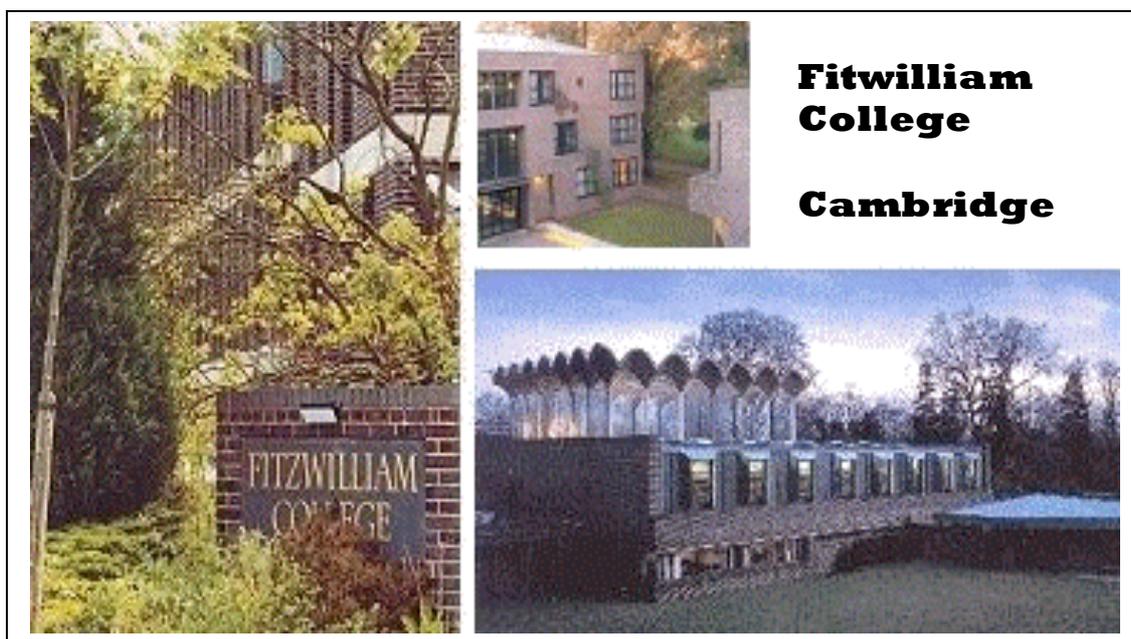


4th Seattle Club Meeting

16th - 17th December 2004



Welcome

Welcome to the 4th 'Seattle Club' Conference for researchers in intellectual disabilities and other developmental disabilities in the UK and the Republic of Ireland. We're very pleased that so many people have submitted, particularly in the same year as the IASSID Conference.

As with previous meetings, the emphasis is on presenting data from research in the behavioural and social sciences. We have maintained a number of features from previous Conferences that seem to be successful: all participants are active researchers, with encouragement particularly to colleagues at an early stage in their careers; research being reported is pre-publication and reflects the cutting edge; there are no parallel sessions, so that everyone can access everything; organisation is electronic to save on cost and to keep fees as low as possible.

In addition, following its successful introduction last year, we have retained a poster session. This is intended to be of equal status to work being presented in the paper sessions and plenty of time has been allocated to view/discuss the posters with their authors.

There are a couple of new introductions. First, we have tried to incorporate more time for discussion, both in the paper sessions, and in a session reflecting on the Conference, which John Taylor has kindly agreed to organise. We hope everyone will take advantage of the additional time. Secondly, because of some careful management by previous hosts, we have been able to offer nine Studentships to researchers at a very early stage in their careers, who have not yet been able to start collecting data. The Studentships were randomly allocated and were awarded to:

David Charnock (Nottingham) Gillian Crawford (Glasgow) Jason Devereux (Bangor)
Margriet Groen (Oxford) Becca Hawkins (Cambridge) Paul Langthorne (Kent)
Jaycee Pownall (Glasgow) Panagiotis Sapierras (Cambridge) Susannah Turner
(Lancaster)

The existence of the Conference is mainly passed on by word of mouth, and there are likely to be many more UK and Irish researchers in intellectual disabilities out there. Please do what you can to distribute information to interested colleagues and contacts. If possible, please join the ID-Research-UK email list at <http://www.jiscmail.ac.uk> so that you do not miss information about future Conferences.

Our grateful thanks go to Sue Hampton-Matthews and Robbie Fountain, who have provided the administrative support that is essential for these events.

We hope you enjoy the Conference.

Ad-hoc organising committee for 2004:

Tony Holland *Department of Psychiatry (Section of Developmental Psychiatry), University of Cambridge*

Isabel Clare *Department of Psychiatry (Section of Developmental Psychiatry), University of Cambridge*

Richard Hastings *School of Psychology, University of Wales Bangor*

Peer Reviewers:

Andrew Jahoda *Division of Psychological Medicine, University of Glasgow*

Isabel Clare and **Tony Holland**

4th Seattle Club Conference on Research in Intellectual Disabilities Fitzwilliam College, University of Cambridge, December 16 – 17, 2004

FINAL PROGRAMME

Thursday 16th December 2004

10.00 – 10.45 am	Registration and coffee	
10.45 – 11.00 am	Welcome – Tony Holland	Reddaway Room
11.00 – 12 noon	Session 1 – Chair: Tony Holland	Reddaway Room
12.00 – 1.00 pm	Session 2 – Chair: Biza Kroese	Reddaway Room
1.00 – 2.00 pm	Lunch	Dining Hall
2.00 – 3.15 pm	Session 3 – Chair: Chris Oliver	Reddaway Room
3.15 – 3.45 pm	Tea	
3.45 – 5.00 pm	Session 4 – Chair: Richard Hastings	Reddaway Room
5.30 – 7.30pm	Poster session	Walter Grave Room
7.45 pm	Dinner	Dining Hall

Friday 17th December 2004

8.50 – 9.00 am	Introduction to second day – Tony Holland	Reddaway Room
9.00 – 10.15 am	Keynote Speech – Eric Emerson <i>Poverty, Socio-economic status and People with Intellectual Disabilities</i>	Reddaway Room
10.15 – 10.45 am	Coffee	
10.45 – 12.00 noon	Session 5 – Chair: Isabel Clare	Reddaway Room
12.00 – 1.00 pm	Lunch (meeting of Seattle Club organising group during lunch)	Dining Hall
1.00 – 2.00 pm	Session 6 – Chair: Andrew Jahoda	Reddaway Room
2.00 – 2.45 pm	<i>Implications for research with people with intellectual disabilities in the UK and the Republic of Ireland</i>	
2.45 pm	Close and tea	

Keynote Speech

Poverty, socio-economic status and people with intellectual disability

Eric Emerson

Institute of Health Research, University of Lancaster

In this presentation I will argue that applied researchers need to pay much more attention to issues pertaining to poverty (and other indicators of socio-economic status) when attempting to understand/improve the lives of people with intellectual disabilities (ID) and those who support them. The main arguments I will use are: (1) there is extensive evidence from the non-ID literature that poverty/low SES is damaging to health and life experiences; (2) poverty continues to affect a significant minority of people in the UK; (3) poverty disproportionately affects people with ID. I will use data from our recent work to suggest that the high rates of poverty experienced by children with ID and their families may go some way to accounting for the poor mental health experienced by children and low levels of well-being experienced by their mothers. I will also present data to suggest that poverty acts to moderate relationships between child characteristics and maternal well-being. Finally, I will discuss approaches to the measurement of poverty that are likely to be relevant to our future work.

Emerson, E. (2004). Poverty and children with intellectual disabilities in the world's richer countries. *Journal of Intellectual and Developmental Disability*, **29** (4), 1-20.

List of Papers

SESSION 1

- Paper 1 On the importance of being consistent: Maternal predictors of improved verbal ability in an at risk sample of two-year-olds.
Rosie Ensor and Claire Hughes
- Paper 2 Sleep problems and daytime challenging behaviour in a clinical sample of children with a moderate to severe intellectual disability and/or autism. The relationship with maternal stress.
Eleanor Chalmers, S. Cheseldine and D. Manders
- Paper 3 Clinical significance of outcome for children, and outcomes for families, after 12 months of early intensive behavioural intervention.
Hanna Kovshoff, B. Remington, R. Hastings, F. degli Espinosa, E. Jahr, T. Brown, P. Filby, M.Lemaic and N. Ward

SESSION 2

- Paper 4 Transition from school to adult life: How do young people with intellectual disabilities make sense of their transition experiences?
Joanna Kirk
- Paper 5 The attributions of teaching staff toward challenging behaviour exhibited by children with intellectual disabilities: A comparison of attributions elicited using real incidents of challenging behaviour and vignettes.
Victoria Lucas, P. Langdon and S. Collins
- Paper 6 Behaviour problems and psychiatric diagnoses from childhood to early adolescence in young people with severe intellectual disabilities.
Oliver Chadwick, Y. Kusel, M. Cuddy and E. Taylor

SESSION 3

- Paper 7 Links between behavioural problems and stress in mothers and fathers of children with intellectual disabilities.
Chris Hill, A. Beck and R. Hastings
- Paper 8 The untreated PKU trial: Testing the effectiveness of a low phenylalanine diet for adults with previously untreated phenylketonuria (PKU) and severe intellectual disabilities.
Allayne Amos, G. Murphy, S. Johnson, P. Lee and L. Robertson
- Paper 9 People with an intellectual disability leaving hospital: deinstitutionalisation and community use.
Peter Baker
- Paper 10 The impact of a vulnerable adult protection policy on the psychological and emotional well being of adults with an intellectual disability.
Corinna Bruder, B. Kroese and S. Bland

SESSION 4

- Paper 11 Genetic diagnosis for intellectual disability: Who wants one and why?
Helen Statham, N. Hallowell, M. Ponder, L. Raymond and M. Richards
- Paper 12 Repetitive behaviour in genetic syndromes.
Joanna Moss, C. Oliver, K. Arron, C. Burbidge and K. Berg
- Paper 13 Autistic Spectrum Disorder and repetitive behaviour in Lowe Syndrome.
Katy Berg, C. Oliver, J. Moss, K. Arron and M. Hooker
- Paper 14 Cognitive and behavioural predictors of referral for dementia assessments in people with Down syndrome.
Dawn Adams, C. Oliver, S. Peters, T. Basra, T. Broquard, S. Kalsy, E. Konstandinidi and S. McQuillan

SESSION 5

- Paper 15 Predicting asphyxiation in adults with intellectual disabilities and dysphagia.
Darren Chadwick and F. Kevan
- Paper 16 Predictors of positive perception in parents of children with intellectual disabilities.
Felicity Greer and I. Grey
- Paper 17 Physical interventions and people with intellectual disabilities: Service user views.
Anne MacDonald, P. McGill and R. Deveau
- Paper 18 The involvement of people with intellectual disabilities in the organisation and delivery of specialist health services.
Bob Hallawell and P. Standen.

SESSION 6

- Paper 19 Face-to-face communication in the self-advocacy movement: An exploratory case study.
Marcus Redley, D. Weinberg and B. Turner
- Paper 20 Investigating the financial decision-making capacity of men and women with intellectual disabilities.
Irenka Suto, I. Clare and T. Holland
- Paper 22 Collation and interpretation of intellectual disability register data for policy and strategic planning purposes.
David Felce

Abstracts of papers

Paper 1

On the importance of being consistent: Maternal predictors of improved verbal ability in an at-risk sample of two-year-olds

Rosie Ensor and Claire Hughes
Centre for Family Research, University of Cambridge

Objectives

Mild intellectual disability is strongly associated with social disadvantage, but the mechanisms underpinning this association are poorly understood. For other child outcomes (e.g., behavioural problems, educational achievement) two consistent findings in the literature concern (i) the cumulative effects of risk (e.g., material and psychosocial risk) and (ii) parental practices and parental well-being as mediators of the impact of social adversity. The present study explores whether similar accounts explain contrasts in children's improvements in verbal ability between the ages of two and three years.

Methods

A sample of 140 children (85 boys and 55 girls) from predominantly low-income families was seen twice in a university lab-setting with an interval of approximately 12-months (ages two and three). During each visit, children were given two verbal ability subtests from the British Abilities Scale while the mothers completed a short booklet of standard questionnaires about her well-being (e.g., depression, stress, self-esteem as a parent). Each mother-child pair was then filmed for 25 minutes in three settings (free play / toy tidy up / structured play), and the videotapes were coded at 30-second intervals for maternal and child talk and behaviour.

Design

Our analyses will focus on children's performances on the verbal comprehension subtest, as it is possible that for some children, problems of non-compliance contributed to low scores for expressive language. First, we examine the correlates of individual differences in verbal comprehension at age two and at age three. Next, we divide the sample into two groups, according to whether difference between these scores was above or below the mean. These two groups ('high gain' vs. 'low gain') were then compared on child and family characteristics that were significantly associated with verbal comprehension at either time point.

Results

These analyses showed that verbal comprehension at both time-points was significantly correlated with both child talk and maternal consistency in responsiveness at time 1. In addition, verbal comprehension at age two was significantly correlated with social background, maternal responsiveness and maternal consistency of positive affect. Comparing the 'high gain' vs. 'low gain' group, group differences were found for time 1 child talk ($t = 2.18, p < .05$) and (marginally) for time 1 verbal ability ($t = 1.80, p = .08$). In addition, mothers of 'low gain' children reported higher rates of daily stress ($F = 4.02, p < .05$) and lower self-esteem in their parental role ($F = 8.82, p < .01$) when compared to mothers of 'high gain' children. Mothers of 'high gain' children were also more likely to show consistent positive affect ($F = 7.79, p < .01$) and responsiveness ($F = 20.13, p < .001$). With the exception of self-esteem, these maternal differences all remained significant when toddler initial verbal comprehension and frequency of talk were controlled.

Conclusions

These findings highlight several specific features of mother-child interactions that are associated with good improvement in verbal comprehension in a diverse sample of very

young children. Interestingly, in contrast with previous reports of a general cumulative impact of risk factors, these findings indicate independent contributions from these maternal characteristics, and so indicate new directions for interventions aimed at improving early language skills in disadvantaged children.

Paper 2

Sleep problems and daytime challenging behaviour (CB) in a clinical sample of children with a moderate to severe intellectual disability and/or autism: The relationship with maternal stress

Eleanor Chalmers, Sally Cheseldine and Duncan Manders
Learning Disability Department, Lynebank Hospital (Fife Primary Care Trust)

Objectives

The prevalence rates of sleep problems have been found to be significantly higher in children with an intellectual disability and/or autism compared with typically developing children and correlated with daytime CB and maternal stress. To date, no study has investigated this relationship and prevalence rates specifically in a clinical population. It was hypothesised that children who had been referred to an intellectual disability service for complex psychological and behavioural difficulties and were, by definition, considered to have problems reaching clinical significance, would have increased sleeping difficulties compared with children with the same degree of disability whose behaviour had not warranted referral. Further, this would have an impact on maternal stress in that stress levels would be again higher in the clinical group.

Design

A questionnaire method was used to analyse between group differences on measures of children's sleep, daytime CB and maternal stress.

Methods

Sixty-seven mothers of children with a moderate to severe intellectual disability and/or autism participated. Of these, 37 parents had a child who was currently being treated by the intellectual disability and autism service. Thirty had a child attending special schools, whose behaviour had not warranted a current referral to a clinical service. Mothers were asked to complete three questionnaires.

Results

Compared with the control group, mothers of children in the clinical group rated their children as having significantly more sleeping problems and daytime challenging behaviour. They also scored more highly on a measure of maternal stress. A correlation was found between all three variables in the clinical group; sleep and maternal stress were not correlated in the control group. Regression analysis suggested that children's sleep problems were the best predictor of maternal stress in the clinical group and daytime CB was the best predictor of maternal stress in the control group.

Conclusions

Clinicians working in this area should be aware of a higher prevalence of sleep problems in children referred to their service. Further, levels of maternal stress should be considered particularly as established literature suggests that this may negatively interfere with treatment outcome.

Paper 3

Clinical significance of outcome for children, and outcome for families, after 12 months of early intensive behavioural intervention

Hanna Kovshoff, Bob Remington, Richard Hastings, Francesca degli Espinosa, Erik Jahr, Tony Brown, Paula Filby, Monika Lemaic and Nicholas Ward
School of Psychology, University of Southampton

Objectives

To examine key outcomes for children with autism and their families after 12 months of intensive Applied Behaviour Analysis (ABA) intervention on the Southampton Childhood Autism Programme (SCAmP).

Design

Data from 46 pre-school children with autism and their parents were gathered at baseline and 12 months into SCAmP. Twenty four children were on ABA programmes and 21 were a standard services comparison group.

Methods

Standard tests of child intellectual functioning and adaptive behaviour, as well as measures of maternal and paternal mental health, stress and positive perceptions were taken.

Results

ANCOVA analyses for child data after 12 months of intervention reveal significant increases in IQ and MA for the ABA group. Using the Reliable Change Index to identify clinically significant change in IQ scores shows that unlike the comparison group, more children in the ABA group meet criteria for clinically significant improvement while fewer children meet criteria for clinically significant regression. ANCOVA analyses show no differences on parental adjustment measures between the ABA group and the comparison group at 12 months for mothers and for fathers. Parents in both ABA and comparison groups show elevated stress over the data collection period but this change was no more or less marked in the two groups

Conclusions

Group and individual child results support the effectiveness of ABA intervention over the comparison group. These data show no additional burden on parents of engaging in EIBI with both groups reporting high levels of stress. Further research is needed to address longer-term outcomes, and to identify programme, child and family variables that predict clinically significant improvement.

Paper 4

Transition from school to adult life: How do young people with intellectual disabilities make sense of their transition experiences?

Joanna Kirk

Community LD Team, South Birmingham NHS Trust

Objectives

The study aimed to answer two research questions:

1. How do young people make sense of their transition from school to work / college?
2. What do they understand the effects of the transition to be?

Design

Interview questions and prompts were developed following discussion with professionals and a focus group pilot study. Single interviews with young people were recorded and transcribed. Data were analysed using grounded theory to explore the richness and diversity of young people's experiences of transition.

Methods

Seven young people with intellectual disabilities were selected from those participating in a follow-up study into transition. All participants were of white British cultural background, aged between 16y 10m and 17y 11m and had left school (4 male, 3 female). Participants were interviewed once using semi-structured interview and visual cues and invited to talk about their experiences since leaving school.

Results

Young people identified differences between school and college / work and most viewed these changes positively. Five main themes developed through grounded theory data analysis: Getting support / feeling safe, Individual's resources, External resources / restrictions, Self-fulfilment and Instability-continuity. These were represented in a model showing links between categories that young people identified.

Conclusions

Most young people initially found the transition frightening but access support and adjust to their new surroundings. The data highlight the need to consider influences of other life events, and ways in which these impact on transition. Recommendations for research and clinical practice are made, in particular identifying support needs of young people and their families.

Paper 5

The attributions of teaching staff toward challenging behaviour exhibited by children with intellectual disabilities: A comparison of attributions elicited using real incidents of challenging behaviour and vignettes

Victoria Lucas, Peter Langdon and Suzanne Collins
School of Medicine, Health Policy and Practice, University of East Anglia

Objectives

The objectives of the study were to elicit the attributions of teachers toward the challenging behaviour of children with intellectual disabilities using two methodologies: 1) vignettes depicting challenging behaviour, and 2) actual incidents of challenging behaviour.

Design

A related samples design was employed. A group of classroom staff reported their attributions towards an actual incident of challenging behaviour that they had experienced. This incident was subsequently transformed into a vignette, and the same staff made attributions toward the vignette at a later time point.

Methods

Seventy-four classroom staff were recruited and took part in the study. Attributions toward an incident of challenging behaviour were reported via a postal questionnaire on the day the incident occurred. Approximately two weeks following this, staff reported their attributions toward a vignette depicting the incident of challenging behaviour they had experienced also via a postal questionnaire.

Results

The results indicated differences in the attributions of staff toward the real incident of challenging behaviour as compared to the vignette. Weiner's cognitive-emotional-action model (1980) was supported following real instances of challenging behaviour, but not the vignettes. There was no evidence to support Weiner's adapted model of achievement motivation. Both staff experience and behaviour topography were found to influence staff responses to challenging behaviour.

Conclusions

There appear to be differences in the attributions staff make toward vignettes as compared to real incidents of challenging behaviour, and there are associated theoretical implications. These findings have implications for the validity of research employing vignette methodology.

Paper 6

Behaviour problems and psychiatric diagnoses and from childhood to early adolescence in young people with severe intellectual disabilities

Oliver Chadwick, Yvette Kusel, Marion Cuddy and Eric Taylor
Department of Psychology, Institute of Psychiatry, King's College London

Objectives

To examine the prevalence, course and persistence of mental health and behaviour problems between childhood and early adolescence in young people with severe intellectual disabilities.

Design

From a sample of 111 children with severe intellectual disabilities who had been identified from the registers of six special schools at 4-11 years of age, 82 were traced and reassessed five years later at the age of 11-17 years.

Methods

Behaviour problems were assessed by means of parental interviews conducted in the family home and parent and teacher questionnaires. Parental reports of psychiatric diagnoses were checked against health records.

Results

With most behaviour problems, including aggression, destructive behaviour and self-injury, there was little difference in rates between the two assessment occasions. However, in spite of this overall pattern of stability, the rates of some behaviour problems, including over-activity, showed significant reductions between childhood and early adolescence. Persistence rates for most behaviour problems appeared comparable to those reported for similar behaviours in general population studies of children. There was no significant difference in the proportion of cases with psychiatric diagnoses between the two assessment occasions, although brief psychotic episodes emerged in three cases in adolescence.

Conclusions

The findings suggest that the prevalence of mental health and behavioural problems in young people with severe intellectual disabilities remains relatively stable between childhood and adolescence, although some specific behaviour problems diminish. However, a small minority of children may develop severe psychiatric disorders in adolescence.

Paper 7

Links between behaviour problems and stress in mothers and fathers of children with intellectual disabilities

Chris Hill, Alex Beck and Richard Hastings
Department of Psychology, University of Wales Bangor

Objectives

To examine the cross-sectional and longitudinal relationships between behaviour problems in children with intellectual disabilities and parental adjustment.

Design

The research incorporates both cross-sectional and longitudinal elements, with families being assessed twice, one year apart.

Methods

140 mothers and 60 fathers participated in the research, completing questionnaire and telephone interview measures. The Behaviour Problems Inventory was completed by the mother and where possible, the father and child's teacher, to investigate the degree and frequency of behaviour problems in the children. The Questionnaire on Resources and Stress was also administered and the subscale 'Parent and Family Problems' used as an indicator of stress in the parents.

Results

In cross-sectional regression analyses, behaviour problems predict parental stress and parental stress predicts behavioural problems after controlling for relevant demographic variables. In longitudinal regression analyses, evidence was only found in one causal direction, namely that behavioural problems drive parental stress over time.

Conclusions

The results of this research concur with other longitudinal data analyses suggesting that behavioural problems are a causal factor in parental adjustment. The present study illustrates the value of longitudinal designs in research with families of children with intellectual disabilities.

Paper 8

The untreated PKU trial: Testing the effectiveness of a low phenylalanine diet for adults with previously untreated phenylketonuria (PKU) and severe intellectual disabilities

Allayne Amos, Glynis Murphy, Sally Johnson, Phil Lee and Lesley Robertson.
Institute for Health Research, University of Lancaster

Objectives

- a) To describe the behaviour of adults with untreated phenylketonuria, and
- b) To assess the efficacy of a low phenylalanine diet for this group.

Design

The study comprises a case finding stage and then a prospective double-blind randomised placebo-controlled crossover trial of 36 adults with untreated PKU over 60 weeks.

Methods

Initial case-finding stage - survey sent to UK healthcare professionals, followed by a questionnaire about e.g. challenging behaviour, communication skills of identified individuals. Main study – this is still underway and will only be briefly described

Results

157 adults with PKU have been identified - significantly lower than expected.

1. 14% are untraceable, 26% are or have been on diet, 38% are untreated.
2. Comparison of reported behaviour of people who are 'on diet' with those that are 'untreated' revealed very few differences.

Conclusions

Many adults with severe intellectual disabilities may have undiagnosed PKU. Benefits of diet treatments are difficult to demonstrate: standard indicators are often insensitive and carers can find diet treatments difficult to manage.

Paper 9

People with an intellectual disability leaving hospital: Deinstitutionalisation and community use

Peter Baker

CLDT, East Sussex County Health Care NHS Trust

Objectives

The purpose of this study was to examine the impact of community use of people moved from a small 'learning disability' hospital, with the expectation that following the move that people would experience greater levels of community use. Furthermore, an examination of the influence individual and service related variables on service use was carried out.

Design

The impact of resettlement for the residents of a small 'learning disability' hospital on their use of their communities and leisure was investigated using a mixed design in which changes in the dependent variable (GCPLA) were measured within-subjects (before and after leaving hospital) and between-subjects (using a comparison group of people who lived in the community throughout the study). In addition, a standard multiple regression design was employed in order to explore the relative contribution of client and service variables to GCPLA scores. Prior to resettlement the following data were collected in relation to all participants: ABS, BPI, GCPLA and a specially designed Goal Rating Scale. The GCPLA was repeated with all participants 6 months after the hospital closure.

Methods

The study sample involved 62 individuals with a severe/profound intellectual disability who were residing in NHS provision. The resettlement group comprised 26 people (13 men and 13 women). The comparison group included 34 individuals (13 women and 21 men) who lived in community residential services run by the same NHS Trust. All participants were of white British ethnic origin.

Results

Resettlement from hospital corresponded with a significant increase in the range and frequency of leisure and community contacts. Community and leisure use were found to be related to place of residence, adaptive behaviour and the robustness of community goals within the service users' individual plans.

Conclusions

In spite of the encouraging results, specific service related factors need to be addressed in order to facilitate acceptable levels of community use for service users with a learning disability.

Paper 10

The impact of a vulnerable adult protection policy on the psychological and emotional well-being of adults with an intellectual disability

Corinna Bruder, Biza Kroese and Sarah Bland

University of Birmingham, and Shropshire County PCT (Services for Adults with a Learning Disability)

Objectives

The study aimed to explore how referrers of vulnerable adults with an intellectual disability understood their clients to be affected emotionally and psychologically by their experiences of going through protection proceedings.

Design

A qualitative design based on grounded theory was chosen. The research was carried out in three stages: data collection through in-depth interviews with referrers, analysis of minutes of the protection meetings for each case, and respondent validation.

Methods

A total of twelve cases were discussed by seven interviewees. Following the qualitative analysis of the interview transcripts and minutes of protection meetings, respondent validation, a constant comparative method and triangulation of data sources was used to check the validity of the generated research model.

Results

A theoretical model was generated that highlighted how the appraisals of the experience as well as the emotional and behavioural reactions of the vulnerable adults were shaped by the nature of the original abuse, the actions taken by protection meetings, the expectations of the vulnerable adults and the availability of support networks. Referrers reported that whilst all vulnerable adults experienced some distress and anxiety, at least some positive aspects could be identified by the end of the protection proceedings.

Conclusions

Referrers understood people with an intellectual disability who were referred to a vulnerable adult protection procedure to engage in attempts of making sense of their experiences and to show emotional and behavioural reactions to their experiences. Limitations of this study will be discussed alongside implications for future research and clinical practice.

Paper 11

Genetic diagnosis for intellectual disability: Who wants one and why?

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

Objectives

To understand family members' motivations for, and expectations of, taking part in a molecular-genetics study which aims to identify genes associated with intellectual disabilities. These families have a number of males with intellectual disabilities: the pattern of occurrence suggests there may be a gene on the X-chromosome, i.e. carried by women and affecting males.

Design

Interviews with family members after joining the molecular study. Follow-up interviews will take place in approximately 1-2 years time when genetic information is, or is not, available.

Methods

Ninety members from 40 families, including grandparents, mothers, fathers, siblings, and men with intellectual disabilities have been interviewed. Recruitment of study participants is ongoing.

Results

Thematic analysis of the first 20 interviews suggests a number of motivations underpinning involvement with genetic research. Families vary in how actively they seek a diagnosis. Most families do not believe a genetic diagnosis will directly impact on the lives of those with intellectual disabilities, although a few individuals hoped it may provide access to specific services. Many families want an explanation, sometimes for others but often for themselves. Some families want genetic information to enable other family members make informed reproductive decisions, including the option to terminate pregnancies. Even for those opposed to termination, reproductive choice is important.

Conclusions

Given these varied attitudes to, and understanding of, genetic diagnosis among those participating in research, there are personal, policy and practice implications if testing becomes more widely available. As with other research, little is known about those who do not participate.

Paper 12

Repetitive behaviour in genetic syndromes

Joanna Moss, Chris Oliver, Kate Arron, Cheryl Burbidge and Katy Berg
School of Psychology, University of Birmingham

Objectives

To investigate the prevalence and phenomenology of repetitive behaviour in genetic syndromes.

Design

A mixed two-way group design was used to compare the prevalence and phenomenology of repetitive behaviour across three syndrome groups (Cornelia de Lange syndrome, Angelman syndrome and Cri-du-Chat syndrome) and a comparison group of individuals with non-specific and heterogeneous intellectual disability.

Methods

The Repetitive Behaviour Questionnaire (RBQ) was developed to record the frequency of 19 different repetitive behaviours including stereotyped behaviours, compulsive behaviours, repetitive speech, obsessions, and insistence on sameness behaviour. Inter-rater reliability of the RBQ ranges from .67 to .811 at subscale level and from .46 to .79 at item level. Test re-test reliability ranges from .80 to .87 at subscale level and from .61 to .93 at item level. Data on repetitive behaviour were collected on 116 individuals with Cornelia de Lange syndrome, 121 individuals with Angelman syndrome, 65 individuals with Cri-du-Chat syndrome and a control group of 54 individuals with non-specific, heterogeneous, intellectual disability.

Results

Data analysis is ongoing. However, preliminary results indicate that individuals with Angelman syndrome score highly on the stereotyped behaviour subscale but show little or no compulsive behaviour, obsessions, insistence on sameness behaviour or repetitive speech. Individuals with Cornelia de Lange syndrome score highly on the compulsive behaviour subscale but not on the remaining subscales. Individuals with Cri-du-Chat syndrome score highly on the obsessions subscale only. Individuals in the control group score highly on the repetitive speech subscale only.

Conclusions

The results indicate that the phenomenology of repetitive behaviour varies across different syndrome groups. The relevance of these findings with regard to specific behavioural phenotypes is discussed. These findings also indicate that, despite commonalities among the features of repetitive behaviours, different forms of repetitive behaviour may have different causal mechanisms.

Paper 13

Autistic Spectrum Disorder and repetitive behaviour in Lowe Syndrome

Katy Berg, Chris Oliver, Joanna Moss, Kate Arron and Michelle Hooker
School of Psychology, University of Birmingham

Objectives

To investigate the prevalence and phenomenology of Autistic Spectrum Disorder in people with Lowe Syndrome.

Design

A mixed two-way group design was used to compare the prevalence and phenomenology of Autistic Spectrum Disorder across two syndrome groups (Lowe Syndrome and Fragile X) and a comparison group.

Methods

The Social Communication Questionnaire (SCQ) and the Repetitive Behaviour Questionnaire (RBQ) was completed by carers of 56 people with Lowe syndrome, 56 people with Fragile X Syndrome and a comparison group of 56 people with intellectual disability of heterogeneous cause. Data were analysed at total, subscale and item level.

Results

The Lowe and Fragile X groups both scored significantly higher than the comparison group on the restricted, repetitive and stereotyped patterns of behaviour domain of the SCQ but not on the reciprocal social interaction or communication domains. Item level analysis of this domain showed significant differences in the prevalence of repetitive speech, odd mannerisms and complex body mannerisms in these two syndrome groups. Item level analysis of the RBQ also showed significant differences in the prevalence of repetitive phrases/signing, echolalia and preference for routine between the two groups.

Conclusions

High levels of Autistic Spectrum Disorder or autistic features are seen in people with Lowe Syndrome. Although the profiles of autistic features in Lowe and Fragile X are similar in many ways they differ significantly in that certain behaviours: repetitive speech, echolalia, odd mannerisms, complex body mannerisms, and preference for routine, are not seen as frequently in Lowe Syndrome. Possible explanations for these findings are discussed.

Paper 14

Cognitive and behavioural predictors of referral for dementia assessments in people with Down syndrome

Dawn Adams, Chris Oliver, Simone Peters, Tarvinder Basra, Murielle Broquard, Sunny Kalsey, Eva Konstandinidi and Sharna McQuillan
School of Psychology, University of Birmingham

Objectives

The increasing need for services for ageing people with intellectual disabilities is resulting in specific services being established. This research aims to appraise the cognitive and behavioural predictors for referral for a dementia assessment to one such service by examining the results of established measures of dementia.

Design

Two groups of participants over the age of 30 with Down syndrome, referred (n=17) and non-referred (n=29), were compared on cognitive and behavioural measures. These groups were matched on age, gender and demographic variables.

Methods

All participants were assessed on the BPVS, VABS, NAID, DMR and AADS. Results were compared using Mann-Whitney tests and mixed ANOVAs.

Results

T-tests and Mann-Whitney U tests revealed that the two groups differed on established informant (DMR) and neuropsychological (NAID) measures of dementia. Mixed ANOVAs explored the behavioural characteristics of the two groups. Behavioural excesses were reported more frequently than behavioural deficits in both groups. Behavioural excesses were reported to have a greater effect on management than the person displaying the behaviour. The contrary was reported for behavioural deficits.

Conclusions

This specialist service for dementia in people with Down syndrome is receiving appropriate referrals. Differences between the groups in reported behaviours suggest that these may instigate referrals. Referrals are being made at a stage where established neuropsychological and informant based measures can detect decline in memory but before it has become too evident. Stronger conclusions may be made with larger samples and longitudinal designs.

Paper 15

Predicting asphyxiation in adults with intellectual disabilities and dysphagia

Darren Chadwick and Fiona Kevan

Department of Psychology and Speech Pathology, Manchester Metropolitan University

Objectives

Adults with intellectual disabilities referred for assessment of their eating and drinking are frequently reported to cough and choke when eating and drinking. The research literature investigating dysphagia has often overlooked asphyxiation, which is a notable oversight due to the prevalence of asphyxia as a cause of mortality in this population. This study aimed to identify the physiological and environmental factors that predict asphyxiation risk in adults with intellectual disabilities and dysphagia.

Design

This was an exploratory study using retrospective data to identify physiological and behavioural characteristics that predict high risk of asphyxiation in adults with intellectual disabilities and dysphagia.

Methods

Data was collected from dysphagia trained Speech and Language Therapists (SLTs) working with the participant adults with intellectual disabilities and dysphagia. The SLTs used case notes, clinical assessment and videofluoroscopic assessment reports to gather the data. Data were collected for 80 adults with intellectual disabilities and dysphagia about problems with the oral preparatory and transfer stages of the swallow, and additional factors incorporated: speed of eating, cramming food, distractibility and level of alertness during mealtimes.

Results

Speed of eating, cramming food, and premature loss of the bolus into the pharynx were identified as significant predictors of asphyxiation in this population.

Conclusions

The findings highlight the importance of maladaptive eating strategies in exacerbating the risk of asphyxiation and choking. These factors should be considered in the assessment of asphyxiation and choking risk and management. The need for joint assessment and management with other members of the multidisciplinary team is advocated.

Paper 16

Predictors of positive perceptions in parents of children with intellectual disabilities

Felicity Greer and Ian Grey
Department of Psychology, Trinity College, Dublin

Objectives

To investigate the possible relationships between variables related to coping and positive perceptions in Irish mothers of 5 to 8 year old children with intellectual disabilities using an adapted version of Taunt & Hastings' (2002) working model as a framework.

Design

The mothers of 36 children with intellectual disabilities from four service locations in the greater Dublin metropolitan area completed five self-report questionnaires that measured (1) demographic factors, (2) severity of behavioural and emotional problems in children, (3) levels of care demand in children, (4) helpfulness of social support, and (5) coping strategies and levels of positive perceptions.

Methods

Hierarchical regression analysis was implemented to determine relationships between variables.

Results

Severity of child behavioural and emotional problems significantly predict perceived levels of care demand; perceived helpfulness of formal support significantly predicts mobilising the family to acquire and accept and help care in the community; and mobilising the family significantly predicts levels of strength and family closeness.

Conclusions

This research broadly supports that conducted previously by Taunt & Hastings (2002) and adds to it by investigating the relationship between severity of behavioural and emotional problems and levels of care demand. Levels of formal support were found to be positively related to positive perceptions. Implications for clinical practice in Ireland are discussed.

Paper 17

Physical interventions and people with intellectual disabilities: Service user views

Anne MacDonald, Peter McGill and Roy Deveau
Tizard Centre, University of Kent

Objectives

To explore the personal and subjective experiences of people who have experience of physical interventions, either through direct experience or by being a witness to the use of physical intervention.

Design

Non-experimental research, utilising qualitative data obtained from direct interviews, gaining a retrospective view on personal experiences.

Results

The findings suggest that service users experience physical interventions as painful, emotionally distressing and as indistinguishable from other abusive practices of staff, or from general violence in the environment. The findings also indicate that some service users attribute negative attitudes to staff carrying out the interventions, and that most service users did not feel that physical interventions were justified – they made practical suggestions for more positive alternatives.

Conclusions

A number of good practice recommendations were outlined with respect to the use of physical interventions, including the importance of positive staff demeanour and attitude as they carry out physical interventions; debriefing for service users following the use of physical interventions; and that physical interventions have the potential to damage relationships between staff and service users as well as having long-term negative effects – they should therefore be used very cautiously.

Paper 18

The involvement of people with intellectual disabilities in the organisation and delivery of specialist health services

Bob Hallawell and Penny Standen
School of Nursing, University of Nottingham

Objectives

This paper will present key themes of user involvement within UK health Trusts and suggest a framework for reviewing organisational level involvement.

Design

A two-phase approach was used to promote the exploration of themes relevant to user involvement. Phase 1 focused on establishing, via questionnaire survey, areas pertinent to research strands identified from a literature review. Phase 2 of the study utilised grounded theory approaches to explore the established areas via semi-structured interviews held at selected Trust sites.

Methods

Questionnaire respondents were providers of specialist health services for adults with intellectual disabilities within the UK who were identified through a text based search of NHS organisational data. Seventy-six questionnaires were analysed in Phase 1. Positive and negative responses to questionnaire items were isolated and used as criteria for Trust selection for Phase 2. Seventeen individuals were interviewed between March 1999 and June 2004 (pre and post Valuing People).

Results

Data was analysed using SPSS in Phase 1 and NUD*IST software in Phase 2. Four themes were found: Aids to Involvement, Hindrances to Involvement, Lack of Clarity and Transition. These themes may be further illuminated via dimensions of power within organisations.

Conclusions

There is a lack of clarity about effective user involvement but power dimensions may be synthesised within a framework that could be used to review organisational level user involvement within health services. Further research would assist confirmation of the relevance of the identified power dimensions to existing health services as well enable further development of the framework as a model that may be applied within services.

Paper 19

Face-to-face communication in the self-advocacy movement: An exploratory case study

Marcus Redley, Darin Weinberg and Bryan Turner

Departments of Psychiatry and Sociology, University of Cambridge

Objectives

To compare claims made about self-advocacy - empowerment, exercising rights, and taking control - with actual self-advocacy talk recorded on video.

Design

A self-advocacy group using the parliamentary model of peer advocacy was videoed. The self-advocates known as Members of Parliament (MPs), are the elected representatives of their peers, service users, in day centres, group homes and employment training. Once elected, MPs represent their constituents in parliamentary discussions with 'decision-makers', senior members of the learning disability partnership and 'guests', other interested professionals. The presentation will focus on a sitting of the Parliament that discussed: bullying and other forms of abuse.

Methods

The video was analysed using techniques derived from conversation and discourse analysis: the sequential organisation of talk and the rhetorical construction of claims and counter claims.

Results

The results document an interactional asymmetry between, on the one hand, MPs and on the other, decision-makers and guests: 1) MPs speak from personal experience while decision-makers and guests speak in terms of abstractions and generalities; 2) decision-makers and guests orientate to managerial problems while MPs have more immediate and personal concerns; 3) MPs are the recipients of unsolicited 'good advice' from decision-makers and guests, this sustains rather than challenges existing in services for people with an intellectual disability.

Conclusions

The claims made by the self-advocacy movement that it empowers people with intellectual disabilities to fight for their rights in a disabling society, were not born out by this empirical analysis. The success of self-advocacy may well depend upon giving greater consideration to: 1) how encounters between people with intellectual disabilities and service providers are organised with respect to turn-taking and speaking rights; 2) the tendency of service providers to focus on and defend existing management practices; and 3) the tendency of service providers to offer individualised advice rather than see the social dimension of abuse.

Paper 20

Investigating the financial decision-making capacity of men and women with intellectual disabilities

Irenka Suto, Isabel Clare and Tony Holland

Department of Psychiatry (Section of Developmental Psychiatry), University of Cambridge

Objectives

We aimed to examine: (i) the assumption that financial decision-making capacity is impaired among adults with intellectual disabilities; and (ii) some cognitive and social factors contributing to this putative impairment.

Design

Recent legislation in Scotland and proposed legislation in England and Wales require that a 'functional' approach is used in assessments of decision-making capacity. In order to adopt this approach, which is poorly understood at present, we developed novel assessment measures.

Methods

We assessed the financial decision-making abilities of thirty men and women with intellectual disabilities and of thirty of their 'general population' counterparts. We also assessed intellectual functioning (WASI), understanding of quantity, numbers and money (novel measures), and everyday opportunities for financial, and other, decision-making (a standardised questionnaire).

Results

Whilst participants with intellectual disabilities were less likely to be judged to have capacity than their 'general population' peers, there were no discrete differences in their abilities: everyone found understanding relevant information, and reasoning with it, to be the hardest parts of the decision-making process. Among adults with intellectual disabilities, path analysis revealed a direct relationship between intellectual ability and understanding of quantity, numbers, and money. Such understanding also related directly to decision-making opportunities, which, in turn, also related directly to financial decision-making abilities.

Conclusions

Based on the findings involving adults with intellectual disabilities, we propose a model of the relationships among some of the multiple interacting factors that affect financial decision-making capacity, and discuss its practical, legal, and social implications.

Paper 21

Collation and interpretation of learning disability register data for policy and strategic planning purposes

David Felce

Welsh Centre for Learning Disabilities, University of Wales Cardiff

Objectives

To use intellectual disability register data to inform policy and strategic planning in Wales.

Design

Analysis of official data.

Methods

Data were abstracted from a single local authority statistical return (SSDA901) concerning the numbers of adults (16 yrs+) by place of residence (own home, family or foster home, lodgings or supported living, residential care: NHS, local authority, private or voluntary, other). Returns were checked for completeness at local authority level but analysed at a national level. Children (under 16 years) were excluded as reporting in relation to children has been inconsistent.

Results

The numbers of people aged 16-64 years and 65 years+ have increased by 20% and 39% respectively since 1990. Numbers in lodgings, supported living and residential care were stable. 504 more lived in family homes in 2003 than 1990 (up 11%). People in their own homes rose by 238% to 1,980, most likely as changes in registration practice reflected changing availability of support. Discounting this growth, the increase in adults living in family homes as a percentage of all adults might represent the best estimate of the increase due to better survival (6% or 0.5% p.a.). Supporting an additional 500 people to be independent of their families in order to return to the 1990 position would cost about £25.2m p.a. A similar increase in day service provision would cost at least £6.6m p.a.

Conclusions

Where resource requirements are significant, strategic planning is needed to create the conditions in which person-centred planning can be meaningful.

Abstracts of Posters

Poster 1

Do people with intellectual disabilities need longer psychotherapeutic treatment durations?

Nigel Beail, Stephen Kellett and David Newman
Keresforth Centre, Barnsley

Objectives

A clinical consensus has emerged suggesting that people with intellectual disabilities need longer psychotherapeutic treatment durations. However, meta-analyses of psychotherapy outcome studies with non-disabled populations suggest that the largest gains are made during the initial sessions of treatment, followed by positive but diminishing returns. This model has not been tested in outcome research with people with ID. This paper presents the first attempt to examine this dose-effect relationship.

Design

The current study employed a naturalistic design to examine and compare the outcomes of three groups of participants with ID and co-morbid mental health problems receiving different lengths (doses) of treatment with psychodynamic psychotherapy. Three measures of psychopathology were completed at assessment and at subsequent eight session intervals until the conclusion of treatment. Each participant also completed a three-month follow-up assessment.

Methods

Twenty participants formed three treatment duration groups which were compared via ANOVA and effect sizes.

Results

The findings were supportive of a dose-effect relationship in that outcomes were generally equivalent regardless of treatment duration. Most change occurred in the first eight sessions of treatment with subsequent outcomes trailing off over time.

Conclusions

The findings reflect those found in non-disabled populations and counter the clinical consensus. The clinical implications of this study are discussed within the context of the methodological limitations identified.

Poster 2

A comparative investigation of support staff and Speech and Language Therapists' (SLT) estimates of the receptive communication of adults with intellectual disabilities who exhibit behaviours that challenge services

Darren Chadwick and Fiona Kevan

Department of Psychology and Speech Pathology, Manchester Metropolitan University

Objectives

The 'hidden' phenomenon of receptive communicative skill (comprehension) is often overlooked in adults with intellectual disabilities by services in favour of more observable behaviours (e.g. expressive communication). The aim of this study was to investigate the concordance between staff and SLTs' judgements of receptive communicative competence for adults with intellectual disabilities and challenging behaviour.

Design

A matched pairs design was used employing survey methods to collect the data.

Methods

Receptive communication estimates were gathered, using a specially devised assessment (a receptive language checklist), from one staff member and one speech and language therapist for 34 adults with intellectual disabilities who exhibited behaviours that challenged services.

Results

There was 78.75% agreement in judgments regarding the understanding of the adults with intellectual disabilities between the support staff and the SLTs, and 21.25% disagreements. Of the disagreements, in 60.61% the support staff judged the adults with intellectual disabilities to understand more than the SLTs. A number of the linguistic categories were considered by SLTs to be rarely understood by adults with intellectual disabilities. For the more complex items, staff tended to overestimate receptive skills whereas for lower level language items, support staff tended to underestimate and overestimate receptive skills.

Conclusions

The findings corroborate previous studies but must be viewed in light of a number of methodological limitations. Receptive communication skills seem difficult to measure and what constitutes difficulty in language is not necessarily intuitive. Further observational work could serve to illuminate the relationship between communication mismatches and challenging behaviour.

Poster 3

Outcome measurement in intellectual disability services

Melanie Chapman, Kate Limb and Kara Greenwood
Quality, Research & Service Development Team, Manchester Learning Disability Partnership

Objectives

To describe and discuss the development and piloting of a psychology outcome measurement system in an intellectual disability service

Design

A descriptive quantitative study of psychology outcomes.

Methods

The system recorded information about: demographics; living situation; level and type of disability; presenting problems; assessment and interventions; factors affecting outcomes. Outcomes were specified and rated using a 5-point scale linked to categories of 'worse', 'same', 'slightly improved', 'moderately improved', 'significantly improved' and 'totally improved'. Psychologists and additional support workers (ASW), clients and carers rated outcomes at discharge. Descriptive analyses were conducted using SPSS (V12, 2003).

Results

Outcomes were completed for 24 people (35 people were referred for assessment only). The most common behavioural presenting problems were physical aggression (N=15), verbal aggression (N=14), and motivational issues (N=7). The most common emotional presenting problems were anxiety (N=13), low mood (N=10) and decline in cognitive functioning (N=8). Interventions included cognitive therapy (N=15), behavioural (N=10), family/systemic (N=5), and psychodynamic (N=1) therapies. Indirect interventions included practical training (N=12), information training (N=10), clinical guidelines and recommendations (N=25). In terms of outcomes, 35% were scored as totally improved, 46% as significantly improved, 11% as moderately improved, 8% as remained the same, and 1% as worse. Service provision factors, changes in medication, health, and lack of staff or client motivation were reported to influence outcomes.

Conclusions

The pilot provided useful information about the:

- Reasons why adults with intellectual disabilities access psychology services
- Range and complexity of the work carried out by clinical psychologists and ASW
- Interventions used with this client group

The vast majority of interventions led to total or significant improvements. Linking the outcomes scale categories to measurable change provides an objective measure which may be of use to other service providers.

Poster 4

The Glasgow Health Improvement Projects: The one year outcome of a health screening programme

Sally-Anne Cooper, J. Morrison, Craig Melville, J. Finlayson, L. Allan, G. Martin and N. Robinson
Section of Psychological Medicine, University of Glasgow

Objectives

To determine the health improvement produced by a semi-structured health screening programme for adults with intellectual disabilities, after a one year period.

Design

This study used a case-control design.

Methods

50 adults with intellectual disabilities who participated in a health screening programme were individually matched for age, gender, and level of ability with 50 adults who had not been offered a health screen. Semi-structured reviews of general practice, medical and nursing casenotes, interviews, and questionnaires, were used to measure health outcomes after a period of 12 months.

Results

At the 12 month point, the individuals that had participated in the health screen had significantly more identified health needs (mean=4.80, range 0-10) compared with the matched controls (mean=2.26, range 0-6). In some cases, unclear responsibilities for person-centred health management resulted in documented health needs remaining unmet over the period. However, the individuals who had participated in the health screen had significantly more met health needs ($t=3.30$, $p=0.001$), met health promotion needs ($t=4.86$, $p<0.001$), and met health monitoring needs ($t=2.10$, $p=0.039$), compared to the matched controls. Over the 12 month period, there were no significant differences between the two groups in use of health care services.

Conclusions

Identifying health need through a semi-structured health screening intervention, and proactive person-centred health management, is required to maximise health improvement for persons with intellectual disabilities.

Poster 5

Body site specificity of self-injurious behaviour in children with severe intellectual disability

Kate Dickson, Eric Emerson, Alan Dowey, Chris Hatton and Sandy Toogood
Clinical Psychology Department, Royal Alexandra Hospital, Rhyl

Objectives

The aim of this study was to further explore the relationship between SIB and body site preference in children with severe ID. The specific objectives were to:

1. Identify whether children with severe ID who self-injure direct the self-injury to specific sites of their body and examine whether these sites correlate with known acupuncture analgesia (AA) sites.
2. Consider age, gender, mobility, level of adaptive behaviour, topography of SIB, length of time that SIB has been present and behaviours that could be indicative of autistic spectrum disorder as covariates of self-injury sites.
3. Investigate whether the body site of SIB can be related to specific functions of behaviour.

Design

A survey design was used to examine body-site specificity of SIB in children with severe ID who were identified via a screening procedure. This was supplemented by non-participant observations.

Methods

School teachers of 30 children with severe ID recorded the distribution of self-injury sites. Standardised measures of adaptive functioning and autistic behaviour enabled investigation of possible covariates of body-site specificity of SIB. Possible relationships between body site and behavioural function were examined via naturalistic behavioural observations.

Results

Significantly more SIB sites overlapped with AA points than expected by chance. Findings indicated that children who self-injured in AA sites were older, more likely to self-hit and had presented with SIB for longer. No statistically significant association was found between behavioural function and body site.

Conclusions

Results tentatively supported the opioid and behavioural hypotheses of site-specificity of SIB. This highlights the need for future research that incorporates behavioural and neurochemical methodologies.

Poster 6

Between the borders: Services for people with intellectual disability and mental health problems

Catherine Dobson
Preston Learning Disability Service, Preston

Objectives

To describe and discuss the ways that 'learning disability' and mental health services in a city in Lancashire have responded to people considered to have the dual presentation of intellectual disability and mental health problems

Design

An ethnographic study utilising case file and discourse analysis

Methods

The study incorporated

- a) reading and analysis of case files of clients considered by staff of services to have the dual presentation of 'learning disability' and mental health problems
- b) semi-structured interviews with staff of 'learning disability' and mental health services, service managers, commissioners and policy leads
- c) evaluation of relevant service developments

Results

The study identified 5 categories of clients based on the presence/absence of ID, mental illness or mental health problems and demonstrated different patterns of involvement with services. Analysis of interview material, organisational histories and structures contributed both to the building of explanations for differing patterns of services and to understanding complexities in implementing health and social care policy.

Conclusions

The study sought to develop explanations for variations in the ways that 'learning disability' and mental health services have provided and continue to provide for people with the dual presentation of ID and mental health problems and confirmed the primacy of the boundary of mental health over intellectual disability. Secondly, the study demonstrated the relevance of ethnographic methods, participant observation and a theoretical framework based on 'boundary critique' and social constructionism as a means of understanding the complexity of service organisations.

Poster 7

The conceptualisation of dreams by adults with intellectual disabilities

Anna Dodd, Dougal Julian Hare and Steven Hendy
Academic Division of Clinical Psychology, University of Manchester.

Objectives

Investigation of dream conceptualisation, mentalisation and psychiatric diagnosis in adults with ID.

Design

Within-group design.

H1: Adults with ID will successfully conceptualise photos (external, physical entities, shared with others) but unsuccessfully conceptualise dreams.

H2: Unsuccessful dream conceptualisation will be associated with increased diagnosis of psychosis.

H3: Dream conceptualisation will be associated with mentalisation abilities.

Methods

Participants were recruited from ID day services and assessed for receptive language, mentalisation and visuo-spatial abilities. A structured interview (Woolley & Wellman 1992) assessed dream conceptualisation and information on diagnosis, medication, ID level and challenging behaviour was obtained from keyworkers.

Results

Initial data from 33 participants [90.9% mild ID; mean age 34.4 yrs; mean age-equivalent BPVS 9.08 yrs]. 43.9% of participants reported seeing dreams, 20.5% stated other people seeing their dreams, and 36.4% reported agency in dreams. 25.8 % stated two people could have the same dream, 27.3% that dreams are private events and 43.9% were inconsistent. 71.2% stated they could dream about real events, but only 51.5% stated they could dream about fictional events. Uncertainty about real vs. fictional events was reported, with 4.5% stating impossibility of fictional events and 12.1% stating non-existence of real events. Mentalisation ability was significantly associated with conceptualising dreams as non-physical and dreaming about fictional events.

Conclusions

People with mild ID did not report homogeneous dream conceptualisation and significant believed dreams were shared or public events, together with confusion of real and fictional events. These findings indicate caution when seeking accurate mental events e.g. when diagnosing psychosis.

Poster 8

Living with intellectual disability: Parents' experiences in families facing two late onset genetic disorders, Huntington's Disease and Myotonic Dystrophy

Claudia Downing

Centre for Family Research, University of Cambridge

Objectives

To establish how intellectual impairment manifests in the everyday life of mothers and fathers in families facing two predominantly late-onset genetic disorders, Huntington's disease (HD) and Myotonic Dystrophy (DM).

Design

A qualitative semi-structured interview study of how parenting is experienced as one parent's risk for a late-onset genetic disorder becomes a certainty through either predictive genetic testing or diagnosis.

Methods

Theoretical sampling (of parents where one is at-risk for, has tested positive, or is starting to become symptomatic for a late onset genetic disorder) and analysis are being guided by a model of responsibility. The model was generated in an earlier study of reproductive decision-making in the face of HD. Analysis is identifying narratives parents construct about concerns that arise for them, such as intellectual impairment, and how they negotiate them.

Results

Intellectual impairment may become a significant aspect of everyday life. In the case of HD intellectual impairment is less visible but signals the onset of the disorder. Its impact interacts with depression. In the case of DM, children with significant intellectual impairment may alert clinicians to consider this diagnosis, which has implications for other family members who can suffer from other aspects of the condition such as heart problems and early onset cataracts.

Conclusions

Intellectual impairment does not occur in isolation but rather is shaped in interactions with other aspects of these disorders such as depression and physical limitations. Understanding how intellectual impairment forms part of a wider clinical and social picture is important in order to best address the limitations that can result.

Poster 9

English National Survey of 'Adults with Learning Disabilities'

Eric Emerson, BMRB and Central England People First
Institute for Health Research, University of Lancaster

Objectives

To describe the experiences of adults with intellectual disabilities in England in 2004

Design

Cross section survey

Methods

Face to face interview with nationally representative sample of 2,750 adults with intellectual disabilities.

Results

Results will not be available until mid-2005. The aim of the poster is to inform interested members of the ID research community of the content of the survey and arrangements for making the raw data publicly available for secondary analysis through the ESRC Data Archive in late 2005 (before the next Seattle Club conference).

Conclusions

These data will constitute of the most comprehensive and representative study even undertaken in England on the life circumstances of adults with intellectual disability. They will provide a significant (free) resource to members of the ID research community

Poster 10

Accessing AAC Services: Parents' Perspectives

Juliet Goldbart and Juliet Marshall

Department of Psychology and Speech Pathology, Manchester Metropolitan University

Objectives

To explore experiences of parents / primary carers of children with severe intellectual and / or physical disabilities in the implementation of Augmentative and Alternative Communication

Design

To generate "a rich conceptual analysis of lived experience" (Charmaz, 1995), ethnographic interviewing was employed.

Methods

Families were recruited through schools and two organisations for families with members using AAC.

Inclusion criteria: Speech was not the child's primary mode of communication; child was aged 3-11 years, either using, or expected to need, a formal AAC system; parent/carer could speak English sufficiently to participate in interview. There were 9 interviews with mothers, 2 with both parents. Parents were white European. Children were 6 girls, 5 boys, 3 - 10 yrs, with cerebral palsy and / or intellectual disability.

Interviews starting with "Tell me about a typical day with your child", were recorded, transcribed, and analysed thematically using Atlas ti.

Results

After open coding, basic codes and associated quotes were organised into thematic networks (Attride-Stirling, 2001). One basic theme: having to be "Pushy" from the organising theme, Demands on Parents, within the global theme - Parents' Views and Experiences - is presented. 7 of the 11 parents described a need to be highly assertive in dealings with professionals expressing concerns as to how this was perceived by others. The remaining parents did not see themselves as pushy, articulating the distance they felt from professionals.

Conclusions

Professionals need to be sensitive to the impact of the scarcity of resources on parents. Parents' social and economic capital may influence how they interact with professionals.

Poster 11

Developing measures of job performance for housing support staff: reliability and validity

Chris Hatton, Sarah Wigham, Jaime Craig and Emma Gudgeon
Institute for Health Research, University of Lancaster

Objectives

To develop measures of job performance for housing staff from the perspectives of four groups: people with intellectual disabilities; relatives; support staff and managers.

Design

Separate measures of job performance were developed using adaptations of the job element method. A survey design was used to determine aspects of the measures' reliability and validity.

Methods

Four expert panels were convened, producing four job performance measures with behavioural anchors for superior, acceptable and unacceptable job performance. Job performance measures were completed by 134 housing support staff (26 items), 82 service users (18 items), 38 relatives (27 items) and 115 managers (23 items). Staff provided data on burnout, planning processes and institutional practices in the home. Service users provided data on adaptive behaviour, choice and satisfaction with various life domains.

Results

All four job performance measures showed adequate internal and test-retest reliability, although they were not associated with each other. All four job performance measures were associated with few demographic characteristics of service users or staff. Higher service user-rated staff performance was associated with lower staff emotional exhaustion, more person-centred planning goals, more satisfaction in social life domains, but lower choice scale scores. Relatives' scores were associated with few measures due to small samples. Higher staff self-rated job performance was associated principally with lower burnout. Higher manager-rated staff performance was associated with fewer institutional practices, greater service user choice and greater service user satisfaction with several life domains.

Conclusions

The measures of job performance developed show promising reliability and validity, although they seem to assess different aspects of staff performance.

Poster 12

Examination of what changes take place during an Art Therapy intervention

Alison Hawtin, Karen Parker, Hilary Pounsett and Suzanne Collins
Learning Disability Partnership, Cambridgeshire & Peterborough Mental Health NHS Trust, Cambridge

Objectives

The objective was to establish if it was possible to gather effective, objective information about changes in clients with intellectual disabilities, during an art therapy intervention, that correlate with the therapist's subjective view.

Methods

Art Therapy sessions were videoed at two month intervals, over a period of one year. The POSER (Dieter Wolke, 1986, unpublished) mother/baby interaction tool was adapted to adult/therapist interactions. This scale generated a profile of the client, therapist and their interactions for each videoed session. These were independently rated. The Mini PAS-ADD was administered with the client's carer before and after the period being studied. The data were analysed and compared with the therapist's case study.

Results

The results were clinically significant as they indicate that change and the process as well as the product can be measured objectively. Significant correlations between the analysis of the video data and the therapist's case study were found.

Conclusions

It is possible to measure change, importantly without detriment to the therapeutic process. In pure research terms, we are not sure how statistically significant these measures are, but in essence feel this work has much to offer further research within the Art Therapy profession.

Poster 13

Social comparison and self-esteem in depressed and non-depressed people with mild and moderate intellectual disability

Pamela Jarvie and Andrew Jahoda

Clinical Psychology Department, Ayrshire Central Hospital, Irvine

Objectives

The current study compared self-esteem and social comparison in participants with intellectual disabilities (ID) who differed with respect to a diagnosis of clinical depression. It was hypothesised that people with ID and depression would (a) rate their self-esteem as lower, and (b) make more negative social comparisons between self and (i) 'general other' and (ii) 'real world' comparison targets than non-depressed individuals.

Design

A between-groups design of depressed versus non-depressed participants was used.

Methods

Depressed participants were identified by clinicians working in specialist ID services. Current diagnosis of depression was determined by the clinician in charge of the individual's care. Non-depressed participants were individuals attending day-services for people with ID, identified by key-workers. Each group comprised 18 individuals (10 female; 8 male).

The following measures were administered in random order; Glasgow Depression Scale for People with Intellectual Disability (GDS-LD); Modified Zung Depression Scale; Rosenberg Self-esteem Scale (adapted); Social Comparison Scale (adapted) – where participants compare themselves with a 'general other'; Identified Target Social Comparison Scale – where participants were asked to compare themselves with individuals they know.

Results

Non-depressed participants scored highly on the Rosenberg self-esteem scale compared with depressed participants. As expected, analysis, using SPSS, showed that depressed participants made more negative social comparisons than non-depressed participants when comparing self to a 'general other' target ($t(34) = -3.31, p=.002$), and when comparing self to identified 'real-world' targets ($z = -3.16, p = .002$). Even when comparing themselves to similar target individuals, depressed participants were more negative than non-depressed individuals ($t(21)=-2.29, p=.03$).

Conclusions

This study provides support for an association between social comparison processes and depression in people with ID. Social comparison may be particularly relevant to cognitive-behavioural assessment and intervention for depression in this population.

Poster 14

A descriptive study of referrals made to an Adult Protection procedure in Shropshire

Biza Kroese, Sarah Bland, Camilla Johns and Michael Hearn
Shropshire County PCT, Services for Adults with a Learning Disability

Objectives

The main objective was to consider the demographic characteristics of referrals made to a generic Adult Protection procedure. Clients referred to this procedure include people with learning disabilities, older adults, people with mental health problems and people with physical disabilities/sensory impairments. Consideration was given to type of alleged abuse (e.g. financial, sexual, physical), characteristics of alleged abuser and the source of the referral. Secondly, the data afforded comparison with data published in similar studies.

Design

A (manual) survey of records of all referrals made to the Trust's Adult Protection procedure was undertaken.

Methods

Data were gathered for the 15-month period up March 2003. A database was constructed which included demographic details such as age and gender of victim, type of vulnerability (e.g. intellectual disability), classification of abuse (e.g. sexual, financial, psychological or multiple), location of abuse, characteristics of alleged abuser (e.g. age and relationship to client) and source of referral.

Results

Of 192 referrals made to the procedure, descriptive statistics showed that 65% of the cases related to female victims. Nearly 40% of referrals related to victims aged over 60-years. Alleged abusers (where identified) were male in 67% of the referrals. Multiple abuse was evident in around 20% of the referrals.

Conclusions

The data suggested different patterns of vulnerability (i.e. type of abuse) across client groups. This has implications for highlighting particular vulnerabilities and for staff training.

Poster 15

Sexual knowledge, locus of control, and distorted cognitions amongst men with an intellectual disability who have committed sexual offences

Peter Langdon and Tiffany Talbot

School of Medicine, Health Policy and Practice, University of East Anglia

Objectives

1. To revise an existing, but outdated, measure of sexual knowledge for use with people who have learning disabilities.
2. To compare sexual knowledge, locus of control and level of distorted thinking about sexual offending across two groups, 1) men with a Intellectual Disability who have a history of sexual offending, and 2) men with a Intellectual Disability who have no history of sexual offending.

Design

A between subjects design was employed.

Methods

Initially, the sexual knowledge questionnaire was revised and administered to three groups: men without an intellectual disability, men with an intellectual disability who have not offended, and men with an intellectual disability who have offended. A structured questionnaire methodology investigated differences between sex offenders with a learning disability and non-offenders with a learning disability on three variables; general sexual knowledge, locus of control, and attitudes consistent with sex offending.

Results

The current results are preliminary as the study is ongoing. However, initial results indicate that the measure of sexual knowledge has high internal consistency and is able to differentiate between groups. Sex offenders with an intellectual disability scored higher on the measure of sexual knowledge, as compared to their non-offending counterparts, while there were no differences between the two groups on the measure of locus of control. Although sex offenders did score higher on the measure of cognitive distortions, this difference did not reach statistical significance.

Conclusions

The preliminary results suggest that the revised measure of sexual knowledge may have potential research and clinical utility. Furthermore, the lack of a significant difference between the two groups on the measure of locus of control has theoretical relevance to our understanding of offending behaviour amongst sex offenders with an intellectual disability.

Poster 16

Parents' constructs about the causes and consequences of helpful and unhelpful factors for access to services for children with intellectual disabilities

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Objectives

To identify factors which facilitate the access to services for parents with children with intellectual disabilities between the ages of 5 and 13 years of age.

Design: A qualitative design was adopted with an opportunistic sample of 23 parents of children with intellectual disabilities between the ages of 5 – 13 years (20 female, 3 male, white Caucasian) recruited by letter of invitation from the database of a voluntary agency. Focus groups were held. To improve content and construct validity the results of the focus groups were given to the parents and those who wished to reconvene in their groups to analyse the results.

Methods

A technique of cognitive mapping based upon Kelly's Personal Construct theory was used. This identified elements and constructs of parents about helpful and unhelpful services for them and their children. The constructs were then ladderized to identify the consequences and causes. Visual maps were generated showing the inter-relationship of elements and constructs in causal chains for each focus group. Themes were then identified.

Results

Five clusters of themes were identified for access to services: professionals, information, finance and resources, diagnosis, and support. Within each of these themes a number of different factors were identified which had a range of consequences for children and parents. Illustrative causal chains of constructs will be described.

Conclusions

Cognitive mapping has been developed within organisational psychology for service design. It was a practical way to gain information. The usefulness of this approach is discussed and implications for policy implementation reviewed.

Poster 17

Two studies on the Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI) in people with intellectual disabilities.

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Background

There have been several developments in research on emotion in people with ID. These have revealed that assessments such as the Brief Symptom Inventory (Kelleff et al., 2004) can be used reliably and validly. To date, little work has been published using the BAI and BDI.

Design

This paper presents two studies, the first of which provides information on the psychometric properties of the BAI and the BDI. The second study addresses differences between ID sex offenders and an ID control group on the BAI and BDI.

Method

Both assessments were appropriately revised for use with persons with intellectual disability and individually administered. A sample of 118 participants from inpatient (n=32) and community (n=86) settings completed the assessments in study one. Participants were all referrals to a psychology department and so it might be inferred that they were considered to have some emotional problems. In the second study, a sample of 37 sex offenders and 56 control participants (all of whom were male) from inpatient and community settings completed both measures.

Results

A confirmatory factor analysis using varimax rotations was conducted on the joint BAI and BDI data. This revealed a two-factor solution corresponding precisely to a depression factor and anxiety factor which provides support for the discriminant validity of these measures. Cohen's alpha computed on each test revealed values greater than 0.9 with item to total correlations above 0.45 indicating any factors to emerge from further analysis are likely to be correlated. Exploratory factor analysis was therefore conducted using oblique (Quatramax) rotation. Results demonstrated that on the BAI 57.7% of the variance was accounted for by a three factor solution corresponding to; cognitive, somatic-temperature and somatic-balance symptoms. For the BDI a three factor solution; cognitive-self, cognitive-affective and somatic symptoms, accounted for 64.3% of the variance. Both solutions were very similar to that reported in the mainstream literature. In study two, it was found that sex offenders reported significantly lower levels of anxiety (mean scores: 9.73 V 20.98) and depression (mean scores: 12.27 V 22.96) than the control group.

Conclusion

The factor structures of the BAI and BDI conform specifically to those found in research with the general population. This result and the finding that sex offenders have lower anxiety and depression than controls is discussed in terms of theoretical developments.

Poster 18

The influence of anger-arousal level on attribution of hostile intent and problem solving capability in an individual with a mild intellectual disability

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Objectives

Recent studies have suggested that cognitive biases may play an important mediating role in aggressive outbursts from people with mild intellectual disabilities (IDs). This has led to the development of a cognitive behavioural model of aggression, incorporating factors both intrinsic and extrinsic to the individual. This study aimed to explore one facet of this model: a putative relationship between anger-arousal level, problem-solving ability and perception of hostile intent in others.

Design

Single-case methodology with measurement of dependent variables of perception of hostile intent and suggestion of possible behavioural responses. An independent variable, anger-arousal, was also manipulated in the study.

Methods

A forty-four-year-old man with a mild ID and a history of difficulties with aggression participated. A series of vignettes, containing potentially provocative social interactions, were read to the participant. His perception of hostile intent, and suggestions of possible behavioural responses were recorded and his level of anger-arousal was manipulated, through autobiographical recall, during the study.

Results

Although not conclusive, results indicate that anger-arousal may act in an interactive fashion to increase perception of hostile intent. No effect of anger-arousal was seen on problem-solving ability; however, floor-effects in the task used may provide an explanation for this.

Conclusions

Future research should take these experimental considerations into account, and continue development of a cognitive model of frequent aggression in those with a mild ID.

Poster 19

The Glasgow Health Improvement Projects: The prevalence of obesity in adults with intellectual disabilities.

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Objectives

To measure the prevalence of obesity in adults with intellectual disabilities.

Design

A cross-sectional population based design was used.

Methods

As part of a comprehensive health check by a multidisciplinary Primary Care Liaison Team, the height and weight of an individual were measured and used to calculate body mass index (BMI).

Results

One thousand adults participated in the health screening programme (60.2%). The mean BMI of women was significantly higher than the mean BMI of men ($t=4.51$, $p<0.001$). Thirty-one per cent of persons that participated in the health check were obese (BMI>30). The prevalence of obesity in this sample is significantly higher in comparison to data from studies of adults who do not experience intellectual disabilities. The mean BMI decreased as the level of intellectual disabilities increased.

Conclusions

Adults with intellectual disabilities experience high rates of obesity. Although the prevalence is highest amongst individuals with mild/moderate intellectual disabilities, a significant number of persons with severe/profound intellectual disabilities are obese, or over weight. It is important that studies investigate the reasons for this finding. Exploring the relationship between obesity and socio-clinical variables will allow the development of targeted interventions and health promotion strategies.

Poster 20

The Glasgow Health Improvement Projects: Outcome of a training intervention for primary health care nurses

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Objectives

To determine the effectiveness of a training intervention to address the measured training needs of primary health care nurses, relevant to the health needs of persons with intellectual disabilities.

Design

A three-group comparison, pre- post- intervention design was used to measure the effectiveness of the training intervention.

Methods

The training needs of primary health care nurses were assessed via a purpose-designed questionnaire. Responses to the questionnaire were used to inform the development of a training intervention - in the form of a training pack, and a parallel 3-hour training event. Primary outcome measures were participant knowledge, self-efficacy and change in clinical practice.

Results

There was a statistically significant improvement in the knowledge scores of nurses who participated in the intervention, compared to nurses that did not participate ($F=5.6$, $p=0.005$). In addition, the post-intervention self-efficacy of nurses who participated in the intervention was significantly greater than the comparison group ($t=2.079$, $p=0.04$). Participation in both components of the training intervention was associated with significantly greater improvements in knowledge and self-efficacy, than receiving the training pack alone. Participants reported changes in clinical practice, as a result of the training intervention.

Conclusions

Initiatives to address the training needs of professionals working in primary health care settings can lead to positive changes in knowledge, self-efficacy and clinical practice. To promote health improvement, there is an ongoing need to develop effective training interventions relevant to the health needs of persons with intellectual disabilities.

Poster 21

Attention to human point-light-displays in infants with and without Down Syndrome

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Objectives

At five months typically developing (TD) infants show a preference for upright human point-light displays (PLDs) and may see these as uniquely human (Bertenthal, 1993). This recognition depends on the development of knowledge constraints and specialist action pathways, and may be constrained by general attentional and symbolic capacities. Do infants with DS show differential, phenotypic responses to these displays?

Design

Six 6-month-old infants with Down syndrome, twelve 4-month-old and fourteen 7-month-old TD infants were tested.

Methods

In a fixed order, infants were presented for up to 36 seconds each (or to habituation if sooner) with: 1) an inverted, scrambled (out-of phase) human PLD; 2) an inverted human PLD; and 3) an upright human PLD.

Results

Both the infants with DS and 4-month-old TD infants showed a decline in peak looking across the first two conditions, and a recovery in peak looking to the final condition, but the infants with DS also looked for longer than the TD infants to this upright display. In contrast, while seven-month-old TD infants also showed a decline across the first two conditions, they looked for shorter durations overall, and made no recovery to the upright human PLD.

Conclusions

These results suggest that 6-month old infants with DS may be relatively spared in their ability to perceive upright displays as human, but confirm previous reports that infants with DS differ from TD infants in looking more to people, and do not show the same decline in interest in human stimuli from the middle of the first year.

Poster 22

Hidden population or hidden services? Investigating the needs of young people with intellectual disability in Colchester

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Objectives

Of the 156,796 people living in Colchester, 3,135 might be expected to have some level of Intellectual Disability. However, a maximum of 1,343 adults have been identified by local specialist services. Our question is: what has happened to the other 1,792? Are they integrated within the broader community, not requiring additional support? Or do they constitute a 'hidden population' with significant unmet need?

Design

Survey of young people who had received a Statement of Special Education Needs for non-specific learning difficulties or autism whilst in school.

Methods

102 participants completed the survey (amounting to a 35.7% response rate). 58 were from females, 40 were from males, and 4 did not indicate their sex. Data on ethnic background were not collected. Surveys were sent to respondents by Essex County Council Learning Services.

Results

37% of respondents had not been helped by any organization since leaving school. Of the respondents who did not get help from any organization, 50% had wanted help. Not knowing who to ask was a key reason given for not getting help.

Conclusions

Although the findings cannot be generalised beyond the population surveyed, this pilot study gives preliminary support to the idea of a 'hidden population' that is unable to access services. At the same time, these findings suggest that the situation may be one of 'hidden services', rather than a 'hidden population'. Improving communication about existing resources, rather than developing new services, might help to address their unmet need.

Poster 23

Do people with intellectual disabilities and psychosis have the cognitive skills required to undertake cognitive behavioural therapy?

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Objectives

To assess the ability of participants to make links between events, cognitions and emotions. To assess the relationship between theory of mind and ability to recognise how cognition mediates emotion.

Design

Assessments included those used previously with people who do not have psychosis with an additional novel assessment designed to assess a participant's ability to recognise behaviours, thoughts and feelings. Receptive language was assessed using the BPVS and 1st and 2nd order theory of mind abilities were tested.

Methods

All participants met diagnostic criteria for psychosis and had mild/moderate intellectual disabilities. Fifty participants were recruited from four sites (three community and one hospital) with 54% male participants and 4% from a non-white ethnic background.

Results

Performance on tasks was compared using correlational and between group analyses (pass/fail groups). Performance was associated with receptive language ability for the emotion recognition, linking events and emotions and some of the cognitive mediation and differentiation tasks. The majority of participants were able to link events and emotions and differentiate behaviours and feelings. Participants found any task involving cognitions significantly more difficult. There was no association between ability to recognise cognitive mediation and theory of mind.

Conclusions

People with intellectual disabilities and psychosis have some of the skills thought to be required to undertake CBT. Recognising cognitions and their role in mediating emotions is particularly challenging. The differentiation task introduced in this study may usefully supplement existing assessments when clinicians are assessing suitability for CBT.

Poster 24

An adaptation of The Play Observation and Emotional Rating System (POSER)

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Objectives

The objective was to establish a measure sensitive enough to show change in adults with multiple disabilities, as well as intellectual disabilities, who were taking part in an art therapy research project. This group of people are not always accepted into therapy because of their limited verbal abilities, and if they are there is little evidence of its efficacy.

Methods

The POSER, originally aimed at mother/baby interactions, was adapted to adult/therapist interactions and three extra dimensions added to capture aspects of the therapy relationship. The scale allowed a profile of the client, therapist and their interactions within art therapy to be generated from videoed sessions over a one year period, which were then independently rated.

Results

The quantitative results indicated positive, negative and no change, which correlated with the qualitative data, images, session notes and case studies.

Conclusions

The findings indicate that this initial implementation of the Amended POSER (2001) was significant in indicating change in three adults with multiple disabilities, both verbal and non-verbal. We plan to refine this measure within further research.

Poster 25

Causes of aggression presented by people with an intellectual disability - Differences in expected outcomes of submissiveness

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Objectives

A main aim of this study was to devise an assessment to explore the expected outcomes of interpersonal conflict held by people with an intellectual disability. This assessment (SGOAS) is used in this study to explore whether differences exist across 20 Aggressive and 20 NonAggressive participants in their: (i) expected outcomes of submissiveness; (ii) expected outcomes of aggressiveness and (iii) social goals.

Design

The study has a group comparison design, comparing Aggressive and NonAggressive participants responses to the SGOAS assessment.

Methods

A series of hypothetical vignettes of hostile interpersonal situations were drawn up. Participants were asked to imagine themselves responding submissively to some vignettes and responding in an aggressive manner to other similar vignettes. They were asked to predict the outcomes of each of these strategies according to pre-defined categories. The social goals underlying their anticipated behavioural strategies were also explored.

Results

No differences were shown in expected outcomes of aggression. However there was some tentative evidence that Aggressive participants held more negative views of submissiveness in relation to outcomes of peer approval, self-condemnation and reducing future hostility for some hypothetical situations. Aggressive participants were shown to hold different social goals compared to their Non Aggressive peers. Within conflict situations Aggressive participants are shown to have a common goal of showing others that 'they can't mess me around'

Conclusions

The notion that Aggressive individuals expect aggression to be of benefit to themselves is undermined. It is suggested that a desire to avoid a submissive social identity may be an underlying influence of aggression for some individuals. Differences in social goals also highlight that Aggressive participants wish to present a forceful social position. These findings suggest that as well as understanding which social outcomes Aggressive individuals with ID value, it is important to understand more about which outcomes they wish to avoid.

Poster 26

Epilepsy and forced normalisation in people with intellectual disabilities

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Objectives

To describe the phenomenology and possible biological basis of forced normalisation in people with learning disabilities.

Design

A case history will be presented to illustrate the clinical phenomena. Recent research literature and previous research by the author will be reviewed to generate a possible mechanistic model.

Methods

A 24-year old male non-identical twin with life-long epilepsy and mild learning disabilities was followed up prospectively for three years. Over this time his mental state, his medical treatment and his seizure frequency were observed.

Results

The man was followed-up prospectively for three years. Over this time his mental state, his medical treatment and his seizure frequency were observed.

Conclusions

Clinical and neurophysiological research suggests that the abnormal neuronal excitability that generates seizures may also, as part of an endogenous anticonvulsant mechanism triggered by a seizure, lead to a short-lived increased release of dopamine, in turn leading to the development of psychotic phenomena.

Poster 27

An investigation into psychiatric illness in people with Prader-Willi Syndrome

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Objectives

The aim of this study is to investigate the finding that psychosis occurs more commonly in people with Prader-Willi syndrome (PWS) caused by maternal disomy of chromosome 15 rather than deletion of part of the paternal chromosome 15. We will investigate the role of family history and life events, and phenomenology of psychiatric illness.

Design

Cross-sectional, retrospective.

Methods

Once adults with PWS from the UK were identified, a telephone-screening questionnaire was carried out containing items on psychiatric illness and medication. With any positive indication of past or present psychiatric illness, the participant was visited to conduct a detailed interview. The assessment tools used were PAS-ADD, OPCRIT, WAIS, Life Events and Family History Questionnaires. Blood samples were collected to determine genetic subtype.

Results

To date, 150 people have been screened. Fifty-one (34%) have a history of psychiatric illness, 35 (69%) of whom displayed psychotic symptoms. Ninety-seven (65%) have confirmed genetic results, divided as follows; 68 (70%) deletion, 26 (27%) disomy, 3 (3%) other. Seven of 35 (20%) with the deletion subtype aged over 27 have a history of psychotic illness, compared with 9 out of 10 (90%) with the disomy subtype aged over 27 (Chi-squared test; $p = 0.001$). This lends support to earlier findings. Results regarding symptoms, course and outcome will also be presented.

Conclusions

This area of research may provide us with insights into a genetic basis for psychosis. It may also enable us to provide better methods of investigation, diagnosis and treatment for psychotic illness in people with PWS.

Poster 28

An evaluation of the use of virtual environments in improving choice reaction time in people with severe intellectual disabilities

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Objectives

This study set out to test whether choice making in a virtual environment would improve the ability of people with severe intellectual disabilities to make choices in other situations. The hypothesis was that making choices in a virtual environment would reduce choice reaction time.

Design

Each participant was paired with another matched on age, sex and ability before being randomly allocated to either an active or passive group. The active group interacted with virtual environments while their matched controls sat at their side and watched. The groups were then compared on change from baseline performance on two choice making tasks.

Methods

22 people with sufficient motor and visual ability to use the equipment were grouped into 11 matched pairs. Following matching six participants dropped out so that two of the active group were without a matched partner. All participants completed three tests of choice reaction time before and after the active group (5m, 4f) received six twice-weekly sessions using the virtual environments while their passive partner (4m,3f) sat next to them watching the computer monitor.

Results

The final reaction times of the active group were significantly reduced on two out of the three tests. The decrease on the third test however did not reach significance. In comparison, the passive group showed a non-significant decrease in choice reaction time for only one of the tests.

Conclusion

Although these results are encouraging, the study needs to be repeated with a larger group and a measure of choice making specifically designed for this purpose.

Poster 29

Family environment links to patient anger and aggression: Effects of volatile Parents on people with developmental disabilities

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Objectives

Children's exposure to inter-parental anger and aggression has been shown in many studies to have long-term adverse effects on a child's development and psychosocial adjustment. Exposure to domestic violence has been found to contribute to children's delinquency and clinical dysfunction, to predict child conduct disorders and personality disorder. In this study the relationship between childhood exposure to parental anger and aggression and anger and violence in later life is explored with a population of adults with developmental disabilities.

Design

The current study incorporated a cross-sectional assessment design using correlational analyses.

Methods

The participants were 110 male forensic in-patients with intellectual and other developmental disabilities. The relationship between patient anger and aggressive behaviour (assessed by multiple self-report, staff-rated, and file measures) and their childhood experiences of parental anger, parental fighting, and abusive victimization was examined.

Results

Patient anger and violent conduct in the hospital were found to be significantly related in convergent analyses to parental anger and aggression and to physical and sexual abuse victimisation. In hierarchical multiple regression analyses, parental anger and aggression was highly predictive of patient anger, controlling for both parental and patient alcohol and drug abuse and for patient physical and sexual abuse victimisation.

Conclusions

The study results have relevance with regard to the development of anger and aggression in this population within a social-learning theory framework. There are implications for clinical assessment and cognitive behavioural anger treatment procedures in terms of clients' threat-sensing anger schemas, and aggressive scripts.

Poster 30

Some aspects of social skills in Prader-Willi syndrome

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Objectives

To examine two particular aspects of social skills in people with PWS: recognition of emotions in other people and detection of inappropriate behaviour in other people.

Design

The use of posed photographs depicting the six basic emotions - a very modified version of the Ekman faces task - and four short stories (attributed to Margaret Dewey) containing examples of appropriate or inappropriate behaviours which the participant is asked to rate as: normal, slightly odd, very odd or shocking.

Methods

20 photographs were presented in Powerpoint on a laptop computer, the six basic emotions being displayed in random order. Each was displayed until some response was elicited. The four short stories were read aloud by the researcher. At key points in each story the researcher paused to ask for a rating of the behaviour in that context.

Results

Overall accuracy on the Ekman faces was about 10%. Apart from happiness (90%), accuracy on the individual emotions ranged from about 46% (sadness) to 23.5% (fear). There was little agreement about normal and inappropriate behaviour: 58% agreed that feeding sandwiches to the birds was normal (23% thought it shocking). The greatest disagreement was for borrowing a comb from a perfect stranger (35% normal, 31% slightly odd, 19% very odd and 15% shocking)

Conclusions

People with Prader-Willi syndrome are impaired in their recognition of other people's emotional states and also in recognition of appropriate and inappropriate behaviours in response to social situations.

Poster 31

Suggestibility and salience in people with intellectual disabilities: An experimental critique of the Gudjonsson Suggestibility Scale

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Objectives

The Gudjonsson Suggestibility Scale (GSS) is based on the recall of information that is of no personal significance to the respondent. Our aim was to investigate whether this factor influences suggestibility in people with intellectual disabilities.

Methods

We created two Alternative Suggestibility Scales (ASS and ASS2), based on real events. In experiment 1, participants were administered both the GSS and the ASS, presented in a counterbalanced order. In Experiment 2, the same participants were administered the ASS2. The Experimental group had witnessed the events described in the ASS and ASS2, which took place 18 months and 1 month earlier, respectively. For the Control group, the information presented in all three tasks was equally unfamiliar.

Results

In the Control group, the GSS, ASS and ASS2 did not differ either in recall of the information presented, or in suggestibility. In the Experimental group suggestibility was decreased, relative to the GSS, by one third for the ASS, and by two thirds for the ASS2; recall was lowest for the GSS, but the ASS and ASS2 showed similar levels of recall.

Conclusions

Suggestibility for events that have been witnessed is less than for arbitrary events, and the decrease is greater for more recent events. However, decreases in suggestibility for familiar material cannot be explained simply in terms of increased recall. The fact that the GSS is likely to over-estimate how suggestible a person is likely to be in relation to a personally significant event has implications for its use in legal proceedings.

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