

Research Project Work Plan - DRAFT**NAME OF PROJECT**

ASD and ADHD Services for Families in Malta

Organisation/s Sponsoring Research

Parliament of Malta

Principal Investigator

Prof Andrew Azzopardi

Technical Advisory Committee

Tbc

Research Officer

Tbc

Research Statement

The European Commission has defined autism spectrum disorders (ASD) as a complex group of related developmental conditions, characterised by persistent challenges in language, perception and socialisation. Autism spectrum disorders are three to four times more common in boys than in girls, and many girls with ASD exhibit less obvious signs compared to boys. It is a lifelong condition requiring access to specialised and long-term services.

A child's autism diagnosis affects every aspect of a family's life. Parents/caregivers of children with ASD are often primary care coordinators for their children, and shoulder considerable responsibilities as they navigate the service delivery system. Moreover, the coronavirus pandemic has created a higher degree of ongoing disruption to life and stress to all families, particularly those living with ASD (Manning, 2020).¹

This study engages the national context by proposing the particular experiences of families who have had a paediatric diagnosis of ASD as a valuable source of knowledge. Notions of family-focused support for ASD and the challenges, limitations, and opportunities available in the sector will be explored and assessed in light of such experiences. In terms of the landscape of services currently available, the study highlights participant voices, by engaging with families' needs, concerns, and aspirations, in order to promote more effective and accessible services.

In parallel we will be researching ADHD services which are pretty much in line with ASD.

Objectives of the Study

To achieve its primary focus on the lived experiences of families who have received an ASD and ADHD diagnosis, and their contact with service providers in Malta, the following objectives have been identified:

- Establishing the demographic dispersal of children in Malta diagnosed on the ASD spectrum and ADHD;

¹ Manning, J., Billian, J., Matson, J., Allen, C., & Soares, N. (2020). Perceptions of Families of Individuals with Autism Spectrum Disorder during the COVID-19 Crisis. *Journal of autism and developmental disorders*, 1–9. Advance online publication. <https://doi.org/10.1007/s10803-020-04760-5>

- Exploring available public, private, and NGO-led services for children and families;
- Engaging with families and affected individuals to discover their experiences accessing ASD and ADHD family-focused services;
- Developing relevant policy and action recommendations which highlight the experiences of research participants.

The above-mentioned objectives shall be attained through a mixed research design, comprising of demographic data extraction and qualitative consultations conducted with pertinent participants. Technical experts in the field of ASD and ADHD and specialist therapeutic practices will be engaged in the project, in order to ensure the best possible outcomes for the identified communities and to ensure the successful execution of the project.

Deliverables

Stage 1 – Literature Review:

A literature review, delving into concepts, theories, policies and practices that are relevant to the area and population under study. Drafting of the literature review also informs subsequent stages of the project.

Stage 2 – Methodology & Research Instruments:

A methodology section, including clear research questions, details on the data-gathering instruments and data analysis methods. This section shall also address details of the strategy to be used to gain access to the field of research and the strategy to be adopted to recruit participants in due diligence of ethical considerations. Moreover, details of the sampling strategy shall also be included.

The development, piloting and eventually the submission of finalised research instruments will also be included in this stage. Ethical clearance shall be requested from the Faculty for Social Wellbeing Research Ethics Committee (FREC) and (if needed) from the University of Malta Research Ethics Committee (UREC). The full list of tasks in the second stage below refers:

- Write-up of the Methodology Section
- Development of schedule and research tool guidelines
- Development of recruitment letters and consent forms
- Obtaining ethical clearance
- Gaining access
- Recruitment of participants
- Piloting of research instruments
- Analysis of piloting outcomes and development of resulting research instruments

Stage 3 – Data Gathering and Analysis

Stage 3 shall be dedicated to the execution of the actual fieldwork of the project, through which all data is gathered. Qualitative data collected through consultation shall go through transcription and analysis, to identify common experiences and to highlight key concerns raised by participants, regarding ASD and ADHD service provision in Malta.

Stage 4 – Interpretation, Reporting of Findings and Policy Recommendations

Finally, in the fourth and last stage of the project, the data analysed in the previous stage shall be interpreted and reported to present the results of the research study and a set of actionable recommendations that reflect the needs of individuals and families within the researched population.

Time Frames

The projected completion for each stage, as of the date of agreement on the project:

<u>Stage 1:</u>	2 months
<u>Stage 2:</u>	4 months
<u>Stage 3:</u>	4 months
<u>Stage 4:</u>	2 months

Costs

	Euros
Principal Investigator	1,000
Technical Advisory Committee	1,000
Research Support Officer	10,000
Faculty Fee	1,000
Research Tools	N/A
Data Gathering	N/A
Insurance /Project Office	500
TOTAL	13,500