



ACADEMY OF
THE SOCIAL SCIENCES
IN AUSTRALIA

“Autism Spectrum Disorder: Predictors of parental levels of distress and cognitive gains in intensive behavioural intervention programs”

I would like to thank ASSA for granting me the research funds to travel to Toronto (Canada) to conduct a research project at Central East Autism Program (CEAP), Kinark Child and Family Services. This project, in collaboration with Dr Rebecca Godfrey (Associate Clinical Director, CEAP), aimed to analyse current and archival data to examine: (1) the Autism Spectrum Disorder (ASD) and family characteristics that best predict the distress levels of parents diagnosed with this condition, and (2) whether certain ASD characteristics are associated with larger treatment outcomes in Intensive Behavioural Intervention (IBI) programs.

To help establish this project, I spent nine weeks (17th July to 15th September 2014)¹ at the CEAP offices at Markham (Toronto) setting up an electronic database for CEAP clients. This involved requesting client files from archive storage and entering the relevant psychological data from these paper-based files into the electronic database. During my stay, the psychological data for 420 children (mean age = 7.34 years, SD = 2.81) and their parents were entered into this database. This psychological data consisted of measures of the children’s general cognitive ability, adaptive behaviour functioning, autism-specific behaviour rating scales, and the parental levels of distress and their coping behaviours. In addition demographic information about the child and the parents (e.g., date of birth, cultural heritage, primary language used at home) as well as family characteristics (e.g., number of children in the family, number of siblings in the family also diagnosed with ASD, order of birth of child with ASD) were also entered into the database. The performance protocols for each of these children on the IBI programs implemented (while receiving services/treatment at CEAP) were also scanned and stored in another database to allow the researchers to analyse this treatment data at a later date.

The creation of this client database means that staff at CEAP can now start to maintain an electronic psychological database for their clients. More importantly, this database will assist CEAP to conduct research evaluating their intervention programs and other aspects of their client service delivery. CEAP are planning to continue with the work I have started on this database by entering the psychological data from remaining archived client files as well as current client files.

During my stay at CEAP, I was also involved in some of the discussions around procedures for accessing this database and ways of monitoring how information from this database is used. The decision was made that access to this electronic client database will be monitored and managed by the Senior Director of Policy and Planning and the Human Research Ethics Committee at Kinark Child and Family Service.



Since returning to Australia (on 17th September 2014), I have conducted some preliminary statistical analyses on this data in relation to the ASD child characteristics that best predict parental levels of psychological distress. This preliminary analysis indicates that after controlling for the influence of the child's age and gender, the significant predictors of parental distress are related to the child's difficulties with (i) expressive language (i.e., the ability to use words and sentences), (ii) personal living skills (i.e., the ability to eat, dress and practice personal hygiene), (iii) domestic living skills (i.e., the ability to undertake household tasks), and (iv) demonstration of responsibility and sensitivity to others. Not surprisingly, the child's overall ASD severity was also a significant contributor to the levels of distress experienced by parents.

Please note that further statistical analyses need to be undertaken to examine whether these relationships are mediated by the type of coping strategies used by the parents. Additional analyses also need to be undertaken to examine the role of parent (e.g., age, heritage) and family characteristics (e.g., number of children, other children with ASD) on the levels of distress experienced by parents. The researchers will also still need to enter the data from the scanned IBI performance protocols so that data analyses can be conducted to address the issue of whether certain ASD characteristics are associated with larger treatment outcomes.

The expected future outcomes for this research project include:

- Publication of at least three publications in psychological and multidisciplinary scientific journals (e.g., Research in Autism Spectrum Disorders, Journal of Autism and Developmental Disorders, Autism). Please note that ASSA's contribution to the research project will be acknowledged in these research publications, and copies of these published journal manuscripts can be made available to ASSA if required.
- On-going research collaborations with CEAP (Kinark Child and Family Services) that builds on the findings of the current project. It is envisaged that these future research collaborations will be supported by Canadian-based research funding organisations. Please note that further research funding will be applied for once we have published the outcomes from the current project.
- Once the researchers (i.e., Dr R. Dyer and Dr R. Godfrey) have produced a body of journal publications that demonstrates their successful research partnership, a research grant application will be submitted to the National Health and Medical Research Council.

Rachel Dyer
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