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COST–BENEFIT ESTIMATES FOR EARLY INTENSIVE BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM—GENERAL MODEL AND SINGLE STATE CASE

John W. Jacobson*[1], James A. Mulick[2] and Gina Green[3]
[1]Independent Living in the Capital District, Inc., Schenectady, NY, USA
[2]Children's Hospital, The Ohio State University, Columbus, OH, USA
[3]New England Center for Children, Southboro, MA, and E. K. Shriver Center for Mental Retardation, Waltham, MA, USA

Clinical research and public policy reviews that have emerged in the past several years now make it possible to estimate the cost–benefits of early intervention for infants, toddlers, and preschoolers with autism or pervasive development disorder—not otherwise specified (PDD—NOS). Research indicates that with early, intensive intervention based on the principles of applied behavior analysis, substantial numbers of children with autism or PDD—NOS can attain intellectual, academic, communication, social, and daily living skills within the normal range. Representative costs from Pennsylvania, including costs for educational and adult developmental disability services, are applied in a cost–benefit model, assuming average participation in early intensive behavioral intervention (EIBI) for three years between the age of 2 years and school entry. The model applied assumes a range of EIBI effects, with some children ultimately participating in regular education without supports, some in special education, and some in intensive special education. At varying rates of effectiveness and in constant dollars, this model estimates that cost savings range from $187,000 to $203,000 per child for ages 3–22 years, and from $656,000 to $1,082,000 per child for ages 3–55 years. Differences in initial costs of $33,000 and $50,000 per year for EIBI have a modest impact on cost–benefit balance, but are greatly outweighed by estimated savings. The analysis indicates that significant cost-aversion or cost-avoidance may be possible with EIBI. © 1998 John Wiley & Sons, Ltd.

INTRODUCTION

As expenditures for social welfare, public health, and specialized human services have increased dramatically over the past two decades, there has been an increasing impetus for understanding the costs and consequences (i.e., benefits) of

* Correspondence to: John W. Jacobson, 627 Plymouth Avenue, Schenectady, NY 12308-3507, United States.

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the investment of public resources in specific programs and services for children with, or at risk for, disabilities. Welfare reform, Medicaid reform (through such initiatives as managed care and home and community-based services waivers), and scrutiny of the rising costs of early intervention, special education, and adult disability services are all manifestations of the need to contain costs and direct resources in the most efficient and effective ways possible. In the area of early intervention and preschool services as a whole, there has been mounting concern regarding cost–benefit (Guralnick, 1998). This concern has most likely arisen because of the perceived wide variations in costs for seemingly similar services available through public providers and private contractors (see, e.g., Schopler, 1998). There are additional likely concerns that possible economies may be lost when substitute financing mechanisms (for example, Medicaid fee-for-service) are used in lieu of system-wide cost-related rates within educational or other specialized public services (see, e.g., Division of Health, 1997; Eisenhofer, Grant, DiPersio, & German, 1998).

The costs and benefits of services for young children with autism or pervasive developmental disorder—not otherwise specified (PDD—NOS, hereafter abbreviated PDD) have come under particularly intense scrutiny of late (see, e.g., Gresham & MacMillan, 1997; Schopler, 1998). Following the publication of research reports indicating that substantial proportions of children with autism or PDD who received early intensive behavioral intervention (EIBI) achieved normal or near-normal functioning (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993), demand for this intervention has increased. The research findings have been controversial, however, for several reasons: they are relatively recent; the studies are subject to methodological criticisms; they have emerged from a small number of research and service projects; and the intervention is intensive, specialized, highly directive, and expensive. Moreover, these findings have emerged at a time when leaders of some philosophical movements in special education are advocating apparently incompatible practices of unproven efficacy, especially under such rubrics as 'total inclusion' and 'developmental appropriateness' (Kauffman & Hallahan, 1995).

Direct and indirect criticisms of EIBI by some of these advocates have focused on alleged negative side effects (see, e.g., Autism National Committee, 1995a; 1995b; Greenspan & Weider, 1997; Wetherby, Schuler, & Prizant, 1997). Despite their frequent citation, these criticisms are not grounded in sound research or established facts; they involve misinterpretations of behavioral intervention, incomplete or inaccurate understanding of behavioral principles and procedures, or are otherwise suppositional and groundless (Cameron & Pierce, 1994; Eisenberger & Cameron, 1996; Lovaas, 1995; 1996; Luce & Dyer, 1996). Additionally, treatments for autism or PDD most often recommended in lieu of

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EIBI typically lack demonstrated efficacy for achieving large and lasting gains (Eaves & Ho, 1996; Freeman, 1997; Green, in press; Smith, 1993; 1996). Thus, for many clinicians and researchers, the question is not whether children with autism or PDD can achieve substantially improved functioning, but what practices lead to the best outcomes for these children and whether the methodology underpinning the research findings on EIBI is sound (see, e.g., Foxx, 1993; Guralnick, 1998; Gresham & MacMillan, 1997; Schopler, Short, & Mesibov, 1989).

This report presents a cost–benefit analysis of EIBI for children with autism or PDD. We estimate costs and benefits of services for children with autism or PDD who receive EIBI relative to those of children without disabilities in general, and children with autism or PDD who do not receive effective intervention or who otherwise continue to need intensive supports. The analysis provides a projection of cost-aversion, that is, the financial costs to society avoided through provision of EIBI services.

Prior Cost–Benefit Analysis

Although critics of EIBI stress philosophical concerns, from a public policy standpoint, the scientifically validated achievement of normal functioning by many children with autism or PDD has profound implications for analysis of the relative costs and benefits of EIBI for these children (see Barnett & Escobar, 1990, for a prospective cost–benefit analysis model). Until recently, benefits could be estimated exclusively in terms of savings that might be associated with decreased, but still persisting, dependency on special service requirements (e.g., supervision) in later childhood and into adulthood. Considering the high cost of specialized educational services for children with autism or PDD compared to regular education or to other categories of special education, potential benefits were confined to relative savings at different levels of care during adulthood. Possible savings reflected comparison of total educational, supportive, and adult services costs with and without EIBI. Because no basis was generally evident for estimating these cost differentials (such as those used by Barnett & Escobar, 1990), the cost–benefit of EIBI for these children has remained unspecified.

EIBI for Autism or PDD

First identified in the 1940s (Kanner, 1943), autism is a disorder of brain development arising before age three, and often identified by that age or shortly thereafter (Bailey, Phillips Rutter, 1996; Rapin, 1997). It is diagnosed

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behaviorally, by observing a child for qualitative impairments in three main areas: disordered social interactions, delayed or disordered communication, and restriction in range of interests and activities. It is also characterized by stereotyped behavior, such as ritualistic or repetitive acts (APA, 1994). Historically, it has generally been found that 50–75% of individuals with autism also have some degree of mental retardation (Freeman, 1997; Rapin, 1997), but the rate at which mental retardation is present among people with autism may be somewhat higher because of difficulties in ascertainment among people with profound mental retardation, and inconsistent access for young children with mental retardation to clinicians familiar with autism spectrum disorders.

The relationship between autism and mental retardation is not well understood. Some children with autism have intellectual abilities within the normal—and, in a small number of cases, the superior—range. However, research clearly indicates that children with both autism and mental retardation tend to enter adulthood with these conditions still present (Eaves & Ho, 1996; Jacobson & Ackerman, 1990; Janicki & Jacobson, 1983; Locke, Banken, & Mahone, 1994). They require lifelong care, services, and supervision. Spontaneous recovery and highly successful rehabilitation through special educational processes are very rare. Educational services for children with autism are among the most intensively staffed and expensive forms of special education available under provisions of the Individuals with Disabilities Education Act. The picture is similar for children diagnosed with PDD—NOS, which has many characteristics in common with autism.

During the past 15 years research has begun to demonstrate that significant proportions of children with autism or PDD who participate in early intensive intervention based on the principles of applied behavior analysis (ABA) achieve normal or near-normal functioning (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993) or significant gains in measured intelligence or other aspects of development (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Birnbrauer & Leach, 1993; Fenske, Zalenski, Krantz, & McClannahan, 1985). Prior to and concurrent with these studies of EIBI, more than 500 studies were published demonstrating the efficacy of numerous ABA techniques for building a wide range of skills in people with autism of all ages (according to the selection criteria used by DeMyer, Hingtgen, & Jackson, 1981; Hingtgen & Bryson, 1972; Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996). While this collection of studies does not represent a unitary program model for children with autism, in the aggregate it is the empirical foundation on which most home- and center-based EIBI programs are built.

The most comprehensive research on EIBI was published by Lovaas and colleagues at UCLA (e.g., Lovaas, 1987; McEachin *et al.*, 1993), but other

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independent investigators confirmed that it is possible for children with autism or PDD to achieve large, comprehensive, and lasting gains (e.g., Birnbrauer & Leach, 1993; Fenske *et al.*, 1985; Perry, Cohen, & DeCarlo, 1995; Sheinkopf & Siegel, 1998). It is important to note that many children in the study samples whose skills did not reach normal levels nonetheless made substantial, functional gains in several core areas, such as everyday living and communication skills. A small proportion (about 10%, across studies) appeared to continue to need intensive intervention beyond the early childhood years. Research is ongoing to better identify the specific child characteristics and instructional and programmatic practices that are related to differential outcomes in these children (Green, 1996b; Guralnick, 1998; Smith, Eikeseth, Klevstrand, & Lovaas, 1997).

With the emergence of research documenting substantial improvements for some children with autism or PDD following EIBI, and confirmatory reports that the effects can endure into later childhood (e.g., McEachin *et al.*, 1993; Perry *et al.*, 1995) and adulthood (Smith, 1998), it has become possible to estimate costs and utilization more specifically. Such estimations are aided by the compilation of costs for adult services in the developmental disabilities service sector by contemporary researchers, data that were not previously available. Thus, costs and benefits for EIBI for autism or PDD may be estimated with reasonable confidence in terms of (i) children who achieve normal functioning, participate in regular education with little or no support, and are vocationally productive as adults, (ii) children who derive sufficient benefit that they are then able to participate in less intensive special education, and evidence persisting but reduced dependency in adulthood (referred to hereinafter as partial effects), and (iii) children who achieve meaningful functional improvements but still require specialized and intensive educational and adult services (referred to as minimal effects).

In the present analyses, costs from the Commonwealth of Pennsylvania are used to develop overall cost comparisons in the calculation of cost–benefit (see appendix A). The model used by Barnett and Escobar (1990) was a prospective analysis of cost and effect associated with early intervention services for a heterogeneous group of at-risk pre-schoolers. The model used for the present analyses, in contrast, entails projection of costs based on economic extrapolations and trends in allocation of services and costs in educational and adult developmental services. Because this method entails economic forecasting rather than cost tracking, it is important to articulate the assumptions that form the basis for the present forecast. The 16 assumptions required to structure these analyses are detailed in appendix B and are indicated as analytic considerations or elements below.

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METHODS

Assumptions in the Present Analysis

The assumptions underpinning the general cost model in this paper are the following:

(i) Current research does not identify characteristics of children with autism or PDD that reliably predict their response to EIBI.
(ii) The proportion of children who achieve normal functioning in all areas is probably somewhat lower than the proportion reported in the literature to date (just under 50%).
(iii) In any group of children with autism or PDD who receive competently delivered EIBI, between 20 and 50% will achieve normal functioning; about 40% will achieve meaningful but moderate gains; and about 10% will continue to require intensive special education and adult services.
(iv) For these reasons, cost–benefit should be couched in terms of marginal benefit, as well as the attainment of normal functioning.
(v) Without EIBI the majority of children with autism or PDD will manifest enduring dependency on special education and adult developmental disability services.
(vi) The mix of costs for EIBI services used here is assumed to be a representative average for both center-based and home-based services.
(vii) Children with autism or PDD who ultimately develop normal functioning are assumed to participate in regular education; those who make moderate gains are assumed to participate in special education; and children who make minimal gains are assumed to participate in intensive special education.
(viii) Because no generalizable mortality data exist for people with autism or PDD, cost–benefit analyses including the adult years are made only to age 55.
(ix) Present costs are used as indicators of future costs, with recognition that future reforms in welfare and public health services may result either in decreased per person rates or expenditures, or in substitution of services.
(x) SSI/ADC costs are used as a summary cost for all utilization of general public benefits outside of the early intervention, educational, and developmental service sectors.
(xi) The average duration of EIBI is assumed to be three years.
(xii) Children with autism or PDD who achieve normal functioning are assumed to use family support services only during participation in EIBI;

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those who make moderate gains or realize minimal effects are assumed to use 18 years of these services.

(xiii) During adulthood, those who achieve moderate gains are assumed to use 18 years of Medicaid waiver (or equivalent) services and 15 years of supported work services. Similarly, for those who achieve minimal gains, 80% are assumed to use waiver services for 20 years, 20% are assumed to use intensive community services for 23 years, and 40% are assumed to use supported work services for 15 years.

(xiv) Supported employment wages are estimated at 20% of the median household annual income.

(xv) This analysis uses costs reported in several sources for the Commonwealth of Pennsylvania (from Table 1).

(xvi) The service costs and inflators used will tend to underestimate costs slightly; the earnings projected will tend to overestimate income slightly.

All savings shown are net of the expense of providing EIBI.

RESULTS

Gross Cost Differentials

Table 2 shows the estimated costs from age 3 years to 22 years for a non-disabled child, a child with an initial diagnosis of autism or PDD for whom EIBI

Table 1. Present (1996) costs for services and income estimates—Pennsylvania model

Estimate or variable	*Value*
Present age of the child with autism	3 years
Beginning calendar year	1996
Early intervention annual cost	$3,284
Family support services annual cost	$1,110
Intensive early intervention annual cost	$32,820
Regular education annual cost	$7,543
Special education annual cost	$12,935
Intensive special education annual cost	$28,806
Home and community based services (adult) annual cost	$31,818
Intensive community services (adult) annual cost	$46,838
Institutional services (or equivalent, adult) annual cost	$56,775
Supplemental security income/aid to dependent children annual cost (estimate for all generic public support costs)	$5,379
Median household annual income	$33,714
Supported wages annual value (% of median income)	$6,743

Note: This table presents a listing of the 1996 costs used in the analysis.

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Table 2. Estimated costs age 3 to 22 years—Pennsylvania model

	Costs with inflation	*Costs in 1996 $*
Nondisabled Child		
Eighteen years of SSI/ADC (10%)	11,768	9,682
Thirteen years of regular education	128,731	98,061
Net	(140,459)	(107,743)
Autism—with normal range effects of early intervention		
Three years of family support services	3,433	3,330
Three years of SSI/ADC	16,380	16,137
Eighteen years of SSI/ADC (10%)	11,768	9,682
Three years of intensive early intervention	101,445	98,460
Thirteen years of regular education	128,731	98,061
Net	(261,717)	(225,670)
Autism—with partial effects of early intervention		
Eighteen years of family support services	27,873	19,980
Eighteen years of SSI/ADC	117,244	96,822
Three years of intensive early intervention	101,445	98,460
Fifteen years of special education	284,916	194,025
Net	(531,478)	(409,287)
Autism—with minimal effects of early intervention		
Eighteen years of family support services	27,873	19,980
Eighteen years of SSI/ADC	117,244	96,822
Three years of intensive early intervention	101,445	98,460
Fifteen years of intensive special education	634,486	432,090
Net	(881,048)	(647,352)

Note: Table shows (expense) only. This table presents findings regarding costs to age 22 years. These include costs for regular education, family support services, SSI/ADC, intensive early intervention, and regular, special, and intensive special education. Costs are attributed according to whether a child is nondisabled, or achieves functioning in the normal range, partial benefit, or minimal benefit from EIBI. Costs are shown separately with inflation and in 1996 dollars.

results in normal functioning, a child with an initial diagnosis of autism or PDD for whom EIBI results in partial (habilitative or remediative) effects, and a child with an initial diagnosis of autism or PDD for whom EIBI results in minimal effects. Costs for nondisabled children include those for regular education and a 10% rate of use of public services (shown as SSI/ADC). Costs for the children with autism or PDD who achieve normal range effects from EIBI include these costs plus costs for family supports, public services, and intensive early intervention. Costs for the children with autism or PDD who realize partial effects from EIBI include the costs for family supports, public services, intensive early intervention, and special education. Costs for the children with autism or PDD with minimal effects from EIBI are the same as those for children with partial effects from EIBI, except that costs for intensive special education are included.

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Table 3. Costs from age 22 to age 55 years—Pennsylvania model

	Costs with inflation	*Costs in 1996 $*
Nondisabled child		
Thirty-three years of SSI/ADC and all other public benefits (10%)	(31,358)	(18,434)
Thirty-three years of wages and other income (75%)	1,768,866	801,039
Net	1,737,508	782,605
Autism—with normal range effects of early intervention		
Thirty-three years of SSI/ADC and all other public benefits (10%)	(31,358)	(18,434)
Thirty-three years of wages and other income (75%)	1,768,866	801,039
Net	1,737,508	782,605
Autism—with partial effects of early intervention		
Five years of family support services	(10,331)	(5,550)
Thirty-three years of SSI/ADC	(313,579)	(184,335)
Twenty-eight years of waiver services	(2,860,063)	(821,734)
Twenty-five years of supported work	346,982	145,121
Net	(2,836,991)	(866,498)
Autism—with minimal effects of early intervention		
Five years of family support services	(10,331)	(5,550)
Thirty-three years of SSI/ADC	(313,579)	(184,335)
Thirty years of waiver services (80%)	(2,390,031)	(610,906)
Thirty-three years of intensive community services (20%)	(948,285)	(309,131)
Twenty-five years of supported work (40%)	138,792	67,430
Net	(3,523,434)	(1,042,492)

Note: Table shows income (expense). This table presents findings regarding costs from age 22 to 55 years. These include costs for family support services, SSI/ADC, home and community based services (waiver services), or intensive community services, and income from regular or supported work. Costs are attributed according to whether a person is nondisabled, or achieves normal skills or functioning, partial benefit, or minimal benefit from EIBI. Costs (expenses) and income are shown separately with inflation and in 1996 dollars.

The sources of costs, public expenditures, are shown in Table 2 and in subsequent tables with inflation (i.e., 'Costs with inflation') and without (i.e., 'Costs in 1996 $'). Throughout the tables, net income is shown without brackets and net expenses or costs are shown with brackets. Costs with inflation are $140,459 for a nondisabled child, $261,717 with normal range effects, $531,478 with partial effects, and $881,048 with minimal effects. Corresponding present values (the amount of money invested in US treasury bonds at 6.0% annual interest at age 3 to 22 years equal to the total costs) are approximately $46,423, $86,501, $175,660, and $291,198.

Table 3 shows the estimated costs from age 22 to 55 years for nondisabled individuals, individuals with an initial diagnosis of autism or PDD for whom EIBI results in normal functioning, individuals with an initial diagnosis of autism

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or PDD for whom EIBI results in partial (habilitative or remediative) effects, and individuals with an initial diagnosis of autism or PDD for whom EIBI results in minimal effects. For nondisabled children and children with autism or PDD who realize normal range effects from EIBI, as adults, both a 10% rate of use of public services (i.e., costs) and income (e.g., wages) are included in the analysis. For adults with partial effects from EIBI, costs are shown for family supports, public services, Medicaid waiver services (including residential services), and supported work. For adults with minimal effects from EIBI, costs or income are shown for family supports, public services, Medicaid waiver services, supported work, and intensive community services.

Estimated costs with inflation are $1,737,508 for a nondisabled adult or adult initially diagnosed with autism or PDD for whom EIBI results in normal functioning, $2,836,991 with partial effects, and $3,523,434 with minimal effects. Corresponding present values (money invested in US treasury bonds at 6.0% annual interest for ages 3 to 55 years) are approximately a retained value (i.e., net income equivalent to investment) of $83,950 and costs of $137,073 and $170,240. Throughout the remainder of this analysis present value (amount of money that would have to be invested by a family at the outset to pay for services over a specified time period), uninflated value (uninflated costs to place costs in the context of the expense of current goods and services), and inflated value (the number of dollars projected to be spent) are presented to allow broad interpretation of the projected costs.

The estimates of cost in Tables 2 and 3 are consolidated in Table 4 to provide a cost–benefit model for ages 3 to 55 years. With inflation, the net income for a nondisabled individual is estimated at $1,597,049 (based on the median income value shown in Table 1) and that for an individual with an initial diagnosis of autism or PDD for whom EIBI results in normal functioning, $1,475,791; corresponding present amounts for retained value invested from age 3 to 55 are approximately $77,163 and $71,305. With inflation, the net expenditures are $3,368,469 for an individual with autism or PDD for whom EIBI results in partial effects and $4,404,482 for an individual for whom EIBI results in minimal effects, with present values of about $162,753 and $212,809. Again, these represent the amount of money to be invested at the onset of services to cover the costs of services for the entire span of time.

Costs at Differing Levels of Effectiveness

In addition to comparisons of potential costs for services to age 55 with respect to differing outcomes of EIBI, it is also important to recognize the

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Table 4. Financial cost–benefit of early intervention—pennsylvania model—ages 3–55 years

	With inflation	*Costs in 1996 $*
Nondisabled child		
Childhood costs	(140,459)	(107,743)
Adult cost or benefit	1,737,508	782,605
Net	1,597,049	674,862
Autism—with normal range effects of early intervention		
Childhood costs	(261,727)	(225,670)
Adult cost or benefit	1,737,508	782,605
Net	1,475,791	556,935
Autism—with partial effects of early intervention		
Childhood costs	(531,478)	(409,287)
Adult cost or benefit	(2,836,991)	(866,498)
Net	(3,368,469)	(1,275,785)
Autism—with minimal effects of early intervention		
Childhood costs	(881,048)	(647,352)
Adult cost or benefit	(3,523,434)	(1,042,492)
Net	(4,404,482)	(1,689,844)

Note: Table shows income (expense). This table combines net costs for ages 3–22 and 22–55 years from Tables 2 and 3. These costs are shown separately with inflation and in 1996 dollars.

varying levels of cost–benefit. Table 5 shows the estimated cost savings that accrue from EIBI services at rates of 20, 30, 40, and 50% achievement of normal functioning. At each level the marginal effects—i.e., the difference in costs between groups for normal range effects or partial effects from EIBI, or between groups for partial or minimal effects from EIBI—are aggregated for 100 people, and then disaggregated to a weighted average (i.e., in the columns titled 'student'). These estimates reflect service effects possibly associated with fidelity of implementation of treatment or with differing case mix. At each level, it is assumed that for 10% of children with autism or PDD, EIBI achieves minimal effects. EIBI is assumed to achieve partial effects for the remaining children.

As Table 5 shows, the average net benefit, as represented by the measure of marginal benefit (e.g., partial versus minimal effects) decreases slightly with an increase in the proportion of children for whom EIBI results in normal functioning. This finding is attributable to the greater difference in cost between nonintensive special education and intensive intervention, compared to the cost difference between nonintensive special education and regular education in this model, based on Pennsylvania cost values. For ages 3–22 years, average per student inflated marginal dollar savings range from $298,651 at 20% effectiveness to $274,709 at 50% effectiveness.

The relationship of level of treatment effectiveness to marginal benefits is markedly reversed for ages 3–55 years, and increased average marginal savings

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Table 5. Financial benefits at different levels of effectiveness, age 3 to 22 years, per 100 children and per child served—Pennsylvania model

	Inflated total	*1996 $ total*	*Inflated/ student*	*1996 $/ student*
At 20% normal range				
20 norm range vs. partial effect	5,395,220	3,672,340	269,761	183,617
70 partial vs. minimal effect	24,469,900	16,664,550	349,570	238,065
10 minimal effect	0	0	0	0
Net	29,865,120	20,336,890	298,651	203,369
At 30% normal range				
30 norm range vs. partial effect	8,092,830	5,508,510	269,761	183,617
60 partial vs. minimal effect	20,974,200	14,283,900	349,570	238,065
10 minimal effect	0	0	0	0
Net	29,067,030	19,792,410	290,670	197,924
At 40% normal range				
40 norm range vs. partial effect	10,790,440	7,344,680	269,761	183,617
50 partial vs. minimal effect	17,478,500	11,903,250	349,570	238,065
10 minimal effect	0	0	0	0
Net	28,268,940	19,247,930	282,689	192,479
At 50% normal range				
50 norm range vs. partial effect	13,488,050	9,180,850	269,761	183,617
40 patial vs. minimal effect	13,982,800	9,544,200	349,570	238,065
10 minimal effect	0	0	0	0
Net	27,470,850	18,725,050	274,709	187,251

Note: This schedule presents a comparison of financial benefits at different levels of achievement of normal skills or functioning achieved by EIBI, for children ages 3–22 years, ranging from 20% of children achieving normal skills or functioning (an assumed minimal rate) to 50% of children. At each level, differing rates of achievement of normal range skills or functioning, as well as partial benefit are estimated. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.

are associated with increased levels of effectiveness (see Table 6). The format of Table 6 is identical to that of Table 5, and differs only in that marginal costs (i.e., benefits) are shown for childhood and adulthood combined. Estimated average inflated marginal savings range from $656,385 at 20% effectiveness to $1,081,984 at 50% effectiveness. Corresponding present values for these inflated marginal savings are $31,714 and $52,279.

Summary

At a rate of normal functioning achieved by 40–50% of children with autism or PDD who receive EIBI (see, e.g., Lovaas, 1987) compared to virtually ineffective intervention, cost savings per child served are estimated to be from

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Table 6. Financial benefits at different levels of effectiveness, age 3–55 years, per 100 children served and per child served—Pennsylvania model

	Inflated total	*1996 $ total*	*Inflated/ student*	*1996 $/ student*
At 20% normal range				
20 norm range vs. partial effect	96,085,200	36,654,400	4,804,260	1,832,720
70 partial vs. minimal effect	72,520,910	28,984,130	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	168,606,110	65,638,530	1,686,061	656,385
At 30% normal range				
30 norm range vs. partial effect	144,127,800	54,981,600	4,804,260	1,832,720
60 partial vs minimal effect	62,160,780	24,843,540	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	206,288,580	79,825,140	2,062,886	798,251
At 40% normal range				
40 norm range vs. partial effect	192,170,400	73,308,800	4,804,260	1,832,720
50 partial vs. minimal effect	51,800,650	20,702,950	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	243,971,050	94,011,750	2,439,710	940,118
At 50% normal range				
50 norm range vs. partial effect	240,213,000	91,636,000	4,804,260	1,832,720
40 partial vs. minimal effect	41,440,520	16,562,360	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	281,653,520	108,198,360	2,816,535	1,081,984

Note: This table presents a comparison of financial benefits at different levels or rates of achievement of normal skills or functioning achieved by EIBI, for people ages 3–55 years, ranging from 20% of children achieving normal range skills or functioning (an assumed minimal rate) to 50% of children. At each level of effectiveness, differing rates of normal range functioning, as well as partial benefit are estimated. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.

$274,709 to $282,689 with inflation to age 22 and from $2,439,710 to $2,816,535 with inflation to age 55.

At $32,820 initial annual cost, the total cost–benefit savings of EIBI services per child with autism or PDD for ages 3–22 years ranges from $187,251 to $203,369 without inflation and from $274,709 to $298,651 with inflation. The majority of savings to schools accrue from children who achieve partial benefit rather than normal functioning, and savings decrease slightly on average with increased rates of children achieving normal functioning. At $50,000 initial annual cost, the corresponding cost–benefit savings of EIBI services per child with autism or PDD ages 3–22 years averages from $131,018 to $151,829 without inflation and from $214,801 to $246,551 with inflation.

At $32,820 initial annual cost, the total cost–benefit savings of EIBI services per child with autism or PDD for ages 3–55 years averages from $656,385

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to $1,081,984 without inflation and from $1,686,061 to $2,816,535 with inflation. The majority of savings to the lifespan-oriented developmental disabilities sector accrue from children who achieve normal functioning rather than partial benefit. Savings increase substantially on average with increased rates of children achieving normal functioning. At $50,000 initial annual cost, the corresponding cost–benefit savings of EIBI services per child with autism or PDD ages 3–55 years averages from $605,385 to $1,030,984 without inflation and from $1,635,061 to $2,765,535 with inflation.

These findings are summarized in Figures 1 and 2. Figure 1 displays the net cost for services for the four childhood groups that were presented in Table 2: nondisabled, EIBI with recovery effects, EIBI with partial effects, and EIBI with minimal (i.e., 'Nil') effects. Figure 2 displays the net income or net cost for services for the same four groups, as adults, that were presented in Table 3.

DISCUSSION

Limitations of Forecasting

Although the model used here is based on a series of reasoned assumptions that are consistent with the state of the current literature on treatment and practice (see the Methods section and appendix B), several limitations should be highlighted. First, the cost differential forecasts assume that current service trends are indicative of developmental disability service trends that may extend as long as 50 years hence. Specifically, these consist of trends toward community-based adult services, and are based on differences in expenditures associated with variations in levels and intensities of services for people with disabilities. These trends appear to be reasonable in the near term but may not hold up in the long term in the context of health care reform and challenges to disability services presented by competition for resources. Further, increasing costs as the general population ages during the next 20–30 years can be expected to present unique demographic challenges to the present system of resource allocation for the community support of people with handicaps of all ages. Specific rational alternative scenarios that lend themselves to quantitative modeling, however, are not readily apparent.

Second, alternative scenarios might involve stringent cost containment practices that would limit service eligibility and tend to lower expenditures for adults with autism or PDD over the long term. In projecting costs (or expenditures) for care to age 55 we have used a compound rate of 3%. This rate, which is lower than recent past rates of growth in health care and related costs,

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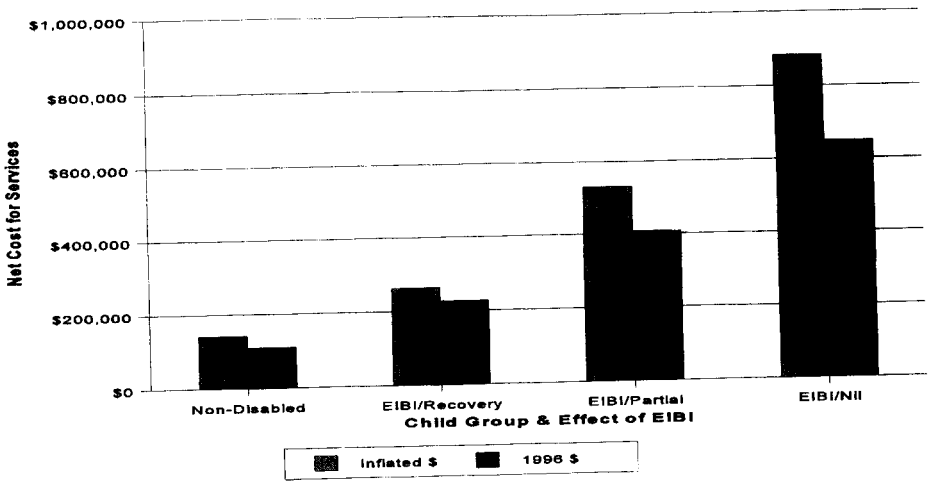

Figure 1. Net average individual cost for early intensive behavioral services ages 3–21 for nondisabled, recovered, partial benefit, and nil benefit groups. Cost is shown as with inflation and in 1996 dollars.

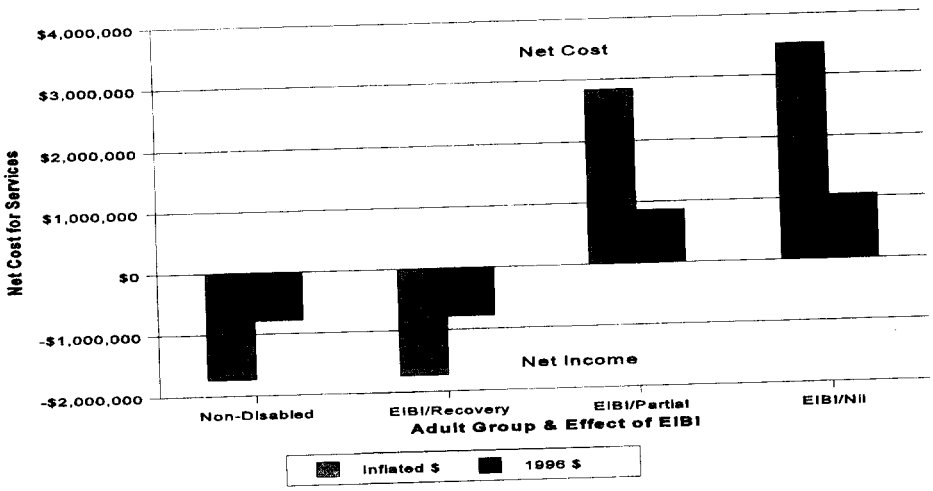

Figure 2. Net average individual cost for early intensive behavioral services ages 3–55 years for nondisabled, recovered, partial benefit, and nil benefit groups. Negative values indicative net earnings (income) and positive values indicate net costs for services. Cost is shown with inflation and in 1996 dollars.

will tend to underestimate future costs; therefore, it is possibly compatible with more stringent cost containment or imposition of limited service eligibility. Moreover, use of a rate of 10% participation in economic supports as a surrogate for all public services at any point in time for nondisabled and normal range effect groups probably represents a substantial underestimate of both

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present and future population cohorts. This will tend to underestimate differences in overall cost between these cohorts and people with autism or PDD who realize partial or minimal treatment effects, but the differences in costs among these groups derive primarily from the use of special education, intensive special education, or adult developmental disability services. SSI costs (the economic supports surrogate cost in the present model) were trended forward at 1.5%, which will also tend to be consistent with more stringent cost containment or limited service eligibility.

At another level, it should also be noted that we used a linear model of EIBI effects, in that gains realized from EIBI by primary school entry were assumed to maintain over the long term. There is no indication that the effects of EIBI are evanescent or ephemeral. On the contrary, existing evidence points to the durability of these effects (McEachin *et al.*, 1993; Perry *et al.*, 1995; Smith, 1998). It is understandable how this can occur if the children enter regular primary school with the skills required to benefit from regular education. The skills and susceptibility to social reinforcement acquired during EIBI would likely be maintained by the contingencies inherent in participation in regular educational, family, and community life. On the other hand, if some children who realize normal range or partial effects from EIBI do not sustain these gains, then our model accommodates this by providing cost and benefit estimates in the range of 20% to 30% normal range effects. The cost–benefits at these levels of outcome remain substantial. However, there is no question that the issues that derive from a simulation can only be resolved effectively by prospective tracking of comparative costs for groups of children over time. Such cost tracking has not been a major focus of research in past analyses of early intervention or preschool services, as is evident by its scarcity in the professional literature.

The Intersection of Cost and Quality

The widely accepted view of autism is that it is a severe lifelong disability (see, e.g., Cohen & Volkmar, 1997; Freeman, 1997; Siegel, 1996). Like effective interventions for other severe or chronic disorders, such as cancer or diabetes, EIBI for autism can be characterized as aggressive and invasive. It most likely does not work well when it is performed piecemeal, briefly, or by individuals with inadequate training and experience. Like effective early intervention for children at risk for various other disabilities, EIBI needs to begin early, be provided for many hours per week and many weeks per year for an extended period, be delivered directly to children, address a wide range of needs, and accommodate individual differences (Guralnick, 1998, Ramey & Ramey, 1998).

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In short, EIBI is relatively costly when it is done properly, and even then it does not produce complete recovery in every case.

On what basis, then, can investment in EIBI for children with autism or PDD be justified? A primary consideration is the availability of other interventions that have been demonstrated to produce comparable outcomes in scientifically sound studies. Countless therapies for autism have been touted to produce beneficial effects, ranging from the small to the near-miraculous (Green, 1996a; Gresham & MacMillan, 1997; Klin & Cohen, 1997; Maurice, 1996; Smith, 1993; 1996). Contemporary proponents of various other treatments and critics of EIBI state that other approaches can produce dramatic improvements (e.g., Gresham & MacMillan, 1997; Greenspan, 1992; Koegel, Koegel, Frea, & Smith, 1995; Mesibov, 1997; Strain & Cordisco, 1994), yet there is little empirical support for these assertions from methodologically sound research (i.e., studies that included direct, objective, valid and reliable measurement of treatment effects; demonstrations of improvements in multiple skill areas; controls for alternative explanations; replication; and long-term maintenance of treatment gains; see DeMyer *et al.*, 1981; Green, 1996a; Schreibman, 1988; Smith, 1993; 1996).

Our analysis suggests that another justification for investing in EIBI is long-term monetary savings for families and for society. Today, however, the resources required to begin EIBI are not always readily available. Even when they are, short-term financial and other considerations often force termination of treatment or reduction in treatment intensity sooner than might be optimal (see, e.g., Graff, Green, & Libby, 1998). Some maintain that the limited resources available for EIBI should be invested only in young children with autism or PDD who are most likely to respond dramatically (e.g., Siegel, 1996). We suggest there is not yet an adequate scientific database on which to base either predictions of treatment responsiveness, or decisions to reduce treatment intensity after relatively brief periods.

While the converging evidence from studies of EIBI suggests that it can produce benefits unmatched by other interventions for autism and PDD, careful research is needed to answer a number of burning questions:

Will the 40–50% rates of attainment of normal or near-normal functioning reported in the initial studies hold up in further replication and follow-up studies?

What child and programmatic variables reliably predict responsiveness to EIBI?

What are the long-term outcomes for the children in the initial studies who did not achieve normal functioning?

Might some children like them attain better outcomes with intensive intervention of longer duration, or intervention that incorporates additional well-tested behavior analytic techniques?

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How intensive does EIBI have to be to produce optimal effects?

What is the operational definition of 'intensive'?

Do other early intervention models that involve high rates of one-to-one interactions between adults and children with autism (see, e.g., Rogers & Lewis, 1989) produce outcomes comparable to EIBI?

Can biomedical research shed light on the limiting factors that might militate against a large and sustainable outcome, or contribute to the effectiveness of behavioral intervention?

A second, related set of questions pertains to the nature of EIBI and who is capable of delivering this intervention competently. Some have suggested that only individuals who follow the 'Lovaas model' and have been trained directly by the Lovaas clinic at UCLA should be considered qualified (Buch, 1996; Families for Intensive Autism Treatment, 1996). However, other behavior analysts have achieved outcomes comparable to those of Lovaas and colleagues, including normal functioning in some children with autism or PDD (Birnbrauer & Leach, 1993; Maurice, 1993; Perry *et al.*, 1995) and other significant outcomes (Anderson *et al.*, 1987; DeMyer *et al.*, 1981; Fenske *et al.*, 1985; Matson *et al.*, 1996; Maurice, Green, & Luce, 1996; Mulick & Meinhold, 1994).

At present, the number of professional-level applied behavior analysts is far too small to meet the growing demand for behavioral intervention for children with autism of all ages. As a result of the demand and supply imbalance, as well as nationwide pressure stemming from implementation of the federally mandated early intervention infrastructure under P.L. 105–17, a kind of cottage industry has developed; large numbers of individuals are simply proclaiming themselves 'Lovaas therapists', 'behavior analysts', or 'behavioral therapists' and extracting large fees from families and other sources for directing and providing EIBI. Fortunately, actions are being taken on several fronts to attempt to remedy this problem. Legally sanctioned, competency-based procedures for certifying professional behavior analysts that have been in place in the state of Florida for many years (see, e.g., Shook, 1993; Shook & Favell, 1996; Shook & Van Houten, 1993; Shook, Hartsfield, & Hemingway, 1995) are being implemented or considered by several other states at this writing. Representatives of several national professional associations have initiated efforts to establish a specialty and proficiency in applied behavior analysis (e.g., Hopkins & Moore, 1993) for licensed psychologists.

In listening to parents, we have discovered that fewer and fewer wish to trust their children with autism and PDD to unproven fad treatments and inadequately prepared service providers (Jacobson, Mulick, & Schwartz, 1995). Many have become astutely discerning consumers once they have learned the relevant dimensions by which to judge treatment effectiveness and professional

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competence (Green, 1996a; Van Houten, 1994). Discerning consumers also recognize that long-term treatment effects are at least as relevant as short-term costs, and that the most expensive treatment is that which is ineffective regardless of the monetary price.

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APPENDIX A: SOURCES OF FINANCIAL INFORMATION FOR PER RECIPIENT EXPENDITURE ESTIMATES—PENNSYLVANIA MODEL

This appendix presents information regarding the sources used in order to develop the estimates used in the cost analysis.

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The source for early intervention, family support services, home and community based services waiver estimates, institutional costs, and community services costs is D. Braddock, R. Hemp, L. Bathchelder, & G. Fujiura (1995). *State of the states in developmental disabilities.* Washington, DC: American Association on Mental Retardation.

The source for intensive community services is annual expenditures for six persons or fewer ICF/MR plus one-half of the difference between this amount and the annual institutional expenditure, from Braddock *et al.* (1995), as above.

The source for special education expenditures is average for all special education types from Barnett & Escobar (1990, p. 566).

The source for regular education expenditures is USDOE (1992). *The condition of education* (NCES 92-096), p. 334.

The source for intensive early intervention is the average cost of seven model programs reported by S. Harris & J. Handleman (1994). *Preschool education programs for children with autism.* Austin, TX: PRO-ED.

The source for median household income is the 1990 Federal Census of the United States. Supported wages are indexed at 20% average of median household income for Pennsylvania.

All amounts are trended at 3%, except SSI/ADC (AFCD or TANF) which is trended at 1.5%.

APPENDIX B: ASSUMPTIONS UNDERPINNING THE GENERAL COST MODEL

(i) Current research does not identify characteristics of children with autism or PDD that predict their response to EIBI (e.g., initial I.Q. within the moderate to mild range of mental retardation is not a good predictor) during the years before school entry, funded as either early intervention or preschool services. Thus, benefit must be gauged upon outcomes as identified in the literature (e.g., Smith *et al.*, 1997).

(ii) The proportion of children who achieve normal functioning in all areas is probably somewhat lower than the proportion reported so far in the behavioral research literature (i.e., just under 50%) because (a) in very young children, when severe or profound mental retardation is present, a conclusive diagnosis of autism or PDD may not be made, and (b) other local or nonspecific factors probably affect whether children are diagnosed or, especially, referred for EIBI.

(iii) In any group of children with autism or PDD who receive competently delivered EIBI, between 20 and 50% will achieve normal functioning.

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About 40% will achieve substantial gains that will result in reduced dependency on special services, but they will continue to need some specialized services and supports throughout their school and adult lives. Ten percent (10%) will continue to require intensive special education and intensive adult services, and the remainder will evidence benefit sufficient to reduce the intensity of required educational and adult services.

(iv) For these reasons, cost–benefit should be couched in terms of marginal benefit, as well as the attainment of normal functioning. Analyses should encompass comparison of costs for children with autism or PDD who achieve normal functioning with costs for serving children without disabilities, and with costs for serving children with autism or PDD who make large gains but do not move into the normal range. The latter group should also be compared with children who make minimal gains.

(v) Without EIBI the majority of children with autism or PDD will manifest enduring dependency on adult developmental disability services. This is consistent with the literature on child, adolescent, and young adult development for people with autism or PDD.

(vi) The costs of EIBI center-based services for children with autism or PDD (including those with a home-based, parent-directed component) may not be comparable or equivalent, on average, with the costs of EIBI home-based services when instruction is comparably intensive, but relative costs and utilization mix are not well established. The mix of costs for EIBI services used here is assumed to be a representative average for both center-based and home-based services. Future research will be needed to clarify this assumption.

(vii) Children with autism or PDD who ultimately develop normal functioning are assumed to participate in regular education; those who make large gains but not sufficient for them to participate successfully in regular education are assumed to participate in special education; and children who make minimal gains are assumed to participate in intensive special education (or the equivalent from a cost perspective). Special education alternatives (e.g., intensive special education) are assumed to be equivalent in cost regardless of whether they are delivered in segregated, partially integrated, related service, or fully inclusive models, based on requisite instructional load requirements for comparable instructional and educational effects. In short, comparable instruction is assumed to cost the same regardless of whether an inclusive approach is used or not. This is done only in the absence of data indicating a rational basis for assigning such costs in another manner despite the possibility that such data may subsequently emerge.

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(viii) Because no generalizable mortality data exist for people with autism or PDD (owing mainly to the advent of the diagnosis in the 1940s and lack of population cohort data), cost–benefit analyses including the adult years are made only to age 55. There is no compelling evidence of marked mortality prior to age 55 years for children surviving to adulthood, and the lifespan of people with autism or PDD may well be similar to that of the general population and appreciably greater than this cutoff age. Therefore, the cutoff point will tend to underestimate adult income from supported or regular employment, utilization of general public entitlements or benefits during adulthood, utilization costs for adult developmental disabilities services, and costs for utilization of aging services and public retirement or income transfer programs for elders.

(ix) Present costs are used as indicators of future costs, with recognition that future reforms in welfare and public health may either result in decreased per person rates or expenditures, or in substitution of services. To compensate, costs have been trended forward at 3% per annum, except for SSI/ADC (Aid for Dependent Children), or the equivalent such as Temporary Assistance for Needy Families (TANF), which is trended at 1.5%. These trend factors probably represent an underestimate of long-term inflationary factors. For example, the average cost inflator for health-related services from 1986 to 1996 was about 4.5%.

(x) SSI/ADC costs are used as a summary cost for all utilization of general public benefits outside of the early intervention, educational, and developmental service sectors (e.g., public housing subsidies, food stamps, child care, temporary assistance, all forms of public assistance, higher-education grants, vocational assistance, public transportation, and Medicaid card services). Although these are not entered as costs for nondisabled children to age 22 years, they are entered as costs for all children with autism or PDD who achieve normal functioning (three years' cost), and partial or minimal effects (18 years' cost). SSI/ADC is also entered as a cost for 33 years to age 55 years for 20% of nondisabled children and children with autism or PDD who achieve normal functioning, and for 100% of children with autism or PDD who make substantial improvements or who benefit minimally.

(xi) The average duration of EIBI is assumed to be three years, a period that is associated in the literature with apparent best outcomes (Green, 1996a). The existing literature suggests that two years of intervention can result in normal functioning for some children, but in this analysis it is recognized that children may participate in 2–6 years of EIBI, and three years is stipulated to be a reasonable average duration.

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(xii) Children with autism or PDD who achieve normal functioning are assumed to use family support services during participation in EIBI. Children who make moderate gains and those for whom minimal effects are attained are assumed to use 18 years of family support services, to age 22 years.

(xiii) During adulthood, those who achieve substantial improvements, but not normal functioning, are assumed to use 18 years of Medicaid waiver (or equivalent) services and 15 years of supported work services. During adulthood, for adults for whom minimal effects are obtained, 80% are assumed to use waiver services for 20 years, 20% are assumed to use intensive community services for 23 years, and 40% are assumed to use supported work services for 15 years. These utilization patterns are a function of variations in individual service needs and potential delays between requests for services and service enrollment associated with waiting lists. With the possible exception of adults with whom intervention has been minimally effective during the preschool years, the cost mixes used are lower than those that are presently typical for intensive comprehensive community services for adults with autism or PDD (e.g., ICF/MR and ambulatory clinic services or equivalent levels of care).

(xiv) Supported employment wages are estimated as comparable for individuals with autism or PDD who achieve substantial or minimal gains, at 20% of the median household annual income. It should be noted that although this probably overestimates income (and thus offset of service costs) for people with minimal benefits, it nonetheless reflects a single-person income level that remains below current poverty level indicators, and a full-time employment (40-hour week) hourly rate of $3.24 hourly in the 1996 base year.

(xv) This analysis uses costs reported in several sources for the Commonwealth of Pennsylvania. Annual regular education costs were $7,543 per year in 1996, special education $12,935, and intensive special education $28,806 (from Table 1). The initial annual cost of EIBI is set at $32,820. To calculate the cost–benefit of this intervention set at a higher level of $50,000, readers may simply subtract $53,100 from inflated benefit totals and subtract $51,540 from uninflated benefit totals.

(xvi) Finally, in composite, the service costs and inflators used will tend to underestimate cost slightly relative to current expenditure patterns, whereas the earnings projected will tend to overestimate income slightly, providing a relatively conservative overall estimate of cost–benefit. All savings shown, however, are net of the expense of providing EIBI.

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