

**MaineCare and Other Supports
for Workers with Disabilities:
A Summary Report of Focus
Group Findings**

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This report is also available in electronic form on the Internet at
<http://choices.muskie.usm.maine.edu/fgroups02.htm>

Executive Summary

The Maine CHOICES project¹ in 2002 made funds available to community organizations that agreed to assist in convening focus groups. The project sought qualitative data from these focus groups, by convening people with disabilities and others to discuss experiences with employment service systems, and important employment supports such as MaineCare. This report provides a summary of these in-depth discussions, which focused on some key employment-related questions about issues faced by people with disabilities.

The CHOICES project offered participating organizations a “mini-grant” to conduct a focus group in any of eight defined topic areas. Five organizations were selected, and six different focus groups were convened. Each of the six groups focused on one of the specific topic listed below:

- **Services to Youth and Families, including transition from school to community**
- **Personal Assistance Service (PAS) Systems**
- **Social Security Disability Insurance (SSDI) Program Work Supports**
- **Work Supports for Workers with Mental Health Issues**
- **Employer Perspectives on Health Insurance Benefits and Disability**

People participating in the focus groups were people with disabilities who had experience in MaineCare and employment service systems. In some cases other individuals were involved, if they knew directly of services received by an individual with a disability with whom they lived or worked. The participants in each group looked at what is currently working, what is not working, and what recommendations for change might be offered.

The findings described in this report include the following highlights:

- Ideas about how MaineCare and the school can support youth with disabilities;
- A look at the effectiveness of PAS supports, including a comparison of the Consumer-Directed independent living model of personal support services with the Home Health medical model;
- Key issues identified by focus group participants related to MaineCare and other health care supports, including eligibility for the MaineCare Option for Workers with Disabilities, the cost of prescription drug coverage, and other concerns about health insurance and care;
- Insights to the services and programs that can best help people with mental health challenges find and maintain employment; and
- Employers’ current experiences with providing health care to employees, as well as hiring and working with employees with disabilities.

¹ Maine CHOICES is a Medicaid Infrastructure Grant (MIG) funded by the federal Centers for Medicare and Medicaid Services (CMS) to the Maine Department of Human Services (DHS). Christine Gianopoulos, Director of the DHS Bureau for Elder and Adult Services, is the DHS lead on the project. Most of the project’s research activities are conducted out of the Muskie School for Public Service, operating under a cooperative agreement with Maine DHS.

I. Background

Maine CHOICES (Continuing Health Options and Incentives via Coordinated Employment Supports) is a multiyear applied research project. The federal Centers for Medicare and Medicaid Services (CMS) funds the project as a Medicaid Infrastructure Grant awarded to Maine's Department of Human Services (DHS). Most of the grant's research activities are conducted out of the Edmund S. Muskie School for Public Service, operating under a cooperative agreement with Maine's DHS.

The Maine CHOICES project focuses on research, outreach and capacity building activities related to a range of systems and programs that provide incentives and supports for Maine individuals with disabilities who wish to work. Its primary focus is on the MaineCare program² and the role it plays in supporting eligible people with disabilities who want to work. From the start of the project in 2000, the project has collected data from MaineCare and from various employment support systems through surveys, eligibility and claims data analysis, and through other means.

Many new employment support programs and policies for workers with disabilities have been created at the federal and state levels over the past ten years. These new programs are designed to address previous policies which defined disability as the inability to work, and which often applied financial penalties to individuals who tried to go to work. One important focus of the new employment support policies identified the need for continued access to the Medicaid health program for people with disabilities who returned to their job following injury, or to those entering the labor market for the first time. The MaineCare Workers with Disabilities Option is one of the earliest state efforts to create work incentives for people with disabilities enrolled in a state Medicaid program.

In 2002 the project set out to obtain in-depth qualitative information from individuals with disabilities who had experience with MaineCare and related employment services and support systems. In some cases other individuals ("stakeholders") were involved in the focus groups, if they had direct knowledge and understanding of the services or support that was received by a specific individual with a disability with whom they lived or worked. Included among these other stakeholders were community-based service providers, consumers' spouses, parents and other family members, employers, and state service agency staff.

Starting in the spring of 2002, the CHOICES Project recruited organizations interested in serving as research partners to help organize and conduct focus group discussions. Organizations were offered a "mini-grant" of up to \$4,000 to cover staff time and other costs of conducting the focus groups. CHOICES Project staff provided technical assistance on focus group methods, obtained clearance for research activities from the Institutional Review Board (IRB), and offered additional supports as needed to design and carry out the focus groups.

² MaineCare is Maine's Medicaid program. An important work support component of MaineCare is the Workers with Disabilities eligibility option, which allows individuals with disabilities to work and earn up to 250% of the usual earnings limit and still keep MaineCare services. Maine's Workers with Disabilities option, which started in August 1999, is one of the first of these Medicaid work incentive programs to be implemented in the United States.

Five organizations were chosen to receive grant awards to conduct focus groups on five issue areas, as shown below:

- **Services to Youth and Families, including transition from school to community** (Maine Chapter of NAMI - National Alliance for the Mentally Ill);
- **Personal Assistance Service Systems** (Alpha One, Inc, and the Maine Chapter of the Multiple Sclerosis Society);
- **Social Security Disability Insurance (SSDI) Program Work Supports** (Alpha One, Inc.);
- **Work Supports for Workers with Mental Health Issues** (Maine Parent Federation), and
- **Employer Perspectives on Health Insurance Benefits and Disability** (Maine Medical Center Department of Vocational Services).

Each organization recruited up to fifteen participants for its focus group, and named a facilitator to conduct its focus group.

Each facilitator structured a group discussion plan using the following list of model questions to be asked of participants:

1. What is working well at present in Maine (what acts as an incentive), in relation to this theme?
2. What is not working well (what acts as a disincentive)?
3. What ideas do you have for improvement of the system?
4. What could the CHOICES Project do to move some or all of these issues/ideas forward?

A total of six focus groups were conducted centered on the five themes. Specific questions for each focus group, as selected discussion points made in each focus group, are contained in the appendices to this report.

II. Findings from the Focus Groups

A. Services to Youth and Families Focus Group

This group focused on participants' experiences with MaineCare and related employment supports for youth with disabilities transitioning to work from home and school. The organization that conducted this focus group was the National Alliance for the Mentally Ill (NAMI). The National Alliance for the Mentally Ill is a nationwide nonprofit organization that provides support, self-help, and advocacy for consumers, families, and friends of people with severe mental illnesses. The Maine chapter of NAMI provides education and support, combats

stigma, supports increased funding for research and advocates for adequate health insurance, housing, rehabilitation and jobs for people with mental illnesses and their families.

The specific questions asked, and a listing of selected responses made during the focus group, are listed in Appendix A.

Participants commented on several aspects of MaineCare and the employment support system that are working well. As a whole, participants stated the role of the school was very important. Some participants stated that schools are beginning to increase communication with students and families about how to access existing services. “Schools are more savvy about Medicaid and encouraging kids/parents to submit Medicaid applications for SCHIP³, etc.” There is increased access to services such as occupational and speech therapy since reimbursement for these services is available in a school setting.

Several participants identified possible improvements. A key theme was the need for greater understanding by all in the school of the needs and accommodations for those with disabilities. It was noted that the Individual Education Plan (IEP) was sometimes not being followed by everyone within the school.

Some participants felt that school personnel need to listen more to students with disabilities. “It’s not that my teachers need training; they need to listen, be attuned, find out how I’m feeling. Even the teachers with training don’t listen to me.”

Other issues and recommendations:

- Increased education and training of staff, students, and others who work in the school system.
- The need for transition planning. Some participants noted the need for transition counselors at both the high school and college levels. “I kept asking for a transition plan, knowing my son would drop out without help...”
- Difficulty with colleges regarding transitioning and accommodating special needs.
- The length of time needed to qualify for MaineCare, causing a gap in services.
- The eligibility and income limits on MaineCare, as well as stigma of accepting MaineCare.

Participants offered several ideas for improving the way MaineCare is administered. Raising the income limits for adult students, providing more intensive case management, and carving out mental illness services were all noted as areas for change. Some participants also recommended improving the link between mental health services and vocational rehabilitation. In addition, better tracking of cases would prevent people with disabilities from getting lost in the system and losing access to services. Finally, participants stressed the importance of increased communication between MaineCare and schools, in order to raise the schools’ awareness of available services, particularly to those with mental illness.

³ Services for children provided under the MaineCare program.

B. Personal Assistance Service Systems Focus Groups

Two organizations, Alpha One, Inc. and the Maine Chapter of the Multiple Sclerosis Society, held focus groups addressing this theme. The purpose of the groups was to gather information on how the personal assistance services program supports workers with disabilities. This report highlights feedback from both focus groups.

Alpha One, a Center for Independent Living, is an organization that provides services to individuals with disabilities in several ways. Alpha One is the administrator of the Consumer-Directed Personal Assistance Services (CD-PAS) Program, which provides MaineCare-funded services. Other Alpha One services include information and referral, benefits counseling, outreach, advocacy, one-to one and group peer support, assistive technology funding, access design, resume workshops and independent living skills instruction.

The specific questions asked, and a listing of selected responses made during the focus group, are listed in Appendix B.

The Maine Chapter of the Multiple Sclerosis Society is part of the nationwide organization that educates, advocates and helps support research efforts concerning Multiple Sclerosis and people with disabilities. Participants were randomly selected from those who participated in the CD-PAS. The focus group consisted of seven individuals, all of whom were offered stipends for participating. The group consisted of two individuals who had used the MaineCare Personal Care Attendant (PCA) program with one caregiver. Three individuals were using the CD-PAS administered by Alpha One with one caregiver. One participant had multiple sclerosis. Two invitees declined because they were not a part of the MaineCare program but had used the CD-PAS system in the past.

The specific questions asked, and major discussion points made at the focus group, are listed in Appendix C.

Overall, participants preferred the consumer-directed independent living model compared to the home health medical model. Participants noted the needs of those with disabilities are often not of a medical nature and are different from the needs of the elderly. Therefore, participants said, there should be a different set of criteria used for these two populations. They stated that having flexibility to control scheduling as well as hiring a personal care assistant allows for more independence by the consumer.

“I must have control over my own life. The Consumer Directed Model allows for me to have that control. The hiring and training of Directed Model allows for me to have that control. The hiring and training of PCAs can be overwhelming, but I have the flexibility to make decisions, build relationships with the people that I hire and build trust with them.”

Some participants noted that they currently receive personal assistance to assist them in work. Participants said employer flexibility around arrival times and changes in schedules are necessary for a person with a disability to work. One participant talked about help getting to

work, "...[I] have to get up at 3:30 am to be ready for work for 8 am because it takes so long to get up and prepared to go out the door. Who is going to get a PCA to come in at 3 am?"

Working from home was also noted as a recommended way to work. In one focus group, all but one participant had computer access. In addition, transportation was also noted as a problem. "Public transportation was always late. Left in the cold waiting for them to show up..." "Lateness becomes a performance issue and will become an issue in three-month review. This creates incredible stress and is not inviting." In addition, other methods of transportation assistance were not always possible due to restrictions on personal care attendants.

Having a PCA was noted as necessary for independent living, yet intrusive at the same time. Having familiar, consistent workers was an important characteristic of PCA services that participants said they look for. However, finding long-lasting dependable workers is often difficult because of the low pay scale, high turnover and burnout rate. Participants stated it was often a concern to lose a PCA if the hours of work they could offer were small in comparison with other PCA jobs available. "The biggest disadvantage is that you can't offer many hours. Sometimes you lose PCAs to a bigger job..." Another issue noted was decreased time allowed for nighttime assistance if the assistant lives within the consumer's home.

Recommendations to improve services included removing the income-based eligibility guidelines as well as retaining program guidelines from year to year. In one focus group, all participants agreed there is a lack of incentives to return to work since they could lose eligibility for PCA services if they increase their work hours. Other recommendations for the program included using the Job Corp program as well as nursing and occupational therapy programs to help recruit PCAs. Several participants noted the importance of increasing awareness of the Consumer-Directed Personal Attendant Services (CD-PAS) program, both among the public and among the medical community. Participants recommended using television or radio to educate the public about this program.

C. Social Security Disability Insurance (SSDI) Program Work Supports Focus Group

The purpose of this group was to explore to what extent SSDI beneficiaries understand the MaineCare Option for Workers with Disabilities, and to what extent these individuals were using the program. Secondly, the group sought to identify to what extent existing health care options were available to these individuals and the adequacy of these options. Alpha One, Inc. facilitated the group of six consumers. Participants in the focus group consisted of three consumers who were employed (one self-employed), two looking for work and one about to start employment. Two weeks before the group meeting, Alpha One gave participants the list of discussion questions (see Appendix D for specific questions asked and a listing of selected responses made during the focus group).

All the participants were aware of the MaineCare Option for Workers with Disabilities. However, they did not qualify for the program due to unearned income amounts above allowable

limits⁴. The source of this unearned income was SSDI benefits. Participants recommended the unearned income cap be eliminated so they could work and access health care coverage. When asked if participants would like to work more, three wanted to work more, two wanted to work enough to keep their health care benefits, and one wanted to limit their work hours to 10 to 20 hours a week because of a commitment to volunteering. For some, fear of losing their disability benefits, particularly health care, caused them to limit the number of hours they worked. “Fear of losing my disability status, and then I would lose Medicare.” “I am in school and I want to stay there.” All participants said keeping their health care benefits guided their employment decisions.

Prescription drug coverage was a major concern among participants. Several stated that they have difficulty paying for prescriptions or for the insurance coverage to pay for their medications. The cost of monthly medications was reported to be as much as \$500 a month, out-of-pocket. The various ways participants pay for their prescriptions included:

- Online Canadian pharmacy (1);
- Healthy Maine Prescriptions (4);
- Medigap insurance policy (1);
- Physician samples (6); and
- Pharmaceutical company discount programs (1)

Participants reported being unable to pay for medicines some months and having to choose which prescriptions not to take. “I can’t always buy all the medications I need. Some months I do not buy all my medicines. I choose to buy food instead.” Three of the six participants agreed with this statement. They recommended making better low-cost prescription coverage available. Beyond prescription drug coverage, durable medical equipment was also identified as difficult for some participants to afford.

Participants noted the difficulty and frustration with the paperwork associated with health care coverage. One key issue they noted included the difficulty in understanding forms, some requiring duplicate information. Another issue is the time and energy often associated with follow-up of submitted forms. “Paperwork is overwhelming; it’s really hard to keep following up all of the time.” Participants recommended MaineCare and Medicare services be more user-friendly.

D. Work Supports for Workers with Mental Health Issues Focus Group

This group focused on the services and programs needed to help a person with mental health issues to find and maintain employment. The group also discussed barriers to work and recommendations for encouraging a person with a disability to work. Seven consumers participated in this group and received a stipend for participating. The Maine Parent Federation facilitated this group of twelve participants. The Maine Parent Federation is a private nonprofit organization that provides statewide information, support, and training to parents and

⁴ Eligibility for the MaineCare Option for Workers with Disabilities requires a person’s unearned income to not exceed the 100% Federal Poverty Level (\$749 as of February 2003). For more information, go to <http://www.state.me.us/dhs/beas/work>.

professionals about specific disabilities, parenting issues, education, services, support groups and other resources available within the home, school and community.

The specific questions asked, and a listing of selected responses made during the focus group, are listed in Appendix E.

Participants were first asked to talk about work supports that are currently functioning well. Within the Vocational Rehabilitation system, participants noted several positive experiences with job coaching, adaptive and work equipment, and counselor support. Another support that is working is the MaineCare coverage through the Workers with Disability Option. This has allowed workers to continue receiving MaineCare benefits while working. One participant stated they are “not feeling threat of losing benefits, even though work full-time for two years.” Participants also noted that benefits analysis by Benefits Specialists is very helpful.

When participants were asked what things were not working for them, several issues were mentioned. They noted the system as a whole, with particular emphasis on different programs having little or no communication between each other or with consumers. Participants also noted the increased financial impact that can sometimes occur when programs such as housing and Social Security process changes at different times. Another financial issue mentioned was the need for a higher amount of support and/or income for those with increased physical disabilities due to insurance not covering all needed services. Participants also said they need savings for things such as buying a home or a car. Getting long-term financial support was also mentioned as difficult to get. Participants stated there is a lack of knowledge about the MaineCare Option for Workers with Disabilities as well as when a person’s MaineCare coverage would end.

Participants were asked how to improve the current system. Changing programs within the system such as the PASS⁵ plan and ASPIRE⁶ were mentioned, with participants stating the programs are too rigid and not individualized. One participant noted that their PASS plan was “denied when asking for two years rather than one year to accomplish goal.” Combining work programs or making them more consistent with one another was also mentioned as desirable. Participants stated this would decrease duplication, confusion and lack of awareness and coordination by consumers, providers and the public. Another key issue participants noted was the need for outreach and education on issues such as youth with disabilities transitioning to work. Some participants spoke about the need for better outreach through radio, TV, information mailed with Social Security checks, and newspapers. In addition, they said that increased education of Vocational Rehabilitation counselors and other service providers that may not be connected with the system is also needed.

Participants said that additional ways of making these suggested changes included holding focus groups and having customer satisfaction surveys. They recommended that focus group participants receive feedback about what is reported and how focus group information will be used. They also said it is important to look more in-depth at the system and when people will

⁵ Plan for Achieving Self-Support (PASS) allows a person to use their income and other owned things to put towards a working goal. For more information, go to <http://www.ssa.gov/pubs/11017.html#1>.

⁶ ASPIRE/JOBS is a program within the Department of Human Services that helps TANF/PaS participants find employment that will pay enough to make it possible for them to get off welfare. For more information, go to <http://www.state.me.us/dhs/bfi/aspire/FAQ%20Aspire.htm>

lose benefits. In addition, outreach of information should be accurate, understandable and reach people in multiple ways.

Lastly, participants were asked whom they depend on for information. The following resources were mentioned: case workers, peer network, the Peer Resource Center, the High Hopes clubhouse, the newspaper, and Vocational Rehabilitation.

E. Employer Perspectives on Health Insurance Benefits and Disability Focus Group

This focus group addressed employer perspectives on health insurance benefits and disability. The Maine Medical Center Department of Vocational Services facilitated this focus group of nine employers, representing various industries. Maine Medical Center provides vocational rehabilitation as well as technical assistance to community rehabilitation agencies, employers, schools, and people with disabilities. This focus group consisted mostly of companies that had fewer than 100 employees (71%). The industries represented included: home care, healthcare, management consulting for government and non-profits, telecommunications, service industry (restaurant), salon and spa (service and retail), and insurance. A parent of a consumer with a disability also participated. Employers in this group said that 93% of their staff worked full-time. Two of the businesses operate in at least five other states and one business noted seasonal fluctuations in staffing. Six participants were currently offering health insurance to their employees. Participants were given a stipend to take part in the focus group.

The specific questions asked, and major discussion points made at the focus group, are listed in Appendix F.

Many in the group talked about the rise of health insurance rates. One participant stated that the cost of health insurance has increased by as much as 54% within the current year. Participants said employee contributions were increasing to cover costs, with levels of health insurance coverage either remaining the same or decreasing. Small companies appear to be facing greater difficulty in affording health insurance coverage for their employees. One participant noted that some employees were deciding to not work so they could get coverage under “the system” (presumably MaineCare).

Participants said some employers have tried to offer a group insurance plan to their employees, but were unable to pay a portion of the premium. The low enrollment led to the health plan withdrawing its coverage. One employer stated, “In Maine the cost [of coverage] has doubled over the past three years to approximately \$200 per month per employee.” Another participant noted they cover 100% of employees’ premium, but the employee must pay for their dependents. In addition, it was also noted that some large companies have a tier system, with higher paid employees contributing a higher percentage of their coverage than others.

Less than half (44%) of participants in the group were familiar with the term “MaineCare.” One employer stated the state’s (MaineCare’s) coverage was more comprehensive than the company could offer with their own full medical care coverage.

Participants noted that people with disabilities often work part-time, so benefits may be available but at a higher cost than for full-time employees. It was noted that part-time positions also allow employers to avoid offering a benefit package. One participant stated that hiring people with disabilities meant more flexibility by the employer to make the situation work. Another participant noted they did not find any difficulties with hiring employees with disabilities.

Other issues raised included the stigma attached to employees receiving MaineCare as opposed to the employer-offered coverage. Understanding the system and how different programs work were noted as very important to the individual receiving benefits as well as the employer and co-workers. They stated that communication and clarity in understanding programs is important, especially for small businesses that often play many roles, including human resources. In addition, the liability to employers was also noted, such as requiring COBRA coverage to be offered to employees leaving the organization. The role of MaineCare was discussed and participants recommended that people be able to buy into coverage through MaineCare in a similar manner as COBRA.

Next Steps

From these six focus groups, the CHOICES Project has gained valuable information about the role of MaineCare and supported employment services for people with disabilities. The rich qualitative detail of this information greatly complements other data that the CHOICES project has collected, both from MaineCare eligibility and claims databases, and from several telephone surveys of MaineCare enrollees.

The focus group findings suggest issues for further study as well as provide important insight into the potential impact of new policy initiatives. Findings will be shared with policy makers concerned with work incentives for people with disabilities to better inform policy discussions about these issues. In particular, the CHOICES Statewide Advisory Group will review these findings and recommend ways to make sure the voices of focus group participants are heard.

The CHOICES Project continues to research these and related issues through telephone surveys, case studies, policy reviews and data analysis. More information about these and other CHOICES initiatives can be found on the project website at <http://choices.muskie.usm.maine.edu>.

Appendices – Questions and Selected Responses

The following is a listing of the questions asked at each focus group. Responses listed are representative of participant's comments during the focus group. Statements may not be direct quotes from participants.

Appendix A

Services to Youth and Families Focus Group

Maine Chapter, National Alliance for the Mentally Ill (NAMI)

Key NAMI staff contacts: Carol Carothers

What is working well?

- Schools are more savvy about Medicaid and encouraging kids/parents to submit Medicaid applications for SCHIP [children's Medicaid services], etc.
- School does tell parents about services that exist
- Teachers talk with me about wanting to work. Asked me if I want to get a work permit

What's not working?

- We really struggled with the school. Not until 4th grade did anyone suggest there was help. Instead the school called and said, "Take him home".
- School personnel don't get it. Can't sort through what's important and needs discipline and what doesn't. And they don't follow the IEP [Individual Education plan]
- Principal wrote me saying my son would lose credits and not graduate because he was late often; but the IEP accommodation was to allow lateness
- I kept asking for a transition plan, knowing my son would drop out without help. School said, "We invited him to the office to talk, but he didn't come down." Final year they kicked him out for making an inappropriate comment. He's working on job #8, in jail a lot since graduation
- Kids have trouble even getting out of school, much less go on to work. They took my son to the police department because the school changed his routine and he didn't understand. "Well, this is a discipline problem. We're done."

What would help to improve?

- "It's not that my teachers need training; they need to listen, be attuned, find out how I'm feeling. Even the teachers with training don't listen to me."
- "Resource rooms should be understood and used by all; not just special education; people see it as play and put it down."
- "Have assemblies for students to learn about special ed. resource room, etc. Handicap awareness needs to include MI."
- Needs to be communication between high school and college – a transition with help... You have to do it all yourself. No one is there to help them get to college or make it through more.

What should be done?

- There should be more help for families to understand what Medicaid will cover. Families have to struggle to know.
- Medicaid should seek input on a regular basis from people on Medicaid about how it's working
- Medicaid needs to put effort into helping people work – transportation to work, helping people get driver's licenses, transition services. Takes too long to qualify for Medicaid and people get into trouble in the interim.
- There's a disconnect between MH [mental health] services and vocational services – workers don't see vocational as a first line approach – the assumption is not able to work, instead of lets get you to work
- Increase training of workers, teachers, etc. re: working with MI [mental illness] services

Appendix B

Personal Assistance Services System Focus Group

Alpha One, Inc.

Key Alpha One staff contacts: Deanna Kneeland, Lynn Gitlow (Husson College)

What do you use these services [Personal Assistance Services] for and how do we expand them?

- ... If not for pca program (used Home Based Care first, now Medicaid Waiver) she would not be here today.
- Another participant agreed with this statement. Most people do not want their family members to have to take care of them, also do not want to live in Nursing Facilities, or Assisted Living situations where someone else controls your schedule and your time. Independence is so important.
- Need incentives for PCA's [personal care attendant] to work -people who are happy with their benefits work better and stay longer. PCA wants a raise more than once every 3 years - this was an absolute need. The cost of living goes up more than once every three years, and the pay rate should go up as well proportionately.
- Home Health Agencies, the con's being -CNAs [certified nurse assistant] not reliable, had 4 yrs of Home Health Care and it was never her say as far as when they would arrive, or how long they would work.

What are the down sides to the Consumer Directed PCA programs?

- PCA's will not show up for work, or quit, and there are times that you may have to keep people working for you that you may not want to keep on, for a short period of time. Finding dependable PCA's is always an issue.
- The problem is that they are not offering a standard 8 hrs per day. The PCA may get 8 hours, but it's broken up over the day. This can be difficult.
- One participant asked how you can get over the fear of placing an ad in the paper. She feels that it's invasive to do so.
- Transportation is always an issue. Do they have a vehicle that the consumer can get into?

Is this [Personal Care Attendant] a primarily female dominated field?

- Most agreed that more females than males apply for this type of work.
- PCA work in all respects is a dead end job, but they may want to step up into the Medical field, and use it as job experience. Turn over rate is very high, going on to other fields, burn out, etc.

What is the longest length of employment of a single PCA?

- 5 yrs.
- 6 yrs.
- 4 1/2 yrs.
- 14 yrs. (10 yrs. on, then somewhere else for 2) then came back.

What different things are provided for with the PCA program, and how would you like to expand it?

- There is wide latitude there. Cleaning, errands, shopping, helping with your activities of daily living, etc. Night time care is a big problem. If a person lives in home, they get less time. Live in or out should be irrelevant. There is again the assumption that the family should help for free, but the fact is that this may not be an option.
- HHA [home health agency] wants one participant to live in Assisted Living, but because she has a live in she is able to stay in her own home, though the PCA's hours are limited because of the rule change.
- Has a problem with the new prohibition against hiring a pca under the age of 16 -that person can do errands, meal prep, etc.
- Transportation is another issue. Every day is a problem before the day starts. "Having a disability is a full time job". At the end of the day if I've put in another 24 hrs. I've been successful.

How can we get the PCA program more known?

- Are there any radio stations doing free advertisements as a non-profit? Does Alpha One have a person in charge of PR [public relations]?
- ... Never seen or heard anything about Alpha One either on radio or TV. Some had, but not all.

How much of the Medical community knows of Alpha One?

- Was approached in Hospital through Social Work, but what about being born with a disability, not in an acute situation?
- Wonders about a way for consumers to get together as personal care advocates and do a lot of outreach? OT [occupational therapy] students are looking for jobs all the time, but they might be interested in having someone come to them as a group.
- Wondered if a professor might be willing to offer extra credit as or I internship as a personal care?

Discuss work schedule.

- has trouble with this, she will schedule pca that is willing to start the , job on time, get her out of the house on time, answering the phone and screening the call if needed so that she can get out of the house. Even so, she may be late to work.
- Sometimes you have to work around the pca's schedule as well. Has two college degrees and sometimes has trouble getting a job. You have to do your best to get there as soon as possible. There's always something that comes up that might interfere.
- Working at home should be expanded a lot more in the society. Get back into the working world with a computer, etc. If that would be pushed it could be helpful to getting people with disabilities back to work.

What work is available?

- MBNA [company name] -very accommodating, DVR [Division of Vocational Rehabilitation] - not helpful.
- Should be reorganized, refocused, and reshuffled. VR [Vocational Rehabilitation] should use their resources to recruit employers, etc.
- DOL not necessarily a good source either.

Appendix C

Personal Assistance Services System Focus Group

Maine Chapter of the Multiple Sclerosis Society

Key MS Society staff contacts: BJ Bangs, Lynn Gitlow (Husson College)

Compare the differences between Consumer-Directed PAS [Personal Assistance Services] and services received through a Home Health Agency. Describe Advantages / Disadvantages of each

- Better to hire your own PCAs [personal care attendants].
- Over time Home Health is not dependable -scheduling problems.
- Less willing to listen to the way the disabled individual wants things done -bring own experience and want to do things the way they've been trained.
- Take instructions from the agency and not from the individual that is receiving the assistance.
- Salary limitations are a problem. People could get paid more flipping burgers at Wendy's or working at Wal-Mart than as a PCA. This makes it difficult to attract and retain people to be PCAs.
- "I must have control over my own life. The Consumer Directed Model allows for me to have that control. The hiring and training of PCAs can be overwhelming, but I have the flexibility to make decisions, build relationships with the people that I hire and build trust with them."
- The management of the advertising, writing up the ads, reviewing resumes, and interviewing can be overwhelming. With Home Health Agency you can just call and get a person to come in.
- More difficult to attract PCAs when economic times are good. Easier when economic times are bad.
- Must keep reminding yourself and the PCA that this is an employer/employee relationship because it's almost like a friendship that develops between the individual and PCA.
- Public transportation is very unreliable.

How long have you used CD-PAS [consumer directed personal assistance services] ?

Do you use PCAs at work – for what tasks? If you do not use them at work, why not?

- "RTP [Regional Transportation Program] closes down when a major snowstorm. Lateness becomes a performance issue and will become an issue in three-month review. This creates incredible stress and is not inviting."
- Have to get up at 3:30 am to be ready for work for 8 am because it takes so long to get up and prepared to go out the door. Who is going to get a PCA to come in at 3 am?
- Even the spouse who helps out with PCA services at home is penalized on their job because of lack of sleep and extra responsibilities, stresses at home.

- "Had horrible experiences when tried to work. Public transportation was always late. Left out in the cold waiting for them to show up. One time, public transportation was so late, my bag overflowed."
- PCAs subject to change. Even with the most wonderful PCAs at work, it's subject to change and creates more stress.

How has the CD-PAS program help you maintain a family and home life?

What defines a “good PCA”?

How do you recruit and keep good PCAs?

What works well for you in managing your own PCAs?

Have you ever had to change your PCA management style...in what ways?

What changes could be made to Maine’s CD-PAS programs to improve services?

- The CD PAS plan is income driven. Over the years, makes the program less appealing.
- Base the PCA program on an independent living model versus a medical model.
- Rule makers should seek input from people with disabilities.
- No benefits for PCAs make it difficult to retain them.
- Pay has caused problems attracting reliable PCAs in the past.
- Disincentives to get ahead with present system. Young person wants to buy a house, move forward. When this happens, the system starts taking things away from you.
- The Home Health Agency homebound requirements removed.
- Need an ombudsman or agency that advocates for PCAs on a state and national level.
- No benefits for PCAs make it difficult to retain them.
- Improve pay scale for PCAs.

What issues did we miss? (Open comments/input from the group)

- Should empower, fund and simplify the system.

Appendix D

SSDI Program Work Supports Focus Group

Alpha One, Inc.

Key Alpha One staff contacts: Zahira Ames-DuVall; Danell Libby

Are you working now? How often do you work?

- 3 currently working 10-20 hours/week (1 self-employed)
- 2 looking for employment
- 1 ready to start employment, has been offered a job.

Do you want to work more often?

- 3 would like to work more but have to watch income or risk losing Medicare and they do not qualify for MaineCare.
- 2 would like to work enough so that they stay eligible for the health care benefits they currently have.
- 1 only wants to work part-time 10-20 hours. "I have volunteer work that means a lot to me."

What prevents you from working more often?

- "Fear of losing my disability status, and then I would lose Medicare." "I am in school and I want to stay there."
- "Health insurance traps us. I feel like the system wants to keep us in poverty. We can earn some but it's never quite enough."
- "I need flexible health care; something that I can afford that will pay for medications and DME [durable medical equipment]."

How does your current level of health care coverage (MaineCare/Medicaid) affect how much you work?

- "Healthy Maine pays *more* after I pay the first \$1,000.00 but it's really hard to pay that. If I make *too* much *money* then I *won't* even be able *to* have Healthy Maine Prescriptions."
- "I can't always buy all the medications I need. Some months I *do not* buy all my medicines. I choose *to* buy *food* instead."
- "Right, I *do* that *too*." This comment was echoed by a total *of* three of the six participants.

How much do your medicines cost each month?

- \$455.00 per month *for* 5 medicines
- \$200.00 with my Healthy Maine Rx card
- \$75.00 with my Healthy Rx card, but one *of* my medicines is not paid *for* by Healthy Maine *so* I have to get that in samples *from* my doctor.
- \$3000.00 without my Medi-gap policy, with my Medi-gap policy they cost \$240.00. I have *to* pay *for* Medicare and my Medi-gap *too* this costs about \$550.00 each month. \$400.00-\$500.00 I get *some from* the Pharmaceutical companies but it's hard because my doctors have *to* fill out paperwork and I can't *do* it, the doctor has to. Sometimes they (doctors) don't have time or want *to*. I think they should have to help everyone that asks

them *to* fill out the paperwork. One medication I get *from* my nurse in samples. The rest I have *to* pay *for*.

How do you manage to pay for prescriptions?

- One woman uses a Canadian Pharmacy on-line
- Three people use Healthy Maine
- One uses Medi-gap, and Healthy Maine
- All report *some* use *of* samples
- One uses Pharmaceutical Company Programs
- Three *of* the six reports being unable *some* months *to* pay for medicines and choose with ones not *to* take
- All group members were interested in purchasing medicines from Canada

On a weekly basis, how much time do you spend filling out health care forms, applications, or other paperwork?

- "There is not much paperwork when everything stays the same. But if *one* little thing changes then there's a mountain of paperwork to do."
- "Paperwork is hard to understand. It is a big stress."
- "The language is hard to understand, they (DHS – Department of Human Services) won't work with me to explain things."
- "I have to make a lot *of* phone calls chasing after paperwork."
- "Paperwork is overwhelming; it's really hard to keep following up all *of* the time."

Are you aware of the MaineCare Option for Workers with Disabilities?

- "My SSDI is too high. I don't qualify."
- "I have some alimony and SSDI; it's too much unearned income. I don't qualify."
- "I have too much money from Social Security, I can't have it."
- "I have too much money too. I get too much SSDI and I only work part-time. I think everyone who is disabled should qualify if they work."

If you could speak directly to the people responsible for the MaineCare Option for Working Disabled, what would you tell them?

- "Higher co-pays would be okay if maybe then more people could qualify."
- "Keep it simple. Why are there so many different programs instead of just one?" "Allow people to earn money and still have Medicaid (MaineCare)."
- "Do away with the unearned income cap. Make fair co-payments. I used to live in Mass. and I could get help with prescriptions. I had to pay a premium of \$75.00/mo. Then all my medicines cost 50 cents each."
- "Give more training to workers in your system." "Make the forms easier to fill out."
- "Make good pamphlets that explain things so I can understand them." "Allow higher earnings."
- "Too many forms too confusing."

Appendix E

Work Supports for Workers with Mental Health Issues Focus Group

Maine Parent Federation

Key MPF staff contacts: Margaret Degon, Ann Long, Debbie Mattson
(Mediation & Facilitation Resources)

What is working well at the present in Maine, in relation to work incentives?

- Vocational Rehabilitation
 - Job coaching,
 - educational opportunities,
 - adaptive equipment,
 - work equipment,
 - apprenticeship,
 - travel to school,
 - provide information and ask for your involvement in finding information,
 - frequent meetings w/VRC [vocational rehabilitation counselor],
 - VRC testing learn strength/weakness,
 - VR counselors empathetic, patient, supportive – long term
- Not feeling threat of losing benefits, even though work full-time for 2 yrs.
- Maintained group housing with 2 yrs of full-time work
- Keeping most of income earned while working
- Benefits analysis from Alpha One

What is not working well?

- Vocational Rehabilitation
 - VR waiting list,
 - VR service vary according to region,
 - VR no funds for graduate education
- Financial disaster going to work – Social Security, HUD [federal Dept, of Housing and Urban Development, Food Stamps, etc. are not connected. Lose money when starting to earn money, systems not connected so total loss is not computed
- Lack of communication between systems and between systems and consumer
- Can't have money in the bank, buying a house requires deposit, cars require saving for money – without savings, it is hard/impossible to plan for the future
- More physically disabled and higher need for services need huge income to pay because other insurances won't pay for needed services

How can the current system be improved?

- PASS [Plan to Assist Self Sufficiency] plan too rigid – MH issues to plan yrs ahead is not always feasible
- PASS plan needs to be more responsive to individual - for example PASS plan denied when asking for 2 years rather than 1 year to accomplish goal
- Combine all work programs – duplication, confusion, lack of public/consumer/providers awareness and coordination

- Housing, Food Stamps, etc. meet together to plan how to help with transition from not working to working
- Program become consistent – if with TANF [Temporary Assistance to Needy Families] can get “good help” for cars, other programs not chance to get car
- 19, 20,21 yr olds not getting help, trying on own and unaware of services
- outreach plan – consistent info – find the people who can use the services
- understand there are non-readers and can’t depend on written material to inform
- All service providers need to be informed esp. for those not connected to the system

What could the CHOICES Project do to help move the suggestions forward?

- Hold focus groups at conferences – not at end of day
- Focus on young adults unaware of services
- Understand risks of going to work and eliminate risks as much as possible (losing housing, Medicaid, ability to save money and plan, etc.)
- Clear understanding of system when lose benefits, etc.
- People who use system should help design system
- Use social clubs to circulate information
- Don’t depend on getting information to consumers through internet
- Disseminate information many times, not just once

Who do you depend on for information?

- Include with Social Security check/ Medicaid/ Food Stamps
- MOCO [Motivational Services agency] case manager
- Peer Resource Center
- High Hopes
- Case worker
- Peer network
- Newspaper
- VR

Appendix F

Employer Perspectives on Health Insurance Benefits and Disability Focus Group

Maine Medical Center

Key MMC staff contacts: Karen Fraser, Richard Balser

What changes have you seen in your health care insurance premium in recent years? Please describe how your employee health coverage has changed.

- Another small employer has experienced increases over the last several years. Three years ago, a 22% increase occurred with no changes in coverage, followed by a 26% increase two years ago with increases in co-pays, and most recently a 54% increase with increased co-pays and changes in prescription coverage. The owner has had to use a vacant position to offset the increased insurance costs for the remaining employees. The result has been that the owner works 60-75 hours per week to cover her position as well as the vacant position. The owner's younger employees tend to "throw in the towel" and opt to go without coverage and hope not to get sick. The owner describes this situation as "devastating" and as "a crisis" that results in a "competitive disadvantage." Worries about experience ratings and the impact of them on insurance costs for small employers were also noted.
- Another employer pays 100% of employee's premium but employee must pay for their dependents. Health insurance costs are 4% of this company's gross income. They offer a cafeteria style plan to employees who are then very careful about what they select for coverage. This company is based in several different states. They were unable to find one carrier to provide coverage for all so they have gone with several different carriers. The coverage is comparable across the different states. The costs in Arkansas are the highest. In Maine the cost has doubled over the past three years from to approximately \$200 per month per employee. This employer is also looking into the cost effectiveness of a catastrophic benefit plan for employees and following new federal legislation that would allow employers to set up a Health Resource Account for employees.

Are you aware of Maine's MaineCare (formerly Medicaid) Option for Workers with Disabilities?

- Forty-four percent of the attendees were familiar with the term MaineCare.

Please identify both incentives and disincentives to hiring people with disabilities in your company. What would make you more likely or less likely to hire someone with a disability?

- One participant noted that many employees with disabilities work part-time, so benefits may be available but at a much higher cost than for full-time employees. Her experience has been that part-time positions also allow employers to avoid offering a benefit package.
- Two employers described having employees request that their pay be "frozen" for years in order to keep state medical benefits. One example given was of an employee with a heart condition. Although the employer offered the employee full medical coverage, it

was not equal to what was provided by the state. It was also noted that these voluntary salary caps resulted in positive employee reviews not being rewarded in the way other employees were rewarded the employee was also described as a "prisoner to his/her disability."

- The healthcare system as it exists does a disservice to the individual. They do not have the option to work full-time in many cases and keep people in poverty to keep benefits. People become depressed and their self-esteem is low. They have no true choice in coverage under MaineCare -the number of available doctors is limited. System creates a no-win situation. People are only allowed to "be normal" to a certain point. The impact is significant to the family of the disabled person. They exhaust sick time and retirement funds. They must be an advocate for the disabled person and educate doctors and insurance companies about the disability and the system. Under MaineCare many things are not covered such as mental health or dental expenses. Co- workers know who is on MaineCare, which creates a class-system within the company. "Regular employees" resent the money they pay towards state programs. Disabled employee changes rating experience, unless you are "community" rated.

Do you have any ideas for improvement with the current healthcare system and/or support of employees with disabilities?

- The transition from going off of state benefits is too steep. Can the "cliff" be made into a more gradual slope of decreasing state benefits?
- Communication seems to be a large issue. The individual receiving benefits, the employer and the co-workers need better information about "how the system works."
- The liability of the employer is frightening. For example requirements to offer COBRA when employee exits. .
- Could a healthy person buy into MaineCare? Allow access to all people.
- MaineCare to become like "COBRA" [federal law authorizing certain extended health benefits] avoid reverse discrimination.