

## Health for people with learning disabilities across the life span.

Welcome to the first issue of *BJLD* for 2020 which presents a wide range of papers as a themed collection on the subject of health and people with learning disabilities across the life span – from early childhood to end of life. Health inequality and inequity continue to be problematic internationally, and affect this group of people disproportionately across their life span. In the UK it has been unequivocally established, and for some time, that people with learning disabilities receive poor care whilst in acute hospitals (Heslop, *et al.*, 2013; Mencap 2012; Michael 2008; Mencap 2007). And it is thought that as many as 1, 200 people with learning disabilities die each year, these are avoidable deaths, often through a lack of training for staff (Mencap, 2018; House of Commons, 2018). And despite continued calls and compulsory training for all NHS staff such atrocities on the scale of a national scandal continue (Mencap, 2018). This makes it imperative that health as an issue remains high on any agenda, whether this relates to specialist learning disability services or the general health services to which most people with learning disabilities rely on as a consequence of inclusion. Their inclusion is to be applauded as long as they are treated in an equitable manner when compared with other citizens. This themed collection of papers explores this assumption through a series of health related papers from across the life span.

The first paper by Mengoni and Redman from the University of Hertfordshire, UK identify that children with Down syndrome have increased risk of health conditions. They assert that published guidelines promote the identification and monitoring of health issues, and that adherence to these could reduce health inequalities, yet as they point out there is limited research as to the extent to which health monitoring occurs. Their study sought to investigate health monitoring of children with Down syndrome aged 0–5 years in the UK. Some twenty-four parents of children with Down syndrome, mean age of 32 months (10–65 months), participated. They completed a questionnaire as to their child's use of healthcare services, diagnoses of health conditions, and whether health checks had been completed at birth and after birth. The results of the questionnaires were then charted and compared to the schedule of checks produced by the Down Syndrome Medical Interest Group UK. Results indicate that these children with Down syndrome made substantial use of health services, and reported significant health issues. There was high adherence to published guidelines for the majority of health checks at birth, although 38% of children had not received all recommended checks. Also and importantly not all health domains had been monitored since birth for all children, particularly breathing and blood (excluding thyroid). Their study suggests that health monitoring after birth and screening for non-diagnosed health conditions is variable for children with Down syndrome and it is clear that further research should examine whether these findings are congruent with records and experiences of clinicians across the UK.

Next Morrison and colleagues from the University of Brighton, UK explore an area of health that receives little empirical attention; that of foot care. They suggest that foot problems are known to be a common health issue for adults with intellectual disabilities, however they suggest that foot problems, as a health issue, in children and young people are less well understood. The aim of their study sought to explore the foot care needs of children and young people with intellectual and developmental disabilities. They adopted an exploratory, cross-sectional online survey that undertaken over a four-month period. A purposive snowball sampling approach was adopted. They piloted the survey tool before it was launched with ethical approval given by the host institution, and all participants provided electronic consent before completing the survey. They collected data from 49 parents and caregivers who reported on behalf of their children. Parents reported foot problems to be common, and pes planus was the most frequent concern.

Twenty-four parents reported difficulties with finding shoes, mismatch between foot shape and the shoe or complications with orthotic devices within the shoe were also identified. Their results demonstrate a potential burden of foot problems in children and young people with intellectual and developmental disabilities. These findings highlight the importance of access to foot care services for these children.

The following paper by Pierce and Maher from Edge Hill University, UK identify that despite well-established benefits of engaging in regular physical activity, children and young people with intellectual disabilities are significantly less active than their age peers. Using semi-structured interviews that were conducted with two teachers of PE, and two learning support assistants who worked in special schools they sought to provide insights into physical activity tendencies of children and young people (CYP) with intellectual disabilities. They identify that despite access to and use of outdoor space being claimed to have a positive impact on the physical activity tendencies of CYP with intellectual disabilities schools visited had limited indoor space, which impacted negatively on the duration and frequency of physical activity that CYP were able to engage in. This was made more difficult when space had to be shared as a consequence of timetabling issues and weather. When it came to the *'type'* of physical activities, individual, self-initiated and self-regulated were favoured. They suggest that there is an onus on teachers and learning support assistants to identify creative ways of using limited indoor space. They counsel the possible use of dining and assembly halls. In addition they recommend more individualised physical activities because they are often better suited to the needs and capabilities of CYP, and can be undertaken where there is limited space.

McKerr and colleagues from the Centre for Behaviour Analysis, Queens University, Belfast, UK, and the Optometry and Vision Sciences, Biomedical Sciences Research Institute, Ulster University, Coleraine, UK identify that children with identified special educational needs are at higher risk than other children of having visual needs that are not adequately met. Their paper evaluates the impact of addressing the visual needs of these children on behaviour as well as academic achievements. Nine children (4–11 years of age, from four classrooms), who attended a special school in a medium-sized town in the UK, took part in the case studies reported. These children were part of a Special Education Eyecare (SEE) Project. Six of these children were selected because they had unmet visual needs at baseline, and required interventions to meet these needs; the other three children were selected because their visual needs had been met prior to the study, and no further adjustments were needed. Repeated direct observations were conducted to assess the impact of the intervention on the children's behaviour in the classroom. The observer was 'blind' to the visual needs of the participants. Both parents and teachers completed the Strength and Difficulties Questionnaire (SDQ) for each child, before and after the intervention. School files were then analysed to assess effects on academic achievement. Subsequent to the implementation of visual adjustments such as - prescription of spectacles, or changed seating in classroom, significant and sustained changes were observed with regard to the children's behaviour. The Strength and Difficulties Questionnaire scores showed improvements in; total difficulties, emotional difficulties, and hyperactivity along with prosocial behaviour. Due to variability of data held in the school files they note that any effect on academic achievements were inconclusive. The case studies they report on have explored changes in behaviour of children with identified special educational needs after their visual needs were met. Their findings demonstrate a positive overall effect on behaviour of these children.

Next Perera and colleagues from Barnet Enfield and Haringey Mental Health NHS Trust, London, UK explore reported increased prevalence of physical and mental health conditions in people with

intellectual disabilities (ID) compared to people without intellectual disabilities. They identify that there are no studies that explore specific health conditions at national level, comparing with areas that are socio-economically disadvantaged. Their study examines and compares prevalence of physical and mental health morbidity in people with and without intellectual disabilities at a local and national level in the UK. Their study is based upon an anecdotal analysis of physical and mental health data and annual health check-up for England (national), London (regional) and Haringey (inner-city borough of London) in 2016/17 using data from the NHS Digital database. They found that patterns of mental and physical conditions for people with and without intellectual disabilities were broadly similar across Haringey, London and England data. However severe mental illness was more prevalent among people with intellectual disabilities when compared with their non-intellectual disability peers. Also certain physical health conditions were found to be more prevalent in people with intellectual disabilities. Certain activities such as monitoring blood pressure, recording body mass index were better in people with intellectual disabilities. This study further highlights the increased prevalence of mental and physical disorders in people with intellectual disabilities compared to people without intellectual disabilities. Increased risk of mental disorders in an inner London borough when compared to national data aligns with existing literature that has highlighted the negative impact of socio-economic deprivation on mental and physical health. They point to the need for further studies to assess the health and social care measures that can reduce the physical and mental health morbidity in people with intellectual disabilities.

Giles and colleagues from the Faculty of Health Sciences and Wellbeing, University of Sunderland, Sunderland, TWR, USA explore point-of-care testing for health. They identify that people with learning disabilities have increased risk of diabetes, cardiovascular disease and hearing loss. Their study explored service users' and health professionals' perspectives and experiences of adopting and using minimally invasive diagnostic and screening devices, known as point-of-care testing (POCT) as a means of improving access and engagement. For their study they adopted focus groups and semi-structured interviews with attendees of a non-healthcare day centre, a specialist learning disability clinical network and national leads, as well as researchers into learning disability and point-of-care issues. A thematic analysis of these data were undertaken which found that there was a lack of awareness and experience of POCT devices across these users and health care professionals. However, this sharply contrasted with the finding that on seeing these devices and discussing their application there was strong support and acceptability across all participants for their use. There was no consistent sense of where this testing should be done but support for the flexibility this could provide in terms of non-medicalised locations and individual needs. Strategies for success included the use of specific adjustments, in the UK reasonable adjustments, such as the presence of a known carer, pre-testing information in an appropriate format, and taking account of an individual's preferences. They assert that POCT is a viable and useful method for improving access to testing for people with learning disabilities. Barriers as why this is not more widely adopted in the field of learning disabilities included lack of POCT awareness and diagnostic overshadowing concerns.

The penultimate paper by Bourne and colleagues from Cumbria, Northumberland Tyne and Wear NHS Foundation Trust, Morpeth, UK, Northumbria and Newcastle Universities, UK suggest that the UK Government's Transforming Care Agenda for people with learning disabilities has struggled to meet its goals of reducing inpatient beds and building community-based support. Their paper reports on the experiences of support staff who attended drama therapy groups developed to assist transitions from an inpatient hospital, and to prevent re-admissions through

post-discharge support. The groups provide ongoing support and a place where relationships can be developed between supporter and those supported. They adopted the use of a focus group with a purposive sample of paid support staff. Data generated was then synthesised using a thematic framework approach. Themes identified from these data include; '*new way of supporting*' and '*hospital connection*'. The groups helped improve social interaction, friendship building, communication and self-confidence; all essential for good mental health. Additional benefits include the pooling of support and a connection with professionals that enables difficulties to be caught early. The support workers involved in this study valued these drama therapy groups and recognised that the intervention helped people with learning disabilities develop relationships as well as providing easier access to mental health professionals. These support staff also found benefits for themselves which included shared support as well as increased understanding and insight into the people they were supporting.

In the final paper Gray and Kim from Northern Illinois University, USA have undertaken a study that has looked at direct care workers who provide palliative care for people with intellectual and developmental disabilities. However they state that contemporary research indicates DCWs are ill-equipped to do this. Their study sought to assess whether these workers palliative care experience and training and their perceived training needs. Staff who were trained as workers in organisations that serve people with intellectual disabilities were surveyed in suburban and rural areas of a U.S. Midwest state. A range of statistical analyses were run on data. These participants reported limited experience in legal matters, yet had substantial experience in assisting people with intellectual disabilities with pain, distress, and bereavement. Whereas their preparation was inadequate they sought training for cultural competence, effective communication, post-death logistics, and legal matters. Those that worked in more rural locations reported less palliative care experience and training than did their suburban counterparts. They conclude a need for specific types of palliative care training among such workers caring for people with intellectual disabilities, and that such training should be prioritised in rural agencies.

I sincerely hope that readers have found something of interest in this issue, and that this collection of papers, as with others previously published in *BJLD* continue to contribute to contemporaneous debate on some of the important health issues faced by this population of people, their parents and carers. It is clear that health issues are important for this group of people from a young age until end of life care, and that much more still needs to be done to make this equitable with the care other citizens receive. Papers in this issue raise important issues from the very young to the very old of this important, but often overlooked, section of our communities. It is important that not only do we collectively work toward promoting good health for people with learning disabilities and support their families and carers in doing so. But also they must know they have a right to equal and equitable health provision throughout their life span, and we have a duty to use all our powers to inform health and social care policy at national level of this, and that this right is inalienable for all citizens, not just those able to advocate for themselves.

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