

Public Comment Responses: By Respondent

ID: 1

Work: "I could really use more help in the education/work department. Healthcare would be helpful because medications are expensive. And you lose your healthcare when you go back to work full-time. And it's hard to find a job that pays well enough to be able to afford your medications and pay your bills. Lot's of times it's really hard to go back to work and you could get a better education to get a better-paying job. That would help considerably."

ID: 2

Transportation: "Probably transportation and education are major."

Education: "Probably transportation and education are major... to be able to get an education on different things I need to learn about my own disability."

Respite/Caregiver: Stated that "physical care" and "home care" were necessary to live well.

ID: 3

Other: "My key interest is advocacy... Not enough advocacy for individuals... More needs to be done to train consumers to know how to advocate for their rights and to do it in a more simplified manner."

ID: 4

Housing: "Better non-credit-based homeownership programs. Not ONE single rental unit in ALL of Maine is set up to address my particular accessibility and personal hygiene needs."

ID: 5

Work: "As I do think work is important, it is not what I need at this point."

Housing: "I think housing as is, it's o.k."

Transportation: "When I can get there, it goes good...This is a big one for me. It's so hard. I live 30 miles from where I get my mental help. I had a car but when you go 60 miles a day, sometimes 3 or 4 times a week, cars don't last. Yes, I get 15 cents a mile but that just is not enough. And, yes, I could call 3 days ahead for a ride, but I don't; I would rather stay home. This makes my mental

health unmanageable, so I end up in respite or the hospital."

Education: "This is important."

Rec/Leisure: "I would like to see funding for a social/support group in the Livermore Falls area...I don't get much. I can't afford it."

Health Care: "When I can get there, it goes good."

Insurance: "This would help a lot."

ID: 6

Other: "None of these philosophies, proposals, needs, problems is new -- I know, as I and many, many others were actively seeking support to put them into action and to point out barriers in doing so. The Olmstead decision is great, but nothing in it is new -- the same things have been said in judgments, mandates and statutes for years and years and years. There are thousands of forests that have been destroyed just making paper for people to use to espouse these old ideas whose time-to-come never makes it into real time. Please let me know how and why your committee will be different and effective. I would like to see implementation before I die, and that date is advancing quickly (years are going by faster than they used to). Hoping not to sound too bitter, but the fact is...[ended here]"

ID: 7

Work: "After experiencing criminal threats and witnessing criminal behavior on the job, I went to the local office for the Department of Labor to complain. The reaction was this: 'I don't want to hear about your problems!' At other times the worker responded with a lecture about resumes and interviews that followed an offer of help. No one ever directly responded to my plea for help. Employers can indulge any foolish tantrum and eliminate any employee. The employee cannot find any justice which forces the employee into public assistance and drains programs. Whoever breaks a contract must pay the other according to civil law. However, all we have is a corrupt group who control everyone and everything in business."

Transportation: "This is an impossible dilemma. A loan for a car will be forever impossible. Transportation by bus restricts my efforts to find a job within a small area in Bangor and Brewer. It also restricts the time for working to a limited amount of time."

Education: "At the University of Southern Maine when I studied music, I encountered terrible hatred concerning entertainment. The faculty and students despised liberal arts and performers. According to them, only idiots and losers would try to be professional musicians. Everyone wants to be rich and famous, which means that most will fail. It's a loser's game. Attempts to consider

working in music were answered with threats. Schedules allowed no time to explore entertainment. From Placement, which connects students with employers, I received a photocopy from a magazine which described jobs with a Liberal Arts degree and nothing else. Efforts beyond that point failed including blinding rage from some people. My health was bad since high school. Therefore, continuing was hopeless. Requesting help from the University of Orono was not allowed. There did not exist any connection between the real market and the student's choice of subject at the University. Study for four years and then a job will instantly appear was the idiotic philosophy."

Health Care:

"I reject and detest the concept of mental illness as publicly stated. In social services, I found that workers for the State of Maine use false diagnoses and incorrect and incomplete treatment as the basis for psychiatric labeling. They reason that since the patient is physically well, then complaining represents mental illness. Then they prescribe a pill that functions as a tranquilizer and produces unconsciousness. We have a total obstruction of justice and complete denial of essential legal protection and defense. Any criminal can ruin a client's life and never pay. Programs are based on the emotional and subjective reaction from a worker and not based on facts and evidence. Reports are passed from worker to worker and from one place to another. None of these people possess any ability to independently evaluate any data. All information is accepted as stated. These workers spent their time listening to reports from clients about daily efforts and provide no navigation or defense when the client is in trouble. These workers are arrogant, ignorant and waste time with endless, ugly arguments."

Insurance:

"In my experience, the State mails a paper for Medicaid for people with medical practice (except eye care) who produce no results. That is wasted money."

Other:

"My license was suspended and later cancelled because no one would complete a report stating that I no longer took psychiatric medication. The last pay stubs that I sent to Human Services were never returned. Because of poor health, I must stop all efforts to find work and seek help. All efforts to save my health have failed. Contact by phone, mail and e-mail with government does not produce results. Efforts to contact anyone in the justice system have been completely blocked. I have never been allowed to file a report and obtain justice concerning my dilemma. You will never have results because you take this information to the professional community and workers in government who have caused the trouble."

ID: 8

Work:

"Providing a suitable role of work and employment for those able and interested must be included in our definition of 'health'. Vocational Rehabilitation is a mainstay of this effort. Additionally, policy makers,

legislators, and other advocates must realize that while making physical accommodations which are measurable in terms of ergonomics seem to be happening in all kinds of employer locations, stigma is still keeping people with mental health disabilities from experiencing these wonderful innovations. Designing jobs where essential functions can be measured and quantified is a scientific process. Designing jobs where the accommodation is more one of tolerance, for behavior that might be socially unacceptable to individual workers, supervisors or business owners, does not constitute accommodation in the same fashion that a table can be lowered or a ramp added. This is a difficult situation because ultimately requiring tolerance of your employees and supervisors cannot be forced. It is achieved through a process of education. More education of the general public and, specifically, employers needs to be part of the solution. We also must realize the limitations that exist in this area. Employers must not be expected to tolerate any behavior that erodes their public trust as a business. This is a slippery slope to business failure. At the same time, employers must be challenged when their lack of tolerance is preference rather than legitimate concern for business environment conflict."

Transportation:

"It has been my experience over the last 20 years as a Vocational Rehabilitation Counselor that the current public transportation system is inadequate for individuals with disabilities who live in rural areas and want to work. While the federal VR program is permitted to assist with this problem, it cannot purchase automobiles for people. I propose a solution to this that involves developing a revolving auto loan program to serve as a guarantee fund for private sector loan originators to secure loans to individuals with disabilities if specific asset is not available or questionable through one of three options: Earmark funding sponsored through a collaborative effort with DOT, credit unions or banks, and agencies who currently service the needs of individuals with disabilities."

ID: 9

Housing:

"Many seniors are fearful of losing the places they live in/own because of high taxes in Scarborough."

ID: 10

Rec/Leisure:

"Locally-based (Ogunquit-Saco) recreation opportunities for an 8-year-old and an 11-year-old - after school and weekends. This is my most pressing need." Would also like to see a Special Olympics in York County.

ID: 11

Work: "Flexible timing schedule to be able to participate actively in your child's therapies. This will ensure education and carryover at home. Will be able to care more effectively for your child."

Education: "Adequate accommodations for a safe environment as far as injury due to furniture in the classrooms. It makes it difficult to move about the classroom for a child who may not be completely immobile but yet has problems with his/her balance."

Rec/Leisure: "Same problem with her safety [as in Education: 'Adequate accommodations for a safe environment as far as injury due to furniture in the classrooms. It makes it difficult to move about the classroom for a child who may not be completely immobile but yet has problems with his/her balance.']."

Respite/Caregiver: "Provide day care services for children with disabilities. It is very difficult to find day care for a child with lifelong seizures. The liabilities make it very difficult as well as educated caregivers availability. ... In-home support to parents/families with children/adults with disabilities need to be more accessible. I don't know where the problem is, but when an in-home support is assigned to a family, they don't stay very long. A program for retention is necessary and crucial. The family goes through emotional rollercoasters as it is."

Insurance: "[Should] cover therapy - speech, occupational, physical therapy without so much checks and balances. If the doctor is recommending it or approving it, this means the child or adult truly needs it."

ID: 12

Insurance: "I can't get my meds. They are \$3 a piece and I am on a lot of them, so if you can find to place to help me."

ID: 13

Housing: "Affordable group homes - i.e., grants for groups of supporting families to buy houses (or rent) for groups of DS adults."

Transportation: "Have an organization similar to Portland's ITN (who now only transports senior citizens and blind) transporting DS adults."

Education: "More local schools that are disability-friendly. Many schools old with few elevators. Lots of stairs."

Rec/Leisure: "For towns to support Special Olympics, etc. through free use of gyms, local pools, skating rinks, etc."

ID: 14

Other: "Greater availability to financial help for families who chose not to place their adult children in group homes. This saves taxpayer large amounts of money but incurs financial hardships on the parents."

ID: 15

Work: "I am a single mom who is trying very hard to provide for my child. All I receive is \$363 in AFDC and \$200 for food stamps. I need to pay bills and try to buy my child the stuff she needs. I am trying] to get my driver's license so that I can look for a job outside of Skowhegan area."

Other: "I really need help with losing weight and eating better."

ID: 16

Work: "Voc Rehab needs to crawl out of their BOXES! Disabled people can be skilled, talented and resourceful. The Voc Rehab 'rules' and policies are not user-friendly, and discourages people from working - especially part-time. Loosen up! Food, flowers and filth are not all we do! Be flexible!"

Housing: "The housing conditions that people on especially fixed incomes are shockingly deplorable. Discharges from hospital into shelters, hotels, or 'unstable, unsubstantiated living conditions' is still prevalent. The State must enforce local government to be accountable in their landlord housing laws!"

Transportation: "It amazes me that rural Maine dumps tons of money into solving 'the transportation problem' that plagues access to good health care. Buy large mobile units! Put together 3 teams of PAs, nurses, social workers and mental health experts. Three mobile health units visiting isolated area 2 times a month. Stipend local people to offer rides to the mobile unit. Most small towns have good volunteer finds/paramedic programs and selectmen who would help this project."

Health Care: "Dental and prescription glasses are not a luxury! People have emergency tooth extractions instead of treatment to save their teeth, made to be in dental emergency with weeks of pain and festering infection, begging a VERY FEW Medicaid dentists to help, or going to ERs for 'pain pills' they shouldn't need in the first place if preventative dental care was available. Searching for free resources for glasses is demeaning!"

Respite/Caregiver: "For respite of adults stipend on call and pay these trained citizens for in-home support or to open their homes for respite, be a 'warm-line phone' or first response to crisis. Give them a cell phone and they can use Crisis Programs for phone TA, support."

Other: "TV interviews for assessments are ludicrous! People in jails or isolated living situations needs a human being 'face to face'. Can you imagine being psychotic and talking to a TV set? Or being so depressed that staying in reality is a deep struggle? Easy to tell a TV set you are safe!... This whole systems needs a TOTAL RETHINK with full consumer voice right at the first planning stages through to quality assurance."

ID: 17

Work: "Support to all employers not just larger businesses who have financial resources to take on the training, support, supervision of individuals with handicapping conditions. Veterinarians, nursing homes, nursery schools, family-run eating establishments, farms, tree nurseries, etc. need financial, educational support to support people with disabilities in finding, securing meaningful and joyful - yes, joyful! - employment."

Housing: "Housing/Living situations that have dignity and create independence through support."

Transportation: "Transportation is inadequate outside of city areas. Getting teens to a variety of vocational settings for these people with disabilities to determine what jobs suit them, are meaningful and satisfying to them, is extremely limited!... Transportation [needed] to jobs, church and recreational activities."

Education: "Education of community on similarities of those with disabilities to ALL individuals. People with disabilities love, hunger, learn, hurt, cry, need, touch, laugh as the rest of us. They are sexual and emotional as the rest of us, need spiritual homes as the rest of us, need relationship and connection as the rest of us."

Rec/Leisure: "I only know of STRIVE in Portland for 15-24-year-olds to have friends, relax, play, connect with others who have disabilities."

Respite/Caregiver: "Better pay and insurance for in-home support staff, CNAs, RNs willing and trained to serve/care for individuals with disabilities.... Support to parents, caregivers, grandparents, friends of individuals with disabilities... Increase respite funds. Families under stress need time to renew."

Other: "Transition issues/communication between children's and adult services need to be improved to better serve individuals with disabilities. Too often seems like 'one hand doesn't know what the other is doing'... Trained and willing physicians, DENTISTS to serve individuals with disabilities...DHS workers are overloaded. It seems they do not have time to do their job to the best of their abilities. Reduce caseload, hire more qualified workers... Legal assistance: Pine Tree is overwhelmed, never get back to me when I call. [Need] help with discrimination, SSI, SSDI, housing, education, health issues."

ID: 18

Transportation: "More assistance with getting my driver's license."

Other: "Overall, I am happy with the services I receive."

ID: 19

Other: "I am satisfied with the services I receive."

ID: 20

Transportation: "Need more transportation."

Respite/Caregiver: "Need more support."

Insurance: "Prices should be lower... Need more of it... Need more insurance."

Other: "Need more money... Need more flexible services!!!"

ID: 21

Work: "I have found it financially impossible to work because I always lose more in benefits that I earn. I hope to use the Ticket to Work program to get someone to subsidize my housing so I can get off Section 8 (HUD). Coordination of benefit programs would be a tremendous help. It's all or nothing...I need a \$35,000/year job to support myself and my family."

Housing: "I hope to use the Ticket to Work program to get someone to subsidize my housing so I can get off Section 8 (HUD)... Clean, safe, subsidized housing for FAMILIES, 2-bedroom or larger (handicapped accessible)."

Transportation: "Dependable, reliable, 24-hours-a-day 7-days-a-week public transportation. Expanded state-wide bus service."

Education: "Funding for education beyond a Bachelor's degree level."

Health Care: "More training in mental health issues for general medical personnel... Mental health treatment in the community... More crisis options; expanded bed space would be a great help."

Other: "Not all services can be accessed directly by mental health consumers, necessitating the use of community support agencies and workers."

ID: 22

Transportation: "Transportation is a real dilemma for seniors. We have no public transportation, so many seniors struggle to get to their appointments and errands with very few options. (KVCAP being the obvious exception.)"

Health Care: "I also receive many calls from seniors with a hearing or vision impairment but NO funds to pay for eyeglasses or hearing aids. There are few programs for these people, but there are long waiting lists. I would think mental health care would be an issue as well, as many disabled seniors are homebound and some seem to be more susceptible to depression as a result."

ID: 23

Work: "I have an LMSW, but can only work 10 hours per week. I need an accommodation from the Social Work Licensing Board so that I can practice under supervision to receive my LCSW (clinical licensure) in 6 years instead of 2. There are no part-time jobs in the Farmington area for people who do not have their clinical licensure. This is not a community-based accommodation, but this is what I need in order to be employed. I have asked for accommodations from the Board in the past, i.e., to find out if their testing site is wheelchair accessible. They refused to tell me, and instead provided me with individual testing locally. That took 8 months (others are tested within one month), and I could not work until I had my testing. The Board does not believe in ADA."

Transportation: "The only transportation for people with disabilities in the Farmington area is for trips to the medical services. No transport to work, shopping or recreation. There are times now when I am unable to drive, and I don't know often until the morning of my MD's appointment. At some point, I will lose my ability to drive, but not my ability to work and be useful."

Rec/Leisure: "Membership to the UMF Fitness Center is prohibitively expensive. There is no other physical activity (handicapped skiing, etc.) in the area in the winter. The town of Wilton blocked off the road to the town beach so that I can no longer swim there. They put in a ramp when reconstructing last year, but the ramp ends in a pile of rocks. The granite stairs are too steep and the railing is too short. This is in violation of the ADA, so all we need is an ADA compliance bureau! The town of Wilton library is inaccessible, and they have no plans for access. With the exception of the Range Pond State Park, there are no accessible state parks. Beaches and bathrooms are not accessible (again, in violation of the ADA)... Access to bathrooms at many of the State parks require only the periodic use of a rake to eliminate the step up to a concrete pad. State park officials say they do not have the time."

Health Care: "The monthly therapeutic massages that I require in order to be able to leave my home are not covered by Medicare. Medicare has a homebound policy that prohibits people who can leave their homes from getting wheelchairs, etc. Maine Medicaid will not supply anything that Medicare refuses to pay for. If I signed my name to this document, I would lose my wheelchair!"

Respite/Caregiver: "My partner and I both have mobility impairments. We care for my 87-year-old mother. When she is ill, I have to give her nursing care for 4 or 5 hours a day! Medicare and home health will only provide 1 hour of service!"

Other: "The Wilton Town Office was rebuilt about 5 years ago and no wheelchair access was included... Education and attitudinal changes would go a long way to bring the State into compliance with the Olmstead Act. Bureaucrats need reprogramming; they seem to be hired for their rigid personalities. I am amazed when I ask someone politely for an accommodation and they don't yell at me! People with disabilities like myself need to be hired by State and local agencies to provide the needed EXPERTISE that able-bodied people lack."

ID: 24

Housing: "Housing is appalling! Old buildings for low-income families! Insect-infested and mold and mildew problems (because the basement is full of water or because the basement has a sump pump). I have been on Section 8 list for over a year and possibly have to wait another year. Why is this list so long? Especially when children are involved. Everyone deserves a decent place to live. Not to live in an unclean home. The neighborhood is also not the best or safest. You have to make sure to lock windows and doors, and put bikes, toys, swimming pool, etc. (these are very easy to steal) away. Making quality housing (as well as safe for all) available faster and for the tenant to choose which place he/she wants and feels that this place would and could be a home! A real home!"

ID: 25

Work: "Although most children 15 and 13 would not still have a sitter, my children need supervision constantly to insure safety. So that I can keep working, I spent \$2700 last summer to pay for a qualified college student. I have no help with this either. Parent who want to keep working need financial assistance, or others who can share the burden."

Rec/Leisure: "There are NO community programs for teen with special needs in my community."

Other: "We have had to travel approximately 15-20 trips to NY and Boston for [daughter's] treatment, and are not eligible for any help in terms of reimbursement for travel, hotels, insurance co-pays... Although most children 15 and 13 would not still have a sitter, my children need supervision constantly to insure safety. So that I can keep working, I spent \$2700 last summer to pay for a qualified college student. I have no help with this either. Parent who want to keep working need financial assistance, or others who can share the burden."

ID: 26

Work: "[Needed] for students and adults with disabilities."
Housing: "[Needed] for students and adults with disabilities."
Transportation: "[Needed] for students and adults with disabilities."
Rec/Leisure: "[Needed] for students and adults with disabilities."
Health Care: "[Needed] for students and adults with disabilities."
Insurance: "[Needed] for students and adults with disabilities."

ID: 27

Education: "I think that it is very important for the parents of disabled children (guardians of all disabled persons) to be educated."
Respite/Caregiver: "Respite is a great program but it should include the whole family, not just the disabled person. Caregivers need a break."
Other: "...It is truly unfair to discriminate against the disabled and/or family of underprivileged people."

ID: 28

Work: "Getting back into society... having the opportunity to get adaptive equipment/transportation, etc. for the disabled to be able to work."
Insurance: "Extremely important... Assist small businesses as well as non-profits with the cost of Workers' Comp. to insure its proper use by employees (rather than hurt a business by increasing cost of Workers' Comp. when employees [are] injured) - may limit actual reports of injury and not an incentive to keep that person working for them."

ID: 29

Work: "There are few and far between accessible work stations in the Presque Isle area."
Education: "The local college campuses need to improve the accessibility both inside and out; the desks and tables are not at the appropriate height. Snow removal is also a major area that needs attention."
Rec/Leisure: "There isn't anything in this area at all for accessible recreation. Same goes for leisure. Most of the businesses in town are either non-accessible or have non-accessible bathrooms. Problem being there is no one to enforce the ADA and other town and state building codes. I have spoken with Presque Isle's Code Enforcement Officer several times and he refuses to enforce any

of these issues. He is even allowing new businesses to be non-compliant."

Health Care: "There is not any reliable medical supply companies in the Presque Isle area. Nor do we have experienced medical staff competent in dealing with SGIs."

Other: "There isn't anything in this area at all for accessible recreation. Same goes for leisure. Most of the businesses in town are either non-accessible or have non-accessible bathrooms. Problem being there is no one to enforce the ADA and other town and state building codes. I have spoken with Presque Isle's Code Enforcement Officer several times and he refuses to enforce any of these issues. He is even allowing new businesses to be non-compliant."

ID: 30

Work: "People need rehabilitation services which focus on training for good jobs. Opportunities for good jobs would be the next good step....The public and people who are hired to implement and administer services need to be trained to be consumer-oriented and good customer service-oriented. Sensitivity and helpfulness are important."

Transportation: "People need reliable and affordable transportation. This is a big problem."

ID: 31

Education: "At present, [my son's] educational needs are being met in the public school system."

Rec/Leisure: "We have difficulty meeting his recreation/leisure needs. Because we live in Raymond, we do not have practical access to therapeutic recreation programs. Portland is just too long a trip for us (nearly 2 hours, round-trip). We would especially like to see something in the way of weekend programming, since that would not interfere with our work/school schedules and would help to provide structure and engaging activity and exercise. (We are concerned that the lack of exercise will have long-term health costs that could be avoided.) Teaching Patrick to swim and involving him in some rigorous activity would have both health and safety benefits, but we have no real access to use a pool during the winter, and lack the expertise/patience to teach him ourselves."

ID: 32

Health Care: "Elderly people who are deaf are placed in nursing homes unnecessarily because they cannot communicate with the people who come into their homes to support them. None of the home health care aides in Maine know

sign language. If that were to change, then Maine could prevent unnecessary institutionalization."

Respite/Caregiver: "Elderly people who are deaf are placed in nursing homes unnecessarily because they cannot communicate with the people who come into their homes to support them. None of the home health care aides in Maine know sign language. If that were to change, then Maine could prevent unnecessary institutionalization."

ID: 33

Other: "How do you plan to train employees, community leaders, church personnel, etc. to be open and receptive to supporting advocacy? Who will coordinate this major effort? ... Where will the funding for the expenses required to support and administer such an extensive advocacy program come from? ...Who or what will be the organizing force to implement this vision for the future?"

ID: 34

Work: Model a program after BEAS SCSEP program that provides training for older workers.

Transportation: Expand Medicaid transit pass program beyond Portland and Bangor to other regions having transit systems.

Other: Recommends revising BDS' grievance procedure (provide better means within BDS for tracking grievances); training consumers about their rights (many people do not know their rights); providing grievance training for consumers (how to file grievances); ensuring that people discharged from hospitals without adequate housing get an interim plan that lists housing as an unmet need; training providers in how to write ISPs (provide monthly training opportunities until all workers are trained); establish a peer advocacy project just for mental health, provide good training, and pay stipends to peer advocates; find ways to increase the number of advocates; community service providers should develop a back-up system so that people do not fall through the cracks when a CM is not available (sick or vacation), have trained substitutes on a per diem basis, if necessary; when needing a new or different community support worker, offer consumer the option to interview replacement (allow for state preferences, i.e., women only) and option to decide who is most likely to have the best working relationship with; have State spend more money honoring people who are trying to do something with their lives (working, for example), model drop-in centers and social clubs after "Fountain House" which holds monthly dinner meetings with awards and entertainment, current US social programs

cater to non-working people and have most of their programming hours during the day.

ID: 35

Health Care: "I was just thinking how wonderful it would be if the Rumford Hospital could build a wing for people with our [bi-polar] needs. When I am experiencing an episode, I need attention quickly. It takes hours and hours for the medical professionals to find an open bed for me to be accepted. Then it takes hours for us to arrive there and get registered. It would be so much more convenient to get the necessary help right here in town."

ID: 36

Housing: "I would like to see the funds they spend on low income housing be made available for homes. Some of these people will feel as if they belong somewhere and also in the long run it may help be an investment. If the federal government pays 600 dollars per month for each person in low income that could be placed on a home if the person has some support system established. Many are paying out more to landlords who are only pocketing the money. By having low interest rates and a small home or even mobile homes where the client can pay one monthly bill for taxes, mortgage and insurance and then have a budget for the oil, electric and basic needs this can work with a support system and make them feel as though they have a home, a place. Sometimes working on one's self-esteem is a major accomplishment. I know my son cannot do it because his income of 540 a month is too low, yet our government pays his landlord 675 a month for his apartment and he pays 153. I think by working together we could look into helping people in all counties become safe and secure."

ID: 37

Education: "What arrangements do you have concerning young people who have what it takes mentally and emotionally but not necessarily financially to achieve a well-rounded education? Is there no hope left for us minimum wage workers or is there some sort of miracle path to follow to enable a person to get the sort of education that makes an entire community proud of their accomplishments?"

ID: 38

Insurance: This woman wrote to relay an incident that occurred with her client. The client was denied DME through Medicare. "Durable medical equipment suppliers declined to provide him with a new low air loss mattress because, according to Medicare Guidelines, Medicare would not pay for the item if he did not have active stage three or four decubiti. Contact was made with the Medicaid Prior Authorization Unit, and they, too, declined to pay for [a] new air mattress because Medicaid follows Medicare guidelines regarding this type of durable medical equipment." Subsequently, the old air mattress that he had deflated in the middle of the night and the client was left hanging upside down in his bed, unable to move or call for help, suffering physical and emotional trauma. "Subsequently, the client authorized his sister to purchase a new low air loss bed mattress using a credit card. He continues to pay off the expense of more than \$4000. He has been ambivalent about requesting the durable medical equipment supplier to request retroactive reimbursement for the low air loss bed mattress because he feels that it will again just be denied."

ID: 39

Other: "Your Idealist aims of Person Centered Services, No Wrong Door, Quality Services, Voice, and Choice and Control of Services can only be obtained through Education of the Attitudes of the Public."

ID: 40

Work: "...consumers feel like they are losing money when they work too much. They have to either pay back money or lose benefits. I would like to see training provided to all guardians and case workers so that they understand the benefits of the consumers working. My understanding is that they do lose some of their benefits but are still making more money."

Housing: "Consumers would benefit from having small group home settings (2 people). I understand that there is no funding available for this. We do have one home that there is only two people who live there. This setting seems to be a more home-like setting than the 4-bed homes. We also have two people who live in apartments. One lives on their own and ones lives with another person. This seems to be working well for both people."

Transportation: "Transportation is provided by our residential programs for the consumers who live there. We also have consumers who live with their parents or on their own. There is no funding available for these people for transportation to events in the evening or on weekends. This is something that comes up at just about all of the consumers' PCP meetings."

Education: "We have people who would like to take driver's education classes or just

learn how to drive. There are classes in this area but they cannot afford the price of the classes. I would like to see funding available for training these people who want to learn how to drive."

- Rec/Leisure:** "This area [Aroostook county] used to have funding available for a recreation coach. This is no longer available. The consumer who lives at home with their parents or on their own could benefit from having someone available to take them out in the evening or on the weekend."
- Health Care:** "The problems with health care in this area is how far one has to travel and how long it takes before a doctor can react to a situation that has arose."
- Respite/Caregiver:** "There is no concern with respite in this area [Aroostook county]."
- Insurance:** "The only problem I see with insurance is what they will pay for and what they won't pay for. I would like to see the insurance companies pay for things that the PCP team meetings see as a need for the consumers... [Consumers feel like they are losing money when they work too much. They have to either pay back money or lose benefits. I would like to see training provided to all guardians and case workers so that they understand the benefits of the consumers working. My understanding is that they do lose some of their benefits but are still making more money."

ID: 41

- Health Care:** Allow legally liable relatives to be surrogate decision-makers for family members who need it (get a waiver if in extreme need); allow families to hire members of the community (e.g., church members) as PCAs and waive some of the training/course requirements; allow consumers and families to self-direct so that there is better supervision of workers; allow more flexibility and consumer/surrogate choice in care plan (e.g., PCAs are required to bathe respondent's mother too frequently which dries her skin out and adds to the fragility of her skin).
- Respite/Caregiver:** Have agencies provide better training and supervision for young workers and make an effort to hire mature workers; change expectations of what workers can and cannot do in the workplace (changing job descriptions to permit more flexibility in worker duties).
- Other:** Have an emergency back-up system in place in Maine.

ID: 42

- Work:** "With the economy waning, it is increasingly difficult to get employers to work with folks who have mental health issues."
- Housing:** "Adequate, affordable, safe housing is an enormous problem in Region 2."
- Transportation:** "A huge issue for all consumers who do not have resources to buy and maintain a vehicle in Maine. The local transportation systems only

transport to medical appointments. The more rural the client, the less accessible all the services are."

Rec/Leisure: "Cost is prohibitive for folks on disability."

Respite/Caregiver: "Need for more support groups for folks who are assisting the disabled."

Insurance: "Services have become Medicaid dependent. Insurance companies do not cover a lot of the services that folks with disabilities need - especially natural supports....Dental health care and resources to help pay for that care as well as dentures. Assistance with the cost of eye care. Resources for folks with mental health issues who have no insurance to pay for their care."

Other: "Funding non-traditional resources but not by reducing funds to traditional resources."

ID: 43

Work: "Expand and/or develop resources for financial assistance, etc. for persons who wish to attend college or technical school. Do not eliminate sheltered workshops and enclaves because these services provide important training opportunities for all skill levels but mostly for those who are chronically ill or severely physically or mentally disabled. Keep them but increase development of mainstream employment opportunities (increase finances for the ability of job coaches, etc.)."

Transportation: "Provide transportation services for after normal business hours and/or on weekends for those who are currently employed."

Education: "Expand and/or develop resources for financial assistance, etc. for persons who wish to attend college or technical school. Do not eliminate sheltered workshops and enclaves because these services provide important training opportunities for all skill levels but mostly for those who are chronically ill or severely physically or mentally disabled. Keep them but increase development of mainstream employment opportunities (increase finances for the ability of job coaches, etc.)."

Health Care: "Requiring providers to assess and evaluate satisfaction with the services they provide and use findings to improve services seem unnecessary as this is already a requirement. How about enforcing and/or reviewing the findings for the development of change rather than recreating what is already there?... In the Roadmap for Change recommendations, where it is noted to eliminate forced medication and involuntary hospitalization - this seems contradictory to the above noted line that reads 'allow surrogate decision makers to direct care for persons not legally competent to direct their own care.'"

Respite/Caregiver: "Need to add 'Coordinate with all consumer initiatives in existence' to the recommendation under Voice."

Other: "Define 'too long' in the Funding and Planning line of the Roadmap where

it is noted that there is a need to develop ways to measure unmet needs for people who wait too long for services. What is too long when someone needs services?"

ID: 44

Housing: "I would say appropriate housing is the biggest piece. Unless this is solved, families are tied down and find it difficult to meet other commitments."

ID: 45

Other: "We [the Deaf community] experience a lot of barriers in the community - such as obtaining interpreters to buy a car, to meet with insurance agents, to meet with financial advisors/planners, to buy a house - things like that - that many people take for granted. We also need more consumer classes/workshops to learn more re: such stuff. Access is very limited - so our knowledge is limited, too."

ID: 46

Housing: "We need more physically accessible housing stock. This means truly physically accessible. Too often what people think is accessible isn't...For example, hallways may be too narrow or grab bars may be missing."

Transportation: "We need more hours of paratransit system operation, including weekends and evenings. We need to develop systems that operate like taxis, but less expensively. A commitment to resolving transportation issues requires more than money; it requires a change in values to recognize that people with disabilities need to be able to get they where they want to go. Transportation affects everything else, like jobs, housing, health care. This importance needs to be highlighted in order for transportation funding to survive budget cuts."

Education: "People who do not have disabilities, or who do not have close family members with disabilities, do not appreciate what day-to-day living is like for a person with a disability. We need more public education, on things such as the fact that for a person with a disability many tasks of daily living take so much longer to complete. After completing the necessary tasks of life, there's not much time left in a day. And for the recreational opportunities that a person may take advantage of, they, too, can take hours longer. For example, just to go to the movies may mean leaving hours ahead of time in order to accommodate the accessible bus schedule to make it to a movie that lets out while the bus is still running. If every person with a disability and every close family member of a person with a disability were to call in sick to work or to school on the same day, maybe then others

would understand just how many people are affected by issues facing people with disabilities."

Insurance: "MaineCare prior approval and appeal process: The processes for obtaining approval for MaineCare reimbursement on items requiring prior approval need to be simplified so that requests subsequent to the first request are not as complex. There should be a renewal process that is simpler than the initial request process. Glasses and durable medical equipment... Coverage for glasses and other durable medical equipment is too restrictive. Flexibility in services... How services are funded and selected needs to be more flexible, giving the user of the service more choice. This needs to be a practice with private as well as public insurance."

Other: "Access to state workers... Some of the state agencies have telephone voice mail systems that are very hard to navigate. Maybe there should be a central message system."

ID: 47

Housing: "Fair housing across the board."

Transportation: "Make 'share a ride' available through radio station broadcast or by computer. Develop a list of people you can count on to call when you need transportation. Expand available public transportation to include rides for things other than work (evening SUFU meetings, social events). RTP picks me up late so I'm late for my programs. Safe transportation (don't feel safe on public transportation, need someone to accompany me)."

Education: "I want to further my education, no one listens to me."

Rec/Leisure: "In rural areas, it's hard to get out [of house & into community]. I was told to move to town. Individualized plan calls for going out 2 times per month, but no implementation, no follow through, no one is listening."

Respite/Caregiver: "Direct care providers should have more training (at least one week). Should consider job shadowing for up to 2 weeks. Alpha One told me I have to hire my own PCAs. They don't show up when they're supposed to, have to live at home, want to live on my own. Need back up plan... Hours are authorized but no one will work with me, want to be able to hire and fire my own staff... Want choice of workers. Person should be asked if he/she likes a staff person before they're hired....Frustrated by lack of funding. Keep promises or explain why you can't do it. Be honest about whether you can or cannot do it. Resources should be there to eliminate waiting lists. Support expanded role for homemaker (take person to store and to laundromat)... Quality of services very important."

Other: "Want to become my own guardian, make my own decisions. At my annual program planning meeting (PCP), I speak up a lot for what I want. Want choice on when and how often to have PCP meetings, and when not to have them any more or on as needed basis only. Quarterly PCP meetings are cut

short because people think our attention spans are short. We want to choose how long we meet (all in one day rather than 2 separate days), inflexible schedules for meetings, then move agenda along without my permission... I'd like to get my own apartment, be my own guardian... Self-advocate for more interpreters and greater availability of assistive technology, including communications boards. One SUFU member has been waiting since May, 2002 for his "talker" to be replaced, he wants to speak for himself, and has to go through yet another evaluation... Adaptive equipment to help member to clean apartment, SUFU member complained that she should have had an evaluation by now... Parents don't listen to me, sweep me under the rug... Winter accessibility (driveways, walkways, etc.)."

ID: 48

Other: "Legal services for independent living rights."

ID: 49

Other: "It would be helpful to acknowledge somewhere in the plan that their 'vision' is intended to serve all persons with disabilities, including older persons with disabilities."

ID: 50

Respite/Caregiver: "These not-for-profit agencies, for the most part, are mini institutions. Management eats up nearly half of these waiver funds. I know first-hand that direct care staff only work in these positions to have access to insurance benefits. Even though [my daughter] is very content in her own apartment, I see far too much of her waiver fund being absorbed by agency management. If I had access to a list of qualified direct care staff, I would eliminate the involvement of a service agency. With all the fund 'freed up' my daughter would have access to a higher quality of direct care staff!!"

ID: 51

Housing: "There is a definite lack of safe affordable housing for the elderly, low income and individuals with disabilities."

Transportation: "Transportation can be a problem for appointments, etc."

Health Care: "Lack of communication can be an issue to the elderly and individuals with disabilities as to what services are available to them."

Insurance: "Insurance and prescription drugs continue to be a major concern."

ID: 52

- Transportation:** Is extremely upset about the DOL's recent decision to cut funding to many parts of the state. "Currently, transportation services transports kids with disabilities to school, adults to work and to necessary medical appointments. I am very worried about the impact of this cut and how it will affect the quality of community living for individuals with disabilities and their independence."
- Respite/Caregiver:** Is very concerned about the lack of caregivers and services available to people with borderline intelligence (defined as those people with an IQ between 71 and 80). The state requires that the individual have an IQ of 69 or below to qualify for services. "I have worked with families with adult children who have IQ from 71-80 and do not receive any caregiver support since agencies cannot provide the services unless they meet diagnostic criteria. This leaves a huge burden on the families to take care of the independent living needs, assist with activities of daily living and plan for the time when as parents, they will no longer be living to take care of their child." Is also concerned with the gap in services offered to those with more severe physical disabilities. "...The max amount of funding Alpha One can provide a single person is only 90 hours a week which does not take care of the person who is disabled and in need of 24-hour care. An additional barrier to this service is that Alpha One gives the consumer money to pay the PCA which is just above minimum wage without benefits make it challenging to hire someone for that position." Another barrier: " ...Alpha One requires that individuals who qualify for PCA services direct their own care. What happens for someone with a speech barrier and is non-verbal? How can they direct their PCA care?"

ID: 53

- Work:** "We need to educate both public and consumers as to what their potentials are."
- Housing:** "Some codes need to change to help make all housing more accessible or friendly to all potential consumers."
- Transportation:** "Money is a barrier for most consumers state-wide."
- Education:** "We need to educate both public and consumers as to what their potentials are. ... I believe special education educators need to have higher expectations and we need to help parents and students transition better."
- Rec/Leisure:** "We are making some great gains but funding expensive equipment can be a barrier."
- Health Care:** "We need to remember people (consumers) need and want to have a life that is not only based around health care needs."

ID: 54

Housing: "Housing for people with disabilities that is affordable and accessible."

Transportation: "Transportation is a huge issue. People need reasonable accommodations to be able to get to the grocery store, shopping for personal items, church, etc. These are basic needs."

ID: 55

Transportation: "Provide monthly transportation vouchers for Maine residents with disabilities who have incomes below 200% FPL. This could be funded by a slight increase in the gas tax."

ID: 56

Transportation: "Transportation is an issue in outlying communities which are too small to offer public transportation. The programs which work for the intown (large) communities should be extended in the same way to the outer townships and more difficult to reach areas of Maine. "

Education: "The level of understanding throughout the state and the level of tolerance needs to be addressed. Disabilities are not always visible and Maine as a whole needs to understand that and hopefully through understanding there will be a higher level of tolerance."

Health Care: Would like to see more services offered in the area of early intervention.

ID: 57

Housing: "More Section 8 vouchers need to be sought after. Not to have huge waiting lists in all counties. Maine was not even listed on a survey of which states get which vouchers. That needs to change."

Transportation: "Public transportation needs to be given at low or no cost around all of Maine for all gatherings, not just medical appointments."

Education: "Public education needs to have a transition plan for all individuals with disabilities in middle schools."

Rec/Leisure: "All beaches state-funded should be accessible using wheelchairs with large wheels."

Insurance: "Increase the earned amount of money over \$22,000 that a person can earn before their MaineCare is taken away."

Other: "Public education needs to have a transition plan for all individuals with

disabilities in middle schools."

ID: 58

Transportation: "There needs to be some way that people with disabilities can get to non-medical events (i.e., church, recreation, entertainment). This would have to include your small towns as well as your cities. I would suggest community vans that have wheelchair lifts."

ID: 59

Transportation: "I would have to say that transportation is the most needed service. You need the availability of transportation in order to access the other services offered."

ID: 60

Transportation: "Transportation... is the greatest barrier in my eyes. Without it, life opportunities in all other areas is limited."

Respite/Caregiver: "I...feel there needs to be more focus on consumer-driven representative programs that offer people with varying cognitive abilities the choice and flexibility to meet their personal care needs at home."

ID: 61

Transportation: "I believe public transportation, especially in rural areas, needs to be improved. I have many consumers who are only able to get transportation to and from medical appointments. This is very limiting."

ID: 62

Work: "To help me get a job without people discriminating against me."

Housing: "I would like to have a program that could help me get a house or an apartment since I don't have any credit."

Education: "To let me go to school and not have to pay very much."

ID: 63

Health Care: "Coordination of services across all dimensions - public/social/medical. A

center to hold it together and simplify the process."

ID: 64

Other: Person was commenting on the video. Expressing that we should have given more contact information out for state people and agencies.

ID: 65

Housing: "I think there should be Section 8 or some type of housing voucher or public housing complexes specifically for people with disabilities who are limited in their housing choices. Apparently, there are a few units set aside in some complexes, but they seldom come available."

ID: 66

Work: "Meaningful work with respect from others, regular support on a definite routine. Haven't always had the constant support needed to stay focused."

Housing: "Affordable housing is a problem, mainly available housing. Needs help paying bills, and general living. Needs to know safety rules living alone."

Transportation: "This is a HUGE problem!!!! Coastal Transportation has had their funds cut and without public transportation in the Brunswick area, she is very limited for jobs, and safety issues, far as walking to and from appointments."

Education: "I think there should be more classes for the disabled, so that they can be more self-sufficient. Computer classes work really well, but not sure how many people can afford the classes."

Rec/Leisure: "Our daughter seems to enjoy the events and outings that are provided. I believe Independence does well for activities, but getting there can sometimes be a problem - as far as getting to the Learning Center where they meet to go on the outings."

Health Care: "Our daughter goes to Sweetser for her mental health needs. But there still are issues with her general well-being for safety, and who her friends are and letting anyone in her home. She is easily taken advantage of. This issue has a large impact on her physical well-being. [She] has had tests done or assignments on her being able to do certain things in her home like turning on the stove and able to wash dishes, but there is more to living on your own than that. She has had a score of '71' and I think the cut-off point is '69' to get better services, or a group home setting where she needs guidelines and limits on her finances and general living. She needs a lot of guidance. These are our main concerns"

Respite/Caregiver: "[My daughter's] father and I are divorced. [My daughter] lives with me. What is really needed is someone we can call when we need help with situations that arise. I don't know how many times things have happened in regards to [my daughter's] safety or just general help I might need with [my daughter] and I don't feel there is anybody I can call. When I have called, I don't get calls back. I know other families I have talked to have said the same things."

Insurance: "[My daughter] has her Medicaid. This has helped a lot with getting medication and with doctor appointments."

ID: 67

Transportation: "Transportation major need"

Health Care: Need "'how to' for seniors - how to access appropriate agencies? what is available? how to access Medicaid and MaineCare? how to locate caregivers who are trustworthy?"

Insurance: "Drug costs"

ID: 68

Housing: Would like safe, accessible housing.

Transportation: Needs transportation to get to and from doctor's appointments.

ID: 69

Work: "Work available for everyone."

Transportation: Would like to see more handicapped vehicles.

Education: Would like to "get points for education for Medicaid personal care".

Health Care: "Health care for all people with health care issues."

Insurance: Would like dentures and glasses to be covered under Medicaid.

Other: Would like "recycled handicapped equipment, canes, toilets, wheelchairs, beds" to be available. ... Would like "clothes made easy for handicapped people to take on and off".

ID: 70

Rec/Leisure: Would like "entertainment that is accessible to get to and affordable".

Respite/Caregiver: Would like companions.

Other: "Grants for [equipment?] designs and repairs, not loans." ... Would like "a

chance to be useful". ... Would like "to be welcomed at community meetings". ... Would like "money to spend".

ID: 71

Health Care: "Great need to let people with disabilities know about services and programs. Highlight those that are consumer-directed. Explain services and programs in detail so you can choose appropriate services you need."

ID: 72

Housing: "People with disabilities need to be able to have a well-rounded life just like everyone else." They "need a good place to live - both accessible and affordable".

Transportation: "People with disabilities need to be able to have a well-rounded life just like everyone else." They with disabilities "need to be able to get to their appointments, do shopping, go to church, etc.".

ID: 73

Housing: "I live in subsidized housing, but often cannot afford heat in the winter time. I receive HEAP Fuel Assistance - but only \$100 a year - and I have electric heat!... I've had to go without heat for 3 winters!"

Transportation: "Transportation is very difficult for me... One thing that might help are ride-boards for transportation."

Rec/Leisure: "Recreation and Leisure is practically impossible as I have absolutely no disposable income. (I receive \$612 a month in SSDI payments.)... A community center to get together with other people, where we can share meals, watch movies, have live music perhaps, a library, a photocopier and computers would be extremely helpful."

ID: 74

Education: "Need for individual or group skills instruction for transition."

Health Care: "Need single access point for service delivery."

ID: 75

Housing: Interested in hearing more about accessible housing.

ID: 76

Education: Need "more awareness of deafness and the need for multi-channel communication - visual, auditory, and tactile - are my top priorities at the moment."

Other: "Universal access and universal design need to be genuinely universal or they become another fraud."

ID: 77

Transportation: "They should expand the Medicare transport pass and take it to the Lewiston and Augusta."

Rec/Leisure: "Recreation should be individuals integrating themselves into their community like everyone else but make sure to make it affordable."

Respite/Caregiver: "There needs to be more respite care for families with children with a disability. This should be provided by the state."

Other: "There needs to be more advocacy for mental health consumers (training also)."

ID: 78

Respite/Caregiver: "Respite care for parents for all children not simply one who has a disability. I work with a mother who is diagnosed with a mental illness has one son who is diagnosed with ADHD and another typically developing son. She can get respite for son with ADHD, but they won't take the younger son at the same time so the mom doesn't usually get a break."

ID: 79

Transportation: "I would have been able to better advocate for her needs if I had respite care, transportation, and funds to travel to meetings." ... "Also a reliable van would have been nice for her to go with me."

Respite/Caregiver: "I would have been able to better advocate for her needs if I had respite care, transportation, and funds to travel to meetings."

Other: "I would have been able to better advocate for her needs if I had respite care, transportation, and funds to travel to meetings."

ID: 80

Work: "Provide a livable wage."
Transportation: "More public transportation. More funding for Medicare transportation."
Education: "More access to child care for low-income students."
Health Care: "More access to oral health services for children and adults."

ID: 81

Housing: "Housing... options are extremely limited and all too often create huge barriers to independence in the community."
Transportation: "Transportation...options are extremely limited and all too often create huge barriers to independence in the community."
Health Care: "A larger barrier however is the perceptions of traditional service providers such as those in nursing care facilities and boarding homes. I am presently working with a consumer whose maximum level of function is being eroded by the people he is working with simply due to active listening and validation."

ID: 82

Other: "I think it is important for residents who are mute and cannot write to have a way to contact you because the facility won't at times when families are not readily available."

ID: 83

Housing: "Safe housing... I just want peace and quiet... The Section 8 let me move in... bad housing... Apt. [#] makes my PTSD get worse... I want money for my pain and PTSD... I've called 774-HELP for stress..."

ID: 84

Other: "Age 11 - out of state. No programs in Maine. Drug-free. Result: Spaulding Youth Center. Age 16 - out of state. No programs in Maine. Signed with Brunswick programs. Lacking funds. Proposal denied. Result: Crocket Mountain, Greenville, NH. Age 18 - signed Woodford's Agency. Waited 1 1/2 years for group home. No training. No program. People sent to my home not trained. Sat and did nothing. Outings only when I took my car. Could not leave home. Age 21 - no programs. Nothing. Have had respite workers. Documented hours not worked. Unsafe vehicles. Did not show up

or call. ... As of now - 6 months. Nothing. My child had to be placed out of state as nothing was available. Brought back home to Maine and nothing. A lot of promises result in nothing ever being proved true."

ID: 85

Education: "I... need help with dealing with [my child's high school]. They suspend him all the time. I'm not saying [my child] is the best kid, but he is not always wrong. He is a very angry boy most of the time. Always out for an argument no matter who it is with. He thinks everything is unfair, very frustrated a lot of the time."

ID: 86

Work: "I would like to work PT, which I can't now because of the unstable housing conditions."

Housing: "I need to be able to stay in a safe, consistent place and not be under constant threat of having to move again, which keeps my blood pressure and blood sugars out of control and makes me very sick."

Transportation: "At some point, I would like some help in getting a vehicle, so I can expand my world and be able to take jobs, visit family, etc. like before I was disabled, when I had a varied, full life."

Education: "I would like to take a course so I may acquire more varied job skills."

Rec/Leisure: "I could use someone to help with exercise to keep my weight, blood pressure and blood sugars at more healthy levels."

Health Care: "With all the pain I have, I would benefit from massage therapy."

Respite/Caregiver: "I would benefit from an in-home support to help me with my homemaking skills."

ID: 87

Education: "More education for the public, better understanding of mental illness, case management or services, outreach for adults and children."

Other: "More legal services for mentally ill people. Better advocacy."
