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CHILDREN AND ADULTS WITH DEVELOPMENTAL DISABILITIES: SERVICES IN WASHINGTON, RESEARCH EVIDENCE

The 2008 Washington State Legislature directed the Washington State Institute for Public Policy (Institute) to . . .

> *". . . conduct a review of research on service and support programs for children and adults with developmental disabilities, excluding special education, and an economic analysis of net program costs and benefits."*[1]

The "bottom line" goal of the study is to provide the legislature with a summary of available research on services and supports for individuals with developmental disabilities, and to estimate the costs and benefits of providing these programs.

This document summarizes developmental disability services in Washington State, including current public expenditure levels. We also review the research evidence regarding services for individuals with developmental disabilities, including comparative cost studies.

Contents

Summary

The Washington State Institute for Public Policy was directed by the 2008 Washington Legislature to estimate the effectiveness, costs, and benefits of programs for individuals with developmental disabilities (excluding special education).

Services and support programs for individuals with developmental disabilities are individualized, which makes evaluation research challenging. However, we did find a number of studies that assessed the impacts of service and support programs using a comparison group design.

Methods

Research evidence. We conducted a systematic review of all research we could locate on programs that:

- target individuals with developmental disabilities or delays;
- intend to improve developmental, behavioral, or cognitive functioning or quality of life;
- have been evaluated with a comparison group that receives no treatment or treatment-as-usual; and
- have measured outcomes with standardized or well-validated measures of symptom improvement, child development, behavior, cognitive or adaptive functioning, or quality of life.

Costs of services. We reviewed the research literature to find the best available evidence on the economic impacts of services for individuals with developmental disabilities.

Findings

- The population of individuals with developmental disabilities is diverse; when evaluating research evidence, we must ask "what works for whom?"
- Of the 400 potentially relevant studies we located, we identified 181 studies for detailed consideration. From this group, 53 met the inclusion criteria for this study.
- Several programs have demonstrated positive impacts on various life outcomes; others have not.
- Residential services in the community for similar groups of adults with developmental disabilities cost less on average than institutional care.
- The cost of supported employment services for adults varies depending on the needs of clients and the intensity of services. In some research, supported employment was found to increase clients' wage earnings and taxes paid, with a reduction in public costs.

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[1] ESHB 2687, Chapter 329, § 610 (17), Laws of 2008.

The report is divided into three main sections:

1) **Overview**. The first section provides an overview of the definition of a developmental disability, and a brief national history of public support and funding to serve those with developmental disabilities. We also describe the services that are provided to qualifying individuals with developmental disabilities in Washington State, along with their costs.

2) **Review of the evidence for program effectiveness**. The second section reviews the available research evidence on programs for people with developmental disabilities. This population is diverse and vulnerable. The state serves people with developmental disabilities by providing individualized services that are tailored to their needs. The goal is to provide clients with the best chance at success and satisfaction with life. The fact that services are individualized and focused on a person's specific needs makes evaluation of those services more challenging.

   For example, although a large portion of the Division of Developmental Disabilities (DDD) budget for services (25 percent) goes to provide personal care, there is little research on the "effectiveness" of personal care.[2] Personal care services address people's basic needs—bathing, dressing, eating, housework, meal preparation, etc. It would be difficult to design an evaluation that compared personal care to no service or a different service, and to select relevant outcomes to measure. In addition, some programs for individuals with developmental disabilities do not lend themselves easily to evaluation according to the criteria set forth in this report.[3]

   Nevertheless, some research has rigorously examined programs using no-service or alternative-service comparison groups. We discuss this research in the following categories:

   a) Children with general or non-specific developmental disabilities or delays (primarily intellectual disabilities);
   b) Children with autism;
   c) Children with cerebral palsy;
   d) Children with Down syndrome;
   e) Individuals with epilepsy that is resistant to drug therapy; and
   f) Adults with various developmental disabilities.

3) **Research on two program categories for adults**. Because there is research on the comparative costs of some programs for adults, this section gives a detailed view of two primary types of services provided in Washington State. These programs are community residential services and employment and day services. We review the research on outcomes of these programs, their comparative costs, and provide examples of how these findings might be applied to Washington.

   This section gives detailed information on the research evidence and comparative costs of various community residential services and supported employment services.

In this assignment from the Legislature, the Institute was asked to review research evidence and analyze the economics of various service and support programs. For other subject areas, the Institute has completed these tasks and provided the legislature with a "Consumer Reports"-style list of programs that "work" and make good economic sense for the topics of criminal justice, child welfare, and K–12 education.

For this study, however, our "Consumer Reports" list does not contain our usual economic analysis. Research regarding people with developmental disabilities tends to focus on quality-of-life outcomes and measures, such as adaptive behavior. These kinds of outcomes are difficult to assign a monetary value, and do not lend themselves to a typical cost-benefit analysis. We also considered conducting a cost-effectiveness analysis. This type of economic analysis aims to demonstrate the relative costs of achieving certain outcomes. However, while the outcomes measured by studies shared broad similarities, there was enough variability in the measures to preclude a meaningful cost-effectiveness analysis. While we were unable to compute long-term costs and benefits or cost-effectiveness results, we do report short-term comparative costs for two types of service programs in Section 3.

Two glossaries are located in Appendix A: one for acronyms used throughout the report, the other for descriptions of services provided in Washington.

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[2] See Section 3 (p. 21) for more details.

[3] Assistive technology is one example of an intervention that we could not include at this time. These technologies are designed to help a person with developmental disabilities perform tasks that would otherwise be difficult or impossible. Research on these technologies often uses a pre-post design, examining individuals' performance of certain tasks with and without a particular technological support.

Section 1: Overview of Developmental Disability Services

Definition

According to Washington State law,[4] a developmental disability is defined as:

A disability attributable to:

- *Mental retardation;*
- *Cerebral palsy;*
- *Epilepsy;*
- *Autism; or*
- *Another neurological or other condition closely related to mental retardation or that requires treatment similar to that required for individuals with mental retardation.*

Which:

- *Originated before the individual turned eighteen;*
- *Continued or can be expected to continue indefinitely; and*
- *Results in substantial limitations to an individual's intellectual and/or adaptive functioning.*[5]

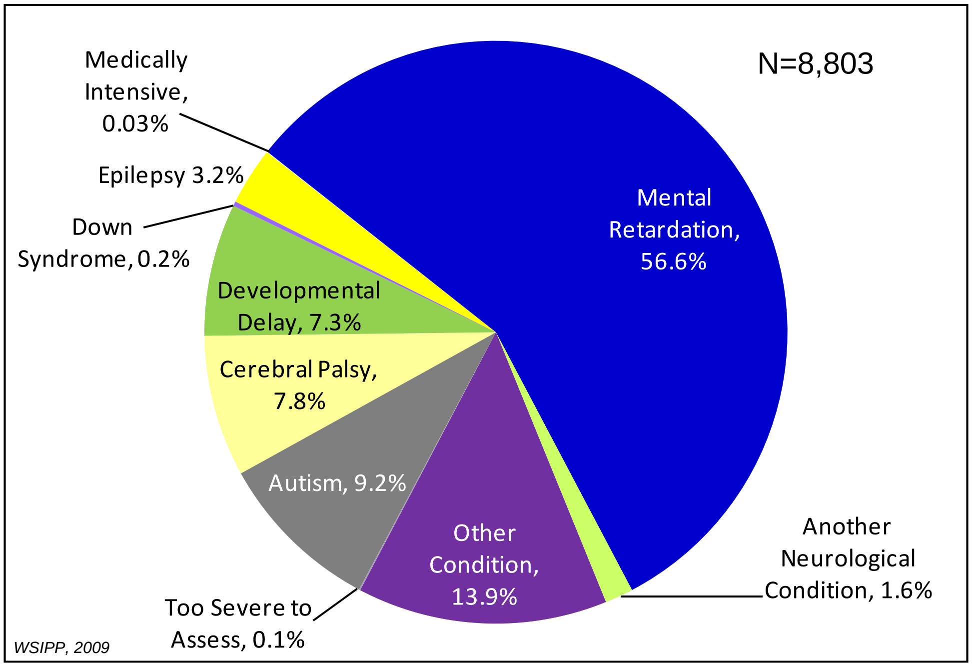
People with developmental disabilities are a diverse group. Exhibit 1.1 displays the eligibility diagnoses of a subgroup of 8,803 clients of the Division of Developmental Disabilities (DDD).[6]

History

Services for people with developmental disabilities began to change dramatically in the 1960s and 1970s, pushed by the advocacy for and by individuals with developmental disabilities and supported by state and federal legislation. The 1971 Washington State Legislature passed HB 90, commonly referred to as the "Education for All Act." This act mandated free and appropriate special education services for children with disabilities, mirroring the federal movement toward the same. In 1971, federal courts ruled that individuals with disabilities had the right to a public education.

Exhibit 1.1

Primary Eligibility Diagnoses for DDD Clients



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[4] Revised Code of Washington 71A.10.020(3)
[5] From DSHS Department of Developmental Disabilities eligibility criteria, available at: <http://www.dshs.wa.gov/ddd/eligible.shtml>

[6] This chart describes the diagnoses that make clients eligible for DDD services, according to the CARE assessment, as of July 2008. This assessment is recent, and not all clients have yet been assessed.

Federally, 1975 brought passage of the Education for All Handicapped Children Act (PL 94-142), which established that children with disabilities have the right to a free and appropriate education in the least restrictive environment possible. This Act has now evolved into the Individuals with Disabilities Education Act (IDEA), most recently re-authorized in 2004. Before the expansion of federal funding in special education, children with developmental disabilities were often institutionalized—the education act expanded the availability of resources in local settings.

Also in the 1970s, a number of federal court decisions began to shift public funding from supporting institutional care to emphasizing care in the community.[7] This decade brought increasing advocacy for and by individuals with disabilities for the opportunity to live independently. This movement sparked the federal initiative to provide care in the community when possible.

The 1975 Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103) required states to provide protections and advocacy for those with developmental disabilities in order to receive grants from the federal government. This act has been amended a number of times since the 1970s.

Services in Washington State

Division of Developmental Disabilities

The entity that provides publicly funded services to people with developmental disabilities in Washington is the Division of Developmental Disabilities (DDD) in the Department of Social and Health Services (DSHS). The mission of DDD is:

> . . . *to endeavor to make a positive difference in the lives of people eligible for services, through offering quality supports and services that are: individual/family driven; stable and flexible; satisfying to the person and their family; and able to meet individual needs. Supports and services shall be offered in ways that ensure people have the necessary information to make decisions about their options and provide optimum opportunities for success.*[8]

State-funded services for individuals with developmental disabilities and their families vary by the age of the disabled person. Some services are Medicaid entitlements, which are “guaranteed” to an individual who meets the eligibility criteria, but the majority of services are limited by both eligibility requirements and availability of funds.

An estimated 79,000 people with developmental disabilities live in Washington State.[9] In FY 2008, the average monthly number of clients identified by DDD as developmentally disabled across the state was 36,916.[10] Of the identified clients, 57 percent received publicly funded DDD services. An additional monthly average of 4,888 children[11] aged 0 to 3 were served by the Infant Toddler Early Intervention Program (ITEIP) in DDD (an unduplicated total of 8,930 children served in 2007–08[12]).

Most DDD clients who receive paid services (95 percent) live in the community, not in an institution. Over three-quarters of those in the community (78 percent) live at home with their families, and the remaining 22 percent live in another kind of community residential placement (briefly described on page 6).

Below, we describe services available in Washington by age group. Exhibit 1.3 on page 7 provides a visual depiction of these services.

From birth to age three, children with developmental disabilities and delays are eligible for services through ITEIP. For qualifying children, ITEIP provides each family with an Individualized Family Services Plan (IFSP) to educate parents about their child’s developmental growth and provide the child with developmental assistance such that they might avoid the need for special education and other services at a later age.

To qualify for ITEIP services, children must have a diagnosis of a developmental disability, or be measurably developmentally delayed.[13] Evaluations and determinations of eligibility are performed by early intervention specialists, facilitated by ITEIP Family Resource Coordinators. The box on the next page describes some unique features of the ITEIP program, and the challenges faced in evaluating the effectiveness of services.

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[7] D. Braddock, M.C. Rizzolo, R. Hemp, & S.L. Parish (2005). Public spending for developmental disabilities in the United States: An historical comparative perspective. In R.J. Stancliffe & K.C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities*, Baltimore, MD: Paul H. Brookes Publishing Co., pp. 23–44.

[8] <http://www.dshs.wa.gov/ddd/>

[9] Based on a 1.2 percent prevalence rate and the state population from 2008.

[10] From DSHS Research and Data Analysis, Executive Management Information System.

[11] From DSHS ITEIP monthly program data, July 2007 to June 2008. Available at: <http://www.dshs.wa.gov/iteip/DataSysAndTrain.html>

[12] ITEIP program data, October 2007 to September 2008.

[13] For specific ITEIP eligibility criteria, see: <http://www.dshs.wa.gov/iteip/Services_Elig.htm>.

The Infant Toddler Early Intervention Program (ITEIP) in Washington

The primary goals of early intervention for children with developmental disabilities or delays are to enhance the quality of life for individual children and their families and to increase opportunities for developmental progress. In Washington, the Infant Toddler Early Intervention Program (ITEIP) provides a framework for services for children with developmentally disabilities and developmental delays, aged birth to three. For a historical perspective, see the 1995 Institute document, "Birth to Three Years Report," available from: <*http://www.wsipp.wa.gov/pub.asp?docid=95-11-2101*>.

ITEIP is governed under the federal Individuals with Disabilities Education Act (IDEA), Part C, which enables states to receive federal funding to *"maintain and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers with disabilities and their families."*[a] Through the ITEIP program, children and their families may receive a variety of individualized services, depending on a child's needs. These services can include:

- Assistive technology devices and services
- Audiology (hearing)
- Occupational therapy
- Family resources coordination
- Family training, counseling, and home visits
- Health services
- Medical services only for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Early identification, screening, and assessment
- Physical therapy
- Psychological services
- Social work services
- Special instruction
- Speech-language pathology
- Transportation and related costs necessary to enable receipt of early intervention services
- Vision services

Services for infants and toddlers are funded through public education, county human service agencies, and the Department of Health. In addition, Medicaid funds and military and private health care coverage are often utilized for these services. ITEIP is the payer of last resort.

The aim of ITEIP is to reduce the need for special education services when the child becomes three years old. According to ITEIP records, 27 percent of the children who transitioned out of early intervention services from October 2007 through September 2008 did not need special education at age three.[b]

Research on interventions for infants and toddlers with developmental disabilities is limited. Most studies on early intervention focus on "at-risk" populations, such as infants in impoverished families, or those biologically at-risk (e.g., born pre-term or at a very low birth weight). Well-controlled comparison group studies have shown long-term educational, economic, and other societal benefits of some early intervention programs for these at-risk populations. For example, see the 2004 Institute report, "Benefits and Costs of Prevention and Early Intervention for Youth," available at: <*http://www.wsipp.wa.gov/pub.asp?docid=04-07-3901*>.

Ethical and legal considerations may pose obstacles to the study of treatments for infants and toddlers with developmental disabilities. In some instances, these obstacles can be overcome when opportunities for comparison group research naturally arise. For example, there may be insufficient resources to treat all children with a particular intervention. A researcher could randomly assign clients to a "treatment" group or to a "service as usual" group, measure the clients at intake, then track the outcomes of both groups over time. Alternatively, clients could be randomly assigned to a waiting list to receive the treatment at a later time. Research as devised above would enable researchers to draw conclusions about the relative efficacy of different interventions.

As the prominent early childhood researchers Samuel Meisels and Jack Shonkoff wrote:

> *"In the end, the major question facing the field of early childhood intervention is not whether young children are worthy of public investment. The critical challenge is how to capitalize on current knowledge and mobilize our collective resources to ensure better health and developmental outcomes. Our task is not to choose between supportive advocacy or critical research. Our mandate is to bring these two perspectives together to promote the well-being of all our children."*[c]

[a] IDEA, Section 633

[b] ITEIP presentation to House Human Services Committee, 1/12/2009. This is a promising statistic, but because there is no equivalent comparison group (e.g., developmentally delayed infants and toddlers who did not receive ITEIP), we cannot be certain that the receipt of ITEIP services is what caused the children to not need special education at age three. It is possible that some of these children would have "caught up" with their peers by age three, even without early intervention.

[c] S.J. Meisels & J.P. Shonkoff (2000). Early childhood intervention: A continuing evolution. In J.P. Shonkoff & S.J. Meisels (Eds.). *Handbook of early childhood intervention* (Second Edition), pp. 3–31. New York: Cambridge University Press.

From age three to 21, individuals with developmental disabilities are entitled to a public education. In the public school system, eligible children and young adults receive an Individualized Education Plan (IEP) and services such as developmentally appropriate preschool, special education, speech therapy, and employment planning.

After age 21, individuals with developmental disabilities may be eligible for publicly funded services such as the DDD employment and day program, which provides training, support, and paying jobs for those who are able. Alternatively, community access services, which include activities and special assistance, are available for those aged 62 and over or who receive an exemption from employment.

Throughout their lifetimes, individuals with developmental disabilities are also eligible for health services and supports through Medicaid, if income eligibility requirements are met. For example, families may qualify for Medicaid Personal Care, which is regular personal assistance with activities of daily living for a person with a developmental disability. This personal care is provided where the individual lives (usually in the family home).

Another service provided to qualifying individuals and their families across their lifespan may include assistance from the state's Individual and Family Services Program. This program covers supports such as respite care, therapy, excess medical costs, transportation, behavior management, and recreational opportunities, among others.

In addition, individuals who meet income and functional assessment requirements may also receive residential care in a number of settings, including (but not limited to):

- Supported living, which helps a client live as independently as possible (with services ranging from limited support to full-time active care) in a rented accommodation shared with one or two others, if shared at all;
- Group homes, which provide shared staff support for a larger group of people living in the same residence; and
- Residential Habilitation Centers (RHC) or community Intermediate Care Facilities for the Mentally Retarded (ICF/MR), which provide full-time active residential care and medical services.

Not all clients receive "paid" services.
In order to receive paid services (publicly funded services through DDD),[14] a person must meet the eligibility requirements for having a developmental disability, and must:[15]

- Meet the eligibility requirements for that specific service (these requirements may include income limitations and/or certain functional impairments); and
- Have an assessed need for that specific service.

Additionally, there must be funds available to provide that service.

Exhibit 1.2 shows that, of the nearly 37,000 individuals who were considered clients of DDD (i.e., they were assessed and were determined to have a developmental disability), over 15,000 (43 percent of the total) were not receiving any paid services in an average month. That is, they were not receiving any publicly funded services; DDD does not keep data on clients who may be purchasing services privately. In some cases, clients not receiving paid services were waiting for funds or slots to become available; other people may not yet have been assessed for specific service needs.

Two examples of clients who do not receive the services they are assessed to need are the 7,236 eligible clients[16] waiting to participate in the Individual and Family Services Program, and the 650[17] young adults waiting to receive employment services after transitioning out of special education services. For both programs, there are insufficient funds to serve every eligible client. In addition, 1,576 eligible clients[18] are on a DDD-maintained waiting list for placement on a Medicaid Home and Community Based Services waiver (discussed on page 10).

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[14] Paid services from DDD are officially defined in the Washington Administrative Code (WAC 388-823-1015) by one or more of the following:

1) Authorization of a paid service within the last ninety days as evidenced by a social services payment system (SSPS) authorization, a county authorization for day program services, a Waiver Plan of Care approving a DDD paid service, or residence in a SOLA, RHC, or IMR (authorization of a State Supplementary Payment through SSPS does not meet the definition of a DDD paid service);
2) Authorization of family support services within the last twelve months.
3) Documentation of DDD approval of your absence from DDD paid services for more than ninety days with available funding for your planned return to services.

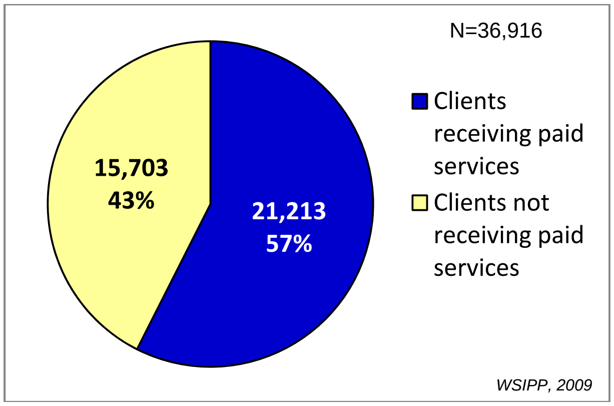
[15] WAC 388-823-0030

[16] As of August 11, 2009, according to DDD.

[17] Estimated number, see page 8 for further discussion.

[18] As of August 12, 2009, according to DDD.

Exhibit 1.2
DDD Client Population, Fiscal Year 2008



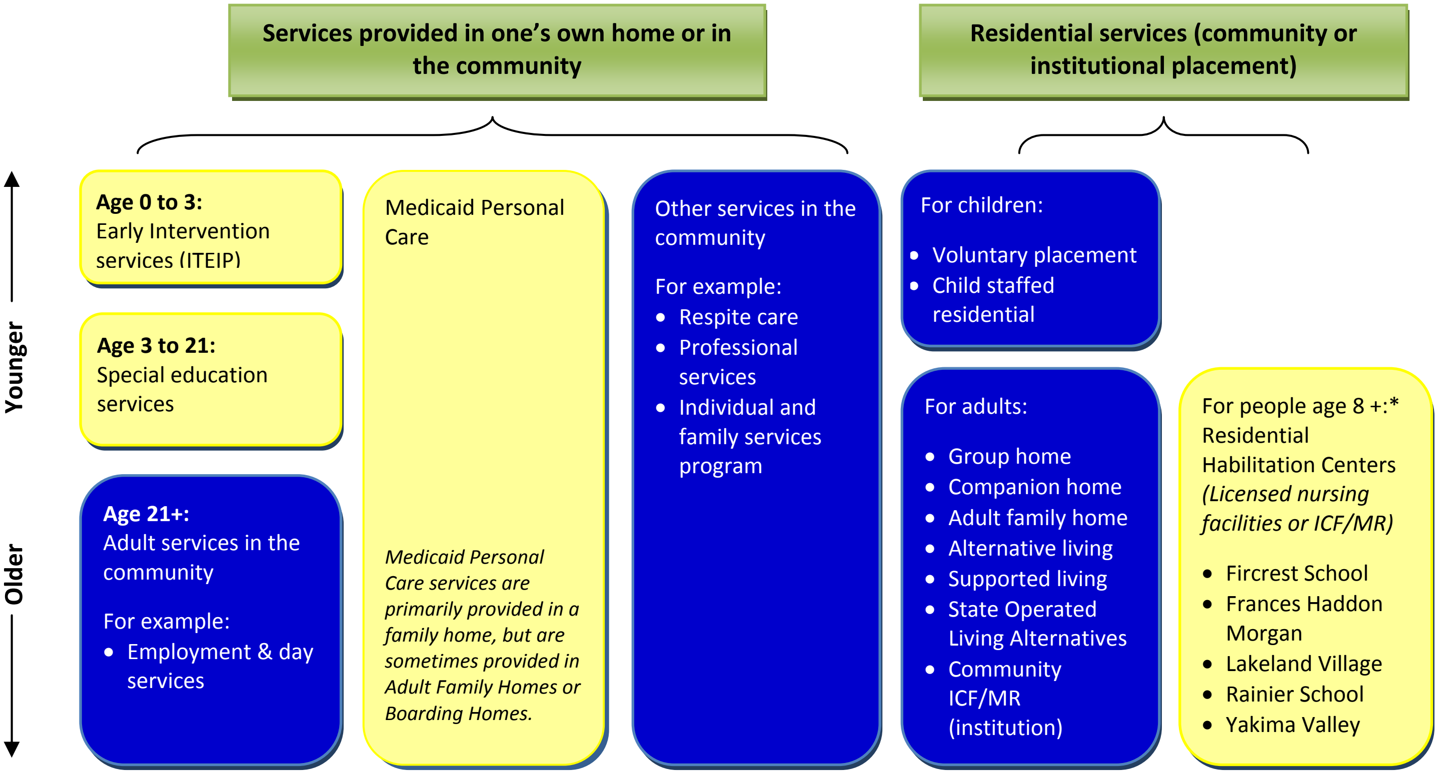
WSIPP, 2009

Clients receiving paid services (with the exception of those living in RHCs) are assessed every year by DDD to ensure they are receiving the right services for their needs. Certain services are entitlements, which spring from the state's participation in Medicaid, meaning that the requirement for available funding does not apply—if a client is eligible, he or she cannot be denied service. For example, any client who is assessed as needing 24-hour residential care in a structured facility and who meets the Medicaid and state eligibility requirements for institutional care is entitled to a place in an ICF/MR. Another entitled service is Medicaid Personal Care; anyone who qualifies must be supported in that program.

Most services are not entitlements, such as employment and day services or individual family support program services. In other words, an individual with developmental disabilities may be assessed to need a service but, due to lack of availability, may not receive that service.

To summarize the preceding discussion graphically, Exhibit 1.3 depicts the publicly funded services available to individuals with developmental disabilities during life phases and in different settings. The illustration is organized with services available to children at the top and those available for adults below. Some services are available across the lifespan. In addition, we have categorized the services into those provided in the home or community, and those that are out-of-home residential or institutional. Finally, the yellow boxes indicate services that are entitlements, and the blue boxes indicate those that are not.

Exhibit 1.3
Services for Individuals With Developmental Disabilities in Washington State



*Although RHCs are intended for adults, there are a small number of children under 18 currently permanently admitted to an RHC.
Note: Yellow boxes indicate entitlement services
WSIPP, 2009

Service Changes

In the previous discussion, we reported that not all clients receive paid services from DDD. In addition, for individuals who do receive paid services, there are three points in the service delivery system where they may potentially lose one or more services: (1) moving between systems, (2) expiration of eligibility, and (3) loss of funding.

Moving between systems. For DDD clients, the entry to and exit from the public special education system are the primary transition points. Children with developmental disabilities are eligible for special education services in the public school system from ages three to 21. Prior to age three, a child may have been a client of the Infant Toddler Early Intervention Program, and it is ultimately the parent's responsibility to ensure that his or her child enrolls in school. Special education services end at age 21 and, although clients may technically qualify for services such as supported employment, they often must wait for funding to become available in order to receive those services.

For example, the Developmental Disabilities Council[19] estimates that historically, 650 young adult DDD clients exit special education each year. In 2009, these individuals might be eligible to receive supported employment services, but there are currently no funds to support them; they must wait for slots to become available.

Another example of moving between systems is when children with developmental disabilities who are in foster care administered by the Children's Administration leave foster care (youth are eligible to remain in care until age 21 if there is no disruption in placement). Upon leaving care, youth no longer receive Children's Administration services, and must be assessed for DDD eligibility before receiving services through DDD.

Expiration of eligibility. Another service transition for DDD clients is when their service eligibility expires.[20] If a client is assessed and determined to be eligible for services before the age of four, eligibility expires on the fourth birthday. If a client is deemed eligible between his or her third and tenth birthday, eligibility expires on the tenth birthday. DDD is required to notify the client three months in advance of the expiration date, but the client is responsible for reapplying for eligibility with the Division.

Loss of funding. In some cases, state or federal funding for certain programs may be reduced or cut. In these circumstances, some individuals may no longer receive services.

Client Data and Assessments

Historically, the needs and abilities of individuals with developmental disabilities in Washington have not been measured or tracked consistently. In 2007, DDD began implementing a standardized assessment to all clients, and in 2008, DDD also implemented a new data system to better track information about clients.[21] At this point, it is not possible to know how the assessment system is impacting services for DDD clients; not all clients have been assessed.

DDD anticipates that periodic assessment of clients with a standardized tool will enable comparison between baseline and progress measures for individual clients. Regular (e.g., annual) assessments could be used to measure change and help ensure that clients are consistently receiving the services that best meet their needs. It is unclear if annual assessments would be feasible given current DDD staffing levels.

Individuals residing in an RHC prior to the implementation of the new assessment will not be evaluated with the standardized instrument. Therefore, it will not be possible to evaluate the distribution of client functioning and service needs within institutions or between institutionalized and non-institutionalized DDD clients. It is often assumed that the clients with the most profound disabilities and the highest levels of need are served in RHC settings, and those with lower levels of need and less severe disabilities are served in community settings. Without a standardized measure of clients across residential settings, this distribution remains unknown.

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[19] Personal communication with Donna Patrick, Director of Public Policy, Developmental Disabilities Council (DDC), July 31, 2009. Washington State Developmental Disabilities Council: <http://www.ddc.wa.gov>. Each state has a DDC, established by the federal Developmental Disabilities Act to "*increase the independence, productivity, inclusion, and community integration of people with developmental disabilities*."

[20] WAC 388-823-1005

[21] A 2007 report from the Joint Legislative Audit Review Committee (JLARC) describes the evolution of these systems: C.L. Forland, & J. Adams (2007). *Division of Developmental Disabilities: Analysis of how services are prioritized.* Olympia: Joint Legislative Audit Review Committee. Available at: <http://www.leg.wa.gov/reports/07-9.pdf>

Expenditures in Washington State

Exhibit 1.4 displays the fiscal year 2008 expenditures for the Division of Developmental Disabilities. The majority of expenditures (approximately three-quarters) are for clients living in the community, either in their family homes or other community residential placements. The remaining expenditures support clients living in Residential Habilitation Centers (RHCs). These are the institutional care settings provided by the state for clients who need 24-hour active treatment or nursing levels of care (although this level of care may also be provided in the community). These Centers may be intermediate care facilities (ICF/MR-certified) and/or licensed nursing facilities.

Among the different categories of services, the largest portion of expenditures (36 percent) are used to serve an average of 4,600 clients per month living in out-of-home community placements, such as group homes, companion homes, supported living arrangements, and state-operated living alternatives. The various living arrangements available from the state are described in detail in Section 3 of this report (page 19).

Together, out-of-home community placements and RHCs account for more than half of DDD expenditures; 26 percent of clients receiving paid services live in one of these settings. The remaining three-quarters (74 percent) of clients receiving paid services live at home with their families. For these clients, the most commonly provided service is personal care (which accounts for about 23 percent of DDD expenditures). Personal care provides people with assistance in their activities of daily living, such as bathing, dressing, meal preparation, housekeeping, etc.

Just over 11 percent was spent to fund other non-residential services, such as supported employment, professional services like physical, speech, or occupational therapies, or other community services.

Exhibit 1.4 displays the overall costs of various services. Many clients receive more than one of the services listed below. One client may receive a comprehensive service package at an RHC, whereas another client with similar needs may receive residential care in an out-of-home placement like a group home, and day services through a supported employment program. Still another client with similar needs may receive personal care in his or her family home, occasional respite care at an RHC, supported employment services, and occupational therapy through professional services.

Expenses for a single DDD client may be large or small, depending on his or her assessed needs and depending on how those services are provided. Some clients need 24-hour care and medical support, whereas others may need only occasional support.

State and federal funds. DDD expenditures include state dollars as well as federal Medicaid dollars. Considering total DDD spending, just over half is funded with state dollars (50.6 percent), and nearly half from federal dollars (47.9 percent). The remaining 1.5 percent comes from local dollars, which support RHCs. The state and federal contributions for each category of service are detailed in Exhibit 1.4

Exhibit 1.4

Washington State DDD Expenditures for Fiscal Year 2008

	FY 2008 Actual Expenditures	Percentage of Total DDD Expenditures	Average Monthly Clients[a]	Percentage Funded by State Funds	Percentage Funded by Federal Funds
Community Services—Residential[b]	$309.1 m	36.0%	4,600	50.0%	50.0%
Personal Care	$200.9 m	23.4%	11,662	48.7%	51.3%
Residential Habilitation Centers	$190.8 m	22.2%	997	43.4%	49.8%
Employment and Day Programs	$65.2 m	7.6%	9,853	72.1%[d]	27.9%
Field Services	$42.3 m	4.9%	n/a	59.1%	40.9%
Other Community Services	$23.3 m	2.7%	n/a	69.1%	30.9%
Infant Toddler Early Intervention Program	$9.2 m	1.1%	4,888[e]	0.2%	99.8%
Professional Services	$8.0 m	0.9%	n/a	52.2%	47.8%
Family Support	$2.8 m	0.3%	711	100.0%	0.0%
Voluntary Placement	$0.6 m	0.1%	14	92.4%	7.6%
Headquarters	$6.8 m	0.8%	n/a	61.5%	38.5%

Source: Office of Financial Management, June 2009. All figures have been rounded.

[a] Source: DATAR Feb 2009. Clients may receive more than one service.

[b] This category includes State Operated Living Alternatives.

[c] Residential Habilitation Centers also have a small amount of local funding that is not included here.

[d] In the 2009–11 biennium, the state percentage for employment and day programs will be reduced, and the federal portion will increase. To maximize use of federal funds, state-only funded clients in employment and day programs will be shifted to a waiver if they meet eligibility requirements, enabling the use of federal matching funds for services like employment.

[e] This number is for FY 2007.

Federal Support for DDD Programs

Currently, Medicaid is the primary federal fiscal support for services for people with developmental disabilities. Traditionally, Medicaid funds were used to support institutional care. In 1981, the federal government established the Medicaid Home and Community Based Care Service (HCBS) waiver program under Section 1915(c) of the Social Security Act. The waiver program is intended to help states support people in their homes and communities as an alternative to institutional care.

Because they are a Medicaid program, HCBS waivers match state funds at the Federal Medicaid Assistance Payment (FMAP) rate (51.52 percent for 2008).[22] In order to qualify for any of the waivers, an individual's income must not exceed 300 percent of the SSI benefit amount,[23] or the individual must be enrolled in the Healthcare for Workers with Disabilities Medicaid program. For children under 18, parental income is not considered in the eligibility calculation.

Individual states are responsible for defining the services available under the waiver program, which may include traditional medical services as well as non-medical services. States are also responsible for determining the number of clients they will serve in the waiver program, subject to approval with Medicaid. HCBS waivers look different in every state that participates in the program. In Washington, there are five waivers (described below); each has its own expenditure cap per individual, based on the services provided. The results of the DDD assessment determine which waiver an individual is assigned to; each waiver serves different needs, and people are assigned to the waiver that is determined to be the most appropriate for their needs.

A note on entitlements: Care in an institution is an entitlement, meaning if a client is eligible, he or she cannot be denied institutional care. When an individual with developmental disabilities participates in the state's waiver program, he or she waives the right to be institutionalized and agrees to receive alternative services in the community. Any

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[22] In FY2010, the FMAP rate rose to 62 percent, increasing the federal contribution and decreasing the state's fiscal responsibility for Medicaid services. This change will be temporary, and was designed to provide some relief to states for the economic downturn.

[23] Annually, $7,644 x 300% = $22,932 in 2008.

client assessed as needing 24-hour active residential care in a structured facility and who meets the Medicaid and state eligibility requirements for institutional care is entitled to a place in an institution. A waiver enables the client to receive the same level of service (24-hour, active care), but in a community setting.

Once an individual is assessed to be eligible for a waiver and there is an available slot, he or she cannot be denied the services that he or she is assessed to need, within the scope of that waiver. Obtaining a waiver slot is not an entitlement in and of itself (e.g., there were an average of 9,237 people in the state receiving waiver-funded services in FY2008, and an additional 1,576 who have asked for a waiver but have not yet been assigned to a waiver); however, once a slot is occupied, that client is entitled to the services provided under that specific waiver. The five Washington waivers are described below.

Basic. The basic waiver provides the least intensive level of services. This waiver generally provides professional services (such as physical or occupational therapy), medical equipment, personal care, and community programs (e.g., supported employment) for individuals living in their family homes or in their own homes. These individuals need some level of care, but do not need out-of-home residential services.

Basic Plus. The basic plus waiver provides the same services as the basic waiver, but at higher levels of service caps. This waiver also includes provision of some out-of-home residential services, such as adult family homes or adult boarding homes. Individuals on the basic plus waiver must be at high risk[24] of being placed out of home or losing their current living situation.

Core. The core waiver is for individuals with higher levels of need, who either require out-of-home residential services, or are at immediate risk[25] of being placed out-of-home. Most people on the core waiver receive out-of-home residential care; the majority are supported within a supported living arrangement, although some live in group homes, companion homes, or other residential situations.

Community Protection. The community protection waiver provides the highest level of services of the five waivers, and is restricted to individuals who must be supervised by staff 24 hours a day to ensure the safety of others. Nearly all individuals on the community protection waiver live in supported living arrangements offered by Community Protection Certified Supported Living providers.

Children's Intensive In-Home Behavioral Supports. This new waiver program began providing services to a limited number of children in May 2009. The purpose is to provide intensive in-home services to children who are at high risk of being placed in an institution; the program provides families, caregivers, and schools with behavioral support training. In addition, children can receive specialized therapies, and families can receive respite care and minor environmental modifications for their homes and vehicles.

DDD Clients Also Receive Other Services

In addition to services provided through DDD, individuals with developmental disabilities often receive services from other DSHS divisions. Exhibit 1.5 shows that the majority of DDD clients were also served by other divisions of DSHS in fiscal year 2007.

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[24] High risk means the person either has high acuity needs and a caregiver is available/present but has requested additional support and/or consideration of out-of-home placement; **or** the person has medium acuity needs and a caregiver has requested out-of-home placement.

[25] Immediate risk means that the person has high acuity needs; a caregiver is unavailable/absent; the person has no available residence.

Exhibit 1.5

Services Provided to Clients With Developmental Disabilities by Other DSHS Divisions, FY 2007

	Number of Clients[a]	Percentage of DDD Client Total[a]	Total Expenditures
Aging and Adult Services	1,782	4.5%	$31.4 m
Alcohol and Substance Abuse Services	470	1.2%	$0.5 m
Children's Services	3,893	9.9%	$36.0 m
Economic Services	15,325	38.9%	$15.5 m
Medical Assistance Services	30,379	77.1%	$162.6 m
Mental Health Services	4,498	11.4%	$27.4 m
Vocational Rehabilitation Services	2,907	7.4%	$5.9 m
Juvenile Rehabilitation Services	24	<0.1%	$0.6 m
Total Expenditures in Other Divisions			$279.9 m
Total DDD (unduplicated)	39,423		

[a] Clients may receive services from more than one division.
Source: DSHS RDA Client Services analysis, fiscal year 2007, available at:
<http://www.dshs.wa.gov/rda/research/clientdata/2007/sharedclients/default.shtm>

Section 2: Review of Evidence for Program Effectiveness

In this section, we discuss the research evidence regarding programs for people with developmental disabilities.

For this study, we reviewed all the research we could find about programs for children and adults with developmental disabilities, excluding special education services.[26] We reviewed studies conducted throughout the United States and other countries. Our goal was to review the available evidence on all programs, regardless of whether or not they are currently offered in Washington.

Inclusion Criteria for This Study

For our review, we assessed the evidence on specific programs provided to people with developmental disabilities. We used three key criteria to determine what studies would be included in our analysis:

1) Evaluation design and methodology;
2) Population of interest; and
3) Relevant outcomes.

Criterion 1: Evaluation Design and Methodology
We concentrated on research that provided the greatest degree of confidence in the results. To meet our inclusion criteria, a study must measure outcomes for a treatment group that participates in a particular program in comparison to an equivalent group that does not participate. The groups do not necessarily have to result from random assignment, but the evaluation must show that any comparison group is indeed comparable to the treatment group on pre-existing variables (such as age, gender, race, type and/or severity of disability) that may influence outcome measures.

At the very least, if a study finds pre-existing differences between groups, the authors must statistically control for these differences in their analysis. Studies that assess a single group's changes from pre- to post-treatment do not meet the criteria, as one is uncertain how the treatment influenced the change as compared to other factors (development, maturation, motivation, etc). For more details on the importance of this criterion, see the sidebar, opposite.

The Value of Comparison Group Research Designs

The literature related to developmental disabilities includes many case studies documenting how individual children responded to an intervention or how a group of adults changed over time after leaving an institution. These studies can provide good information on strategies practitioners might use to help particular clients, or promising directions for designing community living arrangements.

Our goal when reviewing evidence about effective programs, whether in the arena of developmental disabilities, criminal justice, child welfare, or substance abuse, is to provide the legislature with information on programs that can be used to help drive policy decisions. While a case study might help us understand how a program affected an individual, a well-designed comparison group study can give us much more information about the impact of a program over a number of individuals, while controlling for those individuals' personal characteristics.

Single-group studies that follow people over time and measure outcomes before and after an intervention do not allow us to draw conclusions about whether or not an intervention caused a particular change. Individual factors, such as maturation over time or a particularly strong motivation to improve may have contributed to that change, and without a comparison group, we cannot know for certain.

Similarly, evaluations that compare a group of people who happened to receive an intervention against a group that did not receive that intervention, and only measure outcomes after the intervention, might ignore some crucial differences between the groups.

For example, comparing follow-up outcomes of people who moved out of an institution with those of people who stayed in that institution, does not allow us to account for potentially confounding differences between the "movers" and the "stayers." Movers could have left the institution because they chose to, which would create a motivational bias in their favor. The movers and the stayers could have been initially very different in their average adaptive behavior scores (for example), which could change the interpretation of any post-test differences; without a pre-test measurement, there would be no way to know or control for that initial difference.

However, we found a number of research evaluations that tested and statistically controlled for pre-intervention differences, or that carefully matched intervention and comparison group participants on important characteristics, or that randomly assigned program participants to groups. These evaluations increase our confidence that the research findings can be applied to the Washington State population.

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[26] As directed by the Legislature, we excluded special education from our review. See the box on page 15 for more information on special education research.

When evaluating programs for vulnerable populations, such as those with developmental disabilities, researchers often encounter unique difficulties in designing comparison group studies.

In some cases, it may be unethical to withhold a promising treatment in order to create a "no-treatment" comparison group. Quasi-experimental comparison-group research designs that have been used successfully with populations of people with developmental disabilities include:

- Convenience samples with carefully matched groups (e.g., a retrospective examination of groups that happened to receive a treatment or not);
- Carefully matched comparison group in an area that does not have the treatment available.

After an extensive search, we found 53 studies that used a well-controlled comparison group research design.

Criterion 2: Population
As directed by the Legislature, this study focused on evaluations of programs that serve children or adults with developmental disabilities or delays (as defined by the state of Washington). We did not include evaluations of programs for populations of individuals with other kinds of disabilities (e.g., blindness, specific language impairment, traumatic brain injury sustained after the age of 18).

Some programs are designed to serve individuals with a particular type of disability (such as Down syndrome, cerebral palsy, or autism), and others are designed to apply to people across the spectrum of developmental disabilities. We included both specific and general programs for individuals with demonstrated developmental disabilities or delays. We did not include programs that work with "at-risk" populations (such as low birthweight infants or pregnant mothers with a series of risk factors for developmentally delayed children). These types of prevention programs fall outside the legislative direction for this study, as do special education programs (see sidebar, next page).

Criterion 3: Outcomes
As we reviewed studies for this report, we found that most evaluations measured outcomes that do not lend themselves easily to monetization. In previous Institute publications on costs and benefits for programs, we analyzed outcomes such as high school graduation, child abuse or neglect, and criminal recidivism. These outcomes are associated with public expenditures, victimization costs, lifetime wage earnings, and so forth.

Programs for individuals with developmental disabilities, however, do not usually measure these kinds of outcomes, but rather examine improved functional capacity or quality of life. For this population, we included quantifiable, standardized, or well-validated measures that focus on outcomes such as cognitive or motor development (for child populations), adaptive functioning, behavior, or quality of life. See Appendix B for a full description of various outcomes and their relationship to our inclusion criteria.

In recent years, researchers have developed a set of statistical tools to facilitate systematic reviews of the evidence. Our goal was to use this set of procedures—called "meta-analysis"[27]—to combine the findings of numerous research studies and report on the effectiveness of various service and support programs.

Comparative cost research.

In the context of support services for adults with developmental disabilities, programs studied most often from an economic perspective are supported employment services and community residential services (as an alternative to living in an institution or nursing home).[28] We, therefore, discuss the relative costs of services in these two topic areas. These analyses can be found in Section 3. The services we cover in this section make up nearly 60 percent of the total Division of Developmental Disabilities (DDD) budget in Washington.

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[27] Specifically, we analyze the results of studies using meta-analytic methods as described in M.W. Lipsey & D.B. Wilson (2001). *Practical meta-analysis.* Thousand Oaks, CA: Sage Publications.

[28] There have also been a number of studies conducted about the comparative costs of interventions, primarily for three- to eight-year-old children with autism. However, there is not enough research about the specific effectiveness of these interventions to clearly illuminate the economic discussion in this area.

Research in Special Education

As directed by the Legislature, we did not include research about special education in our review. Children with developmental disabilities are eligible for public special education services from age three to 21; these services provide children and their families with a great deal of support in their early lives.

A large body of research exists regarding special education. As examples, studies have examined curricula and teaching methods for children with various developmental disabilities, as well as ways to manage behavior problems in the classroom for children with different developmental disabilities. A number of peer-reviewed journals are devoted to the subject of special education, such as Topics in Early Childhood Special Education, The Journal of Special Education, and the Journal of the American Academy of Special Education Professionals.

An in-depth investigation into special education research could be useful in learning more about effective supports for children with developmental disabilities and their families.

Findings

Of the 400 potentially relevant studies we located, we identified 181 for detailed consideration. From this group, 53 met the inclusion criteria for this study.[29] These 53 studies represented 24 programs that are listed in Exhibit 2.1; 14 of these had more than one evaluation.[30] We place more weight on the results of programs with multiple evaluations; replication of results increases our confidence that the programs would have these impacts were they implemented in Washington.

Programs that have been evaluated more than once are listed in the un-shaded areas of the table; those that were evaluated only once are listed in the shaded sections. Citations for the research described in Exhibit 2.1 are detailed in Appendix E, Exhibit E.2 at the end of this document. Details and descriptions of the evaluated programs are provided in Appendix D.

We have organized Exhibit 2.1 into six categories, based on programs for:

1) Children with general or non-specific developmental disabilities or delays (primarily intellectual disabilities);
2) Children with autism;
3) Children with cerebral palsy;
4) Children with Down syndrome;
5) Individuals with drug-resistant epilepsy; and
6) Adults with various developmental disabilities.

For each program, our results reflect the effect we expect for the “average” implementation of the program. For example, intensive behavioral intervention for children with autism has been evaluated four times; our statistical review estimates the *average effectiveness* of this type of program across these four evaluations.

In Exhibit 2.1, programs are organized by specific populations. A plus or minus sign indicates a statistically significant effect on the indicated outcome. A zero indicates that the outcome was measured by an evaluation, but no statistically significant effect[31] was found, and an “N/A” means the outcome was not measured in evaluations of that program. Each of these symbols may reflect the findings from one or more evaluations.

Many evaluations measured more specific outcomes than we display in these exhibits. For example, to measure quality of life, an evaluation of a community residential program may have measured unmet service needs, general health, and social support. Our analysis included all of these unique outcomes, combined in Exhibit 2.1 under “quality of life.” For a full description of our analysis and program impacts on various outcomes, see Exhibit E.1 in Appendix E.

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[29] For a description of how we worked through the inclusion decision process, see Appendix C.

[30] Many programs had been evaluated only once, so in order to increase the statistical power of our analysis, we sometimes grouped similar programs together. Appendix D has detailed information on specific programs included in certain groupings.

[31] When a program has a “statistically significant” effect, we are 90 percent confident that the result is not due to chance alone.

Exhibit 2.1

Institute Findings: Impacts of Programs for Individuals With Developmental Disabilities

Plus or minus signs indicate a statistically significant effect on the indicated outcome. A plus sign indicates an effect in the desired direction; a minus sign indicates an effect in the undesired direction. A zero indicates no statistically significant effect, and N/A indicates the outcome was not measured.

Type of Population and Name of Program		Measured Outcomes					
Programs for Children With Non-Specific or Various Developmental Disabilities		**Cognitive Development**	**Adaptive Behavior**	**Problem Behavior**	**Quality of Life[a]**	**Parental Well-Being**	**Motor Skills**
Multiple evaluations	Parent support programs (3)	+	*N/A*	*N/A*	+/0[b]	+	*N/A*
	Group-based parent training (for children with behavior problems) (4)	*N/A*	+	+	0	0	*N/A*
	Hanen Early Language Program (2)	*N/A*[c]	*N/A*	*N/A*	*N/A*	+	*N/A*
Single evaluation	Early preschool in a hospital clinic setting (1)	+	*N/A*	*N/A*	*N/A*	*N/A*	*N/A*
	Supportive home visiting (1)	0	*N/A*	0	*N/A*	*N/A*	*N/A*
	Portage Curriculum[d] (1)	+	*N/A*	*N/A*	*N/A*	*N/A*	+
	Cash and Counseling (1)	*N/A*	*N/A*	*N/A*	+	*N/A*	*N/A*

[a] *Quality of Life measures for this group of programs include health, unmet needs, and social support.*

[b] *One study found improvements in social support, but no improvements in measures of general health.*

[c] *Although these studies did not measure cognitive development, one study measured language skills and demonstrated no significant improvement.*

[d] *This program also measured motor activity and found a statistically significant advantage for the program participants compared to the control group.*

Programs for Children With Autism		**Cognitive Development**	**Adaptive Behavior**	**Problem Behavior**	**Autistic Behavior**	**Parental Stress**	**Language Skills**
	Intensive behavioral intervention[a] (4)	+	+	*N/A*	*N/A*	*N/A*	+
	Auditory integration training (3)	0	*N/A*	0	0	*N/A*	*N/A*
	Group- or clinic-based communication training (2)	*N/A*	0	0	0	0	+
	Autism Preschool[b] (1)	0	*N/A*	*N/A*	0	0	+
	Low intensity behavioral training (1)	*N/A*	0	*N/A*	*N/A*	*N/A*	+
	Home-based communication training (1)	0	*N/A*	*N/A*	0	0	0

[a] *One small study also measured special education placement, but did not find a significant advantage for the program group.*

[b] *This study also measured motor skills, but found no significant difference between the program and comparison groups.*

Programs for Children With Cerebral Palsy		**Cognitive Development**	**Adaptive Behavior**	**Motor Development**			
	Intensive vs. “regular” physical therapy (3)	0	0	+			
	Constraint-induced movement therapy (casting) (2)	*N/A*	*N/A*	0			
	Vestibular stimulation (1)	0	*N/A*	0			

Programs for Children With Down Syndrome		**Cognitive Development**	**Adaptive Behavior**	**Motor Development**			
	Developmental therapy (2)	0	*N/A*	*N/A*			

Programs for Individuals With Drug-Resistant Epilepsy		**Seizure Frequency**	**Quality of Life**				
	Cognitive-behavioral therapy (2)	0	+				
	Relaxation training (3)	+	0				
	Biofeedback (1)	+	*N/A*				

Programs for Adults With Various Developmental Disabilities		**Cognitive Development**	**Adaptive Behavior**	**Problem Behavior**	**Quality of Life***	**Income**	**Social Network**
	Community residential placement (vs. institution or nursing home) (13)	+	+	0	+	–	+
	Community residential placement (less vs. more restrictive) (2)	*N/A*	0	0	+	*N/A*	*N/A*
	Supported employment (3)	*N/A*	+	*N/A*	+	+	*N/A*
	Behavioral training for institutional staff (1)	*N/A*	*N/A*	+	*N/A*	*N/A*	*N/A*
	Cash and Counseling (1)	*N/A*	*N/A*	*N/A*	+	*N/A*	*N/A*

**Quality of Life measures include one or more of the following: employment, health, reduction of unmet needs, life satisfaction, as well as standardized measures of life quality.*

Programs for Children With Non-Specific or Various Developmental Disabilities

Many programs we reviewed were not directed at children with a specific developmental disability like autism or Down syndrome, but rather toward children with various disabilities, usually including an intellectual disability. The first three programs—parent support programs, group-based parent training, and communication training—all focus on improving child behavior and functioning by training parents.

Parent support programs: In some evaluations, children of supported parents do better on tests of cognitive development, and parents report feeling less depressed and less anxious. In addition, parents report feeling more socially supported, but their measures of general health are the same as parents from a comparison group.

Group-based parent training programs: Evaluations found significant reductions in the problem behavior of children. In addition, one study found a significant benefit for adaptive behavior skills from participating children.

Communication training: Both evaluations measured language skills after the intervention, but found no significant benefit for program participants. However, one evaluation did demonstrate that parents were less depressed after participating.

Programs with single evaluations: Of the four, two showed statistically significant impacts on cognitive development (Portage Early Education Curriculum and early preschool in a hospital setting), and one had a significant impact on quality of life (Cash and Counseling).

Although these specific programs for children with various developmental disabilities may not be provided in Washington, they are similar to the types of services that families have access to under the Individual Family Services Program. The exception is Cash and Counseling; this type of self-directed assistance is not provided through DDD.

See Appendix D for descriptions of the evaluated programs.

Programs for Children With Autism

Children on the autism spectrum have a unique set of characteristics. There are several types of autistic disorders, including Asperger's Disorder and Pervasive Developmental Disorder-Not Otherwise Specified. The characteristics and functioning of children with these disorders can differ greatly, but the children share impairment in social interaction and repetitive and stereotyped behaviors, with symptoms beginning before age three. Although children with Asperger's tend to have normal language development, others on the autism spectrum also have impairments in communication.

Intensive behavioral intervention: Evaluations showed that, on average, children's language skills, cognitive development, and adaptive behavior skills improved significantly.

Group- or clinic-based communication training: Two evaluations found improvements in language skills.

Programs with single evaluations: Of the four programs that had been evaluated once, two (Autism Preschool and lower-intensity behavioral intervention) had significant impacts on children's language skills.

The group-based and home-based communication training programs are examples of services that might be provided to families under the Individual and Family Services Program in Washington. Although there are providers in the state who conduct intensive behavioral training and others who provide auditory integration training, these are not covered under Medicaid.[32]

Programs for Children With Cerebral Palsy

Children with cerebral palsy have delayed motor development and muscular problems like spasticity, so they are often provided physical therapy to help them gain more muscular control and motor skills. With infants, this is often done by manually moving the child's limbs into different positions to help strengthen muscles that may not be developing as one would expect in a non-disabled population.

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[32] Because of the high number of staff hours required for intensive behavioral training, it is expensive. For example, a therapist providing intensive behavioral services under the new Children's Intensive In-home Behavioral Supports waiver (see page 11) may cost $25 to $60 per hour. Depending on intensity of services, therapist costs alone could be over $7,500 for one month of 30-hour per week treatment.

Three evaluations examined *"intensive" physical therapy* compared with physical therapy as usual; intensive therapy improved motor skills. Two studies evaluated therapy that involves *casting* of a more-functional limb (arm) in order to help develop skills and functionality of the less-functional arm. One study found a large impact on motor skills; that study had a very small sample, so when combined with another, larger study, the effect was not significant. The one evaluation of vestibular stimulation found no impact on cognitive or motor development.

All three of these therapeutic approaches would be included under the professional services category of DDD programs—they are specific, individual therapies provided by a qualified therapist. As far as we know, vestibular stimulation per se is not provided in Washington, although other balance-enhancing exercises may be provided by an occupational therapist.

Programs for Children With Down Syndrome

Although many programs and strategies have been tested for infants with Down syndrome, very few have been evaluated with research designs that meet our criteria for inclusion. Because infants with Down syndrome have delayed motor and cognitive development, they are often provided with some form of therapy to encourage their development, usually a combination of physical therapy and "stimulation" exercises to promote interest in and interaction with their surroundings. We found two evaluations of such programs; neither had a significant impact on cognitive development.

Programs for Individuals With Drug-Resistant Epilepsy

The primary treatment for epilepsy involves medication. Because of our legislative direction to focus on DDD services, we did not examine the research literature on drug therapies. The therapies in our review are not considered standard treatments, and would not be covered by Medicaid in Washington. Several small studies on relaxation training and biofeedback showed improvements in seizure frequency and quality of life measures. All evaluations in this topic area have been conducted with very small samples, so further research is necessary before firm conclusions are possible.

Programs for Adults With Various Developmental Disabilities

The first three programs in this section—community residential services compared to institutions, community residential services compared to each other, and supported employment—include a large number of evaluations, and are described in detail in Section 3 of this report (page 19).

Community residential placements compared to institutions: These evaluations found improved adaptive behavior skills and quality of life measures for people living in the community. Additionally, some studies found improved cognitive skills and expanded social networks compared to people living in institutions.

Community residential placements compared to each other: One evaluation found that supported living improved quality-of-life measures compared to "cluster centers," and another found that people living in community ICF/MR settings had reduced quality-of-life compared to residents living in other community settings.

Supported employment services: Three evaluations found, on average, improved adaptive behavior skills and quality of life.

Programs with single evaluations: Among programs that had been evaluated once, training staff of institutions with positive behavioral support techniques improved residents' problem behavior; also, Cash and Counseling had positive impacts on quality of life measures.

Section 3: Research on Two Program Categories for Adults

Section 3 provides more detail on two kinds of services commonly provided to adults with developmental disabilities. First, we discuss community residential services, and second, employment and day services. For each, we describe:

- the services provided;
- the research evidence summarized in section 2; and
- comparative costs of various approaches.

Community Residential Services in Washington

The vast majority of individuals receiving paid DDD services (95 percent) live in the community, not in an institution. Over three-quarters of those in the community (78 percent) live at home with their families, and a majority of these (74 percent) receive personal care services to help them stay in the family home. However, the remaining 22 percent receiving paid services who live in the community do not live in their family home for one reason or another, and instead live in a community residential placement.

As shown in Exhibit 1.4 (page 10), the largest category of expenditures in the DDD budget is for community residential services, accounting for 36 percent of expenditures. Community residential services include all out-of-home residential care, except for Residential Habilitation Centers (RHCs).

Community residential service settings include:

- Supported living;
- Group homes;
- Alternative living services;
- State-operated living alternatives (SOLAs);
- Community Intermediate Care Facility for the Mentally Retarded (ICF/MR); and
- Out-of-home residential services for children.

The most frequently used model of service (and largest portion of the community residential services budget) is the supported living arrangement. Supported living services are used by 73 percent of those living in the community outside the family home. Clients live in rented accommodations in the community, but services vary widely from client to client, based on clients' needs. All clients receive instruction and support in their own homes in the community, but the hours of service can vary from a few hours per month to full-time (24-hour) access to individual support.

About 7 percent of clients living in the community outside their family home live in a group home. Each group home provides a residence for four to 20 adults; these can be licensed as adult family homes or boarding homes. Residents of group homes have access to 24-hour support.

Alternative living services provide training and instruction to help a client live independently. Alternative living is provided to about 6 percent of community residents, who do not live in their family home, and is similar to supported living, but provides fewer service hours on average. Skills training might include writing checks, shopping for groceries, or a number of other basic living activities. Alternative living services can be provided for up to 40 hours per month.

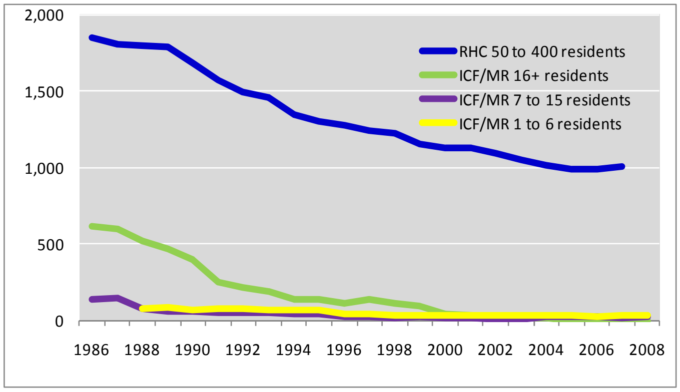
Clients living in state-operated living alternatives (SOLAs) receive nearly identical services as supported living clients. The primary difference is that SOLAs are operated by the state, rather than contracted to private providers. Two percent of DDD clients in community residential placements live in SOLAs.

Just over 1 percent of community residential clients live in a community ICF/MR. This arrangement looks very different from other community residential placements, and is based more on an institutional model than an independent living model. However community ICF/MRs are much smaller than RHCs (each serves seven residents on average compared to 50 to 400 in an RHC), and generally "look" more like group homes than RHCs.

As mentioned in Section 1, the federal movement toward deinstitutionalization was solidified by the 1981 creation of the HCBS waiver program. In Washington State, the number of people living in both large ICF/MR and RHC settings dropped over the last two decades (see Exhibit 3.1, next page).

Exhibit 3.1

Residents of RHCs and ICF/MRs in Washington, by Size of Residence



WSIPP, 2009

A small number of adults (0.9 percent) live in companion homes. This model of service is similar to foster care, but is for adults. These family residential homes provide 24-hour supervision; each home can house no more than one adult client of DDD.

There are some children with developmental disabilities who cannot live in their family homes because of their level of disability. Child-staffed residential care provides care in licensed homes with shift workers rather than families. In many cases, these arrangements serve older adolescents with behavior problems that may be difficult for an individual family to address. In contrast, child foster/group care looks very much like a standard foster care model, usually providing care to one child client of DDD in the home of state licensed foster parents.

Exhibit 3.2 displays the types of living arrangements available through community residential services, as well as the number of clients and expenditures for each kind of service. The exhibit includes expenditures for clients supported by state-only funds, as well as those for individuals supported by the various HCBS waivers.

Exhibit 3.2

Washington State Service Expenditures for Fiscal Year 2008: Community Residential Services

	Actual Expenditures*	Average Monthly Clients	Average Monthly Expenditure Per Client
Community Services—Total Residential[a]	**$307,112,063**	**4,600**	**$5,564**
Supported Living	$247,211,788	3,354	$5,537
State-Only	$4,327,281	171	$2,114
Core Waiver	$197,698,318	2,781	$5,925
Community Protection Waiver	$45,186,189	431	$8,730
Group Homes	$17,805,982	315	$4,710
State-Only	$211,541	7	$2,489
Core Waiver	$17,594,441	308	$4,760
Alternative Living Services	$1,587,895	288	$461
State-Only	$385,313	94	$343
Core Waiver	$1,202,582	194	$518
State-Operated Living Alternatives	$12,795,522	107	$9,973
State-Only	$449,821	3	$12,495
Core Waiver	$11,783,091	100	$9,827
Community Protection Waiver	$562,310	4	$11,715
Child Foster/Group Care (Core Waiver)	$3,030,125	95	$2,653
Child Staffed Residential (Core Waiver)	$7,889,826	70	$9,348
Community ICF/MRs	$4,536,428	58	$6,527
Companion Homes	$2,306,553	44	$4,413
State-Only	$134,798	2	$5,861
Core Waiver	$2,171,755	42	$4,344
Other Community Services[b]		n/a	n/a
State-Only	$560,279	n/a	n/a
Core Waiver	$7,511,817	n/a	n/a
Community Protection Waiver	$1,527,440	n/a	n/a

* *Source: DDD EMIS DATAR report for February 2009. These expenditures differ slightly from Exhibit 1.3, due to differences in the dates the data were pulled, and the differences in accounting between DDD and OFM.*

[a] *The total includes State Operated Living Alternatives.*

[b] *These include cost-of-care adjustments, staff add-ons, and client allowances.*

Research Evidence on Community Residential Services

Due to the policy goal of moving institutional residents into the community, there have been many attempts to track "movers" and measure their progress in relation to similar clients who remained institutionalized. Most studies of community residential services that meet the inclusion criteria for this study are conducted through a matched comparison group design.

In the most rigorous studies, baseline measures were taken before "movers" left the institution. Movers were then matched on those baseline measures (often age, gender, level of intellectual disability, and adaptive behavior skills) with equivalent "stayers," and these pairs were followed over a period of time, as the "movers" were established in community residences.

In Washington, this kind of study would not be possible using existing data. As discussed earlier (see page 8), the new standardized DDD assessment will not be provided to clients who entered residence in an RHC before the implementation of the assessment. If a current RHC resident were to move into the community, we would not have a comparable baseline measure for that person against which to measure change.

In addition to studying outcomes for individuals in institutions compared to those in the community, some attempts have been made to evaluate personal care services. The Campbell Collaboration published two systematic reviews of Personal Assistance (personal care services), and identified both Cash and Counseling (Carlson et al., 2007) and Pennsylvania's domiciliary care pilot (Sherwood & Morris, 1983) as personal assistance programs. In our reading, these evaluations compare (1) self-direction of personal care services (Cash and Counseling), and (2) a specific community residential model including personal care services (domiciliary care), not the effectiveness of personal care services per se.

Most studies in this review compared some kind of community residential placement with institutional living. In Exhibit 2.1, the findings of these studies were summarized under the heading "Community residential placement (vs. institution or nursing home)." Exhibit 3.3 (see next page) provides more detail on the following sub-categories of residential arrangements:

- Various community residential placements (vs. institution or nursing home);
- Supported living (vs. institution or nursing home);
- Domiciliary care (vs. institution);
- Group homes (vs. institution or nursing home); and
- Community ICF/MR (vs. institution).

Two studies compared different types of community placements, the findings of which are summarized under the heading "Community residential placement (less vs. more restrictive)" in Exhibit 2.1. As described in more detail in Exhibit 3.3, these comparisons include:

- Supported living (vs. cluster centers); and
- Community ICF/MR (vs. other community setting).

Exhibit 3.3

Research on Community Residential Services for Adults With Various Developmental Disabilities

Type of Comparison	Studies Included	Description of Findings
Various community residential placements (vs. institution or nursing home)	Stancliffe & Abery, 1997 Stancliffe & Lakin, 1999 Stancliffe & Lakin, 2006	One state's efforts to shift from an institutional to a community model of care were documented in the Minnesota Longitudinal Study. Findings from this study demonstrate that people who moved into the community have larger social networks, more contact with their families, and better "consumer choice" than their counterparts who remain institutionalized. However, the study found that clients living in the community had lower earnings than those in institutions, and were no more likely to be in paid employment.
	Lerman et al., 2005	On average, "movers" in one New Jersey study demonstrated better "multicognition" and self care, but no difference in mobility.
	Rosen, 1985	In Arkansas, one study found that clients who had been randomly assigned to community living after being in an institution had significantly better adaptive behavior than did those who remained in the institution.
	Heller et al., 2002	A long term study of Chicago-area nursing homes found that those who moved into the community had significantly better adaptive behavior and community integration after eight years than those who stayed in nursing homes.
	Conroy & Bradley, 1985 Bradley et al., 1986	The Pennhurst Longitudinal Study in Pennsylvania found that individuals who had moved into the community had better adaptive behavior skills than those who remained institutionalized, but problem behavior was unchanged. The same outcomes were found for a group of individuals in New Hampshire.
Supported living (vs. institution or nursing home)	Spreat & Conroy, 2001 Spreat et al., 1998	In Oklahoma, two studies compared outcomes for people living in supported living arrangements with outcomes for those in institutions or nursing homes. One study examined adults with profound intellectual disabilities, and found that those in supported living had no differences in adaptive behavior compared to those who had never left the institution. Individuals in supported living spent significantly less time in work-related activities, but were more integrated into their communities than were clients in the institution. The second study examined residents of nursing homes who had intellectual disabilities, and compared outcomes for those who stayed and those who moved into the community. "Movers" had better adaptive behavior and more employment-related goals, but there was no difference in challenging behavior between groups.
Domiciliary care (vs. institution)	Sherwood & Morris, 1983	In Pennsylvania, an early experiment in community care was "domiciliary care," provided in small homes where residents were treated as family members. The authors found that this arrangement improved unmet needs and adaptive behavior skills relative to institutional care, but had no significant impact on social support.
Group homes (vs. institution or nursing home)	D'Amico et al., 1978 Davis, 1990	A West Virginia study compared older adolescents and young adults (aged 15 to 25) who had moved to group homes with those who remained living in an institution. This study found better adaptive behavior for the "movers." A Pennsylvania study found that those who moved to community living arrangements (very similar to group homes) did not have significantly different adaptive or maladaptive behavior than those who had stayed in a nursing home, four years later.
Community ICF/MR (vs. institution)	Calapai, 1989	In New York, one study examined outcomes for those who moved from a large institution into a smaller Community ICF/MR with outcomes for those who had remained institutionalized, and found no significant differences in adaptive behavior.
Supported living (vs. cluster centers)	Young, 2006	One study in Australia compared individuals living in "dispersed homes" (similar to supported living in Washington) to a matched group of people living in "cluster centres," a model that clusters seven or eight small group homes (three or four residents per home) around a central administration center with common support staff. This study found no significant differences in adaptive behavior two years after relocation.
Community ICF/MR (vs. other community setting)	Stancliffe et al., 2002	The Minnesota study (as described in the top row of this table) also found that the type of community residence (e.g., community ICF/MR vs. other kind of community setting) did not affect adaptive or challenging behavior, but the size of the residence did: clients living in placements with fewer residents had better behavior outcomes than those living in larger settings.

Comparative-Cost Research on Community Residential Services

In addition to measuring quality-of-life benefits, some researchers have also attempted to compare the economic costs of providing residential services and supports in the community to individuals with developmental disabilities.

In analyses of the relative costs of providing services in the community compared to an institution, there are several approaches. One approach is to survey institutional and community residences of various types and sizes to find out the costs, on average, to provide residential services to each client. These costs might include staffing, facility operation such as utilities, property taxes, administration, medical, food, and so forth.

Another approach is to identify a group of individuals living in the community, add the costs of the services they receive, and then compare these costs with the costs of supporting a similar group of people in an institution.

Comparing the cost of providing services in the community to institutional settings requires attention to factors such as:

- The level of care provided to each client;
- The degree of medical attention required for each client; and
- The intensity of supervision necessary to support each client.

There is wide variation among these factors in both client needs and services provided. For example, a particular institution serving people with high medical needs may have higher costs than an institution that serves people with lower medical needs. Also, some types of residences will be more expensive than others by design. For example, an ICF/MR is designed to provide 24-hour active care, which requires higher levels of staff hours than some supported living arrangements in which staffing is intentionally limited.

The characteristics of the residents and the services being provided must be taken into consideration when drawing conclusions about the cost-efficiency of services.

Two analyses of payment data[33] found that the costs of providing residential services (community or institutional) can depend on a number of specific resident and facility characteristics. For example, the following characteristics can increase the cost of services:

- More staff hours;
- State employees (versus non-state staff);
- Challenging behavior of residents;
- Higher medical and mental health needs;
- Older residents; and
- Providing day activities.

On the other hand, the following factors can reduce the cost of services:

- Better adaptive behavior of residents;
- Less severe intellectual disabilities; and
- Providing supported employment.

Because all these factors and others can influence residential costs, our cost summary focuses on studies that directly compared the costs of serving a group of people in some kind of community residence with the costs of serving *a similar group of people* in an institutional living situation, or in a different kind of community placement. We found four studies that fit this description and an additional study that compared the costs of self-directed care services (Cash and Counseling) with service-as-usual. Exhibit 3.4 summarizes the research findings from these studies.

Although the studies described below compared samples of similar clients across residential settings (i.e., the mix of people with various levels of disability and needs were comparable across residential settings), none of the studies specifically compared the costs of serving clients with the most profound disabilities in an institution to the costs of serving that particular group of clients in the community.

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[33] E.M. Campbell, J.R. Fortune, J.K. Frisch, L.W. Heal, K.B. Heinlein, R.M. Lynch, & D.D. Severance (2005). Predictors of expenditures in western states. In R.J. Stancliffe & K.C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities*, Baltimore, MD: Paul H. Brookes Publishing Co., pp. 175–201.
K.C. Lakin, A. Hewitt, S.A. Larson, & R.J. Stancliffe (2005). Home and community-based services: Costs, utilization, and outcomes. In R.J. Stancliffe & K.C. Lakin, pp. 91–127.

Exhibit 3.4
Comparative Cost Research on Community Residential Services
(All costs expressed in 2008 dollars, per Institute calculations)

Type of Comparison	Studies Included	Description of Findings	Summary of Comparative Costs (annualized)
Various community placements (vs. institution or nursing home)	Spreat et al., 2005	One study in Oklahoma compared paid claims data for a group of people living in institutions (mostly ICF/MRs, but a few in nursing homes) with a similar group of people living in a variety of community settings, primarily supported living, but some in group homes, companion homes, or assisted living. The groups were matched for gender, age, adaptive behavior scores, and frequency of challenging behavior. The authors examined housing costs and program costs to find an average total service package cost for each group. These costs included: housing, case management, day programs (including employment or vocational services), education, and medical expenses.	The study found that the average cost of supporting a resident in the community was **$147,444**, 12 percent less than a cost of **$165,770** for institutional care.
	Stancliffe & Lakin, 1998	In the Minnesota Longitudinal Study, various community settings were compared with institutions for individuals with severe or profound intellectual disabilities. Initial differences between groups in level of intellectual disability, adaptive behavior, and challenging behavior were statistically controlled in the analysis of residential and day program service costs.	After controlling for participant characteristics, the authors calculated an average cost of **$102,779** for community placements, 51 percent less than **$155,675** for institutional living.
Domiciliary care (vs. institution or other community setting)	Ruchlin & Morris, 1983	The domiciliary care pilot program in Pennsylvania provided community placement in a family-like setting, usually in a single-family home serving one to three clients, but sometimes in a larger setting (up to 13 clients). Costs for this study were calculated using the average domiciliary care program operating cost per participant, and adding the number of days each participant spent in other placements, including: acute hospital care, mental health facilities, intellectual disability facilities, skilled nursing facilities, ICF/MRs, and regular community settings. In addition, the costs of providing other community supports and informal care services were summed, including: counseling, meal preparation, homemaking services, transportation, personal care, medical care, visiting nurse care, therapy, and day care.	The authors found that domiciliary care was significantly less expensive than institutional care, but slightly more expensive than other kinds of community care. The domiciliary care sample cost on average **$35,868**, 54 percent less than the **$78,159** for the institutional sample. However, domiciliary care for the community subsample cost **$20,561,** or 18 percent *more* than the **$17,359** for other kinds of community care.

Exhibit 3.4 (continued)

Comparative Cost Research on Community Residential Services

(All costs expressed in 2008 dollars, per Institute calculations)

Type of Comparison	Studies Included	Description of Findings	Summary of Comparative Costs (annualized)
Supported living (vs. group home)	Emerson et al., 2001	One study in the United Kingdom compared the relative costs of three different kinds of community residences: supported living (in a residence with no more than three people with mental retardation), small group homes (with one to three co-residents), and large group homes (with four to six co-residents). The groups of people living in the three types of community placements had different characteristics: individuals in small group homes were significantly younger than those in supported living or large group homes. Individuals in supported living had significantly better adaptive behavior scores than did those living in large group homes. The authors statistically controlled for these variables when comparing costs.	The authors calculated a service package cost for each individual, including: housing, hospital services, community-based services, day centers, and education and training programs. After controlling for participant characteristics, the costs of supported living were higher than the costs of both sizes of group homes. The authors calculated an average annual cost of **$115,542** for supported living, **$109,004** for small group homes, and **$102,984** for large group homes.
Cash and Counseling (vs. service-as-usual)	Dale & Brown, 2007	Cash and Counseling was provided to children and adults with developmental disabilities in Florida. The program provided each individual with a monthly cash payment and a counseling service, to help them create a spending plan for the services they wanted to purchase. This allowed clients more flexibility in choosing their plan of care than did "service-as-usual," where services were more prescriptive. The groups who received Cash and Counseling were different from the groups who received services-as-usual on a number of personal characteristics. The authors statistically controlled for these pre-existing differences, as well as for baseline Medicaid expenditures, diagnoses, and enrollment in other Medicaid programs when comparing costs of services.	Cash and Counseling cost more to provide than did services-as-usual. Total Medicaid costs for adults receiving Cash and Counseling were **$34,224** for the second year of the program, compared to **$30,152** for adults receiving service-as-usual. For children, Cash and Counseling cost **$37,862**, compared to **$34,941** for those receiving services-as-usual.

WSIPP, 2009

Overall, the studies we reviewed found that care in the community is generally less expensive than care in an institution *for similar groups of people*. Two studies found that care in community settings cost 12 percent to 51 percent less than institutional care. A third study found that domiciliary care in the community cost 54 percent less than institutional care.

When comparing different types of community settings, the economics are less clear. There are many different kinds of community placements, and only two studies have directly compared their various costs. One study found that domiciliary care in the community cost 18 percent more than other kinds of community placements, and another found that supported living in the UK cost more than group home services. The available evidence does not provide a clear conclusion about the relative costs of different community placements.

In addition, the studies above do not include possible costs to a client's family that may vary if he or she lives in an institution or in a community setting. These and other expenses may also influence the overall costs of providing residential services in the community.

As noted above, characteristics of clients and of the physical residence have a strong impact on the costs of services, no matter where they are provided.

Employment and Day Programs in Washington

As shown in Exhibit 1.4 (page 10), the fourth largest category of DDD expenditures is Employment and Day programs. DDD contracts with counties to provide these services to nearly 10,000 individuals statewide. The specific services available include three categories of employment services:

- Supported employment;
- Person-to-person services;
- Pre-vocational services;

and two other types of day programs:

- Child development services;
- Community access.

Supported employment provides support to people in different kinds of jobs, as well as job training, job planning, and goal-setting. In Washington, nearly half (46 percent) of people in employment or day programs receive supported employment services. There are two types of supported employment programs:

- *Individual* supported employment offers job development services and on-the-job training and support from a job coach. Over time, as an individual grows more skilled and confident in his or her employment, the involvement of the job coach may decrease. In Washington, the individual model of supported employment is the goal for all clients receiving employment services.[34]

- *Group* supported employment offers employment as part of a team, in a regular business setting. One example might be a mobile landscaping crew that is supervised by county employment staff; another might be a janitorial team.

Person-to-person services (18 percent of clients in employment and day programs) are provided to help people develop a plan for individual employment. Person-to-person clients receive one-on-one support as they explore their employment options and interests.

Pre-vocational services (otherwise known as Specialized Industries, formerly known as sheltered workshops) are provided to 7 percent of employment and day program clients. These are group- or team-based jobs, usually in a large group workshop setting. Clients may perform such tasks as assembling bulk mailings or packaging products for shipping.

Children and older adults may receive day programs. *Child development services* (22 percent of the clients in employment and day programs) provide early intervention services to infants and toddlers and their families.[35]

Community access services (3 percent of the clients in employment and day programs) provide activities, and help to those aged 62 and over. Individuals between 21 and 62 may also receive these services, but they must first receive an official exception to the state's Working Age Adult Policy.[36] Implemented in 2006, this policy states that *"All individuals, of working age, regardless of the challenge of their disability, will be afforded an opportunity to pursue competitive employment."*[37]

Exhibit 3.5 displays the types of employment and day services available through Washington's counties, as well as the number of clients and expenditures for state-only clients and those on the various HCBS waivers.

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[34] Known as "Pathways to Employment," this goal was recommended by the Stakeholder Workgroup regarding adult employment and day program services. The recommendation was published in DDD's 2000 *Strategies for the Future Long-Range Plan Phase II Report* to the legislature.

[35] Child development services are county-funded services for children who meet the criteria for ITEIP services. Not all counties provide funds for child development services.

[36] DDD County Services for Working Age Adults Policy 4.11

[37] There have been no evaluations of the Working Age Adult Policy or similar policies that require employment rather than other day activities. This policy has been controversial; see M. O'Hagan (2007, August 19). People with disabilities face uncertain path to "real" jobs. *Seattle Times*. Retrieved June 30, 2009 from Seattle Times database.

Exhibit 3.5
Washington State Service Expenditures for Fiscal Year 2008: Employment and Day Services

	Actual Expenditures	Average Monthly Clients	Average Monthly Expenditure Per Client
Employment and Day Programs[a]	**$64,796,970**	**9,853**	**$548**
State-Only[b]	$23,563,586	4,908	$400
Total Waiver	$32,101,997	4,768	$561
Supported Employment	$26,533,059	4,573	$483
State-Only	$11,957,212	2,310	$431
Waiver	$ 14,575,847	2,263	$537
Person-to-Person (Waiver)	$12,363,021	1,731	$595
Pre-Vocational Services	$4,788,038	721	$553
State-Only	$801,783	120	$556
Waiver	$ 3,986,255	601	$553
Child Development Services (State-Only)	$6,089,210	2,168	$234
Community Access	$1,616,678	284	$475
State-Only	$439,804	72	$510
Waiver	$ 1,176,874	212	$462
Other County Programs (State-Only)	$4,275,577	n/a	n/a
County/Day Services for Clients in ICF/MRs (State-Only)	$345,985	42	$693

[a] From EMIS DATAR report, February 2009

[b] As mentioned in Exhibit 1.4, clients currently receiving state-only funded employment and day services who are eligible for a Medicaid HCBS waiver are being shifted for the 2009–11 biennium. Therefore, the balance will shift toward more employment and day clients being supported with a waiver, and fewer being supported by state-only funds.

Research Evidence on Supported Employment Services

As mentioned above, the DDD Working Age Adult Policy in Washington emphasizes supported employment services as the primary day service for adults with developmental disabilities between ages 21 and 62. This policy has not been evaluated in terms of client outcomes.

We found four comparison group studies about various kinds of supported employment. We did not find any comparison group studies of day programs such as community access.

Exhibit 3.6 (see next page) provides more detail on the following sub-categories of supported employment research:

- Transitional employment services (compared to services-as-usual);
- Supported employment (compared to sheltered employment); and
- Supported employment (comparing various approaches).

As shown in Exhibit 2.1, our analysis found that people with mild and moderate intellectual disabilities receiving supported employment services (relative to those receiving services-as-usual) had:

- Higher rates of employment;
- Higher wages; and
- Better adaptive behavior.

Exhibit 3.6

Research on Supported Employment Services for Adults With Various Developmental Disabilities

Type of Comparison	Studies Included	Description of Findings
Supported employment (Transitional employment services)	Decker & Thornton, 1995	The Social Security Administration's Transitional Employment Training Demonstration (TETD) program randomly assigned adults with intellectual disabilities (aged 18 to 40) to receive TETD services or services-as-usual. Most of the participants (84 percent) had a mild or moderate intellectual disability. Demonstration services included obtaining waivers to protect Social Security benefits while earning additional wages, job placement, on-the-job training, and job retention services (post-placement support and follow-up). These services lasted up to one year, after which the participants were expected to maintain individual employment without agency support. Six years after participants began receiving services (about five years after those services would have ended), TETD participants were significantly more likely to be employed, and were earning more wages annually, than people who received services-as-usual.
	Kerachsky et al., 1985	The Structured Training and Employment Transitional Services program (STETS) randomly assigned young adults (aged 18 to 24) with a mild or moderate intellectual disability to STETS or to services-as-usual. STETS included three phases of employment support: (1) initial training and support services in a low-stress work environment; (2) on-the-job training in real business environments; and (3) unsubsidized competitive employment with limited follow-up services. Phases 1 and 2 together lasted one year or less. This model is similar to the graduated supported employment model (e.g., the "pathway" to individual employment) used in Washington. Nearly two years after participants had been assigned to the program, they were equally likely as those receiving services-as-usual to be employed in any job. However, STETS participants were significantly more likely than the comparison group to be employed in a "regular" job (e.g., one that was not a training or workshop job). STETS participants also worked significantly more hours per week and earned higher wages.
Supported employment (vs. sheltered employment)	McCaughrin et al., 1993	This study had too few participants to include in our meta-analysis, but we describe the results here. On average, compared with sheltered employment (similar to Washington's pre-vocational services), wages for the ten supported employees (similar to Washington's individual supported employment) were higher. The difference in wages was greater for individuals with a mild intellectual disability than for those with a moderate or severe intellectual disability.
Supported employment (comparing various approaches)	Stephens et al., 2005	In Oklahoma, one study measured adaptive behavior for individuals who had moved from (1) no employment to some kind of employment, or (2) from one type of employment to another. Outcomes for these individuals were compared with those who had remained unemployed or who had stayed in the same kind of employment from one year to the next. The types of employment studied (and their analogs in Washington) were: • No employment • Competitive employment (Individual supported employment) • Supported employment (Group supported employment) • Sheltered employment (Pre-vocational services) Those who moved from unemployment to any kind of employment showed significantly higher adaptive behavior at follow-up than those who remained unemployed. In addition, those who moved "up," e.g., from supported to competitive or from sheltered to supported, also showed increased adaptive behavior skills relative to those who stayed in the same type of employment.

Comparative-Cost Research on Supported Employment Services

In addition to measuring the quality-of-life benefits of programs on people's lives, some researchers have also attempted to compare the economic costs of providing employment services to individuals with developmental disabilities.

The following factors can influence the public costs of providing supported employment:

- Intensity of support services;
- Level of client needs;
- Offset public costs, e.g.:
  - ✓ Taxes paid by employee
  - ✓ Reduced need for public benefits for employee

In the literature, there are two general approaches to the analysis of the costs of supported employment programs. The most rigorous studies employ a matched comparison group design. In these studies, the costs of providing supported employment to one group of people are compared with the costs of providing an alternative service (e.g., sheltered employment) to a similar group. The similarities between groups are key; in order to conclude that any differences in measured outcomes are due to the program, we must be able to rule out the possibility that cost differences could be caused by variation in participant characteristics.

The other common way to examine costs of employment is to calculate average costs for a group of supported employees, then compare those numbers with a hypothetical alternative, such as no employment or sheltered employment, using average costs for these services. This method is not as precise as the method described above, because it does not take into account the variety in participant characteristics that may contribute to differences in program outcome.

Three of the four comparison group studies of supported employment described in the previous section included analyses of the relative costs of program services. The economic findings of these studies are presented in Exhibit 3.7.

Exhibit 3.7

Three Comparison Group Studies of the Benefits and Costs of Supported Employment

(All costs expressed in 2008 dollars, per Institute calculations)

Type of Comparison	Studies Included	Description of Findings	Summary of Comparative Costs
Supported employment (Transitional employment services)	Decker & Thornton, 1995	Over a six-year period, the TETD program cost $9,755 on average. The authors did not calculate the program costs of services-as-usual. Program participants earned $7,459 more than the comparison group in average wages, and received $1,516 less in Supplemental Security Income due to increased income.	Program cost: **$9,755** Average wages earned: **$7,459** more than comparison group. Other public costs: **$1,516** less than comparison group.
	Kerachsky et al., 1985	Over a 22-month period (including program and follow-up), the STETS program cost $12,460 on average, compared to an average of $3,479 for services-as-usual. During that time, participants earned an average of $6,182 in wages. In addition, participants received $1,155 less than the comparison group in other public benefits, including: $527 in Supplemental Security Income, $164 in public assistance, and $464 in Medicaid services. Participants also paid an average of $497 more in taxes, due to their increased wages.	Program cost: **$8,981** more than comparison group. Average wages earned: **$6,182** more than comparison group. Other public costs: **$1,155** less than comparison group.

Exhibit 3.7 (continued)

Three Comparison Group Studies of the Benefits and Costs of Supported Employment

(All costs expressed in 2008 dollars, per Institute calculations)

Type of Comparison	Studies Included	Description of Findings	Summary of Comparative Costs
Supported employment (vs. sheltered employment)	McCaughrin et al., 1993	In this small study, five supported employees with mild intellectual disabilities cost $5,961 to support in the fifth year of the program. Sheltered employment services-as-usual for an equivalent group cost $6,575 on average. In addition, supported employees earned $7,150 more than sheltered employees in wages. Among a small group of individuals with moderate to severe intellectual disabilities, supported employment cost $9,507 compared to $9,670 for sheltered employment. Among these individuals, supported employees earned $1,873 more than sheltered employees.	Employees with mild intellectual disabilities: Program cost: **$614** less than comparison group. Average wages earned: **$7,150** more than comparison group. Employees with moderate or severe intellectual disabilities: Program cost: **$163** less than comparison group. Average wages earned: **$1,873** more than comparison group.

In all three studies, supported employees earned more than those in the comparison groups. Increased earnings also led to higher taxes and lesser reliance on public benefits. The program costs of supported employment in these studies were comparable to or higher than services-as-usual; program costs vary depending on the intensity of services and level of client needs.

Most of the research on supported employment focuses on individuals with mild levels of disability; one study with ten clients (McCaughrin et al., 1993) examined the impact of supported employment services for individuals with moderate or severe intellectual disabilities. Because of this limited research base, we cannot assume that the benefits of supported employment would be equivalent for all individuals.

Example of the Costs of Supported Employment in Washington

In Washington, employment services vary widely, from intensive one-on-one services (provided in person-to-person), to minimal supervision (provided to individual supported employees in competitive jobs). To provide an example, we examined 2008 data from King County.[38] This summary represents only one county in the state, but can serve as an illustration of the varying costs involved in supported employment.

Exhibit 3.8 shows the number of people employed by county-provided employment programs in King County in 2008, and the number earning wages in each category. According to estimates by the King County Developmental Disabilities Division, the average person in individual supported employment who is earning wages worked nearly 22 hours per week, and earned $1,009 in monthly wages. That individual would also receive an additional $212 in Supplemental Security Income (reduced from the standard payment of $674 to reflect earned wages). Of his or her monthly earnings, the wage earner would contribute $76 to Social Security (matched by a $76 employer contribution), and spend approximately $49 in sales taxes, according to King County estimates.

Exhibit 3.8 also displays the average monthly cost per client of providing each kind of employment service (including clients who are earning wages as well as those who are not); the bottom row (shaded) includes the baseline King County estimates of SSI payments and taxes paid by unemployed individuals with developmental disabilities.

This table is based on short-term calculations. The calculations do not include information on how long clients stay in each kind of employment situation, and how often clients move from one kind of employment to another.

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[38] Data provided by Ray Jensen, Director, King County Developmental Disabilities Division, Department of Community and Human Services.

Exhibit 3.8

Example of the Costs of Supported Employment Services: King County, 2008

Type of Employment	Number Employed	Number Earning Wages	Average Monthly Earnings[a]	Average Hourly Wage[a]	SSI Income[a]	Taxes Paid[b]	Average Monthly Program Cost Per Client
Individual Supported Employment	869	819	$1,009	$10.77	$212	$201	$470
Group Supported Employment	105	105	$355	$5.14	$587	$74	$598
Pre-Vocational Services	238	233	$187	$2.30	$355	$90	$601
Person-to-Person	829	285	$260	$6.15	$623	$60	$794
Unemployed Person	n/a	n/a	$0	$0	$674	$27	$0

[a] For those earning wages.

[b] This is a King County estimate, including employee and employer Social Security taxes and estimated sales taxes paid by the employee.

Summary

In our review of the research evidence, we found that the population of individuals with developmental disabilities is very diverse; when evaluating research evidence, we must ask "what works for whom?" Within different sub-populations of individuals with developmental disabilities, we found evidence that there are programs that demonstrate positive impacts on various life outcomes for people. However, we also found that many programs had not been evaluated with rigorous, comparison-group research designs.

Although comparison-group research designs are more difficult to carry out in vulnerable populations, such as individuals with developmental disabilities, they are possible and have been done in numerous settings. Washington would benefit from further research as new kinds of support programs are developed and implemented.

List of Appendices

Appendix A:
Glossary of Acronyms and Terms Used in This Report

Exhibit A.1

Acronyms

DDD—Division of Developmental Disabilities

DSHS—Department of Social and Health Services

HCBS—Home and Community Based Services

ICF/MR—Intermediate Care Facility for the Mentally Retarded

RHC—Residential Habilitation Center

SOLA—State Operated Living Alternative

Exhibit A.2

Terms

Adult family homes
A type of group home that provides out-of-home residential care for up to six residents. Individuals receive room, board, laundry, supervision, and assistance with activities of daily living (personal care).

Alternative living services
For individuals living independently in the community, who need some help with daily living skills. These services provide training and instruction for skills such as writing checks, shopping for groceries, or a number of other basic living skills. Alternative living can be provided for up to 40 hours per month, so although services may be similar to those provided in supported living, alternative living generally provides fewer service hours.

Child foster/group care
For children who cannot be cared for in their family homes. These children are placed out-of-home through the Children's Administration at DSHS, usually for reasons of neglect or maltreatment in their family home.

Child staffed residential
For children who cannot be cared for in their family homes. This service provides care in licensed homes with shift workers rather than families. In many cases, these arrangements serve older adolescents with behavior difficulties that may be difficult for an individual family to address.

Community ICF/MR—Intermediate Care Facility for the Mentally Retarded
For individuals who need 24-hour active support. The ICF/MR is an institutional model, but in the community, the average size is seven residents, and these settings look much more like a group home than a residential habilitation center.

Companion homes
For adults who need access to 24-hour supervision. Companion homes house no more than one adult client of DDD and, therefore, are similar to a foster care model for adults. Residents of Companion Homes pay their providers directly for room and board expenses.

Group homes
For individuals who need access to 24-hour support. People living in group homes contribute toward room and board expenses (generally through their monthly SSI allotments), and generally live with four to 20 co-residents. Group homes can be licensed as Adult Family Homes or Boarding Homes.

HCBS Waivers
A Medicaid-supported alternative to living in an institution; an individual on an HCBS waiver waives his or her right to institutional care, and is instead provided care in their own homes or in another community residential setting. There are five types of waivers in Washington:

> **Basic.** For individuals who need some level of care, but do not need out-of-home residential services. This waiver generally provides professional services (such as physical or occupational therapy), medical equipment, personal care, and community programs (e.g., supported employment) for individuals living in their family homes or in their own homes.
>
> **Basic Plus.** For individuals who are at high risk[39] of being placed out-of-home or losing their current living situation. This waiver provides the same services as the basic waiver, but at higher service cap levels. This waiver also includes provision of some out-of-home residential services, such as adult family homes or adult boarding homes.
>
> **Core.** For individuals with higher levels of need, who either require out-of-home residential services, or are at immediate risk[40] of being placed out-of-home. Most people on the core waiver receive out-of-home residential care, the majority within a supported living arrangement, although some live in group homes, companion homes, or other residential situations.
>
> **Community Protection.** Restricted to individuals who must be supervised by staff 24 hours a day to ensure the safety of others. Nearly all individuals on the community protection waiver live in supported living arrangements offered by Community Protection Certified Supported Living providers.
>
> **Children's Intensive In-Home Behavioral Supports.** New in May 2009, this waiver is for children at high risk of being placed in an institution and provides in-home services to children and their families, caregivers, and schools in the form of positive behavioral support training. Children can also receive specialized therapies, and families can receive respite care and minor modifications for their homes and vehicles.

Individual and Family Services Program
Provides a number of services to help support individuals and families. Families can choose what services they receive, within their allocation. The DDD assessment determines what allocation an individual receives; $1,000, $2,000, $3,000, or $4,000. The service choices include respite care, therapies, transportation, counseling, and behavior management, among others.

Personal care
For individuals who need help with activities of daily living, such as bathing, dressing, meal preparation, housekeeping, etc. This service provides one-on-one assistance with these tasks, to enable an individual to live successfully in the community. Most recipients of personal care live at home with their families, but about 15 percent live in a Group Home setting.

Professional services
Services provided to clients beyond what they can access through Medicaid and any other available private health insurance. These may include nursing care, occupational or physical therapy, behavior management or counseling, or medical or psychiatric services. These services are available only after Medicaid and any other available private health insurance have been accessed.

State Operated Living Alternatives (SOLAs)
For individuals who need help living independently, outside of their family homes. These living situations are nearly identical to supported living (see below), with one primary difference: SOLAs are operated by state employees directly through DDD, not contracted to private providers.

Supported employment

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[39] High risk means the person either has high acuity needs and a caregiver is available/present but has requested additional support and/or consideration of out-of-home placement; **or** the person has medium acuity needs and a caregiver has requested out-of-home placement.
[40] Immediate risk means that the person has high acuity needs; a caregiver is unavailable/absent; the person has no available residence.

Provides support to people in different kinds of jobs, as well as job training, job planning and goal-setting. In Washington, all clients not in individual supported employment arrangements are considered as being on a pathway to individual employment.

> **Individual supported employment.** Offers job development services and on-the-job training and support from a job coach. Over time, as an individual grows more skilled and confident in his or her employment, the involvement of the job coach decreases.
>
> **Group supported employment.** Offers employment as part of a team in a regular business setting. One example might be a mobile landscaping crew that is supervised by county employment staff; another might be a janitorial team.
>
> **Pre-vocational services.** Group- or team-based employment, generally in a large group workshop setting. Clients may perform such tasks as assembling bulk mailings, packaging products for shipping, for example.
>
> **Person-to-person.** Offers help and support to develop a plan toward individual employment. Person-to-person clients receive one-on-one support as they explore their employment options and interests.

Supported living

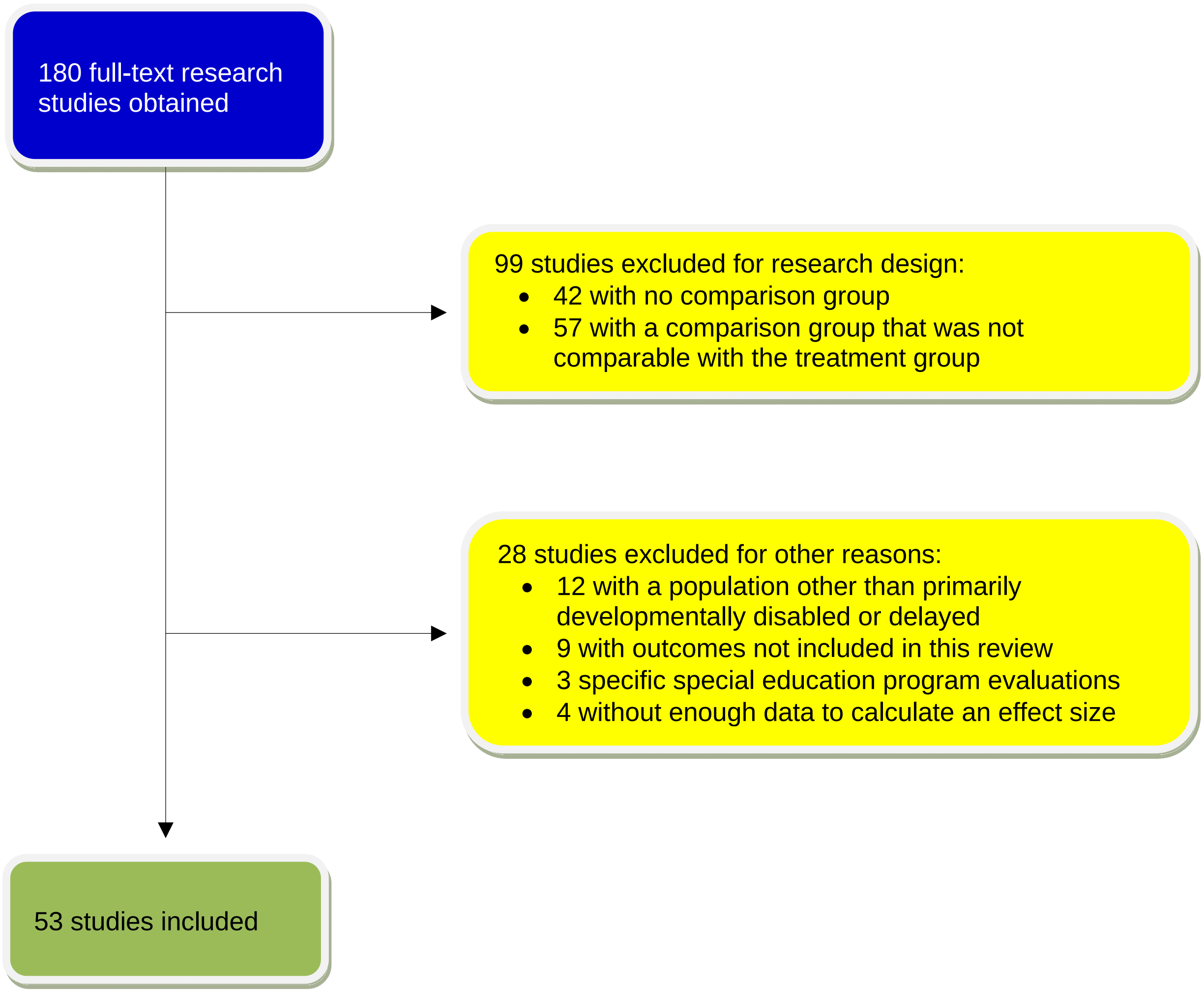
For individuals who need help living independently, outside of their family homes. These services are used by 73 percent of those living in the community outside the family home. Clients live in rented accommodations in the community, but services vary widely; all clients receive instruction and support in their own homes in the community, but the hours of service can vary from a few hours per month to full-time (24-hour) individual support. Supported living clients live independently: they pay their own personal expenses, including rent and food.

Appendix B:
Research Outcomes Included in Our Review

Outcome Type	Measured by:
Cognitive development	Stanford-Binet IQ Bayley Scales of Infant Development (Mental) Early Intervention Developmental Profile Griffiths Scale of Infant Development Leiter International Performance Scale Merrill-Palmer Scale of Mental Tests New Jersey Client Assessment Form (adults) Ordinal Scales of Development Peabody Picture Vocabulary Test Preschool Developmental Profile Wechsler Intelligence Scale for Children Wechsler Preschool and Primary Scale of Intelligence
Language skills	Early Social Communication Scales MacArthur Communication Development Inventory Reynell Developmental Language Scales Sequenced Inventory of Communication Development
Motor skills / activity	Bayley Scales of Infant Development (Motor) Early Intervention Developmental Profile New Jersey Client Assessment Form (adults) Peabody Fine Motor Scales Preschool Developmental Profile Quality of Upper-Extremity Skills Test (cerebral palsy)
Adaptive behavior	Aberrant Behavior Checklist Adaptive Behavior Scale Behavior Development Survey Behavior Screening Questionnaire Camelot Behavioral Checklist Client Development Evaluation Report Developmental Behavior Checklist (parent or teacher form) Family Observation Schedule Inventory of Client and Agency Planning Broad Independence Scale Instrumental Activities of Daily Living Community Survival Scale Minnesota Developmental Programming System New Jersey Client Assessment Form New York Developmental Disability Information Survey (adaptive behavior scale) Oklahoma Developmental Disabilities Quality Assurance Questionnaire Street Survival Skills Questionnaire Vineland Adaptive Behavior Scales
Problem / challenging / maladaptive behavior	Behavior Development Survey Caregiving Problem Checklist Checklist for Challenging Behavior Child Behavior Checklist Client Development Evaluation Report Developmental Behavior Checklist (parent or teacher form) Eyberg Child Behavior Inventory Family Observation Schedule Inventory of Client and Agency Planning General Maladaptive Scale Strengths and Difficulties Questionnaire

Outcome Type	Measured by:
Parental depression	Beck Depression Inventory Depression, Anxiety and Stress Scales
Parental stress / anxiety	Depression, Anxiety and Stress Scales Parental Stress Index Questionnaire on Resources and Stress State-Trait Anxiety Inventory Stress Arousal Checklist
Health	Cash and Counseling client survey General Health Questionnaire Multi-Level Assessment List: Physical Health Scale
Community integration / social support	Involvement Scale Community Integration Scale Oklahoma Developmental Disabilities Quality Assurance Questionnaire Perceived Social Support Scale Survey of service providers
Quality of life—general	Unmet Needs Summary Scale Cash and Counseling client survey Choice Scale Consumer Choice Scale Life Circumstances Questionnaire Washington Psychosocial Seizure Inventory (epilepsy) World Health Organization Quality of Life (Satisfaction With Life scale)
Employment / earnings	Employment agency data Social Security Administration Supplemental Security records Survey of service providers
Autistic behavior	Autism Behavior Checklist Autism Diagnostic Interview Autism Diagnostic Observation Schedule Autism Screening Questionnaire
Seizure frequency	Patient calendar Patient diary

Appendix C:
Evidence Review Process



180 full-text research studies obtained

99 studies excluded for research design:

- 42 with no comparison group
- 57 with a comparison group that was not comparable with the treatment group

28 studies excluded for other reasons:

- 12 with a population other than primarily developmentally disabled or delayed
- 9 with outcomes not included in this review
- 3 specific special education program evaluations
- 4 without enough data to calculate an effect size

53 studies included

Appendix D:
Descriptions of Programs Included in This Review

Program/ Program Type	Studies Included in This Analysis	Name of Specific Programs Included in This Category	Description of Intervention
Programs for Children With Non-Specific or Various Developmental Disabilities			
Parent support programs	Schultz et al., 1993 Seifer et al., 1991 Singer et al., 1989	• Caring for Parent Caregivers	Provide a variety of supports to parents as they raise their developmentally disabled children. These supports include referrals to service, parent support groups with child care, and respite services.
Group-based parent training	McIntyre, 2008 Plant & Sanders, 2007 Roberts et al., 2006 Quinn et al., 2007	• The Incredible Years • Stepping Stones Triple-P • Parents Plus Programme	Provides group instruction and support to parents on how to modify and improve the adaptive and functional behaviors of their children, and how to reduce their challenging behavior. All three of the programs included here are specifically targeted to parents of children with developmental disabilities. Parents learn through direct instruction, modeling, and role-playing, and receive support from their fellow group members.
Communication training	Girolametto, 1988 Tannock et al., 1992	• Hanen Early Language Program	The Hanen Early Language Program teaches parents to verbally engage with their children in a positive manner, with the goals of increasing children's comprehension, vocabulary, and self-expression.
Early preschool in a hospital clinic setting	Goodman et al., 2004		Intensive preschool program (2 to 5 days per week) with parental participation provided in a hospital setting. Families were also provided home visits on an as-needed basis, and some additional treatments (as needed) from medical specialists. Emphasis was on general cognitive development rather than building specific skills.
Supportive home visiting services	Davis & Rushton, 1991	• Parent Adviser Scheme	Provides regular home visits (weekly at first, then at longer intervals) by trained paraprofessionals to parents of children with disabilities. The visitors in the Parent Adviser Scheme primarily provided counseling and family facilitation, along with referrals to professional services when needed.
Portage Curriculum	Thomaidis et al., 2000	• Portage Early Education Curriculum	Weekly visits from an early intervention advisor for two years. Parents were considered to be primary therapists, and worked with advisors to implement the Portage Early Education Curriculum. The goals are: increasing imitation, attentional focus, awareness of space, self-help skills, preacademic skills, and language acquisition.
Cash & Counseling	Carlson et al., 2007	• Cash & Counseling	Provides families with professional advice and a stipend that they can use to purchase the services they want, from providers they choose. This is an alternative to receiving personal care services-as-usual.
Programs for Children With Autism			
Intensive behavioral intervention	Cohen et al., 2006 Eikeseth et al., 2002 McEachin et al., 1993 Smith et al., 2000		25 to 40 hours of one-on-one treatment per week, for one to three years (length of treatment varied by study). Treatment begins in the home, and gradually moves to other environments as time goes on (although the Eikeseth study evaluated treatment that had happened primarily in a one-on-one setting at school). Focus is on teaching children appropriate behaviors, and speech and language skills, primarily using positive reinforcement techniques.
Auditory integration training (AIT)	Bettison, 1996 Rimland & Edelson, 1995 Zollweg et al., 1997		Usually provided to autistic children with heightened sensitivity to some sounds, AIT has children listen to modulated music in a controlled (clinic) setting for 30 minutes at a time, twice a day for ten days.

Program/ Program Type	Studies Included in This Analysis	Name of Specific Programs Included in This Category	Description of Intervention
Programs for Children With Autism (continued)			
Group- or clinic-based communication training	Aldred et al., 2004 McConachie et al., 2005	• Child's Talk • More Than Words	Communication training teaches parents how to engage and direct their children's attention to increase social interactions with their children and, thereby, improve children's social skills and adaptive functioning.
Autism Preschool Program	Jocelyn et al., 1998	• Autism Preschool Program	Children received day care with a one-on-one child care worker, plus 15 hours of educational seminars for parents and daycare workers, 30 hours of on-site consultation to daycare workers, and psycho-educational and supportive work with families, including two home visits.
Lower intensity behavioral intervention	Eldevik et al., 2006		See intensive behavioral intervention above. Lower intensity treatment includes fewer service hours (about 12 hours per week in this study). In addition, most of this therapy took place at school, in a one-on-one treatment room.
Home-based communication training	Drew et al., 2002		Three-hour home visits by a speech and language therapist every six weeks for 12 months. Goal was to train parents as "therapists," teaching attention skills, speech and language skills, and behavior management through structuring everyday routines.
Programs for Children With Cerebral Palsy			
Intensive vs. regular physical therapy	Law et al., 1991 Mayo, 1991 Palmer et al., 1988		Intensive physical therapy (Law provided twice weekly therapy, Mayo provided once weekly therapy, and Palmer paired regular physical therapy with infant stimulation) compared with less intensive therapy.
Physical therapy (inhibitive casting)	Law et al., 1991 Taub et al., 2004	• Constraint-induced movement therapy	Intensive physical therapy to increase motor skills in a child's more impaired arm. Child's less impaired arm is casted to inhibit movement and encourage development of the less able extremity.
Vestibular stimulation	Sellick & Over, 1980		16 sessions of vestibular stimulation over four weeks. Children are physically spun horizontally and vertically to stimulate the vestibular system in the inner ear (which is responsible for balance and spatial orientation).
Programs for Children With Down Syndrome			
Developmental therapy	Piper & Pless, 1980 Sloper et al., 1986		Trains parents to do developmental activities with their children to encourage "normal" development, focusing on physical and mental tasks. The Sloper study was home-based, and the Piper & Pless study was center-based, but both were focused on helping parents do training exercises with their children.
Programs for Individuals with Drug-Resistant Epilepsy			
Cognitive-behavioral therapy	Lundgren et al., 2006 Tan & Bruni, 1986	• Acceptance & Commitment Therapy	Provides a cognitive-behavioral framework for changing thoughts about seizures and adjusting behavioral responses to seizure triggers.
Relaxation training	Dahl et al., 1987 Puskarich et al., 1992 Snyder, 1983	• Contingent relaxation • Progressive relaxation	Gives clients systematic physical relaxation techniques to use when experiencing seizure triggers.
Biofeedback	Nagai et al., 2004		Trains clients to become aware of physical indications of seizure triggers (e.g., by teaching clients to identify and change their physiological arousal levels, as measured by galvanic skin response).

Program/ Program Type	Studies Included in This Analysis	Name of Specific Programs Included in This Category	Description of Intervention
Programs for Adults With Various Developmental Disabilities			
Community residential placement (vs. institution or nursing home)	Bradley et al., 1986 Calapai, 1989 Conroy & Bradley, 1985 D'Amico et al., 1978 Davis, 1990 Heller et al., 2002 Lerman et al., 2005 Rosen, 1985 Sherwood & Morris, 1983 Spreat & Conroy, 2001 Spreat et al., 1998 Stancliffe & Abery, 1997 Stancliffe & Lakin, 1999 Stancliffe & Lakin, 2006		Out-of-home residential placements provided as an alternative to living in an institutional environment. There are many models of community residences, including group homes, supported living services, and adult foster care. In these studies, outcomes are compared between residents in the community and equivalent clients who live in institutions.
Community residential placement (less vs. more restrictive)	Stancliffe et al., 2002 Young, 2006		Some studies that compared one kind of community residence with a more-restrictive community residence. For example, one study compared those living in HCBS waiver settings with those living in community ICF/MRs. The other study compared those in supported living arrangements with those living in "cluster homes."
Supported employment	Decker & Thornton, 1995 Kerachsky et al., 1985 McCaughrin et al., 1993 Stephens et al., 2005	• Transitional Employment Training Demonstration • Structured Training and Employment Transitional Services	Help clients find work in the community. These services can range from one-on-one employment counseling and goal-setting to minimally supported individual employment in a competitive business setting.
Behavioral training for institutional staff	Grey & McClean, 2007	• Positive Behavior Support	Positive behavioral training for staff of institutions; increases focus on individual client needs and abilities, with emphasis on positive reinforcement.
Cash and Counseling	Carlson et al., 2007	• Cash & Counseling	Provides families with professional advice and a stipend that they can use to purchase the services they want, from providers they choose. This is an alternative to receiving personal care services-as-usual.

Appendix E: Meta-Analytic Procedures

To estimate the effects of programs that affect outcomes for individuals with developmental disabilities, we conducted separate analyses of a number of key statistical relationships. In Appendix E, we describe the procedures we employed and the results we obtained in estimating the causal linkage between program participation and various outcomes. To estimate these key relationships, we conducted reviews of the relevant research literature. In recent years, researchers have developed a set of statistical tools to facilitate systematic reviews of evaluation evidence. This set of procedures is called “meta-analysis” and we employ that methodology in this study.[41] In Appendix E, we describe these general procedures, the unique adjustments we made to them, and the results of our meta-analyses.

E1. Study Selection and Coding Criteria

A meta-analysis is only as good as the selection and coding criteria used to conduct the study.[42] Following are the key choices we made and implemented.

Study Selection. We used five primary means to locate studies for the meta-analysis of programs for people with developmental disabilities: (a) we consulted the study lists of systematic and narrative reviews of the developmental disability research literature; (b) we examined the citations in the individual studies themselves; (c) we conducted independent literature searches of research databases using search engines such as Google, Proquest, Ebsco, ERIC, and SAGE; and (d) we contacted authors of primary research to learn about ongoing or unpublished evaluation work. As we will describe, the most important criteria for inclusion in our study was that an evaluation have a control or comparison group. Therefore, after first identifying all possible studies via these search methods, we attempted to determine whether the study was an outcome evaluation that had a comparison group. We also determined if each study evaluated a program within a population of individuals with developmental disabilities or delays, and if the outcomes measured were standardized or well-validated measures of development or quality of life. If a study met these criteria, we then secured a paper copy of the study for our review.

Peer-Reviewed and Other Studies. We examined all program evaluation studies we could locate with these search procedures. Many of these studies were published in peer-reviewed academic journals while many others were from government reports obtained from the agencies themselves. It is important to include non-peer reviewed studies, because it has been suggested that peer-reviewed publications may be biased to show positive program effects. Therefore, our meta-analysis includes all available studies regardless of published source.

Control and Comparison Group Studies. Our analysis only includes studies that had a control or comparison group. That is, we did not include studies with a single-group, pre-post research design. This choice was made because it is only through rigorous comparison group studies that causal relationships can be reliably estimated.

Exclusion of Studies of Program Completers Only. We did not include a comparison study in our meta-analytic review if the treatment group was made up solely of program completers. We adopted this rule because there are too many significant unobserved self-selection factors that distinguish a program completer from a program dropout, and these unobserved factors are likely to significantly bias estimated treatment effects. Some comparison group studies of program completers, however, also contain information on program dropouts in addition to a comparison group. In these situations, we included the study if sufficient information was provided to allow us to reconstruct an intent-to-treat group that included both completers and non-completers, or if the demonstrated rate of program non-completion was very small (e.g. under 10 percent). In these cases, the study still needed to meet the other inclusion requirements listed here.

Random Assignment and Quasi-Experiments. Random assignment studies were preferred for inclusion in our review, but we also included non-randomly assigned comparison groups. We only included quasi-experimental studies if sufficient information was provided to demonstrate comparability between the treatment and comparison groups on important pre-existing conditions such as age, gender, and pre-treatment characteristics such as level of intellectual disability or level of adaptive behavior.

Enough Information to Calculate an Effect Size. Following the statistical procedures in Lipsey and Wilson (2001), a study had to provide the necessary information to calculate an effect size. If the necessary information was not provided, the study was not included in our review.

Mean-Difference Effect Sizes. For this study, we coded mean-difference effect sizes following the procedures in Lipsey and Wilson (2001). For dichotomous measures, we used the D-cox transformation to approximate the mean difference effect size, as described in Sánchez-Meca, Marín-Martínez, and Chacón-Moscoso.[43] We chose to use the mean-difference effect size rather than the odds ratio effect size because we frequently coded both dichotomous and continuous outcomes (odds ratio effect sizes could also have been used with appropriate transformations).

Multivariate Results Preferred. Some studies presented two types of analyses: raw outcomes that were not adjusted for covariates such as age, gender, or pre-intervention characteristics; and those that had been adjusted with multivariate statistical methods. In these situations, we coded the multivariate outcomes.

Outcome Measures of Interest. Our primary outcomes of interest were development, functioning, and quality-of-life; for these outcomes, we recorded all standardized or reliable measures reported in the evaluations (see Appendix B). Relevant outcomes include, for example, adaptive behavior scores, cognitive development scores,

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[41] We follow the meta-analytic methods described in: M.W. Lipsey and D. Wilson. (2001). *Practical meta-analysis*. Thousand Oaks: Sage Publications.

[42] All studies used in the meta-analysis are identified in the references beginning on page 50 of this report. Many other studies were reviewed, but did not meet the criteria set for this analysis.

[43] J. Sánchez-Meca, F. Marín-Martínez, & S. Chacón-Moscoso. (2003). Effect-size indices for dichotomized outcomes in meta-analysis. *Psychological Methods*, *8*(4): 448-467.

and scores on quality-of-life surveys. We did not record process and quality measures such as client satisfaction, quality of services, etc.

Averaging Effect Sizes for Similar Outcomes. Some studies reported similar outcomes: e.g., a variety of quality-of-life measures, or a number of different measures of cognitive development. In such cases, we calculated an effect size for each measure and then took a simple average. As a result, each study coded in this analysis is associated with a single effect size for a given outcome.

Dichotomous Measures Preferred Over Continuous Measures. Some studies included two types of measures for the same outcome: a dichotomous (yes/no) outcome and a continuous (mean number) measure. In these situations, we coded an effect size for the dichotomous measure. Our rationale for this choice is that in small or relatively small sample studies, continuous measures of treatment outcomes can be unduly influenced by a small number of outliers, while dichotomous measures can avoid this problem. Of course, if a study only presented a continuous measure, we coded the continuous measure.

Longest Follow-Up Periods. When a study presented outcomes with varying follow-up periods, we generally coded the effect size for the longest follow-up period. The longest follow-up period allows us to gain the most insight into the long-run benefits and costs of various treatments. Occasionally, we did not use the longest follow-up period if it was clear that a longer reported follow-up period adversely affected the attrition rate of the treatment and comparison group samples.

Some Special Coding Rules for Effect Sizes. Most studies in our review had sufficient information to code exact mean-difference effect sizes. Some studies, however, reported some, but not all the information required. We followed the following rules for these situations:

- **Two-tail p-values.** Some studies only reported p-values for significance testing of program outcomes. When we had to rely on these results, if the study reported a one-tail p-value, we converted it to a two-tail test.
- **Declaration of significance by category.** Some studies reported results of statistical significance tests in terms of categories of p-values. Examples include: p<=.01, p<=.05, or non-significant at the p=.05 level. We calculated effect sizes for these categories by using the highest p-value in the category. Thus, if a study reported significance at p<=.05, we calculated the effect size at p=.05. This is the most conservative strategy. If the study simply stated a result was non-significant, we computed the effect size assuming a p-value of .50 (i.e. p=.50).

E2. Procedures for Calculating Effect Sizes

Effect sizes measure the degree to which a program has been shown to change an outcome for program participants relative to a comparison group. There are several methods used by meta-analysts to calculate effect sizes, as described in Lipsey and Wilson (2001). We use the standardized mean difference effect size for continuous measures and the D-cox transformation as described in Sánchez-Meca, Marín-Martínez, and Chacón-Moscoso[44] to approximate the mean difference effect size for dichotomous outcome variables.

E(1): $$d_{Cox} = \ln\left(\frac{p_e(1-p_c)}{p_c(1-p_e)}\right)/1.65$$

In Equation E(1), d_{cox} is the estimated effect size, which is derived by dividing the log odds ratio by the constant 1.65. *Pe*, represents the percentage outcome for the experimental or treatment group and, *Pc*, is the percentage outcome for the control group.

For continuous outcome measures, we use the standardized mean difference effect size statistic.[45]

E(2): $$ES_m = \frac{M_e - M_c}{\sqrt{\frac{SD_e^2 + SD_c^2}{2}}}$$

In the second equation, ES_m is the estimated standardized mean effect size where M_e is the mean outcome for the experimental group, M_c is the mean outcome for the control group, SD_e is the standard deviation of the mean outcome for the experimental group, and SD_c is the standard deviation of the mean outcome for the control group.

Often, research studies report the mean values needed to compute ES_m in E(2), but they fail to report the standard deviations. Sometimes, however, the research will report information about statistical tests or confidence intervals that can then allow the pooled standard deviation to be estimated. These procedures are also described in Lipsey and Wilson (2001).

Adjusting Effect Sizes for Small Sample Sizes
Since some studies have very small sample sizes, we follow the recommendation of many meta-analysts and adjust for this. Small sample sizes have been shown to upwardly bias effect sizes, especially when samples are less than 20. Following Hedges,[46] Lipsey and Wilson[47] report the "Hedges correction factor," which we use to adjust all mean difference effect sizes (*N* is the total sample size of the combined treatment and comparison groups):

E(3): $$ES'_m = \left[1 - \frac{3}{4N-9}\right] \times \left[ES_m\right]$$

Computing Weighted Average Effect Sizes, Confidence Intervals, and Homogeneity Tests. Once effect sizes are calculated for each program effect, the individual measures are summed to produce a weighted average effect size for a program area. We calculate the inverse variance weight

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[44] Sánchez-Meca, et al., *Effect-size indices for dichotomized outcomes in meta-analysis,* equation 18.

[45] Lipsey and Wilson, *Practical meta-analysis*, Table B.10, equation 1.

[46] L.V. Hedges. (1981) Distribution theory for Glass's estimator of effect size and related estimators. *Journal of Educational Statistics, 6*: 107-128.

[47] Lipsey and Wilson, *Practical meta-analysis*, 49, equation 3.22.

for each program effect and these weights are used to compute the average. These calculations involve three steps. First, the standard error, SE_m of each mean effect size is computed with:[48]

E(4): $$SE_m = \sqrt{\frac{n_e + n_c}{n_e n_c} + \frac{(ES'_m)^2}{2(n_e + n_c)}}$$

In equation E(4), n_e and n_c are the number of participants in the experimental and control groups and ES'_m is from equation E(3).

For dichotomous outcomes, the standard error, SEd_{cox}, is computed with:[49]

E(5): $$SE_{d_{Cox}} = \sqrt{0.367\left[\frac{1}{O_{1E}} + \frac{1}{O_{2E}} + \frac{1}{O_{1C}} + \frac{1}{O_{2C}}\right]}$$

In Equation E(5), O_{1E} and $O_{1C,}$ represent the success frequencies of the experimental and control groups. O_{2E} and O_{2C} represent the failure frequencies of the experimental and control groups.

Next, the inverse variance weight w_m is computed for each mean effect size with:[50]

E(6): $$w_m = \frac{1}{SE_m^2}$$

The weighted mean effect size for a group of studies in program area *i* is then computed with:[51]

E(7): $$\overline{ES} = \frac{\sum (w_{m_i} ES'_{m_i})}{\sum w_{m_i}}$$

Confidence intervals around this mean are then computed by first calculating the standard error of the mean with:[52]

E(8): $$SE_{\overline{ES}} = \sqrt{\frac{1}{\sum w_{m_i}}}$$

Next, the lower, ES_L, and upper limits, ES_U, of the confidence interval are computed with:[53]

E(9): $$\overline{ES_L} = \overline{ES} - z_{(1-\alpha)}(SE_{\overline{ES}})$$

E(10): $$\overline{ES_U} = \overline{ES} + z_{(1-\alpha)}(SE_{\overline{ES}})$$

In equations E(9) and E(10), $z_{(1-\alpha)}$ is the critical value for the *z*-distribution (1.96 for $\alpha = .05$).

The test for homogeneity, which provides a measure of the dispersion of the effect sizes around their mean, is given by:[54]

E(11): $$Q_i = (\sum w_i ES_i^2) - \frac{(\sum w_i ES_i)^2}{\sum w_i}$$

The Q-test is distributed as a chi-square with *k*-1 degrees of freedom (where *k* is the number of effect sizes).

Computing Random Effects Weighted Average Effect Sizes and Confidence Intervals. When the p-value on the Q-test indicates significance at values of p less than or equal to .05, a random effects model is performed to calculate the weighted average effect size. This is accomplished by first calculating the random effects variance component, *v*.[55]

E(12): $$v = \frac{Q_i - (k-1)}{\sum w_i - (\sum wsq_i / \sum w_i)}$$

This random variance factor is then added to the variance of each effect size and then all inverse variance weights are recomputed, as are the other meta-analytic test statistics.

E3. Institute Adjustments to Effect Sizes for Methodological Quality, Outcome Measure Relevance, and Researcher Involvement

In Exhibit E.1 we show the results of our meta-analyses calculated with the standard meta-analytic formulas described in Appendix E2. In the last column of the exhibit, however, we list the “Adjusted Effect Size” that we actually use in our analysis. These adjusted effect sizes, which are derived from the unadjusted results, are always smaller than or equal to the unadjusted effect sizes we report in the same exhibit.

In this section, we describe our rationale for making these downward adjustments. In particular, we make three types of adjustments that are necessary to better estimate the results that we are more likely to achieve in real-world settings. We make adjustments for: (a) the methodological quality of each study we include in the meta-analyses; (b) the relevance or quality of the outcome measure that individual studies used; and (c) the degree to which the researcher(s) who conducted a study were invested in the program’s design.

E3.a. Methodological Quality. Not all research is of equal quality, and this greatly influences the confidence that can be placed in the results of a study. Some studies are well designed and implemented, and the results can be viewed as accurate representations of whether the program itself worked. Other studies are not designed as well, and less confidence can be placed in any reported differences. In particular, studies of inferior research design cannot completely control for sample selection bias or other unobserved threats to the validity of reported

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[48] Ibid., 49, equation 3.23.

[49] Sánchez-Meca, et al., *Effect-size indices for dichotomized outcomes in meta-analysis,* equation 19.

[50] Lipsey and Wilson, *Practical meta-analysis*, 49, equation 3.24.

[51] Ibid., 114.

[52] Ibid.

[53] Ibid.

[54] Ibid., 116.

[55] Ibid., 134.

research results. This does not mean that results from these studies are of no value, but it does mean that less confidence can be placed in any cause-and-effect conclusions drawn from the results.

To account for the differences in the quality of research designs, we use a 5-point scale as a way to adjust the reported results. The scale is based closely on the 5-point scale developed by researchers at the University of Maryland.[56] On this 5-point scale, a rating of "5" reflects an evaluation in which the most confidence can be placed. As the evaluation ranking gets lower, less confidence can be placed in any reported differences (or lack of differences) between the program and comparison or control groups.

On the 5-point scale as interpreted by the Institute, each study is rated with the following numerical ratings.

- A **"5"** is assigned to an evaluation with well-implemented random assignment of subjects to a treatment group and a control group that does not receive the treatment/program. A good random assignment study should also indicate how well the random assignment actually occurred by reporting values for pre-existing characteristics for the treatment and control groups.
- A **"4"** is assigned to a study that employs a rigorous quasi-experimental research design with a program and matched comparison group, controlling with statistical methods for self-selection bias that might otherwise influence outcomes. These quasi-experimental methods may include estimates made with a convincing instrumental variables modeling approach, or a Heckman approach to modeling self-selection.[57] A level 4 study may also be used to "downgrade" an experimental random assignment design that had problems in implementation, perhaps with significant attrition rates.
- A **"3"** indicates a non-experimental evaluation where the program and comparison groups were reasonably well matched on pre-existing differences in key variables. There must be evidence presented in the evaluation that indicates few, if any, significant differences were observed in these salient pre-existing variables. Alternatively, if an evaluation employs sound multivariate statistical techniques (e.g., logistic regression) to control for pre-existing differences, and if the analysis is successfully completed, then a study with some differences in pre-existing variables can qualify as a level 3.
- A **"2"** involves a study with a program and matched comparison group where the two groups lack comparability on pre-existing variables and no attempt was made to control for these differences in the study.
- A **"1"** involves a study where no comparison group is utilized. Instead, the relationship between a program and an outcome, i.e., drug use, is analyzed before and after the program.

We do not use the results from program evaluations rated as a "1" on this scale, because they do not include a comparison group and, thus, no context to judge program effectiveness. We also regard evaluations with a rating of "2" as highly problematic and, as a result, do not consider their findings in the calculations of effect. In this study, we only considered evaluations that rated at least a 3 on this 5-point scale.

An explicit adjustment factor is assigned to the results of individual effect sizes based on the Institute's judgment concerning research design quality. This adjustment is critical and the only practical way to combine the results of a high quality study (e.g., a level 5 study) with those of lesser design quality (level 4 and level 3 studies). The specific adjustments made for these studies are based on our knowledge of research in other topic areas. For example, in criminal justice program evaluations, there is strong evidence that random assignment studies (i.e., level 5 studies) have, on average, smaller absolute effect sizes than weaker-designed studies.[58] Thus, we use the following "default" adjustments to account for studies of different research design quality:

- A level 5 study carries a factor of 1.0 (that is, there is no discounting of the study's evaluation outcomes).
- A level 4 study carries a factor of .75 (effect sizes discounted by 25 percent).
- A level 3 study carries a factor of .50 (effect sizes discounted by 50 percent).
- We do not include level 2 and level 1 studies in our analyses.

These factors are subjective to a degree; they are based on the Institute's general impressions of the confidence that can be placed in the predictive power of evaluations of different quality.

The effect of the adjustment is to multiply the effect size for any study, ES'_m, in equation E(3) by the appropriate research design factor. For example, if a study has an effect size of -.20 and it is deemed a level 4 study, then the -.20 effect size would be multiplied by .75 to produce a -.15 adjusted effect size for use in the benefit-cost analysis.

E3.b. Adjusting Effect Sizes for Evaluations With Weak Outcome Measures. Some evaluations use outcome measures that may not be precise gauges of the ultimate outcome of interest. In these cases, we record a

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[56] L. Sherman, D. Gottfredson, D. MacKenzie, J. Eck, P. Reuter, and S. Bushway (1998). *Preventing crime: What works, what doesn't, what's promising*. Prepared for the National Institute of Justice. Department of Criminology and Criminal Justice, University of Maryland, Chapter 2.

[57] For a discussion of these methods, see W. Rhodes, B. Pelissier, G. Gaes, W. Saylor, S. Camp, and S. Wallace. (2001). Alternative solutions to the problem of selection bias in an analysis of federal residential drug treatment programs. *Evaluation Review, 25*(3): 331-369.

[58] M.W. Lipsey (2003). Those confounded moderators in meta-analysis: Good, bad, and ugly. *The Annals of the American Academy of Political and Social Science, 587*(1): 69-81. Lipsey found that, for juvenile delinquency evaluations, random assignment studies produced effect sizes only 56 percent as large as nonrandom assignment studies.

flag that can later be used to discount the effect. For example, the evaluation of the Cash and Counseling program (Carlson et al., 2007) used a non-standardized survey of clients and caregivers to measure unmet needs, general health, and life satisfaction. If this measure is used to indicate quality of life, then a flag on this outcome measure can be used to reflect the probability that this measure may not be expected to be the best measure. The same survey was provided to thousands of clients and providers across several states in the Cash and Counseling evaluation, so we included it in our analysis; it would have been better, however, to use a survey that had been standardized before the study was conducted.

E3.c. Adjusting Effect Sizes for Research Involvement in the Program's Design and Implementation. The purpose of the Institute's work is to identify and evaluate programs that can make cost-beneficial improvements to Washington's actual service delivery system. There is some evidence that programs closely controlled by researchers or program developers have better results than those that operate in "real world" administrative structures.[59] In our evaluation of a real-world implementation of a research-based juvenile justice program in Washington, we found that the actual results were considerably lower than the results obtained when the intervention was conducted by the originators of the program.[60] Therefore, we make an adjustment to effect sizes, ES_m, to reflect this distinction. As a parameter for all studies deemed not to be "real world" trials, the Institute discounts ES'_m by .5, although this can be modified on a study-by-study basis.

E4. Meta-Analytic Results—Estimated Effect Sizes and Citations to Studies Used in the Analyses

Exhibit E.1 provides technical meta-analytic results for the effect sizes computed for this analysis. Each table provides the unadjusted and adjusted effect sizes for evaluated programs, and lists all of the studies included in each analysis. Exhibit E.2 lists the citations for all studies used in the meta-analyses.

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[59] Ibid. Lipsey found that, for juvenile delinquency evaluations, programs in routine practice (i.e., "real world" programs) produced effect sizes only 61 percent as large as research/demonstration projects. See also:
A. Petrosino, and H. Soydan (2005). The impact of program developers as evaluators on criminal recidivism: Results from meta-analyses of experimental and quasi-experimental research. *Journal of Experimental Criminology, 1*(4): 435-450.

[60] R. Barnoski (2004). *Outcome evaluation of Washington State's research-based programs for juvenile offenders*. Olympia: Washington State Institute for Public Policy, available at <http://www.wsipp.wa.gov/rptfiles/04-01-1201.pdf>.

Exhibit E.1
Meta-Analytic Estimates of Standardized Mean Difference Effect Sizes

Many of these programs have evaluated other outcomes than those shown.

Type of Program (and its effect on outcomes included in our analysis)	Number of Effect Sizes Included in the Analysis (Number of cases in the treatment groups)	*Meta-Analytic Results Before Applying Institute Adjustments*					**Adjusted Effect Size** (estimated effect after adjustments for the methodological quality of the evidence, outcome measure relevance, and researcher involvement)	Notes to Table
		Fixed Effects Model			Random Effects Model			
		Weighted Mean Effect Size		Homogeneity Test	Weighted Mean Effect Size			
		ES	p-value	p-value	ES	p-value	ES	
Parent Support Programs for Parents of Children With Developmental Disabilities, and its effect on:								
Parenting stress / anxiety	1 (14)	-1.133	.01	na	na	na	-0.637	
Parent depression	1 (14)	-1.053	.02	na	na	na	-0.592	
Cognitive development	1 (23)	0.674	.04	na	na	na	0.337	
General health	1 (30)	-0.144	.50	na	na	na	0.000	
Social support	1 (30)	0.469	.03	na	na	na	0.176	
Group-Based Parent Training for Parents of Children With Developmental Disabilities and Behavior Problems, and its effect on:								
Adaptive behavior	1 (17)	0.652	.07	na	na	na	0.367	
Problem behavior	4 (82)	-0.473	.00	0.000	-0.467	0.010	-0.298	
Parenting stress / anxiety	3 (61)	-0.249	.18	0.000	-0.255	0.326	0.000	
Social support	1 (22)	-0.209	.51	na	na	na	0.000	
Communication Training for Parents of Children With Developmental Delays, and its effect on:								
Language skills	2 (17)	0.052	.88	0.444	na	na	0.000	
Parent depression	1 (16)	-0.785	.03	na	na	na	-0.442	
Early Preschool in a Hospital Setting for Children With Developmental Delays, and its effect on:								
Cognitive development	1 (35)	0.734	.00	na	na	na	0.275	
Supportive Home Visiting for Parents of Children With Developmental Disabilities, and its effect on:								
Problem behavior	1 (24)	-0.281	.38	na	na	na	0.000	
Cognitive development	1 (24)	0.218	.50	na	na	na	0.000	
Portage Early Education Curriculum for Children With Developmental Disabilities, and its effect on:								
Cognitive development	1 (12)	1.495	.00	na	na	na	0.747	
Motor activity	1 (12)	1.403	.00	na	na	na	0.702	
Cash and Counseling for Children With Developmental Disabilities, and its effect on:								
Quality of life	1 (378)	0.597	.00	na	na	na	0.448	
Unmet needs	1 (378)	-0.303	.00	na	na	na	-0.227	
General health	1 (439)	0.370	.00	na	na	na	0.278	
Intensive Behavioral Intervention for Children With Autism, and its effect on:								
K-12 special education	1 (15)	-1.299	.17	na	na	na	0.000	
Language skills	2 (35)	0.596	.02	0.652	na	na	0.373	
Adaptive behavior	3 (55)	0.548	.01	0.414	na	na	0.286	
Cognitive development	4 (75)	0.547	.00	0.941	na	na	0.266	
Auditory Integration Training for Children With Autism, and its effect on:								
Problem behavior	3 (62)	-0.194	.28	0.087	na	na	0.000	
Cognitive development	1 (40)	0.012	.96	na	na	na	0.000	
Autistic behavior	1 (40)	-0.071	.75	na	na	na	0.000	
Group or Clinic-Based Communication Training for Parents of Children With Autism, and its effect on:								
Language skills	2 (31)	0.939	.00	0.930	na	na	0.470	
Adaptive behavior	1 (14)	0.588	.13	na	na	na	0.000	
Problem behavior	1 (17)	-0.087	.82	na	na	na	0.000	
Parenting stress / anxiety	2 (31)	0.187	.49	0.149	na	na	0.000	
Autistic behavior	2 (31)	-0.412	.13	0.038	-0.440	.44	0.000	

Exhibit E.1 (continued)
Meta-Analytic Estimates of Standardized Mean Difference Effect Sizes

Many of these programs have evaluated other outcomes than those shown.

Type of Program (and its effect on outcomes included in our analysis)	Number of Effect Sizes Included in the Analysis (Number of cases in the treatment groups)	*Meta-Analytic Results Before Applying Institute Adjustments*					**Adjusted Effect Size** (estimated effect after adjustments for the methodological quality of the evidence, outcome measure relevance, and researcher involvement)	Notes to Table
		Fixed Effects Model			Random Effects Model			
		Weighted Mean Effect Size		Homogeneity Test	Weighted Mean Effect Size			
		ES	p-value	p-value	ES	p-value	ES	
Autism Preschool, and its effect on:								
Language skills	1 (16)	0.936	.01	na	na	na	0.936	
Parenting stress / anxiety	1 (16)	0.013	.97	na	na	na	0.000	
Cognitive development	1 (16)	0.093	.78	na	na	na	0.000	
Motor activity	1 (16)	-0.266	.44	na	na	na	0.000	
Autistic behavior	1 (16)	-0.364	.29	na	na	na	0.000	
Low-Intensity Behavioral Training for Children With Autism, and its effect on:								
Language skills	1 (13)	0.913	.02	na	na	na	0.456	
Adaptive behavior	1 (13)	0.533	.17	na	na	na	0.000	
Home-Based Communication Training for Parents of Children With Autism, and its effect on:								
Language skills	1 (12)	0.639	.13	na	na	na	0.000	
Parenting stress / anxiety	1 (10)	-0.295	.51	na	na	na	0.000	
Cognitive development	1 (12)	-0.270	.51	na	na	na	0.000	
Autistic behavior	1 (12)	-0.087	.83	na	na	na	0.000	
Intensive vs. Regular Physical Therapy for Cerebral Palsy, and its effect on:								
Adaptive behavior	1 (22)	0.177	.54	na	na	na	0.000	
Cognitive development	1 (22)	0.301	.31	na	na	na	0.000	
Motor activity	3 (76)	0.534	.00	0.006	0.747	.07	0.541	
Constraint-Induced Movement Therapy (Casting) for Cerebral Palsy, and its effect on:								
Motor activity	2 (45)	0.487	.03	0.002	1.131	.25	0.000	
Vestibular Stimulation for Cerebral Palsy, and its effect on:								
Cognitive development	1 (10)	0.185	.68	na	na	na	0.000	
Motor activity	1 (10)	0.034	.94	na	na	na	0.000	
Developmental Therapy for Down Syndrome, and its effect on:								
Cognitive development	2 (33)	-0.029	.91	0.513	na	na	0.000	
Cognitive Behavioral Therapy for Epilepsy, and its effect on:								
Quality of life	1 (14)	1.746	.00	na	na	na	1.746	
Seizure frequency	2 (22)	-0.784	.02	0.002	-0.739	.48	0.000	
Relaxation Training for Epilepsy, and its effect on:								
Quality of life	1 (11)	0.607	.27	na	na	na	0.000	
Seizure frequency	2 (18)	-0.573	.10	0.972	na	na	-0.287	
Biofeedback for Epilepsy, and its effect on:								
Seizure frequency	1 (10)	-1.319	.01	na	na	na	-0.990	
Community Residential Placement (vs. Institution or Nursing Home), and its effect on:								
Economic outcomes	2 (196)	-0.515	.00	0.170	na	na	-0.257	
Adaptive behavior	11 (920)	0.291	.00	0.000	0.309	.00	0.169	
Quality of life	2 (96)	0.397	.00	0.155	na	na	0.199	
Unmet needs	2 (104)	0.350	.01	0.030	0.409	.18	0.000	
Problem behavior	4 (344)	0.017	.82	0.427	na	na	0.000	
Cognitive development	1 (150)	0.383	.00	na	na	na	0.191	
Motor activity	1 (150)	0.078	.50	na	na	na	0.000	
Social support	6 (496)	0.639	.00	0.000	0.558	.07	0.279	

Exhibit E.1 (continued)
Meta-Analytic Estimates of Standardized Mean Difference Effect Sizes

Many of these programs have evaluated other outcomes than those shown.

Type of Program (and its effect on outcomes included in our analysis)	Number of Effect Sizes Included in the Analysis (Number of cases in the treatment groups)	*Meta-Analytic Results Before Applying Institute Adjustments*					**Adjusted Effect Size** (estimated effect after adjustments for the methodological quality of the evidence, outcome measure relevance, and researcher involvement)	Notes to Table
		Fixed Effects Model			Random Effects Model			
		Weighted Mean Effect Size		Homogeneity Test	Weighted Mean Effect Size			
		ES	p-value	p-value	ES	p-value	ES	
Community Residential Placement (Less vs. More Restrictive), and its effect on:								
Adaptive behavior	2 (81)	0.179	.23	0.894	na	na	0.000	
Quality of life	1 (30)	1.553	.00	na	na	na	0.776	
Problem behavior	2 (81)	0.122	.41	0.999	na	na	0.000	
Supported Employment, and its effect on:								
Economic outcomes	2 (535)	0.188	.00	0.901	na	na	0.141	
Employment	2 (535)	0.212	.00	0.938	na	na	0.159	
Adaptive behavior	1 (108)	0.946	.00	na	na	na	0.473	
Behavioral Training for Institutional Staff Serving Adults With Intellectual Disabilities and Challenging Behavior, and its effect on:								
Problem behavior	1 (30)	-0.883	.00	na	na	na	-0.442	
Cash and Counseling for Adults With Developmental Disabilities, and its effect on:								
Quality of life	1 (362)	0.330	.00	na	na	na	0.248	
Unmet needs	1 (362)	-0.204	.04	na	na	na	-0.153	
General health	1 (418)	0.237	.00	na	na	na	0.178	

Exhibit E.2
Citations to the Evaluations of Programs Listed in Exhibit 2.1

Programs for Children With Non-Specific or Various Developmental Disabilities

Parent Support Programs for Parents of Children With Developmental Disabilities

Schultz, C.L., Schultz, N.C., Bruce, E.J., Smyrnios, K.X., Carey, L.B. & Carey, C.L. (1993). Psychoeducational support for parents of children with intellectual disability. International Journal of Disability, Development, and Education, 40(3): 205-216.

Seifer, R., Clark, G.N., & Sameroff, A.J. (1991). Positive effects of interaction coaching on infants with developmental disabilities and their mothers. American Journal of Mental Retardation, 96(1): 1-11.

Singer, G.H.S., Irvin, L.K., Irvine, B., Hawkins, N. & Cooley, E. (1989). Evaluation of community-based support services for families of persons with developmental disabilities. Journal of the Association for Persons with Severe Handicaps, 14(4): 312-323.

Group-Based Parent Training for Parents of Children With Developmental Disabilities and Behavior Problems

McIntyre, L.L. (2008). Parent training for young children with developmental disabilities: Randomized controlled trial. American Journal on Mental Retardation, 113(5): 356-368.

Plant, K.M., & Sanders, M.R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. Research in Developmental Disabilities, 28: 362-385.

Quinn, M., Carr, A., Carroll, L., & O'Sullivan, D. (2007). Parents Plus Programme I: Evaluation of its effectiveness for pre-school children with developmental disabilities and behavior problems. Journal of Applied Research in Intellectual Disabilities, 20: 345-359.

Roberts, C., Mazzucchelli, T., Studman, L., & Sanders, M.R. (2006). Behavioral family intervention for children with developmental disabilities and behavior problems. Journal of Clinical Child and Adolescent Psychology, 35(2): 180-193.

Communication Training for Parents of Children With Developmental Delays

Girolametto, L.E. (1988). Improving the social-conversational skills of developmentally delayed children: An intervention study. Journal of Speech and Hearing Disorders, 53: 156-167.

Tannock, R., Girolametto, L., & Siegel, L.S. (1992). Language intervention with children who have developmental delays: Effects of an interactive approach. American Journal on Mental Retardation, 97(2): 145-160.

Early Preschool in a Hospital Setting for Children with Developmental Delays

Goodman, J.F., Cecil, H.S., & Barker, W.F. (1984). Early intervention with retarded children: Some encouraging results. Developmental Medicine & Child Neurology, 26(1): 47-55

Supportive Home Visiting for Parents of Children with Developmental Disabilities

Davis, H. & Rushton, R. (1991). Counseling and supporting parents of children with developmental delay: A research evaluation. Journal of Mental Deficiency Research, 35, 89-112.

Portage Early Education Curriculum for Children with Developmental Disabilities

Thomaidis, L., Kaderoglou, E., Stefou, M., Damianou, S., & Bakoula, C. (2000). Does early intervention work? A controlled trial. Infants and Young Children, 12(3): 17-22.

Cash and Counseling for Children with Developmental Disabilities

Carlson, B.L., Foster, L., Dale, S.B., & Brown, R. (2007). Effects of Cash and Counseling on personal care and well-being. HSR: Health Services Research, 42(1): 467-487.

Programs for Children With Autism

Intensive Behavioral Intervention for Children With Autism

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. Developmental and Behavioral Pediatrics, 27(2): S145-S155.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: A comparison controlled study. Behavior Modification, 31(3): 264-278.

McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. American Journal on Mental Retardation, 97(4): 359-372.

Smith, T., Groen, A.D., & Wynn, J.W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. American Journal on Mental Retardation, 105(4): 269-285.

Auditory Integration Training for Children With Autism

Bettison, S. (1996). The long-term effects of auditory training on children with autism. Journal of Autism and Developmental Disorders, 26(3): 361-374.

Rimland, B., & Edelson, S.M. (1995). Brief Report: A pilot study of auditory integration training in autism. Journal of Autism and Other Developmental Disorders, 25(1): 61-70.

Zollweg, W., Palm, D., & Vance, V. (1997). The efficacy of auditory integration training: A double blind study. American Journal of Audiology, 6(3): 39-47.

Group or Clinic-Based Communication Training for Parents of Children With Autism

Aldred, C., Green, J., & Adams, C. (2004). A new social communication intervention for children with autism: Pilot randomised controlled treatment study suggesting effectiveness. Journal of Child Psychology and Psychiatry, 45(8): 1420-1430.

McConachie, H., Randle, V., Hammal, D., & Le Couteur, A. (2005). A controlled trial of a training course for parents of children with suspected autism spectrum disorder. The Journal of Pediatrics, 335-340.

Exhibit E.2 *(continued)*
Citations to the Evaluations of Programs Listed in Exhibit 2.1

Programs for Children With Autism *(continued)*

Low-Intensity Behavioral Training for Children With Autism

Eldevik, S., Eikeseth, S., Jahr, E., & Smith, T. (2006). Effects of low-intensity behavioral treatment for children with autism and mental retardation. Journal of Autism and Developmental Disorders, 36(2): 211-224.

Home-Based Communication Training for Parents of Children With Autism

Drew, A., Baird, G., Baron-Cohen, S., Cox, A., Slonims, V., Wheelwright, S., Swettenham, J., Berry, B., & Chapman, T. (2002). A pilot randomised control trial of a parent training intervention for pre-school children with autism: Preliminary findings and challenges. European Child & Adolescent Psychiatry, 11: 266-272.

Programs for Children with Cerebral Palsy

Intensive vs. Regular Physical Therapy for Cerebral Palsy

Law, M., Cadman, D., Rosenbaum, P., Walter, S., Russell, D., DeMatteo, C. (1991). Neurodevelopmental therapy and upper-extremity inhibitive casting for children with cerebral palsy. Developmental Medicine and Child Neurology, 33: 379-387.

Mayo, N.E. (1991). The effect of physical therapy for children with motor delay and cerebral palsy: A randomized clinical trial. American Journal of Physical Medicine & Rehabilitation, 70(5): 258-267.

Palmer, F.B., Shapiro, B.K., Wachtel, R.C., Allen, M.C., Hiller, J.E., Harryman, S.E., Mosher, B.S., Meinert, C.L., & Capute, A.J. (1988). The effects of physical therapy on cerebral palsy: A controlled trial in infants with spastic diplegia. The New England Journal of Medicine, 318(13): 803-808.

Constraint-Induced Movement Therapy (Casting) for Cerebral Palsy

Law, M., Cadman, D., Rosenbaum, P., Walter, S., Russell, D., DeMatteo, C. (1991). Neurodevelopmental therapy and upper-extremity inhibitive casting for children with cerebral palsy. Developmental Medicine and Child Neurology, 33: 379-387.

Taub, E., Landesman Ramey, S., DeLuca, S., & Echols, K. Efficacy of constraint-induced movement therapy for children with cerebral palsy with asymmetric motor impairment. Pediatrics, 113: 305-312.

Vestibular Stimulation for Cerebral Palsy

Sellick, K.J., & Over, R. (1980). Effects of vestibular stimulation on motor development of cerebral-palsied children. Developmental Medicine and Child Neurology, 22: 476-483.

Programs for Children With Down Syndrome

Developmental Therapy for Down Syndrome

Piper, M.C., & Pless, I.B. (1980). Early intervention for infants with Down syndrome: A controlled trial. Pediatrics, 65(3): 463-468.

Sloper, P., Glenn, S.M., & Cunningham, C.C. (1986). The effect of intensity of training on sensori-motor development in infants with down's syndrome. Journal of Mental Deficiency Research, 30: 149-162.

Programs for Individuals With Drug-Resistant Epilepsy

Cognitive Behavioral Therapy for Epilepsy

Lundgren, T., Dahl, J., Melin, L., & Kies, B. (2006). Evaluation of acceptance and commitment therapy for drug refractory epilepsy: A randomized controlled trial in South Africa--a pilot study. Epilepsia, 47(12): 2173-2179.

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Programs for Adults with Various Developmental Disabilities

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Exhibit E.2 *(continued)*
Citations to the Evaluations of Programs Listed in Exhibit 2.1

Programs for Adults with Various Developmental Disabilities*(continued)*

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