



A Blind Spot in the System: Health Care for People with Developmental Disabilities

Findings from
Stakeholder Interviews

September 2008

table of contents

Executive Summary	i
I. Introduction	1
Methodology	1
II. Findings	3
Effectiveness of the Current Health Care System	3
Barriers to Health Care	5
Recommended Competencies for Health Care Providers	7
Recommended Competencies for Caregivers	9
Perspectives on Informed Consent	9
Improving Health Care for People with Developmental Disabilities	11
Key Criteria for Improving Care	13
Getting to Systems Change	13
Ensuring Accountability	16
III. Conclusions	19
Appendix A: Workgroup Members	20
Appendix B: Interview Participants	21

Executive Summary

Background

People with developmental disabilities confront numerous barriers to maximizing their health and function. Cognitive and communication challenges increase the complexity of health care delivery, especially in a health care system that is not organized or funded to meet the specialized needs of this population. In 2006, a group of stakeholders from San Francisco and San Mateo came together to discuss barriers to care and to formulate a strategy for improving health care access and quality for this population. In order to build an understanding of these issues, the workgroup commissioned Harder+Company Community Research, a California consulting firm specializing in research and planning for the social sector, to conduct a series of interviews with stakeholders familiar with challenges faced by people with developmental disabilities.

This report presents findings from in-depth key informant interviews with 20 health care providers and representatives of county health departments, county health plans, and community-based organizations. Although limited in scope, this study provides important insight into the experiences of people with developmental disabilities as they seek and use health care. Key findings are summarized below.

Findings

Based on input from stakeholder interviews, the current health care system is substantially deficient with respect to meeting the needs of transition age youth and adults with developmental disabilities. Stakeholders agree that the pediatric system is superior to the system for adults because it includes multiple supports, such as parents, pediatricians, schools, and medical case management and other benefits provided through the California Children Services program. Stakeholders identified a number of barriers to health care for adolescents and adults with developmental disabilities, which can be summarized as follows:

- **Communication issues.** Cognitive and verbal limitations pose a challenge in communicating personal health care needs among people with developmental disabilities
- **Need for personal support to access care.** People with developmental disabilities require substantial personal support to facilitate health care access and treatment.
- **Complex medical issues.** Adults with developmental disabilities experience more complex medical problems relative to the general population and need more care coordination.
- **Lack of provider training and comfort.** Adult health care providers lack training, experience, and comfort caring for people with developmental disabilities.

- **Under-financing.** Reimbursement rates for services for Medi-Cal and other patients are insufficient given the amount of time and skill needed to serve this population effectively.
- **Closure of crisis homes.** The closure of crisis homes results in frequent admissions to emergency rooms or psychiatric hospitals. This is not only ineffective from a cost perspective, but also does not adequately address the needs of the patients.
- **Lack of clear informed consent policies.** Protocols for informed consent for medical procedures, as well as restraint and sedation, are poorly defined.
- **Access to medical information.** The lack of a complete, portable medical record that can be shared across interdisciplinary team members limits the information providers have to make cost-effective medical decisions and leads to inefficient, poor quality care.
- **Accessibility issues.** Transportation and availability of accessible medical offices limits patient choice of providers.

Recommendations

Stakeholders made a number of recommendations with regard to improving health care access and quality of care. These recommendations fall into several categories, as summarized below.

1. Health Care Provider Competencies

Stakeholders recommended a number of competencies for health care providers serving people with developmental disabilities:

- Medical knowledge about developmental disabilities, including co-occurring medical conditions
- Compassion and sensitivity
- Strong communication and observation skills, particularly for patients who are nonverbal
- Understanding of the social service and health care system that supports people with developmental disabilities, as well as the ability to communicate effectively with other providers to access and coordinate services

2. Caregiver Competencies

Recommended competencies for family and paid caregivers are highlighted below.

- Basic medical knowledge, particularly related to medications and potential side effects
- Ability to communicate effectively with physicians
- Understanding of the person for whom they are caring, including medical history
- Knowledge of the rights of people with developmental disabilities, how to exercise those rights, and how to advocate for the individual
- Understanding of the health care system including how to find and contact providers, and how to coordinate with other care providers
- Interpersonal skills such as being nurturing, caring, loving, and kind

3. Informed Consent

Stakeholders also provided recommendations regarding informed consent for adults with developmental disabilities. These included developing a protocol and streamlined way to obtain consent, using the simplest possible language in a form or a discussion with patients, and a need for a procedure to evaluate competency to make medical decisions. A supported decision-making model is another recommendation. Stakeholders emphasized that the principle of self-determination is central to discussions about informed consent for this population.

4. Models of Care

Stakeholders identified a number of models of care that could enhance health care access and outcomes for people with developmental disabilities. Models recommended by participants, which are presented below, were not necessarily mutually exclusive.

Specialized health care clinic. An integrated clinic involves setting aside a special time for doctors and specialists experienced in caring for people with developmental disabilities to make their services available. Advantages of this model are increased quality of care, ease of access and coordination, and linkage to social support services on site.

Automatic managed care enrollment for Medi-Cal beneficiaries. This model would automatically enroll Medi-Cal beneficiaries with developmental disabilities into managed care. This approach would enable better tracking of health care quality and provide access to managed care resources such as a provider directory and call center that are unavailable to those in fee-for-service.

Medical home approach. In this approach, a person's primary care office provides a person's care coordination and is responsible for linking patients to resources.

University-based center. A University-based center combines services with training of students, community clinicians, and caregivers. This approach provides for special medical services and consultation when required.

Physician services agreement. This model combines general practice physicians with salary support to care for patients with complex behavioral and physical health needs.

Federally Qualified Health Center. A Federally Qualified Health Center is a health center that provides medical care to medically underserved populations and receives higher Medicaid/Medi-Cal reimbursement rates.

In addition to these models, stakeholders also recommended health care delivery components applicable to various models of service delivery, including TeleMedicine, care coordination, and health advocacy.

5. Getting to Systems Change

In order to effect systemic changes in health care for people with developmental disabilities, interview participants identified a number of changes that need to happen. These include legislative changes, identifying stable funding, changes in the health insurance system, training of health care providers,

and an increased awareness of the disparities in health care among providers, policy makers, as well as the general public.

While most stakeholders agree that ultimate accountability for the health of adults with developmental disabilities should rest with the government, interviewees also discussed the need for a web of accountability and checks and balances across all levels and stakeholders within the health care system. The different stakeholders in the system include the Regional Center, the county health care system, university medical centers, health care providers, community-based organizations and advocates, and caregivers.

Conclusion

Overall, this report indicates that the experiences of adults with developmental disabilities are a blind spot in the health care system. Those with developmental disabilities are easily overlooked given limitations they face in advocating for their own care. The blind spot occludes perception of a phenomenon that is not only deeply troubling, but also difficult to face in light of the challenges of health care reform. Despite this, findings from this paper suggest that alternatives to the current status quo are not only possible, they are morally and legally justified.

I. Introduction

People with developmental disabilities confront numerous barriers to maximizing their health and function. Cognitive and communication challenges increase the complexity of health care delivery, especially in a health care system that is not organized or funded to meet the specialized needs of this population. While life expectancies for people with developmental disabilities have increased dramatically in recent decades, health care systems have not yet evolved enough to meet the unique needs of this growing population of adults.

In 2006, a group of stakeholders from San Francisco and San Mateo came together to discuss barriers to care and to formulate a strategy for improving health care access and quality for transition age youth and adults with developmental disabilities. This workgroup includes representatives from the San Francisco Departments of Public Health and Children, Youth, and Their Families, the Health Plan of San Mateo, the Golden Gate Regional Center, and the Arc of San Francisco, as well as clinicians from the University of California, San Francisco.¹ The purpose of the workgroup is to identify solutions that will improve health access, experience and outcomes for this population.

In order to build an understanding of these issues, the workgroup commissioned Harder+Company Community Research, a California consulting firm specializing in research and planning for the social sector, to conduct a series of interviews with stakeholders familiar with challenges faced by people with developmental disabilities in accessing health care. The goals of this project were to: (1) provide information to policymakers and other interested stakeholders on the experience of care for people with developmental disabilities, and (2) to inform future efforts to improve health care access and delivery for this population, at the regional level and beyond. Information from this report will also be used by the workgroup to outline a framework for a model system of care and to design pilot programs for implementation in San Francisco and San Mateo counties.

Methodology

Harder+Company conducted 20 in-depth key informant interviews with health care providers and representatives of county health departments, county health plans, and community-based organizations. Given the regional focus of the workgroup, participants

What is a Developmental Disability?

California defines a developmental disability as a condition that originates before an individual turns 18; continues or can be expected to continue indefinitely; and constitutes a substantial impairment in three or more areas of major life activity including: (1) self care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, and (7) economic self-sufficiency. Common forms of developmental disability include autism, cerebral palsy, intellectual disability, and epilepsy.

¹ Names of workgroup members can be found in Appendix A.

were primarily from the Bay Area. However, results are likely relevant to other communities in California. A complete list of interview participants can be found in Appendix B.

The question guide for the interviews was developed under the guidance of the workgroup and focused on the following six topic areas:

1. Effectiveness of the current health care system for people with developmental disabilities;
2. Barriers to care;
3. Competencies needed by health providers and caregivers working with this population;
4. Informed consent issues related to health care delivery;
5. Roles of key groups involved in the delivery of care to this population;
6. Potential strategies and models for improving health care.

Interviews were conducted via telephone during July of 2008.

II. Findings

Effectiveness of the Current Health Care System

Interviews with stakeholders indicate that the current health care system is substantially deficient with respect to meeting the needs of transition age youth and adults with developmental disabilities. Most agree that the system for children is fairly successful, because individuals have multiple supports, including parents, pediatricians, schools, and medical case management and other benefits provided through the California Children Services program. In addition, there is a clearly defined structure in place in terms of roles and legal responsibilities among these entities. On the other hand, the system for adults is considered weak and substantially ineffective. As one doctor reported, “The majority of adults with developmental disabilities are not getting any care at all. Even if they see a doctor very little happens during the visits which might improve health.” Words and phrases used to describe the system for adults included “nonexistent,” “wasteful,” “traumatic,” “dangerous,” “widespread medical neglect,” and “dramatic health care disparities that are unconscionable in this country.”

The point of transition from pediatrics to the adult health care system is a critical falling off point in care for many individuals because the resources available to children and their health care providers are no longer available. For example, pediatricians have mandated training; multidisciplinary assessment, consultation and training clinics; and Developmental and Behavioral Pediatric consultants. Funding sources such as First Five, California Children Services, school districts, and University Centers of Excellence in Developmental Disabilities exist. There is also funding for research infrastructure such as Developmental Disability Research Centers and training grants such as Leadership Education in Neurodevelopment and Related Disabilities grants. There is a division at the Centers for Disease Control, the National Center for Birth Defects and Developmental Disabilities to study epidemiology and effective diagnosis and treatment. As part of standard health care benefits, children also have funding for frequent wellness visits and for developmental screening.

The transition to the adult health care system signals the beginning of the many challenges people with developmental disabilities will confront in their attempts to access health care throughout their adult lives. For example, today’s primary care physician shortage, in which only two percent of graduating medical students plan to work in primary care internal medicine, makes it difficult for any young person transitioning to the adult system to locate a doctor.² Relative to the rest of the population, however, young adults with developmental disabilities are at a disadvantage in terms of finding a provider due to their complex and multi-faceted needs. Once a doctor is located, individuals and families feel that they have to “start over again” in terms of educating a new provider about specific

² Hauer KE, Durning SJ, Kernan WN, et al. Factors associated with medical students’ career choices regarding internal medicine. *JAMA*. 2008;300(10):1154-1164.

“If you can fill your chair with someone who can pay private fees and sit still, versus someone where you get 30¢ on the dollar from Medi-Cal and who takes longer and who you don’t feel comfortable dealing with, it’s obvious who most doctors will choose.”

– Clinician

health care needs and disability-related challenges and in creating a new team of care providers. In some cases, individuals continue to see their pediatricians into their late 20s because the quality of care is higher compared with the alternative. This situation, however, is atypical because most pediatricians are unwilling to see adult patients due to low reimbursement rates for services rendered.

According to some, the current system works for a certain part of the population; that is, those with minimal health care needs get reasonably good care because their needs are similar to the average population. However, as the needs of patients get more complicated – whether this is due to aging, the nature of an individual’s disability, or serious health issues – the system is less capable of responding.

People who are largely not getting care are those with characteristics that make people not well served in a mainstream practice and for whom special medical services have not been developed and funded. According to one doctor, this includes people who have “difficulty waiting, behaviors that limit cooperation, special medical problems, multiple caregivers or complex interdisciplinary teams, people with multiple specialists, mental health problems, challenges getting them undressed and safely on an exam table, communication challenges, those who require diagnosis based on direct observation, and those who require increased time to take history.”

The ineffectiveness of the system is frequently related to the lack of adequately trained physicians to care for people with developmental disabilities. This is both an issue of competency and health care finance. In terms of competency, adult health care providers, unlike their pediatric counterparts, are not trained in how to care for people with developmental disabilities. With regard to financing, there is a shortage of physicians who are willing to see Medi-Cal or Medicare patients because of the low reimbursement rates for services and lack of risk-based fee adjustments. The consequences of this situation, in the words of one health care provider, are that, “Doctors don’t have the resources, tools, training, and funding needed to meet the needs of adults with developmental disabilities.” As a result, illness is often unrecognized, misdiagnosed or undertreated.

The current system, as it stands, is fragmented and not well integrated, and one county public health official noted that clients and families have to “jump through a lot of hoops” to receive services. Some related the quality of care to the level of caregiver support received by a particular individual. In other words, a person’s ability to successfully receive health care is dependent, in large part, on the quality of the support that they are getting from a family member, paid caregiver or case manager. This is because many people with developmental disabilities need help navigating the basic mechanics of seeing a doctor, including making and keeping an appointment, sharing health-related information, complying with examinations and treatment, paying bills, and resolving coverage-related issues. A county public health official commented that, in his experience, most people with developmental

disabilities go without care unless they are living in supportive housing with someone providing active medical case management.

Barriers to Health Care

Consistent with the situation described above, stakeholders identified a number of barriers to health care for adolescents and adults with developmental disabilities. These can be summarized as follows:

- **Communicating about health care needs.** People with developmental disabilities are uniquely challenged when it comes to communicating personal health care needs due to cognitive and verbal limitations. According to those interviewed, individuals are commonly unable to identify pain, describe symptoms of illness, or articulate indicators of discomfort to physicians. Adults with developmental disabilities sometimes become anxious in medical settings or misunderstand physical exams as physical threats. For non-verbal persons, pain may manifest itself as a behavioral issue, a situation which needs to be recognized and addressed appropriately by others. The end result is that pain is often unrecognized, misdiagnosed or undertreated, and serious medical problems are frequently addressed at later stages. One nonprofit executive provided a typical example from his agency: “We sent one of our clients to the hospital and the hospital sent him home. A couple of days later, we find out he has a broken leg.”
- **Need for personal support to facilitate care and treatment.** As indicated previously, people with developmental disabilities require substantial support to access health care. In some cases, parents can provide support to their children. However, this support is limited. A county health plan administrator explained, “Unlike elders, where your kids advocate for you, here are people where their parents are the advocates and their parents get old and tired and they die.” In addition to aging, issues of poverty, literacy, and lack of English-language skills can interfere with parents’ ability to navigate the health care system on behalf of their children. Beyond parents, support may also be provided by a case manager or paid caregivers. However, access to these types of supports is strained due to eligibility limitations, under-financing, and workforce retention issues.
- **Complexity of medical problems and need for care coordination.** Adults with developmental disabilities experience more complex medical problems relative to the general population, according to those interviewed. One county public health worker explained, “Think about how hard it would be to see someone who is non-communicative, in a wheelchair, has a flu, and who also has conditions common with Down syndrome.” Complexity of issues translates into a need for longer patient visits and for more interdisciplinary care management. Stakeholders note a lack of incentive for primary care physicians and specialists to coordinate as there is no reimbursement for this effort. One disability advocate spoke about her personal experience in this regard. She commented, “My daughter has a geneticist, a neurologist, a gastroenterologist and a primary health care provider and they don’t get reimbursed for coordinating.” In managed care environments, physicians are often allotted just 15 minutes per patient, an amount of time which stakeholders view as deeply insufficient for serving this population.
- **Lack of knowledgeable and sensitive providers.** Interview participants overwhelmingly agreed that adult health care providers, including dentists, lack training, experience and comfort caring

for people with developmental disabilities. Many attribute this situation to the fact that typical medical school curriculum does not include training in how to treat this population unless you specialize in pediatrics. A county health plan administrator commented, “Even when you have someone interested in serving people with developmental disabilities, they are the salmon swimming up stream. How do you learn? What do you do?” As a result, providers lack both knowledge about disorders and diseases that can co-occur with specific disabilities as well as comfort in working with people who have developmental disabilities.

“The amount of time it takes to do the same procedure for a person with developmental disabilities as opposed to a run of the mill patient is significant, and doctors are not paid for the difference.”

– Nonprofit executive

- **Lack of doctors willing to care for people with developmental disabilities.** Locating a health care provider willing to treat someone with developmental disabilities is a severe challenge in and of itself. A county health plan representative commented, “Our staff spends a lot of time trying to intervene and beg doctors to see these folks.” According to stakeholders, this situation is a function of multiple and inter-related issues including providers’ lack of comfort working with this population, the amount of time needed to conduct patient visits, and financial disincentives. The current shortage of primary care providers compounds the challenges of finding physicians who can serve adults with developmental disabilities. One clinician explained, “There are just not a lot of people in primary care. Providers can pick and choose who they want, and they won’t choose someone with poor reimbursement.”
- **Low reimbursement rates for health care services.** Deficient financing of health care services used by persons with developmental disabilities is perhaps the most significant barrier to care, according to those interviewed. As one doctor expressed, “Money is the biggest issue. If there were sufficient funding for a visit that included the amount of time it would take, more doctors would see these patients.” Although the number of people with developmental disabilities who are Medi-Cal beneficiaries is unknown, stakeholders estimate that they comprise a substantial proportion of this population. Navigating the eligibility system is difficult and many providers are unwilling to accept Medi-Cal due to low reimbursement rates for services. A San Francisco-based clinician commented that providers who serve patients with developmental disabilities operate at a net loss because current reimbursement rates do not account for the amount of time and skill needed to serve this population.
- **Closure of crisis homes.** The closure of crisis homes is an added barrier for this population. Crisis homes are a place where individuals can be assessed and their medical and mental health problems stabilized. Many homes have closed due to freezes in the rate of Medi-Cal reimbursement for these services. One stakeholder reported that clients who cannot be kept in a residential setting are often admitted to the emergency room or to psychiatric hospitals. According to stakeholders, not only is this an unsuitable environment to address a change in service needs, it is also inefficient from a cost perspective.

- **Lack of clear policies with respect to informed consent, restraint and sedation.** Adults with developmental disabilities may require restraint or sedation for even routine preventive care, such as dental, pelvic and rectal exams. However, procedures for informed consent for these and other procedures are poorly defined and cumbersome. One county public health official noted, “Primary health care providers don’t even know the protocol on how to administer these techniques and obtain consent for these kinds of procedures.”
- **Lack of medical history information.** Clinicians who were interviewed report that it is often difficult to track down the medical history of a patient. Clients have typically received assessments and care in many places and their records are voluminous. No one person is likely to have a complete record and the complete record is usually too large to gather and review. There is no mechanism to develop a portable electronic medical record that can be shared across interdisciplinary team members or an updated medical summary available to all team members. This limits the information health care providers have to make cost-effective medical decisions and leads to inefficient, poor quality care.
- **Need for transportation and physical accessibility.** Other barriers described by interview participants include transportation and physical accessibility of offices. A state disability advocate explained, “The number of accessible providers limits choice. Often, someone with a physical disability will get referred to someone who does have accessible diagnostic equipment. There may be a provider that has accessible equipment, but they are an hour away so then you need transportation.”

One final barrier to the delivery of quality health care noted by some interview participants is the lack of research on access to health care for people with developmental disabilities. There is no national research agenda for best practices or on the cost effectiveness of various service models for serving people with developmental disabilities. There is a dearth of clinical research to answer basic clinical questions regarding health care for adults with developmental disabilities as they age. Overall, this translates into a lack of data that could be used to drive health care reform and related policy change initiatives and to improve care.

Recommended Competencies for Health Care Providers

Given the critical role that health care providers play with respect to the health care experiences of people with developmental disabilities, stakeholders were asked to identify the types of competencies important for serving this population. Recommended competencies are discussed below.

Medical knowledge specific to developmental disabilities. Health care providers first and foremost should have medical knowledge about disabilities, according to those interviewed. Providers should understand symptomology, characteristics, and the natural history of developmental disorders, as well as recognize that there are differences in ability levels of specific individuals who share developmental conditions. Providers should also have knowledge of specific medical conditions that co-occur with known developmental disabilities. For example, adults with Down syndrome often experience immune system problems and heart and thyroid conditions requiring specialty care.

Stakeholders also suggested that providers be educated about physical and psychological issues. Medical providers should also understand diagnostic testing, psychotropic medications, behavioral intervention, and use of adaptive equipment.

Compassion and sensitivity. In addition to basic medical knowledge, interview participants commented that health care providers should be sensitive to the needs and experiences of people with developmental disabilities. This includes having compassion, good listening skills, and maintaining flexibility. Stakeholders further commented on the importance of the provider’s understanding of the contexts in which individuals may live and how that will influence treatment compliance. They should be aware of the challenges that people with developmental disabilities face on a daily basis and the types of accommodations they might need.

“Providers should be familiar with programs that serve adults with developmental disabilities. They should know about legislation and the rights of individuals and families. Oftentimes, families learn these things by trial and error.”

– County public health official

Strong communication and observation skills. Stakeholders further added that health care providers should also have strong communication skills in order to work with clients that are nonverbal. Specifically, providers should have strategies to gain a history, screen and evaluate an individual when the patient does not communicate in typical ways. Providers must also have skills to interact with families or primary caregivers effectively.

Understanding of the health care system. According to stakeholders, health care providers should furthermore have an understanding of the complex system of agencies that support people with developmental disabilities. They should be knowledgeable about how to access additional resources to support the care of patients with developmental disabilities. Interviewees commented that providers needed to be aware of the different players, and how to get patients’ needs met. Importantly, providers must be knowledgeable about community resources and other organizations that serve people with developmental disabilities. In addition to knowing what services are available, health care providers should also have the ability to communicate with these other agencies in order to coordinate services. One medical professor suggested that providers should be trained and encouraged “when they are still at a young and impressionable age” to appreciate having a comprehensive care coordinator role as part of their responsibility of being a good primary care doctor or nurse. Moreover, providers should have legal knowledge, specifically about relevant legislation for people with developmental disabilities, including the rights of individuals and their families.

Medical training and experience. Adequate training is at the heart of these competencies, and stakeholders reported that providers should have exposure and opportunities to work with people with disabilities throughout their medical education. Others suggested that holistic curriculum in medical education would enhance the skill set of health care providers to serve people with developmental disabilities.

Recommended Competencies for Caregivers

Caregivers are also essential healthcare partners for people with developmental disabilities. Recommended competencies for relative and paid caregivers are highlighted below.

Basic medical knowledge. Most interviewees stated that caregivers should have some medical knowledge, particularly related to medications that the individuals they care for are prescribed. They should be aware of potential side effects and how to monitor for them. Additionally, caregivers should understand the need for medication and be able to help with medications and treatment compliance. Caregivers should also have first aid training, an awareness of the medical conditions that are common in people with developmental disabilities and those that are specific to the people for whom they provide care. They should have good observation and assessment skills to recognize illness. Furthermore, training in developmental expectations, particularly as children mature through adolescence, is necessary for caregivers.

Ability to communicate effectively with doctors. Caregivers must also know how to communicate effectively with physicians. Stakeholders noted that caregivers need to know what information to collect and record, and how to volunteer what the doctor wants to know in a short span of time. In addition to this, caregivers should know how to maintain ongoing communication with physicians.

Intimate understanding of the person they care for. Caregivers must understand the individual that they are caring for at a deep level. This includes a detailed knowledge of the person's medical history, and an understanding of potential warning signs to identify when the individual needs help.

Knowledge of health care rights. Caregivers should know the rights of people with developmental disabilities, how to exercise those rights, and how to advocate for the individual. Caregivers should also support the involvement of people with disabilities in their own care to the maximum extent possible.

Understanding of the health care system. Moreover, like health care providers, caregivers should have an understanding of the health care system and how it works. They need to know how to find and contact providers, and when, who and how to call to get assistance. Caregivers should also have an understanding of how to coordinate with other interdisciplinary team members and caregivers caring for the person with developmental disabilities.

Interpersonal skills. Finally, caregivers should have interpersonal skills, such as being nurturing, caring, loving, and kind. Stakeholders added that caregivers must also have the time and energy to dedicate to caring for a person with developmental disabilities.

Perspectives on Informed Consent

According to the American Medical Association, informed consent is “a process of communication between a patient and a physician that results in the patient's authorization or agreement to undergo a specific medical intervention.” In order for a person's consent to be considered valid, physicians must assess whether a patient is competent to make personal health care decisions. The issue of informed

consent for unconserved adults with developmental disabilities who lack capacity to make health care decisions is complex. At present there are no clear guidelines or principles for how to address consent for legally independent adults. For adults that are already in California's Regional Center system, the Regional Center can assign someone to provide informed consent.³ However, this process only covers those adults in the Regional Center system and is cumbersome to access, especially for minor decisions. For those individuals outside of this system, there is no parallel procedure for obtaining consent. Given these complexities, stakeholders were asked to provide recommendations regarding informed consent for adults with developmental disabilities.

Many of those interviewed agreed that improving health care for people with developmental disabilities requires an overhaul of the policy issues around informed consent. Several participants recommended developing a protocol and a streamlined way for obtaining consent. This protocol could include the ability for a patient's family to provide consent provided that they are present, as relatives currently have no legal standing to consent for their children. The protocol should also address steps to take when the person's family is not present, as is the case for many adults with developmental disabilities.

Stakeholders emphasized that central to any discussion about informed consent for individuals with developmental disabilities is the principle of self-determination. Stakeholders argue that people with developmental disabilities have a right, just like anyone else, to make good or bad decisions, and providers should not assume that these individuals are not capable of providing consent without first doing an assessment of capacity to make the specific decision. According to the principle of self-determination, a provider must respect a patient's wishes if the client has the capacity to make informed decisions.

Communication is an essential part of informed consent, and one suggestion offered is that the simplest possible language in a form or discussion should always be used with people with developmental disabilities. A similar recommendation would be to find ways of tailoring the request for informed consent so that it best meets the needs of the individual. Health care providers, social workers, and families must direct their attention to finding the best possible way of communicating with people and what their care needs are. Similarly, informed consent should be a team approach to ensure that as much information is communicated as possible in terms of what is going to have to be done, as people making their own decisions need to have as much information as possible.

Some consider the informed consent to be a legal issue more than a medical issue, and providers report needing more clarity on what people can sign for. In certain medical situations, such as for necessary procedures, the medical intervention supersedes the legal concerns related to consent. However, stakeholders agree upon the importance of legal protections to ensure that the needs of people with developmental disabilities are not ignored and to assure some level of due diligence with respect to obtaining their consent. Tied to informed consent is the need to develop a practical system to evaluate competency, as mental capacity must be defined for the population who retain the legal right to make their own health care decisions.

³ California's Regional Center system, established through the Lanterman Act, is designed to help people with developmental disabilities to get the services they need.

A supported decision-making model is another recommendation for addressing the consent issue for adults with developmental disabilities. One doctor commented that conservatorship is like “taking one individual and giving them power for life” adding that it “is giving one person too much power over another person.” A model for informed consent, therefore, should take into consideration that people’s capacity is flexible and that it is not an all or nothing. For example, it cannot be determined on one date for the rest of the person’s life. Examples of possible legal models for consent include the Montreal Declaration on Intellectual Disabilities and the Mental Capacity Act of 2005 of the UK.

Improving Health Care for People with Developmental Disabilities

Given the barriers and challenges in the current health care system for transition age youth and adults with developmental disabilities, stakeholders were asked to identify opportunities for improving health care among this population. Exhibit 1 provides a matrix of models suggested by interview participants in this regard. It includes a description of the target population for each model, its key components, and advantages and disadvantages of the model. Some of the models suggested by stakeholders are models of service delivery, while others are models of payment. The models listed in the matrix are not mutually exclusive; rather may be able to overlap or co-exist.

In addition to suggested models, stakeholders who were interviewed also recommended health care delivery components applicable to various models of service delivery, as follows:

- **TeleMedicine.** Telemedicine is the use of telecommunications and information technologies to provide health care remotely. One application of this approach is to have a multidisciplinary team meet monthly through video to review charts and come up with a joint assessment and set of next steps. Another application would involve having a dental hygienist go to a group home to collect x-rays, pictures and electronic charts from patients. A dentist can look at a computer screen to make a diagnosis and treatment plan. Telemedicine is a cost-effective method for facilitating access to care and coordinating with other providers.
- **Care coordination.** Care coordination is a process whereby people with developmental disabilities are connected to services and resources in a coordinated effort to maximize the quality and experience of health care. Various models of care coordination exist including dental coordinators, nurse coordinators, and system navigators. In general, they are guided by the same principles of having a professional act as a liaison between patients and social services, managing inquiries and conducting follow-up, and working with caregivers to support prevention and treatment.
- **Health advocate.** The health advocacy model goes beyond care coordination to ensure that people receive preventive care in the form of a partner that is deeply familiar with an individual patient’s needs, history and context. Community-based health advocates also work to inform doctors about caring for persons with developmental disabilities.

Exhibit 1: Models of Care Recommended by Stakeholders

Model	Target Population	Key Components	Advantages	Disadvantages
Specialized clinic	<ul style="list-style-type: none"> Individuals with complex behavioral and physical health needs 	<ul style="list-style-type: none"> Integrated clinic with all specialists at one site available in a specific time frame (e.g., one afternoon per week) Medical & social support services provided on site Care providers develop expertise and devote a range of resources to the clinic 	<ul style="list-style-type: none"> Services provided at one site High quality of care Providers that understand the resources available No delay if need to see a specialist because they are on site 	<ul style="list-style-type: none"> Requires steady, outside funding source Patients may feel stigmatized Potential transportation issues Need to recruit staff
Medi-Cal managed care automatic enrollment	<ul style="list-style-type: none"> Medi-Cal beneficiaries 	<ul style="list-style-type: none"> People with developmental disabilities in two-plan counties are automatically enrolled in managed care (as opposed to fee-for-service) Individuals can opt out of managed care if they prefer fee-for-service 	<ul style="list-style-type: none"> Ability to track quality of care Access to directory of providers which could specify which providers have expertise in developmental disabilities Call center available to troubleshoot issues 	<ul style="list-style-type: none"> Under-funded Patients may not prefer managed care
Medical home model	<ul style="list-style-type: none"> All 	<ul style="list-style-type: none"> Primary care office is care coordinator and links patient and family with resources Checklist of core components (e.g., do they have a medical home, is care patient-centered, is it culturally competent, are they respectful, do they provide referrals when needed, do patients get needed resources, etc.) 	<ul style="list-style-type: none"> Long-term cost-efficiencies Improved quality of and access to care Increased patient satisfaction Supports physicians to coordinate and share information 	<ul style="list-style-type: none"> Lack of resources to start and sustain this model
University-based Center	<ul style="list-style-type: none"> All 	<ul style="list-style-type: none"> Combines services with training of students, community clinicians and caregivers, and consult clinics Training for doctors and caregivers Primary care physicians participate in apprenticeships from multidisciplinary teams Coordination of care philosophy Ability to conduct home visits 	<ul style="list-style-type: none"> Maximizes the use of mainstream resources by providing adequate support Provides for special medical services and consultation when required Diverse funding base (university, state, Medi-Cal waiver funding, federal monies) Mutual accountability among providers 	<ul style="list-style-type: none"> Staff recruitment Potential transportation issues
Physician services agreement	<ul style="list-style-type: none"> Individuals with complex behavioral and physical health needs 	<ul style="list-style-type: none"> Combine general practice physicians with salary support to care for a cohort of complex patients Doctors meet regularly to do quality control and develop clinical guidelines and support 	<ul style="list-style-type: none"> Flexible services can be provided Not bound to one specific clinic or location Accountability and support component Low start-up costs Easy to expand or contract number of people served 	<ul style="list-style-type: none"> Staff recruitment Hasn't been tried
Federally Qualified Health Center Model (FQHC)	<ul style="list-style-type: none"> All 	<ul style="list-style-type: none"> Health clinic within a Federally Qualified Health Center 	<ul style="list-style-type: none"> Higher reimbursement rate Less constraints on appointment length Stable federal funding source 	<ul style="list-style-type: none"> Staff recruitment Potential transportation issues

Key Criteria for Improving Care

Given the multiple approaches to improving health care for people with developmental disabilities, stakeholders were asked to identify criteria or other factors that are important to consider when testing or selecting a potential model of care. Criteria suggested by stakeholders who were interviewed include:

- **Ability to deliver improved health care outcomes.** Stakeholders overwhelmingly agree that selection of a model be based on what will deliver the best outcomes for individuals and that there is evidence of effectiveness. Stakeholders reported a need to identify outcomes appropriate to people with developmental disabilities and then conduct a pilot test to demonstrate results. Suggested outcome areas included health promotion, disease prevention, health status, service quality and accessibility.
- **Patient- and family-centered.** Several stakeholders commented that the model must be able to meet the needs of the patient and be something that the patient wants. According to stakeholders, the model should also be one that gives support to families.
- **Affordability and cost-effectiveness.** Interview participants see sustainability of the model as a key factor, making funding a necessary consideration. Related to this, the extent to which the model can become part of a regulated scheme through the public payer system and embedded in federal policy is also important to consider. Stakeholders remarked that there needed to be an institutional commitment to the program, irrespective of the initial funding source.
- **Political feasibility.** Several stakeholders argued that the model must be politically feasible. It should have the backing and support of key constituencies including health care providers, local government officials and staff, community-based organizations, and individuals with developmental disabilities and their families. This type of support is viewed as crucial for achieving policy change.
- **Coordination and linkage to services.** Other important factors relate to ease with which providers can access one another and provide linkages to community resources.
- **Ability to train other providers.** Some clinicians suggested that one criteria to consider would be the extent to which the model will train physicians and future providers.
- **Self-determination.** Stakeholders further stated that self-determination should be a criteria in selecting a model; that is, the extent to which participation by people with developmental disabilities in decision making related to their health care is maximized.

Getting to Systems Change

Stakeholders agree that health care reform is a priority for everybody, including but not limited to people with developmental disabilities. Interviewees stated the importance of health care, particularly

“We need to fix a broken system. I see this as a legislative process... that has to start at a high national or state level. We are talking about legislators finding this important enough to fund it – not just to say it’s a good idea.”

– County public health official

as health is essential to quality of life. Several stakeholders commented that health care reform is an especially important priority for people with developmental disabilities as this population is aging and there will be an increasing number of people requiring care. As such, the health care reform movement is expected to profoundly affect people with developmental disabilities.

In order to effect systemic changes in the health care system for people with developmental disabilities, interview participants identified a number of changes that need to happen. Most stakeholders identified **legislative changes** as necessary in order to move forward with a new model of health care for this population. The Lanterman Act states that people

with developmental disabilities are entitled to prompt medical care and treatment. However, without funding and an appropriate range of services available, people with developmental disabilities have no way to exercise their right. Legislation must be passed that includes funding, as well as a designation of accountability, and these legislative changes should come from federal, state, and local governments. Legislative buy-in at the highest levels in state government and agencies, including elected officials as well as people who work in the Department of Developmental Services and the health department, is essential to moving forward with health care changes for this population. Moreover, the federal and state governments need to address the resource capacity of having enough funds to provide the caseworkers, outreach, screening, diagnosis, and service provision for Regional Center clients, especially given the growing population of people with autism.

In addition to legislative changes, stakeholders repeatedly emphasized the critical importance of **identifying stable funding** to implement changes in order to ensure sustainability. Central to the issue of funding is adequate reimbursement for providers for the levels of care that are needed for adults with developmental disabilities. As such, in the words of one policy advocate, “We need to change several universes of funding.” These universes include both Medicaid and public health funds. For example, one stakeholder recommended amendments to the Social Security Act to expand what Medicaid covers. Another policy advocate recommended passing legislation that matches program money paid for by private health insurers through public payers, as “it is virtually impossible to influence private health insurance other than targeting federal legislation.”

Related to funding is the need for **changes in the health insurance system**. Interviewees discussed the need for a better insurance system that eliminates bureaucratic barriers to access and denial of needed services. Similarly, stakeholders recommend a risk adjustment or reimbursement of health care costs for people with developmental disabilities. To facilitate this process, one interviewee suggested that providers should have a diagnostic code that links with risk adjustment. Overall, policy change must address the need for increased reimbursement rates for Medicaid patients. These individuals do not have access to health care because they are limited by the number of providers that will accept public

insurance. Providers that do accept Medi-Cal have a limited number of appointment slots for patients with this insurance, as this is often necessary for their practices to stay financially viable.

Moreover, changes to the health care system require **training of health care providers**. Stakeholders agree that providers must be trained in order to effectively serve this population and that providers must know the resources that are available to serve their patients. One suggested a legislative mandate to fund training for additional internists and family physicians. By having training available and giving knowledge to physicians, some stakeholders believe that doctors may be more willing to try to find the time to treat this population.

Looking at the bigger picture, stakeholders stated that in order to bring about systems-level change, there must be an **increased awareness of the disparities in health care** for adults with developmental disabilities and how their needs are not being met in the health community. Interviewees agree that this population is one that needs to be prioritized, and in the words of one doctor, “We need to see a dawning of awareness among health care providers in general that this is an important need that they may not have ever thought about.”

Strategies for Funding

Most stakeholders see political support as essential to obtaining funding for health care reform for adults with developmental disabilities. Interviewees agreed upon the necessity of having a strong advocate for this population and an ally for political support, as reform efforts will require legislators who find this issue important enough to fund. Specific strategies suggested by stakeholders include the following:

- **Educate policymakers.** Ultimately, to successfully fund these efforts, stakeholders agree that policymakers must be educated about barriers people with developmental disabilities face with regard to accessing health care. Stakeholders agree that awareness of these issues is far too low.
- **Solicit input on potential legislative strategies.** One respondent recommended identifying senate and assembly members known for their advocacy on health care issues and approaching their aides to seek advice and input with regard to specific plans for reform.
- **Locate champions.** Many stakeholders identified the need to mobilize leadership and identify champions for this issue. These champions must be at a high level in order for change to happen.
- **Seek allies.** Some stakeholders suggested seeking the support of existing advocacy groups who monitor and take action on legislative issues. Specific groups suggested include the Association of California Nursing Directors and Maternal Child Adolescent Health Action.
- **Launch pilot or demonstration projects.** Several stakeholders suggested implementing pilot projects that would demonstrate successful outcomes for people with developmental disabilities, including cost-effectiveness or cost-avoidance. These could be used as leverage to obtain additional funding from private and government funders.

- **Maximize existing funding streams.** Some stakeholders recommended maximizing use of existing funding streams by finding creative ways to make use of what exists or by using braided funding. Potential sources in this regard include University Center for Excellence in Developmental Disabilities and Federally Qualified Health Center monies.
- **Expand existing funding streams.** Another strategy suggested by participants is to advocate for legislation that would expand existing funding streams, for example, by changing reimbursement rates for publicly-funded insurance. One stakeholder recommended advocating for amendments to the Social Security Act to expand what Medicaid covers.
- **Undertake legal action to create new funding streams.** Some stakeholders discussed pursuing legal actions to obtain results. However, stakeholders felt that this should be a strategy of last resort given the contentiousness and ill will that can be created through this type of action.

Ensuring Accountability

As reported earlier in this document, most stakeholders agree that the system for children with developmental disabilities is fairly successful because accountability for health is vested in a variety of individuals and organizations, including parents, pediatricians, schools, and the California Children Services program. Accountability for the health of adults – including ensuring broad access to care, monitoring the quality of care, and maximizing participation by people with developmental disabilities in their own care – is less clearly institutionalized. In light of this, interviews with stakeholders included questions about who should have ultimate accountability in this regard.

Overall, most stakeholders agree that the ultimate accountability should rest with the government, notably the state. The state should monitor quality and ensure access to care. The federal government should retain responsibility for Medicaid, but should have a national health insurance plan. While some placed responsibility in the hands of the government, others felt that caregivers, primary care providers, and also the individual also have a responsibility in the system. Primary care providers are responsible for health care outcomes and treatment, but are not legally responsible for access to treatment. Still others indicated that the Regional Center should have the ultimate responsibility for ensuring health care access and outcomes for their clients. As a whole, funding for the health care of people should be a responsibility shared by members of society.

Stakeholders discussed the need for a web of accountability and checks and balances across all levels and stakeholders within the health care system. Overall, interviewees identified a need for better communication and relationships between organizations. Respondents indicated the importance of having the different groups work together such that all the stakeholders know what services exist and what are missing. In the words of one advocate, “As a group, organizations have to come together to think about this systemically; they need a unified vision of what to do.” Stakeholders were asked about how the different figures should fit into the system, namely the Regional Center, the county health care system, university medical centers, health care providers, community-based organizations and advocates, and caregivers. Stakeholder comments in this regard are summarized below with respect to all groups except for health care providers and caregivers, which were previously discussed in the section on competencies.

Regional Center

Interviewees most frequently mentioned that the Regional Center should play an advocacy role for individuals who do not have access to a health care provider and assist them in getting needed services. The Regional Center was identified as an expert in what clients need and require. Similarly, participants felt the Regional Center should advocate at the local and state levels to help develop services and supports that advocates in the community say are needed. One doctor stated that the Regional Center should convey to lawmakers the message that, “This is what the advocates say we need but we don’t have enough to provide it.” Likewise, others mentioned that the Regional Center should be active in implementing new systems. One clinician suggested that they could also administer a new information system for medical records if and when such a system is developed.

Most felt that the Regional Center’s primary role should be to provide oversight and serve a quality assurance and auditing role. However, many commented that the Regional Centers are currently under-funded and expressed pessimism about their ability to deliver results in this regard. One health care provider commented that the centers are “overwhelmed by the number of people in their system.” Several referred the strain that has been placed on the Regional Centers due to recent increases in the prevalence of autism.

County Health System

Stakeholders expressed that it is critical for the local county health system, including county managed care health plans serving Medi-Cal or Medicare members with special needs (e.g., Special Needs Plans), to play a lead role in the care of people with developmental disabilities. Several argued that county health systems have the best overview of local community needs given the proportion of adults with developmental disabilities who are Medi-Cal and Medicare beneficiaries. According to interviewees, the county health system should provide affordable health care services for the indigent. One suggested that the county system should have provision within their system to serve people with developmental disabilities who have complex health care needs. One suggestion for this would be to have an interagency group of providers to talk about cases of adults with developmental disabilities, with this group serving as a forum for holding each other accountable. Another participant suggested that the county should survey the adequacy of care in various settings and provide oversight to assure that the care being provided is of highest quality.

University Medical Centers

Interview participants agreed that university medical centers serve to fulfill the roles of research, training, and education. With respect to research, stakeholders credited universities with developing best practices, and conducting cutting edge research to improve services for people with developmental disabilities. As for training, academic medical centers should have a multidisciplinary approach to training, and whenever possible should link students with community based services to provide care.

Universities may also play a role in offering specialty services or running multidisciplinary consult clinics and take the lead on consultation. One participant reported that university clinics should only be as big as needed for training and for research.

Community-Based Organizations and Advocates

Private agencies and advocacy organizations also serve as a partner and play an important role in changing policy through political advocacy. These players should ensure that policies and services that are developed meet the needs of those with disabilities and are culturally sensitive. Moreover, these agencies can provide opportunities for those in clinical training to meet and interact with people with developmental disabilities. Training for caregivers can also be provided through these organizations.

III. Conclusions

The findings from this assessment indicate that the current health care delivery system does not adequately meet the needs of people with developmental disabilities. All stakeholders interviewed reported significant problems with respect to health care access and quality for adults with developmental disabilities. This finding cuts across various health delivery systems including Medi-Cal fee-for-service, Medi-Cal managed care, private managed care, and private insurance. Stakeholders who were interviewed identified significant barriers to care facing this population. These include challenges with patients communicating their health care needs; need for personal support to access and comply with medical care and treatment; need for care coordination given the complexity of medical problems faced by this population and the fragmentation of the health care system; lack of knowledgeable and sensitive providers; lack of doctors willing to care for this population; and low reimbursements rates for health care services.

Stakeholders made a variety of recommendations for improving care for this population. These include suggestions related to alternative models of care; competencies for health care providers and caregivers who work with this population; and protocols and policies for addressing informed consent. However, those interviewed for this report agree that improvements in the system of care are unlikely to happen until state and federal government meet their responsibility to fund the services and supports needed for the health and wellbeing of people with developmental disabilities.

Overall, this report indicates that the experiences of adults with developmental disabilities are like a blind spot in the health care system. Those with developmental disabilities are easily overlooked given limitations they face in advocating for their own care and that of others in their situation. The blind spot occludes perception of a phenomenon that is not only deeply troubling, but also difficult to face in light of the challenges of health care reform. Despite this, findings from this paper suggest that alternatives to the current status quo are not only possible, they are morally and legally justified.

Appendix A: Workgroup Members

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- Dr. Mary Giammona, MD, MPH, Medical Director, Health Plan of San Mateo
- Sandra Grijalva, MPH, Wellness & Aging Services Director, The Arc of San Francisco
- Dr. Clarissa Kripke, MD, Associate Clinical Professor, University of California, San Francisco School of Medicine
- Dr. Megumi Okumura, MD, Pediatrics Fellow, University of California, San Francisco School of Medicine
- Jim Shorter, JD, MBA, Executive Director, Golden Gate Regional Center
- Marlo Simmons, MPH, Adolescent Health Coordinator, San Francisco Department of Children, Youth and Their Families
- Dr. Philip Ziring, MD, FAAP, Medical Consultant, San Francisco Department of Public Health

Appendix B: Interview Participants

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- Twila Brown, PHN, NP, MPH, Director, San Francisco Department of Public Health, Maternal, Child and Adolescent Health Section
- Dr. Bob Cabaj, MD, Director, San Francisco Community Behavioral Health Services
- Dr. Lucy Crain, MD, Clinical Professor Emeritus, University of California, San Francisco School of Medicine
- Phyllis Dinse, MA, Coalition Organizer, Disability Health Coalition
- Juno Duenas, Executive Director, Support for Families of Children with Disabilities
- Alan Fox, MPA, Deputy Director, The Arc of San Francisco
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