

Plus ça change, plus ce'est la meme chose - reflection on access to health care in mainstream services by people with intellectual disabilities in England, UK

Welcome to the March issue of JOID which will briefly outline the papers in this issue and then reflect on access to health care in mainstream services by people with intellectual disabilities in England, UK. In the first paper Doody, Slevin and Taggart present a paper on intellectual disability nursing in Ireland; detailing its development and potential future. They point out that as a profession intellectual disability nursing has often come under scrutiny, and been called into question. Since its inception as an individual nursing profession in 1959, in Ireland both education and service provision philosophies have changed over time. These changes have been in response to national and international reports and changing attitudes. These changes have led to the current position where intellectual disability nurse education in Ireland is a four year undergraduate course. They argue that as the discipline of intellectual disability nursing is unique to Ireland and the United Kingdom, there is a responsibility on intellectual disability nurses to identify their unique identity, along with their responses to the demands placed on them by changing services. Their paper traces the development of intellectual disability nursing in Ireland, and articulates the implications for this specialist field of nursing for the future. Next McClimens, Brewster and Lewis present a paper that reports on the use of a high fidelity patient simulator (SimMan) within a clinical lab setting to teach intellectual disability nursing students about the management of epilepsy. They report on their preparation of these students with verbal discussions on epilepsy management, and then as the simulator began to undergo a seizure small groups of students were required to manage the unfolding scenario. They received written feedback from the students on the experience and with reference to this and to the wider literature they consider the benefits of this approach to patient care. They surmise that lessons learned here could be applicable to trainee professionals from other parts of the professional register for nurses as well as other fields allied to healthcare. They argue that that this could improve care for people with intellectual disability in line with recommendations in the Michael Report (2008) that is briefly discussed at the end of this editorial. Following this Lafferty, McConkey and Simpson

present a paper that explores barriers to Relationships and Sexuality Education. They point out that opportunities for people with intellectual disabilities to participate in relationships and sexuality education (RSE) are often constrained by the attitudes and perceptions of family carers, front-line support workers and professional staff. In order to understand how these barriers might be reduced, a study was undertaken in Northern Ireland drawing from samples from these three stake-holder groups, involving nearly 100 people using group and individual interviews. Although there was agreement on the need for RSE, four barriers were commonly reported: the need to protect vulnerable persons; the lack of training; scarcity of educational resources and cultural prohibitions. They point out that the impact of these barriers could be lessened through partnership working across these groups, involving the provision of training and information about RSE, the development of risk management procedures and the empowerment of people with intellectual disabilities. The penultimate paper by Peer and Hillmand from the USA, point out that research reveals that parents of individuals with intellectual disabilities experience more stress than parents of persons of normal development. They point out that whereas the majority of previous research has measured direct relationships between stress variables and stress perception little attention has been given to the impact of mediating variables. Their study used an indirect pathway model to examine the mediating influence of coping style on the relationship between social support, severity of child disability, parental optimism and stress perception for these parents. Parents of individuals receiving mental health services through an agency in South Eastern Michigan, USA participated in the study. Their results indicate that coping style partially mediated the relationship between social support and stress perception for parents of individuals with intellectual disabilities. Finally, Martin, O' Connor-Fenelon, and Lyons, present the first in a two part series that presents findings of a qualitative study which has explored the experiences of intellectual disability nurses (RNID) communicating with people with an intellectual disability who communicate non-verbally. Their paper reports and critically discusses the findings within the context of major discourses that are shaping policy and service delivery for people with an intellectual disability; namely, person - centredness, inclusion, choice and independence. Essential to each of these is effective communication. Arguably, intellectual disability nurses in

Ireland are the profession who most frequently encounter people with intellectual disabilities and communication impairment. It is in this context that it is considered both appropriate and timely that their experiences of such communication are explored. The results of this research suggest that communication between these nurses and people with intellectual disabilities who communicate non-verbally is both complicated and multifaceted. An overarching category of Familiarity/Knowing the Person encompasses discrete but related themes and subthemes that explain the process. In this the first of two papers, the dimensions of Familiarity/Knowing the Person are presented; the nurse knowing the service user, the nurse /service user relationship and the value of experience. They also point out that from a wider context and policy perspective, people with an intellectual disability, their families and disability services are facing a time of great change. They argue that due to their work in the frontline of these services, nurses will have a crucial role in supporting this transition.

Now let me spend a few moments reflecting on access to mainstream health services by people with intellectual disabilities. In England, UK five years ago Mencap published a harrowing report entitled *'Death by Indifference'* (Mencap, 2007). In this report Mencap asserted that people with intellectual disabilities had died unnecessarily due to institutional discrimination within NHS care. This prompted the then Secretary of State for Health Patricia Hewitt to establish an independent inquiry into access to health care for people with intellectual disabilities; it was clear from this report that this group of people had been failed. Firstly, that people with learning disabilities were facing suffering and sometimes even death because current legislation designed to give them access to health care was not being adhered to. The Report also concluded that there was not a case for new legislation as it was already in place - so the challenge was to make effective use of it for people with learning disabilities. Also that the events described in *'Death by Indifference'* were not isolated. The Report identified examples of good practice but noted that these were 'patchy' and often the result of committed individuals. The Report took evidence from the public, people with learning disabilities, carers, and professionals in the fields of health and social care. All of this ultimately led the Report to make 10 recommendations which were;

- That all undergraduate and postgraduate clinical training must ensure that curricula include training in learning disabilities.
- That all healthcare organisations collect data to allow people with learning disabilities to be identified by the health service so their pathways of care can be tracked.
- That family and other carers should be involved in the provision of treatment and care, unless good reason is given, and that Trust Boards should ensure reasonable adjustments are made to enable them to do this effectively.
- That Primary Care Trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment.
- That awareness training is needed in the health service of the risk of premature avoidable death, and the Department of Health should establish a learning disabilities Public Health Observatory.
- That the government directs the Department of Health to immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make 'reasonable adjustments'.
- That inspectors and regulators of the health service develop and extend their monitoring of the standard of general health services provided for people with learning disabilities.
- That the Department of Health should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care.
- That All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.

- That all Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services, including advocacy services, for those people who happen to have a learning disability (Michael Report 2008, 54-56).

So five years later what has changed? On the 3<sup>rd</sup> of January this year the Guardian newspaper reported on the avoidable deaths of 74 more people with intellectual disabilities who had died while in NHS care (Bawden and Campbell, 2012). It also highlighted a further 17 serious incidents. Families continue to allege that hospital blunders, poorly-trained staff and indifference are to blame. This newspaper, in collaboration with Mencap, have been continuing to campaign to stop people with intellectual disabilities from receiving unequal healthcare. Of the cases highlighted in the report, 59 took place within the last five years. And more recently in the Times newspaper, Barrow (2012) has reported on an interview with Sir Jonathan Michael, who said that, four years later, he still doubted *'that all lives were seen to be equally valuable'* across the health service. This article reports how Sir Jonathan recalled at being shocked by what he found in 2008 saying that there are still concerns over attitudes toward the lives of patients with severe mental illness. Hospitals and GPs were failing to make essential adjustments to ensure that vulnerable patients received the highest standard of care. Sir Jonathan said; *'The number of patients with learning disabilities is relatively small in number but we felt then, as I do now, that if the NHS can't look after the most vulnerable, there is something fundamentally wrong'*

Additionally in this article Dr Peter Carter, Chief executive and General Secretary of the Royal College of Nursing said;

*'We are concerned that people with learning disabilities are being severely let down in some areas. A set of recommendations which sit on the shelf are no good to anyone' and 'we have the frameworks and policies in place it is now a matter of enforcing them. It is vital that people with learning disabilities receive the right treatment in the right way and that we do not see this lead to further increasing health inequalities'*

*'Treatment of patients with learning difficulties was made more difficult by a decline in the number of specialist nurses, he said. 'Over the past 15 years we have seen real under - investment in these nurses, and this trend must be reversed as a matter of urgency.'*

Perhaps there is something much deeper here that might help in explaining this continued devaluing of people with learning disabilities. One might be forgiven for thinking that the more things change the more they stay the same, and that It may just be that one of the Emperors new items of clothing - the policy of inclusion - is gradually unwinding - laying bare some of its naïve assumptions. Perhaps it is timely to ask whether we will ever see a national debate in the UK as to a need for a fundamental review into current central social policy to establish whether the current agendas for people with learning disabilities and their families are serving their best interests or the interest of those who purport them.

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