

Book Review

Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion

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Nind, Melanie & Strnadová, Iva (2020). Belonging for people with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion. Routledge. pp. xvi, 218. ISBN 978-0-367-20295-8 (softcover) \$44.95

Belonging in Education, Research and Communities

As an educator, researcher and philosopher I am always on the lookout for something that can challenge my thinking. Often, I find that books with a narrow scope or with alternative perspectives, tend to ignite reflection and inspire thought. There are books that leave a lasting impression. I was not the same after reading books like John and Evelyn Dewey's (1915) *Schools of To-morrow*, Hans Georg Gadamer's (1975) *Truth and Method*, Henry Petroski's (1989) *The Pencil* and Stephen Halliwell's (2002) *The Aesthetics of Mimesis*. This is one of those books. It peels away the unnecessary and leaves you wondering about important things.

As I have been reading three perspectives have emerged that are of special relevance to me personally. Firstly, this book gives a glimpse into the lives of people with profound intellectual and multiple disabilities. It is a reality of many obstacles and challenges. In contrast, the focus of this book is on the positive possibilities. The message is that if we are willing, people in this situation can have playful lives, agency, choices and feel the joy of belonging. Secondly, I feel recognition as father of a daughter with a severe intellectual disability. We, her core group of

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assistants, teachers and family, are experts on assisting her life. We need to be taken seriously. Living a good life with many challenges is only possible through collaboration between people who know the person in question. Thirdly, this book is relevant for me as a researcher and teacher educator. When we remove what is less important, what we are left with is remarkably similar. We are all deeply dependent on each other. We need to hang out with people who we like and who like us. We need to be interpreted with charity and the best of will. We need to have fun and feel belonging.

At first glance the book might seem to be written for a very limited group of readers. The context is unfamiliar for many. I can assure the potential readers that the questions explored, and the points made are deeply relevant to what it is to be human. The editors Melanie Nind and Iva Strnadová have managed to put together an anthology written by dedicated people. Together they give voice to 'the silent voices of the missing people'

The anthology starts with presenting Johanna De Haas. The book is dedicated to her:

'To us, the editors of this book, Johanna is someone who has influenced our thinking and an example of how people with profound intellectual and multiple disability can be included and empowered to contribute to people close to them, to research and to the community.' (p. v)

The presentation of the contributors and the preface helps the reader tune in to the topic of the book. There are eleven chapters in addition to three short Fellow Traveller Accounts that start each main part. The main three parts of the book are titled *Belonging in education*, *Belonging in research* and *Belonging in communities*. In the first chapter Melanie Nind and Iva Strnadová present a challenging realism about the people this book is about. It is about people who have substantial barriers to learning and participation in community life and children that are often seen as just too impaired to be catered for. It is about how isolation and invisibility play a role in their exclusions from debates. They want to make clear;

'(...) not to entrench low expectations; we need to include reference to what people can do in the best

environments with people who can interpret their communications' (p. 2).

The book wants to push the boundaries for inclusion in education, in research and in communities. An important term is *belonging*. For those unfamiliar with the context, chapter eight by Sheridan Forster can be a good place to start. Forster challenges the reader to imagine what it is like to take contact with a person with profound intellectual and multiple disability for the first time. At the same time, she writes that it doesn't have to be complicated. Sitting alongside is a good first step. She encourages us to look at the following YouTube link: <https://youtu.be/NKzaUuixIQ8>.

Shoshana Dreyfus gives the first *Fellow Traveller Account*. She writes about the school years of her son Bodhi. He went to a special school. He loved going there. It was a place he was known and experienced belonging. She admits that special schools are a paradox. Special schools are a form of segregation. Unfortunately, mainstream schools are rarely equipped to manage the task. Sometimes special schools are the best available solution at a certain time and place.

Ben Simmons in chapter two suggests that belonging is not first and foremost about being included in either mainstream schools or special schools. Belonging is something that needs to be brought into action. It is more than just being present. It is about being seen and taken seriously. It is about getting responsibilities where that is possible. It is less about geography. Belonging is about establishing a place you feel like you belong and building a 'we-mode'.

In chapter three, Bea Maes, Anneleen Penne, Katrijn Vastmans and Michael Arthur-Kelly point out that for a person with a profound intellectual and multiple disability to develop high-quality relationships, they need people around them that know them well. A critical aspect is listening to the parents. *Knowingness* is the key to creating shared meaning and belonging. It may be difficult to recognize or understand the capabilities and repertoire of a person with profound intellectual and multiple disability without this knowledge. Finding the possibilities within all the limitations requires time, patience and closeness.

In chapter four we get acquainted with the Golden Tent. Jill Goodwin creates a physical experimental space for being together with a minimum of distractions. The Golden Tent is a

yellow and gold colored tent. The intention is that it can be a place where we can meet exactly as we are. The people that enter the tent experience it is a space where you don't need to do anything, but where it is enough to exist. It is a room for dialogue without words where belonging emerges by just being together.

In the second *Fellow Traveller Account*, Hilra Gondim Vinha speaks to the heart. At age six she was the big sister of a four-year-old brother with a profound and multiple disability. She literally carried her brother around on her back. She writes:

'I then became an expert in my brother's unique dialect, in order to translate his attempts to communicate with others, and I would only allow children into my friendship circle if they were also friends with my brother' (p. 78).

In chapter five Debby Watson is crossing the wobbly bridge to inclusive research with children with profound and multiple learning difficulties. She teaches us that virtually all children challenged in this way show signs of playfulness. The exceptions are rare. Although playfulness is hard to explain, she claims that you know it when you see it. Her research experience is that operating musical instruments, joking and mucking about are among the activities that arouse the most excitement. It is more fun to do something yourselves than being entertained - although that can be engaging too. Pupils with profound and multiple learning disabilities and their teachers often work hard. A few minutes of playfulness and fun can make a week of stressful work worthwhile.

In chapter six, Noelle McCormack writes about making life stories of people with profound intellectual and multiple disabilities visible. Not only visible to others, but most importantly visible to themselves. What if your only access to the past and your own life story was dependent on the person that assisted you? ... and what if your own and your shared history was lost every time a person departed from your life and a new person entered it? This is often the reality for many people with profound intellectual and multiple disabilities. In most cases they are not able to preserve their own history. McCormack explores making life stories by systematically collecting videos, pictures, artifacts and texts. She sees possible pathways to building life stories last over time and that are less dependent on specific people being present. Being able to access

your own life story and sharing it with others might be a pathway to a greater experience of belonging.

Melanie Warwick uses wearable cameras to get access to preferences and choices. In chapter seven Warwick shows how Sharon is willing to invest physical effort, tenacity and patience to reach her desired goals. Sharon has a profound intellectual and multiple disability. Sharon is very attached to a book about Princess Diana. By wearing a body camera, she shows the researcher her choices. She even shows how she edits her experience of the individual page according to her preferences.

In the third *Fellow Traveller Account*, Clare Palmer and Jan Walmsley ask the difficult question if people with profound and multiple learning disabilities and their families are welcome in the wider learning disability community. Many of the ideas and conversations happening there are often not relevant for people with profound and multiple learning disabilities. At conventions for the intellectual disability community they have experienced that inclusion does not go all the way. Walmsley wonders if there might be a lack of imagination, creativity and patience to include also the most challenged people.

In chapter nine Catherine de Haas, the mother of Johanna de Haas, shares experiences of how families with a member with profound and multiple learning disabilities can be included in society. The reality is often that these families end up with the responsibility of initiating inclusion. She suggests more professional efforts should be directed to help these families. The public often struggles with awkwardness and discomfort and fear they will get it wrong. The public needs knowledge and guidance. Her experience is that building friendships is possible but slow, but the people that accept the challenge feel greatly rewarded.

In chapter ten Liz Tilley, Sue Ledger and Catherine de Haas challenge the silent history of people with profound and multiple learning disabilities. Ethical and legal obstacles are discussed and handled. Through an action research project, they develop an example of how it can be possible for a person with profound and multiple learning disabilities to deposit life story material in a public archive. A young woman with profound and multiple learning disabilities, Cherry Lane, co-produces the decision-making process. She is an artist and loves showing her work. She has had several public art exhibitions. These experiences seem to be valuable when developing her decision-making pathway.

In chapter eleven Strnadová and Nind return to gather the threads. They highlight the right to contribute and the importance of families. They remind us not to think of communities as pre-existing. Belonging is to be included through participation and by getting opportunities for giving something back. Belonging is hanging out with people who know you. Interdependency is not a special challenge for people with profound and multiple learning disabilities, it is a central feature of human relationships. Pushing the boundaries for inclusion is therefore not a special task that needs to be done as charity for a challenged group of people, but something we need to do together continuously as a diverse interdependent community of people that all need to feel they belong.

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