5\textsuperscript{th} Seattle Club  8\textsuperscript{th}-9\textsuperscript{th} December 2005

Chapter Arts Centre
Cardiff

Welsh Centre for Learning Disabilities Cardiff University

Unit for Development in Intellectual Disabilities University of Glamorgan

Intellectual & Developmental Disabilities Research Group
University of Wales Bangor
Welcome

Welcome to the 5th Seattle Club Conference for researchers in intellectual disabilities in the UK and Republic of Ireland.

Although the conference is only in its fifth year, it has established a number of traditions which have been maintained in its organisation this year:

- there is an emphasis on data-based presentations reporting findings gained through appropriate application of scientific methodology and experimental design
- 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 in both
- the total number of participants is constrained 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 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. So please, ask questions, make comments, put forward suggestions and use your time to develop links to make better research more likely.

Studentships were awarded to: Lisa Collis, Mikey Dunn, Sarah Hamilton, Pamela Jarvie, Mike Petalas, Deirdre Reilly, Carol Riddington, Vasiliki Totsika and Kate Woodcock (See page 32)

Ad hoc organising committee and peer reviewers for 2005:
David Felce Welsh Centre for Learning Disabilities, Cardiff University
Deb Carr Welsh Centre for Learning Disabilities, Cardiff University
Richard Hastings Intellectual & Developmental Disabilities Research Group University of Wales Bangor

Administrative support:
Our thanks this year go to Rosy Allcott, Axel Kaehne and Andrea Meek, Welsh Centre for Learning Disabilities, Cardiff University
Thursday 8th December 2005

10.00-10.45 Registration and coffee

10.45-10.55 Welcome - David Felce

10.55-11.55 Session 1 - Health, Mental Health & PBS (Chair: Chris Hatton)

Paper 1 Social determinants of the physical & mental health of young people with intellectual disability
Eric Emerson

Paper 2 Understanding adults with intellectual disabilities’ experiences of mental ill-health
Craig Melville, G Crawford, Andrew Jahoda, Sally-Anne Cooper

Paper 3 A component analysis of Positive Behaviour Support
Brian McClean, Natalie Murray, Mark Stanton, Ian Grey

12.00-13.00 Session 2 - Phenotype studies (Chair Jennifer Wishart)

Paper 4 Susceptibility to the Thatcher Illusion in individuals with autism and Williams syndrome
Deborah Riby

Paper 5 Differences and similarities in the cognitive profile of children with FXS and ASD: An initial baseline
Carrie Ballantyne

Paper 6 The phenomenology of autistic spectrum disorder in Cornelia de Lange syndrome
Joanna Moss, Chris Oliver, Lesley Jephcott, K Berg, G Kaur

13.00-13.50 Lunch

13.50-15.10 Session 3 - Family Issues (Chair Deborah Carr)

Paper 7 Research into the genetics of ID: Consent issues
Maggie Ponder, Helen Statham, Nina Hallowell, Lucy Raymond, Martin Richards

Paper 8 Children with developmental disabilities and sleep problems: Parental beliefs and treatment acceptability
Colin Espie, Ruth Keenan, Matt Wild, Irene McArthur

Paper 9 Predictors of sibling adjustment in families using home-based interventions for autism
Katie Williams

Paper 10 An impossible loss: The experiences of bereaved parents of people with intellectual disabilities
Stuart Todd

15.20-15.40 Tea
15.40-17.00  
**Session 4 - Carers and Services** (Chair Eric Emerson)  

Paper 11  
Carers' experiences of challenging behaviour in people with learning disabilities: an interpretative phenomenological analysis  
*Hayley Pringle, Peter Baker, Victoria Senior*

Paper 12  
The relationship between staff burnout and user lifestyles in housing services  
*Chris Hatton*

Paper 13  
An ethnography of care; managing people diagnosed with Prader-Willi syndrome living in residential care  
*Rebecca Hawkins, Marcus Redley, Tony Holland*

Paper 14  
Too far to go: Out-of-area placements for people with intellectual disabilities  
*Julie Beadle-Brown*

17.30-19.30  
**Posters**  

Psychometric properties and normative data for the neuropsychological assessment of dementia in intellectual disabilities. *Dawn Adams, Chris Oliver, Tony Holland, Karen Dodd, Janet Carr, Vicky Turk, Sunny Kalsy, Sarah Ball*

Working lives: The role of day centres in supporting people with learning disabilities into employment. *Steve Beyer*

The dental health of adults with intellectual disabilities. *Darren Chadwick*

Development of a measure of staff perceptions of team characteristics in intellectual disability services. *Jason Devereux, Richard Hastings, Steve Noone*

Parental Stress, child challenging behaviour and respite: An examination of factors associated with requesting, using and allocating respite services. *Helen Downie, Sally Cheseldine, Duncan Manders*

Self-reported general health status of adults with intellectual disabilities in England. *Eric Emerson*

Injuries, accidents and falls in adults with learning disabilities. *Janet Finlayson, Sally-Ann Cooper, Jillian Morrison, Alison Jackson*

Level of new unmet health need at a subsequent health check. *David Felce, Mike Kerr, Janet Felce, Helen Baxter*

Communication of children using AAC: Parents' accounts and observations. *Juliet Goldbart, Julie Marshall*

Parents experiences of autism diagnosis: findings from a semi-structured interview. *Corrina Grindle, Bob Remington, Hanna Kovshoff, Richard Hastings*

Time understanding in children with autistic spectrum disorders. *Wendy Kellaway, Dougal Hare, Liz Crabtree, Gemma Hollington, Gemma Horridge*

Psychotherapists accounts of their practice with people with intellectual disabilities. *Tom Jackson, Nigel Beail*

Evaluation of a residential and further education service for young people with severe learning disabilities and challenging behaviour. *Paul Langthorne, Peter McGill*

A qualitative evaluation of a training programme and manual for School Health Advisors working with children with intellectual disabilities. *Chris Lawes, Leon Fletcher-Tomenius, Nadine Bearman*
Studies on offenders with intellectual disability (ID) across three forensic settings. **William Lindsay, Todd Hogue, John Taylor, Lesley Steptoe, Paul Mooney, Catrin Morrissey**

Relationships between acceptance, mindfulness, and stress in mothers of children with intellectual disabilities. **Tracey Lloyd, Richard Hastings, Susie Nash**

Stress in mothers of young people with intellectual disabilities. **Vivien Moffat, Jennifer Wishart, Eve Johnstone**

An assessment of the needs of people with a forensic history in community services. **Stephen Oathamshaw**

Outcomes of community living: Semi-independent living & fully staffed group homes. **Jonathan Perry, David Felce, Andrea Meek, Janet Robertson, Renee Romeo, Eric Emerson, Martin Knapp**

Health knowledge and expected outcomes of risky behaviour: A comparative study of young people with physical and intellectual disabilities. **Jaycee Pownall**

Sense of coherence as a modulator variable of stress in mothers of children with autistic spectrum disorders. **Pilar Pozo**

The basis of therapeutic communication: developing mutual understanding with individuals who have intellectual disabilities. **Mhairi Selkirk, Andrew Jahoda, Carol Pert**

Christian faith in the lives of families with an adult with learning disabilities. **Susie Turner**

Developing a measure of the symptoms of traumatic life events for the intellectual disability population. **Sarah Wigham**

The Bangor Life Events Scale for Intellectual Disabilities (BLESID). **Lee Williams, Richard Hastings, Stephen Noone, Susie Nash**

Generalization of anger coping skills, by clients with learning disabilities, from day-service to residential settings. **Paul Willner**

20.30 Dinner at the Happy Gathering, Cowbridge Road East, Cardiff
Friday 9th December 2005

9.00- 9.05  Introduction to second day - David Felce  
Cinema 1

9.05-10.10  Session 5 - Keynote Speech (Chair David Felce)  
Cinema 1

Paper 15  Asking some more interesting questions in intellectual disability research: The case of family adjustment  
Richard Hastings

10.10-10.40  Coffee

10.40-12.00  Session 6 - Challenging Behaviour/Offenders (Chair: Colin Espie)  
Cinema 1

Paper 16  Predicting challenging behaviour in very young children with intellectual disabilities  
Jane Petty, Chris Oliver, Debbie Allen

Paper 17  Sources of anger-arousal for individuals with mild-to-moderate intellectual disabilities  
Kenneth MacMahon, Andrew Jahoda, Carol Pert

Paper 18  A comparison between individual and group interventions for aggression  
John Rose

Paper 19  Structured risk assessment for offenders with intellectual disabilities  
John Taylor, William Lindsay, Todd Hogue, Sue Johnston, Paul Mooney

12.00-13.00  Lunch

13.00-14.00  Session 7 - Biological Issues (Chair Julie Beadle-Brown)  
Cinema 1

Paper 20  Women with intellectual disabilities and the menopause  
Diane Willis, Jennifer Wishart, Walter Muir

Paper 21  Peripheral nerve dysfunction in Cornelia de Lange and Cri du Chat Syndromes  
Lesley Jephcott, Chris Oliver, Joanna Moss, S Seri, S Friess

Paper 22  Patterns of executive function and memory test performance in established and preclinical Alzheimer’s disease in people with Down’s syndrome: Evidence for an early specific impairment in frontal lobe functions  
Sarah Ball

14.00-15.40  Session 8 - Reflections (Chair Julie Beadle-Brown)  
Cinema 1

Stuart Todd

15.40  Close and tea
Social determinants of the physical & mental health of young people with intellectual disability

Eric Emerson

1Institute for Health Research, Lancaster University

Objectives: To examine the contribution of socio-economic position to the poorer health status of children and adolescents with intellectual disabilities in Britain.

Design: National cross-sectional survey using multistage stratified random sample of households in Britain. Participants were 10 438 children aged 5 - 15 years old and their primary carer.

Results: Intellectual disability was a significant risk factor for parent ratings of poorer child general health (OR = 4.5; p<0.001), and ICD-10 diagnosable emotional disorders (OR = 2.0; p = 0.006) and conduct disorders (OR = 7.7; p<0.001). Between-group differences in socio-economic position and household composition accounted for 19% of the increased risk of poor health, 21% of the increased risk for conduct disorder and 35% of the increased risk for emotional disorder.

Conclusions: Socio-economic disadvantage accounts for a significant proportion of the increased risk for poorer health and mental health of children and adolescent s with intellectual disabilities. Policies to reduce disparities in health outcomes between children and adolescents with intellectual disabilities and their non-disabled peers need to address the social conditions in which children with intellectual disabilities are growing up.

Understanding adults with intellectual disabilities’ experiences of mental ill-health

Craig Melville1, G Crawford, Andrew Jahoda, Sally-Anne Cooper

1Section of Psychological Medicine, University of Glasgow

Objectives: To gain a detailed understanding of adults with intellectual disabilities’ experiences of mental ill-health. To explore the impact of mental ill-health on the lives of adults with intellectual disabilities.

Design: Qualitative study using individual, in-depth interviews with adults with intellectual disabilities and carers.

Method: Theoretical sampling was used to identify potential participants from users of learning disabilities psychiatry services. Individuals who chose to participate were interviewed by a researcher, using a topic guide to frame the interviews, which retained an open, unstructured style. Interviews were recorded and transcribed verbatim and data was imported into a software package to aid analysis. All transcribed interviews were analysed independently by two members of the research team, using grounded theory methods.

Results: Ten adults with intellectual disabilities, and nine carers were interviewed. Three central themes emerged from the data – the impact of mental ill-health, support and help for mental ill-health and the interpersonal context of mental ill-health. Further analysis has elucidated the categories and sub-categories within these themes. These have been grounded in the data to inform the development of key concepts, to aid understanding of adults with intellectual disabilities’ experiences of mental ill-health.

Conclusions: Adults with intellectual disabilities provide valuable insight into their experiences of mental ill-health. The results help to inform the development of appropriate interventions, and services, to meet the needs of adults with intellectual disabilities and mental ill-health.
A component analysis of Positive Behaviour Support
Brian McClean¹, Natalie Murray, Mark Stanton, Ian Grey
¹Brothers of Charity Roscommon, Roscommon

Objectives: The purpose of this study is to investigate the components of multi-element
behavioural support that are implemented by typical mediators in everyday service
settings. The rationale for Positive Behaviour Support is that prior functional analysis
yields an identification of functionally equivalent skills and functionally relevant
interventions and that these may predict effective intervention.

Design: A multiple regression analysis is conducted to identify the components of a multi-
element behaviour support plan that best predict effectiveness.

Method: 61 behaviour support plans are coded according to: (1) hypothesised function of
behaviour, (2) type of interventions recommended and implemented, (3) functional
relevance of interventions, (4) goodness of fit interventions and (5) perceived
effectiveness of each implemented intervention. Rates of behaviour associated with each
plan are observed and compared with baseline rates, and additional ratings of behavioural
frequency, severity and management difficulty are made.

Results: Results indicate that behaviour support plans are associated with significant
reductions in behavioural frequency, severity and management difficulty since baseline.
Behaviour change is moderately correlated with ratings of treatment acceptability, a
measure of contextual fit. However, multiple regression predicted only 12% of variance in
behaviour change.

Conclusions: Although there is evidence of the effectiveness of Positive Behavioural
Support, there is no evidence of differential effectiveness of individual components in this
study. Instead, it may be that many combinations of behaviour support plan components
may be associated with effectiveness, or that each behaviour support plan has unique
effective ingredients.
Susceptibility to the Thatcher Illusion in individuals with autism and Williams syndrome
Deborah Riby

1Department of Psychology, University of Stirling

Objectives: The aim was to assess susceptibility to the Thatcher Illusion in groups of individuals with autism and Williams syndrome (WS). The ability to detect this illusion is believed to require the use of second-order relational information in the face. The eye and mouth regions are inverted with respect to the rest of the face and the grotesque nature of the resulting face is reduced by inversion. Here the aim was to see whether individuals could identify the altered face.

Design: Two groups of individuals were individually matched to three groups of typically developing children matched for verbal, nonverbal and chronological ages. The autism group comprised 20 individuals with a mean age 14y 9m whilst the WS group was made up of 13 individuals (mean age 15y 6m).

Method: Participants completed a two-alternate forced choice task picking the face that had been manipulated and with the trial remaining in front of participants until a decision was made. Half the trials were upright whilst half were inverted.

Results: All participants, including those with autism and WS, were susceptible to the Thatcher Illusion. All groups showed equivalent inversion costs for upright and inverted trials.

Conclusion: If the Thatcher Illusion requires the processing of second-order relational information, then the autistic and WS participants in this study were able to compute such information. This study provides more information on how faces are processing by these groups.

Differences and similarities in the cognitive profile of children with FXS and ASD: An initial baseline
Carrie Ballantyne

1Dept of Psychology, Glasgow Caledonian University

Objectives: The study explored the cognitive phenotypes of children with fragile X syndrome (FXS), autism (ASD), and typically developing children (TYP). The study aimed to highlight the possible disparities between groups, focusing on differences in visuo-spatial processing.

Design: 3 groups of children took part in the study (FXS, n=16, ASD, n=16, TYP, n=16). The mixed design study analysed the effects of disorder type and task type on performance.

Method: All children were matched on verbal mental age using the BPVS II (British Picture Vocabulary Scale, 2nd edition) and completed the WPPSI III (Wechsler Preschool and Primary Scale of Intelligence, 3rd edition) and the Children's Embedded Figures test.

Results: The results indicated that the ASD group were more accurate at the visuo-spatial tasks than the FXS group. Notably, the ASD group tended to be more accurate on specific visuo-spatial tasks than the TYP group (e.g. Children's Embedded Figures and the Object Assembly tasks). The TYP group, however, outperformed the other two groups on the vocabulary subtests. The FXS group outperformed the ASD group on the Comprehension task only, but otherwise the two groups performed similarly in the vocabulary subtests.

Conclusion: This study provides an initial insight into the cognitive profiles of children with FXS and ASD. Importantly, it provides the groundwork for subsequent investigations aimed at pinpointing the visuo-spatial abilities impaired and spared in FXS and ASD.
The phenomenology of autistic spectrum disorder in Cornelia de Lange syndrome
Joanna Moss¹, Chris Oliver, Lesley Jephcott, Katy Berg, Gurmeash Kaur
¹St George's, University of London

Objectives: To assess the phenomenology of autistic spectrum disorder in Cornelia de Lange syndrome in comparison to a group of individuals with Cri du Chat syndrome.

Design: A group comparison was employed to assess the prevalence and phenomenology of autistic spectrum disorder in Cornelia de Lange and Cri du Chat syndromes.

Method: The Autism Diagnostic Observation Schedule and the Social Communication Questionnaire were employed to assess the phenomenology of autistic spectrum disorder in 34 individuals with Cornelia de Lange syndrome (mean age = 12.39; SD= 3.82) and 23 individuals with Cri du Chat syndrome (mean age =10.26; SD = 3.60). These groups were comparable with regard to gender, receptive language, chronological age, mental age equivalence, verbal ability and mobility.

Results: 61.8% of individuals with Cornelia de Lange syndrome scored above the cut-off for autism on the Autism Diagnostic Observation Schedule compared to 39.7% of individuals with Cri du Chat syndrome. Individuals with Cornelia de Lange syndrome score significantly higher on the communication domain of the Autism Diagnostic Observation Schedule and the Social Communication Questionnaire (p<.025). These differences were not accounted for by degree of disability, level of receptive language skills and the difficulties of identifying autistic spectrum disorder in individuals with profound intellectual disability.

Conclusions: Individuals with Cornelia de Lange syndrome demonstrate an atypical profile of autistic spectrum disorder that is characterised by impairments in communication skills and the presence of repetitive behaviour with less impaired social interaction skills than would be expected in individuals with autistic spectrum disorder.
Research into the genetics of ID: Consent issues

Maggie Ponder¹, Helen Statham, Nina Hallowell, Lucy Raymond, Martin Richards
¹Centre for Family Research, University of Cambridge

Objectives: To describe how families give consent for a molecular-genetics study of learning disabilities. These families have a number of males with learning disabilities: the pattern of occurrence suggests there may be a gene on the X-chromosome, i.e. carried by women and affecting males.

Design: Interviews with family members after joining the molecular study. This paper focuses on issues of consent.

Method: 113 individuals from 52 families, including grandparents, mothers, fathers, siblings, and men with learning disabilities have been interviewed.

Results: Thematic analysis suggests that agreeing to consent to participate in this research is something that family members do for each other. Where we could ask people with ID there was no evidence that they felt differently. Families involved in the care of people with ID expect to be involved in decisions affecting their relatives and feel excluded if not asked: consent to be part of research is not seen differently from other decisions. There may be some conflict of view between policies aimed at promoting autonomy and family views.

Conclusions: For genetic research there is a need for multiple members of families to take part. Relatives agree to take part in order to help each other; people with ID need to be allowed to be part of this. The Mental Capacity Act has generated debate about consent from individuals who lack capacity. There is a danger that this focus on individual consent may lead to the exclusion of those with IDs from participation in normal family life/decisions.

Children with developmental disabilities and sleep problems: Parental beliefs and treatment acceptability

Colin Espie¹, Ruth Keenan, Matt Wild, Irene McArthur
¹Sackler Institute of Psychobiological Research, University of Glasgow

Background: This exploratory study investigated the relationships between illness beliefs and treatment acceptability among parents of children with a developmental disability who had sleep onset or maintenance problems.

Methods: A within subject correlational design was employed. The parents of 58 children each completed questionnaires assessing their beliefs and attributions toward the sleep problem and the acceptability of two common treatments (behavioural and melatonin).

Results: Parents believed sleep problems to be chronic, to have negative consequences, yet to be potentially curable/controllable. They rated behavioural and pharmacological (melatonin) treatment similarly in terms of acceptability. Behavioural treatment acceptability was related to how long parents believed the sleep problem would last and to a number of causal attributions. Pharmacological treatment acceptability was related to how severe the consequences of the sleep problem were believed to be and to a specific causal attribution. Parents who preferred pharmacological treatment over behavioural believed their child’s sleep problem had more negative consequences on their child’s life.

Conclusions: Specific beliefs held by parents about their child’s sleep problems might influence treatment acceptability and treatment choice. Parents are split between those who would prefer behavioural and those who would prefer pharmacological. However, as the sleep problem becomes more severe, it seems more likely that parents would choose pharmacological treatment.
Predictors of sibling adjustment in families using home-based interventions for autism

Katie Williams

School of Education, University of Edinburgh

Objectives: The study to be reported sought to explore the experiences of typically developing (TD) siblings in families involved in a home-based intervention for autism, Applied Behaviour Analysis (ABA). The aim was to establish whether sibling psychosocial adjustment in ABA families differs from that of siblings in non-ABA families. It also aimed to establish which demographic, psychological and intervention variables best predict variation in sibling outcome.

Design: A questionnaire study of parents of children with autism and their TD siblings.

Methods: Ninety families with a child on the autistic spectrum and a TD sibling (4 – 15 years) participated: 45 families using ABA intervention and 45 non-ABA families. Parents provided information on family demographics and intervention use (e.g. duration, therapist input). They also completed measures of symptomology in the child with autism, sibling behavioural adjustment, sibling relationship quality, social support and parental stress levels. The older siblings in each group (9 – 15 years; total N = 44) completed measures of behavioural adjustment, self-concept, sibling relationship quality and social support.

Results: Preliminary analysis suggests relatively few between-group differences in terms of sibling psychosocial adjustment. It is clear, though, that variation in adjustment levels across siblings is wide, and analysis exploring factors predicting these differences in outcome will be reported. Sibling and parent data will also be compared.

Conclusion: This research highlights the need to consider intervention use from a family-systems perspective. Implications for support of families involved in early intervention programmes will also be considered.

An impossible loss: the experiences of bereaved parents of people with intellectual disabilities

Stuart Todd

Welsh Centre for Learning Disabilities, Cardiff University

Objectives: This research considered the relationship between death, dying and intellectual disability across a range of settings. The focus here are the experiences of parents whose child with intellectual disabilities had died. There exists little research on the bereavement experiences of such parents and that cannot be linked to the increasing life expectancy of people with intellectual disabilities. Early death is not uncommon for this population. This paper examines the experiences of bereaved parents in relation to their on-going support needs and to wider family based research.

Design: The study utilised an opportunistic sampling framework to overcome significant but interesting recruitment difficulties.

Method: Qualitative in-depths interviews were conducted with 15 parents and two siblings of people with intellectual disabilities who had died.

Results: The loss of a child with intellectual disabilities was considerable and far-reaching. However, the extent of this loss was largely unrecognised. Grieving was, therefore, unsupported and private. Furthermore, the death of a child with intellectual disabilities was typically seen by as others as one of relief and as offering an opportunity to return to 'normal' living. For parents, however, the loss included not only the death of a child but also a loss of identity. There was no world to return to.

Conclusion: The experiences of bereaved parents suggest that their loss was complicated and disenfranchised. The data are used: to explore the on-going support needs of parents after their child has died; to reflect upon the social value of people with intellectual disabilities; and the way in which families of disabled children are represented in research.
Carers’ experiences of challenging behaviour in people with learning disabilities: an interpretative phenomenological analysis

Hayley Pringle¹, Peter Baker, Victoria Senior
¹East Sussex County Healthcare NHS Trust

Objectives: To discover more about how care staff experience and understand the challenging behaviours of the people with learning disabilities in their care.

Design: Retrospective design eliciting carers' accounts using a semi-structured interview.

Method: Ten participants were interviewed (six men). All were paid carers working in residential homes in the community for people with learning disabilities. Interview transcripts were subjected to Interpretative Phenomenological Analysis.

Results: Three superordinate themes emerged from the analysis, labelled 'Understanding of Challenging Behaviour', 'Attempting to Intervene' and 'Sources of Knowledge & Support'. Participants whose causal explanations were more restricted also tended to hold the client responsible for their actions and to feel anger toward the client. Exhaustion was linked to failing to identify triggers (so that early intervention was not possible) and a desperate attempt to try and make sense of the incident of challenging behaviour. In attempting to intervene, participants spoke of the immediate need to assess risk. Informal support from colleagues was identified as important in helping care staff to cope with the challenging behaviour.

Conclusions: Findings highlighted a number of factors that could potentially contribute to stress in care staff. Of particular interest was the finding that failure to identify triggers can lead to desperate attempts to make sense of the incident and consequent exhaustion. In the light of this finding, external consultants responsible for designing interventions and teaching Positive Behavioural Support principles are encouraged to review the suitability of messages suggesting that triggers to challenging behaviours are always present and identifiable.

The relationship between staff burnout and user lifestyles in housing services

Chris Hatton¹
¹Institute for Health Research, Lancaster University

Objectives: To assess the relationship between staff burnout and user lifestyles in housing support services.

Design: Cross-sectional survey: up to 82 pairs of service users and support workers.

Method: Completed by staff: Maslach Burnout Inventory (emotional exhaustion [EE] depersonalisation [DP], personal accomplishment [PA]), service user and staff characteristics. Completed by service users: Measure of adaptive behaviour, service user characteristics, Choice Scale, My Life interview.

Results: Using correlations (p<0.05), only greater staff DP was associated with service user characteristics (lower adaptive behaviour, greater challenging behaviour). Of the 26 items in the Choice Scale, greater staff DP was associated with less service user choice on 9 items, greater staff EE with less service user choice on 3 items, and greater staff PA with greater service user choice on 1 item (drinking alcohol). Of the 13 items in the My Life interview, greater staff DP was associated with less service user satisfaction on 4 items. Greater staff EE was associated with service users feeling more left out, and greater staff PA was associated with greater service user satisfaction with leisure activities. Partial correlations, controlling for service user adaptive behaviour and challenging behaviour, revealed fewer significant associations although similar patterns of results.

Conclusions: Despite the methodological limitations of this study, there are robust associations between housing staff burnout and aspects of service quality and service user lifestyle, particularly for the depersonalisation dimension.
An ethnography of care; managing people diagnosed with Prader-Willi syndrome living in residential care
Rebecca Hawkins\textsuperscript{1}, Marcus Redley, Tony Holland
\textsuperscript{1}Developmental Psychiatry Section, University of Cambridge

Objective: To understand the degree and scope to which the regime of intimate daily care, in specialist residential homes for people with Prader-Willi syndrome (PWS), is informed by carers’ medical knowledge of PWS.

Design: A comparative study of two residential settings, one exclusively for people with PWS, the other a mix residence for people with intellectual disabilities and PWS.

Method: Ethnographic fieldwork, combining ten months of observation with interviews and an analysis of documents.

Results: The homes provide specialist care for people whose behaviour (such as over-eating) is routinely considered to be the consequence of having the genetically determined PWS. In spite of this apparently similar behaviours can also be interpreted by staff as ‘self-determined’. For instance, the same staff member can respond to an incidence of over indulgence in food as a genetic determined symptom of PWS or as a wilful act, depending on whether the carer is reporting an incident of over eating or managing the discovery of a resident who has over eaten. The data therefore suggests that the demands of different types of care-activity, as opposed to the strict application of medical knowledge, are influencing the ways that staff members understand the residents’ behaviours.

Conclusion: This presentation demonstrates how the maintenance of an orderly regime of residential care is predicated upon the ability of staff to be discriminating in their attributions of cause and agency to otherwise apparently similar behaviours.

Too far to go: Out-of-area placements for people with intellectual disabilities
Julie Beadle-Brown\textsuperscript{1}
\textsuperscript{1}Tizard Centre, University of Kent

Objectives: This study aimed to estimate the numbers of people placed out-of-area and the reasons and effects of these placements in one county in England.

Design: This mainly exploratory study was a one point-in-time survey of the situation in one English county.

Methods: This study involved a survey of all social care homes in the county; Measures of quality of life/service for random sample of 30 people identified by the survey; Interviews with home mangers, service users, family carers and care managers focusing on the reasons, and effects of such placements; focus groups with members of 4 Community Learning Disability Teams.

Results: The total number of people placed from out-of-area was estimated to be close to 2000 people (1500 were placed by the local authority within the county). The main reason for such placements was lack of good quality local services and cost also seemed important. For many of those who had been in long-stay hospital, locality appeared not to be important. Effects varied but at least 1/3 of people where experiencing very poor outcomes in terms of service quality and quality of life. Family carers generally felt their relative was happy but fear of losing the placement was a strong theme. Distance was a major issue in terms of both family and care manager involvement. For local community learning disability teams some of the main issues were: increased workload, reduced provision for local residences, difficulty dealing with placing authority and the poor quality of the homes.

Conclusions: Challenges for public agencies include the provision of better local services, the management of the cost incentives, especially for London Boroughs, and a system where funding follows the person wherever they chose to live.
Psychometric properties and normative data for the neuropsychological assessment of dementia in intellectual disabilities

Dawn Adams, Chris Oliver, Tony Holland, Karen Dodd, Janet Carr, Vicky Turk, Sunny Kalsy, Sarah Ball

School of Psychology, University of Birmingham

**Objectives:** This research aims to explore the psychometric properties and improve the clinical utility of a neuropsychological test battery for assessing dementia in individuals with Down syndrome.

**Design:** Detailed examination of the reliability of the Neuropsychological Assessment of Dementia in Intellectual Disabilities (NAID, formerly the Crayton and Oliver) was conducted on the results of 66 adults with Down syndrome. Further examination and improvement of the clinical utility of this measure was undertaken on the results from the test battery of over 300 adults with Down syndrome.

**Method:** Split-half reliability was calculated using the Spearman-Brown prophecy formula. The clinical utility was improved by using results from the British Picture Vocabulary Scale and/or Vineland Adaptive Behavior Scales (where available) to produce banded normative data dependent by age and, uniquely, premorbid ability.

**Results:** Split-half reliability is above the accepted level of .70 for all subscales. Examination of the normative data shows the importance of considering premorbid ability in the determining deviation or decline.

**Conclusions:** Conclusions drawn from an assessment are no better than the data on which they are based, therefore psychometric properties of assessments must be carefully examined before they are used in such a difficult diagnostic process. This study has shown that the NAID is reliable and clinically useful for both baseline and longitudinal assessment.

Working lives: The role of day centres in supporting people with learning disabilities into employment

Steve Beyer

Welsh Centre for Learning Disabilities, Cardiff University

**Objectives:** To explore the employment activities and support given by day centres (DCs) and other work organisations, and the views of people with learning disabilities and their carers, to understand how people can be helped most effectively into employment.

**Design:** The study compared experiences of key stakeholders, and delivery models, between 9 local authority areas.

**Method:** Qualitative interviews were conducted across a purposive sample of 27 DCs, 8 work preparation units, and 21 external work services to obtain perspectives of users (158), their carers (20), managers and staff of DCs and managers of employment-related providers within (41), and independent (24) of the LA.

**Results:** People liked work for the same reasons as everybody else and paid work best. People left work because of company closure or dislike for the work. Carers provided and received support to help users obtain employment, mainly resolving benefit issues and helped with transport. They were more critical of DCs than their sons and daughters. Some struggled alone to find jobs and many were powerful advocates for employment. DC models found were: “hands-on services”, “hands-on partnerships”, and “hands-off partnerships” which differed in level, and professionalism, of employment activity. Training programmes and links to the employment world were weak in all but “hands-on services”.

**Conclusions:** Local Authorities (including DCs) should build partnerships with specialist agencies to provide effective support to people get paid jobs. Appointing employment staff within DCs is unlikely to be effective in getting more jobs. LAs need to refocus their employment training on achieving paid jobs.
The dental health of adults with intellectual disabilities

Darren Chadwick¹

¹Department of Psychology and Speech Pathology, Manchester Metropolitan University

Objectives: Adults who have a intellectual disabilities (IDs) may have difficulty in maintaining health related behaviours and accessing health services. Dental health is just one facet of general health that should be considered in this context. This study aimed to identify (i) levels of dental health in adults with IDs (ii) compare them with levels among their same-age contemporaries and (iii) seek demographic and functional correlates of dental health.

Design: The investigation is a pilot study into dental health collecting baseline clinical dental health information.

Method: Questionnaires and simple clinical examinations were conducted in community settings to gather the data. Data was collected from 318 adults aged 18 - 81 with a range of intellectual and physical disabilities living in a variety of residential settings. Dental examination data was available for 294 people.

Results and Conclusions: Seventy-seven percent of adults with IDs had a dental check-up in the previous year. Extensive calculus and poorer oral cleanliness were observed in 11% of participants, though very few participants (<1%) had soft tissue lesions and sepsis. Edentulousness was higher in this group than in the typically developing population and increased with age. Mobility problems were associated with less regular access to dental services. Specific challenging behaviours were not associated with access but were associated with specific dental health conditions. The results of these preliminary analyses indicate that the dental health of adults with ID is relatively good.

Development of a measure of staff perceptions of team characteristics in intellectual disability services

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Objectives: To describe the development of a measure of staff perceptions about their team, and to report preliminary psychometric data for the scale.

Design: Pilot interviews were carried out with staff to explore their perceptions of the staff team and the way that the team works. Statements extracted from these interviews were chosen to represent a range of views and selected for possible inclusion in a new measure of staff perceptions of team characteristics.

Method: 96 care staff from an intellectual disability service rated their views about their team using a 44-item scale. A further 15 staff took part in a test-retest. The measure formed part of a wider survey of staff well-being.

Results: Exploratory factor analysis of the scale suggested that the measure was best thought of as having a single dimension – generally measuring staff positive and negative views about their work team. Internal consistency of the new scale was high (alpha = .96). There was also good evidence of concurrent validity (r = .61 association with a staff support scale), and convergent validity (significant associations with burnout and staff general positive perceptions about their work).

Conclusions: There are very few measures available that might be relevant to the assessment of team characteristics and support in intellectual disability services. Thus, the encouraging psychometric data and good level of face validity for this scale (derived from staff interviews) suggest that it may be useful in a range of research and clinical contexts.
Parental Stress, child challenging behaviour and respite: An examination of factors associated with requesting, using and allocating respite services

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Objectives: The present study hypothesised that parental stress in parents of children with learning disabilities would be associated with higher levels of child challenging behaviour and that families receiving respite care would experience lower levels of stress than similar families who did not receive respite. It was also hypothesised that families who had requested respite would have children with higher levels of challenging behaviour and would be experiencing more stress than families who had not requested respite.

Design: A postal questionnaire based method was used to analyse differences between groups in relation to parental stress, child challenging behaviour and respite use.

Method: Seventy-three parents of children with learning disabilities participated in the study. Thirty-three of these were receiving respite and forty were not. Parents completed four questionnaires relating to: parental stress, child challenging behaviour, respite use and demographic information.

Results: A significant correlation was found between parental stress and child challenging behaviour. Parents receiving respite experienced higher levels of stress and had children with more challenging behaviour. In addition those who had requested respite experienced higher levels of stress and had children with more challenging behaviour than those who had not requested respite.

Discussion: Possible explanations for the higher levels of stress and challenging behaviour in the respite group are discussed along with the implications of the lack of respite for all families who have requested it. Factors associated with the allocation of respite are also discussed together with clinical implications and methodological strengths and difficulties.

Self-reported general health status of adults with intellectual disabilities in England

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Objectives: To examine the contribution of personal characteristics, living conditions, socio-economic position and social support to the self-rated general health status of adults with intellectual disabilities in England.

Design: National cross-sectional survey. Participants were 1 183 adults who answered most of the more complex questions relating to health themselves in the National Statistics survey Adults with Learning Difficulties in England 2003/4 (41% of total sample).

Results: 11% of the sample reported themselves as having 'not good' health. Bivariate analyses indicated higher levels of 'not good' health among: participants from minority ethnic communities (p=0.014); older participants (p=0.003); participants who were living alone or with a partner (p<0.001), unemployed (p=0.001), poor (p<0.001), living in poor neighbourhoods (p=0.003), were less active within their communities (p=0.005) and who saw friends who had intellectual disabilities less often (p=0.028). The results of multivariate analyses will be presented at the conference.

Conclusions: Socio-economic disadvantage accounts for a significant proportion of the variation in self-rated general health among adults with intellectual disabilities. Policies to reduce disparities in health outcomes between adults with intellectual disabilities and their non-disabled peers need to address the social as well as biological determinants of poor health.
Injuries, accidents and falls in adults with learning disabilities
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Objective: To describe the frequency, types and characteristics of injuries, accidents and falls experienced by adults with learning disabilities compared with the general population and to identify associated and predictive factors.

Design: Population-based cohort study of ~600 adults with learning disabilities, re-interviewed after a two-year period.

Method: Face-to-face semi-structured interviews with participants and carers, to detail injuries over a 12-month period. Analysis compared participants with the general population at individual and aggregate levels, and determined associated and predictive factors. Qualitative interviews conducted with a sub-sample of participants with high frequency or severe injuries were analysed to identify key themes on persons’ experiences of injuries.

Results: Analysis of 296 participants (158 M, 138 F, mean age 46, 46% mild learning disabilities, 24% moderate, 15% severe, and 15% profound) demonstrated a higher frequency and different types of injuries, than 256 of their carers (53 M, 203 F, mean age 48), and general population data, all aged 16-74 years. 24% of males and 18% of females with learning disabilities had experienced at least one injury, compared to 11% of male and female carers, and 17% of males and 11% of females in the general population. Men and women with learning disabilities experienced a higher frequency of injuries from falls and other causes, and were more likely to experience burns or scalds. Comparison between participant and carer groups was highly significant ($\chi^2=53.847$, df=1, p=0.000).

Conclusion: The higher frequency and different types of injuries, accidents and falls in adults with learning disabilities demonstrates the importance of determining associated and predictive factors, so that an appropriate range of interventions can be developed.

Level of new unmet health need at a subsequent health check
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Objectives: To ascertain the extent of new unmet need identified at a subsequent health check undertaken in primary care and the association between number of needs identified and the interval between checks.

Design: Group comparison.

Method: 108 adults who had had health checks (at $T_0$) were randomly allocated to two groups: one to receive repeated health checks at $T_1$ and $T_2$; the other to receive a first repeated health check at $T_2$. Health checks were not conducted as planned. Comparison was therefore made between 3 groups: Group 1 (n=39) who received a repeated check at $T_1$ (mean 28 months after $T_0$), Group 2 (n=36) who received a repeated health check at $T_2$ (mean 44 months after $T_0$), Group 3 (n=33) who did not receive a subsequent health check. 30 adults in Group 1 received a second repeated health check at $T_2$ (mean 14 months after $T_1$). New health needs identified were audited.

Results: There were no within or between group differences in the number or nature of health needs identified at $T_0$, $T_1$ and $T_2$. A similar proportion of health needs at the subsequent check compared to baseline might be deemed serious. The correlation between number of new needs identified at the first repeated health check and the interval between that and the $T_0$ check was not significant.

Conclusion: Within the intervals between checks investigated here, there was no reduction in their utility in identifying previously unidentified health need. Annual health checking is justifiable if it is to be undertaken.
Communication of children using AAC: Parents’ accounts and observations
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Background & Objective: Communication intervention for children with severe and profound learning disabilities often involves alternatives to speech such as signing or symbol systems (AAC). Parental involvement in AAC interventions is widely supported; however, for interventions to be sustainable they must fit with the families’ beliefs and values. The aim of the study was to explore the ways in which parents talk about their children’s everyday communication, the priority they give to communication and their reflections on communication itself.

Design: Qualitative, with data collection by semi-structured interview and data analysis by thematic network analysis.

Method: 11 interviews were conducted with parents of children with a diversity of disabilities who use high and/or light tech AAC. Interviews were transcribed then analysed using Atlas ti.

Results: A Global Theme, "The Child’s Communication Or Interaction", emerged, with Organizing Themes: How and about what do parents communicate with their child; The child’s level of communication; Comprehension and intelligibility; Impact of the child’s personality; How the child communicates choices; and The child’s social inclusion or exclusion. Nine of eleven interviewees identified communication as a very high priority for their child.

Conclusions: The quality of parents’ observations confirms previous author’ confidence in parents as informants and contributors to AAC intervention. Interviews seem to be effective in tapping parents’ knowledge and views. Families tend to use light tech/individual systems for quick exchanges at home, but those with high tech systems seem to value them highly.

Parents experiences of autism diagnosis: findings from a semi-structured interview
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Objectives: Most research regarding the diagnosis of autism has concentrated on children’s symptoms and diagnostic criteria. The purpose of the current research was to explore parents’ experiences of receiving a diagnosis of autism for their child.

Design: A qualitative semi-structured interview was used.

Method: 53 parents of children with autism (32 mothers and 21 fathers) were interviewed. Questions focussed on parents’ understanding of the diagnostic process and their cognitive and emotional responses to learning that their child was suffering from autism.

Results: Receiving the diagnosis of autism was deeply upsetting for most parents, provoking intense feelings of helplessness and frustration. Furthermore, many reported encountering a kind of “black hole” in terms of care and support; once the diagnosis had been made, professional help was often absent. For example, almost 60% of parents asserted they had received no information on the condition or advice on treatments available. With so little immediate help forthcoming, many read voraciously, using the Internet or library facilities to learn more. For some, this was a bewildering experience because proponents of different specialist treatments were often dismissive of other approaches.

Conclusions: In the period immediately following diagnosis, parents need support to help to adjust to the discovery that their child has autism and advice regarding the myriad of treatment options available. Psycho-educational interventions in the post-diagnosis period could provide effective psychological support for many parents at this critical moment of their lives.
Time understanding in children with autistic spectrum disorders
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**Background:** Autistic spectrum disorders appear to be associated with a poor intuitive sense of time. This does not refer to objective telling the time, but to the function of ‘internal clocks’ and subjective time perception. To date, there is limited data on these processes in children with ASD.

**Objectives:** To investigate subjective time understanding a cognitive estimation paradigm. The performance of children with ASD was compared to typically developing children and children with intellectual disabilities to determine whether time estimation was a specific area of difficulty for children with ASD or a general feature of intellectual disabilities.

**Design:** A between-group design was used to compare the performance on an adapted cognitive estimation measure (Biber Cognitive Estimation Test-Modified - BCET-M)

**Method:** 73 children aged 8-10 years old completed five measures (BCET-M, British Picture Vocabulary Scale (BPVS II), and three WISC III UK subtests [Information, Coding & Arithmetic]).

**Results:** ANOVA analysis indicated significant difference between all 3 groups on BCET-M total score and the four subcategories (quantity, weight, distance & time). Post-hoc analyses indicated the ASD group had significantly lower scores than TD, and the ID group had significantly lower scores than the other two groups. No differences were found with regard to estimating an actual period of time. Stepwise multiple regression analysis indicated BCET-M time score was predicted by mathematical ability.

**Conclusions:** Children with ASD showed significant, but not specific, cognitive estimation difficulties, including time estimation, which does not support the concept of a specific time processing deficit associated with ASD

Psychotherapists accounts of their practice with people with intellectual disabilities
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**Objectives:** There is an absence of a clear account of the practice of psychoanalytically based psychotherapy with people with ID. This study explored the practice of individual psychoanalytic and psychodynamic psychotherapists. The aim was to explore whether a clear and consistent account exists and to develop a model of practice.

**Design:** A qualitative design was taken employing a grounded theory approach.

**Method:** Eight practitioners were interviewed about their practice. They were asked to provide a narrative account of their practice sequentially from beginning to end. The interviews were subjected to grounded theory analysis. Saturation of themes occurred after eight interviews.

**Results:** A consistent account of the process of delivering psychotherapy to adults with ID emerged from the data. The model that emerged placed importance on philosophical notions of disability, attachments and relationships, and trauma.

**Conclusions:** Links between philosophies and practice are proposed and a speculative model for practice presented.
Evaluation of a residential and further education service for young people with severe learning disabilities and challenging behaviour

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Objectives: The development of services for young people with severe learning disabilities and challenging behaviour remains hampered by a lack of consensus over the form such services should take. The current study evaluates the outcomes achieved by a new local service, designed to meet the needs of four young people with severe learning disabilities and challenging behaviour, all of whom were previously placed in out-of-area services.

Design: A utilisation focused approach to evaluation was employed to engineer stakeholder support and to develop research questions. Stakeholders identified three themes to be addressed; (i) evaluation of long-term outcomes achieved by the students, (ii) evaluation of the quality of staff support, (iii) evaluation of the transition process. An AB quasi-experimental single case study design was adopted to address the first two themes of the research. The final theme of the research was addressed using a thematic analysis of key actor responses to open-ended questions.

Method: Student outcomes and the quality of staff support were measured by direct observation of behaviour and the use of standardised questionnaires/interview schedules, information about the transition process was obtained by questionnaire.

Results: Transition to the new service was associated with increased choice-making opportunities and community presence and reduced frequency of challenging behaviour.

Conclusion: This study provides some support for the development of small, local, community-based services for young people with severe learning disabilities and challenging behaviour. The benefits of adopting a utilisation focused approach to evaluation are also discussed.

A qualitative evaluation of a training programme and manual for School Health Advisors working with children with intellectual disabilities

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Objectives: To (a) assess School Health Advisors (SHA) perceptions of the usefulness of a training programme and manual addressing information about encopresis, doctor-patient compliance and the helping process, and communication with children with intellectual disabilities, and (b) identify changes that might enhance their efficacy.

Design: Two focus groups of SHA were conducted; one immediately after the training programme, the second after one term of use of the manual.

Method: 7SHAs from 2 Districts took part. Focus groups were audio-taped. Qualitative analysis was undertaken using MaxQDA software.

Results: The training and manual were perceived very useful. The communication with children and information about encopresis elements were identified as most useful post training and at follow-up. SHAs felt that the training enabled them to communicate more easily and effectively with children and to enable parents and children to own more of the process, and to use more information and resources. There was a shift in beliefs about their own competence. Problems identified with the training programme and manual mainly concerned design issues, ease of use and length.

Conclusions: An emergent model of use was identified. The training in communicating with children led to an immediate engagement and involvement of the professional with the child and parent. This led to a greater perceived efficacy for both the SHAs and children. Information about encopresis and the helping process was used when it complemented existing patterns of knowledge, work and practice. The manual and training programme has been re-designed to accommodate this use.
Studies on offenders with intellectual disability (ID) across three forensic settings
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Objective: As existing evidence on the prevalence and characteristics of offenders with ID is highly variable, the aim was to apply a range of measures from the criminological literature and compare the characteristics of three cohorts drawn from high secure, medium/low secure and community forensic settings.

Method: Measures of general characteristics, risk assessment, personality disorder (PD) and antisociality were compared for offenders with ID in high secure (n = 73), medium/low secure (n = 70), and community forensic services (n = 69).

Results: Over 50% of all groups had at least one conviction for a sexual offence. Total prevalence of PD was 39.3%. The most common diagnosis was antisocial personality disorder. There was no diagnosis of dependent PD indicating that the assessors were not overly influenced by the developmental disability itself. High security was associated with lower early psychiatric service contact, more complex presentations, more violent convictions, rate of PD and higher PCL-R psychopathy scores. Severity of PD correlated with predicted future violence. The PCL-R had convergent validity with measures of PD, risk and current functioning. Two actuarial instruments, the VRAG and HCR-20, and two dynamic risk predictors, the Short Dynamic Risk Scale and the Emotional Problem Scale significantly predicted of violent incidents. The Static-99 and RM2000 did not.

Conclusions: Measures of antisociality, risk, personality disorder and current functioning can be used reliably. Convergence in predicted directions indicated validity. Except for sexual offences and predictors of sexual violence, severity of symptom variables generally increased with level of security.

Relationships between acceptance, mindfulness, and stress in mothers of children with intellectual disabilities
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Objective: To explore potential relationships between process variables (acceptance and mindfulness) implicated in the development of psychological problems, and stress in mothers of children with intellectual disabilities.

Design: A cross sectional survey design was used.

Method: 92 mothers of school age children attending schools for children with intellectual disabilities provided data about their child (behaviour problems, adaptive skills), and their own well-being. Maternal measures included the Acceptance and Action Questionnaire (AAQ) to measure acceptance of unwanted thoughts/feelings, the Mindfulness Attention Awareness Scale (MAAS) as a measure of attention to the present, the Hospital Anxiety and Depression Scale (HADS), and the Questionnaire on Resources and Stress (Short Form) (QRS-F).

Results: Significant positive associations were found between acceptance and mindfulness variables. Correlation and regression analyses show that both acceptance and mindfulness are independent predictors of maternal well-being. Mothers who report higher levels of acceptance and mindfulness also report more positive adjustment.

Conclusions: This research emphasizes the importance of considering psychological process variables in understanding adjustment to raising a child with intellectual disabilities. An understanding of process may help to focus on new intervention techniques. The present data suggest that acceptance-based behaviour therapy and/or mindfulness-based cognitive behaviour therapy may be beneficial for parents.
Stress in mothers of young people with intellectual disabilities (ID)

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Objectives: To explore the experience of stress in mothers of young people with ID with and without an additional diagnosis of autistic spectrum disorder (ASD). To identify unmet personal and family needs. To test project methodology before enlarging the study group.

Design: A mixed-method study using a self-report questionnaire followed by a semi-structured interview.

Method: 21 mothers of young people aged 13-22 with mild ID, some with an additional diagnosis of ASD, completed a standardised questionnaire on stress. 9 mothers subsequently took part in a semi-structured interview covering challenges/coping strategies and exploring views on support services.

Results: Questionnaires: Mean score on Family Stress and Coping Interview was 32.7 (SD 16.7) in line with reported mean scores for parents of young people with developmental disabilities up to age 21 (32.4), but with scores ranging from 8 to 62. Commonly highlighted stressful issues were: planning emotional and social support, work placements/employment and meeting own personal needs.

Interviews: All mothers identified unmet formal and informal support needs, regardless of level of stress. Mothers of older young people particularly identified needs for improved communication with services relating to work/college placements and housing. Mothers with lower stress scores expressed more positive attitudes to their children. There was a general perception that lack of appropriate provision prevented young people from fulfilling their potential.

Conclusion: Mothers' experience of stress may be associated with perceptions that lack of support and poor communication with service providers hampers their child's progress towards independence.

An assessment of the needs of people with a forensic history in community services

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Objectives: 1) To identify the support needs of people with a forensic history moving back to an inner city learning disability service. 2) To assess the capacity of the service to meet these needs.

Design: Case study design to meet objective 1. and provide in-depth data. Semi-structured interviews to provide data to meet objective 2.

Method: Six case studies were conducted. All participants were male, 5/6 were white. A key informant and/or the participant themselves were interviewed and case files examined. Semi-structured interviews were conducted with five professionals (3 psychologists, 2 nurses; 3 were male, 2 female; 4/5 were white).

Results: Data were analysed using content analysis designed to identify common themes. All the men had a number of convictions and significant previous contact with the criminal justice system. Custodial sentences had been served in secure learning disability provision. Many of support needs of this group were similar to others with learning disability (e.g., good quality day activities, structure, routine) and those additional 'specialist' support could be met from within the capacity of the local service. Robust risk assessment and management processes were a key requirement.

Conclusions: People with a learning disability and forensic history may not present a significantly different challenge to community services and additional support needs may be met by an appropriately resourced community team. People with less previous contact with the criminal justice system may have a greater need for specialised therapeutic intervention. Implications for services will be discussed.
Outcomes of community living: Semi-independent living & fully staffed group homes
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Objectives: To evaluate the lifestyle outcomes of fully staffed (FS) group homes & semi-independent (SI) residential settings for adults with ID.
Design: Matched group.
Subjects: 68 adults in 2 groups of 34 matched on a range of personal characteristics, living in either FS group homes or SI settings.
Method: Groups were compared on a range of lifestyle outcomes concerned with: independence, choice, community & social inclusion, health, safety & satisfaction.
Results: Compared with residents with equivalent levels of adaptive behaviour and challenging behaviour who lived in FS settings, residents in SI settings had significantly higher scores on scales of choice & participation in domestic activity. Levels of satisfaction, social and community inclusion, health & safety did not differ significantly between groups.
Conclusion: Consistent with results reported by Stancliffe & Keane (2000) this study found that some people with mild ID living semi-independently can experience lifestyle outcomes which are as good as, and, in some areas, better than, those experienced by people with similar levels of ID who live in settings which are staffed all the time. Data on resource input has also been collected and, once analysed, will indicate whether one form of support is the more cost effective.

Health knowledge and expected outcomes of risky behaviour: A comparative study of young people with physical and intellectual disabilities
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Objective: Young people learn about health through a number of formal and informal sources. For young people with disabilities, who are more likely to experience social exclusion, the opportunities to talk about health may be fewer and this in turn may impact upon knowledge. This may be more marked for sensitive topics like sexual health. The objective of this study is to explore young peoples knowledge of two ‘public’ health areas (healthy eating, alcohol consumption) and two ‘private’ areas (contraception, AIDS).
Design: Questionnaires and semi-structured interviews were used to elicit both quantitative and qualitative data regarding knowledge of the above four areas.
Methods: 65 young people aged between 15-21 participated in the interviews (36 with a mild/moderate learning disability (LD) and 29 with a physical disability (PD)). Information was collected regarding participants’ social networks and sources of health knowledge.
Results: Initial results indicate that young people with LD had poorer knowledge overall, although this only reached statistical significance for Alcohol (z=-2.73, p=.006) and AIDS (z=-2.17, p=.03). There were no significant within-group differences (across topics) contradicting the prediction that knowledge regarding ‘private’ health topics would be lower than ‘public’ topics. However qualitative data did support this hypothesis and this is discussed in relation to who young people talk to about health. The qualitative data also revealed substantial gaps in deeper conceptual knowledge for both groups, although this was more pronounced for the LD group.
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.
Sense of coherence as a modulator variable of stress in mothers of children with autistic spectrum disorders

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Objectives: This study explores the role of perception in stress adaptation in families of children with Autism Spectrum Disorders (ASD), in particular in mothers.

Design: We propose a simple multi-factorial model that is based on the Double ABCX model of family stress (McCubbin & Patterson, 1983). This is a systemic theoretical model where three factors are interrelated: the factor aA (stressor), the factor bB (family support) and the factor cC (perception of the situation or, in our studies, sense of coherence, SOC). The outcome of these interrelations is the dependent factor xX (level of stress).

Method: 39 mothers of children with ASD participated in the study. They answered four questionnaires relating to the factors above. The data were statistically analysed using path analysis.

Results: The results showed that the empirical data fit the theoretical model well. There existed a direct and positive relationship between stressor and stress. But, also family support and perception of the situation (SOC) had an indirect and negative influence on stress. Both variables played a modulating role in the model.

Conclusions: The effects of characteristics of the child with ASD on maternal stress are influenced by the perception of the problem. This finding could offer some guidance for the professional to buffer stress and to promote well-being in the family of children with Autism Spectrum Disorders: for example, a specific intervention based on the components of SOC (comprehensibility, manageability and meaningfulness).

The basis of therapeutic communication: developing mutual understanding with individuals who have intellectual disabilities

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Objectives: This study explored the patterns of communication during the first phase of Cognitive Behavioural Treatment (CBT), when the main aim is to socialise clients in to the treatment model.

Design: This was an exploratory study, using data from two participants in a larger project investigating process issues in CBT.

Methods: The participants were both male, aged 22 and 45, referred with significant anger problems. They both had mild to borderline disabilities.

Verbatim transcriptions of participants’ therapy sessions 4 and 9 were coded using an initiative-response method of dialogue analysis, described by Linell et al (1988). In this method, each conversational partner’s communicative turn is coded from an interactional perspective, in relation to the other’s.

Results: Differences in interpolated median scores between client and therapist indicated that power was relatively equally distributed in the dyad, and that this balance increased between sessions 4 and 9. By linking the initiative-response analysis to the content of the transcripts, we were able to gain insight into the nature of dialogue within therapy sessions. What was essential to the flow of dialogue was maintaining mutual understanding and working on shared topics.

Conclusion: This method shows promise in understanding the nature of dialogue in CBT. These initial findings point to the importance of considering therapy as a mutual process. This has implications for accommodating clients’ communicative abilities and level of understanding.
Christian faith in the lives of families with an adult with learning disabilities
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Objectives: Religion is often overlooked by researchers when investigating the lives of adults with learning disabilities and their families. However, religion can impact upon the lives of families in both positive and negative ways. This study aims to investigate what role religion plays in accepting and cherishing an adult with a learning disabilities and also ways in which Christian faith may help families cope with the specific stresses and strains they may be under. The study also aims to investigate any negative effects of the role of faith, the church or community on participants.

Design: As a pilot investigation I sought four families who regarded themselves as belonging to the Christian faith. Questions were semi-structured and asked about private faith, prayer, religious background, church involvement and perception of God.

Method: Due to the necessity to conduct two interviews with one family, the pilot narrowed to two groups of participants, one a practising Catholic and a Pentecostal family.

Results: Themes include, faith as a lifejacket or buffer, role of God, fear for the future both practical and spiritual, prayer as a practical aid, criticism of the church and the impact of being part of a church on the life of the family.

Conclusions: No definitive conclusions can be made so far as this is a small pilot sample; however, the study so far has shown that Christian faith is the main means of support for these families and that more research is needed to explore the topic further.

Developing a measure of the symptoms of traumatic life events for the intellectual disability population
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Objectives: The link between mental ill health and traumatic life events is well established in the literature on post-traumatic stress disorder (PTSD), and abuse, and there are numerous assessments of symptoms for the general population. The main objective of this study is to develop new self report and informant measures of the symptoms of traumatic life events, which are relevant and accessible to the intellectual disability (ID) population.

Design: This stage of the study was a pilot to draft the new measure.

Method: Using interviews, questionnaires and focus groups, 6 service users, 2 advocates, 2 family carers, plus 16 staff and clinicians from mental health and forensic ID services in Northumberland, were consulted for their views on the symptoms of traumatic life events. They were also asked which symptoms from existing general population measures (e.g. of PTSD) they considered relevant to the ID population.

Results: Themes are being derived from the data by content analysis. These will be the basis of the items in the new measures. The majority of the emerging symptom themes appear consistent with general population studies. However there are some differences, which have been noted in studies of children, and abuse in ID, such as loss of previously acquired skills, and behaviours that challenge services. Participants also considered some symptoms in the general population measures may be too difficult to reliably access in many people with ID (e.g. depersonalization).

Conclusions: The next stage is to examine the reliability and validity of the new measures.
The Bangor Life Events Scale for Intellectual Disabilities (BLESID)

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Objective: To construct an informant-rated life events (LE) measure for use in research into intellectual disabilities (ID); to explore the feasibility of using informant ratings of impact; exploratory analyses of the validity of the new instrument.

Design: A cross-sectional postal survey design was used.

Method: 43 parents of adults with ID living in the family home completed the Bangor Life Event Scale for Intellectual Disabilities (BLESID), the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) Checklist and the Behaviour Problems Inventory (BPI). Demographic data on the adult with ID were collected.

Results: The most frequently experienced negative life events were being taken to an unusual place, change in daily routine, and bereavement. Participants experienced a mean of 5.05 life events in the previous 12 months. Previously found associations between life events and affective symptoms were partially replicated. Two life events were associated with higher scores on the affective disorder scale of the PAS-ADD: care by non-regular carer (p=.058) and increased arguments (p=.093). Two different (LE) were significantly positively correlated (p<.05) with challenging behaviour: verbal abuse and witnessing physical attack or verbal abuse.

Conclusions: The BLESID has a workable overall structure and is suitable for completion by non-professional carers. The general pattern of associations between life events, as measured with the BLESID, and measures of challenging behaviour and mental health are in agreement with the previous literature. It is unclear from the current data whether informant-rated ‘impact’ is a useful or valid measure for future life events research in this population.

Generalization of anger coping skills, by clients with learning disabilities, from day-service to residential settings

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Objective: To evaluate the extent to which anger management training provided within a learning disabilities day service generalizes to residential settings.

Design: Participants in each of two anger management groups were evaluated, before and after treatment, by day-service staff and by residential carers. The analysis of interest is the comparison between the two evaluations.

Method: The 11 participants attended the same day service. Treatment was delivered by an assistant psychologist and day service staff, using a standard cognitive-behavioural treatment package shown to be effective in earlier studies. Evaluation was by the Provocation Index and the Profile of Anger Coping Skills, which measure, respectively, the potential to react in an angry manner, and the utilization of eight different anger coping skills.

Results: Participants showed a decrease in anger and an increase in anger coping skills, which was maintained at six-month follow-up. Similar changes were reported by day-service staff and by residential carers (and by the participants themselves). At the level of the group, day-service staff and residential carers did not differ significantly, at any time, in their ratings of anger, aggregate coping skills, or individual coping skills. However, individual participants displayed different profiles of coping skills at work and at home.

Conclusions: The results confirm that group-based CBT is an effective treatment for people with learning disabilities and anger management problems. Therapeutic gains are maintained for at least six months and generalize across settings. Different anger-coping skills may be used by different people, or by the same person in different environments.
Asking Some More Interesting Questions in Intellectual Disability Research: The Case of Family Adjustment

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Family members (especially parents, and potentially siblings) of children and adults with intellectual disabilities appear to be at increased risk for negative well-being outcomes such as stress, and mental health difficulties. Given that we have known this for some time, and this knowledge tells us little about what to do about the potential problem, researchers need to be asking some more imaginative questions in this field. In this address, I will focus on three themes in recent and current family research and use my research and that of others to illustrate some ways in which the field might be taken forward. First, I will discuss the finding that child behaviour problems are a reliable predictor of parental adjustment. Key issues here are the specificity of this effect, and the causal status of the evidence base. I will also discuss the evidence that family adjustment may be a risk factor for the development or maintenance of child behaviour problems. Second, I will discuss some data that take the study of families away from the mother-child dyad to consider the inter-dependence of adjustment between the child with ID, siblings, parents, and extended family members (especially, grandparents). Third, given that by no means all families have difficulties adjusting to life with a child with ID, I will focus on two concepts that may have direct implications for family interventions: psychological process variables, and putative protective factors. Rather than establish a separate theme I will, where possible, discuss research studies where a balance is struck between negative outcome measurement and more positive well-being and positive perceptions outcomes.
Understanding adults with intellectual disabilities’ experiences of mental ill-health

Predicting challenging behaviour in very young children with intellectual disabilities

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Objectives: Research has identified ‘risk factors’ for challenging behaviour. Oliver et.al. (unpublished) found several variables predicted self-injurious, aggressive and destructive behaviours in children with intellectual disabilities. High frequency repetitive and ritualistic behaviours predicted the presence and severity of challenging behaviour. The clinical significance of this finding prompted a replication study of a population of very young children, to ascertain whether or not the same predictive risk markers would be identified.

Methods: Parents of 56 children aged up to 4 years 11 months, who were receiving specialist services for children with special educational needs, took part in a postal questionnaire survey. Data were collected on age, developmental delay, health problems, mood, repetitive behaviour (RBQ, Moss & Oliver, 2003) and over-activity and impulsive behaviour (AQ, Burbidge & Oliver, unpublished).

Results: Prevalence rates for self-injury, aggression and destructive behaviour were 50.9%, 63.6% and 50.9% respectively. Higher scores on the AQ significantly predicted the presence of destructive behaviour. A significant positive correlation was found between the number of challenging behaviours displayed and total score on the AQ. Significant positive correlations were also found between severe self-injury and both health problems and RBQ scores. Higher scores on the RBQ significantly predicted the presence of severe self-injury.

Conclusions: The associations between poor health and severe self-injury and between over-active and impulsive behaviours and destructive behaviour are interesting. The roles of repetitive behaviour, health problems and behavioural inhibition in defining models of challenging behaviour are discussed.

Sources of anger-arousal for individuals with mild-to-moderate intellectual disabilities (IDs)

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Objectives: Frequent aggression impacts significantly upon a minority of individuals with IDs and those around them. The common triggers that arouse anger in those with IDs have not been extensively studied. This study examined situational triggers for anger, underlying cognitions and responses from a sample of individuals with IDs.

Design: Semi-structured interview.

Method: 53 adults (28 female) with mild-to-moderate IDs, 29 of whom were considered to have difficulties with frequent verbal or physical aggression, completed the study. Groups were matched on gender and age. Participants were asked to describe situations in which they felt angered, and their feelings and expectations around the event were also examined. Interviews were transcribed and responses on the inter-personal source of conflict, activating event, perception of event, emotion and response were categorised as dependent variables.

Results: Significant (p < .05) differences were evident between the groups on source of conflict and response, with the ‘aggressive’ group conflicting with staff far more frequently, and more likely to respond in an aggressive manner. Notably, the majority of responses (in both groups) identified ‘being treated like a child’ and ‘people don’t think I’m as good as them’ as triggering cognitions in situations of conflict.

Conclusions: This study highlights perceptions of belittlement and stigma as particularly pertinent for individuals with IDs. Relationships with staff members also appear to be key for those deemed ‘frequently aggressive’. Clinicians should consider the underlying cognitions of those who present as frequently aggressive, particularly their views of how others perceive them.
A comparison between individual and group interventions for aggression
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Objectives: There is a developing literature on the efficacy of cognitive-behavioural treatment for individuals with Intellectual Disabilities who demonstrate inappropriate aggressive behaviours. Treatments have been provided in both group and individual formats however, no research exists comparing the efficacy of these two methods of service delivery.

Design: A longitudinal group comparison design was employed. Changes over time in three groups were compared, including individual treatment, group treatment and a control group.

Method: Individuals who were referred to a community psychology service for people with Intellectual Disabilities were assigned to either group or individual anger treatment or a waiting list depending upon service availability. They were assessed using a range of measures, including a provocation inventory, both before and after the group and where possible at follow up. Over the course of a number of years 63 people have completed group treatment, 19 individual treatment and 47 have acted as a waiting list control. All of those on the waiting list have gone on to receive treatment.

Results: A significant decrease in scores on the provocation inventory was found for participants in both individual and group work, compared to the control group. No differences were found between the individual and group treatment outcomes.

Conclusions: This project provides further evidence for the efficacy of interventions for inappropriately expressed anger in people with intellectual disabilities. Little overall difference was found between individuals participating in different forms of treatment, however, this could be due to a relative lack of sensitivity in the measures used.

Structured risk assessment for offenders with intellectual disabilities
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Objective: In recent years the prediction of future violence and recidivism for known offenders through risk assessment has become a socially important issue that has influenced the development of services for forensic clients. However, there are few risk assessment studies that specifically focus on individuals with an intellectual disability (ID).

Methods: 212 men with ID and forensic histories across 3 levels of security (high, medium/low, and community) were assessed using a structured risk judgement measure, the HCR-20 as a dependent measure. In addition, several established static and dynamic risk measures and an emotional problems scale were administered, and file data concerning violent incidents during the previous 12 months was also collected.

Results: The HCR-20 scales showed high levels of internal and inter-rater reliability. Patients in inpatient secure services scored significantly higher than those in community services on the Historical scale of the HCR-20, and participants’ scores on this scale correlated significantly with actuarial risk measures. The HCR-20 Clinical scale correlated significantly with dynamic risk measures. All three HCR-20 scale scores were significantly higher for those clients who had been violent during the previous 12 months, and each scale correlated significantly with conceptually relevant scales of an emotional problems measure.

Conclusions: The HCR-20 scales showed good levels of reliability and convergent, discriminant and postdictive validity. Based on these results, the HCR-20 would appear to be useful framework for making structured clinical judgements concerning violent behaviour by men with ID and forensic histories across a range of security settings.
Women with intellectual disabilities and the menopause
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Objectives: To explore menopausal experiences and understanding in women with intellectual disabilities (ID), relating this directly to carers’ knowledge and perceptions.

Design: 1-1 structured interviews (using pictorial prompts) with pre-, peri- and post-menopausal women with mild to severe ID, with and without Down’s syndrome (DS); parallel interviews with the women’s carers.

Method: To date, (49) women aged (38-63; 14 DS, 33 non-DS) years and 75 carers (9 male, 66 female) have been interviewed. 7 women and 6 carers did not wish to be interviewed, 9 carers refused access and 5 women were excluded because of dementia/severe communication difficulties. Women’s interviews covered general health behaviour/knowledge, menstruation, the menopause and health education experiences. Carers’ interviews covered the same content while also exploring carer knowledge of menopausal issues and their views on training needs.

Results: Preliminary analyses indicate that most of the women had little or no understanding of either menstruation or the menopause, nor of its wider implications. Although aware of the need for healthy living, few could explain its personal relevance. Carers identified difficulties in distinguishing menopausal symptoms from other health/behaviour and highlighted a need for better information and training for both women with ID and for themselves. Few identified any syndrome-specific issues.

Conclusions: Women with ID, even where ID is mild in level, have little understanding of the menopause and its relation to fertility. They also confuse many of its symptoms with more general ageing changes. More appropriate health education materials need to be developed and made available to women with ID, their families and professional carers.

Peripheral nerve dysfunction in Cornelia de Lange and Cri du Chat Syndromes
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Objectives: Recent evidence for the presence of peripheral sensory neuropathy (PSN) has been described in both Prader-Willi and Smith-Magenis syndromes. It has been suggested that this type of dysfunction has been associated with self-injurious behavior due to impaired or abnormal pain perception. In both Cornelia de Lange (CdLS) and Cri du Chat (CdC) syndromes individuals show high levels of self-injurious behavior compared to the general intellectual disability population. To date little is known regarding the peripheral or central nervous systems in both these syndromes. The aim of this research was to investigate the presence of peripheral sensory neuropathy and possible relationship with self-injurious behaviour in both syndromes.

Method: Nerve conduction velocity tests were performed on 52 individuals (30 CdLS & 20 CdC). The presence of self-injurious behaviour was measured using items from The Challenging Behaviour Interview and level of intellectual disability was measured using The Vineland Adaptive Behavior Scale. Experimental analogues investigated the nature of self-injurious behaviours during follow-up visits at the participant’s schools.

Results: Reduced velocity in the peripheral sensory nerves were found in both syndromes. In comparison to age corrected normative values both the Cri du Chat and Cornelia de Lange syndrome groups showed significantly slower nerve conduction in the arms. However, self-injurious behaviour and peripheral sensory neuropathy were unrelated.

Discussion: The presence of a peripheral sensory neuropathy has been confirmed in both syndromes. However, no association between self-injurious behaviour and peripheral sensory neuropathy was evidenced.
Patterns of executive function and memory test performance in established and preclinical Alzheimer’s disease in people with Down’s syndrome: Evidence for an early specific impairment in frontal lobe functions

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Objectives: Our aim is to determine whether informant-reported changes in personality and behaviour, thought to represent an early stage of Alzheimer’s disease (AD) in people with Down’s syndrome (DS), are associated with a specific impairment in executive function (EF).

Design: Cognitive test performance was compared between those with and without diagnosed AD, to establish whether EF was impaired as well as memory. Next, the relationship between informant-reported changes and cognitive function was examined within the non-AD group. Analysis of covariance was used to control for differences in age and general intellectual ability.

Method: 103 people with DS (mean age 49 years, range 36-72) with mild to moderate learning disabilities (ICD-10) took part in the study. Dementia diagnosis was based on the CAMDEX informant interview, conducted with each participant’s main carer. 28 were diagnosed with AD. Number and type of reported personality/behaviour changes (based on Gregory and Hodges (1993) fvFTD criteria) were recorded. Each participant completed a battery of EF and memory tests and the BPVS.

Results: Participants with AD performed significantly worse than those without on all EF and memory tests. In the non-AD group, number of informant-reported personality/behaviour changes was inversely associated with performance on frontal lobe associated tests (but not on tests of episodic memory). Informant-reported memory changes however, were associated with impaired performance on episodic memory tasks alone.

Conclusions: These findings provide evidence for a specific impairment in frontal lobe functioning early in the course of AD in DS. Implications for the assessment, diagnosis, management and treatment of dementia in DS are discussed.
Lisa Collis
My area of interest is Cornelia de Lange syndrome (CdLS). Specifically, I want to investigate ageing in CdLS as there is anecdotal evidence that young adults with this syndrome may show signs of social anxiety and low mood. As there is currently no available measure specifically of social anxiety / sociability for individuals with severe / profound intellectual disabilities, I hope to develop a questionnaire which can be used in this population.

Mikey Dunn
I am a PhD student under the supervision of Dr Isabel Clare and Professor Tony Holland. I am interested in the ethical, social and legal issues of ‘mental capacity’ and substitute decision-making when applied to the fields of learning disabilities and mental health. My PhD examines, in the context of the Mental Capacity Act 2005, the practical application of the principle of ‘best interests’ in substitute decision-making by care staff for adults with learning disabilities in residential care settings.

Sarah Hamilton
I have an academic background in classics, philosophy and applied social research. I moved into research in intellectual disabilities following a year’s experience of one-to-one support-work with adults with intellectual disabilities. Currently employed at the University of Glasgow, I am working on a study investigating methods of measuring food-intake and physical activity levels in adults with intellectual disabilities.

Pamela Jarvie
Through my work with children with developmental disabilities, I have become particularly interested in the relationship between social comparison and mental health problems in children with intellectual and developmental disabilities. I hope to be able to explore the relationships between these factors from a developmental perspective. I am also involved in a project examining the nature of, and influences upon, friendships in young people with autistic spectrum disorders.

Michael Petalas
My research focuses on the development and evaluation of support/parenting interventions for families of children with Autism and other developmental disabilities. The increased stress and mental health problems associated with parenting or caring for individuals with severe disabilities can have severe knock-on effects on both the lives of the disabled individuals as well as their parents or carers. I will be working in collaboration with NAS Cymru in: 1) establishing a programme that addresses the needs of parents and siblings of Children with developmental ASDs, 2) developing and evaluating a parenting skills intervention as well as an adjunct intervention that will focus on parental and sibling psychological distress, 3) and disseminating the results of this research.

Deirdre Reilly
I am currently undertaking research into the effects of bereavement on families who lose a child with a learning disability. A study has recently commenced investigating the bereavement experiences of parents, siblings, and other family members following the loss using both quantitative and qualitative methods. The aim of the research is to highlight the needs of this bereaved group and recommend ways in which service providers can better provide for them.
Carol Riddington
I am a PhD student at the Tizard Centre, University of Kent conducting research on governance and empowerment of service users on learning disability partnership boards. The research will explore how people with learning disabilities and carers contribute to the work of the partnership boards and the obstacles experienced by users to full involvement.

Vasiliki Totsika
My research interests lie in evaluating the effectiveness of staff training in improving the quality of life for adults with an intellectual disability who live in residential accommodation. More specifically I am looking at the implementation of Active Support, a staff training programme, in residential homes in North Wales and the way it impacts on residents’ participation in meaningful activities in their homes as well as the effect on challenging behaviour.

Kate Woodcock
I will be carrying out research into Prader-Willi syndrome. I will be investigating the nature of specific cognitive profiles in individuals with PWS, as well as comparing these profiles between individuals with different genetic subtypes of PWS. Investigation of certain cognitive aspects will be linked with behavioural and genetic characteristics.
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