



**9th Seattle Club Conference
on Research in Intellectual &
Developmental Disabilities**

7th & 8th December 2009
University College London

Welcome to Seattle Club 2009

UCL and the Centre for Health Service Research in Intellectual Disabilities (CHSRID) have pleasure in welcoming you to London for the 9th Seattle Club Conference for researchers in intellectual & developmental disabilities in the UK and Republic of Ireland.

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

- Our focus is on data-based presentations reporting findings gained through appropriate application of scientific methods.
- All oral presentations are in plenary; there are no parallel sessions.
- Oral papers and posters are equally weighted in terms of worth, scientific rigour and status.
- The 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.

Organising Committee

The ad hoc organising committee members for Seattle Club 2009 meeting are: Katrina Scior, UCL (CHSRID); Richard Hastings, Bangor University; Angela Hassiotis, UCL (CHSRID); Andre Strydom, UCL (CHSRID); Peter Baker, Tizard Centre/ Sussex Partnership; Steve Carnaby, Westminster Learning Disability Partnership/ Tizard Centre.

Administrative Support

A big thank you for invaluable help in organising this year's conference to Barbara Smiley, UCL.

We hope you enjoy your time in London. Have an interesting conference, get talking to each other and have some fun!

Seattle Club Studentships 2009

Six researchers this year are attending the Seattle Club meeting as holders of Seattle Club Studentships. They are early in their research careers and do not yet have data to present. Please make them all welcome. We look forward to hearing about their research in future years.

This year's studentship holders, and their research topics, are:

Lisa Cochran, University of Birmingham
Neurodevelopmental disorders and behavioural phenotypes

John Crosbie, University of Edinburgh
The perceived benefits of participation in outdoor education for people with intellectual, sensory and motor disabilities

Jenny Gibson, University of Manchester
A systematic comparison of children with pragmatic language impairment to children who have other developmental disorders with which it shares common features: namely, autism spectrum conditions and specific language impairment

Ceri Jones, Bangor University
Physical health problems and interventions to improve health for adults with LD living in residential settings

Philippa Moss, Institute of Psychiatry
Predictors and correlates of adult outcome for individuals with autism with an IQ in the normal range

Elisa Vigna, Welsh Centre for Learning Disabilities
The role of supported employment in promoting positive health behaviour of people with learning disabilities at work

Index

Programme	p.4
Abstracts:	
Symposium 1 - Neurodevelopmental Issues	p.11
Symposium 2 - Challenging Behaviour	p.13
Symposium 3 - Parenting & Being Parented	p.15
Symposium 4 - Cognitions & Emotions	p.18
Symposium 5 - Social Inclusion & Social Interactions	p.20
Symposium 6 - Service Issues	p.22
Posters	p.24

Monday, 7th December 2009

09:45 - 10:20 **Registration & Coffee**

10:20 - 10:30 **Welcome**
Katrina Scior

10:30 - 11:45 **Symposium 1: Neurodevelopmental Issues**
Chair: Tony Charman

1. *An investigation into the stability of IQ and cognitive profiles from childhood to adulthood in high functioning individuals with autism*
Sarah Savage, Patricia Howlin, Patrick Bolton & Michael Rutter
2. *Exploring the cognitive underpinnings of phenotypic behaviours in Rubinstein Taybi Syndrome: Developmental Trajectory Approach*
Jane Waite, Laurie Powis, Chris Oliver, Ian Apperly & Sarah Beck
3. *Beyond IQ: Cognitive-behavioural profiles in children and young people with complex epilepsy and intellectual disability*
Sara Shavel-Jessop, Sarah Aylett, Will Mandy, Peter Rankin

11:45 - 13:00 **Symposium 2: Challenging Behaviour**
Chair: Angela Hassiotis

1. *Examining the Function of Challenging Behaviour in Fragile X Syndrome. A Multi-Method Investigation*
Paul Langthorne & Peter McGill
2. *The Association Between Gastro-Intestinal Distress and Challenging Behaviour in Autism Spectrum Disorder and Cri du Chat Syndrome*
Kate Eden, Caroline Richards, Jo Moss, Chris Oliver
3. *Using analog assessments to assess the effects of Naltrexone on the environmental mediation of Self-Injurious Behaviour*
Peter Baker, Sarah Wills, Athene Kok, Kris Zakrzewski & Holly Smith

13:00 - 13:45 LUNCH

13:45 - 15:25 **Symposium 3: Parenting & Being Parented**
Chair: Andrew Jahoda

1. *South Asian parents' experiences of adjustment following a diagnosis of learning disability and/or an autism spectrum disorder for their child: a grounded theory Approach*
Alia Ul-Hassan, Gill Kidd & Duncan Manders

2. *Changes in Family Composition and Marital Status in Families With a Young Child with Cognitive Delay*

Chris Hatton, Eric Emerson, Hilary Graham, Jan Blacher & Gwynnyth Llewellyn

3. *Expressed emotion towards children with intellectual disabilities and their siblings: A trait or state-like construct?*

Tracey Lloyd & Richard Hastings

4. *Parenting with support? Parenting with a learning disability in the Bangladeshi community*

Emily Durling, Deborah Chinn & Katrina Scior

15:25 - 15:45 TEA (20 minutes)

15:45 - 16:30 **Key Note Address: Professor Nora Groce**

Leonard Cheshire Chair of Disability, UCL

Global challenges to the rights of persons with disabilities and their full inclusion

Chair: Katrina Scior

18:00 - 19:30

Poster Session & Wine Reception

Evaluation of the ability of people with intellectual disabilities to weigh up information in two tests of financial reasoning

Rebecca Bailey, Paul Willner, Simon Dymond, Rhonwen Parry

Managing serious health risk for adults with intellectual disabilities through the provision of assistance at mealtimes

Sarah Ball, Samuel Panter, Marcus Redley, Carey-Anne Proctor, Katie Byrne, Isabel Clare, Anthony Holland

Access to health care by people with learning disabilities living in Cambridgeshire and Peterborough

Carys Banks, Marcus Redley, Karen Foody, Professor Tony Holland

For mothers of adult children with a learning disability and epilepsy care means balancing the tension between stability and aspiring to a good life

Naomi Bateman, Liz Prince, Marcus Redley, Howard Ring

Communication assessment and intervention with children and adults with profound and multiple learning disability

Darren Chadwick, Juliet Goldbart, Susan Buell, Sue Caton

Transition of students with intellectual disabilities from education into post-school options within the Irish context

Darren Chadwick, Edurne Garcaa Iriarte, Niamh Lally, Patricia O'Brien, Philip Curry

The misdiagnosis of epilepsy in people with intellectual disabilities: a systematic review

Melanie Chapman, Kathy Atkinson, Colin Brodie, Pam Iddon, Duncan Mitchell, Garry Parvin, Steve Willis

Maximising the availability of psychological therapies for people with intellectual disabilities using stepped care

Fleur-Michelle Coiffait, Keith Marshall

Carers' responses to challenging behaviour

Dave Dagnan

Challenging behaviour in children with severe intellectual disabilities

Louise Davies, Anna Mitchell, Rowan Brooks, Chris Oliver

Factors that impact on the sibling relationship

Deborah Davys, Duncan Mitchell

Violence at work: Assessing the prevalence of experiences of violence at work in community learning disability teams in Sussex

Shona Daynes, Peter Baker

The equity perceptions of staff working in services for people with learning disabilities: a review

Philip Disley, Chris Hatton, Dave Dagnan

The use of repertory grids to explore care staff's attributions towards clients with intellectual disabilities who exhibit challenging behaviour

Marianne Durand, Dougal Hare, Steve Hendy, Anja Wittkowski

Diagnostic grouping among people with learning disabilities and autistic spectrum disorders

David Felce, Jonathan Perry, Rina Cianfaglione

Psychological outcomes for mothers and fathers of children with Angelman, Cornelia de Lange, and cri du chat syndromes

Gemma Griffith, Richard Hastings, Chris Oliver, Jo Moss, Penelope Tunnicliffe, Jane Petty

The impact of disturbed sleep in daytime sleepiness in adults with learning difficulties

Dougal Hare, Mei Lye, Leah Vanono

A Story To Tell

Zoe Hughes

Transition protocols for learning disabilities transition partnerships

Axel Kaehne, Stephen Beyer, Mary Clare O'Connell

Using Q methodology to investigate professional views of attachment in people with intellectual disabilities

Axel Kaehne, Stephen Beyer, Mary Clare O'Connell, Dougal Hare, Sam Walker, Andrea Flood

Age related changes in DHEA in adults with Down's syndrome

Jennifer Landt, Sarah Ball, Anthony Holland, Johnny Hon

Inter-person sources of conflict in people with and without mild intellectual disabilities at transition from adolescence to adulthood

Peter Larkin, Andrew Jahoda, Carol Pert

Development of an adaptation of the clinical outcomes in routine evaluation outcome measure for people with a learning disability

Keith Marshall, Simon Willoughby-Booth, Fleur-Michelle Coiffait

Someone might have a PhD in autism

Susie Nash, Gemma Griffith, Vaso Totsika, Richard Hastings

Case formulation-based working in a mental health in intellectual disabilities inpatient service

Mark Oliver, Barry Ingham

Wellbeing and lifelong health in people with a genetic syndrome

Merel Pannebakker, Tony Holland, Marcus Redley, Chris Oliver, David Felce, Felicia Huppert, Pat Howlin, Jo Moss, Angus Clarke, Mike Kerr, Adam Bostanci

Introducing sex aids to single adults with learning disabilities

Clare Passey, Biza Stenfort Kroese, Usha Jayarajan, Michael Hearn

Development of an ethical code of practice for the use of telecare with people with cognitive impairments

Jonathan Perry, Stephen Beyer, Claire Pimm

The sexual understanding and development of young people with intellectual disabilities

Jaycee Pownall, Andrew Jahoda, Richard Hastings

Coping with bereavement

Deidre Reilly, Richard Hastings, Frances Vaughan, Jaci Huws

Creating a message and building a change

Minerva Rivas, Claire Conneely

Not everyone left the institution

Stuart Todd, David Driscoll

The hidden transition: the deaths of adults with intellectual disabilities in Wales

Stuart Todd, Rachel Davies, Maria Parry

Parents of children with autism choosing to implement an EIBI program

Pagona Tzanakaki, Corinna Grindle, Richard Hastings, Carl Hughes, Hanna Kovshoff, Bob Remington

A comparison of residential arrangements for adults with intellectual disability in Hungary

Agnes Turnpenny

Identifying child and family characteristics associated with challenging behaviour in children with severe intellectual disability and/or autism

Darrelle Villa, Sarah Gorniak, Louise Davies, Jane Petty, Chris Oliver

The EnFOLD study

Jessica Wheeler, Anthony Holland, Isabel Clare

Developing measures of the effects of trauma on people with intellectual disabilities

Sarah Wigham, Chris Hatton, John Taylor

Knowledge of Mental Capacity Issues in Community Teams for Adults with Learning Disabilities

Paul Willner, Rosemary Jenkins, Vanessa Griffiths, Elinor John

8.00 Dinner at Terra Restaurant
53 Cleveland Street, London W1T 4JJ

(about a 10 minute walk from the reception)

Tuesday, 8th December 2009

09:30 - 10:45 **Symposium 4: Cognitions & Emotions** - Chair: Biza Stenfert Kroese

1. *An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood* - Marisa Forte, Andrew Jahoda & Dave Dagnan
2. *Emotion recognition ability in autism spectrum disorders in different modalities* - Tony Charman
3. *Talking about real life events: an investigation of the ability of people with intellectual disabilities to make links between their beliefs and emotions within dialogue* - Amy Hebblethwaite, Andrew Jahoda & Dave Dagnan
4. *CBT anger treatment for adults with intellectual disabilities in secure settings: effects of intellectual functioning on outcome. John Taylor & Raymond Novaco*

11:25-11:45 COFFEE (20 minutes)

11:45 - 13:00 **Symposium 5: Social Inclusion & Social Interactions**
Chair: Peter Baker

1. *What makes a good job interview? Understanding aspects of communication in sample job interviews among able young people with autism spectrum conditions* - Evelyn McGregor & Tinatin Surgulatzte
2. *Social inclusion of people with intellectual disabilities from different cultural backgrounds* - Anjali Bhardwaj
3. *Social behaviour in Smith Magenis syndrome* - Lucy Wilde, Jo Moss, Lisa Nelson, Katy Berg, Caroline Richards & Chris Oliver

13:00-13:45 LUNCH

13:45 - 15:00 **Symposium 6: Service Issues**
Chair: TBC

1. *Our health, our care our say? How the wishes of adults who lack capacity are handled during substitute decision-making* - Elizabeth Fistein & Marcus Redley
2. *Service use and cost of mental disorder in older adults with intellectual disability-* Andre Strydom, Angela Hassiotis, Natalia Perez-Achiaga, Renee Romeo, Martin Knapp, Gill Livingston & Michael King
3. *Critiquing the involvement of service users in monitoring/ inspection of services* - Minerva Rivas & Patricia O'Brien

15:00 - 15:30 **Closing remarks and reflections** - Dave Dagnan

Abstracts Symposium 1: Neurodevelopmental Issues

An investigation into the stability of IQ and cognitive profiles from childhood to adulthood in high functioning individuals with autism

Sarah Savage, Patricia Howlin, Patrick Bolton & Michael Rutter

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Background: Little is known about the stability of IQ and cognitive profiles in high functioning individuals with autism. Few studies have addressed cognitive change from child to adulthood (especially later adulthood) and in those that have, results are variable. The main aim of the present study is to explore trajectories of change in IQ levels and cognitive profiles from child to adulthood.

Methods: 37 individuals meeting ADI criteria for autism with a performance IQ of 70 or above in childhood were followed up as adults. Their mean age when first seen was ~7 years (T1), at first follow up was ~22 years (T2) and at second follow up was ~42 years (T3). Differences between scores were adjusted to take account of the different forms of the WAIS and different IQ assessments administered. Data will be supplemented by a further 10 cases scheduled to be tested over the next 2 months.

Results: No significant differences were found in IQ scores between T1 and T2, or T2 - T3. With regard to cognitive profiles, the VIQ<PIQ discrepancy was not found to be significant at T3. Although the characteristic pattern of relatively high scores on Block Design and low scores on Comprehension Scores continued to be apparent at T3, differences between standard scores on these subtests and on the average scores for other subtests did not reach significance.

Conclusions: Initial analyses indicate stability in IQ from childhood to adulthood, while the characteristic pattern of VIQ<PIQ appears to disappear in adulthood. The “peaks” and “trough” cognitive profile often attributed to autism also seems to lessen in adulthood.

Exploring the cognitive underpinnings of phenotypic behaviours in Rubinstein Taybi Syndrome: Developmental Trajectory Approach

Jane Waite, Laurie Powis, Chris Oliver, Ian Apperly & Sarah Beck

Email: jea482@bham.ac.uk

Background: Repetitive behaviour and heightened social approach behaviours are two relatively under studied areas in intellectual disability (ID) research. Impairments of social cognition and executive functioning may underpin these behaviours. Assessing these cognitive processes in people with ID using a developmental trajectory approach may inform strategies for future clinical practice. This study illustrates the utility of this approach with reference to Rubinstein Taybi syndrome (RTS).

Methods: 26 individuals aged 6:9 to 44:5 (mean age= 20.82) with RTS completed a scaled battery of tests to assess social cognition, which included assessments of Theory of Mind (TOM) and early skills that develop prior to ToM acquisition. Participants completed an executive function battery that measured inhibition, working memory and cognitive flexibility. Participants also completed an IQ assessment. Repetitive behaviours were assessed using the Repetitive Behaviour Questionnaire (RBQ; Moss, 2009).

Results: Comparisons with typically developing data indicate that, early developing social cognitive skills dependent upon motivation for social contact are spared relative to mental age. Later developing ToM skills are delayed relative to mental age. Comparisons with typically developing data also indicate a working memory deficit in individuals with RTS ($p < .01$). A strong negative correlation (Spearman's $\rho = -0.81$; $P = < .01$) is found between conflict inhibition and repetitive questioning.

Conclusions: Delayed ToM ability in individuals with RTS may be underpinned by executive dysfunction. We propose that impaired social cognition coupled with strong motivation for social contact may leave individuals particularly vulnerable to others. Repetitive questioning in individuals with RTS may occur because individuals fail to inhibit questioning in social situations.

Beyond IQ: Cognitive-behavioural profiles in children and young people with complex epilepsy and intellectual disability

Sara Shavel-Jessop, Sarah Aylett, Will Mandy, Peter Rankin

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Background: It is well known that epilepsy is a heterogeneous disorder and in those with intact intellectual function, its different variables can have relatively specific effects on cognition, learning, and behavioural function. There is a paucity of scientific investigation, however, into the effects of epileptic variables in young people with intellectual disability (ID), who frequently have the most complex medical, learning and behavioural needs.

Methods: The current study therefore used a number of ecologically valid neuropsychological measures to compare the general intellectual ability, adaptive behaviour, everyday memory, executive function, and social communication abilities of a group of young people with complex focal epilepsy and mild-to-moderate ID or low intellectual ability ($n=21$, ages 12-22 years, mean IQ 61.76) to an age- and IQ-matched group with complex generalised epilepsy ($n=17$, ages 12-23 years, mean IQ 57.24).

Results: Results of face-to-face neuropsychological testing, parental behavioural questionnaires, and examination of medical variables found only small differences in parent ratings of behavioural regulation and adaptive competence, which may be explained by methodological limitations; no other significant differences between the groups were found. Utility analyses also demonstrated that standardised neuropsychological measures were used to good effect in these groups, identifying meaningful strengths and weaknesses.

Conclusions: The findings suggest that young people with complex epilepsy and ID have varied cognitive profiles, elucidated by standardised assessment. The classification of epilepsy as focal or generalised, however, did not appear to differentially affect most cognitive and behavioural outcomes. Clinical and research implications are discussed, highlighting potential for applications to clinical work and future investigations.

Examining the Function of Challenging Behaviour in Fragile X Syndrome. A Multi-Method Investigation

Paul Langthorne & Peter McGill

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Background: Fragile X syndrome (FXS) is the primary inherited cause of intellectual and developmental disability and in comparison to other syndromes, knowledge of the fragile X phenotype is relatively advanced, making it a prime candidate for the investigation of gene-environment interactions (GxE). The current presentation provides an overview of two related studies that aimed to provide an examination of the role of GxE in challenging behaviour in FXS.

Methods: In study one, a cross-sectional between-groups design was used employing indirect methods of functional assessment (the Questions About Behavioural Function scale). Interviews were completed with caregivers of 34 children with FXS, 25 children with Smith-Magenis syndrome (SMS) and 30 children from a mixed aetiology control group. In study two, experimental functional analyses were conducted with 8 children with FXS and six children with SMS.

Results: Both studies, using very different methods of functional assessment, suggested a characteristic pattern of behavioural function in FXS. Both studies reported low levels of attention-maintained challenging behaviours (both when compared 'within-syndrome' against other behavioural functions but also when compared against comparison groups).

Conclusions: The consistency between the findings suggests GxE may play an important role in the initial development and subsequent maintenance of challenging behaviour in FXS. Findings are related to other aspects of the FXS phenotype and a syndrome-specific model for challenging behaviour in FXS is presented.

The Association Between Gastro-Intestinal Distress and Challenging Behaviour in Autism Spectrum Disorder and Cri du Chat Syndrome

Kate Eden, Caroline Richards, Jo Moss & Chris Oliver

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Background: The association between pain and challenging behaviour is attracting increasing interest. High prevalence of gastro-oesophageal reflux disease (GORD), associated with pain and discomfort, has been reported in several syndromes and in individuals with profound intellectual disabilities. In this study we examine the association between GORD and challenging behaviour in Autism Spectrum Disorder (ASD) and Cri du Chat (CDC) syndrome.

Methods: Participants were aged 3-47 years, with a confirmed diagnosis of ASD or CDC syndrome. Level of intellectual disability was assessed using the Wessex Questionnaire, which comprises of a Social and Physical Incapacity scale and a Speech, Self Help and Literacy scale. The Gastro-intestinal Distress Questionnaire assessed behaviour indicative of pain in the oesophagus, stomach and intestines. The Challenging Behaviour Questionnaire evaluated the presence of self-injury, physical aggression and destruction of property over the last month.

Results: After controlling for degree of intellectual disability, there were significantly higher rates of self injurious behaviour (SIB), aggression and property destruction in individuals with ASD who had GORD. Within the CDC group, there were significantly higher rates of SIB in individuals with GORD. When SIB was present in these groups, it was more severe in individuals with GORD.

Conclusions: Results suggest that GORD is associated with increased rates of challenging behaviour in individuals with ASD and increased rates of SIB in individuals with CDC. It is possible that a relationship was not found between other forms of challenging behaviour and GORD in the CDC group because there was insufficient power due to a small number of participants.

Using analog assessments to assess the effects of Naltrexone on the environmental mediation of Self-Injurious Behaviour

Peter Baker, Sarah Wills, Athene Kok, Kris Zakrzewski & Holly Smith

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Background: Symons et al. (2004) in a recent quantitative synthesis of peer reviewed published literature on the efficacy of Naltrexone in the treatment of self injurious behaviour in people with intellectual disabilities reported that 80% of subjects were reported to improve relative to baseline. In spite of this encouraging data they argued that the most pressing needs were to establish which people are responsive to the medication and to have a better understanding of the drug's mechanism of action in different environmental contexts. Studies generally failed to address the effect of environmental mediation and the function of the behaviour on the effect of Naltrexone on self-injury.

Methods: A single case study using a reversal design across analog conditions utilising blind ratings.

Results: Differential responding was observed across analog conditions, whereby the administration of Naltrexone corresponded with reduction in automatically reinforced self injury, whilst the frequency of self injury that functioned to access tangible reinforcement remained unchanged.

Conclusions: This study would suggest Naltrexone could be more effect for individuals whose self-injury functions to access self-stimulation. This has important implications for prescribing practice and the identification of behavioural markers correlated with positive treatment responses. In addition, this study adds evidence in relation to the debate surrounding the nature of the drugs mechanism of action, suggesting that in this case the self injury may be positively reinforced by the release of endogenous opioids, with Naltrexone resulting in opioids being blocked at the receptor site and reinforcement being withheld.

South Asian parents' experiences of adjustment following a diagnosis of learning disability and/or an autism spectrum disorder for their child: a grounded theory approach

Alia Ul-Hassan, Gill Kidd & Duncan Manders
Email: alia_u@hotmail.com

Background: There is a great deal of literature pertaining to White parents' experiences of having a child with a learning disability. Some of this literature focuses on parents' experiences of the disclosure of diagnosis of learning disability and/or an autism spectrum disorder, as well as how they come to accept and adjust to a diagnosis. However, very little research has investigated the experiences of South Asian families.

Methods: This qualitative study used a grounded theory methodology to explore the experiences of seven South Asian parents in relation to the disclosure of diagnoses as well as issues relating to adjustment post-diagnosis. Semi-structured interviews were used to gather data.

Results: The results outline variable experiences in relation to the process of adjustment following a diagnosis. Four core categories were derived from the data to represent stages in a hypothesised model of adjustment. These were: 'obtaining a diagnosis'; 'constructing meanings'; 'exploring possibilities for action'; and 'reconstructing roles and identities'. These core categories were embedded within a number of important contextual influences.

Conclusions: The theoretical and clinical implications of the hypothesised model of adjustment are discussed. A methodological critique is provided before outlining reflections on the findings generated.

Changes in Family Composition and Marital Status in Families with a Young Child with Cognitive Delay

Chris Hatton, Eric Emerson, Hilary Graham, Jan Blacher & Gwynnyth Llewellyn
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Background: Few studies have investigated parental separation, partnering and re-partnering among population-based cohorts of children at risk of intellectual or developmental disabilities.

Methods: Secondary analysis of data extracted from Waves 1-3 of the UK's Millennium Cohort Study. Information on the residence status of parents at Waves 1, 2 and 3 was available for 10,848 families.

Results: Children with early cognitive delay were significantly less likely than other children to be living in households with both biological parents or in households where the mother was married at all time points, including at the time of the child's birth and when children were aged nine months, three years and five years. Although families with a child with early cognitive delay were more likely than families with a typically developing child to experience changes in both family composition and marital status over the first five years of the child's life, the net effect of these changes in family composition and marital status from the time of the child's birth to the time the child was five years old were similar for both groups of families. The increased levels of family change amongst families with a child with early cognitive delay were wholly accounted for by differences in family socio-economic circumstances.

Conclusions: 'Stress reaction' models attempting to account for rates of parental separation may have less utility than general predictive models incorporating socio-economic factors.

Expressed emotion towards children with intellectual disabilities and their siblings: A trait or state-like construct?

Tracey Lloyd & Richard Hastings
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Background: Expressed Emotion (EE) is a construct used to measure family climate. However, recent research presents conflicting evidence showing that EE is a state variable (Beck et al., 2004) or a trait variable (Greenberg et al., 2006). We investigated this issue by comparing EE towards children with ID and their siblings to discover whether EE could account for unshared variance within the family.

Methods: 38 mothers gave speech samples for their child with intellectual disability and for the sibling closest in age to that child. Of the 38 children with intellectual disabilities, 13 had autism, 4 had Cerebral Palsy, 6 had Down syndrome and the remaining 13 had an ID with unspecified aetiology. 50% of the children with ID were older than their siblings and 50% were same gender pairs. Mothers' speech was coded using the Five Minute Speech Sample (Magana et al., 1986) that included a separate coding for maternal warmth. Inter-rater and test-retest reliability in excess of .70 was gained to ensure reliability.

Results: Using all of the FMSS codes and the additional coding for warmth, a number of ID child-sibling differences were found. Mothers expressed more dissatisfaction ($p = .002$), critical comments ($p=.046$), and overall critical expressed emotion ($p= .002$) towards the child with ID, and made more positive comments ($p= .008$) and expressed more warmth ($p= .006$) towards the sibling.

Conclusions: Since mothers' EE towards their child with ID was significantly different (more negative) from maternal EE toward the sibling, we found support for the idea that EE is state-like and may, therefore, be a candidate mechanism for change during interventions for parents.

Parenting with support? Parenting with a learning disability in the Bangladeshi community.

Emily Durling, Deborah Chinn & Katrina Scior

Background: Very little is known about the lives of parents with learning disabilities from ethnic minority communities within the UK. Previous research with people with learning disabilities more generally has suggested that 'learning disabilities' is not a concept that easily translates across cultures. The current research set out to explore how this might impact upon the lives of parents with learning disabilities from an ethnic minority community within the UK, specifically the Bangladeshi community in Tower Hamlets. It also aimed to explore O'Hara and Martin's (2001) finding that parents with learning disabilities within this community are far more likely to retain custody of their children than would be expected from the national average.

Methods: Six members of the Bangladeshi community, four Bangladeshi parents with learning disabilities and four of their family members were interviewed and transcripts were examined using thematic analysis.

Results: Findings suggest that both parenting and learning disability are thought about in this community in ways that makes parenting more accessible for people with learning disabilities, but also create tensions to be negotiated.

Conclusions: These findings and their implications for services are explored.

An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood

Marisa Forte, Andrew Jahoda & Dave Dagnan
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Background: This exploratory study examined the content and salience of worries experienced by young people with mild intellectual disabilities (ID) at transition to adulthood. Self-efficacy and anxiety in relation to worry was also examined. Fifty-two participants (17-20 years) took part; 26 with mild ID and 26 typically developing adults. Participants were recruited from a college in Glasgow.

Methods: Of interest were potential differences between groups in i) worries described, ii) salience of worries, and iii) relationship between self-efficacy, anxiety, and worry within groups. Participants completed a 'worry' interview, the General Self Efficacy Scale-12, Glasgow Anxiety Scale-LD, and Wechsler Abbreviated Scale of Intelligence.

Results: People with ID identified different worries from typically developing people. There were also significant differences in rumination and distress between groups, and associations between anxiety and distress.

Conclusions: Obtaining insight into worries at transition may facilitate guidance opportunities. Clinical applications of the findings are discussed.

Emotion recognition ability in autism spectrum disorders in different modalities

Tony Charman
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Background: Experimental investigations of emotion recognition ability in ASD have been equivocal; hampered by small sample sizes, narrow IQ range and over-focus on the visual modality.

Methods: We tested 93 adolescents (mean age 15;6 years, mean IQ 85) with an ASD and 54 adolescents without an ASD (mean age 15;6 years, mean IQ 88) on a facial emotion recognition task and two vocal emotion recognition tasks (one verbal; one non-verbal). Recognition of happiness, sadness, fear, anger, surprise and disgust were tested. Using structural equation modelling, we conceptualised emotion recognition ability as a cross-modal construct, measured by the three tasks.

Results: There was no significant difference between groups for the majority of emotions and analysis of error patterns suggested that the ASD group were vulnerable to the same pattern of confusions between emotions as the non-ASD group. However, recognition ability was significantly impaired in the ASD group for surprise. IQ had a significant effect on performance for the recognition of all six emotions, with higher IQ adolescents outperforming lower IQ adolescents.

Conclusions: The findings do not suggest a fundamental difficulty with the recognition of basic emotions in adolescents with ASD.

Talking about real life events: an investigation of the ability of people with intellectual disabilities to make links between their beliefs and emotions within dialogue

Amy Hebblethwaite, Andrew Jahoda & Dave Dagnan

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Background: This study explores whether people with intellectual disabilities make links between events, beliefs and emotions in dialogues about real life, emotive events.

Methods: A cognitive-emotive interview was used to assist nineteen adults with intellectual disabilities and nineteen adults without disabilities in generating an account of an emotive, interpersonal event. Participants also completed a cognitive mediation task and an assessment of intellectual and verbal ability.

Results: Participants with intellectual disabilities generated fewer beliefs within their dialogues than those without disabilities and were less likely to provide alternative perspectives on events. The ability to make links between events, beliefs and emotions within a dialogue was not associated with performance on a cognitive mediation task, or with general or verbal IQ.

Conclusions: Participants with intellectual disabilities had more difficulty than those without disabilities in making links between events, beliefs and emotions. Within a therapeutic context, they are likely to require assistance to reflect on events and consider alternative interpretations, which take into account individual and environmental factors.

Cognitive behavioural anger treatment for adults with intellectual disabilities in secure settings: effects of intellectual functioning on outcome.

John Taylor & Raymond Novaco

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Background: Anger has been shown to be associated with aggression and violence in adults with intellectual disabilities in both community and secure settings. Emerging evidence has indicated that cognitive behavioural anger treatment can be effective in reducing assessed levels of anger in these patient populations. However, it has been suggested that the effectiveness of these interventions is affected significantly by verbal ability.

Methods: In this evaluation study the pre- and post-treatment and 12-month follow-up assessment scores of 83 offenders with intellectual disabilities who received cognitive behavioural anger treatment were examined in order to investigate whether participants' responsiveness to treatment was a function of measured verbal IQ.

Results: Patients with intellectual disabilities and offending histories benefited from an individual cognitive behavioural anger treatment intervention as assessed using a range of reliable self- and informant rated measures of anger. Significant improvements recorded following the intervention were maintained at 12-month follow-up. Overall, there was no evidence that responsiveness to the anger treatment was the result of higher verbal ability as reflected in verbal IQ scores.

Conclusions: Verbal IQ is not a significant moderator of treatment effectiveness and cannot be used to predict clients' responses to cognitive behavioural anger treatment reliably. Level of intellectual functioning, along other cognitive and communication skills impairments, need to be assessed carefully so that the intervention is delivered in a manner that is reflexive of the needs of each client.

What makes a good job interview? Understanding aspects of communication in sample job interviews among able young people with autism spectrum conditions

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Background: Even able people with autism spectrum conditions have difficulty in finding employment. A successful job interview is a crucial part of that process but this is an area of specific difficulty for this population for several reasons: it is a highly socially sensitive event that demands high-paced, ongoing spoken communication, excellent knowledge of social rules and a subtle reading of the interviewer's expectations and reactions, evident in their verbal and non-verbal communications.

Methods: This study recruited able young adults aged 18-25 to investigate their understanding of the different elements of communication that contribute to good and bad job interviews. Eight individuals with high-functioning autism or Asperger's syndrome (6 males, 2 females) and six adults without autism (3 males, 3 females) were individually shown filmed scenarios of a successful and an unsuccessful job interview, as a focus for individual interviews.

Results: Transcript analysis indicated: those with autism conditions understood the emotional context of metaphors without understanding their meaning; they could identify with the interviewer or interviewee; they gave more detailed and complex reasons for their answers in judging candidates' behaviour than those without autism. Those without autism made a fine-grained analysis of the word choices of candidates and recognised the social contextualisation of the job position unlike those with autism. Both groups commented in depth on rules of behaviour and language for job interviews.

Conclusions: High functioning people with autism spectrum conditions show insights into the interview process. However, they have a different pattern of strengths and weaknesses from those without autism.

Social Inclusion of People with Intellectual Disabilities from Different Cultural Backgrounds

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Background: Whilst research exists concerning the barriers to social inclusion experienced by ethnic minorities, issues faced by carers, particularly within the health service requires closer inspection. People with learning disabilities (PWLD) from ethnic communities are often overlooked within services and the community itself, causing isolation. Similarly, carers who do not speak English tend to receive less information about their support role thereby experiencing higher levels of stress. There is very limited evidence on the type of support network people with learning disabilities from ethnic minority communities have. Aim: To map the social networks, barriers, expectations and wishes of learning disabled ethnic minority communities with a view to understanding differences in their structure and interaction compared to white communities.

Methods: 50 PWLD (25 white and 25 Asian) and 30 carers (15 white and 15 Asian) were interviewed using a mixed methods approach; social network guide, adaptive behaviour scale and the family quality of life measure, as well as Semi-structured interviews and participant observation with the carers and PWLD.

Results: The emerging themes focused on the views of carers in relation to services. Carers stated that they would benefit from more services tailored to their specific ethnic community, where their needs can be understood more clearly. Carers noted a lack of support from services, regarding diagnosis or practical help to deal with their child on a day-to-day basis and a lack of knowledge of the health system. Network size is significantly different for Asians (mean 21.50) compared to the white community (mean 27.73). There also seems to be a slight difference in the area of life in which the participants' network belongs. More Asians have a network consisting of immediate family and relatives. However, the white community had a much higher network from day centres/clubs.

Conclusions: Overall, a significant difference in social network size between ethnic minorities and white communities is apparent. This is influenced by the type of help received by services that are not always tailored to their needs, greater isolating ethnic minorities.

Social behaviour in Smith Magenis syndrome

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Background: Accounts of the behavioural phenotype of Smith Magenis syndrome (SMS) suggest an atypical pattern of social behaviour, including attention seeking and preference for adult attention. Additionally, there are anecdotal reports of strong attachment to specific people.

Methods: An existing database was analysed, comparing aspects of social behaviour in 22 individuals with SMS, with two matched comparison groups; Down syndrome (DS) and autism spectrum disorder (ASD). Levels of sociability with five targets for social interaction; caregivers, familiar adults, familiar peers, unfamiliar adults and unfamiliar peers (measured using items from the Sociability Questionnaire for people with Intellectual Disabilities) were compared across groups. Attachment to particular people and objects was also investigated, using items from the Repetitive Behaviour Questionnaire (RBQ).

Results: No differences in sociability were found between individuals with SMS and those with DS for any of the targets for social interaction. As expected individuals with ASD were less sociable than those with SMS with the majority of targets. Individuals with SMS were found to have higher levels of attachment to people than those with DS or ASD, who did not differ from each other. This pattern of results was not replicated for attachment to objects indicating high specificity of this behaviour in SMS.

Conclusions: Findings support suggestions that there is a strong drive to interact with particular people in SMS. However, more generalised hypersociability which has been found in other syndromes was not evident.

Our health, our care our say? How the wishes of adults who lack capacity are handled during substitute decision-making

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Background: Consumer choice lies at the heart of current health and social care policy. The Mental Capacity Act 2005 incorporates this “choice agenda”, stipulating that when making substitute decisions for people deemed to lack the ability to decide for themselves, clinicians must give due consideration to a person’s wishes before deciding what would be in the “best interests” of that person. Little is known about how this is achieved in practice. This paper addresses two questions: 1) What part do the wishes of adults lacking capacity play in the process of substitute decision-making? 2) How do decision-makers deal with wishes that seemingly contradict their judgement of what should be done?

Methods: Data were collected at two meetings where clinicians were tasked with ensuring that a person deemed to lack decision-making capacity was in suitable accommodation on discharge from hospital. An advocate (IMCA) represented the wishes of those people. Audio recordings and verbatim transcripts of the meetings were analysed by a sociologist and a clinician, using techniques drawn from Discourse Analysis, to describe some interesting features of talk about the wishes of people who lack decision-making capacity.

Results: 1) Wishes were not first on the agenda. 2) Wishes that conflicted with pre-formed judgements of what ought to be done were “tamed” and overridden. 3) Decisions were based on well-being and resource availability, not wishes.

Conclusions: Patients’ wishes and values may be more influential if clinicians and IMCAs are trained to discuss them earlier in the decision-making process, before considerations of well-being acquire overwhelming force.

Service use and cost of mental disorder in older adults with intellectual disability

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Background: Ageing is associated with increased service use and cost of care in the general population. Dementia and other mental disorders are associated with high costs in older adults. We aim to report service use and costs of care of older people with intellectual disability (ID) and explore the influence of socio-demographic and illness-related determinants.

Methods: We collected data on receipt and costs of accommodation and health and personal care; physical as well as mental illness, dementia, sensory impairment and disability in a representative sample of older adults with ID aged 60 and older (n = 212).

Results: The average weekly cost per older person was £790 (£41,080 per year). Accommodation accounted for 74%. Health care costs, such as psychological, psychiatric and other specialist intellectual disability team support costs constituted a relatively small proportion of the cost. Overall costs were highest for those living in congregate settings. Gender, ID severity, hearing impairment, physical disorder and mental health problems had significant independent relationships with costs. Mental health problems (including significant behavioural disorder) were associated with additional weekly cost (£202), but dementia did not appear to increase overall costs.

Conclusions: Older adults with ID comprise about 0.15 to 0.25% of the population of England but consume up to 5% of the total personal care budget. Interventions which meet needs and which may prove to be cost-effective should be sought, as should interventions for mental health and behavioural problems.

Critiquing the involvement of service users in monitoring/inspection of services

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Background: The National Institute for Intellectual Disability (NIID) Trinity College Dublin was funded to develop 'Critiquing the involvement of service users in monitoring/inspection of services', a project about how people with disabilities, children and older people requiring aged care services have been involved within statutory inspections of residential services. A review of literature and consultation with government officials and consumers who have been involved in the evaluation process was carried out in eight European countries. This paper outlines strategies associated with consumer involvement. It presents a critique of the outcomes of such involvement leading to strategy recommendations for improving consumer involvement in the Republic of Ireland

Methods: Participants of the research were people with intellectual and physical disabilities, young people, and elders as well as policy makers and key informants in the area inspection/evaluation of residential services. Eight European countries were visited. 34 Focus groups and 72 semi-structural individual interviews were conducted.

Results: The full inclusion of users within statutory inspection is seen by Consumers-inspectors as the most effective and meaningful way to meet user's needs. This practise gives a voice to a vulnerable population, enabling them to speak out and advocate for change. At a structural level, we must embrace cooperation between consumers and inspectoral bodies. This promotes participating within services and raising awareness of people rights. It also gives inspectoral bodies first hand experience of the user's perspective. An effective strategy of inspection which involves the consumer brings greater security to consumers in their every day lives.

Conclusions: Promote public participation of users of residential care faces multiple challenges such as the development of communication strategies, training provision and financial sustainability. Results of this research suggest that involving users on a statutory basis, with clear protocols of protection in place, enables them to participate with a greater feeling of security. Participation of users in the inspection of residential care incorporates the perspective of consumers within the legal instrument of control and is a catalyst for improvements in residential care.

Evaluation of the ability of people with intellectual disabilities to weigh up information in two tests of financial reasoning

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Background: An assessment of mental capacity includes an evaluation of the ability to “weigh up” information, but how to do this is uncertain. We have previously used a laboratory decision-making task, temporal discounting, which involves a trade-off between the value and the delay of expected rewards. Participants with intellectual disabilities showed very little evidence of “weighing up” of information: only a third of participants showed consistent temporal discounting performance, and when present, consistent performance was usually impulsive; and the ability to perform consistently was more strongly related to executive functioning than to IQ. The aim of the present study was to replicate these observations and extend them to a more realistic financial decision-making task.

Methods: We administered a temporal discounting task and a financial decision-making task, as well as tests of executive functioning and IQ, to 20 participants who attended day services for people with learning disabilities (mean Full-Scale IQ = 59), and to 10 staff members.

Results: Performance in both decision-making tasks was related more strongly to executive functioning than to IQ. In both tasks, decisions by service users were made largely on the basis of a single item of information: there was very little evidence in either task that information from two sources was being “weighed”.

Conclusions: The results suggest that difficulty in “weighing up” information may be a general problem for people with intellectual disabilities, pointing to a need for psycho-educational remediation strategies to address this issue.

Managing serious health risk for adults with intellectual disabilities through the provision of assistance at mealtimes

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Background: For many adults with an intellectual disability (ID) mealtimes carry significant health risks. While research and allied clinical guidance has focused mainly on dysphagia, adults with a range of physical and behavioural difficulties require mealtime assistance to ensure safety and adequate nutrition. The extent of need for and character of such assistance within the wider ID population has yet to be reported.

Methods: We estimated the prevalence of need for mealtime assistance amongst people with ID in the UK, using a population of 2,230 adults known to specialist ID services (in Cambridgeshire, UK total population 586,900). In a sample (n=69), we characterised the assistance provided, using a structured pro forma to consult support workers and carers providing mealtime assistance, and health and social care records regarding type of and reasons for assistance, and associated health problems.

Results: Prevalence of need for mealtime assistance was estimated at 15% of adults known to specialist ID services or 56 per 100,000 total population. Within our sample (n=69, aged 19 to 79 years, with mild to profound ID), assistance was required due to difficulties getting food into the body (n=56, 82.2%) and risky eating and drinking behaviours (n=31, 44.9%). Need for assistance was often compounded by illness or

physical disability (n=31, 44.9%) and psychological or behavioural factors, such as challenging behaviour, anxiety and depression (n=36, 52.2%).

Conclusions: Mealtime assistance is required by a significant minority of people with ID for complex and varied reasons. These findings highlight need for multidisciplinary approach to mealtime interventions incorporating psychological/psychiatric input. The strategies used have to ensure adequate nutrition provided in a safe manner and in the context of the social environment within which people with ID live.

Access to health care by people with learning disabilities living in Cambridgeshire and Peterborough

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Background: This service evaluation has been informed by extensive national literature that has cited inequalities of and the need for investigation into the provision of health care to people with learning disabilities. The most significant literature includes: Valuing People (Department of Health, 2001); Death By Indifference (Mencap, 2006); Health care for all: Independent Inquiry into access to healthcare for people with learning disabilities (2008); Valuing People Now (Department of Health, 2009); and most recently, six lives: the provision of public services to people with learning disabilities (Ombudsman, 2009).

Methods: The evaluation has qualitative and quantitative components: Firstly, to conduct semi structured interviews with individuals and organisations involved in provision and facilitation of learning disability health care. Secondly, to quantitatively collect data from a Cambridge hospital in order to determine numbers of people with learning disabilities accessing these acute services.

Results: The freedom of choice agenda that is driving social care has repercussions for health care. The effect of which are unmet health needs and difficulties in accessing mainstream primary and secondary health services. Thus, failure to meet social care needs successfully, such as housing, can detrimentally affect access to health services for people with learning disabilities.

Conclusions: Appropriate social and environmental circumstances are integral to the achievement of quality and thorough health care provision for people with learning disabilities. At present, the social care initiative to promote independence for people with learning disabilities fails to achieve the correct balance between giving support and giving freedom of choice.

For mothers of adult children with a learning disability and epilepsy care means balancing the tension between stability and aspiring to a good life

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Background: The qualitative data that we have collected forms part of a wider study looking at care pathways for those with intellectual disability and epilepsy.

Methods: 20 semi structured interviews were conducted with parents of adult children who have epilepsy and ID. The aim was to gain parents experiences caring for a child who has epilepsy and learning disability and focused on experiences of the services they have accessed. Interviews were audio-taped and transcribed.

Results: The interview data suggests the mothers aspire to a “good life” for their child. Whilst their ID and epilepsy can often create barriers to achieving a “good life” neither prevents it. In order to move towards this “good life” the mothers need to be open to change and willing to take action. Our data suggests mothers are cautious

and choose small incremental changes when considering change to their child's epilepsy care. This contrasts to more drastic actions taken earlier in their child's medical history such as brain surgery. Horror stories have been told of early medical experiences around their child's epilepsy and learning disability. This appears to justify the cautious approach taken now.

Conclusions: Mothers desire stability and order in their child's life which must be balanced with the action needed for achieving a "good life". This leads to preferences for clinicians who assist this aim either by letting the mother retain control of the balance whilst providing expert information and support or by taking the control but not upsetting the balance and remaining easily accessible to the mother.

Communication assessment and intervention with children and adults with profound and multiple learning disability

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Background: Significant impairments in language and communication are a core feature of pmlD and while RCSLT Clinical Guidelines make it clear that speech and language therapy should be available to people with pmlD, the evidence base for assessment and intervention in this area is small and fragmented. A review identified six intervention approaches for this client group for which evidence was available. These were direct approaches utilising micro-switch technology, intensive interaction, objects of reference and creative arts therapy, and indirect approaches involving environmental modification and staff and parent training. This study has explored the assessments and interventions used by SLTs with this client group in the UK, together with the rationales for their clinical decisions, thus providing the "expert clinical opinion" component of evidence-based practice.

Methods: The survey was designed in discussion with IASSID's PIMD SIRG. The RCSLT Bulletin was used to invite relevant SLTs to request a copy of the survey. Descriptive and content analyses were employed to explore the quantitative and qualitative data respectively.

Results: 58 surveys were returned. The most commonly used assessments were PVCS (45%) and ACA (38%). Intensive interaction was used by 82% of respondents and Objects of Reference by 70%. Switch-based work, for which there is greatest evidence, was used by only 11%.

Conclusions: There is a need for further research to evaluate the utility of assessments and intervention approaches for this client group, and to explore the (non) use of microswitch-based approaches, especially within adult services.

Transition of students with intellectual disabilities from education into post-school options within the Irish context

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Background: In recent years there have been major changes in disability policy in Ireland, including the Education for Persons with Special Educational Needs Act of 2004. Such policies have called for individualised education plans, inclusion of students with intellectual disabilities (ID) in decisions that impact upon their lives, and inclusive education. However, there is a lack of evidence regarding the effective implementation of these policies and the accomplishment of desired transition outcomes for students with ID. Therefore, the aims of this research project were to review the current educational provision for students with ID regarding transition, the options available to them when schooling ends, and the challenges to successful transition outcomes.

Methods: A mixed methods approach was employed. This involved focus groups with teaching staff, family members and students with ID (N=74), and a national survey of school-based staff involved with senior students with ID (N=310). Collected data were analysed thematically and descriptively.

Results: The emerging findings of this study included: The quality of transition planning and preparation varied considerably within the Irish educational context. There appeared a lack of standardized transition procedures and transition planning, if occurring, was in the last year of school. The main post-school options available to students were transition into disability services and specialised courses. There was an additional lack of knowledge regarding transition options and procedures, shared by all stakeholders.

Conclusions: The findings have implications for the further development and implementation of transition programmes within schools, post school options in Ireland and policies, which will be outlined.

The misdiagnosis of epilepsy in people with intellectual disabilities: a systematic review

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Background: Epilepsy is more common in people with intellectual disabilities (PWID) than the general population. Epilepsy can be difficult to diagnose and may be misdiagnosed in around 25% of cases. A multi-disciplinary team conducted a systematic review to examine: (i) How common is misdiagnosis of epilepsy amongst PWID? (ii) Reasons for misdiagnosis of epilepsy; (iii) The implications of misdiagnosis; (iv) Improving diagnosis and addressing misdiagnosis.

Methods: Studies were identified from electronic databases, experts, the internet and grey literature, and citation tracking.

Results: Eight studies were included in the review and critically appraised. Four broad themes emerged: 1) Methods of diagnosis: Short outpatient studies were useful for diagnosing non-epileptic events and long inpatient studies were useful for diagnosing epileptic events with children with ID. 2) Level of misdiagnosis: there are high levels of non-epileptic events with the potential to be misdiagnosed as epilepsy. Parents and support workers may overestimate epileptic events or not recognise epileptic events. 3) Impact of misdiagnosis: people may be taking unnecessary antiepileptic medication, or may not be prescribed antiepileptic medication when epilepsy is unrecognised. Conditions such as Sandifer Syndrome may remain untreated if symptoms are mistaken as epilepsy. 4) Potential reasons for misdiagnosis: main reasons for misdiagnosis were: non-epileptic events being

mistaken for seizures; epileptic events not being recognised as seizures, and carers' lack of knowledge.

Conclusions: Those working in epilepsy and ID services and families must be aware of the possibility of misdiagnosis. Future research is needed about the misdiagnosis of epilepsy amongst PWID and the knowledge of carers and health professionals.

Maximising the availability of psychological therapies for people with intellectual disabilities using stepped care

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Background: Despite a growing evidence base for the use of psychological therapies for people with intellectual disabilities, mental health within this group continues to be an area of unmet need. Discrepancies exist between access to psychological therapies in the general population and access to equivalent psychological interventions for people with intellectual disabilities. The present study explored how a Scottish NHS community learning disabilities team currently meets the mental health needs of people with an intellectual disability, what challenges they face and whether a model of "stepped care" service provision to increase access to psychological therapies would be beneficial to this group.

Methods: Two focus group sessions explored the experiences, thoughts and attitudes of members of the team. Thematic analysis of discussion transcribed from audio recordings was used to identify themes.

Results: Primary themes that emerged from the discussion concerned a lack of resources, a need for further knowledge, training and supervision in this area, and a wish to formalise existing practice.

Conclusions: The above themes were identified as restricting how the team meets the mental health needs of people with an intellectual disability. The team reported already engaging in aspects of stepped care and judged it a potentially useful model for maximising limited resources and standardising care provision, with some adjustments to make the model more appropriate to this group.

Carers' responses to challenging behaviour

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Background: Weiner's attribution model has been applied to how carers' attributions and emotions affect their actual and intended behavioural responses to the challenging behaviour of people with intellectual disabilities; however the model has received inconsistent support. One possible reason for this inconsistency is that many studies use vignettes that do not relate to real people to generate responses. Recent studies suggested such vignettes might generate different responses compared to data based on actual instances of behaviour or vignettes describing real people; although results from such studies are also inconsistent. This paper offers further data that compares attribution, emotional and intended behavioural responses to unnamed vignettes and vignettes describing behaviour associated with a named and known person with intellectual disabilities.

Methods: Sixty-two paid carers of people with intellectual disabilities completed questions reporting attribution, emotional and intended behavioural responses to vignettes describing behaviour presented by an unnamed person and vignettes describing the same behaviour presented by a named and known person. They also completed a scale of behavioural knowledge.

Results: Carers make more internal and generalisable attributions and identify themselves as less optimistic in response to vignettes relating to specific people than

those relating to unnamed people. However, correlations between the main variables are not significantly different for unnamed and named vignettes and the data from both unnamed and named vignettes support a mediated model for controllability, anger and helping intention.

Conclusions: Unnamed vignettes may underestimate the intensity of carers' responses to challenging behaviour; however this paper finds no evidence that there are qualitative differences in the inter- relationships between variables in data sets obtained from unnamed and named vignettes.

Challenging behaviour in children with severe intellectual disabilities

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Background: The prevalence and persistence of challenging behaviour in individuals with severe intellectual disabilities allude to the potential and importance of an early intervention strategy. Identification of children at high risk of challenging behaviour within this already high risk group would enable risk related resources to be allocated.

Methods: Two large scale survey studies using the Challenging Behaviour Screening Questionnaire (CBSQ) examined the association between child characteristics and the presence of challenging behaviour at screen and 18 months later. Natural observations, questionnaires and actigraph measures were used to assess the concurrent and convergent validity of the CBSQ. Behavioural and environmental characteristics of high and low risk groups were compared using observational methods. The functional and communicative nature of the challenging behaviour demonstrated by participants at high risk was examined using experimental functional and descriptive analyses.

Results: The concurrent and convergent validity of the CBSQ was demonstrated. The relative risk of challenging behaviour at screen and its persistence 18 months later was significantly increased when repetitive, restricted, overactive and impulsive behaviours were evident with different associations for self-injury and aggression evident. The majority of the challenging behaviour demonstrated by high risk participants appeared functional and closely associated with communicative behaviours.

Conclusions: The operant model of challenging behaviour in this population is extended with emphasis on the interaction between child characteristics and environmental variables. The potential success of a targeted early intervention strategy is discussed.

Factors that impact on the sibling relationship

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Background: Sibling relationships are significant in the lives of people who have a learning disability. They usually form a major part of their social network and provide ongoing support after parental incapacity. Services and policy planners need to support siblings so that they in turn are able to provide support. The government acknowledges the significance of family members in the care of learning disabled people however there is a lack of research in this area.

Methods: A literature search of empirically based articles published in peer review journals between 1986 and 2009 was carried out using the key terms "siblings, brothers and sisters, adult, learning disability, developmental disability, mental retardation, mental subnormality, mental handicap and learning activity limitation". Databases searched included Google Scholar, Psychinfo, Ovid, Medline and Cinahl and citation tracking was utilised.

Results: There is a continuum of relationships between siblings and people who have a learning disability. Many factors impact upon this relationship and the nature of relationships varies between families and is affected by the life course. Those factors seen to have a potential impact include gender, the type and level of disability, age, residential status, birth order, family climate and maternal well being.

Conclusions: The relationship between siblings is varied however there are factors that appear to have an impact upon this relationship. Siblings report the need for guidance in their support of disabled brothers and sisters.

Violence at work: Assessing the prevalence of experiences of violence at work in community learning disability teams in Sussex

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Background: The NHS Security Management Service "A professional approach to managing security in the NHS" (2003) highlighted the need for NHS staff to feel safe in order to provide high quality clinical care. As part of essential training within Sussex Partnership NHS Foundation Trust, prevention and management of violence and aggression is recommended for all staff joining the trust, including those working in learning disability services. This study aimed to investigate the prevalence of violent behaviour experienced by staff in community LD teams, and to consider how current training matches the level of need.

Methods: A quantitative "Two Minute Questionnaire" was distributed electronically to all members of Community Learning Disability Teams in Sussex. A sample of respondents will then be interviewed to obtain more in-depth data regarding these experiences.

Results: The results are currently being obtained. However, initial data suggests a response rate of between 39 and 100 %, with approximately 65% of staff reporting to have experienced some form of violence at work. However this is a preliminary figure as the responses are still being received and recorded.

Conclusions: The research is still in the data collection stage so it is too early to make any conclusions at present. However, it is hoped that the research will be useful in allowing training regarding violence at work to be more appropriately targeted to the needs of those working in community learning disability services.

The equity perceptions of staff working in services for people with learning disabilities: a review

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Background: The aim of this study is to review research on the equity perceptions of staff working in services for people with learning disabilities.

Methods: Relevant articles were identified using the PsycINFO computerised database and by conducting manual searches of reference lists.

Results: Six studies were identified. Findings from the studies suggest that relatively high numbers of staff feel under-benefited in their work-based relationships (i.e. with their employers and the service users). Associations have been found between staff equity perceptions and a variety of staff outcomes (e.g. burnout, absenteeism and intention to leave the job).

Conclusions: The implications of the reviews findings are discussed. Recommendations for future research are made.

The use of repertory grids to explore care staff attributions towards clients with intellectual disabilities who exhibit challenging behaviour

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Background: Attribution theory predicts the causal attributions made by care staff about behaviour that is challenging (e.g. whether it is regarded as internality, control, stability) will influence their emotional responses and helping behaviours (Weiner, 1985; 1986). However, studies of carers of people with intellectual disabilities (ID) have provided inconsistent support for this model and the use of vignette and questionnaire-based methodologies has been suggested as leading to these inconsistencies (Bailey et al 2006; Wilner & Smith, 2008).

Methods: Repertory grid methodology was used to explore how 14 nurses and clinical support workers in an inpatient ID service construed clients with and without behavioural challenge, other carers and themselves. A set of elements derived from attribution theory was used, for example, a client who is in control of their challenging behaviour, a client whose challenging behaviour is temporary, etc.

Results: Preliminary analysis of the grids suggested that within the staff team, clients appeared to be construed in a wide variety of ways, indicating that there was not a shared cultural schema in the team regarding behaviour and behaviour change. Important differences included the manner in which the self and staff role were used to construe clients, holding both positive and negative appraisals of clients as being in control of their behaviour, and liking the challenge of working with disturbed behaviour.

Conclusions: The implications of the findings are discussed, with reference to both clinical decision-making and attribution theory, as well as considering the implications for both staff training and clinical leadership.

Diagnostic grouping among people with learning disabilities and autistic spectrum disorders

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Background: A systematic review (Robertson & Emerson, 2006) identified no useful evidence to guide the commissioning of residential provision for adults with autistic spectrum disorder (ASD) in the UK. The aim was to explore the impact of diagnostic grouping among adults with learning disabilities and the triad of social impairments characteristic of ASD on the nature of provision and lifestyle outcome.

Methods: Information on 424 adults with learning disabilities living in 146 staffed houses were available, 157 of whom were assessed as having the triad. Settings where these 157 people lived were categorised as non-congregate (40% or fewer had the triad, n=30) or congregate (60% or more had the triad, n=112); intermediate groupings (n=15) were eliminated. The characteristics of the groups were compared, as were setting size, staff-to-resident ratio, scores on the Working Methods Scale, Group Homes Management Scale, Index of Community Integration and Index of Participation in Domestic Life and observed engagement in activity. In addition, non-congregate and congregate groups matched on Adaptive Behaviour Scale (ABS) score were identified and the comparisons repeated.

Results: The non-congregate group had non-significantly higher ABS scores. They lived in settings with significantly larger groups, lower staff-to-resident ratios, more individualised social milieu and more organised working methods. They had a greater variety of social and community activities and greater involvement in household activities. After matching for ABS, only the differences relating to size of setting and working methods remained.

Conclusions: The findings are consistent with other research that finds few advantages to diagnostic grouping.

Psychological outcomes for mothers and fathers of children with Angelman, Cornelia de Lange, and Cri du Chat syndromes

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Background: Parents of children with rare genetic syndromes have become of increased interest to researchers, and the current study focuses on mothers and fathers of children with three rare genetic syndromes that are relatively unexplored in terms of family experience; Angelman syndrome (AS) Cornelia de Lange syndrome (CdLS) and Cri du Chat syndrome (CdCS). Parents of children with Autism were used as a comparison group to help benchmark the extent of psychological distress among parents.

Methods: All children recruited displayed either aggressive or self-injurious behaviour on a daily basis. Parents of children with AS (n=15), CdLS (n=16), CdCS (n=18), and Autism (n=20) completed questionnaires on both negative (stress, anxiety, depression) and positive outcomes.

Results: Parents of children with AS consistently reported the highest levels of negative outcomes, and parents of children with CdLS the least, although most mean scores were elevated when compared to normative data. Positive outcomes were similar across the four aetiology groups. Severity of child aggression was related to parental reports of negative outcomes.

Conclusions: To the authors' knowledge, this is the only study that has found parents of children with other aetiologies reporting higher negative outcomes than parents of children with Autism. The relation between the severity of the child's aggressive behaviour and parental outcomes suggests that child challenging behaviour has a

negative impact on parents. Further research is needed to determine whether it is the levels of challenging behaviour exhibited by the child or the behavioural phenotype associated with the aetiology of the child that contributes to parental stress.

The impact of disturbed sleep in daytime sleepiness in adults with learning difficulties

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Background: Sleep disturbances are known to be elevated in people with intellectual disabilities and are associated with challenging behaviour and cognitive functioning. However, much work has used indirect methods of assessment, with only a few studies using objective assessment (e.g. Espie et al, 1998; Espie et al, 1999; Hare et al, 2006). To date there has been a paucity of research linking night and day sleep, despite good theoretical and empirical grounds for doing so.

Methods: Actigraph sleep data from 20 participants in Hare et al.'s (2006) study of circadian function was re-analysed to extract specific night-time (sleep efficiency, sleep latency, duration of actual sleep, sleep fragmentation, number of sleep bouts and average sleep bout length) and daytime (number of naps, average nap time and total naptime) sleep parameters.

Results: Correlational analysis indicated sleep fragmentation was negatively correlated with number of naps whilst mean sleep bout length was positively correlated with total naptime. Linear regression analysis revealed fragmentation of sleep was a significant predictor of number of naps ($b = -0.187$, $p = 0.033$), accounting for 22.8% of the variance of number of naps taken. No other significant results were obtained.

Conclusions: The current findings show a more limited association between night-time and day-time sleep than indicated by previous research. Whilst the validity and reliability of the data is high given the use of actigraphy, the current results may be related to the current sample. However, the specificity of the significant associations may indicate specific intervention strategies in the case of excessive daytime sleepiness.

Using Q methodology to investigate professional views of attachment in people with intellectual disabilities

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Background: Attachment style may be protective against future challenging behaviour in adults with intellectual disabilities [ID], but it is also hypothesised that the development of secure attachment could be disrupted in this population due to parental grief, disability factors; or that attachment style impacts on the development of ID. This exploratory study aimed to explore secure attachment in adults with ID as the initial stage in developing an ID-specific assessment measure.

Methods: Thematic analysis highlighted potential constructs that could be related to secure attachment in adults with ID. 34 professionals from different backgrounds performed a Q-sorting task using 105 item Q set.

Results: A principle components factor analysis with varimax rotation was performed on the 34 completed Q sorts. This resulted in a four factor solution, accounting for 72% of the variance of the data set. Factor 1 and 2 were shown to be highly correlated and represented the viewpoint of 32 participants. Factor 3 and 4 were the resultant factors of individual sorts, and could be seen as outlying viewpoints. All of the Q sorts, however, endorsed some elements related to secure attachment theory, especially those of interpersonal relationships.

Conclusions: The study demonstrated that Q sort methodology is a useful tool to illuminate views on what constitutes secure attachment behaviours in adults with ID as held by professionals. The study provided a base for future research on the development of an observational third-party assessment of attachment for this population, in particular identifying the central role of interpersonal relations

A Story To Tell

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Background: This project has been funded by the Irish Research Council for Humanities and Social Sciences. The purpose of the study was to discover what the key events and experiences have been in the lives of older adults with intellectual disabilities in Ireland, and to create an accessible multimedia archive of the stories.

Methods: Researchers worked with people with intellectual disabilities (the 'storytellers') in an inclusive way to capture their stories using life story methodology. There were no interview schedules or set questions, and thus the material gathered emerged organically, and the topics which were discussed are topics which people with disabilities themselves wished to discuss. These stories were then analysed using inductive thematic analysis at the latent level.

Results: The results of this research topic can be seen in the thematic analysis that has been documented and will soon be published as part of the NIID Monograph series. Some of the key topics that many of the storytellers spoke about are their relationships and friendships; life in rural Ireland in the mid 20th Century; the experience of entering an institution; the death of loved ones and the skills and achievements of people with disabilities.

Conclusions: The resulting stories provide an account of the lives and experiences of people with disabilities. Service provision in Ireland has changed significantly in the past 50 years in Ireland; these stories create a narrative of those changes in the voice of the individuals who lived through them.

Transition protocols for learning disabilities transition partnerships

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Background: Governmental guidance for transition advises local transition partnerships to formulate and implement a transition protocol for planning transitions for young people with learning disabilities leaving school. Valuing People and Valuing People Now make clear recommendations about the requirements of the transition process and there is a requirement in Wales for transition protocols to be in place. Our study examined all transition protocols available from Welsh local authorities (total=22; n=21) as to their relationship with those recommendations.

Methods: We conducted a survey of all Welsh local authorities (n=22) to establish how many LAs have a transition protocol and obtained 21 protocols from across Wales. We then analysed all protocols for their compliance with various requirements set by government through guidance: use of PCP, involvement of carers and young people, planning, data sharing and pooling resources across agencies. We then selected 4 Welsh LAs that had developed detailed transition protocols and conducted semi-structured interviews with all transition partners (SENCOs, Social Service transition workers (adult and children), Careers service, college heads, staff of external support agencies). Interviews dealt with the quality and nature of transition work and the effect protocols have had on partnership work.

Results: Our survey revealed that despite clear guidance from the Welsh government, not all Welsh LAs have a transition protocol. Quality and nature of

protocols vary significantly, where they exist. Our in depth study of 4 selected Welsh LAs provides data on the impact of protocols on interagency partnership working.

Conclusions: Transition protocols are necessary yet not sufficient prerequisites for effective transition partnerships in LD.

Age related changes in DHEA in adults with Down's syndrome

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Background: People with Down's syndrome (DS) are at high risk of developing early onset dementia. Recent studies suggest a link between decreased dehydroepiandrosterone (DHEA) concentrations and dementia in the normal population. The current study was designed to investigate the relationship between DHEA and dementia in adults with DS.

Methods: 67 adults with DS and 65 age-matched controls were included in the sample. Blood samples of each participant were collected between the morning and early afternoon and the DHEA blood concentrations were determined.

Results: The results show that the DHEA blood concentrations decrease with age in people with DS as well as in controls ($r = -.490$, $p < 0.01$ in the DS group and $r = -.346$, $p < 0.01$ in the controls). The mean DHEA level of controls was $3.47 \mu\text{mol/L}$ ($SD = 1.41$). The mean DHEA concentration of participants with DS was $2.79 \mu\text{mol/L}$ ($SD = 1.24$) and thus significantly lower ($t = -2.981$, $p < 0.01$). Within the DS population, non-parametric ANCOVA based on ranked data revealed a significant relationship between DHEA concentrations and dementia ($F(1,65) = 4.885$, $p < 0.05$).

Conclusions: The current findings support the assumption that low DHEA concentrations are a risk factor for developing dementia in the DS population.

Inter-person sources of conflict in people with and without mild intellectual disabilities at transition from adolescence to adulthood

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Background: This is an exploratory study into the typical interpersonal contexts of conflict in young people with mild to moderate intellectual disabilities (MIDs). The study investigates whether the experiences of conflict of young people with IDs vary qualitatively from those of their non-disabled peers.

Methods: Semi-structured interviews were completed with 26 young adults (16-20yrs) with and 18 young people without MIDs. Participants were recruited from schools, youth clubs and colleges in the Glasgow area. Participants completed a semi-structured interview about a recent experience of interpersonal conflict that still elicited negative emotions on recall. During the interview, participants were asked to describe (1) the activating event (2) inter-personal beliefs about the event (3) the consequent emotions and responses and (4) any methods employed to control their anger. Interviews were recorded and then transcribed verbatim. Salient categories for each interview item were gleaned from the resultant transcripts by content analysis. Group comparisons were then made for coded responses to each item.

Results: Preliminary descriptive analysis suggests several qualitative differences between the groups, including the following. Firstly, half of the participants with IDs (13 of 26) reported incidents involving peers or classmates that they did not consider friends with the same proportion also reporting incidents at school/college. In contrast, no ND participants reported incidents involving a "non-friend"/ peers/classmates and only one reported an incident at school/college. Instead, the majority (15 of 18) of ND participants reported encountering conflict with people close to them

(friends, partners and family) compared to less than half of the participants with IDs (10 of 26). Over half (15 of 26) participants with IDs described encountering physical or verbal aggression compared with only 3 of the ND group. Also, 9 of the 26 participants with IDs described being personally slighted or stigmatized, while only 2 of the ND group described such incidents.

Conclusions: Preliminary results suggest there may be important differences between the experiences of conflict of young people with MIDs and their non-disabled peers. Findings suggest that young people with IDs may be more likely to be victimized by peers outside their personal network while it is possible non-disabled young people are more likely to experience conflict with people they are close too and away from the school/college setting. These results will inform more focussed future research into how young people with IDs perceive and deal with conflict at this key stage in their development.

Development of an adaptation of the clinical outcomes in routine evaluation outcome measure for people with a learning disability

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Background: Regular outcome measurement is good practice in therapeutic work and is crucial for building on the evidence base for psychological therapies such as CBT for people with a learning disability (LD). Standardised outcome measures are needed that can be used routinely and are applicable to the comprehension needs of people with LD. Outcome measurement is also fundamental to approaches such as stepped care, which can be used to increase access to psychological therapies.

Methods: People with an LD who had mental health issues (N=50) completed three existing measures of psychological distress (Glasgow Anxiety Scale, Glasgow Depression Scale, modified Rosenberg Self-esteem Scale) in addition to the CORE-LD to explore concurrent validity. A control group of people with mental health issues who did not have an LD (N=21) completed the original CORE and CORE-LD to explore reliability.

Results: CORE-LD and CORE scores were highly correlated within the control group and the CORE-LD demonstrated concurrent validity with the three existing measures, indicating its sensitivity to psychological distress.

Conclusions: The CORE-LD is a useful tool in measuring global psychological distress and can be used by a variety of clinicians from different backgrounds. Due to its “pantheoretical” nature, CORE-LD could be used as an integral part of stepped care for increasing access to psychological therapies.

Someone might have a PhD in autism

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Background: The experiences of individuals in middle adulthood with Asperger syndrome has been the subject of little previous research, and nothing is known about how these individuals experience and perceive support services for their Asperger syndrome.

Methods: 11 adults with Asperger syndrome were interviewed about their past and current experiences of support. Interpretative Phenomenological Analysis (IPA) was used to interpret the interviews.

Results: Five themes emerged from the analysis (1) “Some days I do struggle” - Living with Asperger syndrome; (2) “They don’t expect you to have problems with things” - Employment issues; (3) “I just fall through the gaps between” - Experiences

with mainstream support; (4) “They are not catering for the people they are talking about” - Experiences of specialist support; (5) “Raising awareness” – Future steps towards supporting adults with Asperger syndrome.

Conclusions: The findings highlighted the anxiety, depression, and difficulties with communication that people with Asperger syndrome may experience. There are few support services designed for people with Asperger syndrome, and thus much of the available support is unsuitable. A lack of awareness of Asperger syndrome among support services and employers was felt to be a core issue. All participants wanted to remain as independent as possible, and believed an individualised approach to support would be greatly beneficial.

Case formulation-based working in a mental health in intellectual disabilities inpatient service

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Background: A formulation-based working approach was developed and introduced within an inpatient mental health in intellectual disabilities service. The impact of the approach was evaluated amongst direct care nursing staff within the service. The aim was to explore to what extent staff valued formulation-based working, which elements they perceived as helpful or unhelpful, and how their practice had changed following its introduction.

Methods: Participants (n=16) consisted of qualified and unqualified nursing staff who were interviewed using a semi-structured interview. Kirkpatrick's (1959) training evaluation model was used to structure the interview using questions around staff reaction, learning about patients, changes in behaviour towards patients, and changes in patient outcome in response to formulation-based working. Interview data was transcribed and examined using thematic analysis.

Results: Thematic analysis highlighted that participants viewed formulation-based working as valuable. The case formulation product was highly regarded and regularly used. Nursing staff used formulations in innovative ways, e.g. as a teaching aid to help others understand patient needs. Difficulties with the process were identified, e.g. nursing staff found it difficult to consider how formulations had improved patients' wellbeing. The formulation process was perceived as not directly influencing care plans. There was also limited dissemination of formulations to unqualified staff.

Conclusions: Formulation-based working was considered important amongst nursing staff, but with perceived limitations. In particular, its impact was limited to staff reaction and learning about the patients. Assimilation of formulations within the service may need further support to ensure that formulation-based working has an impact through to patient outcome.

Wellbeing and lifelong health in people with a genetic syndrome

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Background: People with a neurodevelopmental disorder associated with an intellectual disability (genetic syndrome) are part of the very heterogeneous group of people with a learning disability. We are investigating whether the knowledge of both the genotype and behavioural phenotypes of genetic syndromes can be used to improve the lifelong health and wellbeing of people with a genetic syndrome.

Methods: The 11 syndromes in our study are: Angelman, Cornelia de Lange, CHARGE, Down, Fragile X, Prader-Willi, Rett, Rubinstein-Taybi, Tuberous Sclerosis,

VCFS and Williams. For each of these, we have conducted semi-structured interviews by phone with five parents of people with a genetic syndrome and one representative from the syndrome support group.

Results: Results from the parent interviews suggest that being diagnosed with the syndrome is important for dealing with having a child with the syndrome, understanding the child's behaviour, early intervention (eg, growth hormone in children with Prader-Willi) and obtaining social and medical care. Results from the representatives' interviews gave us information on causes of death, life expectancy, age profile of their membership and confirm parent reports on the invaluable source of information that these syndrome support organisations are.

Conclusions: These interviews suggest that there is a lot of information to be gained from research into people with a genetic syndrome, particularly regarding longevity, associated pathology, social inclusion, the effects of early intervention and wellbeing. Future research will involve investigating factors improving wellbeing in this group of people.

Introducing sex aids to single adults with learning disabilities

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Background: The literature indicates that potentially self-injurious masturbation with inappropriate objects, by people with learning disabilities, has received little clinical and research attention. Two adults with learning disabilities who displayed this behaviour were referred separately to a clinical psychology team.

Methods: A quasi-experimental approach first involved restricting access to inappropriate objects. During the subsequent intervention, the clients were provided with sex aids as a safe alternative.

Results: Frequency data indicated that during intervention, use of inappropriate objects for masturbation eventually dropped and was maintained at zero levels, concurrent with relatively high frequency of use of the sex aid.

Conclusions: The difficulties of introducing a safe sex aid as an intervention are discussed within the context of the legal and practical issues and the attitudes of staff. Therefore, we have made several suggestions relating to our experiences in implementing the interventions described (in an area that requires a sensitive response these may be helpful in protecting both staff and clients).

Development of an ethical code of practice for the use of telecare with people with cognitive impairments

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Background: Increasingly, telecare (the use of electronic monitoring devices in residential services to enable peripatetic support) is being seen as a potential solution to the service expansion which will be needed as a consequence of changes in the UK learning disabilities population. Putting People First (HM Government, 2007) referred to making telecare integral as opposed to marginal to social care delivery. Despite evidence that telecare can facilitate rational resourcing without detriment to service users' quality of life, there are a number of compelling ethical issues associated with the telecare model.

Methods: The Delphi method was used. A questionnaire was developed following a literature review and consultation with a panel of 15 experts. This was emailed to 115 experts (local authority telecare leads, service providers and commissioners, policy makers, health and third sector representatives, academics and technology

suppliers) of whom 23 responded. Qualitative data analysis software was used. Key themes were submitted to the Delphi group for comment before compilation of a guidance document.

Results: Areas of ethical “relevance” included policy drivers, assessment, consent, risks, sourcing and installation of equipment, privacy, social wellbeing, quality of care and fairness. The impact of each of these areas was considered in terms of the bioethical principles of autonomy, beneficence, non-maleficence and justice.

Conclusions: The data were used to compile a code of practice which will be published and disseminated by the Social Care Institute for Excellence.

The sexual understanding and development of young people with intellectual disabilities

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Background: Developing a sexual identity and understanding are vital aspects of growing up. Families may play a more significant role in supporting the sexual development of their children with intellectual disabilities but there has been little research concerning parents' perspectives.

Methods: Semi-structured interviews were conducted with eight mothers who have a child with an intellectual disability (ID) and a similarly aged same sex sibling without a disability (ND). Mothers' attitudes and experience of dealing with the sexual development of their two children were compared and contrasted. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Results: The themes that emerged were: difficulties and conflict within the family; independence versus control; poor social support networks; coping with their offspring's emerging sexuality; and discussing topics concerning sexual matters. There were both similarities and differences in how mothers dealt with these issues for their child with and without disabilities, and mother's experiences differed widely across these themes. In particular, although mothers acknowledged all their children's need for greater independence, they were more reluctant to relinquish control with their child with ID. The mothers' contribution to their children's sex education was generally ad hoc and reactive. Discussions with their non-disabled offspring tended to concern pregnancy and prevention of sexually transmitted diseases, whereas with their intellectually disabled children mothers focused primarily on issues of safety/vulnerability and appropriate/inappropriate behaviour. Limited opportunities for young people with ID to develop more intimate relationships was another reason why some mothers felt it unnecessary to talk about sexual health. In general, some mothers expressed a lack of confidence about discussing sexual matters with their children, and described feeling fearful, anxious and frustrated. However, these emotions were of greater frequency and intensity when discussing their child with ID.

Conclusions: These insights into mothers' views about their offspring's sexuality highlights the sensitive support families require, and the need for schools, colleges and health professionals to work more effectively in partnership with them.

Coping with bereavement

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Background: Individuals with Down syndrome and a congenital heart condition have considerable health needs, and as a result their parents may be more likely to experience the death of a child. Research investigating the impact of avoidance and problem focused coping on grief typically suggests that avoidance behaviors predict poor long-term adjustment for bereaved individuals, while problem focused coping

and seeking social support are beneficial (Bonanno, Papa, Lalande, Zhang, & Noll, 2005; Hays, Kasl, & Jacobs, 1994).

Methods: Measures of grief, and coping strategies were completed by 38 mothers whose child with Down syndrome and a congenital heart condition had died.

Results: Mothers' reported symptoms of grief up to 23 years after the death of their child, and mothers' reports of grief were unrelated to the age of the mother or child, or the child's gender. A factor analysis (Hastings et al., 2005) has shown that the Brief COPE (Carver, 1997) captures four coping dimensions for parents of children with developmental disabilities: problem-focused, active avoidance; religious/denial; and positive coping. In the current sample mothers who had higher grief scores reported more frequent use of active avoidance coping strategies, and religious/denial coping. In addition a negative relationship between positive coping and grief approached significance ($p= 0.55$).

Conclusions: Findings are discussed in terms of individual coping items, possible explanations for grief intensity, and implications for interventions aimed specifically at this group.

Creating a message and building a change

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Background: This paper describes the application of a team-based technology-mediated learning model to a workshop entitled “Creating a Message and Building a Change”, implemented by the National Institute for Intellectual Disability and the Bridge to College Programme at Trinity College Dublin. Participants engaged in a series of creative project-based activities to explore ways of using multimedia to promote the voice and ideas of people with disabilities.

Methods: The workshop involved 28 participants, of which 15 had an intellectual disability. A group-based pedagogy was followed throughout, with teams made up of a mixture of intellectually disabled and non-disabled participants. An empirical evaluation was undertaken to examine to what extent the workshop was successful in: 1) facilitating the participants’ expression of opinions and ideas through the creative use of multimedia and 2) providing an inclusive and innovative learning environment in order to promote personal development.

Results: Results of the evaluation suggest that the workshop inspired participants to continue to use media to portray their ideas and promote disabilities in the future. The data also strongly points to the efficacy of the team-based model in its affordance of peer-supported and self-directed development, mediated by creative use of technology.

Conclusions: It is apparent that a team-based technology-mediated learning model affords a high degree of inclusivity and maximises the learning opportunity for all. Its application in the field of social inclusion merits further investigation. The participants’ creative work output indicates the potential of multimedia to empower every individual to communicate their opinions and ideas. Public displays of the work produced and formal linkages to broadcasting and communications companies merit further exploration.

A comparison of residential arrangements for adults with intellectual disability in Hungary

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Background: Reviews of research provided evidence of the benefits of deinstitutionalization and community living for people with intellectual disabilities. Studies in these reviews came mainly from the UK, the USA and Australia where community-based services are the most common type of residential support for people with intellectual disabilities. However, many countries still rely on large institutions in the provision of services for people with disabilities. There is a gap in our understanding of residential supports for people with intellectual disabilities in other geographical areas and socio-economic contexts. This study aims to explore the outcomes of different types of residential arrangements for people with an intellectual disability in Hungary.

Methods: Random samples of 15 services and 120 service users were selected to participate in the study. Services completed measures including the Short Adaptive Behaviour Scale, the Aberrant Behaviour Scale, the Index of Community Involvement, Index of Participation in Domestic Life and the Choice-making Scale. Observational measures were completed at site visits.

Results: Confirm that smaller scale living arrangements are superior to institutions and institutions are inherently inadequate to provide a good quality of life for people with intellectual disabilities. Participants in smaller, independent provision: enjoyed more activities in the community; participated more in domestic activities; received better support from staff; spent more time engaged in meaningful activities and relationships.

Conclusions: Results are compared to findings elsewhere. The implications of the results are discussed for deinstitutionalisation and community living.

Parents of children with autism choosing to implement an EIBI program

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Background: Although children with autism have been known to receive early intensive behavioral intervention (EIBI) for decades, very little is known about the process parents go through before they decide to implement such a program.

Methods: We interviewed 30 mothers whose children had been on a home EIBI program for approximately 2 years and asked them about their sources of information concerning the intervention, the reason for choosing to implement it, their expectations prior to the beginning of the program and the procedure of accessing EIBI services. The semi-structured interviews were analyzed using content analysis procedures.

Results: Mothers were informed about EIBI mostly through other parents, books and the internet. The most common reason for choosing the intervention was the evidence of its being an effective method for children with autism. Expectations ranged from the child being cured of autism and indistinguishable from peers to not knowing what to expect. Accessing services and funding was relatively easy for some of the participants whose programs were supported by the local educational authorities (LEAs), whereas other families had to pay themselves for part or the whole program, or received funding after a long dispute with the LEAs.

Conclusions: The implications of the findings for professionals who are involved with young children with autism and their families are discussed.

Identifying child and family characteristics associated with challenging behaviour in children with severe intellectual disability and/or autism

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Background: Challenging behaviour has a negative impact on the lives of individuals with intellectual disabilities and their families as well as significant economic implications for the NHS. This study aimed to replicate and extend a previous study investigating putative risk markers for challenging behaviour in children with severe intellectual disability (SID) and/or autism through the development of a brief screen. Child and family characteristics that are associated with challenging behaviour in SID were investigated.

Methods: Parents/ guardians completed screening questionnaires on 130 children aged between 2 and 12 years. Items in the screening questionnaires assessed potential risk markers including child characteristics (diagnoses, presence of health problems, overactive, impulsive, repetitive and obsessional behaviours) and family characteristics (parental perceptions of efficacy and stress).

Results: Children demonstrating destructive and/or self-injurious behaviour showed significantly higher levels of overactive and impulsive behaviours than those who did not show these topographies of challenging behaviour. Parents of children demonstrating aggressive and/ or self-injurious behaviour reported significantly higher levels of stress and lower levels of parental self-efficacy than parents of children who did not show challenging behaviours.

Conclusions: These results will be discussed in relation to previously supported risk markers for challenging behaviour in SID and the bidirectional relationship between challenging behaviour and parent characteristics.

Developing measures of the effects of trauma on people with intellectual disabilities

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Background: Measures of the effects of trauma for people with intellectual disabilities have recently been developed called the Lancaster and Northgate Trauma Scales (LANTS). The LANTS have been used in a prospective study of the putative causal relationship between adverse life events and trauma.

Methods: Data were collected from 84 service users and 66 informants at Time 1 and 6 months later at Time 2. Self report and informant data were collected regarding adverse life events using the Bangor Life Events Schedules, trauma using the LANTS measures, and social support using a measure devised for this study.

Results: The relationships between the variables were explored using logistic regression. The independent variable responsible for most of the variability in the regression equation and most significantly predictive of Time 1 self-report and informant trauma effects was Time 1 life events. The independent variable responsible for most of the variability in the regression equation and most significantly predictive of self-report and informant trauma effects measured at Time 2 was Time 2 life events. Social support did not mediate the relationship between life events and trauma (as measured on both the self-report and informant LANTS) and there were no significant interaction effects between life events and social support.

Conclusions: The findings indicated that life events during the previous 6 months predicted changes in trauma effects as measured by the self-report and informant LANTS. Evidence for the putative causal relationship between adverse life events and trauma has been created in this study using the new LANTS measures.

Knowledge of Mental Capacity Issues in Community Teams for Adults with Learning Disabilities

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Background: The Mental Capacity Act (2005) has been in force since 2007, but there is very little information about how well it has been assimilated by services. The aim of this study was to evaluate the state of knowledge of mental capacity issues among health and social services professionals working in community teams supporting people with learning disabilities.

Methods: A structured interview was constructed around three scenarios, based on actual cases, concerning a financial/legal issue, a health issue and a relationships issue, as well as a set of ten "true/false" statements. The interview aimed to elicit respondents' understanding in relation, primarily, to assessment of capacity and best-interests decision-making. Forty interviews were conducted (two social workers and two health professionals from each of ten community teams).

Results: Performance of social services and health staff was similar throughout. Fourteen areas of concern were identified where there appeared to be significant gaps in knowledge. Participants, particularly those who had experience of dealing with mental capacity issues, had good insight into the extent of their knowledge, and most participants said that the interview had made them aware of further training needs.

Conclusions: Knowledge of mental capacity issues is still very poor within community teams. There remain significant training needs.

