The economic costs of Autism Spectrum Disorder: A literature review

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Abstract

Autism is associated with a range of costs. This paper reviews the literature on estimating the economic costs of ASD. More or less 50 papers covering multiple countries (US, UK, Australia, Canada, Sweden, the Netherlands, etc.) were analysed. Six types of costs are discussed in depth: *(i)* medical and healthcare service costs, *(ii)* therapeutic costs, *(iii)* (special) education costs, *(iv)* costs of production loss for adults with ASD, *(v)* costs of informal care and lost productivity for family/caregivers, and *(vi)* costs of accommodation, respite care, and out-of-pocket expenses. A general finding is that individuals with ASD and families with children with ASD have higher costs. Education costs appear to be a major cost component for parents with children with ASD.

Key words: Autism, Autism Spectrum Disorder; Direct costs; Indirect costs; Financial burden.

1. Introduction

Autism spectrum disorder (ASD) is a range of neurodevelopmental disorders that are characterized by the following core deficits: impairments in social interaction and communication, and restricted, repetitive behaviours (DSM-5, American Psychiatric Association, 2013). ASD affects people worldwide, irrespective of race, ethnicity or socio-economic status (Sharpe & Baker, 2011; Durkin et al., 2010). Studies and empirical evidence also show ASD is related to many potential comorbidities such as epilepsy, attention problems, gastro-intestinal problems, oppositional behaviour, anxiety and depression, sleeping disorder and feeding disorders (Hodgetts, Zwaigenbaum & Nicholas, 2015; Kogan et al., 2008; Vohra, Madhavan, & Sambamoorthi, 2017). As to the population prevalence of ASD, estimated figures vary depending on the country of study, the period studied, and the estimation method used. Recent estimates range from 1 per 160, 1 per 100, to 2 per 100 (Baird et al., 2006; Baio et al., 2018; Cidav, Marcus & Mandell, 2012; Hughes, 2009; Knapp, Romeo & Beecham, 2009). Most recent estimates for the US as collected by the Autism and Developmental Disabilities Monitoring Network (Centers for Disease Control and Prevention, U.S. Department of Health and Human Services), for instance, yielded overall ASD prevalence estimates varying from 13.1 to 29.3 per 1,000 children aged 8 years with an average prevalence estimate of 16.8 per 1,000 children aged 8 years (Baio et al., 2018). Based on the prevalence estimates of several studies across multiple countries, Lyall et al. (2017) estimated the population prevalence to be around 1.5% in developed countries around the world. As possible reasons for the discrepancy in estimated prevalence figures, studies point out, among other things, that for several countries (e.g., Belgium, Scotland, most of the Arabic countries, etc.) there are no reliable and/or only limited statistics available regarding the prevalence of ASD and that diagnosis in ASD can be difficult or complicated due to no or ineffective screening, and the interactions that occur between development and ASD symptoms. Studies on the prevalence of ASD also show that there is an increasing trend in the percentage of the population that is diagnosed with ASD (Lyall et al., 2017; Jacob, Scott, Falkmer & Falkmer, 2015; Sharpe & Baker, 2007), with more recent studies showing higher estimates of prevalence rates compared to older studies. However, it is unclear whether this increase is due to an actual increase in prevalence of ASD, more broadly defined diagnostic criteria, better public and medical awareness, improved possibilities of diagnosing children at a young age, or a combination of all these factors (Jacob et al., 2015; Kogan et al., 2008; Leslie & Martin, 2007). Studies also showed that a considerable share of the people with ASD have intellectual disabilities. Estimates of individuals with ASD having intellectual disabilities reported by recent studies vary between 30%-50% (Baio et al., 2018; Beuscher et al., 2014; Atladottir et al., 2007; Baird et al., 2006). For instance, recent estimates for the US show that 31% of children with ASD were classified in the range of intellectual disability, i.e. IQ < 70) (Baio et al., 2018; Centers for Disease Control and Prevention). In a study of the costs of ASD in the US and the UK, based on findings of previous studies, Beuscher et al. (2014) reported a 40-60% split (i.e., 40% of individuals with ASD having intellectual disabilities).

The rising number of people being diagnosed with ASD, in combination with the life-long care and support that most individuals with ASD require across multiple domains such as education, healthcare and community services (the need for support depending on the severity of the disorder), makes it a major societal concern involving significant costs for the individual diagnosed with ASD, his/her family, private and/or public health insurance systems, state financial aid programmes, and society, more generally. Having a better understanding of the ASD-related costs is beneficial and informative for several reasons. Firstly, a study of the costs could yield a detailed picture of the size of the costs, the different types of costs, the distribution of the cost burden for the different parties involved, as well as unintended or negative consequences of policies. For example, information about what costs are borne by families and to what extend costs related to ASD are covered by health insurance, the education system or state financial aid programs can reveal the financial burden for families of individuals with ASD. If financial costs are not sufficiently funded by public resources or health insurance programs this might negatively affect the access to certain services for ASD-individuals (or their families) with limited personal financial resources. Secondly, in responding to this challenge of a larger number of people being diagnosed with ASD, those responsible for developing and implementing policies and deciding on resource allocations need to have good knowledge of the consequences of their decisions. A clear overview of the total cost of ASD and all its individual components can help policy makers make informed decisions about public resource allocation and the organization of public services for individuals with ASD. Thirdly, costs related to ASD are not limited to service and healthcare costs. A comprehensive overview of indirect costs, such as informal care and parental lost productivity, might assist policy makers in finding ways to help families through family support systems.

The aim of this paper is to review the literature dealing with estimating the economic costs of ASD. Around 50 papers covering multiple countries (US, UK, Australia, Canada, Sweden, the Netherlands, Egypt and China) are analysed. Six types of ASD-related costs are discussed in depth: *(i)* medical and healthcare related service costs, *(ii)* therapeutic costs, *(iii)* (special) education costs, *(iv)* costs of production loss for adults with ASD, *(v)* costs of informal care and lost productivity for family/caregivers, and *(vi)* costs of accommodation, respite care, and out-of-pocket expenses.

The paper adds to the literature in that it provides a comprehensive overview of the recent literature on ASD costs. To our knowledge, only two studies have actually provided a review of the cost estimation studies on ASD: Amendah, Grosse, Peacock and Mandell (2011) and Sharpe and Baker (2011). Amendah at al. (2011) conducted a literature review on ASD costs thereby following an approach similar to the one used in the present review paper, i.e., screening databases for peer-reviewed literature and additional sources of information on the costs of care for individuals with ASD thereby using a set of key words. However, Amendah et al. (2011) focused primarily on US-based studies (however, due to scarcity of data/studies for the US, also (a limited number of) non-US studies were included for non-medical ASD costs). Though there is some overlap between Amendah et al. (2011) and the present review study (Amendah et al. (2011) reviewed a selection of 40 studies, 13 of which are also reviewed in the present review study), we believe that our paper does add to the literature in that it complements the review study of Amendah et al. (2011) by reviewing the recent literature on ASD costs (period 2011-2017) and also non-US studies on medical costs or expenditures of ASD. Sharpe and Baker (2011) conducted a brief review of a ten studies on autism-related costs, five studies on the US and five studies abroad. All ten studies are also included in our review study.

2. Literature review search strategy and structure

The literature search was conducted using multiple databases (Medline, Web of Science, Scopus and ScienceOpen). In the search for studies to include in the literature review, the key terms '*autism*', '*ASD*', and '*autism spectrum disorder*' were combined with the following keywords: '*costs*', '*economic costs*', '*economic burden*', and '*expenditures*'. Only papers from 2000 onwards were considered in the search process (i.e., the search period covered January 2000 – January 2018). The general terms 'autism spectrum disorder' and 'ASD' were used as an inclusion criterion. Given the broadness of the ASD-spectrum this implies that different types of pervasive developmental disorders (PDD), such as autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome were considered (DSM-5, American Psychiatric Association, 2013).[2] As a selection criterion, it was decided that studies focusing on costs and cost calculations for both children and adults with ASD were to be included. No language barriers were added to the inclusion criteria, although a large majority of the papers were in English. A first screening of the titles and the abstracts (thereby focusing on whether the key terms appeared in the title and/or abstract) reduced the selection with slightly more than two-thirds. During the readings and reviews, it was decided that some papers should not be further considered in the literature review. It concerned mainly studies that didn't list any cost figures or estimations of ASD costs and/or that didn't elaborate on the costs of ASD. Papers that didn't explicitly calculate/estimate ASD-related costs were retained in the selection if they discussed the concept of costs related to ASD at a more general level as these papers are relevant to papers that do explicitly perform cost calculations, for instance, by identifying the cost categories that should be taken into account in such calculations/estimations (e.g., Murphy, Beecham, Craig & Ecker, 2011). This resulted in a selection of 39 papers remaining. To further expand the literature search, reference lists from selected papers were screened for potentially interesting papers. This resulted in some papers and book chapters (9 in total) being added to the selection (e.g., Amendah, Grosse, Peacock & Mandell, 2011; Sharpe & Baker, 2011).

The final selection of papers thus includes 48 papers, with most papers from peer-reviewed journals. Over half of the studies were conducted in the United States. Other studies were carried out in the United Kingdom (e.g. Barrett et al., 2015), Australia (Horlin, Falkmer, Parsons, Albrecht & Falkmer, 2014), Sweden (Järbrink, 2007), Canada (Hodgetts et al., 2015), the Netherlands (Peters-Scheffer, 2015; Peters-Scheffer, Didden, Korzilius & Matson, 2012), China (Xiong et al., 2011) and Egypt (Mendoza, 2011). Note that in the screening of the papers,

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[2] Alternatively, one could opt to include the individual diagnostic labels (autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome) in the search process.

no strong methodological considerations were imposed as to how cost data were collected, used in cost estimations (i.e. which cost estimation technique was used) and/or reported. As to the sample scale, for instance, there are papers in the final selection which collected national-level data from one or multiple national data sources (e.g., Liptak et al., 2006; Ganz, 2007; Leslie & Martin, 2007), whereas other papers used data from lower-level (e.g. county-level) administrative sources (e.g., Mandell et al., 2006; Croen et al., 2006), and some papers even used data as collected from small-sample interviews/questionnaires (e.g., Barrett et al., 2012; Järbrink, 2007). Data were abstracted from the papers using a standard checks list designating what type of information was to be collected and reported into review tables. In particular, for each paper the following information was abstracted: the author(s) of the study, the year of article publication, the country of study, the data source(s) used, ASD cost components per category, reported/estimated cost figures (eventually with ranges). If available, also the following types of information were to be collected: the share(s) of the cost components to the overall ASD-related costs (or, in case of lifetime costs, the cost share for each age period), the base at which costs were assessed/estimated (annual costs, lifetime costs, etc.), and the currency and year in which cost figures are reported. Depending on the article, costs for individuals with the ASD-diagnosis are compared to typically developing children and adults, or to individuals with other mental disorders or physical impairments. Other papers compare the costs for individuals with ASD across age groups, the costs and benefits of different therapies, or the costs for people with ASD with or without intellectual disabilities. If such comparisons were made, both cost figures were provided in the overview tables.

The literature review is organized into sections that correspond to categories/components of ASD-related costs. Different categorizations of the ASD-related costs have been proposed in the literature. Lavelle et al. (2014), for instance, estimated ASD-related costs in three categories: direct medical, direct non-medical costs (especially special education services and behavioural therapies), and caregiver productivity costs (average wage times increased hours of caregiving). Amendah, Grosse, Peacock and Mandell (2011) distinguished between four domains of ASD costs: medical, nonmedical, productivity, and caregiver time. Buescher et al. (2014) assessed seven ASD-related cost categories: accommodation (residential care), medical services, nonmedical services, special education, employer support, lost parental productivity, and lost individual productivity, with employer support and lost individual productivity cost categories only applying to adults with ASD aged 18 and over. Looking for a balance between cost categories that are too broad or narrow, this paper distinguishes between six types of ASD-related costs: *(i)* medical and healthcare related service costs, *(ii)* therapeutic costs, *(iii)* (special) education costs, *(iv)* costs of production loss for adults with ASD, *(v)* costs of informal care and lost productivity for family/caregivers, and *(vi)* costs of accommodation, respite care, and out-of-pocket expenses. In the review of the cost estimation studies, detailed cost figures are reported in Tables 1-6 and general findings are discussed in the text. Note that Tables 1-6 list cost figures in the monetary unit and base year as reported in the reviewed papers as well as in 2018 US$ (in italics). The reason for updating the cost figures to the same base year (i.e., 2018) and the same currency (i.e., US $) is to facilitate comparisons of cost figures.[3]

3. A classification of ASD-related costs

3.1. Medical and healthcare related service costs

The cost category that is mostly examined in the literature is the ASD-related medical or healthcare costs. It concerns costs that are caused by inpatient and outpatient expenses as well as pharmaceutical expenses. Some studies also consider costs related to emergency care, the

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[3] In the transformation of the cost figures, reported cost figures were first inflated to the year 2018. Subsequently, inflated cost figures were all converted to US $ thereby adopting the conversion rate as on 1 January 2018 (£1.00 = $1.3491 US, €1.00 = $1.20 US, $1.00 Canadian = $0.800961 US, $1.00 Australian = $0.788955 US).

use of physicians or other healthcare professionals, and home healthcare services. Table 1 gives an overview of the studies and their cost estimates.

Most of the studies listed in Table 1 calculated and compared the use and costs of medical and healthcare related services for individuals with and without ASD to obtain an idea of how ASD affects the use and costs of such services. Examples include Croen, Najjar, Ray, Lotspeich and Bernal (2006), Liptak, Stuart and Auinger (2006), Ganz (2007) and Shimabukuro, Grosse and Rice (2008). Other studies also estimated and compared the medical and healthcare costs of children and/or adults with ASD with intellectual disabilities with the costs of children and/or adults with ASD without intellectual disabilities or children and/or adults with other types of disabilities (e.g., physically disabled children/adults, mentally disabled children/adults, etc.). Examples of such studies are Järbrink and Knapp (2001) and Knapp, Romeo and Beecham (2009), with both studies using the IQ score of 70 as a cut-off to distinguish ASD children with and without additional learning disabilities.

Although the studies very likely do not provide a complete identification of the cost differentials, they do reveal several general insights. One general finding is that the medical and healthcare costs are significantly higher for individuals with ASD than for the general population. Croen et al. (2006), for instance, reported that the average annual cost of healthcare for children with ASD was three to two times as large as the healthcare costs for children without ASD (depending on whether there was an adjustment for age and gender or for age, gender and psychiatric comorbidities in the cost computations). A similar cost ratio for medical and healthcare costs for children with ASD vs. children without ASD was also found by Ganz (2007). Ganz (2007) reported that, in the US, a person with ASD spends, over the course of his/her lifetime, almost twice as much on direct medical costs as a typical person (without an ASD diagnosis). Croen et al. (2006) also reported that children with ASD and psychiatric comorbidities had higher total healthcare costs than children with just an ASD diagnosis. In their US nationwide study, Shimabukuro, Grosse and Rice (2008) found that total medical expenditures were 4.1 – 6.2 times higher for privately insured children with ASD when compared to their peers without ASD.

Studies highlight multiple factors for these cost differences of medical and healthcare related services for children with and without ASD. One such factor is that ASD using medical and healthcare services more frequently as compared to the general population. Croen et al. (2006), for instance, found that children with ASD more frequently consulted pediatricians, psychiatrists and neurologists as compared to children without ASD. Children with the ASD diagnosis also had significantly more inpatient hospital days and outpatient (same-day) hospitalisations as compared to children without ASD (the difference between both groups being most significant in the group of 15–18 years old). In their calculations of the medical costs related to ASD in the UK, Järbrink and Knapp (2001) reported similar differences in the use of inpatient psychiatric services, with people with high functioning ASD using inpatient psychiatric services at least four times more frequently as compared to the general population. Croen et al. (2006) also found that more children with ASD (40% more) used prescribed medication (especially psychotherapeutic and gastro-intestinal agents) as compared to children without ASD. These findings correspond to the those of Liptak, Stuart and Auinger (2006) and Lavelle, Weinstein, Newhouse, Munir, Kuhlthau and Prosser (2014), who found that the cost of outpatient visits, physician visits and prescription medications were significantly higher for children with ASD as compared to children without an ASD diagnosis.

A second interesting finding is that most studies showed that the overall medical and healthcare costs for people with ASD steadily increase over the lifetime. For children up to 20 years, Cidav et al. (2013) found that expenditures for inpatient care (2%), long-term care (4.4%) and psychotropic medication (9%) increased with each year of age for children during the ages of 3 – 20. The largest increase occurred between the ages of 3 – 6 and 7 – 11. Outpatient expenditures were found to increase between the age period 7 – 11 and 12 – 16 and decline in the age period 17 – 20. Shimabukuro, Grosse and Rice (2008) reported a similar result, i.e. as children with ASD get older, inpatient and medications costs make up a bigger part of the total medical cost and the share of outpatient costs decreases. Buescher et al. (2014) compared the medical and healthcare costs of people with ASD in the UK to those in the US and found that the medical costs were much higher for adults with ASD than for children with ASD in both countries. An opposite trend was reported by Ganz (2007), who found that the total direct medical costs for the average person with ASD in the US were decreasing with age. A decreasing trend was also found for most of the different individual components of direct medical costs (exceptions being the physician and dental costs). Note, however, that Ganz (2007) included the expensive cost of behavioural therapies for children in the medical cost category (the cost of behavioural therapies were only included for individuals 19 years of age and younger), whereas most other studies, like Buescher et al. (2014), categorized therapy costs as a nonmedical service cost. This probably explains the finding of an opposite trend.

A third finding is that some studies found that the medical and healthcare expenditures for individuals with ASD are generally higher than for individuals with other mental health conditions. Leslie and Martin (2007), for instance, found that the average annual healthcare cost figure for children with ASD was higher than the average annual healthcare cost figures of children with different diagnoses. Only the average annual healthcare cost for children with mental retardation was found to be higher. Leslie and Martin (2007), however, noted that, considering the lower prevalence rates of ASD as compared to the other mental health conditions examined, total healthcare expenditures for ASD were lower than total healthcare expenditures made for other (more prevalent) mental health conditions. However, it is difficult to say whether this last finding of Leslie and Martin (2007) still holds today, given the increasing trend in the number of people being officially diagnosed with ASD, better public and medical awareness for ASD, and improved possibilities to diagnose children at a young age (or a combination of those factors).

A fourth interesting finding is that several studies indicated that the medical and healthcare costs make up only a small part of the overall cost encountered by individuals with ASD. For instance, for the UK and Sweden, Järbrink and Knapp (2001), Järbrink et al. (2003), Ganz (2007), Järbrink (2007) and Lavelle et al. (2014) concluded that the costs of medication, hospital services and other health and social services taken together only account for a small fraction of the total incremental cost for individuals with ASD. Järbrink (2007) estimated that the total medical and healthcare cost constitutes only a very small part, less than 5%, of the total societal cost for children with ASD in Sweden.

However, it is important to point out some reasons to be cautious about comparing the ASD-related medical and healthcare cost estimates of the different studies. One reason is that cost estimations are typically limited by data availability and/or imperfections in data sources and analyses. Another reason is that studies utilize different research designs and/or data sources in the cost estimations. As noted by Amendah, Grosse, Peacock and Mandell (2011), differences in ASD-related medical cost estimates across studies are linked to methodological choices made by the authors (using parental surveys vs. administrative data, using a medically diagnosed ASD population vs. a study population that was diagnosed with ASD outside the medical system, the type of insurance plan included in the study, etc.). While some studies use service use and cost data as collected from official databases, other studies use survey data to estimate the user frequency and costs (e.g., Ganz, 2007; Liptak, Stuart & Auinger, 2006). Some studies also include more cost components than others. For instance, in the estimation of the ASD-related medical and healthcare service costs, Liptak et al. (2006) considered the costs of in- and outpatient services, emergency care, physician/general practitioner, other healthcare professionals, pharmacy, and home healthcare in the cost computations, whereas Leslie and

Martin (2007) only included costs of in- and outpatient services and pharmacy. Other complicating issues are the different healthcare systems and financial aid programmes in countries and the fact that costs and prices can vary both between countries and within a country (e.g. across states in the US) as well as over time. As an illustration, Mendoza (2010) estimated direct medical costs of ASD in Egypt to be comparatively low as compared to the costs for their American counterparts (controlling for income and lifestyle differences between Egyptians and Americans). To explain this large difference, Mendoza referred to the trade-offs between household care and institutional sources of healthcare in Egypt. Mendoza also pointed to the restricted provision and financing of healthcare by the Egyptian state which results in a large part of the care for family members with ASD taking place within the household. All the above probably explains the recurrent finding of remarkable variance in the cost estimations across studies.

Before concluding the review of the studies about the ASD-related medical or healthcare costs, mention should be made of some other medical and healthcare expenses which were less discussed (or less explicitly so) in previous studies. One such expenditure is the cost of the ASD diagnosis. Anecdotical evidence obtained from families or individuals with ASD shows that the diagnosis process can be a real struggle, with, among other things, long waiting lists and high upfront costs. Murphy, Beecham, Craig and Ecker (2011) explained that the length of the diagnostic process, the need for expert clinicians and the high involvement of caregivers make ASD diagnosis a costly matter. This is nicely illustrated by Shimabukuro, Grosse and Rice (2008), who found higher levels of healthcare utilization and healthcare costs in the year in which children receive their medical ASD diagnosis. For Australia, Taylor et al. (2016) reported that the median cost of an ASD assessment for families was $580 (SD = $599.47), as computed across all services. However, data revealed considerable variability in the assessment costs across states and service settings, with the cost of ASD assessment to families ranging from $

0 in the public sector to $ 200 - $ 2750 in the private sector. Another example of an ASD-related medical and healthcare cost which was not included in most of the previous studies (notable exception is Järbrink, 2007) is the expenses of healthcare services for relatives, such as counselling and medication costs, which are caused by the child or family member with ASD. Sharpe and Baker (2007), for instance, noted that the increase in stress due to having a child or family member with ASD can result in higher medical costs for relatives and/or other family members.

< Insert Table 1 here >

3.2.Therapeutic costs

With more people being diagnosed with ASD and the subsequent expansion of (public and private) resources that are directed to research on ASD and treatment and care for ASD individuals, there has been an increasing interest in studying the use, the outcomes and/or the cost(-effectiveness) of behavioural treatments/therapies for individuals with ASD. Currently, (early) intensive behavioural intervention/treatment (EIBI) based on applied behaviour analysis principles is considered the treatment of choice for children with ASD. Despite a plethora of research projects and studies having examined the use and the effectiveness of such interventions and treatments (with the focus on the clinical outcomes such as behavioural improvements, increased cognitive skills, language and speech improvements, better social and emotional development, and improved fine and gross motor development, see e.g. Eldevik et al., 2009; Cidav et al., 2017; Peters-Scheffer et al., 2012; Reichow, 2011), only a limited number of studies have estimated and evaluated the costs of ASD-related behavioural interventions and therapies (although, this number has been building up over the past years). Of the studies that did examine the costs of treatment services for ASD, the large majority were performed in the US.[4] The detailed estimates of the ASD-related therapeutic costs made by previous studies are listed in Table 2. In what follows, we discuss some general findings obtained from the review of these studies.

A first general finding is that the costs of EIBI-programmes for ASD are substantial. Most US studies indicate that the annual cost for such programmes range between $40,000 and $60,000. Similar estimates were reported by Peters-Scheffer et al. (2012) and Peters-Scheffer (2015) for the Netherlands. However, there are some studies such as Lavelle et al. (2014) for the US, Järbrink et al. (2003) for the UK and Järbrink (2007) for Sweden, which reported cost estimates for EIBI-programmes for ASD that are considerably lower. One possible explanation for these lower cost estimates are the differences in how studies define and classify costs of ASD-related therapy programmes. Some studies classify costs related to the organization and implementation of ASD therapies as medical costs (Cidav et al., 2013; Cidav et al, 2017; Ganz, 2007; Horlin et al., 2014; Liptak et al., 2006), whereas other studies categorize these costs as non-medical costs or under community support (Barrett et al., 2012; Järbrink, 2007). Other studies categorize therapy-related costs as (special) education costs (Järbrink, 2007; Järbrink et al., 2003; Lavelle et al., 2014). In their estimations of the ASD-related costs, Lavelle et al. (2014), for instance, considered costs for speech/language therapy and physical/occupational therapy to be education costs. One possible explanation for the classification of ASD therapy costs as (special) education costs could be that, in some countries, legislation incorporates ASD therapy into education. In the US, for instance, the federal Individuals with Disabilities Education Act (IDEA) guarantees free appropriate public education (FAPE) for every child with a disability. Note, however, that this explanation is not conclusive as even under IDEA,

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[4] For North America, Payakachat, Tilford and Kuhlthau (2018) found an increase in the use of treatment services for individuals with ASD, with the top three of the most frequently received services including speech therapy (67%), occupational therapy (50%) and behavioural therapies/services (28%) such as ABA, Lovaas therapy, (Early Start) Denver Model, and Discrete Trial Training (DTT).

ABA services are not always offered in the school context due to economic considerations and/or because the IDEA only requires schools to provide disabled children with the tools to achieve a minimum level of accomplishment (Holland, 2010, p. 1270). As such, speech and language therapy are most often offered to children with ASD in the public-school system (Sharpe & Baker, 2007; Sharpe & Baker, 2011). However, additional therapy for children with ASD to help them achieve their maximum (or at least a higher) level of personal accomplishment may well be organized in a non-school context.

A second main finding is that cost-effectiveness studies of EIBI-programmes (Jacobson & Mulick, 2000; Butter et al., 2003; Chasson et al., 2007; Cidav et al., 2017; Peters-Scheffer et al., 2012; Peters-Scheffer, 2015; Motiwala et al., 2006) reported possibly significant cost savings that can be generated by such programmes for individuals with ASD, although with the exact estimate for cost savings differing across studies. To draw conclusions, however, regarding these cost-saving estimates, the review indicates some factors that have to be kept in mind. A first factor is that studies differ remarkably in the model parameters set in the cost-benefit computations (e.g., the intensity of the therapy, the success rate of the therapy, the duration of the therapy, the hourly cost of therapy, etc) which makes comparing cost-benefit estimates across studies difficult. As an illustration, in cost-benefit analysis of EIBI-therapy, Chasson et al. (2007) and Peters-Scheffer (2015) set different duration periods (after 36 months vs. after 27 months of EIBI therapy) and different rates of children with ASD stream into regular or less intensive special education after such therapy (72% vs. 63%). Marcus, Rubin and Rubin (2000) illustrated the importance of the method and the parameters set in the cost-benefit calculations. In particular, in a study of the parameters set by Jacobson and Mulick (2000), they raised several questions about the assumptions made by Jacobson and Mulick (2000) and discussed how Jacobson and Mulick’s modelling choices may have impacted the results of their study. A second factor is that, as indicated by Peters-Scheffer et al., 2012 p. 1764), most studies used high effectiveness rates in the modelling of the outcomes/effectiveness of the EIBI-programmes. Peters-Scheffer et al. (2012) give as an example the study of Chasson et al. (2007) which estimated costs and benefits for the state of Texas across 18 years of education with EIBI, using effectiveness rates for EIBI as obtained from studies with the most positive EIBI outcomes (i.e., 72% of children who receive EIBI eventually mainstreaming into regular education). Peters-Scheffer et al. (2012) discussed that the study of Motiwala, Gupta and Hon (2006) is an exception as it used somewhat more conservative effectiveness rates in the cost-effectiveness analysis of IBI to all autistic children in Ontario (respectively 30%, 50% and 20% streaming into regular education, less intensive special education, intensive special education after intensive behavioral intervention vs. 25%, 25% and 50% after receiving no such treatment).[5] Notwithstanding this exception, Peters-Scheffer et al. (2012) noted that the effectiveness rates used by most studies are probably too positive. Therefore, in order to obtain more realistic cost-benefit estimates of EIBI programmes, they noted that it would be interesting for future studies to consider both optimistic and pessimistic effectiveness rates of such programmes in the computation models.

A third key finding relates to the variation in the use and costs of treatment and therapy services across the lifetime of individuals with ASD. Generally, studies showed that the ASD therapy costs are high during early childhood, with the costs gradually decreasing as the child with ASD gets older. For the US, for instance, Cidav et al. (2013) estimated that the expenditures, measured as Medicaid reimbursements (Medicaid being a US government funded programme that helps people with low income and resources with medical costs), for mental health, social skills and behaviour modification services for people with ASD increased with age, whereas

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[5] In a sensitivity analysis carried out to address uncertainty and lack of good evidence for IBI efficacy, Motiwala et al. (2006) also tested more optimistic and pessimistic efficacy rates for IBI. Based on these parameter settings, Motiwala et al. (2006) obtained estimates of savings that are lower than the figures reported by Chasson et al. (2007) (i.e., between 34.479 and 53.720 Canadian $ per individual vs. 208,500 US $ per child as in Chasson et al., 2007).

expenditures for occupational, physical, speech and family therapy tended to decrease with age. A more detailed picture of the evolution of the expenditures/costs demonstrated that the largest changes in expenditures and use of these ASD-related services occurred between the age groups 3 – 6 and the age group 7 – 11. As noted before, one possible explanation for this change could be that, in the US, the education system organizes and finances some therapies for disabled children (and, thus, also children with ASD). This would mean that the costs for these therapies and services are no longer funded by Medicaid but by the education system or "other public or private programmes" (Cidav et al., 2013, p. 929). Similar results for the US were found by Ganz (2007), who estimated that behavioural therapies are a large cost component within the incremental costs of individuals with ASD, with costs for behavioural therapies being significantly higher for the children with ASD aged 3 – 6. As an explanation for the high therapy costs during early childhood, Ganz (2005) referred to the growing body of evidence in the literature showing that the initiation of behavioural therapies at a young age is associated with positive outcomes for children with ASD, which has led to EIBI becoming often the therapy of choice, with in several countries an increasing number of young children with ASD receiving EIBI-therapies.[6]

We conclude this section with an important general remark about the cost-benefit studies on EIBI-programmes for ASD. Several of these studies performed a cost-effectiveness analysis (CEA) to examine the cost-effectiveness of such programmes (e.g., Penner et al., 2015; Motiwala et al., 2006). In CEA-studies, typically, an incremental cost-effectiveness ratio (ICER) is used as a summary measure representing the cost-effectiveness of the respective ASD intervention or therapy programme(s). It concerns a ratio of the difference in costs (incremental cost) between the evaluated intervention programme and the comparison intervention

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[6] Several cost-effectiveness analysis studies showed that offering EIBI during the first years of childhood results, on average, in cost savings during a lifetime (e.g., Butter et al., 2003; Chasson et al., 2007; Cidav et al., 2017; Peters-Scheffer et al., 2012).

programme, divided by the difference in the effect (incremental effect) of both intervention programmes. As such, it indicates the average incremental cost for each additional unit of the measure of effect.[7] Per definition, ICERs depend on several parameters such as the time horizon that is selected for measuring the costs and the effects of the intervention programmes, the effectiveness rates for the assessed intervention programmes and the costs categories that are included in the computation of the incremental cost difference between the respective programmes (Garber & Phelps, 1997). As to the time horizon, Cohen and Reynolds (2008) and Meltzer (1997) discussed that the outcomes of CEA-studies can be sensitive to the time horizon of the analysis. Ideally, the time horizon should be defined such that it covers the entire period in which intervention-related costs and/or effects can occur. Studies with too short or too long time horizons may very well misestimate ICERs. For ASD intervention programmes, in particular, it is not always clear-cut about what is a proper time horizon to compute the costs and effects of such programmes. Motiwala et al. (2006) and Penner et al. (2015), for instance, set an upper age limit of 65 in their CEA-studies of EIBI, the reasoning being that after the age of 65, costs typically increase for all individuals (ASD and non-ASD) making it difficult to attribute costs solely to the effects of ASD. The definition of the effectiveness rates of the assessed intervention programmes is a second intricate matter (see also above). As indicated above, typically, effectiveness rates are defined based on rates reported in previous literature, with most CEA-studies adopting the more optimistic effectiveness rates in the evaluation of EIBI-programmes. Moreover, it is not always straightforward to compare effectiveness rates as intervention programmes can differ in terms of intensity, duration, format, etc. A third important parameter is the selection of cost categories that are to be considered in the

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[7] It is discussed in the literature (e.g., Garber & Phelps, 1997) that ICERs can be useful as a decision rule in resource allocation particularly for making decision about (relatively new) intervention and/or therapy programmes that are costly but generate improved effects over time. ICERs can be compared with an a priori established cost-effectiveness threshold (i.e., willingness-to-pay value per unit of effect) in order to decide whether the new intervention is an efficient use of resources.

computation of the incremental cost differences. ICERs can differ depending on whether costs and effects are considered from government perspective, societal perspective, or both (Bambha & Kim, 2004). In addition, ICERs of ASD intervention programmes as computed by CEA-studies always depend on the comparison intervention/scenario. By result, it makes little sense for other ASD cost studies to use ICERs of previous studies if examined ASD intervention programmes (and comparison programmes) are not sufficiently similar. Given all the intricacies involved in the assessment and the measurement of the incremental costs and the incremental effects, it is clear that both the adopted ICERs as well as the outcomes of the CEA-studies of ASD intervention programmes should be interpreted with caution (and expertise).

< Insert Table 2 here >

3.3.Education costs

Whilst some children with ASD can attend regular education without much further assistance, most children with ASD require special education or at least extra special education services in regular education. A minority of children with ASD attend residential schools.[8] Several studies have estimated the annual and/or the total education costs for children or adolescents with ASD. Most of the studies focused on the US and the UK. Only a few studies have estimated education costs in other countries. Exceptions include Järbrink (2007) for Sweden and Peters-Scheffer et al. (2012) and Peters-Scheffer (2015) for the Netherlands. The details on the data sources and the education costs estimates for the reviewed studies can be found in Table 3. Below we focus on key findings and (dis)similarities between the different studies.

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[8] Amendah et al. (2011) found that residential schools are more common for children with ASD in Sweden compared to children with ASD in the US.

A first observation is that it is difficult to compare the calculations and estimations of ASD-related education costs that are done by US studies (i.e., Ganz, 2007; Chasson et al., 2007; Lavelle et al., 2014), the main reasons being the differences between these papers about what costs are considered as ASD-related education costs as well as the level of detail in the provided cost estimates. Studies like Lavelle et al. (2014) included a very broad set of services and activities in the education services category, such as speech/language therapy, physical/occupational therapy, vision therapy, social worker services, personal health aid support, community-based training services and summer school services. Similarly, Chasson et al. (2007) estimated the special education costs of ASD, thereby accounting for the costs of a large assortment of educational and therapeutic techniques for children with ASD that are used in various ways across school districts in the US. In the estimations, the authors distinguished between actual and state-budgeted costs for special education. The actual costs of special education include both the state-budgeted costs as well as local, federal and private funds for special education. Ganz (2007), on the other hand, estimated the education costs for children with ASD by averaging multiple cost estimates found in the literature. As to the second reason, Lavelle et al. (2014) reported estimates for ASD-related education costs for different types of special education for children with ASD whereas other studies like Ganz (2007) estimated the education costs for children with ASD more generally.[9]

A second observation is that it is more straightforward to compare the estimates of ASD-related education costs that are provided by UK studies such as Knapp et al. (2009), Järbrink and Knapp (2001), Järbrink et al. (2003), and Barrett et al. (2015), the reason being that these studies focus

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[9] Lavelle et al. (2014) provided detailed estimations of ASD-related education costs by distinguishing between eleven mutually exclusive school placement categories for children with ASD based on type of school (public, private day, residential, home and other), type of classroom (special or general education) and age (preschool age (3- to 4-year olds) or school age (5- to 17-year olds)). The (regression-based) analysis revealed large different estimates of education costs for children with ASD depending on the type of school placement category the child with ASD attended. Based on the cost estimates, Lavelle et al. (2014) concluded that education was the biggest cost category in the total cost for children with ASD.

on the education costs that are directly related to ASD, thus, ignoring non-direct costs such as the costs of regular education (which is also used by typically developing children and, thus, cannot be attributed to ASD directly). Notable exception is the study of Barrett et al. (2012) which included both the costs of regular and specialised education as well as childcare costs in their calculations of education costs for very young children with ASD (ages 2-4). Most of the UK-studies also focused on calculating the ASD-related education costs for children with ASD (only Barrett et al. (2015) examined the ASD-related education cost for adolescents with ASD). A general finding for the UK-studies is that education costs that are directly related to ASD are higher for children with ASD and intellectual disabilities as compared to children with ASD without intellectual disabilities and adolescents/adults with ASD. Estimation results also showed that for children with ASD, both with and without intellectual disabilities, special education cost was the highest cost element analysed in the study. As a possible explanation, Järbrink et al. (2003) pointed out that (young) children with ASD are more frequently enrolled in EIBI-programmes (which are often intensive and, thus, expensive programmes, see previous section). For adults with ASD living in a private household, day care and respite services were amongst the highest cost elements. Another interesting finding was that education costs account for roughly 90% of the total service costs for adults with ASD (Barrett et al., 2015) whereas this cost share is only 45% for children with ASD. As discussed by Barrett et al. (2015), the reason for this difference in estimated cost share is that young children with ASD require much more community health and social/community services (e.g., general practitioner visits, community pediatrician visits, speech and language therapy and social worker visits) as compared to adults with ASD.

For Sweden, Järbrink (2007) included different types of special education, speech therapy, personal assistance within the school, school transport, aid and special diet in the estimates of the estimates of ASD-related education costs. This study found that education costs as well as community support costs contributed most to the total additional cost for children with ASD. Peters-Scheffer (2015) and Peters-Scheffer et al. (2012) estimated the education costs for the three types of education provided to children with ASD (depending on the severity of the ASD) in the Netherlands: regular education, less intensive special education, and intensive special education. Total education costs for less intensive special and intensive special education for children with ASD were estimated to be approximately 70% and 175% more expensive respectively in comparison to regular education.

< Insert Table 3 here >

3.4.Costs of production loss for individuals with ASD

In 2015, the United Nations estimated that more than 80% of adults with ASD are underemployed or not employed at all (United Nations Department of Public Information, 2015). Jacob et al. (2015) stated that 50 – 75% of adults with ASD are unemployed. As the main reason for this high number, the authors pointed out that individuals with ASD experience difficulties in obtaining and maintaining competitive employment due to, among other things, issues of social interaction and communication with supervisors and colleagues. Jacobs et al. (2015) discussed several costs of people with ASD being unemployed. This involves costs for the government, society, employers as well as individuals with ASD themselves. Examples include societal cost of adult care for unemployed adults with ASD and a lower life quality of individuals with ASD as a result of being less independent, not having a sense of purpose and decreased cognitive performance.

The few studies that have focused on estimating the costs of having a high number of individuals with ASD being unemployed, focused predominantly on the cost of production loss. Ganz (2007) estimated the economic value of lost or impaired wages, benefits and household services for individuals with ASD in the US. Järbrink and Knapp (2001) and Knapp et al. (2009) estimated the costs of lost productivity due to ASD for the UK. Buescher et al. (2014) estimated the cost of lost productivity for people with ASD in both the US and the UK. For the US, the assumption was made that 40% of adults with ASD were either in full- or part-time employment. For the UK, in line with Knapp et al. (2009), Buescher et al. (2014) assumed that 15% of the individuals with ASD without intellectual disabilities were employed full-time. As for adults with ASDs and intellectual disabilities, the assumption was made that no adults were in open employment. A general finding in all these studies was that the cost of lost employment/productivity is one of the highest cost elements for an adult with ASD. Ganz (2007) computed that this cost component accounts for 30.7% of the total discounted lifetime costs for adults with ASD.[10] For individuals with high functioning ASD, Järbrink and Knapp (2001) computed that the cost of lost productivity accounts for 17.5% of the total lifetime cost, a cost share that is lower than the one found for the average adult with ASD, yet that is still substantial.[11]

< Insert Table 4 here >

3.5.Costs of informal care and lost productivity for family/caregivers

Several studies have shown that parents, family members and caregivers of individuals with ASD sustain several financial consequences and income-related losses. Using data collected from a national telephone survey in the US, Kogan et al. (2008) showed that most of the American families of children with ASD were impacted by their child’s disorder, with 57.1%

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[10] It is important to note that Ganz (2007) assumed that the cost of lost productivity for individuals with ASD and additional learning disabilities was assumed to be zero. The authors emphasized that this cost figure of zero did not correspond to the real cost figure but was merely due to a lack of available information.

[11] Based on findings of previous studies, Järbrink and Knapp (2001) assumed that individuals with high functioning ASD work in low-skilled, low-paid jobs, often despite a high level of education. For this group, the cost of lost productivity was estimated based on gross wages according to the human capital method (Järbrink & Knapp, 2001, p. 9).

of these families stating that “family members had to reduce or stop employment because of the child’s condition”. The survey data also revealed that 34.9% of the families with children with ASD said that they “needed additional income to cover the child’s medical expenses” (Kogan et al., 2008, p. e1153). While some papers tried to estimate the cost of the lost employment for parents and caregivers, other papers focused more on the estimation of the costs of informal care that was provided to individuals with ASD. As with the previous cost components, most of the studies were conducted for the UK and the US. Table 5 gives an overview of the studies and the detailed cost estimates.

Most of the studies found that the costs of informal care and lost productivity for family/caregivers are substantial and that this cost component makes up a large part of the overall (lifetime) costs related to ASD. For instance, for both the UK and the US, Buescher et al. (2014) found that the cost of lost productivity for parents of children with ASD was one of the biggest contributors to total costs for children with ASD. For Australia, Horlin et al. (2014) even estimated that this cost component made up 89% of the total family cost of ASD. For the US, Ganz (2007) concluded that the costs of the productivity loss of parents of a child with ASD were 28.6% of the total discounted lifetime costs of ASD. A few studies, like Järbrink and Knapp (2001), Barrett et al. (2012) and Järbrink (2007), found relatively small cost estimations for lost productivity and informal care and concluded that these costs constitute only a small portion of the overall total lifetime cost for ASD. Barrett et al. (2012), for example, calculated that this cost made up only 8.92% of the total costs related to ASD. However, both Järbrink and Knapp (2001) and Järbrink (2007) pointed out that their cost estimates for productivity loss and/or loss of leisure time are probably underestimating the real costs of these losses, the reasons being the use of conservative parameters for time losses and the exclusion of other types of productivity losses (e.g. diminished promotion opportunities, early retirement, etc.) in the cost estimations

The figures in Table 5, however, also show large variation in the estimated costs across studies. A review of the papers pointed out a number of reasons which explain for this variation. Firstly, no doubt some of this variation is explained by the different dates on which the studies were conducted as well as by the fact that studies have been performed in different countries. Secondly, it is very likely that some of this variation is due to different cost estimation method being used across studies. As to the former, different methods were used in the literature to estimate the costs of income losses due to lost productivity for the parents, family members or caregivers of children with ASD. Some studies (Montes and Halterman, 2008; Cidav et al., 2012) used regression-type analyses to estimate these costs. As an example, Montes and Halterman (2008) employed ordinal logistic regression analysis to estimate the expected household income of families with children with ASD and families without a child with ASD, thereby controlling for a set of independent variables such as average parent age, type of family (2-parent family or other type), race, level of parental education, urban or rural living area, ASD status, and other disability status. The logistic regression results were used to estimate the loss of income associated with having a child with ASD. Cidav et al. (2012) combined logit and tobit models to estimate the effect of having children with ASD on parental labour force participation and parental earnings. Other studies such as Barrett et al. (2012), Horlin et al. (2014), Järbrink et al. (2003) and Järbrink (2007) used questionnaire and/or interview data as collected among parents or families with ASD children to estimate the time they had lost on paid work, unpaid work and leisure due to their child's ASD diagnosis, etc. In such questionnaires/interviews parents, family members or caregivers were asked whether their employment status was affected by their child's ASD diagnosis. Although the use of questionnaires and interviews surely has some advantages (e.g., collection of quantitative and/or qualitative data among the target group), Järbrink et al. (2003), for instance, noted that generally parents of children with ASD found it difficult to give an accurate indication of time spent on different informal care activities or to identify the number of hours spent on informal care activities due to the ASD-disorder of their child. Illustrative of this was the large standard deviation for time lost on unpaid work as indicated by parents. Obviously, the use of less accurate time loss data will lower the accuracy of the cost estimates. A third factor is that the modelling parameters being set in the cost estimations, differ across studies. The review showed that studies used different parameters for the labour force participation rate of parents of children with ASD, for the time loss incurred by the parents due to the ASD-condition of their child, the value of one hour of paid work and one hour of unpaid work and leisure, etc. As an illustration, using questionnaire and diary data as collected among parents with a child with ASD in the UK, Järbrink et al. (2003) found that parents estimated time loss due to their child's ASD-condition on paid work to be on average 22 hours per week and on leisure activities to be on average 17 hours per week.[12] However, much lower time loss figures were reported by Buescher et al. (2014) who, following insights of Cidav et al., (2012), assumed that parents of children with ASD (≤ 18 years) in the UK worked on average 7 hours less per week as compared to parents of children without ASD.

In sum, although the resulting costs estimates vary among the studies, overall cost estimations show that parents, family members and caregivers of individuals with ASD sustain high costs due to productivity loss, loss of labour income and loss of leisure time related to ASD of their child. In addition, a general finding is that these costs are one of the biggest contributors to total ASD-related costs for families with children with ASD. Studies highlighted multiple reasons for the high income loss and productivity loss suffered by parents, family or caregivers with an ASD child. Montes and Halterman (2008), for instance, referred to the following three issues: (1) poorer-than-expected labour market performance, (2) lower-than-expected labour

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[12] Similar time loss figures were found by Järbrink (2007) for Sweden, with parents reporting that they spend on average 977 hours per year on caring for their child with ASD.

participation, and (3) lower-than-expected savings and investment (Montes & Halterman, 2008, p. e824). Cidav et al. (2012) identified the diversity of care that children with ASD require and how this makes it difficult for parents and particularly mothers of children with ASD to balance the management of this care and their professional career.

< Insert Table 5 here >

3.6.Costs of accommodation, respite care, and out-of-pocket expenses

The cost of accommodation and residential care for individuals with ASD is rarely estimated in the literature. Nonetheless, for individuals with ASD who do not live at home with their family, the accommodation cost can represent a large element in the total costs related to ASD. In this section, we look at the few studies that have estimated the ASD-related accommodation and residential care costs. We also briefly look at estimates given for some other costs related to ASD. This concerns, among other things, costs for respite care and out-of-pocket expenses made by parents (families/caregivers) for children/adults with ASD. Table 6 presents a summary overview of the studies, their data sources and cost estimates for accommodation, respite care, and out-of-pocket expenses related to ASD.

A first general finding is that the cost estimates vary depending on whether it concerns accommodation and residential care for children with ASD or adults with ASD, and whether it concerns accommodation and residential care for individuals with ASD and intellectual disabilities or individuals with ASD without intellectual disabilities. Overall cost estimates show that the costs for accommodation and residential care are higher for adults with ASD as compared to children with ASD, the reason being that a large majority of the children with ASD are living at home. Buescher et al. (2014), for instance, assumed that only 1% of the American children with ASD aged 0 – 5, and 5% of the American children with ASD aged 6 – 17 used residential care (Buescher et al., 2014, p. 723). For Sweden, Järbrink (2007) found similar low percentages, with only 6% of the children with ASD in their sample living in home placement settings. In addition, cost estimates for accommodation and residential care are higher for individuals with more severe ASD, the main reason being that these individuals have a higher need to live in supported accommodation and residential care. For adults with ASD in the UK, for instance, based on findings of previous studies, Buescher et al. (2014) modelled that of the adults with ASD without intellectual disabilities, 16% lived in residential care, 5% in supported accommodation and 79% at home, whereas for adults with ASD and intellectual disabilities, these percentages were respectively 24% (residential care), 27% (supported accommodation), 1% (hospital), and 48% (at home) (Buescher et al., 2014, p. 723).[13]

< Insert Table 6 here >

As for the cost estimations of respite care and out-of-pocket expenses related to ASD, it is not straightforward to compare and interpret the cost estimates of previous studies due to differences in the selections of cost elements. For the estimation of the family out-of-pocket expenses related to ASD, for instance, Järbrink and Knapp (2001) included home improvements or adaptations, consumer durables, special nursing equipment, extra household items, cleaning, repairs, and transports (Järbrink et al., 2001, p. 16). In another study, Järbrink et al. (2003) included, amongst other things, damage, special dietary requirements, clothes, extra laundry, extra help, transport, special activities, additional costs for therapy/education, extra costs for siblings, and court cases/solicitor (Järbrink et al., 2003, p. 399). In their study of parents' out-of-pocket expenses related to ASD, Barrett et al. (2012) included adaptations and security for the home and garden, replacement and repair of damage to house and contents, specialist

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[13] In another cost estimation study for the UK, Knapp et al. (2009) reported similar percentages, i.e. a higher percentage of adults with ASD and intellectual disabilities living in supported living accommodation (7% vs. 5%), in residential care (52% vs. 16%), and in a hospital (6% vs. 0%) as compared to adults with ASD, yet, without intellectual disabilities (Knapp et al., 2009, p. 320).

equipment such as pushchairs and toys, attendance at seminars and training courses, travel to receive health services and assessments abroad, and smaller items such as nappies, bedding, education materials, additional clothing and specialist diets (Barrett et al., 2012, p. 800). Another issue is that cost estimates of ASD-related out-of-pocket expenses may not always be accurate, the reason being that parents forget certain expenses when estimating the expenses retrospectively. As an illustration, Järbrink et al. (2003) found that when parents were asked to estimate the cost of these expenses on a weekly basis in a questionnaire, the average cost was £ 65.91. However, when looking at the out-of-pocket expenses filled out by parents in a diary, the average weekly out-of-pocket expenses turned out to be £ 100.15 (both in 1999 – 2000 £).

To summarize, only a few studies have estimated the costs of (supported) accommodation and residential care and other out-of-pocket expenses. Despite the difficulties in estimating these costs (as reported by some of these studies) and the limited comparability of these cost estimates, studies do show that, generally, for individuals with ASD who do not live at home or with family, the cost of accommodation or residential care can represent a large cost element in the total costs related to ASD. As an example, for the UK, Järbrink and Knapp (2001) concluded that for individuals with ASD and intellectual disabilities as well as for individuals with high functioning ASD, the cost of (supported) accommodation and/or residential care was the biggest cost element in the total lifetime costs for an individual with ASD, accounting for 72.6% and 39.8%, respectively. As for the cost estimates of ASD-related out-of-pocket expenses, studies show that these expenses can become a financial burden for individuals with ASD and their family and, therefore, should not be ignored when reviewing costs related to ASD.

4. Conclusions

About 50 papers were reviewed in this literature review about costs related to ASD. Even though most papers regarding ASD-related costs originated in the US and the UK, this literature review tried to take a broader view, by including papers from the Netherlands, Sweden, Australia, Canada, Egypt, and China. The review was organized into six categories of ASD-related costs: *(i)* medical and healthcare related service costs, *(ii)* therapeutic costs, *(iii)* (special) education costs, *(iv)* costs of production loss for adults with ASD, *(v)* costs of informal care and lost productivity for family/caregivers, and *(vi)* costs of accommodation, respite care, and out-of-pocket expenses.

A recurrent finding was that it is not straightforward to compare the cost estimates across studies. No doubt, one of the reasons for this is that the cost estimation studies differ in the use of data sources, the categorization of cost components, the inclusion and/or exclusion of cost elements, the research method and/or modelling parameters, the period of study, etc. In the selection of the papers for this review, only limited selection criteria were imposed as to how cost data were collected, which cost estimation technique was used, and/or how cost estimates or figures were reported. The advantage of imposing limited selection criteria is that the selection of papers presented in the paper is broad and comprehensively covering the literature on costs of ASD. The disadvantage is that it is not always straightforward to compare findings across papers and/or countries. However, a second and very likely more important reason for why it is difficult and complex to compare and interpret estimations of ASD-related costs across studies, are the differences in how countries organize (or, have organized, given that changes may have occurred during the period 2000-2018) the health care system as well as the financing of that system.[14] These organizational differences typically translate into different ASD policy

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[14] Another possible reason for the cross-country differences in ASD-related costs are the differences in ethno-racial and demographical diversity across countries. For instance, Shattuck et al. (2012) provided empirical evidence which suggests the presence of racial and/or demographical disparities in access to health services across a wide range of health conditions and service systems.

plans and intervention programmes being provided, different financial support mechanisms being available for ASD individuals, etc. Illustrative is the US where typically a higher percentage of GDP is spend on health care as compared to any other country, which of course influences the national absolute ASD cost values. In a study of the aggregated national costs for ASD for the UK and the US, Beuscher et al. (2014) nicely illustrated the impact of the different approaches to organizing and financing the health care system and the education system on the estimates of total ASD costs as well as the contribution of the different cost components. Even though the lifetime cost of supporting an individual with ASD for the US and the UK were largely similar (i.e., $2.4 million and $2.2 million for an individual with ASD and intellectual disability in the US and the UK, and $1.4 million and $1.4 million for an individual with ASD without intellectual disability), it was found that the relative contributions of the costs components to the total lifetime cost of supporting an individual with ASD differed considerably across both countries, with, for the US, 79% of the ASD costs being accounted for by services, 12% by the productivity costs for the ASD-individual, and 9% by caregiver time costs and, for the UK, 56% of the total ASD-costs being accounted for by services, followed by lost employment for the individual with ASD (42 %) and caregiver time costs (2%).

The observation that countries differ in the organization of the health care and education system as well as the financing of those systems, and that such differences complicates comparisons of ASD cost figures across countries, also holds for the EU. In a recent study, Roleska et al. (2018) found that in the EU, under the subsidiarity principle, education and disability policies remain within the competence of EU Member States, with educational standards and provisions for individuals with ASD being determined and implemented at the national level (and, in several countries, even at the sub-national, regional level). Looking at the country policies in the field of education, special education needs and disability, they found that Poland, for example, does not have an autism specific strategy whereas other countries such as the United Kingdom and

Spain have tailored policies and plans for ASD individuals to promote, among other things, inclusive education for ASD children. But also within countries, at the local level, systems can vary considerably in policies regarding services for which children with ASD are eligible, the efficiency and the effectiveness of these services, and hence the ASD-related costs.[15] As an example, Mandell and Palmer (2005) explored the variation among the 50 US states in the administrative prevalence of ASD and factors associated with that variation. Using data for the year 2000-2001, they found that the proportion of children being diagnosed with ASD ranged significantly across the US states (from 0.6 per 1,000 to 4.6 per 1,000).[16]

The comparison issues notwithstanding, this review study revealed some interesting and important insights. Firstly, one key finding was that ASD is associated with a high financial burden in a multitude of domains, resulting in overall lifetime costs of ASD for the average individual with ASD (or family with a child with ASD) that are substantial. Based on the studies reviewed, the overall lifetime costs for individuals with ASD are estimated to be situated somewhere between $ 2.4 million (in 2011 US$) (Buescher et al., 2014) to $ 3.2 million (in 2003 US$) (Ganz, 2007) for the US and from £ 1.5 million (in 2011 £) (Buescher et al., 2014) to £ 2.4 million (in 1997 – 1998 £) (Järbrink & Knapp, 2001) for the UK. As a total figure for the US, Leigh and Du (2015) estimated annual direct medical, direct non-medical, and productivity costs combined to be $268 billion (range $162–$367 billion; 0.884% – 2.009% of GDP) for 2015 and forecast this cost to be $461 billion (range $276–$1011 billion; 0.982% – 3.600% of GDP) for 2025. Moreover, as pointed out by some studies, reported cost estimation

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[15] With *efficiency* we refer to the link between inputs and outputs of ASD services (e.g., how do the resources invested in the organization and implementation of EIBI programmes relate to the number of young children with ASD effectively being able to enter in such programmes), whereas with *effectiveness* we refer to the link between the outputs and the outcomes of ASD services (e.g., how does the number of people being provided with the organized EIBI programme relate to the total number of dependency-free life years (DFLYs) generated by this programme).

[16] A linear regression analysis revealed that the cross-state variation in the administrative prevalence of ASD relate to characteristics of the education and health system with the administrative prevalence of ASD being positively associated with education-related spending as well as the number of paediatricians and the number of school-based health centers in the state.

figures are likely to underestimate true ASD-related costs due to omitted health impacts, omitted economic impacts, omitted impact on social life, and the costs of health actions in other sectors.

A second key finding is that, for the six cost categories studied in the review, estimated costs are higher for individuals with ASD and/or families with children with ASD than other individuals/families. In addition, the estimates of ASD-related costs generally show that costs are higher for individuals with more severe ASD. For instance, costs across the different categories have been found to be higher for individuals with ASD and intellectual disabilities than individuals with ASD without intellectual disabilities (or for families or caregivers with such individuals). Related to this, a recent EU-wide survey of the costs of ASD (ASDEU, 2018) found that type of ASD, age, and comorbidities –intellectual disability especially – are important drivers of the costs of ASD. One reason for this is that individuals with more severe ASD require more medical and healthcare, intensive (early) behavioural treatment, therapy and special education during their childhood. Another reason is that individuals with more severe ASD have a higher need to live in supported accommodation and residential care during adulthood. Parents of children or adults with more severe ASD also sustain higher costs due to productivity loss, loss of labour income and loss of leisure time related to the ASD of their child.

A third general finding was that the cost of (special) education, EIBI and therapy, individual productivity loss, parental productivity loss, and (supported) accommodation and residential care are among the largest contributors to total lifetime costs for an individual with ASD. The recent anonymous online survey for children and adults with ASD organized across multiple EU-countries in a large-scale project (ASDEU, 2018), found similar results, with the cost of special education services being the highest cost component, followed by the costs of tutorial support, especially among younger people with ASD. Medical and healthcare costs related to

ASD have been found to constitute only a small part of the total costs for individuals with ASD, with medical costs being higher for adults with ASD than for children with ASD. Estimates also show that smaller out-of-pocket expenses related to ASD, such as travel costs, cost related to making the house more ASD-friendly, purchase of specialised tools or equipment, etc., cannot be ignored when analysing the costs related to ASD. Summed together, all these out-of-pocket expenses can place a significant financial burden on the family budget. As to the costs of ASD-related therapies, due to the differences in therapy categorization and widely divergent cost estimates for ASD therapies, it is difficult to get a clear picture of the costs of therapy and/or EIBI programmes for individuals with ASD. Nevertheless, the studies that assessed the cost-effectiveness of EIBI for (young) children with ASD found that such therapy programmes are cost-effective and can result in cost savings throughout the lifetime of individuals with ASD.

We conclude the paper with three important remarks. A first important remark is that the present review paper does not discuss all cost elements of ASD. Other ASD-related costs include the costs of vocational rehabilitation programmes (Cimera & Cowan, 2009, 2011), the costs of universal or high-risk screening for ASD (Yuen, Carter, Szatmari & Ungar, 2018) and private insurance premiums for individuals with ASD. For instance, Cimera and Cowan (2009) estimated the costs of vocational rehabilitation programmes for individuals with ASD as well as for non-ASD individuals with similar disabilities using data collected from the federal US Rehabilitation Services Administration “911” database for the period 2002-2006. Estimates showed that compared to all other disability groups in the study, individuals with ASD were among the most expensive in terms of cost per capita for vocational rehabilitation ($ 2,992 per capita, in 2006 US$). In fact, only the per capita cost for individuals with sensory impairments was higher. Among the individuals with ASD, individuals with ASD and learning disabilities or sensory impairments had higher costs for vocational rehabilitation services.[17] In a related study, Cimera and Burgess (2011) found that individuals with ASD who had their cases closed by government-operated vocational rehabilitation agencies and worked in the community, generated more monetary benefits than monetary costs (i.e. average benefit-cost ratio of 5.28 and monthly net benefit of $643.20). Another cost element is the impact of ASD coverage on private insurance premiums. Using the Pennsylvania legislation as an example, Bouder, Spielman and Mandell (2009) estimated this impact to be approximately 1%, with a lower bound of 0.19% and an upper bound of 2.31%. Also interesting is the link between insurance type (private vs. public funded) and costs, accessibility, and use of health care services, medication costs, and therapy services for children/adolescents/adults with ASD (e.g., Young, Ruble & McGrew, 2009; Wang, Mandell, Lawer, Cidav & Leslie, 2013).

A second remark concerns how costing estimates changed over the years and what has driven these changes. We note that it is difficult to say whether estimates of ASD costs made by studies in first decade of the 21st century (even when the cost figures are inflated to the present) are still comparable with and/or representative for the ASD costs today, given the increasing trend in the number of people being officially diagnosed with ASD, better public and medical awareness for ASD, improved possibilities to diagnose children at a young age, changes in the organization and the financing of the health care system and the education system (with, e.g., in a lot of countries more provision of (special) education and EIBI for (young) children with ASD), or a combination of those factors. In that perspective, the literature would benefit from longitudinal study designs that investigate how costs of ASD (as well as the relative contributions of the different cost elements) have evolved over time and look at (and explain)

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[17] As a possible explanation for this higher cost figure, Cimera and Cowan (2009) pointed out that the proportion of individuals with ASD is small (0.55% in 2006) in the overall vocational rehabilitation population. Vocational rehabilitation counsellors might thus be unfamiliar with the ASD population and their unique needs. This could result in a ‘trial and error’ method of providing services” (Cimera & Cowan, 2009, p. 298), which increases the cost of vocational rehabilitation.

how changes in national and/or local policies for services for ASD have affected these cost estimates, etc.

As a final remark, even though the between- and within-country differences as well as changes over time in the organization of insurance policy, education system, healthcare system, etc., make it difficult to give general policy advice in terms of funding for ASD-related costs, two categories of costs related to ASD are worth mentioning when discussing policy recommendations. Firstly, generally, cost-effectiveness studies of EIBI suggests that such programmes are cost-effective and might reduce certain costs that would occur in the future without these programmes. However, the up-front cost of such programmes is very large and, as demonstrated by multiple articles, this might result in parents not being able to offer their child with ASD such a treatment or might result in using EIBI programmes only for a limited number of hours per week. Making EIBI programmes available for as many children with ASD as possible might save governments and society at large other costs. Further research on different types of EIBI programmes and how to best deliver these programmes in order to make them as effective as possible can guide policy makers in resource allocation decisions. Another cost category that is worth mentioning is the cost of lost employment for individuals with ASD. Unemployed individuals with ASD incur high costs, such as costs for day activities and day care provision. Finding suitable employment and providing long-term support for employed individuals with ASD might reduce or eliminate other costs. However, further studies concerning vocational rehabilitation programmes for individuals with ASD might be useful in order to make these services more efficient and effective.

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Table 1: Overview of studies including different types of medical costs

Reference	Country	Data	Cost components	Main findings
Liptak et al. (2006)	US	- Cost data collected from three national surveys	In- and outpatient services, Emergency care, Physician/general practitioner, Other healthcare professionals, Pharmacy, Home healthcare	- Average total annual healthcare cost for ASD with ASD of $ 6,132 (in 1999 US$) *($ 9,242)* - Outpatient expenditures accounted for roughly 65% of annual healthcare cost.
Mandell et al. (2006)	US	- Data from 1994 to 1999 from one large county in Pennsylvania	Medicaid expenditures of children diagnosed with ASD	- Children diagnosed with ASD had on average expenditures 10 times those of other children. - Differences in expenditures largely due to differences in inpatient psychiatric care.
Croen et al. (2006)	US	- Northern California Kaiser Permanente Medical Care Program (large non-profit healthcare plan) for the period July 2003 – June 2004	In- and outpatient services, Emergency care, Other healthcare professionals, Pharmacy, Home healthcare	- Average annual cost of healthcare for children with ASD of $ 2,757 (in 2003 US$) *($ 3,763)* (adjusting for age group and gender)
Ganz (2007)	US	- Costs of medical and nonmedical care related to ASD as obtained from Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey (NHIS)	In- and outpatient services, Emergency care, Physician/general practitioner, Other healthcare professionals, Pharmacy, Home healthcare	- Incremental direct medical lifetime cost for a person with ASD of $ 305,956 (in 2003 US$) *($ 417,541)* - Total direct medical costs for the average person with ASD decrease with age - 40% of the direct medical costs are incurred before age of 21 (for a typical American, this occurs before the age of 65)
Leslie & Martin (2007)	US	- National US database comprising information on insurance claims from private insurance plans of large employers	In- and outpatient services, Pharmacy	- Average annual healthcare cost for a child with ASD of $ 5,979 in 2004 (in 2004 US$) *($ 7,948)* - Increase of 20.4% in healthcare cost estimate for children with ASD (year 2004 vs. 2000)
Shimabukuro et al. (2008)	US	- US nationwide study using the MarketScan® database	In- and outpatient services, Physician/general practitioner, Other healthcare professionals, Pharmacy	- Average incremental medical costs for children with ASD ranged from $ 4,110 – $ 6,200 (in 2003 US$) *($ 8,461 - $ 5,609)* - Medical expenditures 4.1 – 6.2 times higher for privately insured children with ASD
Cidav et al. (2013)	US	- Medicaid data from all 50 US states and the District of Columbia	In- and outpatient services, Other healthcare professionals, Pharmacy, Home healthcare	- No estimation of cost figure - Expenditures for inpatient care (2%), long-term care (4.4%) and psychotropic medication (9%) increased with each year of age for children with ASD during age period of 3–20 - Largest increase between ages 3–6 and 7–11. Outpatient expenditures increase between age period 7–16 and decline in age period 17–20

Lavelle et al. (2014)	US	- Cost data of medical and nonmedical care related to ASD as obtained from Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey (NHIS) - Data on non-healthcare utilization and expenditures obtained from a nationally representative survey among parents of children with ASD and parents without a child with ASD (control group).	In- and outpatient services, Emergency care, Physician/general practitioner, Other healthcare professionals, Pharmacy, Home healthcare	- Average annual medical cost for children with ASD of $ 3,020 (in 2011 US$) *($ 4,045)* - healthcare costs constitute 18% of the total annual incremental cost calculated for children with ASD - Out-of-pocket healthcare costs are significantly higher for children with ASD than for children without ASD (on average $ 154 *($ 206)* higher out-of-pocket expenditures per annum)
Lokhandwala et al. (2012)	US	- 2007 Health Care Utilization Project Nationwide Inpatient Sample (HCUP-NIS)	Hospitalization costs, length of stay	- Rates of hospitalizations were the highest among individuals with ASD aged 10–20 years, males - Individuals with ASD had significantly higher length of stay (6.5 vs. 4.2; $p < 0.0001$) and total charges ($ 24,862 *($ 30,110)* vs. $ 23,225 *($28,127)*; $p < 0.0001$) as compared to those without ASD.
Vohra et al. (2017)	US	- Data for adults (22–64 years) with ASD as collected from three state Medicaid Analytic eXtract (period 2000-2008), cost data in 2008 US$.	Healthcare utilization and expenditures (outpatient office visits, inpatient hospitalizations, emergency room, and prescription drug use)	- Average annual expenditure for outpatient office visits: $ 4375 *($ 5,103)* for ASD vs. $ 824 *($ 961)* for non-ASD - Average annual expenditure for emergency room: $ 15,929 *($ 18,577)* for ASD vs. $ 2598 *($ 3,030)* for non-ASD - Average annual expenditure for prescription drug use: $ 6067 *($ 7,075)* for ASD vs. $ 3144 *($ 3,667)* for non-ASD - Average annual total expenditures: $13,700 *($ 15,978)* for ASD vs $ 8,560 *($ 9,983)* for non-ASD - Presence of psychiatric and non-psychiatric comorbidity increased the annual total expenditures for adults with ASD by $ 4,952 *($ 5,778)* and $5,084 *($ 5,929)*, respectively.
Buescher et al. (2014)	US, UK	- Current data on prevalence, level of functioning combined with mean annual costs of services and support of individuals with ASDs with or without intellectual disability - Literature review	In- and outpatient services, Emergency care, Physician/general practitioner, Other healthcare professionals, Other healthcare professionals, Pharmacy, Home healthcare	- Average annual medical cost for children with ASD of $11,453 (in 2011 US$) *($12,785)* (weighted average for cost estimates stratified by age groups 0-5 and 6-17 years and the presence or absence of co-occurring intellectual disability) - Lifetime cost of supporting an individual with ASD and intellectual disability: in US $2.4 million *($ 2.7 million))* and £1.5 million *($ 2.5 million)* in UK (2011 UK £).

				- Lifetime cost of supporting an individual with ASD, without intellectual disability: in US $1.4 million *($ 1.6 million)* and £0.92 million *($ 1.6 million)* in UK
Järbrink & Knapp (2001)	UK	- Literature review and previously published studies with cost information related to ASD - Two studies by the Centre for the Economics of Mental Health (CEMH)	In- and outpatient services, Other healthcare professionals, Pharmacy	- Medication costs: £ 50 *($ 116)* per year for children with ASD and additional learning disabilities, £ 120 *($279)* per year for children with high functioning ASD (in 1997 – 1998 £) - Costs for hospital services: £ 360 *($ 839)* per year for children with ASD and additional learning disabilities, £ 480 *($ 1,120)* per year for children with high functioning ASD (in 1997 – 1998 £) - Costs for respite care, NHS community services and primary care: £ 1,916 (£ 600) *($4,468 ($1,399))* per year for children (adults) with ASD and additional learning disabilities, £ 750 (£ 300) *($1,748 ($700))* per year for children (adults) with high functioning ASD (in 1997 – 1998 £)
Knapp et al. (2009)	UK	- Multiple sources service use and cost data (e.g., Client Service Receipt Inventory, annual PSSRU compendium of unit costs) as collected from previously published papers as well as own recent studies		- Average annual cost of hospital services: for children with ASD and intellectual disabilities (£862 *($ 1,653)*for age period 4-11 and £ 1,587 *($ 3,044)* for age period 12-17), for children with ASD and no intellectual disabilities (£ 777 *($ 1,489)* for age period 4-17) (in 2005 – 2006 £) - Average annual cost of hospital services: for adults with ASD and intellectual disabilities (£ 4,588) *($8,797)*, for adults with ASD and no intellectual disabilities (£ 14,004) (in 2005 – 2006 £) *($ 26,854)*
Barrett et al. (2012)	UK	- Service use data as obtained from interviews (using CA-SUS) with parents of 152 young children with ASD on their service utilization (using CA-SUS). - Service cost data as collected from various sources such as personal communication with government departments and national surveys, NHS reference costs and mainstream retailers	In- and outpatient services, Emergency care, Physician/general practitioner, Other healthcare professionals, Pharmacy, Home healthcare	- Average total service costs (incl. education costs) were over £ 5,000 (in 2006 – 2007 £) per child per year *($9,194)*. - Average annual service cost for community, health, social and voluntary services: £ 2,050 (in 2006 – 2007 £) *($3,769)* - Average annual service cost for hospital based health services: £ 600 (in 2006 – 2007 £) *($1,104)*
Järbrink (2007)	Sweden	- Postal questionnaire filled out by parents to gather information on the service use of 33 children with ASD	In- and outpatient services, Physician/general practitioner, Other healthcare professionals, Pharmacy	- Total incremental healthcare costs per child with ASD of € 2,361 per year (in 2005 €) *($3,468)* (therapy costs and personal assistance costs not included)

		living in the Swedish municipality Härryda. - Unit cost data as obtained from service providers in the municipality		
Mendoza (2010)	Egypt	- Interviews of 165 Egyptian households representing 174 autistic family members	Direct medical costs of ASD	- No estimation of cost figure - Direct medical costs of ASD in Egypt are low as compared to the costs for their American counterparts (controlling for income and lifestyle differences between Egyptians and Americans)
Xiong et al. (2011)	China	- Survey data as collected from a sample of parents of 227 children (children with ASD, physically disabled children, mentally disabled children and children without disabilities)	Medical costs, caring costs	- Annual medical costs for children with ASD of 3767.38 RMB (base year for the monetary unit not given)

Note: cost figures in italics concern the cost figures inflated to the year 2018 and conversed into US $ (using conversion rates as on 1 January 2018)

Table 2: Overview of cost(-benefit) estimates of different types of ASD behavioural therapy

Reference	Country	Data	Type of behavioural intervention	Cost estimates
Butter et al. (2003)	US	- Studies about the effects of EIBI or behavioural intervention - Experiences with the Comprehensive Autism Center at Columbus Children's Hospital in Columbus, Ohio	Lovaas therapy	- Annual mean cost exceeds $ 60,000 (in 2003 US$) *($ 82,000)* - Cost-benefit models estimate possible significant cost savings during the life span of a person with ASD
Sallows & Graupner (2005)	US	- 24 children with ASD randomly assigned to two groups - Four-year clinical trial (treatment group: clinic-directed treatment services, control group: parent-directed group with consultation treatment services)	Lovaas therapy	- Annual mean cost exceeds $ 50,000 (in 2003 US$) *($ 68,000)* - Similar outcomes after 4 years of treatment (cognitive, language, adaptive, social, and academic measures)
Chasson et al. (2007)	US	- Previously published papers to make assumptions on therapy outcomes and cost figures	- Discrete Trial Training (DTT) as a proxy for EIBI - Parent-directed model of DTT	- Discrete Trial Training: Average yearly cost of $ 40,000 per child (in 2005 US$) *($ 51,430)* - Parent-directed model: Average yearly cost of $ 22,500 per child *($ 28,929)* - 3 years of EIBI during the first years of life more cost-efficient than special education over an 18-year period (age period 4 – 22) - Cost savings of $ 84,300 – $ 208,500 per child over an 18-year period (age 4 – 22) *($108,389 - $268,079)*
Amendah et al. (2011)	US	- Peer-reviewed literature and additional sources with cost information of care for individuals with ASD, with a focus on US	Intensive behavioural interventions	Annual cost estimate of $ 40,000 – $ 60,000 (in 2003 US$) *($ 55,000 - $ 82,000)* for intensive behavioural interventions for children with ASD prior to school age
Lavelle et al. (2014)	US	- National data from the Medical Expenditure Panel Survey linked to the National Health Interview Survey and a study-specific survey	ASD-related therapies (ABA/DTT and TEACHH method) and other family-coordinated services	- Point estimate of annual mean cost (it concerns non-medical behavioural therapies not included under either medical care or special education services) of $ 350 (in 2011 US$) *($ 391)*, with cost estimations ranging from $ 6 to $ 2,143 *($6.7 to $2,392)*, depending on the different ASD-subgroups (Asperger's, PDD-NOS, and mild, moderate and severe autism)
Cidav et al. (2017)	US	- Two-year clinical trial (treatment group: ESDM, control group: usual community care)	Early Start Denver Model (ESDM)	- The average annual cost of ESDM was estimated at $ 45,580 (in 2015 US$) *($ 48,611)* - Higher initial costs in the ESDM-group fully offset within a few years after the intervention

		- Parent interviews collected every 6 months on the service use of their ASD child - Long-term follow-up assessments conducted when the child with ASD was 6 years of age		because of reductions in other service use and associated costs
Järbrink et al. (2003)	UK	- Personal Social Service Research Unit - Previously published papers - Questionnaire and diary filled out by parents of 17 children with ASD	Early intervention therapy	- Annual mean cost of £ 7,508 (in 1999-2000 £) *($16,748)* - On average 33% of the costs of early intervention therapy paid by parents
Järbrink (2007)	Sweden	- Postal questionnaire filled out by parents to gather information on the service use of 33 children with ASD living in the Swedish municipality Härryda. - Unit cost data as obtained from service providers in the municipality	Personal assistance or support worker outside school	- Annual average cost of € 4,088 (in 2005 €) *($6,006)* (it concerns the cost of personal assistant or support worker) - Most of the children with ASD the sample were in special education
Peters-Scheffer et al. (2012)	The Netherlands	- Data obtained from reports, websites and studies by Dutch Government and Statistics Office - Rates provided by the Dutch Association for Autism and obtained	EIBI	- Total cost of € 99,967 *($140,881)* for 33 hours per week for 27 months of EIBI - Long term savings of ± € 1,103,067 *($1,554,532)* from age 3 to 65 years per individual with ASD - For the total Dutch ASD population, cost savings of EIBI are estimated at € 109.2-€ 182 billion *($128 – $214 million)*
Peters-Scheffer (2015)	The Netherlands	- Data obtained from reports, websites and studies by Dutch Government and Statistics Office - Data on intensity, duration, etc. as derived from meta-analytic studies	EIBI	- Total cost of € 101,376 *($ 142,867)* for 33 hours per week for 27 months of EIBI - Long term savings ranging from € 211,821 *($298,516)* to € 980,650 *($1,382,012)* per person with ASD (during the age period 3 – 65 years), with the cost estimate varying depending on the outcome parameters
Motiwala et al. (2006)	Canada	- Government data on the hours and costs of IBI, and costs of educational and respite services - Data on programme efficacy were obtained from the literature	(E)IBI	- Economic evaluation of expansion of IBI programme from current coverage of 1/3 ASD children to all ASD children aged 2-5 in Ontario, Canada - Total cost savings from expansion were $45,133,011 (in 2003 Canadian dollars) *($46,675,757)* - Sensitivity analyses showed mixed results depending on estimation modelling parameters

Note: cost figures in italics concern the cost figures inflated to the year 2018 and conversed into US $ (using conversion rates as on 1 January 2018)

Table 3: Overview of cost estimates of ASD-related education costs

Reference	Country	Data	Cost estimates
Ganz (2007)	US	- Costs of medical and nonmedical care related to ASD as obtained from Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey (NHIS)	- Special education costs for children with ASD declined with age from roughly $ 12,000 *($ 16,377)* per year at age 6, to around $ 6,200 *($ 8,461)* per year at ages 18 – 22 (in 2003 US$)
Chasson et al. (2007)	US	- Data for the cost estimations as obtained through personal communication with the Houston Independent School District	- Distinguish between actual and state-budgeted costs for special education - Annual state-budgeted costs for special education for the state of Texas of $ 11,000 *($ 14,143)* per child with ASD (in 2005 US$) - For the state of Texas, the actual annual costs for special education more or less $ 20,000 *($ 25,715)* per child with ASD
Lavelle et al. (2014)	US	- National data from the Medical Expenditure Panel Survey linked to the National Health Interview Survey and a study-specific survey	- Annual education costs ranged from $ 67,819 *($ 75,709)* for a child with ASD in special education in a residential school to $ 8,259 *($ 9,220)* for public regular education for a preschool-aged child with ASD (in 2011 US$) - Regression-adjusted additional education cost for children with ASD compared to children without ASD estimated at $ 8,610 (in 2011 US$) *($ 9,612)* per child per year (controlling for multiple control variables such as gender, age, household income, presence of a comorbidity not related to ASD, etc.)
Knapp et al. (2009)	UK	- Multiple sources service use and cost data (e.g., Client Service Receipt Inventory, annual PSSRU compendium of unit costs) as collected from previously published papers as well as own recent studies	- Annual cost education for child with ASD and intellectual disabilities: £ 10,326 *($ 19,801)* for children aged 4 – 11 and £ 28,606 *($ 54,854)* for children aged 12 – 17 (in 2005 – 2006 £) - Annual cost education for child with ASD without intellectual disabilities: £ 12,225 *($ 23,442)* for children aged 4 – 17 (in 2005 – 2006 £) - Annual cost education for adult with ASD and intellectual disabilities: £ 2,286 (in 2005 – 2006 £) *($4,383)* - Annual cost education for adult with ASD without intellectual disabilities: £ 2,886 (in 2005 – 2006 £) *($5,534)*
Barrett et al. (2015)	UK	- Data of Special Needs and Autism Project (SNAP) by Baird et al. (2006)	- Adolescents with broader ASD requiring less special education or residential schools: £ 8,121 *($ 14,360)* over 6 months (in 2007 – 2008 £)

		- SNAP-project studied (e.g., interviews) large cohort of adolescents with ASD and other special needs as well as typically developing adolescents. - SNAP-database: ASD-group split into childhood/core ASD group and broader ASD group	- Adolescents with childhood/core ASD requiring more special education or residential schools: £ 10,507 *($18,578)* over 6 months (in 2007 – 2008 £) - Education costs account for nearly 90% of the total costs
Barrett et al. (2012)	UK	- Service use data as obtained from interviews (using CA-SUS) with parents of 152 young children with ASD on their service utilization. - Service cost data as collected from various sources such as personal communication with government departments and national surveys, NHS reference costs and mainstream retailers	- Education and childcare costs roughly 45% of total service costs for children with ASD aged 2 – 4 (£ 1,152 over 6 months in 2006 – 2007 £) *($2,118)*
Järbrink and Knapp (2001)	UK	- Selection of earlier studies - Personal communication with National Autistic Society	- Average yearly cost of special education for children aged 5 – 19 with ASD and additional learning disabilities: £ 10,778 (in 1997 – 1998 £) *($25,135)* - Special education costs 6.1% of the lifetime cost of an individual with ASD and additional learning disabilities - Average yearly cost of special education for children with high functioning ASD: £ 7,216 (in 1997 – 1998 £) *($16,829)* - Special education costs 13.8% of the lifetime cost of an individual with high functioning ASD
Järbrink et al. (2003)	UK	- Personal Social Service Research Unit - Previously published papers - Questionnaire and diary filled out by parents of children with ASD, (recruited from an active parental organization (Parents' Autism Campaign for Education))	- Costs of early intervention programmes, classroom assistance, educational psychologists and additional school fees were included - Average weekly education costs of £ 441 (in 1999 – 2000 £) *($ 983)* for children with ASD and learning disability - Average weekly education costs of £ 71 (in 1999 – 2000 £) *($ 158)* for children with ASD without learning disability
Järbrink (2007)	Sweden	- Postal questionnaire filled out by parents to gather information on the service use of 33 children with ASD living in the Swedish municipality Härryda. - Unit cost data as obtained from service providers in the municipality	- 50% surveyed sample of children with ASD in some form of special education - Average annual education cost for a child with ASD of € 26,263 (in 2005 €) *($ 43,375)* (cost of regular education excluded) - Special training schools, residential schools and schooling at treatment home most expensive categories of special education (more than 75% of education costs)
Peters-Scheffer et al. (2012) Peters-Scheffer (2015)	The Netherlands	- Education cost data for 2007, 2008 and 2009 collected from websites, reports and studies by Dutch Government and Statistics Office	- Three types of education for children with ASD - Regular education (29% of children with ASD), less intensive special education (34%), intensive special education (37%)

	- Total education costs: Regular education (€ 114,500) *($161,363)*, Less intensive special education (€ 193,200) *($272,273)*, Intensive special education (€ 315,600) *($444,769)*

Note: cost figures in italics concern the cost figures inflated to the year 2018 and conversed into US $ (using conversion rates as on 1 January 2018)

Table 4: Overview of cost estimates of production loss for individual with ASD

Reference	Country	Data	Cost estimates
Ganz (2007)	US	- Previously published studies - Statistical data from the US Department of Commerce	- Lifetime cost (age period 3 – 66) due to lost productivity for an average individual with ASD of $ 971,072 (in 2003 US$) *($ 1,325,234)*
Buescher et al. (2014)	US, UK	- Literature review	- For the US: Annual cost for lost productivity of $ 10,718 (in 2011 US$) *($ 11,965)* for average adults with ASD - For the UK: Annual cost for lost productivity of £ 25,644 (in 2011 £) *($ 41,420)* for average ASD adult with intellectual disabilities - For the UK: Annual cost for lost productivity of £ 21,797 (in 2011 £) *($ 35,206)* for average ASD adult without intellectual disabilities
Knapp et al. (2009)	UK	- Empirical evidence of previous studies as well as own recent studies	- Average annual cost for lost productivity for individuals with ASD and with intellectual disabilities £ 22,383 (in 2005-2006 £) *($ 42,922)* - Average annual cost for lost productivity for individuals with ASD and without intellectual disabilities £ 19,785 (in 2005-2006 £) *($ 37,939)*
Järbrink and Knapp (2001)	UK	- Findings of previous studies - UK national figures on average gross wages and indirect taxes and subsidies as collected from Office for National Statistics	- Average annual loss in productivity due to early retirement of £1671*($ 3,896)* between ages of 35-65 for people with high functioning ASD (in 1997 – 1998 £) - Average annual lost earnings due to being employed in unskilled and low-paid work (despite high level of education) of £1932 *($ 4,506)* between ages of 20-65 for people with high functioning ASD (in 1997 – 1998 £, excluding indirect taxes and subsidies) - Average lifetime cost due to lost productivity for individuals with high functioning ASD of approximately £ 137,100 (in 1997 – 1998 £) *($ 319,725)*

Note: cost figures in italics concern the cost figures inflated to the year 2018 and conversed into US $ (using conversion rates as on 1 January 2018)

Table 5: Overview of cost estimates of informal care and lost productivity for family/caregivers with an ASD child/adult

Reference	Country	Data	Cost estimates
Ganz (2007)	US	- Previously published studies - Statistical data from the US Department of Commerce	- Costs of the productivity loss of parents of a child with ASD of $ 904,595 (in 2003 US$) *($ 1,234,512)* over the lifetime of an individual with ASD
Montes and Halterman (2008)	US	- National Household Education Survey – After School Programs and Activities for the year 2005	- Average annual income loss for a household with a child with ASD of $ 6,207.70 (in 2005 US$) *($ 7,981)* or roughly 14% of the annual household income
Cidav et al. (2012)	US	- 2002 – 2008 Medical Expenditure Panel Survey (MEPS) - National representative sample of US households	- Controlling for a multitude of factors (e.g., parent’s age, education level, number of children, etc.), analysis of the MEPS-data showed that, on average, mothers of children with ASD earned 56% (or $ 14,468 per year, in 2005 US$) *($ 18,602)* less as compared to mothers of children with no health limitation - No statistically significant difference in wage earnings of father of children with ASD vs. fathers of children with no health limitation - Family earnings of children with ASD are 28% ($17 763 in 2005 US$) *($22,839)* less than those of children with no health limitation
Buescher et al. (2014)	US, UK	- Review of the literature - Modelling parameters as used by Cidav et al. (2012) for the UK cost estimation	For the UK: - Annual cost of parental loss of productivity of £ 608 (in 2011 £) *($ 982)* for children with ASD aged 0 – 3 - Annual cost of parental loss of productivity of £ 5,314 (in 2011 £) *($ 8,583)* for children with ASD aged 4 – 17 - Annual cost of parental loss of productivity of £ 1,477 (in 2011 £) *($ 2,385)* for parents with adult children with ASD For the US: - Annual cost of parental loss of productivity of $ 18,720 (in 2011 US$) *($ 20,898)* for children with ASD aged 0 – 17 - Annual cost of parental loss of productivity of $ 1,896 (in 2011 US$) *($ 2,117)* for parents with adult children with ASD
Järbrink and Knapp (2001)	UK	- Findings of previous studies - UK national figures on national average disposable income by households as collected from Office for National Statistics	- Average annual cost of productivity loss for parents of children with ASD and additional learning disabilities of £ 528 (in 1997 – 1998 £) *($ 1,230)* - Average annual cost of productivity loss for parents of children with high functioning ASD of £ 192 (in 1997 – 1998 £) *($ 448)*

Järbrink et al. (2003)	UK	- Previously published papers - Questionnaire and diary filled out by parents of children with ASD, (recruited from an active parental organization (Parents' Autism Campaign for Education))	- Average cost for informal care for child with ASD incurred by parents of £ 397 per week (in 1999 – 2000 £) *($ 885)* - Average cost of income losses for parents of children with ASD of £ 231 per week per child with ASD (in 1999 – 2000 £) *($ 312)*
Knapp et al. (2009)	UK	- Previously published studies - Multiple sources on service use and cost data	- Average annual cost of productivity loss for parents of children with ASD and intellectual disabilities of £ 2,059 (in 2005 – 2006 £) for ages 4 – 11 *($ 3,949)* - Average annual cost of productivity loss for parents of children with ASD and intellectual disabilities of £ 2,015 (in 2005 – 2006 £) for ages 11 – 17 *($ 3,864)* - Average annual cost of productivity loss for parents of children with ASD and without intellectual disabilities of £ 216 (in 2005 – 2006 £) *($ 414)*
Barrett et al. (2012)	UK	- Interviews (using CA-SUS) with parents of young children with ASD - Various sources such as personal communication with government departments and national surveys	- Average cost of productivity loss for parents of young children (ages 2 – 4) with ASD over 6 month period of £275 (in 2006 – 2007 £) *($ 506)*
Horlin et al. (2014)	Australia	- Questionnaire among families with children registered as having an ASD at the Disabilities Services Commission Western Australia	- Median annual income loss for parents or caregivers of children with ASD of $ 29,200 (in 2011 AUD$) *($ 26,291)* or 29% of the combined household income
Järbrink (2007)	Sweden	- Postal questionnaire filled out by parents to gather information on the service use of 33 children with ASD living in the Swedish municipality Härryda.	- Total yearly cost of time losses for parents or caregivers of children with ASD of € 7,759 (in 2005 €) *($ 11,399)*
ASDEU (2018)	EU	- Anonymous online survey for children and adults with the condition, collecting individual data on resources and costs.	- The costs of productivity losses among carers, for six months, range from € 307.70 *($ 369)* per carer in Poland to € 4,467.40 *($ 5,360)* per carer in Austria.

Note: cost figures in italics concern the cost figures inflated to the year 2018 and conversed into US $ (using conversion rates as on 1 January 2018)

Table 6: Overview of cost estimates for accommodation, respite care, and out-of-pocket expenses related to ASD

Reference	Country	Data	Cost estimates
Ganz (2007)	US	- Previously published studies	- Cost of travel to medical appointments ranging from $ 81 *($ 111)* for children (aged 3 – 7) to $ 14 *($ 19)* yearly for adults aged 63 – 66 (in 2003 US$) - Home improvement costs ranging from $ 161 *($ 220)* for young children with ASD (ages 3 – 7) to $ 120 *($ 164)* for older children (13 – 17 years) with ASD - Home improvement costs for adults with ranging from $10 *($ 13.5)* (for ages 18 – 22) to $ 3 *($ 4)* (for ages 63 – 66) (in 2003 US$) - Respite care costs ranging from $ 1,100 *($ 1,501)* for children with ASD (for ages 3 – 7) to $ 706 *($ 963)* (for ages 18 – 22) (both in 2003 US$)
Parish et al. (2012)	US	- Child and family data drawn from the National Survey of Children with Special Health Care Needs (N = 2,082 children with autism).	- 78% of families with a child with ASD reported having any out-of-pocket health care expenditures for their child for the prior 12 month - 54% reported out-of-pocket health care expenditures of more than $500 (in 2005-2006 US$) *($ 623)*, with 34% spending more than 3% of their income.
Parish et al. (2015)	US	- Pooled 2000–2009 Medical Expenditure Panel Survey data.	- Average out-of-pocket health care (mainly medication, outpatient services, and dental care) expenditures of $9.70 per $1,000 of income *($ 11.35 per $ 1,170)*.
Buescher et al. (2014)	US, UK	- Cost estimates for residential care from previously published studies	- Additional cost for accommodation for children with ASD ranged from £ 37 – £ 1,240 (in 2011 £) *($59 - $2,003)* per year and increased with age - Annual accommodation cost per adult with ASD and intellectual disabilities of £ 41,512 (in 2011 £) *($ 67,050)* - Annual accommodation cost for children with ASD without intellectual disabilities of $ 952 *($ 1,434)* (ages 0 – 5) and $ 4,758 *($ 7,166)* (ages 6 -17) (in 2011 US$) - Annual accommodation cost for children with ASD and intellectual disabilities of $ 1,903 *($ 2,865)* (ages 0 – 5) and $ 9,516 *($ 14,331)* (ages 6 -17) (in 2011 US$) - Annual accommodation cost for adults with ASD without intellectual disabilities of $ 18,080 (in 2011 US$) *($27,229)* - Annual accommodation cost for adults with ASD and intellectual disabilities of $ 36,161 (in 2011 US$) *($54,460)*

Järbrink and Knapp (2001)	UK	- Findings, estimates and figures reported in previous studies - Information obtained by personal communication with the National Autistic Society	- Annual cost of residential care of £ 29,378 (in 1997 – 1998 £) *($ 68,511)* per individual with ASD and intellectual disabilities - Annual cost of living support per individual with high functioning ASD of £ 4,302 (in 1997 – 1998 £) *($ 10,032)* - Annual cost of day activities and day care provision of £7,793 *($ 18,174)* for an individual with ASD and additional learning disabilities - Annual cost of day activities and day care provision of £1,375 *($ 3,207)* for an individual high functioning ASD. - Annual cost for out-of-pocket expenses for parents of children with ASD of £ 2000 (in 1997 – 1998 £) *($ 4,664)* for individuals with ASD and additional learning disabilities
Järbrink et al. (2003)	UK	- Previously published papers - Questionnaire and diary filled out by parents of children with ASD, (recruited from an active parental organization (Parents' Autism Campaign for Education))	- Weekly cost for out-of-pocket expenses for parents of children with ASD varying from £ 65.91 to £ 100.15 (in 1999 – 2000 £) *($ 147 to $ 224)*.
Knapp et al. (2009)	UK	- Data on accommodation placements for children with ASD and intellectual disabilities from Children in Need (CIN) in England - Data on accommodation placements for adults with ASD as obtained from previous studies - Data on placement distribution of individuals with ASD across different accommodation settings as obtained from Professor Emerson	- Annual cost of accommodation ranging from £ 544 *($1,043)* (ages 0 – 3) to £ 1,082 *($ 2,069)* (aged 12 – 17) (both in 2005 – 2006 £) for children with ASD and intellectual disabilities living in residential or foster care - Annual cost of accommodation for adult with ASD and intellectual disabilities of £ 36,233 (in 2005 – 2006 £) *($69,479)* - Annual family expenses for adults with ASD and intellectual disabilities of £ 762 yearly (in 2005 – 2006 £) *($ 1,461)* - Annual family expenses for adults with ASD without intellectual disabilities of £ 1,494 (in 2005 – 2006 £) *($2,865)* - Annual cost for respite care for children with ASD and intellectual disabilities of £ 2,790 *($ 5,351)* (ages 4 – 11) and £ 3,559 *($ 6,825)* (ages 12 – 17) (both in 2005 – 2006£) - Annual cost for respite care for children with ASD without intellectual disabilities of £ 6,510 *($ 12,483)* (ages 4 – 17) (in 2005 – 2006 £) - Annual cost for respite care for adults with ASD and intellectual disabilities of £ 538 (in 2005 – 2006 £) *($1,032)*

			- Annual costs for day services for adults with ASD and intellectual disabilities of £ 1,998 (in 2005 – 2006 £) *($3,831)* - Annual costs for day services for adults with ASD without intellectual disabilities of £ 2,226 (in 2005 – 2006£) *($ 4,269)*
Barrett et al. (2012)	UK	- Interviews (using CA-SUS) with parents of young children with ASD - Various sources such as personal communication with government departments and national surveys	- Out-of-pocket expenses for children with ASD (aged 2 – 4) of £ 227 *($ 417)* for a 6 months period (in 2006 – 2007£)
Järbrink (2007)	Sweden	- Postal questionnaire filled out by parents to gather information on the service use of 33 children with ASD living in the Swedish municipality Härryda	- Annual cost of home placement of € 913 (in 2005 €) *($1,342)* per child with ASD - Annual cost of respite care (€ 6,843) *($ 10,052)*, camp (€ 1,839) *($ 2,701)*, domestic support worker (€ 463) *($680)*, day outings (€ 78) *($ 114)*, personal assistant or support worker (€ 4,088) *($ 6,006)*, and befriending services (€ 77) *($ 113)* (all in 2005 €)
Raz et al. (2013)	Israel	- A survey among parents of 178 children with ASD aged 4–10 years (of which 87% agreed to participate)	- Average annual out-of-pocket costs (mainly for health services and hours of therapy) of $8,288 *($ 9,252)*, with a median of $4,473 *($ 4,993)* and a range of $0-89,754 (in 2011 US$) *($ 0 - $ 100,195)*. - Higher severity of ASD associated with higher out-of-pocket expenditures.

Note: cost figures in italics concern the cost figures inflated to the year 2018 and conversed into US $ (using conversion rates as on 1 January 2018)