

# Shared decision making in inclusive research: Reflections from an inclusive research team

Kristel Vlot-van Anrooij<sup>1</sup>  | Tessa K. Frankena<sup>2</sup> | Anneke van der Crujisen<sup>1</sup> | Henk Jansen<sup>1</sup> | Jenneken Naaldenberg<sup>1</sup> | Kirsten E. Bevelander<sup>1</sup>

<sup>1</sup>Department of Primary and Community Care, Intellectual Disabilities and Health, Radboud Institute for Health Sciences, Radboud University Medical Center, Nijmegen, The Netherlands

<sup>2</sup>Siza, Long-Term Care Organisation for People with Disabilities, Arnhem, The Netherlands

## Correspondence

Kristel Vlot-van Anrooij, Department of Primary and Community Care, Intellectual Disabilities and Health, Radboud Institute for Health Sciences, Radboud University Medical Center, PO Box 9101, 6500 Nijmegen, The Netherlands.

Email: [kristel.vananrooij@radboudumc.nl](mailto:kristel.vananrooij@radboudumc.nl)

## Funding information

Academic Collaborative Stronger on Your Own Feet; ZonMw

## Abstract

**Background:** Health research is increasingly conducted with the active involvement of the people who are the focus of the research. People with intellectual disabilities also participate actively in research; this is called inclusive research. Collaboration in inclusive research teams requires shared decision-making (SDM). Although inclusive studies frequently refer to decision-making as something the research team does together, the decision-making process is still a black box. This study aims to provide more insight into SDM in inclusive research by reflecting on a 3-year collaboration in an inclusive research team. The research questions are: (1) What kinds of decisions were made by the inclusive research team? (2) How were decisions made by the inclusive research team? (3) What impact did the decisions have on the research project?

**Methods:** To answer the research questions, the inclusive research team members reflected on SDM in their project by looking at the documentation of the inclusive research process and by conducting semi-structured interviews with the team members.

**Findings:** In all research steps, the inclusive research team decided together on the content and procedures of the studies and on role division. Reflecting on SDM resulted in an overview of the types of decisions made, the information needed and the processes involved in making shared decisions. Furthermore, the team provided an account of how SDM positively impacted the quality of the studies and empowered people with intellectual disabilities.

**Conclusions:** This study provides insights into types of decisions, SDM processes and their impact on research. The insights give an overview of opportunities and key components of SDM that can foster conceptual clarity of SDM in inclusive research. In practice, inclusive research teams can use these insights to advance successful ways of sharing power in decision making, having an impact on the quality of research and empowering people with intellectual disabilities.

**KEYWORDS**

inclusive research, intellectual disabilities, participatory research, reflection, shared decision making

**Accessible summary**

- This study is about an inclusive research team making decisions together.
- An inclusive research team includes researchers with and without intellectual disabilities.
- This study describes the kinds of decisions that were made together and how joint decision making influenced the research project.
- The study also describes how the team made decisions together: the information used and the steps taken.
- Making decisions together helped to improve the research.

## 1 | INTRODUCTION

There is a strong interest across different domains to involve citizens and patients in scientific research. Examples include participatory and community-based research projects to improve health and well-being (Abma et al., 2019; Cornwall & Jewkes, 1995). In the last decades, health research has increasingly been conducted with the active participation of people who are the focus of the research (Abma et al., 2019; Elberse, 2012; Harrison et al., 2019). This also occurs in research among people with intellectual disabilities (Bigby et al., 2014; Puyalto et al., 2016; Walmsley et al., 2018). Research in which coresearchers with intellectual disabilities are part of the research team and whose perspectives are included is called 'inclusive research' (Walmsley & Johnson, 2003; Walmsley et al., 2018). Inclusive research studies frequently refer to the activities in their research as something that the research team decides together. To our knowledge, literature is scarce on shared decision-making (SDM) in participatory research approaches such as inclusive research. Therefore, the current study aims to provide more insight into SDM by reflecting on decision making in a long-term inclusive research project.

Previous studies have focused primarily on the facilitators and challenges of collaboration and decision making in inclusive research (Brookes et al., 2012; Buettgen et al., 2012; Chapman & McNulty, 2004; Michell, 2012). Facilitators include competences of researchers and coresearchers, such as communication skills and a strong trusting relationship between (co)researchers (Embregts et al., 2018; O'Brien et al., 2014). Challenges also relate to relationships, in combination with role divisions and power dynamics between the members of the inclusive research team (Embregts et al., 2018; García Iriarte et al., 2014; Nind, 2017; O'Brien et al., 2014). These challenges vary in line with the varying degrees of involvement that coresearchers can have in research projects, ranging from providing advice to having control over the study (Bigby et al., 2014). Frankena et al. (2016) Frankena,

Naaldenberg et al. (2019) found that partnership and SDM power were perceived as crucial in a collaborative form of the inclusive research team. Still, SDM in inclusive research is perceived as challenging because researchers without intellectual disabilities need to support researchers with intellectual disabilities by providing information in language that is easy to understand and guiding the decision-making process without taking control of the decision (Ellis, 2018; Puyalto et al., 2016). These studies highlight that the form of coresearchers' involvement is intertwined with power distribution in decision making and that it is important to find a balance in the inclusive research team to make shared decisions.

Although previous studies have provided examples of research activities by examining the facilitators and challenges of inclusive research, few studies have identified the types of decisions made during inclusive research activities. For example, Flood et al. (2013) reflected on the decisions that they made as coresearchers, such as planning, data collection methods, information sheets for informed consent and supportive materials for researchers during data collection. However, the information and the processes used to make shared decisions during inclusive research activities and the actual impact of SDM on inclusive research remain a black box (Brookes et al., 2012; Buettgen et al., 2012; Michell, 2012).

Inclusive research could learn from the literature on SDM processes in health settings, in which patient-centred care is increasingly guided by patient values and patient participation. Theory and review studies on SDM in clinical settings have produced conceptual frameworks in which key components of SDM are identified (Bomhof-Roordink et al., 2019; McCaffery et al., 2010; Waldron et al., 2020) that show overlap with concepts discussed in inclusive research (Ellis, 2018; McCaffery et al., 2010; Nind, 2017). In general, SDM is based on: (1) understanding the situation and decisions to be made, (2) knowledge transfer and exchange in which awareness of risks, limitations, benefits, alternatives and uncertainties are discussed, (3) identifying individuals' values and preferences and

imagining future (health) states, (4) deliberation and participation in decision making at a desirable level and (5) implementing a shared decision and making it consistent with individuals' values and preferences, or postponing the decision (Stacey et al., 2010). Throughout the SDM process, additional components such as determining roles or next steps, fostering partnership, offering time, tailoring information and taking patient expertise into account are deemed important (Bomhof-Roordink et al., 2019). Similar to the findings about SDM having a positive impact on patient empowerment, decisions, (patient) outcomes and effective use of healthcare (Joosten et al., 2011; Légaré et al., 2014; Schattner et al., 2006), SDM in inclusive research is expected to contribute to the empowerment of people with intellectual disabilities, research outcomes, quality of life and the reduction of health (care) inequalities (Frankena, van Schrojenstein Lantman-de Valk, et al., 2019).

The current study examined decisions, SDM and their impact on research by reflecting on the activities undertaken by an inclusive research team during a 3-year collaboration in a long-term research project. The inclusive research team, consisting of researchers with and without intellectual disabilities, reflected on their collaboration and the SDM processes involved. The aim was to provide insight into SDM in inclusive research by answering the following questions: (1) What kinds of decisions were made by the inclusive research team? (2) How were decisions made by the inclusive research team? (3) What impact did the decisions have on the research project?

## 2 | METHODS

### 2.1 | Setting

In this study, reflections were made on the decisions, the (facilitators of the) decision-making process and their impact on research in the inclusive project 'Healthy Settings for People with Intellectual Disabilities'. The funding organisation encouraged the involvement of coresearchers with intellectual disabilities in the execution of the project, which encompassed four studies on health promotion for people with intellectual disabilities (see Table 1). The core members of the inclusive research team were two coresearchers with intellectual disabilities (Anneke and Henk) and an academic researcher (Kristel, PhD student), all employed by the Radboud University and Medical Centre. They followed a training course for inclusive research teams (Sergeant et al., 2020). The decision making reflected upon in this study was part of a 3-year collaboration by the inclusive research team who worked together on a weekly basis to execute the research project (March 2017–July 2020). During the 3-year collaboration as well as the current reflective study we used a collaborative form of inclusive research. This implicates that the coresearchers were invited to contribute and make decisions in every stage of the research process. As a team, we always decided who would be involved in which stage and activities. Therefore, the team decided together when and whether one or both coresearchers would not be involved in some parts of the separate studies

**TABLE 1** Overview of aims, data collection methods and participants in four studies on healthy settings for people with intellectual disabilities

Study	Aims	Data collection methods	Participants
1	Develop a conceptual framework of healthy settings for people with intellectual disabilities (Vlot-van Anrooij et al., 2019)	Mixed methods: concept mapping	Researchers specialised in healthcare for people with intellectual disabilities or in healthy settings in general
2	Identify assets supporting healthy nutrition and physical activity in care settings for people with intellectual disabilities (Vlot-van Anrooij, Koks-Leensen, et al., 2020)	Mixed methods: nominal group technique	People with mild/moderate intellectual disabilities and proxy respondents <sup>a</sup> for people with severe/profound intellectual disabilities
3	Develop a comprehensive, clear and usable tool for environmental asset mapping that people with intellectual disabilities and other users of support settings for intellectual disabilities can use (Vlot-van Anrooij, Hilgenkamp, et al., 2020)	Mixed methods: interviews, questionnaire, observations and group discussion	Experts, people with mild/moderate intellectual disabilities, proxy respondents <sup>a</sup> for people with severe/profound intellectual disabilities and daily care professionals
4	Provide insight into the extent to which the environmental asset mapping tool is able to provide a comprehensive view of availability, user-satisfaction and dreams regarding assets for physical activity and nutrition and the ability to provide actionable knowledge to improve the health-promoting capacities of support settings for people with intellectual disabilities (Vlot-van Anrooij et al., 2021)	Questionnaire	People with mild/moderate intellectual disabilities, proxy respondents <sup>a</sup> for people with severe/profound intellectual disabilities and daily care professionals

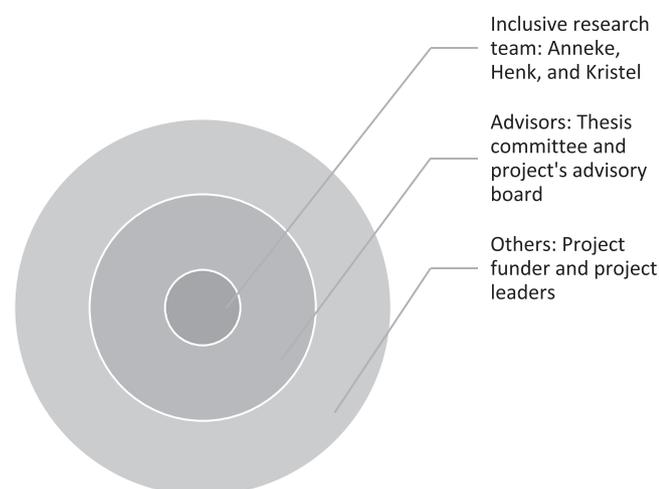
<sup>a</sup>People with mild/moderate intellectual disabilities who were able to communicate verbally could participate. Daily care professionals evaluated this. People with mild/moderate intellectual disabilities could bring a support person during data collection if they wished so. Proxy respondents participated on behalf of people with severe/profound intellectual disabilities.

belonging to this project. For example, when Kristel initiated the decision how they were going to produce the scientific articles, they decided as an inclusive research team that Kristel would write the first drafts of the scientific articles and that Anneke and Henk would provide verbal feedback.

Advisors on the project were the thesis committee and the project's advisory group. The thesis committee consisted of two senior researchers (including Jenneken) and two professors who provided supervision and advice about the scientific content and execution of project. The project's advisory group consisted of two persons with intellectual disabilities, two caregivers, three health professionals and one manager. The advisory group provided feedback about the practical implications of the research project. Furthermore, this study project was part of a larger overarching project called 'Healthy Settings for People with Intellectual Disabilities' that was supervised by the project team that consisted of representatives of all involved projects. Therefore, in addition to the thesis committee and advisory group, the inclusive research team also had contact with the team leader of the overarching project and the funding organisation. Their approval was needed if the inclusive research team wished to make changes to the project's proposal. A diagram of the actors involved is presented in Figure 1. A broad description of research topics, aims and methods are presented in Table 1.

## 2.2 | Materials and procedures

The materials used to identify decisions and reflect on SDM were: (1) documentation developed during the project and (2) semi-structured interviews with the inclusive research team (Anneke, Henk and Kristel). The documentation included: the project proposal, scientific articles on studies within the project, agendas for the weekly meetings, the project plan, a timeline on a poster visualising the team's achievements and a research clock including pictures and

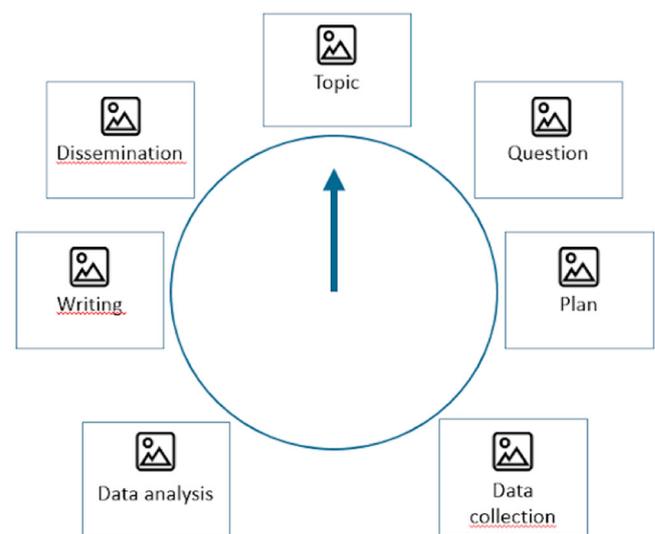


**FIGURE 1** Actors involved in decision making about the inclusive research studies reflected upon in this article

words about the research steps in each study (see Figure 2). The agendas, plan, timeline and research clock were developed by the team to maintain an overview of the project and foster memory and comprehension. The semi-structured interviews focused on how the research phases were conducted, what enabled decision making in inclusive research or made it difficult and the impact of decisions on the project. During the interviews with the co-researchers, the timeline and research clock were used to help them remember the activities that they had undertaken. The team chose Jenneken (member of the thesis committee) to conduct the semi-structured interviews as they thought that her overview of the project and her ability to talk in an easily understood language would be beneficial for the interviews. The interviews were audio-recorded and conducted in November 2019.

## 2.3 | Analysis

The current study was conducted according to the inclusive research methods that we used throughout the entire project. First, Kristel, Tessa (an academic researcher and former colleague of the inclusive research team) and Jenneken identified the inclusive research team's decisions by analysing the documentation and the interviews. Kristel analysed the study documentation to determine the list of decisions made in each research step according to the research clock. Tessa and Jenneken analysed the transcripts of the interviews by coding the text on decisions made. Next, they labelled them to determine the list of decisions made in each research step as shown on the research clock (Figure 2). Tessa, Jenneken and Kristel discussed the similarities and the differences on these lists until they agreed on a final list of decisions made in the research steps in the four studies in this project. Second, a discussion was held amongst the inclusive



**FIGURE 2** Research clock including pictures and words about the research steps in each study reflected upon in this article [Color figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

research team using the list of decisions to further reflect on the information and the processes used to make the decisions and the impact of these decisions on the project. The discussion was audio-recorded and led by Tessa. Finally, Kristel developed a summary of this discussion, structured in line with the research steps, which was again checked by Anneke, Henk and Tessa. The list of decisions and summary of the discussion amongst the inclusive research team were used to describe the results of this study in the next section.

### 3 | RESULTS

An overview of the identified decision types and their impact on the research project are summarised and structured according to the research clock steps across the four studies shown in Table 2. At the start of the project, Kristel mostly identified the decision options and initiated SDM as an inclusive research team. During the project, however, Anneke and Henk gained a lot of experience as coresearchers and increasingly identified and initiated decisions. The activities and information used in SDM are described in the next sections, also ordered by the research clock steps and including descriptions of exemplary situations.

#### 3.1 | Decision making on research topic, aim and questions

For the research topic, aim and questions, the team made decisions on how to familiarise themselves with the topic of healthy settings and how to operationalise the research questions in the project proposal. Activities that the team undertook to make these decisions related to discussing the topic and the project proposal. For example, to familiarise themselves with the topic, the team walked across the university campus to take pictures of what they experienced as enabling or constraining for a healthy setting. Also, in discussing the operationalization of the research question for Study 1, Anneke and Henk indicated that the topic was too difficult to talk about with people with intellectual disabilities. After several meetings and discussions with the team and advisors to identify methods to talk with people with intellectual disabilities about healthy living settings, the team and the thesis committee decided that a preliminary study was necessary; this was approved by the funding organisation. Information that proved especially helpful in this phase included the project proposal, experiential knowledge of conducting research among people with intellectual disabilities and an overview of relevant scientific literature and skills to summarise relevant parts in easily understood language.

The impact of SDM on the research topic, aim and questions included, for example, the addition of Study 1 to the project. In Study 1, the subthemes of the healthy settings topic were identified and translated into an easily understood language to enable people with intellectual disabilities to talk about the different components in a setting that could enable healthy living; this was a prerequisite to

carrying out Study 2 of the project. Further examples of the impact of SDM are provided in Table 2.

#### 3.2 | Decision making on the study plan

For the study plans, decisions were made regarding the research method, inclusion criteria, informed consent procedure and forms, data collection methods and supportive materials for participants and researchers during data collection. For each of the studies, seven steps were taken. First, Kristel gathered and summarised the relevant literature. Second, the team discussed the relevant literature and the study description in the project proposal. Third, the team decided which data collection method to use while building the draft plan, whether and what adaptations and supportive materials were needed for meaningful participation by participants, recruitment and the informed consent procedure. Fourth, Kristel drafted the information letters for potential participants and informed consent forms based on the decisions made and the recommendations for what should be included. Fifth, Anneke and Henk improved the easily understood language in the easy-read versions of the information letters and informed consent forms. Sixth, draft plans were discussed with the thesis committee and the project's advisory group (for Studies 2–4) and adjusted according to their feedback. Finally, the plans, information letters and informed consent forms for participants were submitted to the Medical Research Ethics Committee of the Radboud University and medical centre to request approval.

To make decisions in these phases, information was needed on available scientific knowledge of the research topic and methods and experiential knowledge of easily understood language and the involvement of participants with intellectual disabilities in research. To apply this knowledge together, the team deemed the following as helpful: asking one another questions, explaining, discussing the scientific and the experiential knowledge together in easily understood language and using visual supports.

The impact of these decisions on the project was, for example, that the methods were drafted and evaluated in small iterative steps enabling step-by-step improvements to enable meaningful participation of people with intellectual disabilities as study participants (e.g., in Studies 2 and 3).

#### 3.3 | Decision making on data collection and analysis

For data collection and analysis, content-related decisions were made and roles were divided. Content-related decisions included, for example, how to conduct data analysis inclusively. For Study 2, the focus groups' voice recordings were used instead of transcriptions and data were analysed by making a visual web of ideas on paper instead of using the software. For the role division, team discussions were held to prioritise the tasks and the roles on which the coresearchers would spend their available time.

**TABLE 2** Overview of decision topics and examples of the impact of decisions per research step

Research step <sup>a</sup>	Decisions identified by research team	Examples of impact of the decisions on the research project
Topic and aim	How to become familiar with the topic	The team members familiarised themselves with the topic by using photovoice and group discussions.
Research question	Operationalise the research question and describe it in easily understood language	The development of the DIHASID tool was operationalized in three steps: what improvements can be made to make the tool (1) clear, (2) comprehensive and (3) usable in practice? (Study 3)
	Decide whether the preliminary study is needed to be able to design a method to answer the research question (Study 1 was added)	With approval from the funding organisation, Study 1 was added to the project. This enabled conceptualisation and clarification of the healthy settings topic in sub-themes in easily understood language
Study plan	Define aspects of research plan: choice of research method, adaptations to research method, inclusion criteria for participants, informed consent procedure	For Study 3, the team used the questionnaire appraisal system to develop the interview protocol for the cognitive interviews to improve the clarity of the tool
	Develop research information letters and informed consent forms	In all studies, easy-read information letters and informed consent forms were available for potential participants with intellectual disabilities to enable informed decision making on whether or not to participate
	What to incorporate in draft of the data collection methods	The draft of the DIHASID tool was built on both the experiential and the scientific knowledge of the research team (Study 3)
	How to improve the drafts of the data collection methods	In Study 2, an adjusted nominal group technique (NGT) was tested among the advisory board. The team incorporated their feedback and split the NGT into two sessions to enable the meaningful participation of people with intellectual disabilities as study participants. In Session 1, ideas were generated using pictures of themes. In Session 2, participants voted on the importance of ideas in a step-by-step voting procedure
	What supportive materials to provide for study participants	In Study 2, participants received handouts for the idea generation session and the voting session to facilitate the process
Data collection	Who is involved in data collection, how and when?	Anneke and Henk were involved in data collection in group meetings with people with intellectual disabilities (Studies 2 and 4)
	Roles during data collection	Study participants with intellectual disabilities were supported by Anneke and Henk who made them feel at ease and assisted in talking in easily understood language
Data analysis	Who is involved in data analysis, how and when?	Anneke and Henk were involved in data analysis to identify and sort ideas (Study 2), determine the changes needed to make the DIHASID tool clear and usable (Study 3) and determine what to incorporate in the infographic of the study results (Study 4)
	Roles during data analysis	Experiential knowledge was used to interpret the data gathered among participants with intellectual disabilities, as Anneke and Henk applied their role as expert-by-experience and coresearcher
	How to conduct data analysis inclusively	Adjusted data analysis was used, such as analysing voice recordings and making a visual web of ideas in Study 2
	Content-related decisions during data analysis	Experiential knowledge was used to determine what changes to make to the DIHASID tool based on input from participants (Study 3)

TABLE 2 (Continued)

Research step <sup>a</sup>	Decisions identified by research team	Examples of impact of the decisions on the research project
Writing and dissemination	Content and layout of the summary for study participants	All study participants with intellectual disabilities were reminded about the input they gave in the study by providing them with an easy-read summary
	Whether or not Anneke and Henk are coauthors of a scientific publication and in what form	Anneke and Henk are coauthors of the publications relating to Studies 2 and 3 and the current study
	What information to incorporate in scientific publications	The scientific publications include information on the inclusive research process
	Content and layout of the easy-read summary	For each publication, an easy-read summary was developed
	Other, creative ways of disseminating study results	For Studies 1 and 2, a vlog was made to share the study results

Abbreviation: DIHASID, Discovering Health-promoting Assets in Settings for people with Intellectual Disabilities.

<sup>a</sup>How decisions were made: In all steps of the research cycle, information was made comprehensible and accessible to enable discussion about it among the inclusive research team. During the discussions, there was room for questioning and talking about pros and cons of decisions to be made until the inclusive research team had the feeling they were able to make a decision together.

Information on which the co-researchers based these decisions included their perceptions on costs and benefits of involvement for themselves and the research project. Therefore, by looking at the topics, types of participants, data collection methods and types of data and analyses, the team discussed the roles and the talents that the team members could deploy. Identified benefits of coresearchers' involvement included putting people at ease, supporting the use of easily understood language, practical support, hearing participants' opinions and looking at the data from the perspective of a person with an intellectual disability. The costs turned out to relate to time needed (executing data collection, participants' travel time, data analysis), disturbance of regular working times (flexibility needed) and its impact on work/life balance and adjustments needed to conduct data analysis inclusively; for example, analysing voice recordings instead of transcripts.

The impact of these decisions was that experiential knowledge was deployed in most of the data collection and analysis where people with intellectual disabilities were involved as participants. For example, in the development of the Discovering Health-promoting Assets in Settings for people with Intellectual Disabilities tool (Study 3), both experiential and scientific knowledge was used to determine the changes that needed to be made to improve clarity, based on the cognitive interviews with people with intellectual disabilities.

### 3.4 | Decision making on writing and dissemination

For writing and dissemination, the team made decisions regarding the summaries for study participants, involvement in scientific publications, what information to incorporate in scientific publications, easy-read summaries of publications and other ways of disseminating study results. Activities in these research steps were similar for all four studies. Study participants received a summary of the results and an easy-to-read summary was written. Therefore, Kristel drafted these documents and Anneke and Henk (coresearchers with

intellectual disabilities) improved the text with easily understood language. For the scientific publications, the team and the thesis committee discussed and decided who met the criteria for authorship. Like other coauthors, Anneke and Henk decided whether or not they agreed with the manuscript and provided feedback. To enable them to do this, Kristel explained the manuscript in easy wording in Dutch so that Anneke and Henk could provide verbal feedback. Also, the team, with advice from the advisory board, decided on other ways of disseminating study findings. For example, for Study 2, they decided to develop a video blog.

To make decisions about who should be involved in writing and dissemination, specific attention was directed at each person's interests and talents. All the researchers were interested in informing study participants and people with intellectual disabilities in general about the results, but Kristel also wanted to inform other researchers about the results by publishing scientific articles. Competences needed for this task include English scientific writing skills and skills on easy writing for people with intellectual disabilities.

The impact of these decisions included the team developing easy-read summaries and video blogs on the study results. Also, researchers with intellectual disabilities were acknowledged as coauthors of scientific publications (i.e., Studies 2, 3 and the current study) that provide insight into the inclusive research process.

## 4 | DISCUSSION

This is the first study to examine the types of decisions, information used and processes for SDM and the impact of SDM on inclusive research, by reflecting on a long-term research project. The study provides the potential groundwork for future research on SDM in inclusive research by showing that SDM processes in the inclusive project aligned with key components of SDM in clinical settings.

Our study showed examples of shared decisions made throughout the entire research cycle of the project. To create

understanding of the situation and decision(s) to be made (Stacey et al., 2010), the inclusive research team identified the different decision types that they made together. The decisions ranged from relatively straightforward and previously identified research activities (e.g., planning, development of easy-read information letters and choice of output materials; Flood et al., 2013), to crucial modifications to the research project such as operationalizing the research topic, choosing and adjusting research methods and adding an entire extra study to the research project. The variety of decisions presented in this study provides an overview of the opportunities for SDM that other inclusive research teams could use to realise fully their potential impact on their research project.

The information used for SDM and the processes to foster SDM in inclusive research align with key components of SDM in clinical settings. Knowledge transfer and exchange and discussing risks, limitations, benefits, alternatives and uncertainties (Bomhof-Roordink et al., 2019; McCaffery et al., 2010; Stacey et al., 2010; Waldron et al., 2020), consisted of inclusive research on sharing and discussing scientific and experiential knowledge as a research team; for example, the stepwise development of a research plan whereby the team members complemented one another by each bringing something unique and created what Walmsley et al. (2018) call a shared space to work fruitfully together as an inclusive research team.

Identifying individuals' values and preferences for SDM (Stacey et al., 2010) was also recognised in our reflections on the SDM process. In inclusive research, this was focused on preferences based on interests, values, competences and skills that are helpful for role divisions. For example, the team members indicated with whom and how they wanted to share the results based on what they valued as important and interesting.

Deliberation and participation in decision making (Stacey et al., 2010) consisted of inclusive research discussions during research activities amongst the research team; for example, developing a data collection method and discussions on task division. For the latter, the team looked at their skills and competences and where these were of most added value to spend the limited time effectively, in the literature reflected as a discussion on team members' roles (Frankena et al., 2018). Whereas in some inclusive research studies the aim is to collaborate in every aspect, our approach was similar to other cases where the inclusive research team worked in partnership, with task division based on individual strengths and skills needed for tasks at hand (Frankena, Naaldenberg, et al., 2019; Nind, 2017). For data collection and analysis in particular, coresearchers' costs of involvement (e.g., extra time and disturbance of regular working times) were also discussed in task division to prevent overburdening. This potential risk of overburdening coresearchers aligns with reflections of other researchers in inclusive research (Nierse & Abma, 2011; Turk et al., 2012).

In addition to the key components of SDM, facilitators of SDM mentioned in this study include time for decision making or determining roles and next steps, as also mentioned in the SDM literature (Bomhof-Roordink et al., 2019). Furthermore, individual and team-related preconditions mentioned in this study relate to

literature on facilitators of collaboration in inclusive research teams; for example, motivation and communication skills, knowing one another well, a trusting relationship and awareness of power dynamics (Embregts et al., 2018; Nind & Vinha, 2014; O'Brien et al., 2014). Altogether, we identified similar concepts in inclusive research as in the SDM approach. Interestingly, we also noticed some dissimilarities. For example, SDM in clinical settings usually applies to making one or a few decisions about a personal health situation. In inclusive research, the decisions are not linked to outcomes that affect the coresearchers personally and multiple decisions are made throughout the entire research cycle. This may be the reason that SDM has been presented as a rather linear stepwise approach in making shared decisions whereas the current study shows that inclusive research is an iterative approach. Compared to SDM, the decision-making process in inclusive research goes back and forth across the different stages of SDM. Still, it would be interesting to examine whether an iterative approach also applies to SDM in clinical settings. In addition, a crucial component of SDM in inclusive research is the accessibility and comprehensibility of the content and methods used during the research cycle to make shared decisions while this has not been highlighted in SDM literature. It has been merely identified as additional facilitating elements to the five key components while it could be crucial for SDM in clinical settings as well. We, therefore, believe that SDM in clinical settings could also learn from SDM in inclusive research approaches.

Overall, the impact of the decisions made in the inclusive research project resulted in a transparent research approach in which the inclusive research team deployed individual and team skills. This improved the quality of the studies and empowered people with intellectual disabilities, thereby aligning with potential inclusive research outcomes previously identified (Frankena et al., 2018). Decisions relating to changes to the original research plan and adjusted data collection methods tailored the research project and accompanying studies, thereby facilitating the meaningfulness of the project outcomes in practice and enabling meaningful participation by participants with intellectual disabilities. The involvement of coresearchers in data collection and analysis led to a comfortable environment for participants during data collection and strengthened the quality of data analysis by the inclusion of experiential knowledge. The positive impact of coresearchers' involvement in data collection to create a comfortable environment and of data analysis to include experiential knowledge aligns with the literature (O'Brien et al., 2014; Tilley et al., 2021). Decisions on dissemination facilitated valorisation of the research and led to the availability of easy-read information, information on inclusive research processes and co-authorship of researchers with intellectual disabilities in scientific publications.

The study's findings should be interpreted in light of a few limitations. Although this paper reflected on SDM in four studies, these studies were conducted by one team who conducted one large project. Being critical or negative about the SDM processes might have been difficult for the team members who had a working relationship and knew one another well. To foster open and honest

reflections, the team chose to be interviewed individually by someone outside the team with whom the team members had a trusting relationship. To enable the co-researchers to remember decisions and SDM processes, our reflective study involved two steps. First, we created an overview of decisions based on interviews and document analysis, which helped coresearchers in the second step to remember and discuss how SDM took place, what facilitated the process and what impact it had. Even though this thorough process supported the coresearchers in their reflections, it was still difficult for them to remember all the details of SDM.

To the best of our knowledge, SDM processes of inclusive research teams have not yet been reflected upon by inclusive research teams themselves. Whereas Ellis (2018) explored decision-making processes from the standpoint of an academic researcher, this study provides perspectives of researchers both with and without intellectual disabilities. This inclusive reflection on decision making is a major strength of this study. Previous studies have provided insight into competences needed and role division for collaboration in inclusive research, and this study adds to this knowledge base by providing insight on decision making and SDM processes by using key components of SDM from clinical settings. These insights can contribute to more awareness of decisions and processes that foster fruitful ways of sharing power in inclusive research teams, which is at the centre of inclusive research practice (Walmsley & Johnson, 2003). Furthermore, as this study provides conceptual clarity of SDM, it may contribute to the quality of future inclusive research (Walmsley et al., 2018).

## 5 | CONCLUSION

Reflecting on SDM as an inclusive research team provided insight into the types of decisions that inclusive research teams can make per research step regarding content and task division. The variety of decisions presented in this study provides an overview of the opportunities for SDM that inclusive research teams can exploit to achieve their full potential impact on their research project. Also, the overview of key components of SDM processes, which align with SDM in clinical settings, contributes to more conceptual clarity of SDM in inclusive research. In practice, this can create awareness and foster fruitful ways of sharing power in decision making and collaboration in inclusive research teams.

## ACKNOWLEDGEMENTS

The authors would like to thank ZonMw and the Academic Collaborative, Stronger on Your Own Feet, for funding this study. This study was supported by ZonMw (Nationaal Programma Gehandicapt, Grant number: 355 80-84500-98-118) and the Academic Collaborative, Stronger on Your Own Feet.

## CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

## DATA AVAILABILITY STATEMENT

The data (list of decisions made and summary of group discussion) that support the findings of this study are available from the corresponding author, upon reasonable request.

## ORCID

Kristel Vlot-van Anrooij  <https://orcid.org/0000-0001-5628-7387>

## REFERENCES

- Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. T. (2019). *Participatory research for health and social well-being*. Springer.
- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3–12.
- Bomhof-Roordink, H., Gärtner, F. R., Stiggelbout, A. M., & Pieterse, A. H. (2019). Key components of shared decision making models: A systematic review. *BMJ Open*, 9(12), e031763.
- Brookes, I., Archibald, S., McInnes, K., Cross, B., Daniel, B., & Johnson, F. (2012). Finding the words to work together: Developing a research design to explore risk and adult protection in co-produced research. *British Journal of Learning Disabilities*, 40(2), 143–151.
- Buettgen, A., Richardson, J., Beckham, K., Richardson, K., Ward, M., & Riemer, M. (2012). We did it together: A participatory action research study on poverty and disability. *Disability & Society*, 27(5), 603–616.
- Chapman, R., & McNulty, N. (2004). Building bridges? The role of research support in self-advocacy. *British Journal of Learning Disabilities*, 32(2), 77–85.
- Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine*, 41(12), 1667–1676.
- Elberse, J. E. (2012). *Changing the health research system. Patient participation in health research* (Doctoral thesis). Vrije Universiteit Amsterdam.
- Ellis, L. (2018). Making decisions together? Exploring the decision-making process in an inclusive research project. *Disability & Society*, 33(3), 454–475.
- Embregts, P. J., Taminiu, E. F., Heerkens, L., Schippers, A. P., & Van Hove, G. (2018). Collaboration in inclusive research: Competencies considered important for people with and without intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 193–201.
- Flood, S., Bennett, D., Melsome, M., & Northway, R. (2013). Becoming a researcher. *British Journal of Learning Disabilities*, 41(4), 288–295. <https://doi.org/10.1111/j.1468-3156.2012.00756.x>
- Frankena, T. K., Naaldenberg, J., Cardol, M., Garcia Iriarte, E., Buchner, T., Brooker, K., & Fudge Schormans, A. (2018). A consensus statement on how to conduct inclusive health research. *Journal of Intellectual Disability Research*, 63(1), 1–11.
- Frankena, T. K., Naaldenberg, J., Cardol, M., Meijering, J., Leusink, G., & van Schroyenstein Lantman-de Valk, H. (2016). Exploring academics' views on designs, methods, characteristics and outcomes of inclusive health research with people with intellectual disabilities: A modified Delphi study. *BMJ Open*, 6(8), e011861.
- Frankena, T. K., Naaldenberg, J., Tobi, H., van der Cruijssen, A., Jansen, H., van Schroyenstein Lantman-de Valk, H., & Cardol, M. (2019). A membership categorization analysis of roles, activities and relationships in inclusive research conducted by co-researchers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 719–729.
- Frankena, T. K., van Schroyenstein Lantman-de Valk, H., Cardol, M., van der Cruijssen, A., Jansen, H., Leusink, G., & Naaldenberg, J. (2019). Contributing to inclusive research policy and practice: A synthesis of four inclusive (Health) research projects. *Journal of Policy and Practice in Intellectual Disabilities*, 16(4), 352–360.

- García Iriarte, E., O'Brien, P., & Chadwick, D. (2014). Involving people with intellectual disabilities within research teams: Lessons learned from an Irish experience. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 149–157.
- Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C., & Weiss, R. (2019). Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. *Health Expectations, 22*(3), 307–316. <https://doi.org/10.1111/hex.12873>
- Joosten, E. A., De Jong, C. A., de Weert-van Oene, G. H., Sensky, T., & van der Staak, C. P. (2011). Shared decision-making: Increases autonomy in substance-dependent patients. *Substance Use & Misuse, 46*(8), 1037–1038.
- Légaré, F., Stacey, D., Turcotte, S., Cossi, M. J., Kryworuchko, J., Graham, I. D., & Elwyn, G. (2014). Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews, 21*(9), 1265–1274.
- McCaffery, K. J., Smith, S. K., & Wolf, M. (2010). The challenge of shared decision making among patients with lower literacy: A framework for research and development. *Medical Decision Making, 30*(1), 35–44.
- Michell, B. (2012). Checking up on Des: My life my choice's research into annual health checks for people with learning disabilities in Oxfordshire. *British Journal of Learning Disabilities, 40*(2), 152–161.
- Nierse, C., & Abma, T. (2011). Developing voice and empowerment: The first step towards a broad consultation in research agenda setting. *Journal of Intellectual Disability Research, 55*(4), 411–421.
- Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research, 17*(3), 278–288.
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities, 42*(2), 102–109.
- O'Brien, P., McConkey, R., & García-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: Insights from a national survey. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 65–75.
- Puyalto, C., Pallisera, M., Fullana, J., & Vilà, M. (2016). Doing research together: A study on the views of advisors with intellectual disabilities and non-disabled researchers collaborating in research. *Journal of Applied Research in Intellectual Disabilities, 29*(2), 146–159. <https://doi.org/10.1111/jar.12165>
- Schattner, A., Bronstein, A., & Jellin, N. (2006). Information and shared decision-making are top patients' priorities. *BMC Health Services Research, 6*(1), 1–6.
- Sergeant, S., Schippers, A. P., Sandvoort, H., Duijf, S., Mostert, R., Embregts, P. J. C. M., & Van Hove, G. (2020). Co-designing the Cabriotraining: A training for transdisciplinary teams. *British Journal of Learning Disabilities, 49*(2), 230–246. <https://doi.org/10.1111/bld.12357>
- Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J., & Dunn, S. (2010). Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. *Patient Education and Counseling, 80*(2), 164–172.
- Tilley, E., Strnadová, I., Ledger, S., Walmsley, J., Loblinzk, J., Christian, P. A., & Arnold, Z. J. (2021). 'Working together is like a partnership of entangled knowledge': Exploring the sensitivities of doing participatory data analysis with people with learning disabilities. *International Journal of Social Research Methodology, 24*, 1–13. <https://doi.org/10.1080/13645579.2020.1857970>
- Turk, V., Leer, G., Burchell, S., Khatram, S., Corney, R., & Rowlands, G. (2012). Adults with intellectual disabilities and their carers as researchers and participants in a RCT. *Journal of Applied Research in Intellectual Disabilities, 25*(1), 1–10.
- Vlot-van Anrooij, K., Hilgenkamp, T. I. M., Leusink, G. L., van der Crujnsen, A., Jansen, H., Naaldenberg, J., & van der Velden, K. (2020). Improving environmental capacities for health promotion in support settings for people with intellectual disabilities: Inclusive design of the DIHASID Tool. *International Journal of Environmental Research and Public Health, 17*(3), 794. <https://doi.org/10.3390/ijerph17030794>
- Vlot-van Anrooij, K., Koks-Leensen, M. C. J., van der Crujnsen, A., Jansen, H., van der Velden, K., Leusink, G. L., Hilgenkamp, T. I. M., & Naaldenberg, J. (2020). How can care settings for people with Intellectual disabilities embed health promotion? *Journal of Applied Research in Intellectual Disabilities, 33*, 1489–1499. <https://doi.org/10.1111/jar.12776>
- Vlot-van Anrooij, K., Naaldenberg, J., Hilgenkamp, T. I. M., Overwijk, A., van der Velden, K., & Leusink, G. L. (2021). Gaining actionable knowledge to improve local health-promoting capacities in long-term care support settings for people with intellectual disabilities. *Patient Education and Counselling*. Advance online publication. <https://doi.org/10/1016/j.pec.2021.05.033>
- Vlot-van Anrooij, K., Naaldenberg, J., Hilgenkamp, T. I. M., Vaandrager, L., van der Velden, K., & Leusink, G. L. (2019). Towards healthy settings for people with intellectual disabilities. *Health Promotion International, 35*, 661–670. <https://doi.org/10.1093/heapro/daz054>
- Waldron, T., Carr, T., McMullen, L., Westthorp, G., Duncan, V., Neufeld, S.-M., & Groot, G. (2020). Development of a program theory for shared decision-making: A realist synthesis. *BMC Health Services Research, 20*(1), 59.
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present, and futures*. J. Kingsley Publishers.
- Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 751–759.

**How to cite this article:** Vlot-van Anrooij, K., Frankena, T. K., van der Crujnsen, A., Jansen, H., Naaldenberg, J., & Bevelander, K. E. (2022). Shared decision making in inclusive research: Reflections from an inclusive research team. *British Journal of Learning Disabilities, 1–10*. <https://doi.org/10.1111/bld.12450>