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"Meaningful Activities 4 All (MA4A)" A Human Centered Design Protocol to Support Human Service Workers in Enabling People with Intellectual Disabilities to Engage in Meaningful Activities

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"Meaningful Activities 4 All (MA4A)"

A Human Centered Design Protocol to Support Human Service Workers in Enabling People with Intellectual Disabilities to Engage in Meaningful Activities

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2

ABSTRACT

INTRODUCTION

Meaningful activities have a positive impact on identity, well-being and the degree of participation and inclusion. People with intellectual disabilities attending day-care centres in Flanders depend heavily on their human service workers (HSW) to engage in meaningful activities. HSW on their part are also in need of support, and struggle to enable meaningful activities. Moreover, little is known about the quality HSW offer, about their needs, and what could enable them to provide more qualitative support.

METHODS AND ANALYSIS

In order to develop a solution based on the specific needs of HSW, an innovative and iterative approach is needed. A human centered design protocol is constructed, combined with the strengths of traditional research methods. In a first phase (INSPIRATION phase), the needs of HSW will be mapped based on qualitative and quantitative approaches. In a second creative phase (IDEATION phase), in co-creation with the HSW, people with intellectual disabilities and other stakeholders, a solution will be developed based on the insights of phase one. In the third and final phase, the solution will be tested in the field by means of living labs and a realist evaluation (IMPLEMENTATION phase).By adopting this unique protocol, the functionality, quality, usability, and acceptance is expected to increase, which in turn should result in a decrease of product or service failure. In contrast to other HCD-protocols, this protocol adopts all phases of the HCD process. Moreover, this protocol shows the complementarity of HCD with more traditional research methods. People with intellectual disabilities and the HSW will benefit as the end-result is truly grounded in their specific needs and wishes. This protocol could inspire researchers in other challenging intervention development.

ETHICS AND DISSEMINATION

This study was approved by the Ethics Committee of the University Hospital Ghent, Belgium. The results of this study will be published and presented.

KEYWORDS

Accredited care providers | Disability policy | Innovation | Support Needs | Disability Support Worker

STRENGHTS AND LIMITATIONS

- The support needs of human service workers, working in day-care centres for people with intellectual disabilities, to date, have not been thoroughly investigated and this study will fill that void.

- This study is the first study using the complete Human Centered Design process combining it with the strengths of traditional research methods.

- The involvement of the end-user in research is increasingly encouraged. This protocol aims to become a reference protocol in performing 'human centered design research'.

- By adopting Human Centered Design, the results of this study should be of high quality, functional, applicable, grounded in the needs of the end-users, and therefore be widely and more easily accepted.

- Human Centered Design is relatively new in comparison to traditional research methods and therefore could still be open to some scepticism or criticism.

4

"Meaningful Activities 4 All (MA4A):
A Human Centered Design Protocol to Support Human Service Workers in Enabling
People with Intellectual Disabilities to Engage in Meaningful Activities

INTRODUCTION

It is generally assumed that the prevalence of people with intellectual disabilities (ID) worldwide varies from 1% to 3% based on income, age, origin, with the highest rates to be found in low- and middle-income countries (1). The most widely adopted definition on ID is the one 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 multi-dimensionality of ID (3–5), enabling Human Service Workers (HSWs) to get a more comprehensive understanding of ID, and allowing them to establish a more purposeful approach towards people with ID (2).

People with ID have been excluded for a long time from society due to their limited abilities in both intellectual capacities and adaptive behaviour (6). People with ID need continuous additional support to participate in society as equal citizens (3,7). Therefore, people with ID who are not adequately supported, are at risk of being excluded from society (6). In addition, life expectancy of people with ID increased significantly over the last decade's (8,9). Consequently, nearly half of the people in day-care facilities are of older age (9), and have a life expectancy close to that of people without disabilities. Most people with ID lack age-specific support and when they age this can potentially lead to inappropriate placement and loss of social networks (8).

One of the most important and influential conventions that address this inequality is the *'United Nations Convention on the Rights of Persons with Disabilities'* (UNCRPD) (6). By signing the convention, all member states agree to implement the convention in their national policy on ID (6,10). Since the convention was adopted, 164 countries signed the convention (11) and 94 ratified both the convention and the optional protocol (12). The Flemish Agency for Persons with Disabilities (VAPH) has developed a policy in accordance with the UN Convention and the current vision on ID (13). The 'quality of life supports model paradigm' (14,15), comprised out of 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) 7,100 young people received professional help and 24,677 adults with disabilities received a personal budget (17). Around 15.000 people with a disability are still on a waiting list for care and support.

5

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 people with ID 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"* (18).The focus within those centres is on enabling people with ID to participate in meaningful activities (MA). 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 (19–24). 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 (25,26) and since every person is unique, he or she makes different choices for activities (27). Engagement in MA is also crucial to improve the QOL of people with ID (28,29). 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, people with ID are experiencing deprivation, which is detrimental for their health and well-being (30). Although every person has the right to participate in MA (32–34), this is not always the case for people with ID (35).

In recent years the personal goals, needs and wishes of people with ID became increasingly important in enabling MA (9,35,36). 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 quality-of-life outcome (36), yet not all people with ID are able to explicitly communicate their goals (9,35). Too often people with ID are dependent on HSWs' abilities to communicate at their level and understand them. Therefore HSWs need to depend on their own experience and those of others (family or other proxies) to understand what is meaningful for the person with ID in order to tailor and adapt activities to each individual with ID (9,35). The quality of the communication between HSWs and people with ID is associated with engagement of people with ID 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 (29). Furthermore, people with ID experience activities more meaningfully when they are treated respectfully and as adults (30).

In recent years, support for people with ID has improved significantly. Despite this favourable evolution, many people with ID still remain segregated from society and have fewer opportunities for personal development, participation, and inclusion (38). In addition, it is imperative to understand that people with ID depend upon the quality of support they receive from HSWs (29). More specific, the higher the quality of the HSW, the more personal outcomes for people with ID (39). Sadly, people with ID stay under engaged 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 (30). HSWs seems to be left to fend for themselves too often, which results in poor quality of support (29). Furthermore, a sizeable portion of HSWs are not qualified adequately to provide the required effective support (40). In addition, HSW's are confronted with a great heterogeneity of ID and various roles, duties and tasks

6

that are typically determined by the centre in which they are employed. Depending on their educational background, it is difficult for HSW's to acquire all skills, knowledge and abilities that are required to effectively perform their roles (41). In addition, there is a disconnection between EBP and the competencies of HSW's (40). However, it is important to underline that working with people with ID is very challenging for every HSW's due to the complex nature of ID (42,43), resulting in HSW's being exhausted and not being able to meet de demands related to their job, and even resulting into burnout (44).

The overall objective of this study is to develop a more qualitative support for people with ID, enabling them to participate more in meaningful activities and by extension in society. The foregoing results in the following research question for this study: "What do human service workers, working in day-care centres, need to enabling people with ID 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 human service workers. In doing so, HSW's will be able to meet the complex demands, inherent to working with people with ID. In order to develop such a tool or service, a specific co-creative 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 (45,46). It can be concluded that there is still a research-to-practice gap (45,47). 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 pro-active (47). Therefore, this study 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 (48). 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 (49). HCD is nowadays increasingly accepted in the human services sector (50–52), however, when used, it is not used standardised or reduced to using some features of HCD (53,54). Furthermore, there is no consensus definition (53). Therefore, HCD can best be labelled an 'umbrella term' (54) for all approaches grounded in the needs of their target population, also called the end-user, while developing products or services (50,55,56). In essence, HCD puts the needs, expectations, desires and experiences of the end-user central (53,54,57) and explicitly searches for the 'deep story' (48). 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 (52). By adopting these methods in health care, one clearly steps away

7

from 'one size fits all-thinking' which is reflected in the six principles that characterise HCD (54): (I) The design is explicitly based on the understanding of the end-user. (II) The end-user is involved in the complete process of design and development. (III) The design is refined by the feedback of the end-users. (IV) HCD is an iterative process. (V) The design is an answer to the entire user experience. (VI) 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 researchers embrace the mindsets of HCD. Ideally, the design team consists of multidisciplinary skills and perspectives. IDEO describes seven mindsets that a human-centered designer should master: empathy, optimism, creative self-confidence, making, embracing ambiguity, 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 out of the same tree phases: inspiration, ideation, and implementation (48–50). Each phase has specific tools that can be used to better understand the end-user (49).

HCD should not be seen as a strict alternative to other approaches but as a complementary strategy that adds value (48). In this study HCD will therefore be combined with the strengths of several traditional research methods.

What follows is the concrete HCD protocol for this MA4A-study.

Research team
The HCD research team consists out of one lead researcher (first author), supported by two senior researchers (last two authors). The lead researcher can rely on 7 junior researchers per HCD-phase to prevent researcher bias and to enhance credibility (58,59). 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 second author participate 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 HSWs are seen as the end-users because people with ID are dependent on their quality of care and support. The desired outcome of this study is effective support for HSWs in enabling MA for people with ID. The HSWs in this study are all working in accredited care facilities in Flanders (Belgium), more specifically in day-care centres. The profile of HSWs working in day-care are 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 HSWs as the end-users, the most important stakeholders, the people with ID, should

8

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, part 1A is a qualitative approach, and part 1B, a quantitative approach. In 1A, a wide variety of insights on enabling MA will be sought. In 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 people with ID, 2) minimal 70% of the job description is focused on enabling meaningful activities and 3) minimal experience of 1 year. No criteria are set based on age and diploma. 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 HSWs to complete the survey.

Phase 1 A

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 with workshops' (organisation 2) and the more 'inclusive approach' (organisation 1). In Organisation 1, situated in the province of Antwerp, activities can be observed in the mornings (12h). In Organisation 2, in the province of East Flanders, there are no restrictions, and the researchers have free access to each workshop (24h). The interviews and observations will be performed by the 7 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 qualitative in-depth interviews and observations will be analysed in Nvivo, using an Interpretive Phenomenological Analysis (IPA), since this method is suitable for both qualitative in-depth interviews and for the analysis of observations of small samples (58). In addition, IPA is concerned about how individuals experience phenomena and the psychological interpretation about their experiences (58,59). Both junior researchers and the lead researcher will perform data analysis

9

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 all authors) and will be used as a basis for the start of the quantitative part of the inspiration phase (1B).

Phase 1 B

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 HSWs working in day-care, 8 healthcare students and 8 laymen. The data analysis will be carried out via IBM SPSS statistics 27 by the lead and junior researchers, under supervision of the senior researchers, and in assistance of the statistical expert. Final report will be written by the lead researcher (again with feedback of all authors).

Phase 2 | IDEATION

This phase, must be as 'restriction-free' as possible, mainly to give free rein to the creativity needed at this stage (49). By means of a purposive criterion-based sampling, the development team will be composed. Recruitment of the team will start in the survey (1B). HSWs will be asked whether they are willing to cooperate in this phase. Specific extra profiles will be sought that are assumed to make a unique contribution to the project. Which ones depend on the ideas and concepts that arise in this phase. I.e., for the brainstorm profiles 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 wild, new, and innovative ideas.

The ideation phase consists of three major phases. First (2A) a World Café (WC) 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 (60,61). It facilitates on open and intimate discussion within a larger group of people (60). Different topics inherent to the design challenge will be discussed, guided by the World Café reference Guide (61). Before the start of the WC, the insights from the inspiration phase (both 1A and 1B) are shared with the participants of the WC (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 WC is to further elaborate on the insights of phase 1, and to tune it to every important stakeholder. In the second part (2B), a brainstorm will be held to generate lots of ideas, using de GPS-method (62). Based on the selected ideas in the GPS-brainstorm, the third and last part of this phase (2C) consists of building prototypes in co creation sessions with the end-users and stakeholders. The prototypes will be presented very quick 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"* (IDEO, 2015, p75).

10

	2A WORLD CAFE	2B GPS-BRAINSTORM	2C CO-CREATION
	Description and criteria	**Description and criteria**	**Description and criteria**
	HSWs (n=8) • Working in day-care for adults with ID, • Minimal 50% of the job description is focused on enabling meaningful activities • Experience >2 year	HSWs (n=2) • Working in day-care for adults with ID, • Minimal 50% of the job description is focused on enabling meaningful activities • Experience >2 year	HSWs (n=2) • Working in day-care for adults with ID, • Minimal 50% of the job description is focused on enabling meaningful activities • Experience >2 year
	Supervisor of HSWs (n=4) • Supervising Human service worker working in daycare • Experience >2 year	Supervisor of HSWs (n=2) • Supervising Human service worker working in daycare • Experience >2 year	Supervisor of HSWs (n=2) • Supervising Human service worker working in daycare • Experience >2 year
	Expert in ID and daycare (n=4) • Expert in ID policy • Expert in day-care	Expert in ID and daycare (n=2) • Expert in ID policy • Expert in day-care	Expert in ID and daycare (n=2) • Expert in ID policy • Expert in day-care
	Person with ID (n=4) • Full-time attendee daycare • Experience > 1 year	Expert in Meaningful Activities (n=2)	Expert in Meaningful Activities (n=2)
	Expert in Meaningful Activities (n=4)	Person who has no connenction with daycare or ID (n=2) • Affinity with creative thinking and brainstorms	
	Total n=24	Total n=10	Total n=8

Table 1 – Participants in phase 2

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 (AUAS) 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 WC, the lead researcher will be the 'café host' and the junior researchers will be the 'table hosts'. The lead

11

researcher will facilitate both the brainstorm and the co-creation sessions. Also, the final report will be written by the lead researcher (with feedback of all authors).

Phase 3 | IMPLEMENTATION

Based on the insights of phase 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 (48,49,63). 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 (49). 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 (64). There is no agreed upon definition on living labs but it could be best defined as both an environment and an approach that enables researchers to co-create and develop with the end users and stakeholders (64,65). Both organisation 1 and 2, if necessary supplemented with 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 (66,67) and therefore a realist evaluation (RE) is chosen to understand how contextual factors influence our health interventions. Even though a RE is time-consuming, intensive and challenging, is has proven to be a method that provides a deeper understanding of how, when, and for whom a program works (67). Based on scientific literature, the data of previous phases (1A and 1B), the ideas and prototype of (2A, 2B and 2C), an Initial Program Theory (IPT) will be created. More specific, contextual factors (C), mechanisms (M) and outcomes (O) will be mapped into a CMO-configuration (66) in order to get a better understanding of how, when en for whom the outcome of this HCD-process (figure 1) works.

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 people with ID and the HSW. Firstly, the researchers have all a long-lasting connection with clinical practice and the reason why this study is undertaken is based on concrete questions we received from clinical practice. People with ID, who have a strong and trustful relation with the HSW, indicated that they did not always have access to MA. Contact with Flemish day-care centres showed indeed that HSW needed support in enabling MA. The HSW advocated the patients' wishes with the researchers and from these perspectives the person with ID, as well as the HSW 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.

12

ETHICS AND DISSEMINATION

Ethical application was submitted to the Ethics Committee University Hospital Ghent (Belgium) and approved on 06/02/2020. Reference numbers are 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. To ensure confidentiality, all data obtained from the participants, will be processed pseudonymised. Study results will be written and published. This protocol at all times takes in account guiding principles concerning the rights of people with intellectual disabilities.

DISCUSSION

Developing an intervention is often very complex and calls for a specific approach (47). This HCD research protocol answers to that call and really puts the end-users at the heart of the development process, which is the main aim of HCD (53,55,56,68–70). Research into the application of HCD is not evident as it is constantly used interchangeably with other (similar) methods, which systematically complicates research (53,69). Studies however show that by using HCD in a right way, the functionality, quality, usability and acceptability increases, which ultimately also causes a decrease in product failure (48,51). HCD is very intense and challenging (48,63) and that is why this protocol is so carefully planned. In addition, it is enriched with traditional research methods to reduce bias and enhance credibility. By performing this protocol, not only will the future support for HSWs be grounded in their own wishes and needs, but it will also be established by means of an innovative co-creative approach. An approach that is more likely to be adopted in practice, in comparison to the output of traditional research methods. People with ID will benefit, and other researchers will have a reference protocol that will guide them in their own research. Ultimately, HSWs will receive the proper support they deserve. Because in the end, they are key in enabling people with ID to engage in meaningful activities.

13

CONTRIBUTORSHIP STATEMENT

CW, DVdV and PDV initiated the study, conceptualised the study and designed the first draft of the study protocol. IDC, GVH and JVL reviewed the study protocol and provided feedback for the refinement of the protocol. CW wrote the first draft of the final version of the manuscript. All authors read the manuscript, provided feedback, and approved the final version.

COMPETING INTERESTS

There are no competing interests to be reported.

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14

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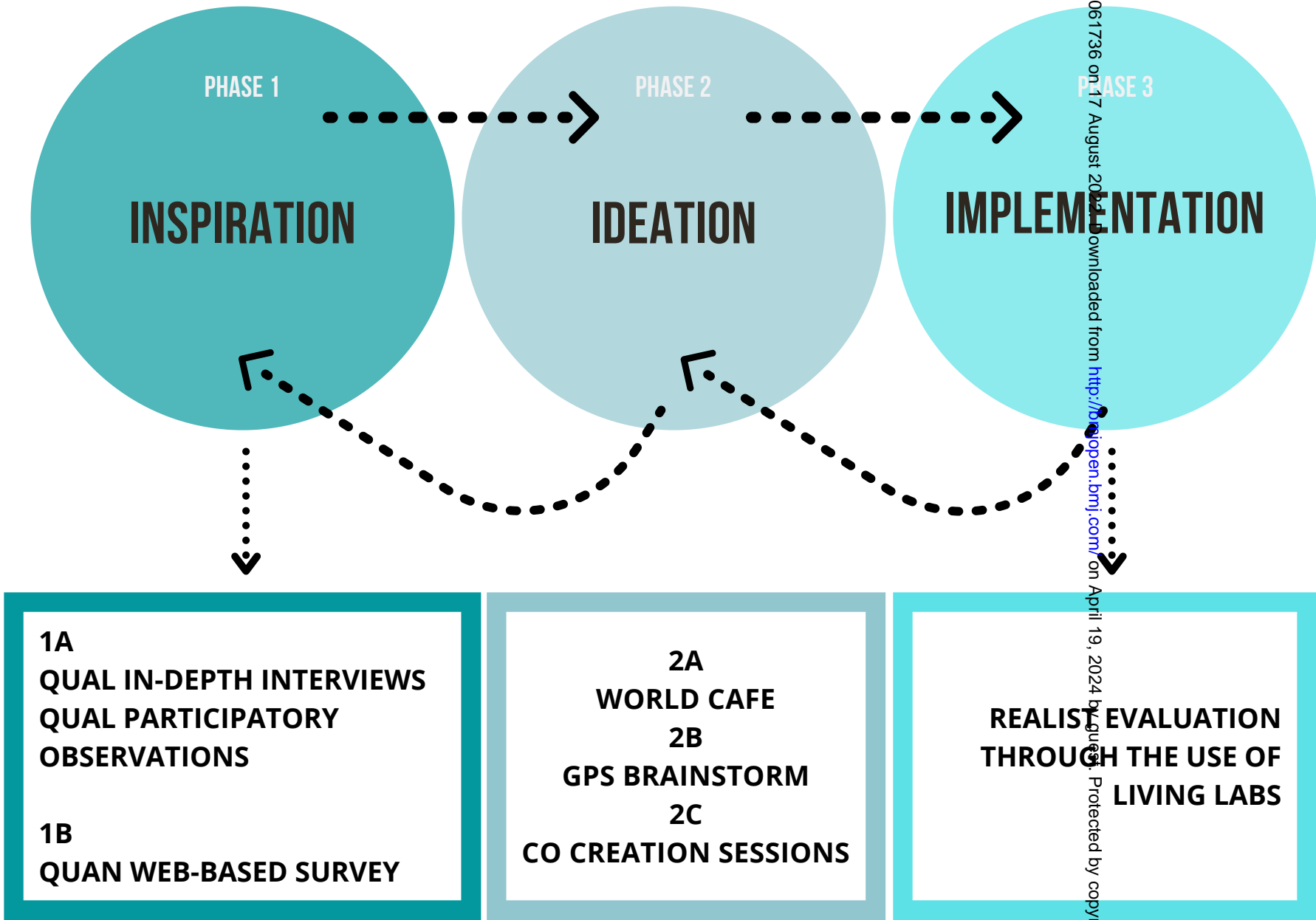
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FIGURE LEGEND

Figure 1 - Overview of the HCD-protocol

18

PHASE 1

PHASE 2

PHASE 3

INSPIRATION

IDEATION

IMPLEMENTATION

**1A
QUAL IN-DEPTH INTERVIEWS
QUAL PARTICIPATORY
OBSERVATIONS**

**1B
QUAN WEB-BASED SURVEY**

**2A
WORLD CAFE
2B
GPS BRAINSTORM
2C
CO CREATION SESSIONS**

**REALIST EVALUATION
THROUGH THE USE OF
LIVING LABS**

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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

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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

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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 one will guide a co-creation 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 is 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.

KEYWORDS

Accredited care providers, Disability policy, Innovation, Support needs, Disability support worker

2

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.
- Co-creation with people with intellectual disabilities is challenging and required accessible co-creation 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.

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 rates to be found in low- 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 multi-dimensionality 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 decade's (11,12). Older PID represent nearly half of all PID (12). Consequently, nearly half of the people in day-care facilities are of older age (12) 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 addresses inequality is the *'United Nations Convention on the Rights of Persons with Disabilities'* (UNCRPD) (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 convention (15) 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 UN Convention and the current vision on ID (17). The 'quality of life supports model paradigm' (18,19), comprised out of 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) 7,100 young people received professional help and 24,677 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). MA are associated with the personal interests of people and are enjoyable by nature (28,30). MA 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 society (31) 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

4

his or her quality-of-life 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 ambiance 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 upon 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 under engaged 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, DSP's 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 DSP's 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 DSP's (41). However, it is important to underline that working with PID is very challenging for all DSP's due to the complex nature of ID (43,44), resulting in DSP's 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 meaningful activities 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, DSP's will be able to meet the complex demands, inherent to working with PID. In order to develop such a tool or service, a specific co-creative and innovative research method is needed.

5

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 pro-active (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 sector (51–53), 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 health care, one clearly steps away from 'one size fits all-thinking' which is reflected in the six principles that characterise HCD (55): (I) The design is explicitly based on the understanding of the end-user. (II) The end-user is involved in the complete process of design and development. (III) The design is refined by the feedback of the end-users. (IV) HCD is an iterative process. (V) The design is an answer to the entire user experience. (VI) 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 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, 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 out 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).

6

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 out of one lead researcher (first author), supported by two senior researchers (last two authors). The lead researcher can rely on 7 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 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 are 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, part 1A is a qualitative approach, and part 1B, a quantitative approach. In 1A, a wide variety of insights on enabling MA will be sought. In 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 meaningful activities and 3) minimal experience of 1 year. No criteria are set based on age and qualification. Final

7

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 1 A

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 7 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 supplementary material 1.

The qualitative in-depth interviews and observations will be analysed in NVivo, using an Interpretive 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 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 1 B

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 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).

8

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 profiles will be sought that are assumed to make a unique contribution to the project. Which profiles depend on the ideas and concepts that arise in this phase. I.e., for the brainstorm profiles 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 brainstorm (63) 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 co-creation 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"* (IDEO, 2015, p75).

2A WORLD CAFÉ	2B GUIDED BRAINSTORM	2C CO-CREATION
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 year	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 year	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 year

9

Supervisor of DSPs (n=4)	Supervisor of DSPs (n=2)	Supervisor of DSPs (n=2)
• Supervising Human service worker working in day-care • Experience >2 year	• Supervising Human service worker working in day-care • Experience >2 year	• Supervising Human service worker working in day-care • Experience >2 year
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 attendee day-care • Experience > 1 year	PID (n=2) • Full-time attendee day-care • Experience > 1 year	
Expert in Meaningful Activities (n=4)	Expert in Meaningful Activities (n=2)	Expert in Meaningful Activities (n=2)
	Person who has no connection with day-care or ID (n=2) • Affinity with creative thinking and brainstorms	
Total n=24	Total n=12	Total n=8

Table 1: Participants in phase 2

Based on the ideal numbers to really get co-creation 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 4, no more than 5, participants per table (62,64). The brainstorm preferably is organised with 12 participants (65) and the co-creation sessions should have a minimum of 6 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 (AUAS) 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 co-creation sessions. Also, the final report will be written by the lead researcher (with feedback from all authors).

10

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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 co-create 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 a 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 of (2A, 2B and 2C), an Initial Program Theory (IPT) will be created. More specifically, contextual factors (C), mechanisms (M) and outcomes (O) will be mapped into a CMO-configuration (69) 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 co-creation tools (74). In addition, to maximise and optimise the input of PID a solid 'architecture of involvement' is needed and pre-planning 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 BMJ 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 pre-planning 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.

11

Finally, research shows the benefits for PID to participate in co-creation (75) 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 a HCD process in the correct way, the functionality, quality, usability and acceptability increases, 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 imply 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 sample size as 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 saturation (59) 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 licenced 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 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, not only will the future support for DSPs be grounded in their own wishes and needs, but it will also be established by means of an innovative co-creative 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 meaningful activities.

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. Firstly, the researchers have all a long-lasting connection with clinical practice and the reason why this study is undertaken is based on 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

12

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 University Hospital Ghent (Belgium) and approved on 06/02/2020. Reference numbers are 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 people with intellectual disabilities at all times.

CONTRIBUTORS

CW, DVdV, and PDV initiated the study, conceptualised the study and designed the first draft of the study protocol. IDC, GVH and JVL reviewed the study protocol and provided feedback for the refinement of the protocol. CW wrote the first draft of the final version of the manuscript. All authors read the manuscript, provided feedback, and approved the final version.

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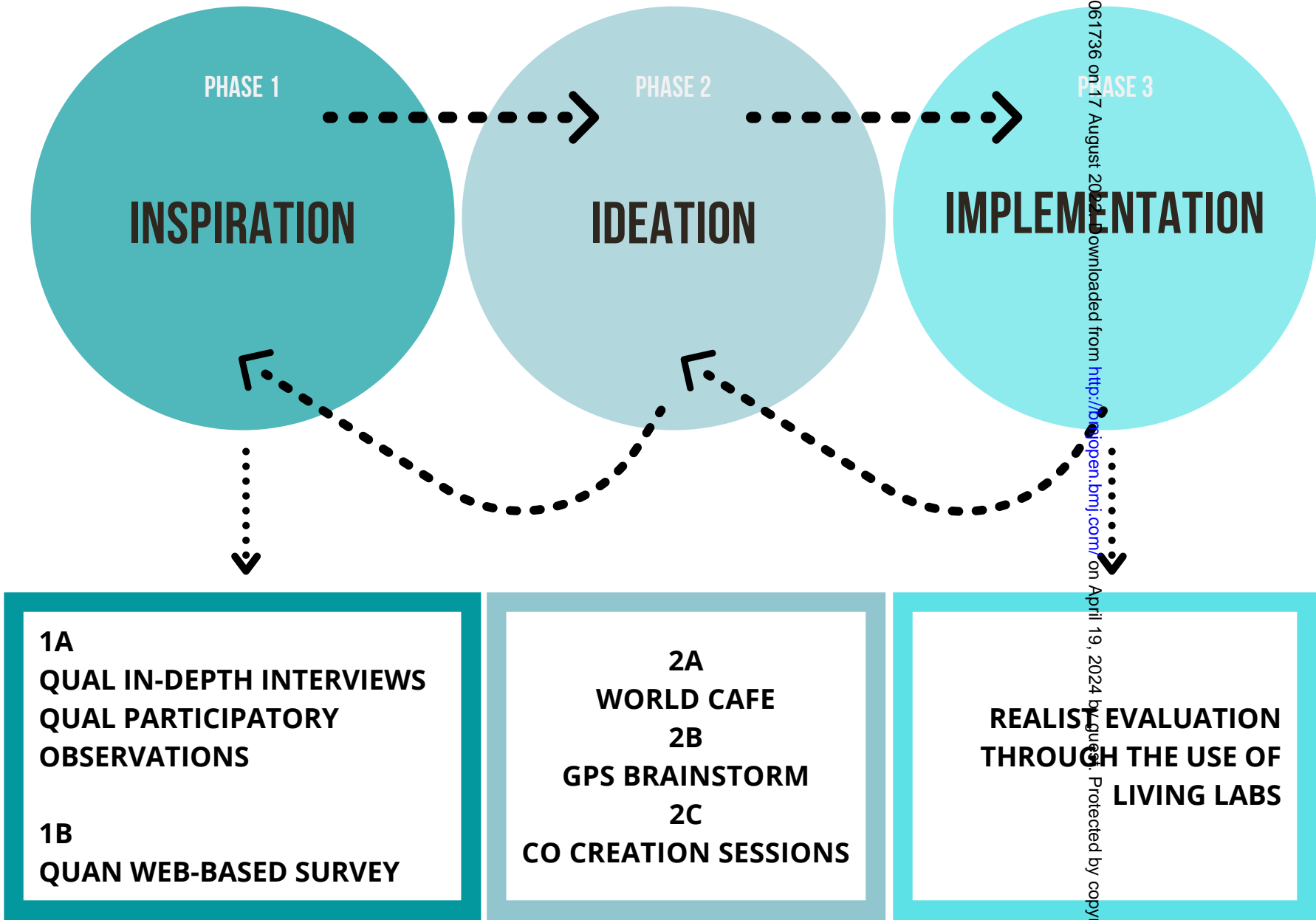40. Schalock RL, Van Loon J, Mostert R. a Systematic Approach To Enhancing the Personal Well-

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FIGURE TITLE

Figure 1: Overview of the MA4A study protocol

17

PHASE 1

PHASE 2

PHASE 3

INSPIRATION

IDEATION

IMPLEMENTATION

1A
QUAL IN-DEPTH INTERVIEWS
QUAL PARTICIPATORY
OBSERVATIONS

1B
QUAN WEB-BASED SURVEY

2A
WORLD CAFE
2B
GPS BRAINSTORM
2C
CO CREATION SESSIONS

REALIST EVALUATION
THROUGH THE USE OF
LIVING LABS

INTERVIEW GUIDE

Important: when answering the questions, think about an average day. Do not think of a special day that only goes on once a year.

Introduction question
- Can you introduce yourself briefly?
- Can you briefly present the organisation you work for?
  - *If the function and job description are not clear; "Can you describe your job within the organisation?*

Transition question
- How did you end up in an organisation for adults with intellectual disabilities?
  - *If length of employment was not mentioned, "How long do you work with people with intellectual disabilities?"*
  - *Have you consciously chosen for people with intellectual disabilities? Why did you or why didn't you?*

Key questions
- How would you describe your job?
  - *Can you give an example of an average day?*
- How do you experience working with adults with intellectual disabilities?
  - *What roles do you take on as a professional caregiver?*
- What do you think your interventions/activities mean for the person with intellectual disabilities?
  - *Can you give an example of a situation in which this is reflected?*
- What are ideal activities for persons with intellectual disabilities according to you?
  - *What conditions should be met to describe it as meaningful daycare?*
- When are activities no longer meaningful?
- What are contributing factors in enabling meaningful activities?
- What are obstructing factors in enabling meaningful activities?
- What support do you need in enabling meaningful activities for adults with intellectual disabilities?
  - *Where do you feel insecure in enabling meaningful activities?*
  - *What information do you still require concerning meaningful activities?*

Final question
- How would you describe 'meaningful activities'?
- Are there things you would like to add to this interview?