Autism Community Services

Final Report

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Introduction

This document presents findings from an evaluation of a parent-led, community-based program for families of children with autism. The work was conducted by the University of Washington Center for Disability Policy and Research (CDPR), under contract to the Washington State Division of Developmental Disabilities (DDD).

Several aspects of the Autism Community Services (ACS) pilot project, which operates in Washington’s Clark and Skamania counties, are unique. The project was initiated largely by a group of 13 families who came together out of the region’s Parent Coalition to promote a new approach to service delivery that would address specifically the needs of people with autism and their families. The approach is essentially a voucher system through which families with children with autism may purchase residential, respite, and day services and supports to prevent the erosion of families’ abilities to care for their children at home. “As parents,” reads a handout prepared for an ACS presentation, “we believed that we were the best equipped to design and direct services for our sons and daughters.” Central to the new approach is a service package reflecting consumers’ understanding of their needs, rather than acceptance of services that happened to be available through state agencies.

Families designed “an alternative services delivery model for people with autism” and brought their model to lawmakers in Olympia during the 1997, ’98, and ’99 sessions. This exercise in state policy-making was empowering to families, who briefed themselves on the legislative process, attended legislative picnics and Lobby Day, and gave testimony at legislative hearings. It also helped to educate lawmakers about the real challenges faced by families of children with disabilities and the shortcomings of much of the state’s service-delivery system. (Since implementation of ACS, families have continued to lobby the 2000 and 2001 legislatures.)
The 1999 Legislature approved the model in concept but did not appropriate money to support it. Instead, it directed DDD to finance the project from discretionary funds for serving unserved families. The initial request for providing services under the ACS model was about $1.2 million for 1999-2001. The DDD Stakeholders Work Group recommended to the Division Director that DDD provide $519,000, including $55,000 for an independent program evaluation. On November 1, 1999, DDD awarded a $464,000 contract for the program to Autism Community Services, which has evolved from an informal parent support group to a non-profit organization. Of the $464,000, all but $174,450 is channeled directly to providers, and the rest is used to finance a salary for a program coordinator, overhead, and operations. With barely a third of the funds it anticipated for the pilot, ACS families scaled back their projected service bundle. They agreed, among themselves, to provide services first to those families in most critical need and whose living situations were best prepared to take on new services. This shared decision-making and responsibility is characteristic of ACS.

Parents who led the pilot project then faced fast-approaching deadlines to line up providers and complete complex contract negotiations: enhanced respite care in November 1999, enhanced day services in January 2000, companion home situations in February and March, and shared parenting opportunities in March and April. During this period—in March 2000—DDD contracted with CDPR, part of the University of Washington Department of Health Services and School of Public Health and Community Medicine, to perform the evaluation of the ACS pilot project.

This document presents findings from initial analysis of DDD service records and three rounds of person-to-person interviews with ACS families and service providers conducted by CDPR staff during June-July and November 2000 and during April-May 2001.
Methods

DDD asked CDPR staff to develop interview instruments to ask individuals with autism, families, and service providers about Autism Community Services at baseline and at 6- and 12-month intervals. CDPR-trained interviewers were to conduct these interviews in person. CDPR also asked the two DDD case managers working with ACS families to fill out service record forms for each of the persons with autism involved in the pilot; the service record data included demographic information, disability level, living arrangements, and services received through ACS.

Case managers’ reports examined at the time of the baseline interviews showed that the average age of persons with autism in the pilot was 18, that 8 of the 13 consumers were male, and all consumers were White. The following is information reported by case managers during summer 2000 about the disabilities of the 13 consumers in the pilot.

- One of the 13 consumers has behaviors associated with autism, but his reported disabilities are mental retardation and epilepsy.
- Of the 13 individuals in the pilot, 85% have disabilities other than autism and 15% have third disabilities.
- Other disabilities reported are mental retardation (8 consumers), mental illness/psychiatric diagnosis (1), and “other” (4).
- Of the 8 consumers with mental retardation, 1 was reported as “mild,” 3 as “moderate,” and 4 as “severe.” For three persons in the pilot, MR levels are unknown or unspecified in the records.

Case managers provided accounts of the “difficult issues” faced by persons with autism in the pilot. These include behavior problems (12 clients), communication (10), health care (9), finding providers (5), and funding (2). The two case managers said that 12 clients are receiving services through ACS that fit their needs better than would similar services through other providers.
DDD reported to CDPR that ACS would provide the following services to people with autism:

- Community guide services for six individuals in their home communities
- Residential support (adult foster care) for two adults, one beginning February 1 and the other beginning March 1, 2000
- Specialized foster home placement (specialized training for providers) for two children
- An enhanced day program (additional opportunities and more pay for providers) for six individuals
- In-home family supports (providers paid at a higher rate) for a minimum of five individuals, each receiving a minimum of 40 hours of respite care each month beginning on November 1, 1999
- Individualized supports as proposed by the program coordinator

CDPR began work on this evaluation in March 2000 by conducting six key informant interviews with people who were experts in autism and the programs that serve people with autism and their families. Staff reviewed recent publications about autism diagnosis and treatment. A list of key informants is shown in Appendix 1. CDPR also interviewed ACS Program Coordinator Monica Meyer.

The purpose of the key informant interviews was to identify issues that should be addressed in the interviews and to help CDPR staff understand better the needs of the families involved in the pilot project. This understanding would help frame the interview instruments for individuals, families, and service providers. From these interviews, CDPR learned that families face ever-changing policies regarding autism diagnosis and treatment. Currently, several experts in the field are at odds over the benefits and costs of intense behavioral therapy for very young children with autism. Behavioral issues present challenges to families particularly in school, public, and work settings. When asked to identify their
greatest needs, families mention respite care, better education and training within school districts, employment support, and independent living support for adults.

Based on the key informant interviews and DDD’s requirements for the evaluation, CDPR developed three interview instruments for ACS participants, which are shown in Appendices 2 and 3. These instruments were designed to facilitate the “subjective and qualitative” evaluation of the program requested by DDD. They focused on four broad issues:

1. What services did families in the pilot receive, and how do these compare with services received before implementation of the program?
2. Are individuals and families participating in ACS satisfied with services?
3. Are persons with autism, their families, and service providers better off than before?
4. What guidance does the experience of ACS individuals, families, and service providers offer for new public policies?

CDPR and DDD refined the interview instruments during March-June 2000. During this period, DDD mailed release forms to individuals and/or families to obtain permission for release of information about their service records from DDD. CDPR then hired five interviewers with experience working with people with developmental disabilities and conducted a training session during which each of the interviewers was made familiar with the interview instruments as well as the broad goals of the evaluation. CDPR contacted individuals, families, and service providers who provided consent to be contacted about participating in an interview.

During the first round of interviews, CDPR staff interviewed 13 families and 9 service providers at locations chosen by participants in Clark and Skamania counties. In the second round, CDPR interviewed 12 families and 11 service providers. In the third round, interviews were conducted with 11 families and 13
service providers. Interviews conducted in the second and third rounds used the same survey instrument, as shown in Appendix 3.

Following the first round of interviews with families, CDPR interviewed the DDD Supervisor for Clark and Skamania counties and the two project DDD case managers. CDPR spoke with Program Coordinator Meyer after the second and third round of interviews.
Key Findings

The findings in this report reflect impressions of ACS over the course of 18 months and three sets of interview visits with families and service providers. Findings from each round of interviews reflect the tenor of ACS at that time, reflecting the program’s evolution from implementation to the conclusion of its first contract with the state.

During the first round of interviews (summer 2000), the ACS program coordinator and other leaders of the pilot were working intensely to line up providers and complete documentation for the state. Key findings from these interviews follow.

- Most of the families interviewed for this evaluation reported that the pilot project had improved their quality of life—in some cases, immeasurably—by helping to secure reliable services for their family members, releasing them from continuous duties as care-providers, and in some cases, helping their family member with autism participate more in their communities. “My husband and I spend a little time together now,” said one parent, an observation repeated in some form by all families receiving services. Another noted that she had “less stress and less work” and that her son now had “a more normal life.” Asked to explain how ACS made her family better-off, a parent responded simply, “Sanity-wise.” Said another, “People are living independently, thriving, at reduced cost to the state.”

- ACS is an ambitious endeavor that explores new approaches to providing services to people with autism. Two of these new approaches are the companion home, in which a service provider shares housing with the person with autism and assists in community inclusion; and the enhanced respite care, through which the program coordinator recruits providers and offers training in issues specific to autism. The value of both of these approaches was supported throughout this evaluation. Even as early as the first round of
interviews, the ACS experience showed the benefit of families taking a
measure of control over their own services.

- Although families receiving services through the pilot expressed satisfaction,
  all of the ACS participants raised the issue of funding for the program.
  Families received less funding than anticipated, which resulted in less or no
  services for some families. “The idea was to fully fund the project, and when
  this did not occur, it caused anguish in the group,” said one parent. Another
  parent explained that his joy over the new living arrangement for his adult
  child with autism was diminished by the understanding that “some families
  really got nothing. Some families still have the pain we remember so well.”

- CDPR discovered major differences among participants’ accounts of services
  received through ACS, case managers’ accounts of those services, and data
  from service records provided by DDD (see charts, pages 17-18). In addition,
  ACS families had different information about which families were receiving
  services and in what volume.

- Both families receiving services through the pilot and participating service
  providers noted that paying service providers about $4 more an hour ($10 per
  hour instead of $6) had attracted more skilled and reliable providers. Service
  providers confirmed that the program afforded better training specifically
  about autism, more flexibility, and more stability. One service provider said
  that without ACS, “I wouldn’t be here.”

- The community guide—an individual who works with families to connect
  people with disabilities to community-based supports and activities—is an
  important element of the ACS model, according to its project proposal. But
  neither DDD records nor the accounts of case managers indicated that any
  ACS client is actually receiving this service. Most ACS families were
  unfamiliar with the term, community guide. At the same time, the interviews
  make clear that many families have received services through the pilot that
  are consistent with those provided by community guides. For example,
  Program Coordinator Meyer assisted families with recruiting and training
providers and in finding opportunities for inclusion in community-based activities.

The second round of interviews (winter 2000) found families settling into the new circumstances supported by ACS. Once again, families receiving services spoke of their new freedom—described by one family member as “time to live as normal people”—and greater community integration for people with autism and their families alike. Following are other issues that emerged strongly in the second round of interviews.

• ACS provided more “stability” in providers, made possible by the enhanced wages and the ACS project’s community outreach. Even with ACS, however, service providers do not generally earn health care and other benefits. One provider reported having to work two jobs because ACS cannot provide health insurance coverage. This necessarily limits the amount of time some service providers can commit to the project.

• The community of Clark and Skamania counties were experiencing greater awareness about autism. One provider explained that the project “has influenced the development of our programs by increasing the rate at which we incorporate more progressive initiatives, trials, practices…. [ACS] is pulling us through the evolution of services for autistic people.”

• Program participants were challenged by administrative refinements to the program. “The early time limits in the project limited choices [and] decisions, because it had to be put together quickly,” explained an ACS parent. Later, the program was able to achieve a better match between families and providers. A service provider reported that “the project is very autonomous and no one is monitoring or overseeing what they are doing—and they need that oversight.” Other participants suggested that DDD could provide assistance in drafting contracts, facilitate more long-term planning “to remove stress and anxiety,” and achieve better communication so they would know “what they could expect” from ACS. Families cited the benefits of regular meetings among the ACS families.
• Funding issues were still preventing some ACS families from receiving services and generating some bitterness among participants. “We need to move forward and add services as we described,” said one project participant. When asked what changes would improve the program, a family member suggested “fully funding every single one of the families who worked so hard to create it.” Looking ahead to lobbying once again for ACS in the 2001 legislative session, a participant noted that it would be a tragedy if the project concluded without every one of the 13 ACS families receiving benefits.

• Program Coordinator Meyer performed multiple roles. Project participants consistently spoke of Meyer’s efforts with respect, but several express concerns that the job is too big for one person. Families noted that Meyer attended both to broad issues of policy and community education as well as addressing the details of each family’s needs and recruitment and training of providers. One family member proclaimed, “We need to get Monica some help.”

• Participants mentioned the need for employment support. Since ACS has helped several families achieve a more stable living situation, some project participants directed their hopes to securing employment for family members with autism. This remained a challenge in Southwest Washington, which some ACS families said had few opportunities for supported employment.

• ACS families were worried about the future. They believed they were delivering a new approach to service delivery for families—one that combines individualized planning with heightened community awareness about autism. Several participants expressed the hope that the Washington Legislature and other state policy makers would recognize the value of this effort and provide it with the resources needed to continue.

By the third round of interviews (spring 2001), participants were lobbying the 2001 Legislature and looking with apprehension to the end of the current ACS contract.
• Participants receiving services once again expressed concern for those families who have yet to receive them. Meyer acknowledged the pressure that the have-have-not situation puts on the ACS families as a group. Another parent noted that “those getting services have been cheerleaders to get the others going back to the Legislature to keep the service coming. They have kept the light shining.”

• During interviews, families once again extolled the ACS for giving them more control over services. “I can’t imagine going back to set services that offer no real choice to family [and] consumers,” said one. “Everybody doesn’t fit into a slot.”

• Two service providers reported that ACS has cost them money: one remarked that a client with autism had caused uncompensated damage to car upholstery and clothing; another was still waiting to be reimbursed for out-of-pocket outlays (rent deposit) necessitated by a sudden change of residence.

• Enhanced respite services continued to receive high marks from families and service providers alike for producing, as one participant explained, “more stability and peace of mind.” But both families and service providers mentioned the need for more effective communication. “There is still some lack of understanding,” reported a parent, “about what [the providers] are supposed to do.”
Interviews with Families

1. Involvement in program development

During the first round of interviews, CDPR asked each family participating in ACS about its involvement in developing the program and encouraging legislators to support it. All but one reported that they had attended meetings going back three years or more, and about half had lobbied in Olympia during the 1998 and 1999 legislative sessions. (The family that had not attended meetings explained that their child’s needs demanded most of their time, but they “wrote many letters, made lots of phone calls and did fund-raising.”) Families provided different accounts of how the parent group began, with some attributing DDD and others saying it was an outgrowth of a local parent coalition. “People really worked …to get this,” said a parent. “There was a time when they wrote every single legislator up to three letters a day.” The effort drew the families into state politics. “Before this, I didn’t know anything about state government,” said one of the parents who lobbied. “Now I know 25 state legislators by their first names.”

Family members discussed during interviews how the parent group, exhilarated by legislative support for their service model, met during the summer of 1999 to adjust service to the funding level provided by DDD. “It was the most painful meeting we ever had,” said one. “But we figured out who needed to get the funding in the first round.” Two families discussed with interviewers how they were prepared to wait for new resources. The parent group has endured the pressure of allocating resources to some, but not all families. But some family members expressed bitterness at what they saw as a funding shortfall: “The money we thought we had requested and legislators had approved—DDD took half of it,” complained one parent.

Many of the families did not understand that the Legislature had not promised any specific funding for the pilot and that the resources that had been made
available were recommended by the DDD Stakeholder Work Group and found within the Division budget.

The funding issue increasingly worried ACS families through the three rounds of interviews. Several families pointed out that it would be tragic if ACS were never funded at a level to provide for all the families who contributed to its creation.

2. Services provided through ACS
Each family was asked to identify the services received through ACS, whether they had received the services before the pilot, and the importance of the services to their family. Most families responded to this question in part by identifying benefits that are not technically reimbursed by DDD. For example, parents mentioned a better flow of information, receiving helpful publications, the benefits of comradeship with the other parents in the pilot, and the fact that many legislators now have an understanding of the needs of people with autism and their families. Parents gave high marks to all services received through ACS.

The tables on the following pages show services provided under ACS; for the first round of interviews, the table shows reports by families, case managers, and DDD service records.
First round of interviews:

<table>
<thead>
<tr>
<th>Type of service received by families</th>
<th>Number of families who reported receiving service</th>
<th>Case managers’ count of families receiving the service**</th>
<th>Families receiving the service as reported in DDD service records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary placement</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Enhanced respite care</td>
<td>6</td>
<td>8</td>
<td>3*</td>
</tr>
<tr>
<td>Residential support (companion)</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Day program</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Community guide</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*3 Families have not used enhanced respite yet due to difficulty finding providers.

** Reports of services provided in DDD service records were not always consistent with written accounts prepared by case managers for CDPR’s evaluation.

In addition to the services identified above, families participating in ACS receive services through other providers. According to case managers’ reports before the first round of interviews, 8 families received regular respite care; 3 received Medicaid Personal Care; 2 received regular respite care, day programs, and vocational programs; and 1 received summer camp.
Second round of interviews:

<table>
<thead>
<tr>
<th>Type of service received by families</th>
<th>Number of families who reported receiving service</th>
<th>Notes on the second round of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary placement</td>
<td>2</td>
<td>One family is receiving Voluntary Placement outside the ACS project.</td>
</tr>
<tr>
<td>Enhanced respite care</td>
<td>7</td>
<td>Families have had more time to find providers.</td>
</tr>
<tr>
<td>Residential support (companion)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Day program</td>
<td>4</td>
<td>Five families in the pilot are actually receiving this service, but one of the parents did not want to be interviewed a second time because she had nothing new to report.</td>
</tr>
<tr>
<td>Community guide</td>
<td>4</td>
<td>Interviews showed continued confusion over what a community guide does and whether one is involved in this project.</td>
</tr>
</tbody>
</table>

Third round of interviews:

<table>
<thead>
<tr>
<th>Type of service received by families</th>
<th>Number of families who reported receiving service</th>
<th>Notes on the third round of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary placement</td>
<td>2</td>
<td>One family is receiving Voluntary Placement outside the ACS project.</td>
</tr>
<tr>
<td>Enhanced respite care</td>
<td>9</td>
<td>An additional family is receiving respite but did not participate in the third round of interviews.</td>
</tr>
<tr>
<td>Residential support (companion)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Day program</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Community guide</td>
<td>3</td>
<td>Although six families responded to questions about community guides, providers were identified for only three.</td>
</tr>
</tbody>
</table>
3. Are families and persons with autism better off?
During all rounds of interviews, families reported that their lives have been improved by their participation in ACS.

During the first interviews, qualitative responses to this question ranged from, “Things haven’t taken off yet,” for families who are yet to receive services, to “a better future for all involved.” The seven families who received respite care and out-of-home placement pointed to their new freedom; one family took its first vacation in more than 20 years. Some parents said that ACS has improved understanding of autism in their community. One pointed to “the greater awareness in government at all levels, communities, friends, neighbors and family.” Others mentioned what one characterized as “the moral support of other families—families who understand the challenges of significant behavioral issues.” Even families who have yet to receive services from ACS showed optimism. Said one, “We are waiting with great hope to the beginning of service.”

These impressions were confirmed during the second and third rounds of interviews. “We are totally new people,” declared one family that had received an out-of-home placement for their adult daughter. “Being able to pay people the increased wage allows us to find providers and allows us to ask them to stay longer,” reported another family receiving services. Parents commended ACS’s assistance in exploring ways to meet their daughter’s employment needs. “New directions and ideas are being developed to try to determine what [our] daughter is interested in and motivated to do.”

By the third round of interviews in spring 2001, families discussed the changes ACS made in their lives and their hopes and concerns for the future. A parent interviewed in the third round said that looking back, she would have had “a nervous breakdown” without the ACS-supported residential program her daughter receives. One participant said she is “starting to see her [child with
autism] in a different light. Starting to see a possible positive future.” A service provider noted that families are experiencing relief in knowing that if ACS continues, their family members “won’t have to be institutionalized.”

Interviewers asked every family to rate whether it was “better off” as a result of participation in ACS and whether their family member with autism was better off. They used a 1-5 rating scale, with 1 representing “not as well off” and 5 representing “better off.” The average ratings in the first round of interviews were 4.15 for families and 4.23 for individuals. Ratings were slightly lower in the second round of interviews: 4.09 for families and 4.18 for individuals. In the third round, the rating increased again to 4.64 for families and 4.55 for individuals.

4. **Community integration**

During all rounds of interviews, family members and individuals were asked to discuss the degree to which ACS helped them engage in activities they chose and to become part of their communities. On a scale of 1 (not at all helpful) to 5 (extremely helpful), the average rating was 3.08 in the first round, a higher 3.36 in the second round, and 4.00 in the third round.

Some pilot participants told of specific advances as early as the first round of interviews. “Until about a year ago, we were trapped in the house,” reported one. The family member with autism “doesn’t like stores, large groups. The project allows us to have qualified, trained people to help him … tolerate more public environments.” One family whose son has received out-of-home placement explains that “working with the foster family…has given us all more of a vision of the things [the son] can do and that we can do with him.” During the second round of interviews, participants expressed their pleasure at seeing their family member with autism take part in more community events, shop, and eat in restaurants.
During the third round, more parents credited ACS with achieving a new level of community integration for their family members. One reported that her child “goes into the community all the time, largely due to the companion home staff.” Another remarked, “Relationships have been built in the community.”

5. (a) Would participants add services?
Of the 11 family members who answered this question in the first round of interviews, 5 said they wanted to see the pilot project fully funded or for participants to receive “the rest of the money.” Two parents specifically requested out-of-home placements, and one asked for the opportunity to “get away overnight.” One parent requested more employment support. One said he would like to see a successful model of community-based service delivery for people with autism and their families “to be duplicated across the state and country.” And one family reported that “the services they asked for,” they received.

During the second round of interviews, 6 of the 11 families said they would make changes: 3 mentioned administrative issues such as oversight, more meetings, and relief for the program coordinator; 2 mentioned full funding of the program so all families would receive services; and 1 expressed the need for a “stronger job developer.” During the third round, three families expressed the need for overnight respite—“Just to get away for the weekend….” Another three mentioned the need for greater employment support.

5. (b) Would participants take away services?
No family members in any of the three interview rounds identified specific ACS-provided services that should be dropped from the pilot.

5. (c) What would participants change about the program?
During the first round of interviews, a parent complained that families “shouldn’t have to do this” to receive services, referring to the lobbying, letter-writing, and other time-consuming advocacy necessary to move the ACS model through the
Legislature. Family members also pointed to the need for streamlining licensing and contracting processes to get providers on board sooner. Two families mentioned, once again, the need to fund the program fully. And one family member raised an important issue for public policy: If her family moves to another community, do the benefits of ACS move with her?

During the second round, five project participants said they would like to see changes, including “full funding” of ACS, provision of weekend out-of-home respite, and better communication “among players.” In the third round, families requested transitioning guidelines for “kids moving in with strangers” and an expansion of ACS to provide respite services to the hundreds of families in the community who need them.

5. **Overall program satisfaction**

Interviewers asked families to rate their satisfaction with the pilot program overall, using a scale of 1 (dissatisfied) to 5 (satisfied). The mean score during the first round of interviews was 4.08; during the second round, the average was 4.45; and during the third round, 4.82.

During the first round interviews, several families complained that the funding issue has undermined general satisfaction with the ACS pilot. “The momentum of the group was lost and it has been difficult to keep parents rallied and wanting to attend meetings,” said a family member. Two parents complained of general “bureaucratic barriers,” including paperwork and politics. Half of the families interviewed expressed satisfaction that other families “are getting exactly what they need.” Two families once again discussed the liberating effects of more reliable services: “Most summers I’m going crazy because I don’t have a break. This year is better than it has ever been.”

By the second round of interviews, families were beginning to look ahead and express worry that the promise of ACS would not be realized without an infusion
of resources and continued political support. A participant explained, “There is [now] an organized effort to make life better for children and young adults with autism.” But as one family member noted, “We need to be able to do more… to overcome bumps in the road.” Families frequently mentioned the need for more resources. No one associated with ACS is surprised that the project’s reach is less than it would have been if they had received all of their original funding request.

By the third round, pilot participants recognized the issue of some families not receiving services and others experiencing the benefit of higher levels of service than in the past. ACS, one parent explained, “has been difficult emotionally but still a great blessing.”

6. **Community guide role**

The community guide’s role in ACS has proved to be a source of confusion. The ACS service delivery model emphasized use of a community guide to connect families with local supports and assist in integrating their family members with autism into their communities. But only about half of the families participating in the three rounds of interviews connect this service with ACS.

Of the 13 families interviewed during the first round, 6 reported that they had not used a community guide or didn’t know what a community guide was. Of the seven other families, two reported that they had worked with a “coordinator” or “facilitator” who performed the community guide role, and that the direction was helpful. The others reported that the community guide (Program Coordinator Meyer) assisted with person-centered and future planning, consumer education, and identifying local providers and other resources. One family member said that Meyer “faced real challenges” because of the dearth of service providers in Southwestern Washington.
During the second round of interviews, nine families discussed the term “community guide” in terms of the work that Program Coordinator Meyer has performed—despite the fact that only four families in the second round of interviews listed “community guide” as one of the ACS services they had received. This discrepancy indicates the general confusion around the community guide issue in the pilot. All nine families credited Meyer with making the program work for them: “She has coordinated training, etc., to promote job-tracking earlier in the school years.” “[She has arranged] future planning and regular employment meetings.” “There is not one aspect of this whole thing that Monica has not been involved with.” “She built [our] plan every step of the way.” The rest of the families appear to be puzzled by the use of the term, “community guide.” One asked, “Is this a person or a process?”

Only three families in the third round listed community guides as a service received from ACS, though six families answered the survey question about rating the community guide. Three mentioned Monica Meyer in response to that question. There appeared to be lasting confusion over the role of the community guide and whether it was Meyer’s job to fill it.

Asked to rate their satisfaction with the community guide on a scale of 1=Dissatisfied to 5=Satisfied, the responses of 8 families in the first round produced a mean score of 4.00. In the second round, nine families provided a mean score of 3.27, and in the third round, the six families gave an average rating of 4.33.
Interviews with Service Providers

1. **Types of services provided**

The following table shows how providers interviewed for this evaluation identified their services.

<table>
<thead>
<tr>
<th>Services Provided through ACS</th>
<th>Number reporting providing service in June-July 2000 (n=9)</th>
<th>Number reporting providing service in November 2000 (n=11)</th>
<th>Number reporting providing service in May 2001 (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day program</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Enhanced respite</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Residential support</td>
<td>2</td>
<td>3*</td>
<td>2</td>
</tr>
<tr>
<td>Voluntary placement</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Community guide</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

* One service provider was replaced during November 2000, at the time of the second round of interviews; we interviewed both the current AND former provider.

Interviewers asked service providers how the pilot program has affected delivery of service. In the first round of interviews, four of the service providers reported that they would not be working with the families were it not for ACS, in part because of the streamlined paperwork and increased compensation. One service provider explained that the additional resources available through the pilot allowed him and one family “to greatly expand a highly positive connection.” Providers reported being better informed, receiving more training specifically about autism, understanding families’ needs better, and working in an atmosphere of greater stability. Only one provider said that its service provision has not changed since implementation of ACS.
During the second round of interviews, service providers commended the work of the program coordinator, noted a higher degree of community integration for persons with autism, and cited the “motivating factor” of ACS. “Without ACS,” said one service provider, “I wouldn’t take the job.” During the third round, service providers confirmed that ACS makes their job easier by reducing stress in families and improving their community’s understanding of autism.

2. Are families better off?
Service providers in all rounds of interviews reported seeing improvement in families’ level of control and integration in their communities, as well as fewer gaps in service. “It is like my own family has grown,” says one service provider. Another reported that “the family is seeing their son progress in a way similar to their other children.” A full-time companion said that ACS has allowed her to participate in an “exciting” model of care. Providers commended the support they receive from ACS, which leads to greater continuity of care. They also reported that they are receiving more training in autism—as one provider explained, in autism “best practices.”

Asked to rate whether families are “Not As Well Off”=1 to “Better Off” =5, service providers gave a mean rating of 4.89 in the first round of interviews, 4.82 in the second round, and 4.85 in the third round. The service providers also said in interviews that persons with autism are better off under the ACS pilot. On a 5-point scale, with “Not As Well Off”=1 and “Better Off”=5 the providers reported a mean score of 4.78 in the first round, 4.64 in the second round, and 4.77 in the third round.

3. Would you make changes?
Two service providers in the first round of interviews and three in the second round noted that medical benefits would support their continued participation in ACS. Providers interviewed in June-July expressed their support for the ACS goals; those interviewed during November also discussed the need for tighter
administration: one mentioned “checks and balances.” During the third round of interviews, service providers gave the program consistently high marks despite a repeated request for health insurance for care providers.

4. **Overall satisfaction**

One a 1-5 scale, with “Dissatisfied”=1 and “Satisfied”=5, service providers assigned ACS an average rating of 4.56 during the first round of interviews, 4.45 during the second round, and 4.54 in the third round. In all rounds of interviews, providers praised the increased compensation, training, focus on autism, and community inclusion for consumers. Only one service provider gave specific examples of “system problems,” including a “slow approval process” and a “fairly long wait” for additional resources.

One service provider in the first round of interviews praised the pilot program as “a big learning experience for all involved. What has been learned is invaluable, so that the project is accomplishing what it is supposed to.”

3. **Community guide role**

Service providers in all rounds of interviews were even more likely than families to associate the program coordinator’s work with that of community guide. Of the 11 service providers participating in interviews in the second round, only 3 reported that they had not worked with a community guide. Seven service providers in the second round specifically mentioned Meyer’s work, all in positive terms, including crediting her with being the “eyes and ears” of ACS, providing coordination and training, keeping a “close knit network” functioning, and for being an “excellent planner.” In the third round, only one service provider discussed interactions with a community guide; two of the providers mentioned Meyer, including one who offered the comment that “She has been there when [the family] needed her.”
CDPR spoke with Meyer about the nature of her work with ACS. “I think I go farther than a community guide would,” Meyer explained, “trying to make myself available to every family” and sorting through issues ranging from day-to-day problems to employment plans. She sees the program’s greatest accomplishments as meeting the initial deadline for out-of-home placements and completing a person-centered plan for each family.

Meyer believes that despite the continual, immediate challenges, ACS is long-term and proactive in its approach: “Kids with autism—they grow up and can have a long life span just like anyone else….This isn’t a quick fix.”

Meyer reported that other regions of the state, including Yakima and Gig Harbor, are contacting her to learn how ACS brought families together and learn how the group persuaded the Washington Legislature and the Division of Developmental Disabilities to support this approach to meeting families’ individual needs. Talking with CDPR at the end of the evaluation in June 2001, Meyer said she continues to hear from families from all of the country, asking how her community managed to develop ACS: “They tell me, I can’t believe you guys are doing this.”