Seattle Club 2007

7th Seattle Club Conference
on Research and People with Learning Disabilities

10th & 11th of December 2007

G12 University of Glasgow

Welcome

Welcome to the 7th Seattle Club Conference for researchers in intellectual disabilities in the UK and Republic of Ireland. We decided not to use the acronym S Club 7, in case too much was expected of presenters.

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

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

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. Oh, and enjoy yourselves!

Ad hoc organisation committee for 2007:

- Andrew Jahoda, Craig Melville and Alison Jackson, Learning Disabilities, University of Glasgow
- Richard Hastings, Intellectual & Developmental Disabilities Research group, University of Bangor
- Chris Hatton, Institute for Health Researcher, Lancaster University

Administrative support:

Many thanks we owe to Kelly Hay, who has played a major role in the organisation of this year's event. Thanks should also go to Afshan Fairley for the support she has provided.

Seattle Club Studentships 2007

Jane Appleby (Birmingham University)

Jane is starting on her PhD studies which will focus on investigating whether executive dysfunction is responsible for the repetitive behaviours seen in two rare genetic syndromes, Cri du Chat and Rubinstein Taybi.

Fleur-Michelle Coffait (Manchester University)

Fleur-Michelle will be carrying out research into the utility and concurrent validity of clinical measures of theory of mind ability with people with Asperger's syndrome.

Laurie Powis (Birmingham University)

Laurie's research is focussed around levels of sociability across individuals with different genetic syndrome.

Rebecca Rodger (Queen Margaret University)

Rebecca is investigating the voice quality of children with Down syndrome and its impact on listener judgements.

Sarah Savage (Institute of Psychiatry, London)

Sarah will be carrying out a long-term follow-up of higher functioning individuals with autism but looking also at outcome for 2 groups of siblings - one group who when younger did not meet criteria for autism but who were assessed as falling within the broader autism phenotype, and another group who when younger showed no apparent signs of autism related problems.

Kate Thorsteinsson (Portsmouth University)

Kate is studying positive social-emotional aspects of dyadic and triadic interactional competence of four-month-old infants with Down Syndrome and typically developing four-month-old infants, comparing how infants interact with mothers, strangers, and objects.

Pagona Tzanakaki (Bangor University)

Pagona will be carrying out research on the use of ABA techniques in educational settings for children with autism.

Jessica Wheeler (Cambridge University)

Jessica's research aims to provide an environmental perspective on anti-social and offending behaviour by people with intellectual disabilities. Her project is a mixed method design, which seeks to both quantitatively and qualitatively examine the geographic, social, and emotional environments of a community-based sample of offenders with intellectual disabilities.

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Session 1: Lifespan and Developmental Issues

Evidence for imprinted gene effects on IQ in Prader Willi Syndrome (PWS).

Joyce Whittington, Anthony Holland and Tessa Webb
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Background: A normal distribution of IQ with a mean of 60 has been observed in a population sample of people with PWS, with differences in the profile of IQ scores between the two main genetic sub-types of PWS (deletions and disomy). The aim of this study was to discriminate between two possible explanations of this finding by studying the relationship with sibling IQ scores.

Methods: The correlations between the IQs of people with PWS and their non-PWS siblings were examined and analysed according to the PWS genetic sub-type.

Results: It was found that those with the main genetic sub-type (chromosome 15 deletions) of PWS differed in their familial relationship compared to those with the less common disomy form. Unlike the observed correlation between non-PWS siblings of 0.5, in the case of those with deletions it was -0.07 and for those with disomy 0.75. Scores on performance IQ in those with disomy had the highest correlation.

Conclusions: Given the genetics of PWS this finding suggests that imprinted genes on chromosome 15 are involved in the development of intellectual ability. The implications of these findings will be discussed.

Developmental trajectories for behavioural difference across genetic syndromes.

Chris Oliver, Jo Moss, Lisa Collis, Sarah Gorniak, Chris Stinton, Pat Howlin, Caroline Richards and Kate Arron
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Background: There is increasing evidence that genetic syndromes are associated with cognitive and behavioural signatures encompassing both difference and disorder. Recently, descriptions of cognitive profiles have extended to include developmental trajectories but this approach has yet to be adopted for behaviour.

Methods: Questionnaire data on hyperactivity, mood, autism spectrum disorder, sociability and repetitive behaviour were collected from carers of children and adults with Down, Angelman, Cri du Chat, Cornelia de Lange, Smith-Magenis, Prader-Willi, Lowe, Fragile X, Rubinstein-Taybi and Williams syndromes and autism spectrum disorder (total n > 1200; age range 2 to 62). Developmental trajectories were developed for each syndrome, for each behavioural domain.

Results: Developmental trajectories differ across and within syndromes for each domain. For example, sociability in Down, Cornelia de Lange and Rubinstein-Taybi syndromes decreases with age at different points, but remains stable in Fragile X syndrome. Hyperactivity decreases with age in Cri du Chat syndrome and shows a different trajectory to that seen in Fragile X syndrome. Autism Spectrum Disorder related phenomena increase in Cornelia de Lange syndrome in the early years before reaching a plateau.

Conclusions: Inevitably, differences in trajectories within and between syndromes and across domains are complex. Together they indicate: 1) the fallacy inherent in the two group approach in the study of intellectual disability 2) the importance of conceptualising behavioural phenotypes as dynamic rather than static 3) the need for greater prominence for an aetiology related, developmental perspective in the field of intellectual disability, with implications for the person-environment fit across the lifespan.

Efficacy of treatment for adults with untreated phenylketonuria (PKU): a randomised-controlled trial.

Glynis Murphy
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Background: PKU is a congenital metabolic disorder that can, if left untreated, lead to severe learning disabilities. Nowadays infants are treated from very early on, with a low phenylalanine diet. But people with PKU who were born before screening (1969) were never offered low phenylalanine diet treatment.

Methods: 36 adults with untreated PKU were recruited. They entered a double blind randomised controlled crossover trial with an eight week baseline, followed by two 24 week special diet phases, one of a low-phenylalanine diet and the other a phenylalanine-containing diet (the order of the diet phases was randomised). Measures included weekly blood phenylalanine levels and daily behavioural records. In addition, once per phase (baseline X 2, diet 1, wash-out, diet 2), standardised measures and direct observations were conducted.

Results: Blood phenylalanine levels were very well controlled by the low phenylalanine diet but there were no significant changes across diet phases in: medical symptoms, challenging behaviours & skills, direct observational data. However, seven of the 14 people who had low phenylalanine diet first withdrew before end of the placebo diet, whereas all ten who had placebo diet first, went on to the end of the low phenylalanine diet (chi-square, $p<0.01$). Also carers made more positive comments at the end of the low phenylalanine diet phase than at the end of the placebo or washout phases (the chi squared, $p<0.001$).

Conclusions: The efficacy of low phenylalanine diet was not demonstrated with any certainty. A follow-up study is planned.

Session 2: Family Life

Caring for an Adult with Williams Syndrome.

Sarah Elison, Chris Stinton, Patricia Howlin and Orlee Urdwin
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Background: Ninety-two adults (age range 19 - 55) with genetic confirmation of a diagnosis of Williams syndrome, were assessed as part of a study on developmental trajectories through adulthood. Participants were identified via the UK Williams Syndrome Foundation.

Methods: As part of the study, detailed semi-structured interviews were conducted with the parent, or main carer of each participant. The focus of the interview was on problems experienced during adulthood and the service needs of this group of individuals, and their carers.

Results: Physical health and psycho-social difficulties were reported by many carers. Annual care from hospital consultants, such as cardiologists, was required by 43% of the adults in the sample. Impaired social functioning was reported in 61% of adults, with difficult behaviours such as compulsions and obsessions being reported to be present in approximately 49%. In addition, self-care skills of the adults included in the study were low with only 8% being reported as having no limitations in their ability to cope with self-care and household chores. Further difficulties, such as accessing adequate financial support and respite care, were also reported. Over half of the families interviewed (52%) reported having had no support from social services during the previous two years.

Conclusions: These findings illustrate the types and rates of difficulties experienced by adults with Williams Syndrome and the resulting responsibilities faced by their carers.

Couples' experiences of the death of their child with Down syndrome and a congenital heart condition.

Deidre Reilly, Jaci C. Huws, Richard Hastings and Frances Vaughan
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Background: Individuals with Down syndrome are at increased risk of co-morbid health problems including congenital heart conditions (CHCs), and mortality is higher in people with Down syndrome and a CHC than those with Down syndrome and no CHC. Consequentially, parents of children with Down syndrome and a CHC are more likely to outlive their child. The bereavement experiences of these parents have not yet been investigated by researchers.

Methods: Semi-structured interviews were used to explore the experiences of six couples whose child with Down syndrome and a CHC had died. The interviews were carried out with each parent separately and analyzed qualitatively using Interpretative Phenomenological Analysis (IPA).

Results: Four themes emerged from the analysis: "one disastrous diagnosis after another"; "we had to make a decision"; "we weren't really going through it together" and "ripples from the Childs life". There was a high degree of similarity of experience within couples. Differences between couples lay in their experiences, or lack of experiences, coping and supporting each other as a couple.

Conclusions: Practical implications include the importance of considering the needs of individual couples, and especially to include support for fathers.

Support for family carers of children and young people with intellectual disabilities and challenging behaviour. How helpful is it perceived to be?

Peter McGill and Gemma Woodhouse
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Background: Family carers of children with challenging behaviour report receiving inadequate and unhelpful support to manage their Childs behaviour. The current study sought to identify why such support, even when provided, was often perceived as unhelpful. It was hoped this would provide a more detailed account of factors influencing support helpfulness.

Methods: Thirteen mothers, caring for a child with intellectual disability who also displayed challenging behaviour, were interviewed. Using a semi-structured interview informed by past research, parental perceptions of professional support they had received were investigated qualitatively. Interview transcripts were analysed using Interpretative Phenomenological Analysis.

Results: A number of themes related to generic support services, including: poor information provision; problems obtaining effective service;, partnership and communication problems; and insufficient provision of respite and speech therapy. A number of further issues were more specific to challenging behaviour support; including an insufficient amount of support; lack of expertise about both intellectual disability and challenging behaviour; ineffective strategies being suggested; and exclusion of the child from services due to their behaviour.

Conclusions: There is limited and rationed support on offer to these carers. There is a strong need to improve training in order to increase professionalism and promote more creative working within the limited resources available. The value of more preventative support should be recognised, with more widespread adoption of effective behaviour support practices. More coordinated, collaborative and respectful joint working between different professionals, as well as more family-centred support is recommended.

Session 3: Cognitive and Social Development

Looking at people: eye training evidence reveals how individuals with autism and Williams syndrome view social scenes.

Debbie Riby and Peter Hancock
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Background: Autism and Williams syndrome (WS) are neuro-developmental disorders associated with distinct social phenotypes. It has been argued that they represent 'polar opposites' in terms of social engagement strategies and here we explore how individuals with each disorder view social scenes containing people.

Methods: Participants with autism and WS and their matched comparison groups of typically developing individuals view a series of 20 social scene pictures presented using a Tobii 1750 eye tracker. Gaze fixation durations are monitored to areas of interest to identify group differences in viewing patterns. We specifically explore the time spent fixating on people and faces within scenes.

Results: The results illustrate that individuals with autism spend significantly less time than is typical fixating on people and faces within social scenes, corroborating previous evidence. Interestingly, and representing the first use of eye tracking with individuals who have WS, those with WS fixate on people in social scenes longer than is typical. An inverse pattern of fixation durations to people and faces in therefore evident in WS and autism.

Conclusions: Gaze fixations to people and faces in social scenes were recorded for individuals with two neuro-developmental disorders associated with atypicalities of social behaviour. The way individuals with autism and WS view people within social scenes, specifically the amount of time fixating on such information, mirrors the typical divergence of social skills and interests reported behaviourally for these groups in the developmental disorder literature.

Visuo-Spatial Construction in the Navon Task: A Comparison between Children with Fragile X Syndrome and Autistic Spectrum Disorders.

Carrie Ballantyne, Maria Nunez and Leigh Riby
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Background: The Navon Task (Navon, 1977) has frequently been used to demonstrate the visuo-spatial abilities of children with autism spectrum disorders (ASD) with a myriad of results. The task however, has not been used to show the strengths or weaknesses in children with fragile X syndrome (FXS). The current study employs the Navon task to investigate the visuo-spatial construction abilities in these two groups of children.

Methods: Five groups of children took part in the study; an FXS group (21 children), an FXS group of 19 children that also fitted the criteria for ASD (AFXS), a group of 20 high functioning autistic children (HFA), 20 low functioning autistic children (LFA) and 80 typically developing children (TYP) . The Navon task consisted of the typical Navon task, and adapted versions using geometric shapes and everyday objects. The children had to copy both the local items and global configurations by either drawing them or placing magnet cut outs onto a white board.

Results: Developmental trajectories were used to compare performance of the atypical groups against the TYP group. Initial results indicate that the HFA group outperformed the TYP group until the age of eleven, when differences disappeared. The LFA group had a tendency to focus on the local items and the AFXS group focused more on the global items of the stimuli.

Conclusions: The current study supports the literature that HFA children are relatively spared in visuo-spatial construction tasks. It also shows that children with FXS and LFA show attentional biases towards either global or local processing.

Why do Adults with Down syndrome talk out loud?

Sarah Samuels, Peter Baker and Paul Camic
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Background: There is a high reported prevalence of talking out loud in adults with Down syndrome. Within the field there is growing concern that this behaviour is being pathologically interpreted as a sign or symptom of mental illness, yet relatively little is known about its presentation or function.

Methods: This research describes a multiple-case study of four adults with Down syndrome who talk out loud. Data was collected through participant and informant interviews, standardised measures and direct observations. Analysis took the form of a functional assessment in addition to explanation building and a cross-case synthesis.

Results: The findings suggest that talking out loud can have various adaptive functions which may be shaped by the environment. Talking out loud appeared to function to regulate affect for all participants. There was also evidence to suggest that talking out loud may have a communicative function. Some participants appeared to have a degree of control over their talking out loud, apparently using it to avoid demands or gain tangible reinforcement. For these participants, talking out loud was a means of comfort and coping with difficult emotions and situations. Various topographies of talking out loud were evident between and within the individuals.

Conclusions: Talking out loud by adults with Down syndrome is shaped by environmental factors and may serve an important role in affect regulation, and environmental change and control.

Session 4: Understanding Challenging Behaviours

Identifying possible risks markers for severe challenging behaviour in children with severe intellectual disability and/or autistic spectrum disorder.

Louise Davies, Chris Oliver and Jane Petty
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Background: Challenging behaviour has a significant impact on the lives of individuals with severe intellectual disability (SID) and their families, with implications for service delivery and early intervention. In this study we investigated putative risk markers for challenging behaviour in children with SID and/or autism through the development of a brief screen based on a reanalysis of Petty's 2006 data.

Methods: Teachers from SID schools completed screening questionnaires on 495 children aged between 2 and 12 years. Items in the screening questionnaires assessed potential risk markers including: diagnosis, degree of intellectual disability, presence of health problems and repetitive, "obsessional", overactive and impulsive behaviour.

Results: A series of analyses demonstrated that children demonstrating aggressive, destructive and/or self injurious behaviour showed significantly higher levels of impulsive, overactive, repetitive and obsessive behaviours than those who did not show these topographies of challenging behaviour (all significant to $p<0.01$). Children identified as having autism, autism spectrum disorder, features or traits of autism were significantly more likely to demonstrate all three topographies of challenging behaviour. Males, older and more mobile children were also significantly more likely to be aggressive. Health problems related to the eyes, digestive system and skin were significantly associated with severity of self injurious behaviour but not other behaviour problems.

Conclusions: These findings confirm those of Petty (2006) who identified health problems, repetitive, impulsive, overactive, obsessive behaviour as possible risk markers for challenging behaviour. The capacity of the screen to predict increases in the severity of challenging behaviour over time is under evaluation.

An investigation of factors predictive of continued self-injurious behaviour in an intellectual disability service.

Adam Danaquah, Kate Limb, Melanie Chapman and Dougal Julian Hare
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Background: Self-injurious behaviour (SIB) is among the most serious problems faced by intellectual disability services, with a reported prevalence of between 2-12%. Up to 25% of SIB appears to be treatment-resistant and mean chronicity rates of 14 years have been reported (Murphy 1993). In the course of a follow-up study of SIB in Manchester, it was observed that some service-users stopped self-injuring whilst others continued. This research aims to identify factors related to the maintenance of SIB over the time period surveyed.

Methods: Based on Wisley et al (2002), data was collected through a survey of service-users identified as displaying SIB. Clinical opinion and a literature review identified potential predictors of continued SIB. Univariate analyses were used to investigate associations between continued SIB and each variable identified. Variables with a significant association with continued SIB were entered into a multivariate analysis to isolate those predicting continued SIB following co-variance of other factors.

Results: Data was collected for 94 service users presenting with SIB. Thirteen potential predictors of SIB were identified of which two, self biting and verbal ability, were found to independently predict continued SIB.

Conclusions: The results of the study are considered with regard to both biological models of chronic self-injury involving endogenous reinforcement (Symons & Thomson 1997) and the role of impaired communication in maintaining SIB (Murphy et al., 2005). The implications for intervention for chronic SIB are also discussed, as well as the need to consider intra-individual factors on SIB in a wider context.

Self-Injurious Behaviour: A twenty year follow-up of the first total population study.

Lorna Taylor, Glynis Murphy and Chris Oliver
Psychology Department
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Background: In 1983/4, a major UK study was conducted by Oliver et al., looking at the prevalence and characteristics of self-injurious behaviour in people with intellectual disabilities in the South East of England. This study is a 20 year follow-up of a sub-set of the Oliver et al cohort.

Methods: The first study included three London boroughs, Kent and East Sussex. This study followed-up only those in the three London boroughs (for reasons of limited resources). Information was gathered for 49 people, using assessment tools employed in the original study, plus an additional quality of life measure, the Life Experience Checklist (Ager, 1990).

Results: Eighty four percent of the sample continued to self-injure after 20 years, with no significant mean changes in number of topographies or severity across the group. Psychological input had increased but so had rates of anti-psychotic medication and anticonvulsant medication. The number of people accessing full - time day activities had reduced. Life Experience Checklist (LEC) scores were substantially lower for those people with severe self-injurious behaviour.

Conclusions: This study has further highlighted the persistence of self-injurious behaviours in people with severe and profound learning disabilities. Even after several decades of research, effective long term strategies are still needed.

Session 5: Transition to Adult Life

Transition and employment support for young people with learning disabilities in school or college in the UK.

Stephen Beyer and Axel Kaehne
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Background: Transition has been a prime focus of attention for regional and national governmental policy for some years. However, employment for young people with learning disabilities is still rarely reported as an outcome of transition supports.
The recent renewed focus on transition for young people with learning disabilities is welcome news. However it only insufficiently addresses the fundamental problems of developing viable employment options for young people with learning disabilities as they leave school or college. Success in gaining and keeping employment for this client group is still well below average (17%) compared to the disabled population as a whole (50%).

Methods: The paper reports the findings of a study on employment and transition support for 145 young people and their carers in two cohorts in the years 2005 and 2006. Fourteen special, one mainstream and five colleges took part in the research and six different models of transition and employment support were identified. Logistic regression analysis was carried out to identify factors influencing gaining employment.

Results: The number of young people entering employment differed significantly between the first (21.2%) and second cohort (11.7%) which highlights the variability of service input and quality across the various models of transition support. The study concluded that qualification-based vocational courses delivered in school or college as well as dedicated efforts to get work experience placements delivered by outside employment transition organisations positively impact on the chances of employment.

Conclusions: Transition support organisations acted as effective promoters of the employment route offering more concrete advice and practical support options. What works is the combination of school/college based qualification courses and efforts to get work experience placements delivered by outside employment support agencies.

Stepping stones: does social enterprise provide the skills needed for mainstream employment?

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Background: The benefits of employment for people with learning disabilities have been documented as increased choice, empowerment and independence. The aim of this study was to evaluate a social enterprise organisation from the view point of workers in relation to their development of skills necessary for future mainstream employment.

Methods: 59 individuals from three social enterprises and three day centres were interviewed using both quantitative and qualitative instruments. Quantitative data was analysed using SPSS. Taped data was transcribed and subjected to thematic analysis.

Results: Results showed significant differences between those working in social enterprises compared to day centres in terms of domains relating to life experience, adaptive behaviour and self-esteem. Differences in knowledge about employment rights were also found. However, no significant differences were found in relation to social networks.

Conclusions: Social enterprises are clearly better training grounds for future employment compared to day centres. However, there is more work to be done especially in relation to social inclusion and employment rights.

Social Exclusion and Sexual Understanding.

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Background: As young people with intellectual and physical disabilities are more likely to experience social exclusion, they are likely to have fewer opportunities to talk about health related issues. This may be more marked for private topics like sexual health that can be difficult or embarrassing to discuss.

Methods: To explore the impact of social exclusion on the health knowledge of the following three groups of young people were compared: (i) 34 with no known disability (ND), (ii) 34 with a mild/moderate intellectual disability (ID), and (iii) 28 with a physical disability (PD). Questionnaires and semi-structured interviews were used to elicit both quantitative and qualitative data. Information was also collected regarding participants' social networks and sources of health knowledge.

Results: Both the intellectually disabled young people and those with physical disabilities had poorer sexual understanding than their non-disabled peers. In contrast, those with physical disabilities had a similar knowledge to their non-disabled peers in other health domains such as nutrition and alcohol use. Young people with intellectual and physical disabilities discussed sexual issues with friends and family less frequently than their non-disabled peers and reported being more reliant upon formal sources of sex education (i.e. school or college).

Conclusions: For private health topics it appears that limited opportunities to socialise with peers and engage in age normative activities has a negatively impact upon knowledge. Negative attitudes and beliefs held by significant others may also have an impact upon young people's sexual adjustment and development.

Session 6: Capacity and Risk

Three tips for improving the assessment of fitness to testify.

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Background: Memory and suggestibility are two significant elements of an assessment of capacity to testify. People with intellectual disabilities are often denied the opportunity to testify because an assessment using the Gudjonsson Suggestibility Scale (GSS) indicates that they remember little and are highly suggestible. This presentation presents some suggestions for improving the assessment, based on experimental studies of memory and suggestibility.

Methods: In a total of five experiments, conducted in learning-disability day services, different modifications were made to the GSS in order to decrease the memory load: two of these involved changes to the presentation procedure; three involved new stories using material that was familiar to some of the participants. In three experiments, in addition to the standard recall measure, a measure of recognition memory was included, based on forced-choice questions with one true and one false alternative. One experiment also included ratings of confidence in answers to assessment items.

Results: All of the experimental manipulations improved recall to a similar extent, and in some cases, but not all, suggestibility was decreased. However, manipulations that improved recognition also reliably decreased suggestibility, in some cases, substantially. The use of a recognition measure improved memory efficiency between two and four fold relative to recall. Confidence ratings did not vary between correct and incorrect items.

Conclusions: (i) As the GSS greatly over-estimates suggestibility in relation to events that are well remembered, it should not be used in the assessment of fitness to testify.

(ii) Confidence ratings may be unrelated to the accuracy of memory performance, so should be afforded little weight.

(iii) Memory performance should be maximized by the use of forced-choice true-false recognition memory items.

Injuries, accidents and falls in adults with learning disabilities.

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Background: Young persons with learning disabilities have a higher rate and different pattern of injuries than the general population, but little is known regarding adults. We studied a cohort of adults with learning disabilities (n = 511) to describe the frequency, types, and impact of injuries experienced in a 12-month period, and to identify potentially modifiable risk factors.

Methods: Face to face interviews were conducted at two points in time, two years apart. Results were compared with general population data from the Scottish Health Survey 2003 (n = 6014).

Results: The incidence of at least one injury that required medical/nursing attention/treatment in a 12-month period was 20.5% (105) or 22.1% (113) including self-injury. Incidence of falls with or without injury was 40.1% (205), and incident fall injury was 12.1% (62). At 18-64 years, injury incidence (excluding self-injury) was 20.4%, compared with 11.5% for the general population, giving a standardized incidence ratio of 1.78 (95% CI = 1.44-217). There were more injuries caused by falls, trips, burns, using equipment, and causes not relevant for the general population, and the injury types included more fractures, burns and poisoning. Incident injury was predicted by having epilepsy, and urinary incontinence; autism and Down syndrome reduced risk. Carers thought clumsiness and season were relevant, and considered injuries from accidents unpreventable.

Conclusions: Further study on fractures/osteoporosis is indicated, and the development of balance, safety, and staff training interventions for high-risk groups.

The Ward and Hudson Pathways Model of the Sexual Offence Process Applied to Offenders with Intellectual Disability.

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Background: The offence pathways model of Ward and Hudson (1998) has had a significant impact on mainstream sex offender assessment and treatment. The model proposes two offender goal classifications (approach and avoidant) and two methods of self regulation (active and passive) leading to four basic pathways to sexual offending. In relation to offenders with intellectual disability (ID), Keeling and Rose (2005) have hypothesised that such offenders will show a predominantly avoidant and passive pathway because of limitations in planning abilities, self esteem issues and possible self regulation deficits.

Method: The present study classified 62 sex offenders with ID according to the four self-regulation pathways. WAIS and QACSO assessments were completed on all participants. Offence specific information was also available for comparison.

Results: Allocation to pathways was highly reliable and, contrary to prediction, all but three participants were allocated to approach pathways. Explicit/active offenders had a higher rate of contact offences and a lower rate of re-offending. Automatic/passive offenders had a lower average IQ. There were no significant differences between groups on victim choice, previous offences or assessment of cognitive distortions.

Conclusions: The results are consistent with previous findings in studies with offenders with ID and contrary to some predictions both from Ward and colleagues and Keeling and Rose (2005).They also suggest that treatment may have a significant impact in improving understanding of society's laws, promoting self-regulation and reducing recidivism for explicit/active offenders. The implications for the hypothesis of "Counterfeit Deviance" are discussed.

A study of emotional expression by people with intellectual disabilities.

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Background: The ability of people with intellectual disabilities to recognise facial expression of emotion has been the subject of considerable research. However, in a therapeutic context the ability to describe one's own emotions is important. This study explores the ability of people with intellectual disability to generate synonyms for emotion words.

Methods: Forty people with mild and moderate intellectual disabilities completed: a task requiring the generation of words describing four emotions; a verbal fluency task; a facial recognition of emotion task; a receptive language task (BPVS raw score); the ability to link emotions with activating events (Reed & Clements); and a depression and anxiety self-report questionnaire (adapted HADS).

Results: Only 15 (37%) participants were able to generate one further emotion word to any of the four emotions; the emotions generated will be presented. The ability to generate at least one emotion word is significantly associated with BPVS raw score, anxiety scores, the Reed and Clements task and emotion recognition. As many of these tasks are associated with language ability, partial correlations were carried out controlling for BPVS score and verbal fluency scores. Significant correlations remain between the ability to generate emotion words with the Reed and Clements task and anxiety score.

Conclusions: People with intellectual disabilities may find it hard to generate alternative words for given emotions. Further research is needed to replicate these findings. Clinical implications will be discussed.

Posters

Communicating with preverbal pupils: Supporting teachers

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Background: The study examined the communication of teachers with children who have complex learning difficulties and communicate mainly nonverbally. Teachers and speech and language therapists recognise that communication with nonverbal children is challenging. Research evidence suggests that modifying interaction styles and using specific strategies supports language learning and that strategies are more effective if they are matched to the child's language level. The aims of the study were to identify use of naturalistic teaching strategies in teacher-pupil interactions and to support teachers in reflecting on their communication styles.

Methods: Video recordings were made of eight teachers working with twelve pupils in two schools over an eighteen month period. Questionnaires were completed by staff from eight schools on prior learning, feedback and reflective practice in relation to working with nonverbal children.

Results: Analysis showed that teachers used a range of strategies to encourage interaction and language development. There were no differences between the types of strategies used dependent on children's level of understanding. The questionnaire highlighted the amount and variation in formal training at undergraduate and post graduate levels for working with children who communicate nonverbally.

Conclusions: Teachers working with children who are nonverbal communicators may be unaware of the evidence from research on early language studies of parent interventions and teaching strategies. Therapists are well-placed to support teachers using video feedback. Reviewing the types of strategies used by teachers, parents and therapists may be a useful focus for joint planning.

Christian faith in the lives of families with an adult with learning disabilities

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Background: There are few UK studies which have looked at the role of faith in the lives of families of adults with learning disabilities. Previous US studies have suggested that religious parents can struggle with resolving their faith with having a child with learning disabilities, e.g. viewing their child as either a blessing or a curse (Fewell, 1986).

Methods: Seventeen parents of adults with learning disabilities were qualitatively interviewed using grounded theory methodology about the role of their faith in their lives and particularly how they resolved their faith with their adult child's learning disabilities.

Results: One novel theme that has emerged from the interviews has been acceptance but not understanding by parents. A theory diagram illustrates the development of this acceptance which comes after a period of flux immediately after diagnosis, where some parents struggle to understand God's role in their child's learning disabilities. This struggle may involve negative attempts such as asking "why me?" and questioning why God would allow this to happen.

Conclusions: Having initially struggled to resolve their faith with their child's learning disabilities does not necessarily prevent parents from experiencing positive outcomes.

Religious research is a marginalised area where judgements are made about the faith status of the researcher. In both academic and service environments often assumptions are made about the invalid nature of faith and belief. This stigma is shared by, if not amplified onto, the researcher.

Assessment of capacity in primary care.

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Background: Informed consent is a necessary prerequisite to receive medical care, excluding emergencies where clinicians take responsibility to safeguard patients' lives. For individuals who do not have the mental capacity to consent, legislation has been introduced that requires a specified individual to make this decision. In primary care, general practitioners have a duty of care to assess their patient's decision making capacity to consent to receive interventions or treatments, and issue a certificate detailing capacity.

Methods: People with intellectual disabilities are being recruited to a study which includes a comprehensive assessment of their physical and mental health, capacity to make decisions about their treatment, and the actual issuing of certificates within primary care.

Results: Preliminary findings indicate 47 out of 52 (90%) individuals required a certificate. Of the 47 individuals, only 10 had a certificate (21%), and in only one case (2%) was it valid in both date and in specifying the treatments it covered. Some others had blanket statements written on certificates (e.g. 'any medical or dental procedures'), or partial statements, rather than specifying the intervention or treatment.

Conclusions: Incapacity legislation does not appear to facilitate routine medical care. Legislation can not adequately protect vulnerable individuals when assessments of capacity for medical prescriptions or treatments are not routinely carried out. It is unclear whether the lack of valid capacity assessment certificates has reduced access to medical care.

Developing a person-centred Psychology Service: talking to potential service users

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Background: This study aimed to increase the involvement of people with learning disabilities in the planning and development of a trust community psychology service and test out focus group formats for (1) people who had already used the service and (2) people who had no previous contact with the service, but would be eligible if they wished to use the service in the future.

Methods: A single focus group for service users was run, whereas 3 focus groups for potentials service users was run. Focus groups for service users were identified to be an unreliable format for gathering feedback. However, the transcripts from 3 potential service user groups did not present with the same problems as the service user feedback groups and were analysed using grounded theory analysis.

Results: The core theme, permeating all other themes was 'prioritising the user's voice'. Master themes that emerged from the data took the form of either barriers (barriers to therapy; service issues) or solutions (knowledge about services, practical suggestions; personal coping strategies, peer support and advocacy, what psychologists can do).

Conclusions: The study has helped the Psychology Learning Disability Service in South London question areas of current practice, such as self-referral, establishing rapport with LD clients and encouraging peer support, which are now being addressed by the service.

Transition adult services for young people with challenging behaviour and intellectual disabilities

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Background**:** This project was undertaken by Camden Community Learning Disabilities to examine local processes of transition to adulthood and associated demands to transition cases as they enter adults services.

Methods**:** A survey of young people aged 16 to 18 years with Intellectual Disabilities and Challenging Behaviour resident in the London Borough of Camden. Quantitive and Qualitative data was collected with regard to the demographics and clinic details, service receipt in addition to parents / carers and service users' impressions of the transition process.

Results**:** Eighteen individuals were identified between the age of 16 and 18; of whom 10 agreed to complete the survey at the time of submission of this protocol. Results show that there is large variation in service usage both with regard to community mental health and social care interventions and involvement in community mental health services professionals. These included individuals who screened negative for mental health difficulties, individuals with one carer in full time employment and individuals living outside the carer's home. Parents were dissatisfied with their experience of transition in particular with regard to problems relating to the procurement of services for the client.

Conclusions**:** Services need to have some impression of the needs of these individuals in order to plan for the future. This project has provided some insight into what local services can anticipate. Important next steps would be to look at the longer term outcomes for these individuals with the view to identifying key factors that predict positive outcomes.

A descriptive investigation of dysphagia in adults with intellectual disabilities.

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Background: Dysphagia refers to eating, drinking and swallowing disorders caused by either neurological, anatomical and iatrogenic causes. Dysphagia may lead to aspiration, asphyxiation, poor nutritional status and dehydration, which, in turn, can potentially lead to constipation, urinary tract infections, headaches, reduced ability to combat infections, respiratory infections and in some cases death. Dysphagia has rarely been investigated in adults with intellectual disabilities (ID).

Methods: This descriptive study collected information about 101 adults with ID, living in community settings, referred for dysphagia assessment. Ninety-nine people were classified as having dysphagia from clinical and videofluoroscopic assessments. This information was used to give an indication of the prevalence of dysphagia in adults with ID and also allowed the prevalence of physiological and anatomical indicators of dysphagia and associated negative health conditions to be identified.

Results: Characteristics and conditions associated with dysphagia problems at different stages of the eating, drinking and swallowing process were identified along with a tentative indication of the current prevalence (8.15%).

Conclusions: Results indicate that dysphagia is a significant issue for people with ID warranting further investigation. The causes and health consequences of dysphagia in adults with ID need to be established and the efficacy and effectiveness of different approaches to dysphagia management in this population need investigation.

A comparative study of psychological distress, appraisal, and coping in people with Asperger's Syndrome and their supporters.

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Background: Significant numbers of people with Asperger's syndrome receive their diagnosis post-eighteen years of age (Barnard et al., 2001). Prolonged failure to attain an appropriate diagnosis can result in mental health problems for them, and distress for their supporters (Tantam, 2000). The Self Regulation Model (Leventhal et al., 1984) and the transactional model (Lazarus and Folkman, 1984) have been applied to schizophrenia populations, and negatively-held beliefs regarding the condition have been found to be related to poorer outcomes in patients and their supporters (e.g. Lobban et al., 2004; Fortune et al., 2005). Because aspects of Asperger's syndrome can resemble schizophrenia, it was hypothesised that appraisals held by these persons and their supporters might resemble those found in schizophrenia populations, and predict supporters distress, particularly where their relatives struggled to adequately express their affective states (alexithymia).

Methods: 25 Asperger's syndrome-supporter dyads completed an adapted measure of health belief (the Perception of Difficulties Questionnaire). Measures of appraisal/coping, and distress (supporters group), and symptomatology, and alexithymia (Asperger's syndrome group) were also completed

Results: The study found that dimensions of the health belief model were significantly associated with supporters distress, as were supporters appraisals of their relatives challenging behaviours. Although the Asperger's syndrome group experienced elevated levels of psychiatric symptomatology, contrary to expectation it was the supporters of those with lower alexithymia scores who experienced greater levels of distress.

Conclusions: The results are discussed with reference to the applicability of health belief, appraisal/coping, and alexithymia models to Asperger's syndrome populations.

Long term outcomes of resettlement

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Background: This study aimed to evaluate the long term outcomes of a resettlement programme.

Methods: Questionnaire surveys of people who were resettled and staff working for supported housing schemes

Results: Eighty six people who were resettled and 31 staff responded.
Move since resettlement: Forty nine percent of resettled people had not moved, 46% had moved once, 6% had moved two or three times. The most common reason for moving was property size. Staff moved more often: property size, relationship and work changes were common reasons for moves.
Relationships: The majority of resettled people (74%) with living family got on "very well" or "fairly well" with their family: however, there was little contact with family. In general, resettled people had fewer friends than staff. No-one who had been resettled was reported as being in a relationship, cohabiting or married.

Participation: Many resettled people were not involved in many domestic tasks. Less than half had total autonomy in the areas measured (except for choosing what to wear). Overall, there were no statistically significant differences in number of regular activities undertaken by people who were resettled and staff. People were usually supervised or accompanied when doing activities. Only six people (7%) had paid employment or voluntary work currently or previously.

Conclusions: Future research and service development could usefully surround: reasons why people do (or do not) move, and how to best support social relationships, involvement in domestic tasks, meaningful activities and employment. The perspectives of people who are learning disabled needs to be central to future research and service development.

Investigating the inter-correlation of pragmatic aspects of Theory of Mind in adults with Asperger Syndrome

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Background: Theory of mind (ToM) assessments primarily developed by Corcoran and colleagues (Corcoran & Frith, 2005) focussing on pragmatic aspects of ToM can reliably identify impaired functioning during acute psychotic episodes. The concurrent validity of these measures for adults with autism with intransient ToM difficulties has not been explored to date.

Methods: This is a pilot study (Asperger syndrome N=6, Neurotypical control group N=21) to investigate the inter-concurrent validity of the Hints, Maxims, Jokes and Projective Imagination tests. H1: Significant between-group differences in test performance would be observed. H2: Test performances would be inter-correlated within each group.

Results: Significant between-group differences were revealed for performances on the hints task, the hints control task, physical and ToM-based jokes. Significant inter-test correlations emerged only within the control group: between the hints control task and physical joke interpretations; and cued and uncued totals on the projective imagination test. Observation suggested that more able AS individuals with increased social awareness performed similarly to NT controls.

Conclusions: Measures featuring understanding of intention differentiated those with AS and NT groups, with significant differences for pragmatic language and joke comprehension. The fact that no significant between-group differences were observed on the other ToM measures and the wide distribution of scores of the individuals with AS could be explained in terms of non-mentalistic learnt compensatory strategies employed by some individuals with AS. Therefore, the tests were insensitive measures of ToM, involving conceptually unrelated mentalisation abilities.

As the last resort: Reducing the use of restrictive physical interventions.

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Background: Use of Physical Intervention (PI) to manage challenging behaviour has been associated with staff and service user injury, pain compliance and restrictive environments. Recent UK initiatives have encouraged policy development and accredited training. However, information on PI use and the impact of these initiatives remains limited.

Methods: A postal questionnaire survey was conducted in the South East of England covering three local government areas. Participants included the managers of all NHS provided and managed residential services in the Trusts covering the three areas (53) and of all registered private, voluntary and Social Service provided residential care homes for adults with intellectual disabilities (489). Questionnaires were sent in September 2005 with non-responders re-sent the package 2 months later.

Results: In summary: Almost 1 in 2 services reported using some form of PI, almost 1 in 3 some form of restrictive PI; Services using PI (especially restrictive) were more likely to have a PI policy and to provide dedicated PI training to staff; There remained, however, significant numbers of services using restrictive PI without a policy (18%) and without dedicated PI staff training (16%); Most services (94%) using PI reported monitoring its frequency and/or restrictiveness and such monitoring was significantly correlated with having a policy and providing training; Services reported less (in fact, zero) use of training based on Control & Restraint than in Murphy et al (2003) survey; Services were almost entirely supportive of the aspiration to reduce the frequency and restrictiveness of PI use and reported employing a variety of strategies (especially staff training, policy, care planning, monitoring and external input) with these ends in mind.

Conclusions: Nearly 400 services using restrictive PI that have not developed a policy to support/manage its use. The findings suggest that there is considerable desire and interest in many services to monitor their use of PI and seek to reduce its use over time. We would argue should now become a more explicit objective, requiring leadership to make it a reality.

Work stress and positive experiences of support staff working with individuals with intellectual disability and challenging behaviour.

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Background**:** Research on staff working in intellectual disability and challenging behaviour settings has emphasised staff stress. This study sought to explore a more holistic picture of staff experiences by exploring staff work stress and also positive experiences.

Methods**:** Semi-structured interviews (N=16) were conducted with staff working with people with an intellectual disability and challenging behaviour. The interview explored staff stressful experiences and coping; staff positive experiences; and staff perceptions of what they had learned from their work. The data were subject to a content analysis with independent rating of transcripts to establish coding reliability.

Results**:** Stressful experiences were identified such as challenging behaviours themselves, aspects of the job design, and with team working. Positive experiences included working with clients, feedback from clients, "making a difference" and also working within the team. Staff also identified some more positive global changes on their lives such as becoming calmer and more understanding, as well as some global negative changes such as becoming emotionally hardened.

Conclusions**:** These data confirm the stresses associated with working with challenging behaviour. However, positive experiences were also identified including perceived global impact on staff lives. Further exploration of the richness of staff experience is necessary, and also of the positive contribution that people with intellectual disabilities can make to those who support them.

Social communication training in adults with autistic spectrum disorder.

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Background**:** To communicate effectively an individual requires, to appreciate and interpret information from linguistic, non-linguistic and situational cues. As people with ASD often have difficulty understanding these areas and behaving accordingly; this can lead to various problems (Jackson 2002). Strategies for facilitating social interaction have been evaluated in children (Bauminger, 2002, Hsiao, 2000) using primarily behavioural or Theory of Mind paradigms. Difficulties remain however, when the individual fails to generalise these skills to unfamiliar contexts.

Haddock, Jones and Noone (2003) designed and piloted a DVD training intervention 1.) to evaluate ability to identify appropriate and inappropriate social scenarios and 2.) to examine whether skills improved after training. Our study incorporated their DVD package within a behavioural training programme to further investigate the efficacy of this approach.

Methods**:** Five young adults with ASD [age range 16 - 26 yrs, mean 22.2 years (sd. 4.49)] and mild/moderate learning disabilities participated 2 hours per week in a six-week social skills course.

Results**:** In all cases there was a significant increase in mean scores on DVD assessment, ranging from 0.5 of a standard deviation to more than 1.0 standard deviation. This suggests clinically significant gain, which is important because, demands are increasing not only for specialist diagnostic assessment but also for clinically effective intervention. The group effect of a mean increase from 28.8 (sd. 9.47) to 35.8 (sd. 8.84) was also statistically significant [t = -7.38 (df =4), p = .002].

Conclusions**:** As this study only involved 5 participants, a follow-up would be useful to determine skills retained.

A general practice based prevalence study of epilepsy among adults with intellectual disabilities and of its association with psychiatric disorder, behaviour disturbance and carer stress.

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Background: The aims were to determine the prevalence and features of epilepsy in a community-based population of adults with intellectual disabilities and explore whether the presence of epilepsy was associated with greater psychopathology or carer strain.

Methods: Data were collected on the age, gender, place of residence, adaptive and challenging behaviour, social abilities and psychiatric status of 318 adults from 40 general practices, together with the degree of malaise and strain of family carers. For participants with epilepsy, a nurse collected information on seizures, investigations, treatment and carer concerns by interview. Association between epilepsy and psychiatric morbidity, challenging behaviour and caregiver malaise or strain was explored by comparing those with epilepsy to a comparison group matched on adaptive behaviour.

Results: Fifty-eight participants (18%) had epilepsy: 26% were seizure free but 34% had extremely poorly controlled seizures. Earlier onset and seizure frequency were associated with adaptive behaviour. Carer concerns were related to seizure frequency and a history of injury. There were no significant differences in psychopathology, carer malaise or caregiver strain between the matched epilepsy and non-epilepsy groups.

Conclusions: While psychopathology and carer strain is common within this population, underlying disability-related factors appear to be more important than the presence of epilepsy per se.

The perceived impact of injuries, accidents and falls on adults with learning disabilities and their carers.

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Background: Adults with learning disabilities have a higher rate and different pattern of injuries than the general population, but little is known about the perceived impact of injuries, accidents and falls on adults with learning disabilities and their carers. Falls are the commonest cause of unintentional (or accidental) injuries.

Methods: We conducted qualitative interviews with ten adults with learning disabilities (and their supporting carers where applicable) who had been severely or frequently injured in a 12-month period, to measure perceived impact and causes. Data was content analysed to identify emergent themes.

Results: Three expressed negative feelings about themselves, including loss of confidence as a result of fall injuries e.g. *[I feel] like a prat*. Three appeared to have accepted their proneness to falling, two of whom had learned to fall in a way to minimise injury risk *e.g. well, if I fall I just go limp…I don't hurt myself as much*. The two participants with injuries outdoors (one fall, and one road traffic accident) had developed fears of walking outdoors unsupported or crossing roads. Only two carers reported any actions to minimise future injuries (following choking and self-harm).

Conclusion: These findings enhance our understanding of injuries, accidents and falls experienced by adults with learning disabilities and their carers, and will help towards the development of interventions to minimise the impact of such in this group.

Involving those who really know: does service user involvement within services and research leave participants standing at the side lines?

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Background: Service organisations have recently been encouraged by policy makers in the UK and across Europe to involve service users effectively in all aspects of support services they receive. In the last couple of decades researchers have also advocated for a more participatory and emancipatory approach concerning research. The aim of this paper is to report on a research project commissioned by a large social care organisation to develop a satisfaction survey which was designed, developed and evaluated using service users.

Methods: Content analysis of service policy documents was followed by 28 telephone interviews with internal and external stakeholders. A range of interviews and focus groups were held with 39 staff and 94 service users who had either learning disabilities, mental health or drug and alcohol problems. Transcribed data was subjected to thematic analysis and key questions across all data sources were computed and built into the questionnaire.

Results: A questionnaire was produced - with key service user questions on staff attitudes, individual care packages and the environment. However, the research team came up against many challenges in relation to a) involvement of service users with learning disabilities b) tensions between what service users and management wanted in the survey and c) the commitment of the organisation to follow through utilisation of the questionnaire.

Conclusions: We conclude by arguing that service user involvement may be another lip service exercise leaving service users on the side lines.

Anxiety and paranoia in adults who identify as having Asperger's syndrome.

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Background: Clinicians and researchers have reported that people with Asperger syndrome (AS) experience frequent paranoid thoughts and associated distress. Models of paranoid thinking developed for non-AS populations have been investigated for their ability to account for the development of paranoia for people with AS. So far none has adequately met this task. The current study tested the ability of Freeman et al's multifactorial model of paranoia to explain the development of paranoid thinking for people with AS. This was considered a good candidate for investigation because of the shared features between the multifactorial model and the presentation of Asperger syndrome (namely, emotional disturbance, anomalous sensory experiences and reasoning biases).

Methods: Respondents were recruited anonymously to either an on-line or postal survey. People who self-identified as having AS completed standardised measures of paranoia, anxiety, depression, evaluative beliefs, sensory anomalies, and a need for closure. The analysis sample had a size of n=200, with an age range from 18 to 73 years old.

Results: The results suggest that negative evaluative beliefs about others, the belief that others have negative evaluative beliefs about oneself, meta-worry and anomalous sensory experiences are strong predictors of paranoia in people with AS in line with the predictions of Freeman et al.

Conclusions: These findings have implications for clinical work with people with AS, in particular indicating that theories of anxiety emphasising metacognitions and negative evaluative beliefs may be particularly relevant when formulating psychological distress of people with AS.

An exploration of staff interpersonal relationships with their clients with severe intellectual disabilities who frequently display aggressive behaviour.

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Background: Research into the attributions of support staff in relation to challenging behaviours has tended to use vignettes, and has focused on the behaviour of individuals with a mild/moderate disability, with staff perceptions of the individual being neglected.

Methods: In the present study, 34 support staff working with 20 adults who had a severe intellectual disability (and frequently displayed aggressive behaviours) completed a measure of burnout. In addition, coded dialogues from Five Minute Speech Sample (FMSS) examining Expressed Emotion, and a Likert rating scale investigated support staffs interpersonal relationship with clients. Support staff were also asked to discuss their attributions of intent regarding a recalled incident of aggression using a cognitive behavioural interview format.

Results: No associations were found between support staff stress, interpersonal relationships with clients, or attributions of intent regarding real life incidents of aggression. However, it was noteworthy that support staff perceived their clients acts of aggression as intentional. Relationships were also found between attributions of intent and supports staffs age, years of working experience, and an inverse relationship was detected in relation to their educational attainment.

Conclusions: This contradicts existing research emphasising the extent of an individual's disability in predicting attributions, and instead highlighted the role of an interpersonal history in influencing staff attributions. The implications of these findings are discussed.

Barriers to recruiting adults with incapacity for research.

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Background**:** Part 5 (Medical Treatment and Research) of the Adults with Incapacity (Scotland) Act 2000 was implemented in July 2002, allowing specified individuals to make decisions on behalf of individuals who do not have capacity. The main implication this legislation has had for research practice in Scotland is that for those individuals who cannot provide informed consent to participate, the individual's nearest relative, as described in the Mental Health Act, or welfare guardian with appropriate powers provides consent.

Methods**:** A longitudinal cohort study of adults with intellectual disabilities invited to participate at baseline, prior to the Act, and at two year follow-up, following introduction of the Act. At follow-up, consent was re-taken in keeping with the new Act.

Results**:** The cohort comprised 1,202 participants to follow-up; only one participant had an allocated welfare guardian with appropriate powers. The Adults with Incapacity (Scotland) Act requirements were unable to be met for 137 of the 1,202 potential participants, thereby necessarily excluding 11% of the sample from follow-up. Participants, who were unable to consent for themselves, had little or no contact or abusive relationships with relatives were necessarily excluded.

Conclusions**:** The specific exclusion of adults with intellectual disabilities who cannot consent and without family contact or welfare guardian arrangements precludes research that may influence clinical practice and service development for this population.

A focus group for fathers with learning disabilities: using grounded theory techniques to develop an understanding of their experiences.

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Background: There is limited research about the experiences of fathers with learning disabilities. Research into parenting by people with learning disabilities is almost exclusively focused on mothers (Booth and Booth, 2002), and fathers with learning disability appear to receive little input from Community Learning Disability Teams (Woodhouse et al, 2001).
The present research aims to gain an understanding of the experiences of fathers who have learning disabilities using a focus group methodology.

Methods: A series of six focus groups were run with three fathers who were known to the Community Learning Disability Team. Sessions were taped and transcribed, and data analyzed according to the technique of open coding described in Strauss and Corbins (1998) account of Grounded Theory.

Results: Six major categories emerged during the analysis: i) a father's role, ii) learning problems, iii) getting angry, iv) treatment by professionals, v) discrimination and stigma, and vi) feeling excluded and isolated.
These categories are described, and a tentative interpretation of how the categories might link into theory is briefly described.

Conclusions: The findings have been presented primarily as a descriptive account and hypotheses have been suggested for testing in further research, in order to better understand and help this client group.
Feeling excluded and isolated emerged as a feeling which united the fathers in the group, and it seems that the group provided a valuable opportunity to share with fathers with similar experiences.

Preliminary examination of the function served by challenging behaviours associated with Fragile X Syndrome.

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Background: Fragile X Syndrome (FXS) is associated with a number of challenging behaviours, and as stereotypy and self-injury. The current study aims to add to the small body of literature to have examined the function served by such behaviours in FXS.

Methods: Using indirect functioning assessment methods (Questions about Behavioural Function Scale), we compared the function served by challenging behaviour served by 25 children with FXS against 30 control participants.

Results: Within syndrome analyses revealed significant differences. Children with FXS had lower scores on the attention subscale of the QABF, than on the fragile or demand sub scales. Again this was focused around self-injurious, aggressive and destructive behaviours.

Conclusions: Implications of these findings for our understanding of the concept of the behavioural phenotype and gene-behaviour editions we discussed.

A project to identify and develop ways in which children with intellectual disabilities and parents can inform, participate and help design services that they receive findings one year on.

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Background**:** The Government as a key priority has identified participation by children and families in service design. However, this very rarely happens, and where it does, there is little change. This research was designed to address some of these issues. The project was completed over a three-year period. Data is now presented, together with a manual, of developments, conclusions and changes in service design in a follow up to last year's Seattle Club presentation

Methods**:** Two groups of parents of children with a intellectual disability and professionals produced process maps, to identify areas for change in services. Techniques were adapted, and developed for a group of children with intellectual disability. The data from these processes were combined with focus groups held with professionals to identify what helped change to occur over a two-year period. The data were thematically analysed within a Framework Analysis approaches using Max QDA.

Results: Analysis of the work with the children, parents and professionals identified a number of key themes and approaches for successful involvement and sustained system change. A manual has been written based upon this work.

Conclusions**:** The research found that children with an intellectual disability and parents could inform, participate in and help design services they use. Their suggestions have made a qualitative difference to the way that some aspects of the child LD service are run. This work also identified new ways of consulting children with an intellectual disability, and involving professionals in changing the systems in which they work.

Parental locus of control in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships with psychological well-being.

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Background: Psychological mechanisms may help to explain the considerable variance observed in parental psychological adjustment in parents of children with intellectual disabilities. In this study, parental locus of control and its role in relation to maternal psychological well-being was explored.

Methods: Questionnaires were sent to 91 mothers of children with ID at two time points, 18 months apart.

Results: Parental locus of control was associated with both maternal positive perceptions and with maternal distress. Regression analyses showed that dimensions of parental locus of control were a significant predictor of negative maternal adjustment. Maternal positive perceptions were predicted by perceived control of the child and belief in fate or chance. These relationships were all significant cross-sectionally only.

Conclusions: Parenting locus of control is a construct that may explain some of the variance in maternal well-being, and thus, is an area that merits further research.

The use of a periodic service review to support implementation of positive behaviour support approaches and reduce levels of challenging behaviour.

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Background**:** Challenging behaviour is commonly associated with poor quality of life and placement breakdown. Staff skills are a key factor in the success of behavioural intervention. Research demonstrates that training alone does not change staff practice or improve quality of support. Achieving long-term positive outcomes after behavioural intervention is also a difficulty. Monitoring of staff practice and providing visual feedback to staff regarding their practice may provide opportunities to ensure consistent implementation of interventions and to achieve long-term changes in levels of challenging behaviour. This paper provides case examples of this approach.

Methods**:** Six clients with challenging behaviour living within the community were all provided with Positive Behaviour Support input. Monitoring took place on a weekly basis and resulted in a percentage score indicating levels of implementation of Positive Behaviour Support recommendations. Levels of behavioural challenges from each individual were also monitored on a weekly basis.

Results**:** High levels of staff implementation of Positive Behaviour Support approaches (as indicated by high Periodic Service Review scores) results in changes in levels of challenging behaviour. This link was demonstrated in all 6 case studies and was sustained for periods of 6 months to over a year.

Conclusions**:** Positive Behaviour Support can be provided in community settings to individuals with behavioural challenges, resulting in decreases in challenging behaviour. Periodic Service Review allows close and regular monitoring of implementation of Positive Behaviour Support approaches. There is a link between consistent implementation of Positive Behaviour Support approaches (as indicated by high Periodic Service Review scores) and decreased levels of challenging behaviour.

Improvements in articulation in children with Down's Syndrome: EPG therapy versus traditional therapy.

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Background: Articulation errors in Down's syndrome (DS) are common and often persistent. Individuals with DS generally prefer visual to auditory methods of learning and may therefore find it easier to modify their speech when given a visual rather than solely auditory model of correct articulatory patterns. One such method is electropalatography (EPG), a technique for recording and displaying the timing and location of tongue-palate contact during speech.

Methods: Simultaneous acoustic and EPG recordings were made for 12 children (aged 10;1 to 17;9, mean 14.63) during completion of the Diagnostic Evaluation of Articulation and Phonology (DEAP: Dodd, Hua, Crosbie, and Holm, 2002) at pre- and post intervention. Children were randomly assigned to one of 3 groups: Group A (n=4) received 24 individualised therapy sessions using real-time visual feedback from EPG; Group B (n=4) received 24 individualised therapy sessions using traditional speech-directed therapy (informed by the earlier EPG assessment), and Group C (n=4) received 'treatment as usual' (no intervention by the research team) over the same 3 month period.

Results: Prior to intervention, the DEAP percentage consonants correct (PCC) scores indicated a range of speech disorders from mild (PCC=88) to severe (PCC=13). EPG assessment revealed errors undetected by perceptual analysis alone and with significant implications for both diagnosis and treatment of speech errors (e.g. distorted sibilants and double articulations). Children from both therapy groups made measurable progress although response to treatment has been highly variable.

Conclusions: Both EPG assessment and therapy are proving to be successful approaches for improving articulatory patterns in children with DS.

The prevalence and incidence of mental ill-health in adults with Down syndrome.

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Background**:** Epidemiology of mental ill-health in adults with Down syndrome research has mainly been limited to investigation of dementia.

Methods**:** A longitudinal cohort study of adults with Down syndrome received detailed psychiatric assessment at baseline (n = 186) and at two year follow-up (n = 134).

Results**:** Prevalence of Down syndrome for the 16 years and over population was 5.9 per 10,000 general population. Point prevalence of mental ill-health, excluding specific phobias, ranged from 10.8 to 23.7%, depending on diagnostic criteria applied. Two-year incidence of mental ill-health of any type ranged from 3.7 to 14.9% depending on criteria applied. The highest incidence was for depressive episode (5.2%) and dementia/delirium (5.2%). Compared with persons with intellectual disabilities (ID) of all causes, the standardized rate for prevalence of mental ill-health was 0.6 (0.4 to 0.8%) and the standardized incidence ratio for mental ill-health was 0.9 (0.6 to 1.4%). These rates decrease to 0.4 prevalence (0.3 to 0.6%) and 0.7 incidence (0.4 to 1.2%), if organic disorders are excluded. Urinary incontinence was independently associated with mental ill-health; other personal factors, lifestyle and supports, and other types of health needs and disabilities were not.

Conclusions**:** Mental ill-health is less prevalent in adults with Down syndrome than for other adults with ID. The pattern of associated factors differs from that found for other adults with ID. This suggests the protection against mental ill-health is biologically determined in this population, or that other factors protective for mental ill-health are yet to be identified for the population with Down syndrome.

Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities.

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Background**:** Carers can have a significant impact supporting people with intellectual disabilities to make healthy lifestyle choices. This study examines carers' training needs on diet and physical activity.

Methods**:** A cross sectional survey of the knowledge and perceptions of carers supporting adults with intellectual disabilities. An interviewer administered questionnaire was used to examine carer knowledge of public health recommendations on diet and physical activity; perceptions of the benefits of healthy diets and physical activity levels; and the carer views on the barriers to change experienced by individuals with intellectual disabilities.

Results**:** A total of 78 carers completed the interviewer administered questionnaire, 11 family carers and 67 paid carers. Overall, carers have a low level of knowledge around public health recommendations on diet and physical activity, and are significantly more likely to have full knowledge of the public health recommendation for consumption of fruit and vegetables than that for physical activity ($z= 37.4$, $p<0.001$). Carers attribute greater importance to the health benefits of diet, than the health benefits of physical activity ($z=-1.99$, $p<0.05$). Twenty one carers (26.9%) said there were no relevant barriers to the participant changing to a healthier diet and 22 (28.2%) believed that there were no relevant barriers to the participant with intellectual disabilities increasing their level of physical activity.

Conclusions**:** Carers supporting adults with intellectual disabilities have significant training needs relevant to promoting healthy lifestyles. This highlights the opportunity to promote health improvement via the development, and provision, of effective training initiatives for carers.

Resettlement outcomes for people with severe challenging behaviour moving from institutional to specialist community living.

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Background: It has been suggested that specialist skills and working methods are critical to effective provision of community services for people with severe challenging behaviour. Research evidence in support of specialist groupings has not demonstrated benefits for those with severe challenging behaviour (SCB).

Methods: Quality of life (QOL) consequences were assessed for a group of 19 adults with SCB (mean ABC score, 62.5) moving from institutional care to community-based purpose-built specialist NHS provision utilising 'state of the art' staff training in positive behaviour support. QOL measures of social and constructive activity, choice, and environmental measures were administered about three months before (T1) and three months after (T2) resettlement and at a 12-month follow-up (T3).

Results: T1/T2 comparisons revealed significant post-move increases in setting homelikeness, staff attention to residents and residents domestic activity. There were no significant differences in other variables, including level of, and staff response to, challenging behaviour. T1/T3 comparisons revealed significant increases in homelikeness, domestic activity, family contact and inter-resident social interaction and a non-significant increase in staff attention.

Conclusions: The results revealed no negative impact of resettlement. Significant beneficial changes between T1 and T3 are consistent with a move from restricted institutional settings to community settings with the increased opportunities they afford. The finding that the increased staff attention at T2 was not present at T3 illustrates the difficulty of active support maintenance. Despite the increased levels of resident domestic activity, the need for specialist residential services for this group might be questioned given the lack of change in challenging behaviour.

Making sense of therapy: clients' views of cognitive behavioural therapy.

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Background: An increasing number of therapists are adapting cognitive behavioural therapy (CBT) for people with intellectual disabilities. If CBT is to be adapted sensitively, then an important starting point is to explore how these individuals experience therapy.

Aim: The aims of this study were to obtain insight into clients' expectations and views of CBT.

Method: Semi-structured interviews were carried out with fourteen participants referred to community based services for CBT with problems of anxiety, depression or anger. They were interviewed shortly after their first and ninth appointments. The interviews were transcribed verbatim and analysed using Interpretative Phenomenological analysis.

Results: Four of the main themes to emerge were as follows:
Support: Clients described what they wanted from support generally and emphasised a wish to be treated with respect. *Therapeutic relationship*: The participants valued the experience of being listened to and understood, and having their problems acknowledged. *Practical understanding*: Whilst the participants grasped the session structure and commonly used therapeutic tasks, few were able to describe the relevance of the cognitive elements of therapy for their particular difficulties. *Therapeutic goals and a sense of control*: Although some participants had goals for therapy, few regarded it as a time limited and goal oriented process, or felt that this was acceptable. Most wanted a long-term supportive relationship with the therapist.

Conclusions: The findings are discussed in relation to efforts to adapt CBT for people with intellectual disabilities.

The perceptions and experiences of siblings with a brother with autism.

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Background: Studies investigating the adjustment and wellbeing of children who have a brother or sister with autism spectrum disorder (ASD) report mixed findings. At present there is limited empirical, exploratory research on the experiences and perceptions of siblings of children with special needs, much less with siblings of children with autism. Moreover there is a distinct lack of qualitative exploratory research with siblings of children with autism during middle-childhood.

Methods: Semi-structured interviews were used to explore the perceptions and experiences of nine typically developing siblings in middle-childhood (ages 8 to 12) who had a brother with ASD. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: The analysis yielded five main themes: siblings' perceptions of the impact of their brother's condition on their lives, siblings' perceptions of the attitudes of others and the influence these attitudes have on them, siblings' tolerance and acceptance towards their brothers with ASD, positive attitudes and experiences of the sibling participants' lives with their brothers, and sources of support for siblings.

Conclusions: Implications for future research and practice with siblings of children with ASD will be discussed, including the importance of these exploratory findings in informing future experimental research and the development of supports for siblings of children with ASD.

Individuals with Williams syndrome are impaired in visuo-spatial and verbal working memory.

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Background: Accumulating evidence suggests that individuals with Williams syndrome (WS) show impairments in working memory (WM). However, to date investigations have tended to focus on visuo-spatial skills, given the consensus of a general deficit in this processing domain. Additionally, there has been limited research exploring central executive aspects of working memory. The current aim was to characterise WM functioning in WS using tasks that tap both visuo-spatial and verbal components, with and without a central executive requirement.

Methods: Twelve individuals with WS (ranging: 12-26; mean age: 21) and 12 chronologically age-matched controls were recruited. Two participants with WS were unable to comply with task demands and their data (and that of their matched controls) was removed. All participants were assessed on verbal (BPVS II) and non-verbal (Ravens Progressive Matrices) ability tasks and verbal and spatial WM tasks.

Results: Individuals with WS were impaired on both executive and non-executive tasks. Surprisingly, compared to typically developing participants of comparable chronological age, individuals with WS showed similar levels of impairment on verbal and spatial WM tasks.

Conclusions: Verbal working memory abilities have not previously been assessed in WS. Our finding of impairment on executive and non-executive verbal working memory tasks adds to growing evidence suggesting that individuals with WS show deficits across a range of verbal tasks. Although early research suggested 'intact' or even 'superior' verbal skills in the profile of cognitive abilities associated with WS, the current evidence suggests working memory deficits within the verbal domain.

Behavioural indices of social anxiety in cornelia de lange syndrome.

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Background**:** Research has indicated that social anxiety may be a component of the behavioural phenotype of Cornelia de Lange syndrome (CdLS) as evidenced by high rates of selective mutism. In this study we experimentally assessed the behavioural presentation of social anxiety in CdLS during controlled social interactions.

Methods**:** Participants were twelve children with CdLS (mean age = 11.00; SD = 5.15) and twelve children with Cri du Chat syndrome (CdCS; mean age = 8.20; SD = 2.86) comparable on key characteristics. Participants were observed during controlled social interaction conditions with an examiner which involved high levels of social demand. Behaviours indicative of social anxiety were recorded in real time along with eye contact and episodes of active social interaction by the examiner.

Results**:** Contrary to expectation the overall duration of behaviours indicative of social anxiety did not differ between the groups. However, lag sequential analysis revealed that unlike participants with CdCS, participants with CdLS were significantly more likely to evidence behavioural indicators of anxiety in close temporal proximity to individual episodes of social interaction.

Conclusions**:** The study indicates that individuals with CdLS demonstrate a heightened probability of anxiety related behaviour during social interaction but only immediately local to episodes of active social interaction. Possible links between social anxiety and compromised expressive communication, early hearing impairment and social cognition deficits in CdLS are explored.

Using computers to improve access to psychological therapy services for adults with Intellectual Disabilities (ID).

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Background: The research is aimed to improve access to psychological therapy services for adults with ID by adapting for their use a Computerised Cognitive Behaviour Therapy (CCBT) programme for anxieties (panic and phobias), called 'FearFighter', and assessing its feasibility and potential effectiveness. 'FearFighter' was approved by the National Institute for Health and Clinical Excellence in February 2006.)

Methods: A mixed-method research design was developed involving the use of computers in: pre-intervention focus groups of adults with ID and specialist ID health professionals; a 6-8 week therapy intervention with one-month follow-up; and feedback interviews with the therapy recipients and caregiver 'therapy helpers'. The study was conducted through Colchester NHS Primary Care Trust's specialist Learning Disabilities Service (now North East Essex PCT).

Results: The study provided indicative evidence of both the 'feasibility' and 'potential effectiveness' of the adapted programme when used in community-based, computer-assisted therapy with four adults with mild and borderline ID. Reductions in both the physical symptoms of anxiety and fear avoidance were recorded in all four cases. Each of the therapy recipients expressed satisfaction with the adapted programme and computer-assisted therapy generally, and said they would use a computer in therapy again. The use of computers helped to engage adults with ID in both qualitative and quantitative research methods, and in the therapy itself, by making information more accessible and, thereby, facilitating communication.

Conclusions: The study has implications for: the development of psychological therapy services for adults with ID; both quantitative and qualitative research with adults with ID; and publishers of anxiety intervention studies.

Investigating the relationship between self-injurious behaviour and sensory dysfunction in people with learning disabilities.

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Background**:** Previous research has identified a possible connection between the presence of self-injurious behaviour (SIB) and sensory dysfunction in those with a learning disability (LD) (Symons and Thompson, 1997; Wisely et al., 2002).

Methods**:** The present study combined data from a small scale pilot study and a larger scale follow-up study. Forty-three care staff from day centres and residential networks for individuals with LD completed four questionnaires assessing the individuals' level of LD, SIB, sensory dysfunction and repetitive behaviour.

Results**:** Significant relationships were found between the level of LD and amount of sensory dysfunction and between external sensory dysfunctions and the self-injurious behaviour poking other orifices. There was no support however for a significant relationship between the level of LD and the amount of SIB shown. Similarly, there was no support for a significant association between the amount of sensory dysfunction and the severity of SIB. Finally, it was predicted that the more SIB that was shown, the more repetitive behaviour that would be shown but the results did not reach significance.

Conclusions**:** The results provide support for the proposed association between the level of LD and sensory dysfunctions, and for the hypothesis that certain SIBs will be associated with specific sensory dysfunctions. Alternative suggestions for the lack of significant support found for the other tested hypotheses are provided by taking a more neurological approach.

Mainstream in-patient mental health care for people with learning disabilities: service user and carer experiences.

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Background: Our understanding of the experiences of adults with intellectual disabilities and their carers who have been admitted to mainstream psychiatric care is limited. Little is known about the impact of policy changes and new initiatives aimed at improving mental health care for this group.

Methods: Qualitative in-depth interviews were conducted with 12 service users and 11 carers who had experienced an in-patient admission to mainstream mental health services. Participants had been admitted to four different inpatient units across a large rural and several urban areas. All interviews were recorded and transcripts analysed following the principles of thematic analysis.

Results: Participants cited the provision of respite and good basic care as the most positive aspects of the admission. Overall the results paint a picture of inpatient services as very hard to access, disempowering and unpleasant environments where little treatment of the type desired takes place. Importantly, participants described the impact of having an intellectual disability as far reaching and a sense that needs arising from their disability were poorly met, while the person was treated as very different during the admission.

Conclusions: The results suggest that mainstream mental health services have a long way to go before service users and carers will perceive them as able to meet the needs of individuals with people with intellectual disabilities. Despite clear national policies and new initiatives which have come into effect over the past five years, participants' accounts in this study suggest that inclusion and choice are far from a reality.

The experience of accessing services for individuals with Asperger Syndrome and their carers.

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Background: Since Lorna Wing first coined the term Asperger syndrome over 25 years ago (Wing, 1981), an increasing number of children and adults in the UK are being diagnosed with this, or other autism spectrum disorders almost every day. Despite the growing acknowledgement of the unique needs of this client group, adults with Asperger syndrome have traditionally found great difficulty in accessing services.

Methods: Two projects investigated the experience of individuals diagnosed with Asperger syndrome after the age of 18 and the corresponding experience of family members. Using a grounded theory methodology, 12 individuals with Asperger syndrome and 12 family members were interviewed about their experiences of accessing services.

Results: Individuals with Asperger syndrome described their therapeutic journeys as fitting broadly into a number of key categories, encompassing the experience of seeking help for an un-named problem, the development of personal identity, the impact of the diagnosis and post-diagnostic support. Family members similarly described categories of experience encompassing pre-diagnosis feelings of getting nowhere, the impact of the diagnosis, the expectations or demands of services post-diagnosis and the services offered in an ideal World. Both service users and family members stressed the significant impact of a diagnosis as a turning point in their experience of services.

Conclusions: The findings of this study appear to support the view that the process of receiving a diagnosis of Asperger syndrome can have a significant psychological impact on everyone involved. The importance of diagnosis and post-diagnostic support should be key areas to consider in future service development.

Psychiatric illness in people with Prader-Willi syndrome.

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Background**:** Psychotic illness is strongly associated with the maternal uniparental disomy (mUPD) genetic subtype of Prader-Willi syndrome (PWS), but not the deletion genetic subtype. This study investigated the clinical features of psychiatric illness associated with PWS. We considered possible genetic and other mechanisms that may be responsible for the development of psychotic illness predominantly in those with mUPD.

Methods**:** The study sample comprised 119 individuals with genetically-confirmed PWS, of whom 46 had a history of psychiatric illness. A detailed clinical and family psychiatric interview was undertaken with each of the 46 individuals using the PAS-ADD, OPCRIT, Family History and Life Events Questionnaires.

Results**:** Individuals with mUPD had a higher rate of psychiatric illness than those with a deletion (22/34 vs. 24/85, $p<0.001$). The profile of psychiatric illness in both genetic subtypes resembled an atypical affective disorder with or without psychotic symptoms. Those with the deletion genetic subtype were more likely to have developed a non-psychotic depressive illness ($p=0.005$) and those with mUPD a bipolar disorder with psychotic symptoms ($p=0.00005$). Individuals with a deletion and psychotic illness had an increased family history of affective disorder. This was confined exclusively to their mothers.

Conclusions**:** Psychiatric illness in PWS is predominately affective with atypical features. The prevalence and possibly the severity of illness are greater in those with mUPD. We present a 'two hit' hypothesis, involving imprinted genes on chromosome 15, for the development of affective psychosis in people with PWS.

Adulthood in individuals with Williams syndrome: Patterns of cognitive abilities, adaptive functioning and mental health.

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Background: Much of what is known about Williams syndrome (WS) is derived from research involving children and adolescents. Relatively little is known about adults with the syndrome. In view of this, two studies were carried out to (1) evaluate the abilities of adults with WS and (2) to examine patterns of abilities between age groups and over time.

Methods: Two groups of adults with WS and their parents/carers completed a series of assessments and interviews to evaluate general cognitive ability, adaptive behaviour skills and psychopathology. Study 1 comprised 92 adults with a genetic diagnosis of WS. Study 2 consisted of 49 individuals with WS who had taken part in a previous study of the syndrome 10 years ago.

Results: Study 1 indicated mean age equivalents of 10yrs and 7 yrs respectively for receptive and expressive vocabulary and mean IQ scores of 62 (verbal), 58 (performance) and 56 (full scale). Age equivalents for adaptive behaviour skills ranged from 6:10 to 8:02. Mental health problems were diagnosed in 24% of the sample. Study 2 indicated that while language and cognitive abilities were similar between age groups and over time, individuals in their 30s had better daily living and social skills than those in their 20s.

Conclusions: Results indicate that adults with WS typically have mild intellectual disabilities, language skills at a 7-10 year level and adaptive behaviour skills at a 7-8 year level. Across time, abilities remain generally stable, with some areas of improvements. Mental health problems were identified in just under a quarter of the sample.

Persistence of challenging behaviours in adults with intellectual disability over a period of 11 years.

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Background: Challenging behaviours in people with an intellectual disability (ID) often develop early and tend to persist throughout life. This study presents data on the chronicity of challenging behaviours in adults with ID over a period of 11 years, and explores the characteristics of people with persistent serious behaviour problems.

Methods: Support staff provided data on 58 adults living in a residential facility using an interview survey schedule assessing challenging behaviours in 1992 and 2003.

Results: Participants presenting with serious physical attacks, self-injury and frequent stereotypy were more likely to persist in these behaviours over time. The relative risk for severe self-injury in 2003 for those self injuring in 1992 was 2.88. The relative risk over this period for physical attacks was 3.21 and for stereotypy 3.49. Individuals with persisting behaviour problems differed from those who did not present serious behaviour problems on the basis of their younger age, increased mobility, and decreased sociability and daily living skills in 1992.

Conclusions: The relatively high persistence of serious challenging behaviours highlights the need to identify the factors related to maintenance of these behaviours over time. The participant characteristics and adaptive behaviours identified in the present study were not consistently related to the persistence of challenging behaviours. Therefore, other factors, including environmental characteristics, are likely to be related to challenging behaviour persistence.

Self-injurious behaviour in Cornelia de Lange syndrome influenced by the presence of pain and discomfort: A case study.

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Background: Cornelia de Lange syndrome (CdLS) is a genetic disorder affecting 1 in 10- 50,000 live births (Opitz, 1985). Mutations on chromosomes 5 (5p13; Gillis et al., 2004; Krantz et al., 2004; Miyake et al., 2005; Tonkin et al., 2004), 10 (SMC3 gene; Deardorff et al., 2007) and X linked SMC1 gene (Musio et al., 2006) have been identified. CdLS is characterised by developmental delay, delayed growth, distinctive facial features, limb abnormalities (Jackson, Kline, Barr & Koch, 1993) and a host of painful medical conditions such as chronic otitis media and conjunctivitis, dental and gastrointestinal problems. Gastro-oesophageal reflux is particularly common in the syndrome (Arron, 2003). Behavioural characteristics include autistic like characteristics, hyperactivity and self-injurious behaviour. Evidence in the literature suggests strong associations between behavioural characteristics such as hyperactivity and self-injurious behaviour with painful medical conditions such as gastro-oesophageal reflux in CdLS (Luzzani et al., 2003).

Methods: The participant (C) is a 12 year old female with CdLS. She was assessed on four occasions over a nine month period, using a variety of observational and interview methods to ascertain the presence and possible function of her self-injurious behaviour.

Results: The participant displayed varying degrees of self-injurious behaviour across the four visits, with greater frequency and severity of self-injury coinciding with parental reports of painful health conditions and subsequent reductions in the level of self-injury following dental treatment and reinstatement of medication for gastro-oesophageal reflux.

Conclusions: The findings clearly demonstrate a change in C's self-injurious behaviour after her dental and reflux treatment, suggesting that her self-injury is, at least in part, associated with pain and discomfort that she is experiencing.

Developing measures of the effects of traumatic life events for people with intellectual disabilities.

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Background**:** Research suggests high levels of adverse life events and associated mental ill health experienced by people with intellectual disabilities. However a systematic review revealed that research has been hampered by the lack of measures of the effects of traumatic life events that are psychometrically validated for people with intellectual disabilities.

Methods**:** Service users, relatives, advocates, and staff gave their views on the effects of traumatic life events seen in people with intellectual disabilities. Data was collected via interview, questionnaire and focus group.

Results**:** The effects described by participants were in the main the same as those seen in the general population. Where differences were noted these were in accordance with effects of trauma noted in intellectual disability research e.g. behavioural problems. The Lancaster and Northgate Trauma Scales (LANTS) have been developed from the data in an informant and a self-report version.

Conclusions**:** The next part of the study aims to examine the psychometric qualities of the newly developed LANTS trauma measures, and to examine putative causal links between life events and trauma effects.

"Fairness of Interview" – A new legal concept.

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Background: The concept of "fairness" with regard to police interviews of mentally disordered offenders has not been described in the legal of medical literature.

Methods: A survey was carried out of sixteen forensic psychiatrist working in high security settings to establish who had been asked to comment on the "fairness of interview" of alleged mentally disordered offenders in 2006. Four reports were found to comment on the fairness of offender's interview and these reports were analysed using a grounded theory approach. All four reports concerned an accused who had a learning disability.

Results: The following six themes emerged: i) the presence of a mental disorder, including the functional level of intellectual ability; ii) the interview format; iii) the interview style, specifically the use of coercion; iv) psychological vulnerabilities of the interviewee, including their suggestibility, acquiescence and veneer of competence; v) the accused's level of comprehension, in particular of the charge and caution; and vi) the presence or absence of an appropriate adult.

Conclusions: Fairness is now a legal test of retrospective consideration by the court on the conduct of a police interview. The authors suggest that the finding of this study have implications for clinicians being asked to assess "fairness of interview".

Does a deficit in attention switching in Prader-Willi syndrome underlie some of the characteristic challenging behaviours?

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Background: The behavioural phenotype of Prader-Willi syndrome (PWS) includes repetitive behaviours and temper outbursts. Our previous research suggests that temper outbursts and repetitive questions in PWS can be associated with change, and that a relationship exists between repetitive questions, resistance to change and a specific deficit in attention switching. We investigated the hypothesis that a deficit in attention switching underlies the resistance to change and that this can cause repetitive questions and temper outbursts.

Methods: Four individuals with PWS participated. Structured Descriptive Assessment (SDA) sessions observed participants at baseline whilst engaging in an established routine or expected activity, and during test sessions when changes were imposed. Analogue sessions exposed participants to controlled, rapidly alternating conditions, in which i) specific routines were followed (no change), ii) routines were changed (change), and using computer games; iii) a high or low demand on was placed on attention switching, or iv) the task demands and the task difficulty were controlled for with no demand on switching. All sessions were filmed and coded for behaviours operationalised for each participant.

Results: Temper outbursts occurred only in SDA sessions in which changes were imposed, also, more questions were asked in these sessions compared to baseline. An individual profile of temper outburst behaviours (including precursors) was constructed for each participant. More questions and more temper outburst behaviours occurred in change compared to no change analogue sessions, and in switching analogue conditions compared to control conditions.

Conclusions: Our results support the hypothesis that the deficit in attention switching in PWS may indeed underlie the resistance to change. Particular behaviours including repetitive questions and temper outbursts can result from this resistance to change.