



UNIVERSITY OF
BIRMINGHAM



Postgraduate Research Opportunities in Neurodevelopmental Disorders and Intellectual Disability (PhD, ClinPsyD, MRes)

The Cerebra Centre for Neurodevelopmental Disorders

Prof. Chris Oliver

on behalf of

*Cerebra Centre for Neurodevelopmental Disorders
School of Psychology
University of Birmingham*



Summary

The Cerebra Centre for Neurodevelopmental Disorders opened in January 2008 and has the overarching goal of furthering the understanding and effective treatment of cognitive, emotional and behavioural disorder in children with genetic disorders and intellectual disability. By the end of the fourth year of funding the Centre has become firmly established as evidenced by the achievements of the staff, students and volunteers at the Centre in the areas of postgraduate research training, research activity and dissemination.

In the first four years of funding the Centre has:

- ~ **developed** the largest database in the world documenting the psychological characteristics of children with genetic disorders and intellectual disability.
- ~ **provided** research training to 32 Doctoral students.
- ~ **established** an award winning volunteer scheme for undergraduate students and psychology graduates.
- ~ **produced** nearly 100 publications including three books and 43 original scientific articles in peer reviewed academic journals
- ~ **delivered** over 100 oral presentations throughout the world, including the USA, South Africa, Canada, Australia, New Zealand, Denmark, Belgium, Italy, Spain, Ireland, Germany, Norway and Taiwan.
- ~ **attracted** more than £750,000 in external funding.
- ~ **disseminated** more than 1,000 individualised research reports to parents

In 2011 we have celebrated the success of team members including the award of PhD's to Caroline Richards and Jane Waite, Clinical Psychology Doctorates to Sarah Hyland and Sarah Weaver and Masters degrees to Gursharan Barth, Hayley Mace, Jill Stevenson (nee Hoddell), Simon Snape and Daniel Silva. PhD student Leah Bull won the Pat Howlin Prize awarded by the Society for the Study of Behavioural Phenotypes (SSBP) and Kate Eden, Lucy Wilde and Leah Bull (all PhDs) won bursaries to attend the international SSBP meeting in Brisbane. Postdocs Dr. Kate Woodcock and Dr. Jo Moss were awarded bursaries for conference attendance in Spain and Denmark. The

research conducted on self-injurious behaviour in children with autism spectrum disorders by Caroline Richards for her PhD was featured on Channel 4 news.

In 2011 team members published their work in leading academic journals including Clinical Psychology Review, The American Journal of Medical Genetics (both Dawn Adams) and The Journal of Autism and Developmental Disorders (Jo Moss) as well as international handbooks (Chris Stinton, Jo Moss, Penny Tunnicliffe and Laurie Powis). In 2011, the team produced a total of 33 publications and made 39 presentations.

The breadth and quality of our research and research training and our emphasis on early dissemination of information to parents and carers demonstrates that the Cerebra Centre for Neurodevelopmental Disorders is the leading Centre in the UK for research that contributes to the wellbeing of children with genetic disorders and intellectual disability.

Introduction

The Cerebra Centre for Neurodevelopmental Disorders is supported by core funding from Cerebra and the School of Psychology, University of Birmingham. This funding was provided to support Prof. Chris Oliver (0.5 fte; Centre Director), one Research Fellow post (one, six year appointment), administrative and technical support, equipment and travel, PhD studentships (six in total) and postgraduate and undergraduate research and clinical placements. The School of Psychology has funded one Research Fellow post in the Centre and has committed to doing so for the life of the grant. The grant funding covers the period January 2008 to December 2013.

The three main activities of the Centre are:

- 1) Longitudinal, cross syndrome data collection to describe and understand the genetic, physical, neurological, cognitive and behavioural characteristics of children and young adults with genetic disorders associated with neurodevelopmental disorders.
- 2) Exploratory and hypothesis driven experimental research projects that seek to discover the causes of and effective interventions for behavioural, cognitive and emotional problems in children and young adults with genetic disorders.
- 3) Dissemination of research findings of relevance to all children and young adults with neurological impairments, intellectual and developmental disabilities who show behavioural, cognitive and emotional problems.

Accommodation and resources

Accommodation. The Centre is located on the first floor of the Frankland building in the School of Psychology. Accommodation comprises two large shared offices (one containing two cubicles used for coding recorded behaviour) with a total of ten workstations and storage space in each office. Between the offices is an observation lab divided by a partition with a one way mirror and equipped with recording equipment. Outside of the Centre there is office space for two staff, ClinPsyD, PhD and MRes students.

Resources. The Centre is equipped with desktop and laptop computers, printers, digital camcorders and cognitive and behavioural tests. In 2009 we equipped the video observation laboratory with camera and computer recording equipment. In addition to the usual office and test consumables, resources are available to conduct large scale postal surveys.

The Team in 2011

Centre Director

Prof. Chris Oliver (funded 0.5 fte by Cerebra).

Post Doctoral Research Fellows

Dr. Jo Moss (funded 1.0 fte by Cerebra).

Dr. Kate Woodcock (funded 1.0 by the University of Birmingham to March, 2011).

Dr. Dawn Adams (funded 0.6 fte by NIHR Fellowship award from March 2011).

Dr. Debbie Allen (funded 0.6 fte by Cerebra from October 2011)

Dr. Chris Stinton (funded 1.0 fte by Newlife, Baily Thomas Foundation and Cerebra).

Research Associates

Krupa Sheth (funded 0.5 fte by Angelman Syndrome Foundation USA for 3 months).

Gemma Warren (funded 0.5 fte by Angelman Syndrome Foundation USA for 3 months).

PhD Studentships (joint funded by Cerebra and the University of Birmingham).

Laurie Powis (2007 – to date; writing up)

Jane Waite (nee Appleby) (2007 - 2011)

Lucy Wilde (2008 - to date; writing up)

Kate Eden (2008 - to date; writing up)

Lisa Cochran (2009 – to date)

Louise Handley (2010 – to date)

Victoria Johnson (2011 – to date, 0.5 funded by CdLS Foundation)

PhD Studentships (supervised within the Centre)

Caroline Richards (2007- 2011; Research Autism funded)

Leah Bull (2009 – to date; Jerome Lejeune Fondation funded)

Mary Heald (2010 – to date; Jerome Lejeune Fondation funded)

Hayley Mace (2011 – to date; ESRC funded)

Efthalia Karakatsani (2011 – to date; funded by the Greek State Scholarships Foundation (I.K.Y))

Students on Research or Clinical Placements

Nineteen undergraduate and postgraduate students (in addition to PhD students) were on placement at the Centre during 2011. During the summer of 2011 two psychology undergraduates, Rachel Carter and Becky Hardiman, worked at the Centre. Five MRes students (Hayley Mace, Jill Hoddell, Simon Snape, Gursharan Barth and Daniel Silva) and nine ClinPsyD postgraduates (Dr. Penny Tunnicliffe, Sarah Hyland, Sarah Weaver, Dr. Tracey Grandfield, Dr. Louise Davies, Dr. Paul Langthorne, Dr. Jane Waite, Laurie Powis, Dr. Caroline Richards and Natalie Jackson) were on research or

clinical placements at the Centre. We also offered placements to Rachel Carter a ‘year out’ student from the University of Kent and Jessica Penhallow from the University of Aston.

The Cerebra Centre Postgraduate Volunteer Scheme

Postgraduate volunteers are valued members of the Cerebra Centre. Volunteers have a first degree in psychology and typically work 0.4 fte in the Centre supporting research projects by organising visits, data collection, data analysis and report preparation.

The postgraduate volunteers who worked at the Centre in 2011 were:

Jessica Tanner	March 2010 – August 2011
Helena Todd	March 2010 – February 2011
Charlotte Jackson	July 2010 – July 2011
Gemma Warren	July 2010 – ongoing
Becky Gallaher	January 2011 – September 2011
Emina Hadziosmanovic	January 2011 – March 2011
Victoria Johnson	January 2011 – August 2011
Natalie Karra	January 2011 – April 2011
Lipi Samanta	January 2011 – June 2011
Anneka Sheikh	January 2011 – June 2011
Krupa Sheth	February 2011 – ongoing
Riddhi Parmar	February 2011 – June 2011
Laura Jones-Campbell	April 2011 – September 2011
Katy Whitcomb	April 2011 – September 2011
Priya Mishra	May 2011 – ongoing
Alice Skelton	May 2011 – ongoing
Amy Mitchell	May 2011 – June 2011
Rosie Sibley	May 2011 – ongoing
Gita Rana	May 2011 – June 2011
Sarah Lynch	May 2011 – ongoing
Emma Cross	June 2011 – December 2011
Vicky Quine	June 2011 – October 2011
Anna Mitchell	June 2011 – ongoing
Leah Glover	October 2011 – ongoing
Leanne Liddell	November 2011 – ongoing

The Cerebra ‘Helping Hands’ Volunteer Scheme

During 2008 the Cerebra ‘Helping Hands’ volunteer scheme for undergraduates at the University of Birmingham was formally established. In 2011 the committee, chaired by Leah Bull and Louise Handley (PhD students) oversaw the work of more than 20 volunteers who support teaching staff in schools for children with severe intellectual disability, accompany PhD students and research staff on visits and undertake administrative tasks associated with the work of the Centre. The volunteers are named in Appendix A.

The Research in 2011

Projects initiated or conducted during 2011. Projects listed here are funded in full or part by the Cerebra grant. Projects conducted in the Centre but funded by other grant awards are not included.

Speech disorders in Cornelia de Lange syndrome. Jill Hoddell (a speech and language therapist) was awarded an MRes for her work on speech production problems sometimes seen in people with Cornelia de Lange syndrome. She identified a specific pattern of speech initiation problems that had not previously been reported.

The behavioural phenotype of Sotos syndrome. A large scale survey study to detail the behavioural phenotype of Sotos. Conducted by Sarah Hyland (ClinPsyD trainee on research placement at the Centre) and Jo Moss. In collaboration with Dr. Trevor Cole (Birmingham Women's Hospital). The project is now complete and two papers are in preparation.

The behavioural phenotype of 8p del and inv dup del 8p and 9q34.3 syndromes. The first detailed study of these syndromes. Conducted by Tracey Grandfield (ClinPsyD trainee on research placement at the Centre) and Jo Moss. In this project we have documented change with age in 9q34.3 (or Kleefstra syndrome) that had only been reported anecdotally previously.

Predictors of parental stress in Autism Spectrum Disorder. A survey designed to build a model of specific and general stressors for parents of children and adults with Autism Spectrum Disorder. Conducted by Sarah Weaver (ClinPsyD trainee on research placement at the Centre) and Jo Moss.

One paper has been submitted, a second is in preparation.

The behavioural phenotype of Rubinstein Taybi syndrome. A large scale survey study to detail the behavioural phenotype in this syndrome. Conducted by Laurie Powis, (Cerebra PhD studentship) and Jo Moss. The analysis has been completed.

Changes with age in the teenage years in Cornelia de Lange syndrome. A follow-up of teenagers with this syndrome to document cognitive and behavioural change. Conducted by Lisa Cochran, (Cerebra PhD studentship) and Jo Moss. This project is half way through. Recruitment of the sample for follow up is progressing well.

Atypical sociability in Smith-Magenis syndrome. Analysis of an existing dataset to provide preliminary data for Lucy Wilde (Cerebra PhD studentship). This project is now complete and a paper is in preparation.

Parent child interactions in Angelman, Cri du Chat and Cornelia de Lange syndromes. An extension to the Big Lottery funded Three Syndromes study examining the effects of child behaviour on parent interaction. Initially conducted by Sarah Beaumont (MRes postgraduate on placement at the Centre). Extended by Jo Moss. A

paper has been submitted for publication.

A four year follow up study of the behavioural phenotypes of Rubinstein Taybi Syndrome, Down Syndrome and Autism Spectrum Disorder. A large scale survey using the cross syndrome database. Conducted by Laurie Powis, Jane Waite (nee Appleby), Lisa Cochran, Lucy Wilde and Kate Eden (all Cerebra PhD studentships), Gursharan Barth, Mary Heald, Jo Moss, Chris Stinton, Dawn Adams and Caroline Richards. This study provides the basis for generating future hypothesis driven, group contrasts within a developmental context in addition to being the largest survey of its type.

Predictors of parental stress in Fragile X, Prader-Willi, Lowe and Smith Magenis syndromes. A survey designed to build a model of specific and general stressors for parents of children and adults with genetic disorders. (Dawn Adams, Jo Moss and in collaboration with Richard Hastings and Gemma Griffith (Bangor)).

Changes in executive function in adolescents and young adults with Cornelia de Lange and Down syndromes. An extension of a PhD studentship funded by the Cornelia de Lange Syndrome Foundation. This study focuses on changes in social behaviour related to executive function in these two syndromes. Conducted by Dr. Donna Reid (ClinPsyD trainee on research placement at the Centre). This project is now complete and a paper is in preparation.

The behavioural phenotype of Tuberous Sclerosis Complex. A large scale survey study to detail the behavioural phenotype of TSC and

provide a first test of a hypothetical link between pain and self-injury. Conducted by Kate Eden (Cerebra PhD studentship). In collaboration with Dr. Petrus de Vries (University of Cambridge). Data collection is now complete and analysis is underway.

The development of executive function in children with Rubinstein-Taybi syndrome. Work on this study has been completed and data analysis is going. Conducted by Jane Waite (nee Appleby; Cerebra PhD studentship). In collaboration with Dr. Ian Apperly and Dr. Sarah Beck (University of Birmingham).

Precursors to theory of mind in children with Rubinstein Taybi syndrome. Work on this study has been completed and data analysis has started. Conducted by Laurie Powis (Cerebra PhD studentship). In collaboration with Dr. Ian Apperly and Dr. Sarah Beck (University of Birmingham). Data collection has now finished and analysis is underway.

Pain, discomfort and challenging behaviour. This project is examining the association between pain and behaviours such as self-injury. Louise Davies and Kate Eden (Cerebra PhD studentship) are assessing the validity and reliability of observational assessment methods to identify pain in children who cannot communicate. Data collection is now complete and analysis is underway.

Gaze avoidance in Fragile X syndrome. This project is examining how gaze avoidance in Fragile X syndrome might be related to challenging behaviour. Paul Langthorne is a ClinPsyD doctoral trainee who is conducting the

experimental work in the children's schools.

Early intervention for challenging behaviour. Louise Handley (Cerebra PhD studentship) is applying a screening instrument in Child Development Centres in order to identify children who might be considered at high risk for developing challenging behaviour. Ethical review is complete, nine volunteers have been trained in data collection and recruitment will soon begin. (Dawn Adams is co-supervising the project in collaboration with Dr. Doug Simkiss, University of Warwick).

Unusually strong attachment in Smith-Magenis syndrome. Lucy Wilde (Cerebra PhD studentship) studied the strong drive for attachment to particular adults that is often seen in children with Smith-Magenis syndrome. This drive is often related to difficult behaviour. This project is now complete and a paper is in preparation.

Attending to social stimuli. Hayley Mace (MRes student, now PhD student) has been working with Jo Moss and Joe McCleery to use eye tracking technology to study attention to social stimuli in Cornelia de Lange and Rubinstein Taybi syndromes. This project is now complete and data are being analysed.

Self-injury and aggression in young children at high risk for self-injury. A new project examining the family and child characteristics of children who are at the highest risk for developing challenging behavior. (Efthalia Karakatsani and Dawn Adams)

Parental perceptions of children with genetic disorders. A new project using models from health psychology to investigate the effects of parental perceptions on help seeking and service use. (Chris Stinton and Natalie Jackson).

Service use and satisfaction for chronic challenging behaviour. A study of children who have shown challenging behaviour for approximately eight years to examine the use of services and parental views on service delivery and access. (Chris Stinton and Jane Waite; ClinPsyD).

Social anxiety in Cornelia de Lange and Fragile X syndromes. A new project investigating the causes of social anxiety in these syndromes. (Hayley Mace, Jo Moss and Joe McCleery)

Cognitive influences on decision making in Cornelia de Lange and Fragile X syndromes. A new project investigating choice and decision making in these syndromes. (Vicky Johnson, Sarah Beck and Jo Moss)

The focus of research in Autism Spectrum Disorder. A review of the last 10 years of published literature on ASD to evaluate the proportion that focuses on the immediate clinical needs of children and their families. (Krupa Sheth).

The development of executive function in typical and atypical development. The development of a battery of assessments to examine specific cognitive domains. Ultimately this battery will be applied to children of

atypical development when the normative data have been generated. (Three MRes students with Kate Woodcock, Krupa Sheth, Amanda Wood, Prof. Chris Jarrold (Bristol) and Dr. Gaia Scerif (Oxford)).

Food related problems in children with genetic disorders. Analysis of data on impaired satiety and other food related problems in six genetic disorders. (Gemma Warren).

Autism Spectrum Disorder and challenging behaviour in Phelan-McDermid syndrome. ClinPsyD students Caroline Richards and Laurie

Powis are conducting the first observational studies in this syndrome.

The nature of temper outbursts in Prader-Willi syndrome. Dr. Penny Tunnicliffe, ClinPsyD research student, is investigating to frequency, form and triggers of temper outbursts in Prader-Willi syndrome.

Social interactions in Smith-Magenis syndrome. Daniel Silva (MRes) and Lucy Wilde conducted a natural observation study of social behaviour in this syndrome and detailed the differences in seeking contact with peers and teachers in children.



Dissemination, Achievements and Collaboration in 2011

Individualised Research Reports for Parents. A key component of our research is to provide parents with individualised research reports at the earliest opportunity. Depending on the study these may contain assessment results with reference to normative data and clinical recommendations. Parents find the reports useful when discussing their children with professionals. The feedback we receive from parents indicates that these reports are highly valued. In 2011 we disseminated approximately 500 reports.

Oral and Poster Presentations. A total of 39 presentations were delivered in 2011. Of these, five were Keynote Lectures, Plenary or Opening addresses by Chris Oliver in Copenhagen, Tel Aviv and the UK to the 6th Cornelia de Lange Syndrome World Conference Scientific Symposium, the Beit Issie Shapiro 5th International Conference and professional and academic audiences. Six presentations were academic peer reviewed papers at scientific conferences in Brisbane, Copenhagen and Cambridge, eleven were invited presentations to academic or clinical audiences and fourteen were presentations to family support groups. Professional workshops were delivered in Oslo, Stavanger (Norway), Brescia (Italy) and Bologna. Additionally, four poster presentations were made. Presentations were made at meetings in the UK, Italy (2), Australia, Denmark, Ireland, Spain and Norway (2). A full list of presentations is shown in Appendix B.

Publications. A total of 33 articles were published or in press during

2011. Of these, 21 were academic peer reviewed articles, four were abstracts from scientific meetings that were published in peer reviewed academic journals and one journal editorial was published. Of the academic peer review articles, four papers were published in leading, high impact journals (Journal of Autism and Developmental Disorders (2), Clinical Psychology Review and American Journal of Medical Genetics). Three chapters for edited works were published or in press (two in international handbooks). A full list of publications is shown in Appendix C.

Cerebra Centre Academic Programme. Well respected external speakers within the fields of neurodevelopmental disorders and intellectual disabilities are invited to give seminars as part of our academic programme which was established in Spring 2009 and runs throughout spring and autumn terms. These seminars are advertised across the University of Birmingham, the Intellectual Disability Research and Intellectual Disability Health networks in the UK. The seminars have attracted a broad range of delegates including professionals from the Autism Centre for Education and Research, University of Birmingham, local NHS services and the West Midlands genetics services. A full list of the nine seminars for 2011 can be found in Appendix D. These seminars encourage new collaborations and provide the Cerebra centre with a mechanism for focused dissemination of its ongoing work.

Prizes and Bursaries. In recognition of the capacity of the Cerebra Centre to

conduct and disseminate high quality scientific research that is of benefit to individuals with neurodevelopmental disorders and their families, six prizes/bursaries were awarded to members of the team in 2011. Kate Woodcock was awarded a travel bursary by the European Science Foundation. Jo Moss was awarded a travel grant by Kings College London and Les Fountain Travel Awards were given to Leah Bull, Lucy Wilde and Kate Eden. Leah Bull won the Pat Howlin Prize at the 14th Society for the Study of Behavioural Phenotypes International Research Symposium in Brisbane. Details of these awards can be found in Appendix E.

Grant applications Three grant applications were successful this year in a very competitive and increasingly restricted financial environment. £27,000 was awarded by the Cornelia de Lange Syndrome Foundation (UK and Ireland) to investigate changes with age in the syndrome. The Rubinstein Taybi Syndrome Support Group awarded £3,000 to the Centre and Jo Moss and Chris Oliver were awarded a grant of £2,000 by the School of Psychology to support pilot development of a website.

Grant applications were made to the ESRC and Leverhulme but were unsuccessful.

Dawn Adams started her NIHR Postdoctoral Fellowship at 0.6 fte at

the Centre for five years from March 2011.

A full list of all grants and Fellowship awards held within the Centre is shown in Appendix F.

Collaboration. Staff in the Centre are engaged in research collaboration with colleagues across the UK and Europe in the Universities of: Kings College London (Prof. Pat Howlin), Bangor (Prof. Richard Hastings), Cambridge (Prof. A. Holland, Dr. P. de Vries), Nijmegen (Prof. R. Didden, Prof. L. Curfs), Cardiff (Prof. David Felce), Oxford (Dr. Gaia Scerif), Warwick (Dr. Doug Simkiss) and Bristol (Prof. Chris Jarrold).

Collaborations within the University include work with Prof. Alan Wing on movement, Dr. Ian Apperly on Theory of Mind, Dr. Sarah Beck on cognitive development, Dr. Joe McCleery on eye tracking methodology and Dr. Sotaro Kita on gestures.

Other Activities. Chris Oliver was appointed to the Editorial Board of the Journal of Developmental and Physical Disabilities and as an external PhD examiner at the Universities of London and Monash (Melbourne, Australia). He was also elected as Chair of the Scientific Advisory Committee to the World Cornelia de Lange Syndrome Federation and as a member of the Prader-Willi Syndrome Scientific Advisory Committee.



Contact

There is more information about our research on our website: www.birmingham.ac.uk/cnnd. If you are interested in a postgraduate research placement (PhD, ClinPsyD, MRes) at the Cerebra Centre then please contact Chris Oliver at c.oliver@bham.ac.uk.

*Prof. Chris Oliver
Director
Cerebra Centre for Neurodevelopmental Disorders
School of Psychology
University of Birmingham*

December 2011

APPENDIX A

Undergraduate 'Helping Hands' Volunteers

Academic year 2009-2010

Emma Clarkson
Jennifer Birch
Georgina Bird
Rose Farrance-White
Sarah Davis
Alicia Griffiths
Laura Spurgeon
Shazia Hussain
Jessica Dorse
Ruth Onions
Rajveer Athwal
Josie Harding

Academic year 2010-2011

Gemma Hartley
Roaa Ali
Tanya Kurt
Sarah Davis
Jasmine Foley
Louise Keogan
Lauren Josephs
Fay Underwood
Lynette Jude
Jess Whiting
Clare Williams
Harriet Maydew
Becky Hardiman
Katy Smart
Hannah Cochrane

Academic year 2011-2012

Roaa Ali
Tanya Kurt
Jasmine Foley
Fay Underwood
Lynette Jude
Jess Whiting
Katy Smart
Harriet Maydew
Hannah Cochrane
Becky Hardiman
Louise Rayfield
Vicky Harris
Amy Barrett
Abigail Trumper

APPENDIX B

PRESENTATIONS IN 2011

ANNUAL LECTURES, PLENARY, OPENING AND KEYNOTE ADDRESSES

- 1) Oliver, C. Challenging behaviour in children with severe intellectual disability. *Keynote lecture. British Association for Community Child Health (West Midlands). Warwick, December 2011.*
- 2) Oliver, C. The cognitive and behavioural phenotype of Cornelia de Lange syndrome. *Keynote Lecture. 6th Cornelia de Lange Syndrome World Conference: Scientific Symposium. Copenhagen, July, 2011.*
- 3) Oliver, C. Challenging behaviour: Before you judge me, take a walk in my shoes. *Keynote Lecture. Beit Issie Shapiro 5th International Conference. Learning from the past, shaping the future. Tel Aviv, July, 2011.*
- 4) Oliver, C. Who is responsible for challenging behaviour? *Keynote Lecture. Association for Child and Adolescent Mental Health National Winter Conference. Child and Adolescent Learning Disabilities. Leeds, January, 2011.*
- 5) Oliver, C. Phenotype-environment interactions in neurodevelopmental disorders. *Keynote Address. Institute of Health and Society and Institute of Neuroscience Research Day. University of Newcastle. January, 2011.*

PEER REVIEWED NATIONAL AND INTERNATIONAL CONFERENCE PRESENTATIONS

- 1) Oliver, C., Lau, J., Moss, J., Cullen, J., Higgs, S., Marr, A. & Cook., F. (2011). Food related problems in children with Angelman, Prader-Willi, 1p36 deletion, Cornelia de Lange and Fragile X syndromes. *Society for the Study of Behavioural Phenotypes 14th International Symposium. Brisbane, October, 2011.*
- 2) Stinton, C. Informant and self-reports of the mental health of adults with Williams syndrome. *The 11th Seattle Club Conference on Research in Intellectual Disabilities, Cambridge, England, December 2011.*
- 3) Heald, M., Villa, D., Allen, D., Adams, D., Tanner, J. & Oliver, C. (2011). The effect of discrimination training on social approach behaviour in children with Angelman syndrome. *The 11th Seattle Club Conference on Research in Intellectual Disabilities, Cambridge, England, December 2011.*
- 4) Eden, K., Oliver, C., de Vries, P., Stinton, C. & Moss, J. Challenging behaviour in Tuberous Sclerosis Complex, *14th International Meeting for the Society for the Study of Behavioural Phenotypes, Brisbane, October 2011*
- 5) Bull, L.E., Woodcock, K.A., Perry, A., Todd, H., Holland, A.J. & Oliver, C. Temper Outbursts in Prader-Willi syndrome: Early intervention and environmental management. *14th International Meeting for the Society for the Study of Behavioural Phenotypes, Brisbane, October 2011*
- 6) Wilde, L., Waite, J., Heald, M. & Oliver, C. Inhibition and impulsivity in children with Smith Magenis syndrome. *14th International Meeting for the Society for the Study of Behavioural Phenotypes, Brisbane, 2011*
- 7) Neilson, E., Oliver, C., Moss, J. and Kita. S. (2011). Gesture utilisation within a social interaction in Cornelia de Lange syndrome. *Cornelia de Lange Syndrome, 6th World Congress, Copenhagen July 2011, Scientific Symposium.*

INTERNATIONAL INVITED PRESENTATIONS (ACADEMIC\PROFESSIONAL)

- 1) Oliver, C. and Wilde, L. The behavioural phenotypes of Smith-Magenis and Phelan McDermid syndromes. *The Frambu Centre for Rare Disorders, Oslo, Norway. December, 2011.*
- 2) Oliver, C. Behavioural phenotypes and challenging behaviour. *Italian Association for the Study of Intellectual and Developmental Disabilities Conference. Brescia, Italy. September 2011.*
- 3) Oliver, C. Challenging behaviour in genetic syndromes associated with intellectual disability. *6th Cornelia de Lange Syndrome World Conference: Professional Symposium. Copenhagen, July, 2011.*
- 4) Oliver, C. Disturbi del comportamento in bambini e adulti con sindrome genetica. *Sindromi malformative complesse con ritardo mentale. 9th Residential Course on Paediatric Genetics. Fondazione Pierfranco e Luisa Mariani. Bologna, Italy, April, 2011.*
- 5) Oliver, C. An assessment strategy for self-injurious behaviour. *Stavanger Hospital, Stavanger, Norway, February, 2011.*

NATIONAL INVITED PRESENTATIONS (ACADEMIC\PROFESSIONAL)

- 1) Oliver, C. Behavioural phenotypes of genetic disorders associated with intellectual disability. *West Midlands Regional Genetics Seminar Series. Birmingham. November, 2011.*
- 2) Stinton, C. and Skelton, A. Genetic syndromes: behavioural phenotypes, mental health and challenging behaviours. *The University of Warwick, November, 2011*
- 3) Oliver, C. Phenotype x environment interactions in neurogenetic disorders. *MRC Centre for Neuropsychiatric Genetics and Genomics Seminars. Department of Psychological Medicine and Neurology, Cardiff University, June 2011.*
- 4) Moss, J. Understanding ASD and social functioning in individuals with genetic syndromes, *Institute of Cognitive Neuroscience, University College London, June 2011.*
- 5) Oliver, C. & Richards, C. Self-injurious behaviour in genetic disorders and autism spectrum disorder. *The Research Autism\ Lorna Wing series of conferences and seminars. The 'autisms': important perspectives on autism. London, May, 2011.*
- 6) Oliver, C. & Richards, C. Self-injurious behaviour in children and adults with autism spectrum disorder, in seven numbers. *Research Autism Board of Trustees, London, March, 2011.*

INTERNATIONAL AND NATIONAL INVITED PRESENTATIONS (PROFESSIONAL AND FAMILY SUPPORT GROUP CONFERENCES)

- 1) Allen, D., Oliver, C., Carter, R., Warren, G., Stamatopoulou, V., Matuszczak, A., Symonds, J., Cousins, J., Yockney, S & Rosen, N. .Remote Consultancy for Self-injurious Behaviour in Children with Autism Spectrum Disorder. *National Autistic Society Academic Network Meeting, London, November 2011.*
- 2) Allen, D., Oliver, C., Carter, R., Warren, G., Stamatopoulou, V., Matuszczak, A., Symonds, J., Cousins, J., Yockney, S & Rosen, N. .Remote Consultancy for Self-injurious Behaviour in Children with Autism Spectrum Disorder. *National Autistic Roadshow, London, November 2011.*
- 3) Oliver, C. The behavioural phenotype of Cornelia de Lange Syndrome: From genes to families. *VIth Congreso Nacional del Síndrome Cornelia de Lange, Burgos, Spain, October,*

2011.

- 4) Oliver, C. The cognitive and behavioural phenotype of Cornelia de Lange syndrome. *Cornelia de Lange Syndrome Foundation Family meeting. York, October, 2011.*
- 5) Welham, A. Adolescence and early adulthood with CdLS: people's experiences and psychological research. *Cornelia de Lange Syndrome, National Conference, York, October 2011.*
- 6) Stevenson, J. Examining Speech and Language in Cornelia de Lange Syndrome. *Cornelia de Lange Syndrome, National Conference, York, October 2011.*
- 7) Oliver, C. Understanding challenging behaviour in Fragile X syndrome. *The Fragile X Society National Parent Conference. Birmingham, September, 2011.*
- 8) Moss, J. Autism spectrum disorders in genetic syndromes associated with intellectual disability. *Cornelia de Lange Syndrome, 6th World Congress, Copenhagen, July 2011, Professional Symposium.*
- 9) Moss, J. Social and behavioural difference in children and adults with Cornelia de Lange syndrome. *Cornelia de Lange Syndrome, 6th World Congress, Copenhagen, July 2011, Family Symposium.*
- 10) Moss, J. ASD in genetic syndromes: Implications for assessment and intervention, *Autism Today 8th National Conference, London, July 2011.*
- 11) Oliver, C. Cognitive and behavioural difference in children and adults with Cornelia de Lange syndrome. *6th Cornelia de Lange Syndrome World Conference: Family Conference. Copenhagen, July, 2011.*
- 12) Oliver, C. and Wilde, L. Understanding challenging behaviour in Smith-Magenis syndrome. *Smith-Magenis Syndrome UK Biennial Conference. West Midlands, May, 2011.*
- 13) Oliver, C. The cognitive and behavioural phenotype of Cornelia de Lange syndrome. *Cornelia de Lange Syndrome Foundation Family meeting. Cork, Ireland, May, 2011.*

POSTERS AT PEER REVIEWED NATIONAL AND INTERNATIONAL CONFERENCES

- 1) Woodcock, K. A, Oliver, C., Milward, S. Tang, C. Sheth, K. & Beck, S. Measuring executive functioning in individuals with neurodevelopmental disorders. *European Science Foundation, Granada, September 2011*
- 2) Sheth, K. and Oliver, C. A Contemporary Review of Publication Trends in Autism Research. *The 11th Seattle Club Conference on Research in Intellectual Disabilities, Cambridge, England, December 2011.*
- 3) Warren G., Moss, J. Lau, J. Cullen, J., Higgs, S., Marr, A., Cook., F. and Oliver., C. Food related problems in children with Angelman, Prader-Willi, 1p36 deletion, Cornelia de Lange and Fragile X syndromes. *The 11th Seattle Club Conference on Research in Intellectual Disabilities, Cambridge, England, December 2011.*

MEDIA

- 1) Channel 4 News. Number of Children on Antipsychotic Drugs Doubles. 9 November, 2011. Interview and coverage of research.

APPENDIX C

PUBLICATIONS IN 2011

PEER REVIEWED JOURNAL ARTICLES

- 1) Richards, C., Oliver, C., Nelson, L. and Moss, J. (In press). Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability. *Journal of Intellectual Disability Research*.
- 2) Oliver, C., Petty, J., Ruddick, L. and Bacarese-Hamilton, M. (In press). The association between repetitive, self-injurious and aggressive behavior in children with severe intellectual disability. *Journal of Autism and Developmental Disorders* doi: 10.1007/s10803-011-1320-z
- 3) Stinton, C., Tomlinson, K., & Estes, Z. (In Press). Examining reports of mental health in adults with Williams syndrome. *Research in Developmental Disabilities*, 33, 144-152. doi: 10.1016/j.ridd.2011.09.002.x
- 4) Sayers, N., Oliver, C. and Ruddick, L. (2011). Stereotyped behaviour in children with autism and intellectual disability: An examination of the executive dysfunction hypothesis. *Journal of Intellectual Disability Research*, 55, 699-709. doi: 10.1111/j.1365-2788.2010.01370.x
- 5) Adams, D., Horsler, K. and Oliver, C. (2011). Age related change in social behavior in children with Angelman syndrome. *American Journal of Medical Genetics (Part A)*, 155, 1290-1297. doi: 10.1002/ajmg.a.33964
- 6) Oliver, C., Kalsy, S., McQuillan, S. and Hall, S. (2011). Behavioural excesses and deficits associated with dementia in adults who have Down syndrome. *Journal of Applied Research in Intellectual Disability*, 24, 208-216. doi: 10.1111/j.1468-3148.2010.00604.x
- 7) Adams, D. and Oliver, C. (2011). The expression and assessment of emotions and internal states in individuals with severe or profound intellectual disabilities, 31, 293-306. *Clinical Psychology Review*. doi: 10.1016/j.cpr.2011.01.003
- 8) Mount, R., Oliver, C., Berg, K. and Horsler, K. (2011). Effects of adult familiarity on social behaviours in Angelman syndrome. *Journal of Intellectual Disability Research*, 55, 339-350. doi: 10.1111/j.1365-2788.2010.01364.x
- 9) Tunnicliffe, P. and Oliver C. (2011). Phenotype-environment interactions in genetic syndromes associated with severe or profound intellectual disability. *Research in Developmental Disabilities*. 32, 404-418. doi:10.1016/j.ridd.2010.12.008
- 10) Taylor, L., Oliver, C. and Murphy, G. (2011). The chronicity of self-injurious behaviour: A long-term follow-up of a total population study. *Journal of Applied Research in Intellectual Disability*, 25, 107-117. doi: 10.1111/j.1468-3148.2010.00579.x
- 11) Hayes, S., McGuire, B., O'Neill, M and Oliver, C. (2011). Relationship between low mood and challenging behaviour in people with profound and severe intellectual disability, 55, 182-189. *Journal of Intellectual Disability Research*. doi: 10.1111/j.1365-2788.2010.01355.x
- 12) Cook, F. and Oliver, C. (2011). A review of defining and measuring sociability in children with intellectual disabilities. *Research in Developmental Disabilities*. 32, 11-24. doi: 10.1016/j.ridd.2010.09.021
- 13) Hoddell, J., Moss, J., Woodcock, K. & Oliver, C. (2011). Further refinement of the nature of the communication impairment in Cornelia de Lange syndrome. *Advances in Mental Health and Intellectual Disabilities*, 5, 15-25. doi: 10.1108/20441281111165562
- 14) Sloneem, J., Oliver, C. Udwin, O. & Woodcock, K. A. (2011). Prevalence, phenomenology, aetiology and predictors of challenging behaviour in Smith-Magenis syndrome. *Journal of*

Intellectual Disability Research, **55**, 138-151. doi: 10.1111/j.1365-2788.2010.01371.x

- 15) Woodcock, K. A., Oliver, C., & Humphreys, G. W. (2011). The relationship between specific cognitive impairment and behaviour in Prader-Willi syndrome. *Journal of Intellectual Disability Research*, **55**, 152-171. doi: 10.1111/j.1365-2788.2010.01368.x
- 16) Oliver, C., Berg, K., Moss, J., Arron K., & Burbidge, C. (2011) Delineation of behavioural phenotypes in genetic syndromes. Comparison of autism spectrum disorder, affect and hyperactivity. *Journal of Autism and Developmental Disorders*, **41**, 1019-1032. doi: 10.1007/s10803-010-1125-5
- 17) Magiati, I., Moss, J., Charman, T. and Howlin, P. (2011). Patterns of change in children with Autism Spectrum Disorders who received community based comprehensive interventions in their pre-school years: a seven year follow up study. *Research in Autism Spectrum Disorders*, **5**, 1016-1027. doi: 10.1016/j.rasd.2010.11.007
- 18) Magiati, I., Moss, J., Yates, R., Charman, T. and Howlin. (2011). Is the Autism Treatment Evaluation Checklist (ATEC) a useful tool for monitoring progress in children with Autism Spectrum Disorders? *Journal of Intellectual Disability Research*, **55**, 302-312. doi: 10.1111/j.1365-2788.2010.01359.x
- 19) Griffith, G. M., Hastings, R. P., Howlin, P., Moss, J., Oliver, C. Petty, J. & Tunnicliffe, P. (2011). Psychological distress and well-being in mothers and fathers of children with Angelman, Cornelia de Lange and Cri du Chat syndromes. *Journal of Intellectual Disability Research*, **55**, 397-410. doi: 10.1111/j.1365-2788.2011.01386.x
- 20) Griffith, G. M., Hastings, R. P., Nash, S., Petalas, M., Howlin, P., Moss, J., Oliver, C. Petty, J. & Tunnicliffe, P. (2011). 'You have to sit and explain it all, and explain yourself'. Mothers experiences of caring for an adult with a rare genetic intellectual disability syndrome. *Journal of Genetic Counseling*, **20**, 165-177. doi: 10.1007/s10897-010-9339-4
- 21) Arron, K., Oliver, C., Berg, K., Moss, J. and Burbidge, C. (2011). Delineation of behavioural phenotypes in genetic syndromes. Prevalence, phenomenology and correlates of self-injurious and aggressive behaviour. *Journal of Intellectual Disability Research*, **55**, 109-120. doi: 10.1111/j.1365-2788.2010.01337.x

CONTRIBUTIONS TO EDITED WORKS

- 1) Oliver, C., Arron, K., Powis, L., and Tunnicliffe, P. (2011). Cornelia de Lange, Cri du Chat and Rubinstein Taybi Syndromes. In: M. Ghaziuddin, P. Howlin and T. Charman (Eds.) The SAGE Handbook of Developmental Disorders.
- 2) Moss, J., Howlin, P. & Oliver, C. (2011). The assessment and presentation of Autism Spectrum Disorder and associated characteristics in individuals with severe intellectual disability and genetic syndromes. In: Burack, J. (Eds.) Handbook of Intellectual Disabilities and Development.
- 3) Stinton, C., & Howlin, P. (2011). Williams syndrome: Adult outcomes and integration into society. In Farran, E.K., & Karmiloff-Smith, A. (Eds.) Developmental Disabilities Across the Lifespan: Williams Syndrome as a Model Disorder. Oxford University Press, UK.

JOURNAL EDITORIALS

- 1) Heussler, H.S. & Oliver, C. (2011). Behavioural phenotypes: from models to intervention. *Journal of Intellectual Disability Research*, **55**, 945-1007. (DOI: 10.1111/j.1365-2788.2011.0

CONFERENCE PROCEEDINGS: PUBLISHED ABSTRACTS

- 1) Oliver, C., Lau, J., Moss, J., Cullen, J., Higgs, S., Marr, A. & Cook., F. (2011). Food related problems in children with Angelman, Prader-Willi, 1p36 deletion, Cornelia de Lange and Fragile X syndromes. *Journal of Intellectual Disability Research*, **55**, 953. (DOI: 10.1111/j.1365-2788.2011.01474_2.x)
- 2) Eden, K, Oliver, C., de Vries, P., Stinton, C. & Moss, J. (2011). Challenging Behaviour in Tuberous Sclerosis Complex. *Journal of Applied Research in Intellectual Disability*, **55**, 951 (DOI: j. 1365-2788.2011.01474_2.x)
- 3) Bull, L.E., Woodcock, K.A., Perry, A., Todd, H., Holland, A.J. & Oliver, C. (2011). Temper Outbursts in Prader-Willi syndrome: Early intervention and environmental management. *Journal of Intellectual Disability Research* , **55**, 950. (DOI: j. 1365-2788.2011.01474_2.x)
- 4) Wilde, L., Waite, J., Heald, M., Tanner, J. & Oliver, C. (2011). Inhibition and impulsivity in children with Smith Magenis syndrome. *Journal of Applied Research in Intellectual Disabilities*, **23**, 954–954. (DOI: 10.1111/j.1365-2788.2011.01474_2.x)

OTHER PUBLICATIONS

- 1) Welham, A., Moss, J. & Oliver, C. Growing up with CdLS: Changes in Adolescence and Young Adulthood. *Special Issue Report for the Cornelia de Lange Syndrome Foundation*.
- 2) Waite, J., Moss, J. & Oliver, C. Understanding Behavioural Characteristics in Lowe Syndrome. *Article for the Lowe Syndrome Association, USA Newsletter*
- 3) Carter, R., Warren, G., Allen, D., & Oliver, C. Assessment and Intervention for Self-injurious Behaviour in Children with Autism Spectrum Disorder: 5 case studies. *DVD for the National Autistic Society*.
- 4) Moss, J., & Oliver, C. The Cerebra Centre for Neurodevelopmental Disorders. *Article for the Society for the Study of Behavioural Phenotypes Newsletter*.

APPENDIX D

SEMINAR SERIES IN 2011

- 1) Prof. Karmiloff-Smith, Birkbeck University of London. *The importance of cross-syndrome comparisons: a neuroconstructivist, domain-relevant perspective.* January, 2011
- 2) Prof. Jeremy Turk, South London & Maudsley Foundation NHS Trust. *An update on fragile X syndrome work and its wider relevance to helping individuals with intellectual disability* January, 2011.
- 3) Dr. Joni Holmes: Northumbria University *Working memory training: Does it work?* February 2011.
- 4) Dr. Chris Stinton, University of Birmingham *Examining reports of mental health in adults with Williams syndrome*, March 2011.
- 5) Dr. Sarah White: Institute of Cognitive Neuroscience, University College London. *Heterogeneity in autism: Does intact task performance equate to intact cognition and vice versa?* April 2011
- 6) Prof. Derek Moore, University of East London. *Are neurobehavioural impairments associated with fMRI gene expansion in carrier males? Exploring divergent pathways across the Fragile X continuum.* April, 2011
- 7) Dr Chris Jones, Ridgeway Partnership (Oxfordshire Learning Disability NHS Trust) *Friendship, romance and possibly more – reflections on setting up a Dating Agency for people with learning disabilities in Oxfordshire* May 2011.
- 8) Vivien Cooper, Challenging Behaviour Foundation. *Getting the right support in the right place at the right time for individuals with learning disabilities whose behaviour challenges services. The work of the Challenging Behaviour Foundation.* October, 2011.
- 9) Dr. Atsushi Senju, Birkbeck, University of London. *Typical and atypical development of spontaneous social cognition.* December, 2011.

APPENDIX E

BURSARIES & PRIZES 2011

- 1) Kate Eden received a Les Fountain travel bursary to attend the SSBP International Research Symposium, Brisbane, October 2011.
- 2) Kate Woodcock received a bursary to attend the European Science Foundation's workshop: "The developing brain: perspectives from typical and atypical development", Granada, Spain, September 2011.
- 3) Leah Bull was awarded the Pat Howlin Prize Lecture at the 14th Society for the Study of Behavioural Phenotypes International Research Symposium, Brisbane, Australia, October, 2011.
- 4) Leah Bull received a Les Fountain Travel Bursary to attend the 14th Society for the Study of Behavioural Phenotypes International Research Symposium, Brisbane, Australia, October 2011.
- 5) Lucy Wilde received a Les Fountain Travel Bursary to attend the 14th Society for the Study of Behavioural Phenotypes International Research Symposium, Brisbane, Australia, October 2011.
- 6) Jo Moss received a travel grant from the Institute of Psychiatry, King's College London to attend the Cornelia de Lange 6th World Congress, Copenhagen, July 2011.

APPENDIX F

GRANTS AND POSTDOCTORAL FELLOWSHIPS ACTIVE IN 2011 IN ADDITION TO THE AWARD FROM CEREBRA

- 1) Behavioural Phenotypes and Family Adjustment in Children and Adults with Genetically Determined Intellectual Disability (Project led by Jo Moss). Baily Thomas Charitable Foundation. £67,877, 30 months.
- 2) Testing a strategy to improve challenging behaviour in individuals with Prader-Willi syndrome using cognitive training and environmental management (Project led by Kate Woodcock). Fondation Jerome Lejeune, €8,500, 36 months, start date October, 2009.
- 3) Self-injurious behaviour in children with Autism Spectrum Disorder. (Project led by Debbie Allen). National Autistic Society, £35,298, 12 months, start date June, 2010.
- 4) Understanding Behaviour Disorder and Family Adjustment in Children and Adults with Sotos Syndrome and Tuberous Sclerosis Complex. (Project led by Jo Moss). Newlife, £14,915, 12 months, start date August, 2010.
- 5) Excessive sociability in Angelman syndrome (Project led by Dawn Adams). Jerome Lejeune Fondation. €0,000 36 months.
- 6) Towards an early intervention strategy for challenging behaviour in genetic disorders. (Dr. Dawn Adams; National Institute for Health Research Postdoctoral award). £322,841, 60 months. March, 2011.
- 7) Cultural and genetic variation in emotion regulation. Marie Curie International Outgoing Fellowship, European Commission (Applicants: Glyn Humphreys, Shihui Han, Chris Oliver; Fellow: Kate Woodcock). €207,616. 36 months. March, 2011.
- 8) Establishing the basic principles of effective intervention for difficult behaviour in Angelman syndrome (Oliver PI). Angleman Syndrome Foundation (USA), \$78,000, 12 months, start date August 2009.
- 9) Extending the behavioural phenotype of Cornelia de Lange syndrome. The Cornelia de Lange Syndrome Foundation (UK and Ireland). (Oliver, PI) £27,000, 36 months, start date October, 2011.
- 10) Extending the behavioural phenotype of RubinsteinTaybi syndrome. The Rubinstein Taybi Syndrome Support Group. (Oliver PI). £3,000. July 2011.