

**Northumbria University**  
**and**  
**Northumberland, Tyne & Wear NHS Trust**

## **Seattle Club 2008**

**8<sup>th</sup> Seattle Club Conference  
on Research and People with  
Learning Disabilities**

***Monday, 1<sup>st</sup> & Tuesday, 2<sup>nd</sup> December 2008***

**The Thistle Hotel, Newcastle upon Tyne**

## **Welcome to Seattle Club 2008**

Welcome to Newcastle upon Tyne for the 8th Seattle Club Conference for researchers in intellectual disabilities in the UK and Republic of Ireland.

Now in our eighth year, the conference has established a number of traditions which we have attempted to maintain in its organisation this year:

- Our focus is on data-based presentations reporting findings gained through appropriate application of scientific methods.
- All oral presentations are in plenary; there are no parallel sessions.
- Oral papers and posters are equally weighted in terms of worth, scientific rigour and status.
- Selection of contributions for oral and poster presentation is designed to achieve a mixture of more established and more recent researchers.
- Participation is restricted to authors and co-authors of accepted oral and poster presentations together with up to 10 researchers at the beginning of their research careers, who have applied for and been awarded Seattle Club Studentships.

The clear focus on research and keeping the size of the meeting to manageable proportions are designed to promote methodological critique, constructive dialogue and collaboration across participants for the long-term benefit of research in intellectual disabilities in our respective countries. Innovations for this year's meeting include the introduction of a second keynote address on day two and a 'Discussion Session' on a topical issue: this year ID research funding.

So please, ask questions, make comments, put forward suggestions and use your time to develop links to make better research more likely.

### *Organising Committee*

The ad hoc organising committee members for Seattle Club 2008 meeting are: John Taylor, Northumbria University; Richard Hastings, Bangor University; Chris Hatton, Lancaster University; Andrew Jahoda, Glasgow University; and Bill Lindsay, University of Abertay Dundee.

### *Administrative Support*

Many thanks for their help and support to: Pat Blakely and Nicola LeDieu, Northumberland Tyne & Wear NHS Trust; and Rebecca Groves, Northumbria University.

We hope you enjoy your time in Newcastle. Have an interesting and edifying conference, but please have some fun as you as do!

## Seattle Club Studentships 2008

Seven 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:

**Dawn Adams** (University of Southampton)

The development and function of smiling and laughing behaviours in children with Angelman syndrome.

**Kate Eden** (University of Birmingham)

The behavioural manifestations of pain and the measurement of pain perception and response in individuals with a severe learning disability.

**Karri Gillespie** (University of Stirling)

Face processing and its relevance when designing learning environments for pupils with autism.

**Marcus Jepson** (Bristol University)

Exploration of the ways in which people with learning disabilities are supported to make everyday decisions in particular relation to the Mental Capacity Act.

**Peter Larkin** (Glasgow University)

Psychosocial sources of aggression in people with learning disabilities.

**Lucy Wilde** (University of Birmingham)

Social and interpersonal behaviour in Smith-Magenis syndrome.

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## Day One: Monday, 1<sup>st</sup> December 2008

**09.15 – 10.20 Registration and Coffee**

**10.20 – 10.30 Welcome and Introduction – John Taylor**

**10.30 – 11.45 Symposium Session 1: Parents and Carers**

Chair: Jo Moss

1. *Socio-economic circumstances and risk of common psychiatric disorders among parents of young children with and without cognitive delay in the UK*  
Eric Emerson, Hilary Graham, Jan Blacher, Gwynnyth Llewellyn and Chris Hatton
2. *Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities*  
Tracey Lloyd and Richard Hastings
3. *Parents with learning disabilities: The lived experience*  
Gillian MacIntyre and Ailsa Stewart

**11.45 – 13.15 Symposium Session 2: Genetic Syndromes, Autism and ASD**

Chair: Debbie Riby

4. *The relationship between socioeconomic status, genetic syndromes, autism and autistic spectrum disorder*  
Sarah Beaumont, Jo Moss, Caroline Richards, Sarah Gorniak, Laurie Powis, Jane Appleby et al.
5. *The impact of autism and severe challenging behaviour on lifestyle outcome in community housing*  
David Felce, Jonathan Perry, Kathy Lowe and Edwin Jones
6. *An experience sampling study of the phenomenology of anxiety in people with Asperger's Syndrome*  
Dougal Julian Hare, Christopher Wood and Paul Skirrow
7. *Self-injurious behaviour in autism spectrum disorder*  
Caroline Richards, Chris Oliver, Jo Moss, Lisa Collis and Laura O'Farrell

**13.15 – 14.00 LUNCH**

**14.00 – 14.45** **Keynote Address I: Professor Chris Oliver, Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham**  
*'Research on Behavioural Phenotypes and Implications for Practice'*

Chair: John Taylor

**14.45 – 15.05** **TEA** (20 mins)

**15.05 – 16.15** **Symposium Session 3: Public Attitudes, Support and Ethnicity**

Chair: Stephen Beyer

8. *Public attitudes towards people with intellectual disabilities: A comparison of white British and South Asian people*

Katrina Scior, Sarah Coles, Rahema Bibi, Martha Kenyon, Anna McLoughlin and Joel Sheridan

9. *RCT of support for young people from South Asian communities with intellectual disabilities and mental health needs*

Raghu Raghavan

10. *Family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and impact on families*

Chris Hatton, Eric Emerson, Suzanne Kirby, Homayra Kotwai, Susannah Baines, Christine Hutchinson et al.

**17.45 -19.15** **Poster Session**

*The influence of Staff Communication Style on Service User Response – An Exploratory Study*

Sarah Andrews, Andrew Jahoda and Sharon Horne-Jenkins

*Screening for Learning Disability in an adolescent forensic population*

Ruth Andrews, Greta Ford, Anne Booth, James Dibden, Samantha Hardingham and Thomas Kelly

*Assessment of executive functioning in people with intellectual disabilities*

Rebecca Bailey and Paul Willner

*The employment and cost outcomes of Supported Employment in North Lanarkshire*

Stephen Beyer

*Influences on the well-being of direct care workers supporting people with intellectual disabilities*

Melanie Chapman and Jennifer Gray-Stanley

*Investigating the inter-correlation of a battery of social cognition measures for adults with Asperger Syndrome*

Fleur-Michelle Coffait, Dougal Julian Hare and Rhiannon Corcoran

*Can Experimental Avoidance of Challenging Behaviour be Measured by Avoidant Eye Gaze?*

Jonathan Crabb

*Control, responsibility and mitigating actors: How do they impact upon carers emotional responses to challenging behaviour presented by adults with intellectual disabilities*

Dave Dagnan, Sophie Williams, Jacqui Rodgers and Kathryn McDowell

*Social support and coping as mediators or moderators of the impact of work stressors on burnout in intellectual disability support staff*

Jason Deverux, Richard Hastings, Stephen Noone, Vaso Totsika, Alison Firth

*Staff inputs and outcomes in services for people with learning disabilities*

Philip Disley, Chris Hatton and Dave Dagnan

*Emotion and identity: An investigation into the nature of face processing impairments in autism*

Carolyn Gracey and Debi Roberson

*Caring for an adult with a rangre syndrome; An IPA analysis of maternal experiences of medical and social services*

Gemma Griffith, Richard Hastings, Susie Nash and Micheal Patalas

*Parenting groups for the parents of children with severe intellectual disability and challenging behaviour*

Annette Hames

*Understanding service charge from the perspective of staff using Q methodology*

Sarah Hyland, Dougal Hare and Rosalyn Hartwell

*The introduction of biopsychosocial formulation based working to an inpatient mental health in intellectual disabilities service: a survey evaluation*

Barry Ingham, Matt Selman and Lesley Clarke

*Research Priorities consultation for Learning Disabilities and autism in Wales*

Alex Kaehne

*The association between indicators of psychiatric disorder and challenging behaviour*

Mike Kerr, David Felce and Richard Hastings

*Carers expectations and views of cognitive behavioural therapy for adults with intellectual disabilities*

Biza Stenfert Kroese, Carol Peart and Dave Dagnan

*Moral Reasoning Amongst Men with Intellectual Disabilities*

Peter Langdon, Isabel Clare and Glynis Murphy

*The use of Repertory Grid techniques to investigate Ziglers intellectual disability personality model*

Alexandra Leonard, Dougal Julian Hare and Steve Hendy

*The barriers and boosters of using the Central Relationship Questionnaire (CRQ) adapted for use with an intellectual disability population*

Miriam Lomas, Jill Porter and Simon Hackett

*And people said they will never do it. Staff stories of resettlement from institutions for people with intellectual disabilities in the North West of England*

Duncan Mitchell and Melanie Chapman

*Establishing the extent of need for eating/drinking assistance among adults with developmental disabilities*

Samuel Panter, Sarah Ball, Marcus Redley, Kaite Byrne, Carey-Anne Proctor, Anthony Holland and Isabel Clare

*An Audit of current needs and challenging behaviour service provision for adults with a learning disability in Telford and Wrekin*

Clare Passey, Gail Thomas, Andy Howe and Richard Smith

*Telecare: its impact on objective quality of life outcomes*

Jonathan Perry, David Felce and Claire Pimm

*Adapting the Antenatal Care Pathway for Parents who have a Learning Disability*

Eleanore Porter, Gill Kidd, Nicola Murray, Alison Spink and Clare Utyman

*Social Exclusion and Sexual Understanding*

Jaycee Pownall and Andrew Jahoda

*Thinking on your feet: Understanding the immediate responses of staff to adults with challenging behaviour in learning disability services.*

Peggy Ravoux, Peter Baker and Hilary Brown

*IMCA Involvement in adult protection cases*

Marcus Redley, Isabel Clare and Tony Holland

*Detecting and utilising information from peoples faces: Eye tracing evidence from Williams Syndrome and Autism*

Debbie Riby and Peter Hancock

*Women with developmental disabilities – are they angry in the same way as men?*

Alison Robertson and John Taylor

*An investigation of the voice quality of children with Down's Syndrome and its impact on listener judgements'*

Rebecca Rodger, Janet Beck, Sarah Wood and Jennifer Wishart

*The development of stereotyped & catatonic behaviour in adolescents with autism spectrum disorder*

Sarah Thorndyke and Dougal Julian Hare

*A group-based Treatment Programme for Fire-Setters with intellectual disabilities*

Ian Thorne and John Taylor

*Autism and intellectual disability: Their effect on children's behaviour and their carers psychological well-being*

Vaso Totsika, Richard Hastings and Eric Emerson

*Measuring the actual levels and patterns of physical activity/inactivity for adults with learning disabilities*

Angela Turner, Janet Finlayson and Malcolm Granat

*Treating the Reliability and Validity of New Measures of the Effects of Stressful Life Events*

Sarah Wigham, Chris Hatton and John Taylor

**20.00**

**DINNER AT GUSTO**

*(Insert address/contact no.)*

## Day Two: Tuesday, 2<sup>nd</sup> December 2008

**09.30 – 10.45 Symposium Session 4: Novel research Methods and Approaches**

Chair: Derek Carson

11. *Living with challenging behaviour: Using discourse analysis to explore the experiences of people with intellectual disabilities in residential services*

Shona Daynes and Peter Baker

12. *An examination of the relationship between looking and pointing in Facilitated Communication using eye-tracking*

Andrew Grayson and Anne Emerson

13. *Temporal discounting by people with intellectual disabilities*

Paul Willner, Rebecca Bailey, Rhonwen Parry and Simon Dymond

14. *Implications for challenging behaviour of a neural basis of a deficit in attention switching in Prader-Willi syndrome*

Kate Woodcock, Chris Oliver and Glyn Humphreys

**10.45 - 11.05 COFFEE (20 minutes)**

**11.05 - 12.05 Discussion Session: UK Intellectual Disability Research – Challenges and Threats**

Chairs: Richard Hastings and John Taylor

**12.05 – 12.50 Keynote Address II: Rob Greig, Chief Executive, National Development Team**

*'The role of research in Intellectual Disability Policy and its delivery in the UK'*

Chair: Chris Hatton

**12.50 – 13.25 LUNCH**

**13.25 – 15.05 Symposium Session 5: Forensic and Legislative Issues**

Chair: Peter Langdon

*15. Pathways into services for offenders with intellectual disabilities: Referral, childhood experiences, diagnosis and offence factors*

Bill Lindsay, Greg O'Brien, Derek Carson, Tony Holland, John Taylor, Jessica Wheeler et al.

*16. The process by which people with intellectual disabilities engage with the criminal justice system*

Michael Hellenbach

*17. Eyewitnesses with mild learning disabilities: Face recognition and description abilities*

Julie Gawrylowicz, Derek Carson, Fiona Gabbert, Bill Lindsay and Peter Hancock

*18. Living 'a life like ours': Substitute decision-making for adults with intellectual disabilities living in residential care homes*

Michael Dunn, Isabel Clare and Tony Holland

**15.05-15.30 Closing Remarks and Reflections – Paul Willner**

**15.30 CLOSE**

# ABSTRACTS

## Keynote Address Abstracts

### **The role of research in Intellectual Disability Policy and its delivery in the UK**

Rob Greig

National Development Team, Bath, Somerset

Email: [rgreig@ndt.org.uk](mailto:rgreig@ndt.org.uk)

This presentation will consider the extent to which formal research influences and plays a role in the development of intellectual disability policy - as well as its usage and application to planning, service development and delivery at a local level. Lessons will be drawn from this analysis for the academic and research community - ranging from decisions about research topics, through research styles, to dissemination.

### **The environmental consequences of genetic research.**

Prof. Chris Oliver

Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham

Email: [C.Oliver@Bham.ac.uk](mailto:C.Oliver@Bham.ac.uk)

The increase in research addressing gene-brain-behaviour relationships in people with intellectual disability reflects a general trend in both serious and popular science toward recognising a broader and more complex role for genetic influence on human development, health and behaviour. Authors such as Steven Pinker have argued that this trend redresses an imbalance in the nature-nurture debate, whilst others, such as Stephen Rose, suggest that the trend cultivates genetic determinism with inevitable consequences for social cohesion. The study of the physical, psychological and social outcomes for single, well defined genetic disorders associated with intellectual disability is not divorced from this context. By its very nature, research that characterises atypical behavioural, cognitive and emotional presentation in people with genetic disorders cannot avoid emphasising difference and, inevitably, impairment. It is important that this research attends to the interpretation, scientific and public presentation and unintended impact of findings that highlight difference and impairment. There needs to be sufficient justification for descriptive and experimental behavioural phenotype research that embraces the wider agenda of social inclusion. This justification requires research in this area to address issues such as the implications of understanding gene-brain-cognition-behaviour-environment pathways in rare disorders for intervention likely to enhance social inclusion, the importance of actively manipulating environments to seek better person-environment fit and the health and social resources available to support people with rare syndromes. Within the intellectual disability research community, the issue of the relevance of aetiology of intellectual disability for different research agendas warrants open debate.

## Symposium Session 1: Abstracts

### **Socio-economic circumstances and risk of common psychiatric disorders among parents of young children with and without cognitive delay in the UK**

Eric Emerson, Hilary Graham, Jan Blacher, Gwynnyth Llewellyn and Chris Hatton  
Institute for Health Research, Lancaster University  
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**Background:** Parents of children with intellectual or developmental disabilities are at increased risk of psychiatric disorder and psychological distress. Our aim: To examine the possible confounding effects of socio-economic circumstances and other variables on the association between child cognitive delay and parental psychiatric disorder.

**Methods:** Secondary analysis of the UK's Millennium Cohort Study using propensity score matching to control for the effects of potential confounding variables

**Results:** Parents of children with cognitive delay had significantly higher rates of probable psychiatric disorder than other parents when their child was age 3 and two years later. Controlling for between group differences in socio-economic position reduced the between group differences in probable psychiatric disorder to non-significance. Controlling for additional confounding effects (e.g., child gender, parental physical health) further reduced between group differences in probable psychiatric disorder.

**Conclusions:** Risk for psychiatric disorder among parents of young children with early cognitive delay appears to be largely related to the social context of parenting and parental characteristics, rather than child delay.

### **Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities**

Tracey Lloyd and Richard Hastings  
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**Background:** Positive psychology is an area gaining credence within the field of intellectual disability (ID). Hope is one facet of positive psychology that is relatively unstudied in parents of children with ID. Hope is a theory of goal-driven action and is comprised of agency and pathways thinking (Snyder, Harris et al., 1991). In the present study, we explore hope and its relationships with parental well-being in parents of school-aged children with ID.

**Methods:** 138 mothers and 58 fathers of children with ID took part in a questionnaire-based study. Parents reported on their feelings of hope and positive affect, other dimensions of psychological well-being (anxiety, depression and stress), and on their child's behaviour.

**Results:** For mothers, regression analyses revealed that hope (agency and pathways) and child behaviour problems predicted maternal depression. Positive affect was predicted by child behaviour problems and by hope agency. For fathers, anxiety, depression and positive affect were all predicted by hope agency. Hope pathways was not a significant predictor of paternal well-being. Hope agency and pathways interacted in the prediction of maternal depression such that mothers reporting high levels of both hope dimensions reported the lowest levels of depressive symptoms.

**Conclusions:** Hope is a construct that merits further investigation within families' research, and is potentially a factor that could be utilised in intervention to help increase familial well-being.

## **Parents with learning disabilities: The lived experience**

Gillian MacIntyre and Ailsa Stewart

Glasgow School of Social Work, University of Strathclyde

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Background: In recent years the number of parents with a learning disability has increased, although exact figures are unknown. Research suggests that parents with learning disabilities are often assumed to be incompetent. (Murphy & Feldman, 2002; Booth & Booth, 1996). The result is that these families become over-represented in child protection figures (Olsen & Clarke, 2003). Research has suggested that advocacy plays an important role in assisting parents to negotiate these systems, allowing their voices to be heard more effectively (e.g. Mencap 2007). This small pilot study aimed to identify the likely demand for advocacy services to support parents with a learning disability living in the Glasgow area. In addition the study aimed to illustrate in depth the lived experiences of parents with a learning disability.

Methods: A survey questionnaire was sent to relevant social work, health and voluntary sector organizations. Interviews were conducted with five parents with learning disabilities, their advocates and with key informants in service provision.

Results: Parents experienced disadvantage in relation to a number of areas including child protection, poor housing and poverty. Interventions to support parents were often provided during a crisis rather than as prevention and a lack of accessible information disempowered parents in a number of ways. Parents often did not meet eligibility thresholds and found it difficult to access support for themselves. Advocacy performed a number of key functions and provided effective outcomes for parents with learning disabilities.

Conclusions: Parents were able to effectively identify successful outcomes as a result of advocacy support. The complexity of their situations meant that long-term advocacy was viewed as the most effective model with volunteer advocates undertaking a complimentary role.

## Symposium Session 2: Abstracts

### **The relationship between socioeconomic status, genetic syndromes, Autistic Spectrum Disorder and behaviour**

Sarah Beaumont, Jo Moss, Caroline Richards, Sarah Gorniak, Laurie Powis, Jane Appleby et al.

University of Birmingham

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**Background:** The relationship between socioeconomic status (SES) and behaviour in people with intellectual disabilities is beginning to receive attention. However, the relationship between SES and behaviour in genetic syndromes and Autism Spectrum Disorder has yet to be explored.

**Methods:** Postcode information was collected for 734 children with genetic syndromes or Autism Spectrum Disorder (ASD) in order to generate an index of SES. The SES of carers who responded within syndrome groups and ASD was examined and the relationship between SES and aspects of the behavioural phenotype within syndromes and ASD was evaluated.

**Results:** Respondents came from higher SES groups. Behavioural characteristics were not associated with SES for those with genetic syndromes. However, those with ASD and a lower SES exhibited more overactive and compulsive behaviours.

**Conclusions:** The results suggest a possible bias in responding in questionnaire studies of behavioural phenotypes but no association between SES and behavioural phenotype. The results are different for the ASD group which is behaviourally defined.

### **The impact of autism and severe challenging behaviour on lifestyle outcome in community housing**

David Felce, Jonathan Perry, Kathy Lowe and Edwin Jones

Welsh Centre for Learning Disabilities, Cardiff University

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**Background:** Autistic spectrum disorders and severe challenging behaviours are reasonably common among adults with intellectual disabilities. The aim was to investigate their impact on lifestyle outcome among such adults living in staff-supported community housing.

**Methods:** Data were collected on the adaptive and challenging behaviour, social impairment, attention from staff, social and community activities, household participation and engagement in activity of 427 adults living in 146 community residences. Categorisation of autism was based on items relating to the triad of social impairments in the Disability Assessment Schedule. Categorisation of severe challenging behaviour was based on scores on the Irritability and Hyperactivity domains of the Aberrant Behavior Checklist (ABC). For each person categorised as having either, a comparison person was selected with a similar score on the Adaptive Behaviour Scale (ABS) and outcomes compared. In addition, multiple regression was used to examine the association between lifestyle outcomes and the presence of autistic spectrum disorders or severe challenging behaviours after controlling for other participant characteristics.

**Results:** After controlling for adaptive behaviour, there were no significant differences between those with and without autistic spectrum disorders. People with severe challenging behaviour received significantly more staff attention but were similar in terms of social, community and household activities. The regression analyses found small negative associations between ABC scores and variety of social and community activities and household participation after controlling for ABS scores.

**Conclusions:** Results support previous findings that low adaptive behaviour has a negative impact on lifestyle outcome. Autism or severe challenging behaviour do not add to this.

## **An experience sampling study of the phenomenology of anxiety in people with Asperger's Syndrome**

Dougal Julian Hare, Christopher Wood and Paul Skirrow

Division of Clinical Psychology School of Psychological Sciences, University of Manchester

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**Background:** Many people with Asperger syndrome (AS) report increased frequency and severity of anxiety, which may be a factor in the development of delusional beliefs in this population. Although cognitive behavioural therapy (CBT) is recommended as treatment of choice for anxiety disorders, little is known about its suitability for people with AS, who may have qualitatively different fears. Research to date has relied on reporting past experiences of anxiety, which may be difficult for people with AS.

**Methods:** Experience sampling methodology (Hektner et al 2006) was used to go beyond single-time self-report and to record multiple perceptions, thoughts and feelings as they occur. The necessary software was written for the current study to run on Palm Pilots. Measures of anxiety, depression and verbal comprehension were also completed. 20 adults with AS and 20 adults without AS took part. Within-subject analysis was used to explore the phenomenology of thoughts occurring in people with AS when they were anxious. Between-group comparisons were also undertaken.

**Results:** The AS group were significantly more anxious than the comparison group, in terms of both amount and severity. Factors associated with feelings of anxiety in the AS group were high levels of self focus, worries about everyday events and periods of rumination lasting over ten minutes. The AS group tended to think using images, but this was not associated with anxiety.

**Conclusions:** The current results have significant clinical implications for psychotherapy with people with AS and also with regard to both to psychological models of AS and cognitive models of anxiety.

## **Self-injurious behaviour in autism spectrum disorder**

Caroline Richards, Chris Oliver, Jo Moss, Lisa Collis and Laura O'Farrell

Centre for Neurodevelopment Disorders, School of Psychology, University of Birmingham

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**Background:** Autism spectrum disorder (ASD) has been identified as a risk marker for self-injurious behaviour (SIB). This study aimed to accurately describe the prevalence, topography and correlates of SIB in individuals with ASD in contrast to several comparison groups. Additionally, the phenomenology of SIB was investigated in a subgroup of able individuals with ASD.

**Methods:** The carers of individuals with ASD (N=174; mean age=9.9, SD=4.9), Fragile X syndrome (N=134; mean age=15.4, SD=8.6), Down syndrome (N=61; mean age=17.9, SD=13.8) and mixed aetiology intellectual disabilities (N=60; mean age=15.8, SD=7.5) completed questionnaires relating to the presence and topography of SIB. Information was also gathered regarding demographic characteristics, affect, autistic behaviour, hyperactivity and repetitive behaviour. From within the ASD cohort a nested case-control study was also conducted comparing more able individuals with ASD who engaged in SIB to a matched control group who did not engage in SIB.

**Results:** SIB was more prevalent in the ASD group than in the mixed aetiology or Down syndrome groups. SIB was associated with significantly higher levels of autistic behaviour within all four groups. Within the ASD group, the presence of SIB was associated with significantly higher levels of impulsivity and hyperactivity, and significantly lower levels of mood. The nested case-control study revealed similar results for the able individuals with ASD

**Conclusions:** The implications of these findings are discussed in relation to theories of executive dysfunction and low mood and pain. The concept of ASD as a risk marker for SIB is extended to consider more specific behavioural risk markers.

## Symposium Session 3: Abstracts

### **Public attitudes towards people with intellectual disabilities: A comparison of white British and South Asian people**

Katrina Scior, Sarah Coles, , Rahema Bibi, Martha Kenyon, Anna McLoughlin and Joel Sheridan  
Research Department of Clinical, Educational and Health Psychology, University College London  
Email: [k.scior@ucl.ac.uk](mailto:k.scior@ucl.ac.uk)

**Background:** The success of current policy aims of Rights, Independence, Choice and Inclusion for people with intellectual disabilities depends at least in part on attitudes in wider society. To date little systematic research has examined whether public attitudes reflect these aims, and even less whether beliefs differ between diverse ethnic communities.

**Methods:** A series of studies used mixed methods to study attitudes towards people with intellectual disabilities amongst young people and adults in the UK. Questionnaire data was gathered from 986 white British and South Asian members of the general population. The results were explored in greater depth in individual interviews and focus groups with 61 participants.

**Results:** Overall attitudes amongst all samples were broadly in line with current policy values. However South Asian participants were less in favour of social inclusion and empowerment than their white British counterparts, were more likely to believe intellectual disability can be "cured" and that parents should bear the main care responsibility. Hindus and Muslims differed in their beliefs, but not always in the direction predicted. The qualitative follow-up identified high levels of confusion about the definition and meaning of intellectual disability, regardless of cultural background. It also highlighted apparent tensions between overtly accepting attitudes and more negative attitudes once complex issues were under discussion.

**Conclusions:** Potential implications of the findings will be discussed in relation to rates of service uptake and the importance of culturally sensitive support. Further research is needed to examine the complex interaction between culture, religion and demographics in influencing attitudes.

### **RCT of support model for young people with intellectual disabilities and mental health needs**

Raghu Raghavan  
School of Health Community & Education Studies, Northumbria University  
Email: [raghu.raghavan@northumbria.ac.uk](mailto:raghu.raghavan@northumbria.ac.uk)

**Background:** Young people with Intellectual Disabilities (ID) and their families experience many difficulties in receiving adequate therapeutic services. Young people with ID from Black and Minority Ethnic communities with behaviour and mental health needs face additional problems in accessing services. There is considerable evidence that inequality and exclusion are characteristics of the experiences of South Asian communities in the UK. The aim of this study was to examine the effectiveness of having a liaison worker, in helping young people and their families' access appropriate services.

**Methods:** Twelve young people were randomly allocated to the treatment group that had the help of the liaison worker and fourteen young people were allocated to the control group without the help of a liaison worker. Baseline measures were undertaken with all the young people and their carers, which were then followed by a nine-month trial, consisting of the liaison worker helping the treatment group to get in touch with and take up appropriate services, mainly in the areas of psychiatric appointments, benefits advice, house adaptations, leisure facilities and support and care for the young person. The control group participants did not have the access to the liaison worker and were accessing services in using the normal routine. Assessments were carried out post-treatment to assess whether the use of a liaison worker had had any effect on the outcomes of the two groups.

**Results:** Twelve young people completed the study in the treatment group and fourteen in the control group. Participants allocated to the specialist liaison worker had statistically significantly more frequent contact with services and with more outcomes, than the control group.

**Conclusions:** The use of specialist liaison services in ensuring adequate access to services for young people with learning disabilities and mental health needs from South Asian community proved to be significant and effective compared to young people and their families accessing services on their own.

## **Family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and impact on families**

Chris Hatton, Eric Emerson, Suzanne Kirby, Homayra Kotwai, Susannah Baines, Christine Hutchinson, Catherine Dobson and Bob Marks.

Centre for Disability Research, Division of Health Research, Lancaster University

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**Background:** A PCT in a Northern English city was concerned about its support to families with adults with intellectual disabilities and challenging behaviour, particularly families from minority ethnic communities. We conducted a qualitative interview study with family members to explore perceptions of challenging behaviour, support, and the impact of the person on the family.

**Methods:** Semi-structured interviews were conducted with 7 family members from majority ethnic communities and 7 family members from minority ethnic communities. All interviews were in carers' preferred language and location, and were analysed by a multi-cultural research team using elements of interpretative phenomenological analysis and grounded theory.

**Results:** Four major themes emerged from the phenomenological analysis. First, all family carers reported a broad range of difficulties with the adult with intellectual disabilities fitting into family life. Second, families reported varied relationships with local communities in terms of acceptance and support. Third, families reported varied but largely negative relationships with support services. Finally, families reported relationships with the person with intellectual disabilities ranging from highly dependent relationships with negative consequences for the person and their family, through to more fulfilling relationships. Positive and negative family paths through these themes were identified, with minority ethnic community families more likely to report negative paths and more affluent families more likely to report positive paths.

**Conclusions:** The PCT's 'challenging behaviour' services need to be considered within a broader social context, both in terms of behaviours considered "challenging" but also in terms of the communities within which families live.

## Symposium Session 4: Abstracts

### **Living with challenging behaviour: Using discourse analysis to explore the experiences of people with intellectual disabilities in residential services**

Shona Daynes and Peter Baker

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**Background:** Much of the previous research into challenging behaviour has been conducted with care staff and/or families. Of the few that have spoken directly with people with intellectual disabilities, most of these have focused on the issue of physical restraint. There have been no studies using discourse analysis to explore the way people with intellectual disabilities use language to construct their sense of self, and the world around them, regarding the issue of 'challenging behaviour' in general.

**Methods:** A Foucauldian discourse analysis was used to analyse transcripts from interviews with five male participants, who were nominated by service managers. Foucauldian discourse analysis allowed the language used by the participants to be explored in terms of the discourses drawn upon, and the different functions performed by the texts. This method also has a particular focus on issues around power.

**Results:** Three main discourses were identified. Two of these highlighted a tension between whether service-users, or services, were constructed as the responsible agents for managing challenging behaviour. The final discourse related to perceived severity of intellectual disability, with the service-user as responsible agent discourse being more strongly evoked for people with a less severe intellectual disability, and vice-versa.

**Conclusions:** The findings are discussed in terms of the implications they may have for the way services are designed and implemented, for example to manage tensions between service-users' empowerment and providing support where necessary. Suggestions for further research include exploring types of service provision and the use of participatory research.

### **An examination of the relationship between looking and pointing in Facilitated Communication using eye-tracking**

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**Background:** Facilitated communication (FC) has mostly been investigated by means of message passing studies, that show evidence that the texts that are being attributed to the FC users, are in fact being inadvertently authored by the facilitators who give them direct physical support while typing. This paper reports a novel research study that uses eye-tracking technology to assess the level of involvement of the FC user (participant) in the communication process. The findings are from a full-scale follow-up to piloting work that was reported at the Seattle Club in 2003.

**Methods:** Systematic observation using fine-grained video analysis and eye-tracking techniques. The timings of finger movements toward a screen were compared with eye-gaze at to-be-typed letters as participants were facilitated to spell words and phrases. From a total of 31 participants data was gathered from 9 people with autism.

**Results:** Participants showed patterns of looking and pointing that were entirely consistent with the proposition that they were authoring the texts that were being attributed to them. For example, there was a consistent effect whereby participants fixated longer on relevant to-be-typed letters than on irrelevant letters, before any forward movement was made towards the letters.

**Conclusions:** The findings give strong support to the assertion that some FC users may be authoring the texts that are being attributed to them, despite receiving physical support from a facilitator. The patterns of looking and pointing which are associated with the construction of the texts are extremely difficult to interpret as resulting from facilitator influence alone.

### **Temporal discounting by people with intellectual disabilities**

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**Background:** Temporal discounting (TD) describes the tendency to prefer smaller immediate rewards over larger delayed rewards, which is a form of impulsive behaviour. Consistent performance on TD tasks requires the ability to integrate information from two independent dimensions (reward value and time).

**Methods:** In the present study, a PC-based suite of TD tasks was presented to people with mild to moderate learning disabilities and, for comparison, to staff members in learning disability services. The tasks, which were based on a TD task developed for use with young children, assessed preferences between small amounts of money (up to 10 pence) over short delays (up to 60 sec), moderate amounts of money (up to  $\approx$  £10) over moderate delays (up to 2 weeks), and large amounts of money (up to  $\approx$  £1000) over long delays (up to 12 months). The service users were also assessed for IQ, financial knowledge and memory, and on two batteries of executive functioning tests.

**Results:** Only a third of the service users were able to perform the TD tasks consistently, though this proportion rose to half when training was provided on practice tasks. Both the quality of performance and the extent to which performance improved with training were related to performance on tests of executive functioning. When service users did perform the TD tasks consistently, they tended to respond in a highly impulsive manner.

**Conclusions:** The study reveals problems with decision making that are likely to be present in real-life decision-making situations, and suggests that the ability to weigh up information may depend on executive functioning ability rather than IQ.

### **Implications for challenging behaviour of a neural basis of a deficit in attention switching in Prader-Willi syndrome**

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**Background:** We aimed to investigate the causes of phenotypic behaviours in Prader-Willi syndrome (PWS). In a group comparison with typically developing children, children with PWS showed a specific deficit in attention switching. A series of studies revealed that this deficit in switching was associated with temper outbursts and repetitive questions via cognitive, physiological and environmental interactions. We aimed to investigate neural correlates of the PWS deficit in switching in order to fully describe a pathway from genes to behaviour.

**Methods:** Eight participants with PWS were compared to age and gender matched typically developing controls (TD). T2 weighted functional images were acquired in a Philips T3 MRI scanner. Participants responded to two tasks either in switch blocks (both tasks) or non-switch blocks (only one task). Areas of neural activity associated specifically with switching were found by subtracting the non-switch block activity, from the switch block activity.

**Results:** Three significant clusters of neural activity were associated with switching in TD control participants: (1) parietal, (2) frontal-anterior cingulate, (3) left frontal polar. ROI analysis revealed that PWS participants only showed significant switch related activity in one (left frontal polar) of these three regions. When compared to TD participants, the PWS group showed significantly more switch related activity bilaterally in the frontal pole.

**Conclusions:** We propose a directional relationship between specific neural abnormalities, cognitive deficit and behaviour in PWS, via particular environmental and physiological interactions.

## Symposium Session 5: Abstracts

### **Pathways into services for offenders with intellectual disabilities: Referral, childhood experiences, diagnosis and offence factors**

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**Background:** In the 1960s and 1970s, a large number of individuals who had committed offending and antisocial behaviour were diverted at an early stage from the criminal justice system into institutions. Since these no longer exist, a range of pathways into services have developed. However, there has been little research to date indicating which personal, service or offence characteristics might determine an individual's pathway.

**Methods:** 477 participants, referred in 2002 (and 2003 for maximum secure) came from a range of services. Participants split into 4 groups 239 (142M, 97F) generic community, 70 (93M, 4F) specialist community forensic, 91 (70M, 21F) low/medium secure, 50 (49M, 1F) maximum secure. Data was collected on referral source, demographic information, index and problem behaviours, diagnosis and childhood abuse.

**Results:** Community and social services referred predominantly to Groups 1 and 2, Tertiary healthcare to Groups 3 and 4. Secondary healthcare systems referred significantly to Groups 1, 2 and 3 but not 4. Specialist forensic services had relatively low numbers of women while participants in Group 1 were just over 40 percent female. The most frequent index behaviours were physical and verbal aggression. Contact and non-contact sexual offences are common. Theft, road traffic offences, substance abuse and fire starting have low frequencies with no significant differences between groups. For diagnosis, ADHD and conduct disorder had the highest incidence in the whole cohort (15.3%), then autistic spectrum (9.9%), schizophrenia (8.8%) and personality disorder (8.4%) with differences between groups only on PD (Group 4 higher). Before aged 15, sexual abuse (10.7%, whole cohort), and physical abuse (12.2%) showed significant differences with Gps.3 and 4 higher than 1 and 2. In the whole cohort, severe deprivation was the most frequent adverse childhood experience (24.3%).

**Conclusions:** Women may be as prone to offending type behaviour as men, but that it may be treated in a different manner when considered in a forensic light. Services based in the community tended to refer to community services while those based in tertiary healthcare tended to refer to secure services. The exception to this was court and offender services who refer to community forensic or maximum security. Aggression is the most frequent index and previous offence while fire setting is not overly represented. Severe deprivation in childhood was prevalent across groups.

### **The process by which people with intellectual disabilities engage with the criminal justice system**

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**Background:** The study is a full time three years PhD research having commenced in September 2007. The project examines procedures by which people with intellectual disabilities engage with the criminal justice system. In this context the construction of intellectual disabilities, decision making processes and the construction of crime and punishment by professionals involved in criminal justice are being analysed.

**Methods:** The study employs an analytical and evaluative framework encompassing an examination of issues associated with concerns of criminal justice professionals and risk assessments undertaken by them. The provision of Appropriate Adult is examined and the process of legal representation evaluated. The sample includes Forensic Medical Examiners, Probation Officers, Custody Sergeants, Prosecutors, Magistrates and Judges. 20 semi-structured qualitative interviews have been completed and it is anticipated that approximately 20 more will have been completed by December.

**Results:** Criminal justice is understood by respondents as being the core value of western civilisation, whereby justice is perceived as thorough punishment immediately following an act of behaviour that has been deemed criminal. The concept of both justice and intellectual disabilities appear to vary significantly among different criminal justice agencies. Objectivity within criminal justice appears to be constructed by respondents through the use of language that is characterised by an emphasis on quantitative targets.

**Conclusions:** The qualitative approach that has been used in this study allowed generating data that complements survey findings of previous projects. The initial data raises tentative issues around concepts of justice and punishment in relation to discourses surrounding intellectual disability and criminal justice.

### **Eyewitnesses with mild learning disabilities (mLD): Face recognition and description abilities**

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**Background:** The prevalence of people with mLD in the UK is high (2.5%) and some researchers claim that people with mLD are disproportionately vulnerable to victimisation and therefore more likely to become witnesses/ victims of crime (Kebbel & Hatton, 1999). It is important therefore to investigate the ability of such witnesses to participate in tasks that are commonly asked of eyewitnesses.

**Methods:** During the present study, the ability of participants with mild learning disabilities (mLD) to recognize and describe faces was compared to that of control participants (age matched without a learning disability). The study comprised three old/new face-recognition tasks and two face-description tasks.

**Results:** Data revealed that participants with mLD performed poorer on both face recognition and face description tasks than controls, but always at above chance levels. Both participant groups mentioned more facial details during the cued recall than during the free recall tasks. Interestingly, trends indicate that, in contrast to controls, participants with mLD mentioned more appropriate details during the cued recall than during the free recall.

**Conclusions:** The fact that the recognition ability of witnesses with mLD was above chance performance suggests that they can participate in eyewitness tasks that involve recognition. The fact that they benefited from the provision of cues with regard to both the amount and accuracy of facial information they provided suggests that further research is needed to investigate the utility of different types of cue on the facial description process with witnesses with mLD.

### **Living 'a life like ours': Substitute decision-making for adults with intellectual disabilities living in residential care homes**

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**Background:** The Mental Capacity Act 2005 (MCA) provides a framework to regulate everyday substitute decision-making relating to the welfare of adults who receive social care support, with support workers in residential settings having a statutory obligation to a) act in the 'best interests' of residents lacking capacity, and b) adhere to these residents' care plans. Empirical data in medical settings has brought into question the validity of established legal and ethical principles for substitute decision-making, however little is known about the dynamics of social care support, including the residential support provided to adults with intellectual disabilities.

**Methods:** Socio-legal analysis incorporating a grounded theory analysis of non-participatory observations of residential care practice and 21 interviews with support workers.

**Results:** In contrast to the narrow legal responsibilities placed upon support workers, it is argued that support workers situate substitute decision-making within a broad moral account of their care role, orientating their support towards helping residents to live 'a life like ours'. In so doing, support workers describe how they a) seek to operationalise facets of the personal decisions they make in their own lives, b) defend this approach in terms of their relationships with residents, and c) negotiate substitute decision-making in response to a series of challenges.

**Conclusions:** There are clear discrepancies between the regulation of substitute decision-making and the ways that support workers describe their support. These discrepancies have implications for implementing the MCA, and the role that support workers' personal values and life experiences play, and should play, in conceptualising and delivering 'good' care.

## Poster Abstracts

### **Screening for Learning Disability in an adolescent forensic population**

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**Background:** Various studies indicate that a high percentage of young people going through the Youth Justice System in England and Wales could fulfill the diagnosis of learning disabilities. Most studies do not consider significant impairment of both cognitive and adaptive functioning. The Youth Justice System does not currently systematically screen for learning disability needs. The Hayes Ability Screening Index (HASI) is a screening tool for cognitive need, which was developed and standardised in the criminal justice system in Australia (2000).

**Method:** 72 young people drawn from 2 Youth Offender Teams, 2 secure inpatient units and a secure children's home completed the HASI together with measures of cognitive functioning (Wechsler intelligence scale (WISC-IV, WAIS-III)) and adaptive behaviour (Vineland Adaptive Behaviour Scales). Assessment of both factors being necessary to clarify a diagnosis of learning disability. The HASI result was compared to the results of the two latter measures to find out the extent to which the HASI was sensitive and specific in identifying those who warrant a more detailed assessment for LD.

**Results:** Kappa analysis of HASI result against LD criteria as measured by FSIQ and adaptive behaviour scores, results in a Kappa value of 0.26 reporting 35 false positive results, showing unacceptably poor agreement with LD classification.

ROC analysis suggested a lower cut-off score, resulting in categorisation at 80.0% sensitivity, and 65.2% specificity. This score was applied in a further Kappa analysis. This resulted in a Kappa value of 0.54, which still represents only a moderate level of agreement between the HASI and actual LD status.

**Conclusions:** The investigators concluded that further work should continue to devise an assessment process to screen for the need to assess learning disability issues in young people going through the youth justice system. This presentation will describe further plans to continue this work.

### **The Influence of Staff Communication Style on Service User Response – An Exploratory Study**

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**Background:** Support staff play a key role in encouraging and developing opportunities for adults with an intellectual disability to communicate. Specifically, staff communicative styles, such as directiveness and responsiveness, may play a role in promoting or inhibiting the communicative responses of service users.

**Methods:** Communication between 28 staff and service user dyads was analysed in a naturalistic context. Videotaped observations were coded in order to investigate the levels of directive and responsive turns taken by staff and the resultant effect on the service user's communicative response.

**Results:** Staff interaction style was not found to affect the subsequent response of the service user. Staff members' interaction style was found to be predominantly directive and was correlated with lower levels of service user ability and less staff experience. However, the overall results masked large variation between dyads in the sample.

**Conclusions:** The way in which staff interact with service users is a complex process, which may vary according to the characteristics of the dyad. The variation in interaction style across the dyads will be discussed.

## **Assessment of executive functioning in people with intellectual disabilities**

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**Background:** In addition to impaired intellectual functioning, people with intellectual disabilities also have difficulties with executive functioning (EF: the ability to formulate, implement and monitor plans of action), which, in the general population, is only weakly related to IQ. Here we compare two batteries of EF tests, the Children's version of the Behavioural Assessment of the Dysexecutive Syndrome (BADS-C) and the recently-published Cambridge Executive Functioning Assessment for people with Intellectual Disability (CEFAID), which includes EF and memory sub-scales (CEFAID-EF and CEFAID-M).

**Methods:** Participants were people with mild to moderate learning disabilities attending day services. Over three sessions they completed the Wechsler Abbreviated Scale of Intelligence (WASI), the British Picture Vocabulary Scale (BPVS), the BADS-C and the CEFAID. Scores on the BADS-C, the CEFAID-EF and the CEFAID-M, each of which contains six sub-tests, were subjected to separate principal components analyses.

**Results:** BADS-C and CEFAID-EF scores were significantly correlated with receptive language ability (BPVS) but not with IQ (WASI). The BADS-C and CEFAID-EF each produced two factors, which in both cases were considered to reflect, respectively, planning and rule-following. The CEFAID-M also produced two factors, labelled recall and recognition. A factor analysis of the six primary factors produced two higher-order factors: the first, labelled working memory, comprised the two planning and the two memory factors, while the second comprised the two rule-following, factors.

**Conclusions:** Both the BADS-C and the CEFAID are suitable for use with people with intellectual disabilities, and appear comparable in what they measure. The CEFAID may be preferable insofar as it was designed specifically for use with adults with intellectual disabilities, and it assesses memory in addition to EF.

## **The employment and cost outcomes of Supported Employment in North Lanarkshire**

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**Background:** Real jobs for people with learning disabilities has been a significant objective of LD policy in the UK for a number of years. High levels of small hours employment has caused problems for the success of employment. North Lanarkshire Supported Employment (NLSE) has reported high levels of employment of people with learning disabilities for 16 hours per week or more, with significant financial benefits to the people concerned. This descriptive study looks at what has been achieved and how.

**Method:** Data was provided by North Lanarkshire Social Work Services on: age; main disability; welfare benefits and allowances received (before employment, after advice given, and after job started); salary deductions; job duration; hours worked; pay. Data for the reformed day service Locality Support Service, and NLSE were budget data for 2007/08. Cost data were compared for NLSE, Day Centre, and Locality Support Service provision, adjusted for inflation to 2007/08 prices.

### **Results**

- People worked 22.1 hpw, with 94.0% working for 16 hours or more.
- People were 94.8% financially better in employment.
- Average wages were £129.60 pw and total income £252.25 pw.
- Earnings represented 50.3% of income in work the rest made up of DLA and Tax Credits.

The cost per job was £7,216 pp pa and £14,998 pp pa. A net cost: benefit analysis found the cost to government for NLSE to be -£6,894 (a saving).

**Conclusion:** To achieve employment of 16 hours per week the key approaches used in North Lanarkshire need to be replicated: Skilled job coaching and Welfare Rights Advice; adherence to an intensive SE process; monitoring of delivery.

## **Influences on the well-being of direct care workers supporting people with intellectual disabilities**

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**Background:** It is estimated that as many as 30 percent of direct care workers who support people with intellectual disabilities may experience high levels of work stress. As well as the health and social consequences for direct care workers themselves, stress at work can impact significantly on the continuity and delivery of care. This research explored influences on work wellbeing in direct care workers supporting people with intellectual disabilities in the USA and the UK.

**Methods:** The research involved four organisations in the North West of Britain and five organisations in Illinois, USA. Interviews were carried out with management and/or human resource departments within each organisation in order to identify organisational resources available to support employee wellbeing. Information on perceptions of work stress levels and available resources for managing work stress was gathered from direct care staff (n = 36 UK, n = 323 Illinois) using self-completion questionnaires and focus groups.

**Results:** Bronfenbrenner's ecological perspective (1977, 1979) was used to provide a framework to examine multiple levels of influence (i.e., interpersonal, intrapersonal, institutional, and community factors, and public policy) in relation to direct care workers' abilities to manage work stress and provide adequate care for clients. Within both country contexts there were similarities and differences across multiple levels of influence, including cultural norms, government policies, organizational and individual resources.

**Conclusions:** Considering multiple influences on work wellbeing may help organisations which employ direct care workers to reflect on how best to support employees to manage potential work stress.

## **Investigating the inter-correlation of a battery of social cognition measures for adults with Asperger Syndrome**

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**Background:** A battery of measures developed by Corcoran and colleagues (Corcoran & Frith, 2005) focusing on pragmatic aspects of Theory of Mind [ToM] reliably identify ToM deficits in individuals with acute psychosis. This paper extends previous (Coiffait, Hare & Corcoran 2007) research into the concurrent validity of these measures in adults with a diagnosis of Asperger Syndrome (AS) with presumed permanent ToM difficulties.

**Methods:** A mixed design with independent samples (AS group N=16; control group N=28) investigated the inter-correlation of measures involving different pragmatic skills believed to be underpinned by ToM. It was hypothesised that (i) significant between-group differences would emerge between the AS and control group on the battery of tests; and (ii) performances across tests would be inter-correlated within each group

**Results:** Significant between-group differences were found on the hints task, the hints control task, interpretation of ToM-based jokes and interpretation of physical jokes. Significant inter-test correlations emerged only within the control group

**Conclusions:** Measures featuring the understanding of intention differentiated between the AS and control groups, with significant differences on tests of pragmatic language and joke comprehension. That no significant between-group differences were observed on the other ToM measures and the wide distribution of scores of the individuals with AS could be explained in terms of non-mentalist learnt compensatory strategies employed by individuals in this group. Moreover, the tests may not have been sensitive enough measures of ToM and/or relied upon mentalisation abilities that were conceptually different to one another, which merits further exploration

## **Can Experiential Avoidance of Challenging Behaviour be Measured by Avoidant Eye Gaze?**

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**Background:** This study explores how people behave when they look at challenging behaviour. It is hypothesised that if carers perceive challenging behaviour as aversive, they are likely to engage in behaviours associated with experiential avoidance such as avoidant eye gaze. If avoidant gaze comes under the stimulus control of an operant behaviour (in this case self-injury) it will follow that a key role of care staff, the capacity to observe and report accurately the behaviour of a client, will be compromised. Also explored is whether experience of working with challenging behaviour changes how people look at this behaviour i.e. is there any evidence of desensitisation due to exposure effect.

**Methods:** 22 participants were recruited from 3 sources. Source 1 comprised 5 post graduate MSc Applied Behaviour Analysis students, all with experience of working with individuals with intellectual disabilities and challenging behaviour. Source 2 comprised 9 experienced multi-disciplinary health workers from a specialist NHS Trust/Local. Source 3 comprised 8 people outside of the field of intellectual disabilities with no relevant experience, recruited as volunteers from the community. Participants individually watched a video of a boy with autism and intellectual disabilities engaging in severe challenging behaviour while an eye tracker was used to measure their visual responses. The video comprised conditions of Play, which served as control and Challenging behaviour. It was shown in alternating format (ABAB or BABA) to minimise order effect.

**Results:** Comparison between conditions shows that people do look away more when viewing challenging behaviour. The data did not support the hypothesis that experienced workers would be desensitised to challenging behaviour due to an exposure effect.

**Conclusions:** This study has taken the first steps in being able to measure experiential avoidance of challenging behaviour through quantification of avoidant eye gaze. It recommends that this area would benefit from further research and suggests that the use of eye tracker technology is an appropriate means with which to facilitate such investigation.

## **Control, responsibility and mitigating factors: How do they impact upon carers emotional responses to challenging behaviour presented by adults with intellectual disabilities?**

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**Background:** Weiner's (1985) attributional model of achievement behaviour has been applied to carer's emotional and behavioural responses to services users with intellectual disabilities and challenging behaviour with mixed results. More recently Weiner (2006) has extended his model to suggest that the attribution of control is moderated by mitigating circumstances in its effect on responsibility (a 'moral' judgement) and that responsibility mediates the effect of attributions of control on emotional consequences.

**Methods:** Four vignettes describing two conditions of control (high or low) and mitigating factors (presence or absence of communication difficulties), were presented to 50 carers who completed ratings of responsibility and emotional responses (anger and sympathy) for each vignette. Moderation was demonstrated by through 2x2 repeated-measures analysis of variance, with responsibility as dependent variable. The further conditions for mediation were then demonstrated using two further ANOVA, first with emotion as the dependent variable and then with the residual of emotion when regressed onto responsibility (i.e. emotion with effect of responsibility removed) as the dependent variable

**Results:** The distribution of scores for anger prevented their analysis in this study. However analysis demonstrates that judgements of control are moderated by a mitigating factor (communication ability) in their effect on responsibility and that their effect upon sympathy is mediated by responsibility judgements; a mediated moderation effect.

**Conclusions:** Findings provide initial support for Weiner's account of the mitigation of control attributions in making responsibility judgements and their effect upon emotions. An approach to staff training will be discussed that utilises this model.

### **Social support and coping as mediators or moderators of the impact of work stressors on burnout in intellectual disability support staff**

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**Background:** Theories applied to work stress predict that coping will mediate and support will moderate the impact of work demands on worker well-being. These relationships have rarely been explored in Intellectual Disability research. In this study we explored the mediating and moderating effects of coping and support on the relationship between perceived work demands and burnout in support staff working with adults with intellectual disabilities.

**Methods:** 96 support staff completed questionnaires that measured demographic factors, perceived work demands, coping, support, and burnout. A sub-sample participated in a follow-up 22 months later.

**Results:** Cross-sectional regression analyses revealed a relationship between work demands and emotional exhaustion burnout that reduced when wishful thinking coping was introduced as a predictor. Exploration of multiple mediator effects using bootstrap methods revealed that wishful thinking partially mediated the relationship between work demands and emotional exhaustion but practical coping did not. Practical coping had a main effect relationship with personal accomplishment, and there was evidence that support moderated the impact of work demands on personal accomplishment (although not fully consistent with theory). Study variables, other than personal accomplishment, were stable over 22 months but no longitudinal relationships between coping and burnout were found.

**Conclusions:** These findings emphasise the importance of coping in managing work demands and for the development of burnout in support staff. There are implications for interventions aimed at developing staff practical coping and reducing wishful thinking coping.

### **Staff inputs and outcomes in services for people with learning disabilities**

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**Background:** Research, set in services for people with learning disabilities, has often found associations between the equity perceptions of staff and their well-being and behaviour. Little attention, however, has been paid to the actual content of these perceptions i.e. what staff believe they bring to (inputs) and receive from (outcomes) various work-based relationships.

**Methods:** Semi-structured interviews were conducted on fifteen staff from a variety of occupational groupings. The interviews explored perceived inputs and outcomes in three work-based relationships (relationships with employers, co-workers and service users). Template analysis was used to analyse the interview transcripts.

**Results:** Themes that emerged relating to staff inputs included personal characteristics, ties to the organisation, support and the treatment of service users. Themes that emerged relating to staff outcomes included development, overt behaviour and feedback/information.

**Conclusions:** A wide variety of inputs and outcomes were identified. Data obtained from this study will be used to develop a scale that measures the equity perceptions of staff working in services for people with learning disabilities.

### **Emotion and identity: An investigation into the nature of face processing impairments in autism**

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Background: The nature of face processing impairments in autism remains a contentious issue. Perceptual theories argue that these impairments are due to an underlying processing bias towards individual facial features and social theories suggest that such impairments are the result of marked social and communicative deficits.

Methods: The present study investigated global and local face processing by examining the processes involved in emotion and identity recognition. A group of adolescents with autism (N=16) was matched to children with moderate learning difficulties (N=15) for verbal ability and to typically developing children (N=10) for chronological age. The groups were compared on several discrimination tasks that involved matching faces either on the basis of emotional expression or on identity.

Results: The results revealed that although autistic children were comparable to verbal mental-age matched controls at emotion recognition, there was a significant impairment on emotion matching tasks. Furthermore, the study showed that whilst the performance of the comparison groups declined as the number of available featured cues decreased, masking the eyes aided in identity recognition for the adolescents with autism.

Conclusions: The findings of the current study suggest that the face processing impairments in autism are related to a specific difficulty in the interpretation and evaluation of the social significance within a face. The present study questions the suitability of perceptual theories to account entirely for the processing impairments associated with autism and highlights the need for an account that encompasses both perceptual and social aspects of face processing.

### **Caring for an adult with a rare syndrome; An IPA analysis of maternal experiences of medical and social services.**

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Background: In the UK, it is estimated that around 50-60% of adults with intellectual disabilities continue to live in the family home well into their middle age (Department of Health, 2005). Little research has been conducted about parents of adults, and their perceptions of formal support. In particular, there is a lack of qualitative family research on rare syndromes.

Methods: Semi-structured interviews were used to investigate mother's experiences of formal support. Eight mothers of adults with rare syndromes (specifically Angelman, Cornelia de Lange, and Cri du Chat syndromes) were interviewed. The transcripts were then analysed using Interpretative Phenomenological Analysis (IPA).

Results: The themes that emerged were: access to medical services, care staff and professionals, communication with services, the impact of their young adults having a rare syndrome, and the psychological impact on mothers. Parental experiences differed widely across these themes. In particular mothers reported the benefits of having care staff who were settled in their jobs, whereas others reported problems due to a high turnover of care staff. In terms of communication, services were often slow to respond to mothers enquiries. Dealing with various services made some mothers feel angry, frustrated, weary, and distrustful. Accessing appropriate medical services was reported to be a lengthy process by some mothers. Generally, mother's reported a lack of awareness of their young adult's syndrome within services, but this did not make a difference in terms of accessing services.

Conclusions: These findings may help inform service providers about how best to support carers of young adults with rare genetic syndromes.

## **Parenting groups for the parents of children with severe intellectual disabilities and challenging behaviour**

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**Background:** There is evidence for the effectiveness of parent-training programmes in improving parents' mental well-being and parenting skills and their perceptions of their children's behaviour. Group-based parent-training programmes are regarded as particularly cost-effective, though need to be supplemented with individualised work for highly-stressed families, and there is little evidence for their long-term effectiveness. There have been no evaluations of such programmes for parents of children with intellectual disabilities. This paper will describe the content and long-term evaluation of a group-based parent-training programme for parents and carers of children with severe and complex intellectual disabilities, presenting with challenging behaviour.

**Methods:** The parenting groups have been running for nine years. The process of the groups are described, including themes that repeatedly arise and the results of pre and post evaluation methods completed by participants from each group. This year, a postal questionnaire was sent to parents and carers who have attended over the last nine years in order to obtain a long-term evaluation.

**Results:** Parents often start groups expressing feelings of loneliness and guilt and with little confidence in their parenting skills. The postal questionnaire identified that 64% of parents and carers thought that the groups had made a difference to their children's behaviour and almost 90% thought that the groups had made a difference to them. Most commonly, parents reported that the groups helped them to feel less alone. Inspection of referral rates to the local clinical psychology service indicated that only 31% of parents who attended groups, subsequently had their children referred for individual help with behaviour.

**Conclusions:** The groups are very effective in increasing parenting skills and reducing children's challenging behaviour. They are particularly popular and effective as they have reduced social isolation of carers.

## **Understanding service change from the perspective of staff using Q methodology**

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**Background:** To date, the impact of community-based and person-centred models of care on the staff who work with people with ID has not been the focus of research, even though the ongoing change to such ways of working has been found to increase levels of burnout (Hatton et al, 1999) resulting from role ambiguity and conflict, which may influence the ability or willingness of staff to instigate or accept policy change. Such stress may have a significant impact on staff perceptions and responses to challenging behaviour, increasing the likelihood that these behaviours will reoccur (Jenkins & Allen, 1998).

**Methods:** The study examined the beliefs of staff working within a community rehabilitation service for people with learning disabilities (PWLD) using Q methodology (Stephenson 1953; McKeown & Thomas, 1988).

**Results:** Following a series of initial grounded theory informed focus groups, twenty-nine members of staff, including team leaders, staff nurses, health care assistants and activity workers, completed Q-sorts using a Q set of 91 items related to their personal experiences and beliefs about the service, clients, working environment and understanding of recent changes in service provision. A Q-factor analysis was conducted from which four narratives were identified - working environment, attitudes towards clients, inclusion/quality of life, and skills/knowledge. Groupings of participants within the narratives were clearly differentiated by the unit the staff worked on rather than factors such as years experience, age range or qualification.

**Conclusions:** The implications of these findings and the use of Q methodology with staff working in such clinical settings are discussed

### **The introduction of biopsychosocial formulation based working to an inpatient mental health in intellectual disabilities service: a survey evaluation.**

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**Background:** The application of biopsychosocial models to understanding distress experienced by people with intellectual disabilities (ID) and mental health problems represents a potentially beneficial development. A biopsychosocial approach was developed and introduced within an inpatient mental health in ID service. Central to this approach was a process for the multidisciplinary development (and reformulation) of case formulations for patients. This study evaluated perceived effectiveness and satisfaction with this biopsychosocial formulation based working process.

**Methods:** Participants consisted of multidisciplinary professionals (n=36) who had been involved with the formulation based working process. A survey questionnaire was designed and administered to examine perceived effectiveness and satisfaction with formulation based working.

**Results:** Participants reported that formulation based working had been beneficial. The majority of participants reported that they would recommend it to colleagues, that it had improved multidisciplinary working and that it had increased their understanding of patients. However, there was some variability in responses (e.g. some participants reported that their understanding of the patient changed only "a little"). Helpful aspects of the process were identified, including development of a shared understanding of patients across the multidisciplinary team. Unhelpful aspects were also identified, including barriers presented when key professionals were absent.

**Conclusions:** The introduction of biopsychosocial formulation based working was perceived as effective by multidisciplinary professionals. Variability in responses may be due to variability across job roles within the multidisciplinary team (e.g. nursing staff working closely with patients may perceive themselves as having a good understanding without formulation development). Future developments will include examining impact on patient care.

### **Research Priorities consultation for Learning Disabilities and Autism in Wales**

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**Background:** The Learning Disability and Autism Network is part of the CRC Cumry. In order to assess the priorities for future research, the network conducted a consultation of all stakeholders in Wales in the fields of learning disabilities and autism.

**Methods:** An online survey was conducted between April and September 2008. The online survey was open to everybody who was concerned by learning disabilities or autism. About 300 members of research and network lists were also directly contacted and asked to complete the survey. In a second phase, focus groups with people with learning disabilities and/or autism were organised across Wales. Their views on research priorities in both fields were recorded. Data from both phases of the consultation, survey and focus groups, were anonymised and analysed through a thematic approach.

**Results:** Survey and focus group data show a wide variety of opinions on what constitutes the most urgent research field. Data from carers and service staff featured strong preferences for service related research, while some people with learning disabilities or autism expressed the need to know more about social attitudes toward people with learning disabilities or possible causes of the impairment.

**Conclusions:** The consultation produced a wide variety of views and opinions about research priorities in Wales in the fields of learning disabilities and autism. Methodological issues impacted strongly on data collection and analysis. The consultation did not result in a simple list of research priorities that can easily be translated into a coherent research agenda but gives impetus to the call for more focus and increased collaboration in research and may assist in formulating a nation-wide research strategy.

### **The association between indicators of psychiatric disorder and challenging behaviour**

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**Background:** Existing studies tend to show a positive association between mental illness and challenging behaviour among adults with intellectual disabilities. However, whether the association is direct or artefactual is less clear. The purpose was to explore the association between psychiatric status and level of challenging behaviour, while controlling for adaptive behaviour and occurrence of autistic spectrum disorders.

**Methods:** Data were collected on the age, gender, adaptive and challenging behaviour, social impairment and psychiatric status of 312 adults with intellectual disabilities. Participants were divided according to psychiatric status, group equivalence in adaptive behaviour and the presence of autistic spectrum disorders achieved, and differences in challenging behaviour explored. Multiple regression was used to examine the association between psychiatric status and challenging behaviour after controlling for other participant characteristics and to test whether the interaction between psychiatric status and adaptive behaviour added significantly to explanation.

**Results:** Challenging behaviour was higher among participants meeting threshold levels on the psychiatric screen. The regression analysis confirmed the association, and demonstrated an interaction between total score on the psychiatric screen and level of adaptive behaviour. This moderated effect showed the relationship between psychiatric status and challenging behaviour to be stronger at lower adaptive behaviour.

**Conclusions:** This study reinforces previous findings that psychiatric morbidity among people with intellectual disabilities is associated with higher levels of challenging behaviour, and supports predictions that this association is more pronounced for people with severe intellectual disability. The precise nature and causal direction of the association requires further clarification.

### **Carer's expectations and views of cognitive behavioural therapy for adults with intellectual disabilities**

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**Background:** Recent efforts to adapt Cognitive Behaviour Therapy (CBT) for people with intellectual disabilities have been shown to have therapeutic benefits. There is a view that involving carers or significant others in the therapeutic process can increase the efficacy of CBT interventions. This study is an initial investigation of carer's expectations of the purpose, content and outcome of the therapy, along with their views about how clients engage with therapy and benefit from it.

**Methods:** As part of a multi-centred research study, concerned with the process of CBT, eighteen carers/significant others of clients were interviewed twice: before treatment commenced and after at least nine sessions of CBT. All clients had been referred with a primary presenting problem of anger, anxiety or depression. A thematic analysis was carried out with the interview data.

**Results:** It was found that carers had little knowledge of the process and aims of CBT and saw themselves as having a limited role in the therapeutic process. More positively, carers were able to identify a range of positive client changes, suggestive of improved psychological well-being. However, the carers were doubtful that these changes would be sustained over the longer term.

**Conclusions:** The results have implications for the role of significant others in psychological interventions for adults with intellectual disabilities.

### **Moral Reasoning amongst Men with Intellectual Disabilities**

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**Background:** The moral reasoning of men with intellectual disabilities (ID) was compared to men without intellectual disabilities. This is the first study in a series, and within this study we examined the moral reasoning of men with ID who have no known history of criminal offending and compared the findings to men without ID

**Methods:** The Moral Theme Inventory, and the Sociomoral Reflection Measure (Short Form), as well as measures of intelligence, expressive vocabulary, socio-economic status, and social desirability were administered to participants across two time points. Comparisons were made between the two groups across time, and the psychometric properties of the instruments were examined.

**Results:** The moral reasoning of men with ID is at an earlier stage than men without ID who are matched for age. Some differences disappeared when factors such as IQ and expressive speech were controlled. The SRM-SF appears to be a reliable instrument for use with men who have ID, while the MTI is problematic.

**Conclusions:** There are benefits and drawbacks to using these methods to measure moral reasoning amongst men with ID. There are also implications for understanding criminal offending by men with intellectual disabilities

### **The use of Repertory Grid techniques to Investigate Zigler's intellectual disability personality model**

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**Background:** Zigler & Bennett-Gates (1999) outline a specific personality structure for individuals with intellectual disabilities [ID], which proposes that individuals with ID will demonstrate higher levels of *positive-reaction tendency, negative-reaction tendency and outer-directedness* and lower levels of *expectancy of success, effectance motivation, creativity/curiosity and obedience*. To date, all research on this model has utilised experimental studies and third-person reports, with no first-person data.

**Method:** An explorative study using repertory grid methodology to explore first-person perspectives on how people with ID viewed self, ideal self and people with/without ID with regards to Zigler's personality structure, using a set of *elements* derived from Zigler's seven personality dimensions. Nine verbally able participants with ID took part, six from a forensic service and three users of community services. Following assessment with the BPVS II, TROG-2, Chocolate Box Task (ToM) and LD Casemix Scale, all participants were able to complete the repertory grids, which were then subject to both individual and comparative analysis using RepGrid IV software.

**Results:** Analysis of the grids indicated a tendency to *not* construe individuals with and without ID as distinctly different, which challenges the notion of a personality typology specific to this population. The study also indicated that people with ID do not self-identify with Zigler's personality model, which suggests limited utility of this model as the basis for psychotherapeutic and other forms of clinical work.

**Conclusions:** The lack of support for the Zigler model and variability in findings indicates the need to explore the more super-ordinate constructs that people with ID use as self-descriptors.

## **The barriers and boosters of using the Central Relationship Questionnaire (CRQ) adapted for use with an intellectual disability population**

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**Background:** There is a growing evidence base for psychodynamic psychotherapeutic approaches with an intellectual disability population (Beail et al 2005). The CRQ is a self-report version of the Core Conflictual Relationship Tool (CCRT; Luborsky & Crits-Cristoph, 1998). This has three components: Wish, Response of Other, and Response of Self.

**Methods:** Language in the instructions of the CRQ was simplified by a trainee clinical psychologist and a clinical psychologist. An evaluation questionnaire was also generated. Both were sent to 17 staff from Northgate Hospital's discharge preparation ward.

**Results:** Results are in qualitative and quantitative format and cover the language used, perceived relevance and the barriers and boosters to use by staff. Perceptions of relevance were high in the following areas: current clinical need, forensic risk awareness, discharge planning and moderately high in the area of day service provision. Boosters: included relevance to areas identified above; fewer questions; more pictures. In contrast, barriers included current language and structure; time to complete; questions re patient understanding; acute mental health difficulties

**Conclusions:** The discussion covers the limitations of this project, general considerations around use and recommendations for future applications or research.

## **“And people said they will never do it!” Staff stories of resettlement from institutions for people with intellectual disabilities in the North West of England**

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**Background:** Since the 1970's the majority of large institutions for people with intellectual disabilities have closed and people are now being supported by statutory and independent agencies in ordinary housing. This study aimed to record staff experiences of this major change in service delivery in order to inform current debates.

**Methods:** Qualitative interviews were conducted with twenty people. Participants had worked with people with intellectual disabilities both within an institution and following resettlement into the community. Interviews covered why participants were attracted to the work, experiences of working in institutions, when they heard of community care, reasons for moving to a community setting, and experiences in the different working environment.

**Results:** Four main themes emerged relating to the institutions: 'shame and pride', deprivation, staffing and work, power and control.

There were national, regional and local drivers for change. Involvement of staff, people with intellectual disabilities and families in planning for change was inadequate. Features connected with the move to working in the community included:

- i) Resettlement was a process not a sudden event
- ii) There could be initial problems living and working in the community
- iii) Contradictory views about freedom and support
- iv) Moving into the community did not lead to immediate shifts in power and control.

**Conclusions:** It is necessary to identify potential drivers for change, clearly communicate reasons for change and involve all stakeholders. Factors influencing reactions to change include information, involvement, positive examples of change and security of terms and conditions.

### **Establishing the extent of need for eating and/or drinking assistance among adults with developmental disabilities**

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**Background:** Mealtimes carry a significant health risk for many adults with intellectual and other developmental disabilities. Eating and/or drinking problems are common and can lead to poor nutrition, choking, aspiration, and even death. Potential risks are managed by providing mealtime assistance, ranging from prompting, and specialist equipment, to percutaneous endoscopic gastrostomy (PEG). In this study, as part of a much larger project, we investigate the extent of need for and receipt of assistance with eating and/or drinking among this group of people.

**Method:** We have tried to identify all men and women (aged 18+) with developmental disabilities, requiring any kind of eating or drinking assistance, whose cases are open to specialist eating and drinking clinics, learning disability teams or physical/sensory impairment teams in Cambridgeshire and North Essex.

**Results:** Issues emerged regarding definition of inclusion criteria. Differences in interpretation led initially to gross differences in prevalence estimates between services. This was resolved by breaking down figures into three categories: A) receiving eating and drinking assistance directly from specialist services, B) open to services for another reason but receiving eating and drinking assistance from elsewhere e.g. a carer at home and C) requiring but not receiving eating and drinking assistance.

**Conclusion:** Our findings are discussed in terms of their implications for service provision. We also reflect on their implications for the remainder of the project, in which we aim 1) to establish the extent of need for eating and drinking assistance among adults with developmental disabilities who live in the community but do not currently receive support from specialist services and 2) to examine the potential tension that exists between requirements for safe and adequate nutrition and the ideal of social inclusion and choice.

### **An Audit of Current Needs and Challenging Behaviour Service Provision for Adults with a Learning Disability in Telford and Wrekin**

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**Background:** In response to the revised edition of the Mansell Report (Mansell, 2007) and Challenging Behaviour: A unified approach (RCP, 2007), Telford and Wrekin's Business Manager and Joint Health and Social Care Commissioner commissioned a review of their current local services. The review included an audit of current needs and services against current best practice standards. The audit identified strengths and needs in current services. This information informed the direction of further consultation and service planning.

**Methods:** 19 health & social care professionals, 3 parent / carers, and 2 service users were interviewed. Quantitative and Qualitative (thematic) analyses were carried out on the data.

**Results:** Preliminary findings indicate that although good in parts, the services for people whose behaviour challenges service in Telford & Wrekin do not currently meet all current best practice standards. Key areas for potential service development were identified. These included needs in relation to multidisciplinary assessment, formulation, and intervention; person centred approaches; increasing local capacity to respond to crises; broadening of current Challenging Behaviour training.

**Conclusions:** The results indicate a number of service developments are required to achieve improvements in the quality and capacity of local services to respond to people whose behaviour challenges services. These developments will be achieved through further consultation & the production of a costed action plan to improve current outcomes.

### **Telecare: its impact on objective quality of life outcomes**

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**Background:** Increasingly, telecare (the use of electronic monitoring devices in residential services to enable peripatetic support) is being seen as a potential solution to the service expansion which will be needed as a consequence of changes in the UK learning disabilities population. Little is known about the impact of telecare on costs and quality of life outcomes.

**Methods:** A pre-post experimental control design was adopted. The experimental and control groups comprised 21 and 19 people respectively. Measures were conducted 3 months before the intervention and repeated 3 months afterwards. Interviews with direct care staff explored engagement in social and community activity, independence and choice, domestic activity, money management, perceived risk of accidents and exploitation and health using a battery of established measures.

**Results:** Following the introduction of telecare staffing levels were reduced significantly in the experimental group. There was no significant pre-post intervention within group difference for either group on the vast majority of outcome measures.

**Conclusions:** These are interim results. However they appear to demonstrate that efficiency has been achieved through the introduction of telecare without detriment to service users' quality of life.

### **Adapting the Antenatal Care Pathway for Parents who have a Learning Disability**

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**Background:** "Accessible information is crucial to enabling parents with learning disability to engage with services and to therefore maximise the chances of children's needs being met".(DoH, 2007) McGaw (1997) estimates there may be around 250,000 parents who have a learning disability in the UK. Often, these parents are expected to fit into existing health services and may, therefore, be disadvantaged when they are presented with complex information regarding pregnancy and birth through to how to care for a young baby. There is a dearth of information in relation to accessible information on antenatal care and consent to medical procedures for parents with a learning disability, despite this being a recommendation by the NHS and Department of Health good practice guidelines (NHS Executive, 1998; DoH, 2007). The current project aimed to redress this balance by developing accessible resources for each part of the existing local antenatal care pathway for a typical pregnancy.

**Method:** Thematic analysis of structured interviews was used to evaluate the accessibility and acceptability of the resources from both the professional (midwives) and service user perspectives. Five mothers who have a learning disability participated.

**Results:** Thematic analysis of the participant interviews indicated nine themes pertaining to their antenatal experience and use of the resources. These were: other life stressors; consent and choice; pregnancy process; role of midwife; adapted resources; family; other resources; outside support and power imbalance. Within each theme, positive and negative experiences were identified. There was a high degree of similarity between the parents' experiences. Positive themes identified within Midwives interviews included; provision of a shared language with clients, increased client self direction, promotion of self confidence, not intimidating, concise, simple and focussed attention within sessions. Negative themes included; concerns about the focus on learning disability, bulky resources and repetitive information.

**Conclusions:** In general, results suggest that the adapted antenatal resources are both acceptable and accessible for parents with learning disability and the professionals who support them. They are helpful in supporting parents with a learning disability to access the typical care pathway and essential information about their pregnancy and in enabling them to make informed decisions about their care. Results also suggest that they support their interaction with maternity services, resulting in a more effective and efficient care process.

## **Social Exclusion and Sexual Understanding**

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**Background:** Traditionally, research examining the sexual understanding of individuals with ID has been based on the assumption that any lack in health understanding arises from cognitive deficits. This often overshadows the effects of the socialisation experience. In the current study, young people's own perspectives on their sexuality, the opportunities they have to form meaningful relationships and the barriers to learning about sexuality were explored.

**Methods:** Questionnaires and semi-structured interviews were used to elicit both quantitative and qualitative data regarding sexual knowledge, sources of information and social networks. Sixty young people aged between 16 - 22 participated in the interviews (30 with a mild/moderate learning disability (LD) and 30 with no known disability (ND)). A sub-group of 10 from each group also participated in a more detailed open-ended interview, to develop a dialogue with participants about their sexual understanding and experience.

**Results:** As expected, young people with LD had lower levels of sexual health knowledge ( $t(58) = -11.375, p = 0.001$ ) than their ND peers. The qualitative data also revealed major misunderstandings in sexual knowledge across both groups although this was more pronounced for the LD group. Young people with disabilities had accessed fewer sources for information about sexual health ( $M = 17.057, p = 0.001$ ) and had less well developed social networks than the ID group. The in-depth interviews revealed that although young people with disabilities spent the majority of their time with family, they felt they could not talk to them about sexual health.

**Conclusions:** If we are to empower young people to make sensible and informed decisions about their health, we must understand both the barriers and facilitators to developing this knowledge as well as the areas and concepts they have difficulty in grasping, and build this into future education strategies.

## **Thinking on your feet: Understanding the immediate responses of staff to adults with challenging behaviour in learning disability services: a grounded theory study**

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**Background:** A gap prevails between the conceptualisation of good practice in challenging behaviour management and its implementation in learning disabilities services. Reasons for this phenomenon are unclear. This study aimed to investigate staff members' perspectives of managing clients with challenging behaviour in residential learning disability services, which have been under-researched.

**Methods:** Semi-structured interviews were conducted with eleven staff working with adults with intellectual disability and challenging behaviour in two services. The interview explored staff members' immediate responses to clients with CB and the processes underlying their decision-making about their responses. Additionally, service documents on CB management were examined. These data were analysed using grounded theory.

**Results:** A preliminary model attempted to capture the processes underlying staff members' decision-making about their responses. The services laid a great emphasis on staff being prepared to manage clients' behaviour in safe and anticipated ways. The immediate responses of staff were conceptualised in this context as the product of complex appraisals, whilst staff controlled their emotions and worked as a team. Staff members' decision-making was understood as the core process of making the right choice and prioritising the best interests of all involved.

**Conclusions:** The immediate responses of staff were understood as a dynamic and retroactive process, where their past and current CB management experiences influenced their responses to clients in the future. A number of factors influencing staff members' decision-making and immediate responses were thus identified in this preliminary model. The nature of their interactions and the complexity of these links however would benefit from further investigation.

### **IMCA involvement in adult protection cases**

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Background: The Mental Capacity Act 2005 was extended giving local authorities and NHS bodies the additional power to instruct an IMCA to act in adult protection cases

Methods: Quantitative data describing national referrals for IMCAs in adult protection cases and detailed data describing 204 people involved in adult protection procedures who had an IMCA. Qualitative interview data from 10 advocacy organisations proving an IMCA service and interviews with Adult Protection leads, and Social Workers

Results: Between 1st April 2007 and 31st March 2008, 13.4% of referrals for an IMCA were for adult protection procedures. The sample of 204 adults referred for an IMCA revealed that the 2 most frequent conditions affecting a person's capacity were dementia (45.1%) and learning disability (24%). The 3 single most common types of abuse were financial abuse (26%), physical abuse (19%), and neglect (17%) but a significant proportion (24%) of adults had experienced multiple forms of abuse. In over half of all cases family members were the alleged perpetrators (57%) while care-staff were identified as the alleged perpetrators in only 11% of cases. The Qualitative data suggests that IMCAs, their managers, Adult Protection leads, and social workers believe that the new IMCA service benefits adults who are subject to adult protection procedures although they identified a number of operational problems.

Conclusions: IMCAs and members of Adult Protection Teams need to identify and clarify the nature and extent of an IMCA's involvement on a case by case basis.

### **Detecting and utilising information from people's faces: Eye Tracking Evidence from Williams syndrome and Autism**

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Background: To communicate in our social world we must detect a range of social cues; a crucial source of such information is the human face. If individuals with disorders of development do not detect cues from the faces of other people social functioning will be impacted upon; as evident in Williams syndrome (WS) and Autism.

Methods: Gaze behaviour was recorded while participants viewed pictures of actors directing their gaze to a target item. Individuals with WS (n=16) and autism (n=22) were individually matched to typically developing participants of comparable nonverbal ability. Stimuli were viewed twice in i) uncued and ii) cued conditions. In the cued condition participants were told to focus on the object of the actors' attention.

Results: Areas of interest were designated to parts of the image; the actor, face, eyes, and target item. Fixation duration in these regions was calculated for each participant and group. Gaze behaviour of all groups was affected by task instruction. For typically developing participants increased cueing shifted attention from the actors face to the target item. For individuals with WS and autism subtle atypicalities of gaze behaviour occurred. Cueing increased face gaze for participants with autism whilst making gaze more typical for individuals with WS.

Conclusions: The results have implications for task design and instruction for individuals developing typically and atypically. We suggest that atypicalities of gaze behaviour are evident from eye-tracking tasks not only looking at face gaze but also on tasks utilising face information, which are likely to extend to real world situations.

### **Women with developmental Disabilities - are they angry in the same way as men?**

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Background: Much research in forensic settings is based on male participants. This study looked at a range of assessment data for women and compared it with the men, both groups being in a forensic in-patient setting.

Methods: This descriptive study explored the nature of anger in a sample comprising all in-patients with a developmental disability in a hospital forensic service, comparing the women (n=26) with the men (n=112). Measures included demographic data, diagnoses, offence types and history, self report anger questionnaires, and records of assault.

Results: Results showed that there were virtually no differences in self reported or staff reported anger, but there were some differences in mental health and more women had assaulted than men during their admission.

Conclusions: It was concluded that women in this service experienced anger in a similar way to the men. There may be a number of explanations for the higher levels of assault in the women.

### **An investigation of the voice quality of children with Downs syndrome and its impact on listener judgements**

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Background: The voice quality of speakers with Down's syndrome (DS) is generally accepted as being unusual. Children with DS have been rated significantly more negatively than typically-developing (TD) peers in a range of abilities and personality traits and judged to be significantly younger than their chronological age. Perceived immaturity and negative perception of ability are likely to lower expectations, which may impact negatively on self-esteem and mental health. More precise description of vocal features and their resulting impact on social interaction is needed; particularly for adolescents with DS, as this is a crucial period for social inclusion and natural change in voice characteristics.

Methods: This is a quantitative study of voice quality, using acoustic analysis (FO, perturbation, spectral tilt), expert perceptual ratings using the Vocal Profile Analysis Scheme and a study of listener judgments of character traits and abilities. For the latter, 45 mainstream and 52 special-needs education staff, and 75 TD peers listened blind to audio-recordings of DS and TD children, and rated them using a specially designed set of semantic-differential scales.

Results: Preliminary findings suggest similar perception of DS and TD voices by mainstream and special-needs education staff; both groups attributing more negative characteristics to the voices of children with DS than to TD children. TD peers showed a strong preference for the company of TD children over those with DS, based on audio-recordings.

Conclusions: Close agreement between mainstream and special-needs education staff suggests that children with DS are no more disadvantaged by the perception of teachers in mainstream settings than in special-schools; however particular difficulties may be evident in the development of friendships with peers.

## **The development of stereotyped and catatonic behaviour in adolescents with autism spectrum disorders**

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**Background:** Catatonia is observed in up to 6% of people with ASD (Wing & Shah, 2000), but the nature of this relationship is unclear. Dhossche (1998) observed a phenomenological overlap in psychomotor symptoms (mutism, stereotyped mannerisms, echolalia and echopraxia) and Hare & Malone (2004) conceptualised autistic catatonia as an extreme manifestation of ASD. However, there remains a paucity of data and this paper reports on the initial stage of an ongoing study investigating the developmental course and correlates of catatonia in ASD

**Methods:** A retrospective within-group design was used with on-line recruitment and data collection. Participants were parents of adolescents with ASD over 14yrs old and were recruited via the National Autistic Society website and through specialist schools. Participants completed the Repetitive Behaviour Questionnaire (Moss & Oliver 2005), Sensory Behaviour Scale (Harrison & Hare 2004) and measure of stimulus bound behaviour, along with demographic data.

**Results:** Pilot data (N=29) indicated that a catatonic presentation in early adolescence was associated with earlier presentation of twirling round and round, holding, manipulating and manipulating objects, hand stereotypy and preference for routines. These findings suggest a common phenomenology relating to fine motor control and internal and proximal sensation (Kinsbourne 1980).

**Conclusions:** The data from the pilot study indicate the feasibility of more detailed analysis of autistic catatonia beyond identifying it as co-morbidity and provide tentative support for such a presentation as an extreme manifestation of the motor dysfunction in ASD, possibly related to dysfunction in the related areas of the primary motor cortex, striatal regions and basal ganglia

## **A Group-Based Treatment Programme for Fire-Setters with Intellectual Disabilities.**

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**Background:** It has been speculated that fire-setting is one form of criminal activity that is more likely to be associated with offenders with intellectual disabilities. Whilst there are several studies which address the prevalence and aetiology of fire-setting behaviour, the description and evaluation of treatment interventions for this client group remains a neglected area of research.

**Methods:** This presentation describes a cognitive-behavioural group treatment programme, developed and piloted on separate male and female groups of adults with learning disabilities (n = 28), detained in hospital under the Mental Health Act (1983). The programme is based upon a functional analytical framework and further incorporates psycho-sexual elements. Emotional, cognitive and situational antecedents are examined and relapse prevention principles applied in the development of appropriate coping strategies.

**Results:** The theoretical basis of the programme is described along with outcome data which indicates significant post-treatment improvements on a number of dimensions including interest in fires, acceptance of guilt, acknowledgement of personal responsibility, understanding of victim issues, awareness of risk factors, anger disposition, and self-esteem.

**Conclusions:** Intellectually disabled offenders with fire-setting histories can successfully engage in group based interventions. Outcome data supports the short-term effectiveness of this treatment. It is acknowledged however, that fire-setting is often an infrequent behaviour, which can lie dormant for a number of years. Longer-term follow-up is therefore essential.

### **Autism and intellectual disability: Their effect on children's behaviour and their carer's psychological well-being**

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**Background:** Children with an autistic spectrum disorder (ASD) are at increased risk for behavioural and emotional difficulties, and their parents are more likely to experience decreased psychological well-being. While increasing evidence supports these findings, their relationship is complicated by two methodological shortcomings of existing studies: a. potential sampling bias, as studies typically recruit from clinical services or parent associations; and b. the confounding effect of ID which is rarely examined separately from ASD effects. We examined the behavioural and emotional problems of children with ASD, and their mothers' well-being while controlling for any associated ID in a large population-representative sample.

**Methods:** Behaviour problems were compared among 51 children with ASD and ID, 47 with ASD, 590 with ID and 17,727 without ASD or ID. Psychological well-being was compared among the respective mother groups. Participants were 18,415 five to 16-year-old children from the two national mental health surveys (Office of National Statistics: 1999 and 2004).

**Results:** ASD, ASD with ID, and ID groups had significantly higher SDQ scores than typically developing children. Effect sizes showed this differentiation to be more pronounced for children with ASD (with and without ID). Within ASD, the presence of ID did not differentiate behaviour. Both ASD groups, however, had more difficulties than children with only ID. Mothers of children with ASD (with or without ID) were more likely to experience an emotional disorder, and negative mental health. Positive mental health levels were broadly similar across groups.

**Conclusions:** The presence of ASD seems to put children at a disadvantage in terms of behavioural development. Similarly, their mothers face more psychological difficulties.

### **Measuring the actual levels and patterns of physical activity/inactivity of adults with learning disabilities**

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**Background:** Adults with learning disabilities have low levels of physical activity compared to the general population. Research is limited however, informed mainly by self-reported data. Using a validated activity monitor (activPAL), we aim to objectively monitor the levels and patterns of physical activity, over a 7-day period, of 50 adults with mild to moderate learning disabilities.

**Methods:** Participants are being asked to wear a monitor for a 7-day assessment period. Self-reported physical activity for the same period is also being collected for comparison.

**Results:** Interim results from data collected on 19 adults (10 males, average age 29, range 18 to 57 years, SD 10.6) show an average number of 8,582 steps per day (range 1,951 to 26,456, SD 5,160). Current recommendations are at least 10,000 steps per day. The average number of sedentary hours (sitting/lying) was 18.62 hours per day (range 14.72 to 21.37, SD 1.92), showing an average of 5.38 hours of standing or walking time per day.

**Conclusions:** Once data collection is complete this will allow for comparison of levels and patterns of physical activity/inactivity between e.g. weekdays and weekends, subjects (e.g. those who live with/out paid support), and with self-reported data collected for the same period. This pilot data will be a step towards informing interventions/extra support measures and guidelines to increase physical activity.

### **Testing the Reliability and Validity of New Measures of the Effects of Stressful Life Events.**

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Background: The aim of this study is to examine the reliability and validity of the recently developed Lancaster and Northgate Trauma Scales (LANTS), which measure the effects of stressful life events on people with intellectual disabilities. The measures comprise an informant version with 47 items and a self-report version with 34 items.

Method: Participants were recruited from forensic, mental health and community settings in Northumberland and Newcastle and completed 99 self-report measures and 89 informant measures. A subset of the participants completed repeat measures.

Results: This poster will report on aspects of reliability of the self-report and informant versions of the LANTS. There were no floor or ceiling effects. 5 items were excluded from the self-report version and 4 items from the informant version because there were a significant number of missing values. In the self-report measure this was related to comprehension of the items, and in the informant measure this was related to the difficulty identifying avoidance behaviours. The self-report and informant measures show good internal reliability. The self report has  $\alpha=.837$ . The informant measure comprises 3 subscales including whether the item was a change from normal for the person ( $\alpha=.821$ ), frequency ( $\alpha=.801$ ) and severity ( $\alpha=.844$ ). Cronbach's alpha also showed that removing any further informant or self-report items would not improve internal reliability.

Conclusions: Given promising reliability the LANTS trauma measures could facilitate research and clinical investigation into the effects that traumatic life events can have on the psychological well being of people with intellectual disabilities.