

In Search of Real Choice and Real Lives

A Report on the Partnership for Change Project

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Executive Summary

Background: In 2003, in collaboration with our larger community, Quality Trust (QT) Board of Directors and staff began planning an initiative to demonstrate how people with developmental disabilities living in Washington, DC, might experience more integrated and fulfilling lives.

Goal: The “Partnership for Change” project focused on five people who had already come to the attention of QT advocates. Its goals were to (a) help them re-craft their support services to be more individualized to their unique needs and (b) fund these services using the District’s Medicaid Home and Community Based Services waiver (“Medicaid waiver”), a federal program that every state is using to provide services in settings other than medical model group homes. (For DC, the Federal government reimburses 70% of waiver funding spent.) Our intent was to identify specific barriers to high quality, individualized services and supports and use this knowledge and experience to suggest opportunities for system-wide improvements.

Key Outcomes:

1. Four of five project participants now experience higher quality, more individualized, supported living arrangements. The situation for the fifth person is slightly improved and is still in process. In almost every instance, the changes that occurred were the direct result of QT advocacy.
2. Funding for many of the critical changes the project made in people’s lives was not possible through the District’s Medicaid waiver, as it is currently written. Instead, the District’s Mental Retardation and Developmental Disabilities Administration (MRDDA) has used local dollars to make up the difference between what the waiver would fund and the real costs of supports.

Related Lessons Learned:

1. As all five people’s stories demonstrate, the MRDDA case managers involved did not serve as advocates. The principles of self-determination were not used to enable people to obtain the supports they require to live the lives they choose in the least restrictive living environment. Consistent advocacy over time (from 165 to 988 hours) from QT staff advocates was required to compel the involved agencies and staff to make the changes people wanted in their lives. The hours expended did not relate directly to the complexity of a person’s issues or degree of disability.
2. As we also learned from all five people’s situations, having been designated as “on the waiver” (approved for waiver-funded services) does not mean a person is receiving waiver funded services.

3. So few providers had been approved to offer “Independent Habilitation” that only two came forward as options for the four people who wanted to move into apartments but required round-the-clock support. In the end, the same provider supported all four people. In the case of LM, a similar lack of options prevented access to discrete services, e.g., chore aid, homemaker, personal care assistance. No project participant experienced being able to choose his/her service provider agency or direct support personnel because too few agencies have been approved to offer the full range of services and supports for independent living.

4. MRDDA services are not person-centered. For people not living in group homes, like LM, TP, EW and RK the process for developing the annual Individual Support Plan (ISP), which authorizes all services, is not person-centered. Rather than being organized and facilitated by people who know the person well, the process is delegated to a contract agency. This makes it difficult for people to exercise their right to design and direct their own services to the greatest extent possible.

5. The District’s waiver, as currently written,

(a) Is not the alternative to the ICF/MR funding stream that Congress intended because it cannot fund 24-hour supports in anything other than congregate settings, which are not person-centered, individualized or the least restrictive environment even for people with extensive health care needs. As we saw for four of five project participants, MRDDA pays the difference between what the current waiver will cover and the full cost of wrap-around supports in local, appropriated, non-Medicaid reimbursable dollars.

(b) Carves much of the support crucial to independent living into enough small, disparate pieces that it is a disincentive to providers to offer these services. Although LM has been eligible for several discrete services, such as chore aid, homemaker and personal care assistance, he still does not have either a provider agency or the direct support personnel to provide these services.

6. The District’s waiver, as it is currently managed across two distinct agencies, did not make it possible to develop a consolidated, individualized budget for any of the people involved in our project.

7. There is also no effective inter-agency (service) coordination for people who receive services from more than one “system”, e.g. MR/DD and mental health services.

Recommendations:

1. Re-name and re-write the “Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978” to ground it in principles of self-determination, least restrictive living environment and respect for individual choice.

2. Realign the responsibilities of MRDDA and MAA to locate within one responsible agency both the design and implementation of supports for people with developmental disabilities and the management and control of funding for those supports.
3. Rewrite laws and rules governing supports and services that the District provides people with developmental disabilities to ensure access to the most individualized supports possible and the maximum Medicaid reimbursement allowable.
4. Create independent, advocacy-based case management or support coordination to offer a viable alternative to the current MRDDA case management arrangement. This support coordination will be grounded in an understanding of the people's right to create lifestyles of their own choosing, respect for their right to design their own supports and services to the greatest extent possible, and a willingness to promote actively whatever it takes to meet these requirements, while assuring that services and supports are of high quality and provided on a consistent basis.
5. Expand the pool of providers approved to offer the full range of supports and services eligible for waiver funding. Streamline the application approval process and empower the responsible agency to guide prospective providers through it quickly.
6. Make transparent efforts to amend the current waiver and prepare the 2007 waiver application and ensure people with disabilities and their families are active participants in this process.
7. Improve interagency collaboration to ensure that service coordination and safeguards exist for all people with developmental disabilities who receive supports from multiple agencies.
8. Require that MRDDA/MAA or a successor agency report annual data that show numbers of people approved for specific waiver services and numbers of people actually accessing those services with waiver funding.

Endnote:

In the last half of 2005, MRDDA convened a Waiver Advisory Taskforce comprised of providers, advocates, people with disabilities, family members and MRDDA representatives. The taskforce reviewed the rules for the current waiver, recommended deleting several services and collapsing others into new services. The recommended changes will greatly enhance the ability of consumers to exercise greater control over their services, receive better advocacy and coordinating support. They will also make it possible for the DC government to maximize federal matching dollars for waiver services provided. The Department of Health must now complete a Fiscal Impact statement and ensure that the proposed changes meet legal sufficiency before going to the DC City Council for approval. If approved, these changes will represent important and significant steps toward individualized, person centered services and supports.

In Search of Real Lives and Real Choice

Introduction

This document reports on a pilot demonstration project recently completed by Quality Trust for Individuals with Disabilities (QT). The project focused on the life situations of five people with developmental disabilities and the effort it took to improve their support services by transforming them into more individualized responses to their specific health, safety and welfare needs. Our goal was to demonstrate that there are viable alternatives to the District's standard practice of using a group home approach that often fails to respond effectively to individual concerns and is routinely more restrictive than necessary. We also sought to demonstrate that the federal Medicaid Home and Community Based Waiver ("Medicaid waiver"), which would reimburse the city for 70% of the cost of these more individualized services, could fund the services. Congress specifically designed this funding stream to keep people out of restrictive, medical model placements, such as nursing homes and ICFs/MR (Intermediate Care Facilities for People with Mental Retardation) medical model group homes. While the conclusions and recommendations in this report are informed and illustrated by the stories of the project's five people, they are also supported by QT experiences with more than 500 people through ongoing advocacy activities. Every day our work reflects and reinforces the major findings of this report.

The structure and framework for services questioned by this report is based on a law [The Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978] that has been in place since November 1978. While there have been dramatic changes in the ways in which people with mental retardation and developmental disabilities are supported in the decades since the District of Columbia (DC) City Council enacted this law, few of them have been codified into law or put into practice for District residents. It is our hope that this report will spark new discussion about the full breadth of fundamental changes it will take to create a system that works.

Background and History

In 1976 a class action lawsuit was filed on behalf of people living at Forest Haven, the District of Columbia's residential treatment facility for people with mental retardation. The suit accused the city of failing to provide even the most minimal care, treatment and training to residents of Forest Haven, located in Laurel, MD. Through subsequent discovery proceedings in the so-called Evans lawsuit, it became apparent that people residing at Forest Haven had been subjected to unconscionable abuse and neglect. Among other substantiated allegations in the lawsuit were that facility residents were over-medicated, beaten, and burned by employees; residents also were: (a) deprived of basic nutrition, adequate medical and dental care, and proper mental health treatment; and (b) denied a free, appropriate education as well as vocational training.

In 1978, the presiding judge in the *Evans* case ruled that the plaintiffs were being denied their “federal constitutional rights, based upon the Due Process Clause of the Fifth Amendment.” He ordered that steps be taken to ensure that all members of the Evans class (current and former residents of Forest Haven) receive habilitative care and treatment appropriate to their needs in the least restrictive setting.

The 1978 ruling laid the foundation for a concerted effort to remedy past deficiencies and substantially improve the range and quality of services furnished to District citizens with mental retardation and other developmental disabilities. Unfortunately, over the succeeding two decades, the District Government failed to fulfill its commitments under a series of increasingly detailed court orders and consent decrees in the Evans litigation. Forest Haven was closed in 1991 and most of the remaining residents were transferred to small, six-to-eight bed, privately-operated group homes located in the District. Many of these homes were certified as Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) in order to capture federal Medicaid financial participation.

In 1999, a series of front page articles in the Washington Post documented the scandalously substandard conditions in many of the community group homes as well as the corrupt practices in which some provider agencies had engaged. Parties to the Evans class action lawsuit entered into another agreement with the District Government. In the 2001 plan, the city agreed to pursue a detailed series of action steps designed to carry out broad aims outlined in the original litigation and to build a service delivery system that adhered to contemporary standards of practices for serving people with developmental disabilities. Quality Trust for Individual with Disabilities was created as a provision of that 2001 agreement.

Quality Trust’s mission is to assist in the creation of a city-wide system that affords people with mental retardation and developmental disabilities high-quality, person-centered services and support, regardless of the extent or severity of their needs. It is organized as an independent, non-profit with people who have these disabilities as its membership. Quality Trust works to accomplish its mission by acting as a catalyst for positive change in the DC disabilities service system, monitoring the operation of that system, and providing advocacy and/or legal representation for the people it represents.

Establishing Quality Trust was a unique and creative strategy well suited for a system in need of dramatic and fundamental change in the way it supports its citizens with disabilities. When QT advocates began to their work, they regularly met and worked with others who did not believe in or embrace the individuality, dignity or basic capacity of people with developmental disabilities. QT advocacy strives to support people with disabilities to be active partners in creating a reliable system of supports that delivers positive outcomes for the people needing assistance. QT staff and board are committed to working in partnership with other stakeholders in efforts to find practical solutions to the problems that confront our system and which ultimately cause harm to people with disabilities.

Project Development:

In 2003, Quality Trust Board of Directors and staff began planning an initiative to focus attention on the life circumstances of people with developmental disabilities living in the District and find effective strategies for helping them experience more integrated and fulfilling lives. We looked within the community of people involved with their services for others who shared our interest in finding new ways to make both government and agencies under contract to provide MR/DD services responsive to people needing this support. Our initial plan was to collaborate on small, learning and demonstration projects that would serve as the foundation from which to promote broader changes in services and supports.

An outline for the project was developed and an initial dialogue meeting held with community members and potential partners on October 7, 2003. Three of the key principles guiding our discussions on the design of potential projects and activities were:

- Ø Focusing on specific people to make the implementation and learning process more manageable and likely to make a difference.
- Ø Seeking to promote supports that were personalized to the unique needs and requirements of each person who participated.
- Ø Building commitment for collaboration throughout the “system” in the process of creating solutions and alternatives to existing approaches.

At the October community meeting, as we talked about how to proceed, a consensus emerged around a priority of

- Ø Working together to figure out how to use the DC Medicaid Waiver as a funding source for the support it would take to enable people to have new and better opportunities in the community.

Meeting participants also agreed that the project ought to focus on understanding the barriers that impeded using the Medicaid waiver to enhance supports.

Need for the Project:

Even though QT was relatively new in 2003, its advocates had already repeatedly documented that what people needed was not easily provided within the existing “system.” This project was intended to demonstrate new ways to use public dollars to support people with disabilities to experience positive personal outcomes. We did not presume to predict whether the changes it would promote might require any additional funding allocations or could be accommodated within the existing budget constraints by shifting costs from current categories to new ones. This information was something important that we hoped to learn through the project experience.

We knew that the District traditionally has used a one-size-fits-all, “program” approach to organizing, delivering and financing services to persons with developmental disabilities. “Bundled” service strategies have been the norm in the city, where people receive services in congregate settings, such as group homes or day treatment programs. These “programs” are responsible for addressing the disparate needs of individuals who are grouped together to facilitate the provision of services, not because they all require exactly the same type and intensity of services. Group homes, for instance, offered “built in” assistance in the form of staff supervision and structured training activities to people who lived in them, regardless of their individual needs or interests. Similarly, we were concerned about people who presented distinct challenges that we saw made worse by a program approach, e.g., people who required services from more than one “service system” or who had histories of being discharged by providers unwilling to try to meet their challenges. In contrast, we knew that person-centered supports would respond to the unique needs of these people.

Hear me out

Quite possibly no one was in a more serious situation when they came into Quality Trust’s (QT) Partnership Project than 45-year-old TP, a woman with significant intellectual and emotional disabilities, who has come to require intensive support to be safe. In past placements – and even in her family home – TP has experienced sexual, physical and emotional abuse by a variety of different people in her life. As a result, she exercises limited control of her temper; she does not like to be told what to do and has learned ways to interact with others to try to manipulate and “control” her environment. Her file says she has “target behaviors” of “hitting, screaming, lying, manipulation and aggression” among other things. Most critically, TP has taken to communicating how unhappy she is by swallowing small non-food items. Although this behavior has been identified as a problem over the years, those closest to TP -- provider staff, psychologists, and MRDDA case managers – and the plans they developed to help her failed to improve her situation.

The first year the QT advocate knew TP, she lived in 3 different homes with support from 3 different provider agencies and also had a stay at St. Elizabeths Hospital. Living in a group home with 6-8 other people only made TP’s situation worse. She was expected to “get along” with roommates and staff who didn’t like her and to compete for their attention, and she used increasingly challenging ways to communicate her dissatisfaction with the lack of control she had over her life and the group home environment. QT advocacy on her behalf centered on pressing for TP to move to an environment that was less restrictive than a medical model group home (ICF/MR).

Another issue we had seen repeatedly was that life moved forward very slowly for many people receiving supports. When they needed or wanted changes in where they lived or spent their daytime, they typically had to wait for it. There was no sense of urgency for people “in the system” because they had some supports in place, even if they were not the ones they really needed. We sometimes encountered the issue that there were no open “slots” in the services particular people needed or, conversely, that what was available did not match the person’s needs and/or interests. The capacity to customize services was severely limited.

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Findings and Conclusions:

QT had originally envisioned that it would provide project partners with support and

facilitation and assist with funding for expert consultants, planning and other support resources to move project activities forward. After the public meeting, lengthy deliberations and an RFP process, QT instead took the lead in implementing the pilot demonstrations.

The Partnership for Change project focused on 5 people who had already come to the attention of QT advocates. Central to the approach was an understanding that the best services and supports are grounded in personal priorities expressed by the people using them. We relied on individualized, person-centered planning, a best practice method of supporting individuals in which consumer input and decision-making guides the development of supports for each person. The project director brought together a team of advocates, providers and government representatives to design support strategies, track individual progress and problem solve around real barriers to their delivery.

The project had 5 specific goals, as follows:

1. Demonstrating success for specifically identified individuals.
2. Learning what needed to change if services and supports in the District were to become person-centered and responsive to individual needs.
3. Documenting the process of creating services needed for each person to identify how the same processes might work for others.
4. Implementing a process for tracking progress with each person and identifying systemic barriers (such as rules or funding limitations) that might have an effect on future implementation of the District's MR/DD Waiver as a funding source for individualized services.
5. Producing a report that illustrated project successes and recommendations from team members and outlines the steps needed to enhance the effectiveness and utilization of the District's MR/DD-Waiver.

This report provides an overview and analysis of our project activities and findings and includes recommendations we believe are essential for improving the system.

The following summarizes our results for each specific project goal.

1. Demonstrating success for specifically identified individuals

QT selected five people for this project. The individual profiles for these people represented different types of situations experienced by people with disabilities needing support:

- (a) Two people had emotional and behavioral issues that made them difficult for

others to support (MS; TP).

(b) One young woman was pregnant, wanted to raise her then unborn child and would require supports to do so, which her provider at that time was not willing to offer (AK).

(c) One person was living in his own home and required limited supports plus mobility aids to lead a higher quality life (LM).

(d) One middle-aged woman was experiencing *serious* multiple medical issues, and she did not want to move into an ICF/MR but to remain living on her own (EW).

From the perspective of achieving person-centered results, the Partnership was successful: Four of the five people involved in the project *now* have supports and services of greater quality that are more individualized to than those they had previously received. The situation for the fifth person is only somewhat improved but still in process.

On the other hand, the effort to use the waiver as the principal funding stream to provide these services and gain maximum federal matching dollars was not successful. Instead, MRDDA used local dollars to make up the difference between what the District's waiver, as currently written, would fund and the real costs of supports.

A chance for a new start

MS is a 38-year-old man who has intellectual disabilities and schizophrenia. He is friendly, loves to talk and is quick with a smile. MS has lived in institutions, such as St. Elizabeths Hospital and The Woods School, on and off since he was 12 years old. In fact, he has lived in institutional settings longer than any other arrangement, including the home of his birth family. MS has also endured and is still trying to process the conflicting feelings he has about his relationship with his father, which involved both verbal and physical abuse. Although there are some day-to-day activities that prove difficult for MS, such as cooking and handling his finances well, neither of his disabilities requires that he live in an institution. In this sense, he is a perfect candidate for Medicaid waiver funded services, even though periods of delusional and/or paranoid thinking have presented some barriers to his ability to maintain the community placements with which he has been presented until now.

2. Learning what needed to change to make services and supports in DC more person-centered and responsive to individual needs.

- Ø We saw repeatedly that MRDDA case managers did not see themselves as advocates for the people with whom they worked; hence, when situations requiring person-centered, individualized responses arose, the case managers did not typically respond from this perspective. The changes that this project brought about in the lives of the five people would not have happened without the efforts of QT advocates who worked with them intensively to keep everyone in the person's life focused on their priority outcomes.
- Ø We also learned that MRDDA services and waiver-funded supports are person-

centered in name only. For some people, a third party contractor with little to no direct knowledge of the focal individuals leads the meetings that are held annually to develop the plans that authorize their services and supports for the year. When someone who knows the person well does not facilitate this process, the resultant plans often contain factual errors and team members/support people do not clearly understand who is responsible for implementation. For MS, the contractor did not invite either his day program staff or his psychiatric team to the first meeting held after MS's discharge from St. Elizabeths because that firm was not aware that they were involved in his life. It took scheduling two more meetings over the next two months to get all the key personnel involved in MS's life together to generate a plan that reflected his real interests and needs. For LM, the QT advocate had to spend considerable time educating him about waiver services and guiding him to make informed choices because neither the contract plan facilitator or his case manager were able to fill this role.

The intense effort of QT advocates needed to affect real changes in people's lives revealed that the District's waiver, *as it is currently written*,

- is not the alternative to ICFR/MR funding that Congress intended because it does not provide funding for 24-hour-a-day wrap-around supports to people living outside congregate settings;
- is not a framework that offers flexible funding to meet individual needs because much of the support crucial to independent living (e.g., chore aid, personal care assistance) are all discrete and separate services making it more complicated and difficult for providers to offer these supports;
- does not provide the District government with the ability to recoup maximum federal matching dollars.

These flaws are demonstrated in many ways. In "Independent Habilitation" (the waiver service used to provide wrap-around supports to individuals living in their own home, the home of an unpaid caregiver or an apartment) there are limitations on the number of hours the waiver can be billed on any given day. This limitation makes it impossible to use waiver funds to cover all the supports for people needing assistance 24 hours a day. The rules for Residential Habilitation define the service as a congregate living arrangement of between 4-6 individuals. The Residential Habilitation regulations mirror existing local regulations governing Community Residential Facilities (CRFs). CRF regulations are also remarkably similar to ICF/MR regulations. The overlap between these two sets of regulations prevents the waiver from offering a viable alternative to the ICF/MR program model because they lack the creativity and flexibility Congress intended to give people and providers to create support options that enable person-centered lifestyles.

There are several other areas in which the District's waiver is limited and produces a disjointed and chaotic response to people's needs. A good example is the local

requirement that prospective Residential Habilitation providers are required to rent or purchase a home, then take all actions necessary for the home to pass the licensing process without any assurances that someone with a disability will move into the home. Not only does this not make business sense, it also undermines the very point of the waiver, which is to offer *people* more choice in the setting, style and amount of services they wish to receive.

The District's structure for implementing Waiver services also contributes to difficulties people experience in using this funding source to secure more individualized supports. MRDDA is responsible for the design and implementation of waiver services and supports and the Medical Assistance Administration (MAA), which is located within a different cabinet-level department, manages waiver funding. This design is problematic because in practice the two agencies have different priorities and potentially competing interests. Spreading these functions between two different DC agencies creates lack of clarity about program and performance requirements.

Internal compartmentalization within MRDDA also works against easy achievement of people's outcomes. Case managers must submit requests to a variety of internal branches to achieve particular outcomes. In one instance, when the QT advocate discussed the possibility of locating a supported living arrangement through the waiver, the MRDDA case manager submitted a request to the residential branch of MRDDA. The advocate followed up several times on the progress of the referral only to be informed that the residential branch only makes referrals to ICF's/MR. After reminding the case manager that the agreement was to "shop" for providers through the waiver, the case manager submitted another request, this time to the Community-Based Services branch, which then sent out a Scope of Services document seeking proposals from providers who might be interested in supporting this man. Approximately 12 months elapsed from the time of the original request until a provider of an appropriate service was located.

There were not enough providers in place to offer people choices among either service providers or direct support staff. This limitation also contributes to MRDDA services not being person-centered. All project participants who received "Independent Habilitation" services are receiving them from one provider agency. One disincentive to providing waiver services is that it involves both obtaining a Medicaid Provider Agreement from MAA and negotiating a Human Care Agreement with MRDDA. Providers report that it has routinely taken even seasoned agencies as long as 2 years to receive MAA approval. Also a possible disincentive is that rates for independent living supports are higher in MRDDA Human Care Agreements than waiver reimbursement rates.

3. Documenting the process of creating services needed for each person to identify how the same processes might work for others.

QT advocates kept extensive documentation that enabled us to tally that it took between 165 and 988 hours of independent advocacy per person to achieve Partnership project results. The time spent was not directly related to the complexity of a person's issues or level of disability, e.g., it took almost 350 hours to realize only limited success for one person who advocates in his own behalf, was already living independently in the community, did not have extensive health-care needs and did not require 24-hour, wrap-around services.

Sample participant stories (see Appendix A) detail the intensive efforts of QT advocates listening to project participants, then educating the person's support team; linking with MRDDA case managers to get needed actions taken; collaborating with residential providers to guide, train and support their staff, and follow-up with MAA staff on waiver requirements that produced the Partnership project's successful results.

For MS and TP, who had emotional and behavioral challenges, MRDDA case managers would not advocate for independent living arrangements eligible for waiver funding. Instead, their QT advocates located willing providers, then advocated for the option to be implemented.

For LM, who required only limited supports, the QT advocate regularly picked up responsibilities that his MRDDA case managers dropped. For example, the advocate navigated two government bureaucracies to ensure that he established LM's eligibility for the waiver, carefully explained the intricacies of the discrete waiver-funded supports for which he might apply to ensure that he could make informed choices and researched various types of mobility aids and vendors, so that he might secure either a power scooter or wheelchair to compensate for his physical impairments. LM has had 3 different case managers assigned during the time the QT advocate has worked with

Just a little help

LM is a 41-year-old man with intellectual disabilities and multiple physical disabilities. Because he is well spoken and active in his own behalf, he sometimes appears to be more capable than he is. For about 18 years following completion of special education in the DC Public Schools and a job training program run by a local disability provider agency, LM lived independently without adult MR/DD services. His mother, who is now elderly and in declining health, was always his primary support person. She assisted him with reading mail, processing information and completing applications.

Over time, his physical disabilities, which include severe osteoarthritis, asthma, joint deterioration (Charcot joints) and fallen arches (pes planus) worsened. In 2001, following frequent hospital visits that forced him to miss work repeatedly, he had no choice but to retire on permanent disability, even though he wanted to continue working.

In 2002, LM accessed MRDDA case management services. By 2003, he requested assistance from Quality Trust (QT) for 3 distinct priorities: First, he needed renovations to his home (for accessibility and other repairs). Although he is often an accomplished advocate for himself, LM had also become frustrated by his inability to arrange waiver-funded support services despite a year of trying. Finally, he needed to secure a subsidized power scooter or wheelchair to compensate for his physical disabilities.

him.

4. Implementing a process for tracking progress with each person to identify barriers (such as rules or funding limitations) that might have an effect on future implementation of the waiver as a potential funding source for individualized services.

Tracking progress for each participant yielded a list of barriers that will have a negative impact on future implementation of the waiver as a potential funding source for more individualized services, unless they are addressed or removed. As a group, the project's 5 participants faced similar barriers when trying to achieve better lives. They include the following:

- Ø A primary barrier to receiving more individualized services was the lack of advocacy-based case management/service coordination within MRDDA.
- Ø Another fundamental concern is that MRDDA does not promote the right of people with developmental disabilities to play a central role in planning their own services, especially if their decision-making capacities are questioned in any way. In almost every instance, QT has found that assessments and plans identify people as incompetent to make decisions that affect any areas of their lives without specific justifications based on actual experiences. This presumption of incompetence is one reason why many people within the service system do not envision the potential benefit of using waiver funding for the people they support.
- Ø The limited number of providers from which people could choose to receive individualized residential services threatens the viability of waiver services. Only one provider agency came forward to provide this service for 4 of the 5 project participants who wanted it. As an example, for MS we saw that it took 16 months of advocacy to bring together a team that could coalesce around his goal to move into an apartment. Advocacy intervention required the following:
 - Convincing team members that the person had a right to more individualized services or the capacity to benefit from them.
 - Finding a provider willing to provide the needed level of supports.
 - Using a person-centered meeting process to foster the vision of how these services and supports might look.
 - Providing follow-along advocacy about the same concepts (e.g., individual rights, capacity, etc.) to educate and support provider staff once he moved into his apartment.
- Ø For LM, who needs only discrete categories of support rather than umbrella services, the shortage of providers and support personnel means that being

counted as “on the waiver” (approved for waiver-funded services) does not translate into receiving any waiver funded services. He has yet to access the discrete services he needs, e.g., chore aide, homemaker, and personal care assistance.

- Ø The District is dependent on local dollars (unmatched by Medicaid) to pay for a large portion of the individualized services necessary for the kinds of “Independent Habilitation” living arrangements several of the Partnership project participants achieved. Due to locally imposed caps and limitations, the waiver could fund only portions of these services. The balance was then supplemented by MRDDA through its Human Care Agreements (contracts). Thus, knowing that a person is receiving waiver-funded “Independent Habilitation” does not mean that s/he is fully waiver funded.
- Ø Specifically, we can point to the cap on hours built into the Independent Habilitation rule or its prohibition on funding certain nursing services. Our data indicate that both the Independent Habilitation and Residential Habilitation rules require dramatic changes to become truly workable vehicles for waiver services. Knowing this, it is not difficult to understand why MRDDA would resist moving more aggressively away from ICF/MR placements and into the kinds of services the waiver is designed to facilitate when it takes a great expenditure of local unmatched dollars to make the waiver, as opposed to ICFs/MR, work.

5. Producing a report that illustrates project successes and recommendations from team members and outlines the steps needed to enhance the effectiveness and utilization of the MR/DD Medicaid Waiver in DC.

The project produced this report and detailed supporting documentation including sample participant stories, advocacy cost estimates and records of advocacy intervention. Recommendations to guide the dialogue about next steps among all key stakeholders are as follows.

Recommendations:

1. Re-name and re-write the “Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978” to ground it in principles of self-determination, least restrictive living environment and respect for individual choice.
2. Realign the responsibilities of MRDDA and MAA to locate within one responsible agency both the design and implementation of supports for people with developmental disabilities and the management and control of funding for those supports.
3. Rewrite the laws and rules governing the supports and services that the District provides people with developmental disabilities to ensure access to the most individualized supports possible and the maximum Medicaid reimbursement allowable.

4. Create independent, advocacy-based case management or support coordination to offer a viable alternative to the current MRDDA case management arrangement. This support coordination will be grounded in an understanding of the rights of people's rights to create lifestyles of their own choosing, respect for their right to design their own supports and services to the greatest extent possible, and a willingness to promote actively whatever it takes to meet these requirements, while assuring that services and supports are of high quality and provided on a consistent basis.
5. Expand the pool of providers approved to offer the full range of supports and services eligible for waiver funding. Streamline the application approval process and empower the responsible agency to guide prospective providers through it quickly.
6. Make transparent efforts to amend the current waiver and prepare the 2007 waiver application and ensure people with disabilities and their families are active participants in this process.
7. Improve interagency collaboration to ensure that service coordination and safeguards exist for all people with developmental disabilities who receive supports from multiple agencies.
8. Require that MRDDA/MAA or a successor agency report annual data that show numbers of people approved for specific waiver services and numbers of people actually accessing those services with waiver funding.

Epilogue:

In the last half of 2005, MRDDA convened a Waiver Advisory Taskforce comprised of providers, advocates, people with disabilities, family members and MRDDA representatives. The taskforce reviewed the rules for the current waiver, recommended deleting several services and collapsing others into new services. The recommended changes will greatly enhance the ability of consumers to exercise greater control over their services, receive better advocacy and coordinating support. They will also make it possible for the DC government to maximize federal matching dollars for waiver services provided. The Department of Health must now complete a Fiscal Impact statement and ensure that the proposed changes meet legal sufficiency before going to the DC City Council for approval. If approved, these changes will represent important and significant steps toward individualized, person centered services and supports.

We end our report with an update on how the three people we highlighted are doing now. While we can't say that QT advocacy efforts to improve services and supports for MS, TP, & LM changed the system forever, we do believe that it helped us and others to learn important lessons about assisting people with disabilities in DC to access real choice and real lives. The recommendations for change included in this report require fundamental rethinking of the systems we use to support DC citizens with disabilities. And, after all, the efforts to change how services and supports are planned, managed, and financed must be about helping people to be safe and live full and meaningful lives.

TP:

TP continues to live in an apartment in Northeast with round the clock staff support. She also attends a day program through the same provider agency. She is excited about a move to a new duplex in Southwest that is scheduled to occur on her birthday in January 2005. She explains this as her gift to herself and is proud because it is the first house she has lived in other than a group home. She enjoys producing artwork at her day program and will at times give it to her staff and friends. Many of the same staff members have remained with her since she moved into the apartment over two years ago. TP also continues to have support from her involved MRDDA Case Manager and attorney. The continuity of having dedicated direct support and other professionals who know her well and respect her accounts for a major part of her success. TP continues to enjoy dancing at the club, listening to records on her new record player, shopping, going to the movies and talking to and visiting friends and family. Her health has improved as she now attempts to follow diet recommendations and exercise. She is proud of her accomplishments and is looking forward.

MS:

MS moved last September from the apartment in which he had been living to a new apartment. The apartment is in an excellent building well ensconced in a vibrant District community. The move to this location was not person-centered, and typifies more of what is wrong with the current system of supports for people. The provider agency decided that the apartment management company at the MS's former complex was not responsive to the needs of the consumers in the apartment, so they located a new apartment and orchestrated the move. Although the provider can be applauded for acting to protect their consumer's interests, MS was not asked if he wanted to leave the old apartment, and minimal effort was expended to help him through the change in routine that occurred. MS was given two brief opportunities to see the new apartment before he moved in. He was not offered opportunities to look at other apartments. MS's case manager was not aware of the move until just before it occurred. He did not meet with MS and ask him if he liked the apartment, relying instead on the word of the provider. Another annual meeting (ISP) was held over the summer, and again the day program and psychiatric providers were not included in the meeting. Again this was explained as a failure of the case manager and the third party contractor who is responsible for writing and orchestrating the ISP to coordinate with each other to ensure all necessary team members were present. Consequently, the meeting failed again to result in creating support team cohesion and knowledge sharing that could truly assist MS to move forward in reaching his personal outcomes.

While the support MS has received are demonstrably better than before, the current provider has repeatedly failed to demonstrate the capacity to support MS using best practice models.

LM

LM has received initial approval for up to \$45,000 worth of renovation and accessibility repairs to his home through the DC Dept. of Housing & Community Development. He is waiting for the scope of work report to be finalized and the loan process to be scheduled. His electric-powered wheelchair has allowed him to be more mobile in the community and not dependent on MetroAccess or others to take him everywhere. He had his Individual Support Planning (ISP) meeting in December 2005, which highlighted the seven services he would like to receive through the Medicaid waiver and he has an appointment scheduled to meet with an identified potential staff person to provide some of the requested services. He is still waiting patiently for a little help.

APPENDIX A
Individual Stories

TP

Quite possibly no one was in a more serious situation when they came into Quality Trust's (QT) Partnership Project than 45-year-old TP, a woman with significant intellectual and emotional disabilities, who has come to require intensive support to be safe. In past placements – and even in her family home – TP has experienced sexual, physical and emotional abuse by a variety of different people involved in her life. As a result, she exercises limited control of her temper; she does not like to be told what to do and has learned ways to interact with others to try to manipulate and “control” her environment. Her file says she has “target behaviors” of “hitting, screaming, lying, manipulation and aggression” among other things. Most critically, TP has taken to communicating how unhappy she is by swallowing small non-food items. Although this has been identified as a problem over the years, those closest to TP -- provider staff, psychologists, and MRDDA case managers – and the plans they have developed to help her have failed to improve her situation.

The first year TP came to the attention of QT advocates, she had lived in 3 different homes with support from 3 different provider agencies and also had a stay at St. Elizabeths Hospital. Living in a group home with 6-8 other people only made TP's situation worse. She was expected to “get along” with roommates and staff who didn't like her and to compete for their attention, and she used increasingly challenging ways to communicate her dissatisfaction with the lack of control she had over her life and the group home environment. Meanwhile, her support teams had missed the messages TP was trying to convey and responded instead by trying to control or change her “behaviors.” And, still providers and MRDDA case management lacked the vision to abandon ICF/MR group home placements, which inherently preclude a more individually focused living arrangement. On the other hand, in TP's situation, they also could not ignore the failure of the ICF/MR model to meet her needs, as evidenced by the many times she had ended up in the emergency room. QT advocacy on her behalf centered on pressing for TP to move to an environment that was less restrictive than a medical model group home (ICF/MR).

The first attempt to provide services to TP in an apartment setting with QT encouragement did not work. The provider agency and its support staff could not provide the patience, vision and creativity TP required and immediately became overwhelmed, despite the QT advocate working with MRDDA and the provider for 4 months to facilitate better programming and supports. A final incident resulted in the provider discharging TP. With no alternative place to live, she was hospitalized at St. Elizabeths, and the QT advocate began discussions with a second provider about her services. That provider agreed to try a 2:1 staffing model, and TP again began living in an apartment. The QT advocate visited TP regularly and worked with her support staff to guide and assist them in understanding her needs. During the most recent 4 months, this new living situation has begun to show real progress.

TP is doing well and continues to benefit from being supported by staff that has

remained in her life despite difficult times. Staff training and low turnover of direct care staff are a significant factor in this recent progress. The Medicaid waiver is funding a portion of the costs of TP's direct care through reimbursable Independent Habilitation, and MRDDA is funding a portion with non-reimbursed, local funding through a budget negotiated with the provider via a Human Care Agreement (contract).

Advocacy support for TP = 559 hours

Conclusions supported by TP's story:

1. Support team members do not always understand the role that services and supports eligible for waiver funding might play in making crucial changes in people's living situations and giving individuals more choice and control over their lives and where they live. It took significant advocacy and regular intervention to ensure that TP got the consistent support she needed to stabilize and begin making progress in her life.
2. The assignment of waiver providers is not person-centered, and people who are enrolled often cannot find providers and/or staff they can trust to offer the services and supports they need. This indicates that too few provider agencies have been approved to offer the full range of waiver-funded independent living services/support activities.
3. Describing TP as being "on the waiver" is somewhat misleading because a significant portion of the money paid to the provider for her services is local, appropriated, non-Medicaid reimbursable dollars. This fact results from how the District's waiver is written. It precludes Medicaid reimbursement for more than a portion of "Independent Habilitation" services, when they are provided on a 24-hour, wrap-around basis.

MS

MS is a 38-year-old man who has intellectual disabilities and schizophrenia. He is friendly, loves to talk and is quick with a smile. MS has lived in institutions, such as St. Elizabeths Hospital and The Woods School, on and off since he was 12 years old. In fact, he has lived in institutional settings longer than any other arrangement, including the home of his birth family. Milton has also endured and is still trying to process the conflicting feelings he has about his relationship with his father, which involved both verbal and physical abuse. Although there are some day-to-day activities that prove difficult for MS, such as cooking and handling his finances well, neither of his disabilities requires that he live in an institution. In this sense, he is a perfect candidate for Medicaid waiver funded services, even though periods of delusional and/or paranoid thinking have presented some barriers to his ability to maintain the community placements with which he has been presented until now.

MS had experienced several failed placements in medical model group homes (ICFs/MR), where he never received the level of individualized or psychiatric support that he required. He was living temporarily at St. Elizabeths in the wake of yet another at the time that he became known to Quality Trust (QT). Over the course of more than 8 initial meetings together, as the QT advocate and MS got to know each other, he revealed that he hoped to live in an apartment, preferably in Southeast, DC. Over the next 16 months, the QT advocate worked to convince MRDDA staff and 2 court-appointed attorneys to accommodate this choice (the first attorney was removed when the QT advocate convinced the court that she was as detrimental to MS's progress as anyone else involved in his life at that time).

The QT advocate encountered reluctance and outright refusal to work toward MS's desired outcome. No one from MRDDA's case management office believed that he had the right or would be safe living outside a restrictive group home setting. Despite the QT advocate's efforts to educate them about the waiver and the principle behind it (that its intent is to offer an alternative approach to people eligible for ICF/MR level of service), MRDDA case management staff continued to recommend that MS live in an ICF/MR group home. After countless conversations and meetings with several members of MRDDA's administration (including case management supervisors, Division Chiefs, and ultimately the Deputy Administrator), the agency agreed to assist MS in obtaining the supports he needed to live in an apartment with funding through the waiver. For the next 3 months after they reached this decision, the QT advocate alternately assisted and pressured MS's MRDDA case manager to work within the bureaucracy to help MS achieve his desired outcome. When he realized the futility of these efforts, the QT advocate took the initiative to call providers on his own. Having been made aware of a specific provider already supporting another participant in this Partnership Project, the advocate cultivated a relationship with its Residential Director, and then asked him to meet with MS at his day program. Following that meeting, he agreed to work with him, and the agency spent the ensuing 3 months in negotiations with MRDDA. Finally, after 16 months of QT advocacy a team was brought together that coalesced around the goal of assisting MS to move out of St. Elizabeths into an apartment with supports.

Since the move, the QT advocate has regularly worked with the provider to ensure that MS is offered the highest quality personalized supports. He has insisted that the provider do a better job of seeing MS as an individual and listening to him. The QT advocate has met regularly with MS's direct support staff and tracked whether management is providing them the training and support it will take for him to be successful. A particular focus of this training is assisting them to confidently embrace the rights of individuals with disabilities to direct their own supports in a community supported living arrangement. Also, important has been including MS in decision making about his personal outcomes and the supports it will take to achieve them. The idea that an individual with disabilities can actually direct his own services is new to many providers, case managers and clinicians in the District.

The QT advocate has also provided crucial oversight and linkages between the residential provider, which is within the MR/DD system, and MS's day program and clinical services, which are within the mental health system, to ensure his mental health issues are addressed and monitored. The limited levels of inter-agency communication and coordination that is typical in cases like this are always to the detriment of the service user. MS was recently assigned a new MRDDA case manager, his third during the time the QT advocate has known him. This could easily threaten both continuity of services and the progress he has made, were it not for the continued presence of the QT advocate.

Advocacy support for MS = 264 hours

Conclusions supported by MS's story:

1. MRDDA services are person-centered in name only. MS has not been supported to direct the development of his services and people who are important members of his support team do not always know what's most important for him.
2. It took over a year of advocacy to get MRDDA and others to believe in the right of MS to access supports in the community and play any role in designing those supports.
3. Often MRDDA case managers do not act as advocates for the people they represent. Two of MS's MRDDA case managers were unable or unwilling to advocate within the agency's internal bureaucracy to ensure that he was able to gain access to the least restrictive living arrangements of his choice in a timely manner.
4. MS did not have a true choice in waiver providers because there was only one willing to work with him. Too few provider agencies have been approved to offer the full range of waiver-funded independent living services/support activities. More providers are needed to make choice real and more meaningful.
5. Describing MS as being "on the waiver" is somewhat misleading because a significant portion of the money paid to the provider for his services is local,

appropriated, non-Medicaid reimbursable dollars. This fact results from how the District's waiver is written. It precludes Medicaid reimbursement for a portion of "Independent Habilitation" services, when they are provided on a 24-hour basis.

6. Inter-agency service coordination is weak. Safeguards must exist for all people with developmental disabilities who receive supports from multiple service "systems," e.g., MRDDA and the Department of Mental Health.

LM

LM is a 41-year-old man with intellectual disabilities and multiple physical disabilities. Because he is well spoken and active in his own behalf, he sometimes appears to be more capable than he is. For about 18 years following completion of special education in the DC Public Schools and a job training program run by a local disability provider agency, LM lived independently without adult MR/DD services. His mother, who is now elderly and in declining health, was always his primary support person. She assisted him with reading mail, processing information and completing applications.

After job training, LM worked at Maurice Electrical Supply in DC, as a porter, for more than a dozen years. In 1998, while he was still working, LM bought a house that he understood was in need of repair through the Home of Your Own program (HOYO). (HOYO was a grant-funded, public-private collaborative designed to guide District residents with developmental disabilities through the home-buying process.) Over time, his physical disabilities, which include severe osteoarthritis, asthma, joint deterioration (Charcot joints) and fallen arches (*pes planus*) worsened. In 2001, following frequent hospital visits that forced him to miss work repeatedly, he had no choice but to retire on permanent disability, even though he wanted to continue working.

In 2002, LM accessed MRDDA case management services. By 2003, he requested assistance from Quality Trust (QT) for 3 distinct priorities: First, he hoped to arrange for subsidized renovations to his home (for accessibility and other repairs), since the pool of renovation and maintenance money that the HOYO program (by then defunct) had promised would be available had never materialized and LM's financial condition had changed considerably, since he could no longer work. Although he is often an accomplished advocate for himself, LM had also become frustrated by his inability to arrange waiver-funded support services despite a year of trying. Similarly, he had tried for several months but failed to secure a subsidized power scooter or wheelchair to compensate for his physical disabilities.

- LM needed to confirm that he had a developmental disability, because he had not been reliant on adult MR/DD services. The school he had attended (Grimke School) had since closed, and DCPS had no pertinent records. The QT advocate assisted by arranged for his mother and a second person to confirm that he had received special education services via notarized letters, which MRDDA accepted in the absence of DCPS records.
- The QT advocate then focused 15 months of effort on LM's application to become eligible for services funded under the Medicaid waiver. When the Medical Assistance Administration (MAA) initially determined that he did not meet waiver eligibility requirements, she worked with the Benefits Director and Medicaid Waiver Chief to correct their misinformation and restart the waiver enrollment process.

While his application was in process, the QT Advocate also sought to educate LM and his MRDDA case manager about the kinds of service he might secure once he became

eligible. After he was enrolled (6/2004), she expended considerable effort working with LM to review carefully the range of Medicaid-funded services and determine which possibilities best met his needs. He applied for 5 services but received none during the remainder of FY 2004.

Because of a series of bureaucratic miscommunications (LM had 2 case managers in FY 2005), he received only 1 of 5 waiver services he requested in FY 2005 (transportation). He was also assigned a provider agency for a chore aide service. The person he selected first missed interview appointments and, later, after having been hired, breached his confidentiality agreement, which caused LM to dismiss him. The provider agency reported it would not be able to replace the aide quickly because it lacked a large pool of personnel from which to select.

For FY 2006, LM's waiver eligibility was reauthorized. He has requested 8 services, is receiving one (transportation) and has selected another provider who is seeking to identify candidates for chore aide, homemaker, and personal care attendant to assist him. (He is also authorized for waiver-funded case management, crisis support/family counseling, dental coverage, and nutrition services.) Meanwhile, LM's second case manager was reassigned, and a third case manager has begun working with him.

- Simultaneously, the QT Advocate spent 20 months following up on requests LM had initiated for a scooter funded through the waiver (three times), a process that involved paperwork lost during transfer between agencies, the case manager's failure to understand that LM also received Medicare benefits and, therefore, that he needed to elect Medicare as the primary payment source, etc. Because LM's MRDDA case manager showed no interest in becoming knowledgeable about durable medical equipment, the QT Advocate assisted LM by researching the variety of equipment and vendors available. She shared the results with LM and the case manager to assist him in making an informed choice. In 11/2005, he received a power wheelchair. (He will also receive a scooter funded in part through Medicare and MRDDA.)
- Also in the same time frame, the QT Advocate worked different options to help LM identify resources to repair and make his home more accessible, so he could continue to live there. First, she, and then a QT Board member, applied to Rebuilding Together ("Christmas in April"), seeking subsidized renovations in his behalf. Eventually, representatives of the Clark Construction Company made a site visit and determined that the structure required more extensive work than that program could provide using volunteer labor.

During the same period, she supported him to re-apply to the DC Housing & Community Development Office for an accessibility grant and a low-interest renovation loan. (The first application had been denied when he did not secure the 3 required bids from contractors during the time allowed.) It was difficult for LM to maneuver through this long, paper-intensive process without consistent support. In 9/2005, he received preliminary approval for a combined \$45,000 grant/loan. He must now go through a separate loan approval process. (Loan repayment is deferred as long as this house

remains his primary residence.)

Advocacy support for LM = 347 hours

Conclusions supported by LM's story:

1. The amount of advocacy it took to achieve successful results for participants in the Partnership Project was not related to the complexity of a person's issues or his/her degree of disability. It took more than 300 advocacy hours to achieve only partial success for a vocal self-advocate like LM, who already lived independently in the community, did not have extensive health care needs or require 24-hour, wrap-around services.
2. Being designated as "on the waiver" (enrolled to receive waiver-funded services) does not mean the person is actually receiving any waiver-funded services. LM spent more than a year authorized for but not receiving any waiver-funded services.
3. Often MRDDA case managers do not act as advocates for the people in their caseload. Many do not understand the role that the waiver can play in fulfilling the choices of people with developmental disabilities to have more control over their lives and more individualized services. Similarly, many are not knowledgeable about services people request and do not take expeditious or appropriate action on requests, e.g., first case manager's failure to assist with supplemental materials to LM's DCHCD submission and second case manager's failure to follow-through on mobility equipment.
4. Too few provider agencies have been approved to offer the full range of waiver-funded independent living services and supports. This means that the assignment of waiver providers cannot be person-centered, and people who are enrolled often cannot find providers and/or staff they can trust to offer the supports they request. Few providers are motivated to offer other than independent habilitation or transportation services, e.g., chore aide, homemaker, personal assistance, because the way in which the District's waiver was written carves the latter type of supports into too many small, disparate pieces makes management more challenging and not cost effective. The list of approved providers the District distributes is not accurate; there are fewer providers than appear on the list.
5. MRDDA services are person-centered in name only. The process for developing the annual Individual Support Plan (ISP) for people not living in ICFs/MR group homes is organized and facilitated by a contract agency rather than people who know the person well.

Appendix B
Glossary of Terms

Glossary of Terms

Developmental disability: Chronic mental and/or physical disabilities which manifest before age 22 and results in functional limitations in at least three of the following areas of life activity: self-care, language, learning, mobility, self-direction, independent living and economic self-sufficiency. Individuals with developmental disabilities require lifelong or extended individual supports. Disabilities include but not limited to autism, mental retardation, epilepsy and cerebral palsy.

Evans class member: A person with a disability who lived at Forest Haven, the District's institution for persons with disabilities and who is afforded specific benefits and protections as a result of the consent orders and settlement agreements in the Evans vs. District class-action lawsuit.

Evans Court Monitor: The person designated to monitor the status for class members by the Federal Court Judge who oversees the Evans vs. District litigation.

HCBS waivers: Home and Community Based Waivers allow the Secretary of CMS authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings. HCBS waiver services are meant to expand on traditional, standard Medicaid services by offering intense home health services, group home care and/or case management, instead of nursing home placement, to a targeted group of individuals with disabilities and the frail aged.

ICF/MR: Intensive care facility for mental retardation, where 4 or more people with mental retardation who require a certain level of support live together and receive an array of services "bundled" together; in many instances people who live in ICFs/MR remain apart from their neighbors and without true community inclusion.

Medicaid: A joint federal and state funded health insurance program for people who are poor and/or disabled. Medicaid is available only to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. It is often the primary insurance program for people with disabilities. Medicaid programs vary from state to state, but most health care costs are covered if you qualify for both Medicare and Medicaid.

Medicare: The federal health insurance program for people 65 years or older, certain younger people with disabilities, and people with End-Stage Renal disease (permanent kidney failure with dialysis or a transplant).

Mental retardation: A disability characterized by significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills. These limitations must originate before age 18.

Person-centered planning: A best-practice method of supporting individuals with disabilities, in which consumer input and decision-making is embraced, to guide the development of supports for each person.

Self-determination: A best-practice process when people with disabilities are free to exercise control over their own lives, to set the goals to which they aspire and to access the support, skills and resources necessary to participate fully and meaningfully in society.

Support team: A group of people including professionals and community members who provide support and assistance to an individual with a developmental disability