

The Economics of Autism in Egypt

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Abstract: Problem statement: This was the first study ever done on the cost consequences of Autism Spectrum Disorder (ASD) in Egypt or any other developing/industrializing country. The following questions were empirically investigated: What are the economic costs of ASD in Egypt and how do they compare with developed/industrialized countries? Why are cost consequences important in formulating ASD policy in Egypt and comparable countries? **Approach:** A statistical sample of 185 households, with at least 1 autistic family member, in the Greater Cairo Region was surveyed. Households were drawn from 3 distinct geographic clusters (urban, suburban and rural). Cluster sampling results were Chi-square (χ^2) tested. In addition, relevant ASD policies were content-analyzed. **Results:** We discovered that care and support for autistic Egyptian children and adults are typically based on a household-provider model, in contrast to western, institution-based models. ASD costs in Egypt largely derive from much higher investments in time, attention and behavioral adaptation on the part of family caregivers. Hence, autism cost consequences in Egypt significantly differ from many developed countries. **Conclusion:** Opportunity and transaction costs, feedback effects and spillover consequences of the household-provider model should be carefully considered in health policy formulation. Making autism care and support available, affordable and reliable should be a major health concern of the state.

Key words: Autism spectrum disorder, autistic, care provider, cost consequences, developmental/learning disability, direct cost, household-provider, indirect cost, health policy, opportunity costs, state, spillover effects, transaction costs

INTRODUCTION

Objectives: First identified by psychiatrist Leo Kanner in 1942, Autism Spectrum Disorder (ASD), better known as autism, is presently the “fastest growing neurobiological condition in the world. With prevalence numbers rising exponentially over the last six decades, more and more families are living with ASD than ever before” (Grossman and Barrozo, 2007).

This is a study about ASD in Egypt. It is guided by the following research questions: What are the economic costs of ASD in Egypt and how do they compare with developed or industrialized countries? Why are these cost consequences important in formulating health policy on ASD in Egypt and comparable countries? Egypt offers an illustrative case in this first study ever done on autism costs in developing or industrializing countries.

Framework and related literature: ASD refers to a range of complex brain development disorders that result in impaired socialization, delayed speech/language acquisition and restricted, repetitive and stereotyped patterns of human behavior. Classical

autism (or Kanner Syndrome) is considered the most severe form of ASD. Other types along the spectrum include Asperger Syndrome (which generally preserves an individual's linguistic development), Rett Syndrome (a sex-linked genetic disorder characterized by social withdrawal, regressed language skills and hand-wringing), Childhood Disintegrative Disorder (characterized by the onset after age 3 or 4 of developmental delays in language, motor skills and social function) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), a milder and non-classical type of ASD that is also known as “atypical personality development” (Muhle *et al.*, 2004; Kuehn, 2006).

ASD occurs in all age, racial/ethnic and socio-economic groups (Muhle *et al.*, 2004; Van Dyke, 2007). Although the exact cause/s of ASD remain/s unknown, genetic and environmental factors are suspected to play an important role (Muhle *et al.*, 2004; Szatmari *et al.*, 1998). It is currently estimated that 3 to 6 children out of every 1,000 worldwide have ASD. Males are 4 times more likely to have ASD than females (Fombonne, 2003).

There is presently no established cure for ASD. Instead, various interventions -- therapeutic and

behavioral -- seek to address specific symptoms and bring about substantial individual improvement. There is expert consensus that the earlier the intervention, the more effective it tends to be (Van Dyke, 2007). These interventions include: Educational and behavioral approaches (e.g., applied behavior analysis, skill-oriented training sessions for social and language development), prescription medication (for specific symptoms, such as anxiety, depression, attention deficit disorder, hyperactivity, obsessive-compulsive behavior) and customized therapies (physical and speech.).

One might reasonably expect that the bulk of autism-related costs derive from behavioral and therapeutic interventions and other treatments in the absence of an established cure. The scholarly literature generally supports this assumption in industrialized countries. However, similar research on the economic costs of autism in developing or semi-industrialized countries is virtually non-existent.

In the United States, where 1 in 100 children is autistic, one study proposes a two-fold cost classification scheme: (1) direct costs include physician and outpatient services, prescription medication, behavioral therapies and direct non-medical costs (e.g., special education, camps); (2) indirect costs consist of lost productivity and potential income. The study points to the need to identify other expenditure sources and link costs to non-financial data to be more relevant to policy-makers, especially since autistic Americans usually receive services from a wide variety of sources (Ganz, 2006). Another study finds that lost productivity and adult care constitute the largest cost components in the United States. Although autism is often considered a childhood disorder, it bears lifetime cost consequences that significantly increase during adulthood (Ganz, 2007).

In welfare states, the main costs of autism to families are generally for living support and day activities, rather than interventions which are often state-covered or subsidized. Studies on Great Britain confirm the lifetime costs of autism. However, they suggest that minor improvements in life outcomes for autistic individuals could substantially reduce lifetime costs (Järbrink and Knapp, 2001; Knapp *et al.*, 2009). Another study finds considerable variations in caseload and spending between British social service and welfare agencies due to case recognition and service provision policies (Bebbington and Jennifer, 2007). In Sweden, the major cost drivers for children with ASD were found within the community for institutional support and schooling (Jarbrink, 2007).

Our study helps fill the current research void on autism costs in developing/industrializing countries by

relying on this literature review to (1) inquire into various expenditure sources and (2) explore non-financial data.

Setting: Egypt is the most populated country in the Middle East and the third most populous on the African continent (2009 population = 83.08 million; median age = 24.8 years). Over 20% of Egyptians live below poverty line (Central Intelligence Agency, 2009). As a middle-income and developing country (2001 Gini = 34.4) (Central Intelligence Agency, 2009), Egypt's socio-economic infrastructure contains both developed and developing country characteristics.

MATERIALS AND METHODS

Multi-stage cluster sampling: Pre-tested and interviewer-based questionnaires were designed by our survey research team for a probability sample of 185 households, of which 165 participated (89.2% response rate) from August-October 2009. An SPSS worksheet function (RANUNI) selected the random household numbers from a pool of qualified households, which were initially identified with the assistance of Greater Cairo's health and education agencies. A total of 174 autistic family members were represented in the 165 participating households, although a few of these individuals resided elsewhere at the time of the survey. Interviews were conducted mostly with parents (84.3% of survey respondents). The randomized households were allocated, based on 2008 population, among 3 distinctive geographic clusters in the Greater Cairo Region to compare autism costs and resources. These were: (1) urban and highly-urban districts (namely, Abbassia, Downtown Cairo, Mohandessin, Nasr City and Sayyida Zaynab); (2) suburban districts (Cairo Airport, Heliopolis, Ma'adi and Misr el-Gedida.); and (3) rural areas (Bahtim and Giza). Geographically-clustered survey data was Chi-square (χ^2) tested for goodness of fit.

Tabulated survey results equate to a +/- 4.0 percentage points error margin for our sample/s (without replacement) at the 95.0% confidence level. Sample non-participation rate was considered negligible by our sampling design committee and did not create any selection bias.

Content analysis: Survey data was supplemented by content analysis of any ASD-related legislation and regulatory policy.

RESULTS

Socio-demographic characteristics: Table 1 classifies the 174 individuals with ASD diagnosis on the basis of

their socio-demographic characteristics. Race/ethnicity was excluded, since Egyptians make up 99.6% of the national population (Central Intelligence Agency, 2009).

No significant socio-demographic variations by geographic setting or cluster were found among autistic individuals in our survey. They were fairly well distributed across the entire age spectrum in a way that approximated the distribution of Egypt's national population. The higher proportions of age cohorts below 30 years old appear to be representative of the lower median ages of Egyptians compared to most North Americans and Europeans. Autistic individuals were also proportionally represented in terms of household income. They were predominantly males with a ratio to females of almost 1:5. About three-quarters of the 174 individuals had classical autism (Kanner Syndrome) diagnosis. Asperger Syndrome accounted for 6.9-14.9% of the total. These findings replicate many of the global ASD trends that had been identified in the scientific literature.

Between 83.3-91.3% of autistic individuals reside at home with their families. Most parents and family caregivers whom we interviewed indicated the scarcity, distance and unaffordable cost of typically private residential placement options (e.g., group home) in their decision to keep their autistic children/family members at home. Many of them also expected to care for their autistic family members at home for an indefinite period of time and well into their adult years.

Although as much as 54.7-62.7% of surveyed individuals with ASD were of school age (4-22 years old), less than a quarter were actually enrolled in various educational levels. The majority of parents and household members cited developmental/learning obstacles and peer ostracism/ridicule in keeping children with ASD at home. Most school-age children were informally "home-schooled" by their parents, siblings, grandparents and emotionally-related individuals.

Survey data concerning residential location and schooling in Egypt collectively represent a point of departure from many North American and European countries. In these countries, families of autistic individuals generally have access to and utilize various residential placement options. Autistic school-age children in these countries are generally enrolled in regular or special education schools (Wall, 1990; Gray, 2002). In contrast, the Egyptian experience with ASD care appears to be based on a "home-grown" service, whose cost implications substantially differ from those in many developed/industrialized countries, particularly in the western hemisphere.

Table 1: Socio-demographic profile of autistic individuals (n = 174)^a

Characteristics	Frequency (%)
Age	
0-9	41 (23.6)
10-19	47 (27.0)
20-29	34 (19.5)
30-39	18 (10.3)
40-49	18 (10.3)
50-59	10 (5.8)
60-69	4 (2.3)
70 and above	2 (1.2)
Gender	
Male	144 (82.8)
Female	30 (17.2)
Household income classification^b	
Stratum 1: Lowest	37 (21.3)
Stratum 2: Low-middle	44 (25.3)
Stratum 3: Middle	40 (23.0)
Stratum 4: Upper-middle	27 (15.5)
Stratum 5: Upper	12 (6.9)
Educational level (if applicable)	
Less than age 4	7 (4.0)
Basic (11 and 4-14 years old)	
Kindergarten (2 and 4-5 years old)	3 (1.7)
Primary (6 and 6-11 years old): Compulsory	13 (7.5)
Preparatory (3 and 12-14 years old): Compulsory	11 (6.3)
Secondary/technical (3 years, ages 15-17)	7 (4.0)
Post-secondary (18 and above)	2 (1.1)
Not in school (school-age and beyond)	125 (71.8)
Residential location	
Home:	
Living with parents/siblings/relatives	129 (74.1)
Living independently (with/out spouse/own family)	23 (13.2)
Residential placement (e.g., special care/group homes, educational institutions)	13 (7.5)
Health/medical facility (e.g., hospital)	5 (2.9)
Other (e.g., church/mission home)	4 (2.3)
ASD diagnosis	
Classical autism	133 (76.4)
Asperger syndrome	19 (10.9)
Rett syndrome	3 (1.7)
PDD-NOS	6 (3.4)
Childhood disintegrative disorder	4 (2.3)
Other (autistic features only)	6 (3.4)

^a: Column totals may not equal 100% due to non-response rate.

^b: Based on Egyptian market research segmentation.

Care providers: Geographic setting (based on urbanization level) appears to slightly affect accessibility and affordability of special needs/ASD-related facilities.

Table 2 segregates by geographic cluster our survey data on residential location, as presented in Table 1. Few surveyed families utilize/d non-household sources of autism care, regardless of geographic setting. However, families in urban/highly-urbanized districts were more likely to avail of (scarce) residential placement options, special needs resources and medical/health care, whether in addition to, or in lieu of, household care for their autistic family members. Conversely, in rural areas like Bahtim and Giza, virtually every individual with ASD stays home with his/her family or extended family network.

Table 2: Care providers for autistic individuals by geographic cluster^a

Care provider	Urban cluster (n = 101)	Suburban cluster (n = 42)	Rural cluster (n = 31)
Household type			
Immediate family (parents, siblings, spouse, children, house help)	87 (86.1)	37 (88.1)	30 (96.8)
Extended family (grandparents, other relatives, in-laws)	23 (22.8)	10 (23.8)	19 (45.2)
Emotionally-related (neighbors, friends, employers)	26 (25.7)	11 (26.2)	10 (23.8)
Special needs facility (group homes and other residential placements and special education institutions)	10 (9.9)	3 (7.1)	0 (0.0)
Medical/health facility	3 (3.0)	1 (2.4)	1 (3.2)
Other (church/mission, adoption center)	7 (6.9)	1 (2.4)	0 (0.0)

^a: Multiple sources may yield column totals that do not equal 100%.

Table 3: Type of care/support for autistic individuals by geographic cluster^a

Care provider	Urban cluster (n = 101)	Suburban cluster (n = 42)	Rural cluster (n = 31)
Accommodation and basic provisions (food, clothing, allowance, recreation, basic skills)			
Household	98 (97.0)	40 (95.2)	31 (100)
Non-household/institutional	26 (25.7)	8 (19.0)	4 (12.9)
Non-household special education and skills training	24 (23.8)	9 (29.4)	4 (12.9)
Employment/income-generation	36 (35.6)	8 (19.0)	5 (16.1)
Non-household recreational and social activities (e.g., sports, camps, field trips)	26 (25.7)	10 (23.8)	1 (3.2)
Other (medical, health, religious/worship, civic)	17 (16.8)	6 (14.3)	2 (6.5)

^a: Multiple types of care/support may yield column totals that do not equal 100%.

Many of our respondent Bahtim and Giza families indicated lack of knowledge or information about ASD interventions, high cost of related services and the need for autistic family members to assist in gainful employment in their decision to dispense with health and educational arrangements. Culture, religion, regionalism, ideology and other social and political variables did not appear to be determinants of care provider choice/s for the vast majority of surveyed parents/families, most of which were also the caregivers for family members with ASD.

Types of care: Table 3 shows that 91.2% or more of autistic individuals in each of the 3 geographic clusters depended on his/her immediate family or household for accommodation and basic provisions, irrespective of the marginal propensity to utilize formal and institutional sources of care.

Non-household care categories figured in only 1 out of 3 or 4 autistic individuals, most of whom remained dependent on their households for other forms of primary and secondary care. Aggregate demand by a few families for classroom-centered educational programs and employment-related opportunities appear to be higher compared to other non-household categories. However, similar to data presented in Table 2, these few families tended to live in urban and suburban areas.

The vast majority of families in all 3 geographic settings cited the following factors for confining and

offering most categories of care and support in their respective households: Lack of financial resources, lack of understanding about ASD and appropriate interventions, scarce/unknown state and community-level autism services and programs and negative outlook (pessimism) concerning their autistic family members' condition. The perspective of one parent from urban Abbassia is insightful: "In Egypt, there is little knowledge about autism and less about effective interventions because no one seems to be willing or able to discuss them. Those who have the knowledge, know that there are no institutions or, if any, are difficult to find and certainly expensive" (our translation from Arabic). Several parents from Downtown Cairo, Nasr City, Heliopolis, Ma'adi and Giza also lamented the seeming lack of state interest in offering assistance to their autistic family members.

Expenditure categories: Table 4 indicates the non-financial costs of ASD care and support to households with autistic members, in the absence of state provision of needed services and resources.

The median extra time spent by surveyed family caregivers on autistic individuals was approximately 1,211-1,239 h a year. Median hours were obtained from our annualized calculations of what these households indicated in Table 4 as direct expenditures in time and personal effort on a daily or weekly basis.

Table 4: Household time allocation by activity (n = 165 households)

Activity	Median time (hours per year)	Frequency (%)
Daily supervision/monitoring and companionship	852.5	155 (93.9)
Behavior control (including counseling)	354.0	126 (76.4)
Medical/health-related (medical check-up, consultation)	7.5	29 (17.6)
Health supervision (buying and administering medicines, checking compliance with doctor's prescriptions)	4.5	21 (12.7)
School work (including "home schooling")	301.0	43 (26.1)
Socialization/social activities	48.5	19 (11.5)
Recreational and sports activities	362.0	109 (66.1)
Employment-related (including skills-training)	649.0	102 (61.8)
Visitation (in group homes and hospitals)	29.0	9 (5.6)
Other (church/worship activities, civic and volunteer work)	24.5	16 (9.7)

We made slight statistical adjustments in these estimates for the nature and severity of diagnosis and health condition. Median total hours in Egypt were significantly higher compared to countries like Sweden, where the estimated annual family expenditure of extra time amounts to about 1,000 h (Jarbrink, 2007). In terms of unit cost by activity, the yearly outlay of time and effort for constant supervision/monitoring and companionship and to a lesser extent, for behavior control and recreation, is significantly greater among surveyed Egyptian families than those in any studied developed country. The number of hours allotted by families for employment and skills-related activities (close to 640 each year) was also much higher, although it might be asserted that a big portion of the median time was intended for household income-generation.

Using survey data summarized in Table 4, we conservatively estimated that at least 51.4-57.9% of the median extra time spent for caring and supporting autistic family members could have otherwise been devoted to paid employment and unpaid work, training and leisure by family caregivers (i.e., opportunity costs). Lost income, productivity and leisure time constitute indirect cost consequences of ASD for individual caregivers in Egypt. However, the economic impact of these losses could significantly vary, depending on the particular economic and social circumstances of the caregiver.

In terms of direct financial costs, our conservative median estimates for the care and help offered by (surveyed) families and households range from LE 171,368-251,303 (US \$31,300-\$45,900) (2009 values). We found these direct financial costs to be higher at ages 7-15 and after age 54. Instead of physician/medical services, prescription medication and behavioral therapies forming the bulk of these costs as in the case of autistic Americans, we found that direct non-medical costs (e.g., skills-training, special education, camps and ad hoc activities), along with some physician and out-patient services, accounted for higher cost proportions for Egyptian families. We

estimated that these same Egyptian families and households would incur about 79.0-88.3% of these costs in the absence of private health insurance coverage and sufficient state aid for developmental/learning disabilities.

Yet, our estimates represent a fraction of direct expenses for individuals with ASD in many western industrialized countries. For example, the typical American is estimated to spend \$317,000 (2007 values) over his or her lifetime in direct medical costs, incurring 60% of those costs after age 65 years. Americans with ASD, on the other hand, incur over \$306,000 in additional direct medical costs alone, implying that these individuals spend twice as much as the typical American over their lifetimes. Autistic Americans also spend 60% of those incremental direct medical costs after age 21 (Ganz, 2007). Controlling for income and lifestyle differences between Egyptians and Americans based on household income classifications reported in Table 1, we find that the comparatively low direct medical costs of ASD in Egypt results from the trade-offs between household care and institutional sources of health care.

Direct (i.e., state expenditures) and indirect societal costs to support a single American with ASD is \$3.2 million over his or her lifetime (Ganz, 2007). Schooling and community support also create significant financial responsibilities for welfare states like Sweden (Jarbrink, 2007). In contrast, autism costs to Egyptian society are generally impractical to calculate for the purpose of this study in view of the household-provider model of ASD care and support. In the Egyptian model, we find that the household assumes much of the burden of what the state would otherwise assume in terms of national and local health and social welfare services, education, subsidies and allowances and community support. For example, our survey data reveals that autism and special needs education are typically private school options that very few in Egypt can afford. Only a small percentage of the Egyptian national population is covered by health or

unemployment insurance, unless they are physically unable to work. As surveyed parents conceded, lack of any insurance coverage in old age makes lost income and productivity of autistic individuals even more costly to immediate and extended family members, who are then expected to shoulder most ASD expenses during an autistic family member's advanced years.

Public health policy: No single legislation or regulatory policy presently exists in Egypt that directly pertains to developmental/learning disabilities. In 1975, Law No. 39 was passed defining disability on the basis of an Egyptian's inability to work and his/her eligibility for state aid and pension coverage. We find an outcome-based and adult-oriented notion of disability neglectful of the comprehensive special needs of autistic individuals of all ages and the importance of periodic evaluation of their health and well-being.

International events since the 1990s have fostered interest in developmental/learning disabilities in Egypt (e.g., International Decade of the Disabled, 2000 International Special Education Congress). These also led to the growth of local associations of parents of children with ASD and related disabilities and some state-supported community-based projects. In 2009, the Egyptian Ministry of Education unveiled a "mainstreaming" program to integrate children with learning disabilities into the regular school system (Rabie, 2009). Our survey results, however, suggest the feedback effects that such a policy would have to overcome: The preference among families of autistic children to keep and educate them at home due to concerns over peer rejection and psycho-social adjustment. An earlier study also suggested that Egyptian privatization policies have tended to offset the limited ASD-related efforts of the state due to reduced spending in welfare and health services and programs and declining private donor interest (North-South INSERM Network, 1997).

The few private and non-profit organizations that exist, such as The Egyptian Autistic Society and Learning Resource Center, help fulfill in some (proxy) capacity what the state is either unable or unwilling to perform: Autism education/information dissemination, family networking and individual needs assessment. Some of our surveyed families indicated familiarity with these groups in promoting ASD awareness and sponsoring special activities. However, content analysis of available information concerning these few organizations reveal that their institutional capacities are extremely limited due to under-funding, in spite of their professional and managerial expertise.

DISCUSSION

Economic theory tells us that aggregate supply creates its own demand. What it does not adequately tell us is why and how the form of supply varies across time and space even if the same level of demand were held constant.

The evolution and existence of the household in Egypt as (practically the sole) supplier of care and support for children and adults with ASD exemplifies a distinctive pattern relative to many developed/industrialized countries, while responding to the same need or demand. Cost issues affecting the availability, affordability and reliability of ASD resources underscore the socio-economic context in which the Egyptian household exists as a (limited) proxy to institutional sources of care and support. The Egyptian household-provider model drives down the financial costs of autism, but the direct and indirect benefits of behavioral and therapeutic interventions and special education are hardly realized (opportunity costs). How to integrate the household as service supplier with the formal health framework to offer autistic Egyptians suitable care and support is the key challenge that the state needs to pro-actively and creatively address.

This study yields several health policy implications that can guide decision-makers toward effective allocation of state resources and increased involvement in welfare delivery. Policy lessons and insights gained from this study are transferable to many other developing countries:

The household as unit of cost analysis: Valuation processes assist decision-makers in the allocation of scarce public resources to key policy objectives and programs. Any valuation method or technique cannot afford to understate the substantial direct and indirect autism costs to the household care- provider. This study has identified some key valuation elements, including caregiver time, direct non-medical expenses and supervised household activities. The Egyptian household as the unit of cost analysis contrasts with the experience of many developed countries, where specialist institutions exist, state support (e.g., subsidies and grants) and health insurance are available for developmental/learning disabilities, scientific research is well-funded and ongoing and ASD interventions are subject to government oversight (e.g., by regulatory agencies). The Egyptian household-provider model is therefore crucial in formulating appropriate policy reforms.

Health care provision by the state: Our interviews with parents and other family caregivers and content analysis of pertinent legislation indicate the restricted role that the Egyptian state plays in health care provision, particularly with respect to developmental/learning disabilities. Provision refers to legislation, financing and pricing of and arrangements for any health services offered or contracted out by the state. One key policy implication we can derive from this study is the need for state financial support to families with autistic members. Another implication concerns the need for state monitoring and regulation of autism services and resources.

Geographic dispersion of ASD resources and information: In many underdeveloped countries, the more urbanized communities tend to have greater access to and utilization of health and welfare resources (World Bank, 1997; Jutting, 2002; Isabel and Paula, 2009). Egypt appears to be of no exception, as the clustered sampling results in this study show, albeit to a lesser extent since few households are inclined to avail of institutional sources of care for their autistic members. Besides the high costs of private services for a typical middle or lower-middle income family in Egypt, transaction costs can be challenging. Search and information costs for ASD facilities and services appear to be higher in rural areas exemplified by Bahtim and Giza, compared to the more urban settings. A proactive role for the state needs to ensure that autism resources are not only affordable but that information about their availability and reliability are geographically dispersed among rural and remote areas of the country to minimize transaction costs.

School integration: The “mainstreaming” objective for school-age autistic Egyptians and other pertinent educational programs, should consider the feedback effects of family care-giving to avoid costly policy outcomes or outcomes with only limited success. Caregivers’ involvement/input in planning and evaluating ASD policies and programs, like school integration, is vital given the opportunity costs of educating autistic children at home.

State partnership with private and non-profit health sectors: Few organizations exist in Egypt to meet the special needs of people with ASD and other developmental/learning disabilities (e.g., The Egyptian Autistic Society is the only one devoted to autistic children). Most of them tend to be non-profit types that possess the relevant expertise and experience (or

comparative advantage vis-a-vis the state). Owing to the limited resources of the Egyptian state and its relatively recent involvement with developmental/learning disability programs, co-production initiatives with competent private and non-profit organizations may be explored (e.g., state accreditation and oversight, organizational incentives through state grants and subsidies, joint scientific research on ASD). These initiatives help drive down autism costs on the part of the state.

Old-age economic security for autistic individuals: Our survey data shows that an extended family network offers autistic Egyptians some advantages in terms of old-age income and support that may not be easily available to their counterparts in industrialized countries. For this reason, some developed countries have considered the need for some form of income replacement or employment insurance during an autistic individual’s advanced years. Further research is nonetheless needed to determine how the opportunity costs of benefits derived from staying at home impact an autistic individual’s gainful employment or relative independence in old age when fewer family members are present to help. The trade-offs between home-based skills training and institution-based interventions may also have profound economic implications for caregivers, as autism costs increase in old age.

Autism care as a merit good: The cost consequences of ASD finally lead us to the notion of merit goods in the economic literature. Merit goods must rely on some social redistribution goals or value orientation to justify government intervention (Mendoza, 2008). It is evident from this study that autism care, like any other merit good, will be under-consumed and, consequently, under-produced in a market economy, if public health policies governing and encouraging their provision and production are lacking. A merit goods approach to autism is not without cost to the state (e.g., additional budgetary outlays). However, positive spillover benefits to society as a whole are achieved when autistic citizens are healthy, educated and productive.

CONCLUSION

Opportunity and transaction costs, feedback effects and spillover consequences of the household-provider model should be carefully considered in health policy formulation. Making autism care and support available, affordable and reliable should be a major health concern of the state

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