

Seattle Club Conference

Kendal 2012

The Cumbria Partnership NHS Foundations Trust and the Centre for Disability Research, Lancaster University have great pleasure in welcoming you to the Riverside Hotel, Kendal for the 12th Seattle Club Conference for researchers in intellectual and developmental disabilities in the UK and Republic of Ireland.

Now for the 12th time, we have continued the Seattle Club traditions of:

- 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.
- Oral papers and posters are equally weighted in terms of worth, rigour, and status.
- The selection of contributions for oral and poster presentation is designed to achieve a mixture of more established and early career researchers.
- Participation is 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.

Organising Committee

The ad hoc organising committee members for Seattle Club 2012 meeting were: Dave Dagnan, Chris Hatton, Richard Hastings and Dougal Hare. Most of the organisation has been done by Ingrid Iredale and Vicky Upright of the Cumbria Partnership NHS Foundation Trust's Learning Network; many thanks to them for their work this year.

We hope you enjoy your time in Kendal and that we'll see you again for the 13th meeting in 2013

Seattle Club Studentships 2012

Eight 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 make them all welcome. We look forward to hearing about their research in future years. This year's studentship holders, and their research topics, are:

Darren Bowring (Bangor University) - Implementation and evaluation of Positive Behaviour Support for individuals with challenging behaviours

Rebecca Hardiman (Tizard Centre, University of Kent) - Challenging behaviour in Fragile X syndrome

Leah Vanono (Tizard Centre, University of Kent) - Prevention of challenging behaviour in adult social care settings

Leen Vereenoghe (University of East Anglia) - Assessing and training CBT skills in people with intellectual disabilities

Arlene McGarty (University of Glasgow) - Impact of physical activity on the health and well-being of children with intellectual disabilities

Lisa Lloyd (University of Manchester) - Attachment in residential settings for people with intellectual disabilities

Supriya Malick (University of Birmingham) - Neural correlates of behavioural change associated with an evidence-based intervention for gesture and language skills in young children with autism

Andrew McCombie (University of Cambridge) - Moral development in adults with intellectual disabilities

Seattle Program
Riverside Hotel, Kendal

Thursday 13th December

Registration and Coffee: 10.00-10.40

Welcome: 10.40-10.45 – Dave Dagnan

Session One: 10.45-12.25pm

Session Chair: Dave Dagnan

10.45-11.10 **Fleur-Michelle Coiffait**, Helen Downie, Karen McKenzie, Nick Gore
Parental locus of control predicts subjective wellbeing in parents who have a child with profound and multiple intellectual disability

11.10-11.35 **Paraskevi Triantafyllopoulou**, Glynis Murphy, Peter McGill
Carers' views of sleep disorders in adults with intellectual disabilities

11.35-12.00 **Myrthe Jacobs**, Lisa Woolfson
Relationships between causal attributions, parenting strategies and child behaviour problems in parents of children with ID

12.00-12.25 **Karen Deakin**, Andrew Jahoda, Derek Moore, Sally-Ann Cooper
Self-perceptions of children with Down syndrome: Mothers' perspectives

Lunch: 12.25-1.15

Keynote Presentation: 1.15-2.15pm

Session Chair: Chris Hatton

Professor Glynis Murphy
Intellectual Disabilities and the Criminal Justice System: Recent Research and Remaining Questions

Session 2: 2.15-3.30

Session Chair: Vasiliki Totsika

2.15-2.40 **Rina Cianfaglione**, D. Felce, A. Clarke, M. Kerr, R. Hastings
CHARACTERISING THE BEHAVIOURAL PHENOTYPE OF Rett syndrome

2.40- 3.05 **Jacqui Rodgers**, Ruth Fleck, Katie Little, Fiona Clark, Emily Tompson (nee Janes), Debbie Riby
Auditory Sensitivity in Children with Williams Syndrome

3.05-3.30 **Dougal Hare**, Louise Mahon, Michelle Lomax, Sheena Aspil, Elaine Cross, Brian Bigger, Kia Langford-Smith, Maria Canal, Ed Wraith, Simon Jones
Sleep and Circadian Rhythms in Children with Mucopolysaccharidosis III

Coffee/Tea 3.30 – 3.50

Session 3: 3.50-5.05

Session Chair: Barry Ingham

3.50 - 4.15 **Louise Handley**, Dawn Adams, Doug Simkiss, Alison Jones, Amy Garrod and Chris Oliver

Investigating potential behavioural risk markers for aggressive and self-injurious behaviour: specificity and associations with parental well-being.

4.15-4.40 **Kate Eden**, Jo Moss, Rachel Carter, Becky Hardiman, Vicky Quine, Chris Oliver

The influence of pain and operant learning processes on challenging behaviour in people with intellectual disability

4.40-5.05 **Lisa Cochran**, Joanna Moss, Lara Clark, Leanne Liddell, Sarah Lynch, Chris Oliver

Changes in autism spectrum disorder phenomenology and repetitive behaviour in Cornelia de Lange and Cri du Chat syndromes:

6.00-7.30 Poster Session

7.30 Dinner

Friday 14th December

Session 4: 09.30-10.45

Session Chair: Craig Melville

9.30-9.55 **David Felce**, Biza Stenfert Kroese, Paul Willner, John Rose, Andrew Jahoda, David Cohen, Pamela MacMahon, Aimee Stimpson, Nicola Rose, David Gillespie, Jennifer Shead, Claire Lammie, Christopher Woodgate, Julia Townson, Jacqueline Nuttall and Kerenza Hood

Evaluation of an anger management intervention delivered in service settings. Acceptability and cost

9.55-10.20 **Paul Willner**, John Rose, Andrew Jahoda, Biza Stenfert Kroese, David Felce, Pamela MacMahon, Aimee Stimpson, Nicola Rose, David Gillespie, Jennifer Shead, Claire Lammie, Christopher Woodgate, Julia Townson, Jacqueline Nuttall and Kerenza Hood

Evaluation of an anger management intervention delivered in service settings. II. Clinical outcomes

10.20-10.45 **John Rose**, Paul Willner, Andrew Jahoda, Biza Stenfert Kroese, David Felce, Pamela MacMahon, Aimee Stimpson, Nicola Rose, David Gillespie, Jennifer Shead, Claire Lammie, Christopher Woodgate, Julia Townson, Jacqueline Nuttall and Kerenza Hood

Evaluation of an anger management intervention delivered in service settings. III. Prediction of outcomes

Coffee/Tea 10.45-11.05

Session 5: 11.05-12.20

Session Chair: Nigel Beail

11.05-11.30 **Joanna Kate Ferrara**, Jan Burns, Hayley Mills, Dr Peter Baker
Public attitudes towards people with Intellectual Disabilities after watching Paralympic/Olympic performance

11.30-11.55 **Georgina Warner**, Patricia Howlin
Autism Symptoms and Behavioural Disturbances in ~ 500 Children with Down Syndrome in England and Wales

11.55-12.20 **Amanda Muir**, Sally-Ann Cooper Elita Smiley, Andrew Jahoda,
Prospective study of the mental health of adults with intellectual disabilities: underlying mechanisms and outcomes

Lunch: 12.20 – 1.20

Session 6: 1.20-2.35

Session Chair: Jacqui Rodgers

1.20-1.45 **Stuart Todd**, Dr Robert Jenkins, Ruth Northway
Services for the dying: end of life events for adults with ID living in services

1.45-2.10 **Sally-Ann Cooper**, Jill Morrison, Alex McConnachie, Marion Baltzer, Laura McArthur, Claire Lammie, Craig Melville, Nicola Greenlaw, Linda Allan
Health checks for adults with intellectual disabilities. Randomised controlled trial

2.10-2.35 **Craig Melville**, Victoria Penpraze, Fiona Mitchell
Get Active, Be Healthy: a pilot study of a multi-component physical activity intervention for children with intellectual disabilities.

Closing Comments: 2.35-2.45

Conference Closes/Coffee

PRESENTATION ABSTRACTS

Fleur-Michelle Coiffait, f.m.coiffait@sms.ed.ac.uk; Helen Downie, Karen McKenzie, Nick Gore

Title: Parental locus of control predicts subjective wellbeing in parents who have a child with profound and multiple intellectual disability

Background: Parenting a child with a disability is associated with higher levels of stress, anxiety, and depression than parenting a typically developing child. However, some parents demonstrate considerable resilience and are able to adjust to this demanding role. This study aimed to explore levels of parental subjective wellbeing in a specific group of these parents: those who have a child with profound and multiple intellectual disabilities (PMID). It also aimed to determine whether two types of parental cognition, parental locus of control and realisation of positive gains of having a child with PMID, were predictive of parental subjective wellbeing.

Methods: A single sample of parents and family caregivers (N=101) completed three quantitative self-report questionnaires as part of a within-participant, cross-sectional survey design. These included the Positive Gain Scale, a modified version of the Parental Locus of Control Scale and the Warwick-Edinburgh Mental Wellbeing Scale.

Results: The median subjective wellbeing score for this group of parents was well below the equivalent value for the general population. Regression analysis revealed that parental locus of control significantly predicted parental subjective wellbeing ($\beta = -.279$, $t(2,99) = 9.419$, $p = .005$), accounting for around 8% of the variance in WEMWBS scores, adjusted $R^2 = .081$, $F(2,99) = 5.474$, $p = .006$.

Conclusions: These results highlight the importance of parental locus of control in influencing the subjective wellbeing of parents of children with PMID. This suggests a role for psychological intervention for parents and families with a focus on promoting an internal parental locus of control. However, further research is needed.

Paraskevi Triantafyllopoulou, pt94@kent.ac.uk; Glynis Murphy, Peter McGill,

Title: Carers' views of sleep disorders in adults with intellectual disabilities

Background: The prevalence of sleep problems in people with intellectual disabilities (ID) is much higher than in the general population. Most of the studies investigating sleep in ID tend to focus on children rather than adults. The aim of the current study is to identify the most common sleep problems that carers believe adults with ID tend to experience; to investigate whether degree of ID affects sleep problems and finally to look at whether the carers' views of the individuals' challenging behaviours correlate with sleep problems.

Methods: The total adult population registered as having ID in a South London NHS Trust and their carers were contacted from whom 162 participated in the study. Carers completed the Children's Sleep Habit Questionnaire (adapted for adults), investigating the adults' sleep patterns; the functional assessment survey, investigating the adults' physical and intellectual abilities; and the short Behaviours That Challenge Checklist, assessing the existence and impact of challenging behaviour.

Results: Carers of adults with ID reported high prevalence of sleep problems. The most problematic areas were found to be: sleep onset delay, sleep duration, night waking and daytime sleepiness followed by parasomnias and sleep disordered breathing. Adults with more severe ID and high challenging behaviours were also found to experience more sleep problems than adults with mild ID and no challenging behaviours.

Conclusions: Findings are in line with previous research in adults and children with ID, confirming the expectation that adults with ID experience sleep problems. Specific sleep problems were highlighted within this population. The expectation that adults with severe ID and challenging behaviours would experience more sleep problems than adults with higher functioning abilities and no challenging behaviours was also confirmed. Future research should concentrate on specific techniques treating sleep problems and perhaps investigate in more depth the correlation between severity of ID, challenging behaviour and sleep.

Myrthe Jacobs, myrthe.jacobs@strath.ac.uk; Lisa Woolfson

Title: Relationships between causal attributions, parenting strategies and child behaviour problems in parents of children with ID

Background: Research suggests that parents' causal attributions for child behaviour are an important aspect related to parenting strategies and child behaviour problems. Using different instruments, two studies were undertaken to investigate relationships between these factors in parents of children with intellectual disability (ID).

Methods: Fifty-one parents of children with ID participated in Study 1 and 35 in Study 2. In Study 1, the Written Analogue Questionnaire (WAQ) measured attributions through direct questions and vignettes while in Study 2 the Parent Cognition Scale (PCS) measured attributions through aggregated scales and asking parents to think back to their child's behaviour. To assess child behaviour, the Child Behaviour Checklist (CBCL) was used in Study 1 and the Nisonger Child Behavior Rating Form (NCBRF, developed for ID groups), was used in Study 2. The Parenting Scale (PS) measured ineffective strategies in both studies.

Results: Study 1 found that attributions predicted strategies. However, strategies did not predict child behaviour. The results of Study 2 are expected to corroborate relationships between attributions and strategies and to provide insight into the underlying structure of attributions in parents of children with ID. Relationships between the PS and NCBRF would suggest the CBCL is inappropriate for ID groups, while absence of associations could suggest that PS strategies have a different meaning in TD and ID groups.

Conclusions: The studies identify parents' attributions as important predictors for strategies and stress that methods developed for TD groups cannot always be applied to ID groups as behaviour and strategies must be seen in a different context.

Karen Deakin, k.deakin.1@research.gla.ac.uk; Andrew Jahoda, Derek Moore, Sally-Ann Cooper

Title: Self-perceptions of children with Down syndrome: Mothers' perspectives

Background: Very little is known about the perceptions children with Down's syndrome (DS) hold about themselves and their disability. The aim of the present study was to explore this topic through the eyes of children's mothers.

Methods: Ten mothers of children with DS took part in 1:1 semi-structured interviews. The interview schedule was designed to explore mothers' views of their child's perceptions of self in relation to siblings, peers and their disability. The interview transcripts were analysed using Interpretative Phenomenological Analysis.

Results: Overall, mothers indicated that they were increasingly aware of differences between their child and his/her siblings and peers. Mothers voiced particular concerns about social difficulties with school peers. In contrast to their own observations, mothers felt their child did not perceive themselves to be different from anyone else. However, mothers' narratives on this topic were fraught with contradictions and uncertainty. Children's knowledge of DS was portrayed as superficial in that, while most young people had heard the term, they were not thought to understand it or its social implications. There was a strong sense throughout that mothers viewed their child's self-awareness regarding DS as important. However, there was also a profound uncertainty surrounding how and when to raise the issue. This meant that many mothers were waiting on a sign from their child as to their readiness to discuss.

Conclusions: The mothers interviewed all demonstrated a deep concern for their child's perceptions of self. However, there was a general feeling of uncertainty over their child's views and how and when such issues should be broached.

Rina Cianfaglione, CianfaglioneR@cardiff.ac.uk; D. Felce, A. Clarke, M. Kerr, R. Hastings

Title: CHARACTERISING THE BEHAVIOURAL PHENOTYPE OF Rett syndrome

Background: Rett Syndrome (RTT) is a neuro-developmental disorder mainly affecting females and usually associated with a mutation of the MECP2 gene. Genetic and neurobiological understanding of RTT has advanced but there is still insufficient understanding of behavioural development. The aim here was to explore behavioural

variation amongst females with RTT across age, severity of clinical phenotype, mutation and age of regression.

Methods: The 91 participants have a clinical diagnosis of Classic RTT, Atypical RTT or MECP2 related disorder. Clinical symptoms were assessed using a simplified Severity Score, RTT behavioural features using the Rett Syndrome Behavioural Questionnaire (RSBQ), mood using the Mood, Interest and Pleasure Questionnaire (MIPQ), impulsivity and overactivity using The Activity Questionnaire (TAQ) and self-injurious behaviours using the Challenging Behaviour Questionnaire (CBQ).

Results: Severity of clinical presentation, activity level (TAQ total score, overactivity and impulsivity subscale) and mood varied across age groups. Mutation and age of regression were associated with the severity score. No significant differences were found in RSBQ score between groups, either based on age, type of mutation or age of regression. Self-injury was reported in 23.7% of the sample and was more frequent in girls with a more severe phenotype.

Conclusions: This study attempted to describe the behavioural phenotype of a group of females with RTT. Although analysis did not reveal differences across sub – groups in the RSBQ, interesting findings were highlighted with other measures. Depression and impulsivity and overactivity have never been reported in RTT, thus these findings add to the literature on RTT.

Jacqui Rodgers, Jacqui.rodgers@ncl.ac.uk; Ruth Fleck, Katie Little, Fiona Clark, Emily Tompson (nee Janes), Debbie Riby

Title: Auditory Sensitivity in Children with Williams Syndrome

Background: Auditory sensitivity is a feature of Williams Syndrome (WS) and includes sensitivity to certain sounds, fear of some sounds and fascination with sounds. Research into the phenomenology of auditory sensitivity in WS is very limited with much previous research focused on prevalence rather than the everyday experiences of families. A limited amount of research has suggested that there may be links between auditory sensitivity and anxiety, fear and repetitive behaviours though little is known about the impact of auditory sensitivity on individuals with WS and their families. This project aimed to explore these experiences with young people with WS and their families.

Methods: Parents of twenty-six children with WS aged 5-15 years were recruited and completed the Hyperacusis Questionnaire (HQ), Hyperacusis Screening Tool (HST), Spence Children's Anxiety Scale (SCAS-P), Fear Survey Schedule for Children (FSSC-R), Repetitive Behaviours Questionnaire (RBQ), and the Sensory Profile – Short Form (SSP). Parents were also interviewed to further explore the phenomenology of these constructs.

Results: Auditory sensitivity was found to be highly prevalent in WS and the phenomenology of this was explored. Auditory sensitivity was related to higher levels of anxiety and repetitive behaviour. Additionally auditory sensitivity had a significant impact on the child and their family.

Conclusions: These findings provide much needed information about the phenomenology of auditory sensitivity in WS, its relationship with other constructs and its impact on family life and highlight important directions for clinical practice and future research

Dougal Hare, dougal.hare@manchester.ac.uk; Louise Mahon, Michelle Lomax, Sheena Aspil & Elaine Cross, Brian Bigger, Kia Langford-Smith, Maria Canal, Ed Wraith & Simon Jones

Title: Sleep and Circadian Rhythms in Children with Mucopolysaccharidosis III

Background: Sleep problems are common in people with MPS III and can significantly affect the quality of life of the person and their family. No previous investigations have collected comprehensive sleep and circadian rhythm information using a combination of actigraphy, sleep diary, sleep questionnaire and melatonin analyses.

Methods: Eight children with MPS III A/B and eight age-matched typically developing children wore an actigraph for 7-10 days/nights to collect data on circadian rhythm activity and sleep. Melatonin prescriptions were ceased two weeks prior to data collection. Saliva samples were

collected at three time points at the start and end of data collection to permit analysis of endogenous melatonin levels. Parents completed a sleep questionnaire and a daily diary. **Results:** Actigraphic data revealed that children with MPS III had significantly longer sleep onset latencies and greater daytime sleep compared to controls, but night-time sleep duration did not differ between groups. In the MPS III group, sleep efficiency declined and sleep onset latency increased with age. Questionnaire responses showed that MPS III patients had significantly more sleep difficulties in all domains compared to controls. Melatonin concentrations showed an alteration in the circadian system in MPS III.

Conclusions: The abnormality of circadian rhythms and melatonin concentration suggests that treatment of sleep problems in MPS III needs to attempt to synchronise the sleep-wake cycle to a more regular pattern. Actigraphy was tolerated by children and this monitoring device can be recommended as a measure of treatment success in research and clinical practice.

Louise Handley, LRH087@bham.ac.uk; Dawn Adams, Doug Simkiss, Alison Jones, Amy Garrod and Chris Oliver

Investigating potential behavioural risk markers for aggressive and self-injurious behaviour: specificity and associations with parental well-being.

Background: Challenging behaviour is associated with compromised parental mental health, most notably anxiety and depression. Identifying children at risk of challenging behaviour early on maximises the opportunity for intervention and could minimise negative long-term effects. Previous literature has highlighted potential risk markers for challenging behaviour, including overactivity and impulsivity, which have been integrated into a screening questionnaire. This study aims to: (1) examine the efficacy of this screening questionnaire in a sample of young children with intellectual disabilities, and (2) report prevalence rates and predictors of parental well-being.

Method: The screening questionnaire and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) were administered to parents and carers attending NHS Child Development Centres. The questionnaires were completed by 325 parents and carers of children aged 2-11 years with developmental delay. In addition 199 of respondents completed a telephone interview to assess their child's ability level, resulting in an intellectual disability sample of 118 children.

Results: Known risk markers were associated with specific topographies of behaviour: aggressive behaviour was associated with overactive and impulsive behaviours, self-injurious behaviour was associated with repetitive and restricted behaviours. Child behaviour was also associated with parental mental health: anxiety was significantly associated with self-injury, depression was associated with aggression.

Conclusions: The findings support the potential utility of the questionnaire as a screening tool for challenging behaviour, as well as highlighting the need to provide more support for parents. The results suggest that topography-specific approaches to both child and family interventions might be particularly effective.

Kate Eden, KEE854@bham.ac.uk; Jo Moss, Rachel Carter, Becky Hardiman, Vicky Quine, Chris Oliver

The influence of pain and operant learning processes on challenging behaviour in people with intellectual disability.

Background: There is robust evidence showing that operant learning processes influence challenging behaviour. However, this theory is insufficient for explaining all challenging behaviour in people with intellectual disability (ID). There is growing evidence that pain may directly cause challenging behaviour, or that pain and environmental factors interact to influence challenging behaviour.

Methods: 40 children (mean age 10.79, SD: 2.92) with ID were included. The Challenging Behaviour Interview was used to identify children engaging in self-injury and aggression. Experimental functional analysis was used to assess self-injury, aggression and property destruction associated with positive reinforcement through attention delivery or negative

reinforcement through demand escape. The number of behavioural indicators of pain expressed by participants was recorded using the NCCPC-R and FLACC observation measures. Pain scores were compared between individuals with and without self-injury and aggression, and between environmentally functional versus non-functional self-injury, aggression and property destruction.

Results: Individuals with self-injury and aggression scored significantly higher on the FLACC pain assessment tool than those not showing these behaviours ($U=31.50$, $p<.001$). An environmental function ($D\text{-stat}>.50$) was identified for 26.32% of cases of self-injury, 47.06% of aggression and 44.44% of property destruction. A moderate negative correlation between function of challenging behaviour and total FLACC score was observed Kendall's Tau = $-.34$, $p<.05$).

Conclusions: For successful assessment and treatment of challenging behaviour in people with ID, it is important to investigate the potential influence of pain in addition to operant learning processes. Failure to identify an environmental function associated with challenging behaviour may signify the possible influence of pain.

Lisa Cochran, LJC986@bham.ac.uk; Joanna Moss, Lara Clark, Leanne Liddell, Sarah Lynch, Chris Oliver

Changes in autism spectrum disorder phenomenology and repetitive behaviour in Cornelia de Lange and Cri du Chat syndromes: A seven year follow up study

Background: Many individuals with genetic syndromes experience changes in associated behavioural phenomenology with age. We evaluated the trajectory of autism spectrum disorder (ASD) phenomenology in Cornelia de Lange (CdLS) and Cri du Chat (CdCS) syndromes over seven years.

Methods: Participants were individuals with CdLS ($N=30$; T1 mean age=12.24, $SD=3.90$) and CdCS ($N=18$; T1 mean age=9.64, $SD=2.72$) in a longitudinal follow up study. Parents/carers completed questionnaires and interviews and participants were assessed with the Autism Diagnostic Observation Schedule (ADOS) and the Social Communication Questionnaire (SCQ).

Results: On the communication subscale of the SCQ, there was a significant time by syndrome group interaction ($p=.016$). The CdLS group showed a significant increase in scores over time ($p<.001$). On the social interaction subscales, the ADOS and the SCQ both revealed a significant time by syndrome group interaction ($p=.021$; $p=.022$). Comparisons showed that the CdLS group was significantly more impaired than the CdCS group ($p<.001$) at T2 only and that scores in the CdLS group were significantly higher at T2 compared to T1 ($p=.006$). On the stereotyped and repetitive behaviour subscales, there were no significant differences.

Conclusions: The results of the ADOS and SCQ analysis suggest that the CdLS group appear to show more autistic symptomatology with time. This highlights a decline in communication and social abilities in the CdLS group, while their repetitive behaviours remain stable.

David Felce, felce@cf.ac.uk; Biza Stenfert Kroese, Paul Willner, John Rose, Andrew Jahoda, David Cohen, Pamela MacMahon, Aimee Stimpson, Nicola Rose, David Gillespie, Jennifer Shead, Claire Lammie, Christopher Woodgate, Julia Townson, Jacqueline Nuttall and Kerenza Hood

Evaluation of an anger management intervention delivered in service settings. I. Acceptability and cost

Background: Many people with intellectual disabilities find it hard to control their anger. This often leads to aggression, which can have serious consequences, such as exclusion from mainstream services and the need for potentially more expensive emergency placements. We have conducted a cluster-randomized controlled trial of a 12-week group-based cognitive-behavioural anger management intervention, delivered within service settings.

Methods: A clinical psychologist trained service staff ('lay therapists') to work with a detailed treatment manual, and gave fortnightly supervision. Participants were 179 service users with mild to moderate learning disabilities, identified as having problems with anger control. They attended 30 services, which were randomly assigned either to anger management groups or to support-as-usual. Interviews were conducted with service users and 'lay therapists' from the intervention groups shortly after the end of the intervention, and with service managers before the intervention and six months afterwards. We also calculated the total cost of participants' health and social care resource use in the three month period before the intervention and 3-6 months afterwards.

Results: All three groups of informants provided overwhelmingly positive feedback about the experience of participating in the group and the impact on the wider service. The cost of service provision was lower post-intervention, relative to the control groups. The difference was not statistically significant, but was approximately the same as the excess cost associated with delivery of the intervention.

Conclusions: The intervention is acceptable to service users and to services, and can be delivered at no, or at worst marginal, additional cost.

Paul Willner, P.Willner@swansea.ac.uk; John Rose, Andrew Jahoda, Biza Stenfert Kroese, David Felce, Pamela MacMahon, Aimee Stimpson, Nicola Rose, David Gillespie, Jennifer Shead, Claire Lammie, Christopher Woodgate, Julia Townson, Jacqueline Nuttall and Kerenza Hood

Evaluation of an anger management intervention delivered in service settings.

II. Clinical outcomes

Background: Anger management teaches people to recognize what makes them angry and learn skills that they can use to cope better with those situations. We report here the clinical outcomes of a cluster-randomized controlled trial (RCT) of a 12-week group-based cognitive-behavioural anger management intervention, delivered by staff ('lay therapists') working in the service settings where the intervention was delivered.

Methods: Participants were 179 service users with mild to moderate learning disabilities, identified as having problems with anger control. They attended 30 services, which were randomly assigned either to anger management groups or to support-as-usual. Before randomization, four months later (post-intervention) and ten months later, service users, their key-workers, and their home carers completed assessments of anger and anger coping. In addition, service users completed a battery of mental health assessments and carers completed assessments of challenging behaviour.

Results: The intervention had only a small, and non-significant, effect on participants' reports on a provocation inventory, the primary outcome measure. However, staff ratings of service users' anger did decrease significantly, as did service-users' ratings on a more personally-meaningful anger measure. Both service users and staff reported increases in clients' anger coping skills, and both staff and home carers reported decreases in challenging behaviour. The intervention did not have a significant impact on mental health measures.

Conclusions: This study provides the first evidence from a robustly-designed and comprehensively-evaluated RCT for the effectiveness of a cognitive-behavioural intervention for people with intellectual disabilities. It also supports the viability of conducting RCTs with this population.

John Rose, J.L.ROSE@bham.ac.uk; Paul Willner, Andrew Jahoda, Biza Stenfert Kroese, David Felce, Pamela MacMahon, Aimee Stimpson, Nicola Rose, David Gillespie, Jennifer Shead, Claire Lammie, Christopher Woodgate, Julia Townson, Jacqueline Nuttall and Kerenza Hood

Evaluation of an anger management intervention delivered in service settings.

III. Prediction of outcomes

Background: Several factors have been hypothesized to influence the outcome of cognitive-behavioural interventions. We have examined the effect of four such factors (IQ, mental

health, 'dose' of treatment, and fidelity of treatment delivery) on the outcome of a cognitive-behavioural anger management intervention.

Methods: Participants attended 30 services that were randomly assigned either to anger management groups or to support-as-usual; after completion of the randomized controlled trial (RCT) and follow-ups, the intervention was delivered to the control groups. Pre- and post-intervention data on anger (Provocation Index: PI) and anger coping (Profile of Anger Coping Skills: PACS) were obtained from ~100 service users (SU) attending 24 centres, and their key-workers (KW). The influence of a battery of potential predictors was evaluated using step-wise multiple regression.

Results: Three predictions were supported, but in each case, effects were seen on only one of the four measures. Higher IQ and better pre-intervention mental health were associated with greater decreases in KW-reported PI scores, and the number of sessions attended predicted a greater decrease in SU-reported PI scores. Contrary to expectations, greater fidelity of treatment delivery was associated with a smaller decrease in SU-reported PI scores. Further analysis indicated that this relationship may arise because therapists who are able to deliver the intervention with high fidelity are also able to create an environment where service users feel comfortable in discussing their feelings.

Conclusions: The SU-PI may not have been the ideal primary outcome measure to evaluate this intervention. We will also present general conclusions and recommendations arising from the RCT.

Joanna Kate Ferrara, ferrara.kate@yahoo.co.uk; Jan Burns, Hayley Mills, Peter Baker

Public attitudes towards people with Intellectual Disabilities after watching Paralympic/Olympic performance

Background: Despite there being some changes to the way that people with Intellectual Disabilities (ID) are viewed in society, negative attitudes prevail. One of the aspirations of the Paralympic games 2012 organisers was to influence the public's attitudes towards disabled people. The aim of this study was to investigate whether stimuli depicting people with ID performing at a Paralympic level of sport can change attitudes towards ID.

Methods: A mixed randomised comparison group design was employed comparing two groups; those who viewed Paralympic level ID sport footage and information, and those who viewed Olympic footage and information on measures of implicit attitudes towards disability and explicit attitudes towards people with ID. One hundred and fourteen students at a UK university were administered the measures pre and post the stimuli presentation.

Results: Implicit attitudes significantly changed in a positive direction from T1 to T2 for both groups.

Conclusions: The findings provide evidence that Paralympic (ID) and Olympic footage plus written information seems to change attitudes towards people with disabilities, at least in the short term. Viewing elite sports information and footage may have at least a short term effect on attitudes towards ID which provides some tentative support to one of the London 2012 legacy promises. Given both types of stimuli proved effective it suggests the possible role of affect in changing attitudes through the media, which warrants further investigation.

Georgina Warner, georgina.warner@kcl.ac.uk; Patricia Howlin

Autism Symptoms and Behavioural Disturbances in ~ 500 Children with Down Syndrome in England and Wales

Background: Recent research shows that a significant minority of children with Down syndrome (DS) also meet diagnostic criteria for an autism spectrum disorder (ASD). The present study explored rates of autism symptoms and associated behaviour problems in children aged 6-15 years with DS in England and Wales.

Methods: Potential participants (N = 1382) were recruited via the UK Down's Syndrome Association. The Social Communication Questionnaire (SCQ) was used to screen for autistic symptoms and the Strengths and Difficulties Questionnaire to explore behavioural difficulties. The survey also investigated developmental regression.

Results: Questionnaires were completed by 499 families (36% of the cohort). The proportion of children who met the cut-off score on the SCQ for ASD was 37.7% (95% confidence interval [CI]: 33.4% - 42.0%) and for autism 16.5% (95% CI: 13.2% - 19.8%). Children who met the cut-off for ASD displayed higher levels of emotional symptoms, conduct problems and hyperactivity than those who scored well below cut-off. Developmental regression, in both language and general skills, was also higher. However, the profile of their autism symptoms on the SCQ was atypical compared to children with idiopathic ASD.

Conclusions: The pervasiveness of ASD in children with DS in England and Wales is substantially higher than in the general population. These children experience significantly greater behavioural problems than children with DS only. Early detection of autistic symptoms is essential for the provision of appropriate intervention. However, the atypical ASD profile may affect the recognition of the disorder and inhibit the implementation of standard autism interventions.

Amanda Muir, a.muir.3@research.gla.ac.uk; Sally-Ann Cooper, Elita Smiley, Andrew Jahoda

Prospective study of the mental health of adults with intellectual disabilities: underlying mechanisms and outcomes

Background: The long-term outcomes and risk factors associated with persistence of, and resilience to, mental ill-health are relatively unknown in adults with intellectual disability. Similarly, it is unclear what role participation in social and daily activities may play in promoting mental health and well-being.

Methods: This is a current PhD project, investigating the long-term outcomes of mental ill-health in a cohort of adults with intellectual disabilities living in the Greater Glasgow and Clyde area. The adults were first recruited during 2002-2004 creating a population-based cohort of 1023 participants; their point prevalence of mental ill-health was 40.9%. During 2004-2006, 651 participated in a second wave of data collection, and two-year incidence of mental ill-health was 16.3%. This third investigation is measuring longer-term outcomes and perceived social support and participation in social and daily activities.

Results: The outcomes of mental ill-health, in terms of stability or change over the past 10 years, will be presented for up to 100 adults with intellectual disabilities. Risk factors associated with an increase in psychopathology and persistent mental ill-health over time will be discussed. Factors associated with maintaining good mental health over time will also be discussed. The relationship between mental health and participation in various activities and social support will be investigated.

Conclusions: People with intellectual disabilities commonly experience episodes of mental ill-health which can be enduring and negatively impact functioning. This study provides evidence of the risk factors associated with such adverse outcomes.

Format

Stuart Todd, stodd@glam.ac.uk; Robert Jenkins, Ruth Northway,

Services for the dying: end of life events for adults with ID living in services

Background: Much research evidence has accumulated and developed on residential services for people with ID in terms of quality of life outcomes and opportunities. Yet, there exists little evidence concerning how well such services support people with ID at the end of their lives. Although evidence suggests that the staff in such services are willing to provide end of life care for their clients, little is known about what happens to people with ID at such times.

Methods: Data were collected on 78 decedents with ID who had been supported in one of five ID services that participated in the study. These services were asked to identify deaths that occurred from their clients over the previous 5 years. Data were collected on the vents of death and dying.

Results: The data suggest an annual death rate in ID residential services of about 3%. The average age of death was 62.5 years (SD 14.7). The most common reported cause of death was respiratory failure (44%) followed by cancer (27%). Although almost half the decedents

had lived in the setting for more than 10 years, only 31% died in the hospital. Most decedents died in institutional settings where they had been in-patients for several weeks. There was little indication that this reflected individual preferences since few (5%) were reported to have been aware that they were dying

Conclusions: This exploratory suggests that death in ID services is not entirely associated with later life and that people with ID face a risk of institutionalised end-of-life care

Sally-Ann Cooper, sally-ann.cooper@glasgow.ac.uk; Jill Morrison, Alex McConnachie, Marion Baltzer, Laura McArthur, Claire Lammie, Craig Melville, Nicola Greenlaw, Linda Allan

Health checks for adults with intellectual disabilities. Randomised controlled trial

Background: Health checks have been advocated as an intervention to address the unmet health needs and health inequalities experienced by adults with intellectual disabilities. However, a recent systematic review highlighted significant limitations in the evidence base; there has never previously been an RCT of health checks for adults with intellectual disabilities in the UK.

Methods: We conducted a matched-pair cluster RCT of health checks delivered in primary carer, versus treatment-as-usual. Randomisation was in pairs, matched on practice size, and at practice-level to avoid contamination of intervention effects. Their registered patients with intellectual disabilities aged 18 and over were recruited. The intervention was a health check delivered by a practice nurse following training; carers recorded information in advance of meeting with the nurse. Outcome measures were the number of health needs detected, number of health promotion needs, and number of health monitoring needs, over the 9 month period following randomisation. Data was collected from primary care records and participants and their carers; then case conferenced by a GP and learning disabilities psychiatrist, blind to group allocation, to determine whether or not detected needs had been met.

Results: 38 practices were recruited, and 33 randomised. 151 adults were entered into the trial. 85 were allocated to the intervention, and 66 to treatment-as-usual. 142 of the 151 completed the entire trial. Data collection is complete. The statistical analysis plan has been written and tested. Data entry is almost complete. Results will be available by the end of October.

Conclusions: Conclusions will be drawn once results are available.

. **Craig Melville**, Craig.Melville@glasgow.ac.uk; Victoria Penpraze, Fiona Mitchell

Get Active, Be Healthy: a pilot study of a multi-component physical activity intervention for children with intellectual disabilities.

Background: Few physical activity (PA) intervention studies have include children and young people with intellectual disabilities. Complex PA interventions with school and home-based components have been found to be more effective than single-component interventions. To inform a future trial, this study examined the feasibility of a PA multi-component intervention, and gathered pilot outcome data.

Methods: One school took part in the intervention immediately (n=28) while the second school acted as the control (n=31). Accelerometers were used for measurement of PA. Height, weight and waist circumference were also measured. The intervention included educational resources for children, a motivational component for parents and families, a 10-week program of structured Physical Education sessions and a DVD for use by teachers in the classroom.

Results: Feasibility issues in using accelerometers to collect PA data were identified. There were no significant differences in overall PA or sedentary behaviours, post-intervention. The experimental group had a significantly lower post-intervention BMI. Post-hoc analysis found differences in school-based PA but no differences in home-based PA.

Conclusions: Although children and their families, and schools were interested in participating in the study, the methods of collecting PA data require further consideration. Pilot data suggests the school component of the intervention may be effective but further work is required to develop an effective home-based component for children and families.

POSTER ABSTRACTS

1. **Susannah Baines**, s.baines1@lancaster.ac.uk; Hazel Roberts; Gyles Glover, Chris Hatton

Autism Self Assessment 2011: Issues from local authorities

Background: In April 2011, all local authorities in England were asked to assess their progress with the National Autism Strategy 'Fulfilling and Rewarding Lives' for 2010-11. The Department of Health asked IHaL to assess the returns.

Methods: 142 local authorities responded. A template was provided which focussed on seven quality outcomes and three 'service ambitions'.

Results: Some overarching themes emerged including:

1. A lack of information concerning the numbers and needs of people with autism, including those not using services.
2. Variation in how local authorities addressed the question of where people with autism 'fit' within existing health and social care structures – neither learning disability nor mental health structures are adequate 'homes' for everyone with autism.
3. Many authorities were concerned about how they can identify and meet the needs of people with high functioning autism or Asperger's, particularly as they are unlikely to meet eligibility criteria for services.
4. Local authorities varied widely in response to every question.
5. One positive message from this wide variation is that there is an increasing number and range of role models from which those authorities which are not so advanced could learn.

Conclusions: The specific area where progress is most widely recognised to be weak is work between local authorities and the Criminal Justice system. The Department of Health should consider whether this is an area where it may want to take a specific initiative in collaboration with the Home Office and the Ministry of Justice.

2. **Nigel Beail**, nigel.beail@swyt.nhs.uk; Tom Jackson, Nik Vlissides, Vanessa Fay, Katie Williams

Development of Psychological Therapies Outcome Scale for People who have ID

Background: The rationale for and stages of development of a new scale to evaluate outcomes of psychological therapies will be described.

Method: Focus groups were held with professionals who provide psychological therapy to determine key outcome areas. Item pools were then generated for each area. The psychometric properties reported in the literature for each item was examined and a short list of items produced. These were then reduced through further review to reduce replication but ensure adequate representation. The scale was then piloted with service users and modified. Further pilot work resulted in a suggestion for an informant version which was produced.

Service user views on the scales were then obtained. Data are now being accumulated for examination of the two scales' psychometric properties.

Results: A 30 item scale was produced covering anxiety, depression, Anger, Interpersonal wellbeing and psychological wellbeing. Professional and service user feedback was positive. Following establishing face validity and utility of the scale it is now being used to generate data for examination of its psychometric properties.

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Results: A 30 item scale was produced covering anxiety, depression, Anger, Interpersonal wellbeing and psychological wellbeing. Professional and service user feedback was positive. Following establishing face validity and utility of the scale it is now being used to generate data for examination of its psychometric properties.

Conclusions: The Psychological Therapies Outcome Scale -ID has undergone considerable development work and this process continues. It is now being piloted in several clinical services in three countries.

3. Jill Bradshaw, J.Bradshaw@kent.ac.uk

Staff attributions of challenging behaviour and perceptions of communication in adults with intellectual disabilities and challenging behaviour

Background: Communication partners have a major role in making interpretations of communicative acts. This research was designed to provide opportunities for these partners (staff supporting service users) to discuss their views, experiences and interpretations of communication and cb, in order to explore the role these play in their interactions and responses.

Methods: Five focus groups, each consisting of between 3 and 4 participants, were transcribed and analysed using a framework analysis (Ritchie and Spencer, 1994).

Results: Participants emphasised the importance of knowledge of and relationships with service users (practical knowledge) over theoretical or professional knowledge. Internal attributions of challenging behaviour were frequent. Participants showed little awareness of the role of conscious communicative intent, but assumptions of intent could be implied from the language used. Participants tended to infer communicative intent for all behaviours.

Conclusions: Drawing on these findings, I argue against a communication hypothesis of challenging behaviour and highlight disadvantages of such understandings. The relevance of a Generic Error-Modelling System (Reason, 1990) and of Communities of Practice (Wenger, 1998) are explored. Participants' failure to value theoretical knowledge may lead to a reliance on concrete rule-based strategies. Interventions need to take account of staff teams' understanding and effect change through the implementation of a learning rather than a teaching curriculum if they are to be successful.

4. Melanie Chapman, melanie.chapman@manchester.gov.uk; Duncan Mitchell; Dene Donalds

Mindfulness sessions for people with intellectual disabilities

Background: Mindfulness is the practice of focussing attention purposefully in a non-judgmental way on current circumstances. It is increasingly used as a tool for managing a range of difficulties, including stress and depression. Mindfulness has not been widely used with people with intellectual disabilities (PWID). However, some small-scale research studies indicate that the use of mindfulness techniques can help PWID to reduce aggression, reduce obesity and to maintain community placements. This study aimed to evaluate one-off mindfulness sessions for PWID.

Methods: People who attended sessions completed an evaluation form. Qualitative interviews were conducted with a subset of these people. Data was analysed using thematic analysis.

Results: Feedback about the sessions was generally positive. Some people had since listened to a CD that was provided and had found this useful. Other people had not listened to the CD for a variety of reasons (e.g. they had not felt stressed or because of their living situation). Participants felt that they would benefit from further sessions and that other PWID would also benefit from mindfulness.

Conclusions: The findings suggest that it would be useful to develop a series of mindfulness sessions for use with PWID and that PWID need support to incorporate mindfulness within their lives.

5. Ceri Christian-Jones, ceri.christian-jones@bangor.ac.uk; Richard Hastings; J. Carl Hughes;

Multi-Component Interventions for Weight Loss in Adults with Intellectual Disabilities: Systematic Review and Meta-Analysis.

Background: A systematic literature search for studies reporting the effects of multi-component weight loss interventions for adults with intellectual disabilities (ID) identified 8 studies.

Methods: A fixed effects model meta-analysis was conducted for changes in weight and BMI.

Results: The meta-analytic standardized mean difference effect size (Hedges' g) between pre- and post intervention revealed non-significant effects for BMI and weight. The changes observed in individual studies were small, and lower than previously reported in meta-analyses in the non-ID population.

Conclusions: Limitations include the small number of studies included and the quality of these studies: only one utilized a control group. Recommendations are made for future research in this field and the implications of this meta-analysis are discussed for theory, policy, and practice.

6. Sally-Ann Cooper, Sally-Ann.Cooper@glasgow.ac.uk; Muriel Caslake, John Evans, Andrew Jahoda, Angela Hassiotis; Anthony Holland, Howard Ring, Alex McConnachie, Jill Morrison, Ciara Stiles, John Starr, Frank Sullivan

Towards onset prevention of cognition decline in adults with Down syndrome: The TOP-COG study

Background: Down syndrome adults have high rates Alzheimer disease (AD). Trisomy 21 causes amyloid precursor protein overexpression, so increasing amyloid β (A β), which is implicated in AD. Statins slow brain A β deposition. Studies suggest they may delay the onset/progression of AD, but there has only been one prospective cohort study with Down syndrome adults, and no trials. Studies with the general population are probably not generalisable to the population with Down syndrome, due to genetic physiological differences. There have been very few RCTs of medicinal products with adults with intellectual disabilities, so there is little available information to inform us about the likely recruitment rate to such RCTs. Also, whilst there are studies with Down syndrome adults on dementia incidence and changes in proxy-reported adaptive functioning over time, very little has been reported on cognitive decline, the early changes, or the best instruments to detect decline.

Methods: This is a feasibility and pilot study of simvastatin for the primary prevention of AD in Down syndrome adults. The variance of the rate of cognitive decline will be estimated, to calculate the sample size required for a definitive RCT. The study will assess recruitment and retention feasibility, factors effecting this, and recruitment sources. It will also determine the most sensitive tools to detect early cognitive decline. The design is an RCT, with a nested qualitative study.

Results: We will provide the trial protocol, recruitment figures and recruitment sources, and discuss the challenges of recruiting to such studies.

Conclusions: We will draw some preliminary conclusions regarding recruitment.

7. Elaine Cross, elaine.cross@postgrad.manchester.ac.uk; Dougal Hare, Sheena Grant, Louise Mahon, Ed Wraith, Simon Jones

An investigation in to the middle and late behavioural phenotypes of Mucopolysaccharidosis type- III

Background: Mucopolysaccharidosis III (MPS III) is a recessively inherited lysosomal storage disorder. It causes progressive physical and cognitive decline and has been linked to high rates of behavioural problems.

Methods: Data relating to the behaviour and adaptive skills of 20 children with MPS III, 5 adults with MPS III and 25 children with Intellectual Disability (ID) (17 included in analysis) were gathered via parental report questionnaire. Questionnaires were sent and returned by post. The frequencies of different types of behaviour displayed by children with MPS III and children with ID were compared across two age categories.

Results: The total frequency of challenging behaviours displayed by children aged 2-9 years with MPS III and ID was not significantly different. Behaviours associated with hyperactivity,

orality, unusual body movements and inattention were seen significantly more frequently in 2-9 year olds with MPS III than ID. Children aged 10-15 years with MPS III showed significantly fewer problem behaviours than a contrast group with ID. The frequency of challenging behaviours displayed by children with MPS III and their adaptive skills was found to decrease with age.

Conclusions: Behaviours relating to hyperactivity, orality, unusual body movements and inattention are part of the behavioural phenotype of the middle phase of MPS III. The late phase of MPS III is associated with low rates of problem behaviour and loss of adaptive skills. Therefore, families with a child with MPS III may benefit from a different type of clinical service when the child is aged 2-9 years, than when aged 10-15 years.

8. Dave Dagnan, dave.dagnan@cumbria.nhs.uk; Richard Thwaites, Chris Hatton, John Masson, Amy Cavagin

Training IAPT therapists to work with people with learning disabilities

Background: National drivers (e.g. No Health Without Mental Health and CQC/Monitor standards) suggest the importance of mainstreaming for mental health services for people with intellectual disabilities. This paper reports the outcomes of training for IAPT therapists in adaptation of Cognitive Behaviour Therapy for people with intellectual disabilities

Methods: A modularised training curriculum was delivered to 32 Primary Wellbeing Practitioners (PWP) and 36 High Intensity Practitioners (HIP) within one IAPT service. A therapy confidence scale, a measure of general therapy self-efficacy and a measure of attitudes to the treatment of people with learning disabilities in mainstream services were delivered pre-training, immediately post training and three months post training. A qualitative interview focussed on how participants had used the training was also carried out with 6 PWPs and 6 HIPs at 3 months post training.

Results: All measures showed significant change pre to post training which was maintained at 3 months follow-up. Qualitative data demonstrated the effective use of the training in clinical cases and thinking. It was interesting that PWPs were consistently more confident and saw themselves as more efficacious throughout the training and follow-up.

Conclusions: A relatively short modularised training approach focussed on CBT for people with learning disabilities has had a positive effect on therapist confidence and attitude to people with learning disabilities.

9. Catherine Dobson, cathdobson_burwain@hotmail.com

Audit of research studies involving participants not having the capacity to consent to their involvement

Background: The Mental Capacity Act (2005) provides the legal framework in England and Wales for actions, including the participation in research, for adults who lack the capacity to make decisions for themselves. The research provisions of the Mental Capacity Act were introduced to ensure that research could both enable participants who may lack capacity to consent could also be safeguarded in the course of their involvement. Researchers intending to include in their studies, participants who may lack the capacity to consent to their involvement, have a number of responsibilities: Scrutiny by specific Research Ethics Committees, Studies must concern knowledge about or treatment of the impairing condition, For prospective participants the researcher must make arrangements for consulting with family, carers or Nominated Consultees

Methods: The author conducted an analysis of studies (sourced from the database held by the National Institute of Health Research) commencing between October 2007 and March 2010, which concerned conditions or diagnoses potentially associated with an impairment of mental capacity, to identify the extent to which studies met the research requirements of the MCA.

Results: The poster presentation will outline findings of the audit. In addition, the presentation will expand upon data specifically concerning studies of participants having intellectual disability, updated to September 2012.

10. Gemma Evans, gemma.evans@postgrad.manchester.ac.uk; Jim Harrison; Dougal Hare

The Youth Sensory Behaviour Schedule: Validation of an assessment tool to explore sensory sensitivities in children with Autistic Spectrum Disorders.

Background: Sensory processing differences (SPD) or sensitivities to sensory information are recognized as a common feature of autism. The sensory Behaviour Schedule (SBS; Harrison & Hare, 2001) is a validated questionnaire which explores SPD in adults with ASD. The current project aimed to determine which items from the original SBS demonstrate appropriate reliability characteristics within a child ASD sample.

Methods: The protocol followed that used by Harrison and Hare (2001). 40 caregivers of 20 children with ASD who were receiving input from a CAMH service were recruited. Inter-rater reliability and intra-rater reliability were assessed by having two caregivers complete the questionnaire for the same child and the first caregiver complete the questionnaire on two separate occasions. All 33-items from the original SBS were administered.

Results: Kappa was calculated to provide reliability agreements for items within the questionnaire. Items with appropriate reliability characteristics were used to develop a shorter questionnaire; the Youth Sensory Behaviour Schedule (YSBS).

Conclusions: This study represents the first stage in the development of a Youth version of the SBS which may be used within CAMHS to explore SPD within children with ASD. This may facilitate service delivery and ensure appropriate environmental conditions for children.

11. Peter Fairlamb, peter.fairlamb@cumbria.nhs.uk; Janet Robertson; Chris Hatton; Sara Mallinson.

The Experiences of People with Learning Disabilities in using the Internet and Social Network Sites.

Background: The aim of the study was to explore the experiences of adults with learning disabilities in their use of the internet and social network sites

Methods: The study employs a qualitative methodology and involves the use of qualitative/ semi-structured interviews, including the use of a topic guide. A purposive sample was identified and interviews were conducted with nine participants, all of whom have learning disabilities to varying degrees.

Results: The data was analysed using thematic analysis and seven themes were identified: motivation issues, barriers, skill development and access, sources of support, usage, risk issues, and training

Conclusions: The results revealed that adults with learning disabilities can and do access computers, the internet and social network sites. Despite there being barriers to people with learning disabilities becoming part of digital society, the participants in this study were motivated to use computers and the internet. However due to limited IT skills and training, there is a reliance on support, including family members and paid carers/ staff, to maintain safety and mitigate risk. In mitigating risk both the participants and their support may take a cautious approach resulting in restricted use.

12. Jan Ferris, jan.ferris@nhslothian.scot.nhs.uk; Jacqueline Geddes; Keith Marshall

Supporting Families: A Qualitative Analysis of Family Members Experiences of Behaviour Family Therapy (BFT)

Background: It is well recognised that family members who support an individual with intellectual disabilities can experience high levels of stress. In many areas of mental health it is established that psychoeducational family interventions can reduce levels of stress. In NHS Lothian Learning Disability Service a project is currently evaluating whether family interventions, and specifically BFT, can reduce levels of stress among family members who support someone with an intellectual disability. This study uses a qualitative approach to investigate the experiences of family members who have completed a course of BFT.

Methods: Four families participated in this study. All families had recently completed a course of BFT. An independent researcher (Trainee Clinical Psychologist) who had no prior contact with the individuals involved carried out semi-structured interviews to establish family members experiences of BFT. Identified themes were pro-rated.

Results: Qualitative analysis identified that all family members who were interviewed were positive about their experiences of BFT. Themes identified included: the value of communicating effectively; developing personal goals; feeling support from services; working as a team.

Conclusions: Some families who support an individual with a learning disability report positive experiences when they have participated in BFT. This is identified in the emergent themes. This small piece of research contributes to our developing understanding of what aspects of psychoeducational family interventions (in both content and process) matter most to families of people with an intellectual disability.

13. Sheena Grant, sheena.grant@postgrad.manchester.ac.uk; Elaine Cross; Simon Jones, Ed Wraith, Brian Bigger, Dougal Hare

The Psychological Impact of Parenting children with MPS III or Intellectual Disabilities

Background: As part of a large scale research project on the presentation and impact of MPS III, the current study examined stress, coping, resilience, general health and social support among parents of children with MPS III and parents of children with intellectual disabilities, and examined the differential effects on family functioning of having a child with MPS III.

Methods: Twenty three parents of children with MPS III and a control group of twenty three parents of children with intellectual disabilities completed postal questionnaires about their child's behaviour and level of intellectual disability, how they cope with these behaviours, their level of perceived social support, and the impact on parental stress, health and resilience levels.

Results: Parents of children with MPS III reported fewer behavioural difficulties as their child aged, more severe level of intellectual disability, and similar levels of perceived social support, coping techniques, stress, anxiety and depression levels as parents of children with ID. Both groups of parents scored above the clinical cut off for anxiety and depression. Parents with children with MPS III rated themselves as significantly less future-orientated and goal directed than parents of children with ID.

Conclusions: Services should develop support packages for parents of children with MPS III that incorporate an understanding of the unique stressors and current-difficulty approach of this population. Future research should examine gender differences between parental psychological functioning and impact on siblings, using mixed qualitative and quantitative approaches, and utilise matched developmental level and typically developing control groups.

14. Jillian Grey, j.m.grey@bangor.ac.uk; Vasiliki Totsika; Richard Hastings;

Families' experiences of finding housing for their adult son or daughter with an intellectual disability

Background: In Wales, approximately 5,602 adults with an intellectual disability currently reside in family homes (National Statistics Release, 2011). Research into housing for adults with intellectual disabilities has tended to focus on the future planning by families for accommodation for their adult children (Blacher, 1990; Bowey and McGlaughlin, 2006; Heller and Factor, 1991). A less explored area is the first-hand experiences of families during this transitional period. The aim of this project was to gain an insight into the first-hand experiences of families who had initiated the process of looking for out-of-family home accommodation for a co-residing adult relative with an intellectual disability.

Methods: Face-to-face semi-structured interviews were conducted with nine family caregivers in six different local government areas across Wales. With the exception of one where the main caregiver was a father, all interviews were carried out with mothers in family homes.

Recurrent themes were identified across the data through thematic analysis.

Results: Themes emerging from the data comprised 1) factors leading to seeking out-of-family-home accommodation. 2) families' experiences with service professionals. 3) Reflection and impact of the process of finding accommodation.

Conclusions: Parents' age, increased care burden and maintaining independence skills were contributing factors to seeking out-of-family home accommodation. However, a lack of appropriate housing acted as a barrier to choice and resulted in stressful experiences for families.

15. Dougal Julian Hare, dougal.hare@manchester.ac.uk; Helena Tucker, Penny Bunton,

Self-concepts in adolescents with autism spectrum conditions and Williams Syndrome

Background: Self-concept is of central importance in one's psychological functioning and fundamental to psychological well-being. The present study explored self-concepts in adolescents with ASC and WS, conditions that present with distinct social phenotypes. The aim was to investigate whether perceptions of self differ in the two conditions and whether awareness and attitude to condition is related to self-image and/or self-esteem.

Methods: The Self-Image Profile for Adolescents (Butler, 2001), interviews and standardised tests were used to explore self-concepts and awareness of condition in 16 adolescents with ASC and 18 adolescents with WS.

Results: No significant differences were found on positive and negative self-image, sense of difference and self-esteem between the two groups, however results suggest trends of more positive construing of self in adolescents with WS. No association was found between awareness and attitude to condition and self-image and/or self-esteem.

Conclusions: A likely positive social reaction towards individuals with WS coupled with positive social bias may be attributed to a more positive perception of self. The need for tailored interventions to promote positive self-concept was highlighted in the light of evidence that behavioural and emotional problems change with increasing age in the two conditions.

16. Chris Hatton, chris.hatton@lancaster.ac.uk; Dave Dagnan; Richard Thwaites, Amy Cavagin, John Masson

Access to IAPT services by people with learning disabilities using First Step in Cumbria

Background: There are concerns about the accessibility of IAPT services to people with learning disabilities.

Methods: As part of a bigger HIEC project, we cross-referenced IAPT data with NHS and Social Services databases to identify people with learning disabilities using First Step IAPT services in Cumbria.

Results: Of 27,064 First Step clients identified in the database, 72 (0.27%) were people with learning disabilities known to LD services.

Clients with LD were on average younger than clients without LD (mean 34 vs 40 years) and evenly split between females and males; most clients without LD were female (63.9%).

Both for people with and without LD, the most common referral source was a GP (81.9% LD; 85.3% non-LD), followed by self-referrals (6.9% LD; 8.3% non-LD) and community practice nurses (8.3% LD; 3.2% non-LD).

For clients with LD, 36.1% had a primary diagnosis recorded. The most common diagnoses were: F32 – Depressive episode (9.7% LD; 13.0% non-LD); F41.2 – Mixed anxiety and depressive disorder (5.6% LD; 6.9% non-LD), F41.1 – Generalized anxiety disorder (4.2% LD; 7.0% non-LD) and F99 – Mental disorder not otherwise specified (4.2% LD; 2.9% non-LD).

In terms of process, the three most common codes for clients with LD were: END-DIS (therapy completed discharge – 31.3%), REF-FTE (referral – failure to engage – 25.0%) and END-SPE (signpost elsewhere – 15.6%). Three clients (4.7%) were referred to the LD service. For clients without LD, the most common codes were END-DIS (39.7%) and REF-FTE (31.4%).

Conclusions: Clients with learning disabilities are accessing IAPT services in Cumbria; the next step is to examine service effectiveness.

17. Olivia Hewitt, olivia.hewitt@berkshire.nhs.uk

A survey of abuse experienced by clients referred to the Psychology Service for People with a Learning Disability in Berkshire

Background: People with intellectual disability remain at increased risk of abuse and neglect. Following the move from institutional to community living, the pattern and risk of abuse for people with intellectual disability is likely to have shifted. Understanding the prevalence of

abuse within this population allows for appropriate planning and service development. Learning more about the type and frequency of abuse (and the perpetrators) facilitates prevention of abuse.

Methods: All clients referred to the Psychology Service over two years were included in this survey. The psychologist involved with the client reported whether the client had experienced any abuse. Information regarding the type of abuse experienced, the relationship to the abuser, and the number of different episodes of abuse was recorded.

Results: Of the 695 clients in the survey 25% had experienced abuse. Similar rates of abuse were experienced by men (46%) and women (54%). 23% of clients were referred to the service as a direct result of the abuse, whilst 77% were referred for another reason. The most prevalent types of abuse were emotional abuse (27%), sexual abuse (24%), physical abuse (20%), neglect (12%)

Conclusions: Prevalence rates within this study are broadly in line with the existing literature. However differences included high levels of emotional abuse, and high frequency of abuse perpetrated by women, and by family members. In-depth research with these clients will be time consuming but is essential to understand the experiences of people with intellectual disabilities today

18. Jo Illingworth, jli22@cam.ac.uk; Howard Ring

Epilepsy in people with intellectual disabilities of different aetiologies: A survey of carer-reported seizure precipitants

Background: Seizure precipitants are commonly reported in the general population of people with epilepsy and there is evidence that the nature of these precipitants varies with seizure type and epilepsy syndrome. However, little is known about seizure precipitants for people with epilepsy and intellectual disabilities (ID). The aim of this research was to find out what are the most common carer-reported seizure precipitants for people with epilepsy and ID of different aetiologies, with a focus on Rett Syndrome and Fragile X Syndrome.

Methods: A carer survey was conducted using online and postal questionnaires, which were distributed by charities representing people with Fragile X syndrome, Rett syndrome and epilepsy.

Results: 112 responses were received. Respondents supported somebody with epilepsy and ID with either Rett Syndrome (n=45), Fragile X Syndrome (n=40) or other aetiology (n=27). Most were family members. Every respondent identified at least one seizure precipitant for the person they support. The most commonly reported precipitants for each group were identified. Illness was a common precipitant in all three groups and was the most commonly reported precipitant overall. The groups differed with regard to the relative prevalence of other precipitants such as constipation and stress.

Conclusions: These findings suggest that an aetiology-based approach to the investigation of seizure precipitants in people with ID may be valuable. Greater understanding of seizure precipitants for people with epilepsy and ID may have the potential to improve epilepsy management for these individuals.

19. Barry Ingham, barry.ingham@ntw.nhs.uk; Gemma Evans

Clinicians' use of case formulation in intellectual disabilities psychological services: an exploratory study

Background: Case formulation is considered to be central to psychological healthcare and to evidence-based psychological therapies in mainstream populations. Its application within Intellectual Disabilities (ID) services has been given wider attention in recent years. However, there is limited evidence on how clinicians in ID services routinely apply formulation. This study aimed to help develop our understanding of this through an exploration of clinicians' perceptions of their case formulation use.

Methods: A qualitative approach was taken using semi-structured interviews undertaken with psychological services staff (n=15) working within intellectual disabilities services. Thematic analysis (Braun & Clarke, 2006) was used to analyse the responses.

Results: A number of themes were identified including the perceived value of case formulation (e.g. underpinning routine practice); methods of applying it (e.g. collaborative development

with clients); the barriers (e.g. limited involvement of family) and boosters (e.g. supervision) to perceived effective case formulation application; variations in practice (e.g. level of involvement of the client) and problematic aspects within case formulation (e.g. its limited evidence-base).

Conclusions: This study provides an initial view of case formulation use within ID services and highlights its perceived importance and wide ranging application. However, there was also variation in its application across practitioners and problematic aspects to using case formulation effectively. Further work is required to establish more consistent, agreed approaches to case formulation which could facilitate a structured approach to the development of an evidence-base for case formulation in ID services.

20. Andrew Jahoda, Andrew.Jahoda@glasgow.ac.uk; Paul Willner, John Rose, Biza Stenfert-Kroese

Development of a scale to measure fidelity to manualised group-based cognitive behavioural interventions for people with intellectual disabilities.

Background: There is a paucity of instruments to assess the fidelity of psychological interventions delivered to people with intellectual disabilities. Consequently, the aim of this study was to develop a scale (the Manualized Group Intervention Check: MAGIC) to measure the fidelity of manualized cognitive-behavioural therapy (CBT) delivered to adults with intellectual disabilities in group-based settings.

Methods: The context for the present study was a cluster randomized controlled trial of a 12-session manualized group-based anger-management intervention, delivered by lay therapists (day-service staff) who were trained and supervised by a clinical psychologist. A 30-item monitoring instrument was adapted from an existing instrument developed to monitor fidelity of individual CBT. One early and one late session for 27 groups were observed by pairs of monitors who had no other contact with the intervention. A total of 16 observers participated, in 15 unique pairings.

Results: Observers recorded high levels of inter-rater reliability (mean = 82%; kappa = 0.64), both overall and for most of the individual items. Inter-rater agreement was also high for global ratings of fidelity to the manual, group process, the principles of CBT, and an overall rating.

The scale had good internal consistency (Cronbach's alpha = 0.86), and principal components analysis was consistent with a single-factor solution. With the exception of one group that received a very low fidelity rating (19%), fidelity of delivery varied between 40 and 86%, with higher scores for fidelity to the manual and group process than to the principles of CBT. Fidelity ratings predicted two key outcomes of the intervention, self-ratings of anger and the acquisition of anger coping skills, and were themselves predicted by the therapists' clinical supervisors.

Conclusions: The MAGIC is a reliable and valid instrument that is easy to use and provides information about delivery that can be used to improve the intervention

21. Leah Jones, leah.jones@bangor.ac.uk; Richard P Hastings; Vasiliki Totsika

Child Behavior Problems and Parental Well-Being in Families of Children with Autism: The Mediating Role of Mindfulness and Acceptance

Background: Research over several decades has confirmed that parents of children with autism report more stress and mental health problems than other parents, and that levels of stress are most strongly predicted by behavior problems as opposed to other child characteristics. Few research studies have explored how or why the psychological distress of parents of children with autism is predicted by the level of their child's behavior problems.

Methods: Seventy-one mothers and 39 fathers of children with autism participated, by reporting on their own positive and negative psychological well-being; mindfulness and psychological acceptance processes; and their child's behavior problems, adaptive skills, and autism symptoms. A new situational measure of mindfulness in the parenting context was developed for the study.

Results: Both maternal and paternal psychological distress (but not positive perceptions) were associated with the severity of the behavior problems displayed by their child with autism.

Neither the child's level of adaptive skills nor autism symptoms were associated with parental

well-being. Psychological acceptance was found to act as a mediator of the relationship between child behavior problems and maternal anxiety, depression, and stress, and paternal depression. General mindfulness and mindful parenting had significant mediation effects for maternal anxiety, depression, and stress. Initial psychometric properties of the new mindful parenting scale were encouraging.

Conclusions: Emerging data suggest that mindfulness-based interventions for parents of children with autism and other developmental disabilities may help to reduce psychological distress. Our results contribute to evidence that mindfulness and acceptance may be important parental psychological processes, with implications for parent support.

22. Claire Kelly, clk32@medschl.cam.ac.uk; Marcus Redley, Karen Thomson, Sara Jones, Angela Thompson, Tony Holland

Understanding barriers to providing effective hospital care to patients with Intellectual Disabilities

Background: Men and women with Intellectual Disabilities (ID) have worse health than adults in the general population, an inequality which can be partially explained by their unequal access to healthcare services. In particular, the quality care and treatment provided to patients with IDs in hospitals has been a focus of considerable concern in recent years. To address this problem, a number of legislative and practical measures have been implemented across UK hospital trusts, and this research sought to better understand how effectively these adjustments compensate for the difficulties in access this patient group experience.

Methods: Semi-structured Qualitative interviews were conducted with 55 stakeholders (30 healthcare professionals; 20 carers; 5 patients) invested in the quality of hospital care that men and women with IDs receive in a single acute hospital trust in the East of England.

Results: The various legislative and practical adjustments did not always translate into real benefits for patients with IDs, as much of their intended impact was lost in the complex international dynamics between patients and professionals in the ward environment.

Conclusions: Healthcare professionals and social carers must be supported to implement the myriad of adjustments in place if these measures are to increase hospital access for patients with IDs.

23. Felicity Larson, fvl20@cam.ac.uk; Anthony Holland; Tessa Web; Digby Tantam; John Arrand; Peter Jones

The association between autism spectrum conditions and psychosis

Background: The historical overlap between autism spectrum conditions (ASCs) and psychosis has been largely confusing and our understanding changes over time. Given high rates of psychosis in people with Prader-Willi Syndrome (PWS), a neurodevelopmental disorder caused by differences on chromosome 15q11-13, and the high rates of 15q11-13 abnormalities reported in ASCs, we hypothesised that people with both an ASC and a history of psychosis would have high rates of genetic differences on chromosome 15q11-13.

Methods: People with ASCs and psychosis aged 16+ are being recruited from mental health services across the UK (target: 120). We are analysing their DNA for differences called copy number variants, where people either have more or less genetic material than people without these conditions, or with one condition alone. We will also explore psychosis in people with ASCs and describe the forms that it takes.

Results: To date, we have analysed 39 samples from people with ASCs and psychosis. One in 39 has a duplication of the PWS region. Other sites of genetic interest are emerging, but we will need to analyse the remaining samples and compare to control groups for these more exploratory findings. Mood symptoms are prevalent in people with ASCs and psychosis, and there is often no history of mental illness in the family of origin. Effects of IQ are also considered.

Conclusions: The genetics and phenomenology of psychosis in ASCs is complex. This interim report on an ongoing study is indicative of the complexities but there are hints at emergent themes.

24. Tony Levitan, tlevitan@yahoo.co.uk; Dave Dagnan; Peter Baker; Celia Heneage

Staff responses to challenging behaviour: A preliminary investigation into their development over the course of an interaction.

Background: Staff reactions to challenging behaviour have typically been investigated using attributional theory. However, such models have received limited support and a number of methodological and theoretical critiques have been levied against them, most notably a lack of ecological validity and difficulties relating cognitive-emotional variables with observed staff behaviour. This study aimed to use video elicitation methodology to address these issues and explore variation in responses over the course of an interaction.

Methods: Staff were interviewed about their cognitive and emotional responses during challenging interactions captured on video. Interview data was subject to qualitative content analysis and an attributional analysis. Staff behaviour was subject to descriptive and sequential analyses to explore their relationship with cognitive-emotional variables.

Results: Staff recalled making causal attributions about service user behaviour, as well as having a number of other cognitions such as anticipating challenging behaviour and evaluating their interventions. Cognitive responses varied over the course of challenging interactions. However, there was less variation in emotion over time. Tentative relationships were found between internal attributions, negative emotions and staff verbal responses and between mixed emotions and staff nonverbal responses.

Conclusions: Staff members made causal attributions of service user behaviour during challenging interactions, which may have contributed to their behavioural responses. Rather than being a stable attribute of the staff member, attributions seem to vary across the course of an interaction, suggesting a lack of consistency in understanding challenging interactions

25. Rachael Lofthouse, pspac2@bangor.ac.uk; Richard P Hastings; Vasiliki Totsika; G Griffith; W.R.Lindsay

Risk factors for aggression: A qualitative analysis of the perceptions of offenders with intellectual disabilities

Background: Research studies report that aggression and violence are the most prevalent challenging behaviours in the histories of offenders with ID, and the most common reason for admission to secure services. There is an absence of literature that examines the cause of aggression from the perspective of individuals with intellectual disabilities.

Methods: Ten adult men with ID were interviewed with a focus on recent incidents of aggressive behaviour and occasions they successfully managed their behaviour without becoming aggressive. Data were analysed using thematic analysis.

Results: Three overarching themes were identified: (a) hospital environment, (b) personal mental health characteristics, and (c) self management.

Conclusions: Analysis suggested that participants identified a limited number of personal characteristics as risk factors for their aggressive behaviour, and they predominantly attributed aggression to external triggers, suggesting a high external locus of control. The findings highlight important risk factors for consideration when assessing and addressing aggressive behaviour by individuals with ID.

26. Pamela MacMahon, pamela.macmahon@ggc.scot.nhs.uk; Andrew Jahoda; Katie Baynham

Family Carers of Adults with Intellectual Disability and Challenging Behaviour: Perceptions and Experiences

Background: Although family carers comprise the largest source of care for adults with intellectual disability (ID) (Metzel, 2005; Thomas, 2007), there remains a paucity of research exploring the experiences and perceptions of family carers supporting adults with ID and challenging behaviour (CB).

Methods: Semi-structured interviews were used to elicit the perceptions and experiences of eight family carers of adults with ID and CB. Interpretative Phenomenological Analysis was used to analyse the data.

Results: A number of key themes emerged, including: 1.) feelings of isolation – ‘the buck stops here’; 2) the emotional impact of caring for an individual with CB; 3.) being a different kind of parent; 4.) dynamic cognitive and emotional responses to CB; 5.) facing the future with fear; and 6.) conflicting roles- the challenge of balancing the needs of one individual with those of the family.

Conclusions: Family carers were committed to caring for their relatives with ID and CB. Participants described the numerous challenges of caring for their adult relative and often portrayed their experience of current support provision as unhelpful or inadequate. Throughout the interviews there was a sense that the cognitions, attributions and emotions experienced by family carers in response to CB were dynamic and often conflicting. Given that carers often have a significant role to play in the delivery of interventions aimed at individuals with ID and CB, the results of this study suggest that services should consider how best to support family carers in this role.

27. Aida Malovic, a.malovic@kent.ac.uk; Glynis Murphy; Peter Langdon; David Heavens;

The people with Asperger Syndrome and anxiety disorders (PAsSA) trial.

Background: There is a body of literature demonstrating that children, adolescents and adults with Asperger Syndrome (AS) and high functioning autism have significant problems with anxiety. These problems may significantly impair their quality of life. There is evidence to suggest that cognitive behaviour therapy (CBT) is an effective treatment for anxiety. The following study is looking to determine whether or not psychological treatments for anxiety can be adapted and used to successfully treat the anxiety experienced by people with AS. The study is set up across two sites in Kent and two sites in Norfolk. Methods: This is a single-blind cross-over trial incorporating pre-, post- and follow-up assessment of anxiety. A mixture of clinical ratings and self-ratings of anxiety are used. The intervention of group CBT will be delivered by trained CBT therapists, and the assessments of anxiety are completed by research assistants who are blind to group allocation. Results: We have completed the collection of the base line assessments, pre-treatment. These include anxiety, depression, fear and phobia measures. The results will be presented at the conference. The first treatment CBT group sessions have also been completed at one of the Kent sites. Conclusions: From the base line measures we have observed that our participants have measured as mildly to moderately anxious. Some of the clinical experiences and issues in delivering the treatment will be discussed.

28. Keith Marshall, keith.marshall2@nhs.net; Jan Ferris

A Cognitive Behavioural System Intervention with a support team who support someone with a learning disability with complex mental health needs.

Background: It is well documented that carers and support workers can be subjected to high levels of stress when supporting someone with a learning disability with complex mental health needs. Enduring high levels of stress can have an impact on coping skills and mental health and subsequently lead to difficulties in supporting and caring for others. Methods: Five members of a community support team took part in a cognitive behavioural system intervention training. This involved attending eight sessions facilitated by a cognitive behaviour therapist, each session lasting ninety minutes. The focus of the intervention covered the following concepts: bio-psycho-social formulation, orientation to cognitive behavioural therapy (CBT) framework, impact of stress on coping skills, information sharing, challenging attributions, enhancing communication skills, problem solving and relapse planning. Each member of the team completed pre and post measures on understanding the formulation and how the team was functioning. Results: After the training program four out of five support team members showed an increase in understanding in relation to the clients formulation. Four out of five of the support workers showed an increase in levels of functioning in relation to communication with each other and general problem solving skills in relation to some of the issues affecting the client. Conclusions: Using a CBT approach with support teams shows promising signs of being able to reduce stress and increase coping skills. Further work needs to be undertaken on the

flexibility of this approach to include family and support team members together, and sessions that could include the client as well.

29. Douglas McConachie, dougmcconachie@yahoo.com; Karen McKenzie; Paul Morris; Bob Walley;

The use of an Acceptance and Mindfulness-based Stress Management Workshop Intervention with support staff caring for individuals with intellectual disabilities

Background: Support staff working with individuals with intellectual disability (ID) and challenging behaviour experience high levels of work-related stress. Preliminary theoretical and experimental research has highlighted the potential suitability of acceptance and mindfulness approaches for addressing support staff stress. This study examines the effectiveness of an acceptance and mindfulness-based stress management workshop on the levels of psychological distress and well-being of support staff working with individuals with ID and challenging behaviour.

Methods: Support staff (n=120) were randomly assigned to a workshop intervention condition (n=66) or to a waiting list control condition (n=54). Measurements were completed at three time points (pre-, post and six week follow-up) for: psychological distress, well-being, perceived work stressors, thought suppression, emotional avoidance/psychological inflexibility.

Results: The results showed that for psychological distress there was a significant interaction effect in favour of the workshop. Thought suppression was found to reduce significantly in the intervention group post to follow-up, although no significant change was found in well-being or experiential avoidance/psychological inflexibility. For individuals with higher levels of psychological distress at pre-intervention (GHQ>11), larger effect sizes for the interaction were found, suggesting a greater impact of the workshops on the most distressed.

Conclusions: Overall, results demonstrated support for the effectiveness of an acceptance and mindfulness-based intervention in reducing distress.

30. Kathryn McDowell, Kathryn.McDowell@cumbria.nhs.uk, Dave Dagnan, Lorna Smith

Not heard and not seen: The level of activities outside of their home of people with intellectual disabilities and low communication abilities.

Background: A study carried out in collaboration with Cumbria People First Independent Advocacy Services' project "Voices of the Voiceless." The project's aim was to extend advocacy services to people who were unable to verbally communicate. Whilst working alongside individuals living in residential settings an observation was made by the advocate that people with lower communication abilities appeared to be less active compared to other residents. This study set out to explore the activity levels of people with intellectual disabilities comparing people with higher and lower communication abilities.

Methods: Participants included 35 men and 19 women (Aged 20 to 80) with intellectual disabilities living in a variety of domestic settings. Depending on ability, either the individual or a carer recorded activities for one week along with the number of activities occurring inside the individual's home and outside of their home. Adapting HoNOS-LD items, ratings were made for 'communication level', 'mobility level', 'practical activities', 'activities of daily living outside of the home' and 'occupation and activities'.

Results: People with lower communication abilities did significantly fewer activities outside of their home (as a proportion of total activities recorded) compared to people with higher communication abilities. The proportion of outside activities did not differ in respect to age; no significant differences were found between groups based on gender and mobility level.

Conclusions: The results suggest that people with lower communication levels are spending more time at home and doing fewer activities outside of the home compared to those people who are able to say what they want to do. These findings suggest that residential services should be considering how they enable people 'without' a voice to engage in more activity.

31. Alison McGarry; alijomcgarry@yahoo.co.uk, Biza Stenfert Kroese, Rachel Cox.

What do doulas do? Referrers' views and experiences of a doula service for parents with an intellectual disability.

Background: The need to provide services to support parents with an intellectual disability (ID) was highlighted in Valuing People (2001) and Valuing People Now (2007) yet most do not get access to sufficient and appropriate support.

A doula provides individualised support throughout pregnancy, labour and the postpartum period (Campero et al, 1998). Recent research highlights the benefits of doula services for parents with ID (McGarry et al, in preparation).

Method: Five ID professionals who had either referred a parent to the local doula service, or had worked with a family where a doula provided support, were interviewed to gain an insight into how they viewed and experienced doula services. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: The themes derived from the interview transcripts suggest that the doula support was viewed as positive, especially the practical and flexible 'hands-on' nature of the role and the good communication and networking skills of the doulas. Participants identified the need for a clearer definition of the doula role.

Conclusions These findings will be triangulated with the experiences of the parents with ID and the doulas who provided the support.

32. Lisa-Dionne Morris, l.d.morris@leeds.ac.uk; Alison McKay, Thomas Cassidy.

An Assessment Toy for Children with Learning Difficulties

Background: There have been numerous studies on the use of toys and games that encourage communication and interaction of children with learning difficulties. However, there are disagreements over the role and impact that toys and games have on the motivation, planning, development and implementation of individual educational plans for pupils with learning disabilities such as Severe Learning Difficulties and Profound and Multiple Learning Difficulties.

Methods: This paper presents results of a design research project whose goal was to develop a toy that could be used to assess cognitive and intellectual capabilities of children with Severe Learning Difficulties and Profound and Multiple Learning Difficulties.

Results: An analysis of four games using sound and light is presented: waiting for a sound, waiting for a colour, waiting for a traffic light and waiting for an image.

Conclusions: The design of a toy and examples of games suitable for primary level children is introduced. Current research is considering the potential for the toy and games to motivate children with learning difficulties and then record their educational progress. In the future this information could be used by teachers, carers and parents to review and assess progress and inform the development of individual care and education programmes.

33. Laura Nicholson, laurarobinson@doctors.org.uk; Sally-Ann Cooper, Matthew Colyer

Recruitment to intellectual disability research: a qualitative study.

Background: Difficulties in the recruitment of adults with intellectual disability (ID) to research studies are well described but little studied. The aim of this study was to investigate the difficulties in recruiting to a specific research project, in order to inform future recruitment to ID research.

Methods: Individual semi-structured interviews were held between September 2009 and May 2010 with people who had been involved as intermediaries in recruitment to the research project. These were transcribed verbatim and were independently analysed by two researchers using the Framework approach, who then agreed upon the key emerging themes.

Results: Ten interviews were analysed. A number of themes arose, including participant factors (interview anxiety, difficulties in understanding the concept of research, worry about negative feedback), the importance of the researcher (using a personal approach, meeting potential participants prior to recruitment) and motivators [enjoyment of the research interview (participant), obtaining a medical assessment (carer)]. The themes were then used to generate strategies to improve recruitment to ID research: these include the research team

applying a more personal approach, developing the recruitment process to allow for multiple meetings with potential participants, and considering motivators for both participants and carers.

Conclusions: This study has used the experiences of intermediaries to identify strategies for improving recruitment to future ID research. This has implications in terms of both time and money. However, successful recruitment is essential to ID research, and we hope that the study will be used by ID researchers to review and improve their recruitment processes.

34, Warren Oldreive, warren.oldreive@berkshire.nhs.uk; Mary Waight

Moving towards an Accessible future for adults with learning disabilities: Identifying barriers and working to find solutions

Background: Accessible information is fundamental to inclusion. Reasonable adjustments are being made, although concerns exist over their efficacy. Assumed understanding increases risk. The poster will summarise on-going work.

Methods: A small pilot audit evaluated reading skills of verbal adults (n=19) with a minimal understanding of three key words. 2 focus groups examined experiences of information provision. The data was combined with feedback from interventions aimed at providing accessible information. A survey was undertaken which examined web sites using pre-determined criteria based on clinical findings.

Findings: Literacy skills were limited. Some individuals found it hard to read words while others could 'read' without comprehension.

Individuals expressed that easy read information had been commonly used in following with previous findings. Not all individuals were able to read the information resulting in the need for it to be 'read' to them with many saying that they could become anxious.

A mixture of positive and negative themes emerged from feedback and focus groups. In summation there were five concerns/barriers and three positive elements. Areas of interest include: the formats used, the language involved and the design of materials. The survey of existing 'accessible' web resources revealed a number of limitations based on the criterion used.

Conclusions: Inherent variability in needs must be reflected in systems designed to enable access. Consideration of individual abilities is pivotal, targets set and review essential. Requirement for flexibility of: content; structure and formats with different roles for staff support. Independent access requires intuitive systems that are available when needed. Balancing the time demands required to develop bespoke resources with the requirement to provide generic resources of appropriate variability. Current formats require modification. Involving individuals is imperative.

35. Cristina Perez, cmp69@medschl.cam.ac.uk; Sarah Ball; Marcus Redley; Adam Wagner; Isabel Clare; Anthony J. Holland

Health service use, morbidity and mortality in adults with intellectual disabilities and mealtime support needs: Results of a UK-based cohort study

Background: It is estimated that 15% of adults with intellectual disabilities (IDs) known to services require mealtime support for eating, drinking or swallowing (EDS) problems (Ball et al., 2011). EDS problems are associated with an increased risk of serious health issues, such as respiratory infections, dehydration and malnutrition. We aimed to establish: the annual incidence of EDS-related health service use, morbidity and all-cause mortality, as well as factors predicting these outcomes in adults with IDs and EDS problems.

Methods: A total of 142 adults with mild to profound IDs and mealtime support needs were recruited at baseline, and their carers were interviewed using a structured pro forma. One year later, 127 adults were alive and followed-up, seven could not be contacted, and eight (5.6%) had died. Data were analysed using descriptive statistics and multivariate logistic regression models.

Results: This population experiences frequent GP and emergency hospital visits, 20% of which are attributable to EDS-related illnesses. One-third of participants experienced respiratory infections each year and 15% had an emergency hospital admission related to eating/drinking. Deteriorating EDS skills and an inability to eat independently were the

strongest multivariate predictors of respiratory infections and emergency hospital visits in this population.

Conclusions: In this under-researched subgroup of adults with IDs, respiratory infections were the principal EDS-related health issue and caused all eight observed deaths. Our findings highlight the importance of sustained monitoring and evaluations of changing EDS skills amongst adults who require mealtime support, to potentially prevent serious health issues, and even death.

36. Michael Petalas, m.a.petalas@live.co.uk; Richard Hastings; Susie Nash; Simon Duff.

Typicality and subtle difference in sibling relationships: Experiences of adolescents with autism

Background: Although researchers have explored siblings' perspectives on their relationships with a brother or sister with autism, there is a lack of research on the perspective of the child with an ASD.

Methods: We conducted semi-structured interviews with 12 adolescents with an ASD. Interpretative Phenomenological Analysis was used to analyse the data.

Results: Two major themes emerged from the analytic process: 1. Adolescents' reports of seemingly typical sibling interactions, and 2. Atypical sibling interactions influenced by having an ASD.

Conclusions: Despite the social context reinforcing views that autism impacts the sibling relationship in an atypical way, the overwhelming sense from participants was of typical sibling relationships. The assumption of atypical relationships in families of children with autism may need to be re-evaluated.

37. Dianne Phipps, d.phipps@chester.ac.uk; Joanne Skellern

Media representations, stigma and learning disabilities

Background: Stigma, defined by Link and Phelan (2001:p363) as "the co-occurrence of its components-labelling, stereotyping, separation, status loss, and discrimination", can have a significant negative effect on an individual's bio-psycho-social well-being (Green, et al. 2005). A research study was undertaken to explore the views of people with learning disabilities on stigma and how stigma can be challenged. This poster represents their choice of medium to challenge stigma faced by people with learning disabilities.

Methods: A semi-structured interview schedule was utilised to facilitate a focus group discussion exploring the definition and experiences of stigma from the perspective of eight participants and their suggestions for challenging stigma. The discussion was audio-recorded, transcribed verbatim and subject to thorough thematic analysis.

Results: The findings confirmed that all participants had experienced stigma within their daily lives and this was predominantly believed to be due to their diagnosis of learning disability.

Three themes were generated by the data analysis; understanding stigma, the reality of stigma and the role of the media.

Conclusions: The research study indicated that the understanding of stigma from the perspective of the service-users with a learning disability is largely based on real-life experience. The participants in the research study acknowledged the lack of representation within the media, specifically within films. The participants of the study created this poster with the aim of challenging stigma through the use of film cover designs

38. Roman Raczka, roman.raczka@lbhf.gov.uk; Kate Theodore; Janice Williams

Pilot evaluation of routine outcome measures PROMS in Hammersmith and Fulham learning disability service

Background: Patient Reported Outcome Measures (PROMS) provide a means of gaining an insight into the way patients perceive their health and the impact that treatments or adjustments to lifestyle have on their quality of life. It is essential that the PROMS that are used are both easy to understand and in an accessible format for people with learning disabilities to use.

Method: A pilot study has been developed to evaluate the usefulness/relevance of several different potential PROMS outcome measures. The three Outcome measures to be used are:
The EQ-5D: The EQ-5D: a widely used self-completed generic Health Questionnaire.
Maslow Assessment of Needs Scales - Learning Disabilities (MANS-LD) The MANS-LD: an 18 item self-completed learning disability specific assessment.
The Adapted World Health Organisation Quality of Life Measure (WHOQOL-8) The WHOQOL-8: an 8 item self-completed generic questionnaire.
An additional accessible prompt sheet has been developed (with Speech and Language Therapists) for all three measures to supplement the existing measures and to further ensure that the questions are presented in a more easy to understand format.
The study examines: The validity and relevance of the adapted/accessible measures at time T1. The correlation between the EQ-5D, MANS-LD and WHOQOL measures at time T1 and across time T1 to T3 (administered at 3 monthly intervals)
Results: Data collection is underway.
Conclusions: The results of the baseline (T1) assessments will be presented in December.

39. Kate Theodore, kate.theodore@rhul.ac.uk; Roman Raczka, Iiris Kleinberg

Developing a joint-working pathway to parenthood: Learning from the lived experiences of mothers with learning disabilities

Background: The numbers of parents with known/suspected learning disabilities presenting to services is increasing (BPS, 2011). These parents face multiple disadvantages in parenting their children successfully, and are still likely to have their children removed from their care (Tarleton et al., 2006). Good practice guidance exists (e.g. DoH and DfES, 2007); however there are limited published studies investigating parents' lived experiences (Conder et al., 2010), and services still struggle to achieve integrated working (MacIntyre & Stewart, 2011).
Methods: In-depth qualitative interviews were conducted with five mothers with learning disabilities; aged 23-38 years and with a total of 16 children between them. Interviews were analysed using thematic analysis (Braun & Clarke, 2006).
Results: Two main themes emerged: the first centred on mothers' desire for parenthood and fulfilling this valued social role, despite often feeling unprepared and facing negative reactions or even victimisation from others; the second focussed on mothers' dilemma between their desire for support from services to develop parenting skills, conflicting with the intrusive and evaluative nature of this support, with the danger that it brought in potential for child removal. These results were disseminated to key professional stakeholders, to underpin development of a joint-working service pathway.
Conclusions: This qualitative project with mothers allowed a powerful narrative of their experiences to emerge. The study builds on the literature already available to develop a joint-working pathway based on local mothers' lived experiences as well as good practice guidance, highlighting areas for cohesive joint-working across the multiple services involved; an area highlighted as still lacking.

40. Stuart Todd, stodd@glam.ac.uk; David O'Driscoll,

Title: Some never left: death and dying in a Victorian ID institution (1915-1940)

Background: Although institutions for people with ID are close to extinct in the UK, they continue to cast a long and dark shadow over modern ID provision and understandings. This has led to a well developed research based history of them that represents them as mechanisms of social control. However less well known is that for many, the institution was not only a place of living, it was a place for living and dying.
Methods: Data were extracted from records held and maintained within an English ID institution. Data were obtained for 1918, 1920, 1925, 1930 and 1940 on; gender, age at death; cause of death and whether the deceased was interred within the institution's cemetery
Results: Data were obtained on 941 deaths, a death rate of 4.7 deaths per week. This rate varied over the study period from 10 to 3.5 deaths week. The earlier rates are attributed to the combined effects of World War One and the Influenza epidemic. The average age at death was consistent across the time period, 44 to 49. The data suggest that high proportion of deaths occurred within the first 12 months of admission but that substantial numbers lived

there for 10 years or more. The numbers of people buried within the institution fell from 66% to 53% across the study period.

Conclusions: Death was a prominent feature of institutional life but was routinised and made unremarkable. In death, it seemed that the identity of people as having an ID was reinforced further by burial in a nameless and overcrowded grave in a special cemetery.

41. Elin Walker Jones, Elin.walker-jones@wales.nhs.uk; Gemma Griffith; Nia Pickering; Lesley Goodson; Ela Cernyw; Richard Hastings

Receiving an assessment and potential diagnosis for Autism Spectrum Disorder. A thematic content analysis of parental experiences.

Background: Background. Having a child assessed for a diagnosis of Autism Spectrum Disorder (ASD) is a significant challenge for parents, and many are dissatisfied with the assessment process (Howlin & Moore, 1997).

Methods: Method. Eight families were interviewed about their experiences of having their child assessed for ASD. The interviews were analysed using thematic content analysis.

Results: Results. Two main themes emerged: 1) Management of ASD assessments, and 2) parental support needs, and eight sub-themes.

Conclusions: Conclusions. Practitioners should consider the support needs of parents during the ASD assessment, and to consider supports that 'bridge the gap' post-diagnosis.

42. Sarah Wigham, sarah.wigham@ncl.ac.uk; Mickle South, Laura Gray, Jacqui Rodgers,

Understanding the Relationship between Repetitive Behaviours and Sensory Processing in children with Autism Spectrum Disorders

Background: Restricted and repetitive behaviours are core criteria for a diagnosis of autism spectrum disorder (ASD), and although they often co-occur with sensory processing abnormalities, the relationship between these characteristics is not understood (Boyd et al, 2010). Research suggests that there may be subcategories of repetitive behaviours and sensory processing that have a unique relationship in individuals with ASD.

Methods: Data were collected from the parents of 23 children with ASD aged 8 to 15 years old and residing in the North East UK, using the Repetitive Behaviour Questionnaire (RBQ) and the Short Sensory Profile (SSP).

Results: There were significant correlations between parent-reported total scores for repetitive behaviours and sensory processing ($r_s = -.385, p = .035$)*. Analyses of the relationships between sub categories demonstrated a significant correlation between RBQ motor behaviours and SSP hypo-sensitivity ($r_s = -.593, p = .001$), and likewise between RBQ insistence on sameness, and SSP tactile ($r_s = -.52, p = .005$) olfactory ($r_s = -.396, p = .031$) and visual ($r_s = -.363, p = .044$) hypersensitivity.

(*low scores on the SSP indicate high sensory processing abnormalities).

Conclusions: Understanding the relationships between repetitive behaviours and sensory processing has implications for interventions related to regulating emotions and behaviour in ASD.

43. Tim Williams, sxswiams@reading.ac.uk; Reason L. Machete

Characterising repetitive behaviour: a preliminary analysis of temporal patterns

Background: Repetitive and stereotyped behaviours are characteristic of problems such as autism spectrum disorders as well as typically developing populations. Some repetitive behaviours are self-injurious whereas others restrict opportunities to take part in everyday activities. Experimental analyses have suggested a range of functions, including "commonly self-stimulation or automatic reinforcement" which begs the question of what internal state is being changed. One possible route to identifying the internal state is by identifying the time-based patterns of the behaviour and comparing those with the behaviour of known neurological systems.

Methods: The behaviour of individuals in a residential 52 week school environment was recorded by staff.

Results: The pattern of gaps between episodes of self-injurious behaviour and gaps between episodes of being upset/crying were examined for one individual with autism and severe learning disability. The gaps between episodes of crying/upset behaviour was found to fit a geometric distribution closely. The self-injurious behaviour did not show such a good fit. The two time series were not correlated.

Conclusions: The use of mathematical analyses of the temporal patterns of occurrence of behaviours has the potential to illuminate biological mechanisms that may be involved. In this case the distribution is similar to that seen in some forms of epilepsy. Discussion focuses on comparisons with similar attempts to model repetitive actions.