Croeso [welcome] to Seattle Club 2010

The Intellectual and Developmental Disabilities Research Group at the School of Psychology, Bangor University have great please in welcoming you to Llandudno for the 10th Seattle Club Conference for researchers in intellectual and developmental disabilities in the UK and Republic of Ireland.

Now for the 10th time, we have continued the Seattle Club traditions of:

- A focus on data-based presentations reporting findings gained through appropriate application of quantitative and qualitative methods.
- There are no parallel sessions - everyone listens to all oral presentations.
- Oral papers and posters are equally weighted in terms of worth, rigour, and status.
- The selection of contributions for oral and poster presentation is designed to achieve a mixture of more established and early career researchers.
- Participation is restricted to authors and co-authors of accepted oral and poster presentations together with researchers at the beginning of their research careers, who have applied for and been awarded Seattle Club Studentships.

Organising Committee
The ad hoc organising committee members for Seattle Club 2010 meeting were: Richard Hastings, Susie Nash, and Sharon Hadley, all from Bangor University.

Especially big thank you goes to Sharon Hadley for carrying out all of the administrative work for the conference and to Ian Warwick for taking the photograph for, and designing, the abstracts book front cover.

We hope you enjoy your time in Llandudno and that we'll see you again for the 11th meeting in 2011.

Seattle Club Studentships 2010

Nine 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:

Helena Tucker, University of Manchester
Self-perception and the nature of self- awareness in children and young people with autism and Williams syndrome.

Sam Chegwin, University of Manchester
Compulsive and perseverative behaviour in people with autism spectrum disorders, and looking at the relationship of these phenomena to obsessional-compulsive symtomatology and perceived free will.

Alison McGarry, University of Birmingham,
How do women with a learning disability experience the support of a doula during their pregnancy, childbirth and after the birth of their child?

Amanda Muir, University of Glasgow
Prospective study of the mental health of adults with intellectual disabilities: underlying mechanisms and outcomes.

Karen Deakin, University of Glasgow
Children and young people with intellectual disabilities' growing awareness of stigma.

Pamela MacMahon, University of Glasgow
Group intervention for families who provide support for adults presenting challenging behaviour.

Amy Hulson-Jones, Bangor University
The basic skills needs of offenders who are under care orders.

Emily Tyler, Bangor University
Implement and evaluate an Internet based reading programme called Headsprout Early Reading across a number of different populations including children in mainstream schools, children and adults with intellectual and developmental disabilities, and children with Autistic Spectrum Disorder.

Leah Jones, Bangor University
Mindfulness processes and mindfulness intervention to support parents of children with autism.

Monday 6th December 2010

09:45 – 10:55 Registration and refreshments

11:00 – 11:15 Introduction and Welcome
Richard Hastings

11:15 – 12:55 **Paper Session 1: Challenging behaviour / Mental Health**
Chair: Katie Cebula

1.	*The use of psychotropic medication for behavioural control: A Q method investigation of the attitudes and beliefs of professional staff* **Sarah Wastell, Dougal Julian Hare, Paul Skirrow**
2.	*Challenges in mounting a randomized controlled trial of anger management* **Paul Willner, John Rose, Andrew Jahoda, Biza Stenfert Kroese, David Felce, Kerry Hood**
3.	Mental Health of Adults with Intellectual Disability and Autism Spectrum Disorders **Jane McCarthy, Lisa Underwood, Elias Tsakanikos**
4.	Cross sectional and longitudinal association of child behaviour problems and maternal well-being in the presence of an ASD and intellectual disability **Vasiliki Totsika, Richard P Hastings, Eric Emerson, Gillian A Lancaster, Damon M Berridge**

12:55 – 14:00 Lunch

14:00 – 15:00 **Keynote Address – "An Ordinary Life: 30 Years On"**
David Felce
Welsh Centre for Learning Disabilities, Cardiff University
Chair: Richard Hastings

15:00 – 15:50 **Paper Session 2: Forensic Issues**
Chair: Marcus Redley

1.	A comparison of offenders with high and low PCL R scores in community and maximum secure settings **Bill Lindsay, Lesley Steptoe, John Taylor**
2.	Prospective dynamic assessment of risk of sexual reoffending in individuals with an intellectual disability and a history of sexual offending behaviour **Rachael Lofthouse, William R. Lindsay, Vasiliki Totsika, Richard P. Hastings, Douglas P. Boer**

15:50 – 16:15 Tea / coffee break

16:15 – 17:30 **Paper Session 3: Definitions of intellectual disability, and stigma**
Chair: Jane McCarthy

1.	Recognition of intellectual disability and schizophrenia: predictors and link to stigma **Katrina Scior, Adrian Furnham**
2.	Self-reported Exposure to Disablism is Associated with Poorer Self-Reported Health and Well-Being among Adults with Intellectual Disabilities in England: Cross Sectional Survey **Eric Emerson**
3.	A floor effects on the WISC-IV and WAIS-III **Simon Whitaker, Shirley Gordon**

18:45 – 20:00 Poster Session

20:00 Dinner

Tuesday 7th December 2010

10:00 – 11:15 **Paper Session 4: Physical health, and genetics**
Chair: Katrina Scior

1.	An investigation of physical activity in individuals with intellectual disabilities, with and without Down syndrome **Alexander Phillips, Anthony Holland**
2.	An open study of the effectiveness of a multi-component weight loss intervention for adults with intellectual disabilities and obesity **Craig Melville, Susan Macmillan, Catherine Hankey, Dimitrios Spanos, Carol Pert, Lynsay Matthews**
3.	An Exploratory Study of the Perceptions of Prenatal Genetic Testing with Individuals with Down syndrome **Barbara Barter, Richard Hastings, Rebecca Williams, Jaci Huws**

11:15 – 11:45 Tea / coffee break

11:45 – 13:00 **Paper Session 5: Families**
Chair: Craig Melville

1.	Treatment resistant epilepsy in adults with an intellectual disability: a qualitative study of a three-way relationship between parent, clinician, and adult at risk of lacking capacity **Marcus Redley, Liz Prince, Naomi Bateman, Howard Ring**
2.	Factors associated with usage of short breaks by families with a disabled child **Chris Hatton, Vicki Welch, Eric Emerson, Janet Robertson**
3.	Down Syndrome and Alzheimer's disease: The views of siblings **James Millington, Robert S. P. Jones, James McGuire, Frances Vaughan**

13:00 – 14:00 Lunch

14:00 – 15:15 **Paper Session 6: Care staff perceptions**
Chair: Robert Jones

1.	Mechanical Restraint: Impact on staff **Nigel Beail, Nicola Bethal**
2.	Evaluating Formulation Development Workshops with Direct Care Staff in Intellectual Disability Services **Barry Ingham, Jenny Riley**
3.	Avoiding the F-word (Friendship): Care workers talk about the personal relationships of people with profound disabilities **Rachel Hughes, Marcus Redley, Howard Ring**

15:15 – 15:20 Closing remarks

15:20 – 15:50 Tea / coffee available before travel for those who need refreshment

The use of psychotropic medication for behavioural control: A Q method investigation of the attitudes and beliefs of professional staff

Sarah Wastell, Dougal Julian Hare, Paul Skirrow
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Background: The use of pharmacological interventions for first line management of challenging behaviour in adults with learning disabilities remains widespread despite clinical guidelines advocating psychological interventions. This exploratory study aimed to discover the views and beliefs held by a sample of relevant NHS professionals relating to clinical decision-making process and the prescription of psychotropic medication to manage challenging behaviour.

Methods: This study used Q methodology to elucidate the factors informing the clinical decision-making process relating prescription of medication to manage challenging behaviour. 55 participants, comprising psychiatrists (n=10), psychologists (n=21) and nurses (n= 24) from a range of community and inpatient services across the North-West of England completed a 104 statement Q-sorting task.

Results: Principle component factor analysis with varimax rotation was performed on the 55 completed Q sorts. This revealed a four factor solution, accounting for 44% of the variance of the data set. The factors are interpreted and discussed under the following headings: 'High quality safe ethical practice', 'Risk as a rationale for reactive prescribing', 'Pragmatic management', and 'Contextual issues'.

Conclusions: The study showed Q methodology to an effective and valid means of illuminating the subjective viewpoints as held by a range of professionals who provide care and treatment to adults with learning disabilities displaying challenging behaviour, with regards to the factors that influence the clinical decision-making process surrounding the prescription of medication. The study particularly indicates a need to identify the wider contextual factors, which may be barriers to the use of less invasive psychological interventions

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Challenges in mounting a randomized controlled trial of anger management

Paul Willner, John Rose, Andrew Jahoda, Biza Stenfert Kroese, David Felce, Kerry Hood
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Background: Anger is a frequent and clinically significant problem for people with intellectual disabilities. We are currently conducting the first large-scale multi-centre cluster-randomized controlled trial (RCT) of anger management for people with mild-to-moderate learning disabilities, evaluating the effectiveness of a manualized, group-based intervention, delivered by support staff in a service setting.

Methods: Services and groups of 4-8 service users were recruited and, following assessment using a range of anger and mental health measures, randomized to either intervention or control arms. At least two staff members in each centre are trained and supervised by a clinical psychologist to deliver the 12-week intervention. Assessments are repeated at 16-weeks post-randomization and 6 months later (following which the control groups will receive the intervention). Other components of the study include assessments with key-workers and home carers, a process evaluation (including independent monitoring of therapy sessions), interviews with service users, lay therapists and service managers, and a health economic analysis.

Results: As planned, 30 centres (179 service users) have been randomized, and around half have reached the 16-week assessment point, with, so far, 3% loss to follow-up. Methodological challenges encountered include construction of a manual and training package, consent procedures, the three interviews, and a fidelity-monitoring instrument. Logistical challenges encountered include delays on recruitment of project staff and centres, periods of assessment overload, staffing issues within centres, and scheduling of monitoring sessions. We currently anticipate completing the RCT on schedule.

Conclusions: The difficulties of mounting RCTs of interventions for people with intellectual disabilities may have been over-stated. The importance of working with a clinical trials unit and a dedicated project manager cannot be over-stated.

Mental Health of Adults with Intellectual Disability and Autism Spectrum Disorders

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Background: There is little evidence on the mental health of adults with intellectual disability (ID) who have autism spectrum disorders (ASD). A better understanding of this group's needs will inform the development of future services.

Methods: A cross-sectional study of a clinic population attending a specialist Mental Health in Learning Disability service in South London was undertaken. Anonymised data were collected from participants' case records. Data extracted included presence of ASD, gender, level of ID, age, ethnicity, residence, psychiatric diagnosis and HoNOS-LD scores.

Results: A review of case records in January 2010 identified 416 service users in receipt of specialist mental health care who were eligible for the study. There were 117 people with a clinical diagnosis of ASD, 45 with autistic traits or suspected ASD who had not received a formal diagnosis and 254 without ASD. Participants with ASD were younger, more likely to be male, less likely to live independently and had more severe ID than those without ASD. Participants with ASD were less likely to have a psychiatric disorder than those without ASD but had significantly lower health and social functioning (as measured by the HoNOS-LD). Among those with an additional psychiatric disorder, there were significant differences in the pattern of specific diagnoses between those with and without ASD.

Conclusions: A significant proportion of service users with ID in contact with a specialist mental health service have a diagnosis of ASD. There are a number of differences in the characteristics and mental health of individuals with and without ASD.

Cross sectional and longitudinal association of child behaviour problems and maternal well-being in the presence of an ASD and intellectual disability

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Background: Recent findings from a study on five to16 year-old children indicated that children with ASD (with or without an intellectual disability) presented significantly higher levels of behaviour problems than children who only had an intellectual disability (ID), or children with neither of these conditions (Totsika et al, in press). In this study, we aim to replicate the above study in a population-representative sample of 5-year old children, to control for any developmental effects on behaviour, and also extend the design to examine potential longitudinal associations between children's behaviour and maternal well-being.

Methods: Participants in the study were families from the Millennium Cohort Study (MCS) when children were aged 5 (N=15,246) and 7 years old (N=13,857). Cross-sectional analyses of child behaviour problems, maternal well-being and their association were conducted at age five. Longitudinal analyses will be conducted using participants from both time points.

Results: At age 5, children with ASD presented the highest levels of hyperactivity, conduct problems, and emotional symptoms. Both ASD and ID were significant independent predictors of behaviour problems even after accounting for a number of confounding factors. There were no differences in mothers' satisfaction with their life, but mothers of children with ASD (those without ID) reported significantly diminished physical health status. Mothers' odds for a serious mental illness increased when their children had an intellectual disability (but not ASD). Controlling for any effects of ASD and ID, maternal outcomes were associated with children's behaviour problems. The longitudinal analysis will include over time associations (path analyses) of child behaviour and maternal well-being at age 5 and 7, controlling for relevant factors when children were nine months old.

Conclusions: The results of the cross-sectional study replicate previous findings of high levels of behaviour problems in children with ASD, and suggest that this disadvantage of ASD is present from a very early age. Given the life-time costs of ASD and challenging behaviours and the poor prognosis for these individuals, it is suggested that behaviour problems in this population should be targeted for improvement early on, similar to targeted improvements in autism symptoms and intellectual functioning.

“An Ordinary Life” 30 years on:
why and how to study the influence of living arrangements

David Felce

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The King’s Fund’s *An Ordinary Life* initiative presaged the policy changes in England and Wales that stimulated deinstitutionalisation. Research evaluating the change demonstrated that there were benefits on a range of outcomes, albeit not all. It also illustrated the considerable variation in outcome between ostensibly similar settings. This presentation discusses why and how to study the influence of living arrangements on the people for whom they are provided. It distinguishes social policy and scientific reasons for doing so and suggests that any endeavour to understand the factors that underlie variation in outcome requires an attention to scientific rigour. As service users are not randomly assigned to the service that they receive, comparison between living arrangements needs to address the possibility of selection bias. Experience suggests that adequate matching of groups to be compared is not easy and that we need to know more about which personal characteristics influence which outcomes. Moreover, living arrangements are complex physical and social environments. Much has been written about how to conceptualise and measure quality of life dependent variables (DVs). However, conceptualising and measuring the independent variables (IVs) that define different living arrangements is as challenging but undeveloped. Moreover, we need to develop the right research designs to link variation in specific IVs to changes or differences in specific DVs. The post-deinstitutionalisation research agenda has gone some way to indicating which IVs are important to which DVs, but more needs to be done if further reform is to be soundly based rather than dictated by the opinions of lobby groups, from fiscal conservatives to the proponents of progressive values.

Abstracts Paper Session 2: Forensic issues

A comparison of offenders with high and low PCL R scores in community and maximum secure settings

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Background: In a series of studies on offenders with ID we have established the reliability, validity and underlying factor structures of a number of assessments used in mainstream offender and mental health settings. These include assessments of personality, risk assessments, DSMIV personality disorder classifications, assessments of emotion and the Psychopathy Checklist Revised (PCL-R). The PCL-R has been established as a measure of risk and deviant personality in a large number of studies. A recent meta analysis has suggested that factor 1 of the PCL-R (the deviant personality characteristics) does not contribute significantly to the predictive value. (Yang et al 2010). We have extracted those with high and low assessed Psychopathy to review why certain individuals with high PCL scores remain in the community while others are in maximum security and, conversely, why some with low PCL scores are deemed to require maximum security while others remain in the community.

Methods: 13 participants with high PCL-R scores (>25) were in maximum security while 7 were in the community. For low PCL-R participants (<15) there were 19 in maximum secure services and 36 in the community. They were compared on a range of measures including current and previous offences, risk assessments (the HCR20, the VRAG), DSMIV personality disorder, the Interpersonal Adjective Scale, the CIRCLE, and the Emotional Problems Scale.

Results: There were strikingly few differences between high PCL-R scorers in the community and maximum security. The community participants had greater contact with psychiatric services before 18 yrs and a higher rate of narcissistic PD. There were no differences in rates of index or previous violence, arson, risk assessment scores, and externalising or internalising emotional problems. For the low PCL-R scorers the maximum secure sample had higher rates of index and lifetime violence, weapon use, institutional violence and average HCR 20 historical scale scores.

Conclusions: The PCL-R has become a central forensic measure in offender settings for assessment of a range of attributed including risk and treatability. In this study there were remarkably few differences between groups on a range of measures. It seems that if community services are familiar with a difficult referral, then they are more likely to accept him. On the other hand, if violence was current in the index offence, a person with low psychopathy was more likely to be admitted to maximum security. We will discuss the implications for the viability of the PCL-R for this group and what services need to retain difficult offenders with ID in relatively open settings.

Prospective dynamic assessment of risk of sexual reoffending in individuals with an intellectual disability and a history of sexual offending behaviour.

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Background: Previous research has primarily focused on measures of static risk to predict recidivism in populations of people with an intellectual disability (ID) and a history of offending behaviour. Emerging data suggest that the use of dynamic risk assessment for violence may be as

good as, if not better than, established static risk tools in this population. The purpose of the present study was to extend this work to consider sexual offending behaviour.

Methods: A dynamic risk assessment for sexual reoffending (ARMIDILO-S), a static risk assessment for sexual offending (Static-99), and a static risk assessment for violence (Violence Risk Appraisal Guide - VRAG) were completed for a sample of 64 adult males with ID and a history of sexual offending behaviour. Measures of static risk were completed retrospectively from file information, and the dynamic risks were assessed at a baseline data collection. Follow up sexual recidivism data were collected over a period of 6 years.

Results: Thirty three per cent of the sample reoffended during the follow-up period. The use of a dynamic risk tool for sexual offenders with ID resulted in the best prediction of sexual reoffending (ARMIDILO-S total score AUC = .92), this was better than an established sexual offending static risk tool (Static-99 AUC = .75). As predicted, a more general static risk assessment for violent reoffending, did not perform as well in predicting sexual reoffending in this group (VRAG AUC = .58).

Conclusions: The results would suggest that dynamic/proximal variables are useful in predicting sexual reoffending with individuals with ID, confirming previous research findings on the prediction of violent behaviour. The ARMIDILO-S is a promising dynamic risk assessment tool for individuals with an ID.

Abstracts Paper Session 3: Definitions of intellectual disability, and stigma

Recognition of intellectual disability and schizophrenia: predictors and link to stigma

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Background: The desire to reduce stigma by increasing public awareness is at the heart of public education campaigns. While research has examined the public's understanding of mental health problems and the effect of increased knowledge on stigma, there is scant evidence on intellectual disabilities, even less so when considering ethnically diverse populations. This claim has been refuted though by recent studies on schizophrenia. The study presented aimed to determine whether the public from different ethnic groups can recognise symptoms of intellectual disability (and schizophrenia) depicted in a vignette as such, and whether recognition is associated with reduced stigma. We also examined what factors predict recognition and whether recognition is linked to stigma.

Methods: A cross-sectional survey was completed in the UK, Hong Kong and Singapore collecting responses from lay people aged 16+ from five ethnic groups (N=818). Logistic regression modelling was used to identify predictors of correct recognition. The association between recognition, different forms of misattribution of symptoms and stigma was examined using t-tests and analyses of variance.

Results: Marked differences were found between ethnic groups in their ability to recognise both conditions. Ethnic origin and prior contact predicted recognition of both conditions, but other demographic predictors varied. Recognition was associated with lower social distance for the intellectual disability condition, but not for schizophrenia.

Conclusions: The low levels of awareness of intellectual disability and schizophrenia among lay people from some ethnic groups suggest a need for more targeted public education campaigns. Caution is called for though in assuming that the potential effects of increased awareness and contact on stigma will be similar across different conditions.

Self-reported Exposure to Disablism is Associated with Poorer Self-Reported Health and Well-Being among Adults with Intellectual Disabilities in England: Cross Sectional Survey

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Background: Little research has addressed the impact of exposure to disablism on the health and well being of people with intellectual disabilities.

Methods: Study Design: Cross sectional survey. Secondary analysis of data extracted from the survey of Adults with Learning Difficulties in England 2003/4.

Results: Both self-reported exposure to bullying while at school and self-reported exposure to overt acts of disablism over the previous 12 months were associated with poorer self-reported health outcomes. In the vast majority of instances these associations were stronger for people with lower levels of material or social resources.

Conclusions: Exposure to overt acts of disablism may contribute to the health inequalities experienced by people with intellectual disabilities.

A floor effects on the WISC-IV and WAIS-III

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Background: Recent evidence has suggested that the WISC-III and to a much lesser extent the WAIS-III are subject to a floor effect due to a scaled score of one being given to very low raw scores. The purpose of this study was to ascertain if the same result would be found for the WISC-IV.

Methods: The WISC-IV (UK) and the WAIS-III (UK) was given to seventeen 16-year-olds in special education.

Results: The distribution of scale scores in the WAIS-III was approximately normal with very few scale scores of one. The WISC-IV had a skewed distribution of scale scores with more scale scores of one.

Conclusions: There is a significant floor effect on the WISC-IV and to a much lesser extent on the WAIS-III. It seems credible to correct for the floor effect on the WAIS-III.

Measuring the physical activity / inactivity of adults with Down syndrome

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Background: Adults with Down syndrome have low levels of physical activity, and they are more likely to experience health problems such as cardiovascular and obesity. Previous research has focused on exercise interventions to promote physical activity of adults with Down syndrome, yet current physical activity recommendations are more relevant to lifestyle physical activity.

Methods: Lifestyle physical activity/inactivity of four community-based adults with Down syndrome were objectively measured over a 7-day assessment period, using an activity monitor. Self-report diaries were also completed prospectively and retrospectively, at the start and at the end of the 7-days, to inform findings.

Results: Three of the participants were Special Olympics athletes, yet prolonged walking in the person's local area was the only activity identified whereby participants were able to achieve more than 10, 000 steps per day, and over 30 minutes of moderate intensity activity. Participants were sedentary in the absence of structured activity, and reported that they require assistance and support to access and participate in physical activities.

Conclusions: Walking is key to increasing the physical activity of adults with Down syndrome. Further research on establishing more suitable physical activity measurement guidelines is recommended.

The Learning Disability Workforce: Health Related Knowledge, Lifestyle Choices, and Working Practices: A Pilot Study

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Background: Staff working in support roles play a crucial role in the health of the people with learning disabilities that they support. Staff knowledge and understanding of health benefits of increasing activity levels is vital. There is an unrecognised importance and complexity to this role and due to the considerable time that staff spend with the people with whom they work it may be that the effect of their own lifestyle preferences could influence the people with learning difficulties that they work with.

Methods: Participants (N=6) who worked in a respite home took part in a semi-structured interview to examine their health related knowledge, lifestyle choices and health related working practices.

Results: Participants were knowledgeable about healthy lifestyles with a tendency to emphasise diet over activity. Despite this some participants were not meeting the ‘five a day’ recommendation, had limited engagement in physical activity and all participants were either overweight or obese. Barriers to optimising healthy lifestyles included time, price, lack of motivation, family, and shift work. Staff were asked for their views on whether the people they support live healthy lifestyles. Participants had fairly negative views but it was often reported that in terms of diet, food prepared in the respite house was better than staff eat in their own homes. Exercise though was limited.

Conclusions: If barriers to healthy lifestyles are strong for support staff, it is difficult for them to adequately support people with learning disabilities in leading healthy lifestyles.

The Perceptions and Experiences of Adolescent Siblings with a Brother with Autism Spectrum Disorder

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Background: Although quantitative research can help us to understand sibling adjustment, we currently know little about how siblings make sense of their circumstances and experiences when they have a brother or sister with autism. Qualitative research studies have an important role to play when we seek to understand siblings perspectives, but there are few such studies focusing on siblings of children with autism.

Methods: Semi-structured interviews were used to elicit the perceptions and experiences of 12 typically developing adolescent siblings who had a brother with autism. Interpretative Phenomenological Analysis was used to analyze the data.

Results: The analysis yielded six themes: 1) Siblings expressed the difficulties and negative impact of their brother's condition, 2) Siblings reflected on how others reactions negatively affected them, 3) They offered accounts of their histories with their brothers, and described how their past contextualized their present circumstances, 4) They expressed acceptance and tolerance towards their brothers, as well as wishes for certain things to be different, 5) Siblings described positive perceptions and experiences with their brothers, and 6) Siblings conveyed thoughts and worries about the future.

Conclusions: The main implications are focused on supporting adolescent siblings by helping them to develop skills in managing others reactions and openly discussing concerns about their brother or sister's future.

Ratings by teachers and parents of ritualised and compulsive like behaviours (RCBs) in children with learning disabilities and autism

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Background: Ritualised and compulsive like behaviours (RCBs) are common in young typically developing children and those with learning disabilities; there is little research, but some evidence that the latter have higher levels of RCBs. Many researchers have regarded such behaviours as functional rather than pathological. We compared the frequency and intensity of RCBs rated by teachers and parents (i.e. in the school and home environment) for those with and without autism.

Methods: Sample The sample consisted of the parents and teachers of 78 children who attended a local special educational needs primary school for children with severe learning disabilities. All teachers and 48 (62%) of the parents participated. Measure The Child Routines Inventory (CRI) (Evans et al 1997). This was modified for ratings by teachers by removing items referring to the home environment.

Results: There were significant positive correlations for both intensity and number between parent and teacher ratings of RCBs. Both the intensity and frequency ratings of RCBs exhibited by the children were significantly higher for parents than teachers. Those children with autism were rated significantly higher. Comparison to previous results showed that the children in this study were rated to have more RCBs than typically developing children but this was largely accounted for by those with autism. Children with Down syndrome were rated to have less than those with autism.

Conclusions: This study adds to the data base on RCBs in children with developmental disabilities and reinforces the need for observational studies in real life settings.

Futures planning, parental expectation and adult sibling concerns within learning disabilities

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Background: People who have a learning disability are living longer than previously and many have profound and severe disabilities. This group of people often live with parents and even when they move away from the parental home, responsibility often remains within the family. Siblings are commonly viewed as next of kin when older parents die or are no longer able to provide previous levels of support.

Methods: A questionnaire to explore the existence of future plans, parental expectation and adult sibling concern regarding people who have a learning disability was distributed via email. Responses were anaylsed using descriptive statistics and thematic analysis.

Results: A full discussion regarding sibling support took place for 12 (57%) of respondents, 7 (33%) stated this discussion had not taken place and 2 (9%) were unsure. 12 (57%) of participants reported no clear future plan however where a plan did exist, 7 (33%) of respondents claimed it was agreeable to both them and their parents. 11 (52%) of respondents reported no difference between their wishes regarding future care and parental wishes. Key themes generated were; satisfaction with services, parental influence, sibling concern about the future, futures planning, the impact of the disabled person upon sibling lives and siblings needs.

Conclusions: The results present a lack of clarity between parents and siblings regarding futures plans, yet siblings are concerned about the impact of care for the future. There is diversity in sibling experience related to perception of services, the degree and openness of parental expectation of sibling involvement in future care. Siblings raise their need for a voice and access to a better quality and range of services.

Including adults with autism and severe learning disability in a sibling research project

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Background: An ESRC funded 18 month qualitative study is exploring the experiences, roles and support needs of 20 adult siblings of people with autism plus severe learning disability. Sibling relationships are two-sided. Despite moves towards more participative research, people with high

support needs are often excluded. Perceived barriers include limited verbal communication, social understanding and increased anxiety of new experiences.

Methods: A literature review identified possible non-verbal methodologies that might enable autistic siblings to take part in the research. A range of resources were developed and adapted to individuals on the advice of non-disabled siblings and key supporters. These included: illustrated social stories to prepare for and agree to meeting the researcher; family photos used to elicit memories and aid communication, making a collage of favourite pictures; a Polaroid camera to record the encounter; a favourite activity with the siblings, such as visiting a cafe, and participant observation of sibling interaction.

Results: Most siblings with autism met a researcher; none did not take part because of refusal or anxiety. Several siblings said their brother of sister 'likes to meet new people'. A close bond and understanding, effective, often light-hearted communication and a shared history was observed between siblings. A one- off meeting does not allow for the gathering of more detailed perceptions from the autistic sibling about their relationship.

Conclusions: Involving people with autism and high support needs as active agents in research about their lives is possible and necessary to gain a fuller picture of their experiences and relationships.

Service users' experiences of Autism Spectrum Disorder (ASD) assessment services

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Background: In 2006 the Welsh Assembly Government launched a strategy to develop better services for children, young people and adults with Autism Spectrum Disorder (ASD), regardless of age, disability or location. However, access to assessment for ASD can be complex. The range of organisations, teams and professionals can be diverse, and poorly understood and integrated. The family undergoing an assessment may already be experiencing distress due to concerns about their child's development and difficulties with behaviour management. In addition, there is a lack of research exploring services users' experiences of the assessment process.

Methods: An audit was conducted to evaluate assessment and diagnostic services within Conwy and Denbighshire, across both CAMHS (Child and Adolescent Mental Health Services) and Learning Disability (LD) /Child Health services. Data were gathered retrospectively from case files of children and young people who underwent an ASD assessment during 2009 across both services and both counties.

Results: Key summary findings highlight major differences between services and geographical regions in assessment processes. There were large and significant gaps in information, thus making it difficult to make service recommendations. Data were gathered on a range of issues, e.g. demographics, referral patterns, referred problems, assessment components, diagnoses given, waiting times and assessment time frames, etc. Service deficits were identified, e.g. lack of specialist Speech and Language therapists. It was also clear that children had waited longer than the recommended waiting time for an assessment and the assessments were taking longer than national recommendations.

Key recommendations include using consistent data recording methodology to enable comparisons to be drawn between a range of services; standardising assessment components as far as possible whilst simultaneously recognising the diverse needs of this population.

Conclusions: These findings have important implications for ensuring equitable ASD assessment services and complying with national standards. Further work is underway to interview a sample of service users in order to explore their experiences of the assessment process and help to identify ways which we can equitably meet the needs of all service users.

Families with a disabled child who use direct payments for short breaks; their characteristics, the short breaks they use and their experiences of the process

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Background: Current policy trends promote the use of direct payments (DPs), including those for families who use short break services. However uptake of DPs has been slow and use of DPs has been socially patterned. Aiming High for Disabled Children in England has recently resulted in a dramatic increase in investment in short break provision including those funded through DPs.

Methods: The paper draws on combined findings from two surveys totalling 348 parents and carers in families with disabled children using short breaks. We investigate associations between characteristics of families, carers and children, short break use and use of DPs. We also draw on open-ended responses which describe family experiences of accessing and using DPs.

Results: A range of benefits from the use of DPs are identified along with problems with accessing and using them. Characteristics associated with use of DPs include the presence of, female carers, more highly educated carers, White British carers, younger children and lower levels of area-based deprivation. Use of DPs is also significantly associated with greater access to social networks and some support services. Various health and well-being indicators for carers and children are not significantly associated with use of DPs.

Conclusions: Direct payments can have a number of benefits for families using short breaks but access to them is currently problematic and socially patterned. If the uptake of DPs is to be increased and made more equitable more attention must be paid to the their promotion and to the support given to individual families.

The Development and Evaluation of the Equity Perception Scale Learning Disability Service.

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Background: The aim of this study is to develop and evaluate a detailed measure of staff equity perceptions that is relevant to individuals working in services for people with learning disabilities. The Equity Perception Scale “Learning Disability Service (EPS-LDS) contains three relationship indices assessing staff equity perceptions about their relationships with service-users, co-workers and the employing organisation. Each relationship index is made up of two subscales (inputs and rewards).

Methods: Qualitative and quantitative methods were used to gather data from staff working in services for people with learning disabilities. Semi-structured interviews (n = 15) were used to generate items for the measure. Focus groups (n = 7) were used to assess the content validity, the face validity and various other aspects (i.e. the layout and clarity of the measure) of the EPS-LDS Postal questionnaires (n = 143) were used to gather data on the reliability, the construct validity and the criterion validity of the measure.

Results: The EPS-LDS subscales were all found to have good internal consistency reliability (Cronbachs alphas = 0.84 to 0.93). The EPS-LDS relationship indices were found to have acceptable test-retest reliability (Spearman r = 0.62 to 0.89) and demonstrated, to varying degrees, evidence of construct validity. Two of the three relationship indices (the service-user and employing organisation indices) showed acceptable criterion validity.

Conclusions: The initial findings on the reliability and validity of the EPS-LDS show promise. Potential uses for the measure and directions for future research are proposed.

Mothers' perceptions of the challenging behaviours of their child with intellectual disabilities

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Background: High rates of depression, anxiety and stress have been reported by parents of children with intellectual disabilities, and although longitudinal research supports a temporal relationship between child behaviour problems and parental psychological distress, there has been less attention to how parental psychological distress affects child behaviour. It is hypothesised that this latter relationship is affected by parenting style or behaviour, or the quality of the parent-child relationship.

Methods: Twenty seven mothers of children with intellectual disabilities and behaviour problems were interviewed about their views of the most problematic behaviours exhibited by their child. Interview transcripts were coded for maternal expressed emotion and spontaneous causal attributions regarding the child's behaviour problems. In addition, data were collected regarding maternal stress and wellbeing, and frequency of child behaviour problems.

Results: Mothers considered high in criticism or low in emotional over-involvement or warmth made attributions that they had some control over their child's behaviour. Critical mothers additionally made more attributions that behaviours were under their child's control, or unique to their child. Maternal stress and depression were associated with high levels of child behaviour problems and more severe intellectual disabilities.

Conclusions: Hence the way mothers in this study perceived their child's behaviour was influenced by their current beliefs, attributional style and expressed emotion, therefore, these must be considered when planning both child and parental interventions.

Improving Health and Lives "Learning Disabilities Observatory: Effectiveness of Health Checks

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Background: Improving Health and Lives "Learning Disabilities Observatory aims to provide better, easier to understand, information on the health and wellbeing of people with learning disabilities.
People with learning disabilities have poorer physical and mental health than other people. One practical step GP practices in England can take to better support people with learning disabilities is to offer them annual health checks.

Methods: Firstly, data collected from PCTs by the Information Centre for Health and Social Care on the uptake of health checks by adults with learning disabilities in 2008/09 and 2009/10 was analysed. Secondly, a systematic review of 38 identified scientific studies of the effectiveness of health checks was undertaken.

Results: In 2008/9, a reported 27,011 adults with learning disabilities received a health check, increasing to 58,919 in 2009/10, an increase of 118%. Part of this rise can be attributed to incomplete PCT returns in 2008/09.

The systematic review found that the introduction of health checks for people with learning disabilities consistently leads to: the detection of unmet, unrecognised and potentially treatable health needs (including serious and life threatening conditions); targeted actions to address these health needs.

Conclusions: While progress has been made in the delivery of health checks, less than 50% of eligible adults received a health check in 2009/10. Targeted health checks should be considered an effective and important reasonable adjustment to primary health care services in the UK.

Sexuality and Sex Education of Adolescents with Intellectual Disabilities: Mothers' Attitudes, Experiences and Support Needs

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Background: Young people with intellectual disabilities (ID) are socially marginalised and have fewer sources of sexual information than their non-disabled peers. Families are important in supporting their adolescents sexual development, but few studies have considered families views about this private matter.

Methods: A between group family comparison was used to investigate both that attitudes and behaviour of mothers of young people with (n=30) and without disabilities (n=30). Both groups were balanced for gender and the mothers and offspring in both groups were of a similar age and socio-economic status. In-depth qualitative interviews informed the development of the questionnaire by the research team.

Results: Both groups of mothers placed similar importance on dealing with their offspring's developing sexuality. However, mothers of young people with ID held more conservative attitudes ($F(1,56) = 38.317$; $p = 0.001$). They reported having spoken about fewer sexual topics with their offspring ($F(1,56) = 5.69$; $p = 0.02$), in less depth ($F(1,51) = 4.60$; $p = 0.05$), and began these discussions when their children were older ($F(1,51) = 4.29$; $p = 0.05$). It was notable that these differences were more marked between the mothers of daughters with and without ID than the mothers of sons. Mothers from both groups reported initiating few conversations with their offspring about sex, although the typically developing young people helped initiate significantly more conversations ($\chi^2 = 10.04$; $df = 2$; $p<0.01$).

Conclusions: The findings from this study should be used to promote a greater willingness of parents to talk about sexual matters with young people, and the style of communication they might adopt to do so most effectively.

"Not everybody memorises the phone book": Representations of autism in psychiatrists' accounts

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Background: Psychiatric conceptualizations of autism have been criticized for a narrow perspective based on an overly medicalised and diagnostic view of the condition. We were interested in exploring the views of psychiatrists when asked to reflect on their understanding of the concept

Methods: In-depth semi-structured interviews were conducted with six psychiatrists working in the specialist field of learning and developmental disability in the United Kingdom.

Results: An interpretative phenomenological analysis of their perceptions of autism revealed four main themes: (1) Diagnostic concordance and ambiguity; (2) Threshold of complexity; (3) Autism as an artificial construct; and, (4) The socio-relational context of care.

Conclusions: While the analysis revealed elements of understanding that matched the application of diagnostic criteria, a more gestalt, contextual understanding of autism was also shown that acknowledged the psychological limitations of diagnosis and its sociological impact. Compared with what we expected to find, a much richer conceptualization of the concept of autism was revealed.

Self-injury and other challenging behaviour at intervention and 10-years on: A clinical case review

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Background: According to Carr et al. (2002) PBS has 9 defining characteristics. One of these is maintenance of behaviour change over years rather than months. Twelve years ago a specialist CB team worked with Tom, a 32 year-old man diagnosed with severe learning disabilities and autism who engaged in high-rate challenging behaviour.

Methods: The specialist team managed Tom's service, conducted functional assessments, designed and implemented multi-layered interventions before transferring responsibility back to mainstream intellectual disability services.

Results: After one year of intervention challenging behaviour reduced from 200 instances per day to zero. Tom's community involvement and engagement in activity increased. Gains at intervention had maintained in mainstream ID services at follow-up 10 years later.

Conclusions: Focused intervention can lead to lasting change in behaviour and quality of life. Service costs can be reduced. The specialist CB service's contribution was in line with Mansell (1992; 2007).

The emerging demographics and characteristics of the Forensic Learning Disability Population in North Wales

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Background: There have been several studies that have been interested in the intellectual disability population who enter or at risk of entering forensic care pathways This study provides data on the emerging forensic intellectual disability population in North Wales.

Methods: A survey design was adopted to collect demographic data and data pertaining to clinical presentation and care packages (i.e assessment/treatment and outcome data). Questionnaires were distributed amongst the six unified learning disability community teams and a range of statutory and independent service providers.

Results: 153 data sets were received and analysed. Prevalence data for forensic issues in adults with an ID in North Wales was estimated at 6%. Analysis of offender characteristics included findings such as strong associations between substance misuse and certain offence types. Other findings included the lack of clinical information about a large proportion of the sample.

Conclusions: As a first attempt to estimate the prevalence of individuals with an intellectual disability that have offended or are in danger of offending initial findings still are likely to be an underestimate of the 'problem.' Given there is a strong literature that supports the need to support individuals in 3 key areas (direct intervention to address offending behaviour; appropriate support systems to facilitate rehabilitation and service co-ordination to minimise future recidivism) this study suggests a need for a more coherent clinical approach to this cohort of individuals and their needs. There is also a need to consider the emerging adolescent population and to better understand their needs.

Decision making in intellectual disability nursing practice: Results from an All Wales Nursing Survey.

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Background: Healthcare employees are under increasing demands to base their decisions on the best available evidence (NMC, 2008). Yet, for intellectual disability (ID) nurses, the information is sparse about their use of evidence to support practice (Parahoo et al., 2000). A previous qualitative study (Williams et al., in press) highlighted the importance of a person-centred approach in decision-making, but it is unclear whether this takes priority amongst practitioners.

Method: A cross-sectional survey was designed to target all NHS nurses (n=465) working in ID services across Wales between April and June 2010. Participants were recruited through senior nurses. The bilingual self-administrated postal questionnaire consisted of items that emerged from the previous qualitative study alongside two validated measures on attitudes towards person centred planning and clinical decision-making. Following postal reminders, 285 (61%) questionnaires were completed and returned.

Results: Compared with previous normative data (Lauri & Salanterä, 2002) the ID nurses are more analytic in their decision making overall. Within the stages of the nursing process, that is, collecting information, handling information, planning and implementing nursing, the ID nurses were most analytic in orientation in the handling information stage.

Conclusions: It is unclear why ID nurses are more analytic than the other nurses who worked in such areas as intensive care (Lauri et al, 1998) and psychiatry (Lauri et al., 1999). However, nursing practice has changed dramatically since these studies with modern NHS reform promoting researched evidence-based clinical decisions to improve the quality of care (Standing 2010).

Evaluation of a 'Communication Day' staff training intervention for carers of individuals with moderate and severe Intellectual Disabilities.

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Background: Attendees of the Communication Day consisted of staff across two ID residential services. The training was facilitated by a Psychologist and Speech Therapist.
Training consisted of three components:

1. Values-based motivational work
2. Increasing insight into experiences of individuals with disabilities.
3. Specific communication techniques

Methods: Fifty one staff members participated in the training day. Outcomes were evaluated using a novel self-report questionnaire, consisting of five items: Putting oneself in the shoes of service users, perceived communication skills, degree of comfort in communication, ability to communicate with residents throughout daily tasks, and the degree to which thoughts and feelings affect job performance. Items were rated on a seven point Likert scale.
Pre-post results were obtained from 51 participants (beginning and end of the day). Follow-up results (3-6 months) were obtained for 30 individuals Paired samples t-tests were utilised.

Results: Analyses demonstrated statistically significant increase in participants ratings on all items except thoughts and feelings get in the way of how I want to do my job. Effect sizes will be discussed in the full text.

Conclusions: Results provide evidence that the programme enabled staff to feel more competent and confident in their ability to communicate with service users.

Further study could look at observational measures of communication within services where staff have received the training. Additional investigation is needed to highlight particular active components of the intervention, as well as development of the questionnaire measure.

Adults with Aspergers' Syndrome: Views on Diagnosis and Identity

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Background: Within an increasing literature into Aspergers Syndrome (AS), relatively little incorporates the perspectives of individuals with AS themselves. This study sought to address this, exploring adults' experiences of diagnosis and knowledge of their condition. The implications of AS for individuals' sense of identity were also explored, as research to date has focused predominantly on children rather than adults.

Methods: Twelve adults with AS (22-60 years) attending an AS support organisation were interviewed individually. Interviews explored experiences of diagnosis, influences on understanding of their condition, school experiences, perceptions of AS as a disability or ability, and the implications of AS for their self-concept and social identity.

Results: Participants described lives marked by continuing challenge: in gaining a diagnosis and post-diagnosis support; in accessing and benefiting from education; and in making sense of and coping with social interactions and the attitudes of others. They also identified a range of interests and strengths some of which they associated with AS; an understanding of AS that evolved with time and appropriate support, and a varied, in some cases notable sense of self-awareness and group social identity. While for some, locating themselves within the AS community aided positive identity development, it was clear that this was only part of a far more complex process of identity construction.

Conclusions: Interviews highlighted both the strengths and challenges in AS, and the role of experience in shaping personal and social identity. The findings have implications for support services and the need for more clearly articulated, earlier diagnostic procedures.

Experiences of services and support in North Wales for young people with Aspergers Syndrome

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Background: The experiences of young people with Asperger syndrome have been the subject of little previous research, especially their experience of services and support.

Methods: Nine young people with Asperger syndrome were interviewed. Interpretative Phenomenological Analysis (IPA) was used to interpret the interviews.

Results: Four themes emerged from the analysis; (1) 'trying to seem normal' - Growing up with AS; (2) ' .....I didn't know what to do Moving on: From education to employment; (3) '..their perspective needs to be changed' - Contact with services; (4) 'I would like to be more independent' - Future concerns. The findings included reports of stress, employment difficulties and socialisation difficulties that people with Asperger syndrome may experience. In addition to this, difficulties with services such as public transport and criminal justice system are reported.

Conclusions: A need for specific and practical support for individuals with Asperger syndrome is discussed, including life skills teaching and a general awareness of Asperger syndrome amongst services.

Identifying emotions from walking gait: a possible link with frequent aggression in young people with mild to moderate intellectual disabilities.

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Background: Research suggests that impairments in emotion recognition may contribute to frequent aggression in some people with intellectual disabilities. Although affect is ordinarily communicated via dynamic cues, studies to date have used static stimuli exclusively and findings have been

inconclusive. The present study re-examined the possible association between impaired emotion recognition and aggression using dynamic stimuli.

Methods: 20 young adults with intellectual disabilities (aged 16 to 20; mean age=18.5, SD=1.39) and 17 typically developing peers (mean age=18.1, SD=1.31) were shown 24 brief movies depicting a person walking in a happy, sad, angry or neutral manner. After each movie, participants were asked to indicate which of the four possible emotional states was being conveyed by the actor. Teacher reports of participants' recent behaviour were used to enable comparisons between aggressive and non-aggressive participants with IDs, (Agg. N=6, Non-agg. N=14)

Results: Aggressive participants with intellectual disabilities were significantly poorer at identifying anger from the movies than the non-aggressive participants (χ^2 (1)=5.92, p=0.015). Significant differences were not found in overall accuracy or ability to identify other individual emotional states. Overall, typically developing participants were significantly more accurate than participants with intellectual disabilities (χ^2 (1)= 14.1, p=<0.001), specifically, at identifying happy movies (χ^2 (1)=5.75, p=0.017).

Conclusions: Results suggest that frequently aggressive young adults with intellectual disabilities may have specific difficulties identifying anger from the gait of others. Young adults with intellectual disabilities may have relative deficits in recognizing emotions from body movements. Implications of these findings and limitations of the study are discussed.

The Presentation of Attention Deficit Hyperactivity Disorder (AD/HD) in Children with Intellectual Disabilities

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Background: Many studies shoe increased AD/HD in children with intellectual disabilities compared to typically developing children when parental report measures are used. However to date the validity of parental report methods has rarely been evaluated. Interestingly, parents are rarely asked about their developmental delay and whether hyperactivity is excessive once their child's developmental level is accounted for.

Methods: This study allocated children with ID into high/low ADHD symptom groups by firstly using the SDQ parental report rating scale. The consistency of this was then compared to a more highly validated parent structured clinical interview (PACS). Finally, to further explore the validity of parental report, the Cookie Delay Task was administered to each child.

Results: When PACS scores were compared with high/low ADHD symptom groups generated by the SDQ, the effect sizes ranged from 3.0 - 4.0, with the high hyperactivity group also generating high hyperactivity scores via the PACS. The group differences remained highly significant even when the presence of an Autism Spectrum Disorder diagnosis and developmental level were controlled for. There was also a large effect size (1.0) when group differences on the Cookie Delay Task were examined however, when Vineland composite scores were controlled for the group differences on the Cookie Delay Task disappeared.

Conclusions: Parents appear to be accurately reporting elevated symptoms of ADHD in their children with ID. However, once developmental delay is taken account of and observed rather than parental report measures are used there appears to be much less of an increased risk of these symptoms.

The development of a learning disability screening tool

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Background: There is a clear need for a brief tool with good levels of sensitivity and specificity to assist in the identification of learning disabilities in primary care health settings.

Methods: An item pool was developed through qualitative analysis following focus groups and analysis of existing screening methods, from which 22 distinct items were extrapolated. This measure was completed by a mixed sample of adults assessed as either meeting established criteria for adult learning disability services (n=161) or not meeting criteria (n=49).

Results: ROC analysis for an extracted 9-item set resulted in a specificity of 90% and sensitivity of 91%. Good levels of validity and reliability for the identification of learning disabilities, when compared with established psychometric measures, are reported.

Conclusions: The authors describe a quick tool to administer with better psychometric properties than reported for any other existing screening tool for use with this clinical cohort.

Imaging Brain amyloid using Pittsburgh Compound B ([11C] PIB) in adults with Downs Syndrome

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Background: Individuals with Downs syndrome (DS) are known to be at high risk of developing dementia in middle age. Prevalence rates are as high as 40% in the 50-59 age group. Amyloid Plaques, one of the key the pathological hallmarks of Alzheimers disease (AD), are observed almost universally in the brains of people with DS by the age 40. Excess amyloid production in DS is believed to be due to an extra copy of the APP gene located on chromosome 21. We investigated the safety, acceptability, and potential utility of PET imaging using [11C] PIB to identify cerebral Î²-amyloid in subjects with DS in-vivo and to determine whether the technique differentiates between participants with and without a clinical diagnosis of AD.

Methods: Nine consenting participants with Down Syndrome aged 25-64 underwent Dynamic PET scanning using [11C] PIB with MRI co-registration. Five participants had a diagnosis of AD.

Results: The technique was found to be feasible, safe and well tolerated. We found significant binding in subjects aged 45 and over across six key regions of interest.

Conclusions: Patterns of PIB binding broadly mirrored those predicted from autopsy studies in people with DS. We observed increased PIB binding in older participants but it was not possible due to small numbers to distinguish between those with and without AD. This technology will enable the longitudinal study of the distribution of amyloid deposition in DS and will potentially inform future drug therapies.

'We are all there silently coping'. Support experiences of parents of adults with Asperger syndrome.

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Background: Parents of individuals diagnosed with pervasive developmental disorders, such as Asperger syndrome, may face greater challenges than parents of typically developing individuals (Schuntermann, 2002). The experiences of parents of adults with Asperger syndrome has not before been explored in the literature.

Methods: Four families were interviewed (three mothers and one couple) and the interviews analysed using Interpretative Phenomenological Analysis (IPA).

Results: Overall, it was found that some parents of adults in middle-adulthood still feel they are their offspring's primary caregivers and yet this is felt not to be understood by wider society and social support services. Parents of less independent individuals feel they are solely responsible for their offspring's care and spend much time helping with routine domestic tasks and encouraging a fuller social life. While some parents enjoy a good relationship with their sons, others continue to struggle to cope with certain aspects of their sons behaviours which adds to feelings of being 'burdened'. Parents feel they are left to cope with their offspring's needs with little support and little understanding from others. However, this is not their primary concern; their primary concern is the continued well being of their offspring.

Conclusions: The findings of this study offer insight into the experience of parents of adults with Asperger syndrome.Suggestions are made for future supports and research.

BEAT-IT: A Pilot Behavioural Activation Intervention for People with Intellectual Disabilities and Low-mood.

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Background: Important work has been carried out adapting Cognitive Behavioural Therapy (CBT) for people with ID. Unfortunately it makes excessive cognitive and communicative demands for many people. Behavioural Activation is less reliant on verbal communication and focuses on increasing activity and reducing avoidance. This pilot study is examining the feasibility of an adapted version of BA for people with ID and symptoms of low mood called BEAT-IT.

Methods: Twenty adults referred with ID with symptoms of low-mood have been recruited from specialist health services in Glasgow. Baseline, post intervention and 3 month follow-up data are being gathered by a researcher independently from the therapist. Outcomes being examined include carer report of depressive symptoms using the Glasgow Depression Scale (Cuthill et al, 2003) and several measures of activity, including an accelerometer. The intervention consists of 10-12 weekly sessions, and the therapist works with the clients alongside their carer(s). Tasks include goal setting, activity scheduling and skills training.

Results: To date six people have completed the treatment programme. Preliminary analysis with 5 participants suggests a decrease in carer ratings of depression on the Glasgow Depression Scale and Intellectual Disabilities Scale. Some increase in regular community and leisure activities has also been shown on the Guernsey Community Participation and Leisure Assessment. Post intervention data will be available for 12 participants by December 2010.

Conclusions: BEAT-IT may provide an effective treatment of low-mood accessible to a range of adults with intellectual disabilities.

Development of the Manchester Attachment Scale – Third party [MAST] for adults with intellectual disabilities

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Background: The current study aims to assess the validity of a measure of secure attachment in adults with intellectual disabilities, the Manchester Attachment Scale – Third party [MAST] and its relationship with learning disability and challenging behaviour. The MAST has been developed from a previous Q methodology study examining secure attachment in adults with ID (Walker 2009). This paper reports on the preliminary data analysis.

Methods: Carers (n=20) completed the MAST, Learning Disability Casemix Scale Part A (level of ID) and Part C (measure of challenging behaviour) an adapted version of the EZ-Yale Personality Questionnaire (EZYP) and an Emotional Rating Scale (ERS). Total scores from the MAST were compared to total scores on the other measures.

Results: Preliminary analysis using Pearson's Correlation Coefficient indicated a significant correlation between scores on the ERS and on the MAST ($r=0.42$; $p=0.041$).There was a significant correlation between scores on the MAST and part A ($r=0.467$; $p=0.019$) and part C of the Casemix Scale ($r=0.666$; $p=0.001$). There was no correlation between scores on the MAST and the EZYP ($r=-0.268$; $p=0.127$)

Conclusions: The results suggest an association between a 'good' relationship as rated on both the ERS and MAST scores and an inverse relationship between secure attachment and level of ID and CB. No association was found between scores on the MAST and the EZYP. This preliminary analysis suggests a relationship between secure attachment and CB and indicates the MAST is measuring constructs related to attachment theory.

Exploring Carer Roles: From Carer Beliefs to Therapeutic Outcomes

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Background: People with intellectual disabilities (ID) living in the community rely on carer support to help them in their daily lives. Over and above their daily roles, carers may also support the delivery of mental health interventions, often acting as the agent of change. Despite the multi-faceted nature of the role of the carer, there has been no research conducted investigating carers' perceptions of their roles. This study aims to explore how carers see their role within the therapeutic process.

Methods: Carers of 15 service users with ID and symptoms of low mood who are taking part in a behavioural activation therapy study delivered by the researcher completed repertory grid interviews. These interviews explored carers' perceptions of their roles and are conducted prior to the start of the treatment. The repertory grid analysis will draw on the method described by Kelly (1955), and allows the key aspects of the carers' roles in relation to individuals' mental health problems to be identified and described.

Results: Initial analyses indicate that carer's 3 main roles in relation to the support of people with intellectual disabilities and mental health problems are i) being a listener, ii) supporting emotional well-being, and iiii) motivating clients.

Conclusions: The present study has implications with regard to providing sensitive and effective support for individuals with intellectual disabilities and mental problems, and support for staff carrying out these roles.

Advocating for services - Experiences & Concerns of family members of people with Intellectual Disabilities in Ireland

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Background: Families remain the primary providers of support for people with intellectual disabilities (ID) in Ireland. Despite this relatively few studies have investigated their primary concerns and looked at their experiences of working with services. This study presents selected findings from a mixed method study exploring the experiences and concerns of families of people with ID.

Methods: Focus groups with 70 family members explored their life experiences and were thematically analysed. From these themes a survey was constructed to identify the main concerns families had, this was distributed via post and available to complete online. 550 Families completed the survey responses were analysed to identify the primary concerns of family members.

Results: Most family members in the focus groups reported they had struggled to get services for their family members and that communication, relationships and attitudes of those working in services were less than ideal. However survey findings revealed that although having to fight and advocate was a major concern of family members, interrelationships with services was a concern for only a significant minority.

Conclusions: The families in the focus groups offered examples of when they felt things were working well with services and some strategies that had been successful and less successful when advocating for their family. It appears that in Ireland many services and families and families do not work well in partnership together and that family centred provision is still absent in many instances.

A visual aid to decision making for people with intellectual disabilities

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Background: Previous studies have shown that people with mild intellectual disabilities have difficulty in 'weighing-up' information, defined as integrating information from two different sources for the purpose of reaching a decision. This was demonstrated in two very different procedures, temporal discounting and a scenario-based financial decision-making task.

Methods: Both tasks were presented to 24 participants who attended day services for people with learning disabilities (mean Full-Scale IQ = 59.8), half of whom were trained to use a visual aid to support decision-making.

Results: Performance of control participants did not change over repeated testing, but use of visual aid substantially improved the quality of decision-making on both tasks: temporal discounting performance became more orderly, and participants were able to provide more information to justify their decisions in the financial decision-making task. The visual aid also substantially improved participants' ability to justify decisions they made about their own lives.

Conclusions: Use of the visual aid can help people with mild to moderate learning disabilities to increase the quality of reasoning that supports a decision. We suggest that the same technique may also have potential as an aid to therapeutic interventions aimed at encouraging wiser decision-making.

The Controllability Beliefs Questionnaire: Psychometric properties when used with carers of people with intellectual disabilities

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Background: The Controllability Beliefs Scale (CBS) was constructed to measure controllability attributions in carers of people with intellectual disability. The psychometric properties of the scale have so far only been reported in carers of older people (Dagnan et al, 2004) however it has been used in a number of studies of attribution of carers of people with intellectual disability (e.g. Kalsey et al, date; Dilworth et al, 2010). This paper describes the psychometric properties of this 15-item scale with carers of people with intellectual disabilities

Methods: Two hundred and fifty-five carers of people with intellectual disability completed the CBS; 72 people also completed the Self-Injury Behavioural Understanding Questionnaire (SIBUQ; Oliver et al, date), 54 completed the Attribution Style Questionnaire (ASQ; Dagnan et al, 1997), and 38 completed the scale twice within a two week period.

Results: The scale has good internal reliability (alpha = 0.89) and a two-factor structure representing positive and negative beliefs about controllability. The scale correlates negatively with behaviourally correct beliefs ($r = -.25$, $p < 0.05$), positively with internal emotional beliefs ($r = 0.46$, $p < 0.001$) both from the SIBUQ, and positively with the controllability scale of the ASQ ($r = 0.36$, $p < 0.01$). The scale has good test-retest reliability ($r = 0.87$, $p < 0.001$)

Conclusions: The scale has very good psychometric properties and measures a single construct in a clear structure; we discuss the use of this scale in clinical and research work.

What is the role and purpose of specialist community-based teams for adults with intellectual disabilities?

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Background: Specialist multi-disciplinary community teams providing assessment, treatment, and support for adults with intellectual disabilities were developed alongside the closure of the long-stay social care hospitals. Recent developments in policy and practice, such as the Primary Medical Services (Directed Enhanced Services) (England) (Amendment) Directions 2009, Putting People

First (HM Government, 2007); and Valuing People Now (Department of Health, 2009), however, have led to some uncertainty about the role and purpose of such specialist teams. To examine this we collected data on referrals to a service based in an English county (population: c. 600,000).

Methods: Case-note data on all new referrals over a period of three months were collected from the five locality-based teams within a community-based integrated NHS and local authority service for adults with intellectual disabilities.

Results: Overall, 291 referrals were identified. Most requests requiring responses from health practitioners in the teams were made for assessment and/or treatment, of mental health and/or behavioural difficulties, followed by support in activities of daily living, with some variation between teams. There were also large numbers of referrals to address the social care needs of men and women who, while probably intellectually disadvantaged, did not necessarily meet the criteria for access to specialist health services for people with intellectual disabilities.

Conclusions: While these referral data provide only a proxy measure of the work of a community-based specialist service, they permit preliminary consideration of the lack of clarity that exists as to the characteristics of, and reasons for, this form of provision for adults with learning disabilities.

Are the Effects of Early Intensive Behavioural Intervention Maintained Two Years After Treatment Cessation?

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Background: Little is known regarding whether the gains in functioning of children with autism produced by Early Intensive Behavioural Intervention (EIBI) are maintained after intervention has ceased. This study therefore followed up a followed up the children who participated in Remington et al. (2007) field effectiveness trial, 2 years after intervention ended.

Methods: Of the children who participated in the 2007 study, study 93% were reassessed on all psychoeducational and behavioural outcome measures.

Results: Intervention group (N=23) vs. Treatment as Usual (TAU) group (N=18) analyses revealed that gains from EIBI were not maintained after 2 years. However, because children had received either university-based (N=14) or parent-managed EIBI (N=9), further analyses explored subgroup outcomes. These revealed (a) that the former had regressed to baseline levels but the latter maintained the gains seen at termination. These differences may have arisen because the parent-managed group (a) had significantly higher baseline scores on IQ, adaptive behaviour, and autism symptoms than the clinic group and (b) had received many more hours of intervention.

Conclusions: Higher functioning children receiving relatively intense EIBI programmes main gain sufficiently from 2 years of intervention to maintain improvements in functioning for at least 2 further years. It is presently unclear whether more intensive or longer lasting interventions would produce similar benefits for lower functioning children.

PIMD: A critique of the social model.

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Background: People with profound intellectual and multiple disability are an almost invisible minority within a minority. By adopting a policy framework of Independence and Inclusion, it is possible the enduring care and support needs of these individuals, may be overlooked. The closure of Intensive Support Units , Day Centres and Respite Centres, to be replaced by informal community activities may not best serve people who need structured, consistent and ongoing therapeutic support ,such as physiotherapy , speech and language therapy , occupational therapy and psychological support for behavioural issues. These people cannot speak up about their needs, as might individuals with less severe learning difficulties. Nor can they participate in emancipatory research, due to the profound nature of their impairments. Hence, one of the main Aims of this study is to contribute to the scant amount of knowledge and in depth understanding of this minority group.

Methods: Qualitative, multiple and triangulated. Focus group discussions and semi-structured interviews were introduced by a short 10 min filmed sequence of an individual with PIMD ; carrying out tasks and activities aimed at illustrating the concepts of e.g. 'independence', 'choice' etc.

Results: The Interviews and Focus Groups already conducted, have demonstrated a strong mismatch between lay understandings of the policy concepts. Rights, Independence, Choice and Inclusion and social theoretical accounts. Critical discourse analysis of policy documents further illustrates these difficulties.

Conclusions: This Study will identify notions of diversity, i.e. diversity of intellectual functioning, as a possible way forward to accounting for individuals, described by Goodley (2001) as 'unaccounted for by sociological analysis'.

The Physical Health Needs of Adults with Intellectual Disabilities living in Residential Services.

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Background: Adults with Intellectual Disabilities (ID) have the same physical health problems as the general population. Research has also shown that adults with ID engage in the same “unhealthy behaviours” as typically developing peers.

Methods: Information from the “OK Health Check” (Matthews, 1997) was used to assess the physical health of 105 adults with ID, aged 18-81. In addition, information was collected on adaptive behaviour (ABAS: Harrison & Oakland, 2003), mental health needs (HoNOS-LD: Roy et al., 2002), depression (GDS-LD: Cuthill et al., 2003), behavioural problems (BPI: Rojahn, 2001; Reiss Screen: Reiss, 1986), and physical activity levels.

Results: The results show that all individuals have additional health needs requiring the use of medication and poly-pharmacy is common. Although annual health checks are completed on all adults with ID in Wales, very few (of those who are eligible) are receiving the well woman and well man checks. Using BMI 80% of the sample were classed as overweight or obese. The results from the physical activity measure suggest sedentary behaviour is common in this sample. Around half of the sample smoke cigarettes (average of 25 cigarettes a day).

Conclusions: This research suggests that more needs to be done to 1) increase the physical activity levels of adults with ID; 2) support individuals who are overweight or obese to loose weight, which would also reduce their risk of further physical health problems; 3) support those who with to stop smoking; 4) improve the uptake of well woman and well man checks by improving health promotion for adults with ID and supporting medical staff in Primary Care to carry out these assessments on a regular basis.

An investigation of physical activity in individuals with intellectual disabilities, with and without Down syndrome

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Background: Compared with the general population, individuals with intellectual disabilities (ID) experience higher rates of mortality, morbidity and also present with specific health problems, directly related to the aetiology of their disability. Worryingly, this is mirrored by low levels of physical fitness and high rates of obesity. Individuals with Downs syndrome (DS) experience higher rates of mortality and morbidity, and lower levels of physical fitness compared to their peers with ID without DS. The high rates of mortality and morbidity, and low levels of physical fitness found in individuals with ID, are often attributed to the fact that they are sedentary. However, there is very little data on the physical activity (PA) levels of individuals with ID, with and without DS.

Methods: The current study objectively measured the PA levels of 152 individuals with ID (79 with DS and 73 with ID without DS) aged between 13 to 70 years with mild to severe ID for 7 consecutive days with the Actigraph GT1M accelerometer.

Results: Results revealed only 3% of participants met current PA recommendations. There were also significant differences in PA levels between males and females, age groups, residential settings, employment/daytime opportunities and participants with and without DS.

Conclusions: In conclusion, this study confirmed that individuals with ID were not meeting PA recommendations and individuals with DS were significantly less physically active than their peers with ID without DS. Specific physiological abnormalities were found in individuals with DS that go some way to explain the low levels of PA found in this group.

An open study of the effectiveness of a multi-component weight loss intervention for adults with intellectual disabilities and obesity

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Background: Adults with intellectual disabilities experience high rates of obesity. Despite this higher risk, there is little evidence on the effectiveness of weight loss interventions for adults with intellectual disabilities and obesity. This study examined the effectiveness of the TAKE 5 multi-component weight loss intervention.

Methods: Adults with obesity using specialist intellectual disabilities services were invited to participate in the study. Obesity was defined as a body mass index (BMI) of 30 kg/m2 or greater. TAKE 5 included a daily energy deficit diet of 600 kilocalories (kcal), achieved via a personalised dietary prescription (PDP). Participants' body weight, BMI, waist circumference and levels of physical activity and sedentary behaviour were measured before and after the intervention.

Results: Fifty-four individuals consented to participate and 47 (87%) completed the intervention in the study period. There was a significant decrease in the body weight [mean difference -4.47 (95% confidence interval -5.91, -3.03) kg; $p < 0.0001$), BMI [-1.82 (95% confidence interval -2.36, -1.29)

kg/m2; p < 0.0001), waist circumference [-6.29 (95% confidence interval -7.85, -4.73) cm; p < 0.0001) and daily sedentary behaviour of participants [-41.40 (95% confidence interval -62.45, -20.35) minutes; p=0.00034). Seventeen participants (36.2%) lost 5% or more of initial body weight.

Conclusions: Findings from the study suggest that TAKE 5 is an effective weight loss intervention for adults with intellectual disabilities and obesity. The effectiveness of TAKE 5 should be examined further in a controlled study.

An Exploratory Study of the Perceptions of Prenatal Genetic Testing with Individuals with Down syndrome.

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Background: Prenatal genetic testing for Down syndrome is commonplace practice in the UK. There are various debates about the appropriate use of genetic technology, however the voice of individuals with Down syndrome is absent from the literature and subsequent policy decision making.

Methods: Four men and four women with Down syndrome, aged between 24 and 49, were interviewed about their perceptions of prenatal genetic testing for Down syndrome.

Results: Interpretative Phenomenological Analysis revealed three major themes with sub themes: 1) A devalued condition and a valued life, 2) A question of want and 3) Another woman' choice. Foucauldian Discourse Analysis of these themes highlighted three main discursive practices: 1) Social deviance, 2) Tragedy and catastrophe of the birth of a baby Down syndrome and 3) Sexuality and gender related discourse.

Conclusions: While the majority of the participants reported that any individual with Down could lead a valuable life, they advocated personal choice of prenatal tests. They highlighted the need for information about the condition to be given to prospective parents and also viewed testing as a means of allowing for preparation for a baby with Down syndrome. The study concluded that individuals with Down syndrome could meaningfully contribute to discussions about prenatal testing. It is not possible to assume that individuals with learning disabilities are unaware of prenatal testing and its implications, and in some cases this may lead to existential questions. Suggestions for future research are made.

Treatment resistant epilepsy in adults with an intellectual disability: a qualitative study of a three-way relationship between parent, clinician, and adult at risk of lacking capacity

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Background: Decision-making in clinician-patient consolations is at the core of health service reform and empirical research, as is substitute decision-making. Overlooked is the involvement of parents in clinical decisions where an adult patient may lack the capacity to make decisions about his or her own care or treatment.

Methods: Qualitative interviews with 21 mothers of adult children with an intellectual disability and treatment resistant epilepsy.

Results: Rather than actively pursuing improvements in treatment outcomes these mothers opt for a tolerable level of seizure activity, and contiguous with this is a marked reluctance to sanction changes in their son or daughters current medical treatment. This finding is corroborated by a single negative case. Evidence also suggests that the reluctance of these mothers to sanction treatment changes is a feature of actual clinical consultations, and that clinicians are willing to agree to, or at least assent to, these mother's wishes.

Conclusions: Opportunities for changing a disabled adult's treatment are being lost, and current law and policy seems insensitive to a mother's role as both career and parent.

Factors associated with usage of short breaks by families with a disabled child

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Background: Substantial investment has been made in increasing the quantity and diversity of short breaks for families with a disabled child in England. This study examines family usage of short breaks across 23 local authorities in England who have received additional investment for short breaks.

Methods: Survey questionnaires covering child and family characteristics, the health and well-being of family members, and family usage of and satisfaction with short breaks, were completed by 336 main carers of a disabled child, 91.9% of whom were reported to have learning disabilities.

Results: Families reported using an average 570 hours of short breaks per year, although there was massive variation in the quantity and nature of short breaks used by families and in how these short breaks were funded. Overnight and centre-based short breaks provided families with more hours of support and were more likely to be used by children who were older, had more complex disabilities, health needs and physical needs, but less actively challenging behaviour. In contrast, leisure-based and non centre-based short breaks offered fewer hours of support to families of children with less complex disabilities, health and physical needs, but more actively challenging behaviour, and were more likely to be used by lone parents and more highly educated carers. Across almost all types of short breaks, families in less financially and materially deprived circumstances had greater access to short breaks.

Conclusions: Even with additional investment, local authorities need to ensure that short break supports are equitably matched according to the needs of children and families.

Down Syndrome and Alzheimer's disease: The views of siblings

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Background: The present study explored the experiences of siblings of people with Down syndrome and probable Alzheimer's disease. In particular, the research examined the impact on the family when they were told about their relative's diagnoses (both the initial diagnosis of Down Syndrome and the later diagnosis of probable Alzheimer's disease).

Methods: Seven people were interviewed and the data were analysed using a grounded theory methodology.

Results: Three categories were identified: Loss, Continuing Care and Service Issues. Responses to the diagnosis of AD were similar to those surrounding the original diagnosis of DS. Feelings of loss and sadness were followed by a scepticism about the value of services and a conviction that whatever care was needed would be provided by the family. At this stage, however, the pressure on older family caregivers (mainly sisters) and the deteriorating nature of AD meant a necessity to engage with services despite this scepticism.

Conclusions: Services need to be aware that many people with DS and AD had their first contact with services in the 1950s and many attitudes towards services reflect this historical perspective.

Abstracts Paper Session 6 : Care Staff Perceptions

Mechanical Restraint: Impact on staff

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Background: Some clients with intellectual disabilities engage in severe self injurious behaviour and have MR in their behavioural support plans. However, the impact on support staff applying the restraints has not been investigated.

Methods: Interviews were carried out with support staff working with service users who engage in severe self injury and have MR in their care plans. The interviews were analyses using content analysis using emergent coding.

Results: All participants described the use of MR as having a negative impact on them. They were concerned as to the public reaction to their use in the community. There were also concerns about training and whether alternatives could be found.

Conclusions: Staff work with clients who have MR in their care plans generally describe this aspect of their job as having a negative impact at and out of work. The study also raised several concerns about the lack of support and training for care staff. Recommendations for practice are made.

Evaluating Formulation Development Workshops with Direct Care Staff in Intellectual Disability Services

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Background: A biopsychosocial approach was developed to inform assessment and treatment within an NHS service for people with Intellectual Disabilities who display significant psychological problems. This involved supporting direct care staff to develop a deeper understanding of their clients through Formulation Development Workshops. Staff were introduced to the concept of formulation and facilitated in development of a formulation for the client they were supporting. Workshops were held for clients within the service and were evaluated primarily using a novel measure aimed at capturing staff understanding of a client (Formulation Understanding Measure, FUM).

Methods: A repeated-measures design was utilised (n=114). Participants completed the FUM before and after each workshop. The Helpful Aspects of Workshops Questionnaire (HAWQ) was also completed following each workshop.

Results: A paired samples t-test was carried out to compare scores on the FUM pre and post Formulation Development Workshops. On average, staff understanding of clients increased from pre (M= 56.55, SE= .854) to post workshop (M= 65.11, SE= .847, $t(112) = -9.40$, $P<.001$). Furthermore, data from the HAWQ indicated that the workshops were positively received and staff found them beneficial.

Conclusions: Staff reported having a better understanding of clients following Formulation Development Workshops as measured by the FUM. More specifically, they reported greater

knowledge of the individual, more empathy for the person, and more confidence in working with them. These findings were positive and supported the use of these workshops to enhance staff understanding of clients. Limitations of the study will be discussed alongside a proposal for future research and clinical implications

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Avoiding the F-word (Friendship): Care workers talk about the personal relationships of people with profound disabilities

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Background: Friendship is widely thought of as contributing to human flourishing. The national learning disability strategy makes it clear that people with learning disabilities, including those with profound disabilities, should be supported to form and maintain friendships. As part of an ethnographic study into the significance of friendship in the lives of people with profound disabilities, we are investigating how care workers talk about their profoundly disabled clients' personal (and non-familial) relationships.

Methods: Transcripts of interviews and notes of discussions with care workers were analysed using an approach based on discourse analysis.

Results: Some care workers avoid talking about the personal relationships of people with profound disabilities in terms of 'friendship'. Instead, they describe relationships between people with profound disabilities and nondisabled people in terms of 'befriending' or 'advocacy'. Relationships amongst people with disabilities are talked of as 'bonds' or sometimes 'peer relationships'. Where 'friendship' is used, its force as a descriptor is often attenuated by the language which surrounds it.

Conclusions: These results could reflect care workers' unease with the idea of friendship in the context of profound disability, or, alternatively, the relative power of 'professional' discourse in care practice. Avoiding the f-word may have practical consequences in the lives of people with profound disabilities. ˜Peer relationships and ˜bonds' arguably have less status and so may be supported less than ˜friendships'. Relationships between people with profound disabilities and nondisabled people may not be approved by care services unless formalised as quasi-professional 'befriending' or 'advocacy' relationships.

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