

Contemporary issues in intellectual disability practice, policy and research.

In this final issue of *Journal of Intellectual Disabilities* for 2011 a range of contemporary issues relevant to family life, the health of young people with intellectual disabilities inpatient use of services by adults with intellectual disabilities, and social policy are all explored. The first paper by Starke reports on interviews undertaken with eleven young adults with intellectual disability her study was aimed at recording their experiences of growing up in homes where at least one parent had the same or a similar disability. Her findings suggest two main themes. The first; the majority of the young adults in her study had positive experiences of family life during their upbringing, secondly, but worryingly these participants described experiences of being bullied and harassed outside the family context. Her study clearly highlights the importance of parents, the family, and informal networks in the bringing of children up and portrays the potential consequences of the participants' negative experiences of peer contacts and their sense of exclusion might have for their prospects in later life. In the second paper Kishore from India explores the impact of disability and coping in mothers of children with intellectual disabilities as compared with mothers of children with intellectual disabilities who also have multiple disabilities. In his paper he points out the importance of understanding this impact and its relationship on parenting and care-giving. To achieve this he compared 30 mothers of children with intellectual disabilities with 30 mothers of children with intellectual disabilities and additional disabilities. Both groups were assessed for disability impact and coping. Despite variations in coping patterns, both positive and negative coping strategies were observed in both the groups. He argues that the results seem to imply that the impact of intellectual disability is so pervasive that with the exception of certain domains parents may not perceive any more negative impact as a subsequence of any additional disabilities. Continuing with the family theme McConkey, Gent and Scowcroft explore critical features of short break and community support services to families and disabled young people whose behaviour is severely challenging. They rightly point out that parenting a child with severely challenging behaviours is very stressful and clearly has a significant impact on family

well-being. They identify that whereas short break (respite) services are commonly provided as a support to families surprisingly little attention has been paid to adapting these services when children and families have complex needs. Their paper describes the model of service that has evolved in three separate locations in Northern Ireland that successfully provides overnight short breaks and/or community-based support to families. This model was documented and validated through individual and group interviews with a range of stake-holders - around 30 in all. These services are embedded within multi-agency partnerships, and they highlight four particular features: the values and ethos underpinning the service; the service procedures, the organisation of short breaks and the role of intensive support/outreach service. Next Allerton, Welch and Emerson present a detailed review of literature that aimed to synthesize evidence on the prevalence and determinants of health conditions and impairments among children and young people with intellectual disability in the United Kingdom. They report on their systematic search of databases for studies conducted with children under the age of 18 living in the United Kingdom and published in 2010-11. Additionally evidence from a 2002 and a 2010 literature review on health inequalities among individuals of all ages with intellectual disability was also reviewed. They conclude a familiar finding related to health issues among the population of people with intellectual disabilities; namely there is an increased prevalence of a number of health conditions and impairments among children with intellectual disability, and evidence that these health inequalities are associated with several preventable environmental determinants. In the penultimate paper Dhillon, Taylor and Yildiran conclude with a most interesting paper that presents a thematic analysis of re-admission into inpatient units for adults with intellectual disabilities in the UK. This paper is based on an audit that explored readmissions into inpatient services for adults with intellectual disabilities, using two case studies. Thirteen semi-structured interviews were conducted with professionals, to elicit a multi-disciplinary perspective, between February and March 2010 and then subsequently analysed using a thematic analysis approach. The aims of this audit were to contribute to good practice, and provide a better understanding of readmission of adults with intellectual disability inpatient services. Finally, Malin and Race present the second of two papers that examines links between policy developments and changes in

professional practice within learning disability services in England. The first article focused on the origins of current policy initiatives over the last twenty years, and it was concluded that there was a growing gap between professional input into children's and adult services (Malin and Race 2010). In this second thought provoking and challenging paper, written one year into the coalition government of the UK, it is argued that the policies of that coalition, especially the large-scale reduction in public expenditure, but also a decline in support for inclusion of children in mainstream education, the rapid growth of academies, and proposals on the re-organisation of the NHS, have exacerbated those trends identified in the first paper and increased their effects in practice, a point made by myself in a previous issue of this Journal in relation to the learning disability nursing workforce in England (Gates 2010), and more recently to the DH for England (Gates 2011). Malin and Race further argue that the interpretation of policy by Local Authorities of their responsibilities under the personalisation agenda, in particular how control over assessment for, and access to, individual budgets, is resulting in assessments of need being based almost entirely on 'service hours' with little or no regard being paid to the quality of those services, or the appropriateness of the qualifications of those people carrying out the direct practice. No doubt this latter assertion will be hotly contested, but perhaps the continuing anecdotal evidence in the UK of wide spread dissatisfaction with the quality of a range of human services *might* result in some reappraisal of the personalisation and inclusion agendas, particularly for people with intellectual disabilities.

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Malin, N and Race, D (2010) The impact of social policy on changes in professional practice within learning disability services: different standards for children and adults? A Two part examination: Part 1. The policy foundations; from welfare markets to *Valuing People*, personalization and Baby P. *Journal of Intellectual Disabilities*. 14 (4). 315-328.