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The Interface of Employment, Health, Family Support, and Human Services for People with Disabilities in Nebraska

Linda E. Jensen

University of Nebraska Public Policy Center

Jeffery Willett

University of Nebraska Public Policy Center

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**The Interface of Employment, Health, Family Support, and Human Services
for People with Disabilities in Nebraska**

**by Linda E. Jensen R.N., M.N., Ph.D.
and
Jeffrey Willett, Ph.D. Candidate**

A Research Report

For the University of Nebraska Public Policy Center

June, 2003

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The Interface of Employment, Health, Family Support, and Human Services for People with Disabilities in Nebraska

A Report produced for the
University of Nebraska Public Policy Center

Executive Summary

Twenty in-depth interviews were held with persons who had a diverse range of disabilities and had been or were currently engaged in competitive employment. The qualitative data was analyzed to gain information about current supports and barriers and to identify recommendations to make it more feasible for persons with disabilities to engage in competitive employment. The sample included 10 men and 10 women with ages ranging from 24 to 60 years including both rural and urban residents of Nebraska. Disabilities represented included various paralysis and/or physical illnesses, sensory disabilities such as loss of vision and/or hearing, psychiatric disabilities such as bipolar disorder or depression, and/or cognitive disabilities that resulted from brain injuries or childhood developmental disabilities.

The research participants told their story of trying to return to work along with the influences of their disability, health, the employment system, government services, families, and friends. A more complete report of the data is available from the University of Nebraska Public Policy Center. The following recommendations were made by the participants to help more people with disabilities return to work. Their suggestions have been divided into those that could be accomplished by state officials within the present federal system and others that would require changes in federal laws or regulations.

Recommendations

Services

All participants had difficulties finding the services that were available and/or accessing services. Most had been dependent on Medicaid and/or Medicare for medical care and/or devices and were concerned about returning to work and losing that coverage so important to their health. All really wanted to work and preferred to be as independent as possible, however accessing adequate medical care was necessary for their survival.

1. There needs to be an easily accessible information center for rehabilitation services that all medical practitioners could use for referral.
2. Improve the flow of information between different offices and different agencies. Participants frequently complained they were told different things by different workers in the same system and/or different systems.
3. Design simplified fact sheets/resource guides for people to use when they want to return to work. Perhaps each agency could designate a caseworker who could be specially trained to serve as the contact person for people trying to return to work.

4. Information about the options for keeping Medicaid health care coverage or using the “buy-in” needs to be readily available, and those options need to be well known by all caseworkers. Most people with disabilities cannot return to work without health care coverage which may not be available through their employer, especially if it is a part-time job.
5. Allow for savings accounts for a house or motor vehicle. Most participants did not know the limit for assets had been increased from \$2000 to \$4000/person and \$6000/couple. Some states exclude accounts for retirement, medical expenses, and for purchasing goods/services to increase employability. Some states allow higher asset limits.
6. Reviews could be less painful and time consuming if the participant could just update the file rather than fill out a lengthy document each time. It is very painful to recount the history of the disability as often as every three months for reviews.
7. Each person should have easy access to his or her Social Security, Vocational Rehabilitation, and Health and Human Services files.
8. Consider the fragile self-esteem of persons with disabilities. Caseworkers in HHSS and in Vocational Rehabilitation may need sensitivity training to assist them in being encouraging rather than discouraging.
9. Part of the vocational rehabilitation services should include benefit counseling. More Benefits counselors are needed. Perhaps this could be accomplished through more training in Benefits so that Vocational Rehabilitation counselors or other caseworkers could be more helpful. Smaller caseloads for caseworkers may help.
10. People should be informed when they begin their trial work period and of the consequences. They should be assisted to identify work-related expenses that could reduce their earned income, because it costs a lot to begin a job such as expenses for clothes, transportation, moving, childcare, and miscellaneous needs.

Employment

All participants wanted to work, however some could not because of the disability, or other health problems. The sample was generally well educated, but most were working below their potential. There were many frustrations with the job services, discrimination and lack of accommodations. Their suggestions were:

11. Using the services for the visually impaired as a model, develop more comprehensive rehabilitation services for people with other disabilities. Services for persons with brain injuries and/or mental illnesses are quite fragmented and lack a rehabilitation focus.

12. Expand the referral system for disabled persons who are looking for work. Doing a better job of linking the existing state and local job service agencies with service providers and employers would facilitate employment opportunities.
13. Disseminate information about incentives for employers who hire disabled workers and investigate ways to also give incentives to governmental and non-profit employers.
14. Disseminate information about governmental assistance with accommodations purchased by employers. The Job Accommodation Network (1999) suggests that over half of all required workplace adaptations cost less than \$500. Even a small subsidy would possibly encourage many employers to make a workplace accommodation.
15. More public education is needed about people with disabilities to lessen the discrimination. Television shows and movies about their struggles and portraying them as heroes would help. More public education is needed about accommodations for various disabilities so that employers would not be so afraid of employing persons with disabilities.
16. Provide assistance on how to work with the disclosure issue and how to access advocacy services through the Americans with Disabilities Act.
17. Find ways to make public transportation available for those who may be working other than daytime hours and on weekends.

Families

Most participants said they could not live as independently as they did, without the help their families gave them. All family members were supportive of them working. Suggestions were:

18. Investigate ways to reduce the marriage penalty that occurs when benefits are reduced because a person receiving SS benefits marries. The living allowances for married couples are much less than the total for two single people. This was a major frustration for those participants who were engaged and planning to be married. Some states do not count the income or spousal assets when determining benefits.
19. Remember that members of the family are also affected by the problems of the person with a disability and help them find support groups and counseling resources or family education classes to assist them in venting their emotions constructively and learning about the disability. They need to be included in benefit planning and case management so they can be more supportive. The family can be the glue that holds this puzzle of accessing services and returning to productivity and/or employment together. Strengthening families can be an important part of recovery.

20. Check to see if there is a way that family members could be employed as caregivers and or case managers when they are performing those functions. If the family member has to take a job outside the home to help pay expenses, they will not be able to perform many of those functions. They know the person very well and may be the best caregiver/case manager for them. Some states have allowed the incorporation of microboards or family led groups to access the funding and contract directly for the services they prefer and need.

Housing

Finding affordable and decent housing was a common problem especially since most Social Security income levels were under \$600/month. These suggestions need to be discussed with the local housing authorities.

21. Housing costs increase if income increases; so many participants said it did not pay to work. It would help to allow some months of work before a rent increase takes effect, and give people a chance to get on their feet. Considering the net income rather than the gross income was also suggested.
22. There is a scarcity of decent, affordable housing in both rural and urban Nebraska. Establishing more assisted living facilities for people with disabilities would be helpful.

Federal system problems

23. Simplify record keeping for individuals returning to work. Sending check stubs to Social Security monthly seems unnecessary when this information could be accessed through their computer files.
24. Use net income rather than gross income when deciding to decrease benefits. The various withholdings from a paycheck can amount to about one-fourth of the total.
25. Investigate the possibility of allowing more than one trial work period, so that you can try out a job without fear of losing your benefits. Perhaps they could choose when their trial work period should begin, so it would not be wasted on a low-income part time job.

It is hoped these recommendations will be carefully considered and investigated to improve the systems to assist more people with disabilities attain and keep jobs. This can be an opportunity to help people with disabilities reach their potential and to be more productive and contributing members of our state.

Report submitted by Linda E. Jensen RN, MN, PhD, Principal Investigator, Assistant Professor, University of Nebraska Medical Center, and Jeffrey Willett, Ph.D. Candidate, University of Nebraska-Lincoln.

**The Interface of Employment, Health, Family Support, and Human Services
for People with Disabilities in Nebraska
Research Report**

The Interface of Employment, Health, Family Support, and Human Services for People with Disabilities in Nebraska

Purpose of the Study

The purpose of this research was to conduct case studies of persons with a diverse range of disabilities who have been or were currently engaged in competitive employment.

The specific aims of this research pilot study were:

1. To collect qualitative data by conducting interviews for case analysis with approximately twenty persons with a diverse range of disabilities;
2. To document experiences of individuals with disabilities regarding competitive employment, the effects of that employment on personal health, the effects of personal health on employment, the role of family support in obtaining and maintaining work, and use of health and human services necessary for work
3. To analyze this data to understand how individuals negotiate a “web of services;” that is, how individuals learn about and enroll in various programs and services and how they ensure that they obtain the services they need in light of the fact that eligibility and access for various programs and services varies; and
4. To gain information about current supports and barriers in the Nebraska Health and Human Services System (NHHSS) and other services and to identify improvements and enhancements to make it more feasible for persons with disabilities to engage in competitive employment.

Background

The University of Nebraska Public Policy Center funded this research to examine perceptions held by persons with disabilities (i.e., consumers) of the supports and barriers to obtaining competitive employment for persons with physical and/or mental disabilities in Nebraska. This research was timely as NHHSS had received a federal grant to study their services and plan for improving opportunities for persons with disabilities to engage in competitive employment. That HHSS grant program was implemented in response to the federal Ticket to Work and Work Incentives Improvement Act of 1999.

Barriers to Employment

People with disabilities face multiple challenges that they must overcome in order to engage in competitive employment. Due to the devastating effects of having a disability, this population tends to be of low socioeconomic status and depends on government assistance and human services. These programs include government health care coverage (e.g., Medicaid or Medicare), housing assistance (e.g., Section 8 & housing authority housing), food stamps, and/or disability cash assistance (Social Security Income-SSI and Social Security Disability Income-SSDI). While disability specific programs provide services for people with disabilities, eligibility for these programs depends not only on a disability determination (medical diagnosis), but also on individual and family income. Often when a person with a disability expresses interest in obtaining competitive work, s/he is discouraged from doing so because the increased earned income may result in loss of eligibility for Medicaid health coverage and other benefits.

Research suggests that the delivery of services needs to be organized in a way that reduces the burden of managing life with chronic illness/disability, and not to add to it (Helfrich et al., 2000). Vocational rehabilitation, a service often utilized by persons with disabilities re-entering the workforce after the onset (or changed condition) of disability, has been found to have very low rates of success in helping people with psychiatric or developmental disabilities return to competitive work (Garske & Stewart, 1999; Noble et al., 1997). Koleski and Sands (1992) found several problems with services for persons with disabilities including: too expensive, not enough services, poor quality services, not suited to individual needs, lacked respect for the dignity of the individual, and the service did not help.

In addition, persons with disabilities who are employed while receiving Social Security benefits such as Social Security Income and Medicaid must limit their earned income levels in order to maintain Medicaid coverage. Loss of Medicaid benefits without being replaced by adequate employer paid health insurance is a serious threat to anyone who already has a disabling and chronic health problem. The cost of specialized medical care, laboratory tests, medications and special equipment to maintain health for people with disabilities is often more than \$25,000 yearly, and relapse costs may be much more. Studies have found a general lack of support from allied health and educational professionals for people with disabilities to return to competitive employment (Akabus & Gates, 2000; Backhouse & Roger, 1999). It seemed important to investigate these issues in Nebraska.

Interface with Health

Studies of the effects of employment on people with disabilities have shown employment to lead to significant improvement in depression, self-esteem, income, and quality of life (Bozzer et al., 1999; Tate et al., 2001). However, there is little research on the effects of employment on the general health of persons with various types of physical and/or mental disabilities and the accommodations important to maintain the health of a person with a disability so that he/she can work. It appears that health issues such as fitness and personal health care have frequently been ignored by specialists who are looking at rehabilitation issues (Maurer et al., 1998; Nosek & Walter, 1998; Tate et al., 2001), yet these issues can make an important difference in whether a person with disabilities can remain in competitive employment. Often disabilities do not exist in isolation. Comorbid diagnoses of physical and/or mental illness may impede compliance with treatment regimes and thereby retard employment efforts (Newman et al., 1998). Many with physical disabilities also struggle with depression while lifestyle risk factors of inactivity, smoking, and diets high in fat and carbohydrates appear to contribute to the development of unnecessary chronic illness, disability, and premature death (Leff, 1996).

In addition, the general health of a person with a disability affects his/her success in competitive employment. Fatigue and other physical symptoms have been found to affect employment status and occupational performance (Dyck & Johngbloed, 2000).

Interface with Family Support

Family support is clearly related to disability adaptation in general, and the ability to work specifically. Strong family support has been linked to greater adaptation to disability and greater likelihood that disabled adults will be employed (Greenberg et al., 1997; Judge, 1998; Reinhardt, 1996; Saddler et al., 1993; Seltzer & Heller, 1997). Family supports are also a key element of successful adaptation for disabled children as they progress through the life course (Mallory, 1996; Morningstar et al., 1995; Seltzer & Heller, 1997). Yet, people with disabilities have been penalized by having benefits reduced when they marry or live with a family member. Family members cannot be paid as caregivers, even though they may be the most competent and caring providers available.

Specifically, families provide informational and material supports to their disabled members. These supports can have a great impact on housing, transportation, service utilization, and other factors related to successful work experiences for disabled people. If family members have not worked through the grief/loss cycle and become stuck in denial, blaming, anger, sorrow, and/or depression themselves, they will have difficulty being helpful to their family member with a disability. Interventions for family members may also help the person with disabilities become successful in competitive employment. This research sought to give policy makers a richer understanding of how family supports affect the employment options of people with disabilities.

Methodology

Sample

A purposeful recruitment of participants with diverse disabilities in two regional locations in Nebraska was conducted by the snowball method. The investigators were well acquainted with people from many advocacy groups and service agencies in Nebraska and discussed the project with acquaintances, colleagues, service providers, and disability advocacy groups. For each regional location study personnel selected individuals who represented a diverse range of disabilities and characteristics; including, physical disabilities, psychiatric disabilities, cognitive disabilities, sensory disabilities, and developmental disabilities; as well as gender, age, employment experience, and race and ethnic origin. The investigators used these regional lists to recruit participants from each area of disability named above while attempting to choose from a diversity of gender, age, employment experience, and race and ethnic origin. Each research participant was an adult with a disability that had been documented by either the Social Security Administration or Nebraska Disability Determinations Unit, and was not currently institutionalized. All participants were adults who had been employed or attempted employment since disability onset. Pediatric subjects were not recruited for the study, as most would not have had significant work experience and would have been at a different level of establishing independence than adults with disabilities.

Procedures

A semistructured interview guide was designed for the interview including the categories of Demographics, Disability, Health, Work, Work History, Service Experiences,

Transportation, Housing, Social Activities, and Quality of Life. All procedures were approved by the University of Nebraska Medical Center Institutional Review Board. The investigators determined through a brief phone or personal screening interview whether the individual met the inclusion criteria and then set up a date, time and place for the interview. Throughout the interview, participants were encouraged to share only information they felt comfortable sharing. The interview guide was used as a tool to make certain specific categories were covered as the participants told their stories. Each participant was paid a \$25 stipend. Interviews lasted one to two hours and were conducted in a private setting (home or office).

Because of concerns that some persons with disabilities may not be considered legally competent to give informed consent, it was also explained to participants that they could bring one guardian, family member, or care provider with them to the interview if they wished. If they had a guardian, proxy consent was also obtained from the guardian. If a guardian, family member, or care provider accompanied the research participant to the interview, that person was asked to help explain the voluntary consent form to the participant and also to sign his/her own consent form. These efforts were made to ascertain the participant understood that participation in this research was voluntary.

Interviews were audio-recorded, transcribed by a research service, and then content analyzed using QSR N6 software for qualitative data. Data were sorted and coded according to the categories of the questionnaire with free and tree nodes developing as the analysis progressed. The nodes were then consolidated into the themes described. The researchers reviewed each other's findings and reached agreement in writing this report.

Results

Findings will be summarized according to the Interview Guide categories (Appendix I) along with some examples of participant responses in each category.

Overview of Research Participants

Table 1 presents the overall demographic breakdown of the 20 research participants. The sample included an equal number of men (10) and women (10), and the ages of the sample ranged from 24 to 60 years with a mean age of 43. Using the definition by the U.S. Office of Technical Assessment (1990), with rural including cities with populations ranging from 1-49,999, or counties of less than 100,000, eleven of the participants resided in rural Nebraska, while nine resided in an urban area.

Disability

Ten of the research participants had physical disabilities such as quadriplegia, loss of limbs, or disabilities caused by arthritis and other diseases. Six of the participants had sensory disabilities such as a total or partial loss of vision or hearing. Four of the participants had psychiatric disabilities such as bipolar disorder or depression. Three of

the participants had cognitive disabilities that resulted from brain injuries or childhood developmental disabilities. Four of the participants reported both physical and sensory disabilities and were counted in both categories. These "multiple risk" respondents may be of particular interest because they could be at a greater social disadvantage due to having more than one disability.

Previous research suggests that the age of disability onset may have an impact on the social and psychological adjustment to disability (Smart, 2001). Among the participants, eight experienced disability before the age of 20 years, five experienced onset between the ages of 20 and 30, and seven experienced disability onset after age 30. Some participants had a motor vehicle accident that changed their lives in a few seconds, while several had lived with their disabilities since early childhood. Others developed illnesses at various ages, which resulted in a more gradual onset of disabilities. This seemed to have effects on career trajectories for some participants as will be noted later in the Employment section.

One participant and his family member told of an accident that changed his life in a few seconds:

A1: Well, one of our gravel trucks from here in town decided to run a stop sign right in front of me.

A 2: On the highway and it was real icy that day,.. they don't really think the ice caused the accident at all. It was namely just the gravel truck ran it and he was so close to him. He hit the dual axles on the back of the loaded gravel truck, so it was like hitting 10,000 lbs.

A 1: I've got a head injury, I've got lung damage, heart damage, anything else?

A 2: Your back, your diaphragm...I mean. Your knees...

Diagnosis of these illnesses sometimes took many years especially if it was a mental illness. For example one participant who had bipolar mental disorder explained:

Q: When did you first begin to experience symptoms of your disability?

A: I would say, probably when I was in elementary, probably.

Q: And how old were you when you first were diagnosed,

A: In my early 20's.

Recent medical advances may decrease the limitations presented by a disability, but they may not allow a respondent to regain lost status.

And just 4 or 5 years ago I got put on new meds, they're more modern meds and it's really helped with my tremor. But the barrier now is that I've just been away from Chemistry too long and if you don't use it, you lose it. And I really can't work as a Chemist anymore because I've been away from it so long.

Even though disabilities were severe enough to have dramatically hindered their life achievements, most participants tried to maintain as much independence as possible and emphasized that independence was important to them. They had found various ways to cope with their disabilities, such as:

A: Everything that happened before the accident, I can remember fine. It's my short-term memory. So, that's why I have a book in my purse where I write down what I do every day and I have a computer. My friend showed me how to make out a thing. And that kind of helps remember, too, when I repeat it and repeat it and repeat it again. That kind of helps me also.

B: I'm pretty much independent and do everything by myself. My caregiver comes in the mornings and kind of helps me get in and out of my shower chair, because it's a little bit precarious. I can do it myself, but if I would fall that would be bad. So, she helps me and she also helps me with like mopping floor and other housekeeping stuff like that, that I need help with, but otherwise I'm pretty independent.

Health

Health is a challenge for most people with disabilities. Most participants emphasized that in spite of their disability, their health was good.”

So, I'm at a little higher risk than a normal person, but otherwise I feel fine.

When prompted, they usually reported other debilitating health problems including: heart conditions, orthopedic problems, high blood pressure, thyroid problems, bowel and bladder problems, headaches, seizures, kidney failure, diabetes, obesity, hearing loss, respiratory problems, and systemic infections. Some of these other health problems were barriers to seeking employment.

Several told of losing full time jobs because they had developed additional illnesses, due to the stress of a full time job and struggling with the demands of their disability. However, most felt work was important to them and worth the extra strain on their health.

Just because I try to do too much...And so, therefore, my body would become run down and get sick. And so, that wears me down, my body down, and then I become more susceptible so, I've had to kind of pace myself.

Disabilities that have periodic flare-ups are particularly problematic in regards to education, working and utilizing social services. As one explained:

First I went to graduate school in Neuropsychopharmacology and I had to drop out because the stress was too much and so I left California when I did that. Then I tried PA school. I tried to get into PA school. I'd just been granted an interview and I got sick when that happened so and then there was Chemistry graduate school about a year and a half ago, and the stress was too much.

All participants needed one or more medications and/or other medical assistance and devices to stay healthy. Several also talked about trying to maintain a healthy lifestyle through diet, exercise, and thinking positively. Most seemed to realize they needed to keep as healthy as possible to lessen their disability. One participant remarked:

Yeah, vitamins, calcium. I would like to exercise, but that's difficult right now. I'll come from work & I'm tired. An 8 hour day at work pretty much kills anything to come home and do a whole lot! And try to watch diet. Try to eat healthy as far as I can. Can't gain weight as that would cause more problems

Many of the participants stated they had struggled with depression for a significant period of time and several had attempted suicide. Several had continued taking antidepressants to help with this depression. Many mentioned that work had been helpful to decreasing that depression and had helped them feel better about themselves. As one participant said:

Well, what started, I believe, between having good doctors and the Good Lord, but myself is I wound up volunteering. Doing some volunteer work and I finally started not laying around the house. Started getting out and I started feeling better. Getting a little exercise, or whatever you want to say, started feeling good about myself.

Most participants reported that the loss of prescription drug coverage and/or other medical care was a primary reason they did not attempt to find better paying jobs.

So and you know the thing I'd like to see happen is to have help with my prescription drugs. That's a big expense. I wouldn't have to worry about having, or paying out ...I can work at any job I wanted to, a part-time job, and not have to worry about health insurance if I had Medicaid because they would pick up the prescription drugs. The drugs are over \$500 a month if I don't have co-pays. Which is just impossible. So if I had Medicaid and Medicare I wouldn't have to, I could pick a job I feel comfortable about, less stressful job and would benefit me in the long run. I wouldn't have to worry about making sure that I get health insurance every place and that would help.

Employment

Overview of Participants' Employment

Table 2 presents a number of employment characteristics for the 20 participants. This table can only briefly summarize the detailed work information that was obtained during the in-depth interviews. The first column of Table 2 presents the ID numbers so the information from other tables can provide more information about each person. The participants' education is presented to show their qualifications for various employments. The third column of the table presents the participants' occupations before disability onset. A participant with NA in that column experienced disability onset before ever being employed. The fourth column presents the participants' work experiences shortly after disability onset. The last column presents the participants' current occupations.

The education of the sample ranged from completing the ninth grade to graduate degrees. It should be noted that overall the sample appeared to have a relatively high level of education. In general, many of the research participants had the education or training to qualify for a number of high status occupational positions (nurse, attorney, engineer). Table 2 shows that many of the participants seem to be underemployed based on their

levels of education. For instance, eight had an education beyond high school but were currently unemployed or employed only part time. Among those were 4 who received bachelor's degrees, one that received a master's degree, and an LPN. Interviews revealed several reasons why these well educated participants were underemployed including the need to retain social service benefits including Medicaid health care coverage, inability to work after disability, and reluctance of employers to hire a person with a disability.

Table 2 also suggests that six (#2,3,4,6,14,19) had dropped from a full-time position before disability to being unemployed or a part-time employee today. A couple of these also experienced a status drop after disability such as #19 (going from nurse to unemployed) and #14 (going from an engineer to only working part-time).

Examining all three of the occupation columns summarizes the work trajectories of the participants. For some, disability onset presented a major interruption to employment. For example, #19 went from being a nurse before onset to home daycare provider after onset and being unemployed today. Others did not seem to have had such major interruptions. For example, #16 provided daycare in her home before disability, then became a cook, and is now a full-time state employee. On the other hand, #11 actually obtained a relatively high status position as a chemist after disability onset, but is now employed as a part-time van driver. Age of onset seemed to have an impact, as those who experiences disability after already establishing a career lost a great deal of occupational status that they did not recover. Younger age onset seemed to prepare more for a disability trajectory. Several of those who had an earlier onset of disability received assistance that enabled them to receive education or job training. However, for some, the employment they eventually found was significantly below the level of their preparation.

Barriers to Work

All wanted to work, because it helped their self-esteem, and made them feel emotionally better. However, some could not be employed because of their disability or health problems. It had been a difficult struggle for each person to negotiate the web to find services and also to find employment.

Programs Intended to Promote Employment

It was found that some programs intended to promote employment were not known about or were less helpful than expected by several of the participants.

Trial work periods. When a person who has been receiving disability benefits becomes employed, their disability benefits are supposed to continue for a trial work period of at least nine months (SSA, 2002). Most had no idea they were using their trial work period until after they had used it up. Several did not know what the trial work period was, even though they had worked after obtaining social security income. Some participants stated there should be accommodation in the trial work period program to take changes in disability severity into account. For instance, one respondent believed his trial work period was wasted on a very low paying, menial job because his health did not allow him to have a more significant job at the time. Now, his disability does not

cause as many limitations in his every day life but he is unable to utilize a trial work period to capitalize on his previous training and experience.

When I got out of the hospital I went to work and when I got on social security I went to work right away. A part-time job. But it was like rolling dough in a pizza place. That was about all I could do when I got out of the hospital. I had to take very menial jobs and I didn't make my \$700 or \$780 cap at all..... I was lucky if I made \$100 but that counted as my trial work period. And now, I'm getting to the point where I can do more. And it's, and I've exhausted my trial work period,it would be nice if I could make more than the cap now because that would lead to maybe permanent employment; if I were to have that now where I could make overhere's what I'm tryingmy suggestion would be to have, after you've gone for your trial work period, have a period of time and then another trial work period or something like that ...I think that'd work out.

Several other participants shared this perception.

Vocational rehabilitation.

Most participants were working at jobs that required significantly less than the education they had attained. Several worked very hard to get education before or after onset of disability, but were unable to find and hold a job where they could use that degree. Most had found their jobs on their own. Vocational Rehabilitation (VR) services had been used, but several expressed frustrations with these services. In some cases, the VR system failed to comprehend how disability onset or progression affected the person's ability to utilize previous training and experience. Some experiences recounted were:

A: That was a joke. They said that he could be a forest ranger. Which I guess...I mean, I don't know. If he can't remember anything, I don't know how you can be a forest ranger if you've never been one. Mortician. A banker. A garbage man too.

B: But they quit, Voc Rehab here quit making people with head injuries go for that testing, because everyone who came back was so mad and so furious at the people there. Because if you can't...they did stuff before, they worked full-time. It wasn't like they were lazy or anything and then all of a sudden you're over there and you're saying, you can't do this and you can't do that. It was more that people looked at what they couldn't do and not what they could do.

C: And I don't think they understand what it means to have something taken away from you like that. And that's their job, to help you get a job..., because if I get a job I don't like, I'm not going to try.... I don't think they match the job with the person.

Only a few participants knew what a PASS (Plan to Attain Self-Sufficiency) was and had used one. Some said the Vocational Rehabilitation worker had discouraged them from seeking that assistance, and that they did not know how to write one.

However, several participants had received payment for advanced schooling, and several people with more visible disabilities seemed to feel that VR did understand their problems.

I should say as far as services, Voc Rehab has been very good. I can say good things about what they've done. They've been very helpful as far as when I was in school, and helping me with any adaptive equipment that I needed. Even just simple things like a reacher to pick things up off the floor. I had a great caseworker so they did a great job.

The services for the visually impaired seemed to have the best model for rehabilitation and were praised by each of those who had utilized them. However, these participants also said that they had difficulty finding out about the special services the state operates for the visually impaired.

Discrimination

All participants felt they had experienced discrimination of some type. Perceived discrimination during job interviews and unnecessary job qualification standards were also reported as a barrier by several participants. Even though they felt they definitely had been discriminated against because of their disability, and were aware of the ADA regulations, they had chosen not to pursue a legal battle because of the stress it would cause them. It was also expressed that a legal battle would label them as a troublemaker and may hinder them from obtaining a future job. Explanations by some included:

A: The person who was in charge of hiring didn't feel like my stamina was good enough. I was there more than what she was. And so, I didn't get that job....told me that they hadn't found a candidate yet.

So, there was that and then I can't prove it, but in a six-month timeframe I went through 37 interviews.

B: When you fill out the application and it does ask you if you're on SSDI or something like that,... sometimes they thinks about people with disabilities differently.

C: You . . . so, you know when they've bringing questions into the interview process that are sort of off the wall, not connected to what the job description says your job was. You almost know that they're developing those kinds of questions to throw you out of the pool. And that kind of thing happened three or four times and I thought, nah, I'm not going to frustrate myself

Most participants with invisible cognitive disabilities had not disclosed their disability when interviewing or taking a job. One participant said she wished there was an easier way to explain your disability so employers could understand and still give you a chance at the job. After being hired, discrimination from employers and co-workers was also reported, as one said:

They think just because you can't see, you don't have any feelings.

However, some also had experienced extra kindness from their coworkers when they knew about the disability. As one participant explained:

Yeah, I was hospitalized three weeks. And I think rather than to discriminate against me there, they're taking that into consideration. And if I get into a bind where I need some help, the boys will help.

Accommodations

Employers' perceptions that they might have to provide expensive accommodations was also reported as a barrier.

Yes, it's a little bit more expensive, but you also try to explain to the employer that there's money out there that's available that could help offset the cost of the accommodation and tax credits, both for the accommodation and as well as a tax credit for hiring a person with a disability. But it still scares employers in a big way.

All participants needed some accommodations and had found that some employers were willing to give those and others weren't. One participant told of losing a job because her medical condition became more debilitating and she could no longer stand for up to 4 hours without a break:

Yeah, I didn't totally quit actually, it's just that they told me they didn't need my services no more because they felt like I missed too much and that I was having to ask them about these accommodations and then I was very upset with them because they said you had to have doctor's notes in order for them to accommodate it. Well, I had like two doctor's notes and one doctor called them and told them personally. It didn't do any good. They don't care. All they cared about is getting my production done. And I came down with the flu on top of it all of it and I missed too many days.

The vast majority of the employed participants had a position with the state government or nonprofit agencies. Overall, the participants reported that the State was more likely to hire people with disabilities and make necessary workplace accommodations.

As one participant said:

That's one thing I do like about the state. They'll accommodate you in any way possible within reason, of course. They're not going to spend thousands of dollars just for one modification, even though they have. But that's to keep up with the ADA.

Services

Overview of Service Utilization

Table 3 presents an overview of the social service programs utilized by the participants. The majority had received, or were currently receiving, SSDI (n=18) and Medicare (n=15). Most had also received some form of assistance from Vocational Rehabilitation (n=17). Over half had received Medicaid (n=13) and less than half had ever received SSI (n=7).

The participants had a wide range of experiences with each of these programs. Feedback was not universally positive or negative for any one program, although all participants

expressed some frustrations and difficulty in accessing services. Analysis of the data revealed that these programs were both a benefit and a barrier regarding employment for disabled people.

What was apparent was the overall lack of understanding of each of these programs by the majority of the participants. Frequently, an individual reported an understanding of one program, but had little exposure to another. For instance, one participant had experience with Social Security and Medicaid but didn't even learn about Vocational Rehabilitation until he had already graduated from college. He suggested that VR services would have been a great benefit had he known about it prior to graduating.

Finding their way to services was difficult for all participants. Many reported being unfamiliar with the specific services provided by different agencies. It was also pointed out that Nebraskans in rural communities have access to fewer service providers, and also have less access to information about the programs.

But there are some pretty well kept secrets, because if you live in a big city, it might be easy to find those secrets, but when you live in a rural area . . . and I don't mean . . . and I would never have found out about the Commission for the Blind and Visually Impaired, but there is a . . . I can remember . . . mom heard something through work.

All participants had received some type of services from government funded disability programs, and had found the application requirements very frustrating. As one explained:

Twenty-seven page application and when you can't see, you don't even know what the . . . and nobody, and I mean nobody bothered to . . . the only reason I knew what was going on because my mom is a . . . counselor type thing, so for her clients, and stuff she has . . . has that experience. Thank God! I mean, that was totally bizarre. Total B.S. I can't . . . remember the number of pages but it was page, after page, after page, after page of the same crap. Same questions. Just different question marks. Ridiculous.

Most participants received Medicaid and/or Medicare benefits to pay their medical bills. Some were unsure which was which. Most had to apply at least twice before they began to receive these benefits, which sometimes meant piling up two years worth of debt and often waiting to receive rehabilitation or other services. Since it is important that rehabilitation services begin as soon as possible after the injury, this delay may have hindered some from reaching their recovery potential and sometimes other illnesses went untreated. One participant had been so frustrated by the process she had even attempted suicide.

A1: It took two years before I got any benefits. We had to apply and reapply and go to the hearing, and reapply.

A2: She went in to Social Services and they just handed her some papers and there was really no help there. ...So, she decided to take her life instead.

Another participant told of the frustrations in trying to find help with feeding her children.

Yeah, because I own my house, I couldn't get any assistance. Because we still owed some on it, but we own it. We didn't qualify for anything And then I go, well WIC wouldn't do me a whole lot of good because both of my kids are allergic to milk and eggs and I know what they give you.

Other participants wished there could be one caseworker who was assigned to keep track of their file and respond to their questions and problems. As one said:

I would like to have one person . . . one worker who is dedicated to that specific client. Every time I needed to talk to somebody, there's always a different person and you have to re-explain the whole situation about what's going on related to your own Social Security income to a different person. I would like to have a caseworker where I can contact this one specific person and that person would know who I am and then we could move on and talk about whatever I need to talk about. Always a different person and maybe I understand that because they have so many people to deal with.

Many participants found the disability review process to be unnecessarily cumbersome or involving too many unnecessary steps.

The most frustrating experience because you get ...this long form that you get to fill out. And it wants to know about how long have you had it, when is it going to stop, is it going to stop, what do you do, what kind of assistance do you need, how long do you do it, how many hours can you stand.... It's just ludicrous! Especially, the whole thing does not apply or doesn't apply well to someone who has a permanent disability. This one isn't going to go away. This is going to get a little worse with my age just because I'm aging. It's not going to kill me, it's always going to be here. Why do I have to keep telling you that I have this congenital disability? You know? And then you send that in and then you get another, I don't know, 14-17 pages that you get to fill out. And you get a form you get to take to the doctor and have them fill out. I was so frustrated by the time I was done, I was bawling in her office because it was just so stupid!

Participants were also frustrated by the painstaking record keeping and reporting of income requirements when they worked part time and still tried to retain their Social Security Disability Income (SSDI). Check stubs had to be sent in monthly even this information was available to the Social Security Administration on their computer system.

So, you have to save all your check stubs and send them in... every three months. And a copy of bank statement. And if you're over just a little bit, just a dollar or then they try to take it away from you...Then the next three months you might not have that. If you're under, they don't give it back to you.

All participants reported that the earnings limit to retain Social Security benefits and/or Medicaid coverage was way too low. One participant reported having a very narrow

range of hours that he could work in order to retain both his Social Security and private health insurance benefits.

But I have to be very careful at the job I am working, because if I go over by an hour or by a dollar they'll re-evaluate me. And that just isn't fair and it isn't practical in the work place. Because some weeks you've got to work more, some weeks you aren't going to work more, and I think if they could take that into consideration. Because there was one day when I fell above work one week, and I went in and asserted myself and said, look, I have a disability and I can't work this much to do it. And so they scheduled a day off during the week that I have and I'm falling under and I have to maintain 24 hours a week to keep my health insurance benefits, my private health insurance benefits with the company. And yet, I can't work that many hours. I've got a window like 24-26 hours that I can work and keep my health insurance to maintain my Social Security. So if I go over 26 hours, I lose my Social Security. If I go under 24 hours I lose my health insurance.

This dilemma was a common frustration among the participants, and was definitely a barrier to them to them becoming more fully employed and independent.

The total assets allowance of \$2000 was also berated as too low, especially for those who owned cars or specially fitted vans for their wheelchairs. They were concerned how they could pay for expensive repairs or even purchase a new or replacement vehicle as they needed it. While a community fundraising drive and/or vocational rehabilitation may have helped buy their initial vehicle, that was not an option for repair or replacements. Several participants expressed a desire to save money for home ownership or to move to take a better job. They could not accumulate any real reserve to do this with the current regulations.

Those who had worked for enough quarters before or since their disability received Social Security Disability Insurance (SSDI). If they had worked for several years, they might receive a monthly income much higher than the Social Security Income (SSI), but this was a mixed blessing as it threw them into the category of Share of Cost to receive any Medicaid coverage for their medical care.

The share of cost usually ran according to what she earned at the time. They had a formula and it would be like three or four hundred dollars a month that she had to pay herself before they would pay any of her medical expenses. And that was when you were making probably maybe not much more than \$1,000 or \$1,100 a month.

Only a few participants in the urban area and none in the rural area had heard of the Medicaid Insurance for Workers with Disabilities program. This program is available in Nebraska to allow workers with disabilities to buy Medicaid coverage after their income is above the limit for Medicaid coverage. The few who had heard of the program seemed doubtful that this program would help their situation.

Overall the participants favored some type of Medicaid reform to make it more possible for them to work without losing their medical benefit coverage. They realized that many

part time jobs did not offer medical insurance coverage. Many of them had found it was too stressful for them to immediately go back to work full time, so they were caught in a poverty trap and could not take the risk of having a relapse or becoming more disabled. All participants needed expensive medical care, medication, and/or medical devices to be able to work.

Transportation

The major source of transportation for all rural and for most urban participants was a private vehicle which they or their family members drove. Some had vans specially fitted for their handicaps. Most who owned vehicles were concerned how they would be able to repair the vehicle or replace it as they could not have more than \$2000 in checking and savings at one time. Some had taken special driver education courses to be able to drive or pass their driver's test. Some had limited themselves to only driving close to home, or not at night. It was also noted that there was generally a lack of parking reserved for the handicapped and winter travel was a particular problem. Several people who had mobility or vision disabilities remarked that the stop/go lights in the urban area did not allow enough time to get across the street safely.

Even in urban areas, public transportation was only available during daytime hours, and didn't cover enough areas and enough times of the day. Public vans with special lifts for wheelchairs were not available on weekends. As one person said:

They couldn't coordinate it to come and pick her up at the right time every week. It was at the same time every week. So finally somebody else had to drive them. So, I don't know how useable the transportation is.

Lack of public transportation definitely limited some participants in more rural areas from working: As one person said:

Because I can't drive myself and I have to make sure that I can get to work.

Housing

All participants lived by themselves or with spouses or roommates. Some lived in apartments or houses with their rent subsidized by federal or state funds distributed to local housing authority programs. Some reported difficulty getting into low income housing program dwellings while others expressed some safety concerns about living in housing projects.

They're all filled up. A waiting list. We figured it was cheaper to live where I'm at than to live in those places. Because my electric bill isn't that high. And I don't have to pay for my heat and I don't have to pay for my water.

One frequent complaint from those who lived in subsidized housing was that when they went to work, their rent went up immediately after they reported their increased income. Their rent was always computed at 30% of their income, even if it was the same apartment. For one participant the rent for her one bedroom apartment had increased to approximately \$600 monthly. She could not search for a cheaper apartment, as she

needed one which was set up for her wheelchair. This was noted by several to be another barrier to work.

Well, part of the problem is, with the housing where I'm at, they're based on 30% income. And the problem is, if you go to work, they take 30% of the gross, so that means you have to earn more to make up for what you get... I don't know why they don't take the 30% after the taxes...It would make a lot more sense because you have the same housing ...to work it costs you a whole lot more. Take 30% of the net instead of the gross... It would make a whole lot more sense.

Some were in the process of buying houses and one participant had been able to buy her own house through a special low interest loan.

I went through the USDA rural development. It was a one percent loan. My counselor set me up with this realtor and it took a while.

All participants appreciated being able to live in their own home. Some had lived in group homes or other institutional settings at one time for treatment and rehabilitation. All mentioned that living in their own home was very important to their quality of life.

Family

Family characteristics may also have an influence on the adaptation to disability. Among the twenty participants, ten were married, five were divorced, three were engaged, and two were single. All of the five divorces happened after the disability. Thirteen of the participants were custodial parents, with only two becoming parents after they experienced their disability. The number of children in the families varied from one to as many as ten children. Several participants had raised their children after their disability. Several of those children were noted to be very bright and high achieving. They seemed to be very resilient young people.

One participant told of the extreme stress the disability had caused in their family:

It tore the kids apart. They still aren't that close though. There was so much jealousy. I think they were so afraid of being left alone... His emotions were so different than before. And I think sometimes because of the injury, they think they're the only ones that are affected. It affected the whole family. And it is a whole different family dynamics now.

Participants lived with spouses, children, and friends. Five lived alone, with some of those who were physically handicapped having personal care attendants according to their assistance needs. Participants told of help from family members including: transportation, giving cars or helping with repairs, helping with home repairs, cleaning, shopping, mowing, snow removal, and occasional meals or cash loans. Most participants who did not live in the same house with their family, talked to the participant at least weekly, and went on family outings frequently. Families were also seen as an important source of emotional support and encouragement.

Some family members were not seen as not helpful because it seemed they didn't really understand what the person was going through. Siblings could be very helpful and were very important to many participants, although some with less visible disabilities such as mental illness or brain injuries said their siblings lacked understanding of their disability. One participant remarked:

She doesn't understand it either. She sees these things through her eyes. She doesn't understand them unless she was in someone else's shoes. You don't know what you go through until you've been there. What made me upset was when she didn't really comfort me.

Most families were very supportive, although at times that may have seemed over protective to the person with the disability. All were supportive of the person with disability working. Some participants told of assistance they were able to give their family members including child care, computer research/assistance, a place to live, an occasional meal out, help with household chores, and emotional support. They seemed to feel good about being able to give back and many stated they could not live as independently without the help of their families.

Social Activities and Friends

All participants had friends who they talked to on the phone or met frequently for socialization or encouragement. Some of these friends also helped with home or car repair & maintenance, personal care needs, and other miscellaneous tasks. Social groups included church groups, and other local organizations.

I just had a whole staff of friends who would come in and help me and what have you, so I've developed some really deep friendships.

Several were active in self-help support and advocacy groups for their disability and praised the value of these groups:

I don't think the community out there has enough education about my handicap, my disability and I think a lot of other disabilities they notice when somebody's on a wheelchair, or on crutches or things, or other handicaps. I think they understand that and know that. But they've never been educated on ----.

However, when asked about their friends, some participants stated that most friends had passed them by—or didn't know how to react to their disability.

Another one that calls and comes around, but most of the friends that I had, I never see them. And haven't heard from either. They're scared....You don't know how to handle that. I'm sure I have to think about myself. Could I do it? I am a good person, I think, but could have I ...a friend of mine who lost his -----, could I go over there, to visit with him, help him, go do something with him?

One of the most common social activities mentioned was the church, even though this was not a specific question. Several participants did report their belief in God and their church had been very helpful during difficult times, although some said they had fallen away from church participation.

Quality of Life

Most participants rated their quality of life as 5 or over, up to 10. One person who rated his QOL as a three remarked:

Well, I live a lonely life. I'm tired of being alone. You know I've lost my family, ... and trying to deal with a lot of medical problems. You kind of feel bad about yourself. You'd like to become more positive. You'd like to earn that paycheck. To be able to do things that other people do, and they earn their paycheck. And I can't do that. There's a lot of barriers there to stop me from living a quality life I'd like to live.

While another person who rated his quality of life as a nine remarked:

I'm one of the lucky guys around. The community has been very supportive of me. My family has been very supportive of me for the most part, and now my fiancée and her family are extremely supportive of me. I've got to experience a lot of things that most people don't get to experience. I've been fortunate to be blessed with a lot of friends and a really good job. That makes it all worthwhile.

Future Research Recommendations

The courage of the people we interviewed was phenomenal. They had endured overwhelming physical and emotional pain and suffering, and were trying to remain as independent as possible. Eighty percent of the research participants were working, although only 35% were fully employed. This employment rate is much higher than seen in the Nebraska 2000 Census Report that shows 65% of those identifying themselves as disabled were employed. The U.S. Census Report 2000 shows only about 50% of persons with disabilities between ages of 21 and 64 are employed. The purposeful selection of this group may have contributed to some bias, as most of the participants were recommended by advocacy groups and were active in these organizations and not newly disabled. Data collected from random selection of cases through HHS records would have been more generalizable. All perspectives were retrospective. Long-term prospective study would be of great interest, although quite painstaking and expensive.

The participants with invisible disabilities such as brain injuries and psychiatric illnesses seemed to have more frustrations and difficulties with the service caseworkers they had encountered. It seemed the rehabilitation systems for these disabilities are less developed in Nebraska and more fragmented. More investigation with people with brain disorders may reveal better ways to design a comprehensive and coordinated treatment and rehabilitation system.

Even though most of these participants probably had higher than average intelligence and family resources, they still had great difficulties in negotiating the web of services and found many problems and gaps. The information they volunteered was very rich in finding opportunities for investigation and improvement of the work incentive programs

in Nebraska. They also volunteered many recommendations that have been consolidated below.

Recommendations for Improving Work Incentives

The following suggestions for improving work incentives were identified by the participants. Their suggestions have been divided into those that could be accomplished by state officials within the present federal system and others that would require changes in federal laws or regulations.

Recommendations

Services

All participants had difficulties finding the services that were available and/or accessing services. Most had been dependent on Medicaid and/or Medicare for medical care and/or devices and were concerned about returning to work and losing that coverage so important to their health.

26. There needs to be an easily accessible information center for rehabilitation services that all medical practitioners could use for referral.
27. Improve the flow of information between different offices and different agencies. Participants frequently complained they were told different things by different workers in the same system and/or different systems.
28. Design simplified fact sheets/resource guides for people to use when they want to return to work. Perhaps each agency could designate a caseworker who could be specially trained to serve as the contact person for people trying to return to work.
29. Information about the options for keeping Medicaid health care coverage or using the "buy-in" needs to be readily available and those options need to be well known by all caseworkers. Most people with disabilities cannot return to work without health care coverage, which may not be available through their employer, especially if the employment is only part time.
30. Allow for savings accounts for a house or motor vehicle. Most participants did not know the limit for assets had been increased from \$2000 to \$4000/person and \$6000/couple. Some states exclude accounts for retirement, medical expenses, and for purchasing goods/services to increase employability. Some states allow higher asset limits.
31. Reviews could be less painful and time consuming if the participant could just update the file rather than fill out a lengthy document each time. It is very painful to recount the history of the disability as often as every three months for reviews.
32. Each person should have easy access to his or her Social Security, Vocational Rehabilitation, and Health and Human Services files.

33. Consider the fragile self-esteem of persons with disabilities. Caseworkers in HHSS and in Vocational Rehabilitation may need sensitivity training to assist them in being encouraging rather than discouraging.
34. Part of the vocational rehabilitation services should include benefit counseling. More Benefits Counselors are needed. Perhaps this could be accomplished through more training in benefits so that Vocational Rehabilitation counselors or other caseworkers could be more helpful. Smaller caseloads for caseworkers may help.
35. People should be informed when they begin their trial work period and of the consequences. They should be assisted to identify work-related expenses that could reduce their earned income, because it costs a lot to begin a job such as expenses for clothes, transportation, moving, childcare, and miscellaneous needs.

Employment

All participants wanted to work, however some could not because of the disability, or other health problems. The sample was generally well educated, but most were working below their potential. There were many frustrations with the job services, discrimination and lack of accommodations. Their suggestions were:

36. Using the services for the visually impaired as a model, develop more comprehensive rehabilitation services for people with other disabilities. Services for persons with brain injuries and/or mental illnesses are quite fragmented and lack a rehabilitation focus.
37. Expand the referral system for disabled persons who are looking for work. Doing a better job of linking the existing state and local job service agencies with service providers and employers would facilitate employment opportunities.
38. Disseminate information about incentives for employers who hire disabled workers and investigate ways to also give incentives to governmental and non-profit employers.
39. Disseminate information about governmental assistance with accommodations purchased by employers. The Job Accommodation Network (1999) suggests that over half of all required workplace adaptations cost less than \$500. Even a small subsidy would possibly encourage many employers to make a workplace accommodation.
40. More public education is needed about people with disabilities to lessen the discrimination. Television shows and movies about their struggles and portraying them as heroes would help. More public education is needed about accommodations for various disabilities so that employers would not be so afraid of employing persons with disabilities.

41. Provide assistance on how to work with the disclosure issue and how to access advocacy services through the Americans with Disabilities Act.
42. Find ways to make public transportation available for those who may be working other than daytime hours and on weekends.

Families

Most participants said they could not live as independently as they did, without the help their families gave them. All family members were supportive of them working.

Suggestions were:

43. Investigate ways to reduce the marriage penalty that occurs when benefits are reduced because a person receiving SS benefits marries. The living allowances for married couples are much less than the total for two single people. This was a major frustration for those participants who were engaged and planning to be married. Some states do not count the income or spousal assets when determining benefits.
44. Remember that members of the family are also affected by the problems of the person with a disability and help them find support groups and counseling resources or family education classes to assist them in venting their emotions constructively and learning about the disability. They need to be included in benefit planning and case management so they can be more supportive. The family can be the glue that holds this puzzle of accessing services and returning to productivity and/or employment together. Strengthening families can be an important part of recovery.
45. Check to see if there is a way that family members could be employed as caregivers and or case managers when they are performing those functions. If the family member has to take a job outside the home to help pay expenses, they will not be able to perform many of those functions. They know the person very well and may be the best caregiver/case manager for them.

Housing

Finding affordable and decent housing was a common problem especially since most Social Security income levels were under \$600/month. These suggestions need to be discussed with the local housing authorities.

46. Housing costs increase if income increases; so many participants said it did not pay to work. It would help to allow some months of work before a rent increase takes effect, and give people a chance to get on their feet. Considering the net income rather than the gross income was also suggested.
47. There is a scarcity of decent, affordable housing in both rural and urban Nebraska. Establishing more assisted living facilities for people with disabilities would be helpful.

Federal system problems

48. Simplify record keeping for individuals returning to work. Sending check stubs to Social Security monthly seems unnecessary when this information could be accessed through their computer files.
49. Use net income rather than gross income when deciding to decrease benefits. The various withholdings from a paycheck can amount to about one-fourth of the total.
50. Investigate the possibility of allowing more than one trial work period, so that you can try out a job without fear of losing your benefits. Perhaps they could choose when their trial work period should begin, so it would not be wasted on a low-income part time job.

It is hoped these recommendations will be carefully considered and investigated to improve the systems to assist more people with disabilities attain and keep jobs. This can be an opportunity to help people with disabilities reach their potential and to be more productive and contributing members of our state.

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APPENDIX I

Tables of Disability Information

Table 1 - Selected Demographic Characteristics of Respondents

| ID | Age | Sex | Disability | Onset Age | Residence | Family | Marstat |
|----|-----|-----|-------------------------------------|--------------|-----------|---------|------------|
| 1 | 34 | F | Bipolar | 8 | Rural | Single | Divorced |
| 2 | 51 | M | Brain Injury | 36 | Rural | Father | Married |
| 3 | 34 | F | Brain Injury | 26 | Rural | Mother | Divorced |
| 4 | 50 | M | Paraplegia | 31 | Rural | Father | Divorced |
| 5 | 59 | M | Bipolar | 22 | Rural | Father | Married |
| 6 | 45 | F | Depression/ Joint degeneration | 40 | Rural | Mother | Married |
| 7 | 30 | F | Developmental Disability | grade school | Rural | Single | Engaged |
| 8 | 30 | F | Osteogenesis Perfecta - Paraplegia | 4 | Rural | Single | Single |
| 9 | 46 | F | Rheumatoid Arthritis | 12 | Rural | Mother | Divorced |
| 10 | 45 | M | Blind | 43 | Rural | Father | Married |
| 11 | 38 | M | Muscular Dystrophy - Paraplegia | 2 | Rural | Single | Engaged |
| 12 | 39 | M | Bipolar | 22 | Urban | Single | Single |
| 13 | 49 | M | CMT Disease*-Physical | 12 | Urban | Father | Married |
| 14 | 48 | M | Blind / Amputee | 32 | Urban | Husband | Married |
| 15 | 51 | F | Cerebral Palsy / Visual Disability | birth | Urban | Wife | Married |
| 16 | 49 | F | Blind | 40 | Urban | Mother | Married |
| 17 | 24 | M | Deaf | birth | Urban | Father | Cohabiting |
| 18 | 36 | M | Blind / Loss of Limb | 20 | Urban | Father | Married |
| 19 | 60 | F | Rheumatoid Arthritis / Nerve Damage | 49 | Urban | Mother | Divorced |
| 20 | 47 | F | Quadriplegia / Speech Impairment | 27 | Urban | Mother | Married |

* CMT Disease is Charchot-Marie Tooth Disease

Table 2 - Education and Occupations of Respondents

| ID | Education | Occupation before onset | Occupation after onset | Current Occupation |
|----|---------------------------|-------------------------|------------------------|--------------------|
| 1 | some college | Nursing assistant | Cashier | Cashier |
| 2 | 2 yr degree | Construction | Carpentry | Unemployed |
| 3 | Beauty School | Beautician | Cleaning | Childcare - PT |
| 4 | BS | Sales | Agency Director | Unemployed |
| 5 | some college | Military | Packing Plant | Custodian |
| 6 | Some college | Food Service | Food Service | Unemployed |
| 7 | High school | NA | Dishwashing | Custodian - PT |
| 8 | MS | NA | Teacher | Sales |
| 9 | BS & some graduate school | NA | Housewife | Social Service |
| 10 | 9th grade | Truck Driver | Factory | Factory |
| 11 | BS | NA | CEO own business | Self Employed - PT |
| 12 | BS | College Student | Chemist | Van driver |
| 13 | 2 Year Degree | NA | | State Employee |
| 14 | MA | Engineer | Social Service | Self Employed - PT |
| 15 | BA | NA | Secretary | Self Employed - PT |
| 16 | some college | Home Daycare | Cook | State Employee |
| 17 | 2 Year Degree | NA | Visual Design | State Employee |
| 18 | MA & JD | Police Academy | Social Service | State Employee |
| 19 | LPN | Nurse | Home Daycare | Unemployed |
| 20 | MA & RN | Nurse | Health Specialist | Social Service |

Table 3 - Program Utilization by Respondents (ever received)

| ID | SSI | SSDI | Medicare | Medicaid | Voc Rehab |
|----|-----|------|----------|----------|-----------|
| 1 | no | yes | yes | yes | yes |
| 2 | no | yes | yes | yes | yes |
| 3 | yes | yes | yes | yes | yes |
| 4 | no | yes | yes | yes | yes |
| 5 | no | yes | no | veteran | yes |
| 6 | no | yes | no | yes | yes |
| 7 | yes | yes | yes | yes | yes |
| 8 | yes | yes | yes | yes | yes |
| 9 | yes | yes | yes | yes | yes |
| 10 | no | yes | yes | yes | yes |
| 11 | yes | yes | yes | yes | yes |
| 12 | no | yes | yes | no | yes |
| 13 | no | no | no | no | yes |
| 14 | no | yes | yes | no | no |
| 15 | no | yes | yes | no | yes |
| 16 | no | yes | no | no | no |
| 17 | yes | no | no | yes | no |
| 18 | no | yes | yes | no | yes |
| 19 | yes | yes | yes | yes | yes |
| 20 | no | yes | yes | no | yes |

SSDI= Social Security Disability Income

SSI= Social Security Income

APPENDIX II
Research Interview Guide

Research Interview Guide

LIST OF QUESTIONS FOR QUALITATIVE INTERVIEWS

Screening for Eligibility (before consent) will be conducted in phone or in person.

1. Are you interested in learning more about this study and possibly being a participant?
2. Have you received Medicaid or other benefits from the Nebraska Health and Human Services System because of your disability?
3. Have you held a job since you began receiving benefits from the Social Security Administration and/or the Nebraska Health and Human Services System?
4. Do you have a guardian who would need to give consent for your participation? May I contact him/her?
5. Determine correct spelling of name, address and phone number.

Make appointment for interview. Mail consent form and questionnaire to potential participant ahead of time along with confirmation of interview time. Encourage participant to discuss participation in the study with family, friends, counselors, guardians, or other confidants before agreeing to be interviewed and before signing the consent form.

I. Consent form and Introduction

First go over the consent form. Review each element of the consent form—read through each element and ask the research participant what s/he understands each element to mean. If there seems to be difficulty in understanding the voluntary nature or other content of the consent form, the interview will not be conducted until and unless proxy consent is obtained.

If a guardian, family member, or care provider accompanies the research participant to the interview, that person will be asked to help explain the consent form to the participant and also to sign his/her own consent form.

Introduction

The purpose of our study is to discuss competitive employment issues with people who have a diverse range of disabilities. We will specifically discuss how your personal health, social service providers, and your family affect your opportunities to work. Other topics that may be related to work, such as transportation and housing, will also be addressed.

Please give as much information as you feel comfortable with about each of these topics. If you do not feel comfortable with a question, or feel uncomfortable discussing that topic, please tell me and we can move on to the next issue. If you need a break, or would like to stop the interview at any time, please tell me and we will take a break or stop as you prefer.

This interview will be tape recorded so we can get an accurate recording of your experiences. If you would like a copy of this tape, let me know and I will make sure you

receive one. My student assistant and I will also be taking a few notes during our discussion so I make sure we cover all of the topics of interest.

In order to insure your confidentiality, and those of others who may be discussed in our interview, it is important to try to avoid using personal names during our discussion. Rather than using individual names, it would be helpful if you would just refer to people by their titles or relationships to you, such as Doctor or brother. Any personal names that you do use will not be used in our analysis.

Do you have any questions before we begin?

II. Demographics

Before we begin the interview, I would like to get a general idea about your background.

1. Record the respondent's gender.
2. Could you please tell me your age?
3. What town/community area do you currently reside in?

III. Disability

I would now like to get a better understanding of your disability.

1. Please tell me when you first began to experience the symptoms of your disability?
2. How old were you when you were first diagnosed with a disability?
3. What disabilities do you experience or have you been diagnosed with?
4. Does your disability present any problems with mobility or communication?
5. Does your disability present any other challenges or limitations during your daily life?
-Please describe all of the limitations you experience on a day-to-day basis.

If not specifically mentioned, follow up with...

6. What problems does your disability cause with activities such as bathing, eating, or cooking?
7. What problems does your disability cause with budgeting or other financial issues?
8. What problems does your disability cause with home management, such as cleaning?

IV. Health

A major concern for any individual is their personal health. In addition to disability, other health related factors might affect your work experiences.

1. How would you describe your overall health?
2. Do you have other health problems besides your disability? What problems have you had?
3. Have you ever had depression or other emotional problems?
4. Please describe all of the methods you use to improve your health or to help you stay healthy.
5. How has work affected your health?
6. How has your health affected your ability to work?
7. What have you done to cope with health problems when working?

V. Work- General

Now I would like to get a general idea about your work qualifications and experiences.

1. What is the highest level of education that you have completed?
2. Describe any other training that you have had.
3. Did vocational services, the PASS plan, or scholarships assist you with your education or training?
4. What are your current employment goals?
5. If you could choose any job, what would be your dream job?
6. What would you need to get that job?
7. Have you ever experienced discrimination or attitudinal barriers regarding employment? Please describe the situations in which you experienced this.
8. Have you ever had problems with obtaining accommodations from an employer? If so, please describe the accommodations you needed and the problems you encountered.
9. Have you used a trial work period? If so, please describe that experience.

VI. Work History

This next section of questions specifically involves your experiences with work. For these questions, we would like you to remember as much specific information as possible about your work experiences. Feel free to take as much time as you need to answer each of these questions.

1. Please describe each job you have held. Begin with the first job and tell me the type of job, the number of hours you worked per week, how long you held the job, and approximately how much you got paid at that job. Was this job supported or competitive employment?
 2. What did you like the most about this job?
 3. What did you dislike most about this job?
 4. Did you have a disability when you had this job? If so...
 - Did you disclose your disability?
 - How did you handle disclosure?
 - What were the reactions of your co-workers when they found out about your disability?
 - What about the reaction of your employer?
 5. Did you have health insurance as part of the benefit package?
 6. Please describe the specific barriers that you may have experienced at this job?
 7. What specific accommodations did you need to perform this job?
 - Did you receive these accommodations? If so, how did you receive the accommodations? If not, why didn't you receive them?
 8. Who helped you get this job?
 9. Please describe your interactions with service providers, such as vocational rehabilitation providers, or social service providers, that related to this job?
 10. What aspects of the social services you received were helpful for this job? What aspects were not helpful or caused you difficulty at this job?
 11. What supports did you need that you did not receive?
 12. Why did you leave this job?
- Repeat for each additional job.

VII. Service experiences

Social services may play a large role in your ability to work. The next set of questions involves your specific experiences with Medicaid, Medicare, Health and Human Services, and other service providers. Let me stress again that any information you provide will be held completely confidential by the researchers. The service providers we discuss will not have access to your name or any information that could be used to identify you.

1. First, tell me when and how you first became eligible for Medicaid or Medicare.
2. Do you currently receive either Medicaid or Medicare?
3. What services do your Medicaid/Medicare benefits pay for?
4. Do you have other medical insurance? If so, is this private or veterans coverage?
5. Do you need Medicaid or other health insurance to be able to work?
 6. Please describe your experiences with Health and Human Services and Medicaid/Medicare.
7. In what ways have your experiences been helpful?
8. In what ways have your experiences been frustrating?
9. Please describe your experiences with the following aspects of HHS and Medicaid/Medicare:
 - Income reporting
 - Coverage when working
 - Savings allowance
 - The review process
10. Are there any other aspects of these services and service providers that you would like to discuss?

VIII. Transportation

The ability to get back and forth to a job is obviously an important issue. The next set of questions is about your access to transportation.

1. Please describe your major sources of transportation when you need to go to work, appointments, or run errands.
2. What is your primary source of transportation?
3. Are you able to drive?
4. Do you have a car, pickup, or van?
5. Please describe your access to public transportation?
6. What are your experiences with public transportation (ease, hours, availability)?
7. What are your current needs regarding transportation?
8. How have transportation issues affected your ability to work?

IX. Housing

The next questions are about your housing situation.

1. Please describe your current housing.
2. Do you live in a house or an apartment? If a house, do you own or rent?
3. Do you live in a group or assisted living environment?
4. Do you live with relatives? If so, please give me the relationships and ages of all the relatives you live with.
 5. Do you live with persons who are not related to you? If so, how many unrelated persons do you live with?
6. Do you receive any assistance with your housing needs? If so, please describe the assistance you receive.

X. Family Section

Family characteristics can also have a major influence over an individual's work decisions and ability to work. Families may provide support to, or make requirements from individual members. The purpose of this section is to discuss a number of family issues that may affect your work experiences.

1. Please tell me about your family and your relationships with them.
2. Without using specific names, please tell me who is in your family.
3. How often do you get together with the close members of your family?
4. How often do you have phone or e-mail contact with the close members of your family?
5. Please describe the types of assistance you receive from your family members. Tell me which family members provide that assistance during your discussion.
6. Please describe the types of assistance that you have provided for your family members.
7. In general, please describe the roles and responsibilities of the members of your household.
8. To what extent are you satisfied or dissatisfied with your family relationships?
9. What are your family member's attitudes towards you working?

XI. Social Activities

In addition to families, other social groups such as church and friends can have an impact on a person's ability to work.

1. What social groups do you belong to or participate in?
2. What types of assistance do those groups provide for you?
3. How many close, personal friends do you have?
4. How often do you get together with your friends?
5. How often do you speak to your friends on the phone or e-mail them?
6. What types of assistance do your friends provide for you?
7. Are you satisfied with your relationships with your friends?

XII. Final thoughts and quality of life

1. Is there anything else you would like to tell me about working and your disability?
2. Is there anything else you would like to tell me about anything else we have discussed?
3. On a scale of 1 to 10 (where 10 is very high and 1 is very low) how would you rate your overall quality of life?
4. Why did you rate yourself as a _____?

XIII. Conclusion

That is the end of the questions we have for you. I would like to thank you very much for your time. Do you have any questions for me now that we are finished with the interview?

Appendix III

**UNMC Institutional Review Board
Letter of Approval and Consent Forms**