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Developmental Disabilities Service Coordination in Nebraska

Final Report Summary
September 2006

Prepared by:
University of Nebraska Public Policy Center

For:
Office of State Senator Dennis Byars
LR 42 Service Coordination Work Group

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– Introduction –

The LR 42 Service Coordination Workgroup, coordinated by the office of State Senator Dennis Byars, asked the University of Nebraska Public Policy Center to conduct a study of developmental disabilities service coordination in Nebraska. The Public Policy Center explored the perceptions and experiences of a variety of stakeholders involved in the service coordination system for people with developmental disabilities. The goal of the research project was to better understand:

- Stakeholder satisfaction with service coordination
- The roles and responsibilities service coordinators currently are fulfilling
- The importance of various aspects of service coordination
- How service coordination may be improved

The project focused on the delivery of service coordination in relation to its impact on consumers. From August 2004 through December 2004, the Public Policy Center gathered information from consumers of developmental disability services, their family members or guardians, Service Coordinators, and Service Provider Employees (Provider staff) regarding developmental disability service coordination in Nebraska. All Service Coordinators and a sample of Service Provider staff were surveyed. Consumers attending the 2004 People First conference were invited to participate in three focus groups. A random sample of family members/guardians was invited to participate in focus groups and individual interviews. This data was supplemented with 2000-2001 National Core Indicators Survey results from surveys of Nebraska consumers.

The “Developmental Disabilities Service Coordination in Nebraska” Final Report is available on the University of Nebraska Public Policy Center web page at <http://ppc.unl.edu/>.

– General Observations –

Analysis of the quantitative and qualitative data gathered from consumers of developmental disabilities services, consumers’ family members or guardians, Service Coordinators, and Service Provider Employees resulted in the following general observations. Observations are grouped according to the four project goals listed above, with the second and third goals combined. A fifth area, “the working relationship between Service Coordinators and Service Provider Employees,” emerged and has been added as an additional category.

Stakeholder satisfaction with service coordination:

- Many respondents make a distinction between satisfaction with service coordination in general and Service Coordinators.
- Families and consumers generally are pleased and feel Service Coordinators try hard and are helpful and available.
- Families, consumers, and Service Coordinators believe more strongly than do Provider Employees that Service Coordination is beneficial.
- Families of consumers believe Nebraska does not provide the range of service options that many other states provide to consumers of developmental disabilities services.
- Consumers’ family members expressed concerns about supervision and the types of activities offered to consumers at day services.
- Consumers’ family members expressed concerns about frequent turnover in day service employees.

The roles and responsibilities service coordinators currently are fulfilling, and the importance of various aspects of service coordination:

- Consumers and their families generally believe that Service Coordinators help consumers and families in a wide range of ways.
- Both Service Coordinators and Provider staff feel they advocate, ask what is important to consumers, and are familiar with the rights of consumers and their families.
- Both Service Coordinators and Provider staff feel they support consumer self-determination.
- Service Coordinators and Provider Employees indicate that Interdisciplinary Teams function well, but Provider Employees are slightly less positive about Teams.
- Service Coordinators rank tasks associated with their job differently when comparing percent of time spent on the task and importance of the task.

The working relationship between Service Coordinators and Service Provider Employees:

- The relationship between Service Coordinators and Service Provider Employees is tenuous, particularly from the perspective of Provider Employees.
- Service Coordinators believe there is a lack of Provider accountability.
- There is ambiguity between the roles of Service Coordinators and Provider staff.
- Overall, Provider Employees don't agree as strongly as Service Coordinators that consumers know their Service Coordinator and can talk with their Service Coordinator whenever they want.

How service coordination may be improved:

- Stakeholders want to see increased funding to add more Service Coordinators and reduce caseloads.
- Increase funding for services for people with developmental disabilities.
- Families, consumers, and Service Coordinators believe changes are needed in the process for determining eligibility for hours and types of services.
- Service Coordinators want processes to improve Provider accountability.
- Greater communication and teamwork is needed between Service Coordinators and Provider Staff.
- Service Coordinators and Provider staff may benefit from additional training opportunities.

– Summary of Open-ended Responses –

Service Coordinators and Service Provider Employees were asked to respond to a series of open-ended questions as part of the surveys they completed. A summary of their responses follows.

Service Coordinators who answered the open-ended question “*Please describe the needs you see consumers have that are not being met, if any*” listed **job coaching** and **employment opportunities** as major needs of consumers. Service Coordinators stressed actual employment opportunities for consumers, rather than employment in workshops.

Many respondents cited a need to increase **funding** and hours and/or saw a need to **reform** the way funding and hours are assigned. Some Provider Employees are concerned there

are consumers who are not assigned the correct priority level initially, or that those assigning the level to a consumer do not allow for the level to change as the consumer's needs change.

Over three-fourths of the Service Coordinators who were asked “*Do you have any other comments about consumer self-determination?*” emphasized the roles the **team** and the various team members (Service Coordinators, Provider staff, family members, and guardians) play in consumer self-determination. The primary concern of Provider Employees with respect to self-determination is the **lack of support** from those close to the consumer. Provider Employees cited the need for more support, from both Provider staff and Service Coordinators and from consumers' families, in order for self-determination to be successful.

One role of a Service Coordinator is to facilitate team meetings and ensure that consumer needs, concerns, and goals are represented and articulated at the meetings. When asked “*How do you support the consumer at team meetings?*” Service Coordinators most often reported they get **direct input** from consumers. Some Service Coordinators recognized that consumer verbal input at team meetings is not possible in all cases, and Service Coordinators need to advocate for such consumers. Service Coordinators also reported supporting consumers at team meetings by making sure consumers have a chance to respond to questions, listening to and considering the consumers' opinions, and getting input from all who attend the meetings.

Provider Employees most frequently responded to “*How do you support the consumer at team meetings?*” by reporting that they encourage consumers to voice their own concerns, wants, and needs. Often they assist the consumer in doing this by talking with the consumer prior to the meetings (a tactic also favored by Service Coordinators) and discussing potential topics and consumer concerns so both the consumer and the employee will be better informed and prepared for the meeting. Some Provider Employees also feel it is their job to communicate consumer concerns to the team for the consumer if the consumer is unwilling or unable to voice their own concerns.

We asked Service Coordinators and Service Provider Employees surveyed to “*Please describe ways in which providers and service coordinators could work together to improve developmental disabilities service coordination.*” Comments from both coordinators and Provider staff revealed the relationship between Service Coordinators and Providers appears to be a **tenuous** one in many cases. A small number of coordinators and staff went so far as to say that an “us vs. them” mentality exists.

Many of the Service Coordinators who answered this question feel an increase in Provider accountability would improve service coordination. Although Service Coordinators have procedures to follow if they feel a Provider is not doing their job, many feel there are no consequences for Providers beyond the filing of the complaint. A number of the Service Coordinators responding also would like to have more **communication** with Providers (regular meetings of the two groups was suggested), and have clearly defined **roles** for Service Coordinators and for Provider staff on the Individual Program Plan team. Service Coordinators and Providers could work together more effectively if each understood the other's responsibilities. Joint training of Service Coordinators and Providers was suggested as one way for the two groups to learn more about each other's roles and responsibilities and to provide some common background.

Provider Employees mainly used this question to focus problems of developmental disabilities service coordination on Service Coordinators, and largely gave answers that spoke to Service Coordinators' problems and improvements Service Coordinators could make. The largest

single response highlighted the importance of increased and better quality **communication** between Providers and Service Coordinators. Although this same suggestion was given by some coordinators, Provider Employees placed the burden for improving communication largely on the Service Coordinators. There were Provider Employees who acknowledged the relationship between Service Providers and Service Coordinators is a good one, with open communication and both parties working for the good of the consumer.

Many Provider Employees who answered placed an emphasis on the importance of working together as a **team**. In a similar context, staff members also felt if Providers and Service Coordinators both advocated for their clients, an improvement in developmental disabilities service coordination would result. Other areas in which improvements could be made are increasing both parties' understanding of each other's job **responsibilities** and of their own job responsibilities, and understanding the system. Some staff members advocated mutual training sessions for Providers and Service Coordinators.

Service Coordinator responses to the question "What makes a good Service Coordinator?" included a wide of range of characteristics, attitudes, and qualities. The single most common response of coordinators indicated the importance of good **listening** skills. The ability to **advocate** for the consumer, and being **knowledgeable** of services, policies, or procedures also were listed as important attributes of a good Service Coordinator. **Kindness, flexibility, communication** skills, **organizational** abilities, and the ability to **work with many types of people** also were frequently mentioned characteristics.

Provider Employees who gave opinions on what makes a good Service Coordinator included those who think a good Service Coordinator is one who **knows consumers**, keeps in **contact** with consumers regularly, **visits** consumers in all settings, or is **involved** with consumers before issues arise. An important characteristic mentioned is good **listening** skills, also the most common response given by Service Coordinators. Other important characteristics included: listening to all parties; working with the **team**; being **unbiased** or open to the ideas of others on the team; having good **communication** skills and the ability to get along with **many types of people**; being a team **leader**; and having the ability to **facilitate**.

It was noted by a number of respondents that Service Coordinators should have good **knowledge** of the developmental disability field. Sometimes this comment was tied to the importance of previous experience in direct care or management. Effective Service Coordinators also need knowledge of developmental disability services and programs.

Service Coordinators were asked two additional open-ended questions about coordinating services. These questions were not asked of Provider Employees.

The first question was "*How, if at all, is your ability to coordinate services affected by consumers on your caseload who present behaviors that are aggressive, destructive, or a threat to themselves or others?*" Service Coordinators reported there are **not enough qualified Providers** willing to provide services for consumers with behaviors that are aggressive, destructive, or a threat to themselves or others. Therefore, it is hard to find services for or to place these consumers, according to many Service Coordinators. Service coordination for these consumers becomes more time consuming than coordinating services for a consumer who has more options for placement with a Provider. Some said this could be detrimental to the quality of services provided to other consumers. It was noted that it may be especially difficult to find appropriate behavioral health services in rural areas. A number of Service Coordinators responding reported little or no effect on their ability to coordinate services for consumers with

such behaviors (often these Service Coordinators mentioned they had some background in Mental Health).

“Please describe the needs you have as a Service Coordinator that are not being met, if any” was the second question asked only of coordinators. Many of the Service Coordinators who answered this question would like to **decrease their caseloads and paperwork** so they can spend more time in direct contact with consumers. Service coordinators suggested that additional support staff would help decrease Service Coordinators’ work load, as would filling cut positions (rather than redistributing work load), and decreasing extra projects.

Respondents also felt they would benefit from more leadership, support, and direction from their **supervisor**. Some Service Coordinators would like feedback on their job performance, as well as consistent answers from their supervisors. Additional **training** (e.g., initial, cross-training on other services in the health and human services field, HHS policies and procedures, techniques for dealing with the wide range of mental health issues), is a need mentioned frequently.

The final open-ended question, “Please describe ways in which service coordination can be improved, if any,” was asked of both Service Coordinators and Provider Employees. Many Service Coordinators echoed an answer given to the prior question regarding any Service Coordinators needs not being met – they need **more time** to spend with consumers. Suggestions to accomplish this included hiring more Service Coordinators, decreasing caseloads, decreasing paperwork, and/or hiring additional support staff.

Improvements in the **funding process** or increasing the **level of funding** also were mentioned as ways coordinators felt service coordination could be improved. Additional improvements include: **training** for Service Coordinators; **Individual Program Plan reform**; Provider **accountability** that includes consequences for non-compliance; and **standardized practices** (i.e., files) across the state’s service areas.

The majority of Provider Employee respondents appeared to interpret the question regarding possible ways in which service coordination could be improved as pertaining to the individual service coordinators. Their answers concentrated on service coordinators rather than on potential improvements to the system of developmental disabilities service coordination as a whole. The main suggestions given by staff were for Service Coordinators to increase **contact** with consumers and/or Providers, to visit consumers in all settings (e.g., home, work, day services), and to know consumers’ situations.

– Summaries of Focus Group Comments –

Consumers of developmental disabilities services met in focus groups to discuss service coordination in Nebraska, as did consumers’ family members or guardians. Brief summaries of comments made in consumer focus groups and family member/guardian focus groups follow.

Consumer Focus Group Summary

Although consumers of developmental disabilities services in Nebraska who attended the focus group sessions indicated that **generally they are pleased** with Service Coordination and feel Service Coordinators try hard and are helpful and available, their **experiences with Service Coordination vary**. Many consumers said they see their Service Coordinator other than at

meetings, sometimes as often as monthly, while others only see their Service Coordinator at annual IPP meetings. When a consumer talks with their Service Coordinator, the contact might be a general check by the Service Coordinator on how things are going in the consumer's life and to ask if the consumer needs anything. At other times, they might cover more specific topics, such as: the consumer getting their programs done well; the consumer's goals; IPP meetings; working more independently; or how the consumer is getting along at work.

Family member/Guardian Focus Group Summary

Most family members/guardians we talked with during the focus group conference calls are **pleased** with their consumer's current Service Coordinator – some coordinators even were described as excellent. There were **some criticisms** of Service Coordinators as well. Some family members feel the Service Coordinator they work with could follow-up more effectively. Some parents stop asking the consumer's Service Coordinator for help with most things if the Service Coordinator doesn't do much except listen. Although most family members had some complaints about service coordination in Nebraska, many **stressed how difficult it would be without service coordination** and the various programs currently available. In their opinion, consumers need the advocacy of a Service Coordinator, especially if the consumer's family is not involved in their care.

Although turnover among Service Coordinators did not appear to be a major concern for family members, mention was made of too much turnover in day service employees. More than one family member also **stressed the importance stability and habit play** in the well-being and happiness of their consumer.

In general, participants in the family member/legal guardian conference calls were **more critical of Nebraska's Health and Human Services System** and the system of service coordination for persons with developmental disabilities than they were of Service Coordinators or Providers. Most felt Nebraska's **options for services fall far short** compared with those offered by other states. The lack of options for services is seen as even worse in western Nebraska. Generally, the conference call participants feel Health and Human Services needs to look at the big picture. A **lack of funding** and **not enough Service Coordinators** contribute to large caseloads, which translate into Service Coordinators not having enough time for each consumer.



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