

**13th Seattle Cub Conference Program
UDID@Cardiff**

Monday 9th December, 2013
Registration and Coffee: 09.50-10.20

Welcome: 10.20-10.30 Stuart Todd

Session One: 10.30-12.25pm

Session Chair: Stuart Todd

10.30-10.55 The Adapted Thinking Skills Programme: content and findings, **Glynis Murphy**, Alison Giraud Sanders and Nzinga Akinshegun

10.55-11.20 Parental overprotection and social anxiety in young adults with and without intellectual disabilities **Cahley Hemm**, Thomas Meyer and Dave Dagnan

11.20-11.45 Measuring health and stress in children with intellectual disabilities, **Sally-Ann Cooper**, Filippo Queirazza, Eva Kocovska, Alison Rennie, Helen Minnis, Jonathan Cavanagh

11.45-12.10 What counts as comprehension? Analysing video data of sex and relationships education for people with intellectual disabilities, **Mick Finlay** and Paul Rohleder

Lunch: 12.10-13.00

Keynote Presentation: 13.00-13.50

Session Chair: Andrew Jahoda

The Confidential Inquiry (CI) into the premature deaths of people with intellectual disabilities in England.

Dr Pauline Heslop
Norah Fry Research Centre
University of Bristol

Session 2: 14.00-15.15

Session Chair: Jane Bernal

14.00-14.25 Factors that affect the safety of patients with learning disabilities in NHS hospitals: emerging findings from a multi-method study **Irene Tuffrey-Wijne**,

14.25-14.50 Using genetic knowledge to improve the health and wellbeing of adults with neurodevelopmental syndromes: views from genetic syndrome support groups and parents. **Marcus Redley**, Merel Pannebakker and Anthony Holland

14.50-15.15 The medication use process & people with intellectual disabilities, **Bernadette Flood** and Martin Henman

Coffee/Tea 15.15-15.35

Session 3: 15.15-16.50

Session Chair: Steve Beyer

15.35-16.00 A mixed methods study of bullying within a residential service for adults with behaviours that challenge **John F Flood**, Garret McDermott and Marelise Spies

16.00-16.25 Domestic violence against women with learning disabilities **Siobhan Hunt**, Michelle McCarthy and Karen Milne-Skillman

16.25-16.50 Living in Fear: Experiences and reporting of Disability Hate Crime: 'I am scared to go outside and people start picking on me for no bloody reason' **Jill Bradshaw**, Lisa Richardson, Julie- Beadle-Brown, Colin Guest, Aida Maolvic and Julian Himmerich

18.00-19.00 Poster Session

19.30 Dinner

Tuesday 10th December

Discussion Session : 09.15-0945

Chair Richard Hastings

'Discussion on the nature and future direction of the Seattle Club' led by Glynis Murphy

Session 4

9.45-10.05 Teaching young adults with Intellectual Disabilities about early attachment behaviours using a DVD, **Tanya Pearson** and Alison McGarry

10.05-10.25 Computerised training as a primer for assessing cognitive mediation skills in people with intellectual disabilities, **Leen Vereenoghe** and Peter E Langdon

10.25-10.45 The relationship between the executive function profile in Cornelia de Lange syndrome and repetitive behaviour and restricted interests, **Victoria Johnson**, Joanna Moss, Jane Waite, Jane Waite, Kate Eden and Chris Oliver

Coffee/Tea 10.45-11.15

Session 5: 11.15-12.30

Session Chair: Chris Oliver

11.15-11.40 Child and family social workers' experiences of working with parents with intellectual disabilities, **Claire Lewis** and Biza Stenfert Kroese

11.40-12.05 Results of a national staff survey about access to IAPT for people with learning disabilities, **Deborah Chinn**, Christine Burke and Elisabeth Abraham

12.05-12.30 Implicit attitudes towards individuals with intellectual disabilities: Their relationship with explicit attitudes, social distance, emotions and contact **Michelle Wilson** and Katrina Scior

Lunch: 12.30 – 1.20

Session 6: 1.20-2.35

Session Chair: Chris Hatton

1.20-1.45 Psychological treatment for sleep problems in adults with intellectual disabilities, **Paraskevi Triantafyllopoulou**, Glynis Murphy and Peter McGill

1.45-2.10 A Q-methodology study of the attitudes and beliefs of clinical psychologists about genetic research and IDD, **Dougal Julian Hare**, Catherine Vahey, Anja Wittkowski and Samantha Walker

2.10-2.35 Self-injury in Rett Syndrome, **David Felce** and Rina Cianfaglione

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Closing Comments: 2.35-2.45

Conference Closes/Coffee

Abstracts (Oral presentations)

Keynote presentation: The Confidential Inquiry into the premature deaths of people with intellectual disabilities in England **Dr Pauline Heslop**

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In 2010 the Department of Health funded a Confidential Inquiry (CI) into the premature deaths of people with intellectual disabilities in England. The principal aim was to establish the extent to which people with intellectual disabilities die prematurely and to detect potentially modifiable contributory factors to premature deaths.

The CI investigated the deaths of all people with intellectual disabilities (aged 4 years and older) who died over a two-year period (2010 -2012) and had been living in an area of South West England. Each case was reviewed by a CI investigator who examined case notes and reports, interviewed professionals and formal carers, and conducted a Root Cause Analysis into the death. ID nurses conducted interviews with family members, and friends/informal carers. Investigation findings were presented at a Local Review Panel meeting attended by professionals who had been involved in supporting the person who had died. The focus of the meeting was to identify what lessons could be learned, evidence of good practice, and recommendations for future care. All case reviews were then scrutinised by a multidisciplinary Overview Panel.

The CI reviewed the deaths of 247 people with intellectual disabilities, approximately 2½ times the number expected. Their median age of death (65 years for men; 63 years for women) was significantly less than for the UK population (78 years for men and 83 years for women). Almost a quarter (22%) of people with intellectual disabilities were under the age of 50 when they died compared to 9% in the general population. Over a third (37%) of the deaths reviewed by the CI met the Office for National Statistics' criteria of avoidable deaths that were amenable to good quality healthcare. The most common issues identified in relation to premature deaths were delays or problems with diagnosis or treatment.

Future mortality reviews should be multi-agency, and need to go beyond desk-top reviews to include discussions with practitioners and family carers. Each person involved in the life of an individual holds different information and a different perspective. From bringing all of these together, the CI concluded that the quality and effectiveness of health and social care given to people with intellectual disabilities was deficient in a number of ways. However it was also able to identify what had worked well for some individuals. The CI made 18 key recommendations which, were they individually and collectively implemented, could lessen the risk of premature death in people with intellectual disabilities.

Session 1

Glynis Murphy g.h.murphy@kent.ac.uk, Alison Giraud Sanders, Peter Oakes and Nzinga Akinshegun

Title: The Adapted Thinking Skills Programme: content and findings

Background: There have been long-term inequities for people with learning disabilities who are convicted offenders in prison in the UK. Very few NOMS accredited treatment programmes (apart from the adapted SOTP) are available for people with IQs in the learning disabilities range.

Methods: The aim of the project was to test the feasibility of adapting the NOMS Thinking Skills Programme for delivery to offenders excluded from mainstream programmes. In the adapted version, the current 3-module structure (self-control; problem-solving; relationships) of the NOMS Thinking Skills Programme has been maintained but the modules have been lengthened and the content simplified. The evaluation included interviews and focus groups with stakeholders, programme managers, programme facilitators and the offenders themselves. In addition each offender was assessed on the Locus of Control scale and the Problem Solving Measure (Goodman et al, 2007) before and after the end of the programme.

Results: The pilot programme was delivered in three prisons in the North East and North West, to 24 prisoners (8 per group). The programme was favourably received by the delivery team and the offenders. The pre-group to post-group changes in the offenders Locus of Control scores and (some of) the Problem Solving Measure scores were significant ($p < 0.05$).

Conclusions: The initial findings appear to support the feasibility of adapting the current NOMS Thinking Skills Programme for delivery to offenders with learning disabilities. Further discussions with NOMS and their accrediting body (CSAAP) are now taking place to decide on the future of adapted TSP.

Cahley Hemm cshemm@hotmail.com Thomas Meyer and Dave Dagnan

Parental overprotection and social anxiety in young adults with and without intellectual disabilities

Background: Up to 22% of young people with Intellectual Disabilities (ID) may experience anxiety disorders; there is growing interest in specific presentations such as social anxiety (SA). Literature amongst non-intellectually disabled (non-ID) populations highlights parental overprotection as a developmental factor thought to be related to the development of SA. It is suspected that this could be more prominent in the lives of people with IDs.

Methods: Twenty-one people without ID and twenty-one individuals with IDs aged 16-24 were recruited. Participants completed the Social Anxiety Scale for Adolescents (SAS-A) with follow-up questions to explore the qualitative experience of social anxiety, the Glasgow Anxiety Scale-ID (GAS-ID) and the parental

overprotection subscale of the Parental Bonding Instrument (PBI) with follow-up questions to explore the qualitative experience of parental protection.

Results: General and Social Anxiety were reported more often by those with IDs than their peers without ID. There was no significant difference in scores on the PBI between groups; however we report qualitative differences in the experience of social anxiety and parental protection. There was a significant relationship found between scores for parental protection with subscales of the GAS-ID and the Fear of Negative Evaluation subscale of the SAS-A, within the ID group.

Conclusions: This exploratory research highlights the potential vulnerability of individuals with IDs to SA due to both social and developmental factors. The results are discussed within the context of informing approaches to psychological therapy.

Sally-Ann Cooper, Sally-Ann.Cooper@Glasgow.ac.uk Filippo Queirazza, Eva Kocovska, Alison Rennie, Helen Minnis, Jonathan Cavanagh.

Measuring health and stress in children with intellectual disabilities

Aim Intellectual level is related to mental health outcomes even when adjusted for potential confounders. “Allostatic load” is a composite measure of physiological stress (physiological “wear and tear”), and may mediate some of these associations. Recently, such adult investigations have been extended into studies in childhood, however, this has not yet been studied in children with intellectual disabilities, despite their higher levels of mental ill-health and stressful experiences. The aim of this study is therefore to study markers of allostatic load in children with intellectual disabilities, and whether they relate to measures of mental health.

Methods Individual interviews with 48 children/parents with intellectual disabilities using the Developmental Behaviour Checklist and Strengths and Difficulties Questionnaire, and analyses of blood samples for inflammatory and metabolic markers of allostatic load. An allostatic load index was constructed. The distribution of scores is examined, and correlations sought.

Results 48 children/parents were recruited and interviewed, and 36 blood samples collected and analysed. The results show interesting correlations between the interview and biological measures.

Conclusions This is a highly novel area of research. Importantly, in children of average ability, early interventions have been found to improve mental health outcomes and such stress markers. We will present findings from this preliminary investigation of the extent to which these lines of enquiry may be fruitful for children with intellectual disabilities.

Mick Finlay mick.finlay@anglia.ac.uk Poul Rohleder

What counts as comprehension? Analysing video data of sex and relationships education for people with intellectual disabilities

Background: Effective sex and relationships education is valuable in many ways. However, provision of sex and relationships education to people with intellectual disabilities involves addressing complex issues of language and comprehension. This paper reports an exploratory qualitative study examining the delivery of sex education to young people with intellectual disabilities.

Methods: Video-recordings of four sex education group sessions were collected (three in a school and one in a youth club). Conversation analysis was used to examine in detail where comprehension problems arose and how these were, and were not, resolved. Interviews with educators (four) and parents (three) were also carried out and analysed using thematic analysis.

Results: Educators and facilitators face a pervasive practical problem: how to anticipate problems of comprehension and how to respond when there is evidence that a person does not understand the activity or the educational message. Problems occurred particularly with verbal activities, abstract concepts, and ambiguous materials. Efforts to resolve the problems often produced a superficial resolution which allowed the group to move to the next activity. Parent/teacher models of comprehension were such as to justify such resolution strategies.

Conclusions: While interviews can allow us insight into contextual issues, strategy, and aspects of sex education which occur outside of the actual teaching sessions, analysis of actual interactions can show us patterns which occur in interactions between educators and learners when comprehension is at issue. Addressing how sex education is delivered in practice and in detail provides valuable lessons about how such education can be delivered more effectively.

Session 2

Irene Tuffrey-Wijne ituffrey@sgul.ac.uk

Factors that affect the safety of patients with learning disabilities in NHS hospitals: findings from a multi-method study

Background: There has been consistent evidence that people with learning disabilities experience health inequalities and poor NHS healthcare provision, leading to avoidable harm and premature, avoidable death. This study aimed to identify the factors that have been barriers and enablers in implementing patient safety measures for patients with learning disabilities in NHS hospitals.

Methods: This was a 21 month study (2011-2013). Data were collected in six NHS hospitals in England, as follows: assessment of policies and procedures; questionnaires to staff (n=990) and carers (n=88); interviews with hospital staff including senior managers, nurses and doctors (n=77), carers (n=37) and people with learning disabilities (n=31); observation of patients with learning disabilities on the wards (n=8); monitoring of incidents involving patients with learning disabilities.

Results: (a) Where safety of patients with learning disabilities is compromised, it is mostly because of delays and omissions of care and treatment. (b) Acute Trusts currently lack effective systems to identify patients with learning disabilities. (c) Involving carers as experts improves patient safety, but support for carers is

haphazard; there is a lack of protocols for shared care. (d) Ward managers, matrons and Learning Disability Liaison Nurses (LDLN) are well placed to ensure that reasonable adjustments are made.

Conclusions: The vulnerabilities of people with learning disabilities lead to compromised safety in NHS hospitals. Further research should include: identifying the most frequently needed reasonable adjustments within the hospital pathways of people with learning disabilities, and their cost implications; and investigating effective ways of flagging patients with learning disabilities across and within NHS services.

Marcus Redley mr382@medschl.cam.ac.uk Merel Pannebakker and Anthony

Using genetic knowledge to improve the health and wellbeing of adults with neurodevelopmental syndromes

Background: Advances in medical genetics herald the possibility of health and social care services being more responsive to people's genotypes. This is perhaps particularly important for those men and women whose learning disability (known internationally as intellectual disability) is linked to a neurodevelopmental condition. An appreciation of this population's physical and behavioural phenotype could radically change the provision of both health and social care.

Methods: With this prospect in mind, interviews were conducted with samples of: opinion formers, persons with nationally recognised clinical and/or academic interests in learning disabilities and genetics; representatives of syndrome organisations that specifically promote the interests of families where a member has a neurodevelopmental condition, and parent-members of these same organisations.

Results: These interviews suggest there is widespread support for services giving greater attention to people's genetic conditions; the importance of integrated health and social care services for people with genetic syndromes, and that the prominence parents give to a son or daughter's neurodevelopmental condition changes, as that child becomes an adult.

Conclusions: This paper, reflecting on many people's fears of eugenics and concerns over the inappropriate medicalisation of people with disabilities, concludes by suggesting that the beneficence of the healthcare profession should be more widely recognised.

Bernadette Flood beflood@tcd.ie Martin Henman

The medication use process and people with intellectual disabilities

Background: People with intellectual disability experience inequalities in health and healthcare. They and their carers know the complexity of their needs. Medication

use is a major therapeutic intervention in this vulnerable population and can be of varying quality.

Methods: The researcher, who is a practising pharmacist interviewed six people with Down Syndrome who consented to participate in this project, which aimed to establish their views and knowledge of medication use. Grounded Theory methodology was used. Ethics approval was received from the university research ethics committee. The project was facilitated by a national support organisation.

Results: People with intellectual disabilities face many challenges when perceiving and coping with illness and medication use. Health literacy in relation to medication use can be seen as a "systems issue" which can reflect the complexity of the health information accessible to people with intellectual disabilities. Good communication between healthcare professionals is required to ensure that a fragmented medication use process does not occur.

Conclusions: Health systems must be designed with the person at the centre of the design process. Individuals with intellectual disabilities must have their needs in relation to medication use met appropriately across all healthcare locations. Effective adjustments must be made to take account of individual intellectual and physical disabilities and behaviour difficulties. Family and professional caregivers want to provide person-centered care for people with intellectual disabilities but are often hindered by a conflict between protecting a person's health and at the same time respecting autonomy.

Session 3

John F Flood floodjo@tcd.ie Garret McDermott and Marelise Spies

A mixed methods study of bullying within a residential service for adults with behaviours that challenge

Background: To examine the prevalence and nature of bullying within a residential service for individuals with intellectual disability and behaviours that challenge

Methods: Key workers in the service completed a survey assessing clients (N=62) bullying behaviours and experience of victimisation. Clients were subsequently categorised as victims, bullies, bully-victims and bystanders. Semi structured interviews were conducted with seven clients, purposely sampled, to explore their perception and experience of bullying, and to gain a richer, contextualised understanding. Data was analysed using a phenomenological informed descriptive-interpretive approach.

Results: A high prevalence of bullying, and bully-victims, were reported. Qualitative analysis identified three domains encompassing: client's construction of bullying, types of bullying experienced, and its perceived impact and aetiology.

Conclusions: Findings indicate that clients in residential services for people with an intellectual disability are at an increased risk for bullying and victimisation, which negatively impacts on psychological and social wellbeing. Participants perceived bullying as arising from multiple causes including psychological distress, malicious intent and a restrictive environment. Results are discussed in terms of the need for tailored anti-bullying interventions, and the promotion of trauma-informed and person centered care.

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Michelle McCarthy and Karen Milne-Skillman

Domestic violence against women with learning disabilities

Background: Domestic violence against women is a common social phenomenon, with profound implications for the individuals concerned, as well as wider social consequences. There is a huge body of evidence regarding domestic violence in the general population and to a lesser extent with women with physical and sensory impairments. However, little or nothing is known about the experiences of women with learning disabilities in relation to domestic violence. This research project seeks to redress that imbalance.

Methods: Focus/advisory groups of women with learning disabilities to help us shape the research questions; Semi-structured in depth interviews approx. 20 women with learning disabilities who have experienced domestic violence. National survey professionals (police, domestic violence workers, adult safeguarding specialists, advocates, etc.) Interviews of key professionals where possible. Results To date 12 interviews and 3 focus groups with women with learning disabilities have taken place. Preliminary analysis of the data suggestions the following emerging themes: Severity of the domestic violence, Troubled family histories of the women; Tight-knit / enmeshed nature of family and community relationships; and Violent partners rarely have learning disabilities, but do have other problems.

Conclusions: The early data suggest that women with learning disabilities experience domestic violence in the same ways as other women, but that their additional vulnerabilities mean they need skilled support in both the domestic violence and the learning disability fields.

Jill Bradshaw j.bradshaw@kent.ac.uk Lisa Richardson, Julie- Beadle-Brown, Colin Guest, Aida Maolvic and Julian Himmerich

Living in Fear: Experiences and reporting of Disability Hate Crime:~I am scared to go outside and people start picking on me for no bloody reason'

Background: Public enquiries and the Equality and Human Rights Commission have highlighted disabled people's experiences of victimisation and in particular, disability hate crime (DHC). However, there is scant research in this area.

Methods: Individuals experiences of victimisation, reporting of incidents and the impact on their quality of life (QoL) were explored in: focus groups with people with intellectual and developmental disabilities (PwIDD) and with carers, a postal survey (n=255), and 27 individual interviews.

Results: Just under half of survey respondents (46%) told us they had been victimised. This group were younger and more likely to report mental health difficulties. Multiple incidents were common. Those without experiences were more often living in supported accommodation or in receipt of staff support. Experiences were not always reported and satisfaction and views of the Police were mixed. The impact of victimisation is vast with the onus on PwIDD to change their behaviour.

Conclusions: The resilience of people should be remarked upon. People were on the whole, getting on with their lives, sometimes having made adjustments to limit contact with potential perpetrators. For some participants, an acceptance that 'bad things were part of their lives and to some extent' to be expected' may have made it difficult to discover whether or not they saw the bad thing as being as a result of their ID.

Session 4

Victoria Johnson vxj757@bham.ac.uk Joanna Moss
Jane Waite, Laurie Powis, Kate Eden and Chris Oliver

The relationship between the executive function profile in Cornelia de Lange syndrome and repetitive behaviour and restricted interests.

Background: It has been suggested that repetitive behaviour in autism spectrum disorder (ASD) could be accounted for by deficits in executive function (EF). Given the high levels of repetitive behaviour in Cornelia de Lange syndrome (CdLS) and the associations with ASD, this study examined the profile of EF and its relationship with ASD symptomatology in CdLS.

Methods: The parents/carers of children and adults aged 5 to 47 years with CdLS (N=25; Mage 18.60) ASD (N=25; Mage= 18.52) fragile X (FXS) (N=25; Mage= 18.48) and Rubinstein-Taybi syndromes (RTS) (N= 25; Mage= 18.60) completed the Behaviour Rating Inventory of Executive Function-Preschool Version (BRIEF-P) and the Social Communication Questionnaire (SCQ).

Results: All participant groups had higher BRIEF-P scores than a typically developing cohort, indicating executive function impairments. No significant differences were found across participant groups in BRIEF-P profiles. Significant positive correlations were found between the SCQ repetitive behaviour subscale and BRIEF-P subscales of: inhibition (CdLS, FXS, $p<.01$), working memory (RTS, FXS; $p<.01$) shifting and emotional control (FXS; $p<.01$). No significant correlations were found in ASD between BRIEF-P and SCQ subscales.

Conclusions: Results suggest high levels of executive dysfunction in CdLS, FXS and RTS, similar to those seen in ASD. The results do not support the EF theory of repetitive behaviour in ASD but do provide tentative evidence for this account of repetitive behaviour in CdLS, RTS and FXS. The next step for this research is to

provide complementary evidence to the BRIEF-P data using direct measures of executive function to separate the components of EF more effectively.

Leen Vereenooghe L.Vereenooghe@uea.ac.uk Peter E Langdon

Computerised training as a primer for assessing cognitive mediation skills in people with intellectual disabilities

Background: The aim of this study was to evaluate a computerised assessment of cognitive behavioural therapy (CBT) skills, and cognitive mediation skills for people with intellectual disabilities (IDs). Additionally, the effects of training in linking situations to feelings and the subsequent impact upon cognitive mediation skills were evaluated and compared to a control group.

Methods: A randomised experimental design was used to evaluate the effects of training on cognitive mediation skills. Blind computerised assessment of cognitive mediation skills was conducted at pre-test and post-test. Assessments consisted of scenarios based on situation, inferential belief, and emotion components.

Results: Sixty-five participants recruited from local day services completed the study. Linking beliefs to situation feeling pairs was found to be more difficult than linking emotions to situation belief

pairs. Likewise, performance in the training group was higher when selecting an emotional consequence to a situation than when selecting the activating event for an emotion. Regression analysis showed that pre-test performance, verbal ability and intervention all predicted post-test performance for cognitive medication involving situation belief pairs, whereas no significant predictors were found for cognitive mediation involving situation emotion pairs.

Conclusions: : People with IDs show a degree of understanding of cognitive mediation and training can further improve some aspects of cognitive mediation skills. Computerised assessments and training are feasible and potentially increase CBT accessibility for people with IDs.

Tanya Pearson tanya.pearson@hotmail.co.uk Alison McGarry

Teaching young adults with Intellectual Disabilities about early attachment behaviours using a DVD

Background: There has been no research exploring knowledge of attachment behaviour between parents and infants in young adults with ID despite previous acknowledgement that research in this area was needed (Tymchuk & Feldman, 1991).

Methods: Using a within-subjects research design, sixteen participants with ID took part in three conditions: pre-intervention, post-intervention and follow up. The intervention comprised an adapted Attachment in Practice DVD (Siren Films, 2009) and a booklet summarising the content of the DVD. Knowledge of attachment

behaviour was measured using seven semi-structured interview questions developed by the authors.

Results: A paired t test showed that a significant increase in mean knowledge scores was observed across the group after the DVD had been presented ($t_{15} = 2.75$; $p = 0.015$). Of the sixteen participants, a third showed either no change or some deterioration, and two thirds showed either some or substantial improvement at post-intervention. A paired t test showed that a non-significant increase in knowledge scores was observed between the pre-intervention condition and follow up ($t = 1.82$, $p = 0.09$). Difference between the pre-intervention and follow-up percentile scores showed that over half of all participants demonstrated either no change or some deterioration in knowledge and just under half showed either substantial improvement or some improvement.

Conclusions: The findings offer empirical support that young adults with ID can be taught about attachment behaviours between parents and infants using a DVD. However, the results must be interpreted within the context of the methodological limitations of this study. Future research and clinical implications are discussed.

Session 5

Claire Lewis clairelewis3@hotmail.co.uk Biza Stenfert Kroese

Child and family social workers' experiences of working with parents with intellectual disabilities

Background: An increasing number of adults with an intellectual disability (ID) are having children. Research evidence suggests that they face an increased risk of being subject to care proceedings and having their children removed. Although parenting interventions can be effective for parents with ID, such services are rarely offered. Decision making in child and family social work is thought to be influenced by social workers' subjective experiences of clients. As such, it was thought that exploring social workers' experiences of parents with ID might enable a greater understanding of why parents with ID face an increased risk of losing custody of their children.

Methods: Semi-structured interviews were carried out with seven child and family social workers who had experience of working on safeguarding cases where at least one parent had an ID. They were asked to reflect on a particular case they had worked on. Interviews were audio recorded and transcribed, and the data were analysed using Interpretive Phenomenological Analysis. Themes were identified within and then across transcripts.

Results: Five super-ordinate themes were identified. These were: 'feeling torn' between parents and their children; experiencing a 'power imbalance' between themselves, 'parents and the local authority'; feeling 'hopeless'; having a sense of 'pride' in their work; and experiencing 'barriers'.

Conclusions: The results are discussed in the context of the increased risk that parents with ID face of losing custody of their children. Recommendations are made regarding clinical practice and future research in this area.

Deborah Chinn deborah.chinn@kcl.ac.uk Elisabeth Abraham

Title: Results of a survey into access to IAPT for people with learning disabilities in England

Background: Decades of research has demonstrated that many pwld (people with learning disabilities) can benefit from talking therapies. Within mainstream provision the IAPT (Improving Access to Psychological Therapies) programme aims to offer timely psychological support to people experiencing common mental health problems. In 2009 the IAPT taskforce produced guidance advising how IAPT services can make "reasonable adjustments" for pwld. This study aimed to evaluate the response of IAPT services to the challenge of including learning disabled clients.

Methods: Semi-structured interviews with specialist learning disability and IAPT staff, service users and carers informed the design of an online questionnaire. The questionnaire was sent to all IAPT services and learning disability services in England. Results: 452 valid responses were received, with approximately equal numbers of learning disability specialists and IAPT staff.

Results suggested that many IAPT staff feel positive about the value of IAPT input for pwld. Learning disability staff are less confident that pwld will receive a good service from IAPT and many report negative experiences of making referrals. Many respondents acknowledged the unsuitability of IAPT materials and measures for pwld. The results also highlighted the need for better communication between services and the importance of training so that all IAPT staff can adapt their skills for pwld.

Conclusions: Support for pwld to access mainstream talking therapies is not consistent across the country, despite the commitment of staff in all sectors to principles of equal access. Although there are many examples of good practice in joint working, clearer guidance and directives are needed from commissioners and service managers.

Michelle Wilson shell_wilson@hotmail.co.uk and Katrina Scior

Implicit attitudes towards individuals with intellectual disabilities: Their relationship with explicit attitudes, social distance, emotions and contact

Background: Implicit attitude research has expanded rapidly over the last decade with the investigation of attitudes towards various social groups has been helpfully expanded on by it. Implicit attitude measures have helped counter biases such as social desirability. Most research in the area of intellectual disabilities (ID) has focused on explicit attitudes alone. This study examined implicit attitudes to ID and also examined their association with emotional reactions and contact, which have previously been found to have a significant influence on attitudes and stigma.

Methods: A web-based study was carried out whereby lay people in the UK completed a Single Target Implicit Association Test, as well as measures of explicit

attitudes, and desire for social distance, emotional reactions towards and contact with individuals with ID.

Results: Implicit attitudes were not significantly associated with explicit attitudes, social distance or emotional reactions. Instead there were small to moderate associations between emotional reactions and explicit attitudes and social distance. Implicit attitudes did not vary according to participants reported level of contact with individuals with ID, type of relationship (voluntary versus involuntary), gender or educational attainment. There were however some differences in explicit attitudes and social distance according to these participant characteristics.

Conclusions: Implicit attitudes held towards individuals with ID are somewhat negative and, unlike explicit attitudes and stigma, do not vary according to participant demographics or frequency of contact. Such attitudes may have a negative impact on the lives of people with ID. As such effective interventions to improve implicit lay attitudes should be identified.

Session 6

Paraskevi Triantafyllopoulou pt200@kent.ac.uk Glynis Murphy and Peter McGill

Psychological treatment for sleep problems in adults with intellectual disabilities.

Background: Sleep is a very important aspect of health and sleep deprivation can affect an individuals' physical and cognitive abilities. Past research has shown that children and adults with ID do experience more sleep problems and difficulties than the general population. The majority of sleep treatment focuses on medication for adults with ID, leaving a gap in the literature for randomised controlled trials looking at the effectiveness of psychological sleep treatment. Therefore, the aim of the current study was to assess the efficacy of psychological sleep treatment for severe sleep disorders in adults with ID and to assess changes in the adults' daytime behaviour in relation to such treatment.

Methods: 64 adults with ID and their carers agreed to take part in the study and individuals were randomly allocated to the treatment (n=30) or the control group (n=34). Sleep was assessed using both objective (e.g. actigraphy) and subjective (e.g. sleep diaries) measures and the individuals' behaviour and intellectual ability was assessed via the Aberrant Behaviour Checklist (Aman & Sing, 1986) and the Adaptive Behaviour Scale – Residential and Community (Nihira et al., 1993) respectively. The intervention included 4 group sessions where treatment techniques such as graduated extinction, sleep hygiene and relaxation exercises were discussed.

Results: No differences were found between the experimental and control groups, however, an improvement in sleep problems of initiating and maintaining sleep was shown for the total sample. Also significant correlations between the participants' sleep, intellectual ability and challenging behaviour were obtained. Finally the data gathered from staff members who took part in the study revealed a type III error and a failure of staff to implement interventions.

Conclusions: It would be worthwhile for future research to re-examine the methods of delivery of the training materials and also include some hands-on training for staff and use implementation assessments.

Dougal Julian Hare dougal.hare@manchester.ac.uk
Catherine Vahey, Anja Wittkowski and Samantha Walker
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A Q-methodology study of the attitudes and beliefs of clinical psychologists about genetic research and IDD

Background: The current study investigated the use of ideas and models from the 'New Genetics' and associated fields of developmental neuroscience and behavioural phenotypes by clinical psychologists working with people with IDD. As well as examining the influence and spread (or lack of) of such ideas, it also examined whether there are barriers, both personal and institutional, to the widespread adoption of such concepts and research findings in services for people with IDD.

Methods: A Q methodology study was undertaken with 31 qualified and 16 trainee clinical psychologists recruited from an LSD SIG and three university clinical psychology departments in the North West of England. An 81 item Q set was developed for the present study.

Results: In line with standard procedures for the analysis of Q sorts, three factors were extracted via principal components analysis and varimax rotation, which were labeled Integration of social and medical models (32% variance), Social model of disability is more helpful (26% variance) and Genetic advances in conflict with recognising the value of people with IDD (7% variance).

Conclusions: The current study delineated the lack of consensus amongst a range of clinical psychologists working with people with IDD, with amount and type of professional experience affecting the factor loadings. The varying attitudes of clinical psychologists towards the 'New Genetics', and the identified factors affecting them, should be considered in the practical application of developments from this field.

David Felce felce@cf.ac.uk Rina Cianfaglione

Title: Self-injury in Rett Syndrome

Background: Rett Syndrome (RTT) is a rare genetic condition affecting females usually associated with a mutation in MECP2 and characterized by developmental regression, gait apraxia, hand stereotypies and breathing abnormalities. Self-injurious behaviour (SIB) is not a diagnostic criterion for RTT but has been found to

occur in 48-73% of survey participants. The aim was to investigate the occurrence of SIB in RTT further using data from a recent UK sample.

Methods: The sample comprised 91 females, aged 4-47 years: 88% lived with family, 76% had classic RTT, 21% atypical RTT and 4% MECP2 related disorder, 78% were known to be MECP2 positive. Mean age of regression was 18.9 months (SD 11.8). Comparison was made to a control group with other genetic conditions (n=66), matched on gender, age and self-help skills. Measurement scales administered included the RTT Severity Score, Rett Syndrome Behavioural Questionnaire, Activity Questionnaire and Challenging Behaviour Questionnaire. A subsample (n=11) was directly observed.

Results: SIB was reported in 27.5% of participants. Those with SIB differed in severity of presentation and level of overactivity and impulsivity. SIB was more common among the control group (45.0%). SIB was observed in 6 of the subsample (54.5%). SIB occurred less frequently for 5 participants when they were receiving adult attention and sequential analysis suggested a possible attention seeking motivation in 3 of them.

Conclusions: Although reasonably frequent, SIB should not be considered as part of the RTT behavioural phenotype. It appears to be associated with factors similar to those found in investigations of SIB more generally.

Abstracts Poster presentations

Victoria Smillie, Christopher Philo, Sally-Ann Cooper

The Moving Landscapes of Learning Disability: residential mobility and decision-making for people with learning disabilities

Background: This PhD project aims to address the following questions:

1. What is the current pattern of residence for adults with intellectual disabilities?
2. Where have they lived previously?
3. How has the process of 'decision-making' affected residency patterns for adults with intellectual disabilities.
4. Who makes the decision regarding the timing and location of home moves, and what decision-making opportunities are available to adults with intellectual disabilities?
5. How does the opportunity to make decisions influence what makes adults with intellectual disabilities feel 'at home'?
6. How and why are connections made in the communities in which they live?

Methods:

1. Geographic Information Systems (GIS) will be used in order to visualise patterns with regards to where adults with intellectual disabilities live within the Greater Glasgow and Clyde region, and inferences from this e.g. proximity to services; types of accommodation, neighbourhood deprivation.

2. A brief purpose-designed questionnaire inquiring about residency and residential moves.
3. Interviews with people with learning disabilities, facilitated by family members/carers, on the subject of home.
4. Interview with family members/or carers, on some of the moves parents and carers have witnessed or made and their reasons behind residential moves or non-moves.
5. Intensive participative case-studies with a small number of adults with intellectual disabilities, to gather in-depth life stories about different residential situations in the past, at present, and looking to the future.

Results:

The data is currently being collected, so very preliminary data will be available. The study plans will be outlined.

Stuart Todd stuart.todd@southwales.ac.uk Sharon Branford, Glynnis Bennet, and Jane Bernal

The events at the end of life in ID care home: a exploratory study in New Zealand

Background: Many people with ID will die or begin the dying transition in ID care settings. These are settings for which there is considerable research evidence and knowledge in terms of their effectiveness in providing good quality of outcomes. Yet their functions and successes as places of death and dying, as well as life and living are much less known. The aim was to investigate the deaths of people with ID over a two year period to outline and examine the events of the last months of life of people with ID living in group home settings managed by a care provider in New Zealand.

Methods: Data were collected for all deaths that occurred within the service. The service supported x people with ID in group home settings. Sixty four decedents were identified who were, at the time of their death, still registered with the service. Data were obtained from service records and, if necessary, by a short telephone interview with a member of the care staff.

Results: The data suggest a low of death in the participating settings (1.5% deaths per year. The average age at death was 62 years and lower than might be expected for an adult population. Deaths had a distinct age profile. Older deaths were compacted to younger more associated with expected deaths

Conclusions: The data suggest that death is not a frequent event and that its impact upon the organisation is further disappointed by the small size of the settings. This suggests that preparing services for the dying phase of an individual's life