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Action Opportunities to Pursue Responsible Digital Care for Persons With Intellectual Disabilities

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Abstract

Background: Responsible digital care refers to ‘including any intentional systematic effort designed to increase the likelihood of a digital care technology developed through ethical decision-making, being socially responsible and aligned with the values and wellbeing of those impacted by it’.

Objective: We aim to present examples of action opportunities for a) the design of ‘Technology’; b) shaping the ‘Context’ of use; and c) adjusting the behaviour of the ‘Users’, to guide the responsible use of digital care for persons with intellectual disabilities (ID).

Methods: Three cases: 1) design of a web app to support preparing meals for groups of persons with ID; 2) implementation of an app to help persons with ID regulate their stress independently; 3) implementation of a social robot to stimulate interaction and physical activity among persons with ID. Twenty-six stakeholders participated in three multi-stakeholder workshops (n=10; 10; 6 for case 1, 2 and 3, respectively) based on the ‘guidance ethics approach’. Stakeholders’ values were identified based on bottom-up exploration of experienced and expected effects of using the technology, and action opportunities were formulated to account for these values in the specific context of use. Qualitative data were thematically analysed.

Results: In total, 232 effects, 33 values and 156 action opportunities were collected. General and case-specific themes were identified. Important stakeholders’ values included: quality of care, autonomy, efficiency, health, enjoyment, reliability and privacy. Both positive and negative effects could underlie stakeholders’ values and influence the development of action opportunities. Action opportunities comprised a) Technology: development of the technology (e.g. optimise user experience, customisation), technology input (e.g. recipes for meals; intervention options for reducing stress; activities, for case 1, 2 and 3, respectively) and technology output (e.g. storage and use of data); b) Context: guidelines, training and support, policy/agreements, and adjusting the physical environment in which the technology is used; c) User: integrating the technology use into daily care practice, by diminishing (e.g. ‘letting go’ to increase autonomy of persons with ID), keeping (e.g. face-to-face contact), and adding (e.g. evaluation moments) certain behaviours of care professionals.

Conclusions: This is the first study to provide insight into responsible digital care for persons with ID, by means of bottom-up exploration of action opportunities to take account of stakeholders’ values in designing technology, shaping context of use, and adjusting behaviour of users. While part of the findings may be generalised, case-specific insights are essential, as well as a complementary top-down approach (e.g. applying predefined ethical frameworks). The findings represent a start/part of an ethical discourse that requires follow-up to meet the dynamism of stakeholders’ values and to further develop and implement action opportunities to achieve socially desirable, ethically acceptable and sustainable digital care that improves the lives of people with disabilities.

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Original paper

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Action Opportunities to Pursue Responsible Digital Care for Persons With Intellectual Disabilities

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Keywords: Ethics; Value-Based Health Care; Digital Technology; Intellectual Disability

Introduction

As digital tools have shown great potential to enhance healthcare and well-being services, digital care has a central role in the policies and plans of governments and care organisations to continue to provide good care efficiently (e.g. [1-3]). Digital care refers to technology and data informing and improving healthcare provision [4]. Unfortunately, today, digital care is often not aligned with the needs and values of its users and other stakeholders [5, 6]. Not aligning digital care with stakeholders' needs and values results in low technology uptake. Even though the importance of involving all relevant stakeholders in digital care innovation is widely accepted [7, 8], they are insufficiently and often too late involved in digital care innovation [9]. Consequently, time and effort are wasted [10], and clinical appropriateness and usability of digital care are compromised [11].

Especially for people with intellectual disabilities (ID) who often receive life-long care, digital care is found to impact people's lives significantly. For persons with ID, technologies are not only applied to promote health but also to enhance independence and quality of life, such as being able to participate in society, which creates more educational, vocational and leisure opportunities [12-14]. In long-term care organisations, integrating technology in daily practice for people with ID requires insight into the needs and values of the people with ID themselves, but also those of their care professionals who guide them through daily life and need to adapt their guiding strategies, the information technology (IT) support staff of the care organisation who provide technical support for the digital solutions, the human resources professionals who need to integrate the technology in their regular training programs within the care organisation, and the data specialists who need to decide on incorporating the data provided by the digital care technology. Considering the increasing influence of digital care on several domains of the life of persons with ID [13], the design and implementation of technologies should be well considered.

Ideally, the design and implementation of digital care for persons with ID are 'responsible': to include any intentional systematic effort designed to increase the likelihood of a digital care technology developed through ethical decision-making, being socially responsible and aligned with the values and wellbeing of those impacted by it [15]. Values, defined as "convictions or matters that people feel should be strived for in general and not just for themselves to be able to lead a good life or realise a good society" [16], are commonly considered within ethical discourse. These values function as moral compasses that guide certain action in, for example, design and implementation of technology. However, the ethics of digital care is not a common object of study [17, 18]. Limited empirical evidence details how to address stakeholders' values within their context, in this case, the context of long-term care for people with disabilities. This is the case, even though it is broadly recognised that responsible design and implementation of digital care requires insight into and sensitivity to specific contexts of use [17, 19, 20]. There is a need for context-specific research on how certain values matter to stakeholders of particular technologies and how these values can be

accounted for in technology design and implementation.

The ‘guidance ethics approach’ [21] is a relatively new method for reflection on, and guidance of the responsible design and implementation of technologies in the context of use, developed by ECP (Platform for the Information Society), the Netherlands. The approach is applied in various fields, like municipalities, government, security/police, and the (health) care sector; and concerning various cases, like a biofeedback app for people with profound intellectual and multiple disabilities and challenging behaviour, or the use of artificial intelligence for nighttime monitoring in disability care [22]. The guidance ethics method contains a multi-stakeholder workshop in which stakeholders’ values are identified based on an exploration of experienced and expected positive and negative effects of using a specific technology. Subsequently, workshop participants mutually formulate action opportunities to account for these values in the specific context of use. For the current study, we used this method to identify stakeholders’ values and formulate action opportunities for responsible design and implementation of specific technologies used in long-term care for persons with ID.

The guidance ethics approach – more extensively described in the methods section – has several advantages compared to other research methods focused on ethics in design. One of the most well-known methodologies considering ethics through values in design is ‘Value Sensitive Design’ [23]. Although the idea of embedding values in technology originated from this method, it does not provide the tools to empirically study values. Guidance ethics, however, is practical and hands-on, allowing stakeholders in a workshop to contribute to identifying values affected by the use of technology. There are tools, such as the ‘interactive technology assessment’ [24] that also provide hands-on tools, but these solely focus on studying values of one user. Guidance ethics enables to involve a diverse group of stakeholders to identify a comprehensive set of values [7] and facilitates stakeholders to better understand the position of others [25]. Even though there are methods, such as an evidence-informed deliberative process approach to a health technology assessment [7, 26] that involve multiple stakeholders as well, this method, in contrary to guidance ethics, does not translate insights into concrete action opportunities for responsible technology use. To our knowledge, guidance ethics is the only method enabling for study of values in multiple stakeholders and directly translating these into concrete action opportunities.

In this study, we apply the guidance ethics approach to three digital care technologies that are currently being developed or implemented within care organisations for persons with ID, namely:
1) the design of the ‘Kookapp for groups’ *(developed by care organisations Amerpoort and Reinaerde; IT company Ilionx, Utrecht)*: a web app to support group workers with the preparation of healthy and tasty meals for groups of persons with ID, from choosing recipes and buying ingredients to cooking and serving the meals;
2) the implementation of the ‘SignaLEREN’ app *(developed by care organisation Koraal and IT company Ivengi, Maastricht)*: this app is used by persons with ID and/or autism spectrum disorder to regularly gauge their emotional state. In case of increased stress, they can choose a personalised stress-reducing activity within the app, like watching a video clip or listening to certain music.
3) the implementation of SARA *(developed by SARA Robotics, Eindhoven)*: a social robot that provides activities during daycare to stimulate interaction and physical activity among older persons with ID.
With these three cases, we aim to present examples of action opportunities to guide the responsible use of digital care for persons with ID.

Methods

Participants

The four care organisations of the three cases participated in the Innovation Impulse programme Disability Care, a 3-year programme initiated by the Dutch Ministry of Health, Welfare and Sport in 2019. This programme aimed at accelerating the digital transformation in long-term care by providing support in implementing technology in the everyday practice of 26 disability care organisations [27]. In each organisation, the implementation started with defining a topical care issue from the perspective of and together with people with a disability, followed by the selection of a technology that contributed to the solution of this care issue. Besides, organisations made a context scan of their IT and organisational readiness to implement the selected technology [28, 29]. The care issues concerned, for example, improving day structure [30] or sleep-wake patterns, lowering stress levels, and more independent living. Digital care technologies included sensors, domotics, social robotics and apps. The Innovation Impulse programme also entailed researching the factors influencing the implementation [31].

All 26 care organisations were invited to apply for participation in the current study. In four of the care organisations, for the above-described three cases, the guidance ethics workshops were carried out. Project leaders of the Innovation Impulse project within each care organisation invited a purposefully diverse group of workshop participants from their organisations, for example, persons with ID, relatives, care professionals, policy advisors, managers, members of the board of directors, IT staff, and technology developers.

In total, 26 participants took part in this study. Participants' characteristics are presented in Table 1. No personal data such as sex or age were collected. Almost all participants had some knowledge about the specific technology: thirteen considered themselves informed, and nine had practical experience with the technology. Four participants were unfamiliar with the particular technology before participating in the workshop.

Table 1. Study participants' characteristics.

	Case 1: Kookapp for groups (*n*)	Case 2: SignaLEREN app (*n*)	Case 3: Social robot SARA (*n*)
Persons with ID (or a representative)	2	0	0
Management / Policy	2	1	1
IT staff / Technology developer	1	2	2
Care professional / Team leader	4	3	2
Other (e.g. project leader, consultant)	1	4	1
Total	10	10	6

Note. ID: intellectual disabilities.

Procedure and materials

This study has a qualitative research design, using guidance ethics workshops to collect data. Three 3.5-hour multiple stakeholder workshops were carried out by trained workshop leaders from ECP (two per workshop). The workshops were attended live in May, June and September 2022. Data was collected by means of a questionnaire (described below) completed on paper by the participants

during the workshop. Additionally, the information that workshop leaders wrote on the flipcharts was collected by taking photographs of the flipcharts. Two researchers (KD and NS or AP) were present at each workshop to observe and explain the study and the questionnaire; they did not engage in the workshop.

The questionnaire - constructed by researchers (NS and KD) for this study - followed the workshop outline (Figure 1). In Stage 1 of the workshop (Case), the project leader presented the case, i.e. description of the technological solution, its aim and the way it works, for which target group and in which daily (care) process. Thereafter, data were collected on the participants' characteristics and their familiarity with the technology.



Figure 1. Outline of guidance ethics approach (Verbeek and Tijink [21]).

In Stage 2 (Dialogue), participants were first asked to call out all actors that are or should be affected by or involved with the use of the technology; the workshop leaders wrote these actors on a flipchart. Second, participants were asked to write down for themselves any positive and negative effects of the technology they could think of, not only from their own perspective but any effect that came to mind. Next, they were asked to all mention an effect until all effects were called out. Again, the workshop leader wrote these effects on a flipchart, and the effects were discussed, supplemented and clustered by the workshop leaders and participants. Third, the workshop leaders related values to the clustered effects, and these values were adjusted in discussion with the participants. Last, in stage 2, each participant determined their top 3 values that they deemed most important for their (professional) role in the particular case. These values were marked on the flipchart and discussed, after which the top 3 values of the total group were determined.

For Stage 3 (Action opportunities), participants were divided into three groups [1], in which a diversity of stakeholders per group was pursued. These groups were invited to come up with action opportunities to achieve a highly value-driven use of the concerning technology in the context of the specific case, using the top 3 values of the group as starting point. The (three) groups were instructed

[1] A slight deviation from the protocol was that the group of the third case (social robot SARA) – which was relatively small – was not divided into subgroups in stage 3 and did not explicitly focus on the top 3 values.

to come up with action opportunities for, respectively: the design of the technology (Technology); shaping the environment or context of use (Context); and adjusting the behaviour of the users (Users). Workshop leaders explained what was meant by ‘action opportunities’ by giving the example of the technology ‘car’. Driving a car should be safe (value): therefore, cars have seat belts and automatic brakes (action opportunities for the technology to improve safety), traffic lights and other infrastructure guide drivers (action opportunities for the environment to improve safety), drivers practice to drive and learn the rules before receiving a license (action opportunities for the user behaviour to improve safety). Participants were asked to write down for themselves action opportunities that came to mind, which were then discussed and collected on a flipchart in the groups. Each group presented their action opportunities, which were discussed plenary. At the end of the workshop, participants were asked to write down in the questionnaire any new effects, values or action opportunities that came to mind that weren’t mentioned during the workshop.

Participants were informed about the study and privacy statement and gave consent by filling out the questionnaire anonymously. The local ethics committee CMO Arnhem-Nijmegen (Oost Nederland) deemed research in the Innovation Impulse programme not subject to the Medical Research Involving Human Subjects Act (WMO; file number 2021-8293).

Analyses

Data from the questionnaires on positive and negative effects, values and action opportunities were entered in Excel (Microsoft Corporation, 2018). The dataset was checked for completeness with notes of the workshop observations, pictures of the flipcharts from the workshops and the workshop reports made by ECP’s workshop leaders. Analyses were conducted bottom-up: participants’ descriptions were the starting point leading to the derivation of themes. First, two researchers (KD and NS) independently derived themes from the ‘effects data’ per case. That is, effects that concerned a similar subject were given a descriptive name. For example, ‘joyous end users’ and ‘end users can experience more enjoyment’ were named ‘enjoyment of end users’, which was then considered an effect theme. The two researchers compared and discussed their effect themes until a consensus was reached. Next, the effect themes of all three cases were written on digital post-its and visually arranged so that related effect themes were near each other. Digital post-its on which values were presented were added for each theme from which the values were abstracted. Further, two researchers (KD and NS) also derived themes from the action opportunity data per case. Next, it was analysed and discussed which values were represented by the action opportunity themes. For example, the action opportunity theme ‘Give the person with ID some self-direction in the use of the technology’ mainly concerns the value ‘autonomy’; or the action opportunity theme ‘keep the goal in mind and deploy technology as a means rather than a goal in itself’ concerns the value ‘quality of care’. The preliminary results were presented and discussed in an interpretation meeting with workshop leaders and project leaders from care organisations (participants from all three workshops were present). Additions and feedback from this meeting were used for further analyses in an iterative process.

Results

The three workshops provided insight into how effects were translated into values and subsequently values into action opportunities for Technology, Context and Users of a specific technology. The numbers of collected effects, values and action opportunities for each of the three cases are presented in Table 2. An overview of their content is provided in Multimedia Appendix 1; for readability, effects and action opportunities were shortened, and similar ones were combined in this overview.

Table 2. Number of participants per case and the amount of collected data.

Case	Participants (*n*)	Effects	Values	Action opportunities
1: Kookapp for groups	10	102	13	74
2: SignaLEREN app	10	66	7	54
3: Social robot SARA	6	64	13	28

Data on values and action opportunities were missing from one participant who could only attend the first part of the workshop. Further, the person with ID from case 1 formulated effects and action opportunities together with a care professional.

Examples of action opportunities

Table 3 presents examples of action opportunities for a) the design of 'Technology'; b) shaping the 'Context' of use; and c) adjusting the behaviour of the 'Users', to guide the responsible use of digital care for persons with ID. Given that describing all results (which can be found in Multimedia Appendix 1) would be too extensive for this paper, Table 3 highlights one example per case based on one of the most prominent values in that case. We describe the effects and action opportunities linked to that value. After the examples, we reflect on general observations within and overarching the three cases.

Table 3. Examples of combinations of effects, a value and action opportunities for the three cases.

Case	1: Kookapp for groups; a web app to support healthy cooking for groups of persons with ID.
Selected value	Quality of care.
Positive effects	Connectedness through choosing, cooking and eating together. Continuity of meal quality; not being dependent on care professionals' skills. Awareness of the importance of good nutrition. More time for the persons with ID. Equality (differences regarding meals for persons with ID between care organisations become smaller when they use the web app).
Negative effects	Excessive focus on health compared to enjoying tasty food.
Action opportunities - Technology	None mentioned regarding the selected value.
Action opportunities - Context (care organisation)	Evaluate efficiency, health, and eating pleasure continuously. Provide care professionals with instructions on how to use the web app, also in a manual.
Action opportunities - Users (care professionals)	Invest in getting to know the web app in order to use it properly. Have a backup plan for situations where the web app does not work. Know the dietary preferences and needs of each person with ID in the group. Know what to do when a person with ID does not want to participate (or experiences less fun) in cooking with the web app.

Case	2: SignaLEREN app; an app to support people with ID in autonomously dealing with stress or anxiety.
Selected value	Autonomy.
Positive effects	For the person with ID: - more self-direction, independence and personal autonomy; - an extra support option besides support from care professionals; - increased awareness of own stress and its causes;
Negative effects	- counterproductive effects of the app on stress if it does not work; - less autonomy when using the app feels obligatory; - the app as a barrier in seeking contact with the care professional.
Action opportunities - Technology	Enable persons with ID to make choices themselves: - set the regularity of question pop-ups in the app; - disregard the notifications on unsuitable moments by choosing the response option ‘I don’t want to answer this question (right now)’; - delete data; - schedule an appointment with their care professional via the app.
Action opportunities - Context	Give persons with ID access to the back office of the app so that they can adjust specific content in the app themselves.
Action opportunities - Users	Give persons with ID some self-direction in the use of the app: - discuss what using the app entails and what happens with the data; - give guidance in setting up and using the app at their own pace; - evaluate app use and effects frequently during coaching moments. Support persons with ID in a different way, e.g. redirecting them to the app first, "Have you completed the app?".
Case	3: social robot SARA; a robot to support physical and social activities for persons with ID.
Selected value	Privacy.
Positive effects	None mentioned regarding the selected value.
Negative effects	Risk of privacy infringement due to storage and sharing of personal data. Insufficient insight into what data are collected and stored when functionalities of the robot are expanded.
Action opportunities - Technology	Make a distinction between accounts for administrators and care professionals using the robot to restrict access to personal data. Establish a maximum storage period for personal data before it is automatically deleted.
Action opportunities - Context	Train care professionals using the robot in accordance with the privacy law. Restrict the number of persons who have access to personal data. Go over the consent statements yearly with persons with ID (or

	their representatives) who use the robot– taking into account any changes in functionalities of the robot and therefore storage of other data. Revise the organisation's privacy policy. When persons with ID use the robot to have contact with relatives, the privacy of both should be protected: - use of headphones during this contact; - create a cosy private 'corner' in the location.
Action opportunities - Users	None mentioned regarding the selected value.

Note. ID: intellectual disabilities.

Observations, differences and similarities between cases

Effects

Part of the effects that were collected was case-specific. For example, only in case 1 (Kookapp for groups) effects regarding healthy food came up; in case 2 (SignaLEREN app), effects regarding insight into the stress of the person with ID; and in case 3 (social robot SARA) effects regarding activation/development of cognitive skills of the person with ID. Apart from case-specific effects, several general themes that were extracted from the effects across all three cases are presented in Table 4.

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Table 4. General (i.e. not case-specific) effect themes, values and action opportunity themes.

	Themes found across three cases (Kookapp for groups, SignaLEREN app, social robot SARA)	Actors to whom the themes mainly apply
Positive effects	Customisation of care	Persons with ID
	Increase in self-reliance or self-direction	Persons with ID
	Ease of work or job satisfaction	Care professionals
	Efficiency/ labour-saving/ time-saving	Care organisations
Negative effects	Dependency on IT infrastructure	Persons with ID, care professionals and care organisations
	Risks related to the storage of privacy-sensitive data	
	Perception of having "yet another system"	Care professionals
	Costs/ time investment	Care organisations
Values	Quality of care	Persons with ID
	Autonomy	Persons with ID
	Privacy	Persons with ID, care professionals and care organisations
	Job satisfaction	Care professionals
	Efficiency/ affordability of care	Care organisations, society
Action opportunities	Keep the content (recipes, interventions, activities) up to date	Care professionals
	Train care professionals on how to use the technology well	Care organisations
	Connect the use of the technology to goals in the individual care plan/ electronic health record	Care professionals and technology developer
	Focus on upscaling (more users of the technology in the care organisation)	Care organisations

Values

Table 5 shows which values were identified as the top 3 values during the three workshops. Note that only in case 1 (Kookapp for groups) participants chose four values. Values identified in all three cases were 'quality of care', 'autonomy', 'privacy', 'job satisfaction' and 'efficiency/ affordability of care' (Table 4). In all three cases, certain values apply to a specific actor. For example, 'job satisfaction' applied to care professionals, whereas 'autonomy' primarily concerned the person with ID. Other values applied to several actors (e.g. 'reliability') or an actor group, for example, 'efficiency/ affordability of care' concerned the care organisation or even society.

Table 5. Top values identified during 'guidance ethics' workshops, based on personal top 3 values of all participants per case.

Case	Top values
1: Kookapp for groups	Quality of care; Efficiency; Health; Enjoyment
2: SignaLEREN app	Quality of care; Autonomy; Reliability
3: Social robot SARA	Quality of care; Autonomy; Privacy

Action opportunities

Action opportunities regarding the Technology comprised the development of the technology itself (e.g. optimise user experience, customisation), the input into the technology (e.g. recipes for meals in case 1, Kookapp for groups; intervention options for reducing tension in case 2, SignaLEREN app; activities in case 3, social robot SARA) and the output of the technology (e.g. storage and use of data). Action opportunities regarding the Context covered the need for guidelines, training and support, policy/agreements, and adjustments to the physical environment in which the technology is used. Action opportunities regarding the Users mainly focused on how care professionals can integrate using the technology into their daily care practice. Some behaviours need to be diminished (e.g. care professionals need to 'let go' instead of 'take over' to give the person with ID more autonomy), some behaviours must stay in place (e.g. face-to-face contact moments), and some behaviours need to be added (e.g. evaluation moments). Although some general themes across all three cases were identified (Table 4), most action opportunities were context-specific.

For case 1 (Kookapp for groups), most action opportunities were listed for the value 'user convenience'. Action opportunities included optimising the user experience with the web app (e.g. use icons and little text) and to provide resources (e.g. place magnets on the kitchen wall to hold tablets while cooking). Action opportunities that stood out because they were brought up by several participants concerned an attractive design and ease of operation of the web app. Though the value 'health' was a top value in case 1, relatively few action opportunities were formulated for this value.

For case 2 (SignaLEREN app), there was not one value that stood out, but four values were evenly represented among the majority of action opportunities: 'quality of care', 'autonomy' (see Table 3), 'reliability' and 'efficiency'. These were the top 3 values, except 'efficiency'. For 'quality of care', action opportunities concerned: keep the goal in mind and deploy the app as a means rather than a goal in itself (e.g. personal goals of the person with ID as starting point for the conversation about how to use the app); train care professionals on the use of the app; have a person-centred approach (i.e. customise the app). Action opportunities for the value 'reliability' included a continuous provision of easily accessible support (e.g. assign SignaLEREN coaches, arrange a 24-hour helpdesk); and the maintenance of the app organised within the own organisation. Lastly, action opportunities for the value 'efficiency' concerned: integrate the use of the app in the care process (e.g. embed the use of the app in a particular care methodology); scale up the use and adoption of the app (e.g. deploy the app with all care professionals to whom it applies); and extract and use data from the app (e.g. built-in notifications in the app for when the person's stress level is likely to become too high). More frequently mentioned action opportunities concerned: give the person with ID access to personal settings of the app (e.g. frequency of prompts, data access rights); secure face-to-face contact of person with ID and care professional; use data from the app to provide insights into stress level trends; connect the app with the electronic health record; assign a SignaLEREN coach.

For case 3 (social robot SARA), most action opportunities related to the value 'privacy' (see Table 3). Action opportunities that stood out because they were brought up by several participants included: link the use of the robot to individual care goals; connect the robot with the electronic health record; and enlarge the content that the robot can present. Even though the value 'autonomy' was a top value in case 3, relatively few action opportunities concerned this value, while relatively many action opportunities linked to 'effectiveness' (e.g. optimise the content that the robot can present; recurrent evaluation), which was not chosen as a top value.

Discussion

Often, the development, implementation and use of digital care does not entail an intentional and systematic effort to include ethical considerations of all involved stakeholders (e.g. [32]). Therefore new technologies, as well as the processes to integrate them into daily practice, are often not aligned with the values and well-being of those impacted [15]. Instead, ethics is merely considered a separate area of attention (e.g. a separate line of investigation or work package within projects) discussed by a distinct group of experts [33].

The current study illustrates what types of insights are gained when various stakeholders are involved bottom-up in reflection on the ethical impact of specific technologies and how this impact can be influenced for the better. This is illustrated with three cases of different digital care technologies for people with ID: a web app for cooking for groups (Kookapp for groups), an app for stress regulation (SignaLEREN app), and a robot for interaction and physical activity (social robot SARA). Our findings may help researchers, innovators and users of technology to move from rather abstract thinking about ethics and responsible innovation towards effective practical approaches in which all stakeholders can be involved.

Principal results

In a short amount of time (three 3,5-hour workshops), relatively much information was gathered in a multi-stakeholder setting regarding a) positive and negative effects for various stakeholders of a specific digital care technology for persons with ID; b) values underlying these effects; and c) action opportunities to take into account important values in the design, implementation and use of the specific technology. Effects were primarily case specific, as they described the implementation of a technology in a specific context, but several general themes were also recognised. The latter included the effects of the technology on customisation of care; dependency on IT infrastructure; self-reliance/ self-direction of persons with ID; risk of privacy infringement; care professionals' ease of work; workload; and efficiency and investment. When all effects were abstracted into values, several values were identified in all three cases and were found to be related to the general effects. These values were: quality of care, autonomy, privacy, job satisfaction, and efficiency/affordability of care. Following the guidance ethics approach, most action opportunities were related to the top values from the regarding cases. Hence, many action opportunities from case 1 (Kookapp for groups) concerned 'enjoyment', 'efficiency' and 'quality of care'. However, relatively few action opportunities involved the top value 'health'. Noteworthy, most action opportunities of case 1 concerned 'user convenience', although this was not identified as a top value. In case 2 (SignaLEREN app), most action opportunities were related to the top values 'quality of care', 'autonomy', and 'reliability', but also to 'efficiency'. In case 3 (social robot SARA), the top values 'quality of care' and 'privacy' were well represented among the action opportunities, but few related to the top value 'autonomy', and relatively many concerned 'efficiency' and 'effectivity'.

While action opportunities can only be detailed in relation to specific sociomaterial contexts [34] (i.e. specific technologies in their contexts of use), our study reveals that, on a higher level, there are similarities regarding effects, values and action opportunities for different cases. It may thus be wise for stakeholders of digital care technologies to not only learn how technologies can be responsibly used within their own context but also to seek inspiration from similar contexts in which other technologies are used, as well as from different contexts in which the same or comparable technologies are used. In doing so, caution should be exercised in generalising case-specific effects, values and action opportunities to a broader scope.

Comparisons to prior work

This is the first study providing a broader overview of actual action opportunities for responsible digital care for persons with ID. In their 2020 reports, the Dutch Centre of Ethics and Health (CEG) advised the Dutch Ministry of Health, Wellbeing and Sport on ethics considering digital care such as apps and robots [35, 36]. The themes discussed in the report regarding apps are: cost savings, increase of autonomy, increase of well-being, unrest, information overload, decrease of human contact, over-emphasis on health that can lead to medicalisation, increase of differences in health and inequality [35]. Notably, the diametrically opposed side of inequality was raised in our study, namely that differences between care organisations would decrease if they would organise meals using the Kookapp for groups. The report regarding care robots discusses: meaningful contact, dignity, autonomy and (in)dependency, privacy, and justice [36]. Apart from information overload and justice, all themes also appeared in one or more of the three cases in our study. This shows that our results covered the majority of essential topics that ethics experts recognised.

Studies on ethics and health often describe themes which have a positive or negative load (e.g. resp., increase of autonomy or increase in inequality) or identify ethical harms [17, 18, 35, 37]. Our data revealed that in most cases two sides of the same coin were considered in the multistakeholder setting. For instance, technology as a facilitator as well as a burden for care professionals' work (all cases); cost or labour savings and higher costs or time investment (all cases); positive and negative effects of the focus on a health theme (Kookapp for groups: awareness of the importance of healthy food vs too much emphasis on health at the cost of enjoying tasty food; SignaLEREN app: improving stress signalling plan vs risk of medicalisation of normal stress); increase and risks of autonomy (SignaLEREN app: person with ID is less dependent on care professional, but possibly also less 'visible'). The advantage of using values – instead of themes or harms – as a starting point for fostering responsible use of digital care is that values are neutral and hence facilitate that both sides of the same coin are considered [38].

Strengths and limitations

As the current study illustrates, the guidance ethics approach can be a valuable and low-key method to gain insight into different stakeholders' experienced and expected positive and negative effects and values affected (or at stake) when using a specific technology, as well as insight into action opportunities for responsible digital care. Yet, we recognise that the insights gained in this respect may fall short in terms of correctness (i.e. being in agreement with facts or with what is generally accepted), concreteness (i.e. being specific and detailed) and completeness (i.e. extent to which all relevant effects, values and action opportunities have been identified) [39].

The correctness of our results on effects may be limited due to, amongst others, a general lack of methodologically sound studies on effects of digital care for persons with ID. Hence, there was no/little evidence from scientific research on the specific care technologies to present in stage 1 of the workshops. Therefore, the collected positive and negative effects are mainly based on subjective effects, but from stakeholders with lived experience with the specific technology. Also, an inherent characteristic of qualitative data analysis is that deriving themes from the data (including identifying values based on the effects of the technology) involves interpretation of the analyst. To limit the subjectivity, values were discussed during the workshop with all participants, and themes were created independently by two researchers and discussed until a consensus was reached. Another discussion point linked to correctness is that the values were discussed and presented as

relatively stable entities, while they are neither stable nor singular [40, 41]. Values may be affected by time and thus constantly defined and redefined (value dynamism), for instance, because users have gained experience with technology [39, 41]. Although it may be challenging for researchers, innovators and other stakeholders to continuously respond to this dynamism, a starting point could be to take regular snapshots of stakeholders' perspectives on effects, values and action opportunities.

The method used in the current study has advantages regarding concreteness. For example, although the values are abstract, their definitions are embedded in the concrete effects from which they are derived. Moreover, the method results in relatively concrete output (action opportunities) compared to most ethics research on digital care (e.g. [42, 43]), and action opportunities apply to the specific contexts of use. However, it was not always deducible from the workshop data what a participant specifically meant by an effect or action opportunity or to whom (e.g. care professional or person with ID) specific insights applied. In the cases for this study, it is not straightforward who is meant with the 'user' of the care technology. To improve this, workshop leaders should be alert to ask participants to clarify whether they mean the care professional or the person with ID.

Regarding completeness, this study did not aim to be exhaustive in collecting effects, values and action opportunities. However, we did aim to include a diverse participants sample. Despite the accessibility of the workshops for persons with ID, only in case 1 (Kookapp for groups) a participant with ID was included. In case 3 (social robot SARA), the person with ID cancelled the morning of the workshop (with a valid reason), and in case 2 (SignaLEREN app), no person with ID was invited. Also, other relevant stakeholders were absent, for example, relatives of the people with ID, the board of directors, or representatives of health insurers. Although all relevant stakeholders that participants could think of were identified during the workshop, and participants were asked to keep them all in mind, some perspectives may be missing in the results. Including persons with disabilities requires special attention, as this is not common in co-design or co-creation of digital care technologies [44], although this is upcoming [13, 45, 46]. To improve stakeholder inclusion in general, it may be useful to consult 'design principles' for stakeholder engagement [47].

Further, the method of deriving values from effects is suitable for identifying 'proximal' values on the micro level that are specific to the technology and context of use [21], but meso or macro level effects and more 'distal' values may be missed [48] (like 'social justice' which is an important theme in studies on ethics and digital care [43, 49, 50]). Whenever missed out in bottom-up ethical dialogues (such as in the current study), proximal and distal values (or principles) from predefined ethical frameworks could therefore be brought in as 'top-down' guidance. At the same time, the bottom-up approach is a strength of the guidance ethics approach, revealing important topics like enjoyment of the person with ID or job satisfaction, which may be missed when an ethical theory is applied to a case instead [17, 51]. In this sense, we argue that top-down and bottom-up approaches are complementary. Hence, we suggest moving back and forth between the perspectives of stakeholders affected by technology when implementing digital care and ethical frameworks and/or perspectives of experts on digital care ethics [19, 52].

Finally, the action opportunities identified in this study require follow-up in practice. After all, responsible use of technology requires being continuously responsive and adaptive to new insights that are gained regarding effects, values and action opportunities, from early design to local implementation and use [53, 54]. Additionally, it is conceivable that trade-offs between action

opportunities need to be made due to value conflicts (e.g. autonomy vs duty of care [55]) and costs. Future research may shed light on how action opportunities, once formulated, are further operationalised and applied by technology designers, user organisations, and individual end-users of the technology, as well as on what factors withhold stakeholders from doing so. Previous research indicated that ethical concerns of stakeholders might considerably slow the pace of digital care innovation, implying that responsible innovation could be a core catalyst for the progress of digital care overall [18]. Through explicit attention to and communication about responsible digital care, not only are ethical concerns taken into account, but also support and acceptance among the involved stakeholders are generated. This increases chances for the successful implementation of socially desirable, ethically acceptable and sustainable digital care that improves the lives of people with disabilities.

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Conflicts of Interest

None declared.

Abbreviations

ECP: Platform for the Information Society
IT: Information Technology
ID: Intellectual Disabilities

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Supplementary Files

Preprint JMIR Publications

Figures

Preprint JMIR Publications

Outline of guidance ethics approach (Verbeek and Tijink [21]).



Preprints JMIR Publications

Multimedia Appendixes

Preprint JMIR Publications

Overviews of effects, values, and action opportunities collected in the workshops for the three cases: Kookapp for groups, SignaLEREN app, social robot SARA.
URL: http://asset.jmir.pub/assets/95ed18f588ea62d953c8b3b76bcc1072.docx

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