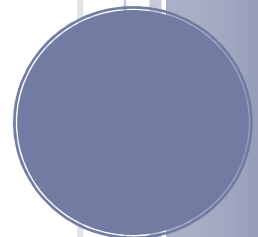


COMMUNITY SUPPORTS PROGRAM (CSP) STUDY REPORT

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28-Feb-10

**Grant Project Funded by the Nebraska Planning
Council on Developmental Disabilities**



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INTRODUCTION

The Community Supports Program (CSP) is a set of community-based services and supports funded through Nebraska's Division of Developmental Disabilities. The CSP offers funding for services to assist persons with disabilities in living, working, and participating in their community. This "consumer-directed" program provides choices of services and providers not previously available for persons with developmental disabilities in Nebraska. These choices are important, as it has been shown that people who feel they have control over their lives, their services, and their supports are more likely to feel and be successful. (Nebraska Department of Health and Human Services: http://dhhs.ne.gov/Developmental_Disabilities/csp.htm)

It is no surprise that participants in the CSP express a high degree of satisfaction, mostly due to the flexibility the program allows. However, the CSP, first piloted in Nebraska in 2003 and implemented statewide in 2007, has been slow to catch on in the state. According to data obtained from the Division of Developmental Disabilities (DDD) in October of 2009, only 121 individuals were participating in the program.

A one-year grant from the Nebraska Planning Council on Developmental Disabilities was awarded to O'Hare Professional Consultation Services in October 2009 to study the use and effectiveness of the CSP. While the CSP is a service option for all DDD eligible adults over age 21, this project focuses on transition age youth with developmental disabilities. The intent of the project is to ensure that transition students are provided accurate and understandable information regarding the CSP as they and their families make plans for life after high school. From the inception of the CSP, it was anticipated that young adults are prime candidates for this program. This grant project is an attempt to identify and address barriers that may prevent them from selecting CSP services and to make recommendations to increase overall utilization and effectiveness of the CSP.

The project began with an information gathering process conducted by the project coordinators to identify effective practices, gaps, and barriers related to the current use of the CSP. This process included the distribution of a written survey to focus groups across the state from October 2009 through January 2010. A total of 25 focus groups were held, with 401 people in attendance. Focus group participants included a variety of stakeholders including family members, school transition specialists and teachers, Service Coordinators, Vocational Rehabilitation staff, transition students, advocacy groups, CSP providers, Division of Developmental Disabilities (DDD) staff, specialized developmental disability providers, consumers utilizing or contemplating the utilization of the CSP, and other interested parties. Basic information regarding the CSP was provided to stakeholders during the focus meetings and discussion was held between attendees and the project coordinators.

This CSP Study Report summarizes results of the first quarter of the grant, including CSP statewide data, focus group feedback, effective practices recognized by other states in offering self-directed services, recommendations for policy changes and dissemination of information, and identification of next steps to accomplish recommendations.

CSP STATEWIDE DATA

At the request of the project coordinators, statewide CSP utilization data was provided by DDD, as of 10/1/09. The following are highlights of the data.

Program Growth

- The number of participants enrolled in the CSP has grown from seven enrollees in Fiscal Year (FY) 2003 to 121 enrollees as of 10/1/09.
- A total of 148 participants have been involved in the program since FY 2003.

Annual Average CSP Costs

- In FY 2009, 99 persons were enrolled in the CSP. The average amount of total funding per participant for the entire year was \$6,375.

CSP Participants

- Most individuals enroll in the CSP during their twenties. Approximately 60% of individuals who enrolled in the program did so while they were in their 20s, with 22% of the total who have enrolled since the programs' inception enrolling at the age of 21.

CSP Utilization by Cities

- Current utilization of CSP is highest in the tri-city area of Grand Island (11 participants), Hastings (13 participants), and Kearney (11 participants). (*Note: these cities were part of the original pilot project for the CSP.)
- Smaller Nebraska rural cities with a significant number of participants include Ainsworth (5), Holdrege (5), and Minden (4).
- The urban area of Lincoln has one participant, while Omaha has 15 participants.

SURVEY RESULTS

A total of 401 participants attended 25 focus groups, with 350 focus group participants completing a written survey. The focus groups were arranged through agencies or held as open public forums. The following summarizes the agency and public forums held.

Agency Meetings

School Transition Groups

1. Transition Practitioners Committee
2. Transition Advisory Committee
3. Nebraska Transition Summit

Service Coordination

1. Western Service Coordination
2. Eastern Service Coordination
3. Central Service Coordination
4. Northern Service Coordination-Session cancelled due to weather, but feedback obtained via email
5. Southeast Service Coordination
6. Service Coordinator Administrators

DDD Central Office Staff

DDD Advisory Committee

Vocational Rehabilitation

1. Omaha (2 different groups)
2. Grand Island/Kearney
3. Norfolk
4. Lincoln
5. Scottsbluff

Public Forums

1. Columbus
2. Grand Island
3. Kearney
4. Lincoln
5. Norfolk
6. North Platte
7. Omaha
8. Scottsbluff

Stakeholders Represented

Focus group participants represented a number of stakeholder groups and interested parties from across the state. An announcement of the focus groups and an attendance list is included in Attachment A. A number of the attendees did not identify their stakeholder group and other attendees identified themselves as representing more than one stakeholder group. The largest stakeholder group represented was Service Coordination, with a total of 140 Service Coordinators, followed by Vocational Rehabilitation staff with 78 in attendance. A total of 53 family members and 29 school transition staff attended the meetings.

The focus groups were provided with an overview of the grant project and also background information and data regarding the current usage of the CSP, followed by a request to complete the written survey instrument. (Attachment B.) As stated earlier, the survey was designed to explore gaps, barriers, and effective practices in the use of the CSP. Individuals unfamiliar with the program were given instructions to complete only the first and last sections which indicated their level of familiarity with the program and the stakeholder group they represented. Tables representing survey results appear in Attachment C.

Vocational Rehabilitation (Voc Rehab) agency staff participating in the focus groups had recently been introduced to the CSP by agency representatives Dennis King and Jack Shepard. Mr. King and Mr. Shepard introduced a recent change in DDD and Voc Rehab policy which allows CSP providers assisting consumers to seek and/or maintain employment to participate in Voc Rehab's Supported Employment Services program. As a result, many of these Voc Rehab staff members had recently been introduced to CSP for the first time.

Once focus group participants completed the written survey, the project coordinators conducted an informal discussion. A list of comments, by focus group, is presented in Attachment D.

Familiarity with CSP

The first question in the survey was designed to solicit information regarding the participant's familiarity with the program, as well as to solicit opinions regarding the adequacy of the materials in making or assisting someone to make a decision regarding participation in the program. The majority of those responding to this question indicated that they had received information regarding the CSP, but many (41%) indicated that the information was not adequate to make or assist someone to make a decision to utilize the CSP.

Parents familiar with the program indicated that the brochure had too much jargon to be understandable and lacked any detail, while the CSP Consumer Handbook was helpful only after a decision had been made to participate in the program. The consensus across many of the focus groups was that the material available did not paint a clear picture of the CSP.

Barriers to Utilizing CSP

Possible barriers to utilizing the CSP were listed on the questionnaire. The barriers represented three distinct constructs: dissemination of information and education; family confidence in utilizing the CSP; and policies governing the CSP. Focus group participants were asked to check all the barriers they perceived to be a reason young adults and their families do not choose the CSP. Overwhelmingly, the construct which was most widely identified as a barrier to families and young adults choosing CSP was information and education. (Figure 1.)

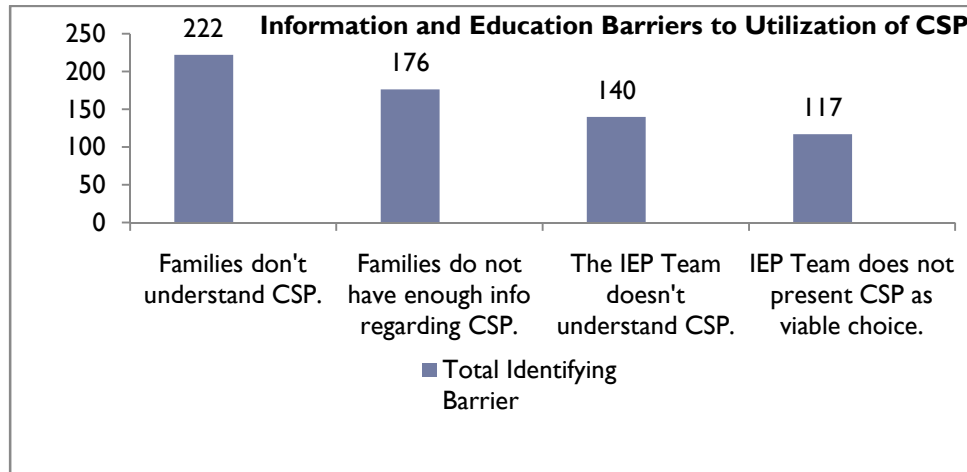


FIGURE 1. INFORMATION AND EDUCATION BARRIERS TO CSP

Families and professionals alike do not have up-to-date and accurate information and education regarding the CSP. Without information and education, families cannot make an informed choice. Professionals (Service Coordination, Voc Rehab staff, and school transition staff) do not have enough education regarding the program to feel comfortable explaining it to families as a viable choice. Throughout the focus groups, many questions were raised about how the program operated, who was eligible, who was responsible for introducing the program to the family, whether more than one provider could be utilized, whether one provider could support two individuals at the same time, who is responsible for making payments to CSP providers, etc. These questions were asked by a variety of stakeholders. It became clear after several focus groups that the CSP is not being offered as an option because professionals do not understand it well enough to answer those questions. Consequently, it is not surprising that family members and transition students are not choosing it. Consider the following quote from a Mom and a teacher:

“As a mother of a special needs student and a teacher, the information I have received has been very low key. This service is available but there is no information in regards to process, paperwork, requirements, etc. Very minimal communication received from DDD.”

Service Coordinators assume the lead in the administration of CSP, yet often expressed a lack of education regarding the operational aspects of CSP, as did Developmental Disabilities Division staff. Since the program is not well understood, it is not being presented as a viable option. Therefore, it is not surprising that it is so underutilized. Currently, it appears that the principal barrier to families and students choosing the CSP is simply a lack of information and education.

The forum in which families and young adults are typically introduced to adult services is in the IEP meetings. Focus group attendees repeatedly stated that CSP was not being offered as an option to families at IEP meetings.

School transition staff and Voc Rehab staff who attend IEP meetings reported that they

“have never heard the CSP mentioned”

and need more information regarding the program so they can at least explain the basics and provide written information to families when Service Coordination is not represented at IEP transition meetings. IEP staff members are understandably reluctant to offer insufficient information because, as one Voc Rehab staff member put it:

“Families trust the IEP team: their word is gold.”

Most focus group participants articulated that it is not common practice for a representative from Service Coordination to attend IEP transition meetings. It is unclear whether Service Coordination is not being invited to IEPs or if they are invited and cannot attend due to other responsibilities. It was expressed in many focus groups that Service Coordinators are overloaded with their current duties and, therefore, probably did not have the time to come to IEP transition meetings. A related comment follows regarding Service Coordinators' roles:

“Service Coordinators are being diluted/diverted into other responsibilities.”

Regardless, more accurate and complete information regarding the CSP is needed at the point when the family and transition student begin to consider post-graduation options. A quote from a family member nicely sums up the need for more information:

“Communication is a big component that is missing from this option—getting from graduation to this service option.”

Focus group attendees, inclusive of all stakeholders, expressed a lack of family confidence in being able to effectively self-direct services. (Figure 2.) In particular, focus group attendees frequently noted that families expressed difficulty securing and training qualified staff. Family members represented in the focus groups also ranked the ability to secure and train qualified staff as a significant barrier to choosing CSP. One mother of a young adult participating

in CSP expressed frustration that Service Coordination could not find a provider for her in a timely manner. It appeared that she had not been coached on how she might go about using her own personal network and connections to find a suitable CSP provider for her son. She was simply waiting for Service Coordination to find someone for her. Throughout focus group discussions, a number of creative ideas were generated regarding how families could find appropriate CSP providers. For example, Voc Rehab staff expressed an interest on behalf of their clients looking for employment who might be appropriately placed as a CSP provider. Retired teachers, paraeducators, and specialized provider staff looking to make some extra money were also mentioned as possible employment pools.

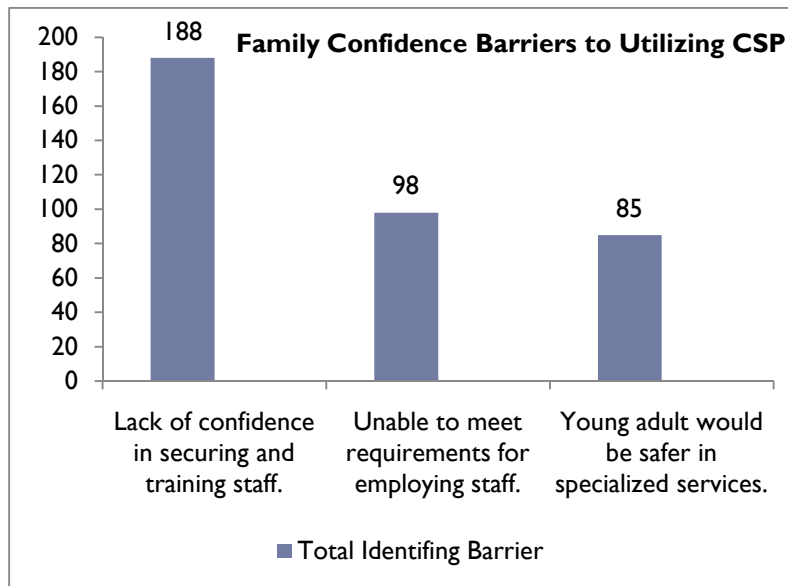


FIGURE 2. FAMILY CONFIDENCE BARRIERS TO UTILIZING CSP

Policy issues were less frequently noted by focus group attendees, most likely because the program is not widely used at this time and they have not had direct experience with it. (Figure 3.) However, once some of the policy issues were explained to the stakeholder attendees, many agreed that there need to be policy changes if utilization of CSP is expected to increase.

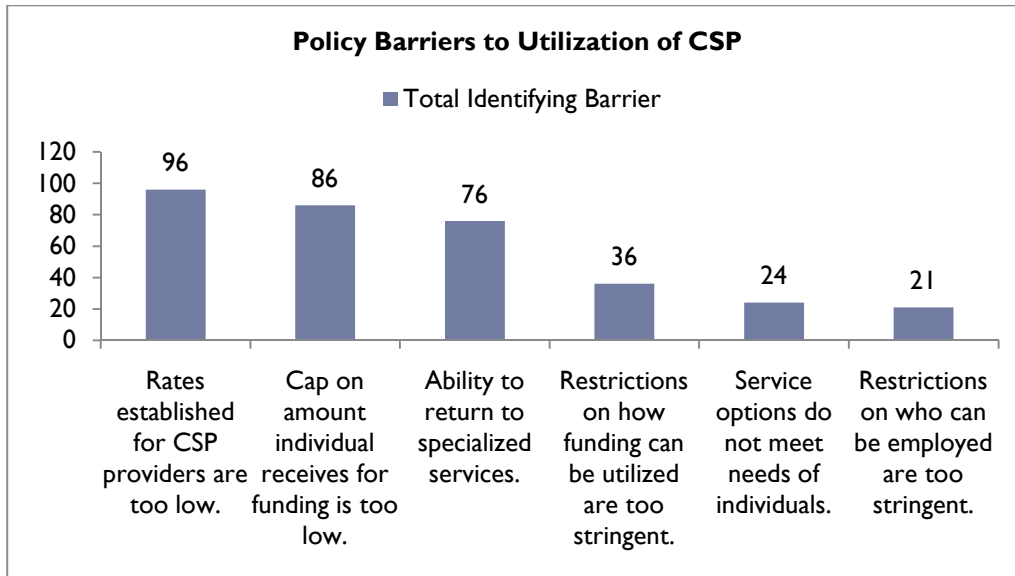


FIGURE 3. POLICY BARRIERS TO UTILIZATION OF CSP

The two most frequently noted policy barriers to the utilization of CSP was the CSP provider wage cap of \$10 per hour is too low to hire qualified staff and the individual cap of \$20,000 is too low for individuals with high medical or behavioral needs to participate in CSP. Some related quotes from stakeholders regarding these barriers follow.

“Since the provider has to pay FICA and taxes, the rate of \$10 per hour is TOO low.”

“I believe the rates are too low to begin to attract people who will successfully provide the service.”

In almost every stakeholder group, the issue of whether or not the young adult can easily switch to specialized services if CSP was not working out was raised. Although this is possible, it was not clear to stakeholders how the process works and how quickly it could occur.

Two issues were repeatedly brought up that were not on the questionnaire: unreimbursed transportation costs and the ability to mix specialized services and CSP. One mother expressed frustration with the lack of transportation reimbursement for the CSP provider to transport her son, who wants to learn to drive, to driving lessons in a city 25 miles away. A round trip would consist of 50 miles and significantly depletes the already low wage of \$10/hour wage which, of course, does not include any benefits. Another CSP provider in Scottsbluff is caring for an individual with significant medical needs. The individual has numerous physician appointments and the CSP provider is the individual’s main source of transportation. The cost of transportation for numerous trips to the physician is eating away at the already low CSP provider’s wage.

Mixing of specialized services and the CSP was also discussed in almost every focus group. Stakeholders felt that many more individuals would access CSP if they could have the safety net of a specialized provider. As one Service Coordinator put it:

“Would have five folks who would be on the program immediately if could mix specialized/non-specialized services.”

Other benefits to mixing the two service types are the socialization and employment opportunities that are offered by specialized providers that are difficult to achieve under the CSP program.

CSP Effective Practices

Through the work of this grant project, discussion was held with stakeholder groups to solicit information on effective practices that have been implemented by current CSP consumers and their families or suggestions for practices which might be effective. Due to the fact that the participants in the stakeholder groups had limited or no experience with the program, there were few ideas shared. It is important to note that there are likely many other positive practices being utilized than are noted in this report. The majority of feedback received on effective practices related to locating providers, as reflected in the following comments.

- Some families have hired paraprofessionals from the school to be their CSP provider.
- Word of mouth works to find providers.
- Hiring staff based on relationship that existed before is more likely to be successful. It is helpful when the individual/family knows potential providers prior to provision of CSP. It is less effective if Resource Development or other entities locate providers.
- Effective practices include follow up by the Service Coordinator, staying connected, encouraging, and sharing “outcomes”.
- Effective hiring practices include conducting multiple interviews with prospective providers before hiring.
- Must maintain a dialogue with the provider, consumer, and natural supports.
- Family member advice: *“When I am out in the community, I am always looking for providers.”*

CSP Training Needs

Focus group attendees identified a number of training needs, including individual and family training on self-directing services; eligibility, funding, and program requirements; general information on CSP; CSP provider training; and hiring CSP staff. (Figure 4.)

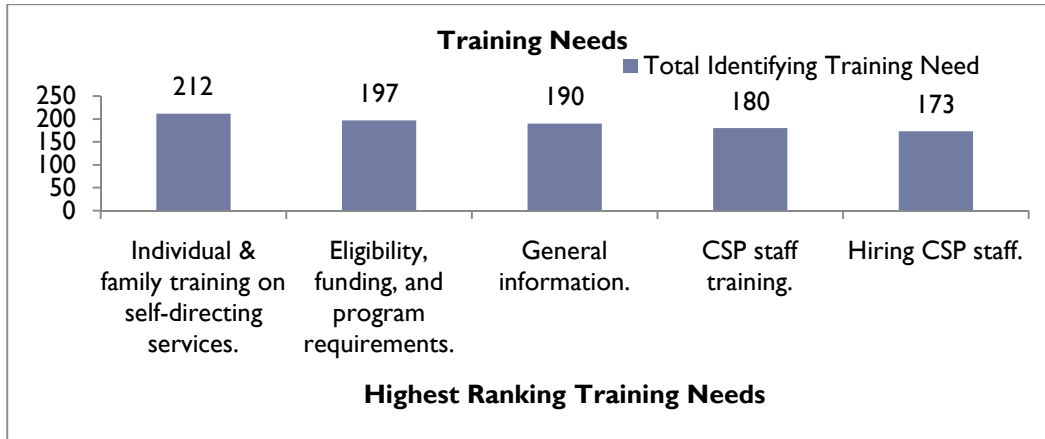


FIGURE 4. CSP TRAINING NEEDS

Additional CSP training was highly requested by focus group members for families/guardians, school transition staff, transition students, Service Coordinators, and current or potential CSP providers. (Figure 5.)

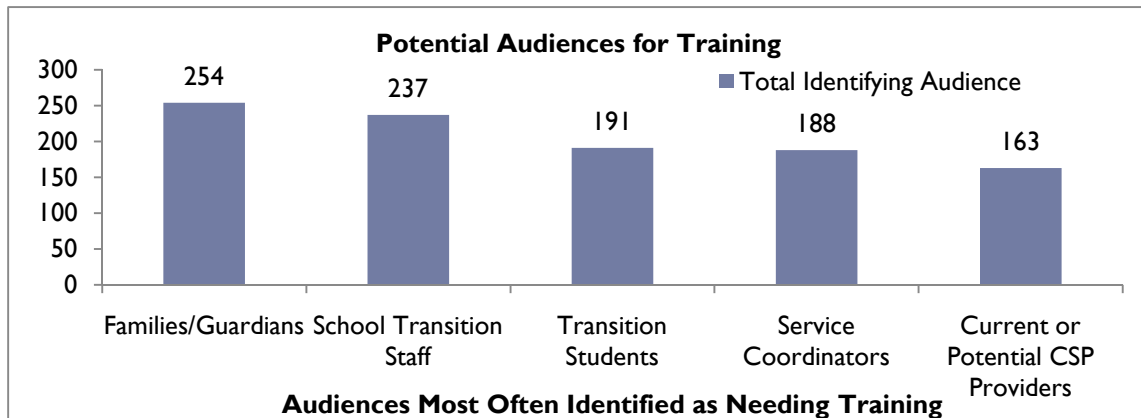


FIGURE 5. AUDIENCES FOR CSP TRAINING

EFFECTIVE PRACTICES

Practices in Other States

In evaluating Nebraska's Community Supports Program, it is helpful to look at practices in similar programs in other states. A recent national study, conducted at the University of Minnesota's Research and Training Center on Community Living and Syracuse University's Center on Human Policy, evaluated the status of consumer-directed services for persons with intellectual or developmental disabilities. A *Policy Research Brief*, published in January 2009, summarized the results of this study. (Policy Research Brief, Implementation of Consumer-Directed Services for Persons with Intellectual or Developmental Disabilities: A National Study, 2009) The study investigated how consumer control is being implemented across 42 states and explored strategies, challenges, and best practices of consumer-directed services and supports in those states. Following is a brief summary of findings from this study.

As would be expected, there is considerable variation from state to state in the implementation of consumer-directed programs. Key variances include:

Eligibility: Many of the states surveyed offer consumer-directed services to both children and adults; a few states offer the option to adults only. Many states currently, or at some point in time, have offered the consumer-directed program option to limited geographic areas or as a pilot project. Some states extend eligibility for consumer-directed services to all those who are eligible for developmental disabilities waiver services; others limit eligibility either to people who are on the waiting list for services or to people who already receive services.

Assistance with Management of Services: States report a need for different types and levels of assistance other than those provided by traditional case management. The two most common models of assistance are a combined service coordinator/broker or a separate support broker.

Combined service coordinator/broker: In this model, individuals have access to a specialized case manager/service coordinator who has received training beyond that which is offered to traditional case managers and who may have a smaller caseload.

Separate support broker: In this model, a support broker works in addition to and distinct from case management. In some of these states, there is particular emphasis placed on the notion that these be "independent" support brokers.

Limited Versus Unlimited Maximum Budget: Consumer-directed programs in most states have established a maximum individual budget capped at the Intermediate Care Facility for the Mentally Retarded

(ICF/MR) rate. A few states, however, have significantly lower maximum annual budget caps, ranging from \$3,800 - \$30,000.

Types of Waivers: States vary in their approaches to incorporating consumer-directed options into their waiver programs. Some states have separate waivers for consumer-directed services, such as Independence Plus or family support/in-home support waivers. Other states have chosen to add consumer direction as a component of existing waivers.

Hiring and Payment of Direct Support Staff: It is common practice among states to establish guidelines about who can be hired to provide services, including restrictions addressing age, relationship (such as prohibiting a spouse or legal guardian), and criminal background requirements. In regard to provider pay, some states offer little or no flexibility in what providers may be paid. In some states, pay is based on set rates; in others, there are predetermined rate ranges. Individuals and families are given greater flexibility in some states, with guidelines such as: “within the normal and customary cost”, “based on community standards”, “reflect good and reasonable decisions”, or that people be “prudent buyers”. Administrators report that there are processes for exceptions to the rate requirements when justification is provided.

Lessons Learned from Other States

The *Policy Research Brief* identified a set of specific lessons for states in implementing consumer-directed initiatives, based upon the findings of the national study. Highlights of the identified lessons are outlined as follows.

Establish a Separate Support Broker Role: The need for a support broker, distinct from a case manager or service coordinator, was identified by many state administrators as an important feature.

Build in Different Levels of Assistance: Many states recognized the need to build in a variety of levels of support for managing services and finances.

Expect a Loss of Flexibility with System-Wide Implementation: As programs grow and are implemented on a larger scale, it was noted that there is a loss of flexibility and the need to create more infrastructure and bureaucracy to support it.

Change Information Technology (IT) Systems: Adapting a state’s information technology infrastructure is a major, but critical, undertaking necessary to help coordinate management and budget monitoring.

Provide Adequate Information, Education, and Support: Providing information and training for individuals and families is critical. This includes the need to “communicate with people and educate them regarding the parameters of the program,” the need to “help people have

understanding and clarity about what their individual budget is and the value of it,” and the need to “help people understand the responsibilities.”

Assess Costs Within the Context of the Whole System: The study found that only a few states have systematically analyzed costs of the consumer-directed option of services. While they have gathered data on who is participating, what services they are utilizing, and cost of services, they have done little analysis of the data.

Adapt Monitoring and Quality Assurance Systems: Some states utilize the same Quality Assurance and monitoring systems for consumer-directed services as for more traditional services. Others use less intense monitoring, with more reliance on the individual and family. Several states have identified the need to revise their quality assurance system and quality indicators to meet the needs of this program.

Collaborate with Stakeholders: Many states noted the importance of collaborating with stakeholders in developing and promoting consumer-directed services.

Anticipate Increased Consumer Satisfaction: While this has not been validated with systematic study or national evaluation, those who use consumer-directed services are reported to be highly successful and satisfied. Themes that were identified through the work of the study include:

- Not having to fit people into program-specific slots.
- Seeing people succeed after experiencing frustration with traditional services.
- Real change has occurred in people’s lives.
- Hiring people of one’s choice, with less staff turnover.
- Reaching more diverse service users.
- More efficient use of resources.
- Collaboration between stakeholders, with increased participation by self-advocates.

The complete *Policy Research Brief* may be found at:
http://hcbs.org/files/151/7525/consumer_direction_developmental_disabilities.pdf

RECOMMENDATIONS

1. Develop and implement a communication plan to increase awareness and provide a clear understanding of the Community Supports Program.

The overwhelming message from all stakeholders is that information needs to be developed and disseminated to increase awareness and provide a clear understanding of the CSP. Information should be provided in a variety of formats (including print and video) and widely distributed to those who may utilize the services, as well as those assisting individuals in selecting and accessing services.

2. Submit recommendations for policy changes to the Division of Developmental Disabilities to address barriers to effective utilization of the CSP.

Three policies were consistently identified by stakeholders as barriers for the CSP:

- A. Provider rates.** The current \$10 cap on the rate that may be paid to CSP providers limits the ability to hire and retain qualified providers. Compounding the issue is the fact that there are no provisions for reimbursement for mileage or transportation costs.
- B. Service mix.** The program's current prohibition on mixing CSP services with "traditional" specialized services limits the ability to develop an effective plan for the individual.
- C. Individual funding cap.** The current funding cap of \$20,000 or the individual's OAP amount, whichever is less, limits the ability to meet the needs of individuals and, in some cases, prevents individuals from selecting the CSP option.

3. Develop and deliver training to address the needs of all groups involved in the CSP.

Stakeholders identified training needs for a wide variety of groups on topics specific to the CSP, as well as the need for more general information related to self-directed services. Focus areas for training include, but are not limited to:

- Self-directed services;
- Program-specific training;
- Provider training; and
- IEP team member training.

NEXT STEPS

Following are the anticipated next steps in this grant project:

1. This report will be disseminated to the Nebraska Planning Council on Developmental Disabilities, the DHHS Division of Developmental Disabilities, focus group participants, and other interested parties.
2. Follow-up with the Division of Developmental Disabilities will be provided, as needed, to discuss any questions regarding this report and recommendations for policy changes.
3. Work will convene with the Project Advisory Committee (see Attachment E) to develop a communication plan to increase awareness and provide a clear understanding of the Community Supports Program.
4. Materials will be developed and disseminated as identified in the communication plan.
5. Recommendations for a plan to address identified training needs will be developed. Future work to be conducted in this area will be dependent upon availability of continuation funding for such a project.

ATTACHMENT A. FOCUS GROUP ANNOUNCEMENT AND ATTENDANCE

DEVELOPMENTAL DISABILITIES COMMUNITY SUPPORTS PROGRAM

The Community Supports Program (CSP) is a set of community-based services and supports funded through the Nebraska Division of Developmental Disabilities. This flexible program offers the opportunity for eligible individuals and their families to direct services to assist them in living, working, and participating in their community.

A grant from the Nebraska Planning Council on Developmental Disabilities is providing funding to study use and effectiveness of the CSP, with emphasis on young adults as they leave high school. Focus groups are being held across the state to gather input from individuals, families, advocacy groups, educators, and service providers. These informal sessions are designed to promote conversation and gather feedback to improve and promote the program.

Please consider attending a focus group near you! If you are not able to attend and would like additional information or to provide your input, contact the Project Coordinators listed below.

2009–2010 FOCUS GROUP SCHEDULE *

Columbus 3:00 p.m. Dec. 15
Educational Service Unit #7
2657 44th Avenue

Grand Island 12:00 p.m. Dec. 4**
Grand Island Public Library Rm. A
211 N. Washington Street

Kearney 4:00 p.m. Dec. 16
1st Presbyterian Church Family Life Ctr.
4511 6th Avenue

Lincoln 4:00 p.m. Dec. 17
Charles H. Gere Library
2400 S. 56th St. Room 2

Norfolk 4:00 p.m. Dec. 7
Holiday Inn Express

920 S. 20th Street

North Platte 12:00 p.m. Dec. 16**
North Platte Community Playhouse
301 East 5th Street

Omaha 12:00 p.m. Jan. 19**
NE Health & Human Svcs./DD Svc. Coord.
1821 N. 73rd Street

Scottsbluff 4:00 p.m. Jan. 28
Panhandle Mental Health Center
4110 Avenue D

*In the event of inclement weather in your area or weather that would prevent Coordinators from traveling from Lincoln, call (402) 730-8469 or (402) 890-0636 for cancellation information.

**Participants are welcome to bring a brown bag lunch to sessions held at noon.

Date	Group	Location	Attendees
10-1	Transition Practitioners Committee	ESU #3 Omaha	22
10-9	Transition Advisory Committee	Country Inn & Suites Lincoln	14
10-21	SC Administrators	State Office Building Lincoln	8
10-27	Central Service Coordination	US Bank Grand Island	26
11-3	Western Service Coordination	State Office Building North Platte	24
11-12	NE Transition Summit	Holiday Inn Kearney	15
11-17	DDD Advisory	State Office Building Lincoln	17
11-20	Omaha Service Coordination	1821 N. 73 rd Omaha	43
11-30	Omaha Voc Rehab	State Office Building Omaha	28
12-4	G.I. /Kearney Voc Rehab	3335 W. Capital Ave. Grand Island	26
12-4	G.I. Forum	Library 211 N. Washington Grand Island	5
12-7	Omaha Voc Rehab	12011 Q Omaha	13
12-7	Norfolk Voc Rehab	1212 Benjamin Ave. Norfolk	13
12-7	Norfolk Forum	Holiday Inn Express Norfolk	2
12-14	DDD Central Office Staff	State Office Building Lincoln	14
12-15	Columbus Forum	ESU #7 Columbus	2
12-16	North Platte Forum	Community Playhouse North Platte	9
12-16	Kearney Forum	1 st Presbyterian Church Kearney	11
12-17	Lincoln Forum	Gere Library Lincoln	6
12-18	Lincoln Voc Rehab	VR Office Lincoln	7
1-19	Omaha Forum	DD SC Office Omaha	5
1-25	Northern Service Coordination	(session cancelled due to weather – feedback obtained via e-mail)	12

1-27	Southeast Service Coord.	Gold's Building Lincoln	56
1-28	Scottsbluff Forum	Panhandle Mental Health Scottsbluff	15
1-28	Scottsbluff Voc Rehab	1517 Broadway LL Scottsbluff	8
TOTAL	25 SESSIONS		401

ATTACHMENT B. COMMUNITY SUPPORTS PROGRAM QUESTIONNAIRE

The Nebraska Developmental Disabilities Planning Council has provided grant funding to O'Hare Professional Consultation for the purposes of improving transition planning for youth with developmental disabilities and their families as they consider adult services. A focus of this grant is to increase awareness and utilization of the Community Supports Program among transition students. The self-directed services available under the CSP are a fairly new option for students with developmental disabilities and we are interested in your input on how usage and effectiveness of the program can be increased. Please take a few minutes to complete the following questionnaire. **Your assistance is greatly appreciated!**

- 1. Have you previously received information regarding the CSP?** Yes ____ No ____
If "No", and you don't have enough information to answer further questions, check here, answer Question #6, and stop. ____

If "Yes", was the information adequate for you to make an informed decision or assist someone in making a decision regarding participation in the program? Yes ____ No ____

- 2. What do you consider barriers to families and students choosing CSP services? Check all that apply.**

- _____ a. Families believe the cap on the amount an individual receives for funding is too low.
- _____ b. Families do not fully understand the way the program works.
- _____ c. Families do not have confidence they can adequately secure and train qualified support staff.
- _____ d. Families do not have enough information regarding the program.
- _____ e. Families feel their young adult would be safer in an agency-staffed workshop or residential setting.
- _____ f. Families feel they are unable to meet the necessary requirements for employing staff.
- _____ g. Families are concerned that they cannot return to "traditional" services if the CSP doesn't work for them.
- _____ h. The IEP team does not fully understand the program.
- _____ i. The IEP team does not present the program to families as a viable choice.
- _____ j. Restrictions on who can be employed as staff are too stringent.
- _____ k. Restrictions on how the funding can be utilized are too stringent.
- _____ l. Rates established for CSP providers are too low.
- _____ m. Service options in the program do not meet the needs of the individual.

Comments or Other Barriers:

- 3. If you are familiar with individuals who have participated in the CSP, what effective practices have you seen utilized to meet the needs of the individual?**

- _____ a. Practices in hiring CSP provider staff.
- _____ b. Practices in training CSP provider staff.
- _____ c. Practices in designing and implementing the services to meet the needs of the individual.
- _____ d. Practices in meeting the necessary requirements in employing staff.
- _____ e. Other (identify): **Please briefly explain any effective practices.**

4. What training is needed in order to provide the information and support necessary to make the CSP a viable option for students and families? Check all that apply.

- ☐ a. General information regarding the program.
- ☐ b. Specific information regarding eligibility, funding, and meeting program requirements.
- ☐ c. Effective practices for hiring staff.
- ☐ d. Effective practices for training staff.
- ☐ e. Effective practices in designing and implementing the services to meet the needs of the individual.
- ☐ f. Training for individuals and families on self-directing services.
- ☐ g. Training for CSP providers on meeting program requirements.
- ☐ h. Training for CSP providers on working with individuals with developmental disabilities.
- ☐ i. Other (list): _____

5. Identify the stakeholders who would benefit from additional information and/or training regarding the CSP. Check all who apply.

- ☐ a. Families/Guardians
- ☐ b. School Transition Staff
- ☐ c. Service Coordinators
- ☐ d. Vocational Rehabilitation Professionals
- ☐ e. Transition Students
- ☐ f. Advocacy Groups
- ☐ g. DD Providers
- ☐ h. Current or Potential CSP Providers
- ☐ i. Other Agency Staff (identify): _____
- ☐ j. Other (list): _____

6. Identify the group or groups you represent:

- ☐ a. Family Member
- ☐ b. School Transition Staff
- ☐ c. Service Coordinator
- ☐ d. Vocational Rehabilitation Staff
- ☐ e. Transition Student
- ☐ f. Advocacy Group
- ☐ g. Current or Potential CSP Provider
- ☐ h. Other Agency Staff (identify): _____
- ☐ i. Other (identify): _____

If you have any further questions or comments, please contact the project consultants:

Lloya Fritz: lloyafritz@windstream.net **Mary O'Hare:** maryohare1@windstream.net.

Completed surveys may be mailed to:

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ATTACHMENT C. SURVEY RESULTS

Question 1. CSP Information		
Have you previously received information regarding the CSP?	<u>Yes</u>	<u>No</u>
	282	58
Was the information adequate for you to make an informed decision or assist someone in making a decision regarding participation in the program	<u>Yes</u>	<u>No</u>
	142	101

Question 2. Barriers to Choosing CSP	Total Identifying Barrier	Rank Order
Families do not fully understand the way the program works.	222	1
Families do not have confidence in securing/training qualified support staff.	188	2
Families do not have enough information regarding the program.	176	3
The IEP team does not fully understand the program.	140	4
The IEP team does not present the program to families as a viable choice.	117	5
Families feel they are unable to meet the necessary requirements for employing staff.	96	6
Rates established for CSP providers are too low.	96	7
Families believe the cap on the amount an individual receives for funding is too low.	86	8
Families feel their young adult would be safer in an agency-staffed workshop or residential setting.	85	9
Families are concerned that they cannot return to "traditional" services if the CSP doesn't work for them.	76	10
Restrictions on how the funding can be utilized are too stringent.	36	11
Service options in the program do not meet the needs of the individual.	24	12
Restrictions on who can be employed as staff are too stringent.	21	13

Question 3. Effective Practices	Total Identifying Practices
Designing and implementing the services.	61
Hiring CSP provider staff.	45
Training CSP provider staff.	24
Meeting the necessary requirements in employing staff.	24

Question 4. Training Needed	Total Identifying Training	Rank Order
Training for individuals and families on self-directing services.	212	1
Specific information regarding eligibility, funding, and meeting program requirements.	197	2
General information regarding the program.	190	3
Effective practices for training staff.	180	4
Effective practices for hiring staff.	173	5
Effective practices in designing and implementing the services to meet the needs of the individual.	145	6
Training for CSP providers on working with individuals with developmental disabilities.	137	7
Training for CSP providers on meeting program requirements.	134	8

Question 5. Stakeholders who would Benefit from Additional Information and/or Training	Total Identifying Stakeholder Group	Rank Order
Families/Guardians	254	1
School Transition Staff	237	2
Transition Students	191	3
Service Coordinators	188	4
Current or Potential CSP Providers	163	5
VR Professionals	155	6
DD Providers	146	7
Advocacy Groups	134	8

Question 6. Focus Group Participants	No. Attendees
Service Coordinators	140
Vocational Rehabilitation Staff	78
Family Members	53
School Transition Staff	29
Advocacy Groups	13
Specialized Providers	11
DDD Staff	10
Transition Students	9
Consumers/CSP Participants	7
Teachers/ESU Staff	4
Corrections	1
Guardian	1
School Administrator	1
PTI Nebraska	1
Waiver Worker	1
Respite Coordinator	1
Legal Aid	1
Panhandle Independent Living	1

ATTACHMENT D. FOCUS GROUP COMMENTS

COMMUNITY SUPPORTS PROGRAM QUESTIONNAIRE & DISCUSSION COMMENTS

10-1-09 State Transition Practitioners Committee (Attendees: 22)

- Have had experiences at IEPs where Transition staff had more info about the CSP than the Service Coordination.
- Have never heard the CSP mentioned.
- SCs don't do a good job of explaining the CSP.
- I've never heard Service Coordination speak of this.
- I know of no participants.
- It should not be the educator's job to explain adult services.
- Program has not been presented in the "right light" to families.
- Need to provide case studies or actual examples from participants to give families a picture of how it can work.
- It is often overwhelming for families to think that they have to manage the whole day for the son/daughter.
- Families who are more involved tend to go for the CSP; lower socio-economic families are less likely to participate in the program.
- Parent reports that there is too much paperwork with the program (add this to the list of potential barriers on the Questionnaire).
- Families are concerned about how to find staff.
- Some families have hired paras from the school to be their CSP provider.
- The move to CSP services can be seamless when it's part of transition planning.
- Educators and families need more information on DDD eligibility requirements (not just CSP).
- DD providers don't seem to know enough about CSP.
- Barrier: people to select from in rural area.
- The brochure alone is not enough.
- Parents may feel overwhelmed with directing the services (acting as a coordinator).
- Socialization opportunities need to be planned, not automatic.
- Need to model after what's been set up within the educational program.
- How to get input on this Questionnaire from others:
 - Post on NDE Transition webpage
 - Regional NASES meetings
 - Post on DD Council website
 - Distribute to The Arc
 - Distribute to PTI
 - Give to NE. Youth Leadership Network (Kristi Berst)
 - Transition Summit

- Suggestions for promoting CSP:
 - Post information on the web
 - Provide more training to Service Coordinators
 - Provide information to the Arcs
 - Train educators through Project NETS/ Summer Institute
 - Provide information to Special Education Supervisors (through NASES)
 - DVD with actual consumer/family stories
 - Develop information to distribute to families at IEPs
 - Participate in agency fairs

10-9-09 State Transition Advisory Committee (Attendees: 14)

- School staff/administrators need more information regarding the program.
- Parents may need more information on effective practices for training staff – a webpage or DVD to see it.
- Need a specific contact – specific name/phone number who can answer questions in a timely manner.
- Other stakeholders who could benefit from additional information: school SPED administrators and Independent Living Center staff.
- School transition staff at Omaha Public Schools requests direct contact for information dissemination.
- Barriers: so many do not know the program exists; families don't have confidence; families feel young adult would be safer in agency setting; provider rates are VERY LOW (not stated in CSP manual).
- People/systems do not know about CSP/waiver.
- Create website of CSP – what it is. Wyoming has excellent web page. Develop web page then send to all entities and ask everyone to forward to everyone.
- Allow/offer incentive of wage increase if support person/job coach has worked/provided, for example 6 months X amount of hours/per week (quality of support).
- Families need a very trusting “state” person whom they can trust and turn to.
- Offer information at age 14-16.
- Service Coordinators must be educated about CSP – not just heard about it. Then they must advocate and “push” CSP!
- Other stakeholders who would benefit from information/training: churches, health care places, colleges, town/city agencies, chamber, parent support groups, pilot parent group, clinics (such as MHCP).
- Parents/families might be hesitant to step outside their comfort zone.
- Emphasize: opportunity to find and have more than 1 support person if wanted and needed; flexibility; opportunity to think outside the box; creativity; so individualized.
- A “bridge” to real life with real choices.
- Increase wage because once support person realizes this is self employment and must save for taxes, they are making less than minimum wage.

- Need to do training to get this info out – even with brochure, need more info to explain.
- Service Coordinators don't understand.
- "New thing" sounds scary.
- Wording in materials can be a barrier (use of the word "consumer").
- Should be SCs job to know about this.
- Need parent-to-parent support network.
- Must get SCs to read the manual.
- Can work when you find the right provider. Word of mouth works to find providers. Takes more work and some families don't have time/energy to manage.
- Need more info on service definitions in an easy, abbreviated manner.
- Families need a specific contact point for their questions – don't want to hunt down answers.
- Need to over-inform staff (lots of training and easy, readable material).
- This is too big to make one person responsible for convening the information.
- Need info sheet with clear descriptions.
- Need this info to get to teachers so they can pass along.
- Need name/number of specific contact person – make sure this doesn't get them to a receptionist.
- Is information regarding the CSP posted on the Hotline for Disability Services website?

10-21-09 DDD Service Coordination Administrators (Attendees: 8)

- Need more training for students/families on self-direction.
- Other stakeholders who would benefit from information/training: CPS, Resource Development staff, NRRD staff, legal representatives.
- People need more than one service – specialized.
- Rates for providers and caps on program are a barrier.
- Additional barrier: inability to develop a back-up plan (safety planning).
- Hiring staff often depends on relationship that existed before.
- Skills of the Service Coordinator drives this; SC needs to embrace this; newer SCs are selling the program.
- Remote areas – more CSP, more growth.
- Need training for SCs, as well as individuals and families, for self-directing services.
- Service Coordination needs facilitation skills.
- Need more info for families and youth.
- Barriers to participation: safety/back-up plans
- Some barriers are dependent upon service area.
- Some are better than others about presenting the option and having access to staff. I think it is getting better as more people are having success.

- Effective practices: relationships that previously exist are more successful; more person-centered/self-directed.
- Many individuals receive more than one service and want some specialized service too.
- Works better when relationship is established between person and provider.
- Barrier: inability to develop a back-up plan – when a provider doesn't show or quits on the spot.
- Barrier: lack of self directed abilities.
- It is helpful when the individual/family knows potential providers prior to provision of CSP. It is less effective if Resource Development or other entities locate providers.
- Discussion of the needs and plans/outcome.
- Training is needed for SCs on facilitation.
- Barrier: restrictions on who can be employed are too stringent – background checks.
- Effective practices dependent upon the skills of the SC.
- Need training for SCs on self-directing services.
- Others who could benefit from training/information: guardians.
- See Voc Rehab job coach/para-educator training materials for provider training format.
- Some areas of the state, the program seems to be growing. Others there is little growth.
- Aged and Disabled waiver rate limits are now higher – also has an exception process for rate-setting.
- Agency screening of providers (background checks) feels safer for families. Feel that others are watching.
- Need combination of specialized and CSP services.
- Program has been effective in areas where services are geographically spread out.
- The more skills the SC has to “hold it together”, the better.
- SCs need to embrace it.
- Newer SCs are selling it more.
- It's all about the facilitation skills of SCs. SCs need training on self-direction, facilitating, and engaging the individual.
- There is a lack of knowledge about self-direction.

10-27-09 Central Service Area Service Coordination (Attendees: 26)

- Barriers: isolation of peers; not as accessible in small rural areas; makes finding providers difficult
- Need to be allowed to have both traditional and CSP services
- Need more Service Coordinators to implement CSP

- Need some public relations type person w/DVD or handouts to get more info out – say something about the cost savings.
- The cap should change according to the needs of the individual.
- The rate of pay should increase in response to cost of living.
- Think more would use it if Service Coordinators believed in it.
- Effective practices: follow up by SC, staying connected, encouraging, sharing “outcomes”.
- Voc Rehab does nothing for anyone we work with, so I see no need to include them.
- Barriers: cost to CSP provider to attend activities; transportation can be a barrier.
- In some situations, it may be appropriate to pay a higher rate for few hours and still maintain cap.
- Effective practice: willingness to try different ideas when one doesn’t work.
- Training needed on IRS/tax information.
- Barriers: Need better public transportation 6 a.m. to 10 p.m., including weekends, in Nebraska; client has too many medical needs; can’t give raise to CSP providers; staff has to pay their own way to movie, use own gas and car.
- Sometimes DD staff aren’t supportive of it.
- Cheryl Cutright (SC) is fabulous. She should be praised for all the work she does. She goes above and beyond and has made the program a success. She attempts to empower the staff, family, and individual.
- Need to have CSP and specialized services go together.
- Effective practices: hiring – multiple interviews before deciding; designing and implementing – maintain a dialogue with provider, consumer, and natural supports.
- I think it would be beneficial for families/individuals to talk about their experiences w/CSP to potential families. Maybe a DVD that schools could show to families.
- Barriers: fear of isolation from peers when on CSP; transportation not a component.

11-3-09 Western Service Area Service Coordination (Attendees: 24)

- Barriers: finding providers; no reimbursement for gas; finding providers in rural areas.
- Barriers: reimbursement in gas.
- Is there a parent handbook?
- What about funds being allotted for medical care – dr. appt, medications, etc.
- Other stakeholders who would benefit from info/training: People First, Arc, parent groups.
- Would like to have more information in the brochure about specifics of providers and what is expected.

- Families in Cozad area have not wanted to go to CSP program and rather are interested in provider agency - South Central Dev. Services whose staff have a reputation of doing a great job.
- Barrier: families finding staff have been a big barrier.
- Have not had a client decide to switch.
- Other stakeholders who need information/training: Resource Development.
- Barriers: difficulty in finding providers; SCs are unsure how to proceed and a little scared.
- Resource Developers in our area have contracted A&D providers, so this was easy for them.
- Barriers: wages; the cap.
- Begin earlier within the IEP and school to find the “supports”.
- Barrier: locating providers.
- Barriers: rural areas – hard to employ providers; gas reimbursements needed.
- Example of use of CSP (Deb Hernandez, SC): helping individual get driver's license.
- Consumer satisfaction is good – major concern is finding/keeping providers.
- Collaboration with Voc Rehab for Supported Employment is good!
- Most successful providers are those with a personal connection to family.
- Training is needed for finding providers
- Need additional training for families – do before they leave school.
- Using RD staff to work with providers has helped.
- Families want SCs to track services billings.
- Scary for families (are we doing it right?)
- Finding providers easier if well connected in the community.
- Need connection with school transition staff.
- People are happy that the local provider (Cozad) is creative in service provision.
- Cap is not an issue – most not at the cap.
- One person was not able to meet safety needs with CSP funding.
- R.D. understanding helps – they sign up providers; SCs process billings.
- Those providers at top rate have trust relationship and do it because of the personal connection.
- Need to build network of support through the IEP before leaving school.
- Should only train students/provide info after found eligible for DDD.
- No reimbursement for transportation is a problem.
- Want to be able to mix specialized and CSP services.
- Time issues for SCs managing the billings.
- Would be good to have a “meet and greet” for families and providers.
- Could use refresher if previously trained.
- Need training for providers in dealing with more challenging behaviors.
- Need help for families who have DD themselves.
- DD providers are anxious about losing consumers.

- Have had DD providers make referrals to the CSP.
- Some families are determined that their person will not go to a workshop.
- Consider having a CSP agency.
- Could have peer/mentor program for people with DD supporting others on the CSP.
- Not using much respite.

11-12-09 Nebraska Transition Summit (Responses: 15)

- As a mother of a special needs student and a teacher, the information I have received has been very low key. "This service is available" but there is no info in regards to process, paperwork, requirements, etc. Very minimal communication received from DDS.
- Rural areas – support programs not available.
- Barrier: DD glosses over it as an option.
- Region II needs to actively promote and get CSP info to families and schools.

11-17-09 Developmental Disabilities Advisory Committee (Attendees: 17)

- I know some families have had success with CSP, but I'm not sure they've networked enough to share effective practices with one another or others who may direct individuals to consider utilizing the CSP program.
- Keep up the good work, ladies!
- Barrier: Families do not want the responsibility of coordinating services, etc. – group homes are easier.
- Training needed: standardized training so it is uniform across state.
- Barrier: Current rate of \$8-\$10 an hour. Would like to see per hour wage rate increase – or fuel allowance or mileage paid for.
- Barrier: Not able to use a combination of services, i.e. day services provider and then CSP weekends, evenings, etc. at home and in community.
- Need training!
- Need more seamless transition from entitlement to adult services.
- It is hard for parents to recognize that they need the supports.
- Need to know that it's safe and can go back to specialized services if needed.
- Need awareness!
- DD administration: CSP is a fill-in when traditional services don't work.
- Service Coordinators are afraid that it means more work for them.
- Can't expect schools to give information on everything to parents.
- CSP is never mentioned at IEPs.
- There is a "wind of change".
- Parent was told when first enrolled in the CSP that it would never work.
- Puts parents in a role that they're not used to – others have taken care of the child from 0-21.
- Education of families and others is a huge piece!

- Barrier: provider tax issue (providers responsible for their own).
- No provider benefits is a barrier.

11-20-09 Eastern Service Coordination (Attendees: 43)

- Barrier: availability of willing providers?? How/where to recruit from?
- Transportation is a barrier. (2)
- Concerned that needs of client not met at employer.
- If CSP could be used in conjunction with specialized DD funding, I think that would be more appealing to families.
- Many families are not interested in employing outsiders.
- Families do not want to lose that “peer environment” provided by a more traditional program.
- Information received regarding the CSP is confusing to me.
- Biggest issue is the cap for funding.
- Barrier: \$10/hourly and \$20,000 cap.
- Barriers: Families can’t find providers. Consumer may not be able to be left alone and if both parents work, it’s unlikely the family can hire enough support.
- Training needed: brief, condensed brochure on services offered and benefits.
- Barrier: hiring/firing own staff.
- Barriers: lack of transportation; insurance isn’t available to CSP providers.
- Effective practices: broad use of funding (because can be out in community); individuals w/family in town works better because family can provide services (as long as they don’t live with them).
- Family hiring a family member can be “awkward”.
- Barrier: families do not have family/friends to provide the CSP service.
- Barrier: not able to identify staff.
- Service Coordinators are uncomfortable with tracking/billing of services; also different paperwork involved.
- Barrier: transportation to/from services.
- What about transportation?
- Effective: very individualized.
- Money is just allotted to day or res.
- Parents (non-custodial/guardian) should be allowed to provide CSP services if their child is not living with them (include children living in basement apartment).
- Barrier: the time to get service started. (2)
- Information/training received: Have received the book; no formal training.
- IEP teams don’t have enough information.
- Need combination of specialized/CSP services.
- Barrier: back-up staff issues.
- Families don’t have enough skills or connections to get staff.
- Families fear that child won’t be taken care of during the day.

- Would have five folks who would to on the program immediately if could mix specialized/non-specialized services.
- Need training for PTI and school personnel.
- Positive that money is not allotted for day and res.
- Families with wide social network are more effective.
- Why are there low participation numbers in Omaha? Not part of pilot; slow to catch on; community network is “watered down” unless families are socially connected.

11-30-09 Omaha Voc Rehab (Attendees: 28)

- Jack Shepard’s presentation regarding VR milestone payments for CSP job coach providers was the first they’d heard of the CSP
- This has not been discussed at any IEPs they’ve attended
- They need to know why someone would select this program.
- This was discussed with one family at an IEP, but there was no clear understanding of the program. Conflicting information was presented to the family.
- It seems too cumbersome to set up a family/friend to be the CSP coach.
- Have never used the program or referred.
- Others who would benefit from training/information: SE vendors who have coaches. Would they allow their SE clients to hire a coach through CSP.
- Barriers: \$20K/yr.; \$10/hr.; no mileage reimbursement; families can’t mix specialized services such as receiving residential from agency.
- I am not familiar with any individuals who have participated.
- Need specific information: how will my child benefit?
- Market directly to the family members who wish to take an active role in their child’s future.
- Family members need to be considered to be care providers!!
- The flyer is ineffective: Doesn’t properly describe a family member or guardian’s role. Needs to be stated in each section of the flyer. Reduce the agency lingo.
- Barrier: providers paid \$10/hr.
- Barriers: 1) For a family member, it may be difficult establishing boundaries if the same person from home also provides employment support. 2) Family or friends understanding employer expectations.
- While in a meeting about the CSP program, a Service Coordinator gave conflicting information about who could be a service provider (e.g. immediate family members) than what I received. Re-training needs to occur or clarifying if this should happen.
- Information I have received was just an overview – could provide basics, but would refer family to DD.
- Am not certain of provider rates.
- Do not know of someone who has utilized program.

- Barrier: current issues about job coach provided for Deaf/HH staff do no uses sign. Mostly use written conversation which would be too hard for individual to understand based on their language skills.

12-4-09 Grand Island/Kearney Voc Rehab (Attendees: 26)

- Need to educate schools on DD services.
- Provider rates need to be increased.
- Need for provider liability insurance?
- Need provider training on tax issues.
- Need proficiency test for providers.
- Barrier: families scared to give up agency providers.
- VR plans to meet with DD SCs to discuss referrals.
- VR needs to better understand DD eligibility requirements.
- Special Ed. departments at Universities need to understand adult agency system.
- Family members are not equipped to manage services.
- Choosing providers is difficult.
- Need to train Special Ed. teachers and ESU staff.
- DD providers are not invited early to IEPs.
- Service Coordinators are not explaining the CSP at IEPs.
- What makes the CSP successful? It is individualized, flexible; allows people to develop their job skills.
- Barrier: just a fear for family.
- Many students that “appear” to be DD eligible, end up NOT being eligible (functional ability is too high).
- Families cannot be assured this CSP program is an option.
- Barriers: continuity of support person; training of support person.
- Need to train families.
- Barrier: qualified providers.
- Provider rates are too low – takes insurance.
- Need to do training in Special Ed programs in state colleges for Special Ed teachers early on. Train Special Ed teachers, ESU’s sites, Directors of Special Ed.
- Barrier: parent/teacher attitudes.
- Our school personnel feel that their student is “more capable” than the DD system and are reluctant to include DD info. They strongly encourage their students of all levels of ability to go to college (causing the window of opp. to close). Failure is devastating to future agency involvement.
- Have seen/heard of many situations where needs were not met due to poor matches of provider and client needs. Reliability issues/family members unable to manage their employee.
- Do you provide supports for families using the program?

12-4-09 Grand Island Forum (Attendees: 5)

- Need more than a brochure.
- Parents need info.
- Knowledge of program varies by IEP team.
- CSP is last thing talked about at IEPs.
- Lack of provider training on how to find job for person; how to work with disability.
- Hiring, trusting staff requires lots of time for family.
- Need provider training!
- Training is HUGE!!
- Need to pay mileage.
- Parents not sure what they can ask potential providers in an interview.
- I have not been impressed with the CSP program to date

12-7-09 Omaha Voc Rehab (Attendees: 13)

- Teachers and families don't have enough info. VR is explaining stuff they shouldn't be because DD SCs don't bring the CSP up at IEPs. SCs only bring list of specialized providers.
- Difference between VR and CSP rates for job coach is a barrier (VR rate \$20-\$25 with mileage figured in).
- Need to mix specialized and non-specialized services.
- CSP is not on the radar for families.
- DD SCs are not attending IEPs.
- SCs are presenting the CSP as a "new program".
- New CSP provider for job coaching has not training – needs lots of VR supports to do the job.
- Need provider training for job coaches!
- DD SCs need training!
- Recent confusion at IEP: family thought they were choosing CSP; SC invited specialized provider to IEP, so family ended up going with specialized services.
- Need someone for parents to call as a "CSP expert".
- DD Service Coordinators do not have the knowledge to inform families about CSP. This is the greatest barrier from the families we work with.
- Need to train DD Service Coordinators in all areas.

12-7-09 Norfolk Voc Rehab (Attendees: 13)

- The first time they'd heard of the CSP was when Dennis King presented information regarding VR milestone payments for CSP job coaches.
- Have to be cautious – want to know they can go back if needed.
- DD, as a system, is a quagmire!

- Knowledge is key – people need to know about the program and understand it first.
- People are intimidated by the paperwork and program requirements.
- Schools may not think students need DD services.
- SCs never bring up the CSP in IEPs.
- Think it's easier to have a provider handle it all.
- Rates are the biggest barrier.
- CSP could help remove stigma of being in DD services.
- Important link is Special Ed. teacher – they need to be sure to invite VR and DD staff.
- Need early communication between DD and school.
- I don't know anyone in the program, so these answers are just guesses. I would think the initial issues though would be just knowing about the program.
- Since the provider has to pay FICA and taxes, the rate of \$10 per hour is TOO low.
- Barrier "IEP team does not present the program to the families as a viable choice" is very important.
- I don't think I even know enough to adequately answer the above. However, most people will buy into something that's "sold", which means we all have to know enough to understand and sell the concept.
- Training/information needed: Case studies – success stories – most of us will learn best from these.

12-7-09 Norfolk Forum (Attendees: 2)

- Should be able to combine specialized and non-specialized services. Combination could provide safety net for families.
- DD providers are often brought in late to transition planning.
- DD providers may fear that CSP will take staff from them (most of their staff are part-time and don't earn benefits).
- May wish to provide option to "buy" training for CSP providers from specialized providers.

12-14-09 DDD Central Office Staff (Attendees: 14)

- Rates are too low.
- Knowledge of the program is biggest barrier.
- SCs lack awareness.
- Most DDD Central Office staff state that they are not familiar with details of the program.
- College of Direct Support may be good training resource for CSP providers.
- Need training on effective practices for dealing with problem staff – shaping behavior, firing.
- Training needed on safeguards when working with persons with DD.

12-15-09 Columbus Forum (Attendees: 2)

- Need to offer mix of specialized/non-specialized services.
- Wages are a barrier.
- Offer incentive to increase wages as providers receive training.

12-16-09 North Platte Forum (Attendees: 9)

- Provider wages too low.
- Costs in Western Nebraska can be higher than in cities.
- Communication biggest barrier.
- Need to remember who we are working/advocating for.
- Parents have to become self-educated.
- Too many acronyms; too much jargon.
- Without strong family support, this won't work.
- Too "new".
- Not enough info; need training for all.
- Need to address services for 18-21 year olds.
- Need help finding jobs.
- Communication is a big component that is missing from this option – getting from graduation to this service option.

12-16-09 Kearney Forum (Attendees: 11)

- \$10 is too low.
- Need training.
- Don't know how to find providers.
- Teachers don't know about program.
- Had to change Service Coordinator to enroll in CSP.
- First had to try specialized services and be unhappy in that program before switching to CSP.
- CSP providers are asking Arc to think of activities to structure day.
- Family member advice, "When I am out in the community, I am always looking for providers."
- Problem that parent can't be paid as provider. Earning potential as parent is hindered by taking care of disabled child.
- Advice to consumers/parents: When told that "you decide", don't look at that as a burden, look at that as freedom.
- More work for parents to be on the CSP.
- Need parent mentors.
- Need to compensate parent for coordinating services.
- Would be perfect program for someone on autism spectrum.
- Teacher said, "CSP looks good on paper, but it'll never work."
- I think some families prefer to take the easy route and select traditional services.

- Families have told me it is hard to find good staff and train them. Yet, I know other families who have done very well. One family with a son with behavioral concerns (aggression) wasn't a good match for the programs and providers would quit.
- It has been very effective with some of the families that I know in the Kearney area. I've seen some adults just blossom.
- I think much more time and resources should be spent on training Service Coordinators. This is their job and it appears they aren't doing it too well.
- It would be helpful for parents to network.
- Barrier: finding provider who will work full or part time for \$10.
- I'm not sure how this would work into/with what we would like to do so far he has been turned down by DDS because of his diagnosis. So although I feel he could use these kinds of services I'm not sure how we can access them for our son. He has a diagnosis of Aspergers – currently (18-21) program has him with a job coach working at Good Sam. Through Project Search. We hope for employment for him.

12-17-09 Lincoln Forum (Attendees: 6)

- Need to eliminate artificial cap; just use OAP amount.
- Not for those without family support.
- Consider support broker model in lieu of SC.
- Job coach would have difficult time placing person in today's environment.
- Parents fear going "outside", but want choices; need to tell them that this is okay.
- Utilize College of Direct Support for provider training.
- Barrier: \$10/hr with no mileage and no taxes withheld.
- I believe the rates are too low to begin to attract people who will successfully provide the service.
- Should increase the cap to OAP and remove the hourly cap, or raise it substantially.
- Success often really depends on the ability and willingness of the parent/family too coordinate services. Should remove requirement that the person has a SC and use that \$ to fund an Individual Support Broker the person chooses to do this work and/or assist the family in doing it.

12-18-09 Lincoln Voc Rehab (Attendees: 7)

- Wage and lack of mileage payment is an issue.
- Frustration for families of students with autism who don't qualify for DD.
- Families trust the IEP team; their word is "gold".
- Lack of knowledge among teachers about who may qualify for DD.
- VR is not always involved with DD eligible students.
- Need provider training!

- Perhaps VR and schools could work together in getting the word out.
- Unsure of the barriers; just started transition services this year but this info will help me speak with more confidence when discussing services with school staff.

1-19-10 Omaha Forum (Attendees: 5)

- Families don't understand the waiver process period.
- Hiring and training providers is overwhelming.
- SCs are the guide to the system and they are not well-versed in the CSP.
- Consider doing an abbreviated Provider Profile for the CSP.
- SCs are being diluted/diverted into other responsibilities.
- Need booth at provider fairs specifically for CSP.
- Need to focus on Special Ed. transition staff.
- Families need to hear the same information from a variety of sources.
- Need to be able to blend CSP services with specialized services.
- Need to address bigger issue of OAP adjustments needed for high need people.
- Cap for the CSP should be the OAP.
- Provider rates shouldn't be capped. If higher rates were allowed, specialized providers could provide services and offer more options for families.
- Cap and provider rates are artificially low.
- Could do training DVD for CSP providers.
- Need to address issues around med administration for CSP providers.
- How do we get information out to ethnically diverse population?
- Need to inform and encourage to act.
- Need family orientation packet, as well as provider packet.
- Designate a DDD Program Specialist as the expert for providers/SCs/families to be able to call as a resource on the CSP.
- What about those with mental health needs?
- I don't know families who have used CSP. I have sent families to DD to ask about CSP. I'm not sure they have gotten the information they need to make a decision.
- The guidelines and resource caps are too limiting to meet the needs of many individuals who could otherwise participate and benefit.

1-25-10 Northern Service Coordination (Responses received: 12)

*Note: Due to weather, this meeting was cancelled. Questionnaires were distributed to Service Coordinators via e-mail.

- Biggest concern: rates established for CSP providers are too low.
- Most frequently mentioned barrier: families feel their young adult would be safer in an agency-staffed workshop or residential setting.
- Effective practice: Setting up a schedule weekly or monthly has worked best for the individuals I assist. It is best to have a plan of what you are going to do that day. I have clients who work specifically on job applications and interviews one

day, then budgeting and bill paying the next, and grocery shopping and errands the next, and cleaning and cooking another day.

1-27-10 Southeast Service Coordination (Attendees: 56)

- Families does not have the time or energy to oversee (hiring, supervising, ensuring a back-up person is available if need be) all that is involved with the CSP.
- The one CSP I've had for the past several years is extremely successful because the individual is quite high functioning, family is VERY involved (mom is a teacher and has the confidence and capacity and resources to hire effective people for her daughter). It's a very small community and the community has embraced "looking out" and helping the individual.
- The handbook is intimidating and families are afraid or overwhelmed to try this program. SCs don't know how to help families feel more comfortable.
- Information to hand out at IEPs would be a great help.
- Transportation cost addressed?
- Barrier: not use specialized provider at same time.
- SC training was a long time ago and I have not had anyone participate in program.
- Families who have considered this program have an OAP amount significantly higher than \$20K per year.
- They also prefer that a DD provider do the work of hiring, firing, and training staff.
- The families I have talked to like being hands off regarding hiring/firing staff and the option of having an agency oversee the services.
- Barrier: finding staff that are not too busy with other employment. Staff needed for day time hours.
- Meeting necessary requirements for employing staff was a long drawn out process.
- Designing and implement services is too confusing for families.
- Training suggestion: go to provider fairs.
- Barrier: difficulty finding reliable providers.
- I agree with comment made about mixing services – if this was an option, I have a handful of folks who would utilize this in a heartbeat if could do one specialized and the other CSP.
- Resource developers in rural areas need training – most don't even know what to do.
- Need training for SCs to handle billing piece and how to facilitate this different IPP with non-specialized provider and no programs.
- I think you should focus on school system to get word out (IEP manager) at age 18. Service Coordination does not typically attend IEPs until the last year. I think with Service Coordination if it could be a simplified process (my SC has had great difficulty with the RD and billing process. This is increase in job duties and thus far not too appealing to SCs – not that they would not do this if it was best.

- Need appropriate training for SCs! We are not fully equipped to go out and “sell” the program. Once a decision is made to use CSP our procedures are not clear!
- The schools (once involved and informed) are very helpful. Staff often are the first to assist and support families, even become providers.
- Need training on possible fraud concerns.
- Training for SCs that need to set up the services and monitor, completing the IPP, oversee billing, services, etc.
- Mechanism needs to be in place to hold staff accountable for services.
- Others who need more info: home health, doctors/nurses working with DD populations, general public, Resource Developers.
- Barrier: more work for the Service Coordinator.
- Families like the supervisory and administrative oversight that the specialized dd providers given them (training, supervision, discipline, investigations, etc.).
- Families want a trained professional to depend on to work with their loved one, not their next door neighbor. Families say why would I home school when I can use professionals?
- I’ve received information but information was never “practiced”.
- SC knowledge is vague.
- Family looking for options have “burned bridges” in community. Most are unwilling to work for mother.
- Barrier: have to be 21 years old to utilize.
- Need to be able to do wage increase.
- Barrier: concern that provider won’t take them back.
- Some families would prefer an option to use day services at a specialized provider.
- Barrier: finding consistent long term staff/providers in small communities.
- Families are concerned that their current provider will be angry and not let them return if CSP doesn’t work.
- Families need a lot of support from SC to implement the program. When giving up using specialized providers, they need/want SC support.
- They like the flexibility of the CSP and they feel they have more control, but still want lots of SC follow up.
- Many who have chosen CSP have done so because they were unhappy with their specialized provider.
- How would this work for those coming out of BSDC?
- Work is complicated for SCs in tracking authorizations for multiple providers. Could use a flow chart for this process.
- Fine line between turning loose in self-direction and making sure that there is no abuse or taking advantage of individual. No good way to monitor CSP staff; little accountability; no quality control; concerns about billing fraud.
- There is a lack of infrastructure in the CSP; diffusion of responsibility.
- Need way for one provider to work with two people simultaneously.

- Examples of current CSP consumers: one with high medical needs can stay home and remain healthy. Another has had improved behaviors since leaving large group setting of specialized services.

1-28-10 Scottsbluff Forum (Attendees: 15)

- Lack of accountability for CSP providers – very little oversight by HHS – great potential for fraud, just as there is in the personal care assistant program for aged and disabled.
- Question for DDD: If you give up your full OAP amount and go for CSP at \$20,000, can you go back to specialized services and get your full OAP amount?
- Is it possible for a provider to work with 2 individuals simultaneously?
- Barriers: no mileage reimbursement; provider need to pay self-employment taxes.
- Families don't think they can find providers.
- Difference in accountability for specialized vs. non-specialized providers.
- The following was submitted via e-mail:

... my daughter ... age 21 , is a consumer in the CSP program. Her provider is ... First I must say this program is a blessing to my daughter and every other young person with a developmental disability that participates in this program. My daughter graduated from Life-Links(a after social graduation school) May of 09. She had learned a tremendous amount of social, job, and living skills from Life Links. The problem was we live in Kimball which is a small community with limited resources. So as a parent I had great concerns as to how (my daughter) was going to continue to progress as a young adult within our community. In the beginning we sat down (my daughter), myself and her program coordinator. (My daughter) made a plan of obtainable goals and we were fortunate to already have our providers ready to go.

As a parent you want your child to be as productive as possible and have a full life. As a parent of a special needs person you wonder how is this going to be possible once they graduate. I was so afraid that my daughter would be sitting around just watching t.v. as life passed her by, as I would not be able to stay home and work on her goals with her during the day. You want the best for your child and that is where CSP kicks in!

(My daughter's) providers have worked with (her) on helping her prepare meals, getting ready for the day, keeping up on her stretches/exercises ,assisting with special computer technology, take her to appointments, the library, grocery store for shopping skills and get her out into the community. It is wonderful seeing them get out there and get things done. Keeping up on life skills and gaining more independence. Recently (my daughter) got a job!! Without her provider assisting her, this would not be possible. A great example of how this program works is recently (my daughter) wanted to do a fundraiser for our library. With the assistance of her provider ..., they sat down , brainstormed, worked on the computer, made a survey, took it to the library for approval and have got (my daughter's) project off the ground and running!! Now that is awesome!

It is so comforting and refreshing to come home from work and see what great things your child has accomplished that day or to get that phone call and hear "Mom guess what I did?" CSP (and a great provider) has made this possible for us and I greatly appreciate this program. It has made a world of difference in our lives and the quality of my daughter's life. Thanks for letting me share our experience with you.

1-29-10 Scottsbluff Voc Rehab (Attendees: 8)

- SCs don't know about the CSP.
- The VR/DD job coach funding process is new, do don't know how to do it.
- Barrier: not graduate of Nebraska high school, so not DD eligible.
- Requirements on employing and finding provider are a burden.
- VR clients would make good providers; VR could provide training for them.
- Can one provider work with 2 individuals at the same time?
- This may be viewed as a "small town" program – not professional, rather "who you know".

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