THE SEATTLE CLUB
CONFERENCE 2015 ● CARDIFF

#SeattleClub15

CONTENTS

WELCOME FROM THE NATIONAL CENTRE FOR MENTAL HEALTH

The National Centre for Mental Health (NCMH) is proud to host the 2015 Seattle club here at Cardiff University's Hadyn Ellis Building.

NCMH was founded in 2011, and is supported through funding from Health & Care Research Wales.

The Centre's mission is to establish a resource to foster high quality research into a wide range of mental health problems across diagnoses and the lifespan.

In an exciting development, the NCMH extended this mission in 2015 to include research into learning disability, with a focus on mental health and challenging behaviour.

The centre has recruited over 5000 individuals in Wales with mental health conditions, and is now in the process of recruiting many more people with a learning disability.

Our volunteers provide us with biological samples and take part in social and psychological assessments, allowing us to build up an invaluable resource that will allow the UK research community to answer the needs of people with a learning disability.

We hope that this meeting is a great success, and we are particularly honoured that the event will also mark the outstanding contribution of **Professor David Felce** to research in this field.

Professor Felce's leadership of research in Wales is internationally recognised and has provided the scientific basis for real changes to the social integration and health care of people with learning disability.

Professor Ian Jones
Director
NCMH

Professor Mike Kerr
Learning Disability Lead
NCMH

PROGRAMME

DAY 1: THURSDAY

9.30   Arrival - Tea/Coffee

SESSION 1

10:00   Welcome and introduction to the meeting, housekeeping.

10:10   K. A. WADE (NIHR CLAHRC East of England at Cambridgeshire & Peterborough NHS Foundation) *Twelve months of medications: medication use in people with intellectual disabilities referred to community teams for support with a mental health and/or behavioural need*

10:35   ANGELA HENDERSON (University of Glasgow, Institute of Health and Wellbeing) *Psychotropic drug prescribing in a cohort of adults with intellectual disabilities in Scotland*

11:00   Tea/Coffee

SESSION 2

11:30   LISA O'LEARY (Institute of Health and Well Being, University of Glasgow) *Life expectancy of people with intellectual disabilities: a systematic review*

11:50   JULIA SHEARN (UDID, University of South Wales) *Individual and setting characteristics influencing end of life care outcomes in a sample of decedents with LD who had lived in LD services in the UK*

12:10   JANET O'FARRELL (Trinity College Dublin) *Equality of care: love, care and solidarity for older adults with intellectual disability in Ireland at end of life*

12:30   Lunch

@ncmh_wales

SESSION 3

13:30   VAL WILLIAMS (Norah Fry Research Centre, School for Policy Studies, University of Bristol) *Taking control? People with intellectual disabilities who use personal budgets*

13:50   PAUL WILNER (Dept. of Psychology, Swansea University) *People with mild-to-moderate intellectual disabilities can talk about their anger as well as university students*

14:10   CLAIRE BATES (The Tizard Centre, University of Kent) *Sharing a Basic Human Need to be Loved- Partner Selection for People with Intellectual Disabilities*

14:30   Tea/Coffee

SESSION 4, INCLUDING THE DAVID FELCE RESEARCH LECTURE

15:00   LAURE ANNE HUGHES-McCORMACK (Institute of Health and Well Being, University of Glasgow) *Health of people with intellectual disabilities in Scotland- a total population study*

15:20   David Felce Research Lecture

MIKE KERR (Institute of Psychological Medicine and Clinical Neuroscience, Cardiff University) *The healing game: interventional health care for people with an intellectual disability*

16:00   Participants set up posters

17:00   Poster session begins with drinks

18:00   Tributes to Prof David Felce, buffet

19:30   End - a venue for socialising in Cardiff for the evening will be announced

DAY 2: FRIDAY

SESSION 5

9:20   Seattle Club business

9:30   CAROLINE RICHARDS (Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham) *Self-injurious behaviour in Autism Spectrum Disorder: Prevalence, Persistence and Risk Markers*

9:50   LEAH VANONO (The Tizard Centre, University of Kent) *Preventing Challenging Behaviour by Implementing The Eight Areas of Social Care Model; Bluebell Grove Case Study*

10:10   ANNE MCDONALD (The Richmond Fellowship Scotland) *An Evaluation of Staff Training in Positive Behaviour Support*

10:30   Tea/Coffee

SESSION 6

11:00   MYRTHE JACOBS (Institute of Health and Wellbeing, University of Glasgow) *Prenatal diagnosis of trisomy and other chromosomal anomalies: a study of pregnancy outcomes of 26, 261 cases*

11:20   JOHN TAYLOR (Northumbria University and Northumberland, Tyne & Wear NHS Foundation Trust) *Developing Discharge Pathways for Detained Patients with Intellectual Disabilities: Improving Discharge Rates and Length of Stay Post-Winterbourne View*

11:40   GEMMA UNWIN (School of Psychology, University of Birmingham) *A mental health promotion programme to improve emotional, social and coping skills in children and young people in special schools: A feasibility study*

12:00   DEBORAH KINNEAR (Scottish Learning Disabilities Observatory, Institute of Mental Health and Wellbeing, University of Glasgow) *The prevalence of physical ill-health in a cohort of adults with intellectual disabilities in Scotland*

12:20   Lunch

13:30 PHILIPPA WISEMAN (Scottish Learning Disabilities Observatory, Institute of Health and Wellbeing, University of Glasgow) *A Sociological Exploration of the Impact of Hate Crime on the Health and Wellbeing of People with Learning Disabilities in Scotland*

13:50 SARAH CASSIDY (Coventry University) *Suicidality in adolescents and adults with and without an Autism Spectrum Condition*

14:10 KATHRINE ELLIS (Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham) *The developmental trajectory of early social cognition skills in children with Fragile X syndrome*

14:30 KATHERINE LANG (NHS Lanarkshire, Department of Psychological Services for Adults with a Learning Disability) *Behavioural Family Therapy with People with Intellectual Disabilities: A Feasibility Study*

14:50 Thanks for coming and announcement of next Seattle Club host

15:00 Close

ABSTRACTS

Twelve months of medications: medication use in people with intellectual disabilities referred to community teams for support with a mental health and/or behavioural need

K.A. Wade, A.J.Holland, Elizabeth Jones, Alison Lillywhite, I.C.H. Clare

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Background
Recently, Sheehan et al. (2015) reported that the proportion of people with ID in primary care treated with psychotropic medication far exceeded the proportion with a recorded mental illness. In our study, we examined this issue among adults with IDs referred to a county-wide service for support with a mental health and/or behavioural need.

Method
Care-givers were asked to complete the medications section of the Client Service Receipt Inventory for sixty-five adults referred to one of the service's five community ID teams. As in Sheehan et al. (2015), the listed medications were classified using the British National Formulary.

Results
While the data are still being analysed, preliminary findings indicate that, consistent with Sheehan et al. (2015), the proportion of the sample for whom psychotropic medication was prescribed was high (89.1%). However, anti-depressants (50.1%), rather than anxiolytics/hypnotics, were the most frequently used of the psychotropic medications. Anxiolytics/hypnotics were prescribed as a regular medication for only 9.4% of the sample, but were reported as PRN for 18.8%. Further details, including the use of medication for different psychiatric diagnoses and/or in the absence of such a diagnosis, and the contribution of psychiatry to community teams, will be illustrated, using case studies.

Conclusions
This, albeit small, study is, as far as we know, the first to examine the use of medication for mental health and/or behavioural needs among service users in community ID teams. Its findings and implications will further inform the debate about medication use for people with IDs and additional needs.

Psychotropic drug prescribing in a cohort of adults with intellectual disabilities in Scotland

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Background
Evidence suggests that antipsychotic medication is overprescribed in people with intellectual disabilities, not correlating with prevalence rates of psychotic illness. A recent large study reported that antipsychotics were being taken by people with challenging behaviour who did not have mental illness. However this study relied on primary health care records rather than systematic review of challenging behaviour and mental health. The aim of this paper is to report the use of psychotropic drugs by people with intellectual disabilities, and their mental health/challenging behaviour status.

Method
The analysis is part of a large prospective, cohort study. Adults with intellectual disabilities living within the geographical area of Greater Glasgow Health Board, Scotland, were identified and recruited to the cohort study. Each participant underwent a comprehensive health assessment. Data analysis generated descriptive statistics about psychotropic drug use and general prescribed drug use of people with intellectual disabilities, and their health status. Age and gender differences in medication used and general health were also examined.

Results
A total of 1,023 people with intellectual disabilities took part in the health assessment, 562 (54.9%) males and 461 (45.1%) females, aged 43.9 years (16-83). 79% took at least one drug. 49.5% took psychotropic drugs, 23.2% took antipsychotics. Of the individuals taking antipsychotics, 17.3% had a psychotic illness, 45% had challenging behaviour and 6.8% had both.

Conclusions
The study's strength is in the comprehensive nature of the health assessments. It confirms the high rate of prescribing of antipsychotic drugs in this population.

Life expectancy of people with intellectual disabilities: a systematic review

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Background
Although life expectancy of people with intellectual disabilities has increased in recent years, it is still thought to remain lower than that of the general population. A systematic review was undertaken to identify the strength of this evidence.

Method
The review was registered with the International Prospective Register of Systematic Reviews (Prospero) registration number CRD42015020161. Five electronic databases (CINAHL, MEDLINE, PsychINFO, Web of Science, and EMBASE) were searched for key words relating to intellectual disabilities AND death. Titles and abstracts were assessed using strict inclusion/exclusion criteria. 5% were assessed by a second researcher. Full papers were then assessed for eligibility. Information relating to design, demographics, data source, method of analysis, findings and limitations was extracted, tabulated and reviewed using narrative analysis.

Results
17,596 potentially relevant articles were identified. 29 of these met the inclusion criteria: Analysis revealed that individuals with intellectual disabilities had lower life expectancy than the general population. Most studies did not present standardised mortality ratios by gender and age groups. Mortality rates were higher in females, and individuals with severe/profound intellectual disabilities or lower functional abilities or Down syndrome. Causes of death revealed a different profile to the general population including likely avoidable deaths. Most studies were limited by relying on administration data, and not undertaking age-gender matched general population comparisons.

Conclusions
People with intellectual disabilities appear to have a shorter life expectancy, and different pattern of causes of death than the general population, but robust comparative data is lacking. The Scottish Learning Disabilities Observatory is investigating this further.

Individual and setting characteristics influencing end of life care outcomes in a sample of decedents with Learning Disabilities who had lived in LD services in the UK

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Katherine Hunt[2], Phil Madden, Kathy Lowe[3], Edwin
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Background
End of life care research on people with intellectual disabilities has increased in recent years. However, little is known about end of life care outcomes for this population or what, if any, factors might influence end of life care pathways within this population. This paper reports a large UK study of recent deaths in UK ID residential services.

Method
39 ID services provider were recruited into the study. These services supported approximately 13,000 people with ID in either registered care homes or supported living settings. The sample could be considered broadly representative of UK service providers in terms of geography, although there maybe a potential bias towards medium to large providers. Deaths in this population were identified every 6 months for 18 months. For each data reported (n=243), core data on the individual were obtained and a request made to a member of care staff to complete an ID sensitive version of VOICES and a supplementary questionnaire. 219 questionnaires were returned (90% response rate)

Results
The death rates in the participant samples were 13 and 8 deaths per 1000 residents supported in care homes and supported living settings respectively. However, the average age of the supported populations were low (late 40s in both settings). The average age at death in these settings was 62.5 in care homes and 59.5 years in supported living settings. 52% and 43% of decedents in care homes and supported living settings died in their usual place of residence. Data are currently being analysed to determine which individual or setting characteristics might have some influence over care pathways and outcomes in the last months of life. Data are also being examined on the extent to which people with ID participated in decisions surrounding their care in the last months of life.

Conclusions
The mortality rate within LD services is low despite the consistent findings that people with intellectual disabilities appear to have a shorter life expectancy. It

appears that these services are able to support people with ID in their place of residence until their deaths but the capacity to do so varies across settings. These differences are currently being analysed but there is a sense that people in supported living settings and people with fewer support needs may experience poorer end of life care outcomes.

Equality of care: love, care and solidarity for older adults with intellectual disability in Ireland at end of life

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Background
Currently, there is not a clear picture of the scale and breadth of the experiences and challenges that are experienced by people with intellectual disability (ID) and their carers supporting them at end of life. IDS-TILDA study presented an opportunity to explore these issues in those deceased since wave 1 of data collection.

Method
A Mixed Methods approach is employed, with an emphasis on quantitative analysis with an embedded qualitative data collection element. Experiences were captured through face-to-face interviews, using an adapted version of the Views of Informal Caregivers Evaluation of Services questionnaire (VOICES), regarding last year of life with 45 close caregivers interviewed as proxy. Analysis was carried out using descriptive statistical and text analysis and discussed in the context of Lynch et al's (2004) framework of social justice.

Results
A profile of ID service residential setting dwelling adults (80.4%), multi-morbid (87%) with primarily moderate, severe or profound IDs (89.1%), supported by paid caregivers at end of life (95%) was established across 19 services. Qualitative data generated was heavily influenced by the impact of relationships established with caregivers at this time, in particular love and caring relationships.

Conclusions
Findings provide an insight into the profile of death and dying as an older adult with ID in Ireland and the systems underpinning end of life care (in)equalities experienced. In particular, the system of affective (in)equality and the domain of love care and solidarity relationships supporting people with ID on life's final journey impacts on access to and quality of care provided.

SESSION 3

Taking control? People with intellectual disabilities who use personal budgets

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Background
Consumerist assumptions underpin the processes in English social care. However, individual models of choice-making are often critiqued when applied to people with ID, where relational autonomy may be the preferred model.

Method
This paper reports on data from a study of 23 disabled people who used personal budgets in England. A series of semi-structured interviews were carried out with each participant, and recordings were made of four support planning sessions, in which a practitioner, the person with ID and a parent were present. A phenomenological analysis was applied to the interview data, and is supplemented by conversation analysis of the naturally occurring data.

Results
A sense of individual moral 'worth' was of prime importance to the nine verbal participants with ID; other people were vital for their decision-making - family, friends and paid support staff. The formal processes of support planning did not make much sense to many of this group, and in the recorded support planning data, 274 extracts were analysed, in which family members self-selected to speak up for their relative. It was found that family members used their epistemic closeness to the disabled person in order to 1) clarify; 2) usurp; 3) prompt; 4) expand; 5) challenge.

Conclusions
Making decisions about a personal budget is a complex process. When there was a conflict, the practitioner and the parent tended to unite in strategies of persuasion. These practices were discussed with a group of people with ID, who suggested counter-strategies to create a more equitable decision-making process.

People with mild-to-moderate intellectual disabilities can talk about their anger as well as university students

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Background
People with intellectual disabilities (PwID) have difficulty in expressing themselves verbally, and historically, this has been a barrier to their participation in talking therapies. However, recent controlled trials of psychological interventions for mental health problems tend to report effect sizes similar to those seen in the general population. Does this mean that, with suitable adaptations, PwID are able to engage with psychological therapies as effectively as others? This study examined one aspect of this question, how well PwID are able to express their cognitions.

Method
The context was an evaluation of a new instrument, The Profile of Anger-related Cognitions (PAC), which is based on interpersonal scenarios identified as personally anger-provoking. A conversational presentational style was used to probe four relevant cognitive dimensions: attribution of hostile intent, unfairness, victimhood, and helplessness. The PAC was administered to (i) PwID identified as having problems with anger control (n=12) and (ii) university students (n=23); its psychometric properties were investigated, alongside independent content analyses of participants' verbal responses, which are the focus of this presentation.

Results
The two groups did not differ significantly in either the word length of their responses or the number of prompts used to elicit them. With a single exception (of questionable significance), they also expressed the identical range and distribution of concepts on all four dimensions.

Conclusions
There is nothing in these data to suggest that people with ID understood the issues any less well than the university students or, when suitably supported and scaffolded, were any less able to express themselves.

Sharing a basic human need to be loved- partner selection for people with intellectual disabilities

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Background
The aim of the research was to understand what adults with intellectual disabilities looked for in a partner. There have been numerous studies which explore partner selection for people without intellectual disabilities but no research which specifically identified the traits valued in a partner by people with intellectual disabilities.

Method
In depth interviews were conducted with eleven participants across two UK sites. All participants were all heterosexual adults with an intellectual disability who had been in a relationship with a partner for over a year. The narratives were analysed utilising hermeneutic phenomenology, guided by the theory of Van Manen (1990).

Results
The findings highlighted how participant relationships typically developed within a segregated environment for people with intellectual disabilities within the past ten years regardless of age. People with intellectual disabilities shared the same human need to be loved, to be treated kindly and to have companionship. However, people with intellectual disabilities did not value attributes such as financial security, social status, education or intelligence. The importance of good staff support was highlighted as fundamental to relationship development.

Conclusions
Differences were identified concerning what the participants valued compared to research for people without intellectual disabilities, this was possibly due to a lack of shared culture with mainstream UK society. The research demonstrated how poorly integrated people with intellectual disabilities are within mainstream society and how dependent they remain on good support from support staff to develop and maintain relationships.

Health of people with intellectual disabilities in Scotland- a total population study

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Background
People with intellectual disabilities are known to experience health inequalities, but most studies have comprised small or incomplete populations. For people with and without intellectual disabilities in the whole of Scotland, this study aims to compare: 1) reported general health status, 2) reported mental health conditions, and 3) other reported disabilities.

Method
We analysed Scotland's Census 2011 data, and generated descriptive statistics about people with and without intellectual disabilities. Age and gender differences in general health, mental health and other disabilities were also examined.

Results
There were 26,349 people with intellectual disabilities; 0.5% of the total Scottish population (n=5,295,403). 15,149 (57.5%) were males and 11,200 females (42.5%); and 5,234 were children (0-15 years), and 21,115 (16-85+ years) adults. Only 50.2% of people with intellectual disabilities reported their health as very good or good, compared to 82.2% of the general population. Mental health problems were more common in people with intellectual disabilities, for both children and adults. Other disabilities were also more common, including visual and hearing impairments.

Conclusions
People with intellectual disabilities rate their health less favourably than the general population at all ages. This is being further investigated by the Scottish Learning Disabilities Observatory.

THE DAVID FELCE RESEARCH LECTURE

The healing game: interventional health care for people with an intellectual disability

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This presentations aims to discuss how we can improve the lives of people with an intellectual disability through healing and ameliorating their complex health conditions. Health care research and delivery is increasingly moving towards individualised medicine.

 The establishment of multi-professional research groupings has led to an increase in high quality interventional research addressing health needs within this population.

Well-proven interventions to improve the health of people with an intellectual disability are increasingly available, especially in public health and in specific conditions such as epilepsy and in some areas of behaviour challenge such as anger. Specific individualised treatments are also becoming available such as in the treatment of specific health conditions associated with Tuberose Sclerosis.

Self-injurious behaviour in autism spectrum disorder: prevalence, persistence and risk markers

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Background
Autism spectrum disorder (ASD) has been identified as a risk marker for self-injurious behaviour (SIB). Longitudinal and cross-sectional studies of cohorts with ASD were undertaken in order to delineate the prevalence, persistence and risk markers for SIB in ASD.

Method
In Study 1, carers of 67 individuals with ASD (median age=13.5, IQR=10.00–17.00), completed questionnaires relating to SIB at T1 and three years later at T2. Analyses were conducted to evaluate the persistence of SIB and behavioural and demographic characteristics associated with persistence. In Study 2, teachers and key workers of 208 children and 216 adults with ASD (mean sample age=24.10, range=6-61) completed brief questionnaires relating to the presence of SIB and key demographic and behavioural characteristics.

Results
SIB was highly prevalent in both studies (Study 1=41.8%; Study 2=47.4%). Study 1 revealed that SIB was persistent in 77.8% of cases. Persistent SIB at T2 was associated with significantly higher impulsivity and impairments in social interaction at T1. In Study 2, SIB was also associated with, and predicted by, overactive, impulsive and repetitive behaviours. Self-restraint was

highly prevalent (41.7%), significantly associated with SIB, and also predicted by the presence of overactive, impulsive and repetitive behaviour.

Conclusions
The implications of these findings are discussed in relation to a role for behaviour dysregulation, as evidenced by overactive, impulsive and repetitive behaviours, in the development and maintenance of self-injury. The identification of possible risk markers for persistent self-injury and subsequent implications for models of early intervention are also discussed.

Preventing challenging behaviour by implementing the eight areas of social care model; Bluebell Grove case study

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Background
Drawing on understanding of the environmental factors associated with challenging behaviour, this project sought to intervene directly in the organisation and provision of social care with a view to altering the factors contributing to challenging behaviour, thus preventing its future occurrence. A systemic model of positive behaviour support was developed in the study named 'Preventing Challenging Behaviour of Adults with Complex Needs in Supported Accommodation'. This focussed intervention in the following areas of social care 'Activities and Skill Development', 'Health', 'Communication and Social Interaction', 'Relationships with Family and Others', 'Management', 'Service Staff', 'Wider Organisation' and 'Physical Environment'.

Method
24 services participated in a randomised control trial study, 11 experimental vs. 13 control. Bluebell Grove was selected as an experimental group service who received specialist intervention using the systemic model.

Results
The team achieved 92% implementation of their intervention plan, over a period of 9 months (163 interventions). The person we support's Aberrant Behaviour Checklist (ABC) score reduced from 67 to 14, the team also won an organisational award for excellence. At follow-up, 18 months later, the person we supports ABC Score reduced further to 7. The person we supports staff team no longer consider her to display 'challenging behaviour'.

Conclusions
The findings of this study are promising and strongly suggest that future research on challenging behaviour should continue to investigate its prevention through intervention in the system of supports surrounding individuals at risk of developing or continuing to display challenging behaviour.

An evaluation of staff training in positive behaviour support

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Background
Challenging behaviour is common for many people with learning disabilities and has a negative impact on the lives of these individuals. It is linked to decreased levels of support from staff, reduced opportunities for inclusion in the community, use of restrictive interventions, and placement breakdown. Equipping staff with the necessary knowledge, skills and experience to support people with challenging behaviour in a positive, respectful and effective way has proved a challenge for care agencies. Positive Behaviour Support (PBS) has been shown to be effective in minimising challenging behaviour. The aim of this study was to evaluate the impact of training managers of social care services in PBS.

Method
A longitudinal training programme in PBS was delivered to 50 managers of community-based services for people with learning disabilities and challenging behaviour. The training programme lasted a year; data were collected pre and post training, and at 6 month follow-up. A non-randomised control group design was used.

Results
Data demonstrated significant reduction in challenging behaviour which was sustained over time. However, there was no change in quality of life for service users, and very limited changes in staff support to service users.

Conclusions
This study has demonstrated that training managers in PBS can have a positive impact on challenging behaviour in people with learning disabilities. However, there are a number of aspects to the results which are unexpected and these are discussed with reference to the relevant literature.

Prenatal diagnosis of trisomy and other chromosomal anomalies: a study of pregnancy outcomes of 26,261 cases

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Background
Previous studies have reported changes in the age at which women give birth and developments in prenatal screening and diagnosis techniques, and their influence on the number of pregnancies diagnosed and terminated with chromosomal anomalies. However, no population studies on the association between diagnosis and pregnancy outcome controlling for maternal factors have been carried out. The aims of this study were to examine: 1) rates of pregnancy termination after diagnosis of chromosomal anomaly in Scotland over time; and 2) the association between the diagnosis and pregnancy termination.

Method
Diagnostic information of 26,261 prenatal invasive tests for chromosomal anomalies from all genetic service laboratories in Scotland from 2000 to 2011 was linked to Scottish Morbidity Records to obtain details on pregnancy outcome. Binary logistic regression was used to test the associations of year and type of diagnosis with the dependent variable, pregnancy termination, while controlling for maternal age, neighbourhood deprivation, and parity.

Result
There were 24,155 (92.0%) normal diagnoses, 1,483 (5.6%) aneuploidy diagnoses (including trisomy and sex chromosome abnormalities), and 623 (2.4%) diagnoses of anomaly that was not aneuploidy (e.g. translocations and single chromosome deletions). Pregnancies diagnosed with trisomy were more likely to be terminated than pregnancies diagnosed with other aneuploid anomalies, but over the study period, fewer pregnancies that were diagnosed with trisomy were terminated.

Conclusions
There has been a reduction in the rate of termination for aneuploidy. This may reflect societal changes with acceptance of greater diversity, but further research would be needed to test this.

Developing discharge pathways for detained patients with intellectual disabilities: improving discharge rates and length of stay post-Winterbourne View

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Background
Government data indicate that a disproportionate number of people with intellectual disabilities (ID) are being detained in hospitals in England and Wales. Further, hospital inpatients with ID are likely to have longer lengths of stay than non-ID inpatients. Following the Winterbourne View scandal reductions in the hospital length of stay for people with ID has become a national priority.

Method
The impact of delayed discharge on people with ID, factors contributing to delayed discharge, and the features of effective partnership working are described. A new approach to discharge planning for, preparation of, and post-discharge management of detained patients with ID is outlined with reference to a systematic framework.

Results
Over the past 4 years this new approach has enabled the clinical team of a specialist hospital rehabilitation unit to accelerate the discharge of a number of complex and vulnerable patients. Thirty-eight long-stay patients (average length of stay approximately 5 years) have been successfully discharged to community services and many more are at advanced stages of discharge planning. This compares to 13 discharges during the previous 4 years. The re-admission rate and lengths of stay have been significantly reduced also.

Conclusions
This service development involved significant changes to the clinical model and culture of a service which has led to significantly increased rates of discharge and reductions in lengths of stay and re-admissions for long-stay patients who present high levels of clinical risk. The implications of this approach for the learning disability transformation programme locally are considered.

A mental health promotion programme to improve emotional, social and coping skills in children and young people in special schools: a feasibility study

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Background
Mental health problems and behaviours that challenge are more common among children with learning disabilities than the general population. Good emotional, social and coping skills can help protect children from developing such problems. This study sought to evaluate a school-based mental health promotion programme designed to improve emotional literacy skills amongst children with special educational needs (SENs).

Method
53 children aged 5-14 years attending SENs schools were recruited to participate in the Zippy's Friends for SENs programme, delivered over the course of an academic year. Pre- and post- quantitative and qualitative data were collected using standardised assessment scales, interview schedules, and emotion recognition tasks to assess typical and maximal behaviour of the children and collect feedback on the programme. Data were collected from children, parents/guardians/care givers and school personnel pre- and post-intervention to evaluate acceptability, feasibility and effectiveness.

Results
Qualitative feedback suggests that the programme is feasible and acceptable, however, it may not be appropriate for all SENs pupils. Teachers enjoyed teaching the programme and felt that the topics were important for children with SENs. They reported that pupils enjoyed and engaged well with the programme. Quantitative results differed according to measure, however, teacher-reported communication, cooperation, assertion, responsibility, self-awareness, social skills and emotional literacy significantly improved over time.

Conclusions
Zippy's Friends SEN programme is both feasible and acceptable, and may be associated with positive outcomes, however, further research with control groups is needed to fully evaluate effectiveness. Researchers should consider measurement selection to ensure sensitivity amongst children with SENs.

The prevalence of physical ill-health in a cohort of adults with intellectual disabilities in Scotland

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Background
People with intellectual disabilities have different health needs and experience greater health inequalities when compared to the general population. Gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, dental disease, musculoskeletal problems, accidents, and nutritional problems are all thought to be much more commonly experienced in people with intellectual disabilities. However, most studies have been small scale, with selected age groups, or methodologically limited. The aim of this paper is to report the physical health conditions of people with intellectual disabilities.

Method
The analysis is part of a large prospective, cohort study. 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 to the cohort study. Each participant underwent a comprehensive health assessment by nurses and three general practitioners. Data analysis generated descriptive statistics about the physical ill-health of people with intellectual disabilities. Age and gender differences in physical ill-health and general health were also examined.

Results
A total of 1,023 people with intellectual disabilities took part in the health assessment. 562 (54.9%) males and 461 (45.1%) females aged 43.9 years (16-83). Gastrointestinal conditions were particularly common, and 98% had at least one condition. Further details will be presented.

Conclusions: Using a robust study design in a large population, we have reported the high prevalence of health problems in this population, and multi-morbidity.

A sociological exploration of the impact of hate crime on the health and wellbeing of people with learning disabilities in Scotland

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Background
The health and wellbeing of people with learning disabilities are shaped and impacted by various social factors such as poverty, social exclusion and discrimination. Central to this will be the targeted violence, hate crime and bullying many people with a learning disability are subjected to. There has to date been little research on how this impacts on the health and wellbeing of people with learning disabilities

Method
We undertook a narrative review of primary theoretical and empirical studies into hate crime and learning disability. Systematic keyword searches were employed across relevant journals and databases which related to learning disability, hate crime, and health. This inductive approach has allowed for reformulations and reflective interpretation of the relevant material.

Results
The narrative review of the literature located several gaps relating to health, hate crime and violence. This paper presents key thematic issues relating to hate crime, learning disability and health and forms part of an on-going qualitative exploration into hate crime, learning disability and health. This paper will examine vulnerability in relation to learning disability, the efficacy of the term itself and the necessity for more focused examination of the relationship between targeted violence, hate crime and health.

Conclusions
People with learning disabilities are subjected to targeted violence and harassment and are also more likely to experience poor health outcomes as a result. The findings presented will highlight the gaps in existing research into hate crime, health learning disability and will add to existing knowledge about health inequalities and learning disability. This is being further investigated by the Scottish Learning Disabilities Observatory.

Suicidality in adolescents and adults with and without an autism spectrum condition

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Background
Adults with Autism Spectrum Conditions (ASC) may be at high risk of suicidality (Cassidy et al. 2014). However, there is little research exploring suicidality in ASC, or whether autistic traits are a risk factor for suicidality in the general population.

Method
25 adolescents and adults with ASC from a specialist clinic, and 43 adolescents and adults without ASC completed an online survey including; the Autism Spectrum Quotient (AQ); age diagnosed with ASC; lifetime experience of suicidal ideation; suicide plans; suicide attempts; and non-suicidal self-injury.

Results
Mean age of ASC diagnosis was 21.4 years (range 13-45, SD 10.7). Participants with and without ASC were matched on age and education status. Self-reported rates of suicidal ideation in the current ASC sample (60%) were not significantly different to rates reported in a UK clinic sample diagnosed with Asperger Syndrome in adulthood (66%; Cassidy et al. 2014). Participants with ASC were significantly more likely to report lifetime experience of; suicidal ideation (60% vs 25.6%, OR 1.8); suicide plans (32% vs 4.7%, OR 3.5); and non-suicidal self-injury (28% vs 7%, OR 2.3); but not suicide attempts (16% vs 4%) than controls. In the control group, self-reported autistic traits were significantly associated with lifetime experience of suicidal ideation, suicide plans, and suicide attempts, but not non-suicidal self-injury.

Conclusions
Results confirm consistently high rates of suicidal ideation in adolescents and adults with ASC, in approximately two thirds of patients, and suggest an association between autistic traits, and increased risk of suicidality.

The developmental trajectory of early social cognition skills in children with Fragile X syndrome

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Background

Although individuals with Fragile X syndrome (FXS) have a heightened likelihood of reaching cut-off scores on assessments of autism spectrum disorders (ASD), fine-grained analysis of ASD-like characteristics highlight their unique socio-behavioural profile. Other disorders with atypical social profiles present diverging developmental trajectories of social cognitive skills, which may underpin their social development. To further this line of enquiry, this study investigated the developmental sequence of early social cognitive skills in children with FXS.

Method

Twenty-two children with FXS aged two to twelve years old (Mage=5.45, SD=2.61) participated in the 'Early Social Cognition Scale' (Powis, 2014), assessing early social cognition skills that typically emerge in a strict developmental order. Tasks included: 'helping' (14 months), 'Re-enactment of Intended Acts' (REI) and 'Point' (18 months), 'Gaze' and 'Tubes-with-handles' (24 months), and 'Trampoline' (>24 months).

Results

The percentages of children who passed each task revealed a divergent developmental sequence: 86% passed 'REI', 82% passed 'helping', 36% passed 'tubes-with-handles', 32% passed 'point', 23% passed 'gaze' and 18% passed 'trampoline'. McNemar's tests with Yate's correction for continuity between the five task pairs that differed in increasing difficulty revealed only the 'helping' and 'tubes-with-handles' tasks significantly differed in difficulty (p=0.03).

Conclusions

Although children with FXS develop early abilities ('helping' and 'REI'), they present an overall deficit in later abilities despite many participants reaching the developmental age that these abilities typically emerge. This suggests that there may be an underlying mechanism other than general cognitive ability disrupting social cognitive development in children with FXS.

Behavioural family therapy with people with intellectual disabilities: a feasibility study

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Background

Behavioural Family Therapy (BFT) is recommended as an evidence-based intervention, recommended within NICE and SIGN guidelines in mainstream mental health services when working with adults with psychosis and their families. BFT is a relatively new initiative in the field of intellectual disability (ID), which has been steadily developing across Scottish Health Boards in recent years, with clinicians trained from a variety of professional backgrounds using the approach. Single-case evidence supports the use of BFT with adults with IDs and their families. The aim of this study was to establish the feasibility of conducting a future effectiveness trial of BFT with adults with IDs and their families.

Method

The study was conducted across five NHS Scotland territorial Health Boards. Case record reviews were used to gather data on treatment and retention rates, reasons for disengagement and consistency between therapists.

Results

Seventy-eight families who have received BFT were identified, with feasibility data gathered for 63 of these families. The mean number of families starting BFT each year (2010 -2015) was 8.3. 45.2% of families did not complete treatment. There were difficulties identifying what constituted treatment completion and fidelity to treatment was found to be difficult to assess. Consistent data on referral rates was not available across Health Boards.

Conclusions

Numbers treated and retention rates suggest that an outcome trial may be feasible; however, standardised methods of data collection and management require to be introduced across Health Boards. The issue of measuring fidelity to treatment, within this formulation-driven intervention, requires to be addressed.

POSTER PRESENTATIONS

Comparison of the HONOS-LD and challenging behaviour interview

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Improving IAPT for people with learning disabilities from service users' and clinicians' perspectives: an action research project

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Profiling the behavioural phenotype of Potocki-Lupski syndrome

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Bringing together improving access to psychological therapies (IAPT) teams and community learning disability teams (CTLDS) to improve use of mainstream mental health services by people with learning disabilities: an evaluation of an action learning approach

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Health problems in adults with profound intellectual and multiple disabilities (PIMD): parents' insights into communication with health staff, accessibility and attitudes

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The use of Lycra splinting garments for people with learning disabilities who fall due to balance and/or gait issues

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The experience and outcomes of an adapted DBT skills training group for adults with learning disabilities

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Impact of practice leadership management style on staff experience in services for people with intellectual disability and challenging behaviour: a further examination and partial replication

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Vision awareness training for health and social care professionals working with people with intellectual disabilities: post-training outcomes

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Placement decisions of families co-residing with an adult relative with an intellectual disability

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Developing an educational infrastructure in Positive Behaviour Support

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The structure of maternal positivity in families of children with severe intellectual disability and the association with child behaviour problems

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Mindfulness-based support for parents of children with developmental disabilities: a pilot evaluation

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A multilevel analysis of relationship satisfaction between parents of children with autism spectrum disorders

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Mental health problems and challenging behaviour among individuals with learning disabilities: The work of NCMH

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Do relational interventions with direct care staff impact on challenging behaviour displayed by patients with intellectual disabilities?

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How do people with learning disability experience the city centre?

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Increasing understanding of the factors that influence the effectiveness of learning disability nursing interventions in Scotland uk: literature review

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"It's different, but it's the same." Experiences of young adults with siblings with intellectual disabilities who live in residential care: an interpretative phenomenological analysis

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The role of parental locus of control and child behaviour on subjective wellbeing for mothers of children with heterogeneous intellectual and developmental disabilities

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Supported work experience and its impact on young people with intellectual disabilities and their families

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Working together to develop research

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An integrated health and social care team in Scotland: staff perceptions of past and future change

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Does perceived parenting style mediate the relationship between anxiety and attachment styles in adult siblings of individuals with developmental disabilities?

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Prevalence and types of unexplained symptoms in adults with intellectual disabilities

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Quality of life in adults and adolescents with genetic syndromes associated with intellectual disability

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Injuries reported for adults with learning disabilities who live with paid support in Scotland: a comparison with Scottish adults in the general population

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Characterising the hospital experiences of adults with learning disabilities (HEALeD)

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Use of information on outcomes and quality of services in decision making about services for people with intellectual disabilities and autism

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Health of people with autism spectrum disorder and intellectual disabilities. A whole country cohort study

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Including supporters in individual therapy with clients with intellectual disabilities: A survey of the practices and views of psychologists

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A case series to examine whether people with intellectual disabilities (ID) can learn to link mediating cognitions to subsequent emotional responses

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Evaluation of the inclusion of teenagers and young adults with ID within the Real Opportunities Project in Wales

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The intellectual assessment of asylum seekers: known knowns, known unknowns and unknown unknowns

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Delineating impulsive behaviour in children with Tuberous Sclerosis Complex

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Determining eligibility for paralympic sports: preliminary findings

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The last months of life for adults with intellectual disabilities: reporting the core data

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Hospital admissions for people with intellectual disabilities: systematic review

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What is the impact of transition on health and wellbeing in young people with intellectual disabilities? A systematic review

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ABOUT THE SEATTLE CLUB

The Seattle Club was born at an informal meeting of UK intellectual disability researchers in Seattle in 2000. Participants were attending the IASSID World Congress, and reflected on the lack of a conference for researchers only in the UK.

The first Seattle Club (as it became known, and reflecting it's origin) conference was held at the University of Birmingham in December 2001. A conference has then taken place every year since and always in December.

Researchers offer to organise the event, and bear many of the administrative costs themselves – ensuring that the delegate fee is low. The conference takes place over two days, with a poster session and a social gathering. From 2015 onwards, the invited lecture is to be known as the David Felce Research Lecture in honour of David's substantial contribution to intellectual disability research in the UK and internationally.

A number of Seattle Club traditions have been in place since the first meeting:

■ All participants must submit a poster or paper that describes the results of a research project (qualitative or quantitative) on intellectual disabilities.

■ The only exceptions to this rule are made for PhD students at the beginning of their projects and other 'early stage' researchers who have not yet had the opportunity to complete a research study via the award of a studentship

■ All papers and posters must include analysis of unpublished data

■ Each participant is only allowed to submit one poster or paper where they are the first author/presenter

■ There are no parallel sessions, so everybody listens to all of the presentations

ACKNOWLEDGEMENTS

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Dr. Stephen Beyer, Dr. Stuart Todd and Prof. Richard Hastings
Conference Planning Team