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Towards Better Outcomes in Autism by Addressing Policy Change

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Background

Autistic individuals and their supporters are experiencing significant unmet need from health and social systems.

- There is urgent need to achieve better outcomes for autistic people and their supporters. At present, diagnostic processes are long and complicated, Quality of Life (QoL) is negatively affected, there are high out-of-pocket health and social care costs, and autism hinders employment opportunities for both autistic individuals and their supporters.

Improving outcomes for autistic individuals and their supporters requires early personalised interventions alongside supportive health and social systems.

- Improved outcomes require a paradigm shift from autism management to early assessment and diagnosis alongside personalised behavioural support. Additionally, lifelong social support systems including education, employment and accommodation should look to prioritise meaningful participation in society for autistic individuals.

Methods

This study used primary and secondary data collection to gather evidence on the social and economic impact of autism and the QoL of autistic individuals and their supporters. Prior to starting data collection, the team conducted interviews with the following stakeholders to understand the needs of various groups: a parent of an autistic child, a clinician working in the field and a representative from an autism charity. A systematic review was beyond the scope of our study and therefore, expanding on an initial narrative review provided by F. Hoffmann-La Roche was the most appropriate search methodology for the secondary data collection. Primary data collection was conducted by means of two web-surveys. The survey for autistic individuals and their supporters was based on a multidimensional questionnaire comprising seven sections which captured: i) diagnosis, ii) support and therapy after diagnosis, iii) education, iv) employment, v) accommodation, vi) QoL and vii) impact on supporters. The clinicians' survey captured evidence around diagnostic tools and pathways including clinical guidelines

Geographic scope

The geographic scope of the research covers Canada, France, Germany, Italy, Spain, the United Kingdom and the United States.

during and post assessment, accessibility and effectiveness of medical and social care, and the cost of these services.

Results

This study demonstrates that autism is associated with a significant socioeconomic impact generated by the high direct and indirect costs, the increased social isolation and discrimination and the poor QoL and social life outcomes exhibited by autistic individuals and their supporters. Given that autism is a lifelong disorder, the costs due to productivity losses both for the individuals themselves and for their supporters are overwhelmingly high, with significant implications for both the financial and physical wellbeing of autistic individuals and their families. There is a clear deterioration in the health outcomes of autistic individuals and their supporters in comparison to the rest of the population, with impact increasing in line with the severity of the disease and presence of mental health related concurrent conditions, particularly depression and anxiety. Our study revealed various determinants of the burden of autism on autistic individuals and their supporters. Key findings include:

Diagnostic and referral pathways

- Delays and shortcomings in the diagnostic process exist across countries. This is due to several factors, including the necessity of many visits to acquire a diagnosis, lack of standardised referral pathways and lack of specific training among the involved healthcare professionals for diagnostic assessment in cases where autism is suspected.
- Autistic adults experience unique autism-specific barriers to accessing care which are less likely to be addressed in modern healthcare systems such as limited autism specialists who treat adults, difficulty attending appointments because of the disruption in their routine and the sensory overload present at doctors' offices.

Quality of Life

- Factors driving QoL impairment in autistic individuals primarily include increased anxiety and depression, difficulty maintaining relationships, and difficulty communicating. Factors positively affecting QoL in autistic individuals are fulfilment from special abilities and creativity, greater ability to focus, and receiving or providing help from or to others, respectively.

Healthcare costs & Social services support

- Although state financed residential and social support services exist, they are often characterised by long waiting lists and/or regional unavailability. As a result, many autistic individuals and their families incur high out-of-pocket costs primarily for childcare, support workers, and privately funded therapy (e.g., behavioural therapy, counselling, and speech and language therapy).
- A significant proportion of medication utilisation in autism comes from antidepressants, anxiolytics, and antipsychotics used to manage mental health conditions associated with autism, while most autistic people do not receive any interventional therapies such as CBT.

Education

- Satisfaction with the educational environment and standards is poor among autistic individuals. This arises due to high rates of discrimination experienced by autistic individuals, especially in secondary school and especially for female individuals.
- High school teachers and educational professionals report a lack of support from their respective institutions to learn about autism.

Employment

- Poor employment outcomes among autistic employees are due to several factors including concurrent conditions, difficulty with communication and other social impairments, social discrimination, and a lack of understanding about autism in the workplace.
- For many autistic individuals it is not necessarily their autism causing a negative impact on their work life but primarily other reasons relating to discrimination in the workplace, colleagues and managers who are unwilling to understand and accommodate autistic individuals' requirements, and lack of support in disclosing autism in the workplace.

Supporters

- Supporters typically have decreased work force involvement, missing eight days of work per month on average due to supporters' responsibilities. The employment related strain is further escalated by the limited support provided for these families by their employers.

- Poor QoL among autistic individuals' supporters is generated by mental health issues, social exclusion and isolation and the emotional stress arising from the constant feeling of fear about the future of the person they care for or the feeling that the person they care for is dependent on them.

Recommendations

Our results, coupled with existing findings from the literature confirm that there is an urgent need to achieve better outcomes for autistic people and their supporters. Evidence suggests that this is possible if policy makers address a series of issues to secure the following goals:

1 *Shift the paradigm in autism management towards provision of early assessment and diagnosis.*

- Ensure wider coverage of diagnostic services and evaluations in cases where autism is suspected: often, high-cost diagnostic services in autism need to be funded privately, leading to a high rate of foregone appointments.
- Minimize the number of visits required for diagnostic assessments to avoid diagnostic delays: the plethora of healthcare professionals involved in autism diagnosis, and the respective multiple visits required for assessments often deters individuals from seeking diagnostic services due to the stress and emotional exhaustion associated with arranging and attending doctors' appointments.
- Raise awareness among healthcare professionals and appointment coordinators about the sensory and emotional challenges that doctors' offices present for autistic people and about the need to accommodate visits accordingly to avoid missed or postponed appointments.

2 *Tailor interventions and behavioural support mechanisms based on a person-centred approach that addresses the personalised needs of autistic individuals and their supporters.*

- Interventional therapies and behavioural support in autism should focus on strengthening individuals' performance in domains that have a positive impact on their QoL, such as encouraging each individual's special abilities & creative skills.
- Treating autism associated mental health conditions through targeted interventional therapies is high priority in autism management. This can help reduce overprescribing

and overspending on psychotropic medication used to manage concurrent mental health conditions and prevent side-effects associated with long-term use of these drugs.

3 *Re-define the priorities of social support mechanisms, while enhancing the availability and quality of existing schemes.*

- Enable people to have control over their lives, education, and accommodation arrangements, through supported living and innovative housing solutions, and support services to direct autistic children in deciding which education pathway they should follow.
- Ensure that state-funded day services provide both timely and quality care and support, through adequately trained people, while also being readily accessible both in terms of geographic location and regional access regulations or bureaucracies.
- Secure local funding and accessibility/availability of: i) public special education institutions or programs and social policies, ii) personalised support measures for autistic pupils whether in mainstream or special education and iii) practice guidelines to guide the implementation of systems for young autistic people, transitioning from school or college to adulthood.

4 *Restructure autism specific training and guidelines for clinicians to optimize the diagnostic and clinical care outcomes for autistic individuals.*

- Set out incentivisation mechanisms for clinicians to follow autism diagnostic guidelines and hence, improve diagnostic pathways and the quality of clinical care provided in autism.
- Increased responsiveness of health care systems and adaptation of guidelines to the most updated evidence on autism is essential for improved diagnostic outcomes but also for strengthening interventions and monitoring practices in autism management and hence, avoiding inappropriate over-prescribing for autistic individuals.
- Establish adult and gender-specific diagnostic protocols in routine clinical practice and implement specific training and referral guidelines for cases with distinct forms of and/or combination of impaired mood dysregulation and anxiety to facilitate accurate and timely diagnoses in individuals with suspected autism.

5 *Educate society, schools, and workplaces on the requirements of autistic individuals and involve these entities in collaboratively achieving better outcomes in autism.*

- Foster greater awareness and understanding of autism among workplaces and employers to achieve better employment prospects for autistic individuals.
- Introduce autism awareness activities for young children, to help prevent the discrimination currently experienced by autistic children within the educational environment.
- Improved training and support for teachers working with autistic children and adolescents is also essential for the improvement of educational outcomes in autism.
- Collaboration between the educational, workplace and social care sectors is essential to form integrated transition pathways for autistic children/adolescents, to support smooth transition to adulthood. Transition planning activities should cover all areas of service provision, including housing and employment support.

6 *Measure meaningful outcomes and generate further robust evidence to inform decision making in the management of autism.*

- Perform real world studies based on national registries to measure the benefit of early diagnosis and hence, early intervention on the long-term outcomes for autistic individuals and their families. This is important because despite the suggested benefit of early, integrated developmental and behavioural intervention on the long-term prognosis in autism there is yet no quantifiable evidence of this benefit.
- Measure and evaluate health outcomes on domains that matter the most for autistic individuals and their supporters. For autistic individuals, these should focus on measuring outcomes on mental health state and satisfaction with social interactions and relationships and for supporters, outcomes on their emotional health and social life status. However, given the large heterogeneity of autism manifestations and characteristics among the autism community, the above aspects should be considered and measured in the context of a more personalised outcomes measurement approach for each individual.

Multi-stakeholder engagement and collaboration in autism relevant evaluation research is critical to ensure measurement of meaningful outcomes in autism; involvement of supporters is specifically important to provide a shared understanding

on the various levels of intertwined outcomes in autism that add value both for autistic individuals and their families.

Conclusions

Findings from our study, combined with existing findings from the literature provide a strong evidence base for the unmet need currently present in autism. Inefficiencies in diagnostic processes and interventional therapies, poor employment prospects and the inability to live independently represent a substantial and growing challenge for some autistic individuals. Additionally, the increased emotional stress and productivity losses exhibited by the supporters of these individuals further contribute to the broader socioeconomic implications of autism.

A fundamental step towards improved long-term outcomes in autism is provision of early diagnosis and assessment. Nevertheless, further evidence from pragmatic studies based on data from national registries is needed to quantify the magnitude of this benefit for autistic individuals, their families and society overall. Additionally, governments and healthcare systems should centre their efforts specifically on adapting infrastructure, training, and clinical guidelines in autism. Funding efficient, person-specific interventions is also essential to provide the best health outcomes possible according to the specific physical, social and behavioural needs of every autistic individual. Finally, the effective collaboration of society, schools, and workplaces is paramount for the smooth transitioning of autistic children and adolescents to adulthood including securing better living arrangements, employment options and achieving a sense of meaningful participation in society for every autistic individual.

The policy recommendations arising from this study highlight that improved outcomes in autism are feasible if policy makers address the key determinants of burden, as identified in our study, for autistic individuals and their families. Of course, as our study was conducted in the early stages of the COVID-19 pandemic, it does not necessarily capture any additional burden arising from COVID-19 for autistic individuals and their families and therefore, more recent, real-world evidence is essential to elucidate the full social and economic impact of autism across countries as it is currently shaped in a post-pandemic environment. Similarly, the findings and recommendations presented in this report should be interpreted with caution, given the sampling limitations of our study. The uneven geographical spread of the respondents, and uneven representation of different autism severity levels in our study sample, mean that our findings may not be entirely representative of the true environment,



experiences and autism care practices followed across the study countries or the true outcomes observed in a largely heterogeneous international population of autistic individuals.