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"Nothing About Us Without Us": the first example of inclusive research in Early Childhood Education in Norway

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Abstract

Il termine ricerca inclusiva è usato in letteratura per descrivere una partnership tra accademici e persone con disabilità intellettive, realizzata allo scopo di condurre insieme la ricerca. Questo tipo di partenariato deve contenere alcuni elementi chiave, come affrontare le questioni che interessano le persone con disabilità intellettive, ed essere condotto con rispetto e in un modo tale da consentire alle persone con disabilità intellettive di presentare le proprie opinioni ed esperienze nella ricerca. Il presente articolo si basa su un "case" in cui, per la prima volta in Norvegia, una persona con sindrome di Down ha partecipato attivamente come co-ricercatore a un progetto di ricerca sull'educazione della prima infanzia. L'obiettivo era aumentare la competenza dei ricercatori riguardo alla capacità di includere tutti i bambini in un'attività ludica con un robot nella prima infanzia. Questo articolo è stato scritto in collaborazione tra due ricercatori, il co-ricercatore e la sua persona di contatto. Il presente lavoro sottolinea l'importanza della ricerca inclusiva, mostrando la conoscenza unica che una persona con disabilità intellettiva può apportare a un progetto di ricerca sull'inclusione. L'articolo analizza il metodo sviluppato nel nostro caso di ricerca inclusiva attraverso la lente della teoria di H. Skjervheim. I risultati evidenziano che tutti e tre gli elementi principali della teoria sono stati realizzati: comunicazione simmetrica, partecipazione degli utenti e cooperazione con le persone di contatto.

The term inclusive research is used in literature to describe a partnership between academics and people with intellectual disabilities, with the aim of conducting research together. This type of partnership must contain some key elements, such as addressing issues that matter to people with intellectual dis-

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abilities, and being conducted with respect and in a way that allows their views and experiences to be given weight in the research. The present article is based on a case in which, for the first time in Norway, a person with Down Syndrome has participated actively as co-researcher in a research project about early childhood education. The aim was to increase the researchers' competence in relation to how to include all the children in an activity with a coding toy in Early Childhood Education and Care. This article is written in a partnership between two researchers, the co-researcher, and her contact person. This underlines the importance of inclusive research, showing the unique knowledge that a person with an intellectual disability can bring to a research project about inclusion. The article analyses the method developed in our case of inclusive research through the lens of Skjervheim's theory. Results highlight that all three main elements of the theory have been realized – symmetric communication, user participation and contact person cooperation.

Keywords: inclusive research, Early Childhood Education, Down Syndrome, coding toys

Parole chiave: ricerca inclusiva, prima infanzia, sindrome di Down, robot

Accessible summary

- Inclusive research describes a partnership between researchers and co-researchers with intellectual disabilities.
- The present study describes the first case of inclusive research in Norway involving a person with Down Syndrome in a research project about Early Childhood Education, technology and inclusion.
- The aim was to increase the researchers' competence in relation to how to include all the children in an activity with a coding toy in Early Childhood Education and Care.
- The present article has been written in a partnership between two researchers, the co-researcher and her contact person.
- The study highlights how the implemented method agrees with an important theory about inclusion.

Introduction

The term inclusive research is used in literature for describing a partnership between academics and people with intellectual disabilities, with the aim of conducting research together[1]. Therefore, this article is written in a partnership between two researchers, the co-researcher, and her contact person. Inclusive research is a concept that embraces different descriptions of how the co-researcher can be involved in a research process: inclusive research, participative research, co-researching, emancipative research[2]. Whatever term is chosen, a research process has to respect some key elements in order to be defined as inclusive research: it has to address issues that matter to people with intellectual disabilities and has to be conducted with respect and in a way that allows their views and experiences to be presented[3]. An explanation of the meaning of inclusive research can be find in the quote "Nothing About Us Without Us"[4], which highlights that no policy or educational programme should be defined without the participation of members that are affected by it. The literature has also clearly presented a relationship between inclusive research and inclusive education[5].

Inclusive research has a long tradition in countries like England and Australia[6] while in Norway it is relatively new[7].

The present article is based on a case in which, for the first time in Norway, a person with Down Syndrome has participated actively as co-researcher in a research project about early childhood education. The aim

[1] K. Johnson - J. Walmsley, *Inclusive research with people with learning disabilities: Past, present and futures*, Jessica Kingsley Publishers, London and Philadelphia 2003.

[2] M. Nind, *Inclusive research and inclusive education: why connecting them makes sense for teachers' and learners' democratic development of education*, in «Cambridge Journal of education», 4 (44/2014), pp. 525-540.

[3] K. Johnson - J. Walmsley, *Inclusive research with people with learning disabilities: Past, present and futures*, cit.

[4] M. A. Stein - P. Stein - D. Weiss - R. Lang, *Convention on the Rights of Persons with Disabilities*, in «European Journal of Health Law», 3 (14/2007), pp. 281-298.

[5] M. Nind, *Inclusive research and inclusive education: why connecting them makes sense for teachers' and learners' democratic development of education*, cit., pp. 525-540.

[6] K. Johnson - J. Walmsley, *Inclusive research with people with learning disabilities: Past, present and futures*, cit.

[7] M. Østby - M. Haugenes, Inkluderende forskning sammen med personer med utviklingshemming: en metodebok [Including research with people with learning disabilities: A method book], Universitetsforlaget, Oslo 2019.

was to increase the researchers' competence in relation to how to include all the children in an activity with a coding toy in Early Childhood Education and Care (ECEC). To confirm that the case is built in a real inclusive environment, the article analyses how the case of inclusive research presented can be seen through the lens of Skjervheim's theory[8].

Theoretical framework

This article is built on the theoretical framework developed by H. Skjervheim[9] This theory, which is strongly critical of objectivism, is important in order to understand how people with special needs are seen and should be seen. Already in the 60s and 70s, Skjervheim highlighted that there are two possible methods for building a dialogue with a person with special needs: the "spectator position" and the "participant position"[10]. Skjervheim starts from a three-part relationship that includes subject, the other and the situation, to describe a conversation/a relationship. When the relationship is only built on a two-part relationship between the subject and the case, it means that the person is not really considered in the development of a common knowledge. The subject derives an analysis based on their own observations, and knowledge does not come from a conversation where the person with disabilities may come up with their own reasons. This is defined as a spectator position, and the person with intellectual disabilities has become the object of discussion. Conversely, when the subject together with the person with intellectual disabilities directs attention to the phenomenon and engages with their problem, a participant position is developed. In this situation, a symmetrical interpersonal relationship between the subject and the person with intellectual disabilities is realized. Skjervheim[11] pointed out the need for more symmetrical communication, and that is a key aspect in relation to the perspective behind special education and inclusive research. It is consistent with the idea that the participant position can move even further, from a

[8] H. Skjervheim, *Objektivismen-og studiet av mennesket*. Gyldendal akademisk 2000.

[9] H. Skjervheim, *Deltakar og tilskodar*, Instituttet for sosiologi, Universitetet i Oslo 1974.

[10] H. Skjervheim, *Objektivismen-og studiet av mennesket*, cit.

[11] S. Hverven, *Hvordan leve med andre?-Hans Skjervheim, objektivisme og natursyn*, in «Norsk filosofisk tidsskrift», 02 (51/2016), pp. 93-106.

peripheral participant position to full participation and membership in a community[12].

Two more dimensions are relevant for realizing a participant position: user participation and parental (or contact person) cooperation. User participation indicates that the person with intellectual disabilities is involved in the decision-making processes. This describes the right and the power to influence the decision-making processes. The last dimension describes how parents (in the case of children) or the contact person (for youths and adults) can be important for supporting both the communication and the inclusion[13].

To establish the inclusive research, we chose to follow the guidelines described by M. Østby regarding this practice. All the terms "ownership", "interests", "collaboration", "control" and "availability" have been put into practice[14].

Ownership signifies that the research question belongs to the co-researcher, while interest means that the research has to be important for persons with intellectual disabilities. Collaboration underlines the fact that persons with and without intellectual disabilities work together, while control highlights that some parts of the project have to be developed mainly by the co-researcher. Availability means that the whole project has to be understandable for all the participants, with or without intellectual disabilities[15].

An example of inclusive research in a research project about early childhood education in Norway

The present article describes a case that has been developed through inclusive research, as part of a long-term research project.

[12] J. Lave - E. Wenger, *Situated learning: Legitimate peripheral participation*, Cambridge university press 1991.

[13] T. Stølen, *Anerkjennelse, subjektivitet, rettferdighet*, in «Agora», (02-03) (29/2011)., pp. 318-323.

[14] M. Østby - M. Haugenes, I*nkluderende forskning sammen med personer med utviklingshemming: en metodebok* [Including research with people with learning disabilities: A method book], cit.

[15] Ibidem.

The DiCoTe project[16] (Increasing professional Digital Competence in Early Childhood Teacher Education with focus on enriching and supporting children's play with coding toys), related to the Norwegian National research centre, FILIORUM-Centre for Research in Early Childhood Education and Care[17], aims to increase digital competence in Norwegian ECEC institutions and to develop resources that will help ECEC teachers to enrich and support children's play with technology. Research shows that this can strengthen children's learning of important skills such as logical thinking, cooperation, inclusion and emotional and social skills[18]. The coding toy chosen is Kubo®[19], a robot that can be programmed by linking puzzle tiles with arrows, without the use of screens (for a more detailed description, see the article published by L. B. Bertel[20]). With the robot and the puzzle tiles, it is possible to use a cardboard sheet where a school, street and other elements are represented, to inspire the children to play (see Figure 1). To effectively include children with intellectual disabilities, researchers and practitioners need to understand more about their challenges. Inclusive research is an important element in this.

For this reason, we applied for funding so that we could create a co-researcher position for a person with an intellectual disability. Our co-researcher applied for this position in the project, after receiving suggestion from the contact person who, in this case, is a special education teacher and speech language therapist. The co-researcher established some conditions for accepting the job. During one of the meetings held to discuss the project, the first author and the co-researcher had the conversation reported below. Part of the same conversation was reported by the co-researcher in the script presented at the workshop.

Co-researcher: *"I have Down Syndrome, so I have challenges in learning. Language is one of them. When I was in ECEC, I got a lot of help with learn-*

[16] https://www.uis.no/nb/forskning/dicote-increasing-professional-digital-competence-in-ecte-with-focus-on-enriching-and.

[17] https://www.uis.no/en/research/filiorum-centre-for-research-in-early-childhood-education-and-care.

[18] E. Pollarolo, Papavlasopoulou, S., F., G., & E., R. (Submitted), *Early childhood teachers and coding toys: views, methods, approaches and children's development. A systematic literature review*, in «Educational Research Review».

[19] https://kubo.education/.

[20] L. B. Bertel - E. Brooks - S. Dau, *Robot-Supported Inclusion and Learning:: A Case Study on the KUBO Robot,* in Early Childhood Education. AAATE 2019.

ing to talk. As well as in the school. Now, I do well. Now I have learned both talking and writing. […] I have challenges with numbers. […] I think that if I had received the same help as for language, I could have done better".

Researcher: *"This is also my opinion. Literature shows that language is supported, but not so much mathematics. I want your help to change this. Can you help me? I need to understand".*

The co-researcher remained silent.

Contact person: *"Have you understood what she means?"*

Co-researcher: *"Not really. My challenges probably make it difficult to find my role here. You speak quickly and use a lot of foreign words. It can make me confused and uncertain. The project is quite large, and I am very unsure about what it is really about. And not least that I can contribute. There is still a part that is unclear to me."*

Researcher: *"How can I help you?"*

Contact person: *"[talking to the researcher] You should talk slowly, and use easy terms. [talking to the co-researcher] You work every day with your hands, but here you can help them to understand how you think. What is important with this toy. How a ECEC teacher can work. They want to work with all children."*

Co-researcher: *"How?"*

Contact person: *"You can have a specific task…"*

Researcher: *"Yes! You can play with this coding toy and prepare an activity for the children".*

Co-researcher: *"Yes, … yes. Yes I can. I'm excited now. It will be fun. I can help".*

While the researcher started to understand how to talk to the co-researcher and to investigate if a child with Down Syndrome could have a good understanding about parts of mathematics not involving numbers, the co-researcher worked with activities.

[…]

Researcher: *"I see you working. You have difficulties with numbers, but not with orientation. Do you think that is right?"*

Co-researcher: *"You are learning how to talk. Yes, that is right".*

The co-researcher then chose precise assignments. We organized some more meetings, both online and in person, to discuss important elements related to the project (definition of key terms, the role of each participant, the responsibilities). As the project was to understand how playful activi-

ties with a coding toy could be included in ECEC, she chose to focus on concrete tasks such as storytelling, which all children could find enjoyable and understandable, regardless of the level of functionality.

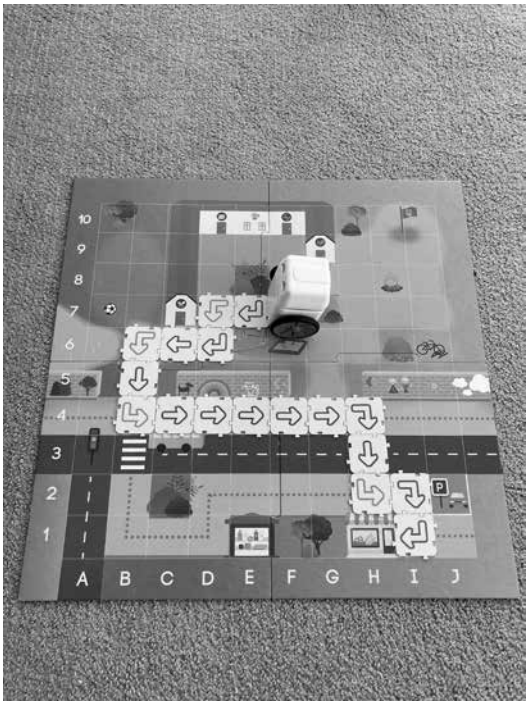
The contact person decided to support the co-researcher in her investigation of the coding toy.

The co-researcher contributed with important perspectives, that had relevance for children's learning, regardless of the level of functionality. The activities prepared by the co-researcher were presented by her in a workshop to 12 ECEC teachers that were invited to use them with children. Afterwards the teachers were asked to give the researchers feedback about children's engagement, learning and inclusion. The activities were made available in the project portfolio on a common digital platform that belongs to the project. She prepared 10 activities in total. The script used by the co-researcher for the presentation was in Norwegian, and it was used, together with notes taken during the meetings, as a source element for writing the citations article. The co-researcher read through the Norwegian version of the most relevant parts of the article. She validated the content, and then it was translated to English.

Co-researcher: "*The researcher said that the children should learn to program Bob (that was the name the co-researcher gave to Kubo) and I then just played freely with him. I said that we can't let him go through a wall or straight through the shop. The board must represent a real world, and we must have rules for where he can go. Otherwise, it will be boring and not enough of a challenge for the child. Imagine playing Ludo or Yahtzee without rules. I wouldn't have bothered!*". She gave a name to the robot, because she realized that could arouse the children's interest, as in fact described in the literature. Then she invented a story, based on the designs present on the cardboard sheet. Such storytelling combined with play with a coding toy has earlier been recognized as motivating for children[21]. The co-researcher's perspectives were child-centred, and these were combined with the other researcher's perspectives which in a larger degree investigated how to support the activities from a theoretical perspective. In this way, the co-researcher and the researchers complemented each other.

[21] F. Granone, E. K. L. Reikerås, *Teachers' support for children's mathematical learning through interactions while playing with a coding toy,* NOMAD. Nordic Studies in Mathematics Education 2023.

One of the examples that she prepared for the ECEC teachers and children is shown below:



"*Bob is sitting in the swing and is bored. Then he suddenly hears a dog barking. He goes to where the sound is coming from, and Bob sees that it is the baker's dog. Bob takes it with him on a leash to the bakery. The baker is happy. Bob receives a cinnamon roll for his job!*"

Figure 1 - An example of an activity with Kubo prepared by the co-researcher

Discussion

In this section we want to analyse the method presented through the methodological approach for inclusive research described by M. Østby[22], but also through the important theory described by H. Skjervheim regarding inclusion[23].

A first important consideration should be about the choice of hiring this specific co-researcher. It is important to note that the literature underscores that having a disability is not enough in order to be considered a researcher[24]. Also, if this discussion is open[25], we decided in any case that it was important to choose a person who had two important characteris-

[22] M. Østby - M. Haugenes, I*nkluderende forskning sammen med personer med utviklingshemming: en metodebok* [Including research with people with learning disabilities: A method book], cit.

[23] H. Skjervheim, *Deltakar og tilskodar*, Instituttet for sosiologi, cit.

[24] C. Bigby - P., Frawley - P. Ramcharan, *Conceptualizing inclusive research with people with intellectual disability*, in «*Journal of Applied Research in Intellectual Disabilities*», 1 (27/2014), pp. 3-12.

[25] K. Johnson, *No longer researching about us without us: a researcher's reflection on rights and inclusive research in Ireland*, in «*British Journal of Learning Disabilities*», 4 (37/2009), pp. 250-256.

tics: to be already involved in activities that had the goal of showing how people with Down Syndrome can contribute to the society, and who was interested in research as a mean for improving children's learning conditions. Moreover, the meetings were designed to allow the co-researcher to develop competence, following the training steps suggested by M. Østby's inclusive research methodology[26].

As described previously, we organized meetings, held both online and in person, to establish the steps that should be followed in accordance with the methodology for inclusive research. As specified in the methodological book[27] about how to succeed in inclusive research, in-person meetings were preferred.

To establish the inclusive research, we chose to follow the guidelines described by Østby about this practice[28].

Discussions among researchers and co-research were developed for reaching a common understanding about programming of the digital toy and about how to use coding toys in ECEC institutions. Based on the assumption that research expertise is never really complete, we positioned everyone involved in the research – researchers and co-researcher – as learners[29]. Discussing and analysing the dialogues between researcher and co-researcher, and the script written by the co-researcher, we identified that all the terms – "ownership", "interests", "collaboration", "control" and "availability" – have been put into practice. She felt that the goal was interesting for her and belonged to her "*I think that if I had received the same help as for language, I could have done better […] Yes, … yes. Yes I can. I'm excited now. It will be fun. I can help*" (Interest and Ownership). In addition, she wanted confirmation that she could contribute actively to research development "*The project is quite large, and I have been very unsure about what it is really about. And not least that I can contribute. […] Yes I can*". At the same time, the researcher learned another important element, "*I see you working. You have difficulty with numbers, but not with orientation. Do you think that is right?*" (Collaboration). Then, we

[26] M. Østby - M. Haugenes, I*nkluderende forskning sammen med personer med utviklingshemming: en metodebok* [Including research with people with learning disabilities: A method book], cit.

[27] Ibidem.

[28] Ibidem.

[29] L.-A Gallacher - M. Gallagher, *Methodological immaturity in childhood research? Thinking throughparticipatory methods'*, in «Childhood», 4 (15/2008), pp. 499-516.

decided together the role that each of us should have in the case, "*While the researcher started to investigate how to talk to the co-researcher and that a child with Down Syndrome can have a good understanding about parts of mathematics not involving numbers, the co-researcher worked with activities.*" (Control).

We constructed the dialogues based on Freire's model, where the dimensions listening, reflecting and transforming were all considered[30]. For success in the dialogue, important elements were considered[31]:

- the time available was chosen in order to have enough time for talking, explaining, understanding and to define the main elements of the discussion.
- the dialogue was focussed on the important elements.
- a contact person participated in the research discussion, both as a reference figure for the co-researcher in a new context and as a support in the dialogue in case researchers and co-researchers needed help to know what the other had understood. Contact person: *"[talking to the researcher] You should talk slowly, and use easy terms. [talking to the co-researcher] You work every day with your hands, but here you can help them to understand how you think. What is important with this toy. How a ECEC teacher can work. They want to work with all children."*

Analysing the method, presented through the lens of Skjervheim's theory[32] can help us to understand if we are developing a spectator position or a participant position.

The method presented sees the researchers and the co-researcher discussing how to work in order to succeed in including all children during play activities with a coding toy. Although we wanted to use the activities developed by the co-researcher for studying the inclusive process in ECEC, the co-researcher is not the object of the discussion. She participates with her unique point of view, and she affects the way in which the activities are conceptualized and developed. This underlines that the communication established is symmetrical. Additionally, she suggested a new approach

[30] P. Freire, *Pedagogy of the oppressed*. Bloomsbury publishing USA 2018.

[31] M. Østby - M. Haugenes, I*nkluderende forskning sammen med personer med utviklingshemming: en metodebok* [Including research with people with learning disabilities: A method book], cit.

[32] H. Skjervheim, *Deltakar og tilskodar*, Instituttet for sosiologi, Universitetet i Oslo 1974.

(the storytelling) that was suggested to ECEC teachers and introduced in the project portfolio. This shows that the dimension of user participation has been developed.

Finally, also the third dimension can be identified. The contact person was always involved in the meeting, and although the co-researcher was completely able to participate independently, the contact person was an important support, both for a sense of security (especially in the initial phase) and for building bridges in case of misunderstanding or not understanding.

An important aspect that we want to highlight is that every segment of the research group learned during the discussions. Researchers and practitioners gained new insight into how children with disabilities can approach a coding toy, while the co-researcher gained increased self-esteem, increased skills, the feeling of being seen and respected, and the experience of having something to contribute. This has as a consequence an impact on ECEC teachers that have to put in practice this new insight, ECTE teachers that should teach ECEC students in order to gain this insight before starting to work in the field of practice, and as a consequence the society that should become more aware about how to realize inclusion.

Conclusions and future development

The present article described a case in which a co-researcher with Down Syndrome worked with researchers to help them understand how children with intellectual disabilities, and in particular with Down Syndrome, could be included in play activities with coding toys in ECEC. The article illustrated the importance of having the point of view of a person with Down Syndrome, who could explain what difficulties were related to the use of coding toys, to the problem solving, and to the verbal interaction, and what mediating approach a teacher should have in those types of situations. The article has highlighted the role of the co-researcher and the level of participation, underlying that it was in line with Skjervheim's theory.

An important element that needs to be highlighted is that the activities prepared by the co-researcher were not just suitable for children with intellectual disabilities, but for all the children. As it happened in litera-

ture already for other methods[33] reflecting about learning approaches for children with intellectual disabilities can help teachers to identify new teaching strategies and methods that can become an enrichment for all children's learning development.

Both researchers and the co-researcher have participated in every step of the process, and the irreplaceable role of each segment of the research group has been analysed. Now it is important to move forward. Research highlights that the focus in inclusive research should move from the analysis of the method to the knowledge generated[34].

For this reason, the research project will move now to a new investigation, that is connected to the challenges that a person with Down Syndrome can encounter in an everyday life, what is easy, what is not, in order to identify methods for supporting children's learning.

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