




BMJ Open Supporting direct support professionals in enabling people with intellectual disabilities to engage in meaningful activities: protocol for the Meaningful Activities 4 All (MA4A) study based on the human-centred design process

Christophe Wille ^{1,2}, Ine De Clerck,² Geert Van Hove,³ Jos Van Loon,³ Dominique Van de Velde ^{1,3}, Patricia De Vriendt ^{2,4}

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For numbered affiliations see end of article.

Correspondence to
Mr Christophe Wille;
chriwill.Wille@UGent.be

ABSTRACT

Introduction Meaningful activities (MA) have a positive impact on identity, well-being, participation and inclusion. Although people with intellectual disabilities (PID) depend on their direct support professionals (DSPs) to engage in MA, the DSPs need support which could enable them to offer more qualitative care and support.

Methods and analysis To identify DSPs' needs, and to develop a tool/service, an innovative and iterative approach is developed, based on the human-centred design (HCD) process, combined with traditional qualitative and quantitative research methods. In the inspiration phase (needs analysis), in-depth interviews will be conducted in two day care centres in Flanders using an interpretative phenomenological analyses, one with a supply-driven approach and the other with a demand-driven approach, followed by a survey sent to all Flemish day care centres. In the ideation phase, the insights of phase 1 will guide a cocreation process (comprising a World Cafe, brainstorm and prototype sessions) with the DSPs, PID and other stakeholders. In the implementation phase, the solution will be tested in the two day care centres from phase 1 by means of living labs and a realist evaluation. By adopting this protocol, the functionality, quality, usability and acceptance are expected to increase. This protocol adopts all phases of the HCD process and shows the complementarity of HCD with traditional research methods. PID and the DSPs will benefit as the end result is truly grounded in their specific needs and wishes.

Ethics and dissemination Ethical approval by the Ethics Committee of the University Hospital Ghent, Belgium (reference numbers: B670202042983 and PA2021-091). All participants will sign informed consent forms. Results of this study will be submitted for publication in relevant peer-reviewed journals and will be presented at relevant conferences.

INTRODUCTION

It is generally assumed that the prevalence of people with intellectual disabilities (PID) worldwide varies from 1% to 3% based on income, age and origin, with the highest

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This Meaningful Activities 4 All study protocol uses a complete human-centred design process and combines it with the strengths of traditional research methods.
- ⇒ The end users will be involved in the whole project from the outset.
- ⇒ Cocreation with people with intellectual disabilities is challenging and required accessible cocreation tools and specific support.
- ⇒ Sample sizes are difficult to determine as there are no exact numbers of direct support professionals working in day care facilities.
- ⇒ Prolonged engagement in practice through living labs facilitates further development and refinement.

rates to be found in low-income and middle-income countries.¹ The most widely adopted definition of ID is taken from the American Association on Intellectual and Developmental Disabilities (AAIDD)^{2 3}: '*Intellectual disability is a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18.*'⁴ The AAIDD emphasises the multidimensionality of ID,³⁻⁵ enabling direct support professionals (DSPs) to get a more comprehensive understanding of ID, and allowing them to establish a more purposeful approach towards PID.² DSPs are called many names such as human service workers, disability support workers and personal care aids.⁶ DSPs are a group of paid workers who provide care for PID.⁷ DSPs work in a variety of settings and provide a wide range of complex services which

include helping people with activities of daily living and promoting physical and emotional well-being. 'DSPs are the "backbone" of long-term services and supports'⁶ and have an important role in health promotion and influencing healthy behaviour.⁷

PID have been excluded from society for a long time due to their limited abilities in both their intellectual capacities and adaptive behaviour.⁸ Even though PID living in communities are associated with having higher levels of quality of life (QOL),⁹ they still need continuous additional support to participate in society as equal citizens.^{3 10} Therefore, PID when not adequately supported are at risk of being excluded from society.⁸ In addition, life expectancy of PID increased significantly over the last decades.^{11 12} Older PID represent nearly half of all PID.¹² Consequently, nearly half of the people in day care facilities are of older age¹² and have a life expectancy close to that of people without disabilities. Most PID lack age-specific support and when they age this can potentially lead to inappropriate placement and loss of social networks.¹¹ Older PID are a profoundly diverse group with different and complex needs,^{12 13} which requires specific assessment and person-centred planning and support.¹² Although specific risk factors such as different life course trajectories, older prejudices, networks falling apart and age-related health problems exist, older PID can be supported in an active way, with specific interventions adapted to their individual needs.¹¹

One of the most important and influential conventions that address inequality is the *'United Nations Convention on the Rights of Persons with Disabilities'*.⁸ By signing the convention, all member states agree to implement the convention in their national policy on ID.^{8 14} Since the convention was adopted, 164 countries signed the convention¹⁵ and 94 ratified both the convention and the optional protocol.¹⁶ The Flemish Agency for Persons with Disabilities (VAPH) has developed a policy in accordance with the United Nations (UN) Convention and the current vision on ID.¹⁷ The 'quality of life supports model paradigm',^{18 19} comprising four core values (equity, inclusion, self-determination and empowerment), is at the heart of the policy. In Flanders, the Flemish part of Belgium with an autonomous government (at the end of 2018), 7100 young people received professional help and 24677 adults with disabilities received a personal budget.^{20 21} Around 15.000 people with a disability are still on a waiting list for care and support.

Despite the fact that Article 27 of the UN Convention states that all people with disabilities have the right to work and employment, the majority of PID do not work in the regular labour market due to their complex needs associated with their disability. Day care is an alternative for those people. The VAPH defines day care as '*assistance and permanence in group during the day, for a number of days per week or a whole week*'.²² The focus within those centres is on enabling PID to participate in activities. This is important since activities are assumed to be essential for all humans to achieve goals in life and to influence

their state of health.²³⁻²⁵ One important prerequisite for having an impact on the state of one's health is the fact that these activities should be meaningful for the individual.^{26 27} Meaningful activities (MA) are activities that an individual consciously engages in to achieve a personal sense of meaning and fulfilment^{28 29} by means of choice, control and belonging.²⁴ MAs are associated with the personal interests of people and are enjoyable by nature.^{28 30} MAs occur in a specific social, family and cultural context and define one as a person and provide us with a sense of identity.²⁸ People who experience meaning in their activities have a greater sense of well-being.²⁴ Engagement in MA of older people specifically enables them to feel more productive and connected with society³¹ and is also crucial to improve the QOL of PID.^{32 33} By participating in MA, they gain a better grip on their own lives, become more independent and have more opportunities to participate in society. If not, PID are experiencing deprivation, which is detrimental for their health and well-being.³⁴ Although every person has the right to participate in MA,³²⁻³⁴ this is not always the case for PID.³⁵

In recent years the personal goals, needs and wishes of PID became increasingly important in enabling MA.^{12 35 36} It is globally accepted that in a person-centred support system, there should be an alignment between the wishes and goals of a person, his or her support needs, the support given and his or her QOL outcome,³⁶ yet not all PID are able to explicitly communicate their goals.^{13 35} Too often PID are dependent on DSPs' abilities to communicate at their level and understand them. Therefore, DSPs need to depend on their own experience and those of others (family or other proxies) to understand what is meaningful for the PID in order to tailor and adapt activities to each individual with ID.^{12 35} The quality of the communication between DSPs and PID is associated with engagement of PID in MA. More specifically, good communication is associated with higher levels of engagement.³⁷ Unfortunately, the bigger the organisation, the lower the commitment in MA.³³

When asked, PID suggest that quality of care is related to their immediate situation in receiving care and services, such as the relationship with the DSPs. In particular, the consistent fulfilment of promises and commitments made by the DSPs. In addition, PID value ambience and cosiness, tailor-made care and being taken seriously regarding their wishes and competencies.³⁸ Furthermore, PID experience activities more meaningfully when they are treated respectfully and as adults.³⁴ In essence, the relationship between the PID and the DSPs is fundamental for providing a high quality of care, especially in long-term care.³⁹

In recent years, support for PID has improved significantly. Despite this favourable evolution, many PID still remain segregated from society and have fewer opportunities for personal development, participation and inclusion.⁴⁰ In addition, it is imperative to understand that PID depend on the quality of support they receive

from DSPs.³³ More specifically, the higher the quality of the DSP, the more personal outcomes for PID.⁴¹ Sadly, PID remain underengaged in MA and research on the topic is scarce. More research is needed in order to establish and understand factors that enable or hinder MA.³⁴ DSPs seems to be left to fend for themselves too often, which results in poor quality of support.³³ Furthermore, a sizeable portion of DSPs are not qualified adequately to provide the required effective support.⁴¹ In addition, DSPs are confronted with a great heterogeneity of ID and various roles, duties and tasks that are typically determined by the centre in which they are employed. Depending on their educational background, it is difficult for DSPs to acquire all skills, knowledge and abilities that are required to effectively perform their roles.⁴² In addition, there is a disconnection between evidence-based practice and the competencies of DSPs.⁴¹ However, it is important to underline that working with PID is very challenging for all DSPs due to the complex nature of ID,^{43 44} resulting in DSPs being exhausted and not being able to meet the demands related to their job, and even resulting in burnout.⁴⁵

The overall objective of this study is to develop a more qualitative support for PID, enabling them to participate more in MA and by extension in society. The aforementioned results in the following research question for this study: 'What do DSPs, working in day-care centres, need to enable PID to engage more in meaningful activities?' The desired outcome for this study is a tool or service that is tailored to the specific needs and wishes of the DSPs. In doing so, DSPs will be able to meet the complex demands, inherent to working with PID. In order to develop such a tool or service, a specific cocreative and innovative research method is needed.

METHODS AND ANALYSIS

Research constantly produces new insights from which products or services emerge. It is generally assumed that only half of these are implemented in practice and that it takes 17 years on average before their use becomes routine.^{46 47} It can be concluded that there is still a research-to-practice gap.^{46 48} To overcome that problem, new approaches to develop complex interventions are needed and should have key principles such as being dynamic, iterative, creative, open to change and proactive.⁴⁸ Therefore, this Meaningful Activities 4 All (MA4A) study protocol is based on 'The field guide to human-centered design (HCD)' developed by IDEO in 2015. IDEO is a global design company that has launched products, services and experiences for the profit sector for decades, focusing on the human perspective, where needs are assessed, and solutions are evaluated based on understanding the needs of customers and getting feedback from them.⁴⁹ In recent years, IDEO has also focused on the non-profit sector because it felt the social sector was ripe for innovation and needed an approach that has the potential to unlock true impact.⁵⁰ HCD is nowadays increasingly

accepted in the human services sector⁵¹⁻⁵³; however, when used, it is not used in a standardised way or is reduced to using some features of HCD.^{54 55} Furthermore, there is no consensus definition.⁵⁶ Therefore, HCD can be labelled as an 'umbrella term'⁵⁵ for all approaches grounded in the needs of their target population, also called the end user, while developing products or services.^{51 56 57} Despite the fact that HCD is sometimes still reduced to a buzzword, there is clear agreement that the 'human' part refers to the participation of stakeholders, and that there is a real commitment and focus on human value.⁵⁵ That, and also the fact that HCD really does focus on equity, has led to make the HCD process central to this MA4A protocol. In essence, HCD puts the needs, expectations, desires and experiences of the end user central^{54 55 58} and explicitly searches for the 'deep story'.⁴⁹ In addition, it especially helps in developing a comprehensive understanding of the context in which the service or tool will be implemented, and thus helps in facilitating implementation.⁵³ By adopting these methods in healthcare, one clearly steps away from 'one size fits all-thinking' which is reflected in the six principles that characterise HCD⁵⁵: (1) the design is explicitly based on the understanding of the end user; (2) the end user is involved in the complete process of design and development; (3) the design is refined by the feedback of the end users; (4) HCD is an iterative process; (5) the design is an answer to the entire user experience; and (6) including the context. Understanding the HCD process is one thing, living it and being able to apply it is another. To fully exploit the benefits of HCD, it is important that researchers embrace the mindsets of HCD. Ideally, the design team consists of multidisciplinary skills and perspectives. IDEO describes seven mindsets that a human-centred designer should master: empathy, optimism, creative self-confidence, making, embracing ambiguity, keep iterating, and learning from failure. In addition, it is important one understands and accepts that HCD is not a linear process. No two processes are the same; however, each process consists of the same three phases: inspiration, ideation and implementation.⁴⁹⁻⁵¹ Each phase has specific tools that can be used to better understand the end user.⁵⁰

HCD should not be seen as a strict alternative to other approaches but as a complementary strategy that adds value.⁴⁹ In this MA4A study protocol, HCD will therefore be combined with the strengths of several traditional research methods.

Research team

The HCD research team consists of one lead researcher (first author), and supported by two senior researchers (last two authors). The lead researcher can rely on seven junior researchers per HCD phase to prevent researcher bias and to enhance credibility.^{59 60} Depending on the needs at the time, the research team will be supplemented with specific profiles. A statistical expert joins the research team in phase 1B for advice in the construction of the survey and analysis of the data. In addition, the

lead researcher followed an intensive training on HCD to learn to master the process and apply it in practice. In phase 2A, the second author participates to facilitate the ideation phase. The third and fourth authors will actively participate in the complete process as experts on ID.

End users

In this study, the DSPs are seen as the end users because PID are dependent on their quality of care and support. The desired outcome of this study is an effective support for DSPs in enabling MA for PID. The DSPs in this study are all working in accredited care facilities in Flanders (Belgium), more specifically in day care centres. The profile of DSPs working in day care is very diverse since the current vacancies do not seek specific education, but rather people who can identify with the job profile. People with a degree in occupational therapy, education, social work and many more can apply for a vacant position. Both people who have completed their secondary education and people with a bachelor's or master's degree are employed in day care centres. In addition to the DSPs as the end users, the most important stakeholders, the PID, should not be forgotten in this process. Their voice counts every step of the way and therefore we include them in the development process step by step, by means of a sounding board, a member of the development team and as the most important partner in the implementation phase.

Phase 1: inspiration

This first phase, the inspiration phase, consists of two major parts; phase 1A is a qualitative approach, and phase 1B a quantitative approach. In phase 1A, a wide variety of insights on enabling MA will be sought. In phase 1B, these insights will be tested in a larger sample.

Sample

In phase 1A, based on a purposive criteria-based sampling, a minimum of 12 respondents will be retained and maximum variation will be strived for. Criteria on which participants will be selected are (1) working in day care for PID (2) minimal 70% of the job description is focused on enabling MA, and (3) minimal experience of 1 year. No criteria are set based on age and qualification. Final selection will be made in consultation with the immediate superior to guarantee the continuity of daytime activities. Furthermore, extra attention will be paid to recruit a diverse population; new colleagues, recent graduates, experienced colleagues and working with different levels of ID. In phase 1B, the quantitative phase, the same criteria will be applied but the percentage of job description is reduced from 70% to a minimum of 50% to allow more DSPs to complete the survey.

Phase 1A

Participatory observations, combined with in-depth interviews, will be conducted in two day care centres in Flanders (accredited care providers by the VAPH). A conscious decision was made to include the two most common forms

of day care centres in Flanders: the so-called 'traditional approach' (more supply driven) with workshops (organisation 2) and the more 'inclusive approach' (which is more demand driven) (organisation 1). In organisation 1, situated in the province of Antwerp, activities can be observed in the mornings (12 hours in total). In organisation 2, in the province of East Flanders, there are no restrictions, and the researchers have free access to each workshop (24 hours in total). The interviews and observations will be performed by the seven junior researchers, under supervision of the lead researcher. The qualitative research protocol, the interview guide and participatory observation forms are prepared by the lead researcher in continuous alignment with the two senior researchers. The topics that will be addressed within the in-depth interviews are related to how DSPs experience enabling MA, which fostering or obstructing factors there exist, and which support needs they have in enabling MA. The complete interview guide can be consulted in online supplemental material 1.

The qualitative in-depth interviews and observations will be analysed in NVivo, using an interpretative phenomenological analysis (IPA), since this method is suitable for both qualitative in-depth interviews and for the analysis of observations of small samples.⁵⁹ In addition, IPA is concerned about how individuals experience phenomena and the psychological interpretation of their experiences.^{59 60} Both the junior researchers and the lead researcher will perform data analysis independently, in continuous alignment with the senior researchers. Member check and peer debriefing is scheduled after data analysis. The final report will be written by the lead researcher (with feedback from all authors) and will be used as a basis for the start of the quantitative part of the inspiration phase (1B).

Phase 1B

Based on the data from the qualitative part of the inspiration phase (1A), a web-based online survey will be prepared using Qualtrics. The survey will be distributed, accompanied with a cover letter, to all accredited care providers specialised in day care (n=260). The survey will be pilot tested. In total, 24 respondents will fill in the pilot questionnaire: 8 DSPs working in day care, 8 healthcare students and 8 laymen. The data analysis will be carried out via IBM SPSS Statistics V.27 by the lead and junior researchers, under supervision of the senior researchers, and with assistance from the statistical expert. Final report will be written by the lead researcher (again with feedback from all authors).

Phase 2: ideation

This phase must be as 'restriction-free' as possible, mainly to give a free rein to the creativity needed at this stage.⁵⁰ By means of a purposive criterion-based sampling, the development team will be composed. Recruitment of the team will start in the survey (1B). DSPs will be asked whether they are willing to cooperate in this phase. Specific extra

Table 1 Participants in phase 2

2A World Cafe	2B Guided brainstorm	2C Cocreation
Description and criteria	Description and criteria	Description and criteria
DSPs (n=8) ▶ Working in day care for adults with ID. ▶ Minimal 50% of the job description is focused on enabling meaningful activities. ▶ Experience >2 years.	DSPs (n=2) ▶ Working in day care for adults with ID. ▶ Minimal 50% of the job description is focused on enabling meaningful activities. ▶ Experience >2 years.	DSPs (n=2) ▶ Working in day care for adults with ID. ▶ Minimal 50% of the job description is focused on enabling meaningful activities. ▶ Experience >2 years.
Supervisor of DSPs (n=4) ▶ Supervising human service worker working in day care. ▶ Experience >2 years.	Supervisor of DSPs (n=2) ▶ Supervising human service worker working in day care. ▶ Experience >2 years.	Supervisor of DSPs (n=2) ▶ Supervising human service worker working in day care. ▶ Experience >2 years.
Expert in ID and day care (n=4) ▶ Expert in ID policy. ▶ Expert in day care.	Expert in ID and day care (n=2) ▶ Expert in ID policy. ▶ Expert in day care.	Expert in ID and day care (n=2) ▶ Expert in ID policy. ▶ Expert in day care.
PID (n=4) ▶ Full-time day care attendee. ▶ Experience >1 year.	PID (n=2) ▶ Full-time day care attendee. ▶ Experience >1 year.	
Expert in meaningful activities (n=4)	Expert in meaningful activities (n=2) Person who has no connection with day care or ID (n=2) ▶ Affinity with creative thinking and brainstorming.	Expert in meaningful activities (n=2)
Total n=24	Total n=12	Total n=8

DSP, direct support professional; ID, intellectual disability; PID, people with intellectual disabilities.

profiles will be sought that are assumed to make a unique contribution to the project. Profiles that depend on the ideas and concepts that arise in this phase (ie, for the brainstorm) will be selected that have nothing to do with healthcare. In doing so, the development team welcomes people who are unbiased and more likely to come up with new and innovative ideas.

The ideation phase consists of three major phases. First (2A), a World Cafe will be organised for a wide variety of stakeholders (see table 1) as it is a suitable way to enhance a collaborative dialogue around questions that matter.^{61 62} It facilitates an open and intimate discussion within a larger group of people.⁶¹ Different topics inherent to the design challenge will be discussed, guided by the World Cafe Reference Guide.⁶² Before the start of the World Cafe, the insights from the inspiration phase (both 1A and 1B) are shared with the participants of the World Cafe (n=24) to make sure they are aware of the needs and wishes of the end users, a basic premise before the search for opportunities begins. The major aim of the World Cafe is to further elaborate on the insights of phase 1, and to tune it to every important stakeholder. In the second part (2B), a guided brainstorm⁶³ will be held. The guided brainstorm is structured in time and approach. It starts with generating ideas, followed by selecting the best ideas. In the final step, the ideas are translated into a project sheet. Based on the project sheet from the guided

brainstorm, the third and last part of this phase (2C) starts and consists of building prototypes in cocreation sessions with the end users and stakeholders. The prototypes will be presented very quickly to the end users. This fast way of asking for feedback is essential and inherent to HCD. ‘You’ll keep iterating, refining, and building until you’re ready to get your solution out into the world’⁵⁰ (p 75).

Based on the ideal numbers to really get cocreation going, to generate as many ideas as possible and to keep the creative process going, the guidelines of each specific method were consulted. The World Cafe will have four, no more than five, participants per table.^{62 64} The brainstorm preferably is organised with 12 participants⁶⁵ and the cocreation sessions should have a minimum of six participants.⁵⁷

Once the team is assembled, an inspiring and nurturing environment will be sought, an environment that welcomes and stimulates creativity. For this study, the entire top floor of the building of the Artevelde University of Applied Sciences will be used for that purpose. In addition, the FabLab (a makers lab), which is also situated in that building, can be used at all times. The complete phase 2 will be facilitated by lead and junior researchers. More specifically in the World Cafe, the lead researcher will be the ‘cafe host’ and the junior researchers will be the ‘table hosts’. The lead researcher will facilitate both the brainstorm and the cocreation sessions. Also, the final

report will be written by the lead researcher (with feedback from all authors).

Phase 3: implementation

Based on the insights of phases 1 and 2, in this final phase, the prototype comes to life and will be taken to the end user in a real-world context.^{49 50 66} In the form of a 'live prototype', the product or service will be tested, followed by a 'pilot', which is a longer test than the live prototype and is one of the final iterations.⁵⁰ In order to realise a working and sustainable end product or service a prolonged test is needed. Therefore, living labs will be created as they are very suitable in fostering partnerships, validation and sustainability.⁶⁷ There is no agreed-upon definition of living labs, but it could be best defined as both an environment and an approach that enables researchers to cocreate and develop with the end users and stakeholders.^{67 68} Both organisations 1 and 2, and if necessary supplemented by two other organisations from different provinces in Flanders, will serve as living labs. As those living labs are social environments, they are subject to human volitions, culture and language,^{69 70} and therefore a realist evaluation (RE) is chosen to understand how contextual factors influence our interventions. Even though an RE is time consuming, intensive and challenging, it has proven to be a method that provides a deeper understanding of how, when and for whom a programme works.⁷⁰ Based on scientific literature, the data of previous phases (1A and 1B), the ideas and prototype (2A, 2B and 2C), an initial programme theory will be created. More specifically, contextual factors (C), mechanisms (M) and outcomes (O) will be mapped into a CMO configuration⁶⁹ in order to get a better understanding of how, when and for whom the outcome of this HCD process (figure 1) works.

Developing a tool or service is often very complex and calls for a specific approach.⁴⁸ This MA4A study protocol answers that call and really puts the end users at the heart of the development process.^{54 56 57 71–73} Within this study, the DSPs are seen as the end users and the PID as the

most important beneficiary or stakeholder, which made it difficult to determine the role of PID and to what extent they should be involved in the process. Working with PID in research can be challenging and asks for accessible cocreation tools.⁷⁴ In addition, to maximise and optimise the input of PID, a solid 'architecture of involvement' is needed and preplanning and training of PID is essential to avoid tokenistic involvement.⁷⁵ Within this MA4A study protocol, PID will be actively involved from phase 2, starting with the World Cafe. Concerning the World Cafe, no specific training is prepared. However, measures will be taken to make the World Cafe accessible for PID. At all times, a visual harvester will be present to visualise the output of the World Cafe. Every participant on the World Cafe is given placemats, which can be drawn or doodled on. This can be helpful for PID who have difficulties communicating in a verbal manner. Each participant with ID can bring a DSP to support them during the World Cafe. The table hosts will be given the explicit instruction to address the PID, rather than his DSP. In phase 3, the PID will be at the centre of the research as the study uses a living lab methodology. Since the organisation of the living labs can only be prepared once the tool or service is known, a specific preplanning and training programme for PID can be developed for phase 3 if needed. In addition, the PID will be in their natural environment, which makes it more familiar and predictable. Finally, research shows the benefits for PID to participate in cocreation⁷⁵ and it also leads to better well-being and job satisfaction for DSPs when they work together with PID.⁷⁶

Research into the application of the HCD process is not evident as it is constantly used interchangeably with other (similar) methods, which systematically complicates research.^{54 72} Studies, however, show that by using an HCD process in the correct way, the functionality, quality, usability and acceptability increase, which ultimately also causes a decrease in product failure.^{49 52} An HCD process is very intense and challenging,^{49 66} and that is why this MA4A study protocol is so carefully planned. In addition, it is enriched with traditional research methods to reduce bias and enhance credibility. The use of traditional research approaches implies that researchers follow a research protocol, such as determining sample sizes and response rates. Within the qualitative part (1A) of the study, it is difficult to determine the sample size a priori because exploratory research looks to explore phenomena in relation to themes one cannot identify in advance.⁷⁷ Thus, within phase 1A, no estimate of sample size can be calculated. The concept of saturation⁵⁹ is more appropriate within phase 1A and therefore the aim is to interview until nothing new is being learnt. In phase 1B, for the web-based online survey, it is difficult to determine the response rate needed to prevent sampling bias because there are no exact numbers of DSPs working in day care facilities. In Flanders, there are 257 licensed care providers but there are no available figures of the total amount of DSPs. The exact number of DSPs depends on the degree of care the person with ID needs (the support

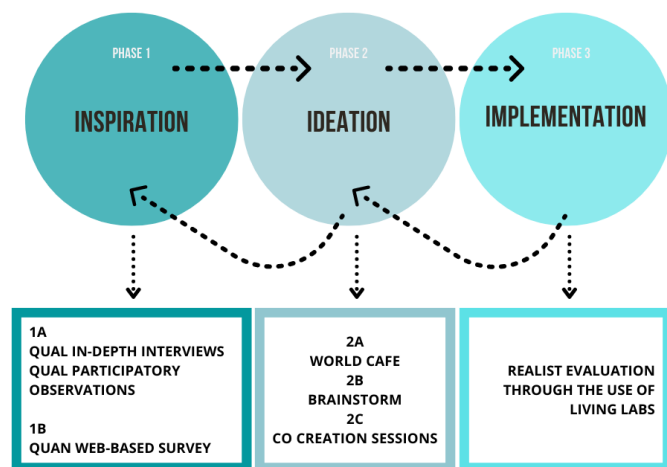


Figure 1 Overview of the Meaningful Activities 4 All (MA4A) study protocol.

budget one receives increases with the degree of support needed) and this in combination with the level of education of the DSPs (the higher educated the DSP, the higher the cost). In short, each organisation is free to fill in the available vacancies, which means it is impossible to know how many DSPs there are in Flanders at any particular point in time.⁷⁸ After the survey is sent, follow-up mail will be sent to enhance response rates.⁷⁹ In addition, findings from the survey will be benchmarked with other published data in order to deal with the fact that analysis prior to sending out the survey is not possible due to the lack of available data.⁸⁰

By performing this MA4A study protocol, the future support for DSPs will be grounded in their own wishes and needs, and it will be established by means of an innovative cocreative approach, an approach that is more likely to be adopted in practice, in comparison to the output of traditional research methods. PID will benefit, and fellow researchers in the field will have a reference protocol that will guide them in their own research. Ultimately, DSPs will receive the proper support they deserve. Because in the end, they are key in enabling PID to engage in MA.

Patient and public involvement

HCD carries patient and public involvement in the core of its approach. In this protocol, we took all possible steps to involve PID and the DSP. First, the researchers have all a long-lasting connection with clinical practice and the reason why this study is undertaken is based on the concrete questions we received from clinical practice. PID, who have a strong and trustful relationship with the DSP, indicated that they did not always have access to MA. Contact with Flemish day care centres showed indeed that DSP needed support in enabling MA. The DSP advocated the patients' wishes with the researchers and from these perspectives the PID, as well as the DSP, were involved in the overall design of the study. The results of the study will therefore be grounded in their specific wishes and the results will have high potential of being tailored to their needs. All results will be shared with all Flemish day care centres from the beginning, during and at the end of the study.

ETHICS AND DISSEMINATION

Ethical application was submitted to the Ethics Committee of University Hospital Ghent (Belgium) and approved on 6 February 2020 (reference numbers: B670202042983 and PA2021-091). Data collection (1A) started in March 2020. The complete process is expected to continue until August 2023. All participants will sign a written informed consent form. To ensure confidentiality, all data obtained from the participants will be processed and pseudonymised. The results of this study will be submitted for publication in relevant peer-reviewed journals and will be presented at relevant conferences. This protocol takes into account the guiding principles concerning the rights of PID at all times.

Author affiliations

¹Department of Rehabilitation Sciences and Physiotherapy, Ghent University, Ghent, Belgium

²Health and Care, Artevelde University College, Ghent, Belgium

³Special Needs Education, Ghent University, Ghent, Belgium

⁴Department of Gerontology and Frailty in Ageing Research Group, Vrije Universiteit Brussel, Brussels, Belgium

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ORCID iDs

Christophe Wille <http://orcid.org/0000-0002-2138-6200>

Dominique Van de Velde <http://orcid.org/0000-0001-6982-1075>

Patricia De Vriendt <http://orcid.org/0000-0003-4861-7838>

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