ high score experimented in everyday life. They made a schema where to each sector of social life/ society correspond a difficulty without an efficient provision of support needs.

**Table 12** Everyday life of people with intellectual disability who have higher IQ Scores (AAIDD, 2010).

<b>Education</b>	<ul style="list-style-type: none"> <li>• Variability among states in identifying student with ID;</li> <li>• high rate of classroom segregation disproportionality;</li> <li>• slightly lower rates of leaving school;</li> <li>• rare declassifications.</li> </ul>
<b>Socioeconomic status</b>	<ul style="list-style-type: none"> <li>• Significantly reduced income in families with a member with ID;</li> <li>• high rate of single parenting (mother) of child with ID;</li> <li>• reduced success for individual in obtaining markers of independent economics (e.g. employment, credit cards, checking accounts, driver's license).</li> </ul>
<b>Employment</b>	<ul style="list-style-type: none"> <li>• Low rate of employment;</li> <li>• low hours, benefits, skill demands;</li> <li>• low career success;</li> <li>• high need for assistance.</li> </ul>
<b>Housing</b>	<ul style="list-style-type: none"> <li>• High poverty and low access;</li> <li>• long waited for housing and supports;</li> <li>• often continue to live with family to other people.</li> </ul>
<b>Health</b>	<ul style="list-style-type: none"> <li>• Poorer nutrition;</li> <li>• higher obesity;</li> <li>• poor access to health care and poor ability to communicate with health providers.</li> </ul>
<b>Friendship and social behavior</b>	<ul style="list-style-type: none"> <li>• Reduced ability to form and sustain mutually beneficial friendships without assistance;</li> <li>• high risk of loneliness;</li> <li>• higher risk of behavior problems if behavioral supports not provided.</li> </ul>
<b>Family and well-being</b>	<ul style="list-style-type: none"> <li>• Most continue to live with parents or others;</li> <li>• challenges in forming own families due to poverty, learning limitations, poor employment and fears by others;</li> </ul>



	<ul style="list-style-type: none"> <li>• difficulties successfully raising their children without assistance.</li> </ul>
<b>Rights</b>	<ul style="list-style-type: none"> <li>• Lack of access to civic education in school and later;</li> <li>• limited knowledge and disability accommodations in the civil and criminal systems;</li> <li>• few specialized legal resources;</li> <li>• low number of affordable advocates with knowledge of disability issues;</li> <li>• long delay in societal recognition of rights.</li> </ul>
<b>Social Judgment</b>	<ul style="list-style-type: none"> <li>• Inadequate response system, interpersonal competence, social judgment, and/or decision-making skills;</li> <li>• reduced intellectual ability and adaptive abilities;</li> <li>• difficulties in problem solving and flexible thinking;</li> <li>• susceptibility to dangers;</li> <li>• reduced abilities and adaption to one's life circumstances;</li> <li>• vulnerabilities to others who may mislead or harm them.</li> </ul>
<b>Inadequate social responding and judgment</b>	<ul style="list-style-type: none"> <li>• Tendency to deny or minimize the ID;</li> <li>• desire to please authority figures;</li> <li>• gullibility when others mislead or harm them;</li> <li>• naïveté or suggestibility.</li> </ul>
<b>Difficulty in thinking and learning</b>	<ul style="list-style-type: none"> <li>• Difficulties making sense of the world through consistent; reliable, socially, mature levels of planning, problem solving, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience;</li> <li>• social stigma;</li> <li>• history of being feared, devaluated, incorrectly stereotyped, and segregated by society.</li> </ul>

The table highlights that ordinary life for subjects with intellectual disability higher IQ is full of limitations. The solution is that for each diagnosis made by professionals corresponds assessment and provision of needed supports to that person. At the end it means public policies implication in this field. Partnerships between government and relevant advocacy and professional groups are required to produce policies and adequate and individual-based systems of support needs.

### **3.1.2.2 Public policies implication in the field of ID**

Public policies impact life of people and therefore life of people with ID. Since public policies are influenced by the changes in practice (AAIDD,2010) the development and implementation are part of a dynamic process. According to what it has been analyzed about ID diagnosis is possible to argue that public policies change because clinical judgment changed with the time. There is a synergy between public policies and classification term (AAIDD,2010): public policies influence the classification and diagnostic process

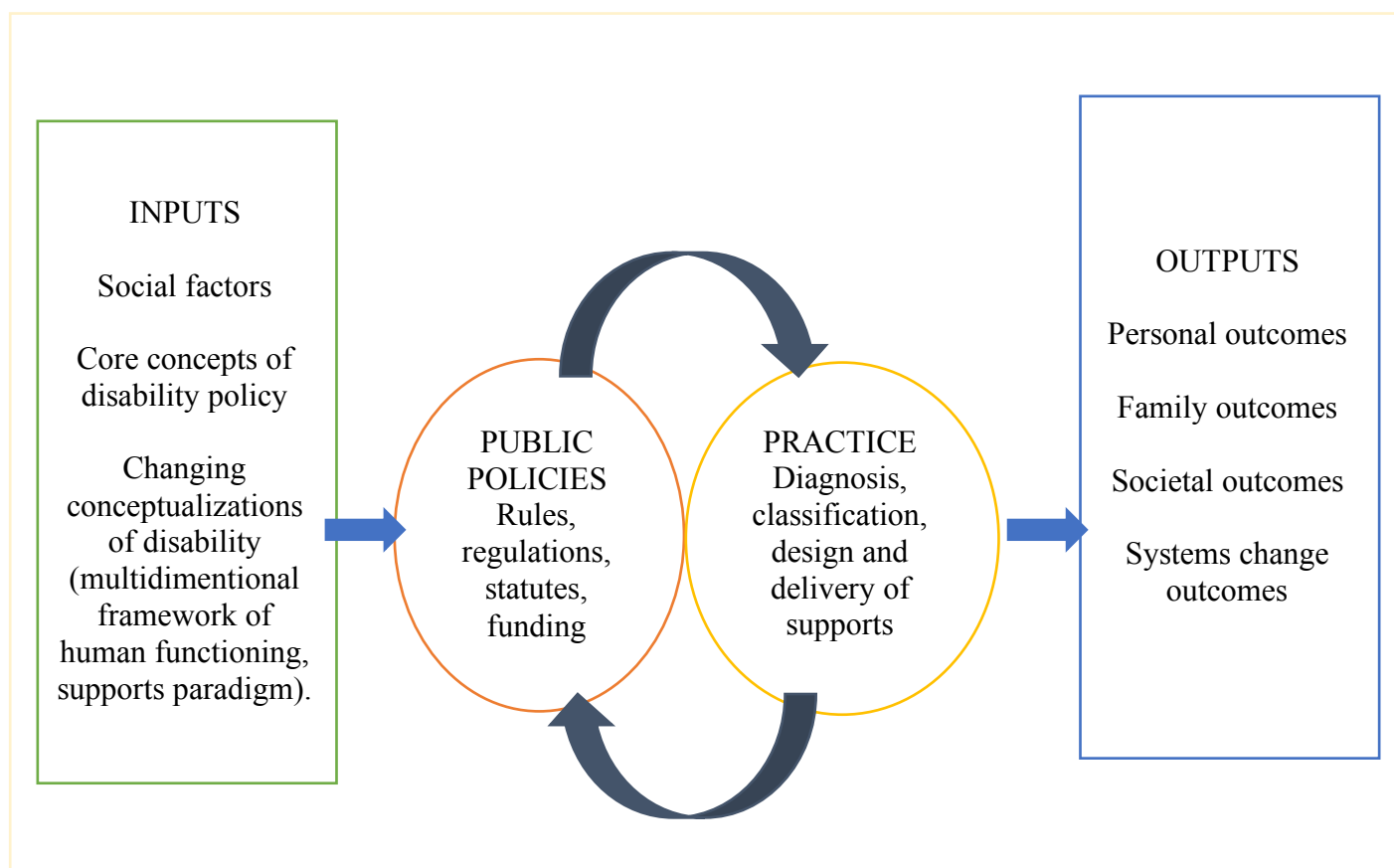
through the guidelines regarding diagnostic criteria and eligibility requirement but on the other change in classification systems and principles that support them influence the perception of the need of people with intellectual disability and as consequence have an impact on how public systems design and deliver support services. For the committee on terminology and classification of AAIDD (2010) in order to achieve the desired policy outcome in the field of Intellectual Disability is important to consider and discuss:

- 1) social factors that influence public policies and its adoption;
- 2) the core concepts guiding disability policy;
- 3) desired policy outcomes stemming from these core concepts;
- 4) a framework for implementing the 2010 definition of ID<sup>22</sup> and its classification to influence the desired public policies outcomes.

Moreover, there are social factors and ideologies impacting on public policies. Social factors and ideology are composed by many dynamics that changed during the years and had a strong impact about regulation for people with intellectual disability. Some examples are: social and political movements, attitudinal changes, judicial decisions, advanced in research regarding the nature of disability that has led to more successful intervention, participatory research and evaluation frameworks and statutory changes.

The following figure made by AAIDD (2010) help to understand the synergy between the public policies, the diagnosis and classification judgment, the inputs and the outputs.

**Figure 18** Interactive relationship between public policy and practice (AAIDD, 2010)



<sup>22</sup>AAIDD definition of ID 2010: “intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability origins before age of 18.”

In order to understand the potential system to influence public policy outcomes, theorized by AAIDD in 2010 and simplified in the figure 3, is useful to mention the Bronfenbrenner's (1979) conceptualization of human development. The inputs (social factors, core concepts of disability policy, changing conceptualizations of disability) should be contextualized through three main dimensions (Bronfenbrenner, 1979):

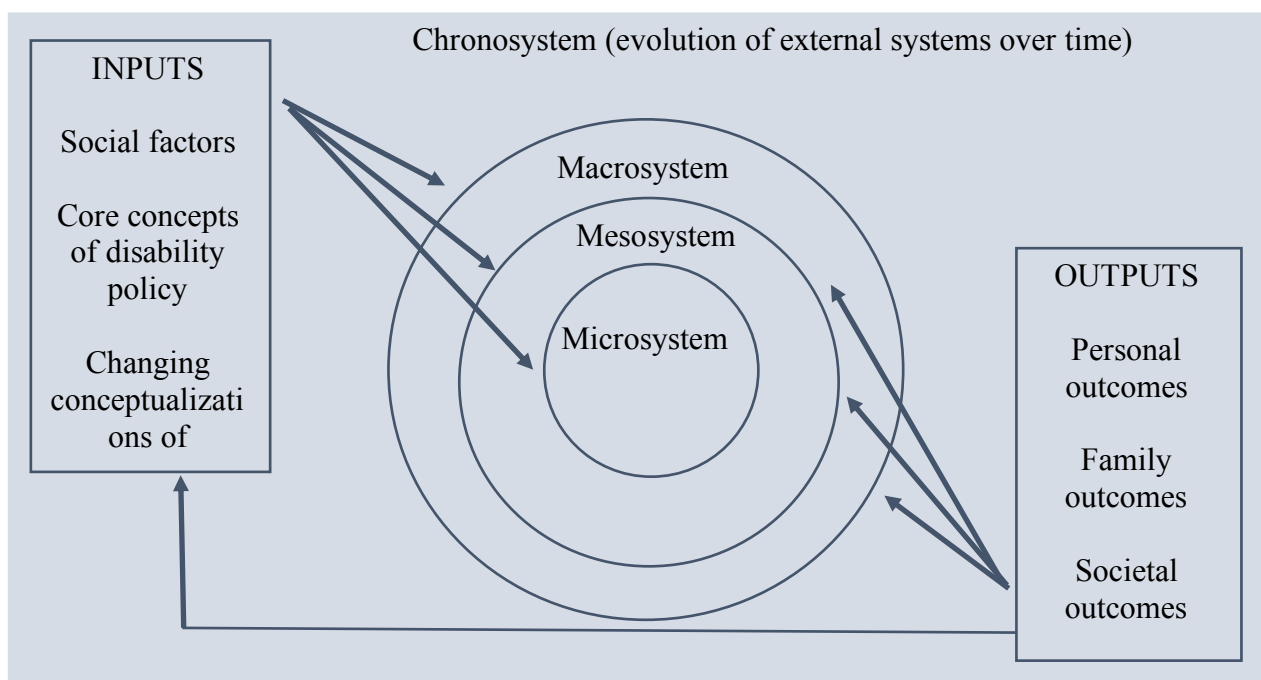
- microsystem: the immediate social setting, including the person, family, and advocates;
- mesosystem: the neighborhood, community or organizations providing education and support;
- macrosystem: the overarching patterns of culture, society, and sociopolitical influences.

There is, moreover, a fourth element, which could be considered a further dimension: the chronosystem, where microsystem, mesosystem and macrosystem act over time.

These three contexts within which individuals function became filters that affect outcomes as inputs of public policy for ID and generally.

The contextual factors of public policies and the 2010 system to influence public policies influenced by Bronfenbrenner model of human development can be summarized in the following schema.

**Figure 19** Contextual factors in public policy (AAIDD, 2010).



AAIDD's analysis for understanding how system can impact public policies outcomes includes six action (2010):

- 1) Establish best practices in the field of ID;
- 2) Achieve greater universal use of a multidimensional approach to diagnosis, classification and support provision;
- 3) Address current policy and system disconnects;
- 4) Implement more widely the policies that are already in existence;

- 5) Focus on personal outcomes and their enhancement;
- 6) Utilize formative feedback generated by the assessment of policy outcomes.

Outcomes data are fundamental element to have feedback and evaluate public policies. The evaluation of public policies in ID is determinant in order to develop society in an inclusive way.

### **3.2 Inclusion and public policies.**

Three Italian word described the process lived from disabled to be accepted in Italian society: *inserimento*, *integrazione* and *inclusion*.

The initial steps “*il primo inserimento*” in favor of disabled were moved in Italy at the end of 60s. The process of integration *integrazione* started at the beginning of 1970. The main reform was the integration of disabled at school in regular class together with “normal” students. A drastic change in terms of integration in Italy went with the Bassaglia Law that closed many of the mental hospital where people with ID lived isolated, considered crazy. During 1970- and 1980 the medical approach was mostly used and the concept of inclusion was still far. the integration was considered as the person with disability that had to find way to be fit for society. At school it wasn't the school approach or the classroom to eliminate barrier for a person with disability but on the contrary was the person with disability to be suitable. With the advent of Social model and the development of disability movement and the CRPD the term inclusion *inclusion* started to be used. The term inclusion (Medeghini, et al., 2013) replace the term special education in school context, integration and the American term mainstreaming.

What is inclusion?

Inclusion means accepting anyone in society looking at the abilities and to the differences as a value.

Inclusions means surely a change in prospective. The deficit and limits should be seen in society more than in the person. The inclusion process starts with a developing of welfare policies at international, European and national level in favor of disability. The inclusive revolution gets away the idea to make people with disability fit for society and instead aim to make society fit for person with disability. Inclusion means provide supports to make every part of society as fit as possible for people with disability and intellectual disability. Individuals with appropriate supports contrasted incorrect stereotypes that the individuals with disability, mostly intellectual disability, are less smart or never have abilities, friends, jobs, spouses or are active citizens.

Even in most developed nations, for many decades and, in some cases still today, the efforts to include people with intellectual disability in society have met with many barriers (Special Olympics, 2009). Some of these barriers are still resistant to change.

In Italy the hardest challenge for inclusion was in Education, as analyzed in paragraph 3.3 of the thesis. One of the most important law in Italy for inclusion as seen in Chapter 2 is the Law 104/92. Law 104/1992, is the main frame for all disability issues: it guarantees people with disabilities and their families the ownership of

specific rights; providing assistance; states the full integration and the adoption of prevention measures and functional recovery; ensures social, economic and legal protection (Petrella).

OECD (2013) clearly defines the main features of an inclusive policies: “ open and inclusive policy making is transparent, evidence- driven, accessible and responsive to as wide a range of citizens as possible. It strives to include a diverse number of voices and views in the policy-making process, including traditional cultures. To be successful, these elements must be applied at all stages of the design and delivery of public policies and services. While inclusive policy making enhances transparency, accountability and public participation and builds civic capacity, it also offers a way for governments to improve their policy performance by working with citizens, civil society organizations (CSOs), businesses and other stakeholders to deliver concrete improvements in policy outcomes and the quality of public services.”

### **3.2.1 Participation in political and public life of people with ID.**

The right to participate in political and public life is guaranteed by Article 39 of the Charter of Fundamental Rights of the European Union, stating that all EU citizens have the right to vote and to stand as a candidate at elections to the European Parliament. Article 40, furthermore, guarantees the right to vote and stand as a candidate at municipal elections. Article 21 recognizes the right to be free from discrimination, including on the grounds of disability, and Article 26 recognizes and respects the right of persons with disabilities to benefit from measures to ensure their independence, social and occupational integration and participation in the life of the community (FRA , 2014). Italy, as the other countries of EU, represents a democratic society, being a democratic society includes to guarantee to all the opportunity to be involved in political life.

A position paper of inclusion Europe started with “taking part in political and public life is about being included in society and having the voices of people with intellectual disability heard” (Inclusion Europe , 2011).

Art. 29 of United Nation Convention on the Rights of Persons with Disability is about Participation in political and public life (2006):

“States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

- a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
  - i. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
  - ii. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

iii. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice.

b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.”

Therefore Art. 29 gives the possibility and ensures the right for people with intellectual disability to become members of political parties or non-governmental organization. In 2014 the European Union Agency for the Fundamental Rights and the European Commission through the academic network of European disability experts (aned) made a survey in order to the level of political participation of people with disability as set out in Art 29 have collected data from across the 28 EU member states (FRA,2014).

The survey found three main results. If the possibility to be active citizens and an accessible environment is given to persons with disability they demonstrate to participate in the political life of their community. A very important tool to guarantee the effective participation of people with disability to public and political life is to provide a more accessible information and processes, as well as better support and reasonable accommodation (FRA,2014).

The second point argued by European Union Agency for the Fundamental Rights and the European Commission through the academic network of European disability experts (aned) are the significant challenges that still remain to the realization of the right to political participation for persons with disabilities remain. In Europe there are still: legal obstacles, such as restrictions on the right to vote for some persons with disabilities, and gaps between the promise of law and policy and their actual implementation (FRA, 2014). Excluding people with disabilities from the opportunity to influence the development of law exclude the possibility for them to influence their own daily life.

The third statement was that barriers excluded some kinds of disabilities more than others to participate in public life. Barriers to political participation do not affect all persons with disabilities equally, those with more severe impairments, as well as people with particular types of impairment in particular, persons with intellectual disabilities face higher barriers to their participation in the political life (FRA,2014).

According with the 2014 survey of European Union Agency for the Fundamental Rights and the European Commission through the academic network of European disability experts (aned) the main obstacles faced by people with disability to access in political and public rights are: lifting legal and administrative barriers to political participation, making voting procedures ,facilities and election materials more accessible, expanding opportunities for participation in political and public life, increasing awareness of the right to political participation of persons with disabilities; collecting data to measure the political participation of persons with disabilities.

Moreover, legal restrictions on the right to vote of some persons with disabilities particularly those with psychosocial or intellectual impairments, Inaccessible and cumber some administrative processes which can deprive persons with disabilities of the right to vote (FRA, 2014).

The case of public and political life participation of people with intellectual disability is very interesting to analyze in terms of inclusion. In fact, the right to vote and participate in public life because of huge barriers such as, lack of accessible information, lack of access to polling stations, lack of awareness among political parties and polling station officials and prejudice about the ability of people to make decisions is in many countries denied to people with intellectual disability (Inclusion Europe , 2011).

A strict link in order to implement Art 29 of UN CRPD is Art. 12 CRPD regarding legal capacity. People with disability and intellectual disability might participate t policies life if measures have been taken to remove the barriers. The position paper of Inclusion Europe (2011) finds two tools to remove barriers and to guarantee accessibility to political life: available information (how to register a vote, the different political parties, the national political system, different type of elections) and improve accessibility through new technologies (electronic voting by computer) or training programs. Moreover, some tools may result helpful not only for people with disability but also for many Italian citizens, students that do not live in their native cities and any time need to pay the trip to be back home and vote. According to Art.29 b) States should promote representatives' organizations of persons with disabilities and providing to these organization with funding and organizational capacity to participate in civil society and political life.

If representative organization of people with disability and intellectual disability exists and are active in public affairs, State should guarantee their participation in policy circle.

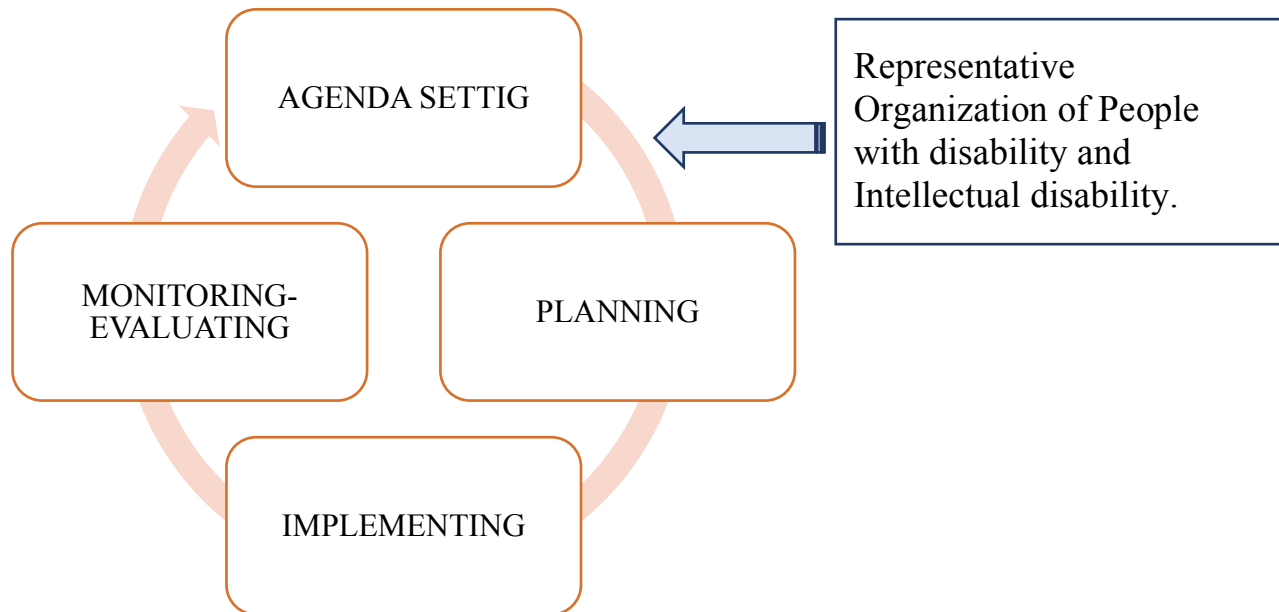
The respect of Art. 29 is supported by Art 33 paragraph 3 of CRPD (2006):

“[...] Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”

Civil society and therefore association of people with intellectual disability are part or should be part of policy circle in all this part: agenda setting, planning, implementing, monitoring-evaluating.

Excluding people with disabilities from the opportunity to influence the development of law exclude the possibility for them to influence their own daily life. addressing these challenges as soon as possible is essential to increasing the legitimacy of public institutions and creating more equitable and inclusive societies in which all members can participate fully.

**Figure 20** Inclusive Policy Cycle (Inclusion Europe, 2011).



This thesis sustains the recommendation of Inclusion Europe in the position paper of 2011 to local, national and European authorities in order to put the recommendation in action:

- 1) To ensure participation of people with intellectual disabilities and their families and/or their representative organizations throughout the policy cycle: in agenda-setting, planning, implementing and monitoring, and evaluating the policies and services that affect the lives of persons with intellectual disabilities and their families.
- 2) To increase participation of people with intellectual disabilities and their families in political and public life at all levels, local, regional, national, European and international in order to fully represent the whole society.
- 3) To recognize the knowledge and the expertise of people with intellectual disabilities and their families in relation to their lives and their real needs.
- 4) To adopt mechanisms to ensure meaningful participation of persons with disabilities and their organizations, through their representation in relevant bodies of public authorities or on advisory boards.
- 5) To ensure meaningful mechanisms of participation and involvement of people with intellectual disabilities using accessible and multiple formats for consultation, making sure that the principle of



reasonable accommodation is respected and that reasonable accommodation is made available where it is necessary.

- 6) To ensure that people with intellectual disabilities, their families and their representative organizations, are involved and participate fully in consultation processes, from the beginning to the end, to ensure a constructive and trusting relationship.
- 7) To provide capacity building and financial resources to disability NGOs, to make sure that they will have the capacity to fully participate and contribute to all relevant policies and consultations.

### **3.2.1.1 People with ID and the right to vote.**

In Art 29 of UN CRPD the right to vote is mentioned as other political rights that States guarantee to people with disability. In Art 29 there aren't distinction between physical and intellectual disabilities.

How and to what degree can people identified as having intellectual disabilities participate in a defining act of the democratic process? Was the question of Marcus Readly in its research project: "The voting rights of adults with intellectual disabilities: Reflections on the arguments, and situation in Kenya and England and Wales".

The debate turns around two argument. The first argument is based upon a State's presumed interest in an educated electorate, and the concern that the participation of the ill-informed citizen might lead to sub-optimal political outcomes (Readly, et al., 2012).

The second argument used against people with ID having voting rights rests on the presumption that they can easily be manipulated, with the consequence that their votes might be misappropriated (Readly, et al., 2012).

Person with intellectual disability are wrongly considered as being "unsound mind" and therefore legally incompetent.

Furthermore, it becomes possible to distinguish between: people with an ID whose decision-making capacity, upon assessment, is functionally unimpaired, and whose decision-making rights should, therefore, be respected; people whose decision-making capacity is functionally impaired, and who might be putting themselves at risk were their choices to be respected; and those people whose decision-making capacity is functionally impaired, but who can, with appropriate support, make an autonomous decision.

A change in the world came with the UN CRPD of 2006. In the world there was a net change with the implementation of UN CRPD.

In 2001 a survey of 63 democratic States found only Canada, Ireland, Italy and Sweden allowed to vote people with intellectual disability (Blais, et al., 2001).

Recently a survey (2010) by European Union Agency for Fundamental Rights on the 27 member States of Europe was based on the following points:

- All people who live in Europe have the right to vote;
- They also have the right to be part of government, this means that every person can help choose the people to run your local area, your country and Europe;
- In some countries in Europe, people with mental health problems are not allowed to vote: this is discrimination; discrimination is when one person or a group of people are not treated in a fair way and do not have the same rights as everybody else.

The survey found that in seven EU country people with disability can vote, in sixteen countries of EU they can't vote and in six the decision is on singular cases.

In Austria, Finland, Italy, Netherlands, Spain, Sweden and United Kingdom people with mental health problems or intellectual disabilities can vote and take part in government.

While in other European countries people with intellectual disability can't vote because the Law affirms "you cannot marry, buy a house, or look after your own money, so you cannot vote". These countries are: Belgium, Bulgaria, Czech Republic, Denmark, Estonia, Germany, Greece, Hungary, Luxemburg, Malta, Poland, Portugal, Romania, Slovakia (European Union Agency for Fundamental Rights, 2010).

In Estonia, Cyprus, France, Malta, Slovenia and Spain a doctor or judge decides if each person with mental health problems or intellectual disability can vote.

The European Union Agency for Fundamental Rights highlighted in 2010 that the jurisdiction regulation on the right to vote should follow some important guidelines:

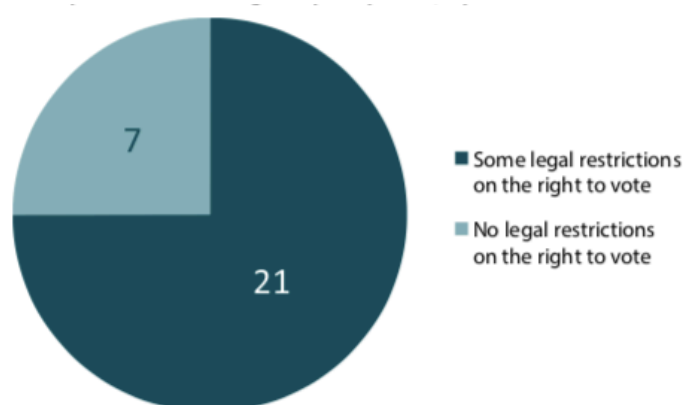
- Art. 29 of UN CRPD;
- Th European Convention on Human Rights;
- The European Convention on Human Rights;
- countries who sign the UN CRPD should ensure that people with intellectual disability have the same rights as the other citizens;
- the European Court of Human Rights said that people with intellectual disability should have the right to vote.

In order to increase awareness on the right to vote in EU was created M.O.TE "My Opinion, My Vote" a website with offered materials and information on the right to vote for citizens of EU included those with intellectual disability.

In Italy people with intellectual disability have the right to vote but the major of time they are confused about that because a lack of information. Recently in Italy born a movement “il mio voto conta”. Thanks to this movement supported by the Italian Association for Down was produced a helpful manual that explain how to vote in an easy way.

According with the 2014 survey of European Union Agency for the Fundamental Rights and the European Commission through the academic network of European disability experts (aned) in the EU members state the capacity to vote is still linked to legal limits.

**Figure 21** Can persons deprived of their legal capacity vote, by EU Member State? (FRA, Waddington 2014)



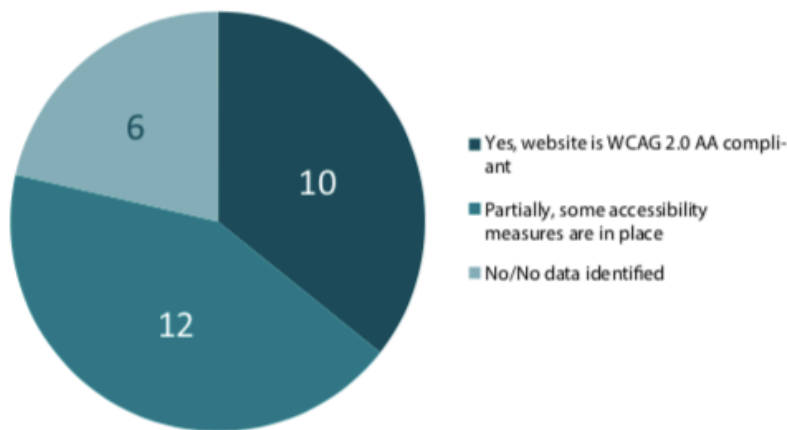
Because of a lack of data regarding the accessibility standards in place for polling stations, it is very difficult to judge if the regulations are properly implemented. Moreover, if there aren't sure data means it is not possible to determine the proportion of polling stations, or public buildings, which are accessible to persons with disabilities (FRA, 2014). The need to establish common criteria to evaluate the degree of accessibility do not allow to be focus on the needs required by persons with disability and intellectual disability. Some problemes in order to guarantee the right to vote for all is also relative to the supports: it is not always possible for the person with a disability themselves to choose who they would like to assist them. A problem that affect Italy as other country of EU is the access to information. Being involved in electoral process is strictly linked to the access of information such as radio, television and internet or print material. Most of the Italian politicians are not translated in LIS (Italian language for deaf) during their public speaking, it means a strong barrier. The availability of audio descriptions or national sign language interpretation is less widespread (FRA,2014).

Firstly, political party should take the duty for making communication and information available for all, making their campaign material accessible to persons with disabilities and trying to create accessible way to share electoral information. Many member states have a lack in this sense.

According with the 2014 survey of European Union Agency for the Fundamental Rights and the European Commission through the academic network of European disability experts (aned), the existing data show that

selected media remain largely inaccessible to persons with disabilities. A clear example is the website providing instruction for voting information on candidates.

**Figure 22** Does the website providing instructions for voting and information on candidates states that meets accessibility standards by EU Member State? (FRA,2014)



Furthermore, people with more severe impairments should be informed of their right to vote to achieve the exclusion from political life. Have the aware of having a right allow people also to practice. The electoral regulation should in future consider all the required support need for disabled, the capacity of political parties and media organizations to make their outputs more accessible. Technology can help for both making pooling station more available for people with physical impairments and for provide the adequate tool to those with an intellectual disability.

Removing barriers to vote means guarantee vote to all and be a social democracy.

*“EU institutions with a mandate to collect data should support and supplement Member States’ efforts to collect statistics and data that reflect the barriers which prevent persons with disabilities from participating fully in political and public life. This should include the further development and implementation of data collection methodologies that are inclusive of all persons with disabilities, including those with more severe impairments” (FRA, 2014).*

### **3.2.1.2 Participation in political and cultural life of people with disability in Italy.**

ISTAT by analyzing the main aspects of everyday life of a person with disability collected data on participation in political life. The main research factor has been:

- 1) If the person with disability were aware of the political situation
- 2) If the people with disability were informed by newspapers;
- 3) If the person with disability were involved in associations.

**Table 13** ISTAT survey on 100 people with same characteristics about political awareness considering age and disability in Italy, 2013.

AWARENESS ON ITALIAN POLITICS	18-44		45-64		OVER 65	
	Without disability	With disability	Without disability	With disability	Without disability	With disability
YES	72,2	78,5	77,6	76,4	68,1	57,1
NEVER	25,6	20,4	20,6	22,5	29,8	42,1
NOT SPECIFIED	2,1	1,1	1,8	1,1	2,0	0,8
<b>TOTAL</b>	100,0	100,0	100,0	100,0	100,0	100,0

For what concern the awareness on politic issues there are differences between people with and without disability. In particular in the class of people 18-44 people with disability is more informed respect people without disability, 78,5% people with disability and 72,2% people without disability.

**Table 14** ISTAT survey on 100 people with same characteristics about newspapers reading considering age and disability in Italy, 2013.

NEWSPAPERS READING	18-44		45-64		OVER 65	
	Without disability	With disability	Without disability	With disability	Without disability	With disability
YES	52,3	55,3	60,6	56,9	57,0	41,4
NEVER	46,1	44,2	37,8	42,2	41,4	58,3
NOT SPECIFIED	1,6	0,5	1,6	0,9	1,6	0,3
<b>TOTAL</b>	100,0	100,0	100,0	100,0	100,0	100,0

Looking at data people with disability (age 18-44) seem to be more informed 55,3% by reading newspapers compared with people without disability 52,3% having the same age (age 18-44) (ISTAT, 2013). On the contrary from 44 to <65 years old people without disability reads more information than those without disability.

A possible reason might be that the condition of people with disability usually became worse by the time while generally people without disability have more time becoming older, but this is not proved.

**Table 15** ISTAT survey on 100 people with same characteristics about being part of at least one social activity considering sex and disability in Italy, 2013

BEING PART OF AT LEAST ONE SOCIAL ACTIVITY.	MAN		WOMEN		MAN AND WOMEN	
	Without disability	With disability	Without disability	With disability	Without disability	With disability
YES	16,2	15,9	14,0	11,0	15,1	13,1

NEVER	83,8	84,1	86,0	89,0	84,9	86,9
TOTAL	100,0	100,0	100,0	100,0	100,0	100,0

The world of associations isn't a lot attended by people with disability (ISTAT, 2013).

Regarding the participation in cultural life there aren't Italian official data from ISTAT regarding the level of accessibility but there are some data on the everyday participation level of people with disability.

People with disability meet their friend less than people without disability during the week. The difficulty to meet often friend for people with disability increase with age. 85% of people with disability under 18 meet their friend in free time at least once per week while the percentage of under 18 without disability is 91%. For what concern over 65 are 45% of people with disability that see their friend often and 59% without disability (ISTAT in OND 2016).

The over 65 with disability that declared to have no friends at all are 5 % while 3,8% in the case of people without disability.

**Table 16** ISTAT survey on 100 people with and without disability about time trend for meeting friends based on age, 2013.

[illegible]

**Table 17** ISTAT age-based survey on cinema, theater and other shows attendance of 100 persons with and without disability, 2013.

PATECIPATION AT CINEMA, THEATER AND OTHER FORMS OF SHOWS	18-44		45-64		OVER 65	
	Without disability	With disability	Without disability	With disability	Without disability	With disability
YES	24,7	21,6	13,9	11,1	8,2	4,8
NEVER	70,5	74,9	81,2	85,0	87,4	92,9
NOT SPECIFIED	4,8	3,4	4,8	3,8	4,4	2,3
<b>TOTAL</b>	100,0	100,0	100,0	100,0	100,0	100,0

Both people with disability and without disability participate in cultural activity such as theater, cinema and others show more in the youth. The increase of age correspond to a decrease of cultural activity for both the categories.

**Table 18** Use of internet in people with and without disability (ISTAT,2013).

USE OF INTERNET	18-44		45-64		OVER 65	
	Without disability	With disability	Without disability	With disability	Without disability	With disability
YES	78,5	76,0	54,4	46,9	15,6	7,3
NEVER	16,2	19,0	40,8	48,4	80,8	90,4
NOT SPECIFIED	5,3	5,0	4,8	4,8	3,7	2,3
<b>TOTAL</b>	100,0	100,0	100,0	100,0	100,0	100,0

The rule of technology nowadays is very important and need to be evaluated. Younger generations use internet more than elder generations in both people with and without disability. Between 18-44 the use of internet is high for both the categories 76% for people with disability and 78,5% of people without disability. It means that technology can be a tool for people with disability.

### 3.3 The inclusion though the sport of people with ID: the case of special Olympics.

Sport has always been an important aspect of education (Costa, 2017) and is a strong opportunity in order to educate young people (Mari, 2017).

When States didn't care about people with Intellectual disability Eunice Kennedy Shriver was a pioneer in the worldwide struggle for rights and acceptance of people with intellectual disabilities (Special Olympics).

Between 1950 and 1960s she starts to faith the discrimination and injustice faced by people with intellectual disability. Eunice had a sister with intellectual disability: Rosemary. Eunice playing sport with her sister Rosemary understand that through sport people with intellectual disability were considered more for their performance then for their impairment and more athletes than disabled.

Eunice started to promote sports for people with ID to unite people from all walks of life, she believed that: “if people with intellectual disabilities were given the same opportunities and experiences as everyone else, they could accomplish far more than anyone ever thought possible”. Eunice Kennedy vision became reality in 1962 by the organization of the “Camp Shiver” and in July 1968 with the first International Special Olympics Games held in Chicago. In 1986 United Nation promotes the international year “Special Olympics, Uniting the World” (Lucattini , 2017).

Meanwhile in Strasburg in 1987 In European Councils sports European Minister were reunited to debate on the European Chart of Sport for All. Sport in Europe become a tool for integration and a way to educate young generations. The European Sport Charter was approved by the minister council in 1992 in Rodi and in 1993 the United Nation General Assembly established the United Nation Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In June 1994, in Salamanca the representatives of 92 governments and 25 international organizations formed the World Conference on Special Needs Education, it was agreed a dynamic new Statement in order to achieve inclusion on the education of all disabled children, which called for inclusion to be the norm.

In 1995 for the first time in the Special Olympics game was launched the Host Town Healthy Athletes.

In 1996 Helios II European program became active entirely dedicated to the best practices to the disabled integration.

In 1998 Special Olympics created a group of 12 people with intellectual disability that became special Olympics ambassadors with the rule to promote the value of sport around the world. The most important step to promote the inclusive sport was done by the United Nation Convention on the Rights of People with Disability Art. Article 30 Participation in cultural life, recreation, leisure and sport:

“ [...] 5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

- (a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
- (b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
- (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- (e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.”



Moreover, in 2007 European Union promote Sport as a tool to educate societies by the white book. Stating that “Essential in a knowledge-based economy is the role of education and training, and policy towards youth and sport. Factors supporting growth and employment by encouraging the emergence of a highly qualified and adaptable population, they also strengthen social cohesion and active citizenship within the European Union (EU). Through education, training, youth and sport programs, the EU is developing and strengthening the European dimension, promoting mobility and encouraging international cooperation. The EU supports and complements Member States’ actions in accordance with Articles 165 and 166 of the Treaty on the Functioning of the European Union” (Eur Lex, 2007).

The most efficient work about inclusion of people with intellectual disability has be done by Special Olympics that became an example for policy maker. Special Olympics is today present in 174 countries, count today 4.7 million people with intellectual disability, 5,169,489 athletes, 103,540 competitions, 1,114,697 volunteers (Special Olympics ). The mission of S.O. is: “to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community” (Special Olympics ).

S.O. should be considered as an example for governments because of its capacity to provide services and programs focused on the ability rather than to play attention to impairments and for its organization.

**Figure 23** Special Olympics Strategy (Golisano and S.O., 2014)



S.O. represent one of the best examples of sensitization in health by the program Special Olympics Healthy Athletes. Since 1997 S.O. according with the 2014 report of special Olympics, Healthy Athletes programs delivered over 2 million free health screenings, 8,5 million people with ID has been treated by 170, trained Doctors, trained more than 260,000 health professionals and students to treat people with intellectual disabilities, 1 millions health exams provided, 1.5 million people with intellectual disability have been implemented in local health programs for a total of 11 millions of people with ID with improved access to health. These providers take these skills back to their practices and provide higher quality health care to people with ID – not just Special Olympics athletes – in their communities. The main areas of care assistance are: audiology, sports physical exam, vision, dentistry, emotional well-being, better health and well-being, physical therapy, podiatry (Special Olympics ).

S.O. meet the needs of intellectual disabilities providing services. In Italy the numbers of schools that promote inclusion by S.O. programs should be increased. Schools seems to be the best place where faith discrimination and promote inclusion (Lucattini P., 2017). Italy have to meet the needs of people with intellectual disability and on way is sport; the goal should be to facilitate the access to sport of people with intellectual disability. Inclusive sports and inclusion sports programs at school promote the value of teamwork and diversity and teach that anyone have the rights to have an applause (Lucattini, 2017).

### **3.4 Inclusion in education of people with ID.**

In 1994 at Salamanca, Spain, 92 governments of UNESCO declared that “every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning”, and the Salamanca Statement and Framework for Action on Special Needs Education was granted (United Nation Educational, Scientific and Cultural Organization (UNESCO), 1994).

Usually people with ID and in particular those with IQ scores were individuated at school, the intellectual and adaptive behavior are clear. In fact, school. When the activities became less intellectual after school bureaucracy do not routinely identify people because intellectual limitations, and needed services and supports are unavailable. This is the reason why most of the information about ID in Italy and not only in Italy came from school age. The needs support eligibility at school vary from country to country.

In comparison with all other disability groups and with “normal” students, pupils with ID spend most the time in separated classrooms away from their peers in general education (AAIDD, 2010).

What is extremely important is to recognize to the pupils with disability an individualized program measured on the student’s unique characteristics.

In the field of inclusion of pupils with ID at school a determinate rule is played by the support teacher and professionals in education. Support teachers should know that pupils with ID have diversities between each other’s but they also have commonalities in their learning characteristic: low IQ scores, difficulties in making academic achievement, mastering academic skills, social competence and communication skills such

as language development or listening and speaking vocabularies, short term memory, abstract thinking and general knowledge (AAIDD,2010).

In this sense is important that the support teachers develop an *ad personam* program with a clear definition of: what to teach, how and where. Namely decide what is important for the child with ID to learn, find strategies to teach to pupils with ID a try to teach specific field including the student with ID in the classroom.

To realize a good personalized empowerment process of the pupils there should be a strong coordination between school, community professionals, educational diagnosticians, school psychologists, school's teachers and family members.

The America Association on Intellectual and Developmental Disability suggests three key elements that form an efficient individualized support need at school: Universal Design for Learning (UDL), Instructional and Assistive Technology and Positive Behavior Supports. AAIDD (2010) states that: "ULD contributes to progress in the general education curriculum by ensuring that all students can access academic content information and can provide evidence of their learning through more than one means. It promotes flexibility in the presentation and representation of content information can be achieved by providing information in a variety of formats (audio or video, movies), or performance formats (plays, skits). The development of curricular materials in digital formats allows for the use of computers to provide multiple output formats [...]" (P.191). For AAIDD the instructional technologies should be used as educational materials for ID students in order to easily tech ideas and concepts. Moreover, AAIDD highlights the importance to have a positive behavior. "An ongoing concern for many teachers working with students with ID managing their classroom to create no disruptive learning environment for all students and to deal with challenging behavior problems exhibited by a few students. The field of positive behavior support reflects another area of intervention and treatment that has advanced from emphasizing the person with a disability as the problem to be fixed to recognizing that treatment and intervention must focus on the social and environmental context and fit between that context and the individual's limitations" (AAIDD, 2010, p. 102-193). Using positive behavior is a significant tool also against any kind of violence at school.

As stated by AAIDD (2010, p.200): "The goal is that students with ID will be members of genera education classrooms and participate both socially and instructionally alongside classmate."

Always remembering what Albert Einstein Sayed: "Everybody is a genius but if you judge a fish by its ability to climb a three. It will live its whole life believing that it is stupid."

### **3.3.2 Inclusion at school in Italy: policies and data.**

According to the Constitution of the Italian Republic:

“All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal and social conditions. It is the duty of the Republic to remove those obstacles of an economic or social nature which constrain the freedom and equality of citizens, thereby impeding the full development of the human person” (art. 3);

“The Republic guarantees the freedom of the arts and sciences, which may be freely taught.

The Republic lays down general rules for education and establishes state schools of all branches and grades [...]” (art. 33);

“Schools are open to everyone [...]” (art. 34)

The Constitution of the Italian Republic together with art 24 of the CRPD ensures education as universal right and therefore people with intellectual disability have the right to education. As seen in the previous paragraph the process of integration of student with disability at school started in 1971. During 50s children with "learning difficulties" and behavioral problems attended separated classes “special classes” and “special schools. Only by Law 118/71, compulsory education has taken place in regular classes, except in case of mental deficiencies or physical impairments, so severe to prevent learning or integration in common classes.” Procedures aimed to integrate people with disability at school were regulated by Law 517/1977 that established the figure of the special teachers.

Assistance, full integration and the adoption of prevention measures and functional recovery, ensures social, economic and legal protection were guarantee to people with disability and their family by Law 104/1992. Law 104/92 stated that any barrier, both sensorial and architectural should be removed and appropriate aids and tools to support pupils with disabilities in education and training were established to be introduced (Petrella, European Agency for Special Needs and Inclusive Education).

ISTAT states that today in Region of Molise and Calabria less than one school on 4 is effectively accessible and without barriers for disabled. The accessible school in Italy are 40% in Nord Italy, 32 % in the center regions and only 26% in South. Only 28,3% of primary and secondary schools in Italy have optical or acoustic signals (ISTAT, 2015), only 3,6% have relief maps and tactile paving. More common is the presence of technological tools 58,7% of primary schools and 56,6 % of secondary schools while the assistive technology and informatic positions fit for students with disability are less 39,3% in primary school and 36,6% in secondary school. Technology is an important tool for students with intellectual disability.

The Ministry of education in 2009 published “the guidelines for the integration of pupils with disability at school”. The main goal was to increase the schools support and the quality of educational interventions for pupils with physical, psychic and sensory impairment (Petrella, European Agency for Special Needs and Inclusive Education). .

Since 1977 with Law 517 separate classes were closed but were not provided measures for pupils attending these classes. Pupils with disability were transferred from special to normal classes without a pedagogic project. Finally, only few years ago Law 2010 stated that students with disability need new way of teaching, according to their personal of learning, not just special teachers. The final goal was to empower subject of disability, meet their needs and remove the barriers to make education truly accessible for all kind of disability even intellectual disability.

A right provision of education support starts from a correct diagnosis and classification of disability.

Owing to this certification the following documents are drawn up(Petrella, European Agency for Special Needs and Inclusive Education):

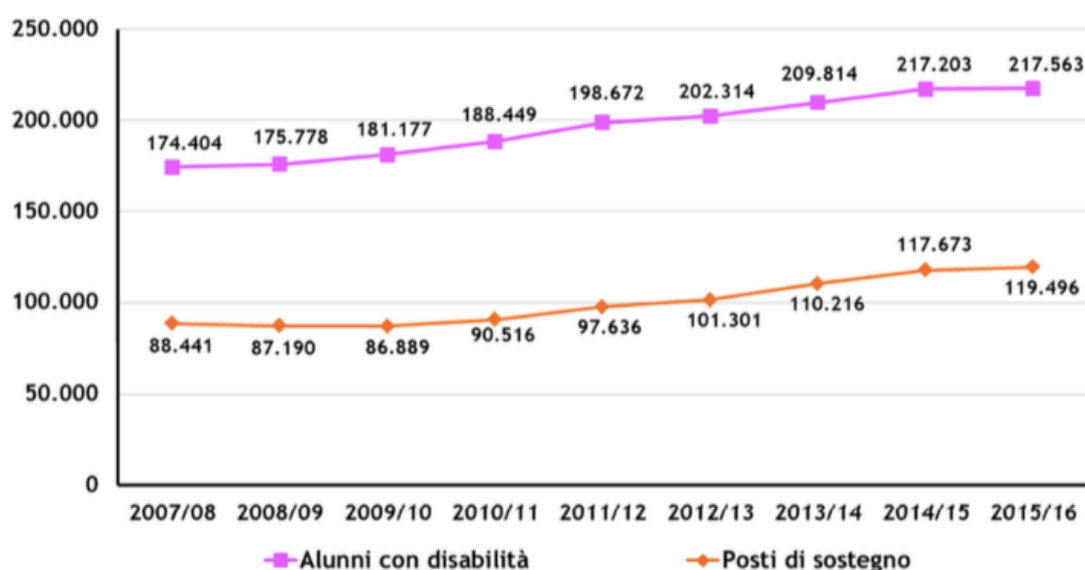
- the functional diagnosis;
- the dynamic-functional profile;
- the PEI (individualized educational plan).

Each class having pupils with disabilities has one or more support teachers *insegnante di sostegno*. Support teachers should be teachers specialized in SEN. Support teachers are determinant support in the process of inclusion of the pupils with disability, its figure became fundamental in case of intellectual disability. School teacher should participate in planning assessment, GDH and are fully part of the teachers’ team of the classes(Petrella, European Agency for Special Needs and Inclusive Education).

Unfortunately, in Italy the regulation about school teacher do not guarantee their deep preparation. Support teacher in Italy are today (ISTAT) 156.000 of which only 90.000 have a specialization in disability/ intellectual disability and SEN. Most of the other are teacher of other subjects that do not have a place to teach in their subject and as a consequence because there is a high necessity in Italy of support teacher they took this place. Other critical problem in schools support teacher change frequently and in the case of ID it is a problem. The support teacher is for the pupil with ID a reference point in all its scholastic activity. Moreover, is a reference point for parents of children with disability. If a support teacher changes frequently the empowerment work on the subject with disability can’t

be done. In order to perform ability people with disability need every day work and frequency. In Italy (ISTAT) 41% of disabled student change the support teachers every year. This is one of the cases that lead disability level increase because barriers are not removed even if international, European and national law state the contrary.

**Figure 24** Italian Historical Trend of support teachers (orange) and pupils with disability (purple) during the school years 2007-2008 to 2015-2016 (MIUR).



Looking at the chart is evident that the numbers of students having a disability is increasing: it was 174.404 in the school year 2007-2008 and raised up to 217.563 in the school year 2015-2016.

As a consequence, the number of support teachers increased from 88.441, school year 2007-2008 to 119.496 in 2015-2016. According to Law 244/2007 Support teacher in Italy should be one every two students with disability. The following table show the ISTAT research about the average of support teachers for each Italian region.

**Table 19** Means of students with disability per support teacher in Italian primary and secondary school

Regions of Italy	Primary school	Secondary school	Total
Piedmont	1,58	1,76	1,65
Aosta Valley	1,46	1,75	1,56
Lombardy	1,89	1,98	1,93

Bolzano	3,30	4,95	4,05
Trento	2,08	2,75	2,37
Veneto	1,74	1,92	1,82
Friuli-Venezia Giulia	1,50	1,90	1,64
Liguria	1,56	1,89	1,69
Emilia-Romagna	1,76	1,84	1,79
Tuscany	1,47	1,68	1,56
Umbria	1,62	1,43	1,53
Marche	1,61	1,71	1,65
Lazio	1,66	1,78	1,71
Abruzzo	1,69	1,75	1,72
Molise	1,16	1,27	1,21
Campania	1,52	1,50	1,51
Apulia	1,50	1,68	1,57
Basilicata	1,27	1,36	1,31
Calabria	1,25	1,43	1,32
Sicily	1,56	1,66	1,60
Sardinia	1,38	1,56	1,45
<b>Italy</b>	<b>1,64</b>	<b>1,77</b>	<b>1,69</b>

In some situations, we are still at risk of seeing pupils with disabilities dealing only with the support teacher instead of all the class.

There are three approaches internationally recognized in order to avoid that students with disability spend all the time at school out of the classroom and far from the classmates: ICF approach, In service teachers training, CTSs. The International Classification of Functioning, Disability and Health was created in 2001. “In order to capture the developmental processes and life circumstances of children and youth in a functional way it was further developed into a version for children and youth, the International Classification for Functioning, Disability and Health for Children and Youth (ICF-CY, WHO, 2007)” (Petrella, European Agency for Special Needs and Inclusive Education). In educational settings “children in need of special support” could be children with disabilities, but also other children who may have a temporary need of special support and children at risk for disability/disorders. The focus is on prevention and intervention, by recognizing both facilitating and hindering factors. In-service training for teachers and school masters. Because school is responsible for offering appropriate educational opportunities for every child. Regarding

this, it is obvious that teaching is a multidimensional profession that requires knowledge and skills in different areas and that teamwork is required. Law 128/2013 has introduced the principle of compulsory in-service training. Since SEN pupils are in charge of all the school staff, teachers and school managers of all school levels receive a specific in-service training for pupils with Special Educational Needs. Training activities focus on topics such as early risk identification, didactic measures to be adopted both with the pupil and with the class-group, assessment procedures and guidance.

Territorial Support Centers (CTSs) are 106 public mainstream schools. They are organized in a network across Italy. The core aim of CTSs is to develop a permanent net of schools at the local level, which is able to retrieve and disseminate the best practices of ICT for inclusion (Petrella, European Agency for Special Needs and Inclusive Education).

In the first two years of their activity, the CTSs have developed 260 training courses, involving more than 13.650 teachers and professionals. Moreover, they produced 26 educational software that can be easily downloaded from the MIUR website.

Now CTSs collect and disseminate best practices, supply schools with technological devices (hardware and software) and support them in purchasing and efficiently using them. They also activate initiatives to promote the correct use of ICT among teachers, school managers, parents and pupils themselves. Moreover, like tutors or supervisors, and through a peer to peer approach, teachers working in CTSs support concretely colleagues working in other schools in managing special needs in their classrooms (Petrella, European Agency for Special Needs and Inclusive Education).

Nevertheless, the development of Law in favor of school inclusion of people with disability during the last years (Disability National Observatory on the Condition of People with Disability, 2016) some interesting data from ISTAT and OND shows the effects of the Italian policies for the effective of people with disability at school.

**Table 20** Analysis based on age, sex, disability and qualifications ISTAT 2013 (values in %).

Qualifications /Degrees.	15-34 years		35-54 years		55-64years		Over 65		Total.	
	Without disability	With disability	Without disability	With disability	Without disability	With disability	Without disability	With disability	Without disability	With disability



Men										
No qualifications	0,4	1,3	0,8	2,4	0,9	2,0	4,7	9,8	1,3	5,8
Primary and secondary school diploma	48,2	50,6	49,1	55,6	58,5	63,7	69,2	72,2	53,1	64,8
Higher education	51,4	48,2	50,0	42,1	40,7	34,3	26,1	18,0	45,6	29,5
<b>Total</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>

Women										
No qualifications	0,5	0,9	1,0	1,7	1,4	2,6	10,7	18,4	2,5	11,5
Primary and secondary school diploma	40,6	40,8	43,6	51,1	60,7	69,5	72,6	72,6	49,8	65,9
Higher education	58,9	58,3	55,4	47,2	37,8	28,0	16,7	9,0	47,7	22,6
<b>Total</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>

Woman and Men										
No qualifications	0,4	1,1	0,9	2,0	1,1	2,3	7,9	15,1	1,9	9,0
Primary and secondary school diploma	44,5	45,8	46,3	53,2	59,6	66,7	71,0	72,5	51,5	65,4
Higher education	55,1	53,2	52,8	44,8	39,2	31,0	21,2	12,5	46,7	25,6
<b>Total</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>

The table clearly shows that there are many differences in terms of level of instruction among people with and without disability. There is a constant relationship between age and the increase of differences: as the people grow up as the level of differences in instruction raises between people with and without disability. In the age group 35-54 years people with disability having a primary or secondary school diploma are 53,2% while people without disability 46,3. The percentage of person without disability increase in the case of higher education 52,8% while for people with disability the percentage decrease to 44,8%. This data shown that the policies of the recent years decreased the inequality in primary and secondary school but the eldest group age are excluded. Moreover, equality policies are mostly applied in primary and secondary education while higher education

have a smaller number of people with disability ( Disability National Observatory on the Condition of People with Disability, 2016).

Moreover, the access to school for people with disability, and in particular for those with intellectual disability, should be improved by a free choice in the kind of studies and schools.

**Table 21** Statistical analysis of kind of attended high-school by students with and without disability during the period time 2007-2013 (ISTAT).

Kind of	Pupils in high-school		Pupils with disability		% of pupils with disability on the total high school pupils.
High-school	Absolute terms	%	Absolute terms	%	
2007					
Professional institute	557.612	20,43	24.163	59,25	4,3
Technical institute	938.200	34,38	8.523	20,90	0,9
Human sciences lyceum-pedagogy	217.757	7,98	2.420	5,93	1,1
Scientific lyceum	605.033	22,17	1.317	3,23	0,2
Classic lyceum	290.365	10,64	712	1,75	0,2
Linguistic lyceum	17.182	0,63	88	0,22	0,5
Artistic lyceum	102.816	3,77	3.560	8,73	3,5
Total	2.729.010	100,00	40.783	100,00	1,5
2013					
Professional institute	535.713	20,20	28.364	53,86	5,3
Technical institute	893.582	33,69	12.949	24,59	1,4
Human sciences lyceum-pedagogy	215.088	8,11	3.508	6,66	1,6
Scientific lyceum	609.351	22,97	2.271	4,31	0,4
Classic lyceum	281.139	10,60	1.302	2,47	0,5
Linguistic lyceum	16.144	0,61	109	0,21	0,7
Artistic lyceum	101.431	3,82	4.155	7,89	4,1

<b>Total</b>	2.652.448	100,00	52.658	100,00	2,0
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Looking at the table is possible to argue that people with disability in Italy have a restricted choice in term of kind of high-school to attend. Moreover, this trend seems to be confirmed from 2007 to 2013 (OND,2013). In 2007 students with disability used to choose professional institute in 45,9% of the total 21%, in 2013 the choice of pupils with disability of professional institute increased up to 53,8% and the total numbers of students decrease to 20,2%. The choice of technical institute done by students with disability increased too: in 2007 the percentage was 16,7% while in 2017 went up to 24,6% (OND,2013). On the contrary, the total numbers of pupils' attendant technical institute between the period time 2007 -2013 decreased from 35,7% down to 33,7%. The average of students with disability attending lyceum is law in both the period time analyzed. National Observatory for the condition of people with disability (2016) concluded that if in the higher education the equality was effective it was expected a low difference in the choice of high school while it is high. Probably the high choice of professional institute and technical seems to be more indicated for students with ID because they will not attend university after.

After many years of hard work in the field of integration the new challenge is inclusion at school. Pupils with disabilities or learning disorders were at risk of being in charge only of special/support teachers. There were still some obstacles in introducing personalization and individualization in learning. Starting from this school year 2013-14, each school has to draft an Annual Plan for Inclusion (PAI) as a base for the POF (Plan of the educational offer). The POF is the basic document describing the curricular, extra-curricular, educational and organizational resources that each school adopts according to its autonomy (Petrella, European Agency for Special Needs and Inclusive Education).

At the end of each school year, schools should monitor and evaluate the efficacy of their inclusiveness.

### **3.5 The right to work of people with intellectual disability and the efficiency of the Italian policies.**

The insurmountable Odds for people with ID and their family comes when they live school and face service discontinuity at best or a total lack of needed support. People with ID are less likely to have a job than “normal” people or people with physical disability. Moreover, people with IQ scores are more likely to be employed then those with ID and lower IQ scores. Unfortunately, in Italy there aren't Data on work inclusion of ID.

Art. 27 on work and employment of United Nation Convention on the Right for People with Disability states:

“1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

- a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
- b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favorable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
- c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
- d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
- e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
- f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
- g) Employ persons with disabilities in the public sector;
- h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
- i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
- j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.”

According to the Art.27 of UN CRPD there are no differences between disability for the right to work. But the reality tells something different. Italy does not have specific regulation for people with intellectual disability. The right to work of people with disability included those with intellectual disability are recognized by Law 68/99. The 68/99 Act state that all the enterprises with more than 15 employees have to assume proportionally to the total number of employees a specific number of workers with disability. The problem is that most of the Italian enterprise does not have more than ten employees.

**Table 22** Industry and services enterprises by size and sector of activity (ISTAT, 2015).

Year 2014

Sectors of activity	0-9 workers	10 workers and over	Total
<b>INDUSTRY (EXCLUDING CONSTRUCTION)</b>	<b>346,925</b>	<b>71,359</b>	<b>418,284</b>
Mining and quarrying	1,775	482	2,257
Manufacturing activities	328,486	67,936	396,422
Supply of electricity, gas, steam and conditioned air	9,916	543	10,459
Water supply; sewage systems, waste management and sanitation	6,748	2,398	9,146
<b>CONSTRUCTION</b>	<b>509,648</b>	<b>19,455</b>	<b>529,103</b>
<b>SERVICES</b>	<b>3,302,087</b>	<b>109,613</b>	<b>3,411,700</b>
Wholesale and retail trade; repair of motor vehicles and motorcycles	1,086,631	36,503	1,123,134
Transport and storage	113,241	12,447	125,688
Accommodation and restaurant services	292,996	19,017	312,013
Information and communication services	91,020	5,977	96,997
Financial and insurance activities	92,831	2,378	95,209
Real estate services	238,492	642	239,134
Professional, scientific and technical activities	698,154	7,741	705,895
Renting services, travel agencies, business support services	128,721	11,177	139,898
Education	27,351	1,737	29,088
Healthcare and social work	270,894	6,401	277,295
Arts, sports, entertainment and recreation and other activities	261,756	5,593	267,349
<b>TOTAL</b>	<b>4,158,660</b>	<b>200,427</b>	<b>4,359,087</b>

As the table shows in case of services, construction and industries are mostly composed by 0-9 workers. It is in contrast with the expected result on disability assumption of the 68/99 Act.

There are many incentives provided for the enterprises which behave conformal to the law: exempting the companies from social security taxes up to 100% and up to eight years proportionally to the disability of the workers to be employed; partially reimbursing the expenses for the adaptation of the work environment; financing activities aimed to support work placement of invalids (Di Liberto ,

2014). The 68/99 Act gives to the provinces the management of the job Center that have the rule to provide services and to facilitate the access to work of disabled by public employment services. In Italy there are 500-600 local job centers and 120 in the region of Sicily (Di Liberto , 2014). The main principle of 68/99 Act is to find for each disabled the right work position and support, in fact, Job Center should include individual job coaching, sheltered workshops and vocational training. Employers with more than 50 employees must meet a 7% disability employment quota:

- At least two disabled workers must be hired in workplaces with 36 to 50 employees;
- Workplaces of 15 to 35 employees must hire at least one disabled worker if they operate new intake.

Technical aids transport support personal work assistance disability pensions (allowing for part-time work) preferential access for job vacancies with public employer's flexible work arrangements employment quota system. As analyzed in chapter 2.

In Italy, the Italian National Statistical Institute (ISTAT,2013) states that there are 2,800.000 people with disability the 4,7% of the Italian population of this percentage there aren't clear information on how many people with intellectual disability lives in Italy. People with sensory disabilities have a higher employment level (16,3%) than people with other disabilities (Di Liberto , 2014).

The majority of people with disabilities is employed in tertiary sector with a percentage of 60,1% for people with a continuous limited autonomy, of 58,6% for the people with an irregular limited autonomy versus a percentage of 63,1% of people without disability (ISTAT,2013). In the Italian industries work the 30,3% of people with a continuous limited autonomy and the 34,8% of people with irregular limited autonomy against the 32,0% of people without any disability. While the percentages of the agricultural sector are respectively of 9,6 % and 6,5% compared to the 4,8% of people without disabilities. 61% of people with disabilities are very or quite satisfied with their job, while 47.7% are little or not at all satisfied.

It is up to the medical commission of the local Provincial Sanitary Agency to formulate a diagnosis order to determine the accommodation of disabled in a job. The idea is to fit as much as possible the work with the characteristic and impairments of the future worker with disability. this organization of work placement is referred to: civil disability up of 45%, working disability up of 33%, total blindness o with blindness a residual of no more than one tenth in both eyes with a correction, deafness at birth or before the speaking learning, war disability, civil disability of war and disability for service.

Most of disabled people with an intellectual disability work in social cooperatives to the cooperative enterprises which are divided in two categories in conformity with art. 1 of Law November 8 1991 n. 381:

Category A - finalized to the management of social-sanitary and educational services;

Category B - with the aim to give job opportunities to disabled persons.

Most type B social cooperatives have been established to provide temporary employment for disabled people and subsequently ensure they are hired by standard companies. However, although the main objective of such cooperatives is to find outside work for disabled people, they may also employ them permanently within their own co-operative or find jobs in other cooperatives when workers are unable to find other employment (Di Liberto , 2014).

ISTAT (2013) state that in Italy only 16% of disabled persons in working age has a proper job against the 54,6% of people with the same age but without disability.

This data underlines a dysfunction. In 2006 the European commission originate a procedure of infringement against Italy. Italy failed the implementation of Council directive 2000/78/CE of November 27th 2000, establishing a general framework for equal treatment in employment and occupation (Papisca, 2013). The Court of Justice condemned the Italian State with the sentence n. C 321/11 of July 4th 2013 because was not implemented the requirement for the employer to take appropriate measures to make the work accessible for people with disability. The measures adopted by Italy for the employment of people with disability. moreover, Italy didn't implement the art 5 of the directive 200/78/EC

Because even when assessed as a whole, do not require all employers to adopt effective and practical measures for all persons with disabilities, covering different aspects of work and enabling them to have access to, participate in, or advance in employment, and to undergo training (Papisca, 2013). Moreover, the word disabled include all the disabilities even the intellectual and usually Italy implemented the inclusion only of those disabled without intellectual disability. In Italy the percentage of those people with disability that don't work and are not looking for is extremely high: 250.000 of which 18% whit severe disability and 8% with less severe impairment.

**Table 23** Work position based on age between people with and without disability in Italy (on 100 persons) (ISTAT,2013).

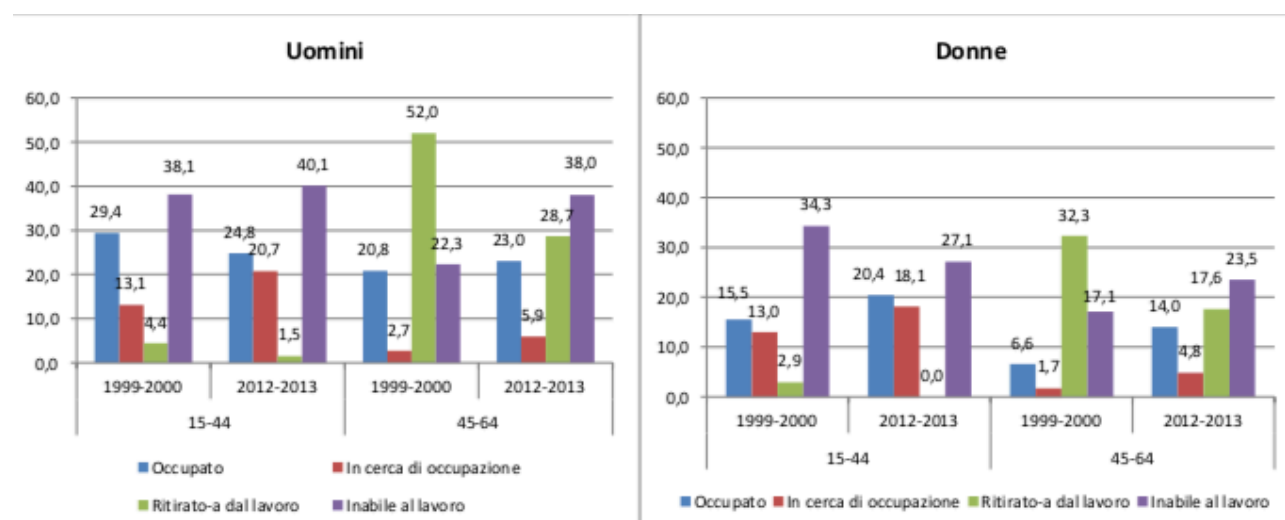
Status	Women and Men							
	15-44 years		45-64 years		Over 65		Total	
	Without disability	With disability	Without disability	With disability	Without disability	With disability	Without disability	With disability
Employed	54,6	22,7	58,7	18	3,2	0,2	45,2	3,7
Looking for a job	17	19,5	8,3	5,3	0,6	0,2	10,6	2,0
Housewife/homemaker	7,1	5,8	15,4	15,7	22,7	35,3	13,2	31,2

Retirement	0,3	0,8	14,2	22,5	72,1	59,7	20,0	51,7
Other conditions	20,7	17,2	2,7	8,7	0,8	0,3	10,5	2,3
Not able to work	0,4	34	0,7	29,9	0,6	4,3	0,5	9,1
Total	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0

In Italy is remarkable, looking at the table, that the numbers of people with disability not able to work corresponds to 9,1% versus the 0,5 of those without disability. Moreover, the majority of workers without disability are employed 45,2 against the 3,7% of those with disability while most of people with disability are housewife/homemaker 31,2% or retired 51,7%. Moreover, as said before the percentage of those people with disability that are looking for a job is dramatically low. Between 2000 and 2013 the numbers of employed with disability in working age increased from 22,3% to 22,7% and even more in the class age 45-64% from 12,6% to 18%.

**Figure 25** Group age 15-64 the percentage of work condition of people with disability between in the span of time 2000-2013 (ISTAT)

(Green =retired; Bleu=employed;Purple=not able to work;Red=looking for a job).



High in Italy is the number of people with disability that found obstacles to be employed where they want 47,7% against the 33,5% of those without disability. People with disability can't access to work because of barriers in 1,2% vs. 0,3% of those without disability.

**Table 24** The main barriers to work for people with and without disabilities (on 100 person) (ISTAT, 2013).

Obstacle	With disability	Without disability	Total
Obstacles to work where they want	47,7	33,5	34,3



Lack of work opportunity	2,1	18,2	17,2
No experiences	0,9	5,3	5,0
Too busy	0,7	5,0	4,7
Health problems	32,6	2,4	4,2
Loss of economic benefit	0,5	0,3	0,4
Barriers to access to work (how to go at work, lack of services)	1,2	0,3	0,3
Difficulty to have part-time job	0,2	0,6	0,5
Lack of self confidence	0,4	0,3	0,3
Other reasons	15,9	8,0	8,5

ISTAT states that many of the Italian

workers with disability can be assisted and can improve their work condition by technology.

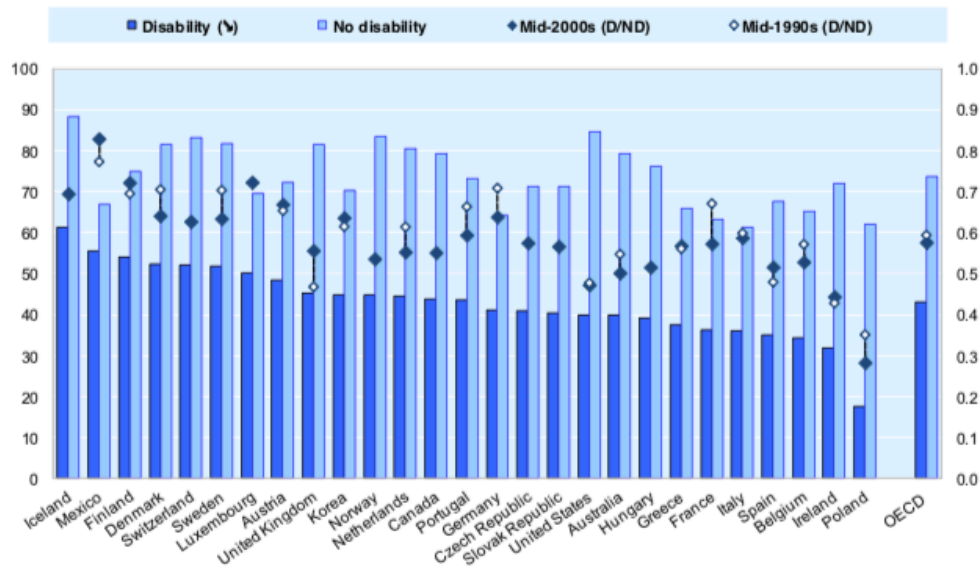
OECD (2009) during the forum of 14-15 May 2009 highlights the main challenges, still faces by OECD countries regarding the inclusion at work of people with disability:

- insufficient labour force participation among people with health problems or disability;
- low income of households with persons with health problems or disability;
- high cost of sickness and disability benefit schemes;
- widespread dependence on permanent disability benefits;
- structural shift towards beneficiaries with mental ill-health, including especially young adults.

Governments should be focused on the employment of people with disability and particularly of those with ID because having a job is a fundamental part of social inclusion. The employment rate in OECD (2009) countries is just above 40% which is just only over a half of the rate for people without disability, which stood at close to 75% in the mid-2000s (Figure 11).

**Figure 26** People with disability are far less likely to be employed all over the OECD.

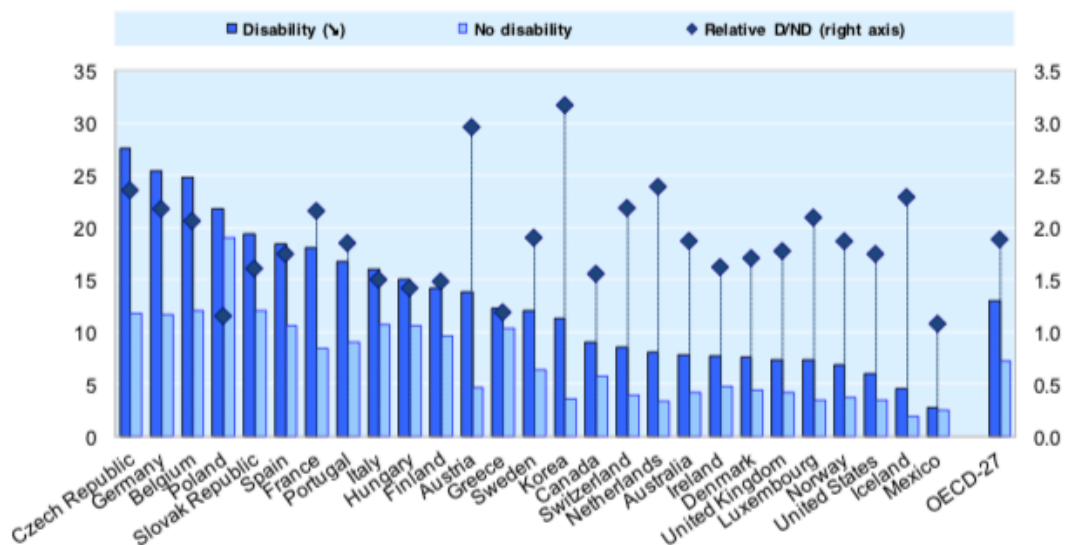
The employment rates by disability status in the mid-2000s (left axis) and trends in relative employment rates since the mid-1990s (people with disability over those without right axis)



OECD underline that the problem of OECD's countries is that higher employment rates of people with disability are not systematically associated with particular employment policies. Employment characteristics generally differ little by disability status. Moreover, even there were efforts to develop inclusion in the OECD countries the rate of employed with disability didn't increase enough (OECD,2009). In most OECD people with disability are more unemployed than those without disability even in good times.

**Figure 27** People with disability are twice as likely to be unemployed, even in good times (OECD, 2009)

Unemployment rates by disability status (left axis) and relative rates (people with disability over those without) in mid-2000s



Then how is it possible to improve condition of workers with ID?

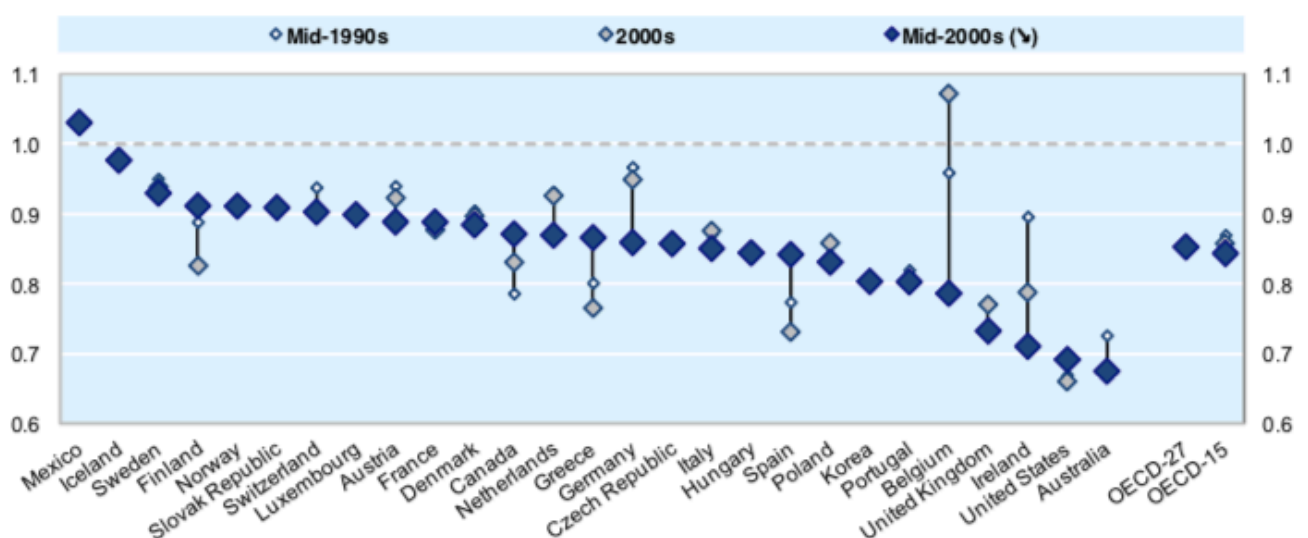
One of the best suggestions came from private enterprises initiatives such as the Geox Valemour project. Valemor project see the realization of Geox collection by Down syndrome workers. The project has involved about 40 people with intellectual disability.

Another best practice came from Barilla, which includes in the team work the Diversity Manager. The diversity Manager has the rule to implement and to promote diversity in the team work of the company. D.M. is responsible to develop and organize training and initiatives to create and foster an open and inclusive environment. Barilla achieved by the figure of Diversity manager great results. In 2014 was 65% the percentage of manager that promoted diversity with a prospective of increase up to 85% in 2020 (Barilla, 2018). Barilla through the diversity managers achieved a better social inclusion: 59% in 2014 with a prospective of 70% in 2020 and more gender balance that with the goal to achieve the 50% and 50% in 2020. The work of Employee resource group of Barilla should become an example to provide more inclusive policies at work, maybe by providing the figure of Diversity Manager also in public structures.

### 3.6 The Italian Budget.

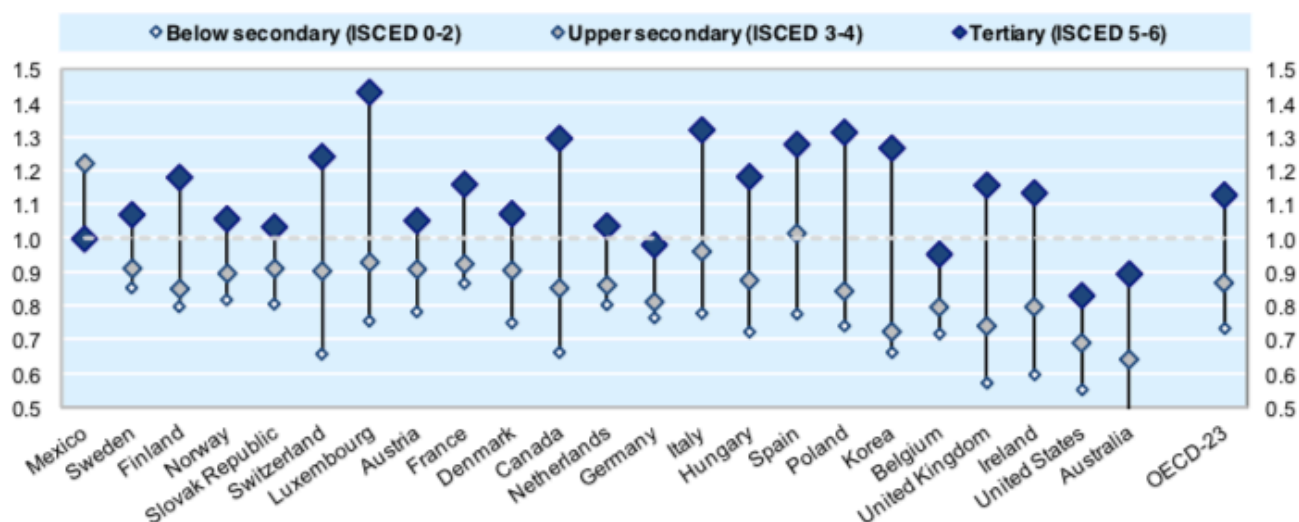
The OECD's survey of 2009 proved that people with health problems or disability have lesser financial resources (2009). In fact, income of people with disability is 12% lower than the national average and in some case 20-30%. As shown the OECD the statistical graph below.

**Figure 28** Trends in income of people with disability as a ratio of average income of the working age population (OECD, 2009).

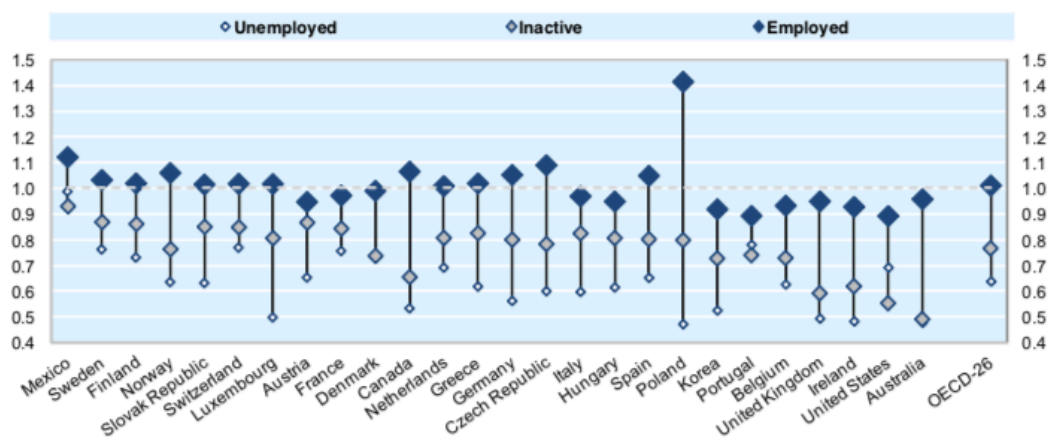


The income of people with disability is proportionate with the level of education in OECD countries included Italy as shown in the following statistical graph (Figure 14 and 15).

**Figure 29** Income levels of people with disability by educational attainment, as a ratio of average income of the working age population, mid-2000s (OECD,2009).

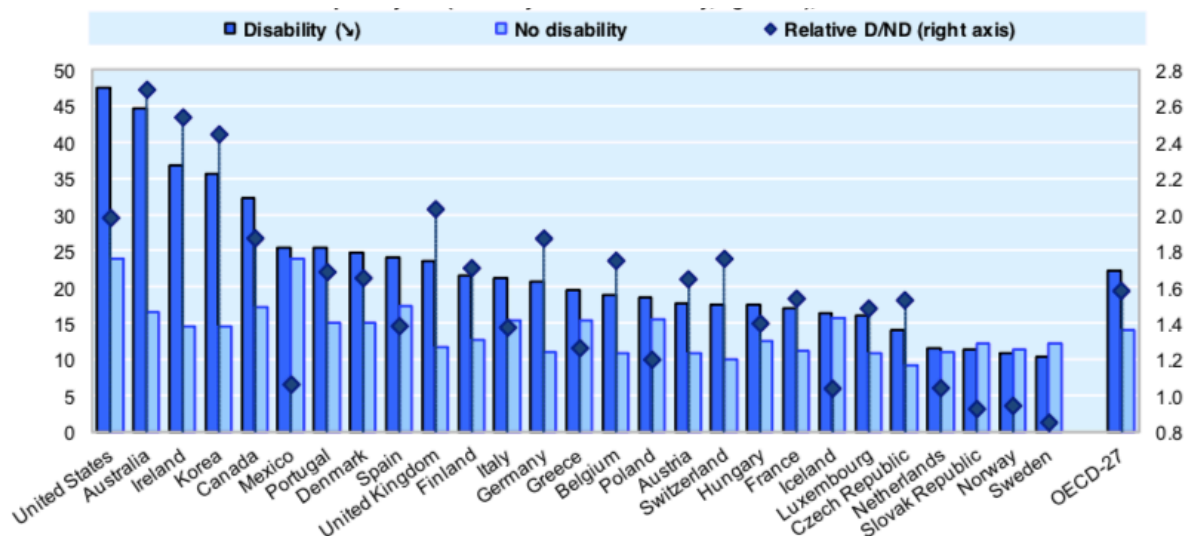


**Figure 30** Income levels of people with disability by labour forces status, as a ratio of average income of the working-age population, mid-2000s (OECD, 2009)



Then people with disability compared with the part of population without disability are more at risk of relative income poverty in most of country of OECD. The situation changes between OECD country. In Italy there are differences between north and the south. The figure below shows poverty rates by disability status in left axis and relative poverty risk in the right axis.

**Figure 31** People with disability are greater at risk of living in or near poverty in the mid-2000s (OECD,2009).



Now it is important to look at the recent years data referred to Italy. The ISTAT and Eusil survey of 2013 count in Italy 4 million 270 thousand families with a member disabled it means the 16,7% of the total Italian families with a presence higher in the south 18% and lower in north 16,2%. The families with at list a person with disability have a median income of 16.349 versus the 18.451 of families without a disabled in the family. According to ISTAT and Eusil the average income of the family that have a member with disability is higher in the north 17,866 than in the south 16.349. In both the case is lower than those family without disabled members 21.507 and 18.451. The median income is even lower in the island 13.876. The consequences are that the monthly expenses are a higher burden in south Italy and island the same regions where there is more weakness in administration and support needs provisions. In the south the family in difficulty are the 63%, the 72% in the island versus the 36% of the north-Est regions, 51% north-West, 47% center. The differences between religions are the same also for those family without a member with disability. The difficulty and the higher rate of poverty for families with a disabled depend on more than one factor, such as the fact that people with disability especially intellectual disability are not independent with salary and work and therefore remain at home. In 2013 the 72% of people with disability in the group age 6-44 lives at home (with parents). In the population with disability aged 45-64 the percentage of those that live with parents decrease. For people without disability the percentage are different 53% of people aged 6-44 live with their parents and only 3% of those aged 45-64. The living choices of people with disability depend on the family economic conditions and by the State's provision of services and economic transfers. This is even more accentuated in case of intellectual disability.

How much the Italian spend?

The Italian State spend a total of 1.694.995.506 for disability of which 888.109.227 are expended in services and 419.464.168 in economic transfers (ISTAT, 2012). The services delivered for integration at work and in school have a cost of 446.984.195 and have a number of users of 102.235 15% of disability population of the same age. In 2013 to the services delivered by municipalities were added 23 million to support services and guarantee the right of independent life.

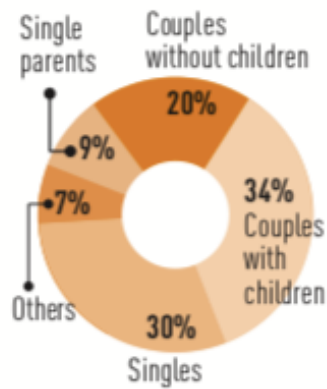
**Table 25** Italian budget for disability services, assistance and economic transfer in 2012 (ISTAT, 2013)

VOCI DI SPESA	Spesa	Utenti	Spesa media per utente
INTERVENTI E SERVIZI			
<b>Totale attività di servizio sociale professionale</b>	<b>54.415.239</b>	<b>213.389</b>	<b>255</b>
<b>Totale integrazione sociale</b>	<b>32.731.755</b>	<b>45.608</b>	<b>718</b>
<b>Totale interventi e servizi educativo-assistenziali e per l'inserimento lavorativo dei disabili</b>	<b>446.984.195</b>	<b>102.235</b>	<b>4.372</b>
Assistenza domiciliare socio-assistenziale	142.358.118	38.833	3.666
Assistenza domiciliare integrata con servizi sanitari	24.546.728	10.671	2.300
Servizi di prossimità (buon vicinato)	156.625	272	576
Telesoccorso e teleassistenza	549.136	2.311	238
Voucher, assegno di cura, buono socio-sanitario	44.754.024	22.468	1.992
Distribuzione pasti e/o lavanderia a domicilio	1.790.387	1.908	938
Altro	19.816.993	6.213	3.190
<b>Totale assistenza domiciliare</b>	<b>233.972.011</b>	<b>82.676</b>	<b>2.830</b>
<b>Totale servizi di supporto</b>	<b>120.006.027</b>	<b>58.457</b>	<b>2.053</b>
<b>Totale interventi e servizi</b>	<b>888.109.227</b>		
TRASFERIMENTI IN DENARO			
Buoni spesa o buoni pasto	565.468	1.635	346
Contributi per servizi alla persona	49.036.461	13.662	3.589
Contributi economici per cure o prestazioni sanitarie	17.879.869	10.271	1.741
Retta per centri diurni	84.702.798	13.430	6.307
Retta per altre prestazioni semi-residenziali	15.305.381	3.430	4.462
Retta per prestazioni residenziali	142.203.160	15.136	9.395
Contributi economici per servizio trasporto	16.126.938	24.412	661
Contributi economici erogati a titolo di prestito (prestiti d'onore)	92.446	46	2.010
Contributi economici per alloggio	2.048.694	1.976	1.037
Contributi economici per l'inserimento lavorativo	17.140.350	10.837	1.582
Contributi economici ad integrazione del reddito familiare	24.692.602	12.980	1.902
Contributi economici per affidamento familiare	12.201.269	3.310	3.686
Contributi generici ad associazioni sociali	14.482.654		
Altro	22.986.078	11.317	2.031
<b>Totale trasferimenti in denaro per il pagamento di interventi e servizi</b>	<b>419.464.168</b>		
STRUTTURE			
<b>Totale strutture a ciclo diurno o semi-residenziale</b>	<b>240.379.196</b>	<b>34.882</b>	<b>6.891</b>
<b>Totale strutture comunitarie e residenziali</b>	<b>147.042.915</b>	<b>13.994</b>	<b>10.508</b>
<b>Totale strutture</b>	<b>387.422.111</b>		
<b>Totale disabilità</b>	<b>1.694.995.506</b>		

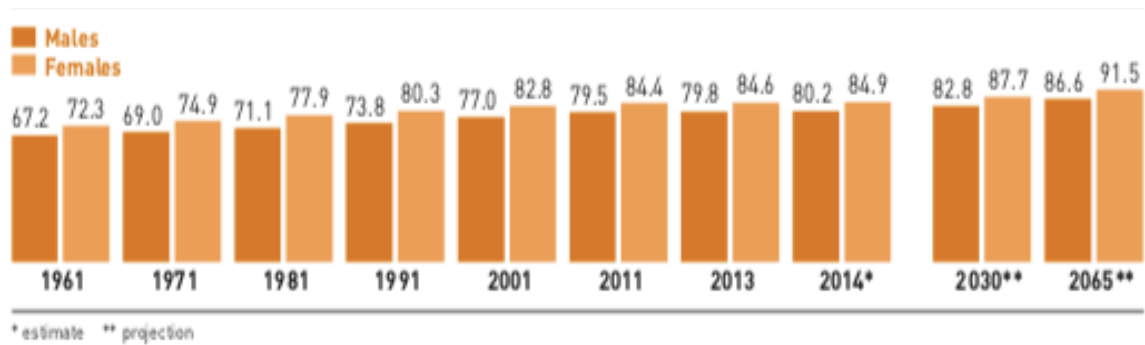
With a future prospective Italy should invest more and more in services and less in economic transfers.

The economic transfers risks to be inefficient because families are less stable and population is going to be elder.

**Figure 32** Main Household types 2013-2014 (ISTAT, 2015).



**Figure 33** Life expectancy at birth sex (1961-2065) (ISTAT, 2015).



Invest on services is what experts recommend and what people with ID and Disability in general need more to overcome the barriers in everyday life. Money transfers can be efficient only if together with the person with disability there is a family to manage the economic transfers. Because as proved by ISTAT families are going to be more stable and less young the Italian state have to invest its welfare on services. Service cost more to the state because in most of the case are delivered by human work resources.

### **3.6.1 Future budget prospects for Italy: assistive technology and universal design.**

Moreover, Italy should invest in assistive technology and universal design. One of the most helpful assistive support came from technology. The development of new technologies requires investments.

Why Italy should invest in Technology for improve life of people with ID?

In 2018 the Department of Information Engineering of the University of Florence presented during an international conference “All in for All” the positive effects that technology has on people with disability but also the input for the development of new technologies that came from disability needs (Mucchi L. & Martinelli A, 2018).

Technology enables people to overcome barriers and achieve results previously unattainable. Many of technologies invented for disabled, have become so usual to everyone that nobody consider where they come from, and how they could be used differently.

“Assistive technology refers to any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals”(Ecta).

There are many assistive technology tools that are present in everyday life of everyone in society but that allow people with disability to improve their lives.

Mucchi and Martinelli (2018) analyzed some of those assistive technology universally used:

- Kitchen Utensils: such as vegetable peelers, can openers, or graters with extra large handles. These large handles make the utensil easy and comfortable to hold, especially if you use them for long periods. It can also reduce cramping. Many people are preferring these utensils over the ones with smaller, "regular" handles.
- Pull-Down Kitchen Shelves where the entire shelf is able to easily be brought down, and stowed back in its place. These shelves are beginning to be used by people who are naturally too short to reach the shelves. It can also benefit children who won't be tempted to climb the bench to reach into the shelves.
- Automatic door openers: most larger stores and shopping malls now have automatic door openers. Not necessarily designed for wheelchair users, they do benefit people with mobility impairments, people carrying many bags, pushing prams, etc.
- Double-drawer dishwasher: In the space normally occupied by a single drawer dishwasher, they put two drawers, independent of each other. This is beneficial for many people:



Individuals who only have small loads of dishes, Individuals with impairments who have reaching issues, Individuals who for religious reasons wish to wash dishes used for meat, and those used for vegetables separately

- Crub Cuts and Ramps: were initially implemented to allow wheelchair users to get on or off the sidewalk. Now, parents pushing prams, or children on skates have an easier time with street corners as well
- Typewriter: it is necessary to thank blind people for inspiring the creation of the computer keyboard, or rather its forerunner: the typewriter. These include a blind Italian aristocrat from the 19th century.

The Italian countess Carolina Fantoni da Fivizzon was something of a muse for Pellegrino Turri, who invented an early version of the typewriter in 1808. She was blind and not able to write legible letters to her sighted friends. The prototype for the typewriter was designed by Turri to solve this problem for her.

- Teletext: In a pre-internet era, teletext offered an on-demand service that TV or radio did not provide at the time. It allowed the public a way of accessing the latest news, as journalists would publish it as soon as they received it. Launched in 1974, the world's first TV-based teletext system Ceefax was developed by BBC engineers exploring ways to provide subtitles for deaf television viewers. While doing so, they found it was possible to transmit full pages of text information in the "spare lines" transmitted on the analogue TV signal.
- Eyetracker: Paraplegics and quadriplegics are already operating computers and wheelchairs using eye trackers. One of the most famous is Prof. Hawking.

Now, the technology is being used more widely, for example alerting drowsy drivers, diagnosing brain trauma and in marketing, where it can help companies analyse how consumers react to their products and advertising

- Chatty Web everyday use products People whose sight is not strong enough to read internet pages currently rely on electronic reading equipment called screen readers. But while a sighted person can quickly scan a page to pick out key bits of information, a screen reader normally has to read out the page in its entirety. IBM developed software with a working title of Chatty Web was designed to allow blind people to scan web pages easily. It is designed to help users interrogate a page by asking questions to quickly identify only the most useful information. Mind reading headset Another project by IBM looks set to harness Electroencephalography (EEG), a technology currently used mainly in medicine for the benefit of people with disabilities. And soon it may be benefitting us all. A simple headset can pick up patterns from the signals in the brain and perform an action based on what it

reads. The software is being developed to send emails, but developers hope it could be enhanced to control a network of household appliances, offering people with conditions like locked-in syndrome more independence.

All this example are in this thesis listed just to understand the power held by technologies to achieve an inclusive society. In the era of digitalization and technological revolution became more and more important invest on technology.

Many expensive services for the state can be in the future optimised by the use of new technologies.

Even were the products were not directly created to assist disabled, but this demographic stands to benefit most from their development. “Technology designed for the convenience of people without disabilities can give people with disabilities unprecedented autonomy and restore the sense of dignity” (Mucchi L. & Martinelli A, 2018).

People do not see the necessity to invest in assistive technology just because there is the stereotype that is designed specifically to/for people with disabilities. As proved by the list of common tools up in this thesis assistive technology means invest on universal design. It is a new way to expand the symbiosis between technology used by/for people with disabilities and everyday products.

The universal design is part of a new inclusive way to organize society. The main point of universal design are (Mucchi L. & Martinelli A, 2018):

- Equitable Use: The design does not disadvantage or stigmatize any group of users.
- Flexibility in Use: The design accommodates a wide range of individual preferences and abilities.
- Simple, Intuitive Use: Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
- Perceptible Information: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
- Tolerance for Error: The design minimizes hazards and the adverse consequences of accidental or unintended actions.
- Low Physical Effort: The design can be used efficiently and comfortably, and with a minimum of fatigue.
- Size and Space for Approach and Use: Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility.

Many recent technological inventions can revolutionate society to allow people with disability and even more those with ID to be not only integrated but included.

“The first challenge is making the business case to technology companies. The tech market reached 3 trillion \$ in 2018, the assistive-tech market is a drop in the bucket compared to the overall demand for technology” (Mucchi L. & Martinelli A, 2018).

The cost of new technologies has an enormous cost. States might take this burden if investments in technologies can mean to optimise in other parts such as the provisions of services. But usually the government intervention is too short to make products available for disability.

Then, the solution might be to give incentives to companies. How can companies be compelled to make products that people with disabilities can easily use?

To overcome it, companies should embrace the principles of Universal Design that is, creating products and services everyone can use and that are, ideally, universally compatible.

### **3.7 The complex issue of ID and sexuality.**

“Sexual Health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled” (WHO, 2006).

Moreover art. 17 of United Nations Convention for the Rights of Disabled on protection of the integrity of the person states:

*“Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.”*

National governments often forget to guarantee the right to lead a sexually healthy and sexuality fulfilling life (Schaafsma, 2013). Sexuality is a part of human being for both non-disabled people, with disability and intellectual disability persons. For many years the sexual policies of disability have been a taboo. One of the first writers about sexuality and disability has been Shakespeare in the far 1966 opening a space for disabled people to talk about their sexual life (Shakespeare &

Richardson, 2018). Most of the time is easier to look at people with disability as asexual perpetual child but they are not; they grow up with their diversity but maintaining their human being.

One of the main problems for people with intellectual disability is a lack in appropriate sex education (Hetzeler, 2016) living this natural need in loneliness, poor option and in worst cases through forced sterilization or illegal way. The problem of disabled sexuality used to be not “how to do it” but “who to do it” (Shakespeare & Richardson, 2018).

In Germany, Switzerland, Netherlands and Denmark the rule of sexual assistant has been regulated by Law. Much of the literature on disability and sexuality focused the attention on the negative feature of sexuality and disability, abuse, consent and capacity whereas the analysis should turn on positive aspects of lived experience (Shakespeare & Richardson, 2018).

Maximiliano Ulivieri one of the Italian promoters for the regulation of sexual assistance in Italy, states that: “The assistance to sexuality of people with disability represent a concept that include simultaneously “respect” and “education” and could represent the maximum expression of “the right to health and psycho-physical and sexual welfare” for a civilized country.”

In Italy the last legislative tentative for the regulation of sexual assistance was done in 2014. The decree law aimed to implemented the human rights of the UN CRPD and to guarantee a sexually health and sexuality fulfilling.

In Italy there is not at the moment a law providing guidelines and protection for people with disability in terms of sexuality. Therefore, all the burden is in charge to the families.

Sexuality should be implemented by policy maker in regulation because is one of the most important aspects of human life. The sexuality of people with intellectual disability is a special case from medical, pedagogical, psychological and ethical point of view because people with intellectual disability don't form a homogenous group. As regards their psychological and sexual development is required a specialist: the sexual assistant.

This sort of operator, defined of “sexual welfare”, has therefore an adequate and qualifying preparation and will not focus exclusively on the “mechanic” process of sex. He/she will carefully promote sexual-affective education directing at best the energies trapped in the body of the disabled people (LoveGiver).

After many years of complete taboo, the sexuality of people with intellectual disability has recently become the topic of professional discussion and public debate. The normalization rule introduced into society made it necessary to understand and accept an intellectually disabled person as a sexual

person. Unfortunately, there is still a lack of knowledge on people with higher degree of intellectual disability (Remigiusz Kijak, 2013)

The Italian most important Association for promoting Sexual Assistance for People with Disabilities is: LOVEGIVER. “Founded in 2013 by a group of people headed by Max Ulivieri promotes the right to health and psychological and sexual well-being through educational projects for operators and welfare professionals, families of people with disabilities and disabled people themselves. In 2014 contributed to the creation of a bill (1442) laid before the Parliament; established the National Observatory on Sexual Assistance directed by Prof. Fabrizio QUATTRINI and published a book ‘Lovability’ Erickson editor. 2014 is the year in which it was launched and completed the selection of the first 30 Sexual Assistants, which will soon begin the first official Italian course. As a committee we struggle to Sexual Assistance profile is recognized as a profession and can operate without limits by the Italian laws” (LoveGiver).

In Italy the problem of disability and sexuality remains unsolved firstly because of cultural barriers.

## **Conclusions**

Cultural barrier is the most difficult obstacle for people with intellectual disability. In too many cases people with intellectual disability are invisible to the wider population. It still happens in many Italian society's sectors. This thesis challenges our society and policy makers to look at people with intellectual disability as equal, because they are. Asking equal rights for people with intellectual disability should not be considered charity. On the contrary it should be at the basis of welfare and social democracies. This thesis aims to open the eyes on a part of reality that if deeply analyzed would show many weaknesses and lacks.

Therefore, this thesis is a research work to critically analyze how life of people with intellectual disability can be improved in Italy and not a call for pity. Hubert Humphrey in one of his last speeches said that "the moral test of government is how government treats those who are in down of life, the children; those who are in twilight of life, the elderly; those who are in the shadows of life, the sick, the needy and the people with disability".

Is Italy ready for this moral test in terms of treating needs of people with ID? How can it change? Why public policies can be the change?

First, this thesis underline that the correct use of vocabulary in front of people with intellectual disability and in law drafting is synonym of respect. Terminology referred to disability has been often used to describe what is abnormal, outof "normality". Examples (Kanter A., 2011) such as "dumb luck," "lame idea," "falling on deaf ears," "blind rage," and "stand up for yourself" are significant for the images they present and are examples present in many world's languages, a "crazy" or "retarded" idea is a bad idea; "blind to the fact" means lacking knowledge or having no understanding; and someone who is "crazy" means someone who is out of control and not someone you would want to get to know (p.434). Languages, words, and actions can help people with intellectual disability to struggle in their daily battles. Words such as "retard", "crippled", "lame", "handicapped" must be replaced with "a person with a cognitive (or intellectual) disability".

After having analyzed all the most important models and approaches on disability, the social model results to be the best approach to include people with intellectual disability in society. Social model

of disability recognizes the impairment of a disabled and the consequent impact on everyday life adding that impairment aren't the only characteristics of disabled. Because ID is a statement that will not disappear during life time, it is society that should become more "able" and accessible. According to Social Model the level of disability is proportionate not with the severity of impairment but with the level of social and physical barriers. Therefore, the more Italy provides policies to remove barriers to develop accessibility for people with intellectual disability, the lower would be the level of disability and inequality. Disability does not deal with persons, but it is about how public policies organize community. As a consequence, public policy in Italy should become a model more socially oriented.

The thesis remarks a lack of Italians academic researchers and experts in the field of intellectual disability with a juridical, socio-political or economical background. Intellectual disability in Italy is mostly discussed by pedagogues or physicians. The consequence is a lack of experts of ID in the policy making process. Furthermore, the thesis evidences the lack of statistical data on the total number of people with ID with a significant underestimation of the people with ID needs. The reason why data on the thesis are not chronologically liner evidence a national and international problem in collecting data referred to ID population. The thesis evidence a substantial lack of information in particular, regarding intellectual disability. Detailed and depth information trend are at national and international level limited. Moreover, the thesis shows that most of the data are focused on the general condition of disability and not specifically on ID at national, European and international level. As expressed by W. Thompson (in AAIDD, 2010) "when you can measure what you are speaking about, and express it in numbers, you know something about it; when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meager and unsatisfactory kind." Without information about people with ID is hard to suggest efficient programs and projects. Then, Italy needs to have regulated tool to collect data on ID. At the moment the only official data about ID came from ISTAT and Italian National Observatory for the Condition of Disabled surveys on sanitary conditions or school. Most of the national and international data on ID are referred to school because school activities required IQ performance and usually people with ID have low IQ score.

The main evidenced problem to collect data on Intellectual Disability are:

1. Confused agreement to link the disability as described in art.2 of CRPD with the statistical information;
2. the statistical data at the base of administrative information's has been generated from different definitions of disability;
3. there isn't enough information to the large vision of rights of CRPD;

4. The concept of equality should be clearly defined in terms of practice to be included in statistical calculations.

Associations, Institutions, cooperatives, schools and hospitals should collaborate to collect data on ID. A network needs to be created. It is not possible that in Italy the percentage of people with ID seems to be lower than other country just because a lack in data tools and law regulations. Without information about population with intellectual disability it is also difficult to achieve a greater consideration by institutions and society at large. Survey to collect information about ID are expensive and require time. Moreover, collect data on disability and particularly in the specific case of ID takes time. It explains why the thesis has gone up and down in the reported and analyzed data and because change often sources. The thesis highlights the importance of giving the possibility to people with ID to access and participate in policy making process. How is it possible to individuate barriers if we don't perceive barriers? Basically, how can we find solutions if we don't face the problem. People with ID know what is best for them. They know what they need.

In December 2006 Prof. Paolo Lucattini, expert of inclusion through sport, made an inclusive experiment. During the All in for All event, he has organized some workshops tables on different issues: technology, inclusive society, how to manage free time etc. In every table different actors were included: people with ID, professors, professions, students, lawmakers, part of local administrations economist parents of child with ID. It was possible to find a range of interesting solutions looking at the Italian challenges from many prospective. The results were higher than expectations. One of the most interesting point that emerged was the reciprocity between people with impairments and technologies. People with disability gave input for the technological progress and technology helped disabled to overcome everyday life barriers.

States in order to overcome the limits of people with intellectual disability need to provide as much as possible supports need. Support needs can be more and where it is possible oriented to technologies.

As proved by a research done by the University of Florence in the department of Information Engineering (Mucchi L. & Martinelli A.) technology enables people to overcome barriers allowing something previously not possible. Assistive technology developed by, or for, people with disabilities become so usual to us that we rarely stop and consider where they come from, and how they could be used differently. Then, many assistive technologies tools moving into everyday use products such as: automatic door openers, double-drawer dishwasher, curbs and ramps, typewriter, teletext, eye tracker, chat web, mind reading headset, internet of things.



This thesis supports the importance for the Italian State to invest in assistive technology as in universal design. Invest in assistive technology means: invest to improve life primely of people with disabilities but also to facilitate those of people without disability. It becomes a question of, what do people with disabilities use the most everyday, and how it can benefit all users. The first challenge is making the business case to technology companies. The tech market reached 3 trillion \$ in 2018, the assistive-tech market is a drop in the bucket compared to the overall demand for technology. Short of government intervention, how can companies be compelled to make products that people with disabilities can easily use? (Mucchi L. & Martinelli A.).

People with disability are not only an input for technology but as the thesis evidence can be a huge contribute in social and political life. Italy too often underestimate the abilities of people with intellectual disability. A great example of the political and social contribution came from Sweden. Greta Thunberg is a sixteen years old Swedish climate activist with Asperger syndrome, OCD and selective mutism. She has an intellectual disability. She said about herself and her ID :“Basically I only speak when I think is necessary” (2018). Because of Asperger syndrome she is able to look black or withe. She believes that autistic syndrome of Asperger help her to deeply understand the importance of climate change crisis. She is not able to understand how world can carry on as before, knowing that the damage is dramatically increased. Maybe thanks to her disability, she made a climate revolution. The Friday for climate manifestation invented by Greta is now lead on by many students and associations around the world. She is participating in the most important conference for climate included those of United Nation. Greta is an icon in the world contributing actively in the social and political life despite her ID.

Economy in Italy needs to be re-defined and focused not only on profit but also on sustainability. One of the best Italian proposal to include all actors in society came from “I Distretti dell’Economia Civile” (Di Addezio, et al., 2018). It’s time to give importance to social sustainability including all part of society in the process even these with intellectual disability.

Italy should cope with the insurmountable Odds for people with ID and their family that comes when they leave school and face service discontinuity at best or a total lack of needed support. People with intellectual disability after school meet their higher barriers being usually totally in charge of families. The thesis underlines a severe lack of work opportunity for people with ID. Unfortunately, this consideration can’t be supported by data because there aren’t Italian statistics on the effective number of people with intellectual disability in Italy and no more on people with ID at work.

The Italian legislative approach has to leave the caritative approach and be less focused on the impairment of people with ID starting to provide way to give value of their abilities.

In the far 1960 Dr. Frank Hayden demonstrated that is the lack of opportunity given to people with intellectual disability to cause their impairment more than medical conditions. This thesis demonstrated that the approach used by policy maker for disability is too much focused on “how to assisted disabled and too less on how to enhance their ability”.

Regarding school one of the most important evidence of the thesis is a lack of inclusive activities and a worse management of support teachers. Regarding supports teachers the thesis underline three main problems:

- They change to many times in the scholastic career of the pupils with ID without providing continuity;
- They are not proportionate to the numbers of students with ID and their necessity to support;
- They are in many cases not qualified to be support teachers (in many cases they can't achieve a job for their subject and as consequence they became support teachers).

To conclude the thesis evidence six main priority for policymaker in Italy, to achieve EU 2020 disability strikes and to better implement the 2006 UN CRPD:

- Accelerate the process to approve Italian sign language or Italian visual language approved only by Senate in 2017 by Ddl. 302.
- work/school reform to provide training courses and prepare after high-school people with ID to became part of Italian workforce;
- Support Teacher monitoring and organization;
- Recognize the rule of sexual assistant as proposed by the decree law 2014 “*disposizioni in materia di sessualità per persone con disabilità*”;
- Invest in assistive technology and universal design;
- Invest in services more than economic transfers;

People with ID don't dare to be themselves because every day they face their impairment in society remembering that they are different. Public policies might increase the self-confidence by guarantee their equal rights. Moreover, being different have not to preclude the possibility to have an active role in society.

This thesis challenges to consider people with intellectual disabilities as integral and essential contributors to every sector of society.

This thesis wants to underline that Italian public policies should aim to achieve equity, giving to everyone the same access more than equality, giving everyone the same thing.

Marcelo Ducart (2018) says that inclusion is like a virus the hope is that the diligent and policy maker classes will be in Italy deeply infected by the contagious virus of inclusion.

The movement started in 1960s “Nothing about Us Without Us” expressing the conviction that people with disability have a voice that must be at the table of any planning process still have many results to collect and reasons to remain active. Anyone has the right to be considered for his abilities.

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## Executive Summary

This thesis is a research project to analyze public policies for people with intellectual disabilities. People with intellectual disability represent one of the largest marginalized and discriminated group of society. They are usually invisible to the wider population and to the institutions.

This thesis wants to provide the main guidelines to analyze the social group of people with ID with a specific analysis of the policies weaknesses that are still present in Italy. The aim is to consider a part of society often forgotten and his required needs. This thesis should be seen as a call for inclusion rather than for pity or charity.

Taking back the model of the disabled movement “Nothing about us without us”, this thesis to communicate the idea that no policy should be decided by representatives without considering all the social groups affected by the policy. People with Intellectual disability are affected by the policies in act and those there are not. Which is the meaning of social-model oriented policy?

This research project tried to critically analyze how life of people with intellectual disability can be improved in Italy, which are the needs and how public policies can be considered a way to improve their lives.

The thesis is divided in three main parts.

The first part is an historical *excursus* of the international theoretical approaches that have been used to study all the aspect of a person with disability.

By looking at all the most important models to approach disability the thesis remarks the importance of the passage between two main models:

- The Medical model: The Medical model namely looks at disability as an individual deficit or defect that can be remedied solely through medical intervention or expert's rehabilitation methods.

Olkin outlines the basic characteristics of the medical model of disability (1999):

“Disability is seen as a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and to the environment). Persons with disabilities are expected to avail themselves of the variety of services offered to them and to spend time in the role of patient or learner being helped by trained professionals”. (p. 26)

Terms such as ‘invalid’, ‘cripple’, ‘spastic’, ‘handicapped’ and ‘retarded’ are all derived from the medical model (Creamer, 2009). In the medical model the diagnosis assumes a central rule and the medical's professions became fundamental.

- The Social Model: examine social, political, cultural, and economic factors that help to determine personal and collective responses to difference. The Social Model do not link having a disability with being disabled. The disability can increase or decrease in relation of the social circumstances. For the social model disability is defined as: “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities [...] Disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people” (UPIAS, 1976).

The passage from the medical model to the social one was moved thanks to many disabled activists in the world between 60s and 70s. With the Social Model of disability as born network of researchers under the group name of Disabilities Studies. DS members had a shared goal: to questioning the medical model on disability. The academic group of DS is still nowadays characterized to be international and interdisciplinary. The aim of DS studies:

"... examines the policies and practices of all societies to understand the social, rather than the physical or psychological determinants of the experience of disability. Disability Studies has been developed to disentangle impairments from the myths, ideology and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social statuses and the assigned roles of people with disabilities are the inevitable outcomes of their condition." (School of Disability Studies, 1999)

The academic group of DS started the process of the inclusion of people with (any) disability in society. Moreover, since the social model start to be known the self-confidence of many disabled changed.

The second part of the third chapter analyzed all the weakness in the legislative way to approach disability. The thesis evidence the structural limits in juridical regulations of people with disability and the strict relation between the legislative framework and the models of disability.

The weaknesses in juridical field have been mainly influenced by the medical approach.

The medical approach resulted to be inefficient for the inclusion of people with disability in society.

This thesis evidence three main weaknesses in medical model of disability:

- First weak point is to look at the differences intrinsically;
- second weak point is related with the concept of the norm. Laws need to state what is into the norm and what differs from the norm;
- third weak point laws aim to assume just one perspective and this is utopic. Disability should be considered and observed without a particular perspective, because anyone has its own perspective and is impossible to unify all.

The thesis that it must not be confused the medical model with the medical judgment and diagnosis. The thesis underlines the importance to produce law in field of disability to emphasize the ability of a disabled person rather than diversity and impairments. In order to achieve a positive and proactive regulation it is necessary to be based on the Social Model of disability. Jurisdiction should become a tool to find ability in themselves and to perform the empowerment process.

The passage from medical to social model was decisive in the definition of disability.

The third part of the first chapter analyzed the international development of disability's definition.

Disability is wrongly defined as the contrary of ability or referred to indicate someone that is out of normality.

Is it better to say "disabled" or "handicapped"? What about "differently abled", "crippled" or "retarded"?

Terminology referred to disability has been often used to describe what is abnormal, out of "normality". Examples (Kanter A., 2011) such as "dumb luck," "lame idea," "falling on deaf ears," "blind rage," and "stand up for yourself" are significant for the images they present and are examples present in many world's languages, a "crazy" or "retarded" idea is a bad idea; "blind to the fact" means lacking knowledge or having no understanding; and someone who is "crazy" means someone who is out of control and not someone you would want to get to know (p.434). Those expressions are often present in everyday common language; it is time to change trend and to use a different vocabulary. Moreover, using disability as a metaphor not only offends certain individuals, but also creates an environment of unease and exclusion and impedes clear communications, perpetuating false beliefs about disability.

Terminology has been influenced from different models and changes as society come up with new solutions.

The interpretation of ID gives by AAIDD agrees with both the International Association for the Scientific Study (AAIDD) and with the recent World Health Organization International Classification of Functioning, Disability and Health.

According to the tenth revision of the WHO (World Health Organization):

“Intellectual disability (ID) is a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development and that contribute to the overall level of intelligence, such as cognitive, language, motor and socialization functions; in this anomaly, adaptation to the environment is always affected. For ID, scores for intellectual development levels must be determined based on all of the available information, including clinical signs, adaptive behavior in the cultural medium of the individual and psychometric findings”. Words such as “retard”, “crippled”, “lame”, “handicapped” have been replaced with “a person with a cognitive (or intellectual) disability”. A Person with disability is the right respectful name, in this matter the person came before the disability.

In this part it has been highlight a marginalization even in the definition of ID. ID still have a confused definition. The definition used in the thesis is the ones provided by AAIDD (2010): “ Intellectual Disability is a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior** (refers to how effectively individuals cope with everyday life demands, and how well they meet standards of personal independence expected of someone of that age and socioeconomic and cultural background), which covers a range of everyday social and practical skills, ID use to enter in the life of one person before the age of 18.” Intellectual disability is a category with an extraordinary wide range of different problems associated to different people.

The problem in definition is linked to a remarked lack of measures and statistical information.

The international process of definitions and codification codes refer to the condition of being disabled has been deeply analyzed. The thesis report the evolution of disability definitions and codification code of the World Health organization from 1980 with the first ICIDH to ICF of 2001.

In order to share and transmit information about disability communication codes are necessary.

The most important international classification systems came from two important organizations: The (WHO) World Health Organization that has elaborated the international classification of diseases (ICD) and the American Psychiatric Association that has elaborated the Diagnostic and Statistical Manual of Mental Disorder (DSM).

Define and classify disability is a critical dimension. Models of disability have been divided during the classification process of disability. The prevalent influence in the classification process came from the social model.

The classification of WHO had a statistical scope and was done at the end of 1800s. The International Classification of Disease (ICD) in origin was focalized on the illness classification, only since the eight-edition intellectual disability started to be present.

In 1980 in WHO in Geneva, after a team work directed by Dr. Philip Wood, has been published the first International Classification of Impairments, Disabilities and Handicaps (ICIDH).

The analysis of codification code identifies the complex conditions that might characterized a person with ID. It often happens that people with ID have overlapped disability. The codifications code helps to sum all the different features of disability in order to facilitate of collecting data and measurement. The first ICDH presents limits because the relations between the three components were not clear. The ICIDH has been revised for the first time in 1993, in 1999 has been released the second ICIDH and completed in years 2000. The New ICIDH-2 included innovations in the language and in conceptual terms

ICIDH-2 presents some limits. Firstly, it doesn't recognize the presence of social barriers in conceptualization of disability (Bickenbach , et al., 1999).

Three are the main areas where ICIDH revealed to be imitated: the approach seems to be based on medical model, the impairments seem to be the main causal element of disability, the representation of impairments as strictly linked to the specialist language (Barnes, 2006).

In 2001 the 54<sup>th</sup> World Health Assembly presented the final version as International Classification of Functioning Disability and Health (ICF). The ICF provides: conceptual basis for the definition and the measurement of disability, a standard language, a common classifications and codes. The ICF integrates the medical model with the social model in a multidimensional model defined as "bio-psycho-social synthesis". Moreover, Using ICF with ICD, International Classification of Diseases (ICD), makes it possible to provide a full picture of health and functioning. The ICF provides a neutral framework that can serve as a bridge between assessments focusing on health, development, curriculum and social dynamics.

Important in the ICF is the recognized role of the environmental factors, the definitions and categories in the ICF are worded in neutral language and the classification can be used to record both the positive and negative aspects of functioning (World Health Organisation, 2013).

The ICF links the quantitative studies for collecting data with the qualitative studies, descriptive data. The aim of ICF is not to decree who is "normal" and who is disabled, on the contrary is to avoid in any way a form of stigmatization, discrimination or labelling to achieve this result ICF providing clears ethical guidelines according to the UN Convention. ICF is inclusive because can be applied across the entire life span and is suitable for all age-groups, in different countries and cultures.

If records, research and statistics about functioning and disability are based on the ICF model and framework, they will more efficiently contribute to a coherent national and international

understanding of functioning and disability and data comparable across settings and time, clarify the relationship between data, information and knowledge, and to build a shared understanding and interpretation of concepts. The ICF provides advantages for population statistics, education, policy and programs and advocacy and empowerment.

The main critical aspects of ICF identified are: the regulatory criteria are still influenced by the medical model, the western culture is the referring culture in ICF and the excessive causative burden assigned to the impairment (Barnes, 2012). Moreover, ICF doesn't clarify officially if the proper term is disabled or person with disability. The international process to classify and define disability is still open.

“The quantity, quality and scope of population statistics on disability is complicated around the world and much more problematic is collecting data on intellectual disability. The majority of nations fail to monitor intellectual disability with any degree of rigor or depth” (Special Olympics, 2009).

The thesis evidences the lack of statistical data on the total number of people with ID with a significant underestimation of the people with ID needs. The reason why data on the thesis are not chronologically liner evidence a national and international problem in collecting data referred to ID population. The thesis evidence a substantial lack of information in particular, regarding intellectual disability. Detailed and depth information trend are at national and international level limited. Moreover, the thesis shows that most of the data are focused on the general condition of disability and not specifically on ID at national, European and international level. As expressed by W. Thompson (in AAIDD, 2010) “when you can measure what you are speaking about, and express it in numbers, you know something about it; when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meager and unsatisfactory kind.” Without information about people with ID is hard to suggest efficient programs and projects. Then, Italy needs to have regulated tool to collect data on ID. At the moment the only official data about ID came from ISTAT and Italian National Observatory for the Condition of Disabled surveys on sanitary conditions or school.

The importance of collecting data also came from the necessity to implement the SDGs and the UN CRPD statement.

The first chapter conclude with an overview of European and Italian data on population with ID. It has been highlighted a severe lack in both Eurostat and ISTAT official institutions for statistical measurement of data and information on ID. Most of the data provided by both the statistics



institution are referred generally to the condition of disability. Italy has not data on the total number of people with intellectual disability. It is very complex to measure intellectual disability because people with intellectual disability: used to have overlapped disability, data on ID are considered sensible and there are still problems with the definition of Intellectual Disability.

The report of OND has identified the problems to organize the statistical system to have clear equality's indicator of disability. The mains obstacles are:

5. Confused agreement to link the disability as described in art.2 of CRPD with the statistical information;
6. the statistical data at the base of administrative information's has been generated from different definitions of disability;
7. there isn't enough information to the large vision of rights of CRPD;
8. The concept of equality should be clearly defined in terms of practice to be included in statistical calculations.

Without reliable and adjoined data, divided in the right way between the different categories of intellectual disabilities the works of institutions, organisms and policy maker became more and more difficult. If the date doesn't correspond to reality the result in terms of policies won't be efficient to answer to the needs of people with intellectual disability.

The second part of the thesis is a legislative overview of the: international, European and national regulations dedicated to the right of people with disability.

At international level the evolution of rights for person with disability has been firstly cultural and then legislative. International Agreement on Human Right before 70s didn't mentioned persons with disability.

The first international Act dedicated to person with disability was the Declaration on the Rights of Disabled Persons adopted by United nations on 9 December 1975. People with disability sow for the first time concretely recognized the same rights as the others persons. The UN CRPD is part of an international process started in 1970. Until 70s and 80s the approach to disability was characterized by having charitable nature, person with disability were considered more "the rest of society" than part of society.

The most incisive and decisive step at international level, the first binding act, has been The United Nation Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (OP) approved on 13 December 2006. The UN CRPD is a profound change in disability policies and laws often neglected by national governments. In chapter two the thesis deeply analyzed most of the Article of UN CRPD and their implementation in the Italian Legislation.

Chapter two also analyzes The EU strategy for inclusion and European Disability strategy 2010-2020: a reward commitment to a barrier free Europe. The aim of the analysis is to highlight all the incentives and policies input coming from EU.

Particularly, the thesis revealed that the EU legislation regards rights for people with intellectual disability is most recent and that is important for Europe to share best practices and policies regarding inclusion between member states.

The legislative research of EU protection of people with disability show that the main tool in favor of disability are:

- The systematic action of EU in favor of disabled people began after the Treaty of Amsterdam on 2 October 1998;
- the Treaty of Nice, Charter of Fundamental Rights of the European Union on 7 December 2000 set up the guidelines for a new European Model of disability;
- the European action plan 2004-2010;
- the European Social Fund ESF;
- long-term EU budget 2021-2027;
- the European Social Fund Plus (ESF+);
- European Disability Strategy 2010-2020.

It has been analyzed in depth the Europe Disability strategy important namely for eight main areas of action still not equal in EU's Member State:

- 1) Accessibility: due to a "design for all", EU support national action to allow the access for people with disability on an equal basis with others, to the physical environment, transportation, information and communications technologies and systems (ICT);
- 2) Participation: EU support national action to achieve a full participation of people with disability in society by three main ways providing quality community-based services, including access to personal assistance, removing administrative and attitudinal barriers to full equal participation and enabling disabled people to enjoy the benefits of EU citizenship;
- 3) Equality: EU support in national action to eradicate discrimination grounds of disability in EU as required in Art.1,21 and 26 OF EU Charter, Art 10 and 19 of TFEU and by Directive 2000/78/EC for banning discrimination;
- 4) Employment: EU support national action to open market for person with disability even intellectual disability to enable those to earn by working;
- 5) Education and training: EU support national action to promote inclusive education for disabled with a particular focus on those with severe disability.

- 6) Social protection: EU Support national action to avoid poorness by social protection system and poverty reduction programs to guarantee decent living condition for people with disability.
- 7) Health: EU support national action to have an equal access to health services including routine medical treatments for people with disability and to promote preventive healthcare;
- 8) External Action

The second chapter give also, an overview of the Italian legislative development for people with intellectual disability.

The analysis of Italian legislation shows that Italy doesn't have constitutional articles specifically dedicated to person with intellectual disability. In Italian Constitution there aren't *ad hoc* mandatory rules on the protection of persons with disability and even less for those with intellectual disability. The hardest part to overcome in the Italians legislations seems to be the definition of intellectual disability and disability in itself.

Two main articles, Article 2 and 3 of the Italian constitution have been judges to be the most reelevates for the legislative development in the specific case of people with intellectual disability. Art 2 and 3 are referred to the full development of human person therefore are important for the process of inclusion and equality of those subjects considered vulnerable by society.

The main Italian regulation referred in general to disability and therefore to intellectual disability are:

- Act 118/ 71 that provides economic benefit for person with biological damage provided economic benefit for person with biological damage;
- Act n.104/92 composed by 44 articles considered as the referential Law, addressing disability in all the possible features and aspect of life;
- Legislative Decree n.469 of 1997 gives to the regions the duty for the job-placement organization for people with disability
- Act n. 517/1977 that established the figure of the special teachers. Law 244/2007 Support teacher in Italy should be one every two students with disability
- Act n. 68/99 for the integration of people with disability in the labour market.
- Law n. 6/2006 that introduce the *amministratore di sostegno*, a support (delivered by a person) that helps the disabled person when and where he/she needs;
- Law 128/2013 has introduced the principle of compulsory in-service training

The thesis evidence two main model that guided the development of disability's regulations:

- Welfare model , *norme di assistenza*;

- Norms to protect, *norme di tutela e protezione*.

The first part of chapter three analyzed the way to build a system of Support through public policies individually-oriented. The thesis aim to look at a process to produce policies able to provide the required needs for people with ID. This part looks at the AAIDD models to pass from the diagnosis of Intellectual disability to public policies design. The three fundamentals moments to build an efficient policy for people with ID are:

- Diagnosis: is part of ID definition and is the basis for collecting data about it.
- Classification: is the moment by which the special need support is established and allocated.
- Planning and developing systems of supports.

This technical part of the thesis examines all the found criteria to organize at the best a public policy that want achieve an improvement in life of person with ID.

Furthemore, the thesis wants underline the complexity of features that must be considered in filed of intellectual disability. The environment results to be a fundamental aspect to consider. Policies are at the moment dedicated generally to people with ID while in many cases people with intellectual disability need specific assessments.

Before to analyze in depth the Italian policies for people with ID the thesis considers which support need have to be evaluated in the policy making process.

In order to produce efficient public policies dedicated to people with intellectual disability, is significant to create a system of support needs based on personal needs. People differ and have something in common, and for people with disability is exactly the same. The main difference between a person with and without disability is that the first one needs supports to be an active member of the society. Thanks to supports needs the impairment is reduced and the social and physical barrier removed.

In the analysis of Support needs particular attention was given to the people with intellectual disability with higher IQ scores.

People with disability with high IQ scores is referred to scores comprised about 80% to 90% of all individuals diagnosed with ID. People with disability with high IQ scores is referred to scores comprised about 80% to 90% of all individuals diagnosed with ID.

Because in everyday life people with higher IQ scores do not have access to needed support they face critical obstacles to live a regular life. Those barriers need to be overcome firstly by the policy maker. This is why people with ID should play a role in the policy making process.

The thesis highlights the importance of giving the possibility to people with ID to access and participate in policy making process. How is it possible to individuate barriers if we don't percept

barriers? Basically, how can we find solutions if we don't face the problem. People with ID know what is best for them. They know what they need.

The evidence is the need of partnerships between government and relevant advocacy and professional groups are required to produce policies and adequate and individual-based systems of support needs.

in order to achieve the desired policy outcome in the field of Intellectual Disability is important to consider and discuss:

- 5) social factors that influence public policies and its adoption;
- 6) the core concepts guiding disability policy;
- 7) desired policy outcomes stemming from these core concepts;
- 8) a framework for implementing the 2010 definition of ID<sup>23</sup> and its classification to influence the desired public policies outcomes.

Outcomes data are fundamental element to have feedback and evaluate public policies. The evaluation of public policies in ID is determinant in order to develop society in an inclusive way.

Because ID is a statement that will not disappear during life time, it is society that should become more "able" and accessible. For this reason the third part of the thesis aim to analyze the process from the diagnosis to policy making and the main public policies for people with ID in Italy.

Inclusion means accepting anyone in society looking at the abilities and to the differences as a value. Inclusions means surely a change in prospective. The deficit and limits should be seen in society more than in the person. The inclusion process starts with a developing of welfare policies at international, European and national level in favor of disability. The inclusive revolution gets away the idea to make people with disability fit for society and instead aim to make society fit for person with disability. Inclusion means provide supports to make every part of society as fit as possible for people with disability and intellectual disability. Individuals with appropriate supports contrasted incorrect stereotypes that the individuals with disability, mostly intellectual disability, are less smart or never have abilities, friends, jobs, spouses or are active citizens.

In Italy the hardest challenge for inclusion was in Education and is in the employment

Italy should cope with the insurmountable Odds for people with ID and their family that comes when they leave school and face service discontinuity at best or a total lack of needed support. People with

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<sup>23</sup>AAIDD definition of ID 2010: "intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability origins before age of 18."

intellectual disability after school meet their higher barriers being usually totally in charge of families. The thesis underlines a severe lack of work opportunity for people with ID. Unfortunately, this consideration can't be supported by data because there aren't Italian statistics on the effective number of people with intellectual disability in Italy and no more on people with ID at work.

The Italian legislative approach has to leave the caritative approach and be less focused on the impairment of people with ID starting to provide way to give value of their abilities.

In the far 1960 Dr. Frank Hayden demonstrated that is the lack of opportunity given to people with intellectual disability to cause their impairment more than medical conditions. This thesis demonstrated that the approach used by policy maker for disability is too much focused on "how to assisted disabled and too less on how to enhance their ability".

Regarding school one of the most important evidence of the thesis is a lack of inclusive activities and a worse management of support teachers. Regarding supports teachers the thesis underline three main problems:

- They change to many times in the scholastic career of the pupils with ID without providing continuity;
- They are not proportionate to the numbers of students with ID and their necessity to support;
- They are in many cases not qualified to be support teachers (in many cases they can't achieve a job for their subject and as consequence they became support teachers).

To conclude the thesis evidence six main priority for policymaker in Italy, to achieve EU 2020 disability strikes and to better implement the 2006 UN CRPD:

- Accelerate the process to approve Italian sign language or Italian visual language approved only by Senate in 2017 by Ddl. 302.
- work/school reform to provide training courses and prepare after high-school people with ID to became part of Italian workforce;
- Support Teacher reform;
- Recognize the rule of sexual assistant as proposed by the decree law 2014 "*disposizioni in materia di sessualità per persone con disabilità*";
- Invest in assistive technology;
- Invest in services more than economic transfers;

People with ID don't dare to be themselves because every day they face their impairment in society remembering that they are different. Public policies might increase the self-confidence by guarantee

their equal rights. Moreover, being different have not to preclude the possibility to have an active role in society.

Sexuality is a part of human being for both non-disabled people, with disability and intellectual disability persons. For many years the sexual policies of disability have been a taboo and therefore is important to cope with this hidden and without regulation part of Italian reality.

This thesis challenges to consider people with intellectual disabilities as integral and essential contributors to every sector of society.

This thesis wants to underline that Italian public policies should aim to achieve equity, giving to everyone the same access more than equality, giving everyone the same thing.

One of the best examples in order to achieve the rights prospective came from the association Special Olympics. Special Olympics, by sport, acts in a way that can be easily considered as a model approach of intellectual disability. Special Olympics athlete Matthew Williams states: “Special Olympics teaches their athletes to be confident and proud of themselves and teach to the world that people with intellectual disability deserve respect and inclusion.”

This thesis supports the importance for the Italian State to invest in assistive technology as in universal design. Invest in assistive technology means: invest to improve life primely of people with disabilities but also to facilitate those of people without disability. It becomes a question of, what do people with disabilities use the most everyday, and how it can benefit all users. (Mucchi L. & Martinelli A.) Many recent technological inventions can revolutionate society to allow people with disability and even more thise with ID to be not only integrated but included.

This thesis support the movement started in 1960s “Nothing about Us Without Us” expressing the conviction that people with disability have a voice that must be at the table of any planning process still have many results to collect and reasons to remain active. Anyone has the right to be considered for his abilities.

This thesis wants to underline that Italian public policies should aim to achieve equity, giving to everyone the same access more than equality, giving everyone the same thing.

Public policie dedicated to intellectual disability should be socially oriented and universally designed.