# 6th Seattle Club Conference on Research and People with Intellectual Disabilities

11-12 December 2006

Brewery Arts Centre
Kendal

LANCASTER UNIVERSITY

# Welcome

Welcome to the 6th Seattle Club Conference for researchers in intellectual disabilities in the UK and Republic of Ireland.

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

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

The clear focus on research and keeping the size of the meeting to manageable proportions are designed to promote methodological critique, constructive dialogue and collaboration across participants for the long-term benefit of research in intellectual disabilities in our respective countries.

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

Ad hoc organising committee for 2006:

- Eric Emerson, Institute for Health Research, Lancaster University
- Richard Hastings Intellectual & Developmental Disabilities Research Group, University of Wales Bangor
- Chris Hatton, Institute for Health Research, Lancaster University

Administrative support:

Our considerable thanks this year go to Gill Betts (Institute for Health Research, Lancaster University).

**Seattle Club Studentships 2006**

Six researchers are attending the Seattle Club meeting this year supported by Seattle Club studentships. All six are beginning their research studies, and as yet do not have data to present. Please do make them welcome. We hope to hear about the results of their research in future years.

The six individuals are:

**Louise Davies** (University of Birmingham)

> Louise is beginning work on a prospective study of risk markers for challenging behaviour in young children with severe intellectual disability and description of a high risk cohort.

**Philip Disley** (Lancaster University)

> Philip is beginning research applying equity theory to staff in services for individuals with learning disabilities.

**Gemma Griffith** (University of Wales Bangor)

> Gemma is beginning research on psychological adjustment in families of children with rare genetic syndromes.

**Alexander Phillips** (University of Cambridge)

> Alexander is beginning research on exercise and the physical abilities of people with Down syndrome. His research is likely to investigate physiological and other factors that may have an adverse effect on activity and how these might be compensated for.

**Penny Tunnicliffe** (University of Birmingham)

> Penny is beginning research on functional analysis of self-injurious and aggressive behaviour in Cornelia de Lange, Cri du Chat, and Angelman syndromes.

**John Yeung** (Glasgow University)

> John is beginning research on the topic of frequent aggression and people with intellectual disabilities.

# Index

| Programme |
|---|

## Monday 11th December

9:45-10:30     Registration & Coffee

10:30-10:40     Welcome & Introduction – Eric Emerson

10:40-11:55     Session 1: Children & Families
                  Chair: Eric Emerson

1. *Unmet need in families of young people with intellectual and developmental disabilities*
Vivien Moffat, Jennifer Wishart & Eve Johnstone
2. *Christian Faith in the Lives of Families with an Adult with Intellectual Disabilities*
Susannah Turner & Chris Hatton
3. *Electropalatography (EPG) Therapy for Articulation Disorders in Children with Down's Syndrome*
Joanne McCann, William Hardcastle, Sara Wood, Jennifer Wishart & Claire Timmins
Discussion

11:55-13:10     Session 2: Life Events & Well-Being
                  Chair: Glynis Murphy

4. *Mental Health of Children with and without Intellectual Disabilities*
Eric Emerson & Chris Hatton
5. *Developing Measures of the Impact of Traumatic Life Events on People with Intellectual Disabilities*
Sarah Wigham, Chris Hatton & John Taylor
6. *Life Events and Psychological Outcomes in Adults with Intellectual Disabilities: Longitudinal Relationships*
Lee Williams, Richard Hastings, Stephen Noone, : Lauren Burns, Jessica Day & John Mulligan
Discussion

13:10-13:55     Lunch (45 min)

13:55-15:10     Session 3: Cognitive Therapy
                  Chair: Dave Dagnan

7. *Group cognitive-behavioural treatment for men with sexually abusive behaviour*
Glynis Murphy & Neil Sinclair
8. *Establishing the building blocks of cognitive behavioural therapy with people with mild learning disabilities: developing a collaborative relationship*
Andrew Jahoda, Carol Pert, Peter Trower, Biza Stenfert-Kroese, Dave Dagnan & Mhairi Selkirk
9. *Motivating Sex Offenders with Intellectual Disabilities*
Vicki Grahame, Bruce Gillmer & John L Taylor
Discussion

15:10-15:30     Tea (20 min)

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|---|---|
| 15:30-16:30 | Keynote Address: |
| | *Whose knowledge is it anyway?  Reflections on inclusive research* |
| | Gordon Grant |
| 16:30-17:30 | Break |
| 18:00-19:30 | **Poster Session** |

*A Functional Analysis of Self-injurious Behaviour in Children with Smith-Magenis Syndrome: 2 Case Studies*
Debbie Allen & Chris Oliver
*Exploring masculinity with young offenders with intellectual disability*
Jonathan Banes & Siobhan Hugh-Jones
*Breaking the barriers of inactivity: Cycling for people with learning difficulties*
Jeff Bartley
*What works in transition from school to a paid job?*
Stephen Beyer & Axel Kaehne
*An exploration of a manual based approach for anger treatment*
Sally-Anne Broughton, Jennie Potts & Anne Necus
*Access to dental care for adults with intellectual disabilities*
Melanie Chapman, Darren D Chadwick, Gill Davies & Samantha Starling
*Low Levels of Physical Activity in Adults with Learning Disabilities*
Janet Finlayson, Sally-Ann Cooper, Jillian Morriaon, Craig Melville, Alison Jackson, Elita Smiley; Linda Allan &  Dipali Mantry
*A study of the work of managers in residential services for people with learning disabilities*
Jane Gifford
*Socio-Economic Position, Social Connectedness and the Self-Reported Well-Being of Women and Men with Intellectual Disabilities in England*
Chris Hatton & : Eric Emerson
*Parental Views on Transition to Employment for young people with Learning Disabilities*
Axel Kaehne & Steven Beyer
*A project to identify and develop ways in which children with intellectual disabilities and parents can inform, participate and help design services that they receive*
Chris Lawes & Leon Fletcher-Tomenius
*The use of the LaVigna Multi-element Model for assessment and treatment of challenging behaviour in a man with severe learning disabilities*
Anne MacDonald, Linda Hume & Peter McGill
*Is the function of challenging behaviour changing over time?*
Peter McGill & Jo Moss
*An Audit of the Shropshire Asperger's Support Group (ASG)*
Paul Moloney
*Early social communication and cognitive functioning in infants with Down Syndrome*
Derek G. Moore, R. Peter Hobson, John Oates & Julia Goodwin
*An evaluation of the effects of a peripatetic challenging needs team on the lives of referred clients and the staff who support them*
Stephen Oathamshaw & Sue Latter
*POMONA-2: Operationalisation & piloting a set of health indicators*

*for people with intellectual disabilities*
Jon Perry & Mike Kerr
*Emotional and Behavioural Adjustment in Siblings of Children with Intellectual Disability With and Without Autism*
Michael A. Petalas, Richard P. Hastings, Susie Nash & Tracey Lloyd
*Health knowledge and expected outcomes of risky behaviour: A comparative study of non-disabled adolescents and young people with intellectual and physical disabilities*
Jaycee Pownall, Andrew Jahoda, Sarah Wilson & Ken MacMahon
*Participation in the 2005 General Election by Adults with Intellectual Disabilities*
Marcus Redley, Helen Keeley, Lydia Luke, Isabel Clare & Tony Holland
*Down Syndrome, and Congenital Heart Defect: Maternal Experiences of Bereavement.*
Deirdre Reilly, Richard P. Hastings, Frances L. Vaughan & Jaci Huws
*Investigating the relationship between self-injurious behaviour and sensory dysfunction in people with intellectual disabilities*
Joanne Schultz, Dougal Julian Hare, Melanie Chapman & Kate Limb
*Speech Articulation Variability in Children with Down's syndrome*
Claire Timmins, William Hardcastle, Sara Wood, Jennifer Wishart & Joanne McCann
*Interactive Training on Active Support: Perspectives from Staff, Managers, and Trainers*
Vaso Totsika, Sandy Toogood, Richard Hastings & Susie Nash
*Understanding antecedents of emotional expressions by children with Down's syndrome*
Katie R. Williams, Jennifer G. Wishart, Diane S. Willis & Tom K. Pitcairn
*Clarification of the memory artefact in the assessment of suggestibility*
Paul Willner

19:30 >        Dinner @ Wetherspoons!

**Tuesday 12<sup>th</sup> December**

| | |
|---|---|
| 9:00-10:35 | Session 4: Well-Being & Mental Health |
| | Chair: Richard Hastings |

10 *The psychological well-being of young people with intellectual disabilities attending specialist and mainstream schools, and their peers without intellectual disabilities*
Anna Ramharakh, Clair May, Biza Kroese, Jo Kirk, Carolyn Henshall & Camilla Johns

11 *Depression, self-esteem and social comparison; the effects of comparison person and comparison dimension*
Dave Dagnan

12 *Low mood in Cornelia de Lange syndrome*
Lisa Collis, Caroline Richards, Joanna Moss & Chris Oliver

13 *The Psychological Impact of a Diagnosis of Asperger Syndrome in Adulthood*
Clare Punshon, Paul Skirrow & Glynis Murphy

Discussion

| | |
|---|---|
| 10:35-10:55 | Coffee (20 min) |
| 10:55-12:10 | Session 5: Well-Being & Mental Health 3 |
| | Chair: David Felce |

14 *Psychopathology in adults with Williams syndrome*
Chris Stinton, Sarah Elison, Pat Howlin & Orlee Udwin

15 *Prader-Willi syndrome: Attentional Profile and The Importance of Predictability*
Kate Anne Woodcock, Chris Oliver & Glyn Humphreys

16 *Examining the functional equivalence and temporal proximity of self-injurious, potentially-injurious, repetitive and communicative behaviours in children with severe intellectual disabilities*
Jane Petty, Chris Oliver & Debbie Allen

Discussion

| | |
|---|---|
| 12:10-13:00 | Lunch |
| 12:30-13:00 | *Open meeting on organisation of the Seattle Club and planning for the 2007 conference:* Chair: Richard Hastings |
| 13:00-15:00 | Session 6: Services |
| | Chair: Chris Oliver |

17 *Motivation to Work of People Using Supported Employment Services*
Simon Russon, Alison McGarry, Biza Stenfert Kroese, Rebecca Lunt, Philippa Drew & Anne Meadon

18 *Outcomes and costs of semi-independent living and fully staffed group homes*
David Felce, Jon Perry, Renee Romeo, Janet Robertson, Eric Emerson & Martin Knapp

19 *Can Local Governance work on Learning Disability Partnership Boards?*
Carol Riddington

15:00-15:30    Closing & Reflections: Andrew Jahoda

**Unmet need in families of young people with intellectual and developmental disabilities**

Vivien Moffat, Jennifer Wishart & Eve Johnstone
Division of Psychiatry, University of Edinburgh
Email: vivien.moffat@ed.ac.uk

Background: Policy makers and service providers are increasingly aware of family needs for people with intellectual and developmental disabilities (ID/DD), including autistic spectrum disorder (ASD), and are committed to developing appropriate services. This study explored mothers' experiences of access to services and how these might relate to individual/family quality of life (qol).

Methods: Mothers of 94 young people aged 13-22 participated.
The young people were either:
1. typically developing controls (n=18)
2. with ID/DD and -ve ASD screening score (n=37)
3. with ID/DD, +ve ASD screening score and ASD diagnosis (n=19)
4. with ID/DD, +ve ASD screening score but no ASD diagnosis (n=20)

All mothers completed standardised questionnaires on family and individual qol and son or daughter's behaviour. The mothers of groups 2-4 also completed standardised questionnaires on stress and service provision, with a stratified sub-sample of 20 interviewed about stressful issues and perceived unmet need.

Results: ASD screening scores were significantly positively correlated with maternal stress and significantly negatively correlated with family and maternal qol. Family qol was significantly lower for groups 3 and 4 than groups 1 and 2. Themes emerging from interviews included: experiences of inadequate support, lack of social acceptance and poor communication with/amongst service providers

Conclusions: Mothers of young people with diagnosed and undiagnosed ASD experience lower individual and family quality of life than mothers of young people without ID and with non-ASD ID. Unmet needs include access to designated key worker and to information. Although consistent with policy that is being currently developed and implemented, these findings suggest that recent initiatives are not reaching all families who would benefit.

**Christian Faith in the Lives of Families with an Adult with Intellectual Disabilities**

Susannah Turner & Chris Hatton
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Background: Religion is often overlooked by researchers when investigating the lives of adults with intellectual disabilities and their families.  However, religion can impact upon the lives of families in both positive and negative ways. This PhD study aims to investigate what role Christian faith plays in accepting an adult with intellectual disabilities, the impact of faith on specific stresses, and any negative effects of the role of faith and the church or community may have on participants.

Methods: Families who self-identified as Christian were asked semi-structured questions around private faith, prayer, religious background, church involvement and perception of God.  Families identified as being either Roman Catholic or from evangelical Christian traditions such as Baptist, or Pentecostal. Twenty families in all are being sought to be interviewed, with 11 families interviewed so far.   As religion and intellectual disabilities is a relatively under researched area, I have used a grounded theory as it is an effective method of exploring the topic.

Results: Themes from the interviews include: faith as a buffer; role of God; prayer as a practical aid; criticism of the church, the impact of being part of a church; struggle to understand their adult child's disabilities in the light of their faith; inclusion/exclusion by the church and separation between church and faith.

Conclusions: The research is not complete however; so far the study has shown that faith and belief are generally viewed positively by families, but it can be hard for some parents to resolve their faith and beliefs with their adult child's disabilities.

**Electropalatography (EPG) Therapy for Articulation Disorders in Children with Down's Syndrome.**

Joanne McCann, William Hardcastle, Sara Wood, Jennifer Wishart & Claire Timmins
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Background: Speech development in Down's syndrome (DS) is typically more impaired than would be expected from levels of cognitive impairment. Articulation errors are common and often intractable. People with DS often prefer visual to auditory methods of learning, therefore we can predict that people with DS would find it easier to modify their speech when given a visual-auditory model rather than only auditory model. One such model is provided by EPG, a technique for recording and displaying the timing and location of tongue-palate contact.

Methods: We are currently carrying out an MRC-funded study using EPG to assess and treat speech disorders in 30 children with DS. Participants are randomly assigned to receive EPG therapy, articulation therapy or no therapy. Progress in EPG therapy will be described for one participant. "Anna" (12 years) presented with distorted sibilants /s, z, sh, zh&#61472;/ (as in "sun", "zoo", "shoe", "measure"). EPG recordings of Anna's speech were taken before and during therapy; therapy is ongoing, post-therapy recordings will be made at a later date. EPG contact patterns (e.g. closures) were recorded for all sibilant targets.

Results: High closure values (>70%) for pre-therapy sibilants indicated that they were realized as either stops ("sun" produced as "tun") or laterals (produced by allowing the airstream to flow over the sides rather than the middle of the tongue). Mid-therapy closure values were lower indicating that the participant was able to achieve correct sibilants.

Conclusions: The results suggest that EPG may be an effective therapy for articulation disorders in children with DS.

**Mental Health of Children with and without Intellectual Disabilities**

Eric Emerson & Chris Hatton
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Background: Existing research has reported higher rates of psychopathology among children with intellectual disabilities. There have, however, been very few studies that have investigated the prevalence of specific psychiatric disorders (defined in accordance with DSM or ICD classification systems) and co-morbidity between psychiatric disorders in well constructed population based samples of children with and without intellectual disabilities. In addition, few studies have explored the extent to which risk factors for psychiatric disorders (and co-morbidity) vary across children with and without intellectual disabilities.

Methods: Secondary analysis of data collected in the 1999 and 2004 Office for National Statistics (ONS) surveys of child and adolescent mental health in Britain. These two cross sectional surveys were based on nationally representative samples of 10,500 (1999) and 8,000 (2004) British children aged 5-15. Psychiatric disorders were identified through well validated structured interview formats undertaken with a primary carer (usually the child's mother) and the child themselves (if aged 11 years or older). In previous studies we have operationally identified children with intellectual disabilities in the 1999 data are reported on the prevalence of psychiatric disorders and relationship between mental health and life events.

Results: In preliminary analyses we have operationally identified children with intellectual disabilities in the 2004 data and, given that there were no marked differences in overall prevalence between 1999 and 2004, merged the data files. The merged file contains approximately 500 children with intellectual disabilities and 17,500 children without intellectual disabilities. Subsequent analyses will: (1) estimate the prevalence of specific psychiatric disorders and combinations of co-morbid disorders among children with and without intellectual disabilities; (2) explore the extent to which age, gender, socio-economic position, household composition and family functioning operate as risk factors for psychiatric disorders (and co-morbidity) across children with and without intellectual disabilities. The latter analyses will involve both simple bivariate analyses and multivariate analyses (logistic regression) to identify the unique contribution of particular factors.

**Developing Measures of the Impact of Traumatic Life Events on People with Intellectual Disabilities.**

Sarah Wigham, Chris Hatton & John Taylor
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Background: The association between mental ill health and traumatic life events is established in the general population literature e.g. post-traumatic stress disorder. The objectives of this study are; a) to gather empirical evidence supporting this link in the intellectual disability (ID) population; and b) to develop relevant and accessible measures of the effects of traumatic life events for people with ID, which can be used in future research and practice.

Methods: The first stage of this study involved a survey of service users and stakeholders and thematic analysis to develop new prototype trauma measures. Using interviews, questionnaires and focus groups, seven service users, two advocates, two family carers, plus sixteen staff and clinicians from mental health and forensic ID services in Northumberland, were consulted about their views on the effects of traumatic life events on people with ID.

Results: Themes concerning the impact of trauma were derived from the data by content analysis. The emergent findings were broadly consistent with general population studies. Differences concerned regression of skills and behaviours that challenge services, and these were in accordance with previous studies. A 36-item assisted-format self-report measure, gauging frequency of effects, and a 46-item informant measure gauging frequency and severity were developed using this procedure.

Conclusions: The next stage of the project is to examine the reliability and validity of the new measures in a multi site prospective longitudinal study of 100-200 people in collaboration with colleagues from the University of Wales, Bangor.

**Life Events and Psychological Outcomes in Adults with Intellectual Disabilities: Longitudinal Relationships**

Lee Williams, Richard Hastings, Stephen Noone, : Lauren Burns, Jessica Day & John Mulligan
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Background: Despite recent increased interest in life events in the field of intellectual disabilities, improvements in measurement of events have been hard to come by.  Measures typically comprise a list of events categorized as negative a priori by researchers.  Studies using these measures have produced associations of modest effect size.  Esbensen & Benson (2006) have emphasized the importance of assessing whether an event is negative in context.

Methods: The Bangor Life Events Schedule for Intellectual Disabilities Informant version (BLESID-I) comprises a list of 38 events, each rated for frequency and impact.  The BLESID-I and several measures of psychological adjustment were completed with carers of 89 people across the range of intellectual disability (preliminary data here; N=40).  The current study was longitudinal (3-year follow-up) to address issues relating to the direction of causality.

Results: Scoring based on our approach of defining events as negative in context yielded the strongest associations with psychological outcomes and was carried forward into further analyses. Five regression models were tested.  Life events significantly predicted anger ($? = .34$, $p = .03$), aggression ($? = .50$, $p < .01$), affective/neurotic symptoms ($? = .50$, $p < .01$), and psychotic symptoms ($? = .54$, $p < .01$), controlling for initial levels of the criterion.  The prediction of adaptive behaviour approached significance ($? = .19$, $p = .05$).  These relationships appear to be uni- directional in this sample.

Conclusions: These data provide further evidence for the importance of life events in the aetiology of psychological disorder and challenging behaviour, and for the BLESID-I as a useful tool for research and potentially, the clinic.

## Session 3: Cognitive Behaviour Therapy

**Group cognitive-behavioural treatment for men with sexually abusive behaviour**

Glynis Murphy & Neil Sinclair,
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Background: Group CBT is the treatment of choice for non-disabled sex offenders and a variety of studies have shown that it is effective for such men. This form of treatment is now widely available in the UK for non-disabled men in prisons, probation and secure services. However, men with learning disabilities are often excluded from such programmes.

Methods: This paper reports on a multi-site project which provided group CBT, specifically designed for men with learning disabilities, to 52 men who had sexually abusive behaviour and mild learning disabilities. The treatment groups ran once per week for 2 hours, over a period of a year. There were baseline measures of diagnostic factors, IQ and verbal skills. There were also measures, before and after the group, for sexual knowledge, victim empathy, cognitive distortions and 're-offending'.

Results: There were statistically significant improvements in sexual knowledge, victim empathy, and cognitive distortions by the end of the group. Most men did not show further sexually abusive behaviour during the period of the group, nor for the six months following the group. However, those who did show further sexually abusive behaviour were statistically more likely to be men with autistic spectrum diagnoses.

Conclusions: We conclude that the CBT method used here (SOTSEC-ID) shows promise in reducing sexually abusive behaviour by men with learning disabilities. Strengths and weaknesses of the research will be discussed.

**Establishing the building blocks of cognitive behavioural therapy with people with mild learning disabilities: developing a collaborative relationship**

Andrew Jahoda, Carol Pert, Peter Trower, Biza Stenfert-Kroese, Dave Dagnan & Mhairi Selkirk
Section of Psychological Medicine, Gartnavel Royal Hospital,Glasgow,
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Background: There have been increasing efforts to adapt Cognitive Behavioural Therapy (CBT) for people with intellectual disabilities. However, this is the first study to look at whether a collaborative relationship can be established between the therapists and clients.

Methods: Sixteen clients with intellectual disabilities and depression, anxiety or significant problems with anger were recruited from specialist community-based services. Therapy sessions 4 and 9 were video and audio-taped. The sessions were transcribed verbatim and the 12,544 communicative turns were then coded using Per Linell et al.'s (1988) method of interactional analysis. This involved coding each conversational partner's turns in relation to the other, thereby making it possible to examine the distribution of power in the dialogue (dominance). Ratings of adherence by an independent expert found the therapists faithful to the CBT model.

Results: Analyses of relative dominance in the interaction between therapists and clients indicated a reasonable balance of power, and that most clients played an active role in the dialogues. Yet it was found that less able individuals produced more fragmented communication turns and most participants struggled to grasp the CBT model. Therapists' use of visual aids and active tasks, such as role-play, did help to make complex components of therapy more meaningful.

Conclusions: The collaborative nature of the therapeutic relationships contradicts the prevailing assumption that therapists should adopt a more didactic or instructional approach to ensure engagement with clients who have intellectual disabilities. The limitations of the approach for this population are also highlighted.

**Motivating Sex Offenders with Intellectual Disabilities**

Vicki Grahame, Bruce Gillmer & John L Taylor
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Background: Whilst it is established that sex offender treatment programmes (SOTP) developed for offenders with an intellectual disability (ID) can be adapted for those who are difficult to treat, no consideration has been given to how groupwork involving risk management for such offenders could be made more motivational by involving offenders.  Motivational interventions should have particular valency as these directly target issues (like denial) that have prevented these men from engaging with conventional programmes.

Methods: This study describes the design and implementation of a manualised group intervention.  A collaborative risk-needs assessment is structured around the stages of change model and employs motivational interviewing techniques to facilitate movement through the stages.  It was designed specifically for sex offenders with an ID who were resistant to conventional SOTPs.  The manual was piloted on a small group of sex offenders.  Participants were assessed pre- and post-group intervention, principally using goal attainment scales (GAS's) across a range of risk and personal agency parameters.

Results: The application of motivational strategies to a collaborative risk management model shows promising results for future development. Appreciable effect sizes were found on all GAS's.  The pilot was aimed at offenders with little desire to change and demonstrate that following treatment these men were more open to engage in risk needs planning.

Conclusions: Motivational strategies structured around a risk needs model yielded promising results.  Further research is required to confirm these preliminary findings.

**The psychological well-being of young people with intellectual disabilities attending specialist and mainstream schools, and their peers without intellectual disabilities**

Anna Ramharakh, Clair May, Biza Kroese, Jo Kirk, Carolyn Henshall & Camilla Johns
Service for Adults with a Learning Disability, Wellington Telford
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Background: Despite increased awareness of the needs of young people with learning disabilities during transition to adulthood, the challenges they face have yet not been adequately addressed by services.

Methods: This study considers the psychological well-being of 52 young people aged 15-16 years. Twenty-two students with mild/moderate intellectual disabilities attending special schools, ten attending mainstream schools and twenty students without intellectual disabilities completed measures of quality of life, aspirations, stigma, social integration, social comparison, and self-esteem. Twenty-three students completed a follow-up approximately one year on.

Results: Students in the three groups did not differ in their how satisfied they were with their relationships with friends and family, prior to leaving school. Students reported a range of fairly typical aspirations for the future. Students attending special schools experienced significantly higher levels of stigma, which was related to poorer social integration. They also made different social comparisons to their peers. No corresponding differences in self-esteem were identified; most students reported relatively high levels of self esteem. At follow-up, many of the trends continued.

Conclusions: The trends that were evident in Year 11 appeared to continue for the young people in the study. A worrying trend for students who attended special schools was that of poor social integration, linked to increased stigmatisation. Nonetheless, young people with intellectual disabilities remained hopeful about the future, evident in their aspirations. The current study was not able to account for the relatively high levels of self-esteem reported by participants, suggesting other factors require consideration. Due to the relatively low numbers of participants, these conclusions are tentative.

**Depression, self-esteem and social comparison; the effects of comparison person and comparison dimension**

Dave Dagnan
Distington,
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Background: Social comparison processes have been shown to be important in considering the well being of people with learning disabilities. This poster describes a study of the impact of making comparisons to people with and without a learning disability on social or achievement dimensions.

Methods: Thirty-nine people with mild and moderate learning disabilities completed adapted scales for Depression, Self-Esteem and a general and specific measure of Social Comparison. A semi-structured social network interview was carried out in the context of which a key comparison person and comparison dimension was identified.

Results: A series of two way ANOVAs were carried out. Significant main effects for the comparison person (less psychological well being when the comparison person does not have a learning disability) were found for depression, and general and specific social comparison, a significant main effect for comparison dimension (poorer comparisons when the dimension is achievement oriented as opposed to socially oriented) was found for specific social comparison, a significant interaction between comparison person and comparison dimension was found for self- esteem (lower self esteem when comparison to person without learning disability on achievement dimensions). There was an association between the proportion of people without learning disabilities in social networks and the person identified for comparison; however taking this association into account only reduced the effect for depression.

Conclusions: This study suggests that the social comparison priorities of people with learning disabilities may have an effect upon psychological well being.  The findings tentatively support interventions within a cognitive framework that might examine the social comparison targets and dimensions of people with learning disabilities.

**Low mood in Cornelia de Lange syndrome**

Lisa Collis, Caroline Richards, Joanna Moss & Chris Oliver
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Background: There is limited research regarding cognitive, emotional and behavioural change with age in Cornelia de Lange syndrome (CdLS). One of the first cross sectional studies found that, unlike other syndrome groups, older individuals with CdLS experienced low mood (Oliver et al., 2005).  The present study involved following-up individuals to examine how mood changed over time.

Methods: Seventy individuals with CdLS from Oliver et al.'s (2005) study were followed up after approximately two years.  Participants' mood was compared across three age bands (0-10 years (n=20); 11-20 years (n=31); and 21 years and over (n=19)) using the Mood, Interest and Pleasure Questionnaire (MIPQ). The change in participants' mood between time point one (Oliver et al., 2005) and time point two (the current study) was then examined.

Results: Mood was analysed using a split-plot ANOVA.  The results indicated a significant main effect of age band ($F_{(1, 67)} = 4.38$; $p < .05$), with individuals displaying lower mood in the older age bands.  However, there was no significant main effect of time ($F_{(1, 67)} = .23$; $p = .635$) and there was no significant interaction between the time and age band ($F_{(3, 67)} = .23$; $p = .872$).

Conclusions: The results indicate no difference in the levels of mood across a two year period but a robust effect of age. Longer follow-up is needed to differentiate the potential cohort effect (possibly related to untreated health conditions in the older cohort) from progressive change.

**The Psychological Impact of a Diagnosis of Asperger Syndrome in Adulthood**.

Clare Punshon, Paul Skirrow & Glynis Murphy
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Background: Asperger Syndrome is a relatively new diagnostic classification, so many individuals have only received a diagnosis in adulthood.  Models of coping have been applied to the experiences of receiving diagnoses of a range of chronic conditions (such as HIV, diabetes).  However, receiving a diagnosis of Asperger Syndrome in adulthood could be described as a unique experience in that individuals have had years of experiencing symptoms without having any understanding of them.

Methods: This study used a phenomenological approach to explore the experiences of ten adults with a diagnosis of Asperger Syndrome.  The data was analysed using interpretative phenomenological analysis.

Results: The results highlighted six major themes: negative life experiences, experience of services prior to diagnosis, beliefs about symptoms of Asperger Syndrome, identity formation, effects of diagnosis on beliefs and the effect of societal views of Asperger Syndrome.

Conclusions: This research has provided an important insight into the experience of adults receiving a diagnosis of Asperger Syndrome.  The results highlighted the importance of providing diagnoses as early in life as possible.  This would prevent individuals experiencing some of the negative life events (such as misdiagnosis).  However, in cases of late diagnosis, individuals described the importance of having effective diagnostic services and post-diagnostic support.  Finally, in an ideal world, individuals wished that the general public would change their perceptions of individuals with Asperger Syndrome in order to make them feel an important and valued part of society.

**Psychopathology in adults with Williams syndrome**

Chris Stinton, Sarah Elison, Pat Howlin & Orlee Udwin
Institute of Psychiatry London
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Background: Individuals with intellectual disabilities (ID) are often reported as being more likely to suffer mental health problems than the general population (Debs et al. 2001). One such example is Williams syndrome (WS), in which reports of anxiety are frequent. To date, no study has addressed psychopathology in this population using assessment measures designed specifically for individuals with ID.

Methods: Fifty seven adults with WS were screened for potential mental health problems via a general questionnaire given to parents. Criterion for further assessment was reports of psychopathology that caused distress/intrusion into the everyday life of their son/daughter. On this basis, forty one of the adults with WS were followed up using the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD; Moss et al. 1994).

Results: Of the forty one individuals assessed, sixteen of the adults with WS received a PAS-ADD diagnosis for at least one type of mental health problem. Types of problems and number experiencing them were as follows: specific phobia (N=13), depression (N=5), agoraphobia (N=4), schizophrenia (N=3), panic disorder (N=3), psychosis (N=2), generalised anxiety disorder (N=1) and social phobia (N=1). Co-morbidity was identified in ten of the individuals, with six individuals receiving two PAS-ADD diagnoses and four individuals receiving three PAS-ADD diagnoses.

Conclusions: The preliminary results of this study add to the limited knowledge of psychopathology in WS, providing additional evidence for high levels of anxiety (in particular phobias), highlighting the existence of other forms of mental health problems and identifying high levels of co-morbidity.

**Prader-Willi syndrome: Attentional Profile and the Importance of Predictability**

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Background: Repetitive behaviours and 'temper outbursts' are common in people with Prader-Willi syndrome (PWS) and may be associated with executive dysfunction. This study aims to explore possible connections between different aspects of the behavioural phenotype and describe characteristics of an endophenotype that may underlie these behaviours.

Methods: Stage 1: Caregivers of 46 children with PWS were interviewed about the environmental context of repetitive behaviour shown by their child. Stage 2: Carers of 28 children with PWS (12 male; mean age 161m) and 28 typically developing children (11 male; mean age 103m) completed two informant report questionnaire measures of repetitive behaviour. Children completed measures of executive attention including a modified Stoop-like computer task that can assess attentional switching.

Results: Stage 1: Of the 80% of carers who reported temper outbursts, 91.9% reported that unpredictability occurred antecedent to these outbursts. Of 93.5% of carers who reported repetitive questions, 83.7% reported that these increased following unpredictability. Stage 2: Group differences in developmental and chronological age were controlled for statistically. A mixed factor ANCOVA of reaction times in the Stroop-like task showed a significant interaction between group and switching ($F(1,52)=9.24$, $p=0.004$). Questionnaire measures showed that various repetitive behaviours differed significantly between the two groups, but only scores on items relating to the importance of predictability were significantly correlated with standard scores of switch-cost.

Conclusions: Children with PWS show challenging behaviours when their environment becomes unpredictable; a deficit in switching attention may underlie this need for predictability.

**Examining the functional equivalence and temporal proximity of self-injurious, potentially-injurious, repetitive and communicative behaviours in children with severe intellectual disabilities**

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Background: Previous research has indicated a strong relationship between self-injurious and repetitive behaviours and the presence of high frequency repetitive behaviour has been found to significantly predict the presence and severity of self-injurious behaviour. The aim of the current research was to a) examine the functional equivalence of self-injurious, potentially injurious and repetitive behaviours and b) examine the temporal association between these behaviours in order to identify potential precursors to self-injurious behaviour.

Methods: Six children with severe intellectual disabilities aged 5 to 14 years took part. Data were collected in their school environment regarding self-injurious, potentially injurious, repetitive and pragmatic communicative behaviours using both naturalistic observation and analogue functional analysis methods. Data were subsequently coded in real time using Obswin software and the functional and temporal relationships between the variables were assessed using lag sequential analyses.

Results: Self-injurious, potentially injurious, repetitive, pragmatic communicative and other challenging behaviours were identified as socially reinforced for some individuals across both experimental functional analysis and naturalistic observations. The identification of functionally equivalent response classes highlighted that when socially reinforced, these behaviours were clustering with other socially reinforced behaviours. Significant precursors were identified for both self-injurious and potentially injurious behaviours across both experimental functional analyses and naturalistic observation data.

Conclusions: The results of the functional analyses confirm the importance of operant theory for the assessment of these behaviours in individuals with intellectual disabilities. The temporal association between naturally occurring pragmatic communicative behaviours and potentially-injurious, self-injurious and other challenging behaviours provides support for the social-communicative theory of challenging behaviour and may also be a critical feature of how challenging behaviours become operant via superstitious reinforcement.

**Motivation to Work of People Using Supported Employment Services**

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Background: It is widely recognised that people with intellectual disabilities face barriers when seeking employment. Individual motivation may be one determining factor. It was predicted that amongst a sample of employment service users, those currently in employment would report significantly higher levels of motivation to work than those still seeking employment.

Methods: The study utilised a 2x2 factorial design with eleven participants with intellectual disabilities (employed=2, unemployed=9) and nine participants with mental health problems (employed=4, unemployed=5). The latter sample was included for means of comparison. Participants underwent a sixty-minute interview during which they were asked to report on their motivation, quality of life, assertiveness and general opinions of the employment services.

Results: Employed participants demonstrated significantly higher levels of motivation than unemployed participants ($Z=0$, $p<.05$). This trend, although evident in both samples, was more pronounced in clients with intellectual disabilities than clients with mental health problems. In particular, employed participants tended to demonstrate a stronger 'work ethic' and a greater desire to perform to the best of their ability. Several unemployed participants expressed concern regarding how employment might negatively affect the benefits they currently received.

Conclusions: Although higher levels of motivation were associated with employed status, the scores achieved by unemployed intellectually disabled participants were almost double those obtained by employed participants with mental health problems. On the basis of this, it is argued that although motivation may predict success in gaining employment, it is unlikely to be a factor that fully explains the low employment rate amongst people with intellectual disabilities.

**Outcomes and costs of semi-independent living and fully staffed group homes**

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Background: Stancliffe & Keane (2000) showed that semi-independent (SI) living delivered better outcomes than fully staffed (FS) group homes for people with relatively low support needs at lower cost. This UK study sought to replicate the comparison.

Methods: 35 adult pairs in SI living and FS group homes were matched on 'short-form' adaptive and challenging behaviour screens and selected so that co-resident characteristics were also similar. Data were collected on (a) 'long-form' participant and co-resident characteristics; (b) setting characteristics, staffing and working methods; (c) participants' outcomes: money management, health, safety/risks, community and household activities, social networks, loneliness, choice and satisfaction; (d) accommodation and non-accommodation costs. Groups differed on long-form participant assessments. Therefore, data were analysed for (a) the full sample using ANCOVA controlling for differences in adaptive and challenging behaviour and (b) two matched sub-samples (SI=27, FS=28). Analysis of cost data employed bootstrapping.

Results: Group size and staff-to-resident ratios were greater in FS group homes. Having a garden and procedures for behavioural assessment and teaching and for activity planning were more common in FS group homes. There were no differences on the majority of lifestyle outcome measures. FS participants had better outcomes in relation to money management and some health indicators. SI participants had better outcomes in relation to community activities undertaken without staff support, social networks, participation in domestic management and choice.
SI living costs were about a third of those of FS group homes.

Conclusions: On balance, SI living appears to offer certain cost-effective lifestyle advantages.

**Can Local Governance work on Learning Disability Partnership Boards?**

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Background: The concept of including lay people on partnership boards is promoted widely within Government policy circles.  In 2001 Government required each local authroity in England and Wales to establish a Learning Disability Partnership Board (2001 White Paper 'Valuing People'). The concept of local governance is explored in this paper.  Particular focus will be on whether or not the format of partnership boards is the most effective method of involving family carers and adults with impaired learning.

Methods: Systematic observations were completed during Learning Disabilty Partnership Board meetings in three local authority areas.

Results: Preliminary anaylsis indicates that the Learning Disability Partnership Boards are not functioning at a strategic level. Public sector 'gatekeepers' are important in contolling the balance of power on these partnerships.

Conclusions: If the rationale for including people with learning difficulties in decision making is to increase local governance and improve the quality of services, then the Learning Disability Partnership Boards are not achieving these goals. It is also questionable how long such partnerships will continue in this current form.

**Lessons learnt from the pilot Independent Mental Capacity Advocate (IMCA) service**

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Background: The IMCA service is a key provision in the Mental Capacity Act (England & Wales) 2005 (MCA), which is due to come into force in April 2007. The MCA provides a statutory framework to empower and protect adults who are judged to lack capacity in relation to decisions that affect their health, welfare, or finances.  It does this by requiring that any decisions made on behalf of these men and women are in their 'best interests'.  Adults who lack capacity and have no family or friends to speak on their behalf are particularly vulnerable.  Such adults, faced with a decision about serious medical treatment (SMT) or a change of accommodation, will be entitled to the services of an IMCA case-worker.

Methods: Quantitative data describing: referrals to the pilot IMCA service; the client groups referred to the IMCA service; the types of decisions to be made; and the duration of IMCA cases. Qualitative interviews with advocates acting as IMCAs, managers of the pilot IMCA services and practitioners in health and social care who have referred decisions to an IMCA.

Results: Understanding the circumstances for which the IMCA service is provided presented problems to both providers of the service and to health and social care practitioners making referrals to it.  Additionally, the IMCAs sometimes had difficulty in understanding the remit of the IMCA role.

Conclusions: The successful implementation of a statutory IMCA service in 2007 will require significant changes in how advocacy and key terminology in the MCA, such as the 'assessment of capacity' and 'unbefriended', are understood.

**Factors associated with criminal justice system involvement: A comparison of referrals to community learning disability teams following problem and offending-like behaviour.**

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Background: This work forms part of a recently completed study, investigating the care pathways of people with learning disabilities (LD) displaying offending or 'offending-like', problem behaviours, and served by a range of health care provisions for people with LD (from community teams to low, medium and high secure hospitals), in three regions of the United Kingdom (the East, North East and East Coast of Scotland).

Methods: Data collected included measures of previous and current problem behaviours, living circumstances, medical diagnoses, and previous life events (such as childhood abuse and deprivation), as well as service provisions over the life course. The dataset is used here to focus on those served by community teams for people with LD in the Eastern region (within two Mental Health Trusts, Cambridgeshire & Peterborough and Norfolk & Waveney), for whom many referrals involved 'problem' or 'offending-like' behaviour, which was neither reported to the police, nor taken up by the criminal justice system (CJS). This allowed a demographic comparison of those individuals whose behaviour, did (N=62), and did not (N=103), trigger CJS involvement.

Results: Level of LD, deprivation in childhood and past living arrangements distinguished, statistically significantly, between groups. The range of previous problem, or offending-like, behaviours displayed also differed significantly between groups. Neither age at referral, gender, autistic spectrum disorders, nor epilepsy, were associated with CJS involvement in this community sample.

Conclusions: These findings are presented in relation to the characteristics of general population offenders, forensic psychiatric community referrals and referrals to secure LD provisions.

# Posters

**A Functional Analysis of Self-injurious Behaviour in Children with Smith-Magenis Syndrome: 2 Case Studies**

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Background: Smith-Magenis Syndrome is a genetic syndrome, caused by a deletion on chromosome 17 (17p 11.2). Previous researchers have reported that 92-100% of individuals with Smith Magenis Syndrome present Self-injurious Behaviours. Common topographies include hand biting, picking at sores, hitting the head or body, and picking finger and toe nails. The role of social factors in SIB in Smith-Magenis Syndrome was examined.

Methods: Two children with Smith-Magenis Syndrome, aged 4 and 5 years participated in the research. Researcher and parent- led analogue assessments were employed to assess the function of each child's self-injurious. Following two inconclusive analogue assessments of SIB, a parent-led structured descriptive assessment was conducted. This included similar conditions to the analogue assessment with the addition of a tangible condition due to parental reports of the occurrence of SIB when preferred items and activities were removed.

Results: For both participants, the results of the first set of researcher-led analogue assessments were undifferentiated. In the second set of analogues, significantly higher rates of SIB were observed in parent-led versus researcher-led assessments for participant one. This finding was also observed for participant two but the difference was much less marked. For both participants, the results were undifferentiated across conditions. The results of the structured descriptive assessments were differentiated to some extent but there were several unexpected observations which led to further analysis.

Conclusions: The results are discussed in terms of the relevance for gene-behaviour interactions and functional analytic methodology.

# Exploring masculinity with young offenders with intellectual disability

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Background: This project sought to determine a reliable method of interviewing young offenders with intellectual disabilities (ID) and then encourage them to provide their own views on the circumstances which affect their behaviour. The interviews aimed to identify grounded hypotheses for research and indicate areas of need for service provision and clinical intervention.

Methods: The pilot phase tested narrative, card-sorting and self-characterisation interviewing techniques, but established focus groups to be the most reliable method of data collection. 13 male offenders aged between 14-17, and with mild LD (mean Full Scale IQ 73.2), participated in three separate focus group discussions in which they discussed relevant topics such as offending, manhood, masculinity and education.

Results: Grounded theory analysis identified the centrality of hypermasculinity in the boys' self-constructions, particularly in terms of ego-protection. Adhering to peer group rules was also vital in maintaining the group's sense of masculinity, and was most effectively emanated through antisocial behaviour. Strong in- and out-group themes were identified, resulting in the need for an impenetrable group and a forceful distancing from alternative masculinities (e.g. homosexuality). Control and choice were also important in evidencing masculinity, even when that meant 'choosing' to disengage from education. The findings are discussed in relation to how ID may compound the difficulties that many young men face in disadvantaged situations.

Conclusions: Group interviewing appears to be the most reliable method of data collection for young offenders with ID. Faced with few options of identity exploration, some young boys with mild ID will align themselves with 'hypermasculine' constructions of identity, which include antisocial and offending behaviour. Suggestions for early intervention, service provision, clinical work and further research are discussed.

**Breaking the barriers of inactivity: Cycling for people with learning difficulties**

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Background: This study investigates the impact of a 12-month long cycling intervention programme upon barriers to physical activity, for people with learning difficulties. The limited evidence available to date shows these barriers to be particularly problematic, leaving people with learning difficulties little alternative but to lead inactive lives.

Methods: A qualitative approach is used but with a methodology primarily framed within the inclusive research agenda of the disability movement. A total of 47 adult men and women with learning difficulties from two day centres, a residential hostel, and six houses in supported living schemes took part in the study A range of adapted cycles was made available for off-road use, at the day centres and at a local sports centre.

Results: The findings highlighted both the barriers to and benefits of cycling. The barriers were shown to be particularly resistant across settings with issues of staff resources and morale/motivation at the service interface between staff and service users providing the main areas of concern. The benefits are based within cycling's ability to accommodate differing and complex impairments.

Conclusions: This study identified two main threads of a complex service dynamic. Increasing staff resources, although helpful, will not necessarily translate into more active outcomes for service users, Rather, it is towards influencing the workplace interface between service users and their 'significant others' that the impact of interventions should be directed. This study shows cycling to be uniquely placed to make such an impact and allow people with learning difficulties to lead active and empowered lives

**What works in transition from school to a paid job?**
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Background: Few young people with intellectual disabilities move into work from school. This analysis is a part of a wider project, to identify the key factors that raise the probability of young people aged 16-19 gaining paid employment on leaving school or college at this age: personal and family factors; in education based training; careers service involvement; and external support from employment organisations.

Methods: A sample of 87 young people leaving school in 2005 was drawn from 6 areas each operating a different approach to transition to employment. Quantitative data were collected on adaptive behaviour, personal characteristics, hours of schools/college and employment services input. A follow-up carried out after 6 months determined subsequent placement and take-up of paid employment. A step-wise logistic regression is used to determine factors influencing employment outcome.

Results: Hours of employment service led, supported, work experience and hours of school led, work awareness courses were significant predictors of paid work. Analysis of sub-samples have reduce power, but indicate a positive influence for "early preference for work by the young person", and "parental support for employment."

Conclusions: Adaptive behaviour did not have a major effect in this study. Work experience organised through school is uncommon and does not figure as a factor. The twin planks of work awareness training and supported work experience while at school should be introduced more forcefully into schools to make jobs fully. Advice provided on transitions outcomes by Careers Services needs more emphasis on employment if attitudinal factors are confirmed by addition of a second cohort.

**An exploration of a manual based approach for anger treatment**

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Background: There was an opportunity to explore the use of an  anger treatment protocol within a community setting. Four men who were 1) at risk of exclusion from services, 2) motivated to participate in an anger management group, were referred to the community team.

Methods: The programme was based on Taylor and Novaco (2005). The men were aged 17-42 years. Eighteen sessions were presented, including psycho-education, cognitive, behavioural and relaxation techniques. Sessions were 90 minutes (including 30 minutes keyworker/carer involvement). Pre, mid and post group anger measures (STAXI and Adapted Provocation Inventory)and an anxiety measure (pre and post treatment phase) were taken. Other data collected were the facilitator's observations and group members accounts of each session.

Results: Numbers were too small to submit the data to a statistical analysis but data were visually compared for individual differences. None of the men reported high anxiety. All found the STAXI (Part C) problematic to complete. The Adapted Provocation Inventory showed that, post-group, members were able to articulate a wider range of coping skills. Certain cognitive aspects of the sessions were difficult to convey to some group members. All members showed an improvement in their application of the relaxation procedure. We are continuing to debate and interpret the wealth of post-session data.

Conclusions: The protocol provided a structured, evidence based approach for people with intellectual disability. The psychometric measures did not elicit meaningful information from the men. Information collected from observations, comments and post-session reports provided a rich source of data to inform future interventions.

**Access to dental care for adults with intellectual disabilities**
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Background: Adults with intellectual disabilities (ID) have poorer levels of dental/oral health than same-age contemporaries without ID.  This study identifies facilitators and barriers experienced by adults with intellectual disabilities and their caregivers in accessing dental services and maintaining dental and oral health on a day-to-day basis.

Methods: For this exploratory investigation an open ended survey was completed with adults with ID and their caregivers.  The survey contained four questions about the facilitators and barriers to (i) accessing and attending dental services, and (ii) maintaining oral health and tooth-brushing.  Number of respondents to the questions ranged from 262 to 371.  The resulting qualitative data was analysed using Thematic Network Analysis (Attride-Stirling, 2001).

Results: Approximately one quarter of respondents reported no problems in accessing dental services or conducting daily care.  Daily care was helped or hindered by: personal factors (knowledge and skills, lifestyle, mental health, behaviour, physical, cognitive and affective factors); caregiver knowledge, attitude and skills; support strategies and tooth brushing routine; and equipment and adaptations.  Access to dental services was helped or hindered by factors relating to: the individual (behaviour, physical, prior experience); dental services (e.g. appointment systems, physical accessibility of building, waiting time); the dentist; financial implications; and caregivers (communication, motivation, attitudes towards dentist, staffing levels).

Conclusions: The study corroborates and extends previous studies.  Barriers to oral care and accessing dental services were evident.  Additional training for caregivers and dentists is needed to highlight and suggest practical ways to overcome barriers to accessing oral/dental care.

**Low Levels of Physical Activity in Adults with Learning Disabilities**

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Background: Lack of regular physical activity increases the risk of developing chronic health conditions, such as cardiovascular disease and type 2 diabetes, and it is one of the most significant risks to global health. The study aims are to: i) Describe the types and levels of regular physical activity undertaken by adults with learning disabilities; ii) Compare results with the general population; iii) Determine factors that predict low levels of regular physical activity.

Methods: Prospective cohort study of 433 community-based adults. Baseline data included demography and supports, ability levels, and physical and mental health. Two years later, a semi-structured interview detailed physical activity undertaken on a regular basis. Data analysis using SPSS, including frequency statistics; $x2$ for comparisons with general population data (Scottish Health Survey 2003); and logistic regression to determine factors independently predictive of low levels of regular physical activity.

Results: 314 (72.5%) undertook regular physical activity of any intensity. Only 150 (34.7%) however, undertook sufficient physical activity of at least moderate activity. This was of shorter duration except walking. The difference between groups when compared with the general population was highly significant ($t = 6.660$; $df = 8296$; $p<0.01$). Older age, immobility, no daytime/employment opportunities, faecal incontinence, and epilepsy were independently predictive of low levels of regular physical activity.

Conclusions: The low levels of regular physical activity highlight the importance of identifying predictive factors, so that an appropriate range of interventions can be developed

**A study of the work of managers in residential services for people with learning disabilities**

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Background: Literature identifies front-line managers as playing an essential role in determining quality of care in residential services, and highlights their considerable influence upon support staff. Despite the centrality of their role, their work and experiences largely have been neglected within the research arena.

Methods: This 'Economic and Social Research Council funded doctoral research draws on a sample of twenty-seven front-line managers from the private, voluntary and local authority sectors. Methodologies include semi-structured interviews and time-budget study.

Results: The impact of the psychological contracts that managers hold with their organisations on their experiences of work; perceptions of roles and responsibilities; time management; and the primary issues faced in residential settings form the basis of analysis and discussions.

Conclusions: This research is of practical relevance, providing insight into the role of front-line managers in residential services, in terms of how they spend their time and the ways in which their employment relationships with their organisations impact upon their experiences of work. This research is also of theoretical interest, introducing the concept of the psychological contract to the social care field.

**Socio-Economic Position, Social Connectedness and the Self-Reported Well-Being of Women and Men with Intellectual Disabilities in England**

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Background: Few large-scale surveys of the subjective well-being (SWB) of adults with intellectual disabilities exist, and there is current controversy over the extent to which indicators of SWB are independent of factors such as personal characteristics, relationships with other people and external living conditions.

Methods: We investigated associations between five self-reported indicators of SWB and the personal characteristics, socio-economic position and social connectedness of a sample of 1,273 English adults with intellectual disabilities, collected as part of a national survey of adults with intellectual disabilities in England (Emerson et al., 2005).

Results: Mean overall life satisfaction was 81% of the scale maximum, marginally higher than typically reported among the general population. Variation in SWB was strongly and consistently related to socioeconomic disadvantage and, to a lesser extent, social relationships. For women, being single was associated with greater well-being on all indicators. For men there was no association between marital status and well-being. Relationships with friends with intellectual disabilities appeared to be protective against feeling helpless. For women, but not for men, increased contact with relatives was associated with greater overall well-being.

Conclusions: The results confirm the generally high levels of SWB reported by adults with intellectual disabilities in the face of objectively poor external living conditions, although within the sample SWB was consistently associated with socio-economic position, suggesting that SWB is not completely independent of the effects of socio-economic disadvantage.

Emerson, E., Malam, S., Davies, I., & Spencer, K. (2005). Adults with learning difficulties in England 2003/4.Leeds: Health & Social Care Information Centre.

**Parental Views on Transition to Employment for young people with Learning Disabilities**

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Background: In the UK, school transitions for people with learning disabilities are often organised in a piecemeal fashion. Parents are important stakeholders in the transition process. This paper reports the views of parents of young people with intellectual disabilities in their last year at school about school, careers service and employment service factors that influence their vocational decisions.

Methods: A purposive sample of 87 young people leaving schools in 6 areas in 2005 was drawn and experiencing one of six different approaches to transition from school to employment. Detailed qualitative interviews with a parent and a follow-up study provided data on where young people were actually placed 9 months after leaving school.

Results: Few families had had employment discussed as an option for their son/daughter at the young person's final transition planning meeting (Fig. 2). Where is was discussed, some were advised to explore short-term work experience (26%), but few had any suggestion of paid job they might do (9%), or the possibility of referral to a supported employment agency (9%). For those for whom employment was not discussed, the main options suggested were moving into a College of Further Education (24%).

Conclusions: Despite parental aspiration for employment of the young person after school, the most common next step is college for young people with LD. Careers advice favoured a college exit route. Specialist employment agencies provided valuable information to parents. Involvement of employment agencies is critical if the option is to be made available to school leavers. Changes are needed in way that government conceptualises vocational development for people with LD.

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

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Background: Participation by children and families in service design has been identified by the Government as a key priority. However, this very rarely happens, and where it does, there is little change.  This research was designed to address some of these issues.

Methods: Two groups of parents of children with intellectual disability and professionals produced process maps, using methods developed by the Modernisation Agency, to identify areas for change in services. These techniques were adapted for a group of children with intellectual disability. The data from these processes were combined with two focus groups held with professionals to identify what helps change to occur.  The data were thematically analysed within a Framework Analysis approaches using Max QDA.

Results: Analysis of the work with the children, parents and professionals identified a number of key themes and approaches for successful involvement and system change.

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

**The use of the LaVigna Multi-element Model for assessment and treatment of challenging behaviour in a man with severe learning disabilities**

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Background: Challenging behaviour is commonly associated with poor quality of life and placement breakdown. Despite this, published studies of assessment and intervention with challenging behaviour in real-life settings remain limited. This paper provides such a report. MM was a 22 year old man with Cornelia de Lange syndrome and a severe learning disability. He lived in his own home with 2:1 staff support 24 hours a day. His support was provided by a social care voluntary organisation.
Referral was made to the organisation's specialist Behaviour Support Team due to high levels of challenging behaviours - self-injury, aggression and property destruction.

Methods: Functional analysis was carried out on MM's challenging behaviours. This concluded that his behaviours enabled him to escape from the confusion and unpredictability he experienced in his support. This allowed the development of a visual formulation. A Multi-Element Behavioural Support Plan was implemented using the La Vigna model. This included Ecological changes, Positive Programming, Focused Support and Reactive Strategies. Periodic Service Review allowed measurement of levels of implementation of the recommended Plan

Results: Data show decreases in challenging behaviour while participation in activities increased. There was a clear link between consistent implementation of the Behaviour Support Plan and increased participation in activity. Changes were maintained over one year.

Conclusions: Behaviour support can be provided in everyday settings, leading to decreases in challenging behaviour and increased participation in activity. Effectiveness is linked to quality of implementation. Periodic Service Review enables monitoring of Plan implementation. There is considerable scope for more widespread use of a similar approach.

**Is the function of challenging behaviour changing over time?**
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Background: Changes in service provision for people with intellectual and developmental disabilities have resulted in exposure to very different environmental conditions over time. Such conditions (e.g. deprivation of attention) may establish motivation for challenging behaviour. It would be expected, therefore, that to the extent that typical environmental conditions have changed there may have been parallel changes in the motivation of challenging behaviour, as measured by its identified function.

Methods: To investigate this hypothesis, the functions reported to maintain the challenging behaviours of 696 participants with developmental disabilities in articles published in four journals during the period 1968-2002 were examined.

Results: There was an overall decline over time in the proportion of reports of social-positive and automatic reinforcement and an overall increase in the proportion of reports of social-negative reinforcement. These changes were more apparent in service than in family settings.

Conclusions: These trends are consistent with evidence that service provision for people with intellectual and developmental disabilities is now more effective at providing social-positive and automatic reinforcement (through increased levels of non-contingent contact from staff and increased availability of leisure materials) but, partly as a consequence, is now more likely to provide conditions (such as demands to participate or interact) that may establish motivation for social-negative reinforcement. The limitations and implications of these results will be outlined.

**An Audit of the Shropshire Asperger's Support Group (ASG)**

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Background: This report describes an audit of a support group comprised of 11 people with a diagnosis of Asperger's Syndrome and high functioning autism, many of whom also shared a diagnosis of mild learning disability. At the start of the ASG it had been agreed that the group would conduct its own review after one year, the purpose of which would be to establish what participants had found to be helpful or unhelpful about the ASG thus far, and, in consequence, what changes (if any) they might wish to make in respect of the nature and aims of the group during the following year.

Methods: The audit was a collaborative process, in which all group members participated in both the generation of key questions about the group itself (for discussion) and in the collection and analysis of qualitative theme based data (Richardson, 1996).

Results: The survey suggested that all of the participants valued the group, and for the things that it was intended to provide: that is - as a place in which they could meet other people, make friends and discuss and share key personal issues that pertained to the experience of having the diagnosis of high functioning AS / ASD and a learning disability.

Conclusions: Our findings indicate that social support groups designed for individuals with a diagnosis of AS / ASD may have a modest but positive role to play in helping some people to make friends and to improve their self confidence. These findings contradict previous claims that individuals with these kinds of difficulties largely prefer to work in small scale settings and benefit most of all from one-one work.

**Early social communication and cognitive functioning in infants with Down Syndrome**

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Background: The aim of this study was to explore the relations between early cognitive and social-relational development in infants with Down syndrome (DS). Specifically we wished to determine whether the social-realational abilities of infants with DS are out of keeping with their non-social cognitive abilities.

Methods: We used the Secondary Intersubjectivity Scale, which is a series of tasks designed to explore abilities to engage in triadic, person-person-world relations with other people.  We conducted three sets of analyses, comparing a) 12-month-old DS infants (n=13) with seven-month-old typically developing (TD) infants (n=26), b) 18-month-old DS infants (n=17) with 10-month-old TD infants (n=35), and c) the same 18-month-old DS infants with 12-month-old TD infants (n=28) for whom data has been reported elsewhere.

Results: The results suggest that among infants with DS, the potential for triadic social relations such as requesting and reciprocal turn-taking with a ball, and (probably) joint attentional behaviour such as gaze- and point-following, develop in line with means-ends and object permanence understanding.

Conclusions: We will discuss the findings in relation to previous reports of the early social-cognitive development of DS infants and the structure of early personal relatedness.

**An evaluation of the effects of a peripatetic challenging needs team on the lives of referred clients and the staff who support them**

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Background: During the 1990's many services established community challenging behaviour teams to work alongside, or replace, inpatient assessment and treatment units. In recent years some services have disbanded specialist teams. This study aimed to investigate staff perceptions of the effects of input provided by a specialist team on clients referred and the staff who supported them.

Methods: A semi-structured interview schedule was administered with fifteen staff who worked in eight houses where the specialist team provided input. Data collected was analysed using thematic content analysis and some data was subject to quantification.

Results: Reported levels of challenging behaviour did not reduce in most cases. There were increases in clients' levels of activities and participation. There were positive effects on staff including enhanced understanding of reasons for clients' behaviour and an increased ability to support them.

Conclusions: Specialist teams can achieve positive outcomes in improving the quality of life of people with severe challenging behaviour and increasing the skills, understanding and confidence of staff. If teams are disbanded services must be confident these benefits can achieved by other means.

**POMONA-2: Operationalisation & piloting a set of health indicators for people with intellectual disabilities (PWID)**

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Background: Despite evidence suggesting that PWID may have poorer health and access to health services than the general population, data on the health of PWID are not collected systematically. POMONA-1 was a collaboration between 14 European countries which developed a set of 18 health indicators for PWID. In POMONA-2 these indicators were operationalised and piloted.

Methods: Partners in 14 European countries developed a questionnaire which comprised items intended to reflect the health indicators identified in POMONA-1. It was translated into 10 languages. The questionnaire was piloted with a small sample of  PWID in each country and reliability data were collected. The pilot sample included people with a range of ability levels and roughly equal numbers of people living in family homes and residential care. Each project partners also completed an evaluation form. Questionnaires were completed for 72 people across 12 countries. Reliability data were available from 9 respondent pairs.

Results: The 18 health indicators appear to have been operationalised successfully. Issues highlighted in the evaluation forms are described, the reliability data and summary descriptive data are presented. These data have not been analysed at the time of writing.

Conclusions: In general, the questionnaire appears to do what was intended. We now have an idea of the kind of information which it will yield. The new instrument will be refined on the basis of the pilot study and administered to a larger sample (n=80) in each country.

**Emotional and Behavioural Adjustment in Siblings of Children with Intellectual Disability With and Without Autism**

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Background: The main aims of the present study were: 1. To compare the behavioural adjustment of siblings of children with autism and intellectual disability (ID) with adjustment in siblings of children with ID, and a normative sample; and 2. To examine factors that may be related to the adjustment of siblings of children with autism.

Methods: Mothers rated the adjustment of the sibling closest in age to the child with ID with or without autism. Data were available on 13 brothers and 13 sisters of siblings of children with autism, and 18 brothers and 9 sisters of children with ID. Mothers completed the Strengths and Difficulties Questionnaire (SDQ), a standardized measure of behavioural and emotional adjustment for children and adolescents, and a number of other measures about themselves and their family. Data are available for 17 siblings of children with autism followed up 18 months later.

Results: Siblings of children with autism were rated as having more emotional problems when compared with siblings of children with ID and also with a normative sample of British children Siblings of children with autism who were younger than the child with autism, had a sister with autism, and whose sibling was older had more reported emotional problems. Socioeconomic deprivation was associated with higher levels of reported emotional and behavioural adjustment difficulties. Over 18 months, behavioural and emotional adjustment (with the exception of problems with peers) was stable for the siblings of children with autism (r values >.70).

Conclusions: These data suggest that adjustment problems in siblings of children with autism and ID may be confined to emotional difficulties. Although a number of correlates of emotional problems were also found, the mechanism for these increased emotional problems is not clear and should be explored in future research.

**Health knowledge and expected outcomes of risky behaviour: A comparative study of non-disabled adolescents and young people with intellectual and physical disabilities**

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Background: As young people with intellectual and physical disabilities are more likely to experience social exclusion, the opportunities they have to talk about health may be fewer and this may impact upon knowledge. This may be more marked for private topics like sexual health that are difficult to discuss.

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

Results: Chi-square tests revealed that although the ID group had poorer health knowledge overall, participants were quite knowledgeable about healthy eating and alcohol. With regard to contraception knowledge both the ID and PD groups had significantly lower levels of knowledge than the ND group, yet performed similarly to one another. This suggests that knowledge deficits were a result of social exclusion, not cognitive ability per se. Young people with disabilities reported significantly fewer social contacts and sources of sexual health information. The qualitative data revealed major misunderstandings in relation to health across groups, this being most pronounced for the ID and PD groups.

Conclusions: Young people have a good grasp of key health messages in relation to healthy eating and alcohol. For private health topics it appears that limited opportunities to socialise with peers and engage in age normative tasks, and poorer access to sources of information, are negatively impacting upon knowledge.

**Participation in the 2005 General Election by Adults with Intellectual Disabilities**

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Background: Voting in general and local elections is a key process through which the rights, independence, choice and inclusion of people with intellectual disabilities can be supported. To date, there has been little research on the extent of electoral participation by people with intellectual disabilities in the U.K.

Methods: A database of the names and addresses of adults, who were known by social care services in Cambridgeshire to have an intellectual disability, was compiled. The database was compared to the electoral registers for constituencies in Cambridgeshire and marked for the May 2005 General Election. For each address, the Index of Multiple Deprivation 2004 score and type of residence were recorded.

Results: Registration rates and voter turnout for adults with an intellectual disability were significantly lower than those for the general population. The type of residence and age of constituents with intellectual disabilities seems to have an influence upon both registration and turnout: people with intellectual disabilities were more likely to vote when living with family in a single-surname house, than in residential care homes or supported living, and, contrary to the trend in the general population for greatest participation among people over 65, voting was lowest among people with intellectual disabilities who were over 65.

Conclusions: People with intellectual disabilities did not participate in the May 2005 General Election to the same extent as the general population. These findings support recommendations made by the Electoral Administration Act 2006 and Electoral Commission 2005 to improve the access and engagement of people with intellectual disabilities in democratic processes.

**Down Syndrome, and Congenital Heart Defect: Maternal Experiences of Bereavement.**

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Background: Congenital heart defect (CHD) has been reported in almost 50% of newborns with Down syndrome. Children with Down syndrome and CHD have been shown to be at higher risk of mortality than children with Down syndrome without CHD. CHD is also one of the most often reported medical disorders on death certificates of adults with Down syndrome, particularly between the ages of 20 and 29. This study aimed to investigate the bereavement experiences across the life span of mothers who lose a child with Down syndrome and CHD.

Methods: 31 bereaved mothers of children with Down syndrome and a CHD were recruited through a support group in the UK. Average time since loss was 10.3 years (SD = 6.61: range 1 – 23). Mothers completed measures of grief, coping, anxiety and depression, and a retrospective measure of their positive perceptions of parenting a child with intellectual disability.

Results: Overall 56.2 % and 28.2% of mothers scored in the possible or probable range for clinical anxiety or depression disorders respectively, which is high compared to the UK population in general. Revised Grief Experienced Inventory (RGEI) scores were similar to previously reported scores for bereaved parents (M = 74.48; SD = 30.79). Mothers reporting higher levels of grief tended to report more positive perceptions of their experience of raising and losing a child with Down syndrome (r = .511; p = .003). Also mothers with higher grief tended to use more active avoidant (r = .475; p = .
006) coping strategies through their bereavement, but use of problem focused coping strategies was not related to grief.

Conclusions: As in the bereavement literature more generally, avoidant coping seems to be maladaptive in relation to mothers' grief experiences. The association between current grief and positive perceptions of the child with Down syndrome requires further exploration but may have important implications for supporting parents through bereavement.

**Investigating the relationship between self-injurious behaviour and sensory dysfunction in people with intellectual disabilities**

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Background: Previous research has identified a possible connection between the presence of self-injurious behaviour (SIB) and sensory dysfunction in people with intellectual disabilities  (ID) (Symons & Thompson, 1997; Wisely et al., 2002).

Methods: The present study was a small scale  (N=12) pilot study to investigate this relationship, in which care staff working with people with  ID completed measures assessing each person's level of ID, SIB, sensory dysfunction and repetitive behaviour.

Results: Trends in the data were identified which were in the direction of previous findings, but there was no evidence of a significant positive correlation between the level of ID and amount of SIB. Likewise, there was no support for a significant positive correlation between the level of ID and degree of sensory dysfunction. No significant results were found to support of a positive relationship between the amount of sensory dysfunction and the severity of SIB. No significant findings were found in support of the hypothesis that specific types of sensory dysfunction would be associated with specific types of SIB however. Finally, as predicted, it was found the more SIB that was shown, the more repetitive behaviour that would be shown but the results did not reach significance.

Conclusions: The results did not provide support for the proposed association between SIB and sensory dysfunction, but this may relate to sample size and the implications of the pilot study for a larger study are discussed.

**Speech Articulation Variability in Children with Down's syndrome**

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Background: Speech errors in young people with Down's syndrome (DS) have been found to be variable (Stoel-Gammon 1981, Dodd & Thompson 2001). Research has indicated that anatomical and structural differences (Miller et al 1995), in conjunction with difficulties with motor control (Frith & Frith 1974, Kumin 1994), may contribute to the variability in speech production errors associated with DS.

Methods: Electropalatography (EPG) is being used to analyse the articulatory patterns of speech production in 30 young people (10-18 years) with DS. Auditory analysis to date has noted phonemic variation for single target consonants at word-level across a wide-range of different contexts. This poster looks at another type of variation: the fine-grained articulatory differences that accompany multiple productions of the same target phoneme in a given context.
Both spatial and temporal measurements were taken of 10 repetitions of word-initial /t/ and /k/ in mono-syllabic words from 4 of the current participants. A variability measure was taken for all targets successfully realised and these measures compared statistically with the same measures from typically developing (TD) matches. The quantitative measures were accompanied by lingual-palatal contact patterns provided by EPG to illustrate the range of articulation.

Results: The analysis found that variability differed in the DS and TD children, with the TD children showing lower variability in articulation than the children with DS.

Conclusions: Fine variation in the articulation of speakers with DS is evident when realising the same phonemic target. This may be a result of the suggested difficulties with speech motor control associated with DS.

**Interactive Training on Active Support: Perspectives from Staff, Managers, and Trainers**

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Background: Active Support (AS) is an organisational technology for people with intellectual disabilities (IDs). Staff in community homes receive AS training in group workshops and in-house Interactive Training (IT). Although the effectiveness of AS for people with ID is established, there are no data on the experience of staff trained to use AS. This study reports on the IT experience of staff, managers and trainers.

Methods: Nine months after IT, 37 staff, 11 managers and 6 trainers engaged in semi-structured interviews which focused on people's experience of IT, how it affected their everyday work and how AS is implemented in their workplace.

Results: Preliminary analyses indicate that for about 90% of staff IT was a positive experience.  One-to-one training was the most frequently reported (about 23%) helpful characteristic of IT.  What people liked most about doing IT was the opportunity to learn a new skill (about 40%).  The most frequently reported difficulty was being observed by the trainers (about 30%). The majority of staff and managers (about 65%) reported using at least one new skill after IT, and about 25% reported that IT increased their awareness about support roles and residents' needs.

Conclusions: Staff views on IT and AS training is an under-researched area. Findings from the present study will be discussed in relation to the social validity of the intervention and to factors related to the implementation and maintenance of the model in a residential service.

**Understanding antecedents of emotional expressions by children with Down's syndrome**

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Background: Previous research has suggested that some children with Down's syndrome (DS) experience difficulties in recognising emotional expressions, but relatively little work has explored their emotional understanding more broadly. This study investigated understanding of the contexts of emotion, using a cartoon task that controlled for story-comprehension ability and general task demands by comparing ability to identify the antecedents of physical versus emotional events.

Methods: Three child groups matched on mental age participated: 21 children with DS and 21 with non-specific intellectual disability (NSID) aged 9 – 19 years, plus 21 typically developing (TD) children aged 3 – 6 years. Groups did not differ on language comprehension or emotion labelling ability. Children were given 20 three-part cartoon stories depicting 4 physical events, 8 emotions caused by a physical action, and 8 emotions caused by a person. Emotions were happiness, sadness, surprise and fear. For each story, the first and last picture were presented and children asked to select the correct middle picture from a choice of three. Children were then asked to tell the story.

Results: Groups did not differ significantly in their ability to select the correct antecedents in any condition.
However, analysis of individual emotions suggested that the children with DS had more difficulty than TD children in identifying antecedents to fearful events. Ongoing analysis of children's stories may reveal further differences in understanding of the causes of emotion.

Conclusions: Findings suggest that while difficulties may exist in emotional understanding in DS, these may be subtle and detectable only in comparison with TD matches

**Clarification of the memory artefact in the assessment of suggestibility**

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Background: The Gudjonsson Suggestibility Scale (GSS) is the only instrument currently available for the assessment of suggestibility. The GSS is based on memory for a story, tested using leading questions. People with intellectual disabilities appear highly suggestible on this test, but an earlier study (White & Willner, 2005) showed that their suggestibility scores are high largely because the story is poorly remembered. However, there were anomalies in the data that left the precise relationship between memory and suggestibility uncertain. The present study was conducted to resolve this issue.

Methods: In two experiments, different modifications were made to the GSS in order to decrease the memory load. In Experiment 1, the task (story recall and leading questions) was presented as two halves; in Experiment 2, the story was presented three times prior to the leading questions. In addition, a set of true-false forced-choice questions was interspersed among the leading questions, in order to provide a measure of recognition memory. In each experiment 8 participants completed both the standard version of the GSS and the modified version.

Results: In experiment 1, the modification increased recall memory but had no effect on recognition memory or on suggestibility. In experiment 2, the modification increased both recall memory and recognition memory and also decreased suggestibility.

Conclusions: The results suggest that suggestibility as measured by the GSS is a function of recognition memory for the story. This supports our earlier suggestion that the GSS may be of limited relevance to suggestibility in relation to events that are well remembered.