# MIND INCLUSION Co-creation Booklet for social educators





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# MindInclusion 2.0 (MI2.0)

### Aim...

Widen the opportunities of people with intellectual disabilities to be involved in the society, by implementing a joint co-creation process settled on a capability approach.

The value...

Relies in the participation of people with disabilities in the design and production of the MI2.0 APP, meaning a focus on cognitive accessibility to the co-creation activities, that should be mindful with participant's requirements for participation.

How...

Through the use of **participatory approaches** and **adoption of agile methodologies** for a truly **user-centred co-design process** and constant involvement of people with disabilities, caregivers and business/services managers in the design, development and testing of a web platform.

Implies **building a network of local action groups** that will be **engaged in the participatory design** through a set of small-scale data collection pilots in Italy, Spain and Lithuania.

# In this booklet you will find...

- 1. Prepare your local action group
- 2. Why undertake a Co-Creation Journey?
- 3. MI2.0 Co-creation framework and inclusive co-creation tools
- 4. Learning by doing

# **Prepare your Local Action Group**

A LOCAL ACTION GROUP (LAG) is a group of volunteer people formed by users, caregivers, relatives and stakeholders, who meet to share experiences and participate in the creation of new ways to foster inclusiveness in their community.

The LAG will be an essential pillar for the co-creation process.



Primary users (centre of the approach):
intellectually disabled people.

- Secondary users:
  - related with IDP: relatives, formal and/or informal caregivers, social and healthcare professionals accompanying the person in different areas of life (health, social, education, labour)
  - related with the community and public spaces: managers and representatives of public spaces.

Tertiary users: decision-makers, advisors, other stakeholders interested in the webplatform and facilitation methodology.

The LAGs will be the ambassadors of the co-creation process and of the results, supporting the scaling up of the solutions that they will help to co-design. Therefore, an important attention need to be given to its constitution and engagement. There are three preparatory steps to consider:

Step 1. Set the purpose Step 2. Set the composition of your LAG Step 3. Set the inclusion criteria for each type of participant

### Let's set up the scene!

### Before planning co-creation activities, be sure that you...

**Understand your role** acting as activator of LAG's for inclusiveness promotion using co-creation as a medium to CONNECT people, STIMULATE needs detection and PROMOTE change.

**Get familiarized with the nearest community**: map the territory and its resources, taking into consideration the aspects that may hinder or motivate participation.

Develop an **engagement strategy** involving potential participants by consulting with them which expectations they may have, how they feel able to participate, and how to get a long-term commitment.

Be attentive to **explore opportunities** for further collaborations with public and private organizations/ associations working in the field of disability in your locality or region.

### Building a successful collaboration means...

Develop safe, trustful and empowering relations among participants (users, caregivers, relatives and stakeholders) **stimulating community belongingness**.

Ensure a **sense of membership to the LAG and its purpose** and a rewarding participation. Facilitate a sense of ownership and co-responsibility on the activities and results.

Establish **clear and regular communication** with the LAG participants. They will be the real Inclusion Ambassadors.

Motivation first!

Rewarding participation

# Why undertake a Co-Creation Journey?

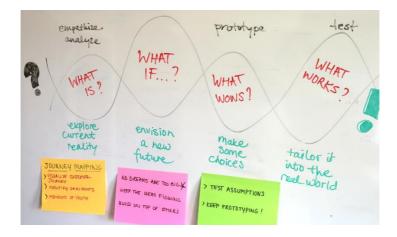
This change in the relationship between citizens/users and researchers, developers and companies is not new, being preceded by a large number of concepts, guiding methodologies, approaches and frameworks such as user-centred design and user-driven approaches with three decades of existence.

Nowadays, is unquestionable the core position of Co-Creation (integrating Co-Design and Co-Production) as a Strategy for socio-health innovation.

Without the insights gained through the lived experiences of people with intellectual disabilities, family carers, business managers, social educators and policy makers, the efforts for increasing wellbeing and inclusive social participation run the risk of not reach the expected impact.

Previous experiences have shown that co-creation with users can promote greater social cohesion, acceptance and empowerment. Through co-creation with users is possible to minimize risk, ensure better results on acceptance and effectiveness by **listening**, **learning and co-create with experts by experience**.

It can be very rewarding by giving the users a more direct say in shaping the projects and the delivery of innovations designed "with" and "by" the people, rather than simply on their behalf. However, it is a journey highly challenging.



### Some concepts you should not miss

#### Participatory Design is...

#### ... a strategy to manage creative practice

It implements co-design methods to define a problem and then define a solution (e.g. create "personas", storyboards and user journeys), following with a co-production process to implement the proposed solution (e.g. prototypes and scenario generation techniques).

#### ... a democratization of the design process & experience-led design

Open design includes users and other stakeholders (those affected by the design) as generators of ideas, decision makers and partners. Users, as "experts" of their own experience, become fundamental in the design process.

#### ... a fundamental change in the designer-user relationship

Allows a wide range of people to make a creative contribution in the formulation and solution of a problem. Facilitators (usually care professionals or designers) provide ways for people to relate to each other, as well as ways to communicate, be creative, share ideas and try new ideas.

#### Mindful design is...

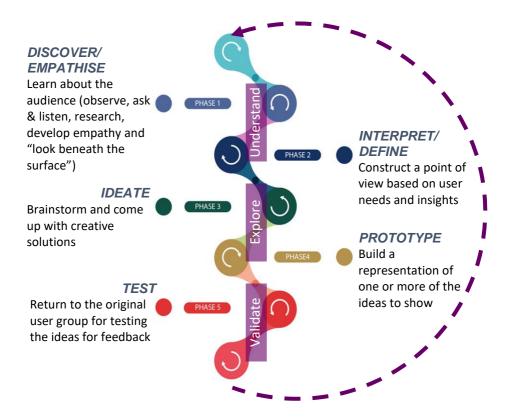
#### ... a co-design accessible process looking to opportunities and people's strengths

It relies on making the co-creation process less demanding, accessible to the participant's cognitive barriers, that centres on the experience at the moment. It uses mindfulness as a mechanism for designing behaviour change, especially in social contexts. It seeks to develop designs based on people's values and life contexts, considering relevant activities and social relationships, as well as encouraging empathic attributes or strategies managed, as the starting point for joint design.

#### Design Thinking is...

#### ... a 5-step method: Empathize, Define, Ideate, Prototype, Test

It helps a designing team to come up with practical, meaningful and creative ideas that solve real issues for a particular group of people.



#### Agile methodology is...

#### ... a process of iterative and incremental software development

With a continuous design improvement and testing based on rapid feedback and change adopted for the development of any kind of solution (product, methodology, service). Iterative planning and feedback results enable the alignment among the development and the desired needs of the clients/users for value optimization.



### Have you heard about Mindfulness?

Mindfulness is about paying attention to your inner or outer experience. It involves attention to certain attitudes, such as curiosity, acceptance and kindness.

#### Let's practice a bit before continuing...

Be aware of the sense of your own breathing. You don't need to change the rate of your breath. Just feel the physical sensation of your breath entering and leaving the body. You can feel the breath in the nose, the throat, the chest or down in your belly. If possible, try and feel the breath in the belly as it's more grounding and is more likely to make you feel relaxed. If you have some thoughts, observe them, without any kind of judgement, and let them go. Do not try to get attached to them. Just let them go, and keep on been aware of your breathing.

How do you feel?

Ready to discover more in this Booklet?

## **MI2.0 Co-creation Framework**

The biggest gap nowadays

According to the ALLIANCE ambient assisted living roadmap (2010), target groups' reluctance to adopt new solutions is caused in most cases by wrongly designed technologies that have been developed without thinking about the real needs and capabilities of the end users. Design requirements have been typically generated in a top-down fashion, rather than being user-led, resulting in severe limitations regarding user acceptability.

### The MI2.0 value proposition

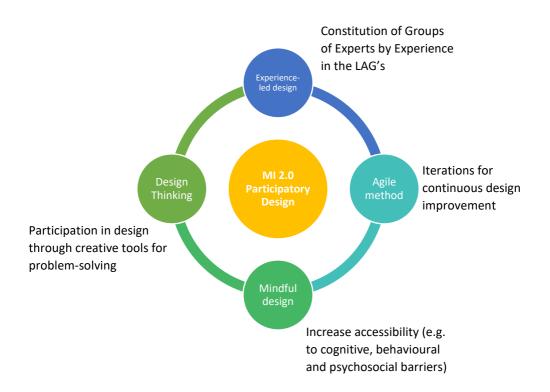
The new paradigm for co-creation "with" and "by" the users instead of just "for" the users is possible making use of the knowledge, tools and methodologies already developed but putting a significant focus of attention to cognitive accessibility of participants.

Cognitive accessibility is the gateway for participation and it means to facilitate co-creation spaces that are respectful and engage the participants to the best of their ability, by reducing barriers, and with appropriate techniques to facilitate participation in the sharing of user experiences and ideas, in order to find new answers to the shared challenges.

For that purpose, a combination of the mentioned methodologies constitutes the MI2.0 co-creation framework, a methodology that evolves from each lesson learned in the implementation process.

"With" and not just "for" the user

Summative approach



MI2.0 representation of the hybrid/summative methodology applied

### The MI 2.0 co-creation concept

The MI2.0 framework goes beyond the usual Participatory Design and requirements elicitation techniques adopted by many EU funded projects, by combining Design thinking techniques and Mindful Design attributes in an agile requirements elicitation and development process.

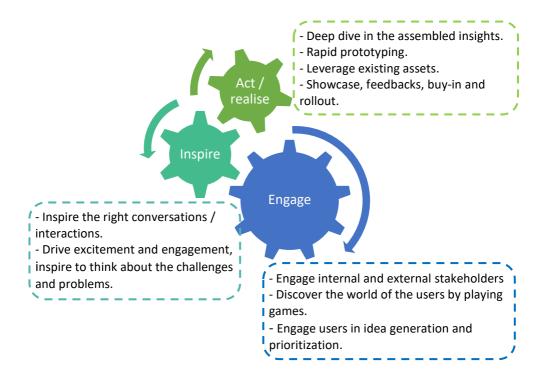
It aims the development of Co-Creation Journeys with people with intellectual disabilities, addressing mindful

Co-creation Journey planning, training and mindful facilitation, as the pillars to support inclusive participation and cognitive accessibility.

The MIND INCLUSION LAGs will ensure users' engagement (e.g. educators, IDP, etc.) requiring the development of **tight bonds** among all the stakeholders and the active participation of the stakeholders' network throughout the co-creation process.

Meaningful participation

There are three step-stones that should be considered in the co-creation process planning: engagement, inspiring and act.



### Inclusive and cognitive accessibility understanding

Inclusion means that all people have the right to be respected and appreciated as valuable members of their communities, regardless of their abilities, disabilities, or health care needs, participating in social life, recreational activities, etc. It

means respectful and fair treatment and equal access to opportunities and resources, by removal of barriers for their participation. It is intrinsically connected with the concept of cognitive accessibility, that implies that people understand the meaning of environments. Different criteria can be listed to support the achievement and assessment of its implementation.

Cognitive accessibility can be defined as a series of requirements to be filled by the communication process favouring participation (Fundación Once, 2008):

- Reduce dependence on memorization.
- Use complementary formats (visual, audio, multi-graphic)
- Reduce the need of the recipient to use complex organizational skills.
- Adapt vocabulary or reading to receiver's comprehension ability.

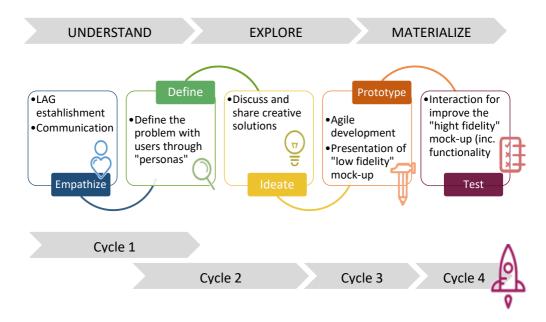
### The co-creation process

In the MI2.0 framework we use Design thinking techniques and Mindful Design attributes for planning and executing co-creation sessions, in combination with Agile Methodology, that implements development loops to collect stakeholder's feedback, validate assumptions and readjust the prototype in accordance. The hybrid methodology is reflected in the structure of the participatory activities that have a format of co-creation cycles/loops.

### MI2.0.co-creation plan

MI2.0. proposed the implementation of four co-creation cycles/loops for a joint design and production of the MI2.0 platform with primary and secondary users.

Accessibility criteria



Each loop implements four activities:

- Preparation & coordination of the plan for the co-creation session and data collection process;
- 2. Internal preparation of the session (including translations or even adaptation of materials; session preparation by facilitators);
- 3. Perform workshop session with users & reporting results using report templates decided;
- 4. Implement Design methods with professionals (results will help to define the content for the next session with users) to transform data into requirements for technical development.

# MI2.0 inclusive co-creation tools

First, main objectives of the different sessions with users were set, dedicating the sessions 1 and 2 to co-design (empathize, define and ideate) and the sessions 3 and 4 to co-production (prototyping and small testing), then co-creation tools were developed, under the cognitive accessibility frame, to support the sessions.

	SESSION 1 empathize/ define	SESSION 2 ideate	SESSION 3 protype and test	SESSION 4 test
PURPOSE	Share experiences. Collect aspects relating to the problems identified.	Insights to define scenarios. Sharing potential solutions.	Insights on critical usability and experience aspects.	Evaluate the improved prototype.
TOOLS	MI2.0 Gameboard MI2.0 Diary.	Adapted empathic map. Exploration activities.	Rough mock-up of the app.	High fidelity mock-up. Exploration activities.
OUTPUT	Refining "personas", a technique that describes aspects of a real or imagined case.	Establish an empathy map and define use scenarios.	Observation grid and session output to refine APP.	Observation grid /compare observation with session 3.

A mindful selection of Participatory Design techniques was made to support participants with intellectual disabilities requirements (low difficulty level, nonspecific design skills), searching for cognitive accessibility in the dynamics.

Guiding exercises and design thinking tools for the 2 co-design and 2 coproduction cycles were co-created by 14 researchers and educators to guide the collection of relevant insights from users and other stakeholders.

#### MI2.0 Gameboard

Adapted game board to play visiting public places based on the traditional monopoly game. It serves to collect insights related to individual interests and barriers found in the near context when accessing public places.

#### MI2.0 user diary

Consists of a set of activities to be performed at home/activity centre in order to reflect over leisure time and places to visit, facilitating the collection of contextual information, what users do and feel.

#### **Adapted Empathy Map**

Helps to create a common vision about users' common thinking and feeling in a preelaborated situation, as well as motivations, attitudes, aspects of interaction, and beliefs.

#### **Exploration activity**

Indoor or outdoor visits to social places facilitating natural experiences and insights on people, communication, interaction and obstacles. The explorer pack included visual activities and cards, instant cameras, other materials that could be selected by participants to make them feel prepared.

**Observation/ Contextual observation** Grids to support semi-structured and casual observation by means of immersions in the natural context of the users.

Web Questionnaire for Business Users

Complementary participation tool.











Although the common proposition made for the cocreation sessions and considering creative ways to promote collaborative working with IDP, each facilitating team need to personalize activities, materials, and facilitation in the co-working spaces to fit the participant's capabilities and other conditions around the group participation.



### Sessions toolkit

A toolkit was prepared for each session, support facilitators with the preparation, implementation and reporting. The toolkit included:

- Invitation to participate.
- Information sheet and informed consent models.
- Instructions for facilitators: it included introduction to objectives for each session, recommendations for facilitators, minimun organization aspects and facilitators roles (e.g. session moderator, sub-group facilitators), list of required materials, instructions for each time slot of the 2 hours workshop.
- MI2.0. co-creation tools and materials for the activities.
- Observation grids.
- Reporting template.

### Embedding results in the prototype development

In a co-creation process with users is important to ensure traceability and transparency regarding user requirements, preferences, expectations and general insights. After each session, facilitators fill the report templates with detailed information and a post-review session is performed for discussing results from the different LAG's. The procedure is repeated for each session with LAGs.

MI2.0 also implements a requirements track template that supports the analysis of results and prioritization of features for the app development, according to a technical feasibility assessment and the use value.

### Exercise

Do you know interesting co-creation tools? List and share with your working partners how they can be used.



And don't get lost in the middle of so many methods!

The simplest, the better!

# Learning by doing

### Guidelines for facilitators

People with intellectual and/or functional disability is a very heterogeneous group (e.g. cerebellar syndrome; mild mental retardation; autism, attention disorder or with autism spectrum disorder; down syndrome; mild cognitive impairment; mild dementia) with different health, activeness/dependency levels, social involvement and technological skills and needs.

Participants with cognitive disability or cognitive decline often show difficulties on one or more of the following aspects: memory, executive functions, perception, reasoning, attention, language, understanding figurative language, literacy, behavioural manifestations, etc. In order to facilitate their and promote respectful and creative dynamics focused in a "capability approach" (improving confidence to participate) a special attention to the **facilitators training** should be given, echoing a key message that challenges are not obstacles but opportunities for being creative and learning with the process.

Facilitators should have experience with the participants, knowing major cognitive characteristics, understanding difficulties and strengths, anticipating barriers for participation, and the best way to engage them.

Is of most importance to feel confident conducting the cocreation sessions by dedicating time to the activities design, prepare facilitating materials and get support.

Ensure mindful conditions for the participatory sessions, thinking in the general and individual needs. Prepare the required adaptations to the space, communication and exercises, offering a variety of possibilities and tasks for participating in a way people feel motivated to join and have fun. Be attentive to verbal and no-verbal communication, prepare supportive materials, act with empathy and optimism adopting a positive style of communication, ensure an easy-to-understand language. Get to know the users

#### **Dedicate time**

Adapt to the needs

Encourage equal participation opportunities in cocreation activities (systematized, integrated, tailored to users), avoid tiring and large in time activities.

Develop safe, trustful and empowering relations, stimulating community belongingness, starting from the LAG. Support a sense of ownership (co-responsibility) by the participants. Help to build collaboration among users and other stakeholders, and facilitate a sense of ownership (co-responsibility) by the participants.

Facilitators should ensure the knowledge, and the skills to observe, support and react appropriately to behavioural manifestations that may affect participation, and to promote participant's self-confidence.

Always work with informed consents and ask permission to record a conversation. Don't forget GDPR regulations.

Embedding mindful preparation and mindful attitudes to the sessions will have positive effect both on the participants and on yourself.

**Curiosity and beginner's mind**: show curiosity about participant's experience, emotions and thoughts around the discussed topic.

**Focus on strengths:** be mindful on participant's strengths and avoid overwhelming activities. You can implement simplification strategies.

Support interaction with warm up activities that **stimulate trust, cheer up participation, and appreciate** participation showing your thanks.

Acceptance: collect information and feel in your skin what others experience look like. Change comes later.

**Team building:** help participants to get to know each other, you can use simple ice breaker games adapted to participant's skills.

**Savouring the moment:** savouring the pleasant aspects of the experience of sharing together, despite the difficulties you may find.

Facilitate collaboration

Community belongingness

Promote confidence

Ethical and legal frame

A matter of attitude

### Mindful Design as a challenge and an answer

Mindfulness in co-design means paying attention with a sense of warmth and kindness, as well as a sense of curiosity and openness. Bring these attitudes to the interactions with and in the LAG and see what happens.

#### Connect with people and connect people in a mindful way, by:

- Being curious and asking questions: do not impose your own perceptions.
- Putting yourself in the user shoes: what would you be like in that person's situation? How would you feel, and what would you want?

### Lessons shared by the MI2.0. team

Discover the possibilities of co-creation with a mix of actors and a main focus on involving people with intellectual disability, empowering them in each contact. It helps to create a common vision on the inclusion and integration challenges and opportunities, establishing a space and moment for learning with each other's experiences.

Co-create tools to facilitate participation and playful activities and interaction.

Participate, listen to others, learn and make a real effort to understand each other motivations and concerns.

Discover the role of educators as co-creation facilitators.

Interaction and communication within the different target groups, with different levels of understanding, living experiences and expectations. Finding a common language was not easy, but effective to facilitate participation and to maintain open attitudes.

High level of heterogeneity of participants (personal and functional conditions) in the LAGs that were constituted in different countries, require a strong exercise of adaptation and personalized support planned prior to co-creation sessions and flexibility in their management.

Translate participant's experiences into user requirements and specifications for the design and development require time, strong collaboration among partners and a method to track requirements progress and the solution response.

Facilitate pleasant co-creation sessions with low stress and participatory constrictions means to place special attention on the joint learning journey were simplifying, clarifying and making understandable interactions, proposed activities, design tools defined, and accessible communication, are key aspects to be addressed.

Focus on user experience and use strategies to avoid tiredness, overload and/or disinterest: work with small groups, understanding individual motivations to participate, empathise with the different participants (IDP and business users) needs and challenges.

Try the tools and activities making adjustments prior to the sessions, plan concrete activities or simulations in places the participants like most (avoiding abstract activities that requires imagination or other cognitive skills that can be diminished). It will result in a meaningful, particularly engaging and a social opportunity in itself.

### The keys to surpass challenges

... bear in mind the differences and common points between the people involved, be flexible enough and do not forget the initial goals.

... plan sessions with enough flexibility, adjust time, number of meetings, activities and logistical aspects to the needs of each single participant of the LAG as most as possible.

... conducting the session, observing, registering and support particular needs can be overwhelming, therefore, a good planning should involve different facilitators and supporters as required and a clear coordination of tasks.

... reinforce each single participant role in the co-creation process and support the creation of a sense of group.

... remember, so or much important is the process and the momentum participants live in the sessions than the results per se.

... empathy with each element of the group and adjusted communication, despite challenges and experiences, can be the best return a facilitator can give.

... co-creation as an open and flexible process do not means not structured, once it requires to establish a decision-making and track procedure.

... the methodology includes results sharing and discussion in the different cocreation loops, and a defined method for tracking LAGs feedback coming from the different sessions, register progress, define priorities, commonalities and specificities, record decisions and confirm achievements related with the user's requirements established.

### Exercise

Define your next co-creation activity

Translate your knowledge into a plan for practice

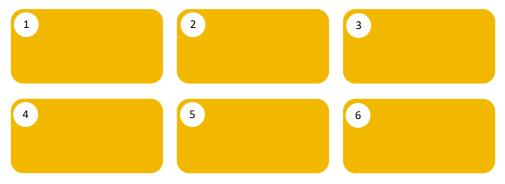
People with whom I want to co-create:

Which are the co-creation objectives / what can we learn from them:

The challenges I can anticipate:



#### The envisioned steps:



### Acknowledgements:

We are especially grateful for the priceless collaboration of the IDP, carers, business users, and facilitators that compound the four Local Action Groups (LAGs) constituted in the MindInclusion 2.0 Project. These groups were established in Sandrigo (Italy), Valladolid (Spain), Valencia (Spain) and Vilnius (Lituania), coordinated by project partners: Cooperativa Margherita, Fundación INTRAS, PoliBienestar y Viltis, respectively. The implementation, adjustment of the methodology and lessons learnt were not possible to reach without the strong engagement of each single participant in the LAGs.

### **References:**

Eley, R.M. (2016). Telling it as it is: involving people with dementia and family carers in policymaking, service design and workforce development. Working with Older People, Vol. 20 Issue: 4, pp.219-222, https://doi.org/10.1108/WWOP-09-2016-0026

Garde, J.A., Voort, M.C.v.d., Niedderer, K. (2018). Design Probes for people with dementia. Proceedings of DRS 2018 International Conference: Catalyst, 6, pp. 2607-2621. Proceedings.

Jacono, T., West, D., Bloomberg, K., & Johnson, H. (2009) Reliability and validity of the revised Triple C: Checklist of Communicative Competencies for adults with severe and multiple disabilities, Journal of Intellectual Disability Research.

Niedderer, K., Tournier, I., Colesten-Shields, D., Craven, M., Gosling, J., Garde, J.A., Bosse, M., Salter, B., Griffioen, I. (2017) Designing with and for People with Dementia: Developing a Mindful Interdisciplinary Co-Design Methodology. In: Proceedings of the IASDR international Conference 2017, Cincinnati, USA, 31October-3 November 2017. doi:10.7945/C2G67F Proceedings



This booklet aims to be used as a light version of the MI2.0 co-creation methodology. It aims to inspire social educators and other professionals to get to know the benefits of implementing co-creation processes with users, and undertaking this journey. It offers brief guidelines finalizing with testimonies.

MI2.0 co-creation methodology allows to work alongside people with cognitive disabilities and gain rich understanding and insight about what is valuable to them. Everyone can be involved, it is up to the organizers and facilitators to create accessible conditions.

#### **Project partners:**





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