18th Seattle Club Conference Programme

Hosted by members of the School of Psychology, University of Birmingham and the Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick

at University Centre Shrewsbury

3rd and 4th December 2018

http://seattleclubconference.org/conferences.html
Welcome

We are very pleased to be able to welcome you to the University Centre Shrewsbury for the 18th annual Seattle Club conference for research on intellectual and developmental disabilities. We hope that the two-day programme will provide you with the ideal opportunity to hear about new research within the field of intellectual and developmental disabilities and to network with colleagues working in this field. We have tried to schedule the talks and posters to provide as much opportunity for networking as possible and the conference meal on Monday evening also provides the perfect chance to make new connections and forge future collaborations (as well as catch up with old friends!)

In keeping with the Seattle Club theme, we have kept the conference small (we are expecting around 80 delegates) and only active researchers attend the conference. We have supported some excellent early career researchers to attend on studentships and the conference has just one session (no parallel sessions) so that everyone can attend all presentations. This year we have one large poster session on Monday in the late afternoon.

We hope that you will find the conference intellectually stimulating and enjoy your time in Shrewsbury. We have an excellent team of postgraduate helpers who are on-hand to assist you during the two day conference so please just ask if you have any questions or need assistance.

Conference Meal

Your conference registration includes the conference meal on the evening of Monday 3rd December and this will take place in the historic Lion Hotel in Shrewsbury. We are pleased to be able to bring you a 3-course sit down meal (with wine!) that will begin at 7.30pm. The hotel has also provided us with bar facilities after the meal. See page 46 for further details (e.g. map) for the conference meal.

Best wishes
Biza Stenfert Kroese
Samantha Flynn
Organising team
DAY 1: Monday 3rd December

9.30AM Arrival and registration (Business Lounge)

10AM Welcome: Prof Anna Sutton, University Centre Shrewsbury (room SGH026)

SESSION 1 Chair: Samantha Flynn (room SGH026)

10.10AM Morag Ritchie - The Challenge of Navigating Complex Sexual Risk while Promoting Sexual Rights in People with Learning Disabilities in Cumbria

10.30AM Elisabeth Gale - Female experiences and behavioural presentations of Autism Spectrum Conditions: A Systematic Review

10.50AM Claire Bates - The Love Project: exploring support for people with Intellectual and Developmental Disabilities (IDD) to find loving relationships

11.10AM Tea/coffee (Business Lounge)

SESSION 2 Chair: Andrew Jahoda (room SGH026)

11.30AM Fran Mooney and Samantha English - Getting involved in the community - what stops us; findings from an inclusive research project

11.50AM Elisa Vigna - Outcomes of the Engage to Change Project- supported employment for young people with a learning disability or ASD

12.10PM Liz Tilly - Transfer of DLA to PIP; implications for people with a mild learning disability

12.30PM Lunch (Room SGH019)

SESSION 3 Chair: Katie Cebula (room SGH026)

1.30PM Darren Chadwick - Experiences of online support group use by family carers of people with intellectual disabilities
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<tr>
<td>1.50PM</td>
<td>Molly Batchelor</td>
<td>“They just get it”: An exploration of fathers’ experiences of a support group for men caring for children with disabilities and/or developmental delay</td>
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<td>2.10PM</td>
<td>Amanda Gillooly</td>
<td>Siblings of Children with Williams Syndrome: Factors associated with psychosocial adjustment and sibling relationship quality</td>
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<td>2.30PM</td>
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**SESSION 4**  
Chair: Biza Stenfert Kroese (room SGH026)

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<tr>
<td>3PM</td>
<td>Georgie Agar</td>
<td>The Prevalence and Profile of Sleep Difficulties in Rare Genetic Syndromes: A Meta-Analysis</td>
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<tr>
<td>3.20PM</td>
<td>Concepcion Padilla</td>
<td>Mapping Amyloid Deposition and Cortical Atrophy across the Down’s Syndrome’s Brain: A Longitudinal Study</td>
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<td>3.40PM</td>
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**SESSION 4**  
4th DAVID FELCE LECTURE  
Chair: Prof. David Felce (room SGH026)

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<tr>
<td>3.50PM</td>
<td>Professor John Rose</td>
<td>Is it possible to effectively treat sex offenders with an intellectual disability?</td>
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**SESSION 6**  
POSTER SESSION (room SGH019)

*Please add your posters to poster boards, or give your poster to a member of the organising team, by the end of lunch (12.30pm – 1.30pm).*

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<tr>
<td>4.40PM</td>
<td>Poster session</td>
<td>commences (with wine)</td>
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*Evening meal arrive for 7.15pm to be seated for 7.30pm meal – The Lion Hotel, Shrewsbury*
**POSTERS: Monday 3\textsuperscript{rd} December**

**Nigel Beail** - Development and Psychometric Properties of the Psychological Therapies Outcome Scale – Intellectual Disabilities (PTOS-ID) carer/informant version

**Jane Bernal** - End of life care and Down Syndrome

**Naomi Broadhead** - Promoting IAPT therapists’ knowledge and confidence in working with people with Intellectual Disabilities

**Laura Brougham** - Exploring the ability of individuals with an Intellectual Disability to generate and use a compassionate image

**Susan Buell** - A review of diagnostic and education services to children with autism in Bolivia

**Jon Codd** - Having a child with an intellectual disability transition to adulthood: A parental perspective.

**Kirsty Dunn** - A systematic review and meta-analysis on the mental health of fathers of a son/daughter with intellectual disabilities

**Nicola Elson** - School/college perspectives on the transition from residential education to adult support

**Nikita Hayden** - Supporting siblings of children with a disability: an evaluation of Sibs Talk, a one-to-one intervention delivered by mainstream school staff

**Olivia Hewitt** - A Systematic Review of IPA Studies Exploring the Experiences of Parents who have a Child with an Intellectual Disability

**Chloe Hurrell** - Designing the optimal model for transition from child to adult services for young people with disabilities and/or developmental difficulties

**Chrysovalanto Kyriacou** - Clothes, sensory issues and people with Autism: is wearing the right fabric important?

**Peter McGill** - Young people with learning disabilities / autism leaving residential school in England – what happens and where do they go?

**Sinead Morrison** - Developmental cognitive trajectories in 22q11.2 Deletion Syndrome

**Edward Oloidi** - Public perceptions of sexual relationships and intellectual disabilities: researching the influence on social care workers’ attitudes, beliefs and behaviours: stage one

**Linda O’Neill** - The mediating effect of self-esteem upon the relationship between anxiety and depression in adult siblings of individuals with developmental disabilities
Ciara Padden - Experiences of adults with intellectual and developmental disabilities receiving life skill training

Liz Randell - SenITA: A pragmatic RCT of sensory integration therapy for children with sensory processing difficulties and ASD.

Kelly Rayner - ‘Big Feelings’: Adapted DBT Skills Groups for People with Learning Disabilities

Rebecca Reid - Walking The Line: Educating People with Learning Disabilities on Sex, Relationships and Internet Use

Victoria Stafford - Survey of Staff Support and Trauma in Relation to Challenging Behaviour

Catherine Stanford - Relationships between maternal psychological distress and child externalising behaviour in neurodiverse families

Julie Sutton - Sleep hygiene education (SHE) and children with developmental disabilities (DD). Findings from an experience based co-design (EBCD) study.

Leah Vano - A Systematic Review: The Efficacy of Using the Periodic Service Review in Service’s Supporting Adults with Intellectual and Developmental Disabilities

Kelly Wade - Developing an observer checklist to detect gastric distress in non-verbal children with Intellectual Disability

Francesca Wicks - Recruitment of 2600 individuals to Intellectual Disability and Mental Health: Assessing the Genomic Impact on Neurodevelopment (IMAGINE ID) Study

Katie Williams - Improving Service Response to Sexual Exploitation of People with a Learning Disability: Exploring professionals’ experiences.

Grace Woolway - Exploring Psychiatric Comorbidities in the National Centre for Mental Health (NCMH) Learning Disability Cohort.
### DAY 2: Tuesday 4th December

#### SESSION 7  
**Chair:** Peter McGill  *(room SGH026)*

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<th>Time</th>
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<tr>
<td>9.30AM</td>
<td>Emma Jackson</td>
<td>Are Behaviour Support Teams interventions leading to quality of life improvements for adult service users with intellectual disabilities across community teams?</td>
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<tr>
<td>9.50AM</td>
<td>Faye Banks</td>
<td>Exploring the role of informal culture for direct care staff providing support to people with intellectual disabilities</td>
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<tr>
<td>10.10AM</td>
<td>James Clarke</td>
<td>'He Meant to Do That': A study of factors that influence the perception of behaviours from individuals with intellectual disabilities, as challenging or offending</td>
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<td>10.30AM</td>
<td>Serena Tomlinson</td>
<td>Family carer and professional perceptions of the use of telehealth methodology for behavioural support for people with intellectual / developmental disabilities in the UK</td>
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<td>10.50AM</td>
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<td>Tea/coffee  <em>(Business Lounge)</em></td>
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#### SESSION 8  
**Chair:** Deborah Kinnear  *(room SGH026)*

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<tr>
<td>11.20PM</td>
<td>Amy Russell</td>
<td>The REMAIN project: Development of REsources based on reasonable adjustments to MAINstream diabetes and obesity care for adults with a learning disability</td>
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<tr>
<td>11.40PM</td>
<td>Stuart Todd</td>
<td>Forgotten lives, lost deaths: People with ID living and dying in non-ID care settings</td>
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<td>12PM</td>
<td>Katrina Scior</td>
<td>Intellectual Disability Stigma and Initiatives to Challenge it around the Globe</td>
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<tr>
<td>12.20PM</td>
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<td>Lunch  <em>(room SGH019)</em></td>
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#### SESSION 9  
**Chair:** Nigel Beail  *(room SGH026)*

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<tr>
<td>1.20PM</td>
<td>19th Annual Seattle Club Conference Announcement: Richard Hastings</td>
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<tr>
<td>1.25PM</td>
<td>Dave Dagnan</td>
<td>Psychometric properties of PHQ-9, GAD-7 and WSAS when used with people with intellectual disabilities within an IAPT service</td>
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<td>1.45PM</td>
<td>Vaso Totsika</td>
<td><strong>Social well-being of children with an intellectual disability: the role of parental investments in the early years</strong></td>
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<td>2.05PM</td>
<td>Paul Willner</td>
<td><strong>Protocol for a randomized controlled trial of EMDR for people with ID and PTSD</strong></td>
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<tr>
<td>2.25PM</td>
<td>Thanks for coming:</td>
<td>Richard Hastings</td>
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Studentships

Each year at the Seattle Club conference, organisers allocate a number of non-presenting places for researchers who do not yet have data to present. These individuals are early in their intellectual disability research journey and might include postgraduate students, research assistants, professional trainees engaging in research, and practitioners starting research projects.

This year’s Studentship holders, their academic affiliations, and research interests are listed below:

**Rebecca Cooper** [University College London] - Becky is an early career researcher currently in the final year of her Doctorate in Clinical Psychology. For her doctoral thesis Becky is assessing the long-term outcomes of 'Standing up for Myself' (STORM), a psychosocial group intervention designed to enhance the capacity of people with ID to manage and resist stigma.

**Mary Drozd** [University of Wolverhampton] - Mary's research focuses on people with an intellectual disability who have experienced orthopaedic or trauma hospital care. Musculoskeletal conditions and injuries are more prevalent in people with an intellectual disabilities with more complex cases involving potential surgical interventions. Her research will focus on the experiences of people with intellectual disabilities of such hospital treatment and the experiences and perceptions of nurses of providing such care to this group of people. She has completed her data collection for her first study but has yet to finish her analysis and is currently writing her literature review.

**Steve Easter** [Tizard Centre, University of Kent] - Steve’s research is focused on young people with intellectual and development disabilities (IDD) enabling them to express their views about citizenship. The research process will explore the extent that a sample local support services, have adapted evidence based practice, to enable the implementation of citizenship outcomes.

**Melanie Howell** [Tizard Centre, University of Kent] - Melanie's research aim is to develop and test an assessment tool to be used by teachers of pupils with autism in special schools. The focus of the assessment will be to enable teachers to show pupil progress in areas outside of or alongside the usual curriculum assessments. The research aims to address the gap in conventional assessments currently used in special schools, many of which often do not take account of the specific difficulties associated with autism.

**Andrea Thomas** [University of Birmingham] - Andrea is a first year PhD psychology student at the University of Birmingham. She started her PhD 1st October 2018 and therefore does not yet have data to present. Andrea will be researching the behavioural phenotype of CHARGE syndrome under the supervision of Dr. Caroline Richards and co-supervision of Prof. Chris Oliver, School of Psychology, the University of Birmingham.

Welcome to the Seattle Club, and we look forward to hearing more about your research at future conferences.
Is it possible to effectively treat sex offenders with an intellectual disability?

Prof. John Rose
Consultant Clinical Psychologist
School of Psychology, University of Birmingham
& St Andrews Health Care

The efficacy of interventions for men who sexually offend has received considerable attention particularly after a recent study investigating the outcomes of prison based sex offender treatment programmes suggested that programmes do not reduce offending and may have a negative impact on participants. This result was established using composite data for nondisabled prisoners across a large number of programmes and the results received national coverage in the press for several weeks in 2017. A number of changes have been made to prison programmes as a result.

The sex offender treatment programmes provided to people with an intellectual disability are largely based on adapted mainstream programmes. The outcome literature specific to men with intellectual disability is modest in comparison however there are now sufficient studies to consider whether these interventions are effective. The nature of the interventions for people with intellectual disabilities will be described and their impact on participants considered. The data from studies involving men with intellectual disabilities will then be set in the context of what we know from research with nondisabled sex offenders. By broadening our approach in this way it is possible consider what are likely to be the most effective approaches and to set a clear agenda for research and developing effective treatment in the future.
Session 1

Presenter: Morag Ritchie
Title: The Challenge of Navigating Complex Sexual Risk while Promoting Sexual Rights in People with Learning Disabilities in Cumbria

Email: M.Ritchie2@newcastle.ac.uk
Affiliation: School of Psychology, Newcastle University
Co-authors: Kelly Rayner (Cumbria Partnership NHS Foundation Trust)

Background: Caregivers are known to experience challenges in managing risk while promoting sexual rights (Rushbrooke, Murray & Townsend, 2014). In Cumbria, service providers sought support from the community learning disabilities team to help navigate these issues. As part of wider service development, this project explored staff attitudes and readiness to enable their clients to access an area of their lives that has historically been neglected.

Methods: Nine members of staff across two sites from a service providing residential support for people with learning disabilities and complex mental health and/or forensic needs were interviewed individually using a series of vignettes. These generated discussion around issues of consent, capacity, risk, and personal views/attitudes. Thematic Analysis was used to analyse the transcripts.

Results: Four key themes emerged. 1. Sex and relationships an intrinsic need. 2. Safeguard from harm. 3. Tension between personal and professional views. 4. Fear and uncertainty. Staff unanimously held the view that promoting sexual rights among their clients was important. In navigating the challenge this brings, they expressed concern for service users’ vulnerability, fears about positive risk taking going wrong, difficulties reconciling a person’s right to make unwise decisions with their personal views, and a lack of confidence in managing these complexities.

Conclusions: This study highlighted the willingness of staff to promote the sexual rights of their clients and their openness to receiving training in this area, whilst also acknowledging that the personal and professional tensions the subject can engender can create barriers to facilitating these rights. Implications for training and supervision are discussed.

Presenter: Elisabeth Gale
Title: Female experiences and behavioural presentations of Autism Spectrum Conditions: A Systematic Review

Email: eeg6@kent.ac.uk
Affiliation: Tizard Centre, University of Kent
Co-authors: Jill Bradshaw (Tizard Centre, University of Kent), Fiona Gullon-Scott (Tizard Centre, University of Kent), Peter Langdon (Tizard Centre, University of Kent)

Background: Females are typically diagnosed less and later than males. There is little consensus regarding female presentations of autism. This research explored the presentation of autism in adolescent and adult females, with particular focus on experiences and behavioural presentations.

Methods: A systematic review of the literature was conducted. Four databases were searched. The search terms included autism*, female, women and girl. Inclusion criteria: Adult/Adolescent participants, all research designs (except case studies), peer-reviewed, focusing on experiences or behavioural presentations. Papers on genetics and cognition were excluded.
Results: Twenty-three papers were included. Differences in diagnosis and presentation were explored. As females are generally expected to be more socially skilled than men, autistic women reported less acceptance of their social difficulties. Camouflaging and imitation were specific coping strategies that developed. Females were reported to have fewer identified repetitive/restricted interests but it remains unclear whether repetitive/restricted interests are present but less likely to be identified. Females reported higher levels of mental health difficulties.

Conclusions: Improvement in awareness of female presentations, and access to diagnostic pathways may improve with screening tools that are designed to identify people (including women) who are more difficult to diagnose, taking into account issues identified above.

Presenter: Claire Bates
Title: The Love Project: exploring support for people with Intellectual and Developmental Disabilities (IDD) to find loving relationships

Email: c.bates@kent.ac.uk
Affiliation: Tizard Centre, University of Kent
Co-authors: Michelle McCarthy (Tizard Centre, University of Kent), Rachel Forrester-Jones (Tizard Centre, University of Kent), Karen Milne-Skillman (Tizard Centre, University of Kent), Nicola Elson (Tizard Centre, University of Kent), Siobhan Hunt (Tizard Centre, University of Kent).

Background: Everyone has the right to a loving relationship but people with intellectual and developmental disabilities (IDD) frequently experience challenges in this area. The aim of this research project is to explore different models of relationship support currently in use in the UK, with a particular focus on the use of specialist dating agencies for people with IDD, as well as support provided by family carers and social care staff, including the development and maintenance of relationships.

Methods: Semi-structured interviews with 40 adults with IDD. Interviews with personnel from 10 dating agencies who specialised in supporting adults with IDD. Four focus groups were conducted with 27 social care staff who were either support workers or frontline managers.

Results: Initial emerging themes suggest that adults with IDD experience difficulties in both forming and maintaining loving relationships. Adults with IDD are often able to identify the support they require surrounding relationships and the barriers they face in establishing and maintaining them. Staff provide substantial support to enable people with IDD to find an appropriate partner but also to develop the nuanced social skills necessary to develop and maintain them. Staff often raised concerns regarding safeguarding and risk and also reported a lack of training or polices to support them.

Conclusions: The results of this study will contribute to our understanding of the supports available to, and required by, adults with IDD to find and sustain loving relationships and how social care providers can best support people in this area.
Session 2

Presenter: Fran Mooney and Samantha English
Title: Getting involved in the community - what stops us; findings from an inclusive research project

Email: liz@building-bridges-training.org
Affiliation: Building Bridges Research Group
Co-authors: Nazia Rafique (Building Bridges Research Group), Satnam Singh (Building Bridges Research Group), Vanessa Hulbert (Building Bridges Research Group).

Background: Tackling social exclusion which can lead to social isolation and loneliness is an important current issue. People with a learning disability have a right to be full members of their communities, yet often experience social exclusion. It is therefore important to know what the barriers that prevent their full inclusion.

Methods: A group of researchers with a learning disability held three focus groups to identify some of the barriers to getting involved in local community activities and events. They used pictorial cards to analyse the data, and thought about some ways forward based on the findings.

Results: Most people had some experience of participating in local events and found people there to be welcoming and supported their inclusion. The main issues that prevented wider community engagement related to fear of harm in the wider community, anxiety, challenges of travelling independently, family barriers, and lack of accessible information about what is available locally. Money, i.e. disposable income needed to participate was also an issue for some people.

Conclusions: There needs to be more accessible (easy read) information available in community venues such as the doctors. There needs to be wider use of the safe places scheme and more initiatives to support community safety whilst travelling to places.

Presenter: Elisa Vigna
Title: Outcomes of the Engage to Change Project- supported employment for young people with a learning disability or ASD

Email: vignae@cardiff.ac.uk
Affiliation: NCMH - Cardiff University
Co-Authors: Stephen Beyer (NCMH - Cardiff University), Andrea Meek (NCMH - Cardiff University)

Background: The Engage to Change project helps young people with a learning disability or ASD in Wales to get placements and paid jobs, using supported employment and internship methods. The paper presents data on placement and job outcomes over two years of E2C operation.

Methods: Data was collected on 340 young people registering on Engage to Change over two years, on the placements they attended and the paid jobs they achieved. The nature and level of job coach involvement was collected and related to outcome. Data was collected on iPads by job coaches for everyone on the project. Research interviews were conducted with a 10% sample of young people reaching the placement and employment stage and with their families.

Results: The results describe the variety of jobs people are employed in and how the Engage to Change project impacts on young people, families and employers. The results so far suggest that there are positive relationships between job outcomes and hours of job coach input, time spent on job finding, and workplace support.
Conclusions: Job coach solutions can improve vocational skills, engage employers positively and gain paid jobs for people with a learning disability and/or ASD. Job coaching needs to be delivered at particular levels and incorporate key actions if it is to be successful. Strategies for changing investment to “what works” are briefly discussed.

**Presenter:** Liz Tilly  
**Title:** Transfer of DLA to PIP; implications for people with a mild learning disability

**Email:** Liz.Tilly@wlv.ac.uk  
**Affiliation:** University of Wolverhampton

Background: The Department for Work and Pensions (DWP) has changed its main disability welfare benefit from DLA (Disability Living Allowance) to PIP (Personal Independence Payment). This research project explored whether people with a mild learning disability lost or gained disability welfare benefit income following their reassessment, due to there being no replacement for the DLA ‘low rate’ care component in PIP. The research project also explored whether access to and type of support received during the reassessment process affected the assessment outcome. This hidden population already face financial hardship due to the combined effect of not being eligible for learning disability services, living long-term on welfare benefits and having poor budgeting skills.

**Methods:** 17 people with a learning disability completed a questionnaire about their DLA and PIP rates, and the level and type of support they received, and later shared their PIP assessment results and scores. Case studies were also compiled from the participant’s accounts of their personal assessment journey and how they experience it.

**Results:** 14 people retained or gained increased disability benefit income following their assessment. Three people were allocated no points and needed to appeal at a benefits tribunal. Most people found the experience of assessment to be very stressful.

**Conclusions:** This small research project found most people with a mild learning disability have maintained or increased their disability welfare benefit after the transfer to PIP. However it indicates the importance to have practical and emotional support to complete the PIP assessment form and attend the assessment.

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**Session 3**

**Presenter:** Darren Chadwick  
**Title:** Experiences of online support group use by family carers of people with intellectual disabilities

**Email:** d.chadwick@wlv.ac.uk  
**Affiliation:** University of Wolverhampton  
**Co-authors:** Rachel Mackley (University of Wolverhampton).

Background: Carers of people with intellectual disabilities (ID) may face considerable challenges, stresses and caregiver burden which can affect their wellbeing. Use of online support groups (OSG) may help mitigate these challenges. However, despite its increased availability and use, little research has focussed upon the use of OSG by family carers of a person with an intellectual disability. This investigation aimed to explore the experiences of family carers of OSG use and how use served to enhance and hinder emotional wellbeing and support.
Methods: A cross-sectional online survey gathered self-report qualitative and quantitative data regarding motivations to use OSG, OSG use, and positive and negative experiences of using OSGs from a self-selected sample of carers of people with ID. Data was analysed descriptively and using thematic network analysis.

Results: Seeking online information, belonging and support were primary motivators for OSG use. Thematic network analysis of the qualitative data uncovered support as a global theme, comprising positive organising-themes of belonging/connectedness, information sharing, support seeking and convenience as aspects of OSG use and motivations for using OSG. The additional organising theme, negative interactions characterised more negative experiences of OSG use.

Conclusions: Carers of people with ID can accrue support benefits from OSG use, including emotional, networking, informational and esteem supports. However these online forums are not without their challenges with carers reporting some negative experiences when using OSG. Suggestions for reducing more negative OSG experiences are provided.

Presenter: Molly Batchelor
Title: “They just get it”: An exploration of fathers’ experiences of a support group for men caring for children with disabilities and/or developmental delay

Email: molly.batchelor@wales.nhs.uk
Affiliation: Sparkle Serennu Children’s Centre

Background: Support groups are available to parents/carers of a child with a disability or developmental delay (DDD), but are predominately attended by mothers and provided by women, with a lack of support for fathers. This research aims to explore the perceived value and experiences of men who attended a father’s psychological support group.

Methods: All 15 members from a monthly group for fathers/male carers of children with DDD were invited to take part in semi-structured qualitative interviews, of which seven participated (attendance duration 1-48 months). Interviews were recorded and transcribed. The data was analysed following Braun and Clarke’s (2006) thematic analyses framework.

Results: Preliminary themes included i) belonging, ii) support, iii) problem-solving, iv) socializing, and v) male-identity. Fathers perceived a sense of exclusion at multiple levels; from support groups dominated by women, from society by having a child with DDD, from conversation of dads of non-disabled children. Perceptions were that dads group helped address these needs by providing the opportunity to receive and give support to others, a social experience with men in similar situations and permission to talk about how they feel as fathers. Elsewhere, there was often a pressure to fulfill the traditional role as protector of their family, while their own needs were not addressed.

Conclusions: Accounts of fathers revealed that current support groups may be neglecting the needs of fathers, where issues around parenting are often gender specific, which fathers cannot relate to or be involved in. There are potential benefits in providing a fathers psychological support group more widely.

Presenter: Amanda Gillooly
Title: Siblings of Children with Williams Syndrome: Factors associated with psychosocial adjustment and sibling relationship quality

Email: amanda.gillooly@ed.ac.uk
Affiliation: University of Edinburgh
Co-authors: Katie Cebula (University of Edinburgh), Deborah Riby (Durham University), Laura Coulthard (Durham University), Richard Hastings (University of Warwick).
Background: Outcomes for neurotypical siblings of children with developmental disabilities can be influenced by family demographic and psychological variables, as well as by the behavioural phenotype of the child with a developmental disability. To date, this has not been explored in relation to Williams syndrome (WS). This questionnaire study examined the demographic, psychological, and phenotypic predictors of the behavioural adjustment, well-being, and relationship quality of siblings of children with WS.

Methods: 41 mothers and 30 neurotypical siblings (6-18 years; 23F7M) of children with WS (4-17 years; 26M15F) participated in the study. Parents and siblings completed questionnaires measuring: social functioning, anxiety, behavioural and emotional adjustment of the child with WS and the neurotypical sibling; quality of the sibling relationship; social support and parental wellbeing.

Results: According to parent report, sibling behaviour \( t(28) = -1.09, \text{NS} \) did not differ from the normative population, but sibling anxiety was higher \( t(29) = 2.20, \text{p = .036, d = .42} \). Sibling self-report on behaviour did not differ from the normative population \( t(29) = .52, \text{NS} \), but self-report anxiety was higher \( t(29) = 5.15, \text{p < .001, d = .81} \). The parent-reported behavioural adjustment of siblings was associated with the behaviour \( r = 0.44, \text{p = 0.005} \), and social functioning \( r = 0.40, \text{p = 0.01} \), but not the anxiety \( r = 0.16, \text{NS} \) of the child with WS.

Conclusions: The current findings emphasise the need to take both a behavioural phenotypic and a family systems approach to understanding the developmental outcomes of neurotypical siblings of children with WS.

Session 5

Presenter: Georgie Agar

Title: The Prevalence and Profile of Sleep Difficulties in Rare Genetic Syndromes: A Meta-Analysis

Email: gxa295@student.bham.ac.uk

Affiliation: Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham

Co-authors: Chloe Brown (School of Psychology, University of Birmingham), Sean Coulborn (School of Psychology, University of Birmingham), Chris Oliver (Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham), Caroline Richards (School of Psychology, University of Birmingham).

Background: Sleep difficulties are reportedly more common in people with intellectual disability (ID) than in people of typical development (TD). This is likely driven by the inclusion of people with genetic syndromes in ID populations. Therefore, synthesising the prevalence and profile of specific sleep problems in genetic syndromes will further our understanding of ‘risk’ and aetiology of sleep problems in ID. Synthesis of these data will also progress our understanding of syndrome-specificity, and within/between syndrome heterogeneity.

Methods: The method followed PRISMA guidelines for meta-analysis. 31,838 references were identified through literature searching for sleep terms in 22 syndromes. After initial abstract screening, 550 articles underwent full-text screening for inclusion and quality. 213 papers were included, producing a total of 372 prevalence estimates across five ICSD-defined sleep problems as well as ‘general’ sleep difficulties.

Results: Quality-effects models were calculated for prevalence of each sleep problem in each syndrome. Sleep disordered breathing, excessive daytime sleepiness, sleep bruxism and ‘general’ sleep difficulties were heightened in specific syndromes. However, none of the syndrome groups were more or less likely to experience insomnia or sleep enuresis, suggesting equivocal genetic vulnerability.
Conclusions: Taken together, the differing prevalence rates for each type of sleep difficulty suggest differing potential causal mechanisms. These will be discussed alongside the quality of evidence. The results highlight the need for a more detailed ‘syndrome-specific’ sleep profile to be considered as part of assessment and intervention for sleep difficulties. Where the meta-analysis has highlighted a lack of robust syndrome-specific sleep data for rarer syndromes, further research is warranted.

Presenter: Concepcion Padilla
Title: Mapping Amyloid Deposition and Cortical Atrophy across the Down’s Syndrome’s Brain: A Longitudinal Study

Email: cfp31@medschl.cam.ac.uk
Affiliation: University of Cambridge
Co-authors: Elijah Mak (University of Cambridge), Tiina Annus (University of Cambridge), Madeleine J. Walpert (University of Cambridge), Shahid H. Zaman (University of Cambridge), Anthony J. Holland (University of Cambridge).

Background: Down’s syndrome is a genetic disorder caused by the triplication of the chromosome 21. The extra copy of the amyloid precursor protein gene localized in this chromosome leads to an overproduction of the beta-amyloid protein, which has been linked with a high risk of developing Alzheimer’s disease in people with DS, usually showing their first clinical symptoms in their forties (Holland et al., 1998).

Methods: We used PET imaging with 11C-labelled Pittsburgh Compound-B radioligand for measuring beta-amyloid accumulation and structural MRI to investigate the consequences of amyloid burden on cortical morphology in a cohort of 11 adults with DS (aged 34 - 51). These participants took part in our study at baseline and after a two-year follow-up. We investigated the global and region-to-region relationships between the baseline amyloid deposition and the change in cortical thickness over two years.

Results: After two years there was a pronounced decrease in temporo-parietal cortical thickness and an increase in thickness in the frontal cortex. Conversely, the amount of amyloid deposition at follow-up and baseline did not show a significant difference, which might indicate that amyloid deposition is reaching a plateau. Nevertheless, correlation analyses showed that amyloid deposition still kept increasing, whereas cortical thickness decreased at a higher rate. Multiple regressions confirmed that the concentration of amyloid deposition at baseline predicted the degree of cortical thinning after two years, but the converse was not true. More importantly, we found that there was a robust correspondence of baseline amyloid deposition with atrophy in temporo-parietal regions.

Conclusions: In summary, this study supports evidence for the consequence of amyloid deposition at baseline resulting in significant cortical thinning in specific temporo-parietal regions after a period of two years.
Session 7

Presenter: Emma Jackson
Title: Are Behaviour Support Teams interventions leading to quality of life improvements for adult service users with intellectual disabilities across community teams?

Email: EJJ773@student.bham.ac.uk
Affiliation: University of Birmingham and Birmingham and Solihull Mental Health Foundation Trust.
Co-authors: Ben Hobson (Learning Disabilities Community Specialist Health Service), Andy Sheen (Heath Lane Hospital)

Background: The Behaviour Support Teams (BST’s) within the Learning Disabilities Community Specialist Health Services are commissioned to support service users with exhibiting behaviour that challenges. BST’s implement Positive Behaviour Support (PBS) approaches which aim to reduce behaviour that challenges and improve quality of life for service users. The aim of the service evaluation was to establish the effectiveness of Behaviour Support Team intervention across a Learning Disabilities Division, in leading to quality of life improvements for service users and to review the collection of outcome data across the teams, to make recommendations for improvement.

Methods: The data set was obtained from a shared drive across the Division, collected by the BST’s as a Service standard. Guernsey Community and Leisure Participation Assessment-revised (GCPLA-r) scores were statistically analysed before and after the BST’s involvement.

Results: Results from a Sign test show that there was a statistically significant improvement ($Z = -6.862, p = .000$) in GCPLA-r initial scores, before the involvement of the BST ($m = 64.13$, SD = 25.085) compared to GCPLA-r scores at close of input ($m = 78.82$, SD = 27.600). A Sign test also showed a statistically significant improvement ($Z = -5.293, p = .000$) in GCPLA-r initial scores ($m = 61.7$, SD = 22.39) compared to GCPLA-r scores at 3-month follow-up ($m = 71.9$, SD = 24.24). Treatment outcome analysis showed 11.83% (N=11) of service users GCPLA-r scores got worse, 81.72% (N=76) improved and 6.45% (N=6) showed no change.

Conclusions: BST interventions appear to be effective in leading to significant quality of life improvements for 81.72% of service users with intellectual disabilities.

Presenter: Faye Banks
Title: Exploring the role of informal culture for direct care staff providing support to people with intellectual disabilities

Email: f.banks2@ncl.ac.uk
Affiliation: Newcastle University
Co-authors: Amy Fielden (Newcastle University), David O’Sullivan (Newcastle University), Barry Ingham (Northumberland, Tyne and Wear NHS Foundation Trust)

Background: It has been suggested that a key factor contributing to the occurrence and management of behaviour that challenges (BTC) in residential intellectual disability (ID) services, is the informal culture operating within direct care staff (DCS) teams (Hastings, 2005). Research in this area has mainly focussed on group homes providing support to adults with severe IDs in Australia. The current investigation sought to understand the informal culture operating within a residential ID service in the UK, exploring how aspects of the informal culture influenced the management of BTC by DCS.
Methods: Semi-structured qualitative interviews were conducted with ten DCS regarding their experiences of working in the service. Interview transcripts were analysed thematically using template analysis.

Results: Themes regarding leadership, perceptions of managers, team functioning, and relationships between DCS and service users, were identified as important aspects of the informal culture which influenced ways of working in the team. Whilst the themes corroborated aspects of informal culture cited in the existing literature, additional themes relating to being aware of the risks posed by service users and the impact of BTC, were also indicated.

Conclusions: The findings suggest that the unwritten rules which guide day-to-day ways of working in DCS teams, may become particularly powerful within the context of heightened anxiety and uncertainty (e.g. where strong formal leadership is lacking). Whilst this has implications for operational managers and clinicians working with DCS teams, further research is required to explore the transferability of the findings in wider contexts.

**Presenter:** James Clarke  
**Title:** ‘He Meant to Do That’: A study of factors that influence the perception of behaviours from individuals with intellectual disabilities, as challenging or offending

**Email:** jamespclarke1@gmail.com  
**Affiliation:** University of Edinburgh  
**Co-authors:** Conor Coman (UoE)

Background: Research indicates that multiple factors influence causal attributions of challenging behaviour in people with an intellectual disability. There is a paucity of research exploring these factors in a criminal context. This study aimed to examine the influence of gender and severity of intellectual disability on attributions of violent behaviour as being challenging or offending. The influence of being employed in Criminal Justice System (CJS) and levels of empathy were also explored.

Methods: Fictional vignettes and an attribution scale were used to measure the causes attributed to specific violent behaviour, and then a behaviour consequences scale was used to indicate participants level of agreement to the consequences that could result from such behaviour. The Basic Empathy Scale for Adults was used to measure empathy levels of participants as this was predicted to influence attributions.

Results: CJS participants were more likely to attribute a behaviour as offending and were more likely to favour offending behaviour outcomes. The gender of the vignette character and the severity of intellectual disability of the vignette character were also predictive of attributions and outcome preference.

Conclusions: Being male influences offending behaviour consequences. Individuals employed within the CJS are more likely to judge behaviour as being premeditated and to favour outcomes that involve police contact. This result indicates a difference in subsamples which may have implications for legislation and policy. More research is needed to understand the reasons for this difference.
**Presenter:** Serena Tomlinson  
**Title:** Family carer and professional perceptions of the use of telehealth methodology for behavioural support for people with intellectual / developmental disabilities in the UK

Email: s.tomlinson@kent.ac.uk  
Affiliation: Tizard Centre, University of Kent  
Co-authors: Nick Gore (Tizard Centre, University of Kent), Peter McGill (Tizard Centre, University of Kent).

Background: The use of telehealth to provide behavioural services for people with intellectual / developmental disabilities (IDD) is increasing, with high levels of social validity (see Tomlinson et al., 2018). However, there are no prospective evaluations of stakeholder perspectives relating to the use of telehealth for behavioural support, which may have implications for uptake of such services. This study aimed to identify factors influencing family carer and professional willingness to use telehealth for behavioural support in the UK.

Methods: A Delphi consultation involving four rounds was conducted with two panels, aiming to reach consensus on the most influential advantages and disadvantages / barriers to participant’s willingness to use telehealth. Panel one consisted of 11 professionals with experience of providing support to family carers about their relative’s behaviour, and panel two consisted of six family carers of people with IDD.

Results: Thirty-six and 22 items reached consensus as being influential for professionals and family carers respectively. Factors identified by each panel differed, with professionals focusing on the logistics of support and ethical issues, whilst family carers highlighted issues relating to the quality of support and professional practices. Each panel identified solutions for overcoming barriers, with a common solution focusing on combining in-person and telehealth methodology.

Conclusions: A range of factors were identified that are influential to professional and family carer willingness to use telehealth for behavioural support. These factors suggest advantages to maximise and barriers to overcome in order to increase uptake of telehealth services in the UK.

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**Session 8**

**Presenter:** Amy Russell  
**Title:** The REMAIN project: Development of REsources based on reasonable adjustments to MAINstream diabetes and obesity care for adults with a learning disability

Email: a.m.russell@leeds.ac.uk  
Affiliation: Leeds Institute of Health Sciences  
Co-authors: Louise Bryant (University of Leeds), Allan House (University of Leeds), Vicky Ward (University of St Andrews), Catherine Stones (University of Leeds), Karl Witty (University of Leeds).

Background: Most adults with a learning disability and diabetes receive their diabetes care in health services where reasonable adjustments are lacking. We developed evidence-based resources to support the commissioning and delivery of services adjusted to the needs of this group. Here we describe resource development, methods to optimise uptake by practitioners, and a preliminary exploration of their implementation into clinical practice.

Methods: [1] A project reference group which included adults with a learning disability and health professionals, provided input into the content and presentation of resources. Resources were designed to align with the NHS Rightcare Diabetes Pathway. Diabetes UK hosted the resources in an area dedicated to learning disabilities within the Professionals area of their website. [2] The creation
of a network map of national stakeholders facilitated targeted distribution of physical resources to 500 stakeholders and clinicians. [3] A professionally-developed communication strategy optimised awareness of the resources via social media, national and local networks. [4] Diabetes UK provided analytics of resource downloads and an evaluation survey was conducted.

Results: Between 15/02/18 and 27/07/18, over 9,900 resources were downloaded from the Learning Disabilities area of the Diabetes UK website. Qualitative feedback from an online survey indicated the resources were of practical benefit to clinical staff and commissioners.

Conclusions: It is possible to engage clinicians and commissioners in the findings of research and to translate these findings into materials to support reasonable adjustments in practice. Web analytics show that if materials are placed on trusted and regularly visited websites they have the potential to influence care.

Presenter: Stuart Todd
Title: Forgotten lives, lost deaths: People with ID living and dying in non-ID care settings

Email: stuart.todd@southwales.ac.uk
Affiliation: University of South Wales
Co-authors: Jane Bernal (University of South Wales), Katherine Hunt (University of South Wales), Sarah Brearley (University of Lancaster), Mary McCarron (Trinity College Dublin), Julia Shearn (University of South Wales).

Background: End of life care in ID research has focused on death and dying in ID services as important places of care at the end of life. However, a substantial proportion of people with ID will die in long term care settings for older adults. Their deaths are not identified within the generic care research and overlooked by ID researchers.

Methods: Out of 480 settings contacted, 70 successfully participated in the study. Data were obtained on the ID (n=132) and non ID population (n=1838). 6 months later these settings were asked to provide data on any important changes in the lives of people with ID.

Results: People with ID were, on average, 12 years younger (68.6 years) than other people (80.9 years) in the care settings studied. The highest proportion had moved from an ID service (30.3%). 18.9% had moved from another care setting. Almost a half had moved from another care setting. One in four people with ID were reported to be at risk of death within the next 6 months. At time 2, 50% of those had died. Only 11% of those people considered not to be risk of dying within 6 months had died at T2.

Conclusions: This study suggests that the oldest of the old within ID are largely living in non ID services. At a population level such settings may play a minor role in supporting people with ID. However, these settings are the places of care at the end of life for a substantial proportion. As such the generalisability of mortality and end of life studies is undermined if they fail to include this population.

Presenter: Katrina Scior
Title: Intellectual Disability Stigma and Initiatives to Challenge it around the Globe

Email: k.scior@ucl.ac.uk
Affiliation: Research Dept of Clinical, Educational and Health Psychology, University College London
Co-authors: Maria Kett (Leonard Cheshire Disability and Inclusive Development Centre UCL Institute of Epidemiology and Healthcare), Aseel Hamid (Research Dept of Clinical, Educational and Health Psychology, University College London), Richard Hastings (CEDAR, University of Warwick), Shirli Werner (Centre for Disability Studies, The Hebrew Univ of Jerusalem).
Background: Stigma has been identified as one of the key challenges to the achievement of equal rights and full participation of people with intellectual disabilities in society. Evidence on stigma associated with intellectual disability is patchy though and largely limited to high income countries. This study set out to gauge the extent to which intellectual disability continues to be stigmatized and to which initiatives are in place to tackle such stigma around the globe.

Methods: Data were collected using a web survey from 667 experts and organisations in the (intellectual) disability field pertaining to 88 countries and covering all world regions.

Results: Survey responses indicate that the general public in many parts of the world broadly support the fundamental principle of inclusion of children and adults with intellectual disabilities, yet negative attitudes persist. High levels of stigma and denial of fundamental rights are still a reality in many places. Initiatives to tackle stigma appear patchy and least in evidence where they are most needed.

Conclusions: More action is needed to challenge negative attitudes, and promote active engagement and regular social interactions between persons with intellectual disabilities and their fellow citizens without intellectual disabilities. There appears to be a particularly urgent need for such efforts in low and middle income countries where stigma is often severe but actions to tackle it are often very limited and reliant on parents.

Session 9

Presenter: Dave Dagnan

Title: Psychometric properties of PHQ-9, GAD-7 and WSAS when used with people with intellectual disabilities within an IAPT service

Email: dave.dagnan@cumbria.nhs.uk
Affiliation: Cumbria Partnership NHS Foundation Trust Community Learning Disability Services
Co-authors: Luke Boothroyd (Tees Esk and Wear Valley NHS Foundation Trust), Steven Muncer (Durham University), Richard Thwaites (Cumbria Partnership NHS Foundation Trust)

Background: The PHQ-9; GAD-7 and WSAS are required core measures used in English IAPT services. The accessibility of these measures has been identified as a possible barrier to people with intellectual disabilities in accessing these services. There has been discussion of how the measures could be adapted for use in IAPT services; however, there are no data on how the un-adapted measures work with this client group

Methods: Data from an IAPT services in the north of England were available for 92 people with intellectual disabilities identified from GP register data, for which total scores for the three measures were available and 42 people with intellectual disabilities for whom item level data had been recorded. These were compared with data from over 20,000 people without intellectual disabilities who had used the service over the same period.

Results: The pattern of inter-correlations and between the three scales and Cronbach’s alpha was broadly similar between the groups with and without intellectual disabilities. Comparison of other internal reliability measures, item and total scale scores show few significant differences between the two groups.

Conclusions: Whilst the scales need more research when used for people with intellectual disabilities, this initial analysis of their internal reliabilities and inter-relationships suggest that the scales function in a similar way for people with intellectual disabilities and those without intellectual disabilities.
Background: Social well-being in children with intellectual disability (ID) can be lower compared to typically developing children. Various clinician-led interventions target social well-being in this population. Family psychology theories propose that another route is through parental investments.

The present study tested whether parental investments in the early years mediated the impact of the family’s resources at nine months of life on children’s social well-being at age 7.

Methods: A series of simple mediation models (path models) were fitted to data from 555 children with ID identified in a population survey in the UK. Risk factors at nine months were family income poverty and low parental educational level (below degree level). Potential mediators were nine parental investments between three and five years of life. Child social well-being at the age of 7 included levels of prosocial skills, independence, and cooperation.

Results: The two parental investments that significantly mediated the path from early life family resources to social well-being at age 7 were the home learning environment at age 3, and playing with friends socially across the ages of 3 and 5 years.

Conclusions: Social and prosocial skills in childhood appear to be sensitive to frequent opportunities for peer play and home learning in the pre-school period. Income poverty and low parental educational level in the first year of a child’s life appear to impact social well-being following a similar route.

Presenter: Paul Willner
Title: Protocol for a randomized controlled trial of EMDR for people with ID and PTSD

Email: p.willner@swansea.ac.uk
Affiliation: Swansea University

Post-traumatic stress disorder (PTSD) is prevalent – though frequently unrecognised – among people with intellectual disabilities, caused in part by the high levels of abuse that they experience. Eye movement desensitization and reprocessing (EMDR) is an effective treatment for PTSD in the general population. This presentation will describe the protocol for a randomized controlled trial of EMDR for people with ID and PTSD, which has been submitted in response to a call for proposals from the National Institute of Health Research.

Particular features of the study are:
- The use of ICD-11 rather than DSM-5 to diagnose PTSD, because ICD-11 enables separate identification of PTSD and complex PTSD, a more difficult to treat condition that is typically associated with a history of abuse;
- Training and supervision of experienced ID clinicians to deliver the intervention, rather than hiring EMDR therapists unused to working with PwID;
- Feasibility and internal pilot studies preceding the main trial;
- Inclusion of a prolonged phase of psycho-education and stabilization prior to commencing EMDR;
- Adaptation of the EMDR protocol;
- Evaluation of a range of outcomes, including measures of PTSD, mental health, quality of life, challenging behaviour and carer burden;
- Collection of health economic data to enable a cost-effectiveness analysis.

There are 13 co-applicants, comprising expertise in ID, PTSD and EMDR, and support systems including patient/public involvement, health economics and a clinical trials unit. If funding is approved, the trial will run for four years from mid-2019, aiming to recruit a total of 144 participants, randomized to EMDR or treatment as usual, in 4-5 NHS Trusts in the home counties and West Midlands.
Abstracts – Poster Sessions (alphabetical order)

**Presenter:** Nigel Beail  
**Title:** Development and Psychometric Properties of the Psychological Therapies Outcome Scale – Intellectual Disabilities (PTOS-ID) carer/informant version

Email: nigel.beail@swyt.nhs.uk  
Affiliation: South West Yorkshire Partnership NHS Foundation Trust Adult Learning Disabilities Health Service  
Co-authors: Nik Vlissides (South West Yorkshire Partnership NHS Foundation Trust), Scott Roache (South West Yorkshire Partnership NHS Foundation Trust), Yasmine Olabi (South West Yorkshire Partnership NHS Foundation Trust), Tom Jackson (South West Yorkshire Partnership NHS Foundation Trust).

Background: There are few valid and reliable psychological therapy outcome measures available for use with people with intellectual disabilities (ID). The Psychological Therapies Outcome Scale – Intellectual Disabilities (PTOS-ID) is a recent development, however, it was developed as a self-report measure of psychological distress and wellbeing. Feedback in its development included that some clients with ID could not participate in its completion. A request was made to develop an informant version. Here we report on the development and some psychometric properties of a carer/informant version.

Methods: The PTOS-ID self-report version was rewritten into a format for an informant. All questions were converted to parallel versions and piloted with carers of people who have ID. The PTOS-ID self-report version was completed with people who have ID accessing specialist ID services and the informant version was completed by someone who knew them well. A sub-group also completed the informant version on two occasions. Internal reliability, test retest reliability and inter-test reliability was then examined.

Results: This preliminary study suggests that the PTOS-ID informant version has good face validity, good internal consistency, and good interest reliability. The test re-test data is still in the process of collection.

Conclusions: This preliminary study suggests that the PTOS-ID is a psychometrically robust measure of psychological distress and psychological wellbeing that can be used with people with ID. Further research is required to assess its construct validity and ability to detect change.

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**Presenter:** Jane Bernal  
**Title:** End of life care and Down Syndrome

Email: sjbernal@btinternet.com  
Affiliation: University of South Wales  
Co-authors: Edward Oloidi (University of South Wales), Stuart Todd (University of South Wales), Rachel Morgan (University of South Wales), Katherine Hunt (University of Southampton).

Background: Research on EoLC has looked at people with ID in general and focused on cancer related deaths. Given the unique mortality profile of adults with DS and the high prevalence of dementia, the end of life care needs of and outcomes for this population are seldom studied.

Methods: Data are presented on the deaths of 43 adults with DS and who had lived in ID social care settings. They were identified from a representative sample of 222 deaths of people with ID living in those settings across the UK. Core data were obtained from service providers for all 43 deaths.
More detailed data were obtained on care at the end of life using a modified version of VOICES-SF for 33 (75%) of those deaths.

Results: The majority of decedents (72.7%) with DS had died before the age of 60. Only 2 were aged over 70 (4.6%). Dementia was given as the cause of death for a third of those deaths. Twice as many (67.4%) were reported to be living with dementia. Most decedents with dementia (75.8%) died in the setting in which they had lived. Those without dementia were more likely to die in a hospital setting (50.0%). The deaths of those living with dementia were more anticipated (76.1%) than those who did not have dementia (18.1%). More than three quarters of decedents were reported not to have known they were dying, given a preference for place of care or contributed to their end of life care plan.

Conclusions: The data confirm a view that adults with DS have distinct deaths. Outcomes at the end of life were more positive for those adults with DS dying with dementia. Yet although their deaths are amongst the most anticipated in an ID context, there was little evidence to suggest that this translated into any greater individual involvement in decision making and planning. Although there is evidence of supportive services for people with DS and dementia, approaches to greater involvement are still required.

Presenter: Naomi Broadhead  
Title: Promoting IAPT therapists’ knowledge and confidence in working with people with Intellectual Disabilities  
Email: Naomi.Broadhead@swyt.nhs.uk  
Affiliation: Wakefield Learning Disabilities Service, Southwest Yorkshire Partnership NHS Foundation Trust  
Co-authors: Alison Davies (Calderdale Learning Disabilities Service, Southwest Yorkshire Partnership NHS Foundation Trust)

Background: Since 2005 the IAPT programme has aimed to promote increased access to psychological therapies. In 2009 good practice guidance promoting access for adults with learning disabilities was produced. This was updated in 2015, and proposed a range of reasonable adjustments that IAPT services could make.

This study assessed the knowledge of IAPT staff working in one team in West Yorkshire (n=36) around working with adults with intellectual disabilities, and evaluated the impact of training on promoting IAPT therapists’ confidence in working therapeutically with adults with intellectual disabilities.

Methods: Prior to the training participants completed a knowledge of intellectual disabilities survey and also a therapist confidence scale- Confidence in working therapeutically with people with learning disabilities (Dagnan et al, 2014). The scale was re-administered following the training.

Results: Results of the survey found a number of deficits in knowledge about intellectual disabilities, including overestimation of population size and confusion between Autism (ASD), specific learning difficulties & global intellectual disabilities. Participants showed good understanding of life experiences typical for many adults with intellectual disabilities. Improvements in therapists’ confidence were reported following the training, and a high number of participants stated that the training had positively impacted on their practice.

Conclusion: This study found that intellectual disability specific therapy training positively impacted on IAPT therapist confidence in working with this client group. However significant knowledge deficits were seen, indicating that greater focus in IAPT training on working therapeutically with adults with intellectual disabilities may promote their engagement with IAPT services.
**Presenter:** Laura Brougham  
**Title:** Exploring the ability of individuals with an Intellectual Disability to generate and use a compassionate image

Email: Laura.Brougham@ggc.scot.nhs.uk  
Affiliation: NHS GGC  
Co-authors: Andrew Jahoda (University of Glasgow), Carol Pert (NHS GGC)

Background: There is a growing interest in adapting 3rd wave therapies such as Mindfulness for use with people who have Intellectual Disabilities. This study will consider the adaptation of Compassion Focused Therapy and aims to explore the ability of individuals with an intellectual disability to generate and use a compassionate image.

Methods: The cohort for this exploratory study consisted of nineteen people with an intellectual disability and twenty people without. Participants were recruited from colleges of further education. A technique from Compassion Focused Therapy was specifically adapted for this study to assess if individuals with intellectual disabilities could generate a compassionate image. A vignette based approach was used to help participants generate and use their own compassionate image within a range of hypothetical distressing situations.

Results: Participants with intellectual disabilities were able to generate their own compassionate image when given appropriate support. Furthermore, when they were asked to imagine themselves in a distressing situation they could use this compassionate image as a means of self-soothing.

Conclusions: This study found that individuals with intellectual disabilities were able to understand the rationale of this task and engaged meaningfully. The findings suggest that further studies would be useful to explore the use of Compassion Focused Therapy with this client group.

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**Presenter:** Susan Buell  
**Title:** A review of diagnostic and education services to children with autism in Bolivia

Email: s.buell@uea.ac.uk  
Affiliation: University of East Anglia

Background: A drive for 'inclusion' in education in Bolivia over that last six years has led to the closure of most special education centres in the region but there is little or no strategy or support for teachers who are now expected to include children with autism in mainstream settings.

Methods: Two participatory workshops were implemented with 20 professionals who worked with children with autism in public and private services in one city in Bolivia. Questions were presented that related to the theme ‘Making things better’. A further four families were interviewed. Their four children underwent diagnostic assessments for autism. Qualitative data from workshops, interviews and assessments was systematised and analysed using a thematic approach.

Results: Professionals identified a lack of accurate diagnoses of autism spectrum disorders and recognised that there was limited knowledge of how to support families. Parents reported that those who did assess their children provided little explanation of outcomes or what these meant. They also reported meeting fierce discrimination within the education system where children experienced repeated difficulties. Three out of the four children assessed for autism had previously been identified with intellectual disabilities and/or ADHD but the parents were not aware of these issues. Three children were above the age of six and only one was pre-school.

Conclusions: A clear need was identified to improve the process of early diagnosis of autism and co-morbid conditions in Bolivia. For improved quality of life, support to families of children with autism was a central theme.
**Presenter:** Jon Codd  
**Title:** Having a child with an intellectual disability transition to adulthood: A parental perspective.

**Email:** jon_x_codd@hotmail.com  
**Affiliation:** Oxford Institute of Clinical Psychology Training & Berkshire Healthcare NHS Foundation Trust  
**Co-authors:** Olivia Hewitt (Berkshire Healthcare NHS Foundation Trust)

Background: Transition to adulthood is an important time for young people and may be a particularly challenging time for people with intellectual disabilities. However, there has been little research in the UK regarding the experiences of parents who have child with an intellectual disability transitioning to adulthood.

Methods: The study used Interpretive Phenomenological Analysis to explore the lived experiences of ten parents who had a child (aged 18-25 years) with an intellectual disability.

Results: Three superordinate themes were generated from the data: 1) Transition: The good, the bad and unknown; 2) Striving for independence; and 3) Supporting the supporters. Parents experienced many difficulties and uncertainty related to their role, their child’s independence, navigating services for their child, and accessing support for themselves.

Conclusions: Increased collaboration and consistency from statutory services is required in addition to providing emotional support to parents and facilitating parent support networks.

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**Presenter:** Kirsty Dunn  
**Title:** A systematic review and meta-analysis on the mental health of fathers of a son/daughter with intellectual disabilities

**Email:** k.dunn.1@research.gla.ac.uk  
**Affiliation:** University of Glasgow  
**Co-authors:** Deborah Kinnear (University of Glasgow), Andrew Jahoda (University of Glasgow), Alex McConnachie (University of Glasgow).

Background: Most studies of parent carers mental health have focussed only on mothers as carers, have been small scale, or methodologically limited. It is important to include fathers in this discussion as they are increasingly taking a more active caring role within the family. The purpose of this study was to summarise the evidence related to the mental health of fathers compared to mothers, and to fathers in the general population.

Methods: A systematic review was undertaken of all studies published between 01/01/2001 and 01/07/2017 in MEDLINE, PsychINFO, CINAHL and EMBASE using terms on intellectual disabilities, mental health and father carers. Papers were selected based on pre-defined inclusion/exclusion criteria.

Results: Of 5,544 results, 7 studies met the inclusion criteria for meta-analysis. Significant effects were found for the following: Pooled effect size (95%CI) of general mental health among fathers vs mothers was -0.38(-0.56,-0.20) with heterogeneity (I²=0%). Pooled effect size (95%CI) of depression among fathers vs mothers was -0.46(-0.68,-0.24) with marked heterogeneity (I²=66%). Pooled effect size (95%CI) of anxiety among fathers vs mothers was -0.30(-0.50,-0.10) with heterogeneity (I²=0%). Pooled effect size (95%CI) of stress among fathers vs mothers was -0.32(-0.46,0.19) with heterogeneity (I²=0%). Pooled effect size (95%CI) of depression among fathers vs fathers in the general population was -0.22(-0.39,0.04) with heterogeneity (I²=0%).

Conclusions: There is a significant difference between studies comparing mental health of fathers and mothers, with fathers exposed to a lower risk of depression, stress, anxiety or poor general mental health.
Presenter: Nicola Elson  
Title: School/college perspectives on the transition from residential education to adult support

Email: n.j.elson@kent.ac.uk  
Affiliation: Tizard Centre, University of Kent  
Co-authors: Peter McGill (Tizard Centre, University of Kent), Serena Tomlinson (Tizard Centre, University of Kent), Nick Gore (Tizard Centre, University of Kent).

Background: In the UK some children and young people with intellectual and developmental disabilities spend part of their childhood in residential schools/colleges, often some distance from their homes. As part of a larger project on their transition to adult support, this paper explores the perspectives of school/college staff on the transition process and investigates the factors perceived to influence the type and location of the support received after transition.

Methods: Fifteen semi-structured interviews were carried out with residential school/college staff particularly involved in the transition process. Interviews were transcribed and thematically analysed.

Results: Interviewees described a range of difficulties in planning and organising good transition experiences. Out-of-area adult placements were reported to arise especially where there was a lack of specialist local provision in young peoples’ home areas whilst other factors relating to placement location included the characteristics of the young person, the family context and specifics of adult social care providers.

Conclusions: The results contribute to our understanding of transition processes and support the further development of arrangements that enable young people, as far as possible, to receive the support they need within their own communities.

Presenter: Nikita Hayden  
Title: Supporting siblings of children with a disability: an evaluation of Sibs Talk, a one-to-one intervention delivered by mainstream school staff

Email: n.hayden@warwick.ac.uk  
Affiliation: CEDAR, University of Warwick  
Co-authors: Monica McCaffrey (Sibs), Claire Fraser-Lim (Sibs), Richard Hastings (University of Warwick).

Background: There are few evaluations of interventions designed to support siblings of children with developmental disabilities and none we are aware of in school settings. Sibs Talk is a ten-session, one-to-one intervention approach for schools to complete with key stage 2 children who have a brother or sister with a disability developed by the UK charity Sibs.

Methods: Evaluation questionnaires were returned for 55 children from 11 schools. A pre-post intervention design was used. The sample siblings’ brothers and sisters had a range of disabilities, the largest proportion (49.1%) had Autism. The teacher-reported psychological well-being and behaviour of the siblings was assessed using the Strengths and Difficulties Questionnaire. Siblings’ self-reported attitudes to school were also measured using the “How I Feel About My School” questionnaire. These measures were analysed using paired sample t-tests. Written comments were also collected from siblings and analysed using content analysis.

Results: The findings indicate small improvements in outcomes between the two time points for the participating siblings on each measure and sub-score. However, only the SDQ hyperactivity scores (p<0.001), prosocial behaviours (p=.002), total difficulties (p=.009), and emotional problems
(p=.016) were statistically significant. The changes in the HIFAMS score and SDQ conduct problems, peer problems and overall SDQ impact scores were not statistically significant. The findings from the content analysis identified four themes: learning and understanding; communication and relationships; coping strategies; and challenges and responsibilities.

Conclusions: Overall, the data presented in this evaluation indicate that Sibs Talk may contribute to improvements for children who take part in the intervention.

**Presenter:** Olivia Hewitt  
**Title:** A Systematic Review of IPA Studies Exploring the Experiences of Parents who have a Child with an Intellectual Disability

Email: olivia.hewitt@berkshire.nhs.uk  
Affiliation: Berkshire Healthcare NHS Foundation Trust  
Co-authors: Jon Codd (Oxford Institute of Clinical Psychology Training & Berkshire Healthcare NHS Foundation Trust).

**Background:** Interpretive Phenomenological Analysis (IPA) has been increasingly used to explore the experiences of parents of children with intellectual disabilities. This review aimed to systematically identify, synthesise and evaluate the quality of this research.

**Methods:** Twenty studies were eligible for review, grouped into three categories and findings were compared. Studies were appraised against a quality checklist.

**Results:** Four overall concepts were evident: the difficulties of parenting a child with an intellectual disability; support from others; parent coping and self-care; and knowledge, certainty and control. Studies showed strengths in most areas of methodological rigour. Areas for improvement included reflexivity, ethical considerations, justification of research design, and use of an inclusion and exclusion criteria in participant sampling.

**Conclusions:** Parents experience a range of difficult emotions and practical difficulties, and the level of parent coping and external support received has an important influence. Future research using IPA with parents who have a child with intellectual disability requires increased researcher reflexivity and all studies should clearly state ethical approval. Research should be conducted across a wider number of countries and cultures and with an increased focus on the experiences of fathers and older parents.

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**Presenter:** Chloe Hurrell  
**Title:** Designing the optimal model for transition from child to adult services for young people with disabilities and/or developmental difficulties

Email: chloe.hurrell@wales.nhs.uk  
Affiliation: Serennu Children's Centre

**Background:** Transition into adulthood for young people with disabilities and/or developmental difficulties is problematic, and continues to lead to poor experiences and outcomes. We aim to inform an optimal model for transition by exploring professional’s experiences of transition from child to adult services including barriers, facilitators and potential improvements.

**Methods:** Semi-structured interviews were conducted with 40 professionals across primary and secondary care, education and social services in South Wales. Interviews were recorded and transcribed before commencing Braun and Clarke’s (2006) thematic analysis framework.

**Results:** Participants identified a number of key barriers, facilitators and improvements. Barriers include external pressures conflicting with clinical priorities, child and adult services functioning
through two different models, poor engagement and disjointed working between agencies and parent/young person anxiety around transition. Facilitators comprised of the presence of a specialised transition support officer, collaborative transition planning, good relationships between agencies, implementing a person-centred approach and assuming a shared responsibility for transition. A number of recommendations were also identified; preparing parents for transition; increasing the number of specialised transition support officers; a review of statutory responsibilities, anticipatory support for parents, timely information sharing, and meaningful data sharing between agencies.

Conclusions: Multiple factors prevent transition from being optimal. Across agencies, professionals are mutually unaware of each other’s procedures thus families, unsurprisingly, become anxious. A new communication model utilised by professionals, parents and young people is necessary to improve support and empower its users during the transition process and a counselling service would address parental/caregiver and young person anxiety, providing a holistic model of support.

Presenter: Chrysovalanto Kyriacou
Title: Clothes, sensory issues and people with Autism: is wearing the right fabric important?

Email: valanto_kyriakou1994@hotmail.com
Affiliation: University of Kent
Co-authors: Rachel Forrester-Jones (University of Bath), Paraskevi Triantafylloupolou (University of Kent).

Background: Many people with Autism Spectrum Conditions (ASC) experience sensory irregularities, but the tactile modularity is the least investigated.

Methods: The current multi-component, explorative study aimed to understand the subjective experiences of 10 university students with ASC regarding tactile defensiveness and fabrics, using semi-structured, in-depth, one-to-one interviews. Participants were provided with seven samples of fabrics and were asked to explain the effects that these may have had on their life. They were also asked to bring their ‘favourite’ fabric(s) to express their feelings and thoughts about their choices.

Results: Using Interpretative Phenomenological Analysis and Content Analysis, the findings showed that some fabrics can have an impact on individual’s reported wellbeing. However, students’ experiences with several stimuli appeared to have helped them implement coping strategies.

Conclusions: By understanding tactile defensiveness, society should be able to move towards increasing autism-friendly approaches with appropriate fabrics. Recommendations for future research, policy and practice are discussed.

Presenter: Peter McGill
Title: Young people with learning disabilities / autism leaving residential school in England – what happens and where do they go?

Email: p.mcgill@kent.ac.uk
Affiliation: Tizard Centre, University of Kent
Co-authors: Serena Tomlinson (Tizard Centre, University of Kent), Nick Gore (Tizard Centre, University of Kent), Jessie Humphreys (Tizard Centre, University of Kent), Nicola Elson (Tizard Centre, University of Kent).

Background: A significant number of young people with learning disabilities or autism are placed in residential schools in England, however little is known about their transition to adult services. This is in spite of emerging recognition of the link between residential education and out-of-area adult
placements, and a clear policy emphasis on reducing out-of-area adult placements. This research therefore aimed to provide information about outcomes for young people with learning disabilities / autism following transition from a residential school, and factors influencing whether their subsequent placement was out-of-area relative to their home area.

Methods: Residential schools in England were asked to complete questionnaires about young people with learning disabilities / autism (aged 16+) who had transitioned within the past 3 years. Questionnaires focused on the young person’s characteristics, their residential school placement and placements following transition.

Results: Questionnaires were returned for 251 young people. Of these, 240 had a learning disability and 178 had an Autism Spectrum Condition. The majority of educational placements were out-of-area, as were around half of the adult placements following transition, and some significant predictors of out-of-area adult placement emerged.

Additional findings are presented about the characteristics of young people, and their placements following transition.

Conclusions: These data provide an overview of transition outcomes for a large sample of young people who have recently transitioned from a residential school. Significant predictors of subsequent placement out-of-area emerged suggesting key areas of focus for reducing the risk of young people being placed out-of-area following transition from a residential school.

Presenter: Sinead Morrison
Title: Developmental cognitive trajectories in 22q11.2 Deletion Syndrome
Email: morrissm@cardiff.ac.uk
Affiliation: MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University
Co-authors: Samuel Chawner (MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University), Michael Owen (MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University), Marianne van den Bree (MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University).

Background: 22q11.2 Deletion Syndrome (22q11.2DS) is one of the strongest known genetic risk factors for schizophrenia, and is a valuable model for understanding trajectories of cognitive development which may be associated with vulnerability for later psychosis development.

Methods: At three timepoints IQ measures and a neurocognitive battery of processing speed, working memory, sustained attention, visual search and planning tasks was administered to individuals with 22q11.2DS (mean age at Time 1 (T1) 10.2, Time 2 (T2) 12.7, Time 3 (T3), 15.4) and their control siblings (mean age at T1 10.7, T2 13.0, T3, 13.9). Trajectories of performance were compared with linear mixed model analysis.

Results: Raw scores on all cognitive functions increased in both groups over time. Vigilance measures such as sustained attention, processing speed and visual search tasks appeared to be relatively spared in individuals with 22q11.2DS over time, and although they might present with an initial impairment this may remain stable or even catch up with controls. In contrast, performance on tasks associated with retrieving knowledge and maintaining representations, such as working memory and verbal reasoning appears to lag in individuals with 22q11.2DS in comparison to controls.

Conclusions: We did not find evidence for an absolute deterioration in scores over time in 22q11.2DS, but rather deficits that were stable from childhood, or lags which widened over time between individuals with 22q11.2DS and controls. The lag in some cognitive domains may be related to increasing psychosis risk as individuals enter late adolescence.

Presenter: Edward Oloidi
Title: Public perceptions of sexual relationships and intellectual disabilities: researching the influence on social care workers’ attitudes, beliefs and behaviours: stage one

Email: edward.oloidi@southwales.ac.uk
Affiliation: University of South Wales
Co-authors: Ruth Northway (University of South Wales), Jane Prince (University of South Wales), Michelle Culwick (University of South Wales).

Background: Research demonstrated how people behave towards people with ID is influenced by social attitudes and beliefs (Gilmore and Chambers, 2010) and carers are also affected by such attitudes (Lafferty et al, 2012). However, the impact of this on personal and sexual relationships amongst persons with ID (Jorrisen and Burkholder, 2013) has not widely been researched.

Methods: This paper reports stage one of a sequential mixed method study. Method used at stage one included 18 semi-structured interviews based on critical incident technique (CIT). Thematic analysis of all 18 transcripts was completed.

Research questions and/or focus of enquiry:
To determine;
• How societal perceptions of ID might affect SCWs’ attitudes, beliefs and behaviours towards intimate relationships amongst adults with ID.
• If such perceptions lead to imposition of conditions that, limit personal and sexual relationships amongst this population.

Results: Four dominant themes emerged: socio-cultural factors, the practice-policy gap, fear, and prioritisation of safety needs.

Conclusions: Analysis of the interviews identified four themes and indicated that sociocultural factors influence the other areas. Concerns that legislation appears to reflect social mind-set seems to create gap in policy and practice. Anxiety about what could go wrong and society’s ‘blame culture’ generated fear amongst SCWs. Consequently, SCWs prioritise perceived needs for safety above an individual’s personal and sexual relationship needs. Improved policies and practice-based support that reduce staff fear regarding supporting personal and sexual relationships for people with ID are required. However, the extent to which these factors influence SCWs was expanded upon at stage two before conclusions are drawn. Improved policies and practice-based support that reduce staff fear regarding supporting personal and sexual relationships for people with ID are required.

Presenter: Linda O’Neill
Title: The mediating effect of self-esteem upon the relationship between anxiety and depression in adult siblings of individuals with developmental disabilities

Email: Loneill@chester.ac.uk
Affiliation: University of Chester
Co-authors: Lindsay Murray (University of Chester)

Background: The study examined whether self-esteem could act as a mediator between adult siblings of individuals with developmental disability and levels of anxiety and depression.

Methods: 132 adult siblings of individuals with a DD, recruited from UK disability charities and 132 closely matched adults who did not experience having a sibling with DD. Age range 18 -71 (mean 35.39, SD 11.62). 98 (74.2%) female, 34 (25.8%) male. Analyses tested for differences between the
groups, then using PROCESS we tested the mediating effects of self-esteem on the relationship between having a sibling with disabilities and anxiety and depression.

Results: Significant differences were reported between the groups with the sibling group reporting higher levels of educational qualifications \( (t (257) = -4.03, p < .001) \), anxiety \( (t (262) = -4.14, p < .001) \) and depression \( (t (262) = -3.43, p = .001) \), but lower levels of self-esteem \( (t (254) = 2.66, p = .008) \). A significant indirect effect of having a sibling with disabilities on anxiety through self-esteem, \( ab = 0.72, BCa CI [0.20, 1.34] \). The mediator could account for around a third of the total effect, \( PM = .33 \). A further significant indirect effect of having a sibling with disabilities on depression through self-esteem was found, \( ab = 0.54, BCa CI [0.15, 0.96] \). The mediator could account for just under a half of the total effect \( PM = .43 \).

Conclusions: Self-esteem levels in siblings may partially account for their increased risk of psychopathologies in comparison to the general population. Due to self-esteem being a fluctuating trait, this may have implications for therapeutic interventions.

**Presenter:** Ciara Padden  
**Title:** Experiences of adults with intellectual and developmental disabilities receiving life skill training  
**Email:** c.m.padden@kent.ac.uk  
**Affiliation:** Tizard Centre, University of Kent  
**Co-authors:** Peter Baker (Tizard Centre), Gillian Eaglestone (Tizard Centre).

**Background:** While life skills training for adults with intellectual and developmental disabilities (IDD) may at times be considered a stepping stone towards securing employment, the development of life skills is also important for increasing independence and could potentially serve the purpose of personal development in its own right. However, little is known about the objectives or outcomes of such programmes, or how they are experienced by adults with IDD. Thus, this study aims to explore the experiences of adults with IDD who receive life skills training, and to explore expectations, outcomes, benefits and barriers in relation to such training.

**Methods:** Qualitative methods were employed, with three different components to the study: (1) Semi-structured interviews with adults with IDD who are currently attending, or have recently attended, life skills training; (2) a focus group and semi-structured interviews with family members of adults with IDD who receive/have received life skills training; and (3) semi-structured telephone interviews with service providers that deliver life skills training.

**Results:** Thematic analysis will be conducted, and preliminary research findings will be reported.

**Conclusions:** Practical implications and future research directions will be discussed.

**Presenter:** Liz Randell  
**Title:** SenITA: A pragmatic RCT of sensory integration therapy for children with sensory processing difficulties and ASD  
**Email:** randelle@cardiff.ac.uk  
**Affiliation:** Centre for Trials Research, Cardiff University  
**Co-authors:** Rachel McNamara (Centre for Trials Research, Cardiff University), Sue Delport (School of Healthcare Sciences, Cardiff University), Rhys Williams-Thomas (Centre for Trials Research, Cardiff University), David Gillespie (Centre for Trials Research, Cardiff University).

**Background:** Research suggests Sensory Integration Therapy (SIT) might be helpful for some children with Autism Spectrum Disorder (ASD) and Sensory Processing (SP) difficulties. In this study we are
interested in whether, compared to treatment normally offered to families (‘usual care’), SIT improves the child’s behaviour socialisation and daily functioning.

Methods: The pilot phase of a full scale RCT of SIT versus UC (1:1 randomisation) ultimately aiming to recruit 216 children. Progression criteria being reported as well as a description of usual care in this population. SIT is delivered by Occupational Therapists as one-to-one contact in the form of 24 face-to-face sessions, 2 telephone sessions over 26 weeks in this study. Follow up assessments at 6 and 12 months.

Results: Progression criteria were met, and in some cases exceeded, with the exception of the overall recruitment target for the pilot phase. Once recruited, adherence to the intervention and retention are high. Fidelity of delivery as scored according to the current protocol is slightly below what was anticipated however there is clear rationale to address this process. The trial intervention is significantly different from routinely delivered NHS care for this population, and our data indicate there is considerable carer demand for additional intervention for sensory difficulties.

Conclusions: Following successful completion of the pilot phase, the full NIHR HTA funded RCT is in progress. Currently there are 52 children randomised with recruitment continuing into 2019.

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**Presenter:** Kelly Rayner  
**Title:** ‘Big Feelings’: Adapted DBT Skills Groups for People with Learning Disabilities

**Email:** kelly.rayner@cumbria.nhs.uk  
**Affiliation:** Cumbria Partnership NHS Foundation Trust  
**Co-authors:** Rhiannah McCabe (Cumbria Partnership NHS Foundation Trust), Louise Prentice (Cumbria Partnership NHS Foundation Trust & The University of Newcastle), Isabel Jackson (Cumbria Partnership NHS Foundation Trust), Faye Banks (Cumbria Partnership NHS Foundation Trust & The University of Newcastle).

Background: Skills in emotion regulation, interpersonal effectiveness and distress tolerance are fundamental to living a psychologically healthy life. Skills in these domains are typically learnt through positive attachments with caregivers in childhood and interactions with others, including peers, as we progress through childhood into adulthood and beyond. We build, maintain and lose relationships and develop the skills to manage ‘Big Feelings’ including frustration, sadness and jealousy. It may be that due to their additional needs, people with Learning Disabilities (LD) miss out on formative experiences that would allow them to develop these skills. DBT Skills Groups have been shown to be a useful way of building these skills in adults with Personality Disorder (PD), including those with comorbid LD (Lew et al., 2006). This pilot reports on people with skills deficits secondary to LD without PD.

Methods: A DBT Skills Group has been adapted for people with LD within a Community LD Team. The 12 week ‘Big Feelings’ group is described. Group content was amended to aid accessibility by simplifying exercises, reducing metaphors and shortening the duration of sessions.

Results: Session content, pre and post group measures of emotional wellbeing and self-identified mastery, along with qualitative feedback from clients is presented. Group members appreciated the social contact that the group provided.

Conclusions: A DBT skills group can and should be adapted for people with LD, and can be an effective wellbeing intervention for those without identified PD traits. The importance of providing skills for this population to manage Big Feelings is emphasised.

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**Presenter:** Rebecca Reid  
**Title:** Walking The Line: Educating People with Learning Disabilities on Sex, Relationships and Internet Use
Email: rebecca.reid@cumbria.nhs.uk
Affiliation: Cumbria Partnership NHS Foundation Trust
Co-authors: Isabel Jackson (Cumbria Partnership NHS Foundation Trust), Faye Banks (Cumbria Partnership NHS Foundation Trust & The University of Newcastle) Richard Want (Cumbria Partnership NHS Foundation Trust & The University of Cumbria), Laura Bulman (Cumbria Partnership NHS Foundation Trust)

Background: Historically, adults with learning disabilities (LD) have been viewed in one of two ways: asexual and infantilised (Thompson, 2003), or promiscuous and prone to risky sexual behaviour (Olney & Kuper, 1998). For these reasons, it is often felt that they should not be encouraged to engage in romantic or sexual relationships, despite this being a recognised Human Right. Likewise, despite its ubiquity, the potential risks presented by internet use often see people with LD denied online access due to risk aversion of families and supporters (Chadwick, Wesson & Fullwood, 2013).

Methods: Legislation and rulings from the Court of Protection support professionals to walk the line between empowering clients and promoting their rights while ensuring they are not placed at unnecessary risk. An important aspect of both empowerment and safeguarding is education; with this in mind a 12 week Sex and Relationships Group and a 7 week Internet Safety Group emerging from routine clinical practice within a busy CLDT are described.

Results: Group content is presented along with clinical outcomes and reflective feedback. Attendees demonstrated enhanced knowledge and confidence around sex, relationships and safety and reported that they had enjoyed learning in a group setting and developing social skills and contacts. The clinical information gathered was highly valued by members of the MDT and external agencies and contributed to risk assessment, positive risk taking and empowerment of individual clients.

Conclusions: This work highlights the importance of facilitating access to healthy relationships and sets out steps professionals can take in safeguarding the clients they support.
**Presenter:** Victoria Stafford  
**Title:** Survey of Staff Support and Trauma in Relation to Challenging Behaviour

Email: V.F.J.Stafford@kent.ac.uk  
Affiliation: Tizard Centre, University of Kent  
Co-authors: Peter Baker (Tizard Centre, University of Kent)

Background: Challenging behaviour has a prevalence rate of 5-15% for people with intellectual disabilities in educational, health and social care services. The impact of exposure to challenging behaviour on staff's psychological wellbeing is complex and only partially understood, and some research suggests work environment characteristics may have an effect on staff response and wellbeing.

Methods: 126 educational or residential support staff were asked to describe an incident of CB within the last 6 months, before completing questionnaires based on this incident, (Impact of Events Scale-R, a bespoke staff wellbeing questionnaire relating to perceptions of organisational support and emotional resilience and the Challenging Behaviour Exposure Measure).

Results: 113 participants fully completed the IES-R questionnaire: 69% (78) scored below the clinical-cut off on the IES-R; 10.6% (12) gave scores which indicated clinical concern; and 20.4% (23) had scores suggestive of PTSD. 106 participants fully completed both the staff wellbeing questionnaire and the IES-R questionnaire, and these were significantly correlated: rp(105)=.420, p<.01 (p<.001).

Conclusions: Overall around a third of staff displayed symptomatology of either clinical concern, or suggestive of PTSD. A significant positive correlation was found between wellbeing scores and IES scores – as staff perceptions of support improved, their trauma scores declined, suggesting organisational support may be a protective factor.

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**Presenter:** Catherine Stanford  
**Title:** Relationships between maternal psychological distress and child externalising behaviour in neurodiverse families

Email: catherine.stanford.22@gmail.com  
Affiliation: Durham University  
Co-authors: Deborah Riby (Durham University), Heather Archer (Durham University), Sarah Page (Durham University), Richard Hastings (University of Warwick), Katie Cebula (University of Edinburgh)

Background: Child behaviour problems have consistently been found to be associated with maternal well-being in families of children with developmental disabilities, perhaps more so than core features of neurodevelopmental disorders (e.g. autism severity). Existing research has examined these associations in families without considering broader neurodiversity i.e. families where multiple children have varying neurodevelopmental disabilities.

Methods: Mothers from 12 families, including at least two children with differing neurodevelopmental conditions (e.g. autism, Down syndrome, ADHD) were included in the qualitative research phase. There were 35 children across families (28 with diagnoses; 7 neurotypical). Mothers completed standardised questionnaires to assess the relationship between maternal psychological distress (Hospital Anxiety and Depression score) and the average externalising behaviour of their children (externalising sub-scale score of the Strengths and Difficulties Questionnaire). Eleven of these mothers, and an additional three, participated in interviews discussing ‘parenting’ e.g. positives and challenges, ‘family interactions’ e.g. amount of time spent as a family, and ‘behaviour’ e.g. impact of different behaviours. These were analysed thematically.
Results: Correlations indicated a small, but non-significant, relationship between maternal psychological distress and the average of all their children’s externalising behaviour (r=.331, p=.293), but a larger relationship when considering only diagnosed children (r=.594, p=.042). Thematic analysis indicated externalising behaviour as a pervasive sub-theme, alongside a sense of divided family life, negatively impacted mental health, positive sibling relationships, and the diversity of expression of feelings.

Conclusions: The research suggests that more investigation is needed to understand mothers’ experiences of externalising behaviour problems across multiple children with neurodevelopmental conditions in the same family.

Presenter: Julie Sutton
Title: Sleep hygiene education (SHE) and children with developmental disabilities (DD). Findings from an experience based co-design (EBCD) study

Email: jsutton@chester.ac.uk
Affiliation: University of Chester
Co-Authors: Jaci Huws (Bangor University), Chris Burton (Bangor University).

Background: SHE has been routinely implemented for years with families of children with DD and sleep problems, despite being an inadequately conceptualised intervention supported by theories based on popular wisdom. The UK’s prudent healthcare agenda calls for a greater understanding of what makes interventions work effectively, to enhance professional’s consciousness of care delivered. The aim of this EBCD study was to develop a systematic understanding about what SHE does, how it is delivered and how it is supposed to work to improve sleep.

Methods: Underpinned by a participatory methodology, this study brought together eight parents of children with DD and six sleep practitioners as equal research partners in June 2015. Co-designers debated an ‘audio trigger podcast’ developed from an earlier exploratory study and co-created a SHE tool, programme theory and logic model which explains how SHE works to improve sleep.

Results: A systematically developed SHE tool underpinned by a nuanced programme theory, evidenced by mid-range theories of change. Explanatory analytical themes demonstrating SHE complexity: the need to legitimise children with DD’s sleep problems and consider the nature of customisation, knowledge exchange, health expectation and impact of sleep service rationing and gaming strategies on implementation success.

Conclusions: This study makes explicit the nature of complexity embedded in a SHE intervention. Policy and practice implications include a need to raise the public profile of children with DD’s sleep problems and promote parental involvement in intervention implementation. Research implications include a need to test out this theory driven framework for evaluating SHE.

Presenter: Leah Vanono
Title: A Systematic Review: The Efficacy of Using the Periodic Service Review in Service’s Supporting Adults with Intellectual and Developmental Disabilities

Email: ltv7@kent.ac.uk
Affiliation: Tizard Centre, University of Kent
Co-authors: Jill Bradshaw (Tizard Centre, University of Kent), Peter McGill (Tizard Centre, University of Kent)

Background: The Periodic Service Review (PSR) was developed to be a useful management system for the effective implementation and monitoring of Positive Behaviour Support (PBS). The PSR
comprises of four interconnected components; Performance Standards, Monitoring, Feedback Loop and Staff Training. The PSR aims to make improvements to both “Staff Performance” and “Quality of Services”.

Methods: The purpose of this review was to gather and assess the quality of evidence in respect to the PSR’s efficacy. Systematic searches were carried out across databases (10+) using search combinations of key terms, identifying a total of 21 eligible studies, from seven countries. These were evaluated in terms of quality using the ‘The Quality Assessment Tool for Quantitative Studies’ (Thomas, 2003).

Results: Fifteen articles reported using 3-4 components of the PSR system. 100% of the studies reported improvements in at least 2 of 4 sub-categories of “staff performance”, with 11 of 15 articles reporting evidence of 3 (or more) staff performance outcomes. A similar pattern of results emerged in relation to “improvements in the quality of services”. 14 out of 15 articles reported 1-4 intervention outcomes being achieved, with over half of the sample providing evidence of achieving outcomes relating to all 4 sub-categories.

Conclusions: Using more components of the PSR system was associated with achieving substantially better intervention outcomes, in terms of improving staff performance and the quality of services. These findings have important implications for utilising the entire system, upon application and calls for researchers and clinicians to publish additional process data, e.g. intervention integrity scores.

Presenter: Kelly Wade
Title: Developing an observer checklist to detect gastric distress in non-verbal children with Intellectual Disability

Email: kxw888@bham.ac.uk
Affiliation: University of Birmingham
Co-authors: Chloe Brown (University of Birmingham), Joseph Scanlon (University of Birmingham), Caroline Richards (University of Birmingham)

Background: A high proportion of people with Intellectual Disabilities (ID) experience painful health conditions; gastro-oesophageal reflux disease (GORD) is a common cause of pain and discomfort to people with ID. Despite available effective treatments, GORD is likely underdiagnosed and undertreated in children with ID due to compromised expressive communication and the invasive nature of confirmatory endoscopies. Previous research has resulted in the development of the Gastric Distress Questionnaire (GDQ) which has shown promise in distinguishing children with a diagnosis of reflux from other children with ID, but is reliant on the availability of a reliable informant who can report on the child’s recent behaviours. The current study attempts to develop an observer version of the GDQ, suitable for use in clinical settings.

Methods: Footage of 43 children with ID was observed and coded for behaviours related to gastric distress. This behaviour rating scale obtained high inter-rater reliability. Scores obtained from the observation scale were correlated with GDQ scores collected from parents and independent measures of pain collected from parents.

Results: Preliminary analysis demonstrates that it is possible for independent observers to reliably identify child behaviours that associate with parent’s reports of pain and GORD specific behaviour. Conclusions: The delineation of behavioural indicators of GORD, could allow for earlier assessment and a reduction in unnecessary intrusive medical procedures and further medical conditions (e.g. Barratt’s oesophagus) thus improving both recognition and treatment outcomes for GORD in children with ID. We will progress this study by undertaking validation studies of these behavioural indicators, collaborating with Paediatric Gastroenterologists.
Presenter: Francesca Wicks  
Title: Recruitment of 2600 individuals to Intellectual Disability and Mental Health: Assessing the Genomic Impact on Neurodevelopment (IMAGINE ID) Study  
Email: fc426@cam.ac.uk  
Affiliation: Cambridge Institute for Medical Research (CIMR)  
Co-authors: Amy Lafont (University of Cambridge), Marie Erwood (University College London), Hayley Tilley (University of Cambridge), F Lucy Raymond (University of Cambridge), IMAGINE ID Consortium (University of Cambridge, University College London & Cardiff University).

Background: IMAGINE ID aims to assess the genomic impact on neurodevelopment, intellectual disability (ID) and mental health in a cohort of individuals, largely from the UK. The study collects phenotypically rich information about these individuals, mostly online, via primary carers and correlates this with genomic diagnoses made within the health care system.

Methods: Individuals aged 4 years or over with generalised ID caused by a genetic condition were recruited to the study through referrals from NHS Regional Genetics Centres (RGCs), charities and self-referrals by carers over a 2-4 year period.

Results: 2635 individuals were recruited. 1927 (73%) consented via 22 RGCs across the UK. The numbers of individuals recruited per centre ranged from 2-238. 620 (24%) consented via charities or other research projects and 88 (3%) consented via the project’s website/social media channels. IMAGINE ID hosted two workshops open to staff at RGCs to consider the barriers and facilitators to ID/genetic research. At workshops held in 2016 and 2017, 39 staff from RGCs attended. Recruitment barriers identified were lack of recruiting staff and resources, informed consent conversations and research saturation for staff. Facilitators included simple consent processes, support from management and hearing positive research participant feedback.

Conclusions: Inequity of access to ID research exists across the UK, as demonstrated by the range of numbers of individuals recruited across RGCs. However, enrolment through clinical services remains the most successful method when recruiting to large-scale projects. Allocation of grant funds to supporting recruitment within NHS services, particularly when focusing on post-genomic diagnoses, is recommended.

Presenter: Katie Williams  
Title: Improving Service Response to Sexual Exploitation of People with a Learning Disability: Exploring professionals’ experiences.

Email: umkwi@leeds.ac.uk  
Affiliation: University of Leeds  
Co-authors: Ali Davies (Calderdale Learning Disabilities Service, Southwest Yorkshire Partnership NHS Foundation Trust)

Background: People with a Learning Disability (PwLD) are more vulnerable to becoming victims of sexual exploitation (SE); they often depend on the care of others which can create power imbalances in their relationships which can transfer onto their personal and sexual relationships (Sullivan, 2012). Implementation of national guidelines aimed at protecting PwLD from sexual exploitation can be inconsistent across local services.

Methods: Interviews with five local professionals were conducted, all had experience of supporting someone who had been sexually exploited and who had a learning disability. Exploration of their experiences were gathered via semi-structured interviews. In addition, a staff survey was distributed around the local Learning Disability Team consisting of a variety of disciplines, a total of 32 members
of the team completed a 10-item questionnaire. The survey aimed to evaluate self-reported levels of knowledge, skills and confidence in relation to managing cases of sexual exploitation.

Results: 47% of participants stated that the way professionals respond to cases of sexual exploitation required improvement. 50% of the respondents felt that services also needed to improve the way in which they supported PwLD who had been victims of sexual exploitation.

Results from interviews and qualitative analysis found three main themes, 1) Barriers to accessing services for PwLD 2) Hidden complexities when working with PwLD and 3) Attitudes and beliefs of professionals affected services offered to PwLD.

Conclusions: Improvements to local services are required in order to respond more effectively to victims of sexual exploitation who have a learning disability. More sophisticated training is recommended to highlight the added complexities present for PwLD as well as how sexual exploitation can manifest in this population.

**Presenter:** Grace Woolway  
**Title:** Exploring Psychiatric Comorbidities in the National Centre for Mental Health (NCMH) Learning Disability Cohort.

**Email:** WoolwayG@cardiff.ac.uk  
**Affiliation:** National Centre for Mental Health, Cardiff  
**Co-author:** Stephen Beyer (Learning Disability Research, National Centre for Mental Health).

**Background:** The National Centre for Mental Health (NCMH) is a Welsh Government funded Research Centre, based at Cardiff, Swansea and Bangor Universities, investigating neurodevelopmental and psychiatric disorders. NCMH aims to better understand the causes, triggers and course modifiers of mental disorders. In this poster the Learning Disability Cohort will be explored.

**Methods:** One hundred and fifty three participants have been recruited into the Learning Disability Cohort at NCMH. Recruitment methods consist of systematic clinical referrals and non-systematic advertisements such as posters, leaflets, and charity adverts. Assessment tools include a brief assessment constructed by lead psychiatrists in Learning Disability Research and the Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities (Mini-PAS-ADD).

**Results:** Psychiatric comorbidities will be investigated within the Learning Disability cohort in NCMH. Demographic information will also be described and presented to demonstrate trends in the data.

**Conclusions:** The prevalence of psychiatric comorbidities will be described and reviewed in relation to previous research in other Learning Disability cohorts and the general population. The implications of mental ill health in individuals with a Learning Disability will be discussed.
Information about WiFi access will be provided by the University Centre Shrewsbury on the day.
Useful Information (travel and maps)

Conference Venue: Room SGH026
University Centre Shrewsbury
The Guildhall
Frankwell Quay
Shrewsbury SY3 8HQ

The registration desk for the conference will be located outside the main lecture theatre (SGH026) where all talks will take place. To find it, please enter the building through the main entrance and the registration desk will be in the Business Lounge, outside room SGH026.

Finding the University Centre Shrewsbury:

The University Centre Shrewsbury is located on the bank of the River Severn next to Frankwell car park (Pay and Display car park - maximum of £5.60 for a full day). The main entrance for the University Centre Shrewsbury is located on Frankwell Quay and can be accessed from the town centre by a footbridge across the river. The map below indicates the location of the University Centre Shrewsbury. This map also indicates where the local train and bus stations are in relation to the University Centre Shrewsbury. Further details on public transport are provided below.
Travel by public transport

If you are arriving into Shrewsbury by train, the University Centre Shrewsbury is a 10 minute walk from the train station.

If you arriving into Shrewsbury by bus, the University Centre Shrewsbury is a 7 minute walk from the bus station.

Travel by taxi

If you plan to use a taxi for local travel, we recommend pre-booking your taxi, particularly for your departure on the afternoon of Tuesday 4th December, as this is a busy time for the taxi companies.

Suggested taxi companies

<table>
<thead>
<tr>
<th>Firm name</th>
<th>Location</th>
<th>Telephone number</th>
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</thead>
<tbody>
<tr>
<td>Shrewsbury Taxis</td>
<td>Shrewsbury</td>
<td>01743 244477</td>
</tr>
<tr>
<td>Comet Cars</td>
<td>Shrewsbury</td>
<td>01743 292238</td>
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<tr>
<td>Go Carz</td>
<td>Shrewsbury</td>
<td>01743 441144</td>
</tr>
<tr>
<td>Access Cars</td>
<td>Shrewsbury</td>
<td>01743 545454</td>
</tr>
</tbody>
</table>
**Conference dinner location**

**Venue:**
The Lion Hotel  
Wyle Cop  
Shrewsbury SY1 1UY

*We will do a walking bus from the University Centre Shrewsbury main entrance / reception area to The Lion Hotel at 7pm if you are unsure where to go*

The Lion Hotel is a 10 minute walk from the University Centre Shrewsbury. Please see the map below for directions.

![Map of Shrewsbury](image_url)

Leave the University Centre Shrewsbury through the main entrance, and turn right to follow Frankwell Quay. Cross the footbridge over the River Severn and turn right onto Smithfield Road then turn right onto Roushill. Follow Roushill and then turn right onto Roushill Bank. At the end of Roushill Bank, turn left onto Mardol Head and then immediately turn right onto High Street. Follow High Street which will turn into Wyle Cop. Turn right onto Barracks Passage and you will arrive at The Lion Hotel.