

***INTRODUCTION TO VERMONT'S DESIGNATED
DEVELOPMENTAL SERVICES SYSTEM***

By:

William H. Ashe, Ed.D.

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Introduction to Vermont's Designated Developmental Services System

Executive Summary

This paper is written to provide an overview of the system that provides services and supports for persons with a developmental disability in the State of Vermont. These services are currently funded and overseen by the Vermont Department of Aging and Independent Living which is part of the larger Agency of Human Services. The majority of funding within this system are Medicaid dollars that are expended according to Vermont's Global Commitment Waiver as approved by the Federal Government.

Developmental Services: What is it, Who Benefits, and What Services are Provided

Developmental Services (DS) are long term care services, and as such people who enter the DS System will generally require supports throughout their lifetime. The needs of individuals within the system are highly varied ranging from relatively low cost support models, to people who are maintained successfully in community settings only with intensive levels of structure and assistance. People who enter the DS system are individually evaluated to assure that the service package offered an individual meets his/her needs as presented, providing only the level of assistance needed for the person to live successfully within a Vermont community.

The people who rely upon the developmental services system in Vermont are persons who have an intellectual or developmental disability. The average IQ score in the United States ranges from 90 – 100. The individuals served in developmental services have a measured IQ of 70 or below (unless on the autism spectrum), in conjunction with significant deficits in what is referred to as adaptive behaviors. These deficits must have occurred prior to the persons 18th birthday. According to the American Association of Intellectual and Developmental Disabilities, in their discussion of developing of a tool to measure these adaptive behaviors:

Adaptive behavior is the collection of conceptual, social, and practical skills that all people learn in order to function in their daily lives. DABS [Diagnostic Adaptive Behavior Scale] measures these three domains:

- Conceptual skills: literacy; self-direction; and concepts of number, money, and time
- Social skills: interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, following rules, obeying laws, and avoiding being victimized
- Practical skills: activities of daily living (personal care), occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone

These adaptive skill areas are the ones that all of us rely upon in order to live our lives safely. People who are significantly deficient in these areas do not have skills that are sufficiently

developed to allow them to live safely without the assistance of others. These individuals are also persons who have difficulty learning these skills, along with difficulty generalizing these skills across different environments. For some people this means they need total assistance in most if not all of these adaptive behavior areas. For others the need for assistance may be limited to a few areas, however, without this assistance, the individual is unable to demonstrate skills that enable them to live safely in their community.

The Developmental Services System in Vermont is based upon the needs of each individual who is served. Depending upon these needs, services that may be provided include the following categories:

- Case Management: Assistance in assessing need areas and determining strategies for addressing each need area through a Person Centered Plan. Assistance in locating and recruiting resources that are able to meet the needs as assessed. Coordination between the individual and the community resources being relied upon. Periodically updating the Person Centered Plan to assure it remains relevant.
- Home Supports: Either providing supports to an individual or family to enable the person to remain in his/her own home, or providing a residential option for the person within the community. This may include locating a person who will share their home with the person who has the disability, staffing a person within an apartment setting, or placing the person within a group home setting. The selection and design of the residential model is based upon the assessed needs of the person.
- Employment Supports: Generally staff supports that assist a person to locate a paid job in the community, and supports to assist the person as needed to learn and perform the job to the expectation levels of the employer.
- Community Supports: Assistance to support the person in learning how to access and use the resources that his/her community offers, including ongoing staff supports to assure that the individual is able to utilize community resources in an appropriate and safe manner.
- Clinical Supports: Based upon the needs of the individual, clinical supports may include psychiatric consultation, behavior support, therapy support, or other clinical services that are essential for the person to live in his/her community safely.
- Respite Support: Supplemental resources to augment or provide relief for a primary care giver(s) to assure that care provision is stable over time.

Flexibility in Funding

Currently the funding model used in the DS system is a bundled payment model which enables individual funding packages to be developed that are capable of addressing an individual's specific needs. Everyone is different, and a one size fits all model of funding, or only authorizing certain services within the framework of a fee for service funding system, would functionally eliminate the ability to organize services in a manner capable of meeting the needs of people in a holistic and interdependent manner. The funding must be flexible and be able to bend when the needs of a person change. The current funding methodology used in DS is progressive, functional, and effective. It should be the funding model looked to by healthcare reformers who desire to focus on valued outcomes as the basis for payment reform.

Organization of the Paper

Vermont has progressed through a number of program model iterations, and based on these experiences, Vermont has come to understand that effective services and supports must be based around the unique needs of every individual needing assistance. Consequently, the Vermont DS system has been designed to provide support services that are based on “person centered planning” approaches. People are “whole beings” and effective supports must be conceptualized through the lens of “holism”, recognizing that all aspects of the person function within an integrated web of interdependencies. It is these interdependencies that must be understood and considered for the person to be healthy within his or her community. If a person with a medical condition is lonely, or without economic means to live in a safe environment, or does not possess the skills to live a safe and productive life absent supports of various kinds, then simply treating the medical condition will not improve the individuals overall health. These social determinants of health must be a central part of the overall service approach in order for successful outcomes to be realized.

This paper is separated into sections for ease of reading. Section 1 presents two case studies to assist the reader in understanding the types of circumstances faced by families who reach the point of needing assistance from a public system in order to care for a family member with a disability. These case studies are provided as examples only, and as will be seen, each are very different. This is important in the sense that all situations are unique, and must be evaluated and understood from these unique perspectives. There is a common theme between them, however, and this is the absence of an adequate support network around the person with a disability that can enable them to live safely and successfully within the communities of Vermont. Using case studies in this manner is a way to provide the reader with a broader understanding of why a public system is even necessary. Further the case studies are intended to present the context within which services and supports for people with disabilities are designed and implemented.

Section 2 provides a brief overview of how services for people with intellectual and developmental disabilities have evolved over time. People with such disabilities have been part of all populations throughout history, and have been recipients of the societal responses, of the time, for how people with such disabilities should be treated. While this section is not intended to be a deep analysis on each iteration of societal response, a brief overview of how services arrived at the present day structure in the United States is relevant to the contemporary work of practitioners and social planners.

Section 3 provides the reader with information about the values and principles that underlie the DS system in the State of Vermont. As the closing of the Brandon Training School in 1993 represented the formal shift and commitment to embracing a community based system of care, a great deal of thought was given to what a full community based system of care should look like. This process involved stakeholders from across Vermont and resulted in legislation known as the Developmental Disabilities Act of 1996. This legislation has served as a guide and framework for the evolution of community based services in Vermont from the mid 1990’s to the present day. Vermont has been, and continues to be a national leader in the design and delivery of community based approaches.

Section 3 also provides information about service outcomes and about the costs of services. Most of the discussion about health care reform thus far has focused on the acute care system (i.e. medical care provided through hospitals, physician practices, etc.). The developmental services system in Vermont is a long term care system although it is commonly thought that (due in large part to its reliance on Medicaid for funding) it will be included in the overall planning for health care reform. Among the things that make the developmental services system highly unique in this discussion is that people who are supported by this system, for the most part, enter services not for medical support reasons, but for social support reasons. Certainly the people served through the developmental services system interface with the acute care system on an as needed and preventative basis, but these services are not the dominate need. These dominate needs remain in the social realm. This distinction is also true when compared to other long term care models such as nursing homes, where principally one enters a nursing home primarily for medical reasons. Another distinction with the developmental services system is the length of time that someone remains in services. When people need the supports of the developmental services system, these are typically lifelong.

Section 4 of this paper provides an overview of the current practice and regulatory framework in Vermont for how a person with an intellectual or developmental disability applies for services, and how decisions are made about the nature and amount of support a person ultimately receives. As will be seen in this section, not all people with an intellectual or developmental disability are approved to receive funded supports. Vermont uses a system of triage called “Funding Priorities”. These priorities establish the need thresholds that must be met in order for a person otherwise found eligible for services in Vermont to actually receive them. For the most part these thresholds revolve around the degree to which a person’s natural network of supports (primarily family) are able to provide the care, supervision, and support that an individual requires in order to be safe and successful with his/her community. In Vermont the actual services someone receives are unique to the particular needs of the person. Vermont does not take a “one size fits all approach” to service design and delivery.

Section 5 begins a discussion of the social model approach to wellness and how the agencies that support people with intellectual and developmental disabilities develop service strategies that are based upon the social determinates of health. In this section the interdependencies between these social determinants and the resulting effect on one’s overall state of physical health will be emphasized. The relevancy of this socially based approach to the broader notion of health care cost containment through a wellness model methodology is also presented. People who use health care resources are not individually driven in their lives by the goal of “bending the curve” in health care spending. When people feel they need access to health care for themselves or for a family member, their interest really is in having that need satisfied. People also are likely not to share the perspective that their personal use of health care resources may at times not be justified. The wellness approach promoted in this narrative recognizes that physical health is influenced greatly by the strength and stability of the persons overall life. One of the outcomes of this approach is to balance the utilization of resources designed for physical health by assisting a person to achieve stronger supports, connections, and overall wellbeing across all life domains.

SECTION 1

DS System: Setting the Context

There are over 4000 people receiving supports through the developmental service system in Vermont, each of whom have unique stories and a unique set of needs. The two case studies that follow are typical examples how one's circumstances lead to a reliance on the publicly funded system. While these examples are very different they both come to the public system with the shared characteristic of an inadequate personal support system capable of providing the necessary support and supervision to live a safe and successful life. **These Case Studies, while built upon the actual experiences of numerous individuals, are not real people. The names used in the Case Studies were selected randomly. Any resemblance to specific individuals or families is completely coincidental.**

Case Study 1: Jeffrey McCarthy

The McCarthy's have a long history in Vermont, having run a family farm in the middle of the State since the early 1900s. This farm, like so many others has been a family based operation, passed down from one generation to the next. This dairy farm was a vibrant enterprise for most of the 20th century. The majority of the work on the farm was provided by family members, with the occasional need to hire some additional help during the busy times of the year. No one was getting rich with this venture but the McCarthy's were strong and inter-dependent, and farming was an inter-generational passion for most of the members of the family.

In 1986, the eldest McCarthy son, Robert along with his wife Brenda gave birth to their second son. Jeffrey was born with Down Syndrome, and at birth the prospects of Jeffrey's surviving were quite doubtful. In addition to Down Syndrome, Jeffrey was also born with a serious cardiac abnormality that would require complicated surgery to repair. This defect, which is common for children born with Down Syndrome resulted in holes in the heart wall separating the major chambers. This news was a traumatic realization as Robert and Brenda were not the least bit prepared to have a child with Down Syndrome, let alone a child who also was challenged by a life threatening cardiac condition. They had no previous experience with Down Syndrome, or for that matter any other disabling condition. They did not know what to expect. They had little concept of what Jeffrey's future would be, or even if he would have one. Then there was this issue of the heart defect. The Doctor's told Robert and Brenda that the heart could be repaired, but even with the repair it was likely that Jeffrey would be a lifelong burden, never being able to thrive in the world, probably needing close to total care. An institutional placement was suggested as a possible alternative, assuming that Jeffrey had the heart surgery and survived. The option of not treating the heart condition was mentioned as a possibility which would of course lead to Jeffrey's eventual death. Couched within this option was the suggestion that Jeffrey's passing may actually be a blessing as his death would be from natural causes, and that the family and Jeffrey would avoid a lifetime of burden and despair. Robert and Brenda were told that raising a child with Jeffrey's disabilities would be enormously expensive and would permanently alter their future. They were encourage to begin thinking about an institutional option such as the Brandon Training School.

After some private conversations that included other family members, Robert and Brenda decided that Jeffrey would have the surgery, and that they would deal with future events and struggles as they came. This decision, while heart wrenching, did not take them long to make.

With the cardiac issue resolved, Jeffrey's early life was not plagued by life threatening medical conditions. However, the level of care and supervision that Jeffrey needed was far different than other children. Developmental milestones were not achieved in similar timeframes, and Jeffrey was not developing any skills to use his environment safely. By age 6 Jeffrey was still in diapers, had no reliable language, was able to walk but with an unsteady gait, was not safety aware in any setting, and would not sit in one place for more than a minute or so at a time. In addition to these needs, Jeffrey would become very violent when redirected away from something of interest to him. The violence which emerged early in Jeffrey's life was becoming much more difficult as Jeffrey was getting bigger and stronger. When he was little, his mother could literally pick him up and move him to a safe area. Now at 6 years of age Jeffrey was too big and too strong. Even at age 6, it was at times impossible for a single person to contain Jeffrey when he became angry, and these events were now occurring on a daily basis. They at times were predictable, and at other times seem to come out of nowhere.

As Jeffrey aged these episodes were getting more intense. The biting was the worse. Jeffrey seemed to have enormous stamina when these events occurred. He would rage unabated at times for 30 minutes or longer. Robert and Brenda were reaching out for help but there was little assistance available to them. There were times that Robert and Brenda wondered if the decisions they had made when Jeffrey was first born were the right ones. Their lives were increasingly being dominated by Jeffrey and his intense needs.

One of the only breaks Robert and Brenda were getting was the 4 - 6 hours each weekday when Jeffrey attended his school program. This allowed both Robert and Brenda to increase their attention to the duties of the farm. This was also becoming more challenging as the financial pressures of running a small farm in Vermont were themselves becoming way more unmanageable. They were falling behind on some of their payments and were not in a position to maintain and replace a lot of their aging machinery. They were not alone. Small family farms all across Vermont were struggling and many were going out of business. Robert and Brenda wondered if this would be their future as well. The world was changing rapidly and competing with large conglomerate operations was becoming impossible. The McCarthy's were needing to make some very difficult decisions in the near future about how to generate an income that could support their family.

While Jeffrey was in school, the challenges that Jeffrey posed there were very much similar to the ones Jeffrey was experiencing at home. The school believed that Jeffrey was incapable of being in a regular classroom so they had created a separate space within which he was expected to spend his day. The school had hired a full time aide to be with Jeffrey but this person did not have any specialized training prior to this assignment. There had been some in-service training which had helped considerably, and there was a special education teacher who was available to the aide. This teacher was responsible for the creation of the daily educational plan, but she did not work with Jeffrey directly. There was also a limited amount of direction provided by school consultants (behavioral and speech primarily), who had prescribed specific programmatic

approaches when working with Jeffrey. These were helpful but at times very difficult for the aide to follow. Further, the aide was not feeling that she was really seeing any changes in Jeffrey's knowledge and abilities.

As was true in the home, Jeffrey's behavior was the most difficult. When Jeffrey would "go off" it was necessary for the in-school crisis team to be notified. This "code red" would result in at least two male school staff members responding to Jeffrey's classroom area where he would be physically escorted to a special room into which he would be placed. The room was devoid of windows, sharp objects, and anything that could potentially be used as a weapon. The walls were covered with carpeting, and the lone door had a single small window through which Jeffrey could be observed. While the door was not locked, it opened outward thus giving the staff outside of the room the ability to hold it closed which prevented Jeffrey from exiting. The protocol was to keep Jeffrey in this area until he able to be calm for a minimum of 30 minutes. When this level of calm was achieved the plan was to transition Jeffrey back to his classroom area where his aide would resume his educational plan.

By age 10 Jeffrey had made some minimal gains. He had become toilet trained and this was a huge development, both at home and at school. While he was no longer in diapers, he still required someone in the bathroom with him to assist with essential hygiene care. He was also beginning to recognize some basic signs, although his communication was very limited and often quite unreliable. People working with him were encouraged about the evidence (as basic as it was) of some emerging language ability but no one had a clear sense of where this might lead. The people who knew Jeffrey well could anticipate his desires and interests far better than those who did not know him. His communication was highly idiosyncratic and very closely linked to his violent behavior.

At 10 years of age, it was now impossible for a single person to manage him when Jeffrey became violent. While still problematic, Jeffrey's behavior was better at home and this was due to the strong relationship that existed between Jeffrey and his family. Despite this, when these episodes did occur they were very violent, often resulting in some (mostly) minor injury along with significant property destruction. As in earlier years Jeffrey's stamina and commitment to these battles was significant, now often lasting for nearly an hour.

During the teen age years the struggles with Jeffrey continued without significant improvement. The school had finally convinced Robert and Brenda that Jeffrey could not be supported in the public school any longer due to his unmanageable behavior. They had arranged for Jeffrey to be served by an Alternative School that specialized in working with students with challenging behaviors. This program was more highly staffed than the public school which gave them the ability to physically manage Jeffrey when he lost control. There was additionally some marginal success with Jeffrey's communication (he had learned to vocalize some words), and was able to use a bathroom without assistance, but his behavior was still highly problematic. He was aging out of school based services and local agencies that worked with individuals with disabilities were becoming involved. School based services would discontinue when Jeffrey turned 22 years of age.

Robert and Brenda held onto their farm for as long as they could. First in 2002 the economics of their small farm required Brenda to enter the work force. As a woman about to turn 50 with no real work history outside of farming, she was only able to find part time work for a low hourly wage. She had been able to piece together a couple of different jobs, and this income, as small as it was, assisted in allowing Robert to keep the farm going for a few more years. Finally in 2006 the McCarthy's needed to sell the farm. They were left with very little as the farm had been deeply mortgaged. They also had significant debt in addition to their mortgage. When all was said and done they had a small amount of cash remaining but this was insufficient to buy another home. They needed to move into an apartment along with Jeffrey.

Robert was able to find a decent job as a mechanic but his single income was less than what was needed to support the household. While Jeffrey was in school, Brenda's part time work schedule was for the most part coordinated with Jeffrey's school day, allowing her to work. As Jeffrey moved towards graduation, and with Robert's full time employment, it appeared increasingly likely that Brenda's ability to maintain a work schedule would be improbable once Jeffrey was no longer eligible for school. His aggressive behavior was still a concern and he was a young man who needed to be kept busy. He had some minor outside relationships while the farm was still operating, but now in this apartment setting there was no readily available assistance to help supervise Jeffrey while she was working. Jeffrey's brother had relocated when the farm closed so he was no longer able to assist either.

In 2008, Brenda needed to quit her job when Jeffrey no longer could attend school. This loss of income placed increased hardship on the McCarthy's family. Robert sometimes worked long hours and often worked on Saturday as well. This limited Brenda's ability to find work but over time she was able to pick up part time hours at a local convenience store working during times when Robert would reliably be home. She had also been connected to a developmental disability program operated by the local Designated Agency. They had completed an assessment and had received funding for 20 hours of weekly respite support. The agency also had a case manager assigned to Jeffrey and this person was able to assist Brenda in locating some staff who were willing to provide respite care within Brenda's home. This enabled Brenda to secure more regular work hours which made things easier on her family financially. Jeffrey, however, was not doing as well. He was obviously bored as he had very little to do. The respite provider would take him out of the home, however, there was no routine to these events. What Jeffrey really needed was a job, but to manage this he would need a lot more assistance than what was available through the respite funding.

As challenging as their life had become the respite support and assistance the McCarthy's were receiving through the Designated Agency enabled Robert and Brenda to work enough hours to make it possible for them to make ends meet. They didn't have much left at the end of the month but their life was certainly acceptable. Jeffrey also was receiving a monthly SSI payment that assisted them in making all of their financial ends meet. Everything suddenly changed in 2014 when at the age of 67 Robert had a major stroke. This incident left Robert unable to speak, and he was paralyzed on his left side. Being unable to care for himself, or assist in Jeffrey's care, the full burden fell to Brenda. Brenda was not able to care for both Robert and Jeffrey. As difficult as the decision was, it was clear that a new living arrangement would need to be arranged for Jeffrey. Brenda approached the Designated Agency with the plea that they assist in finding an

alternative living arrangement for him. Jeffrey was in a situation where his only care providers could not care for him. Clearly he could not care for himself. The dire nature of this situation meant that Jeffrey's needs had risen to the State's funding criteria. A proposal for support was developed by the designated agency that included funds for a residential placement, respite support, time for structured use of his community, regular case management support, and clinical consultation to assist in the management of his challenging behavior.

Case Study 2: Diane Bevins

Diane Bevins is the daughter of John and Mary Bevins who reside in northern Vermont. John is an engineer working for a major construction company and Diane is an attorney practicing with a local law firm. Both John and Mary are successful in their chosen fields and they lead understandably busy lives. Diane, born in 1994, is their only child. Diane's birth was unremarkable, however as time passed there were discernable differences with Diane's early development. Diane did not seem to be progressing socially as indicated by her seeming lack of interest, limited responses to parent interactions, slow development of communication skills, and the emergence of some repetitive motions. Diane's physician was also concerned with these developmental signs and arranged for a formal screening that resulted in a diagnosis of autism just prior to Diane's 4th birthday. This diagnosis was very disheartening to the Bevin's, however both John and Mary were committed to providing every opportunity for Diane to receive the treatment that she needed in order to live a fulfilling life.

Diane's early behavior at home was very difficult to manage as she was very resistant to physical contact of nearly every kind. She was extremely difficult to console. Even simple things such as dressing and bathing were arduous tasks often including Diane lashing out by hitting, kicking, and attempting to bite. She would also become quite self-abusive biting her forearms and slapping her face. She would frequently ball her fists and strike herself on the side of her head just above her ears. She was the calmest when in her own room, mostly when she was alone. Her early speech development was also much delayed. She would at times scream at the top of her lung capacity for intervals of a half hour or more. Her ability or willingness to follow directions was very limited, and while physical touch was challenging for her, this was often the only way to get her to move from one setting or task to another.

Diane was able to receive services through her early childhood program and this included intensive training and support supervised by a professional with advanced training in Applied Behavior Analysis. This training was available for up to 20 hours each week from Diane's 4th birthday through age 6. The benefits of this training were very significant, more in the first year than the second, but her progress over this period was such that John and Mary were comfortable with Diane being integrated within her regular school facilitated by the presence of a 1:1 aide. This aide was both trained and supervised by a behavior specialist. The orientation of the behavioral support offered Diane was one that emphasized positive reinforcement principles.

Throughout school, Diane gained significantly in her ability to communicate. She also became much more tolerant of having familiar people in her physical space. Her self-injurious behavior diminished greatly overtime as did those occasions of her lashing out against others. She clearly

preferred to be off to herself whenever possible and she very much avoided situations where there were loud noises or chaotic settings. She eventually developed the ability to use the bathroom independently but needed to avoid public restrooms. At home she was able to dress herself but needed assistance with selecting appropriate clothing. She needed bathing assistance and this was easily provided by her mother. Despite all of these gains, Diane still was not able to be left unsupervised for any substantial length of time. She did not demonstrate home safety awareness skills, and she was unable to make any meals for herself. She was also quite curious, and if left alone, she would be prone to venturing outside. Once outside she was at risk of wandering away. She was not street safe and would be very unpredictable around strangers.

Until Diane turned 6 and was involved in a full time school program, Mary had worked a very part time schedule for her law firm. When Diane entered school Mary felt she would be able to return to full time work. This was made possible because of an allocation of funds through the Children's Personal Care program. These funds enabled the Bevin's' to hire staff supports that would come into the home on a regular weekly schedule, timed for those hours when Diane was not in school and when Mary needed to be in the office. At times when Diane needed to be home from school due to illness, school vacations, or teacher conference days, either Mary or John would be able to adjust their schedules so that Diane was never without someone being with her. This was essentially the way that the Bevin's managed their lives with Diane up to the point that Diane reached the end of her eligibility for school services at age 22.

As Diane approached her 22nd birthday plans needed to be put in place for Diane's support once she was no longer in school. As a 22 year old young woman, Diane remained in need of supervision as she was still not safe at home or in the community. She had made considerable advances over her school years and was now able to engage in basic conversation. She was not nearly as fearful of strangers, but she did not understand boundaries – particularly with people she did not know. This actually made her somewhat at risk without supervision being available for her. Her incidents of aggressive behavior towards others had all but disappeared, On occasion she would still exhibit some self-injury (i.e. biting and hitting her head) although these instances were generally limited to times when she was ill or otherwise under significant stress.

Both John and Mary had decided that they wished to have Diane remain living with them once Diane graduated from high school. To make this happen, however, Diane would still need regular in-home support while she was at home and her parents were at work. With the school's assistance, in concert with the local Designated Agency (DA), Diane had acquired a paid job for 18 hours a week doing light janitorial work within a local office building. This was a good match for Diane as the work environment was fairly quiet and predictable. Diane needed someone with her, however, as without this support she would not initiate and satisfactory complete her work tasks. Through the intake and assessment process of the DA Diane had been found eligible for Developmental Services. The DA prepared a proposal to the State of Vermont's Department of Aging and Independent Living. This proposal asked for 18 hours a week of job coach assistance, 20 hours weekly of regular respite support (covering the hours when both parents were working), and 24 days per year of overnight respite (2 days per month). The proposal also requested Service Coordination support for 2 hours weekly to be responsible for the development of a person centered plan, and to assist the parents in coordinating the various elements of this plan following the guidelines established by the State of Vermont.

These cases are typical for how people enter Vermont's DS system. Each story is unique with the common theme always being the lack of an adequate natural support system that is capable of providing care and supervision necessary for an individual who is unable to care for him/herself. This may happen when a primary care giver is no longer able to provide care as was true in the first Case Study. Or as in the second Case Study, there is a lack of resources and expertise to maintain someone within a partially intact support network. There are numerous other circumstances as well that also necessitate funding and support from a public system for someone to live safely and successfully within their community. Each of these must be assessed individually through a person centered process in order to determine the correct mix of supports to meet the individual's priority need areas.

SECTION 2

DS System: Evolution of Services

Currently in Vermont all services and supports for people with developmental disabilities are based within typical Vermont communities. Individuals may receive the support they need from their families, from friends, from supports provided from an agency, or a combination of these support types. The goal for all of these supports is to enable a person with a developmental disability to live successfully within the same communities as non-disabled persons, enjoying a lifestyle that is typical for the community within which the person resides. This community focus for supports is fairly new from a historical perspective, however.

Throughout most of the 20th century the primary service option for persons with developmental disabilities who could not live on their own or with family, was an institutional option. (Note: until recently the terms Mental Retardation or the Mentally Retarded were used to label both the individuals being supported as well as the system that supported them. These terms over the years became to be viewed as pejorative terms, and have been replaced with Intellectual or Developmental Disabilities). The peak of institutional care in the United States was reached in the late 1960's. Nationally, many states continue to operate institutional settings of various sizes. This is not the case in Vermont as the only institution in Vermont's history for people with developmental disabilities (The Brandon Training School) was closed in 1993.

Beginning in the mid to late 1800s the establishment of public institutional settings for the "care and treatment of the feebleminded" were established in every State. These settings, were initially conceptualized as short term placements where individuals with intellectual disabilities (using today's terminology) could be protected from the ills of society. The intent was to enable these individuals to develop the skills needed to live successfully in the broader community, having learned essential skills during their stay within these new institutions. In reality this reintegration function never really happened and the size and prevalence of institutional settings grew until reaching their peak in the United States in 1967. The role of the institutions also shifted in the public eye to become a place where people who could not live within society would be placed with the goal increasingly becoming one of protection of society from a class of people who were inferior and potentially harmful. The literature is full of descriptions of policies that led to inhuman treatment within these facilities. For example organized efforts to limit the "spread of these defectives" have been well described (e.g. the eugenics movement which resulted in the forced involuntary sterilization of an estimated 60,000 persons in the United States).

Toward the latter part of the 1960's and into the 1970's the inhumane living conditions found within these institutions were chronicled in print (Christmas in Purgatory by Burton Blatt, Springfield Union expose on Belchertown State School) and on film (e.g. Willowbrook on Staten Island; Pennhurst State School in Pennsylvania). Class action Federal lawsuits were filed in numerous States, including here in Vermont requiring massive improvements in the living conditions, staffing supports, along with major programmatic changes within the institutions. Some of these institutions were closed in favor of re-orienting the service system from an

institutional model to a community based service system. This was the case in Vermont and its only institution, The Brandon Training School, was closed in 1993.

In Vermont, nearly all of the individuals with an Intellectual Disability served through the Developmental Services system are being supported by either natural families or community organizations. Most of the organizations are agencies that have been evaluated by the State of Vermont (The Department of Aging and Independent Living and the Department of Mental Health), and based upon these evaluations, have been designated by the State as either as Designated or Specialized Services Agencies. Each of these organizations are re-evaluated every four years to assure that all of them meet Vermont standards for program quality and effective management.

During the 1990s through the present, the focus and approaches for service models has increasingly moved towards individualized approaches. Vermont recognizes that each person needing support is a unique individual and that the only way to support the individual successfully is to address the support needs that are specific to the person. Getting to this point, however, was an evolutionary process which has seen large congregate alternatives replaced by more individualized options. The congregate models which dominated in the 1980's provided a place for people to spend their day, but fell far short of being able to offer supports that would truly assist people to live and work within local communities. These congregate settings did not have the ability to really respond to individual needs (staffing ratios were very high), and people for the most part could not exit these models into something that would enable them to participate in community life. Often these settings were not even safe.

In Vermont, three primary service models developed in the early 1980's, became foundation points for how the overall service system in Vermont evolved; The Developmental Home, The Family Support Model, and the Supported Employment Program. The first of these (Developmental Home Model) was the initiation of an early foster home program originally referred to as a Professional Parenting Program. This terminology was subsequently changed to a Developmental Home/Shared Living program and this model continues to be the primary residential service model in Vermont today. This model has demonstrated an ability to support people of nearly all needs levels in typical Vermont homes. Usually a developmental or shared living home will support a single individual, but never more than two people. This model of service presently supports 1,352 people across Vermont (Developmental Disabilities Services Annual Report, 2015). Other residential options available in Vermont include supervised and independent living options (N = 239), staffed living options (N = 46), and group home alternatives (N = 97).

Family Supports designed to enable a family to maintain their disabled family member within their homes also evolved during this time. These supports may include a variety of services ranging from very small grants of funds (Flexible Family Funding amounts of up to \$1000 annually), Respite supports, Case Management supports, and more intensive supports that under an option here in Vermont, enables families to either self-manage their services rather than use

one of the Designated or Specialized agencies, or share the management responsibilities for services with one of the Designated or Specialized Service Agencies.

Supported Employment in Vermont began in 1980 with a pilot program located in Barre. This program was based on a model of supporting people with intellectual disabilities in regular jobs in the community. This model has greatly expanded over the years where currently supported employment is the primary day service option for people who are of working age. This model is extremely significant in Vermont's history as it recognized that individuals with Intellectual and Developmental Disabilities did not need special places to be because of their disabilities. Rather these individuals could participate within their communities along with people without disabilities, doing things that brought value to themselves and their communities. This has had a major impact on the life qualities of many people in Vermont – both people with disabilities as well as those without. Vermont has become one of the leaders nationally in supported employment based services with over 1200 individuals currently participating in supported employment services (Developmental Disabilities Services Annual Report 2015).

SECTION 3

DS System: Values, Outcomes, and Costs

Under current Vermont Statute, people who are eligible for funded support and assistance from the State of Vermont through the developmental services program administered by the Department of Aging and Independent Living (DAIL) are those persons who prior to age 18 have either an intellectual disability (note: the term intellectual disability has replaced the former term mental retardation due to this term's pejorative connotation) or a pervasive developmental disorder. Not included would be individuals who experienced some temporary deficit in cognitive function prior to the age of 18. Similarly, cognitive deficits that occurred by events after the individual turned 18 years of age are not considered an intellectual disability or pervasive disorder for purposes of becoming eligible for services in the State of Vermont through the developmental services program as presently structured. So what does this eligibility criteria actually mean in practice?

In 1996, the State of Vermont adopted legislation known as the Developmental Disability Act (V.S.A. Title 18 Chapter 204A). The purpose of this act was to establish the following:

It is the policy of the state of Vermont that each citizen with a developmental disability shall have the following opportunities:

- (1) To live in a safe environment with respect and dignity.
- (2) To live with family or in a home of his or her choice.
- (3) To make choices which affect his or her life.
- (4) To attend neighborhood schools, be employed, and participate in activities, to the extent that this purpose is not construed to alter or extend rights or responsibilities of federal laws relating to special education.
- (5) To have access to the community support and services that are available to other citizens. (Added 1995, No. 174 (Adj. Sess.), § 1.)

Through this ACT, the term developmental disability was defined thusly:

- (2) "Developmental disability" means a severe, chronic disability of a person that is manifested before the person reaches 18 years of age and results in:
 - (A) intellectual disability, autism, or pervasive developmental disorder;
and
 - (B) deficits in adaptive behavior at least two standard deviations below the mean for a normative comparison group.

The DS system has historically been a value based system that recognizes that the individual with the disability should be always at the center. These values were written into Vermont statute to reflect the standards to which programs should comport, and to provide referent points that would enable focused quality goals to be recognized and worked towards. Environments into which people were placed needed to be safe, dignified and respectful. To the fullest extent possible, people should be able to exercise choices over those things that affected their lives, including where to live, where to work, who to associate with, and how to spend leisure time. Essentially this statute made it clear that individuals supported through the developmental services system should enjoy the same access to their communities, and the services available within them, as did other Vermonters.

This Act further goes on to establish principles of service which in part state:

1. Children services. Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment....
2. Adult services. Adults regardless of the severity of their disability, can make decisions for themselves, can live in typical homes, and can contribute as citizens to the communities where they live.
3. Full information. In order to make good decisions, people with developmental disabilities and their families need complete information about the availability, choices, and costs of services, how the decision process works and how to participate in that process.
4. Individual support. People with developmental disabilities have differing abilities, needs and goals. To be effective and efficient, services must be individualized to the capacities, needs and values of each individual.
5. Family support. Effective family support services shall be designed and provided with respect and responsiveness to the unique needs, strengths and cultural values of each family and the family's expertise regarding its own needs.
6. Meaningful choices. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values and needs and assure that each recipient is directly involved in decisions that affect that person's life.
7. Community participation. When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.
8. Employment. The goal of job support is to obtain and maintain paid employment in regular employment settings.
9. Accessibility. Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services....

10. Health and safety. The safety and health of people with developmental disabilities is of paramount concern.
11. Trained staff.... All individuals who provide services to people with developmental disabilities and their families must receive training....
12. Fiscal integrity. The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities

First, one might ask why such statutory language was considered necessary as this content does not establish any rights that go beyond the rights that are assured other citizens of Vermont. The reasoning here was in part recognition of the (recent) history in Vermont and elsewhere of the poor conditions and models of support that had been typical of services for this vulnerable population. Secondly, the Statute was written to provide guidance for how services and supports for this population should evolve. While never perfect, this legislative guidance has been the foundation for system growth and improvement. These values and principles are additionally aligned closely with the social determinates of health which will be discussed in detail in Section 5 of this paper. The DS system has been organized around a holistic view of the people it supports for more than twenty years. As such the DS system is uniquely qualified to provide guidance and service within the broader health care arena as the values and principles for health care reform should not differ significantly from the foundations that the DS system has been based upon.

Outcomes

Many outcomes from the DS system have been demonstrated in a variety of ways including Vermont based consumer satisfaction surveys, participation in the National Core Indicators project, reporting on outcomes that are required through the contracting mechanism with the State of Vermont, and outcome measures that are reported on through Vermont Care Partners. These outcomes, for the most part are intentionally broad so as to encompass both specific measures (e.g. number of hours working, documentation of visits with a primary care practitioner, length of time for an intake process, etc.), as well as broad measures of satisfaction that address various aspects of one's life.

For example the 2014 Vermont Satisfaction Survey (N = 558) which was conducted by an independently contracted survey team (contracted by the Department of Aging and Independent Living) reported in part that:

- 90% of those surveyed were satisfied with their residential setting
- 95% of those surveyed were satisfied with the neighborhoods they lived in
- 80% of those surveyed were satisfied with their work
- 82% of those surveyed were satisfied with the community supports they received
- 85% of those surveyed were satisfied with the social support they received
- 86% of those surveyed were satisfied with the community services they received

(Full survey found at:

<http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/dds-publications-satisfaction-reports/consumer-survey-rpt-2014>)

During a similar period (2104-2015) very detailed survey results from the National Core Indicators project (N = 300+), also conducted by independently contracted surveyors, in part reported:

- 88% of those surveyed reported that their staff treated them with respect
- 91% of those surveyed reported that they have enough privacy at home
- 73% of those surveyed reported that they had a flu vaccine in the previous year
- 85% of those surveyed reported that they had a physical exam in the previous year
- 98% of those surveyed reported that they had a primary care physician
- 89% of those surveyed reported that their staff had the right training to meet their needs

Full survey found at:

http://www.nationalcoreindicators.org/upload/core-indicators/2014-15_ACS_Vermont_Report.pdf)

Similarly for the Fiscal Year ending (June 30, 2015) the Vermont Care Partners Outcomes report demonstrated in part the following:

- 1,213 recipients of service were employed (47% of people served)
- Savings in Social Security payments due to employment totaled \$1,699,763
- Individuals employed contributed \$4,270,506 in wage and payroll taxes
- 88% of people served report they participate in deciding their daily schedules
- 93% of people participate in deciding how to spend their free time
- 88% of people served report they are treated respectfully

Full Vermont Care Partners Outcome Report is found at:

http://www.vermontcarepartners.org/portfolio/files/8-39360_VCP_Outcomes-Report-FY2015_WEB%20050416.pdf

The Developmental Disabilities program in Vermont is very committed to excellence in the services and supports provided to citizens of Vermont who experience an intellectual or developmental disability. This commitment includes an understanding of the importance of being able to demonstrate outcomes. Vermont has been among the leaders nationally in providing integrated community based services for people with intellectual and developmental disabilities, and this includes having the ability to report on outcomes that document both individual and system achievements. For example, in Vermont 47% of people served between the ages of 21 and 64 are employed which is among the highest percentages in the nation. As reported in the Developmental Disabilities Services Fiscal Year 2015 Annual Report, Vermont is number 1 in the nation for the number of people with intellectual and developmental disabilities employed per 100,000 population (174 per 100,000 in Vermont compared to 31 per 100,000 nationally).

What does the Vermont DS System Cost?

The best source of cost data for developmental services in Vermont is the Developmental Disabilities Services State Fiscal Year Annual Report (January 2016) published each year by the Department of Disabilities and Aging Services. This is an excellent overview of the entire DS system in Vermont, including information about costs of services. The most recent report covers Fiscal Year 2015 and was released in January of 2016. This report is easily accessed online at:

http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/dds-publications-annual-report/dds-annual-report-fy15_final_posted.pdf.

According to this report the annual per-person cost of individual service models (as mentioned early in this paper) were \$13,899 for Supervised/Semi-Independent Living (N = 239), \$31,271 for Shared Living (N = 1352), \$87,557 for Group Home (N = 97), \$107,318 for Staffed Living (N = 46), and \$224,622 for an Intermediate Care Facility/Developmental Disability (N = 6). This last option is a highly specialized residential setting for people who are extremely fragile with very high medical needs. Overall, the average cost of service (including all of these models) in FY 2015 was \$56,672. When adjusted for inflation this level of per person support has remained stable for the past 15 years (Developmental Disabilities Services State Fiscal Year 2015 Annual Report, January 2016).

The DS system is a program of long term care. The other long term care system in Vermont is the Choices for Care program which includes a variety of service options geared towards the elderly (community based service options up through and including Nursing Homes). Both of these systems support populations of people who differ significantly which makes meaningful comparisons between them very difficult and not particularly reliable. Choices for care is more frequently for people who already live integrated lives in the community and are likely to be near the end of life, while people who use developmental services are developing skills and seeking opportunities to live active integrated lives in their communities through employment, social, spiritual and recreational activities. Therefore, their services are generally more comprehensive.

The DAIL annual report for FY 2015 does provide some comparative data between Vermont and Developmental Services programs in other States, however. According to this report, Vermont ranks 15th nationally in per capita spending (\$110 per Vermont resident) on persons with an Intellectual or Developmental Disability, and among the New England States, ranks in the middle of this grouping (Range = \$92 - \$211). In terms of the percent of State dollars spent on the budget supporting people with an Intellectual or Developmental Disability, Vermont is well below the national average (38% in Vermont compared to 46% nationally) and is lower than all New England States except for Maine (Range = 36% in Maine to 67% in Massachusetts).

It is difficult to make direct comparisons of costs even between State systems given the difference in reporting methods and in the different mix of services between States. For example, numerous States still maintain dual systems (Institutions as well as Community

programs). In Vermont virtually all individuals are served within community based programs. Not included in the above discussion is any reference to an institutional model in Vermont as there is no sentiment that a return to an institutional based system would be desirable. Such a model would run counter to the values and principles adopted as part of the DD Act of 1996. Further, institutional settings apart from concerns about quality, are extremely costly. In Fiscal Year 1994 (the year that Brandon Training School closed) the per-person annualized cost was \$328,837 (Developmental Disabilities Services State Fiscal Year 2015 Annual Report, January 2016).

SECTION 4

DS System: Practice and Regulatory Framework

Who Gets Served

The Regulations that have been adopted to implement the Developmental Disability Act (2011) provide a useable explanation by defining an intellectual disability for purposes of Vermont eligibility as a “significantly sub-average cognitive functioning documented by a full scale score of 70 or below on an appropriate standardized test of intelligence and resulting in significant deficits in adaptive behavior that were manifest before age 18.” (p.2) Adaptive behavior for the purposes of eligibility are also measured through a standardized assessment and include behaviors involving communication, self-care, home-living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, health, or safety. For eligibility a person must have significant deficits in two or more of these areas.

For a person to be eligible as someone with a pervasive developmental disorder, they must have a diagnosis in one of the following areas; (a) Autistic Disorder, (b) Asperger’s Disorder, (c) Pervasive Developmental Disorder, Not Otherwise Specified, (d) Rett’s Disorder, or, (e) Childhood Disintegrative Disorder. In addition to the diagnosis an individual must have significant deficits in two or more of the adaptive behavior categories listed above as do people with an Intellectual Disability. Unlike people with an Intellectual Disability, a person found eligible as the result of a pervasive developmental disorder does not have an IQ score requirement.

The diagnosis determinations must be made by a person who is credentialed to do so. These requirements are also defined in the Regulations Implementing the Developmental Disabilities Act of 1996 (2011) and in general includes licensed physicians or licensed psychologists. In the case of diagnoses of a pervasive developmental disorder, the licensed clinician making this diagnosis must have “specific training and experience in child development, pervasive developmental disorders, other developmental disorders, and other childhood psychiatric disorders.” (p.9)

The purpose of the above is to provide the reader with an overview of who is receiving supports from the developmental disability system in Vermont and how the decisions are made about who is able to receive supports and why. The process of determining that someone is eligible for services is rigorous and is based upon a criteria that is consistently applied. A qualifying diagnosis must be made by a properly trained and licensed clinician. Based upon a diagnosis that comports with the requirements of the regulations, an eligibility decision is made by the appropriate Designated Agency.

There is a big difference between the number of people in Vermont who are eligible for services and the number of people who actually receive services. There is no consensus on what the

prevalence data are for the number of people in Vermont who have an intellectual disability or a pervasive developmental disorder, but overall numbers in the 2% range are easily defensible. Using this percentage as a benchmark estimate, there may be over 12,000 people in Vermont who would be found eligible if they were evaluated in accordance with the regulations (the 2014 population in the State of Vermont was 626,562). From the Fiscal Year 2015 annual report on Developmental Disabilities Services in Vermont (January 2016) a total of 4,408 individuals received services in Fiscal Year 2015. This represents an approximate penetration rate of 0.007% of the Vermont population. These are the individuals who are the neediest within the overall population of individuals who would otherwise be found eligible for services.

Currently in Vermont, a person with a developmental disability who has been determined eligible for services must additionally have needs that meet certain thresholds in order for funding to be authorized. These thresholds are defined in a State document called the State System of Care Plan. These thresholds function as a triage system, separating individuals who are eligible for services into two groups – those whose needs equal or exceed the funding thresholds and those who do not. Those individuals in the first group are likely to receive funding support while the latter group most likely will not (until or unless their needs change to a level that equals or exceeds the funding thresholds). These thresholds are called funding priorities and currently include the following:

1. Ongoing direct supports or supervision to prevent an imminent risk to the persons health and safety
2. Ongoing direct supports or supervision to prevent a person who poses a risk to public safety from endangering others
3. Ongoing direct supports or supervision to prevent institutional placements
4. Ongoing direct supports or supervision to prevent or end placement in an inpatient private or public psychiatric hospitals
5. Ongoing direct supports or supervision to enable a youth to maintain employment
6. Ongoing direct supports or supervision needed to for a parent with developmental disabilities to provide training to help keep a child under the age of 18 at home

Over time these funding priorities have been altered by the State in order to control access to services, which has in turn provided the means to limit expenditures. With the exception of funding priorities 5 and 6, the thresholds have become substantially more restrictive over time. For example, one of the early priorities was to prevent someone from experiencing a regression in skills or behaviors. This priority was eliminated early on as a means to limit the number of people who could receive funding. The result has been a far more reactive system as people who can now receive support often have needs that are far more costly to support than what may have been the case if interventions could have been instituted earlier.

SECTION 5

DS System: The Social Model of Support and Care Coordination

Agency Roles and their Connection to the Broader Community

The Designated and Specialized Services agencies are all non-profit organizations located within communities from whom their Board of Director's are drawn. This organizational structure provides a platform for community awareness and connections to the communities within which they are located. Further, and perhaps most importantly, for the most part the agencies themselves do not provide services within their organizational spaces. Most of the services are based within the communities themselves and use these community resources as the locus for program delivery.

Individuals live in typical homes and residences that are mostly indistinguishable from residences that are occupied by other community members. If someone is learning skills necessary for life (e.g. budgeting, banking, shopping, travel, recreation, medical support, and religious fulfillment, employment, and friendship connections, etc.) the same resources that are the ones used by non-disabled people are the ones accessed for teaching and using skills that are essential for the person's wellbeing and happiness. Participating within ones community and developing relationships and friendships with non-disabled people is a huge focus for how services are arranged and supported. The people supported by the Designated and Specialized Services Agencies are part of the communities within which they live, work, and recreate, and this serves as a continuous and expanding web of connection points between the provider agency and the local communities.

These agencies are responsible for providing or arranging for the services and supports that an individual needs in order to thrive within their chosen communities. This involves regular and ongoing use of community resources. In some instances, an agency may establish particular working relationships with a community resource (e.g. a local health center, and medical practice that has a particular specialty such as dental or psychiatry, etc.). In these instances there are direct connections between an agency and a community provider that enhance access to community services. In most other instances the agency is in a supportive role with the individual directly. In this capacity, however, the process of assisting a person to fully utilize his her local community immerses each agency within all levels of an individual's community participation.

Each agency takes a holistic view of each person being supported and understands that a healthy individual is one who is healthy in all aspects of his or her life. Medical wellbeing is interrelated with economic wellbeing, emotional wellbeing, social wellbeing, spiritual wellbeing, safety and security of where someone lives works and plays, and the opportunities for self-development. A lot of emphasis in health care reform is being placed on improving health and controlling health

care expenditures. We believe that trying to intervene only within the medical arena will not produce these outcomes because the holistic needs of the individual are not being addressed. A comprehensive and integrated approach that considers how all of the social and medical domains intersect will be the best and most cost efficient approach for health care reformers to utilize.

Social Determinants of Health

According to the World Health Organization, the achievement of health equity must embrace the ideas that daily living conditions, physical and social environments, working conditions, social protection, and health care, as being interwoven constructs. In Vermont, the Designated and Specialized Service agencies recognize that these “Social Determinants of Health” (i.e. one’s social circumstances, environmental exposures, behavioral and patterns), must be addressed in a holistic manner in order for services to be provided in an effective and integrated manner. Research demonstrates, and local experience confirms, that unmet basic needs (i.e. affordable healthcare, food, housing, transportation, etc.) are strong contributors to poor health and rising health care expenditures. The physical, social, and economic context in which people live are key determinants of their overall health and wellbeing.

The Designated and Specialized Services agencies are structured to provide services and supports through a holistic context that addresses the social determinants of health as fundamental components for each person being served. How these social determinants are addressed varies from person to person and are defined within an individualized plan that is person centered. These plans include goals and service objectives that are considered important for the persons overall wellbeing. These plans are updated no less frequent than annually. Through an active case management approach, the individual is provided with direct assistance to achieve their defined goals. The overall medical plan is developed in conjunction with a Primary Care Physician along with other medical specialists are deemed necessary. The case manager works directly with the recipient to insure that all medical recommendations are followed through on, and that access to medical services occurs as needed and as appropriate.

The nature of support provided within Vermont’s Developmental Services System. Not all individuals with intellectual and developmental disabilities need to rely upon organized public supports in order to live within typical Vermont communities. Only those individuals whose needs are beyond the capacity of their social and family networks to support them require services from the public system. The types of support these individuals receive are focused on enabling the individual to participate in the communities within which they live. The former era of placing these individuals apart from the rest of society (as was the case in the institutional era) is no longer an option. Consequently, individuals who are part of the DS system use their communities in the same basic manner as do typical community members. People who are in the DS system use the same primary care physicians, work in similar places of employment, attend a Church of their choosing, use stores, recreational opportunities, and develop friends and social networks. These are things that we all do in our own lives, and this is the goal for the DS system; to assist individuals to attain a life style that is typical of other community members. The intent is to make sure that each person has the ability to achieve a lifestyle where the social determinants of health are in balance most of the time.

For each individual participating in the DS system, there is a person centered plan that is developed. This plan seeks to identify, for each individual, the aspects of the social determinants that need to be specifically addressed. This plan also identifies the supports that will be needed in order for the individual to have a realistic ability to achieve the goals that have been delineated within this person centered planning process. The supports provided by the Designated or Specialized Services agency are the ones needed to assist the individual in reaching these goals through accessing and participating in their communities. The most critical service provided is case management and coordination. This support component is responsible for the development of the person centered plan, along with the coordination of other supports that are needed. This may include someone to assist an individual with the performance of work tasks without which the individual could not participate in employment. It might include providing a support person to assist the individual to access and learn about the community within which the person lives. In many cases this involves locating and supporting a place where the individual will reside (as most people supported in the DS system do not have the ability to live and be safe within a household without the availability of immediate supports). Case management support will also connect a person with a Primary Care Physician, and will provide assistance and training to the individual as well as other involved support persons to assure that the follow through on medical recommendations occurs. In other words the case manager must have a holistic view of the entirety of needs that an individual has in order to live a life that is healthy, safe, and rewarding.

Lastly, this person centered plan is not a one-time event. This plan is reviewed and updated no less frequently than annually to assure that the assistance being provided at any point in time is responding to the ongoing needs of the individual. This is a key difference in a system that is based upon individualized supports rather than being based on programs.

Why are Services in Developmental Disabilities Long Term?

Referring back to the case studies earlier in this document, Jeffrey McCarthy (Case Study 1) is a young adult with Down Syndrome. He is not independent in his personal care abilities, needing direct supervision and assistance in most areas of personal care and hygiene. He is someone whose skill levels are not at a point where he can be left alone for any significant period of time. He is not able to prepare meals independently, is not street safe, has no independent ability to get from one location to another, is not able to use a phone, is largely non-verbal, and would not have the skills to respond in any type of emergency. In addition to these skill limitations he also has explosive behavioral episodes that typically result from frustration that derives from his difficulty with communication. In order for Jeffrey to be safe he must have someone with him nearly all of the time.

Jeffrey's intellectual limitations are not correctable. His ability to do things can certainly be improved upon, and in fact he has a lot more ability in his early 20s than was the case earlier in his life. He will continue to show gains in his skill level as time goes on. This will be particularly true if the people who support him use good teaching methods. However, Jeffrey's disability is life long and he will require supports throughout his adult life. While in most cases it is not possible to predict future impairments, Jeffrey does have Down Syndrome. There have been very significant medical advances in the last 40 years and Jeffrey can now expect to live a

near normal life span. However, with Down Syndrome comes a very high likelihood that signs of dementia will be noted much earlier than the normal population. So Jeffrey's support needs will perhaps lessen slightly over the next 20 years, but after that they are likely to increase; perhaps significantly through the end of his life.

Jeffrey is but one example of a person with a significant Intellectual and Developmental Disability, and in his case the disabling condition is Down Syndrome. There are numerous other diagnostic labels that result in lifelong learning challenges that are very similar to the ones that Jeffrey experiences. As with Jeffrey, these individuals for the most part will require some type of life long support. The degree of this support will vary based upon the characteristics of each person. This is why individualized supports are so essential. It is important to provide the right amount of support, not too much and not too little. A small percentage of individuals will develop the skills needed to leave organized services, although this is not the outcome that can be expected for the majority of people being served. While all people can learn some things, the cognitive challenges faced by most of the people served in the DS system limit the amount of skill development that would be needed for living without supports. However, the individualized based system in Vermont enables all individuals to develop in many ways that allow most persons to contribute in a positive fashion within their communities. Many DS systems elsewhere are based on group models. These systems tend to be very costly and outcomes are less robust than what has been achieved here in Vermont.

Specialty Health Home

The approach taken by the Developmental Service system is to recognize that the overall needs of the whole person must be addressed. The view of the person must be through the lens of all of the social determinants of health, and not just selected components. All of these social determinants are completely interconnected with each other. They cannot be separated out of convenience with an expectation that the persons overall health state will improve in any type of sustainable fashion. Most people have the ability (most of the time) to self-regulate and manage these social determinants on their own. They are able to balance the management of a medical need with their employment or with their social expectations, if not on their own, with the assistance of their own intact social and family networks. For others who do not have the personal skills or an intact social and family network to rely upon, there must be an external presence available in order to make all of this work for the individual. This is what the DS system has been designed to do.

Using a medical need as an example, a person with limited abilities without the presence of an intact social and family network, may not seek medical attention until a problem has progressed to a point where the treatment is very complicated, very lengthy, and very expensive. All too frequently, the access point for the person without a support network is the hospital emergency room, which provides excellent medical care but at a very high cost. If the person who does not have an intact social network is discharged back to a setting that is not prepared to support the persons recovery needs, or to support essential life style changes that have contributed to the medical condition, the individual is likely to get worse instead of better. This will often lead to a circular involvement with the medical system resulting in a continuation of declining health. In

this example, the problem is likely not the medical condition, nor the quality of the medical care. Rather it is the inability of the individual to manage in an effective way his/her own health care requirements, coupled with an absent or ineffective support system. In other words, it is not just the person's medical condition that is at issue, but the lack of supports that can keep the social determinants of health in balance. The holistic approach taken by the DS system is an integrated approach that is designed to support all of the needs that a person has, within the context of a conceptual understanding that all social determinates are interrelated and must be understood as such.

Within the context of health care reform, the approach and structure of the DS system is really one of a Specialty Health Home. It is specialized because it recognizes the interrelated nature of the social determinants of health, and it is set up with practice standards (e.g. person centered planning, health and wellness guidelines, etc.) that provide a basic structure for supporting people with complex needs to live and prosper within Vermont communities. The coordinative role played by the case management approach embedded within the DS system is the essential element that makes this work for each individual who participates. The Designated and Specialized Service organizations are highly organized structures that are specifically designed to provide their supports in a decentralized manner. While it is possible for a service recipient to "come to the agency" the vast majority of service and supports are provided within the environments where people live, work, and recreate. This "house call" model of case management is essential as the people supported through the DS system need direct involvement in order to build a social network and use community resources successfully. Absent this direct involvement, the quality outcomes that individuals achieve within the DS system could not be reached.

Within the broader health care world, the absence of this type of an integrated approach to health care is one of the reasons (perhaps the largest) for why so many individuals consume many excessive and expensive health care resources. They are people who, like the people supported within the DS system, do not have a life that is holistically balanced. They do not have a sufficiently intact social/family network that is able to support them in ways that keep their lives on a stable platform. These are people who very often are lonely. They are disconnected in many ways from the supportive elements of their broader communities. These individuals need more than phone call support and encouragement. They too, need a person centered plan that holistically looks at their lives within the context of all of the social determinants of health. Then they need direct support, encouragement, skill development, and facilitation to make their person centered plan more of a reality.

Summary

What Happened to Jeffrey McCarthy (Case Study 1) and Diane Bevins (Case Study 2)?

The case study of the McCarthy's is a unique but typical example of how someone comes into the world with an intellectual or developmental disability, how a family comes together to support their family member, how this experience contains both rewards and struggles, and how at some point in time the ability of the family to be the primary care giver begins to erode. In some instances, this erosion happens early in life and in other instances the erosion happens much later. The case study used in this paper is one where the families capacity to be the primary support for their son is lost due to a medical complication of one of the primary care givers. In this example, Jeffrey was 28 years old and his parents were in their 60s.

At the time of Mr. McCarthy's stroke, the family had been receiving some funding through the State's Medicaid Waiver program. This enabled the family to hire some staff support to provide Jeffrey with a few hours each week of respite support enabling the family to have a needed break from Jeffrey's significant needs for care and for supervision. Jeffrey also had available to him enough funding for his developmental services agency to provide Jeffrey with 15 hours of structured community support each week. Together, between the respite and the community support, Jeffrey's mother was able to hold down some regular hours of work that provided needed income to the family. Jeffrey also received about \$700 each month in Supplemental Security Income which assisted with room and board related expenses within the household. The developmental services agency was able to assign a trained case manager to work with Jeffrey and his family, 2 hours each week, assisting with both the coordination of the various services and supports that Jeffrey required on a regular basis. The developmental services agency was also able to provide some consultation support from a behavior analyst in order to assist Jeffrey and his family, along with his support staff, to develop a better understanding of the reasons for and purpose of his challenging behavior. This level of support was sufficient to maintain Jeffrey in his home and community – that is until his father had the debilitating stroke.

With Mr. McCarthy no longer being able to work, and in need of significant care himself, Mrs. McCarthy was not able to maintain her hours of employment, and was not able to care for Jeffrey as she was now the primary care giver for her husband as well. No other family member was in a position where they were able to take responsibility for Jeffrey. The institutional options that had been explained to her (by physicians) when Jeffrey was born were not an option in Vermont. There were out of state institutional options but accessing them would necessitate a significant financial commitment from the State of Vermont coupled with a determination that less restrictive in-state options were not available. Clearly Vermont had the ability to support Jeffrey using Medicaid funds so long as Jeffrey's needs reached the level of the State funding priorities (see page 7). So Jeffrey's mom approached her Designated Agency asking for assistance in finding Jeffrey a safe place to live.

The Designated Agency evaluated the change in need that had occurred for Jeffrey as a result of Mr. McCarthy's stroke. They were able to verify that Jeffrey could no longer be cared for by Mrs. McCarthy. The McCarthy's apartment was small and the extent of supervision and support

required by both Mr. McCarthy and Jeffrey was very significant. This level of support simply could not be provided by Mrs. McCarthy alone. In order for Mrs. McCarthy to keep both her husband and her son with her, there would need to be extensive staff support sent into the home on a daily basis. The likelihood of finding consistent staffing for the number of hours needed for care and supervision was very unlikely, and would in the very least be very costly. In evaluating this entire situation it was evident that the best and most cost effective alternative would be to locate a shared living home for Jeffrey in a location that was reasonably close to the McCarthy's residence. It was very important for everyone that the essential relationships that existed between these family members be maintained. Based on this needs assessment, a proposal to add the funding for a shared living home to the bundle of supports that Jeffrey was already receiving was developed and submitted through the funding review process used by DAIL. Following this review, the funding package was approved.

The outcome of this case study was Jeffrey finding an appropriate home with a family located only a couple of miles from Jeffrey's parents. Jeffrey was able to maintain regular contact with his family while living in a safe setting that provided him with the care and supervision that he required. The focus of the case management changed some, now being focused on assisting the shared living provider to support Jeffrey, and assisting in making certain that essential connections with his natural family were maintained. This involved coordinating all medical services, coordinating the development of a person centered plan that addressed each area of the social determinants, assuring ongoing connection and involvement with Jeffrey's family, continuing to work with Jeffrey on developing self-regulation skills, assisting in the development of strategies that would enhance Jeffrey's communication skills, and finding ways for Jeffrey to participate in his broader community. The goal for Jeffrey, as is the case with all individuals supported through the DS system is to have a balanced and rewarding life. This Jeffrey was able to attain.

Diane Bevins' situation was substantially different than Jeffrey McCarthy in that her need for supervision and support was less intense, but still essential for her wellbeing. She also had a stable home support network that was interested and able to provide much of the care and supervision that Diane required. What the parents needed to make this work was direct assistance for supervision and support of Diane on her job, some respite assistance to bridge the time variances between the Diane's work schedule and that of her parents, some additional family respite that would enable the parents to have a monthly break from their care duties, and case management support to make sure all of these parts worked well together in a coordinated and supportive manner. In this circumstance a shared management model was used where the parents hired and supervised the respite portions of the plan, while the Designated Agency employed the staff person who assisted Diane on the job site. The Case Manager coordinated the development of the Person Centered Plan, made sure that the job site support was stable, assisted the parents as needed in securing the respite supports, and assisted with the coordination among other community resources including healthcare resources. Other areas of involvement also included expanding her connections within her community to increase the extent to which she was a full participant – leading a typical life for a young woman in a typical community,

The system in Vermont that supports people with intellectual and developmental disabilities is designed to assist individuals to live successful and healthy lives within typical Vermont communities. This work is based upon a person centered planning model that recognizes that the needs of the whole person must be addressed for an individual's wellness needs to be met. The Developmental Service System in Vermont is a mature system that has developed solid approaches to enable several thousand Vermonters with intellectual and developmental disabilities to lead successful lives. In earlier times, these are people who would have relied upon the types of institutional options which have subsequently been proven inadequate and extremely costly. The approach taken in developmental services in Vermont is to use the same existing community structures as everyone else uses, rather than duplicating them in some model where the underlying premise is that people with disabilities need to be supported in settings that have been established especially for them. This has been tried time and again throughout history and has failed on both social and fiscal grounds.

Vermont's developmental services model has not only been an efficacious model for people with developmental disabilities, but it is a model for health care reform more broadly. Developmental Disability services is a long term care model, but so is health care. In the DS world, there are occasions when some life event occurs that changes the equilibrium of the person in some acute way. In the first case study which began this paper, one such life event for Jeffrey McCarthy was being born with a cardiac abnormality that would have ended his young life but for a surgical intervention. Later in his life, another critical life event occurred when his father suffered a stroke. This event required a different type of intervention but one that was essential for his stability. There are of course other critical life events that happened in Jeffrey's life, as is the case with each and every one of us.

Most of us, most of the time, are able to effectively keep our own lives in order and in balance. When a significant life event occurs, most of us, most of the time, are able to figure out an effective way to manage these critical life events, whether they be of a medical, economic, or social origin. In doing this we often access our own social networks (which for most people are quite extensive) for guidance and support as we work our way through these real life occurrences. We naturally work to keep our lives in balance throughout this process as we are concerned (sometimes selfishly) with our whole being. The critical events in our lives may take center stage but usually only for a while.

Often people who are served within Vermont's DS program need outside assistance to keep their lives in balance. Despite this, it is no less important for the person in the DS world to have their lives balanced around those things which are important to them. Great care must be taken to assure that the person's sense of self does not become balanced by the preferences and beliefs of the "external balancer". For example, should this "external balancer" not be neutral but be a representative of a single social determinant arena, the likelihood increases that this single arena will become the dominant force in one's life at the expense of the other social determinants which are of equal importance. For example within DS history there has been many examples of a medical model becoming the dominant arena, and this has typically severely compromised the other social determinants. The resulting imbalance and the negative effects on service models is

well documented in the DS literature. It is from these experiences that the current DS service model has evolved.

The Person Centered Planning model is at the core of present practice standards within developmental services. This model recognizes that the most important “balancer” in the life equation is the person him/herself. External assistance (in the DS world is the case management function) must recognize that each social determinant area plays a significant role and must be balanced within the context of the whole person as defined by the person centered plan. This balancing role must also be very flexible as significant life events occur, often without adequate warning or preparation. During these times, one arena may become dominant over the others, but as is the case with most of us, this dominant arena must return to a state of balance within the context of the persons overall life needs and goals.

As is the practice within developmental services, the wellness needs of an individual must be approached from a similar holistic perspective. The elderly person living semi-independently may be using an ambulance too frequently because of loneliness, or not having someone to talk with. This person may not be taking medication properly due to a lack of understanding of the intent of the medicine, or the instructions. Perhaps the person may be rationing medicine because of how expensive they are. Possibly the person is not managing his/her life well and has not been able to keep their home warm during winter. There are many possible reasons and combinations of reasons that must be sorted out on a person by person basis. This is what a Person Centered Planning approach is designed to accomplish.

The developmental service model is extremely effective supporting several thousand vulnerable people to live successful lives within Vermont communities. This holistic model, one that embraces the social determinants of health could serve as a framework for supporting additional populations of people in Vermont who similarly have challenges managing their health care needs. These are the people who make excessive (and very expensive) use of health care resources like emergency rooms, ambulance services, and other specialty medical resources. People who live lives that are in balance, and who have assistance as needed to help them manage critical life events, and people who have intact social networks are more likely to use medical resources appropriately. This is where Vermont’s developmental services system could be of immense assistance in helping to control rising health care expenditures that are related to less than optimal personal healthcare practices.

For more information about the Developmental Service System in Vermont, and information about how the Developmental Services model could be of benefit to other systems, please contact:

**Vermont Care Partners
137 Elm Street
Montpelier, Vermont 05602**

(802) 223-1773