

## Editorial

In this issue of *Journal of Intellectual Disabilities* the first three papers present different aspects of the lived experience of intellectual disabilities, and each of these is undertaken through the use of different methodological approaches. These experiences are the predominant feature in this issue, and are expressed through mothers and informal carers as well as through people with learning disabilities themselves. This is followed by a 'case note' follow up study concerning sterilisation of women with intellectual disabilities. The final paper moves to a 'scoping review' based on existing literature to explore the role, if any, for social care practitioners in the process of annual health checks for adults with learning disabilities in England.

In the first paper Mikaela Starke reports on the encounters mothers with an intellectual disability have with professionals. Seven Swedish mothers with an intellectual disability were interviewed for this exploratory study which aimed at charting such mothers' views and experiences of their encounters with different health and social service professionals. From this study they report on three distinct themes that emerged from the interviews. Firstly, the mother's experience of interaction seemed to be marred by lack of comprehensibility, and this resulted from inadequate information, and their perception of not being treated properly. Secondly, despite their reservations about the nature of their interactions, several of the mothers also reported receiving support that had strengthened their parental abilities, and had been experienced as empowering. Thirdly, several of the mothers also clearly perceived themselves as people who needed support. These results, overall, indicated that the interaction between the mother and the professionals suffered from parentalistic attitudes of professionals. I can't help reflecting that I seem to have heard much of this before through the work of Tim and Wendy Booth (1994). This is not a criticism of the paper but it does indicate how impervious professionals are to changing their practice. In the next paper Ian Mansell and Christine Wilson report on the findings from a study that sought the views of informal carers on a wide range of topics that included respite services; access to health and social care information and services; work; leisure; accommodation and

current concerns. They report that their paper presents issues that are relevant to the current concerns of these informal carers. The study on which this paper is based was a mixed method triangulated design that has yielded both quantitative and qualitative data. N = 647 members of a parent/carer federation were sent a questionnaire which included a separate section on 'current concerns'. The response rate for the questionnaire survey was 23% (151 participants). Additionally two focus groups were conducted with 15 carers who had previously completed the questionnaire. These carers identified a number of issues that were causing them concern. These included access to health and social care information and services; quality and quantity of respite care; suitable educational provision; independence/quality of life (for person with a learning disability), and, 'what would happen' to person with learning disabilities when they were no-longer able to carry out their caring role. Despite the low response rate to the questionnaire, within the context of the 'big ideas' and 'talking big' by current reformers concerning recent 'transformations' of support and care for people with learning disabilities and their families particularly within the UK, the continuing presence of parental concern remains worrying. Clearly they have not read all of the available policy documents; for surely if they had they would know how much better things are for them!

In the next paper Steve Mee reports on an intellectual disability nursing course at the University of Cumbria, England. This course bases one module on an oral history project. The oral histories used for the project are those of the people who had lived for many years in a long-stay institution. They report on a recent Nursing and Midwifery Council for the UK audit that evaluated this course as 'outstanding', with particular reference made to this project, and the corresponding website. Student evaluation of the module provided records evidence of 'rich learning', and a resultant change in students practice as a consequence of undertaking this module. Their paper discusses the nature of oral history and the effects the module has had on student nurses. Evidently the experience of the oral history project caused these students to perceive people with an intellectual disability in more positive ways. In particular they learned to listen and empathise in new ways.

In the penultimate paper Meera Roy presents a case note audit that was conducted to follow up women with intellectual disabilities who had been referred for contraceptive sterilisation 20 years ago. She reports that none of the women had been sexually active or had become pregnant. Further, that two of the women had hysterectomies for medical indications at a younger age. She concludes that women with intellectual disability may use reversible and less invasive methods of contraception before considering contraceptive sterilisation. It is also interesting to note that although the assessments predated the Mental Capacity Act 2005, they were nonetheless largely compliant with it. This is a truly fascinating paper and provides much food for thought concerning capacity to consent, best interest's assessment as well charting an historical change in attitudes towards such the contentious practice of the sterilisation of women with intellectual disabilities.

Finally, Jill Manthorpe and Stephen Martineau competently explore the role for social care practitioners in annual health checks for adults with learning disabilities? It is widely acknowledged that the promotion of health checks for adults with learning disabilities in England has become government policy, and that this in itself is based on the need to address the lack of access to health care services along with poor health outcomes for people with learning disabilities. Their paper reports the findings of a scoping review of the literature conducted in 2009 that explored the implications of a national system of health checks for the work of practitioners in social care services. Perhaps not surprisingly, in my view, their review found little in the research literature relevant to social care practice, and concluded that there is a need to consider the possible roles of social care staff in initiating health checks; their possible involvement in decision making around issues of consent; social care practice in recording and implementing the recommendations of such checks; possible roles as escorts, chaperones and supporters with communication, and the presence of regulatory scrutiny of their participation in this activity. However, it does seem to me that the range of roles best suited to Health Facilitation and annual health checks might be better suited to practitioners in health care services.

It is an unexpected pleasure and privilege to back with *Journal of Intellectual Disabilities* but I will only be here for a very short period of time. This is to enable Owen and his family much needed time together. It is good to see the regard that this Journal continues to hold in the field of intellectual disability; it is not only used by the many professionals and students from a wide range of different backgrounds but is also trusted by them to the extent that they continue to submit high quality papers; thus sharing the excellent work that is being undertaken with others. I am confident that by publishing and sharing such excellent papers as those within this issue, that *JID* continues to make its own contribution in bringing about a better understanding of people with intellectual disabilities and the issues that affect their lives.

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Booth, T and Booth, W (1994) *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham. Open University Press.