



PICTURED ABOVE: RESEARCHING SUPPORT TO WORK (see page 2)

Centre for Research in Inclusion

8: Summer 2020

About us

The Centre for Research in Inclusion (CRI) in the Education School at the University of Southampton is committed to internationally significant research towards the inclusion of children, adults, families, and practitioners in education. We work with a strong network of collaborators in research that addresses inclusion and engages with the needs of participants and research users. CRI is unusual in working with teachers, young people, disabled and other marginalised groups to carry out the research. See our [Centre for Research in Inclusion video](https://tinyurl.com/yc28fpur) [<https://tinyurl.com/yc28fpur>].

people with learning disabilities will be invited to respond to papers, thereby supporting dialogue between stakeholders in learning disability research.



Professor Melanie Nind now editing British Journal of Learning Disabilities

CRI grant success

[Dr Vasilis Strogilos](#) has been awarded a British Academy grant for the project *Co-teaching between Mainstream and Special Schools*. The aim is to describe and evaluate a partnership between a special and three mainstream primary schools deploying a collaborative model for the inclusion of pupils with special needs and disabilities (SEND) in mainstream schools/classrooms. The researchers and the school participants will use a collaborative research approach to explore what could provide an alternative to the commonly used teacher and teaching assistant model. The project will produce professional development materials and guidelines for schools and policy makers to use.

CRI News

[Professor Melanie Nind](#) has become the new Editor-in-chief of the [British Journal of Learning Disabilities](#). This role is a great fit with the ethos the research centre and Melanie's work in inclusive research. The journal has a strong tradition of including papers co-authored with people with learning disabilities and ensuring that the academic community engages with - and works for - their interests. Melanie is introducing *In Response* pieces, in which



CRI welcomes Dr Henry Wood

[Dr Henry Wood](#) is a Research Fellow in the Centre working as part of the ACoRNS team. Henry also works as an Educational Psychologist in West Sussex. His interests lie in autism, inclusive education, person-centred planning (PCP), and promoting positive outcomes for individuals with special educational needs and disabilities (SEND).

CRI resources

If you are looking for practical solutions for supporting assessments and transition planning in the early years during this difficult time, please check out these new resources from the ACoRNS team:

<https://autismtransitions.org/how-to-make-your-own-2/>

The resources are based on the team's Digital Stories work which offers a strengths-based approach to thinking about the individual capabilities and preferences of autistic children, as well as looking at where and how support is needed. There are tips on how to create simple Digital Stories, and guidance that can be used to support thinking and discussions with children, families, staff, and other professionals.

Finding a way to work in a pandemic

Everyone has been struggling with the unprecedented change to our lives brought about by the Covid-19 situation. Here some of CRI's doctoral researchers report on how this has been affecting them.

My research concern is with people with intellectual disabilities, who are often excluded from employment with huge implications for the structuring of their lives and development of their relationships, capacities and identities. I am interested in with people who may need ongoing and finely personally tailored support to work, particularly those who employ a personal assistant to access and support a working role that fits their interests and abilities. I hoped to investigate their experiences by filming them in their work situations and using the film with them to examine and reflect on the learning and inclusion processes under way. Only a small number of people are currently working in this way – and they were not easy to find. My recruitment efforts - a short film about participation, an accessible website, hundreds of emails and posts – went on uncomfortably longer than I had scheduled. By March this year I had

my participants and had started filming including in an animal rescue centre and a community food co-op.

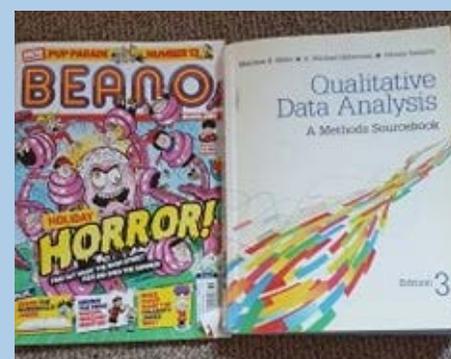
This was when we were all trying to hang on to normal life as the bad news rolled in. Looking back at the footage, with handwashing and current affairs conversation in the background ("I'd like to think the government know what they're doing – I hope they do ..."), I think I have snapshots of a historic moment. And it was dismaying to have everything swept aside. In theory, it was simple enough to pause fieldwork and turn to reading and writing, but truthfully, covering the survival basics came first, and I wasn't always productive in the face of the compelling news stories and the needs of unsettled and under-occupied family members.

The footage I have is not enough to proceed with interviewing, but it has been a pleasure to re-view. The teamwork between the key participant and his personal assistant in the food co-op (see front page photo) is amazing to watch – so smooth and complementary, it looks choreographed. I really hope we can pick up the pieces in time – they make a fabulous case for working together in this way.

Abigail Croydon

I am carrying out research on social justice theories with Specific Learning Difficulties (SpLD) tutors in various UK universities. I was halfway through my fieldwork when the lockdown was announced. I count myself lucky in that I was able to switch from face-to-face data gathering to online group meetings. In the Collaborative Inquiry Circle discussions we have found great solace in looking at theory, particularly the work of Sara Ahmed. As one person put it, 'it takes me away from what is happening out there'. Many of the people involved have also expressed an interest in doing thematic analysis of their research data during the summer, saying that it would be good to learn a new skill while being 'stuck at home'. Their boredom has been my research gain.

While my research life is continuing, my writing life is slow (see photo) – the constant juggle between home-schooling, food shopping and part-time work is taking its toll. I do SpLD consultancy work with junior doctors for Health Education England and while I may despair about the slow pace of my writing, I am uplifted by the resilience and dedication of these doctors. One of them said to me, 'it's a marathon not a sprint', so this is now my mantra for my research in these COVID times.



The competing attentions of the PhD parent

Sadhbh O'Dwyer

I am researching how the inclusion of young children with severe learning difficulties in Early Years settings is supported by inter-professional collaboration. I use a Critical Communicative Methodology, which involves collecting data through egalitarian dialogue with participants (communicative classroom observations, in-depth interviews and focus groups within two mainstream nurseries). Until the official closure of schools in March, I had managed to spend more than a month within the settings. I was confident that I had developed strong relationships with the staff and children and had familiarised myself with the setting's routines. A couple of the participants would be leaving their roles so their interviews were prioritised and scheduled for the end of March. To those people, I never managed to say goodbye and unfortunately their contribution will be absent from my project. Things moved so quickly I did not have the chance to

negotiate with participants to collect data online. Therefore, I have had to pause data collection.

The last couple of months have been overshadowed by concerns for my health and that of my loved ones, cancelled holiday plans and the emotional impact of self-isolation and global death toll. My partner is working from home, which means that we also had to negotiate our working space and schedules. The first weeks of the lockdown involved coming to terms with potentially prolonging the length of my studies, checking the news every five minutes and somewhere in-between finding time to do some research. Although I was used to working from home, I found it exceptionally hard to concentrate during this time. While friends 'advertised' this as an opportunity for self-reflection and reading, I found myself working twice as hard to get some work done. My research involves human beings, some of whom struggle with mental and physical health issues, but my ethical protocol does not allow me to contact them directly to check on them.

Despite all the challenges, I have taken this opportunity to refocus on writing thesis chapters. I have now embraced the possibility that my research might not go ahead with the current participants. The prospect of recruiting new ones is far from ideal as I spent considerable time ensuring their involvement. I am however confident that this time was not wasted. I still had the chance to learn Early Years routines, reconsider some aspects of my data collection and build a network. I have also explored my alternatives: recruiting participants in the new academic year or adapting my initial topic or parts of it. I continue within an unprecedented terrain of insecurity: How will Early Years settings look in September? Will participants be willing to engage in research given the changing learning environment and responsibilities? What if a second wave occurs in England? Should I prepare for exclusively online data collection?

Angeliki Katramadou

The aim of my research is to develop understanding on how multidisciplinary collaboration can support the inclusive education of two children with severe learning difficulties in one primary school in Scotland. I will apply the principles of Critical Communicative Methodology approach so that knowledge will be co-constructed with the participants, reflecting on their reality and how they can work towards eradicating the exclusion of the participant children with disabilities from the mainstream class.

My initial plan was to meet the participants in August 2020. I have spent the last few months working on my methodology chapter with the hope that this will still be possible. The closer I get to the new academic year, the more I realise the possible impact of the pandemic on the progress of this project. It is now clearer that the Covid-19 crisis may affect the way I will go about conducting this study, either by having to suspend data collection or re-design the study taking into account social-distancing measures. I believe that the health and wellbeing of the participants should be my priority and guide my decisions from now on.

This pandemic is leading us all to reflect on how we do things. The community spirit has proven to be really valuable in helping us cope with this crisis; I hope that this community spirit will also guide the research community. Discussions with other qualitative researchers have shown that most of us have to deal with the same issues. Maybe if we all work together, we will find innovative ideas/solutions to keep us going.

Anastasia Voulagka

The lockdown caused some initial disruption and concern about the future of my research. In the initial hiatus, I cancelled two interviews and had to park the data collection for about four weeks. This was frustrating. As a part-time research student, I had been building-up to this since 2016. My research involves interviewing professionals, young people and their parents regarding outcomes for young people who have

been in prison. The young people I plan to involve have multiple needs and experience considerable marginalisation and deprivation. All indicators suggest Covid-19 is amplifying this disadvantage. Given the challenges and uncertainty of the lockdown, it is unlikely I will be involving young people and their carers until 2021.

Interviews with professionals are still a viable prospect. Following amendment to the ethics submission, I have been able to rebook the cancelled interviews and I have completed three online interviews. My assumption was professionals would be too overwhelmed to participate but I have found the opposite. The momentum is now greater than before the lockdown. I have a growing number of interviews booked in and professional participants seem eager to participate in research that represents continuity beyond the lockdown. Online interviews have been easier to schedule and organise under lockdown with people at home. The 'new normal' of online communication is also firmly established. The interviews have been just as productive as face-to-face interviews undertaken pre-lockdown - shorter but more focused. The lack of a face-to-face dynamic, with its potential for rapport building, does not seem to be a significant factor in generating rich data. I feel very hopeful of my research and believe it is now back on track.

My concern about engaging with young people for this research remains. I am concerned a lot of time will be lost. My challenge will be to try to recruit young participants, given the complexities involved, in the post-lockdown era. This is a small example of the 'before and after' nature of this crisis. I have no doubt the Covid crisis is having an especially profound impact on this vulnerable group. In the event I am able to recruit young people to participate, Covid will be a factor in the way interviews are conducted and the findings generated. My skills as a researcher will be fully tested.

Gavin Tucker

Belonging for People with Profound Intellectual and Multiple Disabilities

May 2020 sees the publication of an important new book: *Belonging for Individuals with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion*. The book is an international collection of chapters edited by [Prof Melanie Nind](#) from CRI and [Prof Iva Strnadova](#) from University of New South Wales Sydney, a former international visitor to CRI. The book shows how attention to people with profound disabilities can help us ensure that belonging as a concept and a reality is inclusive of everyone.

The changing culture around the rights of people with learning disabilities (known in other countries as intellectual disabilities) is evident around us. Children with learning disabilities can be found in ordinary school classrooms, adults with learning disabilities are engaging in research, and they are pushing the boundaries of all aspects of community life to establish their rightful place as citizens. Yet this expansion of what is possible in terms of inclusion has largely failed to reach people with profound and multiple learning disabilities (PMLD). The 2010 Mansell Report *Raising our Sights* showed how they and their families were 'written off, as not worth bothering with, as too difficult to support well and as people for whom the poor standards of the past are all that can be achieved'.

In *Belonging for Individuals with Profound Intellectual and Multiple Disabilities*, readers can find a current overview of the state of play in terms of inclusion for this group. The short entries from family members illustrate how some of the barriers are very real for them still. They show the effort it takes them to negotiate belonging for their son,

daughter and brother. But more than this, the book shows what is possible. The idea for it came from seeing people pushing the boundaries in exciting ways – Johanna DeHaas a young woman with profound disabilities and her mother co-presenting together at a conference – and doctoral researchers insisting that people with PMLD can be active participants in their research. The Belong Manifesto was also influential. The manifesto, launched by two UK organizations, [Books Beyond Words](#) and [Access All Areas](#), advocates pledging simple and practical things we can each do to help people with learning disabilities belong. What belonging looks and feels like when you have PMLD is at the heart of the book.

The book has three sections: Belonging in Education, Belonging in Research and Belonging in Communities. In addition, Melanie and Iva as editors provide the historical and general context and the discussion of the concept of belonging. Ben Simmons' chapter shows primary school children involving their peers with PMLD in their play routines enabling their belonging in the class. Melaneia Warwick's chapter tells how she set about seeing the world through the perspective of someone with PMLD wearing a body-worn video camera to contribute her (literal) point of view to the research. Other chapters show people with PMLD contributing to historical archives, doing life story work, enjoying an art installation, participating in the local choir and just hanging out with others. Repeatedly the book provides accounts of people finding and experiencing their common humanity, learning how to 'be' together.

Melanie has found working on the book to be a hopeful project. It captures people's commitment to the ethic of belonging. It moves between philosophical reflection on what it means to belong and very practical steps people take to make it happen. Belonging is there in the UK PMLD Core and Essential Standards. The contributing authors illustrate the action that goes with setting expectations that everyone should enjoy the benefits of belonging, of feeling at home in their community, of feeling connected, of being at the heart of things.

[Belonging for People with Profound Intellectual and Multiple Disabilities](#) is published by Routledge. It is dedicated to the memory of Johanna DeHaas who very much belonged and who died in 2019. Look out for details of the book launch on the [CRI website](#).

Open access papers

Chalachanová, A., Nind, M., Østby, M., Power, A., Tilley, L., Walmsley, J. & Westergård, B. with Torill Heia, Alf Magne Gerhardsen, Ole Magnus Oterhals and Matthew King (2020) Building Relationships in Inclusive Research in Diverse Contexts. *Scandinavian Journal of Disability Research*, 22(1), 147–157. DOI: <https://doi.org/10.16993/sjdr.681>

Nind, M. (2020) Not a journal about people with learning disabilities without people with learning disabilities. *British Journal of Learning Disabilities*, 48(2), 81-83. <https://onlinelibrary.wiley.com/doi/pdf/10.1111/bld.12328>