Seattle Club @ Tizard 2014

at the Canterbury Cathedral Lodge, Canterbury CT1 2EH

11th & 12th December 2014
The Tizard Centre at the University of Kent (www.kent.ac.uk/tizard) is delighted to welcome you all to the 14th Seattle Club Conference at the Cathedral Lodge, Canterbury. The conference offers a rare opportunity for researchers in intellectual and developmental disabilities in the UK and Republic of Ireland to meet and share current work and to plan and discuss future collaborations.

In the tradition of the Seattle Club there will be:

- A focus on data-based presentations reporting findings gained through appropriate application of quantitative and qualitative methods.
- No parallel sessions – everyone listens to all oral presentations
- Equal weight in terms of worth, rigour and status attached to oral papers and posters. The selection of the contributions for oral and poster presentation is designed to achieve a mixture of more established and early career researchers.
- Participants restricted to authors and co-authors of accepted oral and poster presentations together with researchers at the beginning of their research careers, who have applied for and been awarded Seattle Club Studentships.

Many thanks must go to Dr Stuart Todd who seems to have single-handedly organised last year’s event held at the Radisson Blue Hotel in Cardiff under the auspices of the University of South Wales.

We hope that you will have an excellent time in Canterbury and enjoy the fantastic venue located in Canterbury Cathedral grounds.
Seattle Club Studentships 2014

83 researchers this year are attending the Seattle Club meeting as holders of Seattle Club Studentships. They are early in their research careers and do not yet have data to present. Please extend a warm welcome to them all. We look forward to hearing about their research in future years. This year’s studentship holders are:

- Clare Melvin
- Rosin Magee
- Lauren Nicholas
- Hayley Marwood
- Melina Malli
14th Seattle Club Conference – Canterbury 2014

Canterbury Cathedral Lodge, Foyer/Kentish Barn

Thursday 11th December 2014
Registration and coffee: 10.00 – 10.30
Welcome: 10.30-10.45 – Prof Glynis Murphy

Session 1 (Clagett Auditorium): 10.45–12.25

Session Chair: Glynis Murphy


12.00 -12.25  An evaluation of positive behaviour support Training. Anne MacDonald, Peter McGill.

Lunch (Kentish Barn): 12.25 – 13.15
Keynote Presentation: 13.15 – 14.15

Claggett Auditorium

How does research have an impact on the daily lives of people with intellectual disabilities?

Prof. Chris Hatton
Centre for Disability Research, Lancaster University & Co-Director of the Public Health England Learning Disabilities Observatory.

Session 2 (Claggett Auditorium): 14.15-15.30

Session Chair: Andrew Jahoda


14.40-15.05 What are the experiences of young people who have a cleft lip/palate in addition to a learning disability? Amanda Bates, Rachel Forrester-Jones, Michelle McCarthy.

15.05-15.30 Understanding the support needs and priorities of people with intellectual disabilities from minority ethnic groups. John Rose, Gemma Unwin, Biza Stenfert Kroese, Michael Larkin.

Coffee/Tea (Kentish Barn): 15.30-15.50
Session 3 (Claggett Auditorium): 15.50-17.05

Session Chair: Peter McGill

15.50-16:15 A national survey of Rett Syndrome: clinical severity, current abilities and health. David Felce, Rina Cianfaglione, Mike Kerr, Angus Clarke, Richard Hastings, Chris Oliver.


16.40-17.05 Development of the Autistic Catatonia Questionnaire and the empirical investigation of catatonia in people with autism spectrum disorder. Dougal Hare, Jennifer Breen, Penny Trayner.

18.00-19.30 Poster Session (Kentish Barn) – with wine
20.00 Dinner (Claggett Auditorium)

Friday 12th December 2014
Session 4 (Claggett Auditorium): 9.30-10.45

Session Chair: David Felce

9.45-9.55  HTA Funding – update, Paul Willner

9.55-10.20 My health my say: making the Friends and Family Test accessible for adults with intellectual disabilities. Roman Raczka, Janice Williams, Kate Theodore.

10.20-10.45 Computerised training in cognitive behavioural therapy skills: a randomised experiment. Leen Vereenooghe, Peter Langdon.

Coffee/Tea (Kentish Barn): 10.45-11.05

Session 5 (Claggett Auditorium): 11.05-12.20

Session Chair: John Rose


11.30-11.55 Investigating arousal and challenging behaviour in Fragile X Syndrome. Rebecca Hardiman, Alison Bratt, Peter McGill.
11.55-12.20 Medical student attitudes towards healthcare for people with learning disabilities. Travis Ryan, Katrina Scior.

Lunch (Kentish Barn): 12.20-13.20

Session 6 (Claggett Auditorium): 13.20-14.35

Session Chair: Peter Langdon

13.20 -13.45 Paralympic competition – the impact of intellectual disabilities on athletic performances. Jan Burns


14.10-14.35 Can active support improve job satisfaction amongst direct care staff in learning disability settings? Jennifer Rhodes, Sandy Toogood

Closing Comments (Claggett Auditorium): 14.35-14.45

Conference Closes. Tea/Coffee: 14.45

Abstracts: Oral presentations
**Session 1**

**Presentation 1: John L Taylor** [john.taylor@ntw.nhs.uk](mailto:john.taylor@ntw.nhs.uk)  Raymond W Novaco, Bruce T Gillmer, Toni Brown.

**Title:** Reductions in aggression and violence following cognitive behavioural anger treatment for detained patients with intellectual disabilities.

**Background:** Aggression is a significant problem amongst people with intellectual disabilities, particularly those residing in hospital settings. Anger is related to aggression in secure services working with people with intellectual disabilities and the effectiveness of psychological interventions in reducing anger has been demonstrated in this population. However, no studies have systematically examined whether levels of aggression reduce following anger treatment with people with intellectual disabilities detained in secure settings.

**Methods:** This programme evaluation study concerns individually-delivered cognitive anger treatment delivered to 50 patients (44 men and 6 women) with mild intellectual disabilities, delivered twice weekly for 18 sessions in a specialist forensic service. Aggressive incidents and physical assault data were obtained from records 12 months pre-treatment and 12 months post-treatment.

**Results:** Following completion of treatment the total number of aggressive incidents recorded in patients files fell by 34.5% and the post-treatment reduction in the number of physical assaults was 55.9%. Analysis of the data partitioned into 6 month blocks over the 24-month study period using repeated measures ANOVA showed that significant reductions in aggressive and violent incidents directed at others occurred in the assessment intervals following anger treatment. Further, in hierarchical regressions, reductions in physical assaults were found to be associated with pre- to post-treatment changes in anger levels.

**Conclusions:** These findings reinforce the efficacy of cognitive behavioural anger treatment for patients with intellectual disabilities and histories of aggression; and despite its methodological limitations the study indicates the ecological validity of this treatment approach.

**Presentation 2: Peter McGill** [P.McGill@kent.ac.uk](mailto:P.McGill@kent.ac.uk)  Leah Vanono, Will Clover, Emmett Smyth, Vivien Cooper, Lisa Hopkins.

**Title:** Preventing challenging behaviour of adults with complex needs in supported accommodation.

**Background:** Does improving the quality of social care in areas associated with behaviour that challenges prevent and reduce the severity of challenging behaviour and improve outcomes for service users and the staff supporting them?

**Methods:** Twenty four settings were randomly allocated to experimental or control group. Within the experimental group social care practice was reviewed. Improvement programmes were operationalised as standards to be achieved during intervention. Their achievement was supported through a range of activities centred on coaching managers and staff to enhance their performance and draw more effectively on existing resources. Progress was monitored monthly over approximately 9 months with a visual record of change being fed back to each setting. Data on people with learning disabilities and the staff supporting them allowed comparison of experimental and control groups before and after the intervention.

**Results:** 75% of standards set were achieved across settings. Structured observations blind to group membership showed substantial improvements in staff performance (e.g. in provision of activities, choice, demand presentation). Participation in meaningful activity by service users increased significantly. Ratings of challenging behaviour showed very substantial reductions in the
experimental group and this was echoed by the structured observations. Staff reported a better quality of working life and many said they had gained skills and found the intervention enjoyable. **Conclusions:** Some challenging behaviour in social care settings may be prevented by relatively simple interventions which attend to the quality of social care support, especially with respect to communication, health, activities, relationships and the wider social and physical environment.

**Presentation 3: Ian Brown**  
ian.brown16@nhs.net  
Gyles Glover, Anthony Holland.

**Title:** Variations in use of in-patient psychiatric care for people with intellectual disabilities: observations and implications.

**Background:** The Health and Social Care Information Centre (HSCIC) undertook a census of all psychiatric inpatients with intellectual disabilities or autism in England in September 2013. We undertook a secondary analysis. Here we present findings about the detailed variation in prevalence around the country, and implications for provision of services to move care from hospital to community settings.

**Methods:** Census data were supplied by HSCIC; we drew population denominator data from GP practice learning disability registers and school special educational need data. We used Chi-square and logistic regression to identify correlations and control for confounding.

**Results:** Overall prevalence of inpatient psychiatric care for adults with a LD was 30% that for the general population. Regional prevalence in the North East was four times that in the South West. 6 out of 10 regions deviated significantly from the overall England figure. Stay-to-census times were more evenly distributed suggesting that differences in admission rates underlie this. The paper examines inter-regional variations in reason for admission, ward type, security level, treatment plans and legal status. Groups with specifically worrying combinations of characteristic are considered.

**Conclusions:** The paper considers the implications of these findings for the current government policy to achieve substantial and rapid reductions in the numbers of inpatients.

**Presentation 4: Ann McDonald**  
amacdonald@trfs.org.uk  
Peter McGill.

**Title:** An evaluation of Positive Behaviour Support training.

**Background:** Challenging behaviour has a negative impact on the lives of individuals with intellectual disabilities. It is linked to decreased levels of support from staff, and to reduced opportunities for inclusion in the community. Positive Behaviour Support (PBS) has been shown to be effective in minimising challenging behaviour; however there is still limited use of PBS and specialist teams are limited in scope and coverage. There is therefore a need to build the skills of ordinary staff in local care organisations. The aim of this study was to evaluate the impact of training social care managers of community-based intellectual disability services in PBS.

**Methods:** A university-accredited longitudinal training programme in PBS was delivered to 50 first level managers of community-based services for people with intellectual disabilities and challenging behaviour. The training programme lasted a year, and was delivered over 2 cohorts. Data were collected pre and post training, and at 6 month follow-up, for managers, their staff teams, and the service users they support. A non-randomised control group design was used.

**Results:** Initial data demonstrate reduction in severity and frequency of challenging behaviour and increased service user engagement, although these changes were not fully maintained over time. Staff data show increased positive contact and assistance to service users, with this increasing further at follow-up.
**Conclusions:** This study has demonstrated that training social care managers in PBS can change how staff support people with intellectual disabilities, and can also have a positive impact on the lives of people with intellectual disabilities who have challenging behaviour.

**Session 2**

**Presentation 1:** Deborah Chinn [deborah.chinn@kcl.ac.uk](mailto:deborah.chinn@kcl.ac.uk) Tony Levitan.

**Title:** Equity in social care provision for people with intellectual disabilities? Distribution of social care funding across and within local authorities in England.

**Background:** In children’s services, variations in socioeconomic deprivation between local authorities (LAs) appear to explain large discrepancies in resources expended on interventions. Moreover, in some areas of provision there is evidence of an “inverse care law” within LAs with citizens in better-off neighbourhoods securing more extensive input. We conducted two studies to explore relationships between social care provision to people with intellectual disabilities (ID) and their place of residence. On a national level we compared better off and more deprived LAs, while a local audit analysed the distribution of social care resources within one very economically diverse metropolitan LA.

**Methods:** National data was sourced from publicly available reports of spending of 151 English LAs for 2010/2011 and from their Index of Multiple Deprivation (IMD) scores. For the local audit the local authority database provided data on individual characteristics of service users with ID (n=328), their individual social care budgets, and IMD scores associated with their own and family of origin home addresses.

**Results:** Nationally, more deprived LAs were found to support fewer people with ID. The local audit data indicated that most service users were living in more deprived neighbourhoods, but did not suggest any relationships between service user or family postcode IMD scores and social care allocations.

**Conclusions:** In England people with ID appear to experience social care inequalities with those in more deprived LAs having a lower chance of receiving social care funding. At a local level allocation of individual care packages appears to be a complex, multi-factorial process.

**Presentation 2:** Amanda Bates [ajb61@kent.ac.uk](mailto:ajb61@kent.ac.uk) Rachel Forrester-Jones, Michelle McCarthy.

**Title:** What are the experiences of young people who have a cleft lip/ palate in addition to a learning disability?

**Background:** Present at birth, a cleft lip/ palate affecting 1 in 700 births, requires a number of interventions (e.g. surgical, speech and language therapy) from birth until late adolescence. Increased psychosocial problems have been reported in the literature for young people with an additional condition(s) to a cleft lip/ palate (CL/P) (Billaud-Feragen and Stock 2014). However, the presence of a learning disability (LD) in addition to a CL/P remains unexplored. How young people with LDs experience their different appearance, their surgery and treatment and their social support is unknown. It is therefore difficult to identify what their needs are and if additional support is required.

**Methods:** Semi-structured interviews (n= 16) were carried out with young people (aged 9-16) who had a CL/P in addition to an LD. The data is being analysed using thematic analysis.
**Results:** Emerging themes include experiences of bullying and worries about cleft surgery/treatment. Data analysis is underway at the time of writing, but by the time of the conference in December, it will be possible to present themes and results for the first time.

**Conclusions:** When a child has an additional condition to an LD which requires medical intervention, a number of difficulties can occur. Appropriate care and support in addition to health professional awareness and training must be carefully planned and tailored to the needs of the individual child.

**Presentation 3: John Rose** j.l.rose@bham.ac.uk Gemma Unwin, Biza Stenfert Kroese, Michael Larkin.

**Title:** Understanding the support needs and priorities of people with intellectual disabilities from minority ethnic groups.

**Background:** To explore the views and experiences of social care/support services among adults with intellectual disabilities (ID) from minority ethnic communities (MECs). To use this information to develop a set of resources called Tools for Talking to facilitate service delivery.

**Methods:** Semi-structured interviews were completed with 32 adults with ID from MECs. The interview transcripts were analysed using a phenomenological-informed approach. A template (thematic map) was derived from analysis of a sub-sample of transcripts and then refined through application to the rest of the sample. Our analyses focused upon the personal and context-sensitive understandings which emerged regarding culture, good support, independence, relational networks, and activities. A partnership event, attended by over 40 service users and service providers was convened to gain feedback on initial results and to co-develop the Tools for Talking.

**Results:** Cultural identity was understood in complex ways. Some held mono-culturally consistent positions on issues such as religion, diet, relationships and family; others drew upon multi-cultural frameworks. Participants had few complaints about the cultural appropriateness of the services they received for them; this was not the critical issue for deciding whether a service was good. Good support was personally-attuned and often assessed against specific individuals, most often, key support workers about whom the participants were generally very positive. Independence was an important topic comprising a specific set of skills as well as being able to do what you want, when you want. Understandings of independence varied across participants and was a source of tension with services who were perceived as playing a key role in decision making and planning.

**Conclusions:** Diversity was prominent in our participants’ accounts. We developed illustrative narratives, digital stories (short films) and a series of activities for service providers to use with people with ID for each of the themes to facilitate service planning and delivery. These Tools for Talking (www.ToolsforTalking.co.uk) may help service providers to better understand service users’ identities, needs, preferences and expectations.

**Session 3**

**Presentation 1: David Felce** felce@cf.ac.uk Rina Cianfaglione, Mike Kerr, Angus Clarke, Richard P. Hastings, Chris Oliver.

**Title:** A national survey of Rett syndrome: Clinical severity, current abilities and health.

**Background:** As part of a wider study to investigate the behavioural phenotype of girls and women with Rett syndrome (RTT) and its relationship to parental well-being, the development, clinical
severity, current abilities and health of a national sample were analysed in relation to diagnostic, clinical and genetic mutation categories.

**Methods:** The sample were 91 girls and women with a diagnosis of RTT, aged from 4 to 47 years (mean =20.5 years), of whom 80 (87.9%) lived at home and 11 (12.1%) lived in out-of-family placements. Measurement included early development, adaptive behaviour, health, pain and a RTT specific severity score. The location of a MECP2 mutation was known in 78.0%.

**Results:** Early Truncating mutations or Large Deletions were associated with greater severity. Early regression was also associated with greater severity. All three were associated with lower current abilities. Epilepsy and weight, gastrointestinal and bowel problems were common co-morbidities. Participants with classic RTT had greater health problems than those with atypical RTT. A substantial minority of respondents reported fairly frequent signs of possible pain being experienced by their relative with RTT.

**Conclusions:** Overall, the study provides new data on the current abilities and general health of people with RTT and adds to the evidence that the severity of the condition and variation of subsequent disability, albeit generally within the profound range, may be related to gene mutation. The presence of certain co-morbidities represents a substantial ongoing need for better health. Felt pain requires further investigation.

**Presentation 2:** Dawn Adams [d.m.adams@bham.ac.uk](mailto:d.m.adams@bham.ac.uk) Mary Heald, Louise Handley, Doug Simkiss, Chris Oliver.

**Title:** The impact of behaviour in children with intellectual disabilities on parental mental health: a longitudinal analysis.

**Background:** Parents of children with intellectual disabilities are at a greater risk of experiencing both depression and anxiety. Whilst there is now an extensive literature noting the association between parental mental health difficulties and challenging behaviour, few studies have looked at the influence of more specific behaviours on parents’ levels of psychological distress.

**Methods:** A longitudinal design was used to collect data from 40 mothers of children, aged 2–11, attending NHS Child Development Centres across two time points, 12-18 months apart. Questionnaires were used to gather information on challenging behaviour, parental mental health and behavioural difficulties.

**Results:** At time 1, prevalence rates were 85% for aggression, 65% for destruction of the environment and 40% for self-injury. Rates of persistence were 85% for aggression, 81% for destruction of the environment and 56% for self-injury. Rates of onset were 21% for destruction of the environment and 17% for both aggression and self-injury. Levels of maternal depression were 52.5% at time 1 and 59% at time 2. Anxiety rose from 32.5% at time 1 to 45% at time 2. Binary logistic regression analyses indicated that different forms of behaviour impact differently upon parental anxiety and depression, with overactive and impulsive behaviours and restricted and repetitive behaviours having more significant impact over time on parental mental health than challenging behaviour.

**Conclusions:** It is important to consider more than just challenging behaviour when working with families. Specific behaviours, including overactivity and restrictive and repetitive behaviours may have a more significant impact upon family life than previously recognised.
Presentation 3: Dougal Julian Hare  
dougal.hare@manchester.ac.uk  
Jennifer Breen, Penny Trayner.

**Title:** Development of the Autistic Catatonia Questionnaire and the empirical investigation of catatonia in people with autism spectrum disorder.

**Background:** 6-8% of young people with Autistic Spectrum Disorder (ASD) experience the onset of catatonic-like symptoms in adolescence and are diagnosed with autistic catatonia. Autistic catatonia is an under-researched neurologically-based condition with little known about the presentation and variation of symptoms. The current study investigates autistic catatonia in children and adolescents with ASD using a new measure, the Autistic Catatonia Questionnaire (ACQ) developed for clinical and research purposes. A secondary aim of the study is to complete preliminary investigations into the usefulness of the ACQ as a clinical measure.

**Methods:** Caregivers or parents (n=99) completed the ACQ, the Repetitive Behaviour Scale and the Carer Supplement to the Glasgow Depression Scale for people with Learning Disability.

**Results:** 20% of those present reported an existing diagnosis of autistic catatonia. ROC curve analysis of the ACQ data indicated an autistic catatonia continuum and a cut-off score of three core symptoms was identified to support screening for a diagnosis of autistic catatonia. An association between autistic catatonia and measures of depression and repetitive and restricted behaviours was also identified.

**Conclusions:** The ACQ appears to have utility as a both a clinical measure and research tool and provides for the empirical investigation of autistic catatonia in a way that has not been hitherto possible, thus opening up the possibility of the development of effective evidence-based treatments.

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**Session 4**

**Presentation 1: Paul Willner – HTA Funding update**

**Presentation 2: Dr Roman Raczka**  
roman.raczka@lbhf.gov.uk  
Janice Williams, Dr Kate Theodore.

**Title:** My health my say: Making the Friends and Family Test accessible for adults with intellectual disabilities.

**Background:** The NHS Friends and Family Test (FFT) was introduced to give patients the opportunity to provide feedback on the care they had received, ultimately to improve services. Seeking feedback from vulnerable hard to reach groups is a target.

**Methods:** Through collaboration between local health services, the Rix Centre and HF Mencap, funded by NHS England, this project developed a digital version of the FFT, accessible for people with intellectual disabilities, using an iPad. This was piloted with 153 service users. A randomised proportion of service users completed an easy-read paper version and the others used the iPad. Congruent validity was investigated using the Patient Satisfaction Scale (Hojat et al., 2011). The use of peer test administrators to enhance service users’ ability to give feedback was also evaluated.

**Results:** The iPad App was rated as highly acceptable. 96% said they liked using the iPad App and 92% found it easier to complete than the paper version. The adapted FFT question showed good congruent validity. Feedback from Discussion groups with Peer Test Administrators included: People enjoyed using the iPad because it was much easier to answer the questions. The iPad is a good way for the person to express themselves. At the end the fireworks are quite nice!
Conclusions: An accessible digital version of the FFT was developed with good congruent validity. Feedback from people with intellectual disabilities was overwhelmingly positive. Recommendations for its development and further use are presented.

Presentation 3: Leen Vereenooghe L.Vereenooghe@uea.ac.uk Peter E Langdon.

Title: Computerised training in cognitive behaviour therapy skills: A randomised experiment.

Background: Suitability for cognitive behaviour therapy (CBT) has been described in terms of cognitive, interpersonal and introspective skills. This study aims to train two of the required cognitive skills using a computerised approach: the ability to differentiate between thoughts, feelings and behaviours, and cognitive mediation skills.

Methods: A randomised experiment was conducted to compare the effects of a computerised training programme to an attention-control intervention on three skills essential to undertaking CBT. Fifty-seven participants with mild and moderate intellectual disabilities (IDs) were recruited and assigned to a training or attention-control intervention using matched pairs randomisation, stratified by IQ. Outcome measures included the thought-feeling-behaviour questionnaire (TFBQ) and two tasks assessing cognitive mediation skills.

Results: Baseline assessments showed significantly lower performance on the TFBQ than on the cognitive mediation tasks. Strong correlations were found between TFBQ scores and IQ. Computerised training improved participants’ ability to differentiate between thoughts, feelings and behaviours when compared to the attention-control group. The effects of training on cognitive mediation skills were less clear.

Conclusions: Differentiating between thoughts, feelings and behaviours may be more difficult than understanding cognitive mediation; however, computerised training can be used to improve differentiation skills in some people with IDs. Particular attention should be given to improving CBT skills in people with moderate IDs to increase their accessibility and suitability for CBT.

Session 5

Presentation 1: Barry Ingham barry.ingham@ntw.nhs.uk Heidi Mayer, Stephen Barton, Jeremy Parr.

Title: An exploration of the mental health needs of adults accessing autism diagnosis services.

Background: Autism diagnosis services are well established for children and adolescents; however, the national autism strategy has been a key driver in developing autism diagnosis services for adults, particularly those who do not routinely access specialist mental healthcare. A local NHS Trust has developed a diagnostic approach with adults using a semi-structured interview which gains a developmental history and allows social pressures that elicit information for comparison with autism diagnostic criteria. This development has given an opportunity to better understand the mental healthcare needs of adults with autism who do not routinely access secondary healthcare services.

Methods: A notes review was undertaken on a sample of clients (n=45) who had recently accessed an autism diagnosis service. This was undertaken using a number of criteria to identify a range of demographics including mental health diagnoses (using ICD-10 criteria), healthcare interventions and social care support received.

Results: Approximately a third of adults diagnosed with autism also experienced depression and a third also experienced anxiety. Another 40% experienced other difficulties such as ADHD, personality disorder and sleep problems. The majority of people experiencing depression received
antidepressant medication with a smaller proportion having had or currently receiving psychological therapy.

**Conclusions:** The findings suggest that there are high levels of mental health need within those accessing autism diagnosis services. This is of particular interest as this is a group who do not routinely access secondary mental healthcare services. There are potential implications for identification of needs and appropriate care pathways for adults with autism.

**Presentation 2: Rebecca Hardiman**  
**Title:** Investigating arousal and challenging behaviour in Fragile X Syndrome

**Background:** Atypical physical reactions to stressors are hypothesised to play an important role in the behavioural phenotype of Fragile X Syndrome (FXS). For instance, atypical levels of arousal may enduringly raise the motivation to escape from potentially stressful situations, such as the onset of demands. As such, individuals with FXS may be more likely to engage in challenging behaviours in these situations. The aim of this study was to preliminarily investigate arousal and behavioural function in individuals with FXS, in a naturalistic setting.

**Methods:** Fifteen boys with FXS and fifteen unaffected siblings (eight females) participated. Spit samples were collected at six time points during a typical school day, in order to assess the diurnal profile of cortisol (the output of the endocrine stress system and alpha-amylase (an enzyme indicator of autonomic activation). On the same day data was gathered on the function of FXS participants’ challenging behaviours using Functional Assessment Observation Forms.

**Results:** Statistically significant group differences were observed in levels of cortisol, particularly following awakening. Furthermore, the FXS group showed highly variable alpha-amylase profiles, compared to the sibling group. Within the FXS group, a high frequency of challenging behaviours were observed, including high levels of escape-maintained behaviour and automatically reinforced self-injurious behaviour. Potential relationships between the behavioural and physiological measures will be explored.

**Conclusions:** This study supports that individuals with FXS exhibit atypical levels of stress-related arousal, relative to their siblings. In addition, it provides detailed naturalistic data on the environmental influences on challenging behaviours, which may themselves be influenced by atypical arousal.

**Presentation 3: Travis Ryan**  
**Title:** Medical students’ attitudes towards healthcare for people with learning disabilities.

**Background:** People with learning disabilities experience health inequalities that are avoidable and therefore unjust. Health inequalities are partly due to institutional discrimination, whereby health professionals do not provide care to people with learning disabilities in a manner that appropriately accounts for their health needs. As tomorrow’s doctors, medical students’ attitudes towards healthcare for this group are critically important. Therefore, this research aimed to better understand medical students’ attitudes towards healthcare for people with learning disabilities, and develop and evaluate a measure of this psychological construct.

**Methods:** In Study 1, interviews with 17 medical students were thematically analysed to better understand medical students’ attitudes towards people with learning disabilities. In Study 2, 609 medical students training in the United Kingdom completed an item pool measuring this
psychological construct. Data underwent exploratory factor analysis, confirmatory factor analysis, reliability analyses, and tests of validity.

**Results:** Key themes were identified in Study 1 (e.g., medical students are especially anxious about working with this group and would benefit from more teaching and direct experience with people with learning disabilities). Study 2 detailed the development and evaluation of the new scale whose psychometric properties indicate its suitability for future research.

**Conclusions:** Medical schools’ curricula should be reviewed and opportunities for direct contact and clinical experiences with this patient group increased to better prepare medical students for their role as healthcare providers. The newly developed measure is suitable for determining the efficacy of interventions that aim to enhance medical students’ beliefs about healthcare for this group.

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**Session 6**

**Presentation 1: Jan Burns** jan.burns@canterbury.ac.uk

**Title:** Paralympic competition - the impact of intellectual disabilities on athletic performance.

**Background:** London 2012 saw the re-inclusion of people with intellectual disabilities into the Paralympics. To gain re-inclusion the regulations of the International Paralympic Committee had to be met, including being able to demonstrate athletes have an ID (primary eligibility) and be able to demonstrate how having an ID impacts on the specific sport (performance impairment).

**Methods:** This paper will explain how primary eligibility has been achieved through the collection and scrutiny of cross-cultural diagnostic data of over 3,000 athletes. Intellectual impairment on sports performance has been investigated experimentally within three main events, swimming, table tennis and athletics.

**Results:** From these studies it is clear that whilst there is not a direct association between IQ and sports performance, elite performance for athletes with ID is impaired and they do not meet the standards of performance of non-disabled peers with similar training histories.

**Conclusions:** A summary of these results will be presented and how they relate to the classification system adopted by the IPC will be explained, in addition to further developments in preparation for Rio 2016. This work raises many interesting questions about the label ‘intellectual disabilities’ and how we assess impairments both in the world of elite sports performance but also within clinical contexts.

**Presentation 2: Philippa Appleton** pappleton@hssd.gov.gg  Peter Baker, Rosie Williams, Will Jones

**Title:** Facilitating relationship building in Active Support.

**Background:** Active Support (AS) should arguably promote positive relationships between staff and service users, in addition to increasing engagement in meaningful activities. This study evaluated an enhanced package of AS (Baker & Shephard 2010), which included standard AS training and an additional relationship building component involving video informed reflective practice.

**Methods:** An enhanced AS training package was implemented in 4 residential homes, using a multiple baseline across environments design. Training consisted of a 1 day workshop, and follow-up coaching. Coaching used a video reflective format, to focus on elements of relationship building in addition to standard AS components. MTS was used to measure engagement levels. A new observational tool was piloted to code the presence of negative and positive interactions by staff.

**Results:** 3 of 4 environments showed large effects for engagement level. The 4th showed a ceiling effect. Positive interactions increased, and negative interactions decreased, following training.
Conclusions: AS training that includes an emphasis on relationship building can promote a positive interactional style by staff, in addition to increasing service user engagement levels.

Presentation 3: Jennifer Rhodes  [jenny.rhodes@ntw.nhs.uk](mailto:jenny.rhodes@ntw.nhs.uk)  Sandy Toogood.

Title: Can Active Support improve job satisfaction amongst direct care staff in learning disability settings?

Background: Job satisfaction affects staff turnover and the quality of services provided to people with Learning Disabilities (Coomber & Barriball, 2007; Hatton et al, 2001). One intervention that could help improve job satisfaction is Active Support (AS); a model for training direct care staff to work more effectively with people with Learning Disabilities (Toogood, 2008). AS appears to target key areas which lead to dissatisfaction at work, for example, lack of training and feedback, and lack of time spent with service-users (Ford & Honnor, 2000). The purpose of this study is to explore if the implementation of AS can improve job satisfaction amongst direct care staff in a Learning Disability setting.

Methods: Utilising a single group, repeated measures design, 37 members of direct care staff were trained in AS. Data was collected on the quality of AS (using the Active Support Measure, Mansell & Elliott, 1996) and job satisfaction (using the Staff Satisfaction Questionnaire, Ford & Honnor, 2000) before and after AS. A sample of 19 participants were followed up after 12 weeks.

Results: Statistical analysis showed a significant increase in job satisfaction following the implementation of AS. Subscale analysis revealed that the most significant increases were related to areas directly targeted by AS.

Conclusions: This study has demonstrated that AS can benefit both service-users, who receive better quality interactions, and direct care staff, who feel more satisfied at work. Clinical implications and areas for future research are considered.
Abstracts: Poster presentations

Susannah Baines s.baines1@lancaster.ac.uk  Chris Hatton, Eric Emerson, Gyles Glover.

What do JSNAs tell us about people with learning disabilities?

**Background:** The Health and Social Care Act 2012 made it a statutory requirement that health should be considered on a local level through Joint Health and Wellbeing Strategies based on Joint Strategic Needs Assessments (JSNAs). This study sought information in JSNAs about people with learning disabilities and compared the data to a previous JSNA report published by IHaL in 2013.

**Methods:** Between April and August 2014 Joint Strategic Needs Assessments were sought for all 152 local authority areas using key words in an internet search engine. 137 JSNAs were found. We used a coding template to record for each JSNA the extent and nature of the information they contained on the health and wellbeing of children and adults with learning disabilities.

**Results:** There was a reduction from 82% in 2013 to 72% of the number of local authorities who made any mention of people with learning disabilities. However 65% of local authorities included a specific section (however small) on adults with learning disabilities in their JSNA, up from 48% in 2013. The percentage varied considerably by government office region (from 100% of local authorities in the East Midlands to 43% in Yorkshire and Humber). Considerably fewer local authorities had specific sections on children with learning disabilities (13%, compared to 9% in 2013) or sections on older adults with learning disabilities (11%, compared to 8% in 2013).

**Conclusions:** Overall the number of local authorities including information on people with learning disabilities in their JSNAs has increased, although the amount of information held in JSNAs about people with learning disabilities and accessibility of the JSNAs varies widely between local authorities.

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The behavioural phenotype of Potocki-Lupski syndrome

**Background:** Clinical features of Potocki-Lupski syndrome (PTLS) are reported to include mild to moderate intellectual disability, language delay and infantile hypotonia; however the behavioural phenotype of PTLS is less well defined. Hyperactivity, inattention and obsessive tendencies are noted, together with high rates of Autism Spectrum Disorders. However, further empirical research is required to increase understanding of this relatively recently identified disorder.

**Methods:** Caregivers of children and adults with PTLS were invited via syndrome support groups to complete an online survey, including standardised measures of behaviour. These included measures of demographic information, challenging behaviour, over activity and impulsivity, repetitive behaviour, and a screening tool for features of Autism Spectrum Disorders. Forty caregivers, of 31 children and 9 adults with PTLS, responded to the survey.

**Results:** Findings indicated that over 60% of individuals with PTLS exceeded cut-off scores for Autism Spectrum Disorders and over 25% exceeded the more stringent autism cut-off. Repetitive behaviours included high levels of repetitive questioning. Self-injury was shown by 22.5% of individuals and over half displayed aggression. Impulsivity and over activity ratings exceeded clinical cut-offs for 12.5% and 11.1% of individuals respectively.

**Conclusions:** These results support suggestions that features of Autism Spectrum Disorders are common in PTLS and further indicate that repetitive questioning may be particularly characteristic of the range of repetitive behaviours shown. Challenging behaviours, particularly aggression, were evident. However, hyperactivity at a clinically elevated level was not as prominent as anticipated.
Quality of communication support for people with severe IDD living in supported accommodation settings

Background: Good communication should be part of providing skilled support.
Methods: As part of a wider research project into skilled support (Beadle-Brown et al, in submission), information about communication was collected using a range of measures. These included observations of social interaction and contact from staff, the use of alternative and augmentative communication (AAC), reviews of written information, questionnaires about the needs and characteristics of the people supported and interviews with managers.
Results: Over two thirds (69%) of participants were reported not to use verbal communication and nearly one fifth (18%) were reported as not understanding verbal communication. Those people who were rated by staff as non-verbal were:

- more likely to have objects of reference used with them
- less likely to have appropriate forms of communication used with them
- less likely to have communication that was effective in getting staff attention and a response.

During observations, communication was rated as consistently matching participant level for just over one third of people. Just under half of people (49%) were rated as consistently having their communication responded to. The theme ‘using communication to enable access to information’ emerged from the thematic analysis of the interviews.

Conclusions: There was variability in the quality of support and outcomes but where people with more severe disabilities received consistently good active support they had better outcomes and received better support in other areas, in particular around communication. More research is needed to understand what makes staff good communicators and whether improved communication is an inevitable outcome of person-centred active support.

The effectiveness of positive, function-based interventions for young children with intellectual or developmental disabilities who display challenging behaviour: a systematic review and meta-analysis

Background: Positive behaviour support (PBS) is increasingly recognised as the most effective framework for supporting individuals who have an intellectual/developmental disability (ID/DD) and display challenging behaviour. PBS is well evidence based for adults; however the evidence relating to young children has not been systematically examined. This meta-analysis aimed to identify how effective PBS based interventions are in relation to reducing challenging behaviour for young children with an ID/DD, and what may influence the effectiveness of these interventions.
Methods: Forty articles were identified which presented findings from PBS based interventions for children aged under 7 with an ID/DD. Thirty-three of these were single case design studies, whilst seven presented data from group training based interventions. Data was extracted from the articles and effect sizes were calculated relating to reductions in challenging behaviour. Methodological quality was also examined using the Evaluative Method.
Results: Interventions were generally highly effective. Single case design studies achieved an average 97.51% reduction in challenging behaviour with an average standardised mean difference effect size of 2.3, and group design studies were associated with an average delta effect size of 0.64. Few variables were found to significantly influence effectiveness, with the exception of topography and function of behaviour for single case designs. Subtle, non-significant, differences in effectiveness were also identified. For group designs, interventions which trained family carers in isolation were most effective.

Conclusions: PBS based interventions for young children with an ID/DD are generally highly effective, however more research is needed, particularly in relation to stakeholder training interventions.

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Solicitors’ experiences of representing parents with intellectual disabilities in care proceedings: where is the support for vulnerable and stressed parents?

Background: In contested public law care proceedings involving parents with intellectual disabilities (ID) solicitors may provide legal advice and act for the parents; thus they are in a unique position to comment on the difficulties that parents with ID encounter prior to and during proceedings. This paper reports on an exploratory study of the role of solicitors acting for parents with intellectual disabilities (ID) in public law proceedings.

Methods: In-depth semi structured interviews with eleven solicitors and a subsequent focus group were used to collect data. Thematic analysis was utilised to draw themes from the data.

Results: Three of five themes that emerged will be described here. They are entitled ‘Where’s the support?’ ‘They (Child and LD services) don’t talk to each other’ and ‘Parents- ‘Vulnerable, labelled and stressed.’’

Conclusions: Findings demonstrate that support for parents with ID remains inadequate or non-existent. Possible causes of this are discussed, including the stigmatization and processes of punitive labelling that hamper appropriate support being provided and cause stress that impede parent’s ability to navigate care proceeding systems. Parents with ID continue to be denied opportunities to parent their children in part due to poor understanding and training of professionals and underlying prejudice within systems toward people with ID.

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Using Planning Live as a tool to enhance communication and reduce inpatient admissions

Background: Preventing admission into assessment and treatment units is a national priority for Intellectual Disability services. Planning Live is a Person Centred Planning Tool based on the Essential Lifestyle Planning (ELP) model (Smull & Burke Harrison, date). It has been used by our Enhanced Support Services to increase communication and information sharing between community and inpatient services, and thus to aim to reduce the number and length of inpatient admissions.

Methods: A Planning Live Meeting is a facilitated reflective space which uses a series of flexible guiding questions to support listening to and valuing the contributions of all present, including family members, as experts in the lives of the individual. The aim is to consolidate knowledge about a person, to identify gaps in knowledge and understanding, to stimulate further questions and to formulate an action plan to support the person and those who know and care about them. The meetings are attended by as many people as possible involved in the person’s immediate and extended care.
**Results:** Initially, written feedback from those attending the meetings has been gathered. Feedback suggests that the meetings are seen as helpful by participants. Participants indicate that they would recommend Planning Live to others. However, further data is required before any conclusions can be made about the ability of Planning Live to prevent or reduce length of admission.

**Conclusions:** Further data collection and analysis will reveal whether the intervention reduces the number of inpatient admissions or reduces the length of a person’s stay in hospital.

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**Psychometric properties of the Health of the Nation Outcome Scales (Learning Disabilities)**

**Background:** The Health of the Nation Outcome Scale for People with Learning Disabilities (HoNOS-LD) was developed to measure clinical and social outcomes for people with intellectual disabilities. The scale has been widely used and has been recommended as an outcomes scale for use with people with intellectual disabilities. The properties of the scale have not been well reported.

**Methods:** Data for HoNOS-LD were available for 676 people with intellectual disabilities from an intellectual disability service in the North of England. The service operates with a broad pathway based structure and, based on initial referral and assessment, allocates people with intellectual disabilities into one of four pathways (forensic, challenging behaviour, mental health and physical health). Factor analysis was carried out for the total group and for subgroups based on gender, age, and basis of referral. The ability of the scale to differentiate people allocated into the four pathways was explored.

**Results:** Complete HoNOS-LD data were available for 565 people. A four-factor solution was indicated from the scree-plot, accounted for 49.5% of variance and was robust across subgroups of the data. The factors are tentatively labelled ‘challenging behaviour’, ‘severe intellectual and physical disability’ and ‘mood and mental health’ and ‘social isolation’. The scale differentiated people allocated to each of the pathways with each pathway confirmed by visual profiles across the factors and ANOVA.

**Conclusions:** The HoNOS-LD has a four-factor structure which initially differentiates across groups clinically defined as having primary needs in areas of forensic, mental health, challenging behaviour and physical health.

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**I know it’s wrong but I can’t change it: A pilot Women’s Assertiveness Group intervention for women with mild/ borderline intellectual disabilities**

**Background:** Many women with mild intellectual disabilities (ID) face a variety of practical and emotional challenges in their lives, and can struggle with the consequences of these challenges, often leading to significant emotional distress and negative self-beliefs. Recognizing this, an Assertiveness group intervention was designed and piloted, aiming to promote increased assertiveness with professionals, family, friends and partners.

**Methods:** The pilot included women with mild/borderline ID, living independently, who identified difficulties in asserting themselves in a screening assessment. The women completed a ten week pilot course. All sessions were designed to be accessible to women with limited literacy.

**Results:** Six women began and completed the pilot course. Participants completed the CORE-LD, the Adapted Rosenberg Self Esteem Scale and scaling questions targeted at each participant’s specific difficulties. Increase in knowledge was also measured and participant feedback gathered.
Participants reported improved general self-esteem, improved confidence in asserting themselves and general well-being. Participants’ knowledge around assertiveness and their rights also improved. **Conclusions:** Participants who completed the pilot reported significant difficulties with partners, family, friends and professionals at the start of the intervention. Results demonstrated that a targeted group intervention was able to increase knowledge, improve general self-esteem and also confidence in acting assertively. Furthermore, participant feedback suggested addressing Assertiveness for women in a group format was valued by participants.

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**Low Arousal approaches for the short term management of challenging behaviour in people with intellectual disabilities: developing a Low Arousal Questionnaire**

**Background:** Challenging behaviours are mediated for participants, staff and service users, by their state of physiological/emotional arousal (often heightened) and responding in crisis situations is one of the most difficult areas of supporting people with challenging behaviour, suggesting its high priority. One description of potential ethical, effective responses is Low Arousal (LA). Four key areas of LA include: reduction of staff demands and requests in a crisis, avoiding potentially arousing triggers (direct eye contact, touch) exploration of staff beliefs about the short-term management of challenging behaviours and emotional support to staff.  

**Methods:** The Staff Perceptions of Challenging Behaviour Questionnaire (SPCBQ) was developed by practitioners and trainers in behavioural management to examine staff views related to LA. A single point in time survey was administered within four Irish organisations (152 responses). The SPCBQ was administered with: The Controllability scale (Dagnan et al., 2013) The Difficult Behaviour Self-Efficacy scale (Hastings & Brown, 2002) and the Five Facet Mindfulness Questionnaire (e.g. Baer et al., 2008).  

**Results:** A variety of descriptive and psychometric statistics will be reported e.g. correlation and internal reliability.  

**Conclusions:** Will be reported at the conference.

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**‘Good Things’ and ‘Bad Things’ about medicine use: what people with intellectual disabilities can tell us**

**Background:** People with intellectual disabilities (PWID) have multiple morbidities and many are users of multiple medications. For safe medication use it is important that PWID and their carers can recognise medication side effects. Education and information on medication are important and should be provided by the prescriber, pharmacist, nurse and others. The aim of this project was to establish the knowledge PWID had about the medicines they were taking.  

**Methods:** Ethics approval was received from the university Research Ethics Committee. Six PWID consented for themselves to take part and were interviewed using a semi structured tool. The interviews took place in a location familiar to each person. All participants were accompanied by a counsellor. No technical recording of the interviews was allowed. A Grounded Theory approach was used to analyse the interviews.  

**Results:** All participants had some knowledge of the medication they were taking. Participants were not familiar with the term ‘side effects’. They did relate to the terms ‘good things’ and ‘bad things’ and were able to articulate accurately how they felt about medicines. Four participants reported that they have never received accessible information from the doctor or the pharmacist.
Conclusions: Pharmacists have a responsibility to ensure that all patients including those with intellectual disabilities obtain the maximum positive health outcomes from their medications. Grounded theory is ideal for exploring social relationships and group behaviour in the medication use in the population with intellectual disabilities. Clinicians and carers discussing medication use should consider using language accessible to PWID.

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Breastfeeding duration amongst children with and without intellectual disability: A secondary analysis of the UK’s Millennium Cohort Study (MCS)

Background: Children with intellectual disability experience poorer health and wellbeing relative to their typically developing peers but between 20 and 50% of this difference may be accounted for by increased exposure to socio-economic disadvantage. Little is known however about mediating pathways or factors that may support resilience in this area. Duration of breastfeeding in infancy has been found to predict health outcomes in the general population. The current study therefore compared the extent to which a cohort of children with intellectual disabilities were breastfed (both in terms of whether they were ever breastfed and duration of breastfeeding) relative to their non-disabled peers and the socio-economic factors that were associated with this.

Methods: The study is based on secondary analysis of the first four waves of data collected by the UK’s Millennium Cohort Study (MCS). Children with intellectual disability were predominantly identified based on cognitive test scores that were 2 standard deviations or more below the mean. Those with ASD were identified based on parental report. Breastfeeding, based on parental report at nine months was identified in terms of whether the child had ever been breast fed and additionally whether they had been partially or exclusively breast fed at 3 months and 6 months. Information was also identified relating to Household Poverty and Neighbourhood Deprivation, Maternal Resources and Maternal Health & Wellbeing.

Results: The results of our study indicate that: (1) children with intellectual disability were significantly less likely than their peers to be ever breast fed, breastfed at three months, exclusively breastfed at three months and breastfed at six months; (2) they were also significantly more likely than their peers to be exposed to environmental conditions associated with lower rates of breastfeeding (income poverty, family hardship, no adult in the family working, neighbourhood deprivation, low education, single parent household and mother being a current smoker; (3) adjusting for these between-group differences in exposure to these environmental risk factors reduced the risk of children with intellectual disability not being breastfed to statistical insignificance for all indicators of breastfeeding.

Conclusions: Children with intellectual disability are at risk of not being breastfed, but that this appears to be due to the less advantageous social circumstances of their family (rather than because they have intellectual disability). There is some suggestion that breastfeeding could be one of the mediating pathways through which the less advantageous social circumstances faced by children with intellectual disability leads to poorer health.
Body image dissatisfaction in people with learning disabilities: presence and phenomelological presentation

**Background:** Body image dissatisfaction is thought to exist on a continuum, at the clinical end of which lie eating disorders (ED) and body dysmorphic disorder (BDD). Despite suggestions of a greater prevalence of mental health issues in general in people with learning disabilities, the presence or absence of body image dissatisfaction in this population has not been previously explored. The aims of this study were to a) establish the presence of body image dissatisfaction in adults with mild learning disabilities and b) explore the content of this dissatisfaction using the contexts of eating disorders, BDD and physical disabilities.

**Methods:** Eight people with a mild LD aged between 27 and 46 years engaged in two sessions. Session one encompassed a range of questionnaires assessing potentially confounding variables. Session two comprised a semi-structured interview measuring body image dissatisfaction and its impact upon cognition, affect and behaviour.

**Results:** All participants (n=8) expressed body image dissatisfaction, with a range of severity. All rated investment in appearance as at least ‘quite important’ and all reported some level of worry concerning their appearance. Participants who displayed greater severity of body image dissatisfaction reported a greater range of safety-seeking and camouflaging behaviours. Participants reported a range of reasons for dissatisfaction, reflecting weight/shape and feature-specific dimensions and the functional and aesthetic impact of physical disabilities.

**Conclusions:** Phenomenology of body image dissatisfaction in this sample included salient cognitions, affect and behavioural attempts to manage distress that are reminiscent of those in mainstream ED, BDD and physical disability literatures.

Using repertory grid techniques to measure change following Dialectical Behaviour Therapy with adults with intellectual disabilities: two case studies

**Background:** There is a move to support adults with intellectual disabilities accessing appropriately adapted psychological therapies, including DBT amongst other treatments. However, to date there has been little published research regarding the efficacy of Dialectical Behaviour Therapy (DBT) for adults with learning disabilities, despite it being recommended for the treatment of Borderline Personality Disorder (BPD). Extant research in this field primarily focuses on measures of behavioural and psychiatric change, with little emphasis on the psychological changes that occur.

**Methods:** Two case studies utilising repertory grids completed before and after completing a DBT programme.

**Results:** The repertory grids were formally analysed using the Idiogrid software package. This indicated changes in overall construing of self and others, changes in evident self-esteem and a number of important implicative dilemmas in both cases.

**Conclusions:** The contrasting case studies demonstrate the complexity and idiosyncrasy of the experiences of individuals with intellectual disabilities who received DBT. The Repertory grid technique also appeared to have face-validity for the participants. A key strength of repertory grid data is that it provides a rich source of information that may not have been within the awareness of the individuals prior to its assessment. Such information can be used by clinicians and individuals to contribute to psychological formulations and collaboratively develop an understanding of how each person sees themselves within their environment.
Alterations in personal constructs following Dialectical Behaviour Therapy (DBT) for adults with intellectual disabilities

**Background:** Dialectical Behaviour Therapy (DBT) is recommended for the treatment of Borderline Personality Disorder (BPD). There is evidence that psychological interventions can be successfully adapted for the needs of individuals with intellectual and developmental disabilities (ID/D), however little research has been conducted regarding DBT for people with ID/D. Repertory grid methodology, based on Personal Construct Theory (PCT), provides a structured tool to gain understanding of how individuals perceive themselves and others. There is evidence that suggests that this personal construing is related to self-esteem, cognitive complexity and psychological distress, and is influenced by factors including a history of trauma. Construing can change following therapeutic interventions, and repertory grids can be used as an outcome measure.

**Methods:** The current study explored changes in personal construing, as measured using repertory grids, following DBT for seven adults with ID/D. Two participants disengaged from therapy; however the outcomes for the remaining five are reported.

**Results:** Following DBT, there was evidence that personal construing had changed, and of improvements in self-esteem. There was no evidence that participants had altered tightness of construing. Three participants had resolved dilemmas in their construing following DBT, however one participant developed new dilemmas. Both participants who disengaged had implicative dilemmas, suggesting that they may have found some changes threatening to their sense of self.

**Conclusions:** The study demonstrates that repertory grids can successfully capture psychological change in adults with ID/D who complete DBT.

Dialectical Behaviour Therapy for people with mild intellectual disabilities

**Background:** Dialectical Behaviour Therapy (DBT) is a multi-modal treatment that has been shown to be effective for individuals with Borderline Personality Disorder (BPD) in the general population. There is evidence that psychological therapies can be adapted for individuals with Intellectual and Developmental Disabilities (ID/D), however there is little research regarding DBT for adults with ID/D to date.

**Methods:** Data was analysed for N=18 adults with mild ID who participated in an adapted DBT programme run over a three year period. DBT was offered to service users identified as having long-standing difficulties including self-harm, para-suicidal behaviours, use of alcohol and substances as a coping strategy, anger and aggression, and relationship difficulties. The Glasgow Depression Scale, Novaco Anger Scale (Northgate Modification) and the Cognitive Affective Mindfulness Scale- Revised were routinely completed over the course of the DBT programme.

**Results:** The current study found significant reductions on measures of depression, anxiety and anger on completion of the DBT programme. Participants also had increased mindfulness skills following DBT. There were some additional improvements in anxiety and mindfulness for participants who repeated the DBT skills group.

**Conclusions:** The findings from the current study show that DBT can be successfully adapted for adults with ID/D, however future research needs larger sample sizes and further explorations regarding which aspects of DBT are effective and for whom the intervention is most useful.
A systematic review of the processing of facial expressions of emotions in individuals with Down Syndrome

Background: Previous studies have identified that although children with DS have relatively good social skills, they may have some difficulties in identifying facial expressions of emotions, when compared to non-specific intellectually disabled and typically developing individuals.

Methods: A systematic review was conducted for studies investigating the ability to recognize facial expressions of emotion in individuals with Down syndrome. Web of Science, MEDLINE, Embase and PsycINFO were searched and after initial identification of 147 papers, N=13 studies were included in the current review.

Results: Most studies concluded compared to TD control groups, individuals with DS systematically make more errors when assessing facial expressions of emotion. Individuals with DS appeared to perform better when tasks did not require specific receptive or expressive language ability. Although there were some differences between the results of the papers reviewed, the reviewed studies suggest that while individuals with DS have specific strengths identifying happiness, they also have specific weaknesses identifying negative emotions (sad, angry, scared) as well as neutral faces and these difficulties could be due to more complex processes rather than just global developmental delay.

Conclusions: While the findings are tentative, there is evidence to suggest that individuals with DS have specific difficulties assessing the facial expression of emotion, during research tasks. There is a need for further investigation using high-quality research designs to determine whether these difficulties in emotion recognition are due to specific cognitive factors or secondary phenotypic factors.

Attachment in adults with intellectual disabilities: Investigating the relationship between attachment security and trauma symptoms

Background: This study explored whether attachment security accounted for variation in reported traumatisation in adults with mild to moderate intellectual disabilities and whether attachment security and trauma symptoms varied in adults who were ‘looked after children’ (LAC) compared with those who lived in the family home prior to adulthood. Additional data regarding the Manchester Attachment Scale Third Party was also collected.

Methods: Twenty-seven staff and service-users pairs were recruited from NHS and independent learning disability services. Service user participants completed a self-report trauma measure and staff completed measures about service users’ attachment, trauma symptoms, traumatic experiences and mood. The relationship between key variables was examined.

Results: No statistically significant relationships were found between secure attachment behaviours and traumatic symptoms or number of traumatic events experienced. Statistically significant differences were not found in attachment security or self-reported trauma symptoms between adults who were once ‘looked after children’ compared with those who remained in the family home.

Conclusions: The current study did not find a relationship between attachment security and the development of trauma symptoms in response to traumatic events in adults with ID, nor differences in attachment security and trauma symptoms between adults, who prior to adulthood were LAC or remained in the family home. However, caution is needed when interpreting the findings given
methodological limitations including method of recruitment and measures used and further research is required in this area.

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A case example: Reflecting on the process of introducing ‘Active Support’ into a group home with a gentleman with multiple and profound disabilities

Background: Research indicates that individuals with intellectual disabilities living in supported community homes spend a large proportion of their time doing nothing (Emerson & Hatton, 1996). Active Support aims to increase individuals’ opportunities to participate in their own lives, with appropriate levels of assistance from staff. Literature indicates this approach can also be effective in improving the quality of lives of individuals with severe intellectual disability (Jones et al., 1999).

Methods: John had severe intellectual disabilities and multiple physical disabilities. He lived in a shared house, supported by 8 staff members. John was referred to a specialist challenging behaviour service due to concerns regarding a number of behaviours that were considered difficult to manage. An initial workshop with John’s care staff was followed by individual adapted coaching sessions, lasting between 60-90 minutes.

Results: Staff supported John in a range of household activities that he had never taken part in before. Observations of ‘on-task’ engagement from staff and John were completed before coaching sessions, at 10 second intervals. Before coaching, staff were ‘on-task’ 62% of the time, and John 30% of the time. At one month follow-up, staff were rated as ‘on-task’ 96% of the time and John 54%.

Conclusions: Improvements to John’s quality of life were observed. However, there were challenges to maintaining the longer term motivation of the staff team, when progress was slow. Further reflections on the process of adapting Active Support for a client with multiple severe and profound disabilities are presented in the discussion.

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Residential support workers meeting the health needs of older people with learning disabilities: an exploration of their developmental and support needs

Background: There is a growing body of evidence which illustrates the greater health needs of older people with learning disabilities in comparison to the general population. However there has been little research on the implications of this for social care providers in terms of the skills and knowledge of support staff. The study aims to explore the experiences and training needs of residential support workers regarding meeting the health needs of older people with learning disabilities.

Methods: The first stage of the study involved 14 semi-structured interviews with house managers from a number of Third sector organisations in South Wales. A group of older people with learning disabilities also contributed their views on the subject. Themes identified at this stage have informed the development of the Stage 2 questionnaire. This will be piloted outside of Wales and then circulated to 1,500 support workers and house managers from third Sector organisations in Wales.

Results: The interviews revealed that there were inconsistencies across and within organisations regarding training available for support workers. Also there appeared to be little or no specific formal training available to staff for supporting older people with learning disabilities across the organisations.
Conclusions: The research highlights that a more consistent approach to training and qualifications could be implemented across Wales to ensure that all support workers receive a standard level of training in order to help to prevent further health issues for older people with learning disabilities.

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Brief parent-mediated developmental behavioural intervention for toddlers with ASD

Background: Deficits in attention, communication, imitation and play skills reduce opportunities for children with autism to learn from everyday routines. These delays are evident from an early age, long before a diagnosis is provided for some families. It is essential to include parent training in early intervention programs because parents generally represent the most proximal and powerful environmental influence during early childhood. However, although research has established the effectiveness of parent-implemented interventions for children with a variety of developmental disabilities, only a small number of these studies have included children with ASD.

Methods: A single-subject multiple baseline design across participants (parent-child dyad) was used to demonstrate the efficacy of a brief 12-week parent-mediated intervention. Additional pre-post measures were used to demonstrate changes in the child’s behaviour and parent stress levels.

Results: Results demonstrated that parents acquired fidelity with the teaching strategies. Furthermore, their levels of responsivity and the quality of their interactions with their child improved. Finally, the children demonstrated change and growth in social communication behaviours.

Conclusions: Findings are discussed in relation to providing an intervention model that may equip parents with the necessary skills to engage, communicate with, and teach their young children with autism.

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Professionals’ perceptions of the difficulty implementing Positive Behaviour Support

Background: Evidence demonstrating the effectiveness of behaviour support practices is increasingly mounting (Dunlap & Carr, 2008); however, the question of sustainability remains largely unexplored. There is a lack of evidence to accurately describe the factors that impede or support this from a professional’s perspective (Kincaid et al 2007). Allen (1999) recommends that further research relating to professionals’ attitudes about carers is conducted and to consider the influence this may have on intervention success. The purpose of this study was to explore these factors.

Methods: 16 participants were recruited from specialist teams across Scotland. Specialist teams for the purpose of this study were teams whose specific remit was assessment and intervention with challenging behaviour displayed by people with learning disability. Focus group discussions were used as a method of data collection and thematic analysis was used to analyse the data.

Results: There were a number of prevalent themes across all teams which are summarised in two distinct categories. Those factors which were clearly described as barriers:

- Assessment process is time consuming.
- Do not understand behaviour has a function.
- Lack of support for staff.
And the second category describes the themes that were perceived as enablers:

- The need for Multi-Disciplinary working.
- The need for skilled managers present in the service.
- The need for better outcome measures.

**Conclusions:** This study adds to the limited research of professionals’ perceptions of barriers to implementing behaviour support. What has emerged from data is evidence of a lack of systemic planning to the structures and processes that underpin the key components of successful implementation of positive behaviour support.

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**Rapport Rating Scale: Simplifying the previously developed Indicators of Rapport measure**

**Background:** This study follows previous work on rapport and the development of the Indicators of Rapport Measure (IRM). The IRM proved to be time consuming and complicated to use. The current study was conducted with a simplified version of the IRM 'The Rapport Rating Scale' (RRS).

**Methods:** Role plays were undertaken and filmed to show examples of a good, poor and neutral rapport between a person with an intellectual disability and staff. Volunteer observers were asked to use the RRS to rate one five minute clip of film which was depicting good, neutral or poor rapport. Volunteer observers were blind to whether they were rating a film depicting good, poor or neutral rapport.

**Results:** The results show that group mean scores did vary for the volunteer raters, dependent upon whether they were rating the good, neutral or poor rapport film. An ANOVA of participant total scores from the groups viewing each of the three films, showed convincing evidence that the rapport rating scale groups are different.

**Conclusions:** The findings indicated that professionals, or trainees, in the fields of health /psychology/applied behaviour analysis, were able to identify indicators of a good, neutral or poor rapport towards their carers, from a role play of person with an intellectual disability, using the RRS.

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**Health, place and intellectual disability: thinking through the therapeutic landscape concept and moving image methodologies**

**Background:** Despite recent efforts to encourage marginalised groups to access outdoor environments for physical and mental health benefits, people with intellectual disabilities remain largely absent from this agenda. This is paralleled by a distinct lack of research on people with intellectual disabilities place experiences and ways in which these experiences impact on health and wellbeing. Using insights from recent post-phenomenological research in cultural geography, this PhD project is examining the wellbeing effects of participation in community farming projects for people with intellectual disabilities over the longer term, through an exploration of the wider impact that this activity has on the everyday lives of people with ID. This study also seeks to contribute to work on therapeutic landscapes by taking seriously the body, and embodied experience, in the creation of therapeutic geographies.

**Methods:** A range of qualitative methods of data collection is being employed longitudinally over a 10-month period. This includes extensive field notes taken through ethnographic participant observation and semi-structured interviews. In addition, this study is incorporating a visual
methodological element, specifically video-ethnography and video participation and elicitation techniques.

**Results:** Drawing on data collected during the first phase of this project, consideration shall be given to ways in which the use of film enables the researcher to capture those more-than-representational aspects of lived experience, including embodied and situated practices as well as bodily movement and exchange, so often neglected in examinations of the relationship between health and place. This paper shall also reflect on the potential of video methods to more effectively engage people with ID in the research process.

**Conclusions:** Whilst there are some distinct advantages in using moving image methodologies for a study on the place experiences of intellectually disabled people, there are some practical and ethical implications that must be considered. This includes video’s potential intrusiveness and the relative suitability of using video in ethnographic research, which must be assessed on an individual basis.

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A Pilot RCT on the effects of reciprocal imitation training on spontaneous imitation in children with autism: methods and preliminary data

**Background:** Children with autism exhibit pervasive social and communication difficulties, including particular deficits and delays in imitation skills. Evidence suggests that imitation difficulties have negative impacts upon the development of other skills in this population. Reciprocal Imitation Training (RIT) is a play-based behavioural intervention focused on increasing imitation skills and gesture use in children with autism. Previous research has demonstrated RIT to be effective for increasing spontaneous object and gesture-based imitation, and also suggests that this intervention has positive collateral effects on language, pretend play, and joint attention skills, in young children on the autism spectrum (Ingersoll, 2010; Ingersoll, 2012; Ingersoll & Schreibman, 2006).

**Methods:** Participants were 16 children with ASD aged 2 to 6 years. All participants were administered the Mullen Scales of Early Learning (MSEL), Vineland Adaptive Behaviour Scale, Autism Diagnostic Observation Schedule (ADOS), and two experimental behavioural change measures: a structured imitation assessment and an unstructured imitation assessment. All participants were also assessed using two electroencephalography (EEG) measures. Children were then randomised into two groups: immediate intervention versus wait-list control. The intervention group received 20 sessions of RIT over a period of 12 weeks. Both treatment and wait-list group were invited back after 12 weeks for a post-assessment which included repeat of the verbal scales of MSEL, the ADOS, both imitation measures, and the EEG measures. The children in the wait-list group received intervention after post-assessment for the same duration of 20 sessions.

**Results:** Behavioural measures of imitation change associated with intervention will be reported.

**Conclusions:** We hypothesize that the results obtained will provide further evidence for the efficacy of RIT for effecting change in social imitation skills in young children with autism. Also there is little evidence of effects of intervention on non-verbal children with autism and severe intellectual disability. This study will add to our understanding of this often neglected population.
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Keep Safe: group intervention for young people with ID and harmful sexual behaviour

Background: Between 25% and 35% of sexually abusive acts are perpetrated by individuals under 18 (Masson & Erooga, 2006). Children and young people with intellectual disabilities (ID) are overrepresented as both perpetrators and victims (Hackett et al 2013). There is a lack of assessment and intervention programmes, and very little research, for children & young people with ID and sexually harmful behaviour (SHB). Group CBT is an effective intervention for non-disabled adult sex offenders and children with problematic sexual behaviours. SOTSEC-ID (Sex Offender Treatment Services Collaborative- Intellectual Disability), a modified CBT programme, for men with ID and sexual offending seems to be successful, with high completion rates > 90%. Post intervention, evaluation showed sexual knowledge & victim empathy increased, while cognitive distortions & offending reduced (Murphy et al 2007, 2010). Youth subgroup (ySOTSEC-ID) was established in 2012, for those working with children and young people with ID, so as to develop a similar intervention programme for adolescents. ySOTSEC-ID has been successful in securing a 2 year grant for the development of Keep Safe, a CBT group based intervention and feasibility trial treatment for adolescents with ID who display SHB.

Methods: Aims: Select &/or adapt appropriate assessment tools; Develop the Keep Safe group intervention programme; Conduct a feasibility trial of Keep Safe.

Keep Safe programme

- A group CBT intervention, incorporating Good Lives.
- 36 weekly sessions, term-time, 1 year.
- Family/Carer involvement - 10 sessions.
- Build on SOTSEC-ID experience and child and adolescent sources.
- Ensure it is developmentally appropriate and accessible for adolescents (concrete, active, visual).

Results: Data collection about to commence.

Conclusions: N/A

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An analysis of staff knowledge, skills and confidence in working with people with dementia and a learning disability

Background: Due to increased life expectancy, individuals with learning disabilities are increasingly vulnerable to age-related illnesses such as dementia. Learning disability is also heighted as a general risk factor for dementia. Within Scotland, there has been a drive to improve services for people with dementia through the National Dementia Strategy. Expected standards of knowledge and training have been published for those staff, within Health and Social Services, working with people with dementia.

This study had the following aims:
1) To develop a self-report audit tool to identify staff levels of confidence and skills within a multi-disciplinary learning disability service.
2) To identify whether self-reported levels of skill met national standards.
3) To identify the level of knowledge of dementia amongst staff.
Methods: A self-report rating tool and brief knowledge questionnaire was developed and distributed to all members of the NHS Lanarkshire Learning Disability Multi-Disciplinary Team (MDT). Response rate was 46% (32 responses). All responses were anonymous.

Results: Members of the MDT generally identified that they had the requisite skills, but levels of confidence in these skills were relatively low in some areas. Levels of actual knowledge were generally good.

Conclusions: Results suggest that staff may possess the knowledge and skills to work in this area, but confidence in practice is lower. Focusing training on the direct implementation of skills may support staff to feel more confident in their actions, and hence deliver a better service to clients and their families.

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Heterogeneity within adult day services: A focus on centers that serve younger adults with intellectual and developmental disabilities

Background: As the population of younger adults with intellectual and developmental disabilities continues to grow, adult day services are positioned to be key providers of community-based care and support. This poster reports a US comparative study of adult day centers for younger adults with intellectual and developmental disabilities verses day centers serving older and mixed age groups.

Methods: Using data drawn from the MetLife National Study of Adult Day Services 490 adult day service centres (split between 'IDD Specific Centres'; Blended Centres' and 'Older Adult Centres') were subjected to one-way analyses of variance and post hoc analyses.

Results: Analysis revealed significant differences in terms of participant, staffing, and organizational characteristics with Blended and Older Adult Centres generally being better resourced than IDD Specific Centres.

Conclusions: These findings have important implications for service providers, researchers, and policy makers when developing, staffing, and funding adult day services.

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Support for ex-offenders with intellectual disabilities on leaving prison

Background: Little is known about the services and support available for people with intellectual disabilities (ID) when they leave prison. It is unclear whether they receive any support to promote successful resettlement.

Methods: Men screened positive for ID in prison were interviewed within one month of leaving prison (T1), and nine months later (T2). Interviews established their living situation (e.g. accommodation), daily activities (including employment), social networks, quality of life, health and wellbeing. The utilisation of services and the occurrence of risky behaviours/re-offending were also recorded (these data were checked with their care managers or offender managers). Statistical analysis will examine whether social care support and services (including the costs) are associated with lower rates of re-offending and better quality of life.

Results: Findings so far have suggested that most men with ID are very under-supported when they leave prison, and many get re-arrested and return to prison very quickly. Family members appeared to be a key part of the men’s social network, though they did not always provide positive support or influence. Extremely few men had a social worker, were in contact with CLDTs or received social care support of any kind.
Conclusions: The project suggests many men are under-supported when they leave prison and are at high risk of re-offending. Policy changes in the UK mean that this may change in the next year and the project will form a ‘natural experiment’ to test the effectiveness of the new policy for this group of ex-offenders.

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Relationships between care workers and service users with severe learning disabilities: a case study

Background: Staff have reported the importance of good relationships when working with people with learning disabilities (e.g. Martin et al., 2010). Staff have also acknowledged that some care staff can form particularly strong relationships with service-users with learning disabilities (Forrester & Iacono, 2008). Yet, the literature does not appear to examine what these close relationships look like with people with severe-profound learning disabilities, how such relationships are formed or the potential benefits and drawbacks for the people in them. This study seeks to address this.

Methods: A mixed methods approach was used. Video recordings of Luke, a 46 year old male carer and Jenny, a 42 year old service-user with severe learning disabilities were examined by completing frequency counts of Jenny’s behaviours and using Conversation Analysis (CA). In addition, a semi-structured interview was completed with Luke. This was analysed using Interpretative Phenomenological Analysis (IPA).

Results: Frequency counts: The analysis is on-going but preliminary frequency counts suggest there is a difference between the communicative behaviours Jenny uses when Luke is and is not present.

CA Analysis is on-going. Four themes emerged from the data: communication, responding, personal qualities and appreciation of abilities and limitations.

Conclusions: That Jenny demonstrates more communicative behaviours in the company of Luke, particularly those associated with happiness (e.g. smiling). The IPA findings suggest possible prerequisites for strong relationships with people with severe-profound learning disabilities.

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The opinions which count: A participatory approach to understanding the care giving experiences of parents of adult sons and daughters with a learning disability

Background: There is considerable research into the experiences of parents caring for children with an intellectual disability that highlights the burden of care. However, little has been published on parents whose child is now an adult. Given how many adult service users remain living at home there is a need to address this.

Methods: This paper explores the care-giving experiences of parents who have an adult son or daughter with an intellectual disability. Seven families took part in semi-structured interviews which aimed to elicit information about their care-giving experiences.

Results: Through thematic analysis 5 main themes and 9 sub themes were identified. Inter rater reliability was achieved at 95% for over 20% of the data. The main themes were 1. Love, 2. The struggles of caring (worries; impact of poor health; response to others; emotional impact on family; coping strategies), 3. Health and social care services (positive; negative), 4. Parental role (advocate/expert; value of carers), 5. An ideal service.

Conclusions: This paper supports previous research (Griffith and Hastings, 2014); that caring for an adult son or daughter with intellectual disabilities can be hard but despite describing a burden of care, parents also expressed a deep love and commitment for their son or daughter. The identified
themes are discussed in relation to how services may develop to be more responsive to families within the current challenges of service delivery.

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Health and health service access: impact of change in living arrangements for older people with an intellectual disability

Background: Recent policy initiatives in Ireland focus on moving people with an intellectual disability from congregated to community settings. Multiple types of moves persist and the motivation for and impact of the full range of moves is unclear. This paper examines the process and impact of change in living arrangements on the health and health services access for older people with an intellectual disability.

Methods: Secondary data analysis on Wave 1 (n=753) and Wave2 (n=701) of the IDS-TILDA (Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing). Data collection involved face-to-face interviews.

Results: There were 66 lateral, 15 more restrictive and 31 more community based moves made. The decision to move involved multiple stakeholders for the majority of movers. The most prevalent reason for move for lateral movers was to accommodate service (34.8%), change in health status (53.3%) for more restrictive movers and a result of service policy for more community based moves (61.3%). Overall, there was a decrease in use of social work, dental, psychiatry and day services, with increased use of neurological, speech and language, OT and personal care attendant for movers.

Conclusions: Movement to a different living arrangement resulted in changes in use of health services with different types of moves leading to different health service experiences. In light of ongoing de-institutionalisation, further tracking of why, how and where older people with an intellectual disability are moving and consideration of the implications for the health and health service access is needed.

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Quality of life and quality of support for people with severe intellectual disabilities and autism

Background: Studies addressing issues of quality of life (QoL) for people with autism illustrate that outcomes for adults can be poor (Howlin et al, 2004, 2013), especially for those with more severe intellectual and developmental disabilities (Lord and Bailey, 2002). This paper explores the quality of support (QoS) and QoL for people with a severe intellectual disability (ID) and autism.

Methods: Data on QoL and QoS across a range of measures were collected for 110 people living in 35 residential and supported living services. Of the 110 people 46 people had autism, of which 27 also had a more severe ID (ABS score below 151).

Results: People with autism were reported to be more able and to show more challenging behaviour (CB). Few differences in the QoL and QoS were found between those with and without autism. Of the 27 people with autism and a more severe ID only five were receiving good Active Support (AS). Unlike other studies of AS no relationship was found between adaptive behaviour and engagement or AS. There was variation in how well elements of the SPELL framework for autism friendly practices were implemented, these tended to be misunderstood.

Conclusions: Very few people with autism were receiving good quality support despite the need for more specialist provision to prevent CB and improve QoL. The absence of skilled support can further
disable people with autism and restrict their QoL. Services need to provide person-centered support that combines different approaches as appropriate for the individuals they are supporting.

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Improving care in the community: An evaluation of three clinical processes utilised to deliver stepped care to individuals with challenging behaviour

Background: A key aim of community teams for people with intellectual disabilities is to deliver effective care and treatment in the community and wherever possible prevent inappropriate admission to hospital. To deliver this a flexible service response is required that will enable care to be ‘stepped up’ and down in response to changing need. This study describes the implementation and outcomes of three clinical ‘step up’ processes within a typical community team.  
Methods: Over a three month period recorded actions and outcomes from three clinical processes, i.e., daily clinical review meetings, a duty nurse system and urgent multi-disciplinary meetings were scrutinised and cross checked. Data was descriptively analysed and thematic analysis conducted.  
Results: Results suggest that the three clinical processes are embedded within the team and trigger a range of increased clinical activity. The primary indicator that increased support from the team was required relates to deterioration in the individual’s behaviour or well-being, increased risk to self or others and a risk of placement breakdown. Key step up actions included an increase in the frequency of contacts and multi-agency liaison and coordination. There was 1 hospital admission during this period compared with 3 during the same time period in 2013 and 2 in 2012.  
Conclusions: This evaluation captures the proactive, flexible and fluctuating response required to deliver effective community services. It highlights the importance of the multi-disciplinary team to provide increasing intensity of support when required.

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Is there a relationship between role-identity, work demands and burnout in direct care staff working with individuals with intellectual disabilities?

Background: Previous literature has identified a relationship between work demands and burnout. However, the nature of this relationship is complex and it is likely that a number of different variables mediate this relationship. The aim of the study was to investigate whether there is a relationship between work demands and staff burnout, and to explore whether role-identity or self-determination mediate this relationship.  
Methods: Seventy staff completed self-report measures of burnout, role-identity, self-determination and work demands.  
Results: Significant positive correlations were found between work demands and emotional exhaustion and depersonalisation, and role-identity and personal accomplishment. A significant positive correlation was found between self-determination and personal accomplishment and a negative correlation was found between work demands and self-determination. Regression analyses demonstrated that role-identity and self-determination did not mediate the relationship between work demands and burnout.  
Conclusions: The results confirm a relationship between increased work demands and emotional exhaustion and depersonalisation. Role-identity and self-determination are associated with personal accomplishment. It is suggested that an individual’s view of themselves at work is important particularly in relation to their perceived accomplishments at work.
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**Characterising the hospital experiences of adults with learning disabilities (HEALeD): a mixed methods study**

**Background:** People with learning disabilities (LD) are known to have difficulty accessing appropriate healthcare services and experience substantial inequalities in health outcomes. Acute hospitals now face strong political and legal pressure to provide equitable healthcare for people with LD. This has resulted in the widespread (but not uniform) implementation of initiatives including: Hospital passports; Information in accessible formats; LD awareness training; Flags/alerts to identify patients with LD; LD liaison nurses.

**Methods:** Describing and benchmarking hospital use using routine data; describing and mapping the care and treatment of patients with LD in hospital, in order to establish: whether appropriate reasonable adjustments are being made, and using interviews to explore whether patients, caregivers and hospital staff share similar perspectives on hospital care.

**Results:** No results yet as this poster describes a project that has only just started, and is not due to complete until March 2017.

**Conclusions:** It is important to know whether recent initiatives to improve hospital experiences for men and women with LD are leading to discernible and meaningful improvements. And to provide those actively campaigning for better hospital care and treatment for these adults, both within and outside the NHS, with information and insights gathered from empirical research.

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**Children and young people with Learning Disabilities (CYP-LD): earlier interventions for emotional well-being, adapted FRIENDS for Life groups**

**Background:** Although CYP-LD have higher rates of emotional and behavioural problems than peers without LD, research shows they have less access to services and support (FPLD 2002; Emerson and Hatton 2007). Research into effective interventions is urgently needed. FRIENDS for Life teaches CYP techniques to cope with anxiety and promote well-being, social and emotional skills and resilience. Developed in Australia (Barrett, 2001) from Kendall’s evidence-based anxiety interventions, FRIENDS is usually delivered in school-based groups. It is the only programme of its kind endorsed by the World Health Organisation (2005) with reductions in anxiety and depression and increased coping skills and self-esteem maintained up to 6 years. (Barrett, 2006, 2013; Stallard et al 2007, 2014). Andrews et al, 2010, Rossiter et al 2011 found CYP-LD could participate in and progress through school-based groups which drew on adapted, accessible CBT.

**Methods:** The FRIENDS for Life LD Development Project adapted the evidence-based FRIENDS activities to be accessible for CYP-LD using research, expert opinion, multidisciplinary combined experience (70+ years) and feedback from pupils, families and session leaders across 10 school based pupil sessions and 2 parent/carer sessions in a school for pupils with severe learning disabilities.

**Results:** Attendance, concentration, comprehension and participation data, qualitative feedback and examples of most successful activities and learning will be presented. Methodological issues including reliable and valid outcome measures are discussed.

**Conclusions:** CYP-LD could participate in adapted FRIENDS-LD activities. The feasibility of adapted FRIENDS-LD needs to be systematically evaluated prior to planning a fully-powered trial to evaluate effectiveness.
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Clinical psychologists’ experience and understanding of the consultation they offer to professionals within the LYPFT Learning Disability Service

Background: The NHS is undergoing transformation and reform within a commissioner-led framework; consequently, the role and indeed the way clinical psychologists work is changing. New Ways of Working for Applied Psychologists (NWWAP) highlights the importance of consultation and leadership. The ‘Leadership Framework’ (posited by the Division of Clinical Psychology within BPS) reemphasises consultation and leadership as core skills (BPS, 2007b). As evidence-based practitioners clinical psychologists have an ethical and professional responsibility to ensure that the consultation process, which is delivered within services, is both effective and efficient.

Methods: Seven psychologists across the 3 tiers of the LD service consented to take part in individual semi-structured interviews. All had experience of providing consultation. Interviews were audio recorded and transcribed by the researcher. Qualitative content analysis was used to analyse the data (Forman and Damschroder, 2008).

Results: Psychologists understood consultation as a process by which to facilitate psychological thinking by providing support to the MDT. Differences were observed in identifying the client within the process and in psychologists’ experience of the process; some felt they were in charge and largely responsible for the work discussed in consultation sessions, others felt the consultee lead the process and therefore held overall responsibility for the work.

Conclusions: The analysis revealed some inconsistencies in the way that psychologists understand and experience the process of consultation. This evaluation highlights a number of opposing themes, which psychologists will need to balance if consultation is to be understood, delivered and experienced in a consistent manner.

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People with learning disabilities and the interpersonal construction of self-determination

Background: People with learning disabilities experience limited self-determination and have little opportunity to take control and make choices affecting their own lives (Stancliffe and Wehmeyer, 1998). In recognition of this, government policy emphasises the importance of empowering people with learning disabilities to influence their own lives (DoH 2001, 2009). In order to meet the values set out in policy, the interactions between people with learning disabilities and the staff who support them is of particular importance.

Methods: Four service users initially agreed to take part in the research, staff member participants were subsequently recruited by the service user participants. Each pair was video recorded during 1:1 interaction. Discourse analysis, informed by principles of discursive psychology, was used to examine the data. The analysis revealed a number of actions present within the talk that served to facilitate or limit self-determination.

Results: Staff frequently occupied a position of power in influencing the available opportunities for self-determination. Actions used within the talk included but were not limited to: recruitment of parental view, colluding to enable choice, coaching, using constructions of competence and incompetence. Repertoires of incompetence and competence, protection and independence were identified. Ideological dilemmas around protecting service users vs encouraging self-determination and autonomy were also found.

Conclusions: Findings suggest that the policy goals of facilitating choice, control and enhancing service users’ self-determination are complex to achieve in practice. A number of clinical
implications are identified including the use of video material as an effective training tool for interventions aimed at developing staff confidence and competence in empowering practices.

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First glimpses into the last months of life of people with ID living in ID services across the UK.

Background: An enduring feature of ID research has been the quality of life of people with ID living in services. Yet, often these services will be the places of both living and dying. There exists very little data about what happens to people with ID and the quality of care they receive at the end of their lives. There is a willingness amongst staff to support people, although they may have an over idealised view of end-of-life care. This paper will provide initial data on what is happening at such times in UK ID services.

Methods: Data was collected from 39 services across the UK. Every region of the UK has a service involved in the study and at a level representative of the UK population. The services involved provided support for over 12,000 people living in ID services. Core data on early identified deaths will be presented, as will data on end-of-life care that has been obtained using an ID enhanced version of VOICES.

Results: The population supported by these services will be described. The provisional analysis will look at death rates across ID settings and examine relationships between place of death, cause of death, age at death and degree of support. Views about the quality of end-of-life care and factors relating to death will also be presented.

Conclusions: As data are currently being collected and analysed, we cannot, at this moment outline conclusions from the study. However, these will focus on methodological issues concerning research on death, dying and ID.

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Measures for assessing cognitive distortions in people with intellectual disability at risk of sexual offending.

Background: There has been considerable recent interest in the treatment of men at risk of sexual offending who have an intellectual disability. Development of adapted measures has lagged behind this work, with the exception of the QACSO, developed by Bill Lindsay and colleagues in Scotland. Reliability estimates for these measures, again with the exception of the QACSO, have also been neglected. The SOTSEC-ID treatment programme was the subject of a long-running national study in the UK over 8 years from 2003 to 2010, and adopted 3 main proxy measures for recidivism. These were the QACSO, the SOSAS, and the VESA.

Methods: Reliability estimates for these measures were investigated by assessing 29 participants who had completed the SOTSEC-ID programme across 6 sites using a repeated measures inter-rater and test-retest design with a two-week gap between measurements. Reliability estimates were calculated for inter-rater, test-retest and Internal consistency for each assessment.

Results: Inter-rater reliabilities using ICC's were 0.99 for all three measures, while test-retest reliabilities for the QACSO, SOSAS and VESA were 0.96, 0.74, and 0.90 respectively, and Cronbach's alpha as a measure of internal consistency was 0.94, 0.61, and 0.84 respectively.

Conclusions: The QACSO showed excellent psychometric qualities and is recommended for continued use, the VESA also shows promise, while the SOSAS was disappointing, apart from the Minimization subscale.
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A data driven approach to implementing a positive behaviour support plan: A case study in an adolescent low secure setting

Background: Positive Behaviour Support (as defined by Gore et al, 2014) is a data driven approach utilising Applied Behaviour Analysis to assess behaviour. It is imperative to collect accurate recordings of behaviours and use of positive skills which are identified in the individual's Behaviour Support Plan (BSP); thus providing continuous monitoring of progress. Presented is the pilot of an electronic recording system designed to provide continuous recordings of identified behaviours and positive skills throughout admission to an inpatient unit using a case study of a service user.

Methods: Following development, the system was extensively trialled by nursing staff on a secure adolescent learning disability ward and in January 2014, the system became the primary source of everyday behaviour recordings. The system has been continuously developed to reflect the service user's changing needs, behaviours and targets set in the BSP. Ongoing feedback is also collected from the nursing team to ensure the recordings are accurate.

Results: Reliability checks show the system consistently records a wider range of behaviours more accurately than traditional methods (clinical notes and paper charts). Data from the system has been used to develop a BSP, reflect on the service user's progress and evaluate specific treatment goals.

Conclusions: The recording system forms part of a rolling process of implementing PBS within the ward by facilitating the evaluation of interventions and occurrence of functionally equivalent behaviours. Future development will aim to further increase the level of integration the system has in BSP’s and to trial the system further.

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Co-producing knowledge with the 'differently normal': early reflections on research on the residential geographies of learning disability

Background: Most adults are able to take some control over where they live and can reflect on locational histories, those places where they have lived, and places that they might aspire to occupy in the future. Such life-altering decisions are made autonomously or negotiated in conjunction with significant others. For some adults, most notably those with learning disabilities (LD), these life-decisions are partially, if not wholly, made on their behalf. This paper grows from research into decision-making opportunities afforded to people with LD regarding their home-spaces, including reflections upon those homes and neighbourhoods where they have been (re)located.

Methods: Identifying the need for a sensitive co-production of knowledge about their ‘moving landscapes’ between researcher and learning-disabled participants, this paper considers alternative devices for communication and participation ‘partly suggested by specialist LD researchers’ which seeks to de-mystify the grounded realities of living with a LD. By embracing lives which are ‘differently normal’, the paper challenges the role of ‘expert’, seeking both to create a research process and suite of specific methods (from ‘talking mats’ to ‘walking-talking’) that partially blur the distinction between researched/researcher.

Results: This paper seeks to discuss initial analysis of questionnaire data, drawing out the potential impacts of quantitative trends. It will also begin to document preliminary findings from follow-up interviews with a focus on ‘home’ and ‘decision-making’.
Conclusions: Using a mixed methods approach, this study endeavours to understand more about the role of decision-making and its impact on how those with LD feel about their home situations; past, present and future.

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Promoting participation of people with intellectual and developmental disabilities in social care research: developing an adapted version of ASCOT for self-report

Background: This research aimed to develop and test an adapted version of the Adult Social Care Outcomes Toolkit (ASCOT) for use as a self-report questionnaire with people with intellectual disabilities (ID) or autism. The ASCOT measures social care related quality of life giving an indication of how well people’s needs are met by services. It is used in social care user surveys in England.

Methods: A working group of five people with ID and/or autism was consulted about the first draft of the questionnaire. The revised instrument was then discussed in seven focus groups, recruited through self-advocacy and service provider organisations. The final version was tested in interviews with 22 participants with ID and/or autism.

Results: There were a number of challenges to the task in hand, including: choosing appropriate wording and pictures to optimise understanding; reducing length and complexity of questions; and issues around ‘translating’ more abstract concepts (e.g. control, dignity etc.) that formed part of the original questionnaire and represent key domains of quality of life. Findings from working group, focus groups and interviews will be presented.

Conclusions: Implications and recommendations for the development and pre-testing of questionnaires accessible to people with ID and/or autism will be presented.

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Sleep in children with Angelman syndrome: parents’ concerns and priorities

Background: This study explored the perceived child and parental impact of sleep quality in children with Angelman syndrome.

Methods: Structured interviews were completed with fifty parents of children with Angelman syndrome aged 16 months to 15 years. The interview assessed parental perceptions of the most stressful aspect of their child’s sleep. The nature of desired future interventions was also explored with parents.

Results: Parental well-being and ability to function during the day was rated as the most stressful impact of child sleep disturbances (42%) rather than the impact on child daytime functioning (18%). Both parents/caregivers in the household were considered to be equally impacted by their child’s sleep quality (as rated by the primary caregiver in the absence of the other parent). The majority of parents stated that they had tried a combination of medication and behavioural strategies to improve their child’s sleep. A range of areas for further support were highlighted by parents, but the single strategy most cited by parents was support with developing a behavioural intervention (28% of parents). A further 26% did not feel the need for any additional support.

Conclusions: Parents felt that the impact of their child’s sleep quality was most detrimental to their own functioning. Parents stated that they would seek a range of additional strategies to improve their child’s sleep quality.
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Why are adults with intellectual (learning) disabilities referred to Community LD Teams?

**Background:** The Winterbourne View scandal has refocused attention onto the work of locality-based Community Teams for adults with Learning Disabilities (CTLDs) in England. The aim of this study was to examine the type of work that such Teams are asked to do.

**Methods:** A standardised pro-forma was used over 3 months to collect information about referrals from external sources to each of the five specialist locality-based CTLDs in one large county.

**Results:** There were 292 referrals (49% women), across a broad age range (17-78 years). The referral information available from GPs, care-givers, and day-activity staff was often poor and difficult to categorise. However, most referrals seemed to fall within Lindsey’s (2002) typology of the roles of CTLDs, in that they involved: (i) supporting access to the health and/or social care services available to the rest of the population; or (ii) providing specialist expertise and experience to meet the health and social care needs associated with an intellectual disability. Nevertheless, the distribution of referrals was unequal: the single largest proportion were requests for specialist assessment, treatment and/or support of mental health and/or behavioural needs (including illegal behaviours).

**Conclusions:** The findings of this proxy measure of CTLDs’ activities suggest that they continue to carry out the roles described by Lindsey (ibid). It appears that CTLDs still require the expertise of a range of health practitioners together with social care and/or care management practitioners in order to meet the specialist needs of adults with intellectual disabilities.

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Managers’ and staff perspectives of skilled support

**Background:** As more people with severe intellectual disabilities and complex needs live in the community, staff are required to be more skilled in their support. This paper explores the manager and staff perspectives of skilled support.

**Methods:** As part of a study on skilled support, managers were interviewed and staff questionnaires administered in 35 services for people with severe intellectual disability and complex needs. Staff questionnaires focused on experience, and training as well as their views on skilled support. Interviews with the managers examined the role of the service, the approaches used, and managers’ views of the differences between skilled and unskilled staff.

**Results:** Findings from the thematic analysis of 93 staff questionnaires and 35 manager interviews will be presented, exploring views of what constitutes skilled support, whether staff are seen by themselves and managers to be skilled and what are the differences between skilled and unskilled staff. Differences in perceptions between staff and managers in services where support was observed to be ‘skilled’ compared to those where support was weaker will be presented.

**Conclusions:** Implications for both further research and practice in terms of staff training, practice leadership and service inspection.

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Last months of Life study: the population at risk
**Background:** An enduring feature of ID research has been the quality of life of people with ID living in services. Yet, often these services will be the places of both living and dying. There exists very little data about what happens to people with ID and the quality of care they receive at the end of their lives. There is a willingness amongst staff to support people, although they may have an over idealised view of end-of-life care. This paper will provide describe the study population and the risk of death within it.

**Methods:** Data was collected from 39 services across the UK. Every region of the UK has a service involved in the study and at a level representative of the UK population. The services involved provided support for over 12,000 people living in ID services. Data on the distribution and characteristics of this population will be presented.

**Results:** There are more men than women living in ID services. However, there are more women than men living in nursing homes settings. The population of people with ID living in ID services is a relatively young one but also includes a higher proportion of older people than found in register based populations. Yet there still exists a sharp decline in the population after the age of 65. The death rate across settings types will be presented after data analysis is complete.

**Conclusions:** The age distribution of people in ID services is a distinct one in terms of care home provision. There were however differences found across setting types. Yet despite being a relatively young population there are a larger than expected number of deaths. The death profile in ID services presents challenges for research and service providers in preparing to accept death as a part of ID providers’ responsibilities and development. These challenges will be highlighted.

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**Implementing computer programmes in therapy: exploring the attitudes of clinical practitioners and people with intellectual disabilities**

**Background:** Studies have shown that some of the necessary skills to undertake cognitive behaviour therapy (CBT) can be trained using computer tasks. This study aims to explore the attitudes of clinical psychologists and people with intellectual disabilities (IDs) towards implementing such computer programmes in therapy.

**Methods:** Semi-structured interviews were conducted with clinical psychologists (N = 3) and people with intellectual disabilities (IDs) who had participated in a previous research study using computer training in CBT skills (N = 3). A thematic analysis was performed to identify participants’ attitudes towards the use of computers in therapy, identify any potential advantages, disadvantages and concerns.

**Results:** Participants with IDs responded positively towards the use of computer tasks and saw them as both fun and as a means of learning. Clinicians identified the benefits of such tasks in terms of improving patient engagement in therapy. Participants were in agreement that the presentation of tasks should be very visual and would ideally involve a range of media types that can be adapted to the individual. Other emerging themes were the need for adaptability and individualisation of programme content. In addition, both participant groups raised concerns regarding confidentiality of patient data.

**Conclusions:** The interviews revealed that both clinicians and people with IDs would welcome the use of computer tasks as an addition or component of therapy, but not to serve as its replacement. Further research is necessary to evaluate the feasibility of implementing such tasks in therapy.
Attention to social and non-social stimuli in Tuberous Sclerosis Complex

**Background:** Tuberous Sclerosis Complex (TSC) is associated with increased rates of Autism Spectrum Disorder (ASD). Studies indicate that processing of social stimuli may be atypical in ASD, with reduced attention to people. Because of increased prevalence of ASD in TSC atypical social processing may also be evident in this disorder. This study examined spontaneous attention allocation to social versus non-social stimuli in children with TSC.

**Methods:** Eye tracking methodology was used with 17 children with TSC and a contrast group of 25 typically developing children of comparable mental age. Children viewed paired video clips presented side by side, with one social video (showing a person) and one non-social video (showing an object). Half of these paired videos were directed (subjects facing the camera) and half were non-directed (subjects not facing the camera).

**Results:** Dwell time and time to first fixation to social and non-social videos were analysed and ‘preference’ for social versus non-social videos was compared. No differences were found between groups in dwell time. An interaction for time to first fixation indicated that when videos were directed preference for social videos (over non-social videos) did not differ between groups, but when they were non-directed preference for social videos became significantly weaker in children with TSC in comparison to typically developing children.

**Conclusions:** Findings suggest potential atypicalities in allocation of attention to social and non-social stimuli when stimuli are less salient (i.e. not directed at the individual), with children with TSC showing reduced social preference for less salient stimuli.

A method of analysing single cases in clinical practice

**Background:** In practice clinicians are often asked to judge whether interventions are having an effect on the behaviour or health of an individual. Data that is collected in such situations is difficult to analyse by conventional statistical tests because it often contains serial dependency (one data point predicts the next) and the measures often fail to meet assumptions of standard statistical testing e.g. normal distributions. Recent developments in non-parametric tests have made routine testing of intervention effects feasible using a web based calculator. The tau-u statistic is distribution free and simultaneously can allow for a systematically varying baseline and compare it with a post intervention phase in terms of both slope and level of a numerically assessed health condition or behaviour (e.g. number of fits; frequency of challenging behaviour).

**Methods:** Medical and psychological interventions were tested for their effects on behaviour and health using the tau-u statistic. The data is collected routinely in schools for children with autism and severe learning disability.

**Results:** The effects of intervention changes on the health and behaviour of 3 individuals with autism spectrum disorder and severe intellectual disability will be presented to illustrate the use of tau-u as a decision tool for services.

**Conclusions:** Some decisions about resource allocation for interventions can now be based on a firmer statistical footing. Given the new emphasis of CQC and Ofsted inspections on value for money when placing people, these results enable organisations to provide more robust evidence of effectiveness.
Assessment of anger-related cognitions

Background: Interventions for anger represent the largest body of research on the adaptation of cognitive behavioural therapy (CBT) for people with intellectual disabilities. The extent to which the effectiveness of these interventions reflects the behavioural or cognitive components of CBT is uncertain. This arises in part because there is no good measure of anger-related cognitions.

Methods: The Profile of Anger Cognitions (PAC) is built around interpersonal scenarios that the participant identifies as personally anger-provoking. A conversational presentational style is used to approach ratings of anger experienced in those situations and four relevant cognitive dimensions: attribution of hostile intent, unfairness, victimhood, and helplessness. Three studies were conducted in which the PAC, and other measures, was administered to (i) people with ID identified as having problems with anger control (n=12) and (ii) university students (n=23); and (iii) clinicians (n=6) were surveyed for their impression of using the PAC in the assessment of clients referred for help with anger problems.

Results: The PAC has good consistency and test-retest reliability, and the total score on the four cognitive dimensions correlates significantly with anger ratings. The predominant cognitions reported were perceptions of unfairness and helplessness. People with ID and university students were in most respects very similar in both the psychometric analyses and content analyses of their verbal responses. The PAC had high acceptability both to people with ID and to clinicians.

Conclusions: The PAC may be a useful instrument for both clinical and research purposes. Personal relevance and the conversational mode of administration are particular strengths.

Dealing with social threat: Examining behavioural responses to anxiety-provoking situations for young adults with mild intellectual disability

Background: People with intellectual disabilities may respond differently to social stressors due to differences in social experience and acquisition of skills. The present study examined whether there are differences in their responses to socially stressful situations.

Methods: Forty-one participants aged 16 to 22 took part in this study; 20 typically developing young adults and 21 with mild intellectual disabilities were recruited through local further education colleges. The participants were interviewed and were asked how they would cope in a series of 6 ‘social threat’ scenarios, using pictorial vignette stimuli. Responses were content analysed and categorised.

Results: The typically developing young people endorsed more sophisticated social and emotional responses but overall the coping responses suggested by both groups were broadly similar. Both groups reported a high rate of ‘emotion-focused’ responses to situations involving risk of social rejection, and this appeared to reflect that these situations were particularly stressful for both groups.

Conclusions: This study suggests that those with intellectual disabilities do possess a variety of strategies to deal with situations of social stress, although these strategies may be less sophisticated at times than those used by their non-disabled peers.
Dynamic risk and violence in individuals with an intellectual disability: Tool development and initial validation

**Background:** Without a violence risk assessment designed for people with an Intellectual Disability (ID), assessors are reliant upon tools developed for mainstream offenders or develop their own tools.

**Methods:** This study describes the early stages of development of the Current Risk of Violence (CuRV); an informant reported measure of dynamic risk for aggression in adults with an ID. The pool of items was generated from a multitude of sources. Predictive accuracy for aggression was tested prospectively among 64 adults with an ID and history of aggression.

**Results:** The 34-item CuRV was found to be a brief, uncomplicated risk assessment. Initial findings revealed good predictive validity over a five-month period: AUC range from .72, 95% CI [.59, .85] to .77, 95% CI [.66, .89].

**Conclusions:** These preliminary findings suggest that the CuRV may assist staff to perform assessments of risk in busy clinical settings. Future research effort is needed to more fully explore the psychometric properties of the CuRV.

Effectiveness of behavioural interventions for sleep problems in intellectual disabilities: a novel approach to evidence synthesis

**Background:** Behavioural interventions are considered effective in improving sleep problems. However, the evidence on their effectiveness for individuals with an intellectual disability (ID) has not been reviewed. The present study aimed to bring together all available evidence on the effectiveness of behavioural interventions to improve sleep problems in this population.

**Methods:** Systematic review and meta-analysis of studies that evaluated the efficacy of behavioural interventions in ID using either a group design or a single case study design (SCED).

**Results:** Seven studies were identified for inclusion in the review. They included 134 individuals receiving a behavioural intervention. Four studies used a group design (2 were RCTs and 2 were single group studies) and 3 studies were multiple baseline SCEDs. Group studies showed large significant gains following intervention (overall SMD=.93, 95% CI: .70, 1.15) and very large gains at follow up (SMD=1.57, 95% CI=1.23, 1.91). SCEDs showed a 53% improvement over baseline after intervention (overall TAU-U=.53, 95% Cls:.35 to .70), but gains were not maintained at significant levels at follow up, especially for night waking, total time asleep and falling asleep in own bed.

**Conclusions:** Behavioural interventions appear effective in improving sleep problems in ID, at least in the short term. Synthesising all available data is important in ID research, where RCTs are rare and SCEDs frequent. The two approaches can provide complementary information.