'If it's about us we should be able to write in it': creating accessible information for people to write in British Journal of Learning Disabilities: Issues of accessibility.

Welcome to this the final issue of BJLD for 2019, and this my last editorial which I share with The Journal Project, formed of self-advocates Lucy, Tracy, Sam, Aisha and Colin, alongside Marsh Stitchman from Lewisham Speaking Up, and Annabel Head and Susan Carroll from the South London and Maudsley NHS Foundation Trust, London. As of this issue my tenure as Editor in Chief of BJLD comes to an end, and so I would like to take this opportunity to thank all those who have contributed to the work of the Journal; the authors and reviewers as well as the readership more widely. The last six years have in the main been enjoyable, but they have not been without their challenges. I know I am not alone in that many other Editors face similar challenges in trying to keep Journals, such as BJLD, buoyant, and often with little support-save some dedicated colleagues on the editorial board, and those who offer their unconditional support through peer review of numerous submissions of manuscripts; it is to these people I am indebted to. So for this issue it is our intention to do two things. The first is to explain the background, and outcome of an exciting project for BJLD that has been ongoing throughout this year, and that has been concerned with making our author guidelines more accessible. So what has the project concerning accessibility been about? And it is here that I hand over to my colleagues in The Journal Project.

We wanted to write an article about a group we ran with Lewisham Speaking Up (LSUP), a local self-advocacy group. We wanted to write it with some of the people with learning disabilities who had been in the group. We decided the BJLD would be a good place to tell the story of the group. When we asked BJLD if they had guidelines for authors that are accessible, we realised they didn’t so the editor asked us to get a new group together to make their guidelines more accessible. As one group member said about the journal; ‘if it’s about us we should be able to write in it, otherwise what’s the point?’ Co-production is higher on the agenda than ever before – it means getting people who use services (such as health services or social support) to be involved in planning how those services run. It’s really important for people with learning disabilities to have a say in what works and doesn’t work for them, and the things that are important for their lives. We went to LSUP and asked for some volunteers for our new group; ‘The Journal Project’. Five self-advocates said they wanted to join. We met four times to develop the ‘Information for Writers’ guide. Being equal is a key part of co-production (SCIE, 2015) so it was important for us to make sure everyone had their voice heard about the guidelines. The self-advocates said that information in BJLD was too small – they said; ‘you’d need a magnifying glass to see that!’ One group member said; ‘if you gave me that [author guidelines], I wouldn’t know what to do’. The group had lots and lots of ideas – about the words that we used, about the pictures, the layout and how to make the process clear for people who want to write for the journal. One big idea was to have a form to fill out – group members told us that forms help them to structure things which are really complicated. Then we tried out our new form as a group to help write this editorial!

What we found out: As one member said; ‘it’s not easy to make things easy read!’ We realised it takes a lot of time to go over things, and to really make things meaningfully co-produced. Some of the things that we as professionals thought would make sense, were actually really hard to understand, so we made lots of changes. It made us realise how important it is to get people with learning disabilities to check the things that we, as professionals, might think are accessible.

What does this mean? The self-advocates found the group ‘interesting’, and one person said ‘it made me want to write my story of my life for the journal’. However, they said that they still found it hard to read the journal, as there aren’t often pictures in it.
As professionals, we noted that even with the guidance, there are still a lot of barriers to writing for a journal. As one group member said; ‘if I wrote in it, I would want some help with that’. We wondered if someone with a learning disability would be able to write in a journal on their own, as it is both a complex concept to understand, and a complex system to work through. But writing with other people also has its own downsides – will people with learning disabilities be compensated in the same way for their time and effort in as the professionals they are working with? We think there is still a long way to go. But we hope that the guidelines are one step in the right direction to helping people with learning disabilities share their stories and opinions. We would be really interested to hear from anyone who uses the guidelines, please get in touch!

The second intention of this editorial is to introduce the papers comprising this issue of BILJD; in the first paper Southby from Leeds Beckett University, England, UK points out that leisure time for adults with learning disabilities is often diversionary and spent doing passive, solitary or family-orientated activities. Befriending, as a hybrid ‘natural’ support, may help adults with learning disabilities overcome the barriers to participation in non-segregated leisure. For this study four case studies of pairs of ‘befrienders’ and ‘befriendees’ were recruited. Participant observation was carried out with each case, followed by semi-structured interviews with participants and relevant stakeholders. Data were then analysed using thematic analysis. They found that befriending activities were mostly limited to enjoyable yet ‘casual’ leisure activities that adults with learning disabilities might already participate in with family and paid service providers. Negotiating the befriender role between friend and professional was found to be an ongoing challenge. They conclude that the outcomes of leisure–befriending relationships for adults with learning disabilities are linked to both the nature of relationships as well as the types of activities undertaken. There are four proposed ideal types of leisure–befriending relationship, yet repeating familiar ‘casual’ leisure activities means adults with learning disabilities risk missing out on novel leisure and social experiences.

In the second paper Doody and colleagues from Limerick, Ireland assert, quite rightly, that adults with intellectual disabilities should be involved in decision-making about their care. However, little is known regarding their experience of engaging in care planning within health services. In a rapidly changing healthcare environment, the relevance and necessity of demonstrating care delivered, and care outcomes is essential for all professionals, and their review highlights the need for intellectual disability nurses to prioritise disseminating this evidence beyond the practice environment. This they explored by undertaking an integrative literature review. Whereas they found that no study met the inclusion criteria for nursing care planning of the literature that did make it to the full-text review stage two key aspects emerged; relevance and categories of plans, and disseminating evidence of practice. They conclude that their integrative review provides evidence that the experiences of adults with intellectual disabilities involvement in care planning within health services are absent within the literature. Whereas guidance exists regarding involving adults with intellectual disabilities in planning care, there is confusion, ambiguity and an interchangeable use of terms that makes it difficult to distinguish between nursing care plans, person-centred plans, individual programme plan, individualised support plan, health action plans, personalised support plans and personalised plans.

Next Mooney and colleagues form the West Midlands, UK explore social isolation in the lives of people with learning disabilities. They state that there is an association between social exclusion and feeling lonely, an issue that has been highlighted in England as a growing concern, and one which needs to be addressed both in the media, and by the government. They report on the work of The Building Bridges Research Group who undertake inclusive research projects about
the issues that are important to them. They undertook a project to identify some of the specific barriers that prevent community inclusion as well as the opportunity to develop friends. The people involved mainly lived independently, and did not use learning disability services, with the exception of evening clubs, so they needed to use universal services. Using pictorial cards, made by one of the group, and using photographs they organised the data into themes. These included; ‘transport’, ‘fear and anxiety’, ‘limits on choice and control’, ‘risks and personal safety’. They conclude that their inclusive research design enabled people with learning disabilities to contribute to all stages of the research project, from identifying the issue, gathering data, the analysis and writing up. They also made suggestions of ways to increase social networks, friendships and well-being, and so hopefully decrease loneliness. These suggestions include; more access to easy read information, more support and advocacy and measures to address community safety including a wider roll-out of the Safe Places scheme. They also suggest that there needs to be further research undertaken with other people with a learning disabilities in different areas to widen the understanding of the impact of these barriers on people’s lives.

Next McClean and Guerin from University College Dublin, Ireland report on psychologists’ views of the experience of death and bereavement among children with intellectual disabilities. Using twelve psychologists with experience of working with children with intellectual disabilities as proxy for the children’s experiences they completed semi-structured interviews, and this was followed by a thematic analysis of the data collected. They found that psychologists were in favour of concrete and factual explanations of death for children with intellectual disabilities, as opposed to metaphorical or vague explanations. These psychologists reported that intellectual disabilities did not prevent the child from experiencing grief, but did impact their expression of grief. The challenges identified by these psychologists included; overcoming assumptions about the capabilities of a child with intellectual disabilities, understanding and experiencing grief, and enabling and encouraging families to include the child in the bereavement process. Finally, these psychologists emphasised the need to normalise grief making it part of life. They conclude that their study benefitted from a sample rich in relevant experience, and from the rigorous process of thematic analysis. However, they caution that there can only be considered as a proxy study as there is no way to be certain the views of the psychologists actually reflect the experiences of grieving children. This is an area worthy of further research.

Next Sitter and colleagues from the Universities of Calgary and Waterloo in Canada assert that sexual rights are human rights, but that people with developmental disabilities are often excluded from developing positive sexual health due to societal attitudes, stigma, a lack of education and limited opportunities. As a part of a 12-month participatory action research study in a western Canadian province, nine adults with developmental disabilities and three allies created videos that explored dimensions of sexual health, as experienced by people with developmental disabilities. Participants were involved in all stages of the filming process. The filming topics identified by the participants emerged as the core research themes. They found that people with developmental disabilities often have limited opportunities to develop and nurture intimate relationships. Participants identified that; lack of support from caregivers, lack of education about sexual health, ableist spaces, and an absence of agency policies acknowledging and protecting sexual rights created further obstacles. They conclude on the importance of inclusive practice where the sexual rights of persons with developmental disabilities are respected and celebrated. For many agencies, this requires reframing policies and programmes that include acknowledging and protecting the sexual rights of persons with developmental disabilities. Whereas providing accessible pedagogical opportunities about sexual health was identified as important, ensuring
curriculum delivery for support workers, as well as educating families and caregivers about the importance of sexual health and inclusion, is paramount, where the views and opinions of persons with developmental disabilities are at the forefront of the process.

Next Tinney and Smith from Dublin, Ireland point out that models of service delivery for adults with an intellectual disabilities in Ireland increasingly focus on delivering services within local communities. Preparation for this transition often focuses on practical skills. Our service received complaints about unacceptable behaviour, shoplifting, by some service users. Although such behaviours are relatively common in the general population, they found little research on this topic related to individuals with intellectual disabilities. The Speech and Language Therapy Department surveyed families of individuals attending the service to explore the prevalence of concerns about such behaviours and any actions families had taken. They found that over 34% of families who responded reported at least one incident of stealing. Such behaviours occurred within the home and in the community. Families had attempted a range of strategies to eliminate the behaviour, most often invoking a negative consequence. They conclude that a combination of; changed opportunities arising from new service structures, and potentially reduced self-control and, or, immature self-regulation, along with inconsistent responses from the environment, forms a triad of influences that contributed to a risk of stealing for some individuals with intellectual disabilities. They outline the strategies adopted by their organisation to address this issue.

In the penultimate paper Torro from Italy reminds us that a Snoezelen room provides a multisensory environment for people with learning disabilities. A study of thirty-five residents were recruited from a convenience sample of people living in a residential centre. Using a repeated-measures, within-subject design she evaluated the participants during three conditions; the Snoezelen room, control period, and whilst watching television. The outcome measures used were digit span memory tests and Romberg balance tests. Adopting a one-way repeated-measures ANOVAs and paired-samples t tests were performed on the data. The ANOVA indicate that there was a significant effect over time in the amount of digits remembered, and in balancing ability between the three conditions. The T tests confirmed that the Snoezelen condition was responsible for significant improvements in memory and balancing ability. It is concluded that participants performed significantly better with memory tasks, and balancing skills after having attended multisensory stimulation in a Snoezelen room. This may be due to improved mindfulness, which is correlated with improvements of concentration, learning ability and motor skills caused by neurophysiologic changes of the brain. This is interesting as the use of such sensory environments are still subject of derision as to their therapeutic effects.

In the final contribution to this issue that is a clinical paper Walton and colleagues from Wales, UK point to the continuing inequality and unmet needs of people with learning disabilities. They state that Vitamin D deficiency can increase the risk of bone disease, muscle weakness and fractures. Subsequently they undertook a systematic review to assess for the prevalence of Vitamin D deficiency in people with learning disabilities. They adopted and used the ‘Preferred Reporting Items for Systematic Reviews and Meta-analyses’ checklist was followed where possible. They report on the eight studies included in their qualitative synthesis. They report that the quality of the studies was assessed using the ‘Appraisal of Cross-sectional Studies’ tool. The prevalence of inpatients with learning disabilities and deficient vitamin D levels ranged from 41% to 92%. This is equal to, and likely higher than, the rate for institutionalised adults in the UK. 49%–77% of individuals with learning disabilities living in the community had inadequate vitamin D levels. In comparison to the general population. They assert that this suggests that people with learning disabilities might have increased risk of inadequate vitamin D levels. They conclude that because
of the low number of studies, and the heterogeneous populations of the included studies, firm conclusions could not be drawn. However, the results show that people with learning disabilities have at least an equal risk of vitamin D deficiency, when compared to the wider population. There is provisional evidence to suggest that the prevalence could be higher for people with learning disabilities, and therefore, there is a need for further population-based studies.

I am indebted to all members of The Journal Project for ably assisting me with this Editorial, and commend the work they have achieved that can now be found online at [https://onlinelibrary.wiley.com/page/journal/14683156/homepage/forauthors.html](https://onlinelibrary.wiley.com/page/journal/14683156/homepage/forauthors.html). So to close this editorial - if you value the contributions that this Journal makes to the advancement of our understanding of learning disabilities then please do support the new incoming editor. I hope that you have found something of interest in this issue, the continued submission of high quality papers are testimony that *British Journal of Learning Disabilities* traverses professional boundaries, as well as academic disciplines concerning learning disabilities, and will I hope to for many years to come. The Journal continues to welcome engagement from all, both from the UK and wider afield. This might be through following and, or, subscribing to the Journal, submitting high-quality contemporary papers, volunteering to review papers for us, or submitting a guest editorial. Equally the Journal, I am sure, will remain open to suggestions for special issues on major topics, or submissions of reviews of books and, or, training materials, as well as your own views to the letters section; please do continue to feel that you can contribute. Let me close by offering seasonal best wishes to all, and my very best wishes for the forthcoming year.

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