

L-Università ta' Malta
Faculty for Social Wellbeing

Persons with Autism & Persons with AD(H)D

The need to understand and improve
services for families in Malta



Agenda

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- The Team
 - Research Objectives
 - Research Design
 - Data Collection
 - Research Findings
 - Recommendations

The Team

The Research Team



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A study commissioned by the Parliament of Malta

Research Objectives

1. Establishing the demographic dispersal of people with Autism Syndrome Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) in Malta
2. Exploring available public, private and NGO-led services
3. Engaging with families and individuals to discover experiences as they navigate the services; discovering instances of discrimination
4. Provide recommendations for policy and action
5. Locate any discrimination surrounding the experiences of persons with Autism or ADHD



Research Design

1

Literature Review

2

Development of
Research
Instruments & ethical
approval

3

Data Gathering
(qualitative and
quantitative) and
Analysis

4

Interpretation of
Findings

5

Reporting on
Findings and
Recommendations
for policy, practice
and research

Data Collection

Qualitative Data Collection

- **Service User & Caregiver Interviews**
- 6 interviews with Autism service users or caregivers of persons living with autism. (3+3)
- 6 interviews with ADHD service users or caregivers of persons living with ADHD. (3+3)

Quantitative Data Collection

- **Service User & Caregiver Questionnaire**
 - 64 responses from Service Users (89% ADHD, 3% Autism & 8% combination of both)
 - 163 responses from Caregivers (including parent caregivers)
- **Service Provider Questionnaire**
 - 33 responses from Service Providers, Autism
 - 25 responses from Service Providers, ADHD

This research was carried out in conformity with the University of Malta's Research Code of Practice and Research Ethics Review Procedures.

Research Findings

Persons living with autism and/or ADHD, encounter challenges throughout their development from children into adulthood impacting their performance and wellbeing

Diagnosis

- **56.25%** of service users and **58.28%** of care givers were not satisfied* with the diagnostic process.
- *Even more difficult for women and adults.*

Lack of Services following diagnosis

- **75%** of service users and **81.59%** of care givers were not satisfied* with such services.
- **91%** of service users and **82%** of care givers received no information of support following diagnosis.

“ None of them [professionals] knew. The information was in no way accessible. I searched but there was nothing about this [diagnosis] for adults. ”

Adult service user

“ You were scrambling around in the dark/ You had to find your own way. ”

Care Givers

Research Findings (cont'd)

Services after diagnosis

- **84.39%** of service users and **87.12%** of care givers were not satisfied* with the links between services
- **26.56%** of service users and **50%** of care givers were satisfied with the services received in the past 6 months.

| Services Received in last 6 Months (top 3) - Service Users | |
|--|-----|
| None | 58% |
| Medication | 11% |
| Therapy/ Counselling | 11% |

Accessing services

- Both care givers and service users listed *'waiting lists'*, *'lack of trained professionals'* and *'cannot afford services'* as the major barriers to accessing services.
- Satisfaction with services decrease over the life course, with respondents feeling **90% dissatisfied** with services for older people, whilst being less than **50% dissatisfied** for primary school age services.

“ Doctors are not aware. [...] They think, ok, so autism is the stereotypical five-year-old boy who doesn't speak. [...] The spectrum is a lot more complicated than that **”**

Adult Service User

Research Findings (cont'd)

Views on life outcomes

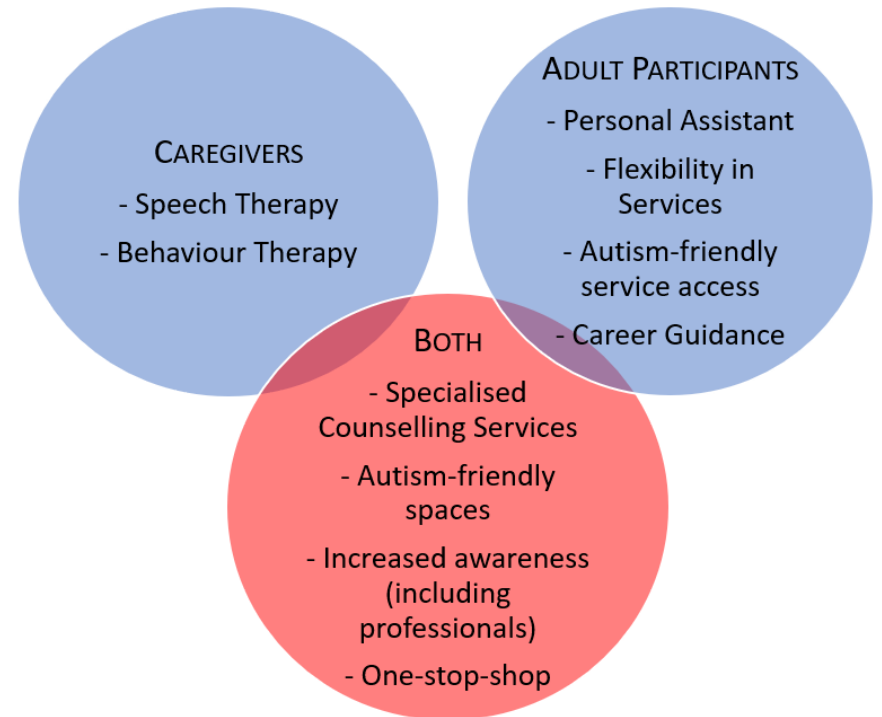
- Over **70% dissatisfaction** in social, independent living and employment opportunities. For care givers this dissatisfaction increases to over 80%.
- Lack of prospects for lifelong fulfilment, concerns about services not catering for different age groups.
- Critical reduction in services available for adults when compared to younger ages

“Why is it so difficult for me? Why is everything that other people do with no issues so exhausting for me? Why is it like I don't have the instructions to life, and they do? And I just kept thinking, like, with is this? What is wrong with me?”

Adult Service User

Services Needed

- Top services identified as per group:



Research Findings (cont'd)

Service Providers

- 44% of ADHD services providers cater for less than 100 clients. Nearly 40% of ASD service providers cater for less than 200 clients.
- ADHD service providers provide mostly services to minors. Only 10 out of 25 organisations offer adults services. Autism services seem to be more available for very young ages - even babyhood.
- 60% of ADHD service providers and 54.5% of ASD service providers said they have waiting lists .



| Type of Organisation | |
|----------------------|-----|
| Education | 16% |
| Social service | 28% |
| NGO | 16% |
| Public Health | 24% |
| CRPD | 4% |
| Private Practice | 12% |



Autism

| Type of Organisation | |
|-----------------------|-----|
| Education | 18% |
| Social Service | 21% |
| NGO | 27% |
| Public Health Service | 15% |
| CRPD | 3% |
| Private Practice | 12% |
| Employment | ~3% |

Recommendations

This research study made **over 70 recommendations** for policy, practice and research

Policy

- Approach autism and ADHD as a **part of normality**, through changed discourse.
- **Align services** through approaches such as, Multi-agency planning, Key worker as a client's point of reference, Life-coaching buddy systems and a One-stop shop.

Health

- Ensure primary care providers are adequately trained to ensure a **timely diagnosis**.
- Provide useful information and adequate **recommendations for support** and treatment.

Education

- Ensure educators and other professionals are familiar with early indicators and referral pathways for **early detection**.
- Ad-hoc **career guidance support** available to young, diagnosed people.
- Create a **transition centre** for students who have been previously expelled order to improve their return to school.

Recommendations (cont'd)

Social Services

- Increase **measures and incentives** that provide **regular or daily support**.
- Ensure members of staff involved in the provision of services are **trained and understanding** towards autism and/or ADHD.

Employment

- Incentivise and **support companies to employ diagnosed individuals**.
- Provide assistance to employers to gain more **awareness and understanding**, while enabling channels of communication with sources of support.

Research

- Develop **guidelines** for autistic individuals and those living with ADHD in the context of the local scenario, to assist them through major key milestones.
- Understand **gender differences** related to autism and ADHD so as to improve earlier diagnosis of autism in females.
- Explore **counselling approaches** and techniques which are better suited.

Thank you



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