

Centre for Educational Development, Appraisal and Research (CEDAR)

University of Warwick

## **Cerebra Family Research Group**

### **Annual Report January 2021 – December 2021**



Centre for Educational Development  
Appraisal and Research

## 2021 Highlights

### Positive Family Connections project

Our Cerebra-funded *PosFam* project has made excellent progress in 2021. The intervention, after close consultation with family carers, is now called *Positive Family Connections*. *Positive Family Connections* is designed to enhance family relationships and wellbeing in families of children with developmental disabilities. Five family carers worked with **Dr Jo Griffin** and the rest of the research team across four workshop meetings, and additional small meetings and email feedback, to co-design the intervention and produce an intervention manual and resources. The intervention is a group intervention for families, delivered online by two trained family carers. From September to November, we carried out the initial piloting of the *Positive Family Connections* intervention with 14 family carers (in two groups of seven).

Following the pilot study and extensive feedback from family carer participants, and those delivering the intervention, the intervention manual was revised ready for the next stage of the research.

**Daniel Sutherland** was appointed as a PhD student working on the project starting in October, and very helpfully he was also able to join the pilot project before his official start date. Daniel led the submission of the research ethics application to the University of Warwick (submitted in December) for the next stage of the *Positive Family Connections* project – a feasibility Randomised Controlled Trial (to begin in 2022). The project is progressing along the proposed timeline so far.

### Cerebra 1000 Families Study

The 1000 Families Study has continued to be the core of our family-based research carried out with direct Cerebra funding support.

During 2021, we completed the first follow-up (Wave 2) of participating families, approximately 2.5 years after the families first took part in Wave 1. In total, 650 families took part in Wave 2. **Caitlin Murray** (Research Fellow) and **Caitlin Williams** (PhD student) also worked hard to clean the databases from Waves 1 and 2 and clarify data queries so that we now also have data files that include data linked between the first two waves of the study.

Caitlin and Caitlin also led the research ethics application to carry out the third wave of the study. We are pleased to say that this received full ethics approval from the University of Warwick during the year, and we have also begun Wave 3 data collection. Over 700 families are eligible for Wave 3 and will be invited to take part in the follow-up. This number is higher than the 650 families who took part in Wave 2 because we will have a version of the survey for families whose young person is now over 16 years of age, and also we did a lot of work to follow up families who did not feel able to take part in Wave 2. Some of those families were still happy to be invited for Wave 3.

Although we have not had new publications from the 1000 Families Study since our 2020 report, there are currently **nine** research papers using Wave 1 data, or Waves 1 and 2 data, under review with research journals or in draft stage. Thus, the potential of the 1000 Families Study to (continue to) contribute significant new high quality research knowledge is very clear.

## COVID-19 Research


A major focus of our research in 2021 has been on COVID-19 related research. We continued with and completed our MRC/NIHR funded project on the experiences of adults with learning disabilities and their families during the pandemic. This work included survey data collection with 250-300 family carers of adults with learning disability across all four UK nations, at three times (Dec 20/Jan 21; April/May 21; July 21). Publications (appendix 1) 1, 8, 9, 10, 11, and 12 reported data from this research and research summaries (including easier to read versions) and additional reports are all available on the project website: <https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/>

We also received funding from ESRC (Appendix 2) for a COVID-focused study on school attendance of children with learning disability and/or autism during the pandemic. The focus of this research is a survey of parents of school age children; both children registered with a school and those not. We successfully recruited over 1000 parent carers for this research, and this was in large part due to very helpful support from Cerebra in promoting the research study. Thank you to Cerebra staff for their help and to families who took part. We are currently working on the analysis of the data. Information about the study can be found on the project website: <https://www.ucl.ac.uk/psychiatry/research/epidemiology-and-applied-clinical-research-department/school-attendance-and-home-learning>

During 2021, we also updated the COVID self-help mental health booklets that we produced in 2020 – the booklets were updated to address changes to the restrictions and accessing vaccines. We also carried out an evaluation of the impact of these booklets that supporters (family carers or staff) can use with individuals with learning disabilities. The results of the evaluation of the impact of these booklets have been accepted as a paper for publication (Paper 4). The booklets are still available for free: <https://www.sclد.org.uk/covid-19-guided-self-help-booklet-series/>

## Other highlights

- In addition to the research papers mentioned above, we have published or had accepted for publication a *further 7 scientific journal papers* focused on family research or including family variables since our previous Report to Cerebra (see Appendix 1). Notable studies include the results of our early intervention programme for families of children with developmental delay (E-PAtS; Early Positive Approaches to Support) (Paper 7), and also a review of research on a sensitive but important topic for family carers – understanding suicide in family carers (Paper 13)
- We secured more than £400k in additional research funding for projects that include a significant family research component and working with family carers to inform the research (see Appendix 2)
- We continued to contribute to sharing family research with families and professionals, and working to use family research evidence to influence policy and practice. In 2021, **Richard Hastings** presented at an early intervention policy event that was focused on key influencers in England and was organized with *Cerebra*, the *Council for Disabled Children*, *Mencap* and the *Challenging Behaviour Foundation*. A policy briefing from this event is being produced. Richard also gave keynote or invited presentations on early intervention for children with



learning disabilities at a research conference in Italy, to trainee intellectual disability psychiatrists at their annual conference, and for practitioners and families at a workshop for Anglesey local authority. Richard and research team colleagues have also given more than 20 presentations to policy makers, professionals, and family carers about the findings of our COVID-19 survey study

- We welcomed new research group members during 2021: **Daniel Sutherland** to study for a PhD funded by Cerebra and the University of Warwick on the *Positive Family Connections* project; **Wenyuan Liu** to study for a PhD funded by the University of Warwick on families of children with autism; **Emma Scripps** to study for a PhD funded by ESRC and Herefordshire and Worcestershire NHS Trust; and **Caitlin Murray** and **Nikita Hayden** (already both research team members) were both appointed to work part-time on the new Pears Foundation funded project on online mindfulness support for family carers. Dr Tom Bailey left CEDAR during the year and his role supporting the quantitative analysis of data from the 1000 Families Study has moved to our new colleague **Dr Paul Thompson** who joined us from the University of Oxford
- **Richard Hastings** (7<sup>th</sup> in the world in the research field of “Rehabilitation” - covering developmental disabilities research), was listed by a Stanford University led team in the top 2% of researchers in the world by citation impact. The analysis, based on *whole career* impact so far, was originally reported in the journal PLOS Biology and has been updated for 2021 data.
- **Richard Hastings** was also given the 2021 International Award for his contribution to developmental disabilities research by the *American Association for Intellectual and Developmental Disabilities*

## Appendix 1. Publications

### In press/2021

1. Flynn, S., Hatton, C., Hastings, R. P., Hayden, N., Caton, S., Heslop, P., Jahoda, A., Todd, S., Oloidi, E., Beyer, S., Mulhall, P., Taggart, L. and the Coronavirus and people with learning disabilities study team. (in press). Access to and use of health and social care services for people with learning disabilities during COVID-19: A longitudinal study. *Tizard Learning Disability Review*.
2. Giesbers, S. A. H., Hendricks, A. H. C., Hastings, R. P., Jahoda, A., Tournier, T., & Embregts, P. J. C. M. (in press). Perceptions of people with mild intellectual disability and their family members about family-based social capital in the Netherlands. *Health and Social Care in the Community*.
3. Griffith G. M., & Hastings R. P. (in press). Bangor Mindful Parenting Scale (BMPS). In: Medvedev O. N., Krägeloh C. U., Siegert R. J., & Singh N. N. (Eds), *Handbook of Assessment in Mindfulness Research*. Springer, Cham.
4. Maguire, R., Pert, C., Baines, S., Gillooly, A., Hastings, R., Hatton, C., Dagnan, D., & Jahoda, A. (in press). Adapted guided self-help booklets for supporting the well-being of people with intellectual disabilities during the COVID-19 pandemic: An evaluation of impact. *Tizard Learning Disability Review*.
5. Tournier, T., Hendricks, A. H. C., Jahoda, A., Hastings, R. P., Giesbers, S. A. H., & Embregts, P. J. C. M. (in press). Family networks of people with mild intellectual disability with and without challenging behaviour. *Journal on Developmental Disabilities*.
6. Albaum, C., Chan, V., Sellitto, T., Vashi, N., Hastings, R. P., & Weiss, J. A. (2021). Redressing the balance: A systematic review of positive psychology in the intellectual disability literature. *International Review of Research in Developmental Disabilities*, **60**, 1-54.
7. Coulman, E., Gore, N., Moody, G., Wright, M., Segrott, J., Gillespie, D., Petrou, S., Lugg-Widger, F., Kim, S., Bradshaw, J., McNamara, R., Jahoda, A., Lindsay, G., Shurlock, J., Totsika, V., Stanford, C., Flynn, S., Carter, A., Barlow, C., & Hastings, R. (2021). Early Positive Approaches to Support (E-PATs) for families of young children with intellectual disability: A Feasibility Randomised Controlled Trial. *Frontiers in Psychiatry*, **12**:729129.
8. Day, J. J., Hodges, J., Mazzuchelli, T., Sofronoff, K., Sanders, M. R., Einfeld, S., Tonge, B. J., & Gray, K. M., MHYPeDD Project Team. (2021). Coercive parenting: Modifiable and nonmodifiable risk factors in parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, **65**, 306-319.
9. Flynn, S., Bailey T., Hastings, R. P., Hatton, C., Abbott, D., Beyer, S., Bradshaw, J., Caton, S., Gillooly, A., Gore, N., Heslop, P., Jahoda, A., Maguire, R., Marriott, A., Oloidi, E., Mulhall, P., Scior, K., Taggart, L., & Todd, S. (2021). *Coronavirus and people with learning disabilities study Wave 1 Results: March 2021 (Full Report)*. Coventry, UK: University of Warwick. ISBN: 978-1-871501-36-0
10. Flynn, S., Caton, S., Gillooly, A., Bradshaw, J., Hastings, R. P., Hatton, C., Jahoda, A., Mulhall, P., Todd, S., Beyer, S., Taggart, L. and the Coronavirus and people with learning disabilities study team. (2021). The experiences of adults with learning disabilities in the UK during the COVID-19 pandemic: qualitative results from Wave 1 of the Coronavirus and people with learning disabilities study. *Tizard Learning Disability Review*, **26**, 224-229.
11. Flynn, S., Hatton, C., and the Coronavirus and people with learning disabilities study team. (2021). Health and social care access for adults with learning disabilities across the UK during the COVID-19 pandemic in 2020. *Tizard Learning Disability Review*, **26**, 174-179.
12. Flynn, S., Hayden, N., Clarke, L., Caton, S., Hatton, C., Hastings, R. P., Abbott, D., Beyer, S., Bradshaw, J., Gillooly, A., Gore, N., Heslop, P., Jahoda, A., Maguire, R., Marriott, A., Oloidi, E., Paris, A., Mulhall, P., Scior, K., Taggart, L., & Todd, S. (2021). *Coronavirus and people with learning disabilities study Wave 3 Results: September 2021 (Full Report)*. Coventry, UK: University of Warwick. ISBN: 978-1-871501-37-7
13. O'Dwyer, S. T. O., Janssens, A., Sansom, A., Biddle, L., Mars, R., Maras, K., Slater, T., Moran, P., Stallard, P., Melluish, J., Reakes, L., Walker, A., Andrewartha, C., & Hastings, R. P. (2021). Suicidality in family caregivers of people with long-term illnesses and disabilities A scoping review. *Comprehensive Psychiatry*, **110**, 152261.



Appendix 2. Research and Impact grants and PhD studentship funding awarded with a focus on, or significant elements of, research on families of individuals with learning disabilities/autism

### Research grants

**Baily Thomas Charitable Fund 2022-2024.** Bissel, S., Richards, C., Agar, G., Hastings, R. P., de Vreus, P., Bagshaw, A., & Hill, C. *Objective Actigraphy Study in Sleep of Children with Intellectual Disability and their Siblings (OASSIS-IDS): Direct assessment of sleep in children with intellectual disability, complex health needs and their siblings.* **£88,247**

**Economic and Social Research Council (UKRI Ideas to Address COVID-19 grant call) 2021-2022.** Totsika, V., Gray, K., Hastings, R. P., Melvin, G., Heyne, D., & Tonge, B. *School attendance among children with neurodevelopmental conditions a year after the COVID-19 pandemic.* **£194,448.**

**Pears Foundation 2021-2023.** Hastings, R. P., & Flynn, S. *Improving well-being for family carers of children and adults with learning disabilities: Addressing the implementation gap.* **£52,213.**

### Funded PhD Studentships

**ESRC (Economic and Social Research Council) Midlands Doctoral Training Partnership Collaborative Studentship/Down Syndrome UK 2021-2025**

Gray, K., Hastings, R. P., Langdon, P., Devapriam, J. & Buttery, M. *Parenting interventions for parents of adolescents with intellectual disabilities.* Approx. £70,000.

**Warwick Collaborative Fellowship/Cerebra 2021-2024.** Flynn, S., Hastings, R. P., & Hitchcock, B. *Strengthening the family system through building relationships and activities in families of children with intellectual disabilities.* £61,232.