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A membership categorization analysis of roles, activities and relationships in inclusive research conducted by co-researchers with intellectual disabilities

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Abstract

Background: Inclusive research is studied mainly in short-term collaborations between researchers with and without intellectual disabilities focusing on practicalities. Structural study of long-term collaborations can provide insight into different roles of inclusive researchers, thereby contributing to a collective approach.

Method: Interviews with inclusive research team members ($n = 3$), colleagues ($n = 8$), and managers ($n = 2$) and three group discussions within the inclusive research team were held. Data were analysed following membership categorization analysis (MCA) adapted to the needs of the inclusive research team.

Results: This MCA provides insight into the complexity of inclusive research, reflected in the multitude of identified roles and activities. Analysis indicates that researchers with and without intellectual disabilities complement each other.

Conclusions: The activities identified in this study provide valuable information for discussing roles and responsibilities from the outset, so that dialogue starts at the core of inclusive research: the process between researchers with and without intellectual disabilities.

KEYWORDS

emancipatory research, Inclusive research, intellectual disabilities, membership categorization analysis, participation, participatory research, reflection

1 | INTRODUCTION

Inclusive research promotes the active involvement of people with intellectual disabilities in research concerning their life and their health. The first generation of inclusive research established its urgency; the second generation now aims to improve and reinforce inclusive approaches (Nind, 2016b). Sharing individual contributions

is viewed as an important aim of inclusive research (Walmsley, Strnadová, & Johnson, 2017), and many research papers focus on sharing practicalities of inclusive research in order to support others in conducting inclusive research (Riches & O'Brien, 2017). Examples include a paper by Tyrer et al. (2016) on their collaboration with service users with intellectual disabilities in a diabetes screening study in the UK, a paper by Puyalto, Pallisera, Fullana, and Vila (2015) that

explores the experiences of advisors with intellectual disabilities while collaborating in a project on the transition to adulthood and a paper by Beighton et al. (2017) studying the perspectives of people with intellectual disabilities and their parents on their involvement in a study on annual health checks.

Inclusive research is a process that takes place between researchers with intellectual disabilities and researchers without intellectual disabilities. Identities and relationships influence how researchers with and without intellectual disabilities collaborate during inclusive research projects (Nind, 2016b). To date, the structural study of roles and relationships within inclusive research has received little attention and has focused mainly on short-term projects. Structured study of long-term collaborations can provide additional insights that can contribute to the development of a collective approach to inclusive research (Nind & Vinha, 2014), for instance, on the purpose, effect and identity of inclusive researchers and people with intellectual disabilities (Tilly & Money, Friends and Making Ends Meet Research Group, 2015). This present research aims to gain in-depth insight into inclusive research teams by systematically studying the roles, associated activities and relationships between different actors present within an inclusive research project. In order to do so, this study adopts membership categorization analysis (MCA) and adapts this method to facilitate researchers with intellectual disabilities in conducting this reflection on their research project.

2 | METHOD

This paper studies the long-term (four-year) inclusive partnership between two co-researchers (Henk and Anneke) and a PhD researcher (Tessa)¹. We jointly decided to use our first names throughout this paper to contribute to its readability. We adopted an inclusive approach with the aim of having a meaningful collaboration in which everybody's perspective is of importance, where decision-making power is shared, in order to propagate inclusive research.

2.1 | Setting

The long-term inclusive partnership took place between April 2014 and April 2018. During this collaboration, we worked on a structured interview survey (Frankena, Naaldenberg, Bekkema et al., 2018), a Delphi study (Frankena et al., 2016), a case study (Frankena,

Naaldenberg, Cardol, vanderCrujisen et al., revisions submitted), a consensus statement (Frankena, Naaldenberg, Cardol, Garcia-Iriarte et al., 2018) and the study described in this paper. Tessa, Henk and Anneke worked together every Wednesday between 10.00 and 14.00 hr. After a lot of hard work, Henk and Anneke were given an appointment at the university. Meetings generally started with talking about how each team member felt, after which the programme for the day was discussed developed during the previous meeting. The membership categorization analysis section provides an example of how we collaboratively made the study inclusive, based on all team members' needs. More information on the inclusive partnership in this study as requested by the consensus statement on inclusive health research (Frankena, Naaldenberg, Bekkema et al., 2018) is interwoven through this manuscript. In order to prompt memory and celebrate achieved goals, we created a timeline of our partnership called "on the road to research," with flowers representing milestones in our work (Figure 1). This timeline was used to support the memory of the researchers involved in this study while discussing their collaboration.

2.2 | Data collection

Data for the present study were collected by means of interviews with stakeholders and group discussions with the inclusive research team, reflecting on the developed timeline. Several steps were taken in order to make data collection inclusive. First, stakeholders were identified and visualized (Figure 2) during discussions between Henk, Anneke and Tessa: (a) inclusive research team members ($n = 3$), (b) direct colleagues ($n = 8$) and (c) management staff ($n = 2$). Next, interview questions and consent forms were developed, after which interview tasks such as completing the consent form, asking pre-set questions and asking probing questions were identified and divided. The interviews were semi-structured and focused on roles, associated activities and relationships by asking questions about stakeholders' activities regarding the inclusive study, who made decisions and how collaboration was shaped. During the first interviews, Henk and Anneke preferred Tessa to take the lead; after two interviews, Henk and Anneke took more control over the interviews with Tessa in a supportive role. Henk, Anneke and Tessa themselves were individually interviewed by a different interviewer (MC) to reduce interviewer bias. Additionally, Henk, Anneke and Tessa held group discussions to discuss and reflect on the developed timeline.



FIGURE 1 Timeline "on the road to research" [Colour figure can be viewed at wileyonlinelibrary.com]

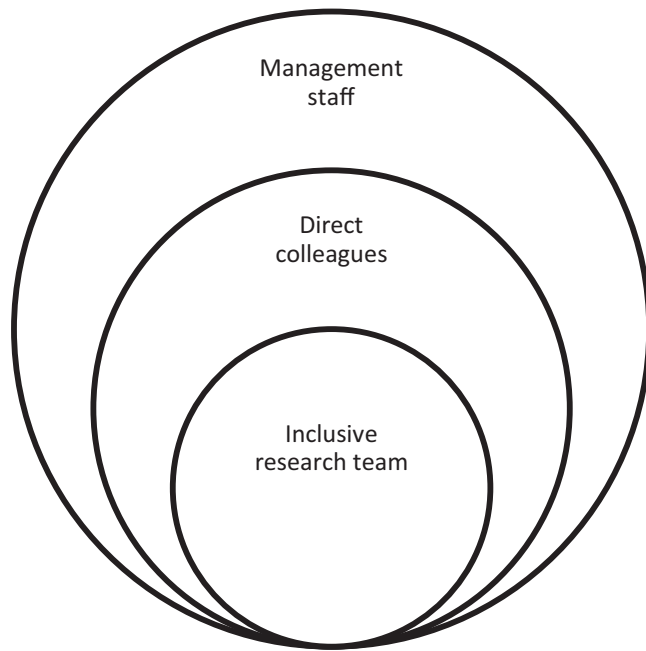


FIGURE 2 Circular model of stakeholders

Data were collected between November 2016 and January 2017. Interviews and group discussions were audio-recorded.

2.3 | Membership categorization analysis

To facilitate the researcher and the co-researchers in the data analysis phase, a research methodologist (HT) was consulted to advise on an appropriate data analysis approach and on the tailoring of this approach to the research aim and needs of the inclusive research team. The objective was to structurally analyse the actors, roles, activities and interactions within an inclusive partnership. The options were discussed with co-researchers Henk and Anneke, and it was decided to use membership categorization analysis (MCA).

Membership categorization analysis categorizes activities into roles in order to gain insight into a phenomenon, in this case, the inclusive research process (Schegloff, 2007). The activities that form a role are called membership categorization devices (MCDs; King,

2010). For example, in “the farmer is ploughing the fields,” ploughing the fields is an activity that forms part of the farmer role. The combination of the activities “ploughing the fields,” “sowing crops” and “harvesting crops” constitutes the MCDs for the farmer role. In other words, if a person is not ploughing, sowing or harvesting, she/he might not have a farmer role. MCA consists of three steps: (1) collecting roles, (2) collecting-associated activities and (3) identifying MCDs (Baker, 1997; Schegloff, 2007). These MCA steps were adapted and explicated to fit the needs of the inclusive research team, resulting in identifying (a) roles, (b) related activities and (c) relationships between categories. Table 1 provides an overview of the steps taken during this inclusive MCA.

During the analysis, it became clear that the co-researchers preferred to listen to recordings rather than read transcripts. Two approaches were tested in the first two analysis meetings to assess the workability of performing steps 1 and 2 simultaneously for each interview or first following step 1 for all interviews and then moving on to step 2. Taking steps 1 and 2 simultaneously per interview made it easier to recall what was discussed within each interview, and Henk and Anneke preferred this approach. Analysing all recordings was a strain for Henk and Anneke and proved unfeasible within the timeframe, as analysing one transcript took one 4-hr meeting. Therefore, for steps 1 and 2, at least one recording from each stakeholder group and the group discussion were analysed by Henk, Anneke and Tessa, allowing a large set of roles and related activities to be defined. The other recordings were analysed by Tessa, and any newly identified roles and activities were discussed with Henk and Anneke. The recordings from the inclusive research team itself were analysed by another team member involved with this paper (JN), following the set of roles and activities constructed by Henk, Anneke and Tessa to prevent bias in the analysis. The findings were added to the overall analysis, and again, any new roles were discussed with Henk and Anneke.

For step 3 of the inclusive MCA, relationships between categories were mapped by using the family function of ATLAS.ti, after which a visual map was constructed during discussions between all analysing researchers (Henk, Anneke, Tessa and JN). These discussions were visually supported by sticky notes of the roles and activities on flip charts, the relationships between roles and activities

TABLE 1 Inclusive MCA

Step	Aim	Action	Result
1 + 2	Identify roles	<ul style="list-style-type: none"> • Listening to an interview recording • Identifying roles • Ordering roles 	Roles and MCDs of inclusive research (section 3.1)
	Identify activities	<ul style="list-style-type: none"> • Listening to an interview recording • Identifying activities • Placing activities under roles 	
3	Identify relationships	<ul style="list-style-type: none"> • Constructing a visual map of roles and activities • Discussing the visual map • Discussing relationships between roles and categories • Rearranging roles and activities until consensus on MCDs was reached 	Relationships between categories (section 3.2)

Note. MCA: membership categorization analysis; MCD: membership categorization device.

were discussed, and the roles and activities were rearranged until consensus on MCDs was reached about which set of activities formed one role. The discussions resulted in rigorous restructuring of the map and rearranging of the activities: some roles were split and others were merged, resulting in the development of new roles. During these discussions, three overarching categories were identified: researchers with intellectual disabilities, researchers without intellectual disabilities and general. The categories researchers with intellectual disabilities and researchers without intellectual disabilities address the roles of these researchers, respectively. The category general applies to all those involved in inclusive research, including researchers with and without intellectual disabilities and support staff. Each category consists of several roles, and each role consists of associated activities (i.e., MCDs), as described in the results section.

3 | RESULTS

Figure 3 provides an overview of the roles found in this study, subdivided into the three categories: researchers with intellectual disabilities, researchers without intellectual disabilities and general. The results section of this paper firstly presents roles and MCDs (i.e., the set of activities that are part of a role) for the researchers with intellectual disabilities, the researchers without intellectual disabilities and the general category. Thereafter, the relationships between categories are elaborated upon. The terms used for roles and activities

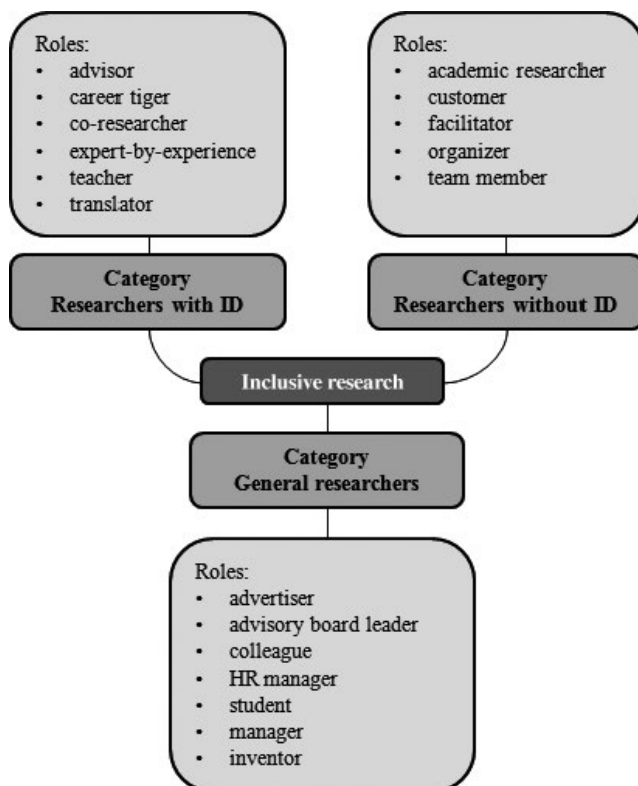


FIGURE 3 Membership categorization analysis of inclusive research

presented in the results are a direct translation of the Dutch terms used by Henk and Anneke during the MCA. In another context or research setting, these terms might have a different meaning; however, the explanations in Tables 2–4 clarify what the co-researchers meant.

3.1 | Roles and MCDs of inclusive research per category

3.1.1 | Researcher with intellectual disability category

The researcher with intellectual disability category includes all the roles that a person with intellectual disabilities can have when working in an inclusive research team. This category consists of the roles: advisor, career tiger, co-researcher, expert by experience, teacher and translator. The career tiger role needs further explanation, as this is a direct translation from a Dutch term meaning: a highly motivated person career-wise. This person is a go-getter and knows what she/he wants when doing a job. One fulfils a particular role if one meets the MCDs as presented in Table 2, which provides a summary of the activities found for researcher with intellectual disabilities (for a complete list Table A1). For example, if someone prepares and gives presentations, in different formats and for different groups, and creates awareness through these presentations, she/he has a teacher role. Anneke gave a guest lecture for students at Wageningen University in October 2014 on an inclusive approach towards research, using a PowerPoint presentation. Students attending her lecture were not aware that it was possible to collaborate with a research group as such. These combined activities make up the MCDs of the teacher role that Anneke propagated at that juncture.

The majority of the roles associated with researchers with intellectual disabilities such as advisor, co-researcher and teacher encompass activities that are easily visible in the work of a co-researcher. Some roles, such as career tiger, consist of MCDs that are very emblematic of the role of co-researcher but at the same time are harder to make visible and put into words. This role consists of MCDs such as handling unfamiliar things and identifying strengths and weaknesses, which are vital to research, and these qualities are necessary to be able to grow as a co-researcher. It also portrays the eagerness of some people with intellectual disabilities to become co-researchers. For example, a co-researcher who found it difficult to deal with the unfamiliarity of research and had difficulties addressing his own challenges eventually left his co-researcher position. He was not enthusiastic enough about the co-researcher job to deal with this; he did not meet the roles needed to remain a co-researcher. As Anneke noted: “research is not everybody’s cup of tea.”

3.1.2 | Researcher without intellectual disability category

The researcher without intellectual disability category consists of roles attributed to academic researchers who conduct inclusive

TABLE 2 Roles and MCDs of researchers with intellectual disabilities

Roles	MCDs
Advisor	Giving advice in different ways, about different topics, and with different motivations for giving advice
Career tiger	<ul style="list-style-type: none"> • Handling new/unfamiliar things • Helping others • Communicating • Identifying strengths and weaknesses
Co-researcher	<ul style="list-style-type: none"> • Employment activities • Workplace accessibility • Research activities • Research accessibility • Getting used to, and gaining, experiences • Being appreciated
Expert-by-experience	Emphasizing what people with intellectual disabilities experience and need, being aware that you cannot speak for all people with intellectual disabilities
Teacher	Preparing and giving presentations in different formats and for different groups and creating awareness through these presentations
Translator	Translating different types of text in different ways and for different reasons

Note. MCD: membership categorization device.

TABLE 3 Roles and MCDs of researchers without intellectual disabilities

Roles	Activities
Academic researcher	<ul style="list-style-type: none"> • Academically trained • Providing room for others (in research project) • Having shortcomings
Customer	Providing and explaining assignments but making the final decision on how to use co-researchers' advice
Facilitator	<ul style="list-style-type: none"> • Sensitive to the needs of co-researchers • Accessible communication • Curious and open, and feeling for co-researchers • Adapting your attitude towards people with intellectual disabilities • Taking the limited time into account
Organizer	Organizing finance, transportation, practical conditions and job appointments
Team member	<ul style="list-style-type: none"> • Preparing and planning activities • Accessibility activities • Identifying strengths and weaknesses • Gaining experiences • Shared decision making

research. From the MCA, roles within this category are as follows: academic researcher, customer, facilitator, organizer and team member. Table 3 summarizes the MCDs for each of these roles, and a complete list of MCDs for researchers without intellectual disabilities is available in Table A2. Similar to the researcher with intellectual disability category, the researcher without intellectual disability category contains a research-related role: the academic researcher.

The analyses resulted in a division between customer and team member. The customer role applies to researchers without intellectual disabilities who give assignments to researchers with intellectual disabilities but are not members of the researchers with intellectual disabilities' core research team. In this role, the customer makes the final decision on how to use co-researchers' input. For example, a direct colleague asked Henk and Anneke to give advice on a script

she had written for an information video for people with intellectual disabilities. After Henk and Anneke gave their advice, the colleague decided what she wanted to process within her available timeframe. The customer role shows how co-researchers can become part of research groups beyond their core team and research project. The team member role applies to researchers without intellectual disabilities who collaborate structurally with researchers with intellectual disabilities. As team members, the researchers with and without intellectual disabilities make decisions together. In the case of Henk and Anneke, Tessa was a team member until April 2018, as they worked together structurally on several research projects.

The facilitator and organizer roles both contribute to the involvement of researchers with intellectual disabilities, with the facilitator focusing on the accessibility of the study and the organizer focusing on

TABLE 4 Roles and MCDs of general researchers

Roles	Activities
Advertiser	Recommending inclusive research to others
Advisory board leader	Organizing, facilitating and taking input from the advisory board for one's own research
Colleague	<ul style="list-style-type: none"> • Talking and having fun, and having a good relationship • Creating awareness as colleagues with intellectual disabilities • Dealing differently with colleagues with intellectual disabilities
HR manager	<ul style="list-style-type: none"> • Responsible for employees, contracts and salaries • Working harder for appointment of co-researchers in light of, for example social benefits and travel costs • Collaborating with other organizations
Inventor	Accepting a challenge, persevering and doing what has never been done before
Manager	<ul style="list-style-type: none"> • Arranging things • Having affinity with inclusive research/wanting to employ people who do not have ready access to the labour market • Indirectly involved with co-researchers • Making decisions on financing and employment of co-researchers • Having to comply with rules and regulations, and sometimes being creative with them
Student	Learning about inclusive research and the added value of co-researchers

practical conditions around the workplace. For example, as a facilitator, Tessa made sure that she communicated research topics in an accessible manner, by using drawings and accessible texts. As an organizer, Tessa ensured the physical accessibility of the workplace by arranging a customized desk and keyboard for Anneke and a ramp to access the building in a wheelchair.

3.1.3 | General category

The roles within the general category are as follows: advertiser, advisory board leader, colleague, HR manager, inventor, manager and student. Table 4 provides a summary of MCDs for each of these roles, and a complete list is available in Table A3. Although they might come across as specific, the roles found for the general category apply to everybody involved in and around the inclusive research project. For example, the activities under HR manager do not only apply to the organization's HR manager. In the case of the collaboration reflected upon in this study, the direct manager and Tessa took on HR activities such as sorting out how salaries could be arranged with regard to social benefits. Together, these roles contribute to an inclusive work environment in an academic setting, with not only physical (e.g., wheelchair accessibility) but also social (e.g., welcoming environment) inclusiveness.

3.2 | Relationships between categories

3.2.1 | Researcher with intellectual disabilities versus researcher without intellectual disabilities

A number of notable points can be made with regard to the relation between the researcher with intellectual disability category and the researcher without intellectual disability category. These categories

are mutually exclusive; if one is a researcher with intellectual disabilities, one cannot be a researcher without intellectual disabilities. The roles fulfilled by the researcher with intellectual disabilities when collaborating with a researcher without intellectual disabilities depend on the assignments they get from customers or the project on which they are working with team members. For example, when Henk and Anneke were asked by a colleague to give a presentation about their experiences of having a disability, they tapped into the roles of expert by experience and of teacher. When they collaboratively developed easy-read research material with Tessa, they took on the roles of co-researcher and of translator. In this way, the researcher with intellectual disability category is responsive to the situation.

The relation between the researcher with intellectual disabilities and the researcher without intellectual disabilities is characterized by roles that support the collaboration. For the researcher without intellectual disabilities, supportive MCDs are found in the regulator, facilitator, customer and team member roles. For the researcher with intellectual disabilities, one role consists of supportive MCDs: the co-researcher role. This indicates that the researchers with and without intellectual disabilities complement each other and that researchers with intellectual disabilities are likely to need more support in conducting research than researchers without intellectual disabilities.

3.2.2 | Researcher with intellectual disabilities and researcher without intellectual disabilities versus general category

Within the general category, several roles are included that ensure that pre-conditions of inclusive research are in place, such as HR manager and manager. The colleague role consists of activities that contribute to social pre-conditions, which are stressed by

interviewees as important to inclusive research. On the one hand, it relates to the researcher with intellectual disability category by making such researchers feel at ease and by facilitating collaboration. On the other hand, the colleague role affects the researcher without intellectual disability category by, for example emphasizing the difference between the relation between doctors and patients and the relation between colleagues. In the case of our research group, several colleagues are doctors for patients with intellectual disabilities. Their collaboration with Henk and Anneke made them aware of the difference between a doctor–patient relationship and being colleagues of people with intellectual disabilities.

The inventor and student roles encompass activities that illustrate the novelty of inclusive research to academia and apply to researchers with and without intellectual disabilities but also, for example to managers who have to figure out how to shape inclusive research in their department. For example, in the inventor role, Henk, Anneke and Tessa felt that they had pioneered ways to conduct data analysis together. The MCA in the present study is a good example of this. The advertiser role portrays the enthusiasm displayed by interviewees in this study about participating in inclusive research by trying to persuade others to collaborate in research. One of the interviewees called this “spreading the collaboration virus” amongst direct colleagues and researchers outside one's own department.

4 | DISCUSSION

This research aimed to gain in-depth insight into inclusive research teams by systematically studying the roles, associated activities and relationships between different actors present within one inclusive research project. Following an inclusive MCA approach, this study identified three categories in inclusive research: researcher with intellectual disabilities, researcher without intellectual disabilities and general, consisting of different roles and MCDs. The results of this study provide insight into how inclusive research is structured through roles and activities and how these relate to each other. The results of the inclusive MCA include not only roles that can be expected within the researcher with intellectual disability category such as co-researcher, teacher and expert by experience, but also several roles that maybe less evident, such as career tiger and translator. These roles consist of activities that are very emblematic of the role of co-researcher but at the same time are harder to make visible and put into words. With regard to the relation between categories, it was found that the researcher without intellectual disability category consists mainly of facilitative activities for co-researchers, besides doing research. This indicates that the researcher without intellectual disabilities focuses more on the accessibility of research compared with the researcher with intellectual disabilities. The general category consists of roles and activities applicable to all those involved in inclusive research and facilitates both physical and social inclusiveness.

One of the strengths of this study is the inclusive approach adopted through the partnership between two co-researchers and

an academic researcher. The aim was to collaborate meaningfully in every step of the study, providing Henk and Anneke room to take the lead where preferred. Henk and Anneke took the lead in the second half of the interviews and the data analysis. Tessa took the lead in writing the English publications, and sections were frequently discussed with Henk and Anneke, who are co-authors, to ensure that it was representative of their work and ideas. We acknowledged one another's skills (i.e., Tessa's academic skills and Henk and Anneke's expert by experience perspective and critical view). However, it should be emphasized that the divisions of roles and tasks were not merely based on skills but also if the researchers felt comfortable with the task and if it was practically feasible. For example, as mentioned in the Methods section, doing the full analysis was a strain for Henk and Anneke and proved unfeasible within the timeframe.

An accessible video was developed by the inclusive research team to make dissemination of the study results more inclusive and share them in an accessible manner. Collaborative data analysis was especially challenging as not many examples of such inclusive data analyses were available in published literature, possibility due to its complexity. With the support of a methodologist, MCA procedures were adapted to this inclusive partnership. In this regard, the data analysis was innovative, as we “replicate familiar processes of data analysis while adapting them to be suitable to the challenging contexts in which they are used” (Seale, Nind, Tilley, & Chapman, 2015, p. 490). The long-term collaboration of our inclusive research team provided room to adopt different inclusive methods and grow as inclusive researchers over time. Future research adopting inclusive MCA can build on the knowledge gained in this study.

The complexity of inclusive research is reflected in the multitude of roles and activities identified in this study. Of the 18 roles described in this study, 11 have been previously identified and described in the literature. The roles found in our study can be linked to the identities as found by Nind (2016b, p. 190): “team member, co-researcher, inclusive researcher or advocate for inclusive research, proper researcher, lead researcher, expert by experience, research supporter, coordinator, advisor.” Other studies more implicitly describe roles within inclusive research. For example, Nind (2016a) in the title of her publication sees inclusive research as “a site of lifelong learning” for all involved; this corresponds with the student role. Similarly, the social activities relating to the colleague role are repeatedly described in the literature. Nind and Vinha (2014, p. 42) state that “strong collaboration was often depicted in terms of good knowledge of each other, having fun and spending time together, even being friends or a kind of family.” Riches and O'Brien (2017) identified togetherness as an important quality of inclusive research. Relational aspects are seen as one of the most important sides to inclusive research (Tilly & Money, Friends and Making Ends Meet Research Group, 2015). This study takes a next step by structuring and explicating inclusive research roles. The seven roles that were not found in previous studies are as follows: career tiger, customer, team member, advertiser, advisory board leader, manager and inventor; these all describe more implicit and

tacit activities. However, this could also be a peculiarity of the inclusive partnership described in this study. Nevertheless, insight into both the explicit and implicit roles and related activities of inclusive research is important for understanding every facet of inclusive research, and it assists in assigning responsibilities within an inclusive research team.

Discussions in the literature on terminology (Ollerton, 2012), training (Di Lorito, Bosco, Birt, & Hassiotis, 2017), and participatory and emancipatory research (Strnadova & Walmsley, 2017) suggest that one of the goals of inclusive research is for co-researchers to approximate an academic researcher's job as closely as possible. However, the researcher with intellectual disabilities and researcher without intellectual disability categories found in this study encompass roles and activities that are very different from each other. The researcher with intellectual disability category consists of more roles, and especially activities, compared with the researcher without intellectual disability category. This might be because the researcher with intellectual disability role is rather new and still in a developmental stage. The researcher without intellectual disability category consists of more facilitating roles and activities compared with the researcher with intellectual disability category; this is in line with previous research (Ollerton, 2012). The results of this study suggest that researchers with and without intellectual disabilities complement each other, implicating that roles and activities cannot be exactly the same. In addition, differences between researchers with and without intellectual disabilities are not based solely on their roles in inclusive research, but on their personalities and personal lives as well (Nind, 2016b). In addition, there is a qualitative difference between the roles of researchers with and without intellectual disabilities and one cannot simply add up their roles and draw a conclusion; we expect the whole to be bigger than the sum of its parts. The MCDs identified in this study provide a valuable basis on which to discuss roles and responsibilities at the start of an inclusive research project. By doing so, the dialogue starts at the core of inclusive research, the process between researchers with and without intellectual disabilities. Sharing these dialogues in publications helps to create shared learning between inclusive researchers and to establish a more solid knowledge base in this field.

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APPENDIX 1

TABLE A1 Roles and activities of researchers with intellectual disabilities

Roles	Activities
Advisor	<ul style="list-style-type: none"> • Giving advice in different ways • Giving advice about different topics • Having different motivations to give advice
Career tiger	<ul style="list-style-type: none"> • Handling new/unfamiliar things • Helping others • Communicating • Identifying strengths and weaknesses
Co-researcher	<ul style="list-style-type: none"> • Applying for the job • Becoming familiar/searching • Making decisions about your contract • Making the work environment accessible • Planning • Preparing research • Asking questions • Responding/adapting to other co-researchers • Conducting research (in different ways) • Getting assignments from colleagues • Being of added value • Being appreciated • Adapting research to the possibilities • Dividing tasks • Gaining experience in research • Feeling responsible/not being responsible • Meeting new people • Gaining experiences
Expert-by-experience	<ul style="list-style-type: none"> • Telling what you are experiencing • Knowing what people with intellectual disabilities need • Putting people with intellectual disabilities in the centre • Putting yourself in people with intellectual disabilities' position • Following expert by experience training • Being aware that you cannot speak for everyone with intellectual disabilities
Teacher	<ul style="list-style-type: none"> • Preparing for presentations • Giving different types of education/presentations • Giving education/presentations for different groups • Growing in teaching/presenting • Having different experiences with teaching/presentations • Creating awareness • Receiving a gift or a gift voucher
Translator	<ul style="list-style-type: none"> • Having experience with translating • Translating in different ways • Translating for different reasons • Translating different texts

TABLE A2 Roles and activities of researchers without intellectual disabilities

Roles	Activities
Academic researcher	<ul style="list-style-type: none"> • Having academic training • Learning to let go (of your research project) • Having shortcomings • Doing research/knowing how to do research
Customer	<ul style="list-style-type: none"> • Coming with (different) assignments • Explaining the assignment • Taking the lead/making decisions • Preparing for collaboration • Being appreciated
Facilitator	<ul style="list-style-type: none"> • Responding to the needs of co-researchers • Listening to co-researchers • Being open and aware • Feeling responsible • Adapting your attitude towards people with intellectual disabilities • Working step by step • Being curious • Being of added value • Taking the limited time into account • Asking for clarification • Communicating accessibly • Taking the input of co-researchers into account
Organizer	<ul style="list-style-type: none"> • Organizing finance • Organizing transportation • Organizing practical conditions • Organizing the appointment of co-researchers • Gaining experiences
Team member	<ul style="list-style-type: none"> • Preparing collaboration • Planning/using an agenda • Dividing tasks • Making research accessible to co-researchers • Identifying strengths and weaknesses • Gaining experience of collaboration • Seeking (in the beginning) • Making decisions together • Experiences of collaboration

TABLE A3 Roles and activities of general researchers

Roles	Activities
Advertiser	<ul style="list-style-type: none"> • Telling others about our collaboration (through various media) • Recommending collaboration to others • Spreading the “collaboration virus”
Advisory board leader	<ul style="list-style-type: none"> • Organizing/putting together the advisory board • Discussing different things with the advisory board • Experiencing added value from the advisory board • Preparing advisory board meetings
Colleague	<ul style="list-style-type: none"> • Talking with each other • Dealing differently with co-researchers • Finding the co-researcher to be a fun person • Being colleagues makes collaborating easier • Having a good relationship • Doing fun stuff together • Having people with intellectual disabilities as colleagues puts them at the centre • Having fun • Having a different relationship than a doctor–patient relationship
HR manager	<ul style="list-style-type: none"> • Letting co-researcher make own decisions • Sorting out travel costs • Taking social benefits into account • Working harder for appointment of co-researcher • Being responsible for employees • Having different experiences with HR work • Sorting out the contract • Sorting out the salary • Involving other people and organizations in HR issues
Inventor	<ul style="list-style-type: none"> • Doing work that has never been done • Going on an adventure/taking up a challenge • Persevering
Manager	<ul style="list-style-type: none"> • Making decisions on financing co-researchers • Organizing a lot of things • Having affinity with inclusive research • Looking for the right employee • Using co-researchers’ knowledge • Having annual interviews with employees • Setting up new (inclusive) studies • Complying with rules and regulations • Facilitating inclusive research • Providing a supportive work environment • Being indirectly involved with co-researchers • Discussing co-researchers via team members • Employing/having to employ people without ready access to the labour market • Being creative with rules and regulations • Appreciating co-researchers as employees • Making decisions about the employment of co-researchers
Student	<ul style="list-style-type: none"> • Learning about inclusive research • Learning about the added value of co-researchers • Reflecting on collaboration • Other people learning from our collaboration