

Centre for Educational Development, Appraisal and Research (CEDAR)

University of Warwick

Cerebra Family Research Group

Annual Report January 2020 – December 2020



Centre for Educational Development
Appraisal and Research

2020 Highlights

- We have almost completed the first follow-up of the 1000 Families Study, approximately 2.5 years after the families first took part. This follow-up will be completed in January/February 2021 and we will begin planning a second follow-up (Wave 3) to obtain ethical approval in 2021.
- The *Cerebra 1000 Families Study* has started to fulfill its promise of high quality research outputs. In our report in early 2021 on the outcomes from our first phase of Cerebra funding, we reported that we had published a Cohort Profile for the 1000 Families Study in the journal *BMJ Open* (the first 1000 Families scientific publication). Since that report, five additional scientific papers have been published or accepted for publication (see Appendix 1 for numbered publications).
 - Paper 1 is an analysis of 1000 Families Wave 2 data collected before and during the COVID-19 UK lockdown led by Dr Tom Bailey (Research Fellow part-funded by Cerebra)
 - Paper 5 was from Mikeda Jess's Cerebra funded PhD and compared maternal well-being in families of children with Down syndrome with mothers of children with general intellectual disability
 - Paper 6 was from Emma Langley's Cerebra funded PhD and looked at the quality of family dyadic relationships (parent-child, sibling, couple/partner) that best predicted a sense of overall positive family functioning
 - Paper 8 was from Caitlin Murray's Cerebra funded PhD and we were able to test whether a general mental health measure for children (the Strengths and Difficulties Questionnaire) "works" reasonably well for children with intellectual disability
 - Paper 19 also from Mikeda Jess's PhD used 1000 Families data as a part of an analysis of a scale for measuring the positive impact of a child with severe disability on parents (the Positive Gains Scale)
- We published or had accepted for publication a *further 16 scientific journal papers* (and one book) focused on family research or including family variables since our previous Report to Cerebra (see Appendix 1)
- We secured more than £2.4 million 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 2020, Richard Hastings was appointed to an expert committee for *Special Olympics International* on Early Childhood Development. He also gave presentations to a conference for practitioners on access to early intervention for autism run by *Ambitious About Autism*, and to a conference for family carers and professionals on autism at Newman University. Working with the *Challenging Behaviour Foundation* and *Positive and Active Behaviour Support Scotland*, Richard also secured funding from Research England and the University of Warwick for an event at the Houses of Parliament on reducing restrictive interventions for children with intellectual disability. Richard also delivered the *Peter Dempsey annual public lecture* at the University of Cork in Ireland on the topic of early development and intervention for children with intellectual disability
- We welcomed new research group members during 2020: **Caitlin Williams** to study for a PhD funded by Cerebra and the University of Warwick; **Tammy Rutter** to study for a PhD funded by Down Syndrome UK and the ESRC Midlands Doctoral Training Partnership; **Caitlin Murray**

(current PhD student) was appointed to a Research Fellow position to manage Wave 3 of the 1000 Families Study; and **Jo Griffin** was appointed to lead the co-design of, and then train other family carers in, our new positive family intervention (project also funded by Cerebra). Jo also runs a Hub focused on family carer well-being - <https://www.affinityhub.uk/1/Welcome.html>

- **Barah Alallawi** was awarded her PhD that included research on mothers of children with autism from Arab countries and cultures living in the UK, and **Nikita Hayden** (research on siblings of children with intellectual disability) passed her PhD viva with minor corrections to complete
- **Richard Hastings** (9th *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, has been reported in the journal PLOS Biology <https://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.3000918>

COVID-19

Because our department’s research projects are applied in focus and often involve evaluating interventions, many had to be paused during the current pandemic or were revised to use online methods for data collection. Thus, CEDAR’s research overall has been affected significantly by the pandemic.

Our Cerebra funded research though has been relatively unaffected. We were fortunate that PhD students already had their data or were able to revise their plans to use data that were already available (e.g., by analysing Wave 1 data from the 1000 Families Study). Our new *PosFam* positive family intervention project was due to start in October 2020 and we have been slightly delayed by 3 months only in starting the key appointment (**Jo Griffin**). The first part of the project focuses on co-production of the intervention with family carers, and so this work will move to online meetings. This may in fact facilitate family carer involvement since travel will be eliminated and meetings will be shorter and can be arranged for times that family carers may find more suitable.

We did pause the ongoing Wave 2 data collection for the *1000 Families Study* for a few weeks after the first lockdown in March 2020, but decided to re-start the data collection soon after. In the end, this has proved to be a good strategy since we have seen good retention of families into the study (although we will of course never know if some families did not take part because they were too stressed during the pandemic). A key challenge is that some Wave 2 data were gathered before the first lockdown, some during lockdown, some in the period where UK restrictions were somewhat less severe, and some during the current 2021 lockdown period. We will need to account for when data were collected in all future use of the Wave 2 data. We have carried out an initial comparison of changes in well-being for parents, children with intellectual disability, and siblings between Waves 1 and 2 of the study (comparing those who completed Wave 2 surveys before and during the initial lockdown). We actually found little evidence of negative effects, and a scientific paper based on these analyses has been accepted for publication (Paper 1, Appendix 1). Overall, the 1000 Families Study did end up being delayed by approximately two months compared to our original plan, but mainly because remote working has created challenges for accessing our secure databases of contact details for participating families.

We have also contributed to a number of projects designed to offer practical support during the pandemic, and to learn from the experience of the pandemic:

- The Early Positive Approaches to Support (E-PATs) intervention materials were adapted in a collaboration with family carers for the online environment to offer support to families: <https://www.positiveapproachestosupport.co.uk/covid-19-support-for-carers>
- The guided self help depression booklets for people with intellectual disability used in our NIHR funded research with adults were adapted to be used in the pandemic and made available free to access: <https://www.sclid.org.uk/covid-19-guided-self-help-booklet-series/>
- Working with the *Challenging Behaviour Foundation* and using funding from the *Sharland Foundation*, we have been carrying out research with family carers to identify supports relating to behaviours that challenge that have worked well during the pandemic and so might be continued in future

Finally, some of our ongoing research had increased relevance during 2020 in the pandemic context. We released positive findings from our randomised trial of an online mindfulness course to improve carer well-being (Appendix 1, Paper 16). We are seeking new funding for a major study of this intervention. Similarly, we had already been collaborating with colleagues in Canada to test the virtual delivery of mindfulness based stress intervention groups for carers of adolescents and adults with developmental disabilities (Paper 7). Again, we plan to seek new funding to further test this intervention model. Our findings are encouraging and suggest that high quality and effective online (mindfulness) support is possible to deliver to family carers.

Appendix 1. Publications

In press/2020

1. Bailey, T., Hastings, R. P., & Totsika, V. (in press). Impact of COVID-19 lockdown on parent-reported psychological outcomes of parents, siblings, and children with intellectual disability. *Journal of Intellectual Disability Research*.
2. 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. (in press). Early Positive Approaches to Support (E-PATs) for families of young children with intellectual disability: The E-PATs Feasibility RCT. *Public Health Research*.
3. Gore, N. J., McGill, P., & Hastings, R. P. (in press). Personalised goals for Positive Behavioral Support: Engaging directly with children who have intellectual and developmental disabilities. *Journal of Child and Family Studies*.
4. Hastings, S. E., Hastings, R. P., Swales, M., & Hughes, J. C. (in press). Emotional and behavioural problems of children with Autism Spectrum Disorder attending mainstream schools. *International Journal of Developmental Disabilities*.
5. Jess, M., Flynn, S., Bailey, T., Hastings, R. P. & Totsika, V. (in press). Failure to replicate a robust Down syndrome advantage for maternal well-being. *Journal of Intellectual Disability Research*.
6. Langley, E., Totsika, V., Hastings, R. P., & Bailey, T. (in press). Family relationships and their associations with perceptions of family functioning in mothers of children with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*.
7. Lunsy, Y., Albaum, C., Baskin, A., Hastings, R. P., Hutton, S., Steel, L., Wang, W., & Weiss, J. (in press). Group virtual Mindfulness-Based Intervention for parents of autistic adolescents and adults. *Journal of Autism and Developmental Disorders*.
8. Murray, C. A., Hastings, R. P., & Totsika, V. (in press). Clinical utility of the parent-report Strengths and Difficulties Questionnaire as a screen for emotional and behavioural difficulties in children and young people with intellectual disability. *British Journal of Psychiatry*.
9. Rixon, L., Hastings, R. P., Kovshoff, H., & Bailey, T. (in press). Sibling adjustment and sibling relationships associated with clusters of needs in children with autism: A novel methodological approach. *Journal of Autism and Developmental Disorders*.
10. Sapiets, S., Totsika, V., & Hastings, R. P. (in press). Factors influencing access to early intervention for families of children with developmental disabilities: a narrative review. *Journal of Applied Research in Intellectual Disabilities*.
11. Stanford, C. E., Hastings, R. P., Riby, D. M., Archer, H. J., Page, S. E. & Cebula, K. (in press). Psychological distress and positive gain in mothers of children with autism, with or without other children with neurodevelopmental disorders. *International Journal of Developmental Disabilities*.
12. Tournier, T., Hendricks, A. H. C., Jahoda, A., Hastings, R. P., Giesbers, S. A. H., & Embregts, P. J. C. M. (in press). Perspectives of people with intellectual disability about their family networks: A comparison study with key support worker proxy reports. *Journal of Intellectual and Developmental Disability*.
13. Tournier, T., Hendricks, A. H. C., Jahoda, A., Hastings, R. P., Giesbers, S. A. H., Vermulst, A., & Embregts, P. J. C. M. (2021). Family network typologies of adults with intellectual disability: Associations with psychological outcomes. *Journal of Applied Research in Intellectual Disabilities*, **34**, 65-76.
14. Alallawi, B., Hastings, R. P., & Gray, G. (2020). A systematic scoping review of social, educational, and psychological research on individuals with Autism Spectrum Disorder and their family members in Arabic countries and cultures. *Review Journal of Autism and Developmental Disorders*, **7**, 364-382.
15. Coulman, E., Hastings, R., Gore, N., Gillespie, D., McNamara, R., Petrou, S., Segrott, J., Bradshaw, J., Hood, K., Jahoda, A., Lindsay G., Lugg-Widger, F., Robling, M., Shurlock, J., & Totsika, V. (2020). The Early Positive Approaches to Support (E-PATs) study: study protocol for a feasibility cluster randomised controlled trial of a group programme (E-PATs) for family caregivers of young children with intellectual disability. *Pilot and Feasibility Studies*, **6**:147

16. Flynn, S., Hastings, R. P., Burke, C., Howes, S., Lunskey, Y., Weiss, J. A., & Bailey, T. (2020). Online mindfulness stress intervention for family carers of children and adults with intellectual disabilities: Feasibility randomized controlled trial. *Mindfulness*, **11**, 2161-2175.
17. Giesbers, S. A. H., Hendricks, A. H. C., Hastings, R. P., Jahoda, A., Tournier, T., & Embregts, P. J. C. M. (2020). Family-based social capital of emerging adults with and without mild intellectual disability. *Journal of Intellectual Disability Research*, **64**, 757-769.
18. Grindle, C. F., Hastings, R. P., & Wright, R. J. (2020). *Teaching early numeracy to children with developmental disabilities*. Sage: Thousand Oaks, CA. ISBN: 9781526487537
19. Jess, M., Bailey, T., Pit-ten Cate, I., Totsika, V., & Hastings, R. P. (2020). Measurement invariance of the Positive Gains Scale in families of children with and without disabilities. *Research in Developmental Disabilities*, **103**, 103662.
20. Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2020). Intellectual disability stigma and initiatives to challenge it and promote social inclusion around the globe. *Journal of Policy and Practice in Intellectual Disabilities*, **17**, 165-175.
21. Stanford, C. E., Totsika, V., & Hastings, R. P. (2020). 'Above and beyond': The perceptions of mothers of children with autism about 'Good Practice' by professionals and services. *Research in Autism Spectrum Disorders*, **77**, 101615.
22. Totsika, V., Hastings, R. P., Dutton, Y., Worsley, A., Melvin, G., Gray, K., Tonge, B., & Heyne, D. (2020). Types and correlates of school non-attendance in students with autism spectrum disorders. *Autism*, **24**, 1639-1649.

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 LD/autism

Research grants

Medical Research Council (UK Research and Innovation – Department of Health and Social Care COVID-19 Rapid Response Grant) 2020-2021. Hastings, R. P., Hatton, C. (joint PIs), Abbott, D., Beyer, S., Bradshaw, J., Gore, N., Heslop, P., Jahoda, A., Marriott, A., Scior, K., Taggart, S., & Todd, S. The impact of the COVID-19 pandemic on people with learning disabilities and factors associated with better outcomes. £763,431.

National Institute for Health Research (Health Services and Delivery Research) 2021-2025. Hastings, R. P., Gillespie, D., Bradshaw, J., Gore, N., Liew, A., Lovell, M., North, S., Richards, C., Seers, K., Petrou, S., Langdon, P., Cooper, V. & Shurlock, J. Mapping and Evaluating Services for Children with Learning Disabilities and Behaviours that Challenge (MELD). £1,245,271.

National Institute for Health Research (Health Technology Assessment) 2020-2022. Gray, K. M., Hastings, R. P., Langdon, P., Williams, T., Bunning, K., Liew, A., McNamara, R., & Playle, R. Specific phobias in children with learning disabilities (SPIRIT): An adaptation and feasibility study. £199,993.

National Institute for Health Research (Health Technology Assessment) 2020-2022. Langdon, P., Gray, K., Hastings, R. P., Rai, D., Bunning, K., Jahoda, A., Gillespie, D., & McNamara, R. Behavioural interventions to treat anxiety in adults with autism and moderate to severe intellectual disabilities (BEAMS – ID). £197,422.

Funded PhD Studentships

ESRC (Economic and Social Research Council) Midlands Doctoral Training Partnership Collaborative Studentship/Down Syndrome UK 2020-2024. Hastings, R. P., Stinton, C., & Enoch, N. Families' experiences of genetic testing for Down syndrome. Approx. £70,000.

Warwick Collaborative Postgraduate Research Scholarship/Cerebra 2020-2023. Hastings, R. P., Bailey, T., & Hitchcock, B. Longitudinal study of psychological adjustment in families of children with intellectual disabilities. £60,196.