

DELIVERY OF HEALTH CARE FOR PEOPLE WITH “DUAL DIAGNOSIS”: FROM THE PERSON TO THE POLICY

I. LESLIE RUBIN, M.D.,¹ JEFFREY J. FAHS, M.D.²
& JOAN B. BEASLEY, PH.D., L.C.S.W., L.M.H.C.

¹The TEAM Centers, Chattanooga, TN

²TNSTART, Chattanooga, TN

³Consultation and Training Services, Chestnut Hill, MA

This paper will examine the complexity and challenges in providing effective delivery of physical and mental health care to people with developmental disabilities. We will highlight a model of service delivery that focuses on “behavioral” crisis intervention and prevention which leads to a comprehensive set of interdisciplinary services and supports as well as a network of community linkages that facilitate the delivery of services. Suggestions will be offered for improving the systems of health care that will address the multiple levels of service delivery and ultimately improve the health care for people with intellectual and developmental disabilities more effectively and more efficiently and reduce the health disparities in our society.

Keywords: behavior, developmental disability, intellectual disability, mental retardation, psychiatric, services

The delivery of health care for individuals with intellectual and developmental disabilities presents with some challenging complexities.^{22,24,27} Individuals with developmental disabilities often have associated multiple and complex physical and mental health related problems. The presence of intellectual disabilities may result in difficulties understanding, interpreting, and remembering aspects relating to their health care. In light of the often multiple and complex health care issues, people with developmental disabilities are likely to encounter many different health care providers who are not necessarily familiar with the physical and mental health care needs of individuals with developmental disabilities and may be even less likely to be versed in dealing directly with individuals or their caretakers. In addition, families and other caretakers often find it difficult to keep track of and coordinate the health care needs and health care providers, particularly across a lifetime. The existing systems of health care delivery and health care financing do not adequately support the needs of individuals with developmental disabilities, which results in significant health care disparities.

For individuals with developmental disabilities who have additional mental health problems the challenge is even greater. Behavioral manifestations that are brought to the attention of health care providers are often those of a dramatic

nature and are associated with threats to the well being of the individual in question, to other individuals in the environment or to the environment itself.^{25,32} The “behavioral” manifestations may result from any number of factors that could result from a physical or medical condition, a psychiatric disorder, environmental forces or emotional reactions that may be associated with immediate or remote events. In the situation of a crisis that presents with a behavior disorder, it is often very difficult to obtain a good history from the individual with the developmental disability; it may also be difficult to obtain accurate and objective information from the people who provide day to day care for the individual. Consequently, if there is a lack of accurate historical information, it may be difficult to establish an accurate diagnosis, which makes it difficult in turn to determine the best possible plan of management. Furthermore, a plan of management, especially if it involves additional medication, may result in aggravation of the symptoms or the expression of additional symptoms, which further complicates the clinical assessment, diagnostic formulation and outcome.³²

Given the challenges presented above, it becomes important to develop strategies to deal with the multifaceted and multilayered set of conditions that prevail, and address the needs of the individuals with the intellectual and

developmental disabilities, the families and direct care professionals, the health care providers, the programs, organizations and institutions that provide services and the public policies that determine quality of care and how the care is financed.^{18,31}

In this paper we will describe a model of service delivery that responds to the needs of individuals with developmental disabilities who have associated mental health needs that reach a crisis point. We will also describe how it can be adapted in modified form to include a variety of settings and implemented to help prevent crises from occurring in the future. We will conclude with a brief discussion of the public policy implications of our experiences.

TNSTART—A MODEL FOR SERVICE DELIVERY

In the *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation 2002*, the START Program of Massachusetts was highlighted as a model of service delivery. The START program (Systemic, Therapeutic, Assessment, Respice and Treatment) was developed in 1988 to provide community-based crisis intervention and prevention services to individuals with developmental disabilities and mental health care needs.^{5,9} Interventions are effective when there is communication and cooperation in assessment, planning and decision-making between those individuals and agencies which provide services and those who use the services. The program emphasizes collaboration between agencies and their operating systems along with coordination of services to assure continuity of care through an often complex set of public and private community-based services. This operating philosophy shares many principles with the Medical Home concept of the American Academy of Pediatrics.^{20,30}

The program is then established as a community-based infrastructure of services and supports for individuals with intellectual and developmental disabilities who present with a crisis of a behavioral nature that threatens their own safety and the safety of others. The crisis response component of the operation then sets about to diagnose and define the situation and propose a plan of immediate management with a strategy for individuals, their families and service providers to follow during periods of difficulty. A system of monitoring and coordination is then

instituted to ensure that the guidelines are followed, the systems are in place and operational and that the individual is in a stable and healthy condition in a safe and least restrictive environment with appropriate services and supports to reduce the likelihood of recurrence. Not only does the system provide for the optimal management of the individual and the crisis but in doing so, it promotes the strengthening of the components of all elements in the service delivery system.⁷

TNSTART (Tennessee START) was established in 2005 with funding from the State of Tennessee, Division of Mental Retardation Services (DMRS) to The TEAM Centers of Chattanooga, TN to establish a program to improve the system of services and supports for individuals with developmental disabilities and associated mental health conditions living in eastern Tennessee. Although the infrastructure of services and supports as well as the population bases are substantially different in Chattanooga, TN compared to northeast Massachusetts, the underlying philosophical approach was consistent with the original START program and other models around the country.^{10,11,13,28} These are:

1. The establishment of an infrastructure of community linkages and collaborative relationships to form the basis for the smooth and seamless transfer and transition processes that are critical to effective and sustained health care delivery. The components of this "cross systems" collaborative include state and local public agencies and resources as well as private agencies and individual providers of services. Although the population base and available resources were not as numerous and varied in eastern Tennessee as in eastern Massachusetts, good working partners were identified, cultivated and eventually recruited to participate in the program.
2. An interdisciplinary clinical team was formed to provide opportunities for consultation, education and individualized treatment planning. The TNSTART team includes a psychiatrist (who is also the Program's Director); a primary care physician specialized in developmental disabilities, psychologists specialized in behavior management, social workers and mental health counselors.

3. Respite services are a critical component of the original START program, however, although TNSTART does not currently provide crisis or planned respite services, access to needed respite services is emphasized through advocacy and affiliation and linkage agreements.⁵

Service Delivery Components of TNSTART

1. **CRISIS RESPONSE.** TNSTART provides 24-hour mobile crisis services to assist in times of crisis, with after-hours (5:00 P.M.—9:00 A.M.) Monday through Friday and all weekend. TNSTART on call personnel provide assistance to families, DMRS psychiatric pre-screening teams, and residential providers 24 hours a day, 7 days a week.

2. **CROSS-SYSTEMS CRISIS PREVENTION AND INTERVENTION SERVICES.** This involves the active engagement of collaborative partners in the crisis management and ongoing maintenance and is reinforced through regularly scheduled meetings to discuss process and practice.

3. **BEHAVIORAL RESPITE PRESCREENING AND SUPPORT SERVICES.** This requires the availability of respite services at a time of crisis or following discharge from a psychiatric facility. Coordination and collaboration are critical elements particularly with transitions.

4. **OUTPATIENT SERVICES.** These include diagnostic and ongoing psychotherapy, developmental medicine, and psychiatric services to serve the individual's needs as well as provide knowledge, expertise and understanding to the community agencies towards ensuring optimal health and well-being and prevention of further crises. TNSTART does provide outpatient neuropsychiatric services to more than 70% of all clients referred to the program and also offers comprehensive primary medical consultation and coordination, a service not provided in the original START program.

5. **OUTREACH SERVICES.** These are critical to the entire operation requiring clinicians to facilitate relationships with community partners and assure the quality of ongoing services. Regular community visits and meetings occur over the continuum of services. This includes working with families as well and requires orientation and training to assure stability and security. Consistent with the original START program in Massachusetts,⁴ it is important to note that more

than 40% of the individuals served live with and rely on their families. Therefore, the mission of TNSTART includes active collaboration, support and outreach to family caregivers.

6. **CROSS-SYSTEMS COLLABORATION, TRAINING, AND EDUCATION SERVICES.** This component operates both informally on an ongoing basis as well as periodically at formal levels. Regularly scheduled meetings are all considered opportunities for teaching and learning among all participants in the process and are encouraged at all times. The learning relates to multiple factors including the availability of resources, configuration of resources, clinical and practical management and given by the TNSTART team members at local, regional and national meetings, workshops and conferences.

Approach to Management

The approach to the management of a crisis situation in which there is a significant disruption in the status quo, to the extent that there are serious threats to people or property, generally follows the outline presented above. The network of services and the interdisciplinary team assure an approach that is interdisciplinary, comprehensive, coordinated and person centered as well as being community-based and culturally sensitive to the individual, the family and the community.

The focus of management is based on the appreciation and understanding that the individual with the developmental disability has a limited means of expression and that the change in behavior which has culminated in a crisis may have a set of potential factors that have been operating over the course of time in addition to the immediate situation.^{3,8,16} The presentation varies from individual to individual and relates in part to the nature of the causative factors, the individual's innate patterns of communication and behavior, and to an underlying central nervous system disorder, such as autism or tendency to a mental illness. It may be helpful to consider that any stressful situation may result in the physiological responses that may be characterized as a *fright, flight or fight reaction*, and the expression of each individual will usually follow a familiar pattern. The clinical challenges, daunting as they may be, follow a simple logic:

Understand the lifestyle of the individual,
review the pattern of behavior and responses in

the past, particularly how the environment, the physical health and medical conditions, and the behavioral and psychiatric conditions have been expressed.

Examine and explore the current physical health, mental health and environmental factors that may have been the cause of the stress or distress.

Develop strategies for managing the acute presentation as well as the long-term maintenance and work with the cross systems team to ensure that the process is followed and that the outcome is positive.

As can be seen from this outline, a thorough, thoughtful, systematic, organized and sustained approach is critically necessary to the achievement of success as measured by optimal physical and mental health for the individual, living in an environment which assures as much security, predictability and freedom from stress and distress as possible.

At a simple level the approach to management should follow the following paradigm as closely as possible:

Assessment → Diagnosis → Treatment → Outcome

Assessment

The first order of business is to understand what the presenting problems are, what factors precipitated the crisis, and the nature of the behavior that constituted the crisis. These questions are critical to beginning the process of understanding the individual and his or her environment. It is very important to consider three critical elements in the process:

1. Environmental factors that have an impact on the feelings and reactions of the individual. These may relate to family dynamics, interpersonal dynamics, changes in the environment, such as moves or losses, and generally to the opportunity for individual choices and options in vocational, recreational or community activities and relationships.
2. Physical or medical conditions that affect well being that may be of an acute nature, a chronic nature or may be the consequence of a medication or treatment.
3. Psychiatric conditions that are part of the individual's existing condition, or those that may

emerge and arise as result of innate tendencies or precipitating environmental factors. It is also important to bear in mind that these factors often operate in tandem and it may be difficult to tease out the strands, but with a systematic, organized and rigorous plan of action, there is a greater likelihood of success.

At a practical level, the process requires a comprehensive review of historical information, including a family history, medical history, history of where the person has lived, what changes have occurred in the environment and extensive review of existing documents including hospitalization records, previous psychiatric and psychological evaluations, medical specialty evaluations (e.g., genetics, neurological), laboratory and neuro-imaging results, and a medication history, particularly psychiatric medications. It is very helpful to pay particular attention to the beneficial and/or detrimental effects of any prior psychiatric, behavioral, social, or environmental interventions, especially as they may relate to the current crisis.

The culminant element in the process is the interview and examination of the individual, preferably in his or her natural environment but a clinical situation will suffice. This represents the only opportunity to try to understand the situation from the point of view of the individual in question. Although the individual may have limited ability to communicate his or her feelings and needs to the extent that would be desirable, an appreciation of the way in which the individual communicates and behaves is most important to an understanding of the dynamics of the situation and in informing the diagnostic formulation. The physical examination is, of course, critical to determining whether there is a medical or neurological condition that could explain some or all of the symptoms.

Diagnosis

A comprehensive review of the presenting problems and the review of the historical information and records and ultimately interview with the individual and family or care providers, will allow for a formulation of what the possible causes may be and how they are operating. This constitutes the diagnostic possibilities or *Diagnostic Formulation*²⁶ which should include the medical and psychiatric diagnoses as well as functional behavioral and environmental factors.

TABLE 1. MOST COMMON PSYCHIATRIC DIAGNOSES

PSYCHIATRIC DIAGNOSIS	% OF CLIENTS
Autistic Disorder	37
Bipolar Disorder	23
Major Depressive Disorder	14
Mood Disorder Not Otherwise Specified	8

TABLE 2. MOST COMMON MEDICAL DIAGNOSES

MEDICAL DIAGNOSIS	% OF CLIENTS
Adverse reaction to medication, foods, etc.	16
GERD (Gastroesophageal reflux disorder)	16
Seizure Disorder	14
Constipation	13

It is this diagnostic formulation that will help to determine the plan of management. Tables 1 and 2 show a brief list of the most common medical and psychiatric diagnoses seen in the TNSTART program (from an unpublished manuscript, TNSTART annual report, April, 2007). As can be seen from the results, the most common psychiatric conditions are those of autism and mood disorders while the most common medical conditions relate to adverse effects of medications, gastrointestinal disorders specifically gastroesophageal reflux and constipation and seizure disorders. Awareness of these conditions can provide a very helpful guide to determine the medical and psychiatric causes of behavior disorders.

Treatment

The approach to management is multifaceted and will inevitably depend on the diagnostic formulation and include an approach to the environment, to the “behavior” and to the medical and psychiatric elements as indicated. Of all, the medical conditions may be the most straightforward, and the behavioral and the psychiatric more challenging especially if psychopharmacological treatment is to be a consideration. It is generally the case that for any given psychiatric disorder there may be a number

of treatment options which will be influenced by the diagnosis, the individual’s treatment history, potential adverse effects, and other factors. As a critical part of the comprehensive approach to treatment, environmental changes will be considered and behavior management plans will be developed and instituted.

It is important to set expectations and map out how the clinical picture will change, over what period of time, and to what degree. Additionally, it is very important to institute processes to monitor selected elements in the clinical profile. These may be in the form of data collection systems (such as frequency counts of “target behaviors”), the use of a rating instrument (such as the *Aberrant Behavior Checklist—Community* version), the use of an analog device, or the use of a calendar or other simple diary.^{17,19,29} If psychotropic medications are prescribed, it is also necessary to monitor for potential adverse effects using standard rating scales (e.g., Abnormal Involuntary Movement Scale [AIMS] for neuroleptic medications), regular weights and appetite logs, sleep record, and laboratory testing including drug levels where indicated.^{15,21,23}

Outcome

A focus on the comprehensive treatment strategy and close monitoring of the individual’s

progress with appropriate adjustments where necessary will more often than not assure a desired positive outcome. This will mean that ultimately the individual is in good physical and mental health and living in the least restrictive environment with appropriate personal choices in vocational, recreational and social activities. Outcome is also considered in relation to the satisfaction of the families and other care providers who are critical to the well-being of the individual and the long-term success of the intervention towards preventing crises from recurring.

In a survey of families who participated in the TNSTART program, the majority of family members expressed satisfaction with their service experiences and with the services they received. Additionally, the families were very helpful in pointing to important areas in which improvements could be made. At a service delivery level there is a general lack of service options and service providers and a specific need for behavioral respite services and day programming. The results also indicate that although families feel that they are invited to participate in planning and services, the service system failed to address issues confronting families as a whole. Families expressed a need for more information, education, and support services, especially in home and after hours. These findings are invaluable in guiding the future direction of the development and integration of new services and programs into the service delivery network.⁴

Case Example

Mr. A was diagnosed with autism at a relatively young age. He was nonverbal, had limited eye contact and communication, and preferred to be on his own. Although he did know and relate to his family members, he did not care for unfamiliar people. He had very specific likes and dislikes that included a real dislike for noises and bright lights. He also had repetitive mannerisms and patterns of activity. His medical conditions included a seizure disorder, which, was managed on medication, and constipation, which was managed by diet.

Mr. A lived at home with his parents until they passed away when he was 40-years-old. His two devoted sisters arranged for him to live in a community residence where they could visit often. When his sisters brought him to the home, they reported that he needed 12 hours of sleep and

that if he did not have enough sleep, he became agitated. They also reported that he became agitated with constipation or any kind of pain. They described some obsessive elements and some self-injurious behaviors, particularly if he became anxious.

Mr. A seemed to do well in the home for about four years when he experienced a sudden change in behavior. Whereas in the past he liked to sit in a rocking chair and rock back and forth, he now paced the floor. In fact, his intense and persistent pacing would cause him to sweat, to lose weight and ultimately develop a stress fracture of his foot. In addition, his sleeping patterns changed. His need for sleep seemed to diminish, and he only needed a few hours sleep. Sometimes, he did not sleep at all and instead paced all night. Because of his insomnia, lorazepam was prescribed, which worked initially but soon its positive effects ceased. The dose was steadily increased until it reached a dose of 2mg. in the morning and 4mg. at night.

Mr. A was also having behavioral outbursts day and night, which were managed with lorazepam prn, and, if this medication did not work, he was given haloperidol pm. Mr. A was seeing a psychiatrist for his challenging behaviors and was treated with a variety of other psychoactive medications. In addition, Mr. A's seizures had increased, so his neurologist had modified his anticonvulsants.

At this point he was brought to the TNSTART program by his sister and the members of his residential program. At intake a review of his history was obtained by a clinician and he was then referred to the TNSTART physician and psychiatrist. Interviews and appointments were conducted with Mr. A, his sister, attendants from his residential program; the TNSTART clinicians and physicians met both individually and as a team.

An initial review of Mr. A's history revealed that multiple physicians were prescribing medications—his primary care physician, the psychiatrist and the neurologist. The first order of business was to establish a single contact physician—in a sense a Medical Home—so that the TNSTART team could communicate with the one individual and all changes in clinical condition and management could be facilitated. The most logical role for this situation was to identify his primary care physician as the primary medical contact, particularly to deal with the

prescription of medication and coordination with the specialty physicians.

When Mr. A was first seen by the team, he was in a wheelchair, was drowsy and drooling, his foot was in a cast for his stress fracture and he was accompanied by his sister and two staff people from his residential program who had been working with him for some time and seemed to know him fairly well. Despite being drowsy he suddenly got out of his wheelchair and began to walk. His sister and one of the attendants immediately rushed to assist him, one on each side, as he lurched forward to pace back and forth in the room. It was clear that he was compelled to walk but that the stress fracture and his drowsy state posed significant risks for falling and injury. The management followed 3 tracks with the team psychiatrist reviewing and managing the psychiatric medication, the team primary care physician exploring the medical issues, while the clinicians worked with his sister and the residential program to assure continuity of care in the residential setting, attendance at appointments and follow through with TNSTART and community physician visits.

The first order of business was to review his psychotropic medications and reduce his drowsiness while trying to maintain "good behavioral control." The team psychiatrist felt that the lorazepam was clearly not helping Mr. A sleep as much as he should and was making him drowsy and weak. The medications given as prn for behavioral outbursts were not only not helping but set up a viscous cycle for incremental dosing. For this reason, he was quite rapidly weaned off the lorazepam and haloperidol. Once this had been accomplished and he was less drowsy and his behaviors were not worse, the management of the other medications was addressed and modified to give him the most effective management with the least number of medications at the lowest possible dosages.

As the psychiatric management was in process, the team primary care physician addressed the medical problems. Given the history of constipation, a review of the bowel movement revealed infrequent bowel movements and an X-ray of his abdomen was obtained. The X-ray revealed stool throughout his ascending transverse and descending colon. Aggressive management of his constipation was immediately recommended. In addition, he was referred to a gastroenterologist where a workup revealed

gastroesophageal reflux and infection with *Helicobacter Pylori*, both of which were treated.

As the management of his medication and medical conditions took place, he began to improve, and, in fact, when he came to the visits, he was quite calm and reasonably cooperative. His sister and the residential staff, however, reported continued problems and brought a videotape of his behavior to demonstrate that he was continuing to have difficulties with intense pacing and emotional outbursts which made it difficult to manage him. In fact, the problems which initiated his contact with the medical profession were unchanged—he was only less drowsy but as active if not more so. For this reason the staff brought a videotape to demonstrate that not only had we not helped him, but that he was back to where he had started.

A review of the videotape of Mr. A's behavior demonstrated his pacing back and forth in his residence with his left hand cupped over his left ear, the thumb of his right hand inserted into his right ear while his fingers were spread over his eyes as if to shield them from seeing. Thus, the videotape clearly demonstrated what the staff had been saying. However, the videotape also provided significant information on the residential setting, and in the background, one could hear loud noises from a television set and from many people talking and shouting. Clearly, Mr. A was trying to block the noise and bright lights.

On direct questioning his sister reiterated that he liked to sit in a dimly lit quiet room and rock on a chair; the residential staff also recalled that Mr. A preferred quiet and dark environments and had been happy for the first four years in the residence. Apparently, when Mr. A first moved into the residential facility from home, his roommate understood and respected his need for darkness and quiet and would even tiptoe around when he was near. This roommate was then moved from the residence, and a new roommate took his place. The new roommate liked to play the guitar, listen to the radio, and keep the lights on. If Mr. A would try and switch off the lights, the roommate would turn them back on. This change coincided exactly with Mr. A's change in sleeping patterns, pacing back and forth, increased outbursts of agitation, and change in seizure activity, which resulted in changes to his medication and the worsening of his symptoms.

In light of this knowledge, Mr. A's living arrangement was changed, his roommate was

moved out, the television set was kept off when Mr. A was there, and the lights were dimmed. After the treatment of Mr. A's gastrointestinal problems, the rearrangement of his environment, and the reduction in his medication, his sleep pattern and behavior began to improve. He was also slowly weaned off all of his psychotropic medication, until he was only on anticonvulsant medication to control his seizures, and his behavior had returned to its original status.

COMMENT

This particular case report was chosen because it is not an uncommon situation and because it represents not only the story of how challenging clinical problems present, but also how we often need to tease out the physical, psychiatric, environmental and even the iatrogenic elements from each other. As can be seen from the story, the challenge for the providers of care—whether they were his family, his direct care staff or their supervisors, or his nursing and medical care providers—was to try to interpret and manage changes in his behavior that clearly required attention and potentially could have caused harm to himself or others. The initial reaction was to view this change in behavior as a psychiatric problem that needed to be solved. The solution was to give him medication to manage his behavior.

Too often, psychotropic medication may lower the threshold for seizures with an increase in seizures requiring modification and possibly increase in seizure medication.¹ Psychotropic and anticonvulsant medication may have adverse behavioral and medical side effects that may include aggravation of constipation. Constipation has been reported to result in significant changes in behavior and so we can see a vicious cycle emerge. This resulted in a vicious cycle of increased symptoms with greater complexity and a corresponding increase in the number and dosage of medications.^{17,29}

In the case of Mr. A, we see this play itself out quite dramatically, particularly with the added complication of fragmentation of medical care. It is clear in retrospect to see what factors prompted the change in behavior and how easily and rapidly a trajectory of management became the inexorable path towards increasing complexity and debility. It also illustrates the critical importance of obtaining a detailed clinical history that includes medical, environmental and social aspects and a

constant attention to the smallest and sometimes seemingly insignificant details not only to help to inform the diagnostic formulation but also the plan of care and plan of management. In addition, a collaborative team process is essential in managing individuals with significant developmental disabilities and complex behavioral and emotional reactions and/or medical conditions.

The coordination of care through the Medical Home concept is invaluable in the situation of individuals who have complex medical, behavioral and social factors. In these situations, the individual requires a number of providers often representing a number of different agencies all working together to support the individual during the crisis as well as assisting with transition to a less restrictive environment. Furthermore, there is a need to constantly re-evaluate and re-assess the situation as new factors come to light and the interventions are put in place. The satisfactory outcome in this case was the result of a) a comprehensive, coordinated, consistent interdisciplinary and community-based approach which included a crisis response system which could be contacted by the family, the program staff or any other provider of services; b) a crisis response team that could initiate the process, health care professionals experienced in dealing with individuals with developmental disabilities who had medical and psychiatric conditions who worked collaboratively in a functioning team that met on a regular basis; and c) a system of monitoring and management that included significant communication between people in the different organizations and a long term plan of management with transition to the community. Not only is the approach to management beneficial to the individual with the developmental disability, the family and other service providers, but it saves on the cost to the health care delivery system by reducing expensive treatment and services such as additional staffing, hospitalizations and collateral damage.^{2,6,12} In the process of managing this challenging situation, all involved parties were educated by learning about behavioral and psychiatric presentations and management, medical conditions and their complications and manifestations, community resources, and group process, among others. Thus the system not only benefits the individual with the developmental disability and the family, but also the associated service providers and

ultimately, by extension, the health care delivery system and the whole community.

CONCLUSION

As we had discussed, the challenges in developing and implementing a suitable, comprehensive, coordinated community-based and person-centered system of delivery of health care requires consideration of working parts that communicate with each other regularly and consistently. The goals are to assure optimal health and well being by applying best standards of practice in a cost effective and cost efficient manner.

In order to achieve these goals, we need to look at strategies that do not merely address short term outcomes, but think systematically and develop approaches that represent an investment in long range plans that require cooperation, communication and coordination of strategies that address the multiple aspects and facets of the whole picture.²⁷ This requires thought, time and financial commitment to a shared future of improved health care for all citizens, with those with developmental disabilities serving as a prototypic model since they represent individuals with greater needs, thereby challenging our traditional practices of developing systems for those with the least needs.

As a society, we need to address the needs of our vulnerable populations and begin to look at a comprehensive approach to remedying the situation through a process of education for all constituencies including:

1. Individuals with developmental disabilities in understanding their health and health care needs, especially primary prevention through healthy lifestyles;
2. Family members and other direct care providers in understanding the health care needs and services;
3. Health care providers on order to develop understanding and skills in serving individuals with developmental disabilities in their communities;
4. Agencies and corporations that design, develop and provide the health care services within appropriate systems of health care delivery; and
5. Legislators and financial institutions that plan and implement health care reimbursement

structures and about models of effective and efficient systems of service delivery.

Once we are dealing with an informed and discerning community, we must assure them that knowledge and information about the health care needs of individuals with developmental disabilities and the resources to meet those needs are available and accessible to all who need to know. This requires that there is clear and consistent communication and coordination between all involved parties to assure that all health care needs are addressed and that there is no unnecessary duplication of services or confusion about the plan of management.^{14,31} The Medical Home concept embodies these principles and has been shown to enhance quality of care and reduce health disparities particularly for those individuals with complex medical conditions and adverse life circumstances.² In addition, a quality enhancement system must be in place to monitor the practices and systems in order to assure optimal delivery of health care.

This comprehensive approach requires resources and a commitment on the part of our legislative leaders and policy makers to develop and implement effective and efficient programs and systems of health care delivery; a more reasonable compensation strategy will inevitably lead to improved health in this population and reduce the current level of health care disparities.

In 2002, the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation (*A National Blueprint to Improve the Health of Persons with Mental Retardation*) concerning the challenging nature of the health care needs of individuals with developmental disabilities, was presented and models of service delivery were explored. One such model was the START program of Massachusetts along with other program models.³¹ Unfortunately, in the 20 years since the original START program was developed, and the five years since the report was published, there has been very little progress at a policy level. Programs like TNSTART continue to be considered "demonstration projects" and emerge in isolation, serving small local populations, while the majority of the population in need still deal with continued crises and the costs to the system continue to be spent on dealing with crises instead of developing the infrastructures that will help to prevent the crises. In order to effectively serve people in greatest need, public policy planners must consider an

investment in the permanent reduction of structural barriers in service delivery as a top priority in providing more cost-effective and efficient care and treatment.

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CORRESPONDENCE: I. Leslie Rubin, M.D., 776 Windsor Parkway, Atlanta, GA 30342; tel.: 404-303-7247; fax: 404-303-7837; email lrubi01@emory.edu.