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# Our Lives, Our Health Care

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Self-Advocates Speaking Out About Our  
Experiences with the Medical System

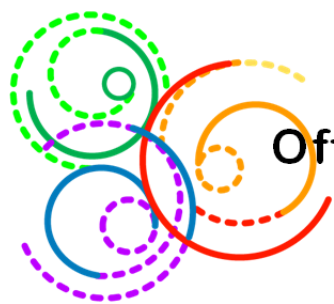
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## Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

The Office of Developmental Primary Care is a program in the Department of Family and Community Medicine at the University of California, San Francisco. Our mission is to build the capacity of the health care system to serve adults with intellectual and developmental disabilities (I/DD). We do this through clinical service, advocacy, research and training.

The UN Convention of the Rights of Persons with Disabilities calls for inclusion of people with disabilities in all aspects of society. To end health disparities, we need research that is produced with organizations run by people with I/DD. Learning from people with lived experience helps us ask the right questions. It helps us maintain the right priorities. And it helps us implement the right policies.

The World Health Organization recently set priorities for research in health care for people with I/DD. That process revealed two trends. First, better understanding of basic science alone will not improve health. To improve well-being, we also need to understand social exclusion, discrimination and disadvantage. Second, health is not just about access to quality medical care. It is about access to power, wealth, education and employment. (1)

We are pleased to partner with the Autistic Self Advocacy Network, People First of Washington and Green Mountain Self Advocates to develop this paper. We look forward to future collaboration. As Surgeon General Satcher said over a decade ago, “Reports don't have arms and legs. Like many others, this report will just sit on shelves unless we turn it into action...[T]o listen and not respond with determined action will only heighten the injustice this community has too long endured.” The Office of Developmental Primary Care is committed to responding with action.

In partnership,

Clarissa Kripke, MD, FAAFP  
 Director, Office of Developmental Primary Care  
 Clinical Professor Family and Community Medicine

1. Tomlinson, M. et. al. Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *J Intel Dis Res.* 2014.



The last fifty years have seen tremendous strides forward for people with intellectual and developmental disabilities (I/DD). We have gone from a system in which members of our community were segregated away in institutions to one in which the majority of people with I/DD are supported to live in the community. Today, fifteen years after the Supreme Court's landmark *Olmstead v. L.C.* decision, we are seeing the idea of community integration being applied to residential, employment, day, transportation and countless other types of services that are accessed by people with I/DD. Yet, at the same time, we continue to face significant barriers in accessing quality health care.

The self-advocacy movement was built to be a voice for people with disabilities seeking to have our own views represented in the national and international conversation about our lives. Just as self-advocate activism has changed where people with disabilities live, how we are spoken about, what we do with our days and many other aspects of our lives and supports, the power of the self-advocacy movement can bring about long-needed changes in the health care options available to people with I/DD. As we enter into a post-Affordable Care Act world, we must begin to articulate an agenda for health care equity and equality for people with disabilities.

In this document, we take the first step. By working with state and local self-advocacy groups, we have collected critical information on the needs and perspectives of self-advocates with I/DD interacting with the health care system. It is our hope that by clearly spelling out the challenges faced by people with I/DD seeking to access quality health care, we can set the stage for meaningful activism, advocacy and policy change to support our full inclusion in this aspect of society.

As we enter a new chapter for America's health care system, we stand ready to take on the challenge of equal access for all. Standing with you, we know we can succeed.

Regards,  
Ari Ne'eman  
President  
Autistic Self Advocacy Network

*“Attitudes are better. Years ago things were different. Now people are more considerate, more accepting than eleven years [ago]. Having us be out in the community has brought the awareness that we all are the same and we all need help at different times.”*

*“The care I need seems to be determined by the insurance more than by the doctor.”*

*“They should go back to school and learn more about how to treat a patient with disabilities nicely, not going too fast and acting like you know everything.”*

*“Can’t find Medicaid doctors and dentists: A big problem!”*

-Quotes from Group Participants

## **Background**

In the 24 years since the passage of the Americans with Disabilities Act, considerable progress has been made to facilitate the full integration of people with intellectual and developmental disabilities (I/DD) into society. Between 1960 to the present, approximately 200 institutions for people with I/DD were closed and their residents supported to live in the community. Today, thirteen states have no state-run institutions for people with I/DD, and a smaller number have ended the use of private institutions as well, operating an entirely community-based system. Research spanning over several decades has found that people I/DD who have moved into homes in the community enjoy better quality of life, more control over their own choices and decision-making and greater skills and abilities as compared to those living in institutions.

Considerable progress has been made for people with intellectual and developmental disabilities in accessing high quality long-term services and supports in the most integrated setting. Despite this, comparatively little focus has been given towards improving the health outcomes of people with I/DD. People with I/DD continue to face significant problems in accessing culturally competent health care services. This has resulted in our community experiencing a number of health disparities. Adults with cognitive disabilities have high rates of chronic medical conditions such as diabetes, arthritis, cardiovascular disease, osteoporosis, dental caries,

gastrointestinal disorders and asthma. People with cognitive disabilities may be more likely to have medical conditions associated with their disability such as seizures and mental illness. However, much of the disparity in health status is unrelated to the underlying disability. It can be reduced with improvements in health behaviors such as nutrition and exercise; better caregiver support and better access to trained clinicians and screening and prevention services.

## **Introduction**

As our country implements the Patient Protection and Affordable Care Act of 2010, we are entering into a new era in which our nation aspires to make quality health care available to all Americans. For this dream to be realized, people with I/DD must have access to high quality, accessible health care from disability-competent providers. As health insurance coverage becomes more broadly available, the gaps faced by people with I/DD will become even more evident. For the I/DD community, the biggest problem has never been accessing health insurance – most (though not all) people with I/DD have access to public health insurance coverage through the Medicaid or Medicare programs. Instead, our challenge has been accessing health care in a system that is knowledgeable about our needs and attentive to hearing our voices about what we need in our care.

For decades, disability rights advocates have worked to overthrow the medical model of disability services. We have rightfully pointed out that it is the opinions of people with disabilities ourselves rather than those of medical professionals that should decide where we live, work and play as well as how and with whom we spend our time. This advocacy has been the source of many of our movement's greatest triumphs. Now, if we are to enjoy equal access to quality health care, the self-advocacy movement will need to engage and partner with the same medical profession that we have often been in conflict with in the past. We recognize that it is in the interest of the self-advocacy movement to communicate our experiences and needs to those health care professionals that wish to be our allies, and help them get the resources and policies they need to provide us with quality care.

### **Self-Advocate Convenings**

As a result, the Autistic Self Advocacy Network and the Office of Developmental Primary Care at the University of California, San Francisco chose to partner to gather information from self-advocates about their experiences with the health care system. ASAN developed group preparation materials for local self-advocacy groups, then selected four potential locations for meeting implementation. Three sites agreed to hold a meeting, with two sites holding multiple meetings in their region. In total, six groups were facilitated by state and local self-advocacy groups contracted with by ASAN. In addition to general groups conducted by each organization, several meetings were held for particular under-served populations in the I/DD community. For example, ASAN-Boston held a group specifically for women with I/DD. Green Mountain Self Advocates held a meeting for autistic users of Augmentative and Alternative Communication technology.

Groups conducting meetings were given a list of guiding questions to use in facilitation. Each group adapted the questions into language they determined was most likely to be cognitively accessible to their members. The original questions were as follows:

- What interactions have you had with the health care systems that were related to your disability?
- What other interactions have you had with the health care systems?
- What interactions, if any, made you feel safe, respected, or accommodated?
- What did they do to make you feel safe, respected, etc.?
- What interactions, if any, made you feel unsafe, disrespected, or discriminated against, and why?
- What training would you like to see healthcare providers receive about how to treat patients with disabilities?
- Is there any other thought others have that they would like to share on the topic of navigating the health care systems as a person with a disability?

- How would your views on the health care system be different if you did not have any way of communicating with your health care providers?”

The participating self-advocacy groups were People First of Washington State, the Autistic Self Advocacy Network of Boston and Green Mountain Self-Advocates (Vermont). Each group received a \$2,000 stipend to cover costs and time associated with implementing the meetings(s). After the groups occurred, follow up interviews with select self-advocates about their experiences expanded on the issues raised in group discussions.

After interviews were conducted, the following document was developed by the Autistic Self Advocacy Network in consultation with the Office of Developmental Primary Care, summarizing characteristics of the health care experiences of participants and describing what we need for policymakers and health care professionals. The goal of this document is to provide a ready resource for self-advocacy organizations, policymakers and health care professionals seeking to speak out on or learn more about what is important for members of our community trying to access health care. Our findings and recommendations are listed throughout this document, in hopes that they will be heard and acted upon by our allies and partners in the medical and related professions.

### **Accessing Providers**

*“I need a doctor to know about having a disability.”*

Before people with I/DD can access health care, they must locate a provider that is willing and capable of serving their needs. Too often, this is the first of many challenges faced by members of our community seeking access to care. Self-advocates who spoke up in the groups pointed out many barriers to accessing providers, some of which suggest necessary changes in public policy while others point out the need for change on the part of clinicians and other health care professionals. Many participants discussed challenges with transportation, public policy and discrimination that prevented them from getting to a doctor’s office in the first place. One participant commented that, *“When I moved, I was calling to find a new doctor. One clinic said*



*they did not take people with disabilities.*” Several participants discussed transportation as a major barrier to their seeking more frequent medical care. One participant discussed difficulties they found in accessing Vermont Health Connect, the online marketplace created by the Affordable Care Act for the state, saying the site *“is very confusing and hard to use.”* Another frequent topic of discussion was the difficulty in finding a health care provider who took Medicaid.

Many self-advocates commented on the physical inaccessibility of many doctor’s offices, hospitals and other health care settings. One participant connected this issue with the larger topic of transportation, saying, *“[There is] no accessible transportation after 5 pm. I use a wheelchair all the time. I was at the hospital and I could not get my wheelchair home with me when I left. I had to leave it at the hospital and send someone to get it the next day.”*

Participants talked about not just looking for a provider, but looking for one that would understand their unique medical needs and/or make appropriate reasonable accommodations. One self-advocate commented, *“I don’t feel respected when they only see me for 15 minutes,”* repeating an often discussed difficulty many participants had with the short amount of time they were given to interact with their primary care physician. Many participants were frustrated by their clinician’s lack of knowledge of their disability, stating that they often found themselves needing to explain things to their doctor. As another self-advocate put it, *“I need a doctor to know about having a disability.”*

Several participants commented that they had more positive experiences with clinicians who had more recent training. For example, a self-advocate in the Boston area group mentioned that they had only been diagnosed on the autism spectrum after acquiring a new primary care physician in 2005, stating of the clinician (who had recently completed her residency), *“She was up there in terms of knowledge about Asperger’s syndrome. I was never diagnosed properly until I met her, I was in a psychological crisis – suicidal crisis...She picked up that I was on the autism spectrum and she made an initial diagnosis of Asperger’s syndrome.”*

A few common themes emerged in our discussions about challenges faced by people with I/DD in accessing health care providers. We have summarized them below:

- **Transportation:** For self-advocates not living in urban areas – and even for many who are – simply getting to the doctor’s office is one of the biggest barriers to seeking health care. Several group participants reported delaying or forgoing medical care due to the challenges associated with navigating public transportation or finding a ride from a family member or friend. Even self-advocates who had access to Medicaid-funded medical transportation reported this experience, noting the difficulties associated with navigating the bureaucracy necessary to access that service.
- **Locating a Disability Competent Provider:** Like most people with I/DD, the majority of self-advocates who spoke about their health insurance status in the groups had Medicaid insurance. Finding an available provider is difficult for many Medicaid beneficiaries, given the low rates the Medicaid program pays doctors compared to Medicare and commercial insurance. For people with disabilities, who must select clinicians who understand their medical needs from this already small pool, this challenge is even greater.
- **Discrimination:** Several group participants shared stories in which health care providers refused to serve them on the basis of their disability. Although such actions are illegal under the Americans with Disabilities Act, the results of our groups and interviews suggest that health care professionals may be unfamiliar with their obligations under federal civil rights law.
- **Physical Accessibility:** Inaccessibility was a frequent discussion topic among group participants, citing challenges in accessing hospitals, doctor’s offices, examination equipment and other critical aspects of the health care system.
- **Cognitive Accessibility:** Navigating the health insurance system that pays for health care can be a difficult and bureaucratic process for all Americans, but for people with I/DD it can often be the access barrier that prevents seeking necessary health care. Interacting with insurers, selecting a health plan, finding a provider, navigating pre-authorization requirements and other challenges associated with the health care system are particularly

difficult for many in our community. Lack of cognitively accessible materials to help people make use of their health insurance coverage represents a sizeable challenge for many self-advocates with I/DD seeking out health care.

### **Medical Practice**

*“I would like doctors to get to know you a little bit and ask us what we need assistance with.”*

Once at the doctor, self-advocates reported a variety of different experiences. Many self-advocates participating in groups indicated that they had strong positive relationships with a longtime clinician who took the time to explain their medical needs to them in an accessible fashion. Unfortunately, many also reported being disrespected, confused or having their needs ignored by their doctor. Several self-advocates talked about the difficulty they had explaining their needs to the doctor as a result of their own lack of awareness about their disability. One commented, *“When I go to the doctor, I just do check-ins. It’s frustrating because it’s hard to explain how you feel. I don’t know what my disability is.”* Another commented, *“I had to go to the doctor to tell them about my stomach issues that cause anxiety. I had to explain this to them and it has been very difficult. It’s been difficult to go to the doctor since it’s hard for me to explain things to them.”* Some of the most interesting exchanges came between group participants. For example, when one participant commented, *“They talk to my parents about my disability because it might be hard for me to explain so my parents explain. I am their son but as a child I did not have rights to say things,”* another responded by stating, *“You should have rights to say what you want, to speak.”*

Many self-advocates reported having staff members or providers go to the doctor with them to help explain medical issues both to them and to their doctor. Stated one participant, *“My home provider comes with me. She shares the information and the problems I may have as far as my diabetes goes. That way I can understand. And the doctors can understand. Usually I have questions but my home provider talks to the doctor.”* Some self-advocates indicated that they were the primary person that communicated with their clinician, but had the support of a provider when something needed clarifying. Another participant stated, *“I go to the doctor’s appointments and I talk to the doctor myself. If it is something that I can’t explain my caseworker*

*will help me know what to ask my doctor. It is really good to have someone with you.”* A third participant, a user of a voice output communication device, stated, *“I have been going to Dr. Tony Williams for many years. He takes lots of time listening to my typing. I really think he had a better understanding of my communication once he saw Wretches and Jabberers.”*

Another often-reported problem was the sense that many doctors did not have adequate knowledge about I/DD. Multiple participants expressed a desire for a doctor to check their whole body rather than the usual quick examination. Several wished their doctors would pay attention to self-diagnosis suggestions they made, saying that listening to their own reports was part of respecting self-advocacy. Another participant talked about their bad experiences with medication side-effects, saying, *“The doctor should always review the side effects of the consumer’s prescribed medications.* In Boston, a participant commented that her clinician often suggested major lifestyle changes without thinking about how her disability might make that challenging for her.

Younger self-advocates were particularly concerned about how they would be able to take more control over their own health care as they began to transition into adulthood. One participant who was approaching high school graduation said, *“I am worried about how my disability is going to affect my life after graduation.”* Another older self-advocate in the same group added, *“I learned about my condition and what makes me unique. I wish for more information. I hope doctors listen well.”* One self-advocate highlighted a frequent problem for youth with I/DD, stating that doctors need to learn how to *“help make the transition from Pediatric doctors to Adult doctors happen earlier instead of staying with Pediatricians until 21.”*

Many common themes emerged in our discussions of medical practice. We have endeavored to summarize a select group of them below:

- **Stable Relationships with Providers:** Almost all of the group participants who reported positive health care experiences talked about having a longstanding relationship with a particular doctor or health care professional who understood their needs. Like patients

without disabilities, patients with I/DD benefit from stable long-term relationships with providers that understand and communicate well with them.

- **Dignity and Respect:** Many group participants discussed frustrating experiences where their doctors and other health care professionals talking to family members or providers without acknowledging or communicating with them first. In addition, many patients reported that general health problems they faced were often presumed to be connected to their disability, leading to them to lack access to the same quality of general health care enjoyed by the general population.
- **Hearing Patient Input:** A consistent theme of group participants was a desire for their health care professionals to be more attentive to their self-reports about the impact of their disability on various health care experiences, including illness unrelated to their disability.
- **Adequate Time for Examination and Discussion:** Many people with I/DD require more time than the average patient for check-ups and other doctor's visits. In order to acknowledge both the medical complexity faced by many people with developmental disabilities and to ensure that adequate time is provided to facilitate communication between self-advocates and health care professionals, more time than the typical appointment may need to be allotted for patients with I/DD.
- **Access to Support:** Many group participants reported making use of a family member or provider as a primary or secondary means of communicating with their doctor. Supported-decision making structures for health care represent a critical area of future work to allow people with I/DD to self-direct their own health care while still having access to necessary external supports.
- **Disability Self-Awareness:** A large number of participants, particularly youth, reported having limited knowledge of their own disabilities, leading to challenges in being an active participant in their own health care. Youth with I/DD would benefit from higher quality education on self-advocacy and the ways in which their disabilities may impact their health care and support needs.
- **Transition to Adulthood:** Groups included substantial numbers of youth with disabilities, many of whom discussed anxieties and concerns regarding managing their own health care. Multiple participants talked about challenges associated with

transitioning from pediatric to adult primary care physicians. Broad interest existed in learning more about how to self-direct one's own health care.

### **Communication**

*“Just because I'm on the autism spectrum doesn't mean I have no agency over my conditions”*

Respectful and accessible communication was a frequent topic of both positive and negative experiences shared by group participants. In a group discussion specifically for augmentative and alternative communication users, many participants reported that their parents or providers were the ones that doctors spoke with, despite a desire to communicate their own needs. One alternative communication user commented, *“I don't get to talk to my doctors. Mom does the talking. It's hard because she goes by observations, not what's really wrong.”* While some report positive experiences, a disturbingly large number of self-advocates indicate that their doctors either do not recognize their communication or that they are not allowed to take necessary communication supports, such as an iPad or other augmentative voice output device, into a doctor's office or other health care setting. Some self-advocates indicate that while they are sometimes able to use speech, they communicate more effectively through the use of alternative and augmentative communication devices. For those self-advocates who do report positive experiences with having their communication respected, allowing for additional time in a doctor's visit is a critical accommodation. To quote one participant, *“I have longer appointment times to allow more time for my typing. I feel like my doctor is interested in my whole health. He asks about my work. It makes me feel like he cares.”*

Even for self-advocates who do not use alternative and augmentative communication strategies, concerns were raised over clinicians disregarding self-advocates due to body language. For example, several commenters in the Boston group expressed frustration over the clinicians insisting they make eye contact with them or ignoring their preferred communication styles. Others report challenges in understanding their doctors' communications to them. For example, many clinicians do not take the time to explain in an accessible way how they should go about managing their health care needs, assuming that family members or providers will control that

process. At times, self-advocates will receive conflicting information from different health care professionals with little opportunity for follow up questions to clarify any confusion. This is a source of significant frustration for self-advocates. As one participant commented about their feelings on clinicians, *“They should go back to school and learn more about how to treat a patient with disabilities nicely, not going too fast and acting like you know everything.”*

Other self-advocates raised challenges in understanding the communications of and having their communication understood by non-medical staff working in health care settings, such as receptionists and other gatekeepers who patients often must interact with before accessing medical care. To quote a group participant in Boston, *“Even when doctors understand disabilities, the front desk staff may not understand.”*

Select common themes on the topic of patient-provider communication included:

- **Presume Competence:** Patients with I/DD, particularly users of alternative and augmentative communication, frequently experience lack of respect or acknowledgement of their agency when visiting health care settings. For patients who require support in understanding the communication of their doctor or in making their communication understood, a presumption of competence is critical to communicating a respectful doctor-patient relationship.
- **Access to Support:** Many patients benefit from bringing trusted friends, family or support personnel with them to medical settings to help support their health related communications and decision-making. While health care professionals should always communicate with the patient first, they should be open to including designated supporters in their communications as well.
- **Respect for Communication Styles:** Whether it be communication through methods other than speech or a need for longer processing time, many people with I/DD will require communication-related accommodations to fully access health care services. The provision of such accommodations can greatly enhance a person’s ability to manage their health care needs inside and outside the doctor’s office.

- **Non-Medical Personnel:** Before interacting with a doctor, nurse or other health care professionals, patients typically communicate with a variety of support staff and non-medical personnel, ranging from receptionists, intake staff, insurers and many more. Efforts to enhance cognitive accessibility and the ease with which patients with I/DD can manage their health care must also include interactions with non-medical personnel.

### **Policy Issues**

While group participants were not asked direct questions on public policy issues, many of the groups' topics entered into this arena. Given the significant role that public programs play in health care generally and in particular health care for people with I/DD, this is not surprising. Self-advocates described their experiences with different insurers, payment delivery models (including managed care), eligibility and enrollment processes and other critical issues in health policy. Many self-advocates expressed significant frustration with the difficulties associated with finding a qualified provider who would take Medicaid. Low reimbursement rates in the Medicaid program are a significant barrier for people with I/DD seeking to access some providers with expertise. In rural areas, finding any doctor who takes Medicaid within an easy to access distance can be a challenge.

For nearly all self-advocates who discussed their interactions with insurers, eligibility and enrollment processes and other related issues, cognitive accessibility was a huge problem. Particular concerns were raised regarding the newly created insurance marketplaces associated with the Affordable Care Act. Information on whether or not one qualified for insurance subsidies, what plans offered particular benefits and how to navigate the website was not presented in an accessible format for most self-advocates who communicated on this issue. One self-advocate in Boston discussing their experiences with the state's dual eligible demonstration noted that lack of clear instructions on eligibility requirements led to him accidentally losing money by attempting to enroll in a state insurance reimbursement program that he was not actually eligible for. When it came up, the shift to managed care was a source of particular anxiety for many group participants, and there was a fear that longstanding support arrangements might be disrupted by the transition away from fee-for-service Medicaid. Members of the



discussion groups indicated that even small increases in co-pays could make it less likely for them to access needed health-care. One participant discussed his problem with rising co-pays in his state, stating, *“If you go to the Emergency Room you have to pay \$25. Co-pays for doctor visits is going up. Co-pays for meds going up from \$2 to \$5.”*

Many self-advocates described their use of provider staff to help them access health care settings and communicate their needs to doctors. This raises the critical issue of whether or not assistance from providers in navigating health care services will be reimbursed by state Medicaid programs. Recent guidance from the Centers for Medicare and Medicaid Services has discussed the circumstances under which community-based services can be used to assist a person with a disability in navigating a hospital environment during a short-term acute care stay. Given the significant role that paid service-providers play in helping people with I/DD access health care and communicate their needs to clinicians, clearer guidance on this topic may be important.

Self-advocate group participants also acknowledged that their health was related to many factors beyond traditional medical care. Issues like nutrition, stress, mental health, relaxation and work-life balance came up in discussions about health care. One participant said he was looking for help in quitting smoking. Another stated, *“I [would] probably benefit from a little bit of help keeping my life together. Even little things like, “how much am I supposed to sleep at night?” “How I balance work and personal life?” “How do I even maintain a personal life?” That sort of thing – so, in general I could benefit from a little life coaching there.”* Just as the general public looks to a more comprehensive array of health related services to manage their wellbeing, people with I/DD also deserve access to health promotion resources.

A few critical issues emerged regarding public policy and access to care for people with I/DD. We list them below:

- **Cognitive Accessibility in Eligibility and Enrollment:** Many self-advocates reported that the complexity involved in enrolling for many forms of health insurance coverage and gaining approval for certain health care procedures presented a significant access

barrier for them in accessing care. Lack of acknowledgement of the need for cognitively accessible materials and procedures that acknowledge the executive functioning challenges faced by many self-advocates with I/DD is a significant problem in improving health outcomes for the I/DD community.

- **Reimbursement Rates:** Self-advocates reported that low Medicaid reimbursement rates made it difficult for them to find and keep providers on a consistent basis. This was particularly true in rural areas and for self-advocates who did not have a stable relationship with a particular doctor or other health care provider. These challenges made it more likely for self-advocates to access clinic or emergency room care rather than have consistent and stable relationships with a physician who knows them and their needs well.
- **Cost-Sharing Requirements:** Consistent with the academic research, self-advocates participating in the groups reported that even small increases in co-pays could make it less likely for them to visit their doctor. Many self-advocates expressed frustration with out-of-pocket costs in Medicare and were concerned that changes in Medicaid might lead to similar increases beyond what they could afford. For people on fixed incomes, increases in cost-sharing is a source of particular anxiety and concern.
- **Access to Paid Support:** For people with I/DD without access to sufficient natural supports from family and friends, paid support can play a critical role in improving the quality of self-advocate health care experiences. Clearer information is necessary to help educate providers on how and under what circumstances they should support those they serve in traditional medical settings. Information on supported decision-making in health care settings is particularly important.
- **Access to Non-Medical Services:** In order to improve health outcomes experienced by people with I/DD, patients must have access to more than just high quality medical care. Accompanying services, such as nutrition, mental health care and smoking cessation services, are particularly important towards achieving positive health outcomes. Self-advocates recognize this and providers of health promotion services must adjust their offerings to make available accessible content for the I/DD community.

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