The theoretical foundations of the Mind-Inclusion facilitation methodology

Intellectual Output 2

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Content

1. Introduction

This manual is part of the Mind-Inclusion 2.0 project (2018-1-IT02-KA204-048425), funded by the Erasmus + Program of the European Union whose main objective is to increase the level of social inclusion of people with intellectual disabilities in their community through the design and use of an innovative application called "Mind Inclusion APP". The main objective of the Mind Inclusion APP is to widen the opportunities of people with intellectual disabilities to be involved in the society and participate in activities of their community for which it can be a favourable and supportive tool.

In order to facilitate the work of educators working with people with intellectual disabilities in the field of social inclusion, the Mind Inclusion 2.0 project has developed two manuals, a Theoretical manual and a Facilitation manual, which can orientate and guide the use of the application developed for all those who want to use it in their community.

In particular, this document presents the theoretical foundations on which the Mind Inclusion APP has been rooted for its development in order to promote the social inclusion of people with intellectual disabilities in their community. These theoretical foundations strongly depart from the capability approach and other theoretical approaches that consider the environment as a key factor when it comes to social inclusion.

To this end, the following document is divided into four main sections. Section one presents the main theories and methodological principles that have guided the development of the Mind Inclusion APP and its associated Facilitation methodology which details how to use it. The third section briefly presents the design and development process of the Mind Inclusion APP, and finally, the last section highlights the main observations and conclusions.

2. Methodological Part

2.1. Theoretical foundations

The Mind Inclusion facilitation methodology intends to promote and to foster the social inclusion of people with intellectual disabilities in their community. To achieve this goal, this methodology has taken into consideration the real needs of people with intellectual disabilities to develop the Mind-Inclusion APP. This fact has been possible thanks to the participation of the people with intellectual disabilities in the whole process of co-design and co-productions by using participatory methodologies which have been cognitively adapted to participants requirements.

Therefore, the Mind-Inclusion facilitation methodology departs from participatory methodologies in order to identify real needs and search for solutions though a collaborative scheme involving end –users and other community agents and stakeholders.

In order to foster the social inclusion of people with intellectual disabilities, the theoretical bases of the Mind-Inclusion facilitation methodology are rooted in the interpretation of "disability" under the social model of disability, the Ecological theory and the capability approach and agency in which disability is a phenomenon that makes sense by considering the environment where people live. Therefore, this interpretation goes beyond individualistic perspectives in which the disability is an individual problem.

Table 1: Mind Inclusion's theoretical foundations

The Mind Inclusion's theoretical foundations
1.   Participatory methodologies
2.   The capability approach and agency
3.   The Ecological model
4.   The concept of disabilities

Source: Own elaboration

2.1.1. Participatory methodologies: design thinking, mindful design framework, agile method

A participatory approach has the main objective to empower people in order to transform social processes and promote shared reflection and collective resolution of problems (Amnistía Internacional, 2011). Therefore, there is a democratization of the process in which all the people affected by a particular challenge, in this case the inclusion of people with intellectual disabilities, work together in order to solve it. Mind-Inclusion methodology has been rooted in participatory methodologies for its design and production. The idea behind it is to provide a product, which in this particular case is an APP co-designed by final users with the aim to meet real needs.

During the co-creation process of the Mind-inclusion APP, end-users, including people with intellectual disabilities, their educators, families and further stakeholders were involved. In particular, the Mind inclusion methodology takes into account the participation of two groups: a) Primary users, people with intellectual disabilities, and b) Secondary and tertiary users such as educators, family members and other stakeholders.

During the co-creation process of the Mind-inclusion APP the following co-creation and participatory methodologies have been used:

- Design thinking (DT): it is a 5-steps method – Empathise, Define, Ideate, Prototype, Test – that helps a designing team to come up with practical,

meaningful and creative ideas that solve real issues for a particular group of people. This method consists of 5 steps:

- o Empathise: learn about the audience (observe, ask and listen, develop empathy)
- o Define: construct a point of view based on user needs and insights
- o Ideate: brainstorm and come up with creative solutions
- o Prototype: build a representation of one or more of the ideas to show
- o Test: return to the original user group for testing the ideas for feedback. It takes into consideration the needs and the perspective of the person / patient in the beginning of a design.

- Mindful design framework[1]: the mindful design framework focuses on how design can influence the quality and nature of social interaction, with mindfulness being used as a key mechanism for designing behaviour change, especially in social contexts (Almeida et al., 2017; Niedderer et al., 2017). Through this method we try to develop projects based on people's values and their life contexts. The interdisciplinary method of co-design developed and applied in the MinD projects contains distinct research tools:

- o Initial data collection;
- o Idea generation taking into account mindful values and scenarios identification;
- o Task analysis with the purpose of interrogating potential design openings, to understand the various opportunities, challenges, and potential mindful strategies and solutions;
- o Mindful co-design (symposiums; MinD workshops with PPI groups; MinD design workshops).

- Agile method: Adopted to offer a lightweight support structure. The use of iterative planning and feedback results in teams that can continuously

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[1] For more information, see: https://designingfordementia.eu/resources/publications

align a delivered product that reflects the desired needs of a client. Through it the software can be developed by small teams or in small progressive development cycles, improving the design with feedback and changes. Its most important features:

- o Focused on people
- o Encourages collaboration rather than control
- o Informal communication
- o Reduce risks related with non-acceptance or lack of utility

2.1.2. Capability approach and agency

Under the *capability approach* (Nussbaum 1997; Sen 1993), the Mind Inclusion 2.0 project aims to widen the opportunities of people with intellectual disabilities to be involved in the society. Capability as originally defined by Amartya Sen is "the substantial freedom to obtain alternative combinations of functioning". The capabilities of a person are meant as their freedoms, intended as opportunities to promote and reach the beings and doing dimensions he/she evaluates positively (Biggeri and Bellanca, 2010). In social work this approach translates into the design of actions and experimental models of educational and supports paths external to day care centres and with a view projected to the self-determination [and hence independent living] during their life (DGR 739/2015 Veneto region).

Specifically, the capability approach is an important and emergent theoretical framework strongly correlated to the concepts of human development approach and development of freedom. It involves two factors: first, the freedom to achieve the "beings" – the dimensions of being - and second, that freedom to achieve the "doings" – the dimensions of doing - that a person values (Sen, 1985). The capability approach is generally conceived as a flexible and multi-purpose framework, rather than a precise theory of well-being (Robeyns, 2016). Sen and Nussbaum studied this approach in depth: Sen called capability as human ability to use social networks and relationships (social capital) focusing on the relation

humanity-world and person-context. Social context is a factor that determines the capability, and relationships are strongly significant. Nussbaum (2001) focused also on capabilities like individual abilities that a person wants to self-realize such as memory, identity, awareness, with more attention on the unicity of every single individual. Therefore, capability approach considers both individual components, social context and resources through an ecological approach (Morris, 2009; Pastena 2009). Deeping this approach, there are three key terms:

1. *Functionings* that indicate what person manages to do or to be, more directly related to living conditions and environment. They include activities and states that make up people's well-being in which some may be very basic (being nourished, literate, clothed) and others might be quite complex (being able to play a virtuoso drum solo, being able to eat caviar). Some may be focused on survival, work and material well-being, and others focused on relationships, empowerment, and self-expression (Trani et al., 2011; Welch Saleeby, 2007).

2. *Capabilities,* individual's potential to achieve certain functionings or the various combinations of what a person can do or be: they are the real actual possibilities open to a person. The notion of capability is closely related to freedom: Sen, in fact, defines freedom as 'the real opportunity that we have to accomplish what we value'. Freedom, he argues, has two aspects: the opportunity for the ability of a person to use the ability to achieve those things that she/he has reason to value; and the process aspect for the freedom involved in the process itself. The notion of capability refers to the opportunity aspect of freedom (Alkire, Deneulin, 2009; Trani et al., 2011; Welch Saleeby, 2007).

3. *Human agency*, related to people-centered approach, which puts human agency (rather than organizations) at the centre of the stage (Drèze, Sen 2002). It underlines the central role of people to be agents of their own lives, being active subjects, deciding what kind of development they want, defining their local priorities and realizing their goals. Agency refers to the personal process aspect of freedom and well-being: in order to be agents of their own lives, people need freedom and possibility to choose from several opportunities (Sen, 2012).

Furthermore, agency is related to self-determination and it is possible to refer to team-agency in which collective well-being is prosecuted (Pelligra, 2007). Clearly, the opposite of a person/group with agency is someone who is forced, oppressed, or passive (Alkire, Deneulin, 2009; Trani et al., 2011). At the end, the question is: What the community can do for a person with a disability? What can the person with disability do for the community? (Colleoni, 2014). Referring to these questions, it has been considered the difference between strong agency and weak agency: *strong agency*, in fact, is the individual responsibility and *weak agency* that refers only to personal capability.

2.1.3. Ecological Model

The Mind-Inclusion facilitation methodology is also rooted in the Ecological theory of Bronfenbrenner, giving strong importance to the environment when it comes to the social inclusion of people with disabilities. Considering this theory, not only one variable can cause a problem but several ones. Under a systemic approach, causal relationships are understood in terms of circular relationships, rather than in terms of linear relationships.

The Bronfenbrenner's theory considers that the development of a person takes place in the context where there is an exchange of relationships between the closest environment (family) and the not so close environments such as school and community.

In particular, this model considers the relationships between several systems, each one included in the previous one, such as the microsystem, mesosystem, exosystem and the macrosystem. Therefore, this model includes the following systems: microsystems as the most internal system where a person develops diary actions and interaction (i.e. Family); mesosystems, defined as the bidirectional relationships between two or more microsystems in which the person participates, such as the family and school; exosystem, defined by the Ecological Theory as systems in which the person does not actively participate but in which things that happen might affect the person; finally, the macrosystem is a system

that includes the microsystem, mesosystem and exosystem as well as cultural aspects such as religion, and political and social organization.

According to Cifre and Esteban (2012) the Bronfenbrenner's model highlights the importance of the community as a key factor that can affect the well-being and quality of life of people. Therefore, interventions which include the community are an opportunity for the inclusion since they intend to encourage social participation with the aim to share ideas, empower people and make the most of the community resources (Fernandez-García and Egido-Díaz, 2014; Alvarado, Moreno, and Rodríguez, 2009).

2.1.4. Concept of disability

There is little research that considered the application of the capability approach to disability and health research (Morris, 2009).

On the other hand, two important definitions of disability have been claimed:

- ICF (International Classification of Functioning, Disability and Health, 2001) considers disability as an umbrella term for impairments (the loss or abnormality of bodily function and structure), activity limitations (difficulties individuals may have in executing activities), and participation restrictions (problems that individuals may experience in involvement in life situations).

- ONU (UN Convention on the Rights of Persons with Disabilities, 2006) considers disability a concept in constant evolution. Disability is defined as a result of interaction between people with impairments, environmental and behavioural barriers which prevent effective social participation within a community.

Generally speaking, when studying the field of disability, the bio-psycho-social model is considered. This model claims a holistic approach putting emphasis not only on biological factors among which impairments, disease, illness, but also on relevance of environment and social context. It goes beyond the traditional

medical and assistance model that concentrates primarily on the biological factors and functioning of the individual via various functional assessments and outcome measures (Welch Saleeby, 2007).

However, this model does not consider what is important for individuals with intellectual disabilities, their individual characteristics and their capabilities. For this reason, it is relevant to start to consider the capability approach in intellectual disabilities that evaluates the active role of the people with disability to reach their goals through opportunities to choose and to self-determinate. This permits to include the point of view of the person, considering his/her well-being (Sen, 2012; Trani et al., 2011).

2.2. Methodological principles

The Mind- Inclusion facilitation methodology is based on several methodological principles which guide the application and the transfer of this methodology to other contexts. In particular, the methodological principles leading the application of this methodology are shown in Table 2.

Table 2: Mind-Inclusion methodological principles

1.	Inclusive environment and community
2.	The role of environment and community
3.	Cognitive accessibility
4.	Role of educator
5.	Capability approach and agency
6.	Disability
7.	Self determination

Source: Own elaboration

2.2.1. Inclusive environment and community

Increasing international attention devoted to inclusion is a consequence of globalization, liberalization, and democratization. The concept of *social inclusion* has been evaluated as a multidimensional, complex and dynamic construct, without a clear definition yet. In fact, there are many similar terms

widely used such as integration, community participation, community belonging, social network and social capital, with a lack of consensus in literature. Social integration and social inclusion should, however, contribute to making societies more cohesive (Amado et al., 2013; Louw et al., 2019; Martin et al., 2011; Neely-Barnes et al., 2016; Simplican et al., 2015; Van Asselt et al., 2015; Wilson et al., 2016).

Considering the 2030 Agenda for Sustainable Development, social inclusion is the principle according to every person should reap the benefits of prosperity and enjoy minimum standards of well-being. This is also captured in the 17 Sustainable Development Goals that are aimed at freeing all nations and people and all segments of society from poverty and hunger and to ensure, among other things, healthy lives and access to education, modern energy and information. In this case, social inclusion is defined as the process of improving the terms of participation in society for people who are disadvantaged through enhanced opportunities, capabilities to fulfil normatively prescribed social roles, social bonds, access to resources, respect for rights and solidarity. Social inclusion may refer to a process encouraging social interaction between people with different socially relevant attributes to participation in all spheres of social life (Silver, 2015).

Consequently, understanding and promoting social inclusion faces various challenges (EU-CoE youth partnership policy sheet):

- The process has many stages forming a continuum from total isolation to active inclusion.
- Social inclusion affects various life domains: economic, political, cultural, social. The integrating processes do not act independently of one another.
- A complex array of factors such as gender, health, ethnicity, religious affiliation, and sexual orientation acts to enable or constrain social integration.

Focusing on social inclusion and people with *intellectual disabilities* (ID), under the 2030 Agenda for Sustainable Development, persons with disabilities are recognized as a vulnerable group and a commitment is made to enhance the capacity-building support ex-tended to developing countries by 2030. Generally,

the results have demonstrated that they still have relatively small social networks. Specifically, the only contact with people without ID tends to be family and paid professionals (Bigby et al., 2011; Simplican et al., 2015; Van Asselt-Goverts et al., 2013; Wilton et al., 2017).

In the last years, the phenomenon of social inclusion and ID have been studied through the social ecological approach, which defines the concept of social inclusion as a series of complex interactions within a dynamic dimension such as:

- Socio-political factors: laws and rights
- Economic and sanitary factors
- Environmental factors: size and geography
- Personal/individual characteristics: self-esteem and loneliness
- Interpersonal factors: relationships with others, level of trust and respect, support, social networks
- Social roles and community recognition

Therefore, social inclusion is a continue interaction between the person with ID, the environment and interpersonal relationships; it is not just physically inclusion but it becomes a more complicated concept (Amado et al., 2013; Malaguti, 2019; Martin et al., 2011; Overmars-Marx et al., 2018; Van Asselt-Goverts et al., 2013). For this reason, social inclusion includes two main characteristics, which they are possible to define as:

- *Structural characteristics:* being socially included and active in the community through the size of the own network and frequency of interactions with network members (the degree of inclusion).
- *Functional characteristics:* feeling socially included and participate in the community through being part of a network of relationships that includes people with and without intellectual disability - finding emotional support and having a sense of belonging (Amado et al., 2013; Bigby et al., 2011; Bigby et al., 2015; Merrells et al., 2017; Van Asselt-Goverts et al., 2013; Wilson et al., 2016).

In conclusion, an *inclusive community* involves urban life where there are interpersonal relationships not only with paid staff, family and disabled people, but with strangers in public spaces such as consumers, local shops and

shopkeepers. This aspect recognizes the importance of public and consumption spaces, which could help for a totally inclusive society where everyone has a social role and identity in the community. The space and location do not have to be barriers; on the contrary, they have to help:

- to feel autonomous
- to be familiar with environment
- to enhance relations with relatives and friends but also with unknown people as staff's stores
- to enhance quality of life and well-being

Therefore, spaces and environment are part of social inclusion, and this is also important for public places to learn how to relation to disabled people without discrimination them (Bigby et al., 2011; Malaguti, 2019; Overmars-Marx et al., 2018; Šiška et al., 2018; Van Asselt et al., 2015; Wilton et al., 2017).

2.2.2. Cognitive accessibility

Regarding the cognitive accessibility, there is no accepted single explanation and it is common to use the term without a clear one. Actually, International Organization for Standardization (ISO) has promoted a definition that claims: "Extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of characteristics and capabilities to achieve a specified goal in a specified context of use" (Johansson, 2016).

Furthermore, the UN Convention on the Rights of Persons with Disabilities in 2006 established articles to eliminate obstacles and barriers to accessibility, with the aim at including people with ID in the society. Specifically, having intellectual disabilities is often connected with risks of exclusion and alienation. For this reason, digitalization and cognitive accessibility could help them to social inclusion, social participation and autonomy. Technology works to permit access for all to leisure and social activities (Arab, 2016; Johansson et al., 2011; Johansson, 2016).

Specifically, cognitive accessibility does not include only technology but also environments and materials that incorporate design features to ensure that people with limitations in cognitive abilities - including language ability and auditory reception, reasoning and idea production, memory and learning, visual perception, cognitive speed, and knowledge and achievement - are able to access those environments and use the technology and materials. Therefore, the aim of cognitive accessibility is at narrowing the gap between personal capacities and demands of the environment and the context (Wehmeyer et al., 2010).

In fact, being outside the digital society for people with ID is not a self-selected choice, rather a consequence of poor accessibility: it is difficult to learn, understand, remember and recall how devices and interfaces work. For this reason, cognitive accessibility for people with ID is an important challenge (Johansson et al., 2011).

2.2.3. Active participation

Active participation implies that the citizens of a community can be leaders and agents of social change when there is an issue, by analysing problems, making decisions to solve them and playing actions to change and remove barriers in a creative and energetic way.

Then, one of the main pillars of the Mind-Inclusion facilitation methodology is the figure of the facilitator as a person that can promote and help the participation not only of people with disabilities but also of the rest of the community members in fostering an inclusive community.

Active participation means to respect all the participants and collectives and their opinions, avoiding discrimination, stereotypes and prejudices since each single person is unique and has their unique capabilities (Amnistía Internacional, 2011; ANUIES, 2002).

2.2.4. Self-determination

Self-determination is a crucial matter that it is possible to define as the capacity to choose between several opportunities and use these choices to determine one's own personal actions (Deci, Ryan, 1985). The skills associated with self-

determination include: choice-making, decision-making, problem-solving, planning, goal-setting and attainment, self-management, self-advocacy, self-awareness, and self-knowledge. Specifically, self-determined actions are classified in three essential characteristics (Shogren et al., 2018):

- *Volitional actions* reflect self-initiation and autonomy when people make intentional, conscious choices based on their preferences
- *Agentic actions* are defined by self-direction and pathways thinking when people regulate their progress toward goal and navigate around challenges that emerge
- *Action-control belief* develops as people grow to understand and integrate understandings of the relationship between one's actions, when people act with positive control expectancies, with self-realization, and in a psychologically empowered way.

Usually, people have a natural inclination to psychological develop, overcome challenges and implement self-determining behaviours (Deci, Ryan, 1985). Self-determination, in fact, highlights two important human functioning: autonomy and relatedness, that are related to a supportive environment; it is the context that has to provide opportunities to reach these functions (Frielink et al., 2018).

Considering people with disability, self-determination is involved, for example, during activities, where they have to feel free to do them without pressure and constraints. To be self-determining, in fact, means to engage in an activity with a full sense of wanting, choosing, and personal endorsement, with self-determined behaviour that refers to previous actions:

- A person acts autonomously according to preferences, interests and/or abilities, independently and free of external influence or interference. It should not be confused with self-centred or selfish behaviour; behaviour(s) are self-regulated and individuals are able to examine their environments and their repertoires of responses for coping with those environments to make decisions about how to act, to evaluate the desirability of the outcomes of the action, and to revise their plans as necessary;

- A person responds to the event(s) in a psychologically empowered manner, that includes perceived control about personal efficacy and motivation;
- A person acts in a self-realizing manner as "tendency to shape one's life course into a meaningful whole".

These actions describe the function of the behaviour that makes it self-determined or not. In addition, self-determination does not reflect an absence of influence or even interference from others, instead, it reflects choices and decisions made without interference or influence.

In conclusion, it is important to keep in mind that research claimed that adults with disabilities are less self-determined than their peers without disabilities (Wehmeyer, 1999).

2.2.5. Person-centred approach

Under the social model of the disability, this approach is focused on the person and not on disability, and their knowledge and capabilities. The environment should not be a limitation for people but a way to foster their abilities and capabilities without the disability being   a limit for development of human beings . In addition, the person-centred approach emphasizes the decision-making of each participant and their self-determination (ANUIES, 2002).

Considering the person-centred approach, the Mind Inclusion facilitation methodology, together with the Mind-Inclusion APP, aims to provide enough tools to strengthen the self-determination, potentiate the autonomy and promote the capabilities of people with intellectual disabilities.

3. Conclusions

This Manual has been elaborated within the framework of the European Project Mind Inclusion 2.0 (2018-1-IT02-KA204-048425), funded under the Erasmus + Programme of the European Union. The final goal of this project is to increase the level of social inclusion of people with intellectual disabilities through the design and use of the Mind Inclusion APP.

In the Mind Inclusion project the whole process of promoting inclusion with the use of the APP is accompanied by a Facilitation Methodology. This methodology has been developed in order to help and guide educators, social workers or other professionals working with people with intellectual disabilities to promote the social inclusion of people with intellectual disabilities in their community while raising awareness of the local opportunities and the rights of people with intellectual disabilities. To achieve this purpose, the Facilitation methodology has been rooted on several theoretical foundations which have been presented in this Manual.

Since the Mind Inclusion Facilitation methodology pretends to foster the social inclusion of people with intellectual disabilities in their community, this methodology has been based on two main theoretical approaches in its design: a) participatory methodologies and b) the capability approach and the social interpretation of the concept of disability.

On the one hand, the use of participatory methodologies, such as the Design thinking and the Agile Methodology, have permitted the constant involvement of all the potential stakeholders, such as disabled people, caregivers, educators and business owners. Following a participatory approach has permitted to identify the real needs of disabled people when it comes to social inclusion.

On the other hand, theoretical foundations such as the Ecological theory and the capability approach and agency, and a social interpretation of "disability" highlights the importance of considering the environment and the community for social inclusion. Therefore, foundations of the Mind inclusion APP and its facilitation methodology goes beyond individualistic perspectives in which the disability is an individual problem and, instead, it pays special attention to the role of the community.

Therefore, the methodological criteria that guide the implementation of the Facilitation methodology and its application are strongly oriented to obtain more inclusive and cognitively accessible and understandable environments for everyone, regardless of their abilities, in which people can fulfil freely the exercise of their rights.

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