

# 16TH SEATTLE CLUB

## BOOK OF ABSTRACTS

Deeprise Lecture Theatre  
Glasgow Caledonian University  
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## ORAL PRESENTATION ABSTRACTS

**Title:** The importance of love to people with learning disabilities

**Author:** Claire Bates [C.Bates@kent.ac.uk](mailto:C.Bates@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Background:** Love is important aspect of life, including to people with learning disabilities both historically (Craft and Craft 1979) and more recently (Rushbrook et al. 2014). Participants value the companionship, support and social status associated with a partner. Relationships are considered mechanisms to meet certain needs including feeling loved, company, intimacy and enabling individuals to marry and have children (Rushbrook et al. 2014). This article examines the importance of love to people with learning disabilities in relationships

**Method:** A hermeneutic phenomenological study, guided by the theory of Van Manen (1990), was conducted using interviews with eleven people with learning disabilities examining the importance of romantic love

**Results:** Love was important to participants, specifically the companionship and support it provided. The physical expression of love was valued, especially kissing/ cuddling. Most participants had experienced abuse but it appeared that a partner's love was reparative. Participants' highlighted the role staff play in supporting them to fulfil their romantic needs. The romantic relationship needs of people with learning disabilities were examined in relation to Maslow's Hierarchy of Needs.

**Conclusion:** The hierarchy was revised to reflect the value of having a loving relationship to people with learning disabilities and to identify the support they required to facilitate and maintain this.

**Title:** Expecting death? Expected and unexpected deaths of adults with intellectual disabilities in social care settings in the UK

**Name:** Jane Bernal [sjbernal@btinternet.com](mailto:sjbernal@btinternet.com)

**Affiliation:** University of South Wales

**Co-authors:** Stuart Todd, Rhian Worth, Julia Shearns

**Background:** The expectedness of death is relevant to end of life care; the involvement of the person in decision making and the ways in which services should develop to accommodate those who are dying. Deaths reported to the Coroner; deaths that happened suddenly or after a very short illness and certificated deaths from certain causes have all been used as markers for unexpected death. 1

**Method:** As part of a larger study we approached UK service providers for adults with ID supporting 13,199 people. We sent 2 questionnaires, VOICES; and another designed for this study, to a member of care staff (carer) requesting more information about the person who died, the death; and the setting. Data were obtained on 157 deaths over 18 months.

**Results:** Carers had expected 73 of the 157 deaths. 59% of deaths were referred to the Coroner. More deaths were sudden or occurred after a short illness than for the general population. Detailed analysis will be presented.

**Conclusion:** Nearly half all deaths in ID social care settings were unexpected by carers. Other markers for unexpected death were also higher in this population.

**Title:** Challenging behaviours in adults with an intellectual disability: a total population study in Jersey

**Name:** Darren Bowring [d.bowring@health.gov.je](mailto:d.bowring@health.gov.je)

**Affiliation:** University of Bangor

**Co-authors:** Vasiliki Totsika, Richard Hastings, Sandy Toogood, Gemma Griffith

**Background:** Considerable variation has been reported in the prevalence and correlates of challenging behaviour in adults with intellectual disabilities. To provide a robust estimate of

prevalence, we identified the entire administrative population of adults with ID in a defined geographical area and used a behaviour assessment tool with good psychometric properties.

**Method:** Data from 265 adults who were known to services were collected using a demographic survey tool and the BPI-S. The prevalence of self-injurious, aggressive/destructive, stereotyped, and overall challenging behaviour was evaluated. We explored the potential of developing Cumulative Risk Indices (CRI) to inform longitudinal research and clinical practice.

**Results:** The prevalence of overall challenging behaviour was 18.1% (95% CI: 13.94%-23.19%). The prevalence of self-injurious behaviour was 7.5% (95% CI: 4.94%-11.37%), aggressive and destructive behaviour 8.3% (95% CI: 5.54%-12.25%), and stereotyped behaviour 10.9% (95% CI: 7.73%-15.27%). Communication problems and severity of ID were consistently associated with higher risk of challenging behaviours. CRIs were significantly associated with challenging behaviours and the five methods of CRI development produced similar results.

**Conclusion:** Findings suggest a multi-element response to challenging behaviour is likely to be required that includes interventions for communication and daytime activity. Exploratory analyses of CRIs suggested these show promise as simple ways to capture cumulative risk in this population. This is especially useful in clinical practice that aims to predict and prevent challenging behaviour.

**Title: What effects do linguistic simplification and mediation have on the comprehension of 'easy read' text by people with intellectual disabilities?**

**Name:** Susan Buell [s.buell@uea.ac.uk](mailto:s.buell@uea.ac.uk)

**Affiliation:** University of East Anglia

**Co-authors:** Peter Langdon, Gabriela Pounds, Karen Bunning

**Background:** Recent legislation in the UK (Accessible Information Standard) has established 'easy read' material as one form of reasonable adjustment within health and social care. Increased production of such documents parallels popular demand and a range of guidelines for design and use are available. This study, used a 2X2 between subjects factorial design to test the effect of linguistically simplified text and literacy mediation on the construction of meaning from 'easy read' health related information.

**Method:** Sixty adults with IDs undertook The Easy Read Task, each allocated to one of four conditions (with and without simplified language/ with and without mediation). The study aimed to answer: What effect does linguistic complexity and literacy mediation have on the reading comprehension of 'easy read' information by people with IDs? Analyses of variance (ANOVA) were conducted on the data, testing for main effects of linguistic complexity and mediation on comprehension.

**Results:** Neither linguistic complexity of the text nor mediation independently or combined made a significant difference to the understanding of information. However, when receptive vocabulary was controlled using analysis of covariance (ANCOVA), a significant interaction was present between simplified text and mediation.

**Conclusion:** Constructing meaning needs to extend beyond a consideration of form as found in 'easy read' documents to address a better understanding of the relevance of individual capacity for language processing.

**Title: Experiences of online risk among adults with intellectual and developmental disabilities**

**Name:** Darren Chadwick [d.chadwick@wlv.ac.uk](mailto:d.chadwick@wlv.ac.uk)

**Affiliation:** University of Wolverhampton

**Background:** The digital world is a central part of current human existence that can bestow both benefits and risks to those who engage with it. Online risk research has primarily focused on young people with little research considering online risk for adults with intellectual and developmental disabilities. Perceived vulnerability of this group of people may increase their digital exclusion and

the digital divide. Risks have previously been classified into contact, conduct and content related risk but little is known about the experience of these specific types of risk for adults with disabilities. This study presents a qualitative study exploring experiences of risk of adults with intellectual and developmental disabilities.

**Method:** Individual interviews were conducted with thirteen adults with intellectual and developmental disabilities who all identified themselves as self advocates. Interview discussions considered online experiences including experience of online risks as well as the benefits of being online and using social media. Data were audio recorded and analysed using thematic analysis.

**Results:** Overarching themes of risk experiences, understanding risks, negotiated risk, risk management and positive risk taking were identified in the interviews. Accounts also identified fears and concerns around online risks as a potential instrumental factor in digital exclusion.

**Conclusion:** Adults with intellectual and developmental disabilities with low support needs in the study appeared more able to manage online risk than may be presupposed by a vulnerability-focused perspective. Enabling people and their carers to better understand and manage online risk appears a way forward for research and practice.

**Title: A pilot randomised controlled trial of community led anti-psychotic drug reduction for adults with learning disabilities (ANDREA-LD)**

**Author:** David Gillespie [gillespied1@cardiff.ac.uk](mailto:gillespied1@cardiff.ac.uk)

**Affiliation:** Cardiff University

**Co-authors:** Elizabeth Randell, Rachel McNamara, Aude Espinasse, Kerry Hood, Michael Kerr

**Background:** Prescribing of anti-psychotic medication in adults with learning disabilities (LD) is high. There is concern about over use of anti-psychotics for reasons other than psychosis in this population (e.g. to manage challenging behaviour). There is a lack of strong evidence regarding both the use of anti-psychotics to manage challenging behaviour, and the safety and efficacy of withdrawing patients from them.

**Method:** We assessed the feasibility of conducting a two-arm individually-randomised placebo-controlled trial of gradual anti-psychotic drug reduction compared to treatment as usual. Participants were adults with LD, on risperidone, and without a history of psychosis. We recruited through primary care and community LD teams. Following randomisation, intervention participants went through four stages of blinded reduction (controls maintained starting dose). All participants were followed up at six and nine-months.

**Results:** Twenty-two participants were randomised from 32 screened (69%). Participants were on a median dose of 1.5mg of risperidone prior to randomisation (IQR: 1.0 to 2.0mg), and generally had low clinical scores at baseline on scales measuring aggression, challenging behaviour, and mental health. Thirteen participants progressed through all four stages of the drug reduction (59%), and follow-up data were obtained for 17 (77%). Intervention participants had slightly higher scores on average for aggression, challenging behaviour, mental health, movement disorders, and PRN at follow-up. Reported anti-psychotic side-effects and dose of anti-psychotic medication was lower for those in the intervention group at follow-up.

**Conclusion:** These findings suggest that anti-psychotic drug reduction is possible and safe in this population. However, focused support and alternative interventions may be required.

**Title: Mental capacity to consent to research? Experiences of consenting adults with intellectual disabilities**

**Name:** Jahnese Hamilton [Jahnese.Hamilton@ntw.nhs.uk](mailto:Jahnese.Hamilton@ntw.nhs.uk)

**Affiliation:** NIHR Clinical Research Network (Mental Health) North East and North Cumbria Wolfson Research Centre Campus for Aging and Vitality, Westgate Newcastle upon Tyne

**Co-authors:** Barry Ingham, Iain McKinnon, Jeremy Parr, Louise Tam, Ann Le Couteur

**Background:** Conducting applied research with people with intellectual disabilities raises complexities around capacity to consent. This has led to a call for the development of specific capacity assessment tools. We asked clinical researchers how they currently approach informed consent and capacity assessments for research, and what they would recommend.

**Method:** Clinical researchers who conduct research with NHS patients with intellectual disabilities participated in a survey (n=22). Questions focused on their experiences of informed consent and capacity assessments for adults with intellectual disabilities, and their opinions and ideas about developing a tool to facilitate the assessment of capacity. A thematic analysis was conducted on the responses.

**Results:** A number of themes were identified: (i) People with intellectual disabilities who lack capacity were often excluded from research; (ii) Some researchers viewed participant engagement with tasks as demonstrating implicit consent to participate; (iii) Written consent was often used; (iv) Common adaptations to enhance accessibility included easy read materials and verbalising information; (v) Perceptions of ethical and legal conduct varied; (vi) The majority of responses indicated support for developing a research tool to guide this process, some concern was expressed about adding extra burden and confusion to the consent process.

**Conclusion:** To achieve full and effective participation in research by people with intellectual disabilities, researchers need robust methods to assess capacity to consent. Researchers reported some innovative procedures, welcomed the proposal of a research tool and highlighted several challenges. Researchers acknowledged that this is a challenging aspect of including adults with intellectual disabilities in applied research.

#### **Title: Adulthood and Fragile X Syndrome: A UK Survey**

**Name:** Becky Hardiman [rh432@kent.ac.uk](mailto:rh432@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Jenn Howard, Peter McGill

**Background:** Fragile X Syndrome (FXS) is the most common inherited cause of learning disability and presents with lifelong effects, including cognitive, behavioural and physical features. However, there is a paucity of data exploring the experiences of adults with the condition.

**Method:** A survey was disseminated online and postally via The Fragile X Society. The survey consisted of existing measures and questions developed with key stakeholders to cover key topics including: support received; services and benefits; physical health; mental health; behaviour; communication; sensory issues; functional skills; social and leisure; work and education. Data was collected on 126 adults (107 men) with FXS, between the age of 18-74 years (mean=33). The majority of survey respondents were relatives or caregivers, though 7 people with Fragile X responded directly.

**Results:** A broad range of findings were collected. Illustrative results include: 63% of men with FXS lived in the family home; 13% of men with FXS are in paid employment

(1-40 hours per week), though 36 were being paid below minimum wage; though a high number of health issues were reported, only 35% had received an Annual Health Check; on the Guernsey Community Participant and Leisure Assessment, mean scores from the FXS sample comparative to others with a learning disability.

**Conclusion:** Barriers to access to services reported included anxiety-related issues, which relates to the FXS phenotype. The results highlight a need for greater support for this population on this, and other issues, to ensure access to work, support and social opportunities.

#### **Title: A randomised controlled trial of a multi-component weight management intervention for adults with intellectual disabilities and obesity**

**Name:** Leanne Harris [Leanne.Harris@glasgow.ac.uk](mailto:Leanne.Harris@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Catherine Hankey, Nathalie Jones, Carol Pert, Heather Murray, Janet Tobin, Susan Boyle, Craig Melville

**Background:** Multi-component weight management interventions (MCWMI) including a personalised energy deficit diet (EDD) are recommended by clinical guidelines for the treatment of obesity. However, there is little evidence of the effectiveness of MCWMI for adults with intellectual disabilities (ID), with current interventions focussed on a health education approach. TAKE5 is a MCWMI which satisfies clinical recommendations, is specifically designed for adults with ID and obesity, and implemented with support from carers wherever possible. The aim of this study was to conduct a single-blind randomised controlled trial comparing TAKE 5 to a health education intervention, WWToo.

**Method:** This 12 month study was delivered on a one-to-one basis by two trained research dieticians. Outcomes (including change in body weight, BMI, waist circumference, physical activity levels, sedentary behaviour and well-being) were measured at baseline, six months (after a weight loss phase) and twelve months (after a six month weight maintenance phase).

**Results:** Recruitment was effective with 50 participants were randomised. Both interventions were acceptable to adults with ID, evidenced by high attendance and retention rates. Fifty percent of the participants in TAKE 5 achieved a clinically significant weight loss of 5-10% of initial body weight. TAKE 5 also significantly reduced BMI, waist circumference and percentage body fat. There were no significant improvements in any outcome for the WWToo intervention.

**Conclusion:** A personalised EDD approach to weight management in adults with ID may be more effective in comparison to the current approach based on health education and warrants further research in the form of a full-scale trial.

**Title:** A decade of psychotropic prescribing in Scotland

**Name:** Angela Henderson [angela.henderson@glasgow.ac.uk](mailto:angela.henderson@glasgow.ac.uk)

**Affiliation:** Scottish Learning Disabilities Observatory

**Co-authors:** Deborah Kinnear, Jill Morrison, Linda Allen, Sally-Ann Cooper, Colin McCowan

**Background:** Studies report high rates of prescribing of psychotropic medications to people with intellectual disabilities (ID), not correlating with reported rates of mental illness. This research analyses trends in the use of psychotropic drugs for adults with ID in Scotland.

**Method:** This analysis of psychotropic prescribing trends draws on two sources of data about adults with ID in the same Scottish health board area over 10 years: a large prospective cohort study (n=1023); and electronically extracted primary care records (n=4,345). Demographics and health status were analysed to identify potential influencing factors.

**Results:** In 2002-2004, antipsychotic drugs were prescribed to 23.2% of adults in the cohort, the majority of whom did not have psychosis, and some of whom had no identified mental health problem. The extent of antipsychotic prescribing progressively fell in 2004-2006, and further again in 2014/15. Over the same period, prescribing of antidepressants increased substantially, as has also been the case in the general population.

**Conclusion:** There have been changes in psychotropic drug prescribing over 10 years however these drugs are still prescribed at higher than expected rates. This study includes data from comprehensive mental health assessments enabling some analysis of the association between rates of mental illness and psychotropic prescribing.

**Title:** Management of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: a comparison over time

**Name:** Laura Hughes-McCormack [Laura.Hughes-McCormack@glasgow.ac.uk](mailto:Laura.Hughes-McCormack@glasgow.ac.uk)

**Affiliation:** University of Glasgow



**Co-authors:** Nicola Greenlaw, Linda Allan, Angela Henderson, Jill Morrison, Sally-Ann Cooper

**Background:** The UK general practitioners contract included a pay for performance element for management of long-term conditions, according to best-practice indicators, defined by the Quality and Outcomes Framework (QOF). This study uses QOF to measure good practice for adults with intellectual disabilities compared with the general population at two time points.

**Method:** Patient records of adults with intellectual disabilities registered with participating general practices were extracted and analysed in 2010 (n=721) and in 2014 (n=4,066) to determine management of long-term conditions according to QOF indicators. Comparisons at both times were made with the general population from the same health board. Additionally, prevalence of long term conditions was determined, and associations with age, gender, ability, type of accommodation, and neighbourhood deprivation were investigated via logistic regression analyses.

**Results:** Adults with intellectual disabilities received poorer management of long-term conditions compared to the general population on 53/57 (92.9%) indicators in 2010, and 38/54 (70.4%) indicators in 2014. Improvements were found at 2014 as achievement was high (76-100%) for 19.6% of adults with intellectual disabilities in 2010, compared to 74.1% in 2014. Adults with intellectual disabilities had higher rates of epilepsy, psychosis, hypothyroidism, asthma, diabetes, and heart failure; with little association with ability, accommodation-type or neighbourhood deprivation.

**Conclusion:** High quality management of long term conditions is essential to maintain and improve health. The healthcare inequality gap between people with learning disabilities and the general population narrowed between 2010 and 2014, though people with intellectual disabilities still experienced poorer management of their long term conditions.

**Title:** Supporting adults with learning disabilities during admission to general hospital: the different experiences of family carers and paid support staff

**Name:** Isabella Lancaster [iml26@medschl.cam.ac.uk](mailto:iml26@medschl.cam.ac.uk)

**Affiliation:** University of Cambridge

**Co-authors:** Adam Pitt, Isabel Clare, Tony Holland, Marcus Redley

**Background:** People with learning disabilities (LD) are known to have difficulty accessing appropriate healthcare services and experience inequalities in health outcomes. Hospitals now face strong political and legal pressure to provide equitable healthcare for them, resulting in implementation of LD initiatives.

**Method:** Aim to understand the recent experiences of family carers (FC) and paid support staff (PSS) when supporting an adult with LD following admission to general hospital, in one of two East of England NHS Trusts. Semi-structured interviews, with 20 FC, and 8 PSS working in community residential services, addressed the hospital experiences of patients with LD. Transcripts of the interviews were examined for content, with emergent themes identified and coded.

**Results:** FC portrayed themselves as playing a vital role in admissions. This included: being actively involved in care and treatment decisions; being a source of clinically important information, and where necessary, protecting their family member from perceived weaknesses in the hospital environment. PSS, in contrast, felt they had to justify their presence on a hospital ward, despite their intimate knowledge of the patient, while also managing what they considered to be unreasonable expectations from hospital staff concerning the frequency and type of support they could provide.

**Conclusion:** FC and PSS feel that hospital staff neither fully understood their concerns for the patient, nor appreciated the extent to which they can contribute. The implications for practice of our findings are unclear, but they reveal the many complexities of caring for this potentially vulnerable patient population.

**Title:** DSM IV, DSM-5 and the Five Factor Model (FFM): The diagnosis of personality disorder with intellectual and developmental disabilities

**Author:** Bill Lindsay [bill.lindsay@danshell.co.uk](mailto:bill.lindsay@danshell.co.uk)

**Affiliation:** University of West of Scotland

**Background:** In DSM-5 there has been a move to dimensional PD diagnosis incorporating personality theory in the form of the FFM. DSM-5 retains DSM-4 categorical criteria but also proposes an alternative system where the assessor uses a four stage process based on Diagnostic indicators and the FFM. Paris (2013) commented it is a complex process with “unfamiliar terminology for busy clinicians”. The staged process assesses: 1. severity of personality functioning; 2. maladaptive personality traits, 3. any of six retained PD diagnoses (antisocial, avoidant, borderline, narcissistic, obsessive-compulsive, schizotypal), and 4. dysfunctional traits (conforming to the FFM). Studies previously reported substantially different rates (7% to 91%) of PD on similar populations of individuals with IDD and Alexander & Cooray (2003) concluded this variation “is too large to be explained by real differences”. Lindsay et al (2017) found structured assessment more valid than diagnostic interview.

**Method:** Two men and two women illustrate the assessment of PD using the International Personality Disorder Examination (IPDE). Three sources of information (recommended by Alexander & Cooray 2003) combined for composite PD assessment: participant interview; interview with key nurse; observations of participant. The NEO-PI adapted by Lindsay et al (2007) assesses personality based on the FFM. Cases illustrate PD assessment using the DSM-5 alternative method.

**Results:** PD ratings (self, staff and observer) tended to converge for borderline, antisocial and narcissistic PDs. NEO-PI ratings converged on Neuroticism, Extraversion, Openness with discrepancies on agreeableness and conscientiousness (staff rating lower).

**Conclusion:** A structured DSM-5 system is easily usable but takes more time than diagnostic interview.

**Title:** Measurement of side effects of anti-epileptic drugs (AEDs) in adults with intellectual disability: A systematic review

**Name:** Rachel McNamara [mcnamara@cardiff.ac.uk](mailto:mcnamara@cardiff.ac.uk)

**Affiliation:** Cardiff University

**Co-authors:** Lauren Copeland, Andrea Meek, Mike Kerr, Michael Robling, Kerry Hood

**Background:** There is concern about the presence and impact of side effects of anti-epileptic drug (AED) treatment in people with Intellectual Disability (ID). However research has concluded that measurement of side effects in this population is hampered by reliability of available measures. The aim of this review is to identify research on measurement and impact of AED side effects in the adult epilepsy population with and without accompanying ID.

**Method:** A systematic literature search was conducted in MEDLINE In-Process, MEDLINE, EMBASE, SCOPUS and Web of Knowledge. The review identified studies in adults with epilepsy, and a subset of adults with ID taking an AED, which included a measure of potential AED side effects.

**Results:** 460 papers were identified and 93 met inclusion criteria. Of 107 measures identified, six were appropriate for use with adult ID populations, although only two of these were specifically designed for use in this population. Seven studies investigated adults with epilepsy and ID and examined side effect domains of behaviour, functionality and quality of life. The focus of these measures however is broader than side effects alone and therefore may not pick up the full range of side effects of importance in this group.

**Conclusion:** Side effects of AEDs are inconsistently and inadequately measured in ID populations and are overly reliant on carer report. There is a clear lack of established and validated assessment scales for patients with ID and epilepsy.

**Title:** Are people with Intellectual and Developmental Disabilities who lack capacity to consent at risk of being excluded from research? Ethical implications of the UK Mental Capacity Act 2005



**Author:** Nicole Palmer [N.R.Palmer@kent.ac.uk](mailto:N.R.Palmer@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-author:** Rachel Forrester Jones

**Background:** The Mental Capacity Act 2005 (MCA) came into force in 2007. It covers 'intrusive' research involving participants who lack capacity, that is, any research that would normally require the consent of a participant in order to be lawful. The Act requires NHS REC review for this research and has thus brought a large section of social care research, including that seeking to involve people with intellectual and developmental disabilities (IDD), into a formalised regulatory process which has been designed to deal with interventional clinical research (Dingwall 2006; Haggerty 2004; Parker et al. 2001). Establishment of the Social Care REC in 2009 was intended to provide specialised knowledge and expertise for social science research applications falling within the MCA, but there is concern that people with IDD are still at risk of being excluded from research participation.

**Method:** Retrospective review and content analysis of REC decision-letters for applications involving people with IDD who lack capacity to consent, over a three-year period. In-depth interviews with researchers who have experienced REC review of projects seeking to involve people with IDD.

**Results:** The most common issue raised in REC decision-letters was methodological questions. Interviewees report experiencing a 'challenging', 'confrontational' and 'disproportionate' ethical review process that has directly led to decisions to exclude people with IDD from their research projects.

**Conclusion:** Improvements in knowledge and skills for both REC reviewers and researchers are likely to lead to better inclusivity in research for people with IDD who lack capacity to consent.

### **Title: A meta-analysis and exploratory interview to examine the prevalence and phenomenology of anxiety in Williams Syndrome**

**Name:** Rachel Royston [rxr180@bham.ac.uk](mailto:rxr180@bham.ac.uk)

**Affiliation:** University of Birmingham

**Co-authors:** Jane Waite, Patricia Howlin, Chris Oliver

**Background:** There is general consensus in the literature that anxiety is significantly elevated in Williams Syndrome (WS). However, reported prevalence estimates vary considerably between studies. Moreover, whilst there are an abundance of measures available to assess anxiety, these are usually developed specifically for the general population, and may be unable to detect subtle or atypical behaviours related to anxiety in genetic syndromes associated with intellectual disability (ID). Therefore, the utility of these measures to conceptualise anxiety in WS is uncertain.

**Method:** A systematic review of the literature and meta-analysis to generate pooled prevalence estimates was conducted in accordance with PRISMA guidelines. Using a theoretically driven approach, a clinical bottom-up interview was developed to delineate the profile, process and presentation of anxiety in WS. The interview was conducted with 13 parents of individuals with WS (mean age=21.92, SD=11.12).

**Results:** Anxiety disorder prevalence in WS was high, although elevated rates were mainly associated with specific phobias (39%) and generalised anxiety disorder (10%). Individuals with WS were also at a significantly higher risk of developing these two disorders compared to the heterogeneous ID population and the general population. The interview identified behaviours and triggers that have not been previously captured using standardised psychiatric assessments.

**Conclusion:** The distribution of anxiety disorders in WS follows an unusual trend compared to the TD population and the heterogeneous ID population. The interviews demonstrate the utility of a bottom-up approach in the investigation of psychiatric conditions in genetic syndromes and ID groups, particularly in cases where anxiety presentation may be atypical.

**Title: Deciding on the suitability of marriage for a person with a learning disability within a South-Asian community: Staff and mother experiences**

**Name:** Najma Sultana [NXS666@student.bham.ac.uk](mailto:NXS666@student.bham.ac.uk)

**Affiliation:** University of Birmingham

**Co-author:** Biza Stenfert Kroese

**Background:** Safeguarding people with a learning disability from forced marriage has recently come to the forefront of policy agendas. The majority of these cases are said to occur in the South-Asian community and involve people who have questionable capacity to consent to marriage. Parents and staff members are likely to be most involved in decision making yet little is understood about how both groups experience this decision making process.

**Method:** Nine participants were recruited and took part in this study. Five were healthcare professionals recruited from a community team. Four were mothers of a person with a learning disability recruited from third sector organisations. Semi-structured interviews were undertaken with all participants and interviews were analysed using Interpretative Phenomenological Analysis.

**Results:** The analysis across the two groups revealed three shared superordinate themes. The first theme, 'An uncertain future' sets the context for why mothers consider marriage as an option. The second theme, 'Managing multiple roles, commitments and responsibilities' describes similarities and differences in mothers' and staff's experiences of their roles and responsibilities. It elaborates upon how both groups perceive marriage as a risky option for a number of reasons. 'Navigating through muddy waters' elaborates upon the difficulties each group experiences during the process of deciding whether or not marriage is a suitable option.

**Conclusion:** These results are considered in the light of psychological theories relating to stigma, tolerating uncertainty and decision making.

**Title: Sensory profiles of adults with autism: A comparison with the general population and adults with dyspraxia**

**Name:** Jessica Tame [jessicatame@btinternet.com](mailto:jessicatame@btinternet.com)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Paraskevi Triantafyllopoulou, Frances Beaumont

**Background:** Many adults with Autism Spectrum Conditions (ASC) and dyspraxia experience sensory processing difficulties, yet research has been limited in this area. The two main aims for this study were to investigate the sensory profiles of adults with autism spectrum disorder (ASD) and compare these findings with the sensory profiles of adults with dyspraxia and the general population.

**Method:** The Adolescent/Adult Sensory Profile (Brown and Dunn, 2002) was used to measure sensory responses in adults with ASD (n = 32), dyspraxia (without ASD or ADHD co-diagnosis, n = 37) and the general population (n = 35). Participants were recruited via universities and relevant organisations. The data on dyspraxia was collected prior to this study.

**Results:** There was a significant difference between the three groups. Participants with ASD were more likely to be sensitive to and avoid sensory input. Also, adults with ASD differed significantly on the sensation seeking and sensation avoiding quadrants when compared to adults with dyspraxia.

**Conclusion:** Sensory processing difficulties are highly evident in adults with ASD but also in adults with dyspraxia. Further investigation is needed to examine the persistence of sensory processing difficulties in adulthood for people with ASD.

**Title: Evaluation of a Discharge Protocol Intervention in a Locked Rehabilitation Service: Impact on Discharge, Readmission, Medication and Restraint**

**Name:** John L Taylor [john.taylor@ntw.nhs.uk](mailto:john.taylor@ntw.nhs.uk)

**Affiliation:** Northumbria University and Northumberland, Tyne & Wear NHS Foundation Trust, UK.

**Co-authors:** Susan Breckon, Christopher Rosenbrier

**Background:** Building the Right Support is a national plan to develop community services and close hospital beds for people with intellectual disabilities (ID) and autism who display challenging behaviour. Essential components of this plan include reducing lengths of stay and (re)admissions to hospital services.

**Method:** The impact of a newly developed discharge pathway protocol was evaluated by comparing discharge and readmission rates and use of PRN medication and restraint during 4-year periods prior to and following the introduction of the protocol.

**Results:** In the post-intervention period the rates of discharge increased significantly (12 vs. 37), readmission rates reduced markedly (7 vs. 3) and significant reductions in the lengths of stay, use of PRN medication and physical restraint were reported.

**Conclusion:** This service development which involved significant changes to the clinical model and culture of a service has enabled the service to accelerate the discharge of a number of complex and vulnerable long-stay patients who present high levels of forensic risk. The implications of this approach for the Building the Right Support plan are considered.

**Title: The methodological challenges in assessing the effectiveness and impact of breaking-bad-news training initiatives**

**Author:** Irene Tuffrey-Wijne [I.Tuffrey-Wijne@sgil.kingston.ac.uk](mailto:I.Tuffrey-Wijne@sgil.kingston.ac.uk)

**Affiliation:** Kingston University & St. George's University of London

**Background:** Many people with intellectual disabilities are affected by death, yet staff in ID residential/supported living services tend to avoid conversations about death. We conducted an interview study with ID staff to gain understanding of the context and reasons for avoiding such communication. Staff fear, cultural influences and inexperience with death-related conversations were major communication barriers. Based on these results, we developed a one-day staff training course aimed at increasing ID staff confidence and skill in death-related communication with people with ID.

**Method:** Three one-day courses were attended by 114 staff and evaluated through (a) feedback forms immediately after the course and (b) Likert-scale questionnaires assessing confidence and perceived skill, administered before (n=108), immediately after (n=108) and three months after the course (n=24).

**Results:** Scores and comments on the feedback forms were overwhelmingly positive. The questionnaires showed significant increase in confidence and perceived skill immediately after the course; some, but not all of this improvement was sustained at three months, but this lacked statistical significance; response rate at three months was low.

**Conclusion:** Training initiatives are often evaluated through self-report delegate questionnaires close to the training event, but sustainability of any improvement is more difficult to assess. Even more challenging is the evaluation of impact on delegates' practice (rather than on self-reported confidence and skill). Methodological challenges in evaluating the effectiveness of breaking-bad-news training will be discussed.

**Title: Executive Functioning and Temper Outbursts: Evidence from Lowe syndrome**

**Name:** Jane Waite [j.e.waite@bham.ac.uk](mailto:j.e.waite@bham.ac.uk)

**Affiliation:** University of Birmingham

**Co-authors:** Hayley Crawford, Alicia Kutsch, Lucy Wilde, Chris Oliver

**Background:** Lowe syndrome (LS) is an X-linked disorder that occurs in 1 in 500,000 live births. Temper outbursts are highly prevalent occurring in 80% of individuals. Deficits in executive functioning (EF) have been implicated in temper-outbursts in genetic syndromes. This study explored associations between EF and temper outbursts in Lowe syndrome (LS). Exploring these associations

may inform models of behaviour, which may be applicable to broader intellectual disability populations.

**Method:** Twenty-six males with LS (mean VABS Language Composite = 5 years 10 months; range: 2.5-10 years) completed a battery of EF tasks including two delay of gratification tasks. Parents completed the Behaviour Rating Inventory of Executive Function - Preschooler Version (BRIEF-P). Temper outbursts were measured using an adapted version of the Challenging Behaviour Questionnaire.

**Results:** A high proportion of participants showed temper outbursts (75%). Poorer performance on a delay of gratification task was associated with a higher temper outburst composite score ( $R = -.52, p = .006$ ). Greater executive dysfunction as measured by the BRIEF-P was strongly associated with a higher temper outburst score ( $R = .82, p < .001$ ). Further analyses indicated that this association was underpinned by the inhibition, working memory and emotional regulation subscales. These associations remained significant once adaptive behaviour was controlled for.

**Conclusion:** Individuals with LS may have difficulties with inhibition, particularly in emotionally salient contexts when asked to wait for something they find gratifying. Further research is needed to explore the phenomenology of temper outbursts in LS and to inform understanding of pathways from cognition to behaviour.

**Title: Exploring the right to vote during with people with intellectual disabilities, family and paid-carers during the Scottish referendum**

**Name:** Diane S Willis [d.willis2@napier.ac.uk](mailto:d.willis2@napier.ac.uk)

**Affiliation:** Edinburgh Napier University

**Co-authors:** Isla McGlade, Mark Gallagher, Colin Menabney

**Background:** Voting is a human right for every citizen yet Mencap (2015) suggests that only one in three people with intellectual disabilities (ID) use their vote. Many more do not vote or have little support to exert their right to vote. This work explores the wider aspects of voting against the backdrop of the Scottish referendum.

**Method:** Three focus groups were undertaken using participants from one geographically-diverse area in Scotland. The groups consisted of people with ID, family-carers and paid-carers. Question topics included asking about the voting process, facilitators and barriers to voting and exploring issues around the referendum. Thematic analysis was undertaken.

**Results:** The groups consisted of people with ID, (12), family-carers (7) and paid-carers (5). What are we voting for, looked at issues that people with intellectual disabilities raised in terms of voting and the referendum, Who should I vote for explored the influences that people with ID might be exposed to; while Enhancing voting identified how they could be supported to make an informed choice.

**Conclusion:** This study identified that people with ID were very aware of the referendum and wanted to participate in political decision making. However, they needed help to exercise their right to vote. For this to happen more appropriate information for carers and people with ID is needed. It also highlighted deficits within the current electoral process that impact on current and future voters with ID.

**Title: Health and Wellbeing during Transition from School: A Qualitative Study**

**Author:** Genevieve Young-Southward [G.young-southward.1@research.gla.ac.uk](mailto:G.young-southward.1@research.gla.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Christopher Philo, Sally-Ann Cooper

**Background:** Transition from school may be a period of vulnerability for young people with learning disabilities. Within the literature poor outcomes across employment, independent living and social domains are documented. A recently-conducted systematic review revealed a gap in the literature on transition and health and wellbeing outcomes in this population. This study aimed to gain insights

into the transition experiences of young people with learning disabilities through semi-structured interviews with young people and their parents.

**Method:** Semi-structured interviews were conducted with 20 parents of young people with learning disabilities aged 16-24, and with 11 of their children. The interviews explored whether the experience of transition had affected young people's health and wellbeing, in what particular ways, and what services were useful in supporting a healthy transition. Interviews were analysed using thematic analysis through Nvivo software.

**Results:** The key health impact of transition on young people was on mental health, with young people experiencing high levels of anxiety during the transition period, and often exhibiting challenging behaviours or a loss of acquired skills as a result. Themes identified as contributing to these mental health difficulties included a lack of appropriate daytime activity following school exit; inadequate supports and services during transition; and the struggle to adjust to expectations for more 'grown up' behaviour.

**Conclusion:** Transition planning should be better supported and started earlier in a young person's school career in order to ease anxiety for young people and their families during this difficult period.

## POSTER PRESENTATION ABSTRACTS

**Title:** An examination of the impact of witnessing non-violent crimes on the suggestibility of adults with intellectual disabilities

**Name:** Rebecca Aitken [rebecca.aitken@cwp.nhs.uk](mailto:rebecca.aitken@cwp.nhs.uk)

**Affiliation:** Trafford Community Learning Disability Team

**Co-author:** Steve Hendy

**Background:** Individuals with intellectual disabilities (ID) experience cognitive difficulties which include impairments in memory (Carney, 2013). These difficulties can affect the reliability of statements obtained during interrogative interviewing. Interrogative suggestibility is one factor demonstrated to be linked to the reliability of witness and suspect statements. This study examines whether suggestibility is greater in the ID than the non-ID population, if there are differences in memory recall between the two cohorts, and whether suggestibility is affected by crime type.

**Method:** Adults with mild to moderate ID (n=20) and age matched non-ID staff (n=20) were shown three separate video clips of different event types. Participants were scored on their free memory recall of the clip they witnessed. This was followed by an adapted version of the Gudjonsson Suggestibility Scale 2 (GSS2) (Gudjonsson, 1987; 1997).

**Results:** Participants with ID had lower memory recall and were more suggestible. Significant differences in suggestibility levels across crime type were also found; participants were more suggestible after viewing the criminal damage event than when they viewed the burglary event. These differences were unaffected by ID.

**Conclusion:** Individuals with ID yield to misleading information, likely to be linked to their deficits in memory, they also change their answers in response to negative feedback. Participating in interrogative interviews for certain criminal event types contributes to increased suggestibility for all individuals. Findings suggest that individuals with an ID require reasonable adjustments and there should be guidance to support people in the context of different criminal events.

**Title:** The dietary and nutritional habits of people with learning disability who live with and without paid support

**Name:** Hassan Al Attar [Hassan.attar@gcu.ac.uk](mailto:Hassan.attar@gcu.ac.uk)

**Affiliation:** Glasgow Caledonian University

**Co-authors:** Janet Finlayson, Philippa Dall, Alan Candlish

**Background:** It is widely mentioned that people with learning disabilities who live with paid support in the United Kingdom (UK) have a high prevalence of poor diet and nutritional intake. As well, there is a lack of information in the literature on the dietary habits of people with learning disabilities who either live on their own, or with their families. In addition, few interventions to improve diet in this population have been developed with people with learning disabilities' carers as co-participants, however many people with learning disabilities require support from their carers to meet their dietary needs. The dietary habits of people with learning disabilities who live with or without paid support therefore, is an under-researched area. In regards to nutrition, people with LDs have been reported to do quite poorly.

**Method:** On November 30th, 2015 the main programmed literature search of electronic databases was performed in five different electronic databases were included in the study CINAHL (Current Nursing and Allied Health literature), Amed (The Allied and Complementary Medicine Database), PubMed, PsycINFO and MEDLINE. This literature review uses a mixed methods approach.

**Results:** The literature review search yielded 117 relevant studies. Result from the literature reviews were concerning diet change/ and modification intervention studies and Training/awareness/acquiring skills intervention studies. Other studies were concerning Diet



supplementation (e.g. fibre or vitamins) most of these papers are relevant to specific conditions (PICA, Down syndrome, and PKU). Additional studies associated with specific condition such as dysphagia management and environment during meals (Pethna case study).

**Conclusion:** The study will focus on aspects of education, information provision and training in food preparation for the people with LDs and their supportive carers.

**Title: CQC inspection reports for acute NHS Trusts: What do they tell us about hospital services for people with learning disabilities? An analysis of 30 Trust inspections**

**Name:** Susannah Baines [s.baines1@lancaster.ac.uk](mailto:s.baines1@lancaster.ac.uk)

**Affiliation:** Lancaster University

**Co-author:** Chris Hatton

**Background:** The Public Health England Learning Disabilities Observatory (PHELDO), with the support of the CQC, decided to undertake an analysis of CQC inspection reports of NHS acute Trusts based on their new inspection regime. This was a repeat and extension of a study undertaken in 2015.

**Method:** CQC reports for 30 NHS Trusts and their related specific site reports were examined with the following research questions. 1. Do CQC inspection reports mention people with learning disabilities? 2. Where issues concerning people with learning disabilities are reported in CQC hospital inspection reports, what issues and reasonable adjustments are reported? 3. Are there any relationships between comments made in the inspection reports and CQC ratings of the Trusts?

**Results:** 29 of the 30 Trust wide inspection reports (97%) and 56 of the 61 specific site reports (92%) had at least one mention of people with a learning disability/learning disabilities in the report, an increase from 54% in 2015. In the chief inspectorate's letter and summaries most comments were positive irrespective of the overall CQC rating, although the proportion of positive comments drops as CQC ratings become less positive (outstanding/good 94%; requires improvement 73%; inadequate 70%).

**Conclusion:** The inspection reports showed that more attention had been paid to learning disabilities but that the overall rating did not always reflect the care of people with learning disabilities.

**Title: Investigation of the applicability of trauma as a framework for understanding staff response to challenging behaviour presented by people with intellectual disabilities**

**Name:** Peter Baker [p.a.baker@kent.ac.uk](mailto:p.a.baker@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-author:** Rebecca Hardiman

**Background:** The impact of the psychological wellbeing of staff who are exposed to challenging behaviour when supporting people with intellectual disabilities is complex and only partially understood. The impact upon staff has not yet been investigated through the framework of trauma. There is clearly a need for clarity in this area and this study attempted to ascertain the extent to which staff are experiencing involvement in incidents as traumatic, what characteristics of the incidents are difficult, what supports are currently being provided, what they find useful (and not useful) and finally what supports they believe would be helpful.

**Method:** 43 members of staff from different services in one organisation were interviewed using the Impact of Events Scale- Revised (IES-R. Weiss, 2007: self-report measure that assesses subjective distress caused by traumatic events), Challenging Behaviour Exposure Measure (Hastings & Brown, 2002) and a questionnaire designed to assess perceived levels of support in the workplace.

**Results:** In the IES-R, 12.8% of participants fell in clinical concern category and 23.1% very significant concern for Post-Traumatic Stress Disorder, based on their response to their experiences of challenging behaviour in the workplace. Described experiences of behaviour varied widely in terms

of nature and topography, as did the reported support received. Preliminary investigations are being conducted to examine possible factors associated with subjective experience.

**Conclusion:** The high proportion of clinically significant scores on the trauma scale highlight the validity of exploring staff experiences in this framework and demonstrate a need for further research.

**Title: An Evaluation of Outcome Measures Used In Services for Individuals with Learning Disabilities**

**Name:** Luke Beardmore [luke.beardmore@cwp.nhs.uk](mailto:luke.beardmore@cwp.nhs.uk)

**Affiliation:** Cheshire and Wirral Partnership NHS Foundation Trust

**Co-authors:** Rebecca Aitken, Helen Elford, Steve Hendy

**Background:** Current guidelines emphasise the importance of evidenced-based practice and a need for services to demonstrate the effectiveness of the psychological interventions they deliver. However, there are limited guidelines on the use of outcome measures for individuals with Learning disabilities (LD). The aim of the current study is to evaluate the effectiveness of outcome measures utilised in routine clinical practice.

**Method:** A case study format was used to present the data collected. A selective sampling method was employed and all instruments were administered to (n=4) service users' pre and post treatment, by trainee or assistant clinical psychologists. The materials used included the Health Equalities Framework (HEF), Clinical Outcomes in Routine Evaluation: Learning Disabilities (CORE-LED), Health of Nation Outcome Scale (HONOS): Learning Disabilities, and Goal Attainment Scaling. Each case was reviewed to consider the reason for referral, input from professionals, the duration of intervention, and the generation of pre and post descriptive statistics and qualitative impressions.

**Results:** Quantitatively, the HEF (particularly the Genetic and Social determinants) demonstrated most change pre to post treatment, followed by the HONOS which received more qualitative feedback in terms of sensitivity to psychological intervention. Qualitative data identified that these measures may be sensitive to the broader interventions completed by the MDT (e.g. care planning, risk assessment, MDT work), while psychological interventions may need to outcome measurement more specific to the intervention. The CORE-LED was felt to be clinically useful in some cases dependent on the context of the referral.

**Conclusion:** Findings suggest the outcome measures used vary in their reflection of service user quality of life and the effectiveness of psychological intervention. The potential development of a new outcome measure which can be piloted within local NHS services is discussed.

**Title: Improving Access to Psychological Therapies (IAPT) for people with intellectual disabilities (ID) from service users' and clinicians' perspectives: An Action Research Approach**

**Name:** Kate Bexley [kate.bexley@addaction.org.uk](mailto:kate.bexley@addaction.org.uk)

**Affiliation:** Addaction

**Co-author:** Kate Theodore

**Background:** IAPT aimed to reverse inequalities regarding who accesses psychological support. Arguably however, there remain limits to the extent that people with ID are seen as 'candidates' for IAPT (Chinn et al., 2014). This project not only investigated what changes IAPT could make to improve accessibility for people with ID, but also implemented and evaluated these changes.

**Method:** Action research design comprised of (1) planning, (2) action and (3) evaluation. Seven service users with ID and 12 clinicians (within an inner-London IAPT service) were interviewed using the Green Light Toolkit (NDTi, 2013) as a guide. Qualitative data was analysed using Thematic Analysis.

**Results:** Phase one: Common themes were identified from both service users' and clinicians' perspectives regarding how the service was already 'doing well' and recommendations for

improvements. All clinicians additionally expressed uncertainties regarding IAPT's ability to offer a good-enough service to people with ID, and that other service pressures and priorities meant that this work did not feel like IAPT's 'core business'.

Phase two: Implementation of recommended actions based on these themes, including staff training and resource development.

Phase three: Evaluation: All service users and clinicians reported progress made, and suggested recommendations for further improvements. Clinicians posited the need for increased exposure to work with people with ID to consolidate training and clinician confidence, and for a broader 'cultural shift', and reflected on the limits to flexibility within the IAPT framework, impeding work with this client group who require increased adaptations to ensure reasonable adjustments.

**Conclusion:** Clinical / policy implications of results discussed.

**Title: The Characteristics of Residential Educational Settings in England for Young People with Intellectual or Developmental Disabilities**

**Name:** Serena Brady (Tomlinson) [s.r.l.brady@kent.ac.uk](mailto:s.r.l.brady@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Jessie Humphreys, Peter McGill, Nick Gore

**Background:** Little is known about the characteristics of residential educational settings for young people with intellectual or developmental disabilities (IDD) in England. Previous research has focused on the characteristics and experiences of the young people attending such settings (i.e. Pilling et al., 2007) rather than the setting itself; therefore an overview of national provision is needed.

**Method:** As part of a larger project, data were collected about all residential schools and colleges in England. Data relates to settings offering residential provision for at least 4 nights per week for 30 weeks per year, either at the school / college itself, or in an associated residential home. Due to the remit of the main project, settings offering placements only to young people aged under 16 were excluded. Data were collected from a range of sources, including school / college websites, Ofsted and Department for Education resources, and liaison directly with the setting.

**Results:** In total, 357 residential educational settings were identified with 61 of these offering post 16 provision only. A range of data is presented about these settings, including: location, placement numbers and types available, age range catered for, SEN categories registered for, and governance arrangements (e.g. LA maintained, privately owned, charitable organisation).

**Conclusion:** These data provide a national overview of residential educational settings for young people with IDD. This enables a clearer picture of the location and type of provision offered and allows comparisons both within and between areas.

**Title: An investigation of the adapted GAD-7 and PHQ-9 clinical measures of mood for adults with intellectual disabilities (ID)**

**Name:** Jenny Breen [Jenny.breen.2014@live.rhul.ac.uk](mailto:Jenny.breen.2014@live.rhul.ac.uk)

**Affiliation:** Royal Holloway University of London

**Co-author:** Kate Theodore

**Background:** People with ID arguably continue to face barriers to accessing psychological support such as IAPT services, due to a lack of 'reasonable adjustments' (NDTi, 2012). One significant issue to accessing IAPT specifically has been that whilst the standard clinical questionnaires used by services to measure recovery from anxiety and depression (IAPT's 'minimum dataset', including GAD-7 and PHQ-7), have been reported to be suitable for people with ID, these measures have not yet been specifically tested with people with ID (Foundation for People with Learning Disabilities, 2015), and both service users and clinicians report they can be difficult to use in the standard way for many people with ID.

**Method:** The initial stage of this research used a Cognitive Interviewing approach to investigate whether adaptations to two measures used frequently to assess mood as part of IAPT's 'minimum dataset', the GAD-7 and the PHQ-9, help to make these measures more appropriate for use with adults with ID. Initially ten people with ID who have experience of accessing IAPT services will be interviewed, using a Cognitive Interviewing approach, which will lead to further adaptations to the measures, which will be further evaluated through five further Cognitive Interviews with service users.

**Results:** The results of the Cognitive Interviewing and the resulting adapted GAD-7 and PHQ-9 measures will be presented.

**Conclusion:** The findings of the initial Cognitive Interviewing study will be discussed in relation to the next stage of the study, which will be an investigation into the initial psychometric properties of the adapted GAD-7 and PHQ-9.

**Title:** *'I wish I had kept myself safe'. Sexuality and relationships education (SRE) for people with Autism Spectrum Disorder*

**Name:** Mark Brown [mb666@kent.ac.uk](mailto:mb666@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-author:** Glynis Murphy

**Background:** Nationally, sex and relationships education has been integrated into the National Curriculum for schools for the past two decades, but tends to be mainstream orientated. There has been a limited amount of research into the appropriateness of present SRE programmes for pupils with ASD, especially considering the impact of ASD upon a pupil's social skills results in difficulties recognising social rules linked with sex and sexuality, including "sexual scripting". The study has explored the effectiveness of SRE programme for pupils with ASD, including implementation, evaluation and the need for adaptation.

**Method:** The literature Review performed showed very little research in the area, and subsequent face to face interviews with head teachers or PSHE co-ordinators from 15 schools catering for pupils with ASD in London, Surrey and Sussex highlighted issues in relation to the effective implementation of School based SRE programmes, particularly socio-sexual issues. Focus groups incorporating pupils with ASD were performed to gain pupil insight into the SRE programmes they had received.

**Results:** Thematic analysis of focus groups identified themes; including lack of appropriate mainstream SRE programmes for pupils with ASD, issues relating to social and relationship aspects of sexuality, and inconsistency in implementation of SRE resulting in insufficient levels of skills being learnt by pupils with ASD to keep safe.

**Conclusion:** Next stage is the implementation of pilot SRE programme for pupils with ASD.

**Title:** *Identifying and Characterising Adults with Type 2 Diabetes Mellitus and Intellectual Disability: outcomes of a case finding and observational study*

**Name:** Louise Bryant [l.d.bryant@leeds.ac.uk](mailto:l.d.bryant@leeds.ac.uk)

**Affiliation:** University of Leeds

**Co-authors:** Amy Russell, Allan House, Rebecca Walwyn, Amanda Farrin

**Background:** This study developed and evaluated a case-finding method for adults with mild/moderate Intellectual Disability (ID) and Type 2 Diabetes (T2DM) for a feasibility RCT of a supported self-management intervention. We aimed to characterise the population in terms of diabetes control, living circumstances and the role of supporters in diabetes management.

**Method:** A cross-sectional observational study in West Yorkshire (2013 to 2016).

Participants were 18+ years old, with T2DM (not on insulin) with a mild to moderate ID, not living in a hospital setting. Recruitment was through primary and secondary care and the third sector. Data

were collected by a researcher on a home visit. Medical record information was requested from the participant's GP with the participant's consent.

**Results:** 325 unique referrals were received, yielding 147 eligible participants (24% of the target population), 70% from primary care. HbA1c levels were average for the T2DM population in the study locality although self-reported medication adherence was variable. Obesity rates were high with 20% having a BMI of 40+; self-reported activity levels were very low. There were low rates of knowledge about foot checks and retinal screening. Low mood was common. 88% had a nominated supporter involved in diabetes care or helping with shopping/cooking.

**Conclusion:** Many people with an ID and T2DM are not managing their health well, whether or not they have a supporter. Patchy recording of people with ID on GP registers means it is difficult to identify people who need reasonably adjusted care T2DM pathways.

**Title: Conceptualising the therapeutic alliance: Exploring the relevance of Bordin's model for adults with intellectual disabilities**

**Name:** Dr Sarah Cameron [sarah.cameron@lanarkshire.scot.nhs.uk](mailto:sarah.cameron@lanarkshire.scot.nhs.uk)

**Affiliation:** NHS Lanarkshire

**Co-authors:** Dave Dagnan, Jacqui Rodgers

**Background:** In general adult samples, research suggests a strong therapeutic alliance (TA) is related to positive outcomes in psychological therapy. The TA is also viewed as important factor within therapy with people with intellectual disabilities (IDs), however there is an absence of research conceptualising the TA in this population. The present study aimed to explore how well a prominent TA model, Bordin's model (1979) conceptualises the TA with clients with IDs. Bordin's model outlines three areas, which determine the strength of a TA: agreement of goals, assignment of tasks and development of the bond.

**Method:** Interviews were conducted with six clients with mild IDs and the six therapists delivering psychological therapy with these clients. Thematic analysis was used to analyse interview data.

**Results:** Themes were generated from the interviews. Therapists highlighted the TA as an integral aspect of psychological therapy with clients with IDs. A client-therapist relationship characterised by listening, respect, honesty and trust, was important to both groups. Clients can view a personal relationship with their therapist. Furthermore, themes indicated the potential for a power imbalance in the client-therapist relationship. Therapy tasks and goals were discussed and collaboration was strived for, although therapists suggested a direct approach in guiding clients is often necessary. Systemic factors can influence the TA and therapy overall; there can be advantages to involving others in supporting the therapeutic process, however disadvantages include challenges to confidentiality.

**Conclusion:** The results suggested many similarities with Bordin's model, however with important differences; namely the systemic factors and nature of the client-therapist relationship.

**Title: "I love it...I love that story": The experiences of families of children with Down's syndrome as the children learn to read**

**Name:** Katie Cebula [katie.cebula@ed.ac.uk](mailto:katie.cebula@ed.ac.uk)

**Affiliation:** University of Edinburgh

**Co-author:** Sarah McGeown

**Background:** Whilst the cognitive and linguistic skills associated with reading ability amongst children with Down's syndrome are relatively well established, less is known about the experiences of the children themselves, and of their parents, as the children learn to read. Such exploration is important in tailoring support and intervention-design to the practicalities of family life. This qualitative study explored parent and child experiences of the children learning to read, focusing on: the kinds of approaches that parents take to support their children's reading development; their

experience of available educational and informal reading support; and the place they perceived reading as having within the child's life.

**Method:** Semi-structured interviews were conducted with 10 mothers of children with Down's syndrome and 9 children with Down's syndrome (aged 5 – 13 years; 7 girls and 2 boys). Parent interviews explored the topics outlined above. The child interview format varied to suit the individual child, though often included a 'book tour' of the child's favourite books and a picture-based discussion of reading helpers and the emotions associated with reading.

**Results:** Themes emerging during preliminary analysis include: the balancing of parenting with teaching; issues of home-school communication around reading; challenges surrounding the use of digital technology; the emotional experiences of shared reading; the place of reading in adolescence.

**Conclusion:** Whilst the study is small-scale, preliminary findings point to the need to further explore reading support for adolescents, the use of technology to create reading experiences which are appealing for children, and reading interventions which fit comfortably into family life.

**Title: Staff considerations of the role non-aversive approaches**

**Name:** Craig Chalmers [craig.chalmers@outlook.com](mailto:craig.chalmers@outlook.com)

**Affiliation:** Edinburgh Napier University

**Co-author:** Linda Hume

**Background:** The role of direct care staff is a key factor in the quality of support people with an intellectual disability. Currently, there continues to be a role for services for people whose behaviour is perceived as challenging; however, as the evidence base for frameworks such as positive behaviour support grows we should have made significant progress to have moved away from using aversive approaches to responding to crisis incidents. There continues to be a high rate of the use of restrictive practices such as restraint within services. This conceptual paper aims to appraise if further research is needed to understand the attitudes of untrained staff of the role of non-aversive approaches.

**Method:** This paper will review the relevant literature on outcomes of positive behaviour support training in services. It will review the type of outcomes reported in the studies on the impact PBS training has for staff, particular attention will be paid to outcomes for non-registered staff.

**Results:** The findings of the literature found that there are no specific studies that consider the rationale for unqualified staff responses to behaviour escalation. Additionally, the use of restrictive practices continues to be of concern.

**Conclusion:** Untrained staff's perceptions, attitudes and other phenomenology should be taken into account within the context of behaviour management and investigated to identify a baseline of knowledge, attitudes and issues around the use of PBS. This area of research may then help to inform services what is required in terms of training and support to effectively enhance the use of more non-aversive approaches to managing and responding to crisis incidents.

**Title: 'It was kind of scary'. The experiences of children and young people with an intellectual disability of undergoing clinical procedures in healthcare settings**

**Name:** Greg Cigan [cigang@edgehill.ac.uk](mailto:cigang@edgehill.ac.uk)

**Affiliation:** Edge Hill University

**Co-authors:** Lucy Bray, Barbara Jack, Axel Kaehne

**Background:** Children and young people with an intellectual disability are among the most frequent visitors to healthcare settings where they undergo clinical procedures that can be painful and invasive. There is currently little empirical evidence to investigate how clinical procedures are experienced by children and young people with an intellectual disability and their parents.

**Method:** This ongoing study has adopted a qualitative research design underpinned by Classic Grounded Theory methodology. To date, 26 semi-structured interviews have been conducted with a



convenience sample of children and young people who have a mild to moderate learning disability and are between the ages of 6-15 (n=11) and their parents (n=15).

**Results:** Preliminary data analysis suggests that children/young people and their parents often feel worried and upset before and during clinical procedures.

Children/young people report that they dislike being physically held still for procedures and that they prefer to be told about what will happen before a procedure takes place. Parents report other factors which contribute to the worry that they and/or their child experiences such as prolonged waiting periods and unclear communication between themselves and healthcare practitioners.

**Conclusion:** Clinical procedures are challenging events for children and young people with intellectual disabilities and their parents. Where possible, practitioners should aim to make reasonable adjustments that respond to the concerns of children and young people and parents as highlighted by this study.

**Title: Lycra splinting garments for people with learning disabilities who fall due to balance/gait issues: A feasibility study**

**Name:** Jennifer Crockett [Jennifer.Crockett@ggc.scot.nhs.uk](mailto:Jennifer.Crockett@ggc.scot.nhs.uk)

**Affiliation:** NHS Greater Glasgow and Clyde

**Co-authors:** Janet Finlayson, Ben Stansfield, Shiv Shanmugam

**Background:** Falls and fall injuries are a serious problem for people with Learning Disabilities (LD), therefore interventions to reduce/prevent falls are warranted. People with LD experience similar high rates of falls as the elderly in the general population, but at a younger age. Falls are the commonest cause of injury in this population and poor gait/balance is one of the main reasons people with LD fall. The aim of this study was to investigate the acceptability and feasibility of Lycra Splinting Garments (LSG), which are worn to improve posture, movement and function, for people with LD who fall due to poor balance/gait.

**Method:** The study was a feasibility trial of wearing LSG with people with LD who fall. The study was exploratory in design to determine the acceptability and feasibility of the intervention of LSG with people with a LD and the use and responsiveness of suitable balance and gait measures. Nine participants had their gait and balance recorded. Baseline and then repeat intervention measures were used: not wearing/wearing LSG following a period of six weeks wear.

**Results:** Outcomes were reported on a case by case basis and across the group. The use of LSG was found to be feasible and acceptable for some people with LD who fall. The outcome measures for balance; minimum foot clearance and components of gait were not always found to be reliable and a degree of interpretation of the results was required. A number of positive changes were reported e.g. a possible reduction in falls for some participants; and a change in foot clearance during walking.

**Conclusion:** The findings suggest that LSG may be a useful treatment to reduce falls in people with LD who fall due to balance/gait issues but further study is required and warranted. The usability, the clinical condition, and the type of garment worn are important to their success.

**Title: The Sheffield Learning Disabilities Outcome Measure: A Factor Analysis**

**Name:** Lauren Delahunty [lauren.delahunty@ed.ac.uk](mailto:lauren.delahunty@ed.ac.uk)

**Affiliation:** Child Life and Health, Edinburgh

**Co-authors:** Gill Kidd, Fiona McCrohan

**Background:** The Sheffield Learning Disability Outcome Measure (SLDOM) is routinely used across clinical services in the UK, despite not yet providing evidence of psychometric validity. However, it is reported that the SLDOM demonstrates good face validity, and represents a valuable tool for providing useful information around the parent-child relationship in the context of having a child with learning disability (LD). Thus, more evidence supporting its psychometric validity is needed in order to ensure clinicians use the tool effectively and for the purpose for which it was designed.

**Method:** 263 parents or carers of a child with LD completed the pre intervention measure of the SLDOM. Results then subjected to factor analysis.

**Results:** These findings suggest that the SLDOM could be viewed as a tool that measures two concepts: 1) internal factors central to the parent in relation to having a child with LD and 2) external factors in terms of the context and environment surrounding a child with LD.

**Conclusion:** To our knowledge, this study is one of the first to investigate the psychometric properties of the SLDOM. This has implications in terms of building evidence to support the clinical and research use of this tool; to provide evidence-based clinical services, and overall, to gain a better understanding of patients and their families, which will allow for optimum service provision.

**Title: The physical and mental health of people with comorbid autism and intellectual disabilities in Scotland**

**Name:** Kirsty Dunn [kirsty.wright@glasgow.ac.uk](mailto:kirsty.wright@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Ewelina Rydzewska, Laura Hughes- McCormack, Angela Henderson, Sally-Ann Cooper

**Background:** Little is known about the physical or mental health status of people with comorbid autism and intellectual disabilities in whole country populations. This presentation will discuss general health status, as well as the prevalence of other disabilities and physical or mental health conditions, of people with co-morbid autism and intellectual disabilities. This health data will be compared against health data on the general population.

**Method:** We analysed data from Scotland's Census 2011, and generated descriptive statistics on physical and mental health of people with both autism and intellectual disabilities, and the general population.

**Results:** People with comorbid autism and intellectual disabilities (n=5,709) comprised 0.1% of the total population of Scotland (n=5,295,403), 18.0% of the whole population of people with autism in Scotland (n=31,712) and 21.7% of the whole population of people with intellectual disabilities in Scotland across all ages. People with comorbid intellectual disabilities and autism were more likely to report a mental health condition (31.3% vs 4.4%), physical disability (43.2% vs 6.7%) and other long-term illness or disease (49.6% vs 18.6%) than the general population. More people with intellectual disabilities and autism reported two or more health conditions than those in the general population (54.9% vs 8.6%).

**Conclusion:** Health is poorer for people with comorbid autism and intellectual disabilities than for people in the general population. The Scottish Learning Disabilities Observatory is conducting further analysis on data from the Scotland 2011 census.

**Title: The developmental trajectory of social cognitive abilities in individuals with CdLS across the lifespan**

**Name:** Katherine Ellis [KRE061@student.bham.ac.uk](mailto:KRE061@student.bham.ac.uk)

**Co-authors:** Sissy Stefanidou, Laurie Powis, Jo Moss, Ian Applerly, Chris Oliver

**Background:** Individuals with Cornelia de Lange syndrome (CdLS) have a unique socio-behavioural profile that changes with age. Other disorders with atypical social profiles, including Rubinstein-Taybi syndrome and autism spectrum disorders (ASD), evidence divergent developmental trajectories of social cognitive skills, which may underpin their social development. This study investigated the developmental sequence of social cognitive skills from infancy into adolescence in individuals with CdLS.

**Method:** 37 individuals with CdLS aged 2 to 49 years old (Mage=12.6, SD=10.8) participated in one of two batteries of tasks assessing social cognitive skills that emerge in a strict developmental order. The 'Early Social Cognition Scale' (ESCS) assessed understanding of others intentions (typically

developing between 14->24 months), whereas the 'Theory of Mind Scale' (ToMS) assessed understanding of other's mental states (3->9 years).

**Results:** The order that participants passed tasks in both batteries diverged from typical development. Children participating in the ESCS passed tasks requiring understanding other's simple intentions (86% passed '*Reenactment of intended acts*', 82% passed '*helping*'), but few passed tasks involving developing shared intentions with others (36% passed '*tubes-with-handles*', 32% passed '*point*', 23% passed '*gaze*' and 18% passed '*trampoline*'). In contrast, children and adults participating in the ToMS showed heterogeneous developmental progressions that differed between one another.

**Conclusion:** Early social cognitive skills are considered to provide the foundations for later abilities. Early social cognitive deficits may lead to each individual with CdLS to develop idiosyncratic ways of understanding others mental states, leading to heterogeneous performance in the ToMS.

**Title: Family interventions: A qualitative study**

**Name:** Jan Ferris [jan.ferris@nhslothian.scot.nhs.uk](mailto:jan.ferris@nhslothian.scot.nhs.uk)

**Affiliation:** NHS Lothian

**Co-authors:** Ken MacMahon, Jennifer Hadden, Emma Sharp, Josephine Hutchison

**Background:** Studies have found family interventions (FIs) to be effective in reducing stress and relapse rates for a variety of mental health conditions. However, implementing FIs into clinical practice is challenging. Studies have suggested levels of stress within some families of people with intellectual disabilities can be high. However, little is reported about the use, and implementation of FIs, such as Behavioural Family Therapy (BFT), in adult intellectual disability services.

**Method** A qualitative methodology was employed, using semi-structured individual interviews with BFT therapists from Nursing and Allied Health Professional backgrounds ( $n=9$ ). Data were analysed thematically.

**Results:** Two overarching themes were identified: positivity and frustration. Implementation of therapy was identified as broadly successful but with some underlying challenges (wider organisational issues and issues specific to working with adults with intellectual disabilities).

**Conclusion:** Findings suggest a perceived benefit of using BFT as a framework to work with adults with intellectual disabilities.

**Title: Psychological and pharmacological interventions for people with severe intellectual disabilities and mental health problems: A systematic review**

**Name:** Samantha Flynn [s.flynn.1@warwick.ac.uk](mailto:s.flynn.1@warwick.ac.uk)

**Affiliation:** Centre for Educational Development Appraisal and Research (CEDAR), University of Warwick

**Co-authors:** Leen Vereenooghe, Richard Hastings

**Background:** Mental health problems affect people with intellectual disabilities (IDs) in rates similar to the non-IDs population. People with a severe ID have a greater prevalence and incidence of mental health problems, which are likely to be constant over time. This study reviews the literature concerning the availability and effectiveness of psychological and pharmacological interventions aimed at the prevention and treatment of mental health problems in individuals with severe ID.

**Method:** A systematic search covering 10 scientific databases was conducted to identify peer-reviewed publications that met the following inclusion criteria: a) participants with severe or profound ID, b) delivery of a pharmacological or psychological intervention for mental health/well-being, c) a quantitative outcome measure of mental health, and published in English, German, Dutch or French between 1980-2015.

**Results:** The search identified 24,883 unique articles. Following title and abstract screening, 467 full-text articles were screened for relevance. Subsequently, data from studies eligible for review ( $n=6$ )

was extracted and papers subjected to a quality appraisal. Pharmacological interventions (n=4) had typically small samples, usually male adults, and interventions were usually less than 12 weeks in duration. The quality of these interventions was variable, with only half including a control condition. Both psychotherapeutic interventions were single cases with a female adolescent/adult, methods were largely behavioural and had multiple iterations of the sessions.

**Conclusion:** There are comparatively few recent studies focussing on this population, thus more primary research is required to establish empirically-validated treatments for mental health problems in individuals with severe ID to guide clinical practice.

**Title: Developmental disability: A mixed methods analysis of the “lived” parental experience**

**Name:** Jane Goodwin [jane.goodwin@uon.edu.au](mailto:jane.goodwin@uon.edu.au)

**Affiliation:** University of Newcastle

**Co-authors:** Lynne McCormack, Tracy Dudding-Byth, Linda E Campbell

**Background:** The aim of this research is to describe the experience of parenting a child with a developmental disability, particularly the more positive psychological aspects. A concurrent mixed methods design was used in order to explore the intricacies of positive psychological outcomes.

**Method:** Participants were recruited online. A cross-sectional survey analysed predictors of psychological growth in 432 parents of children with a variety of developmental disorders through a regression model. Then, semi-structured interviews informed by the methodology Interpretative Phenomenological Analysis (IPA) sought to understand whether this psychological growth was possible when parenting a child with a widely variable and often tardily diagnosed disability, 22q11DS.

**Results:** Over 75% of survey participants experienced some psychological growth. Positive reappraisal, coordinated and comprehensive healthcare, and child’s age predicted greater psychological growth. The qualitative analysis revealed that parents who had a young child with 22q11DS experienced anticipatory traumatic distress and systemic stigma. However, they were able to redefine their unanswered fear, guilt, loss and grief in these early years through hope for the future. Parents with an adult child with 22q11DS felt guilt, loss and grief. Ill-informed hierarchical structures triggered angry advocacy for their child. In time, psychological growth was viewed as part of the journey, identified through empathy, humility, gratitude, and pride.

**Conclusion:** This research demonstrates that: a) positive psychological outcomes are realistic for parents whose children have a developmental disability and should not be neglected; b) medical frameworks often poorly support the biopsychosocial needs of families; and c) healthcare professionals are well-placed to promote positive psychological outcomes.

**Title: Goals and Outcomes for Intervention (Go-For-IT)**

**Name:** Nick Gore [n.j.gore@kent.ac.uk](mailto:n.j.gore@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Background:** This project explored the experiences and priorities of 12 family carers and 14 young people with learning disabilities who displayed challenging behaviour

**Method:** Family carers and young people were interviewed using an adapted version of the Constructional Questionnaire presented via Talking Mats and tailored to the meet individual communication needs. This covered, challenging and prosocial behaviours displayed by the child, parenting behaviours, quality of life and service-related preferences

**Results:** Family carers and the majority of young people engaged in discussions about quality of life, the impact of challenging behaviour and goals for the future. Interactions between these areas were explored.

**Conclusion:** It is possible, when using tailored communication and the methods explored in the current study, to involve some young people with learning disabilities in pre-assessment discussion

and goal setting in relation to challenging behaviour and life quality. When done in conjunction with the parental interviewing methods this has the potential to inform service delivery and increase the social validity of interventions.

**Title: The Lifespan Trajectory of Mood, Interest and Pleasure in Cornelia de Lange syndrome**

**Name:** Laura Groves [LXG502@student.bham.ac.uk](mailto:LXG502@student.bham.ac.uk)

**Affiliation:** University of Birmingham, Birmingham,

**Co-authors:** Jo Moss, Lisa Nelson, Chris Stinton, Chris Oliver

**Background:** People with Cornelia de Lange syndrome (CdLS) are often described as experiencing low mood which appears to worsen with age (Nelson et al., 2014). We aimed to assess the trajectory of mood in CdLS over a seven year follow up period and to evaluate behavioural correlates of this change.

**Method:** Caregivers of individuals with CdLS (n=44; Mage=18.39) and fragile X syndrome (FXS; n=95; Mage=17.29) completed questionnaires at Time 1 as well as 3 and 7 years later (Time 2 and Time 3). Questionnaires assessed participants' mood and interest and pleasure (IP), Autism Spectrum Disorder (ASD) symptomatology, and insistence on sameness.

**Results:** The CdLS group scored significantly lower on mood compared to the FXS group at each time point. There were no significant group differences in relation to IP at any time point ( $p > 0.05$ ). Growth curve modelling revealed mood in CdLS and FXS and IP in FXS remained stable across the lifespan, whereas IP in CdLS significantly decreased. Spearman's Rho correlations showed that the severity of repetitive behaviour was correlated with mood at Time 1, and that ASD symptomatology and insistence on sameness were significantly associated with IP. However, only ASD symptomatology and insistence on sameness remained significantly correlated with Time 3 IP scores.

**Conclusion:** Mood and IP differed in severity, trajectory and were associated with different behavioural correlates in CdLS. These findings suggest that these constructs may be dissociable in CdLS.

**Title: Physiological Arousal and Escape behaviour in Fragile X Syndrome**

**Name:** Becky Hardiman [rh432@kent.ac.uk](mailto:rh432@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Peter McGill, Alison Bratt

**Background:** Fragile X Syndrome (FXS) is the most common inherited cause of learning disability (LD). A substantial minority of males with FXS engage in challenging behaviours such as self-injurious behaviour or physical aggression. The most common social function for these behaviours has been found to be escape. It has been hypothesised that atypical or exaggerated physiological 'stress' responses to demands may lead to an increase in the reinforcing value of escape or avoidance of these demands, and so influence the likelihood of developing behaviour with an escape function.

**Method:** 24 boys with FXS and 15 children with a LD participated in this project. Participants engaged in a series of 10-minute sessions of structured academic demands with conditions which varied in difficulty and degree of eye contact during the tasks. Behaviour is being analysed during these sessions using ObsWin, including: eye contact, challenging behaviours, fidgeting, task engagement. Physiological responses to the first demand session were assessed through saliva samples (pre-demand and 5, 20 and 60 mins post-demand) and assayed for cortisol and  $\alpha$ -amylase

**Results:** Results are currently being analysed with the aim of investigating group differences in behaviour (including differences between conditions) and physiological responding to the demands. Preliminary investigations on the relation between physiology and behaviour will also be investigated.

**Conclusion:** It is hoped that these findings will help to better understand gene x environment interactions in FXS and the possible influence of atypical stress-related responding upon behaviour.

**Title: Sexual activity and sexual health among young people with and without intellectual disabilities**

**Name:** Chris Hatton [chris.hatton@lancaster.ac.uk](mailto:chris.hatton@lancaster.ac.uk)

**Affiliation:** Lancaster University

**Co-authors:** Eric Emerson, Susan Baines, Janet Robertson

**Background:** There is much concern, but little is known about the sexual activity and sexual health of young people with mild intellectual disabilities in mainstream schools

**Method:** Secondary analysis of Waves 1-7 of the Next Steps longitudinal cohort survey of 21,000 people from early adolescence to adulthood, including 527 people identified in the National Pupil Database as having Moderate Learning Difficulties.

**Results:** Overall, people with intellectual disabilities were less likely to have had sexual intercourse by age 19/20 than their peers. If they were sexually active then: (1) girls with intellectual disabilities were significantly less likely than other girls to have had their first experience of sexual intercourse below the age of 16; (2) boys and girls with intellectual disabilities were significantly more likely to commonly have unsafe sex; (3) girls with intellectual disabilities were more likely to have been pregnant; and (4) were more likely to be mothers. Although young people with intellectual disabilities were more likely to experience social and economic adversities than young people without intellectual disabilities, socio-economic variables had fewer associations with sexual activity and health for young people with intellectual disabilities than young people without intellectual disabilities.

**Conclusion:** Interventions concerning sexual activity and sexual health with adults need to be accessible to and effective for adolescents with intellectual disabilities.

**Title: Impact of carer groups for challenging behaviour**

**Name:** Cahley Hemm [Cahley.Hemm@ntw.nhs.uk](mailto:Cahley.Hemm@ntw.nhs.uk)

**Affiliation:** LDCTT, Monkwearmouth Hospital, Sunderland

**Background:** There is increasing evidence that Positive Behaviour Support (PBS) can be an effective approach for people with Intellectual Disabilities who present with behaviour that challenges. PBS emphasises a collaborative approach with carers and family members. In this study parents of adults with an Intellectual Disability and behaviour that challenges attended a two day parent training group based on the principles of PBS.

**Method:** Interviews were conducted with five parents after attendance at the parent training group. The interviews focussed on parent experiences of the group. Transcripts of the interviews were analysed using thematic analysis.

**Results:** Parents reported helpful aspects of attending the parent training group, including the opportunity to share experiences with other parents. Barriers to attending the parent training group were also discussed, including other demands, time, and location. Parents also spoke about their previous experiences of support. Wider support was discussed, including the need for both support at home and respite care.

**Conclusion:** A core principle of PBS is collaboration with carers. Information about parent experiences of support is needed to improve the care we provide for both service users and those who care for adults with Intellectual Disabilities who present with behaviour that challenges. Information from this study will inform further development of parent training groups with aim of increasing access to groups, facilitating collaboration and better supporting service users, parents and carers.



**Title: The effectiveness of Headsprout phonics-based reading intervention at improving reading in pupils with learning difficulties**

**Name:** Emma Herring [eh2g14@soton.ac.uk](mailto:eh2g14@soton.ac.uk)

**Affiliation:** University of Southampton

**Co-authors:** Corinna Grindle, Hanna Kovshoff, Rina Cianfaglione

**Background:** Education for individuals with Intellectual Disabilities (ID) has historically focused on sight-word approaches to reading. In 2000, the National Reading Panel reviewed the evidence-base and proposed that phonemic awareness and letter-sound knowledge are central skills for learning to read. Reviews by Joseph (2004) and Browder (2006) emphasised the need to implement and investigate the effectiveness of phonics-based approaches in teaching reading to individuals with ID.

**Method:** Eight participants (aged 7:07 to 19:01) attending a school for students with severe learning difficulties were recruited to use the phonics-based computerised reading intervention Headsprout for 2 sessions per week for 19 weeks. The participants were organised into three groups. Group one, consisting of four students, completed all parts of Headsprout. Group two, consisting of two students, did not complete the negation activities which gave users a complex series of instruction to follow. Group three consisted of two non-verbal students.

**Results:** All participants in group one showed positive, reliable changes in their ability to identify initial sounds of words and recall letter sounds. In group two, both participants showed reliable change in their letter-sound knowledge, one made reliable change in their initial sound skills and the second showed an improvement which was approaching the reliable change threshold. The two non-verbal participants in group three showed small improvements in word recognition but found the intervention challenging to access.

**Conclusion:** Phonics-based reading interventions can help students with ID develop their early reading skills, however access to all components of the intervention may still pose a challenge for some individuals.

**Title: Supported Self Management for adults with a mild or moderate intellectual disability and Type 2 diabetes: the OK Diabetes feasibility RCT**

**Name:** Allan House [a.o.House@leeds.ac.uk](mailto:a.o.House@leeds.ac.uk)

**Affiliation:** University of Leeds

**Co-authors:** Louise Bryant, Amy M. Russell, Alexandra Wright-Hughes, Amanda Farrin

**Background:** People with an intellectual disability have high rates of obesity and Type 2 diabetes. It is not known if supported self-management is a cost-effective strategy; the present study was designed to determine whether a Phase 3 pragmatic RCT would be feasible.

**Method:** 82 adults with a mild or moderate intellectual disability and Type 2 diabetes not using insulin were individually randomised into a feasibility RCT of supported self-management vs usual care. The intervention involved reviewing lifestyle and diabetes management, goal setting and review and included a supporter when possible. A diabetes specialist nurse visited participants' homes 3-4 times.

**Results:** Mean age of participants was 56 years; 42 (51%) were female. 58 (71%) identified a supporter who helped with day-to-day living and diabetes. Mean HbA1c was 56 (sd15.7) 56mmol/L; mean BMI 34. Participants set goals mainly for dietary change or being more physically active. Only about half had consistent input from a supporter during the trial but 77 (94%) stayed in to completion and provided outcome data. Both candidate primary outcomes (HbA1c, BMI) showed changes in the self-management group with an effect size; 0.3, indicating sensitivity to change. There were many missing data in secondary outcomes collected from GP records.

**Conclusion:** With reasonable adjustments it is possible to recruit and retain participants in an RCT. A definitive trial with 90% power (0.05) requires a sample size of 194 per arm. We estimate this would require 18-24 months recruiting from a population of 9 million.

**Title: Systematic Review of Cognitive Behavioural Therapy (CBT) for Anxiety in Individuals with a Diagnosis of a Learning Disability**

**Name:** Isabel Jackson [isabel.jackson@cumbria.nhs.uk](mailto:isabel.jackson@cumbria.nhs.uk)

**Affiliation:** Cumbria Partnership NHS Foundation Trust

**Co-authors:** Lucy Eastlake, Dave Dagnan

**Background:** The recent NICE guidance for 'Mental health problems in people with learning disabilities' identifies limited evidence for cognitive therapies for anxiety with this population. This systematic review focuses in identifying published clinical interventions in this area.

**Method:** The search strategy implemented for this systematic review was grounded in the guidance available in the Cochrane Handbook for Systematic Reviews of Interventions. Five databases were searched using terms based on concepts drawn from the research title.

**Results:** The initial search identified 3,202 possible papers. Titles, abstracts and full papers were screened and filtered according to a set of predetermined criteria leaving 18 papers to be reviewed. The majority of studies were single case designs reporting interventions with individuals with mild learning disabilities. There were a range of presenting problems, with six studies not reporting a specific anxiety presentation, five reporting PTSD, three reporting on 4 reporting on other presentations. Therapy approach varied widely with the most common cognitive technique reported being psycho-education. All but one study reported a positive outcome and six reported a significant change

**Conclusion:** CBT for anxiety with people with learning disabilities is being applied to a range of presentations; there should be further consideration of the relative effectiveness of generalised interventions for anxiety disorder compared to interventions that are specific to particular presentations.

**Title: Poor oral health in adults with intellectual disabilities and its determinants**

**Name:** Dr Deborah Kinnear [Deborah.Kinnear@glasgow.ac.uk](mailto:Deborah.Kinnear@glasgow.ac.uk)

**Affiliation:** Scottish Learning Disabilities Observatory

**Co-authors:** Jill Morrison, Linda Allan, Sally-Ann Cooper

**Background:** Adults with intellectual disabilities experience extensive health inequalities compared with the general population. There is some evidence suggesting that they also have greater dental treatment needs. They may experience poor oral health because of conditions linked with dental disease (e.g. diabetes), use of certain medications (e.g. antipsychotics) and poor dental hygiene. Oral health influences psychological wellbeing and satisfaction in the general population, and there is no reason to suggest that this is any different for people with intellectual disabilities. We investigated the prevalence and determinants of poor oral health in adults with intellectual disabilities.

**Method:** The adult population (aged 16 years and over) of people with intellectual disabilities living within the geographical area of Greater Glasgow Health Board, Scotland, were identified and recruited. Each participant underwent a dental examination. Data analysis generated descriptive statistics about the oral health of people with intellectual disabilities and determinants of poor oral health.

**Results:** 579 adults with intellectual disabilities took part twice, in 2002-2004 and 2004-2005. 309 (53.4%) males and 270 (46.6%) females aged 46 years (18-81). 31% were edentulous. Further analysis will be presented.

**Conclusion:** Using a robust study design in a large population, we reported the high prevalence of poor oral health in this population and its determinants.

**Title: Exploring the Emotion Regulation Strategies used by Adults with Intellectual Disabilities**

**Name:** Mark Littlewood [markgofly@hotmail.com](mailto:markgofly@hotmail.com)

**Affiliation:** Cumbria Partnership NHS Foundation Trust

**Co-authors:** Dave Dagnan, Jacqui Rodgers

**Background:** Emotion regulation difficulties are a common factor in the development and maintenance of numerous mental health problems in the general population and different emotion regulation strategies have different outcomes with some being more adaptive or beneficial than others. Whilst there is considerable evidence in the general populations, relatively little is known of the emotion regulation strategies used by people with intellectual disabilities.

**Method:** This study took a qualitative approach to explore the emotion regulation strategies used by adults with a mild intellectual disability in interpersonal experiences. Semi-structured interviews were conducted with 11 participants with the transcripts analysed using Thematic Analysis.

**Results:** Three main-themes and associated sub- themes were identified; regulatory talk (sub-themes 'self-talk' and 'expressing emotions in beneficial'), avoidance (sub-themes 'avoidance can be good' and 'avoidance is bad') and cognitive strategies (sub-themes 'cognitive distraction' and 'cognitive appraisal').

**Conclusion:** Participants has a repertoire of strategies to select from and were able to appropriately apply them. Participants described using individual strategies and situations that required strategies to be combined. Having the ability to choose from a variety of strategies and apply them dynamically in this manner considerably increases their effectiveness. The findings suggest emotion regulation strategies have been acquired through experience and learning; thus people with intellectual disabilities have the potential to learn emotion regulation skills given the right conditions. The study suggests that interventions focusing on improving emotion regulation skills might have potential benefits.

**Title:** **How effective are risk assessments/measures for predicting future aggressive behaviour in adults with intellectual disabilities (ID): A systematic review and meta-analysis**

**Name:** Rachael Lofthouse, [rachael.lofthouse@yahoo.co.uk](mailto:rachael.lofthouse@yahoo.co.uk)

**Affiliation:** Forensic Outreach Service, Lancashire Care NHS Trust

**Co-Authors:** Laura Golding, Vasiliki Totsika, Richard Hastings, William Lindsay

**Background:** Risk assessments assist professionals in the identification and management of risk of aggression. The present study aimed to systematically review evidence on the efficacy of risk assessments for adults with intellectual disabilities (ID).

**Method:** Electronic and hand searches identified 14 studies. Standardised mean difference effect sizes Area Under Curve (AUC) were calculated for studies. Random effects subgroup analysis was used to compare different types of risk measures, and prospective vs. catch-up longitudinal study designs.

**Results:** Overall, evidence of predictive validity was found for risk measures with ID populations: (AUC) = .702, 95% CI [0.639, 0.766]. There was no variation in the performance of different types of risk measures, or different study design.

**Conclusion:** Risk assessment measures predict the likelihood of aggression in ID population and are comparable to those in mainstream populations. Further meta-analysis is necessary when risk measures are more established in this population.

**Title:** **Safe on the Streets?**

**Name:** Alex McClimens [A.McClimens@shu.ac.uk](mailto:A.McClimens@shu.ac.uk)

**Affiliation:** Sheffield Hallam University

**Co-author:** Jacqui Brewster

**Background:** People with intellectual disability are now established within their local communities. This can mean that some individuals are subject to increasing levels of anti-social, criminal and discriminatory behaviours and practices. The legal category of hate crime is a recent legislative

response to this phenomenon. Here we report on an evaluation of one English city's efforts to instigate a street-based scheme to offer some security and protection to its intellectually disabled citizens.

**Method:** We made unannounced visits to 26 of the premises signatory to the scheme to check on their awareness, knowledge and implications of their membership. The visits took place on six occasions in late 2015. We approached staff, acting as members of the public, curious about the scheme. We asked what it was and gauged their responses

**Results:** Collaboration between the police, the local authority and the scheme's managers would produce evidence on its uptake, the locality of any incidents and provide an opportunity to establish any patterns of behaviour. There is also a need for sharing of best practice.

**Conclusion:** Collaboration between the police, the local authority and the scheme's managers would produce evidence on its uptake, the locality of any incidents and provide an opportunity to establish any patterns of behaviour. There is also a need for sharing of best practice.

### **Title: An Organisational Approach to Reducing Restrictive Practices for People with Intellectual Disabilities**

**Name:** Anne MacDonald [amacdonald@trfs.org.uk](mailto:amacdonald@trfs.org.uk)

**Affiliation:** The Richmond Fellowship Scotland

**Background:** Challenging behaviour is common for many people with intellectual disabilities and has a negative impact on the lives of these individuals. It is linked to the use of restrictive interventions, such as physical restraint, seclusion and psychotropic medication. Following the Winterbourne abuse scandal, there is an obligation on care organisations to record and monitor any use of restrictive interventions. In particular, the Department of Health report, Positive and Proactive Care (2014) spells out a number of key actions in order to reduce use of restrictive interventions with individuals with intellectual disabilities.

**Method:** An organisational initiative based on the principles contained in Positive and Proactive Care was launched by a large social care provider in Scotland. This included a new policy and procedure, as well a programme of training on the legal and ethical implications of restrictive interventions, which was delivered to over 300 managers. An awareness-raising programme was also held with Executive Directors and at board level. A systematic process for reducing restrictive interventions was introduced across the organisation.

**Results:** 2 years on from the introduction of this initiative, data from results will be presented and themes discussed. In addition, lessons learned about how best to implement a structured restraint reduction programme within a large care organisation will be shared.

**Conclusion:** Successful implementation of the recommendations in Positive and Proactive Care requires a full organisational commitment in order for restrictive interventions to be successfully reduced. Restrictive intervention reduction programmes must be rooted in a context of Positive Behavioural Support.

### **Title: Autism Spectrum Conditions and Offending: A Systematic Review of Treatment**

**Name:** Clare Melvin [clm34@kent.ac.uk](mailto:clm34@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Peter Langdon, Glynis Murphy

**Background:** Theoretical suppositions suggest a potential vulnerability in individuals with autism spectrum conditions (ASCs) to offending, with possible barriers to treatment from the features of ASCs. A systematic review was conducted to identify empirical evidence and examine the effectiveness of treatment programmes for offenders with ASCs.

**Method:** Search terms covering ASCs, offending and treatment/therapy were used to identify existing literature. Research studies meeting specific inclusion/exclusion criteria were included and the Mixed Methods Appraisal Tool (MMAT) was used for quality evaluation.

**Results:** A small body of literature on ASCs and offending was identified, with little empirical evidence found. Case studies emphasised the role of ASCs in offending, with some examples of barriers to treatment. However these aspects were not measured or quantified, and there was little or no direct comparisons to offenders without ASCs.

**Conclusion:** The influence of ASCs in offending and any potential impact on treatment is yet to be assessed in any systematic or controlled way. This review highlights the need for further research in this area, particularly as treatment outcomes can be influential in care pathway/discharge planning.

**Title:** [Adapted sex offender treatment programmes for men with autism spectrum conditions: clinician and service user views](#)

**Name:** Clare Melvin [clm34@kent.ac.uk](mailto:clm34@kent.ac.uk)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Glynis Murphy, Peter Langdon

**Background:** Difficulties with social interaction, social communication and victim empathy may create barriers to treatment for those few individuals with autism spectrum conditions (ASCs) who commit sexual offences. This research explored offender and clinician views of the effectiveness of adapted sex offender treatment programmes for men with ASCs.

**Method:** Semi-structured interviews were conducted with men with ASCs who have completed an adapted sex offender treatment programme to explore their views and experience of the treatment. Clinician interviews were also undertaken to ascertain their opinion on the effectiveness of the treatment for the individual with ASC and, in general, for men with ASCs who sexually offend.

**Results:** The clinician and offender interviews highlighted some of the complexities of treating individuals with ASCs, such as difficulties with victim empathy and the need for external management of risk behaviours. The data gathered provides support to existing literature on the challenges presented by the cognitive and behavioural profile associated with ASCs to the treatment of sexual offending behaviours, however the findings also illustrate a number of similarities between men with ASCs who sexually offend and those with learning disabilities alone.

**Conclusion:** These results contribute to a developing evidence-base addressing the question of whether the treatment needs of men with ASCs are met by existing adapted sex offender treatment programmes.

**Title:** [Facilitators and barriers to the physical activity participation of children with intellectual disabilities: a systematic review of parental perceptions and correlates](#)

**Name:** Arlene McGarty [Arlene.McGarty@glasgow.ac.uk](mailto:Arlene.McGarty@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Victoria Penpraze, Mark Kelson, Craig Melville

**Background:** Physical inactivity is a major worldwide health concern, with many children with intellectual disabilities at risk from negative health outcomes due to inactivity. Hence, the promotion of active lifestyles in this population is ever-increasing. Evidence in line with the socio-ecological model illustrates parents of typically developing children have a “gatekeeper” role in promoting childhood activity. However, little is known about the influence of parents on the physical activity levels of children with intellectual disabilities. Therefore, this study aims to systematically review qualitative and quantitative studies to identify parental factors or perceived factors which are facilitators and barriers to physical activity for children with intellectual disabilities.

**Method:** EMBASE, MEDLINE, Web of Science, ERIC, and Google Scholar were searched up to and including February 2016. Studies were included if they: 1) reported qualitative data from parents of

children with intellectual disabilities regarding facilitators and barriers to their child being active, or 2) measured parental factors correlating with their child with intellectual disabilities physical activity levels. Screening, data extraction, and quality assessment were independently conducted by two researchers. Qualitative data were interpreted using a meta-ethnography approach and a narrative synthesis used to report the quantitative findings.

**Results:** The search identified 2146 studies. Ten full-text articles met the criteria and were included in the review. Results will be presented for the third-order themes generated from the meta-ethnography and the parental correlates extracted from the quantitative studies.

**Conclusion:** Results will be discussed in relation to previous research and future implications.

**Title: Preparing Adult Nursing students to be better equipped to work with people with intellectual disabilities and those who support them**

**Name:** Isla McGlade [Isla.mcglade@gcu.ac.uk](mailto:Isla.mcglade@gcu.ac.uk)

**Affiliation:** Glasgow Caledonian University

**Co-authors:** Mark Gallagher, Dianne Willis

**Background:** Students from Glasgow Caledonian University and University of Glasgow attended a two day event of interactive presentations. In addition students from UoG were offered an additional two days in a third sector intellectual disability setting

**Method:** Participants Year 1 Adult Nursing students (n=48) from UoG and Year 1 Intellectual Disability Nursing students from Glasgow Caledonian University- data collection evaluation forms. Analysis descriptive statistics and thematic analysis. Ethical approval granted from both HEIs

**Results:** 55% completion rate, Increased knowledge reported of services, information and roles. Valued talks from users and carers.

**Conclusion:** Exposure to services for pwld can increase awareness for staff not trained in this area. Increased confidence.

**Title: Talking about Learning Disability: The development of a school based resource to reduce the bullying of people with learning disabilities**

**Name:** Roseann Maguire [roseann.maguire@gla.ac.uk](mailto:roseann.maguire@gla.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Andrew Jahoda, Alastair Wilson

**Background:** Despite longstanding attempts to promote the inclusion of people with learning disabilities in mainstream school settings, these young people continue to be some of the most socially excluded and bullied pupils in the school system (DSCF, 2010, Naylor et al, 2012). Furthermore, many adults with learning disabilities who are victims of hate crime e groups living in the wider community report that the perpetrators are young people (Lemos and Crane, 2012). This poster describes the development of a school-based resource for secondary school pupils aimed at counteracting bullying by promoting understanding and acceptance of people with learning disabilities.

**Method:** Three forms of enquiry informed its development: A literature review of generic anti-bullying intervention; A review of current practice; and, Case studies, capturing the experiences of young people with learning disabilities and their families and schools which had tackled the issue.

**Results:** The evidence suggested that we needed a resource with a broader focus than bullying alone. While reactive interventions may address some of the issues that arise for young people with learning disabilities there remains a need to tackle prejudicial bullying. Research studies that have looked at young people's acceptance of peers with learning disabilities suggest that a good way to challenge discriminatory views is to increase young people's awareness of the particular difficulties their peers face (Fredrickson,2010).



**Conclusion:** Whilst an anti-bullying message is at the core of the resource we developed, our starting point is 'talking about difference' and an aim to reduce the social gap between young people with and without learning disabilities.

**Title: Living circumstances and health of people with learning disabilities**

**Name:** Joanna Miler [Joanna.Miler@glasgow.ac.uk](mailto:Joanna.Miler@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Myrthe Jacobs, Sally-Ann. Cooper

**Background:** People with learning disabilities experience poorer physical and mental health than the general population. This study investigates whether living conditions and their changes over time are different for people with learning disabilities compared to the general population, and whether these are related to general health status.

**Method:** Secondary data analysis using the Scottish Longitudinal Study, which links information obtained on 5% of the population at Scotland's Census 2011 with their information at Census 2001 and Census 1991. Matched-control design (age, sex) with 4 matches per person with learning disabilities. Learning disabilities and general health status were identified from responses to the questions at Census 2011. The study recently commenced; this poster describes the aims and methods in more detail.

**Results:** 993 individuals had learning disabilities and a record in both Scotland's Census 2011 and at least one of Census 2001 and Census 1991. 136 (13.7%) lived in communal establishments in 2011. 103/735 (14.0%) people with learning disabilities were living in communal establishments in 1991 and 114/923 (12.4%) in 2001. Further details will be presented on living circumstances, and its relationship to health.

**Conclusion:** It is important to identify the factors that impact on health that might be improved. The 20 year longitudinal study design allows residential types and movement to be tracked and linked to health status.

**Title: Trends in antipsychotic prescribing in children and young people with autism and/or learning disabilities in Scotland, between 2009 and 2013**

**Name:** Marian Okon [Marian.Okon@glasgow.ac.uk](mailto:Marian.Okon@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Sally-Ann Cooper, Angela Henderson, Mike Flemming, Daniel McKay, Jill Pell

**Background:** A small number of studies have reported high rates of antipsychotic prescribing in children and young people with challenging behaviours. However, no study has been found to analyse the rates of antipsychotic prescribing for children and young people with intellectual disabilities and/or autism, compared to the rates in the general population. This study will analyse trends in the rate of antipsychotic prescribing in children and young people with intellectual disabilities and/or autism between 2009 and 2013 in Scotland.

**Method:** The 'Pupil Census' which consist of information from publically funded primary, secondary and special schools in Scotland and the 'Prescribing Information System' which contains information on all children and young people who have received antipsychotic drugs will be linked and used for this study. The association between antipsychotic prescribing in children and young people with autism and/or learning disabilities and in those without additional support needs will be examined using logistic regression models.

**Results:** Data collation and linkage is ongoing. On completion, descriptive statistics for key variables such as age, additional support provided, number and class of antipsychotic prescription as well as odds ratios will be reported.

**Conclusion:** The substantial health impacts of antipsychotic medications are well documented. This study will provide valuable longitudinal evidence on the use of antipsychotic medications in children

and young people with intellectual disabilities and/or autism compared to those without additional support needs. Comparison of prescribing practices across Scottish health boards will enable targeted action to ensure that antipsychotic prescribing is in line with good clinical practice.

**Title:** Life expectancy and causes of death of people with Down Syndrome: a systematic review

**Name:** Lisa O'Leary [Lisa.O'Leary@glasgow.ac.uk](mailto:Lisa.O'Leary@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Kirsty Dunn, Laura Hughes-McCormack, Sally-Ann Cooper

**Background:** People with Down Syndrome are thought to have a lower life expectancy and different cause of death profile compared to the general population. A systematic review was undertaken to evaluate this evidence.

**Method:** The review was registered with the International Prospective Register of Systematic Reviews. Five electronic databases were searched for key words relating to Intellectual disability/Down Syndrome AND death. Titles, abstracts and full papers were assessed using strict inclusion/exclusion criteria. 5% were assessed by a second researcher. Information from the eligible studies was extracted, tabulated and reviewed using narrative analysis.

**Results:** 35/17,828 potentially relevant articles met the inclusion criteria. Down Syndrome life expectancy was up to 28 years lower than the general population. Life expectancy increased at a faster rate over time in the Down Syndrome population, compared to the general population. Infant mortality was significantly higher in the Down Syndrome population. Low birth weight, congenital heart defect, black and minority ethnicity, and comorbidities were associated with lower life expectancy and higher mortality rates. Respiratory illness and congenital heart anomalies were the leading causes of death in most studies, and more common than in the general population. Most studies were limited by relying on administration data, and death certificates (known to have potential inaccuracies), and not undertaking age gender matched general population comparisons.

**Conclusion:** People with Down Syndrome have a shorter life expectancy, and a different cause of death profile than the general population, but robust comparative data is surprisingly lacking. The Scottish Learning Disabilities Observatory is investigating this further.

**Title:** Divorce in families with different disability diagnoses compared to typically developing families

**Name:** Linda O'Neill [Loneill@chester.ac.uk](mailto:Loneill@chester.ac.uk)

**Affiliation:** University of Chester

**Co-author:** Lindsay Murray

**Background:** This study examined whether there are differences in parental divorce rates in families with a disabled child and whether disability type could predict parental divorce. Age at divorce, contact and parental education levels were also considered.

**Method:** Individuals with Down's syndrome (DS, n = 59), Autism (ASD, n = 31), Prader-Willi syndrome (PWS, n = 26) and undiagnosed (n = 16) were compared to a closely-matched control group (n = 132, females = 75.8%) to examine if disability type could predict parental divorce.

**Results:** Tukey's post hoc analysis showed that PWS and ASD reported significantly higher levels of parental divorce than DS. Around 60% of all absent parents remained in contact and this remained constant between groups. Parental education was significantly higher in DS than in those who remain undiagnosed and the control. There was a significant inverse prediction of parental divorce in DS. There was a non-significant trend predicting parental divorce in the ASD group.

**Conclusion:** Disability type has a significant impact upon the well-being of the family unit. Interestingly, having DS has a negative predictive effect upon parental divorce and the child is older if divorce does occur. It is not clear if this ameliorative effect is something within the nature of the child with DS or if it is due to the parents having higher educational attainment and therefore

perhaps better able to deal with problematic situations. Contrary to anecdotal evidence families who have a child with ASD are no more likely to divorce than the rest of the population.

**Title:** [Everyday lives: exploring the experiences of people with a learning disability in the early stages of the new Social Services and Wellbeing Act \(2014\) Wales – Challenges when developing a systematic review protocol.](#)

**Name:** Daron Owens [sop80b@bangor.ac.uk](mailto:sop80b@bangor.ac.uk)

**Affiliation:** Bangor University

**Background:** The purpose of the research is to explore the impact of the new Act in terms of safeguarding and protection and the effect this may have on promoting greater independence for people with learning disabilities.

**Method:** Since beginning the project in July 2016, the focus has been on developing a protocol for a systematic review. Using the SPICE framework, two detailed review questions were developed. Inclusion and exclusion criteria were considered and key terms have been discussed and refined. The development of the search strategy is ongoing.

**Results:** The main challenges were: A) Searching for relevant studies -it became apparent that identifying qualitative evidence can be problematic with the sole reliance of electronic databases. Consequently it was decided to also rely on searching grey literature and hand-searching journals and bibliographies in addition to contacting experts in the field. B) Deciding on a method of synthesis as discussion of systematic review methods for qualitative research is limited. Therefore, thematic synthesis was selected as a tried and tested method (Thomas & Harden, 2008).

**Conclusion:** The findings from the systematic review will inform the second phase of the PhD. Mapping the field to discover what information is already available has proved especially important for this particular project, as information is scarce considering the timeframe since the implementation of the Act.

**Title:** [Development and validation of the Learning Disabilities Needs Assessment Tool \(LDNAT\), a HoNOS-based needs assessment tool for use with people with intellectual disability](#)

**Name:** Jon Painter [J.Painter@shu.ac.uk](mailto:J.Painter@shu.ac.uk)

**Affiliation:** Sheffield Hallam University

**Co-authors:** Liam Trevithick, R. Hastings, B. Ingham, A. Roy

**Background:** In meeting the needs of individuals with intellectual disabilities (ID) who access health services, a brief, holistic assessment of need is useful. This study outlines the development and testing of the Learning Disabilities Needs Assessment Tool (LDNAT), a tool intended for this purpose.

**Method:** An existing mental health (MH) tool was extended by a multidisciplinary group of ID practitioners. Additional scales were drafted to capture needs across six ID treatment domains that the group identified. LDNAT ratings were analysed for the following: item redundancy, relevance, construct validity and internal consistency (n =1692);test–retest reliability (n = 27); and concurrent validity (n =160).

**Results:** All LDNAT scales were deemed clinically relevant with little redundancy apparent. Principal component analysis indicated three components (developmental needs, challenging behaviour, MH and well-being). Internal consistency was good (Cronbach alpha 0.80). Individual item test–retest reliability was substantial-near perfect for 20 scales and slight-fair for three scales. Overall reliability was near perfect (intra-class correlation =0.91). There were significant associations with five of six condition-specific measures, i.e. the Waisman Activities of Daily Living Scale (general ability/disability), Threshold Assessment Grid (risk), Behaviour Problems Inventory for Individuals with Intellectual Disabilities-Short Form (challenging behaviour) Social Communication Questionnaire (autism) and a bespoke physical health questionnaire. Additionally, the statistically significant correlations between these tools and the LDNAT components made sense clinically. There

were no statistically significant correlations with the Psychiatric Assessment Schedules for Adults with Developmental Disabilities (a measure of MH symptoms in people with ID).

**Conclusion:** The LDNAT had clinical utility when rating the needs of people with ID prior to condition-specific assessment(s). Analyses of internal and external validity were promising. Further evaluation of its sensitivity to changes in needs is now required.

**Title: Risk factors for injuries for adults with learning disabilities who live with paid support in Scotland**

**Name:** Evangelia Petropoulou [Evangelia.Petropoulou@gcu.ac.uk](mailto:Evangelia.Petropoulou@gcu.ac.uk)

**Affiliation:** Glasgow Caledonian University

**Co-authors:** Janet Finlayson, Dawn Skelton

**Background:** Adults with learning disabilities (LDs) experience higher rates of injury compared to the general population with falls (the commonest cause of injury in this population) occurring at a younger age than the general population. There is limited research exploring risk factors for injuries and fall-related injuries among people with learning disabilities. Providers of supported living services to adults with LDs in the UK have procedures in place to monitor injuries; this provides the opportunity to learn more about the risk factors of injuries in this population.

**Method:** Three service providers in Scotland operate a standard electronic injury reporting and recording system. Injury data for 536 adults with LDs who live with paid support was collected from these service providers and analysed retrospectively. Sixty-four potential risk factors were examined, and potential predictors were identified using univariate analysis and entered into a multiple logistic regression.

**Results:** The adults with LDs experience a higher rate of injury. Almost half the sample (n=266; 49.6%) were injured at any time, and almost 50% of injuries were caused by falls. Logistic regression showed that poor coordination, polypharmacy, heart condition, special aids in bathroom, being female were, among others, statistically significant associated with an increased rate of injuries.

**Conclusion:** Our findings revealed a number of significant injury risk factors which are important considerations in the strategy for effective injuries intervention in this population. Further research is needed to develop assessment tools and prevention strategies.

**Title: Early findings from the Autism Spectrum Cohort-UK: Adults' mental health**

**Name:** Alexander Petrou [Alexander.Petrou@newcastle.ac.uk](mailto:Alexander.Petrou@newcastle.ac.uk)

**Affiliation:** Newcastle University

**Co-authors:** M. McConachie, H. Le Couteur, A. Ingham, B. Hamilton, J. Berney, T. Garland, D Parr,

**Background:** The Adult Autism Spectrum Cohort–UK (ASC-UK) is a longitudinal research project aiming to investigate the life experiences of adults on the autism spectrum. We examined the mental health/neurological health of autistic adults and its association with employment status.

**Method:** Adults were recruited through health teams, voluntary sector organisations, and the autism community. They completed questions on their current mental/neurological health and their employment status. By July 2016, 576 adults had joined ASC-UK (males=319, females=245, other gender=12; median age=38 years, range=17-86; 16-25 years=123, 26-40 years=192, 41-60 years=217, 61+ years=44).

**Results:** Autistic adults reported high rates of depression (46.9%), anxiety (49.7%), ADHD (12.2%), OCD, (10.2%), and bipolar disorder (4.7%). 71.9% reported that they had previously tried to access services, of whom 40.6% reported accessing the necessary services. Reasons for not accessing services they needed included a lack of available services and of referral route into services. Mental health/neurological conditions were not associated with employment status in autistic adults aged 16-25, 26-40 and 61+ years. However, a key finding was that unemployed autistic adults aged 41-60

years reported more mental health diagnoses than those who were employed (Mann-Whitney  $U=2350.5$ ,  $z=-4.2$ ,  $p=.000$ ).

**Conclusion:** Mental health/neurological conditions are common in autistic adults who, despite trying to access services, have difficulty getting the services that they need. Employment may be relatively protective for autistic adults between 41-60 years of age. Advice to employers and mental health intervention availability may be particularly helpful to prevent individuals dropping out of employment in their 40s and 50s.

**Title: A school based intervention to promote positive attitudes towards and social inclusion of children with intellectual disabilities: A feasibility and pilot study**

**Name:** Maria Qureshi [maria.qureshi.10@ucl.ac.uk](mailto:maria.qureshi.10@ucl.ac.uk)

**Affiliation:** University College London

**Co-author:** Katrina Scior

**Background:** The study aimed to develop a complex intervention to change attitudes towards and improve social inclusion of children with SEND; evaluate the feasibility of implementing the proposed intervention in a primary school setting; and explore the process of implementing the intervention, including identifying barriers to facilitation.

**Method:** The intervention was delivered to 117 children across four classes in a primary school over five weeks. The children engaged in activities that helped raise their awareness of intellectual disabilities, develop empathy, and build their confidence and self-efficacy. Measures of peer-acceptance, self-efficacy and peer interaction networks were completed at baseline, post intervention, and at two-month follow-up. Interviews were also conducted with teachers alongside classroom discussions to gain feedback on the intervention.

**Results:** The intervention was deemed feasible as determined through recruitment and retention of pupils, and completion of measures. Preliminary outcomes found no changes on the self-efficacy scale, and modest changes on the peer acceptance scale which were not sustained at follow-up. Qualitative interviews with teachers found the intervention challenged perceptions but required further revision to improve effectiveness including delivery by teachers that would allow scope for sharing personal stories. Analysis of classroom discussions showed children enjoyed the opportunities for active learning and learned valuable lessons, but would welcome greater variety and more opportunities for joint working.

**Conclusion:** The study successfully designed a complex intervention, the implementation of which was feasible. Although the preliminary findings showed modest change was not sustained over time, a number of process issues were identified to aid further development.

**Title: Community led ANti-psychotic Drug REduction for Adults with Learning Disabilities (ANDREA-LD): non-efficacy based barriers to withdrawal**

**Name:** Elizabeth Randell [randelle@cardiff.ac.uk](mailto:randelle@cardiff.ac.uk)

**Affiliation:** Cardiff University

**Co-authors:** Rachel McNamara, Fiona Wood, David Gillespie, Kerry Hood, Michael Kerr

**Background:** Antipsychotic prescribing rates for challenging behaviour in adults with learning disability (LD) cluster around 50%, yet effectiveness has not been demonstrated for this indication. Results reported here are taken from a qualitative sub-study within a pilot trial of a blinded antipsychotic withdrawal programme for adults with LD without psychosis, to explore non-efficacy based barriers to withdrawal.

**Method:** Qualitative interviews (face-to-face or telephone) were carried out 4-6 months post-randomisation with 16 carers, 7 clinicians and 4 patients. All interviews were audio-recorded, transcribed, anonymised and analysed using thematic analysis facilitated by NVivo.

**Results:** Results suggest that all stakeholders agreed this is an important research question, that study procedures were acceptable, and that support from the research team was good. Issues that caused more concern included: consenting arrangements (carers' concerns about acting as a personal legal representative), whether the study inclusion criteria were appropriate (e.g. whether to include participants with autism) and the size of the study medication. Some carers also reported that participants experienced a number of negative behaviours during the study period. However, these behaviours were not always attributed to drug reduction and many were not new within the study period.

**Conclusion:** There remain significant barriers to reducing medication in this population despite stakeholder agreement that potential overuse of antipsychotics needs to be addressed. However, carer perceptions around impact of withdrawal were not necessarily related to arm allocation. Stakeholders' views of trial participation were on the whole positive, indicating that trials in this population are feasible.

**Title: A systematic review of resilience in adults with an intellectual disability**

**Name:** Elizabeth Raye [e.a.raye@wlv.ac.uk](mailto:e.a.raye@wlv.ac.uk)

**Affiliation:** University of Wolverhampton

**Co-author:** Darren Chadwick

**Background:** Resilience, a dynamic psychological process of positive adaptation in the context of significant adversity, is seen as a key element in maintaining wellbeing. Adverse life-events can negatively affect wellbeing and research suggests that people with intellectual disabilities experience higher rates of trauma than their non-disabled counterparts. Despite this, resilience is still under researched in the intellectual disability population.

Research has begun to explore resilience in this population with focus on the role of environmental and social aspects of resilience. Dispositional approaches to resilience which have prevailed in traditional resilience research ignore these factors, disadvantaging people with intellectual disabilities and making it impossible for them to be perceived as resilient. This systematic review collects all evidence to date about resilience in people with intellectual disabilities.

**Method:** An electronic database search was performed using EBSCO and Web of Science. Searches combined terms for intellectual disabilities and resilience. Results were reviewed by both researchers and 12 empirical studies and 9 non-empirical papers were selected.

**Results:** Themes generated from the review of the articles were 'Risk factors associated with resilience' and 'Factors associated with promoting or building resilience'. The review also reflects on the notion of positive risk taking and overprotection in this population which may serve to inhibit the development of resilience.

**Conclusion:** The review discusses a need for reframing of the concept of resilience to be more inclusive of people with intellectual disabilities. This review will inform a series of studies into the way people with intellectual disabilities understand and experience resilience themselves.

**Title:** Vision Champion training for learning disabilities health professionals: A qualitative evaluation

**Name:** Nicola Robinson [Nicola.Robinson@ggc.scot.nhs.uk](mailto:Nicola.Robinson@ggc.scot.nhs.uk)

**Affiliation:** NHS Greater Glasgow and Clyde

**Co-authors:** Joanne Dick, June Neil, Janet Finlayson

**Background:** As part of a training initiative to increase awareness of the vision needs of people with learning disabilities amongst health and social care professionals, people with learning disabilities and their family or paid carers, RNIB has been providing practical Vision Champion training to community learning disabilities health professionals in the Greater Glasgow and Clyde area. RNIB has trained 18 of these Vision Champions.



**Method:** Of 18 Vision Champions who were trained during the evaluation period, 10 (56%) chose to take part in qualitative interviews 3 months after they had completed their training, to share their views and experiences of training outcomes, for themselves and for their clients with learning disabilities. Qualitative data was analysed using content analysis.

**Results:** Vision Champions felt that the main benefit of their training was that, it helps them think more deeply about vision when assessing their clients' needs. They also felt that the training was helpful for considering visual problems as possible reasons for behaviours that challenge. Vision Champion training helped these professionals to be more confident, and more likely to challenging existing attitudes and practices. In terms of outcomes for their clients with learning disabilities, Vision Champion training enabled professionals to conduct a more comprehensive assessment of their vision needs; from modifying the environment to ensuring they were wearing their correct glasses, and from reducing behavioural issues to preventing falls.

**Conclusion:** Vision Champion training for community health professionals has demonstrable positive outcomes for both the professionals themselves, and importantly, their clients with learning disabilities. More work is needed however, to understand and maximise the Vision Champion role with community learning disabilities teams.

**Title: Understanding the support needs and priorities of people with intellectual disabilities from minority ethnic groups: Topics of concern and resources for services**

**Name:** John Rose [j.l.rose@bham.ac.uk](mailto:j.l.rose@bham.ac.uk)

**Affiliation:** University of Birmingham,

**Co-authors:** Gemma Unwin, Michael Larkin, Biza Kroese

**Background:** Adult social care survey data suggests that people from minority ethnic groups are less likely to be accessing or satisfied with social care services. Family carers often express some dissatisfaction with existing social care services however there has been little research that access the views of people with ID themselves. This research aimed to discover the views of individuals with ID about social care services and develop a set of materials to facilitate discussions about service access and delivery.

**Method:** Semi structured interviews were conducted with 32 adults with ID from minority ethnic groups and they were transcribed verbatim and analysed using a phenomenologically informed approach.

**Results:** Five key areas of analysis were identified. People were generally satisfied with their support but were able to reflect on the quality of their support and the nature of their support. Participants identified themselves as having complex identities. A range of tools were developed from the stories told by participants to support a culturally sensitive person centred dialogue about service planning. These were used and refined within a partnership event with service users.

**Conclusion:** The analysis suggested that the participants were not as dissatisfied with services as previous research would suggest however, there was scope for improved communication. The tools that were produced are available to develop a dialogue and improve understanding between people with ID and their care providers.

**Title: Measuring Quality of Life in Adults with Type 2 Diabetes Mellitus and Intellectual Disability: experience from the OK Diabetes study**

**Name:** Amy Russell [a.m.russell@leeds.ac.uk](mailto:a.m.russell@leeds.ac.uk)

**Affiliation:** University of Leeds

**Co-authors:** Louise Bryant, Allan House, John O'Dwyer, Claire Hulme

**Background:** To mainstream intellectual disability (ID) research it is important to assess the feasibility of using standardised measures, assessing meaning and relevance for people with an ID. A

good example is quality of life measures, used to derive QALYs. One of the most commonly used measures is EQ5D, which we used in a feasibility RCT with people with an ID and type 2 diabetes.

**Method:** Observational study in West Yorkshire (2013 to 2016). Qualitative interviews and post interview journals exploring experience of EQ-5D in context of an RCT.

Participants were 18+ years old, with T2DM (not on insulin) with a mild to moderate ID, not living in a hospital. Data were collected by a researcher completing ease of use questions and producing a journal of experiences for a sample of participants. Content analyses was used on ease of use data and thematic analysis on journal data.

**Results:** Over a third of participants experienced difficulty completing the EQ-5D. The most common problems were terminology used, conflicts with supporter perceptions of ability and EQ-5D examples being incompatible with a person's life.

**Conclusion:** This talk outlines a key point in ID research; we want to get ID research into the mainstream and to do this we have to make reasonable adjustments. Standardised measures like EQ-5D are not readily understandable and they do not allow for modification of the questions. Thus they are currently exclusionary and need further research to suggest alternatives that are both standardised and capture meaningful aspects of participants' lives.

### **Title: Demographics of people with intellectual disabilities in Scotland. A whole country cohort study**

**Name:** Ewelina Rydzewska [ewelina.rydzewska@glasgow.ac.uk](mailto:ewelina.rydzewska@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Laura A. Hughes-McCormack, Angela Henderson, Sally-Ann Cooper

**Background:** At the level of the whole population, little is known about the characteristics of people with intellectual disabilities (ID). For the populations with and without ID in the whole of Scotland, this study investigated the following demographic factors 1) age and gender distribution 2) employment 3) housing 4) family environment 5) other characteristics such as country of birth, ethnic group and language spoken.

**Method:** We analysed Scotland's 2011 Census data, and generated descriptive statistics about people with and without ID.

**Results:** People with ID (n=26,349) comprised 0.5% of the total population of Scotland (n=5,295,403). There were 15,149 (57.5%) males and 11,200 (42.5%) females, and 5,234 (19.9%) children aged 0-15 and 21,115 (80.1%) adults aged 16+ with self-reported ID. 11.6% of people with ID were in paid employment and 51.6% lived in socially rented households compared respectively with 58.0% and 21.5% of people without ID. 37.2% of people with ID of all ages were a member of a single parent family (33.9% being a child aged 0-15 and 3.3% a parent), compared with 17.5% of people without ID (10.5% being a child and 7.0% a parent). Most people with ID (97.2%) were born in the UK, similar to the population without ID (93.0%). They were also mostly white (97.4%) compared with 96.0% of the population without ID. The majority lived in a home where English was spoken (90.29%), compared with 92.6% of the population without ID.

**Conclusion:** People with ID were less likely to be in employment, but more likely to live in socially rented accommodation. The Scottish Learning Disabilities Observatory is investigating this further.

### **Title: Predictors of Self-Determination in Transition-Age Individuals with Mild to Moderate levels of Intellectual Disability: A Systematic Literature Review**

**Name:** Emily Salt [e.salt.1@research.gla.ac.uk](mailto:e.salt.1@research.gla.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Andrew Jahoda, Craig Melville

**Background:** Self-determination is considered by both policy-makers and practitioners alike to be a key transition outcome for young adults with intellectual disabilities. The aim of this systematic

review was to find and analyse all quantitative studies that investigate the predictors of self-determination specific to 16 to 30 year olds with mild to moderate intellectual disabilities.

**Method:** Five databases produced 774 papers once duplicates had been removed. Title and abstract screening excluded 731 papers, leaving 43 papers for full article analysis. Three papers were included in the final data synthesis.

**Results:** Global self-determination was significantly associated with five variables: physical intensity of leisure activities, duration of recreation activity, total time in recreation, IQ, and intellectual impairment level. Of the four subscales of self-determination, self-regulation was predicted by physical intensity of leisure activities, total time in recreation, and IQ.

Psychological empowerment and behavioural autonomy were also both predicted by IQ, as well as academic achievement. No variables were shown to predict self-realization.

**Conclusion:** Despite being commonly referred to as one of the most heavily researched populations in the self-determination field, there is a deficit of descriptive studies that report predictive data that is specific to young adults with intellectual disability. Though additional correlative research has been undertaken in mixed age and disability samples, the potential for conflation between these different groups is significant. Until the most salient predictors for this population have been discovered, the potential efficacy of interventions designed to increase self-determination in this age group will no doubt remain limited.

**Title:** [The applicability of the Assessment of Motor and Process Skills \(AMPS\) in a dementia assessment protocol within a Scottish Intellectual Disability service](#)

**Name:** Emilly Scott [emillyscott@hotmail.co.uk](mailto:emillyscott@hotmail.co.uk)

**Affiliation:** University of Edinburgh

**Co-authors:** Kenneth MacMahon, Sarah Broxholme

**Background:** People with an intellectual disability are at an increased risk of developing dementia, however, there is no standard dementia assessment protocol used within the UK for this population. As part of an evaluation, an assessment of functional skills such as the Assessment of Motor and Process Skills (AMPS) may be utilised, although there is, as yet, no evidence on its applicability for this purpose. The primary aim of the study was to ascertain whether it is clinically useful to include the AMPS in one dementia assessment protocol. The secondary aims sought to examine whether the AMPS showed concurrent validity with other measures and to discover which of the protocol measures was most strongly correlated with diagnostic outcome.

**Method:** Data from one intellectual disability service from 2000 to 2009 was analysed with the focus being the use of the AMPS within this protocol. The AMPS comprises two elements, motor and process, and is used to assess an individual's ability to carry out daily living tasks. Data was gathered from case records of 29 individuals with intellectual disabilities who received assessments for dementia. Twelve records were discarded due to incomplete datasets.

**Results:** The process element of the AMPS neared statistical significance when correlated with diagnostic outcome.

The AMPS motor scores showed concurrent validity with the Learning Disabilities Dementia Battery (LDDDB), which was shown to correlate with diagnostic outcome.

**Conclusion:** The study provides some limited support for the use of AMPS in the diagnostic process for dementia in this population.

**Title:** [Recruitment challenges: conducting a large scale randomised controlled trial of individual psychotherapy for adults with intellectual disabilities](#)

**Name:** Katie Scott [Katie.Scott@glasgow.ac.uk](mailto:Katie.Scott@glasgow.ac.uk)

**Affiliation:** University of Glasgow

**Co-authors:** Andrew Jahoda, Kim Appleton, Dawn Knowles, Chris Hatton

**Background:** Despite the high prevalence of mental health problems in individuals with intellectual disabilities, there is a paucity of evidence-based psychological interventions. There have been few large scale randomised trials of psychological therapies for people with intellectual disabilities. This is due, in part, to the perceived challenges of recruiting to large-scale randomised trials. This poster concerns recruitment to a randomised control trial of behavioural activation for depression.

**Method:** Recruitment data was systematically collected throughout the course of the Beat-it trial. The Beat-it trial is a multi-centre single-blind randomised controlled trial comparing a behavioural activation intervention to a guided self-help attention control for the treatment of depression in adults with mild/moderate intellectual disabilities. Therapy was delivered to the client with an intellectual disability alongside a significant other in their life, who acted as a 'supporter'.

**Results:** Target recruitment was almost reached, with 161 participants randomised. Moreover, the cumulative totals increased steadily over the recruitment period. However, this belied the difficulties encountered. Data relating to four challenges to recruitment for the trial will be presented: i) delays with set up, ii) identifying supporters for participants, iii) therapist capacity, iv) therapist retention, and v) participant attrition.

**Conclusion:** These findings highlight that it is possible to recruit, randomise and retain a large sample of participants with intellectual disabilities and depression in a randomised control trial of psychological interventions. It is hoped that the insights obtained into the recruitment challenges will be of help to future research teams, when planning similar studies.

**Title: Using Talking Mats to experiences of person-centred active support**

**Name:** Kitty Stewart [Kristianne.Stewart@gov.gg](mailto:Kristianne.Stewart@gov.gg)

**Affiliation:** Tizard Centre, University of Kent

**Co-authors:** Jill Bradshaw, Julie Beadle-Brown

**Background:** Subjective experience is a critical when evaluating the effectiveness of interventions which aim to improve Quality of life (QoL). Talking Mats (TM) provide a framework to facilitate the views of people with intellectual disability (PWID).

**Method:** TMs were used to explore PWIDs experiences and perceptions of changes in the Quality of Support (QoS)(measured quantitatively) and impact on QoL, during the implementation of Person Centred Active Support (PCAS).

**Results:** There was inconsistent implementation of PCAS. Participants expressed both positive and negative views about QoS and QoL across three themes; My life, My support, and Self-determination.

**Conclusion:** TM should be used to enable PWID to express their views and experiences of QoS and QoL. Their views need to be reflected in adaptations made to PCAS.

**Title: Interesting and Important Aspects of Psychological Therapy: Perceptions of Clients with Intellectual Disabilities and Their Therapists**

**Name:** Laura Surley [laurasurley@gmail.com](mailto:laurasurley@gmail.com)

**Affiliation:** Cumbria Partnership NHS Foundation Trust

**Co-author:** Dave Dagnan

**Background:** There is increasing interest in the quality of care of people with Intellectual Disabilities. Process research has aimed to increase the effectiveness of psychological therapy by understanding and demonstrating how therapy works. In this study clients and therapists were asked about their perceptions of interesting and important aspects of therapy using a novel method, the Burford Review Process.

**Method:** Seven client-therapist dyads participated. For each dyad a routine therapy session was video recorded, then separately reviewed by clients and therapists. The review session followed the Burford Review Process, whereby participants were first asked to indicate whenever they noticed an interesting or important aspect of the recording. Each identified aspect was then watched again and

participants were asked to describe why they had found that part of the recording interesting. The review session was audio recorded and transcribed, then analysed using thematic analysis.

**Results:** Themes from the client data referred to perceptions of the therapy relationship, disability, current concerns, observations and the experience of therapy. Themes from the therapist data referred to perceptions of the therapy process, disability, progress, and new insights.

**Conclusion:** Clients and therapists were able to provide detailed narratives about their perceptions of interesting and important aspects of therapy. The importance of the therapeutic relationship and issues related to disability were highlighted in both groups. There is a clear need for further research to investigate what works in therapy for people with Intellectual Disabilities, and their inclusion in research is essential in achieving this.

**Title: Daughters of Fortune: Stories of Parents with Intellectual (Learning) Disabilities**

**Name:** Kate Theodore [kate.theodore@rhul.ac.uk](mailto:kate.theodore@rhul.ac.uk)

**Affiliation:** Royal Holloway University of London

**Co-authors:** Joyce Lee, Lisa Mallaghan, Daniel Foulds

**Background:** The numbers of people with intellectual disabilities becoming parents in the UK are reported to be increasing, yet, as a group, they are known to face multiple disadvantages in their parenting role, are very likely to have their parenting abilities formally assessed by social services (McGaw & Candy, 2010), and remain disproportionately likely to lose custody of their children (McGaw & Newman, 2005). An innovative project funded by the Wellcome Trust has allowed Mind the Gap, the largest UK inclusive theatre company for people with intellectual disabilities, to collaborate with a researcher, to collate and share stories about the experiences of parents with intellectual disabilities, through academic research alongside a number of different creative processes (including forum theatre and a national touring theatre production).

**Method:** Ten parents with intellectual disabilities were interviewed by a small research team, including a principle researcher with intellectual disabilities. This user-led research methodology allowed collection of detailed accounts of the parents' experiences. The audio-recorded interviews were transcribed and analysed qualitatively using Thematic Analysis (Braun & Clarke, 2006), with continued involvement from researchers and participants with intellectual disabilities, to enhance research quality.

**Results:** Themes from the qualitative analysis of the parents' experiences will be presented, together with feedback regarding the impact of sharing these stories via the theatre production.

**Conclusion:** Conclusions will be drawn from the stories shared by parents, as well as reflections made by the research team on the process of inclusive research and the impact of involvement of researchers with intellectual disabilities on the research process.

**Title: Hidden lives and deaths: People with ID living and dying in non-ID care settings**

**Name:** Stuart Todd [stuart.todd@southwales.ac.uk](mailto:stuart.todd@southwales.ac.uk)

**Affiliation:** University of South Wales

**Co-authors:** Jane Bernal, Sarah Bearley, Katherine Hunt, Julia Shearn, Rhian Worth

**Background:** Very little is known about people with ID living in non LD (generic settings). This sector provides care to a small but significant proportion of people with ID. However, their role in providing care at the end of life to people with ID is more common. their role in providing such care is under-researched.

**Method:** A cross sectional survey was adopted to provide data from 70 generic care homes. Data have currently been obtained on 156 people with ID across the UK.

**Results:** analysis is underway and still current. The data show that the death rate in this population may be 8 times higher than in ID settings and this reflects important differences in age structure.

Data on EoLC care outcomes have not been analyzed but about 1 in 4 of these residents were considered at risk of dying in the next 6 months.

**Conclusion:** The first important conclusion is the difficulty that exists in identifying this population. This population are or became unknown to LD providers and are not identified as having ID by generic care commissioners. They are also likely to be the oldest of the old in ID terms and their absence in mortality and EoLC studies significant.

**Title: Evaluating the effectiveness of Active Support - establishing the platform: A systematic review**

**Name:** Vaso Totsika [V.Totsika@warwick.ac.uk](mailto:V.Totsika@warwick.ac.uk)

**Affiliation:** Centre for Educational Development Appraisal and Research (CEDAR), University of Warwick

**Co-authors:** Samantha Flynn, Richard Hastings, Kerry Hood

**Background:** Active Support is a person-centred model aiming to improve the quality of life of adults with a learning disability (LD) by maximising meaningful engagement in daily life activities. Previous reviews have suggested that Active Support improves engagement in activities, and increases staff support, but were inconclusive regarding other potential effects (e.g. challenging behaviour). These reviews were not comprehensive or systematic, and new research has been published recently, making an updated and systematic review synthesis timely. This review will evaluate outcomes from quantitative studies of Active Support interventions for adults with LD in social care.

**Method:** A systematic search covering 10 scientific databases will identify publications meeting the following inclusion criteria: a) participants are adults with LD in community settings, b) implementation of Active Support, c) a quantitative study, and published in English. Data will then be extracted using a standardised form and summarised using the appropriate meta-analytic methods. Quality assessments will be undertaken on included studies.

**Results:** The review will summarise the effect of Active Support on all assessed outcomes, including: engagement in daily life activities, staff support, challenging behaviour, and mental health. Work is currently ongoing, and an overview of the review protocol will be presented at the conference.

**Conclusion:** Results from this review will enhance our understanding of the effectiveness of Active Support and ultimately inform the development of further evaluative work. In practice, findings will enable the better informed use of Active Support as an intervention to improve the quality of life of adults with LD.

**Title: Sleep quality in children with neurodevelopmental disorders varies on a night by night basis; novel insights using actigraphy**

**Name:** Jayne Trickett [jxt292@bham.ac.uk](mailto:jxt292@bham.ac.uk)

**Affiliation:** University of Birmingham

**Co-authors:** Caroline Richards, Mary Heald, Hayley Denyer, Chris Oliver

**Background:** Sleep problems are described frequently in paediatric populations with intellectual disability. However, lack of standardisation of assessment and the heterogeneity of samples of children has limited the detailed description of the both the prevalence of sleep problems in children with specific neurodevelopmental disorders and the degree of inter-daily and inter-child variability of sleep problems.

**Method:** Standardised questionnaire and seven night actigraphy assessments were completed by families of 20 children with Smith-Magenis syndrome (SMS, mean age 8.89) and 20 with Angelman syndrome (AS, mean age 9.39) and 20 age-matched typically developing (TD) children for each group.

**Results:** Children with SMS had shorter sleep onset latencies, total sleep duration, earlier bedtimes and wake up times and longer night waking periods than TD children. Total sleep time was more



varied both between nights for the individual child (coefficient of variance: 14%, versus TD 9%) and between children with SMS across the assessment period relative to TD children (14% versus 9%). Children with AS also had significantly greater inter-daily (14% versus 9%) and inter-child variability (17% versus 8%), than TD children. The average total sleep duration and the duration of night waking did not significantly differ between the children with AS and TD children.

**Conclusion:** Individual differences and inter-daily variability in sleep quality across children with neurodevelopmental disorders need to be acknowledged; these findings mandate that detailed individualised assessments be conducted to ensure that interventions are targeted.

### **Title: Understanding and Experiencing Ageing: The Perspectives of Older People with Intellectual Disabilities**

**Name:** Anna Whiteley [anna.whiteley@nhs.net](mailto:anna.whiteley@nhs.net)

**Affiliation:** University of Edinburgh & NHS Dumfries and Galloway

**Co-authors:** Ethel Quayle, Ken MacMahon

**Background:** Adults with intellectual disabilities are living longer. The experience of ageing for those individuals with intellectual disabilities may be different from that of those without such disabilities. Particular societal indicators of ageing, such as retirement, may not be as prevalent for those with intellectual disabilities. This study sought to identify and address gaps in our understanding of the lived experience of ageing for adults with intellectual disability.

**Method:** Semi-structured interviews were completed with ten participants (age range 60 – 74 years, five female) with intellectual disabilities, who were living in the community. Nine transcriptions were analysed using interpretative phenomenological analysis.

**Results:** Three major themes emerged from the data: 'Not changed by ageing', 'Thinking about the ageing process' and 'What happens when people get older'. However, there was a general sense that participants struggled to speak about aging, particularly during the early parts of interviews. Participants appeared to have a lack of awareness of the process within themselves.

**Conclusion:** Participants' difficulties speaking about ageing may reflect that there had been little opportunity to do so during their lives. Many participants did not describe themselves as feeling older and emphasised that they were still involved in the same activities as they always had been. When ageing was referred to it was, in the main, with respect to others. Discussion of ageing is encouraged in the future.

### **Title: Antipsychotics and Behaviour: Towards Personalised Prescribing**

**Name:** Tim Williams [timothy.williams@reading.ac.uk](mailto:timothy.williams@reading.ac.uk)

**Affiliation:** Reading University

**Background:** RCTs have not always demonstrated replicable results for individuals with learning disability. In part this may be because they are under-powered (groups are too small to demonstrate an effect) but it may also be the result of the wide variety of pathologies underlying the learning disability which may affect the bio-availability and mechanisms of action of the medications used. For instance, Risperidone was found to be effective in the RUPP trial (2002) but not in the NIHR funded trial in this country (Tyrer et al. 2008). An alternative methodology is to examine the effects of medication on an individual basis, and use statistical techniques to determine if a significant effect has been demonstrated.

**Method:** A review of three years antipsychotic prescribing decisions in a residential school for children with autism and severe learning disabilities was carried out. The behavior records maintained by school staff were examined and the changes in behaviours analysed to estimate whether the changes seen subsequent to prescribing decisions were statistically significant.

Results: 6 children were affected. Of these 4 showed evidence of improvement in behavior, although a minority did not. One child could be shown to have deteriorated following antipsychotic prescription.

**Conclusion:** Routinely collected data can be interrogated using statistical methods to aid decision making when prescribing anti-psychotic medication. Prescribing clinicians should be using such analyses to support decisions when deciding on which medication to use in the control of behavior in intellectual disability.