

**2nd Seattle Club Conference
on Research in Intellectual
Disabilities**

16-17 December 2002

University of Birmingham

ABSTRACTS

Welcome

Welcome to the second “Seattle Club” Conference on Research in Intellectual Disabilities. As with last year’s conference, the emphasis is on data from behavioural and social sciences research that focuses on issues relating to intellectual and developmental disabilities. We have maintained a number of features of the first conference generally agreed to be successful, and that we might consider to be characteristic: research only, pre-publication research reflecting the cutting edge, no parallel sessions (so that everyone listens to everything), affordable, electronic organisation, and attempts to encourage the attendance of junior colleagues.

There have also been some significant changes. In particular, the poster session has been replaced by a keynote address. Attendees from the 2001 event will also notice a threefold increase in attendance. In many ways this is excellent news. However, as the existence of the conference is passed essentially by word of mouth, there are likely to be many more UK and Irish researchers in intellectual disabilities out there. Please do what you can to distribute information to interested colleagues and contacts. If possible, please join the ID-Research-UK email list at <http://www.jiscmail.ac.uk> so that you do not miss information about future conferences.

Our thanks go to the team at Birmingham who have done a great job in organising the practical aspects of this conference, especially *Sharon Siviter* and *Jane Petty*.

We hope that you enjoy the conference.

Ad-hoc organising committee for 2002:

Richard Hastings (School of Psychology, University of Wales Bangor)
Chris Hatton (Institute for Health Research, Lancaster University)
Chris Oliver (School of Psychology, University of Birmingham)

2nd Seattle Club Conference on Research in Intellectual Disability
University of Birmingham 16/17 December 2002

Final Programme

Monday 16 December

- 10am – 11am Arrival, coffee, and registration.
- 11.00 – 11.20 **Dr Richard Hastings:** Introductory Remarks – Some Data on the Impact of UK and Irish Research in Intellectual Disabilities
- SESSION 1 Chair: Dr Biza Stenfert-Kroese
- 11.20 – 11.40 **Rose** – Anger intervention
11.40 – 12.00 **Taylor** – Anger assessment
12.00 – 12.20 **Willner** – Anger coping skills
12.20 – 12.40 **McDowell** – Depression in adults with ID
- 12.40 – 13.40 LUNCH
- SESSION 2 Chair: Professor Tony Holland
- 13.40 – 14.00 **Oliver** – Cornelia de Lange syndrome
14.00 – 14.20 **Willis** – Collaboration/problem solving in Down's syndrome
14.20 – 14.40 **Carr** – PECS and communication in autism
14.40 – 15.00 **Charman** – Autism and Rett syndrome
15.00 – 15.20 **Lindsay** – Personality in intellectual disability
- 15.20 – 15.40 AFTERNOON TEA
- SESSION 3 Chair: Professor Jennifer Wishart
- 15.40 – 16.00 **Emerson** – Challenging behaviour services
16.00 – 16.20 **Perry** – Residential service quality
16.20 – 16.40 **Felce** – Resourcing and productivity in services
16.40 – 17.00 **Tennyson** – Parents' views of residential services
17.00 – 17.20 **Hawkins** – Social validity of physical interventions

17.45 – 18.45 KEYNOTE ADDRESS

Chair: Professor Chris Oliver

Professor Tony Holland

(PPP Foundation Chair in Learning Disabilities, Cambridge University)

Gene expression, brain function, and behaviour: the value of “behavioural phenotypes”

From 19.30 OPTIONAL BALTI MEAL (Costs not included in registration)

Tuesday 17 December

SESSION 4 Chair: Dr Andrew Jahoda

9.00 – 9.20 **Espie** – Sleep disorder
 9.20 – 9.40 **Hare** – Actigraph technology
 9.40 – 10.00 **Hay** – Challenging behaviour and sleep disorder
 10.00 – 10.20 **McClellan** – Challenging behaviour intervention
 10.20 – 10.40 **Garbutt** – Exercise and stereotypy

10.40 – 11.00 COFFEE

SESSION 5 Chair: Professor David Felce

11.00 – 11.20 **Hatton** – Life events and psychopathology in children
 11.20 – 11.40 **Todd** – Death and dying
 11.40 – 12.00 **Jahoda** – Workers’ perception of aggression
 12.00 – 12.20 **Raczka** – Staff stress and challenging behaviour (CB)
 12.20 – 12.40 **Dagnan** – Carer responses to CB: cognitive model

12.40 – 13.00 Professor Chris Hatton: **Closing Remarks**

13.00 - LUNCH and HOME

- Title** An Investigation into Factors Associated with the Efficacy of Interventions for Anger
- Authors** John Rose
- Affiliation** University of Birmingham (j.l.rose@bham.ac.uk)
- Abstract** **Objectives.** There is a growing literature suggesting the efficacy of cognitive behavioural interventions aimed at reducing inappropriately expressed anger by people with intellectual disabilities. However, many interventions are small scale and provide little information about which aspects of the individual or their environment may be contributing to the overall efficacy of the approach. This paper sets out to investigate the relationship between personal and environmental variables and outcome.
- Design.** A cross sectional regression method was used to explore the relationship between change in a provocation inventory score over the course of an intervention and a number of other variables.
- Methods.** Data was collected from 53 participants who attended a series of groups with the aim of reducing aggressive behaviour. Outcome was measured by a provocation inventory, which was administered pre, post group, and at follow up. Other variables were also measured including, receptive vocabulary, age, gender, experience of primary therapist and whether staff accompanied participants to the group or not.
- Results.** Regression analysis indicated that 17 per cent of the variance in change of provocation inventory scores could be accounted for by the independent variables. Being accompanied by a member of staff and increased receptive language scores contributed significantly to the variance.
- Conclusions.** Reduced expressed anger was more likely to occur if the participant was accompanied by a member of staff who knew them well and if they had a higher score on the test of receptive vocabulary. The implications of the results will be discussed and the relatively large amount of variance that is not accounted for will also be considered.

- Title** Development of an Imaginal Provocation Test to Evaluate Treatment for Anger Problems in People with Intellectual Disabilities
- Authors** John L Taylor, Raymond W Novaco, Claire Guinan, Nicola Street
- Affiliation** Northumbria University (john2.taylor@unn.ac.uk)
- Abstract** **Objectives.** Anger is a significant clinical issue for many people with intellectual disabilities (ID). There is limited evidence to support the use of cognitive-behavioural treatments to reduce anger problems in this client group. However, robust assessments of anger in people with ID have been slow to emerge. This has impeded systematic evaluation of anger interventions in routine practice settings. This study sought to develop a quick and easy to administer anger assessment using imaginal provocation scenes that is relevant to the context in which treatment takes place, and provides a method of sensitively evaluating clinical and statistical change following intervention.
- Design & Methods.** An anger reaction inventory was administered to a hospital population of 114 men with ID and offending histories. The five items that achieved the highest mean ratings were used to develop brief 3-4 line scenarios. Forty direct care staff independently rated the provocation value of each of the scenarios. Four scenarios that had similar provocation value were used to develop parallel forms of an Imaginal Provocation Test (IPT). In a small anger treatment outcome study the newly developed IPT was administered to participants in anger treatment (AT) and routine care (RC) conditions. Two scenes were presented before and two following cognitive behavioural treatment in random order.
- Results.** The IPT was able to detect statistically significant different anger scores and large effect sizes for emotional reaction, behavioural reaction and anger regulation indices following treatment for the AT group, compared to the RC control group. No between group differences were found, however, for imaginal clarity or scene recall measures. The IPT was also able to highlight marked clinical improvements for a higher proportion of treatment condition participants than for control group participants.
- Conclusions.** It is both possible and practical to develop and use a clinically relevant and sensitive assessment to evaluate the effect of anger treatment on individuals and small groups of clients in dynamic clinical settings.

- Title** A Novel Instrument for the Assessment of Anger Coping Skills
- Authors** Paul Willner, Nick Brace
- Affiliation** Bro Morgannwg NHS Trust (p.willner@swansea.ac.uk)
- Abstract** **Objectives.** Recent controlled studies have confirmed the effectiveness of anger management training for people with learning disabilities. This report describes an evaluation instrument designed to assess their usage of specific anger coping skills.
- Design.** The Profile of Anger Coping Skills (PACS) is designed for completion by a staff member or carer. Three situations are first elicited in which a client frequently displays anger. The respondent then rates each situation for the extent to which the client deploys each of eight behavioural and cognitive coping skills.
- Methods.** In a preliminary reliability study, 20 users of a learning disabilities day service were rated independently by two staff members, with one of them completing the assessment on two separate occasions. The PACS was subsequently used, in a different day service, as part of the assessment pack administered before and after a 12-week anger management group, with a parallel assessment of an untreated control group.
- Results.** The PACS has good test-retest reliability and lower, but still acceptable, inter-rater reliability. Increases in PACS-rated anger coping skills were seen in all participants in the anger management group, but not in the control group. There were differences in the extent to which different coping skills were acquired by the treated group, and there were also individual differences in the specific skills acquired.
- Conclusions.** The PACS is a reliable instrument for assessing anger coping skills, particularly when used repeatedly with the same informant. It provides information that is useful for both individual care planning and the design of future anger management programmes.

-
- Title** Negative evaluative beliefs, social comparison and depression in adults with learning disabilities
- Authors** David McDowell, Dave Dagnan
- Affiliation** Community LD Service, Cumbria
(davemcdowell@bullgill.freeserve.co.uk)
- Abstract** **Objectives.** Research with people with learning disabilities has not previously examined the influence of global core beliefs on depression. This study examines the relationship between self-referent negative evaluative beliefs, social comparison and depression in adults with learning disabilities. The study uses two measures of depression; the Zung Depression Scale which measures a number of physiological, cognitive and affective aspects of depression and an adapted form of the Hospital Anxiety and Depression Scale which measures depression as characterised by anhedonia (a central diagnostic criteria for depression that has no overlap with the cognitive areas also studied).
Design. A cross sectional, correlation and multiple regression design
Methods. A sample of 43 people with mild to moderate learning disabilities completed self-report measures of negative evaluative beliefs, social comparison and depression.
Results. The findings support the main hypotheses. Negative evaluative beliefs about how the person sees themselves (e.g. ‘I am a bad person’) were negatively related to social comparisons in the dimension of social attractiveness. Negative evaluative beliefs about how other people see them (e.g. ‘other people think I am a bad person’) were related to social comparison on the group-belonging dimension. Social comparisons on achievement and social attractiveness dimension were related to depression (when measured using the Zung but not the HADS). Negative evaluations both for how the person sees themselves and how they think others see them were related to depression. Regression analysis showed that depression was significantly and independently predicted by negative evaluative beliefs (Zung and HADS) and social comparison (Zung only).
Conclusions. Depression is strongly associated with negative evaluative beliefs and social comparison in people with learning disabilities. This suggests that cognitive therapies need to develop methods of working with core evaluative beliefs and their impacts upon social comparison for people with learning disabilities. The study also identifies the importance of considering the specificity of the constructs measured in research of this type. The Zung is a widely used measure in learning disabilities research, however its content may overlap with other measures in cognitive research leading to some difficulty in interpreting resulting associations.
-

- Title** The behavioural phenotype of Cornelia de Lange syndrome.
- Authors** Chris Oliver, Kate Arron, Jenny Sloneem, Scott Hall.
- Affiliation** University of Birmingham (c.oliver@bham.ac.uk)
- Abstract** The behavioural phenotype of Cornelia de Lange syndrome (CdLS) was investigated using a group comparison design. 54 participants with CdLS were compared to 46 individuals with intellectual disability matched for age, gender and degree of intellectual disability. Assessments included: Vineland Adaptive Behavior Scale, Aberrant Behavior Checklist, Challenging Behaviour Interview, Compulsive Behavior Checklist, Gilliam Autism Rating Scale and direct natural observation using real time computerised data capture. Analyses revealed that close matching had been achieved and the results of a logistic regression showed no differences between the groups on any assessments except for higher scores on compulsions and a specific expressive communicative deficit for the CdLS group. In contrast to the conclusions of previous reviews self-injury was no more common in the CdLS group, although a trend was evident (odds ratio of 1.78). Observational data revealed no differences between the two groups in terms of self-injury (duration, topography or body site) or the association between social/environmental events and self-injury. However, a trend was evident with the CdLS group showing weaker associations between self-injury and social environmental events. These results illustrate the importance of adequate group matches in behavioural phenotype research and the importance of considering environmental influences on behaviour. The increased prevalence of compulsions in the CdLS group warrants further attention.

- Title** Peer collaboration and problem solving in children with Down's syndrome
- Authors** Diane Willis, Jennifer Wishart, Katie Williams, Tom Pitcairn
- Affiliation** Moray House School of Education, University of Edinburgh
(d.willis@ed.ac.uk)
- Abstract** **Objectives.** To investigate whether the experience of collaborative problem solving enhances individual problem solving in children with Down's syndrome (DS).
Design. The study is based on Garton and Pratt's (2001) paradigm in which 4- & 7-year-old typically developing (TD) children worked independently on a block-sorting task, collaboratively on a 4-and 6-room furniture sorting task, and were then re-tested on the block task. The design was extended to children with DS and children with non-specific learning disabilities (NSLD) in this same developmental age range and standardised measures of cognition, language and adaptive behaviour added in to allow exploration of effects of these on collaborative outcomes.
Methods. Children were paired for collaborative sessions on their initial block-sorting scores, with the DS child always paired with a higher ability NSLD peer of similar chronological age. A second group of higher/lower ability NSLD-only dyads were also tested to explore possible effects of specific language impairment in the DS/NSLD pairings.
Results. 12 DS/NSLD and 6 NSLD/NSLD dyads have been tested to date. While Garton and Pratt found that the collaborative experience facilitated problem solving in the lower ability TD partner, preliminary findings suggest the beneficiaries are the higher ability partners. Analysis of video records may help explain factors influencing these differential outcomes.
Conclusions. Collaborative learning is rarely used in special educational contexts despite its high profile within TD education. This is possibly because collaborative work is assumed 'too demanding' for children with cognitive impairments. While the data so far suggest this may be true for the less able partner in any LD/LD dyad, collaboration may benefit the more able partner.

- Title** The early effects of PECS on the communicative interactions of children with autism: Preliminary data from an independent ongoing study.
- Authors** Derborah Carr, Janet Felce
- Affiliation** Welsh Centre for Learning Disabilities (deb carr60@hotmail.com)
- Abstract** **Objectives.** A major aim of the ongoing study is to investigate the immediate impact of mastery of the Picture Exchange Communication System (PECS) to Phase II on the communicative interactions of children with autism.
- Design.** A within-subjects measure is provided by three separate two-hour classroom observation sessions recording the children's communicative initiations and responses. The three observations occur: 1) 6 weeks prior to teaching, 2) during the week immediately prior to teaching, 3) during the week immediately following teaching. Two, two-hour observations with children in a non-intervention control group are separated by a six-week interval without PECS teaching.
- Methods.** Participants are children aged between 4-7 years, who have a formal diagnosis of autism made by a clinical practitioner and who have received no previous PECS teaching. Participants receive a total of 15 hours of teaching from two workshop-trained researchers over a five-week period. Teaching is conducted in the children's classroom on a sessional basis amounting to one hour per teaching day, covering multiple activity contexts and generalisation of their use of PECS to their classroom staff
- Results.** Preliminary data with fifteen children in the intervention group indicate that their communicative initiations and their responses to communication increased significantly immediately after the teaching period. Frequency of communicative initiations and responses was also significantly higher for the intervention group compared with controls
- Conclusions.** Preliminary data suggest that the early phases of PECS teaching are highly effective in increasing the participation in communicative interaction by children with autism.

- Title** Features of autism in Rett syndrome and severe mental retardation.
- Authors** Tony Charman, Rebecca Mount, Richard Hastings, Sheena Reilly, Hilary Cass
- Affiliation** Institute of Child Health, UCL (t.charman@ich.ucl.ac.uk)
- Abstract** **Objectives.** It has long been recognized that there is phenotypic overlap between Rett syndrome (RS) and autism. Advances in our clinical and genetic understanding of RS over the past decade have made clear that the cause and course of RS and autism are distinct (except perhaps in a few cases). Despite this, further delineation of the phenotypic overlap between RS and autism is warranted to enhance clinical decision-making and to further understanding of neuropathological development in both disorders.
- Design and Methods.** The present study measured autistic symptoms using the Autism Behavior Checklist (ABC) in a sample of girls with RS and a comparison group of girls with severe and profound mental retardation (SMR).
- Results.** Controlling for developmental level and motor ability, girls with RS scored more highly than those with SMR on the Sensory and Relating subscales. In contrast, there were no group differences on the Body and Object use, Language and Social and Self-help subscales.
- Conclusions.** Further work on the characterisation of the behavioral phenotype of genetic disorders such as RS and autism may aid in identifying the neuropathogenic processes that lead from gene-to-brain-to-behavior.

- Title** Difficulties in the Measurement and Interpretation of Personality.
- Authors** Bill Lindsay, Jacqui Law
- Affiliation** University of Abertay Dundee (bill.lindsay@tpct.scot.nhs.uk)
- Abstract** **Background.** The best researched assessment of personality in people with intellectual disabilities is the EZPQ (Zigler et al. 2002) which has 7 factors of positive reaction tendency, negative reaction tendency, expectancy of success, outer directedness, efficacy motivation, obedience and curiosity/creativity. It is immediately noticeable that these are predominantly task and person oriented and therefore do not fit easily with the big 5 factors derived from mainstream personality research – extraversion, neuroticism, openness, agreeableness and conscientiousness. The most surprising difference is that emotion is not a notable feature in the EZPQ factors. This study employed a variant of the most commonly used personality assessment of the big 5 personality traits the NEO-PI (Costa and McCrae 1995), to investigate personality constructs.
- Method.** Twenty questions reflecting the Facet Scale used by Norman (1963) were extracted from the NEO-PI. There were 4 questions from each of the 5 factors. The questions were altered and tested to ensure understanding and were then administered to 100 subjects.
- Results.** Using a principle components analysis with VARIMAX rotation, we evaluated 3, 4, 5 and 6 factor solutions. A task orientated/conscientiousness factor emerged consistently as did a neuroticism/task decisiveness factor. An extraversion/person oriented factor also emerged. A 5 factor solution seems the most satisfactory although, clearly, these factors do not correspond with the big 5 factors.
- Conclusions.** We confidently expected the big 5 factors to emerge since they have been found consistently across samples and cultures. That they did not is significant in itself and the EZPQ factors allowed us to make some sense of the emerging structure. It may indeed be that there are fewer abstract/reflective/emotional aspects to personality structure in this client group. The results will also be discussed briefly in terms of the relationship between personality and the developing work on personality disorder.

- Title** Quality and Costs of Community-Based Residential Supports for People with Learning Disabilities and Challenging Behaviour
- Authors** Eric Emerson, Janet Robertson, Lisa Pinkney, Emma Caesar, David Felce, Andrea Meek, Deborah Carr, Kathy Lowe, Martin Knapp, Angela Hallam
- Affiliation** Lancaster University (eric.emerson@lancaster.ac.uk)
- Abstract** **Objectives.** To compare the quality and costs of two approaches to providing community-based residential supports to people with learning disabilities and challenging behaviour: non-congregate settings where the minority of residents have challenging behaviour; and congregate settings where the majority of residents have challenging behaviour. **Setting.** Community-based residential supports for people with learning disabilities and challenging behaviour. **Design.** Longitudinal matched groups design. N=25 per group. Data collect at two points in time separated by 12 months. **Main Outcome Measures.** The costs of service provision, the nature of support provided, the quality of life of residents (including choice, activities, social networks, risks and community involvement), the views of families, the views of neighbours, and staff stress and morale. **Results.** Congregate care was associated with higher costs, higher staffing ratios, and better quality internal working practices. However, these inputs did not translate to better outcomes for residents. Non-congregate care was associated with greater access to day activities, less reliance of medication and physical restraint to control challenging behaviour, and less risk. Levels of staff contact and participant engagement were low across both models of care. **Discussion.** The results suggest that non-congregate settings are more cost effective. Further, having a greater proportion of people with challenging behaviour in a setting is associated with a range of poor outcomes. The results reinforce the existing 1993 guidance that care should be taken to avoid congregating together people with challenging behaviour (Department of Health, 1993). Partnership Boards should take this into account when developing Housing & Support Strategy for people with learning disabilities (Department of Health, 2002).

- Title** Predictors of residential service quality.
- Authors** Jonathan Perry, David Felce.
- Affiliation** Welsh Centre for Learning Disabilities (perry@cf.ac.uk)
- Abstract** There is evidence of considerable variability in the quality of residential services. It is also known that objective quality of life outcomes experienced by the users of residential services tend to covary with resident ability level. This study investigated the extent to which a number of setting structure and process variables predicted subjective and objective quality of life. Multivariate statistical procedures were used to control for the confounding effect of ability level. The quality of life of a random sample of 154 people living in 47 small-scale community residences was assessed using 14 subjective and objective indicators. Information on setting structure, processes and staff working methods was also collected. Predictors of resident outcomes in the domains of choice, activity, and social and community well-being were modelled using multivariate regression. There were few significant predictors of subjective quality of life. Resident ability had a strong and pervasive effect across objective measures. Private sector provision was generally identified as having a negative impact on outcome. Greater homeliness and physical integration were positive attributes. The number of residents and staff per setting had little explanatory power. The level of staff attention received by residents was the most pervasive positive factor after resident ability. Other staff working methods had an inconsistent impact.

- Title** Rational resourcing and productivity in community-based supported accommodation for people with intellectual disabilities.
- Authors** David Felce, Edwin Jones, Kathy Lowe, Jonathan Perry, Clare Bowley
- Affiliation** Welsh Centre for Learning Disabilities (felce@cardiff.ac.uk)
- Abstract** The aim was to establish the extent to which staff resources per resident were related to the ability/disability characteristics of residents or contributed to improved staff performance or resident outcome. Sixty settings were selected randomly from those accommodating 6 or fewer people with intellectual disabilities in Wales. Nine settings withdrew and information from the remaining 51 was obtained on resident ages, gender, adaptive behaviour, physical and sensory disabilities, social impairment and challenging behaviour. Details of allocated staff hours and staff:resident ratios at different times of the day were obtained by interview with house managers. Resident receipt of attention from staff and resident activity were observed. A financial questionnaire was completed (only by 33 settings) to give estimates of the actual staff hours worked and their associated costs. Multiple regression analyses against resident and setting characteristics were conducted with respect to allocated staff hours/resident, actual staff hours/resident, costs of staff/resident and the percentages of time residents received attention from staff or were engaged in activity. About a third of the variation in staffing/resident was explained by resident characteristics, most strongly challenging behaviour. Smaller size of setting was associated with higher staffing/resident. Staffing and costs were also related to fewer months since opening. Higher staff/resident was associated with marginally higher resident receipt of attention but not increased resident activity. The results show that resources could be more closely to resident needs. In particular, as staffing was less sensitive to differences in adaptive than challenging behaviour, settings for relatively independent people may be too intensively staffed. As neither size of setting nor staff/resident were strong influences on service quality, there appears to be grounds for establishing a cost-effective size. Periodic review of staffing arrangements may smooth out arbitrary effects of the year of provision.

- Title** Parents whose children attended 52-week residential schools. Their perceptions of services received and expectations for the future.
- Authors** Alan Tennyson, Peter McGill, Vivien Cooper.
- Affiliation** Tizard Centre, University of Kent (p.mcgill@ukc.ac.uk)
- Abstract** **Objectives.** The objective of this study was to gather data in three principle areas, support and services received prior to entry into 52-week education, perceptions of the quality of care and education provided by residential schools and finally parental concerns for the future care and welfare of their children.
- Design.** A postal questionnaire, comprising of five point Likert scales, yes / no responses and qualitative responses was administered. Following this telephone interviews were conducted using a semi structured interview schedule. Use of the questionnaire provided data, which could be analysed statistically, while the telephone interview generated greater understanding of the topics addressed by the questionnaire.
- Methods.** 73 parents completed the specially designed questionnaire. The telephone interviews were conducted with 14 parents.
- Results.** Responses demonstrated that parents were critical of services and support received prior to entry into the residential education. Residential schools scored highly across all the indicators of quality presented with no indicator scoring significantly higher or lower than any other. Parents expressed high levels of concern about the future across all the indicators presented in the questionnaire and telephone interview. A significant relationship was found between distance of the school from the parental home and the frequency of parents' visits (Chi-square = 71.26, $p < 0.0001$).
- Conclusions.** The report concludes by suggesting that further research with this population is necessary in order to understand the relationship between exclusion from local services and the need for 52-week care. Furthermore it is considered that when 52-week care becomes necessary it should be provided locally in order to maintain parent child contact.

- Title** Assessing the social validity of physical interventions – exploring service user views.
- Authors** Sarah Hawkins, Rosemary Jenkins, David Allen.
- Affiliation** Welsh Centre for LD (David.Allen@bromor-tr.wales.nhs.uk)
- Abstract** **Objectives.** Recent years have seen an increasing focus on devising ethical behavioural management responses to severely challenging behaviour. This movement has come about largely as a reaction to methods of physical intervention that depend upon inflicting pain upon service users for their effectiveness. Previous research concerning user views on physical interventions is extremely limited, but an overarching theme has been that service user experience of more aggressive reactive procedures is primarily negative. The present study explores user responses to a physical intervention programme that was designed as an alternative to pain-compliance strategies.
- Design.** The research employed a qualitative model, utilising an exploratory design drawn from a ‘Grounded Theory’ approach to data collection and analysis.
- Method.** Data were collected using semi-structured audio taped interviews with eight service users. These were conducted following episodes of challenging behaviour in which the users were subject to restrictive restraint procedures. A series of visual prompts were used to help users recall the procedures used and to identify sites of any physical discomfort.
- Results.** NUD*IST4 was used to explore transcribed data. Core categories emerging from the data related to user’s understanding of the process surrounding restraint use (including their role in the event), the actual experience of restraint (emotional and physical responses), and coping strategies. Despite limited evidence that past exposure to pain compliance procedures could result in more positive evaluations, user’s overall experience of the physical interventions remained negative.
- Conclusions.** Implications for the further proactive and reactive improvements in the programme were identified.

- Title** Disorders of Sleep Homeostasis or Circadian Timing in People With Intellectual Disability: New Hypotheses and New Tools to Aid Clinical Formulation?
- Authors** Colin Espie.
- Affiliation** University of Glasgow (c.espie@clinmed.gla.ac.uk)
- Abstract** **Objectives.** Historically, it has been problematic to obtain valid and reliable concurrent data on endogenous patterns and behaviours in people with intellectual disabilities. There has been progress in observational methodology, but now there are also available non-intrusive systems for monitoring endogenous sleep/ wake functions. This paper illustrates the feasibility and potential benefits of such technology, and identifies areas for further research investigation. **Design.** Single case series of six adults with intellectual disabilities. **Methods.** Case studies of adults with intellectual disabilities are presented to illustrate the clinical and research potential of Actigraphy (minute by minute gathering of body movement data, recorded by microprocessor-linked accelerometer units worn on the wrist or ankle for up to 40 consecutive 24-hour periods: Cambridge Neurotechnology) and EEG neural network analysis (second by second analysis of cortical activity divided into wake/ light sleep/ deep sleep signals for either night or daytime periods: Oxford Biosignals). **Results.** The cases demonstrate the range of problems associated with circadian dysregulation that can be identified (eg. irregular sleep-wake schedule disorder, bipolar affective disorder) and better described (eg. demand avoidant aggression) using these approaches. It is suggested that such disruption of endogenous rhythms may be common in people with severe intellectual disability, and may help to explain not only problems in sleeping and in maintaining daytime alertness, but also some characteristics of behaviour and affect. **Conclusions.** Further, systematic investigation seems warranted to consider circadian dysfunction as an explanatory mechanism for attention, behavioural, mood and sleep disturbances.

-
- Title** The use of actigraph technology to measure activity levels and circadian rhythm functioning in learning disabilities and autistic spectrum disorders.
- Authors** Dougal Hare, Steven Jones, Kate Evershed.
- Affiliation** University of Manchester (dougal.hare@man.ac.uk)
- Abstract** **Objectives.** Sleep-wake cycles and circadian rhythms (fluctuations in activity levels across an approximately 24-hour period) have been an important focus for research into a range of developmental and psychiatric conditions. Recent developments in the technology available for measurement of circadian rhythms and general activity levels permit both greater acceptability to more diverse and representative patients groups and more sophisticated analysis of data obtained. The current year-long research project aims to investigate the utility and feasibility of actigraph technology in the investigation of circadian rhythm functioning in adults with autistic spectrum disorders with and without accompanying learning disabilities, building on previous studies of children with learning disabilities and developmental disorders (e.g. Wiggs 1996).
- Design and Methods.** The results from the ongoing research project are presented in the form of a case series comprising eight participants (two with learning disabilities, three with autism and learning disabilities and three with autism). Having obtained consent, each participant wore the actigraph for seven days and no difficulties were reported with this procedure. Analysis of the data thus obtained was carried using Actiwatch Sleep Analysis 2001 software [v1.9] (Cambridge Neurotechnology 2001) to provide the following information for each participant: Non-parametric circadian rhythm analysis (van Someren et al 2002) - circadian chronicity (stability and variability) over seven days; Sleep parameters - time of sleep onset, sleep latency, efficiency and duration, activity during sleep, time awake after sleep onset; Periodicity of sleep/wake cycle (min. period 23 - max. period 25) over seven days.
- Results.** Initial results indicate that all participants showed circadian rhythm functioning within normal parameters, but that the individual sleep parameters were more variable.
- Conclusions.** To date, the project has demonstrated that the use of actigraph technology is both practical and appropriate to the investigation of circadian rhythm functioning in people with learning disabilities and autistic spectrum disorders. The availability of such non-invasive and discreet measurement technology allows a range of clinical and research questions to be more objectively investigated in a manner more acceptable to people with learning disabilities and their carers.
-

- Title** Form and function of challenging behaviour in people with severe intellectual disabilities and sleep disorders.
- Authors** Kelly Hay, Frederick Furniss.
- Affiliation** Peterborough & Cambridgeshire Mental Health Services NHS Trust (kelly@annhay.freeseve.co.uk)
- Abstract** **Objectives.** The relationship between behavioural and sleep disturbance in people with intellectual disabilities may be explained by a common neuropathology, or in terms of sleep deprivation as an establishing operation increasing the aversiveness of events and thus increasing escape-maintained behaviour. In the first case, the behaviours of those with and without sleep disturbance should differ in form but not in function; in the second, in function but not systematically in form. Our aim was to evaluate these alternative accounts.
- Design.** Young people (n=69) with severely challenging behaviours were assessed using an informant-rated measure of sleep patterns and assigned to sleep-disturbed and non-sleep-disturbed groups using standardized criteria. Groups were compared on standardized measures of the forms and functions of their challenging behaviour.
- Methods.** The Adaptive Behaviour Scale was completed for each participant, and a brief measure of behavioural function (Questions about Behavioural Function Checklist, QABF) was completed for each challenging behaviour reported by carers.
- Results.** A series of t-tests on data from 34 initial participants showed no differences between groups on age or scores on any ABS domain in Parts 1 or 2. Preliminary analyses on QABF severity scores showed higher ratings for the sleep-disturbed group on escape and social-positive functions, but not for tangible or automatic reinforcement, by comparison with the non-sleep-disturbed group
- Conclusions.** Our results are consistent with the position that sleep disturbance increases challenging behaviour by strengthening the reinforcing value of social events maintaining these behaviours, but suggests that both demand escape and attention may be thus strengthened.

- Title** Particular Case Training: A model for delivering positive behavioural supports to people with challenging behaviours.
- Authors** Brian McClean, Caroline Dench, Ian Grey, Sean Shanahan, Elaine Fitzsimons, John Hendler, Maria Corrigan.
- Affiliation** Brothers of Charity Roscommon (bmclean@indigo.ie)
- Abstract** **Objectives.** To define Particular Case Training as a model for delivering Behaviour Support Services for people with challenging behaviour. To evaluate the effectiveness of Positive Behavioural Support delivered through Particular Case Training. To explore some of the factors that might predict the effectiveness of positive behavioural support in typical service settings
- Design.** Significant improvement is defined as reduction by at least 70% in the baseline rate of the behaviour. Data is presented in terms of the numbers of people who made significant improvement and in terms of the percentage change in behaviour. A One Way Anova Repeated Measures (N = 138) is used to test for change over time. A multiple regression analysis is used to attempt to identify variables associated with extent of behavioural improvement.
- Method.** Sample is referred from prioritised waiting lists in services for four catchment areas over a five year period. A disproportionate number of challenging behaviours are severe and of long standing. Behavioural frequencies are recorded continuously *in vivo*, and baseline frequencies are compared with monthly average rates 3 months after implementation and at follow up (mean = 22.5 months after implementation).
- Results.** Results indicate that the implementation by staff of behaviour support plans are associated with significant improvement in 77% of cases, suggesting that Particular Case Training may be an effective model of service delivery.
- Conclusions.** Particular Case Training is a cost effective way of achieving positive behavioural outcomes in typical service settings. Its advantages may be greater contextual fit than specialist designed intervention plans and the capacity for coverage of the population of people with challenging behaviours. Results must be interpreted with caution in the absence of control group.

- Title** Short-term increases in stereotyped behaviour following exercise.
- Authors** Nathalie Garbutt, Ashleigh Kilbride, Anil Mistry, Steven Halford, Frederick Furniss.
- Affiliation** Leeds Older Peoples Psychology and Therapies Service
(nathaliegabutt@hotmail.com)
- Abstract** **Objectives.** A number of studies have reported reductions in stereotyped and self-injurious behaviours following physical exercise. The predominance of single-case or small group designs makes further replications desirable, and our aim was to study the effects of exercise on high-rate stereotyped behaviours.
- Design.** A combined reversal and short-term pre-post design was used. Participants were observed on three occasions in the week before an exercise programme commenced, twice a week during the five weeks of the programme (immediately before and after exercise sessions), and three times in the week after the programme ended.
- Methods.** Participants were two 17-year-olds with severe intellectual disabilities and autism. Observations lasted 30 minutes and used a one-minute partial interval system to record levels of individually defined stereotyped behaviours: interobserver reliability averaged over 80%. The exercise programme involved five 20-minute gym sessions per week using various exercise machines.
- Results.** No changes were seen in levels of stereotypy for either participant across baseline, exercise, and follow-up. The short-term effect of exercise was however to increase levels of stereotypy for one participant following three out of five sessions, and for the other following three out of four sessions, by comparison to pre-exercise levels. Overall, stereotypy increased by 16% of observation time for the first participant, and by 5% for the second, following exercise.
- Conclusions.** Exercise can produce short-term increases in stereotyped behaviour. Exercise may produce diverse neurotransmitter effects, including dopamine priming, with complex effects on behaviour. We discuss our findings in the context of other likely benefits of exercise.

- Title** The relationship between life events and psychopathology amongst children with intellectual disabilities.
- Authors** Chris Hatton, Eric Emerson.
- Affiliation** Lancaster University (c.hatton@lancaster.ac.uk)
- Abstract** **Objectives.** To examine the relationship between life events and psychopathology amongst children with and without intellectual disabilities
Design. Secondary analysis of the 1999 ONS survey of the *Mental Health of Children and Adolescents in Great Britain*, a cross-sectional survey.
Methods. The 1999 ONS survey was a multi-stage stratified random sample of 10,438 children between 5 and 15 years in England, Scotland and Wales. Secondary analysis was undertaken of the relationship between life events involving the child and ICD-10 ratings of psychopathology, reported by 245 mothers of children with intellectual disabilities and 9,481 mothers of children without intellectual disabilities.
Results. Over the course of the child's life, children with intellectual disabilities were more likely than children without intellectual disabilities ($p < 0.01$) to have experienced: parental separation; parents being in trouble with the police; serious illness requiring hospitalisation; and a close friend dying. There were no differences between groups in: parents experiencing a financial crisis; the child having a serious accident; a family member dying; a grandparent dying in the past year; a pet dying in the past year; and the break-up of a boy/girlfriend relationship in the past year. Amongst the children with intellectual disabilities, there were small (approximately $r = 0.2$) but significant associations between the number of life events experienced by children and child anxiety, conduct disorder and emotional disorder. These correlations were stronger than those reported for children without intellectual disabilities (approximately $r = 0.1$). Children experiencing two or more life events seemed to be at particularly high risk for experiencing psychopathology.
Conclusions. The relationship between life events and psychopathology amongst people with intellectual disabilities requires greater research attention than it currently receives.

- Title** When there's no more to be done there's a lot more to do: death, dying and intellectual disability.
- Authors** Stuart Todd.
- Affiliation** Welsh Centre for Learning Disabilities (toddsp@cf.ac.uk)
- Abstract** **Objectives.** This paper aims to draw attention to one obvious but overlooked inevitability: people with intellectual disabilities will die! A co-relate of the increasing life expectancy of people with intellectual disabilities is that as well as living longer people with intellectual disabilities will also die longer. Thus, a dying phase can be expected to be a part of an individual's life course. This has several cultural and applied implications for researchers and service providers. The paper draws upon empirical data to examine how dying and death are responded to by service providers and carers.
- Design.** A qualitative approach was adopted in this study to raise issues and explore the experiences of caring for people with intellectual disabilities who are dying
- Methods.** Semi structured interviews and focus groups were conducted with staff in 13 residential services who have cared for a person with intellectual disabilities who was dying and with 15 bereaved parents of people with intellectual disabilities.
- Results.** The data suggest that support staff are given little support from within and outwith their own services to care for clients who are dying. Support tends to be promised in the post-mortem period, but pre-mortem they have to rely upon their own personal resources. These resources are insufficient to deal with the dilemmas and issues provoked by caring for the dying. Bereaved parents are also given little support from the service world and from the emotional community around them. The service world withdraws at death. For parents, death provokes identity loss and unrecognised grief.
- Conclusions.** The study indicates that death and dying are difficult areas for care staff and relatives of people with intellectual disabilities. These are areas that the service world has shunned at considerable cost to people with intellectual disabilities and their relatives and carers. The data highlight a need for greater research sensitivity to death and dying and for increased applied attention to resolve the dilemmas and costs of death and dying.

- Title** Knowing you: workers' interpersonal perceptions of aggressive individuals with mild to moderate learning disabilities.
- Authors** Andrew Jahoda, Lilian Wanless.
- Affiliation** University of Glasgow (aj26r@clinmed.gla.ac.uk)
- Abstract** **Objectives.** Staff attributions concerning challenging behaviour have been found to play a role in determining their responses. The emphasis in the literature has been on staff beliefs about the challenging behaviour itself. However, workers who support these individuals on a daily basis build relationships with them, and view them as persons. The aim of this study was to look at the workers' perceptions of individuals who are frequently aggressive.
- Design & Methods.** Thirty eight staff members working with individuals presenting problems of frequent aggression participated in this study. They were interviewed about an incident of aggression involving the person they worked with. The semi-structured interview, based on a Rational Emotive Therapy format, aimed to tap into the emotions aroused in the staff members and inter-personal appraisals that they made at the time of the incident. The responses were content analysed.
- Results.** The strength of the staff member's emotional reactions were noteworthy. However, the strength of these emotions were not necessarily related to the seriousness of the aggressive incident that was discussed. Furthermore, approximately half of the staff members believed that the aggressive individuals' actions were directed at them personally. In turn, the majority of staff members described the aggressive individuals in negative terms.
- Conclusions.** The findings suggest that inter-personal perceptions may have a role in determining staff responses to individuals who behave aggressively. Consequently, the nature of views that staff hold about clients could have implications for clinical assessment and intervention.

-
- Title** Staff stress and challenging behaviour: The relationship between stressor personality, coping strategies, behavioural knowledge and psychological distress in care staff.
- Authors** Roman Raczka.
- Affiliation** Hammersmith and Fulham Primary Care Trust
(Roman.Raczka@hf-pct.nhs.uk)
- Abstract** **Objective.** This research study investigated relationships between factors that influence the experience of psychological stress by staff working in residential services supporting adults with learning disabilities and challenging behaviours. A psychological model was developed that related the personality traits of direct care staff with their personal coping style, behavioural knowledge and emotional reaction when exposed to environmental stressors and investigated the impact on psychological distress experienced.
- Design.** A self-report questionnaire study on sixty-nine direct care staff working in an independent sector community based service for adults with learning disabilities and severely challenging behaviours. Correlational and regression analyses were employed to examine the relationship between the different factors.
- Method.** Staff completed a battery of measures versions of the Eysenck Personality Questionnaire (EPQ-R), Ways of Coping – Revised Questionnaire (WCQ-R), the General Health Questionnaire (GHQ), Knowledge of Behavioural Principles (KBPAC), Staff Emotional Reactions to Challenging Behaviours and Work and Client Stressors Checklist.
- Results.** Staff reported high levels of stress. A significant association was found between Neurotic personality type, the use of wishful-thinking coping strategies, a negative emotional reaction to challenging behaviours and greater levels of psychological distress. No association was found between knowledge of behavioural principles and stress.
- Conclusions.** Support was found for the proposed psychological model for staff stress. Clinical implications were discussed that have a direct influence on the way in which staff working in services for people who challenge are supported by clinical psychologists. Suggestions were made for future research in the area.
-

- Title** Exploring a cognitive model of carer response to challenging behaviour: The impact of carers' recollection of their interaction with their own parents.
- Authors** Dave Dagnan, John McGowan.
- Affiliation** Community LD Service, Cumbria (davedagnan@btinternet.com)
- Abstract** **Objectives.** A cognitive model would suggest that rules and assumptions that carers call upon to guide their behaviour in caring situations are established through earlier, similar experiences, one of which will be their experience of being cared for during childhood. We test the impact of carers' recollection of their interaction with their own parents upon their reported attributions, emotions and potential behaviour towards people with learning disabilities and severe challenging behaviour.
- Design.** The study is a cross-sectional interview design using regression techniques to explore predictive relationships.
- Methods.** 45 carers of adults with learning disabilities completed adapted versions of the Attributional style questionnaire, ratings of their emotional response to challenging behaviours and their likelihood of offering help. In addition they completed the Parental Bonding Inventory (Parker et al, 1979).
- Results.** Correlations between attributions, emotions and behaviour were as found in previous studies consistent with Weiners (1985) model, with the attribution of controllability and the emotion of anger being highly correlated and both relating to the likelihood of putting further effort into helping. In general, the PBI dimensions for relationship with father correlate with attribution dimensions and the PBI dimensions for relationship with mother correlate strongly with the emotion of sympathy in respect to challenging behaviour. A regression analysis that explored the independent prediction of helping behaviour identified that the attribution of controllability and the recollection of an overprotective relationship with both parents are predictive of the likelihood of offering help.
- Conclusions.** The results will be discussed in terms of their implications for cognitive models of carer behaviour towards people with learning disabilities and challenging behaviour and associated interventions. In particular we will discuss factors that influence the development of the rules and assumptions that carers bring to caring situations and consider the importance of taking these into account in training approaches and when formulating mediating factors in challenging behaviour.