

Advocacy, Self-Advocacy and Quality-Monitoring

a report prepared by Maine's Work Group for Community-Based Living

For the purposes of this report, when we speak of advocacy we mean self-advocacy (individuals speaking for themselves), individual advocacy (advocating on behalf of an individual with a disability), peer advocacy (an individual with a disability speaking for people with similar needs), and group advocacy (advocating on behalf of groups of people with disabilities).

Individual Advocacy and Rights

Every person with a disability should know his or her rights and have the skills and confidence to speak up for his or her own interests and the interests of others.

Findings

Everyone should know their rights and have the skills and confidence to speak up for themselves. For people with disabilities, the need to speak up is even more pressing. Having a disability makes it more likely one will have encounters where rights need to be asserted, whether it be with providers, state agencies, housing authorities, or a bus driver. At every encounter, a disability very often makes it more difficult to assert a right and have it understood, respected and addressed. Many people with disabilities experience exclusion, intolerance, and insensitive treatment at the hands of other members of their community.

With providers, the barrier might be lack of respect for the patient's or client's right to make decisions about care and services— some providers assume they know what a person needs, without asking for, listening to, or respecting that person's perspective. This problem is worse when a provider assumes that a person's disability reduces even further that person's ability to make choices. Providers need to be trained not only in the delivery of quality services but also to recognize that consumers and/or families are decision-making partners in the planning, delivery and evaluation of services. This training may be more effective when delivered by people with disabilities.

Findings from the focus groups confirm that having a disability increases the likelihood one will need to fight for a legally entitled service or for flexibility responsive to individual needs. Service programs are so complex and fragmented that often many people, including many providers, do not know what services are available. Many people may not know their rights. Even knowing what services are available and the right to receive them is only part of the battle. One focus group participant said "You have to fight and beg and dig for all you are entitled to." Parents of children receiving special education services reported that they often find themselves educating school administrators and teachers about their children's rights, and fighting to have those rights enforced.¹

¹ Ormond, C., Ziller, E. and Richards, M. (2001) *Living in the community: Voices of Maine consumers, a report of findings from focus group discussions*. Edmund S. Muskie School of Public Service: Portland, ME.

Taking part in everyday community activities—*e.g.*, being a student in a classroom, developing a circle of friends, working at a job, going to church, living in a residential neighborhood—offers other challenges to be overcome. An individual needs to have the confidence to assert his or her right to take part in community and the ability to educate people on how they can make accommodations. It takes an extra dose of confidence to make these assertions when confronted with prejudice or condescension.

Recommendations

We recommend that:

- Providers actively recruit consumers, family members, and advocates for participation in all aspects of the organization, including decision-making, program design, program implementation and evaluation of services provided.
- Provider agencies and state programs eliminate barriers to consumer participation and input by making accommodations available as needed, including readers, note-takers, drivers and personal-care attendants and by providing reasonable reimbursement to consumers.
- The State require publicly-financed providers to support self-advocacy. Providers should be required to complete training programs for self-advocacy and peer support.
- Provider agencies and state programs create and strengthen consumer advisory boards which review significant programmatic and policy issues and agencies and state programs provide leadership training programs for consumers on governing boards.
- In a collaborative manner, the State, provider agencies, and advocacy organizations train employers, community leaders, churches, and others on the rights of individuals with disabilities, as individuals who have little or no representation.
- Agencies and advocacy organizations make advocacy materials more user-friendly so it makes it possible for more people to advocate on their own.
- The State support development of a user-friendly guide to educate people about their rights and to support the expansion of legal resources to advise people on how to protect rights, including their housing and employment rights. We recommend that the State also support expansion of resources to provide alternative dispute resolution to people with disabilities.
- The State support training programs to educate people about their rights. The training programs for rights and self-advocacy should focus on different topics (*e.g.*, housing, employers, public accommodations, eligibility for services, how to complain or file a grievance about providers, state agencies, or schools).
- The State use grants or contract incentives to develop and support peer support systems which are designed and delivered by peers.
- Advocacy services that are independent and autonomous should be available.

Participation in Policymaking Process

For people with disabilities to fully participate in the public policy-making process and use opportunities to affect policy decisions, support for their involvement to has be organized and improved.

Findings

In a world of finite resources, competition for public funding dollars is great. The Americans with Disabilities Act (ADA), reinforced by the *Olmstead* decision, provides the disability community with a useful legal tool for competing for resources by holding states accountable for supporting community integration. Ultimately, however, legal or court-enforced tools are limited. Without the political will, the State will not make the investment it needs to, no matter what a court says or does. The political will needs to come from pressure put on legislators, the Governor, local communities, housing authorities and others that control the flow of public dollars. The pressure has to come from people with disabilities, advocates, and the general public.

The State should seek out the voice of people with disabilities and support their inclusion in the policy making process. People with disabilities have historically been excluded from the political process through architectural and communication barriers, stigma, and other limitations.

Supporting consumer participation is challenging. Finding the time to participate is a challenge. Probably representing the experience of many others, one focus group participant said “Having a disability is a full-time job.” The experience of parents of children with disabilities is similar, with many having to give up their paid employment to take on the full-time job of advocating for their child’s right to services.

Many of the problems that need to be addressed create other barriers to participation. For example, for the focus groups, we only heard from the people who had transportation and other needed supports to make it possible to participate. The experience of the Work Group itself confirms some of the challenges to consumer participation — *e.g.*, one member attended meetings by phone because she did not have accessible transportation; a parent missed several meetings when she lost in-home supports during meeting time; another member missed meetings because her son needed to be transported to medical appointments.

Many consumers also face financial challenges to participating in the policy making process. In many cases, consumer participation means bearing the out-of-pocket costs for things like transportation, childcare, or support services. In other cases, the voluntary contribution of time for public policy, can mean less time for earning money or vacation time. And for those that receive SSI (Supplemental Security Income benefits) and MaineCare, being paid for participating is not an option because earning even a small amount of money can put eligibility for benefits in jeopardy.

While some of these barriers might be present for anyone, whether with a disability or not, if the State wants to support the consumer voice, these barriers must be addressed. Overcoming the barriers to consumer participation will make it easier for advocates to know what their

constituents want and give them a more powerful voice in communicating those interests. A stronger consumer voice will also play a role in educating the public, to build the political commitment to investing in home and community services. Consumer participation at the local and community level as well as the state level can have a powerful influence on the political process.

Recommendations

We recommend that Maine:

- eliminate access barriers to participation in policy making, including physical barriers and communication barriers. Other accommodations include support services such as readers and notetakers, drivers, and personal care attendants).
- make available funding to address some of the economic barriers that discourage participation, including transportation, childcare and other out-of-pocket expenses.
- develop and publicize alternative means for giving input into the political process with use of technology and assistive technology.
- support coalitions of advocacy groups around key issues.
- support clearinghouse/information exchange.
- support leadership training.
- support the recruitment and training of consumers to participate on public housing boards and in public housing authority annual or 5-year planning processes.
- support the recruitment and training of consumers to participate in consumer advisory boards for regional transportation organizations; petition for regional transportation boards to develop consumer advisory boards if they do not already exist.
- support the recruitment and training of consumers to participate in other boards, including consumer advisory boards, quality improvement boards for mental health and other provider agencies, etc.
- create and support independent regional and state-wide consumer advisory organizations which advise state agencies about policy direction and programs.

Participation in Quality Assurance

The State should implement mechanisms for increasing consumer participation in quality assurance efforts and have an opportunity for input into the development and implementation of quality assurance mechanisms for providers and services for people with disabilities.

Findings

According to basic principles of quality improvement, there should be a feedback loop between the customer and a provider or a customer and a state agency. However, to a large extent there is no feedback loop for consumers to tell the State how well the system is performing. Important

information that could be used to improve the way things are done is lost. For providers, licensing and contract performance reviews need to incorporate the consumer voice. The State needs a quality management system that responds to consumer feedback across programs. That means the State needs a quality management system that includes measuring quality from the consumer's perspective.

Quality Indicators that embrace the philosophical framework that consumers of services and their families are partners in the planning, delivery and evaluation of services are critical components of a quality assurance system. Examples of the type of quality indicators, modeled after the S.M.A.R.T. Exchange Program² include:

- a commitment to the belief that the satisfaction of people with disabilities and family members (if appropriate) is of primary importance in achieving success.
- program services are designed to ensure that consumers and their families (if appropriate) have the greatest involvement and governance possible in the design, delivery and evaluation of services.
- a commitment to and demonstration of the practice that individuals with disabilities are provided with the opportunity and the necessary supports to be integrated with non-disabled peers in school, at work and in the community.
- practices that value the outcomes of enhanced independence, integration and productivity of individuals with disabilities.
- a system which evaluates organizational effectiveness and consumer and family satisfaction with the services, supports and assistance provided.

Recommendations

We recommend the State have a quality-management system in place that is:

- *Consumer Driven.* How quality is defined should be determined by the individual. What is most important to the person? What does the person want and need?
- *Comprehensive.* The definition of quality should include a complete view of a person's life, including home and family, school, work and daily activities, and social and community living.
- *Integrated.* Measurements of quality should integrate the contributions of all supports in a person's life at home, at work, or in daily activities, and community.
- *Value-Based.* Measurements of quality should focus on what the person values as being most important and what enhances the person's experience.

Through contracts or by regulation, providers should be required to:

- assess and evaluate consumer satisfaction with the services they provide;

² Available: <http://128.104.192.129/taproject/library/atq/knowning.htm>

- use their findings from surveys and other quality measurements to improve services;
- develop their satisfaction surveys and other components of their quality improvement systems with the help of consumers, families and advocates;
- allow consumers, families and advocates to take part in evaluating services;
- include consumers, family members, or advocates on decision-making boards or committees;
- include consumers, family members, and advocates in all aspects of the organization, including decision making, program design, implementation and evaluation of services provided.