

# Positive Living for Spec



## OUTCOME TEAM ROSTER

### Richard DeLon

Montgomery County  
Frail Elderly Services  
Advisory Committee  
Co-Champion

### Amy Luttrell

Goodwill Easter Seals Miami Valley  
Co-Champion

### Alan Cochrun

Access Center for Independent Living

### Mark Gerhardstein

Montgomery County Board of  
Mental Retardation/Developmental  
Disabilities

### Sharon Honnert

Parent

### Douglas McGarry

Area Agency on Aging

### Dennis Moore, Ed. D.

SARDI-WSU School of Medicine

### Joseph Szoke

ADAMHS Board for  
Montgomery County

### Joyce Young

Montgomery County  
Frail Elderly Services  
Advisory Committee

## STAFF:

Diane Luteran, OFCF

Donna Nettles, OFCF

## DEFINITION OF SPECIAL POPULATIONS

People of any age with significant disabilities who need assistance with basic daily living skills to live in the most appropriate, least restrictive community setting possible and avoid inappropriate institutionalization. This group includes people who are frail and elderly; adults with severe and persistent mental illness; children with severe emotional disabilities; persons with alcohol and other drug dependency; persons with mental retardation and developmental disabilities; and others who cannot perform basic life functions without assistance.

## VISION

With support from the community, special populations have the opportunity to participate in every aspect of community living that they desire. People with significant disabilities live, learn, work and participate in typical accessible community settings. The community respects and protects their rights and includes them as contributing members.

## POSITIVE LIVING FOR SPECIAL POPULATIONS (PLSP) OUTCOME TEAM REPORT

The designation "special populations" is a broad one, touching most families in some way and encompassing people of all ages with all kinds of disabling conditions. Many people have more than one disability and may be served by more than one system, while some people are not served by any system. The need for a Positive Living for Special Populations (PLSP) Outcome Team results from the natural tendency of the other FCFC outcome teams to focus on community issues that affect the broader population, rather than the often numerous people in the community who have these special needs.

During 2006, the Positive Living for Special Populations Outcome Team first revised the PLSP definition to more clearly identify the groups comprising "special populations." It then identified the major issues affecting special populations, and developed several areas of focus for work by the PLSP Outcome Team, as well as identifying two community issues which require a multi-team focus. This work culminated in an Interim Progress Report to the FCFC in November, with presentations being made by the PLSP Outcome Team Champions in December.

# Special Populations



## Major Issues That Affect Special Populations

With one in five persons in Ohio having some level of disability and one in ten persons having a severe disability (2000 U.S. Census), there are thousands of individuals in Montgomery County of all ages who need assistance in order to live as independently as possible and to participate in every aspect of community living that they desire.

As it narrowed its focus in 2006, the PLSP Outcome Team continually was challenged with the many competing needs of special populations in the community. Examples of these unmet needs include:

- Substance abuse treatment needed to improve family stability and self sufficiency
- Senior citizens who are frail and elderly who need supportive services to live in their homes or other community setting
- Aging parents who currently are caring for their children with mental retardation and developmental disabilities
- Few services for certain persons, or no system at all serving them, including persons with brain injury, spinal cord injury, mild mental retardation/learning disabilities (outside of the MRDD system), and other physical or sensory disabilities
- Persons with disabilities who would like to work but cannot risk losing their Medicaid insurance benefits, which are vital to their health and well-being

The PLSP Team found that public systems already pay billions of dollars statewide to help meet the physical, mental, medical, housing, caregiving, and other supportive needs of special populations. However, federal and state laws, rules, regulations, and funding requirements often limit choices for special populations and are biased toward institutional settings (e.g., nursing homes and other long term care facilities), even though most persons in special populations (but not all) can live successfully in the

community. When people wish to leave institutional settings, money often does not follow them to the community setting. Also problematic is that most funds for special populations are spent on intervention and treatment and not on prevention. For example, addressing developmental delays and disabilities through early intervention when a child is very young can help the child be more successful in school and in life. Another example: Instead of housing the 80% of people in jail for felonies who have been using illegal drugs or abusing alcohol regularly, that money could be used at the front end for prevention efforts, or to provide early treatment before substance abuse wrecks lives.

It also became evident to the PLSP Team that people within special populations and their family members and caregivers need help in navigating service systems. The PLSP Team heard that individuals can spend countless hours trying to find help, many unsuccessfully. Case management coordination also is important, as many people may have more than one case manager. For those who do not readily fit into a service system, there is no one to assist them to locate the few services that exist to meet their needs. The PLSP Outcome Team found that “the system” really is many systems with no roadmap.

## PLSP OUTCOME TEAM AREAS OF FOCUS

**Legislative and regulatory advocacy.** Since state and federal requirements dictate choices available, advocacy on behalf of special populations is of particular importance. The PLSP Team’s initial efforts will be focused on:

- **Supporting Ohio’s application to the Federal Centers for Medicare and Medicaid for a “Money Follows the Person” grant.** Ohio is applying for a share of \$1.75 billion available to help relocate persons from institutions to the community. Based on the PLSP Team’s advocacy, the FCFC submitted a letter supporting the state’s application to the federal government and requested our participation on the state steering

committee for the grant. It is important that this federal initiative ultimately does not become an additional demand on our already strained local resources.

⦿ **Medicaid Buy-In.** Persons with disabilities are much more likely to be unemployed and living in poverty. The PLSP Team is advocating that Ohio join 34 states which have adopted “Medicaid Buy-in” legislation. A Medicaid Buy-in law in Ohio would eliminate the need for Ohioans with disabilities to have to choose between a job and losing their Medicaid insurance benefits, which are critical to their health and well-being. (Increased income makes them ineligible for Medicaid.) Having workers buy into Medicaid on a sliding scale will allow more people to achieve self-sufficiency and become taxpayers.

⦿ **Mental Health Parity.** Lack of insurance for mental health services can impact needed treatment for special populations. The PLSP Team supported requiring the same health insurance coverage for mental illness, as is provided for physical illness (often referred to as “parity”). The PLSP Team was pleased that Ohio just joined 37 states when it passed mental health parity legislation at the end of 2006. The Outcome Team will continue to monitor this issue because Ohio’s legislation is less comprehensive than that of many other states.

⦿ **Consumer Choice.** Safety and choice are essential to the well-being of special populations. The PLSP Team will advocate consumer choice in all areas of service to allow persons to choose the service, the service provider(s), and the settings in which services are provided. This includes advocacy for quality community supports that consumers and their families can rely on. The PLSP Team also will follow Ohio’s progress in implementing the recommendations of the Ohio Commission to Reform Medicaid and will, at appropriate times, request FCFC to take a position on selected issues to advance these reforms.

**Community Education.** Too often, special populations are marginalized and do not participate in community life. As both a cause and effect of this fact, many people have no understanding of people who have a disability, including their desire and potential to work, live independently, enjoy the same recreational activities that others do, and add value to the community. The PLSP Team is beginning a process of better educating our community about special populations, including:

- ⦿ **Media partnerships to bring stories of individuals within “special populations” to the general public on a more frequent basis.** Bringing more frequent human interest stories on special populations to the media will add to the public’s understanding and acceptance of people with disabilities as “people first”, not defined by their disability.
- ⦿ **Heighten community awareness/access to services available for infants/toddlers.** Since the benefits of prevention and early intervention have the most impact early in life and the first three years of life is a time of incredible brain development, the PLSP Team will strive to educate the community regarding the importance of developmental milestones for children under age three and whom to contact for help if there are concerns.

**System Navigation.** People need help in navigating systems serving special populations, as “the system” is really a confusing maze of systems with no roadmap. The PLSP Outcome Team will:

- ⦿ Investigate best practices and ways of simplifying the language and navigation of the multiple systems that exist for special populations;
- ⦿ Offer its assistance to improve information on local services for special populations listed on the web portal The Beehive (operated by the Washington, D.C. non-profit One Economy Corporation); and
- ⦿ Promote increased coordination among systems, including cross-training of case managers on resources available for special populations. This will better serve consumers and their families.

## COMMUNITY ISSUES WHICH REQUIRE A MULTI-TEAM FOCUS

There were two particular issues identified during the PLSP Team's work which impact several FCFC outcome areas. Successfully addressing affordable housing and substance abuse will require broader community participation beyond the PLSP Outcome Team.

### Affordable Housing

Affordable subsidized housing is a major barrier to community relocation of special populations from institutional settings. Other housing needs include: supportive housing for people with mental illness and/or mental retardation and developmental disabilities; housing available to people with substance abuse; and housing that is accessible to people with physical disabilities. Our community also has recognized through the *Community 10-Year Plan for Ending Chronic Homelessness and Reducing Overall Homelessness* that mental illness and substance abuse are significant factors contributing to homelessness. Given these overlapping community needs, the PLSP Outcome Team recommended a linkage with the Homeless Solutions Policy Board (through a PLSP Team member and FCFC staff working with that Board) so that housing efforts in our community can be coordinated.

### Drug and Alcohol Dependency/Treatment

The limited availability of treatment for drug and alcohol dependency is exacerbating problems within all six FCFC outcome areas, in addition to the Homeless Solutions work. The PLSP Outcome Team, acting alone, cannot resolve this problem, but the combined efforts of Montgomery County's leadership should be able to make an impact in identifying possible solutions. Our community already is paying for untreated substance abuse, both with dollars and with broken lives. People who request treatment should be able to get that treatment without a lengthy wait. Due to the magnitude of the impact that unchecked substance abuse has on Montgomery County, the PLSP Team recommended that the FCFC adopt drug and alcohol dependency and treatment as a special multi-outcome area of focus.

### 2007

In January 2007, Emmett Orr will replace Dick DeLon as Co-Champion, and will work with Amy Luttrell on this outcome area. In 2007, the Positive Living for Special Populations Outcome

Team will work on developing and implementing a work plan for the areas of focus identified in its November 2006 Interim Progress Report. This will include:

- Legislative advocacy by the FCFC involving issues affecting special populations
- Convening a work group with appropriate expertise to develop community education activities, including media partnerships
- Developing a proposal to submit to the FCFC for funding for community education and awareness activities, including promoting the abilities of persons with disabilities, as well as promoting awareness of and linkages to early intervention for children under age 3
- Developing a systems navigation proposal to submit to the FCFC for funding to help persons served by more than one system, or for people who are not currently served by any system
- Working in conjunction with others on the multi-systems issues of affordable housing and drug and alcohol dependency/treatment



## HELP ME GROW

### HELP ME GROW CENTRAL INTAKE & REFERRAL 208-GROW (4769)



*Help Me Grow* is a state and federally funded early intervention initiative for eligible Montgomery County children under age three and their families. Services focus on infant and toddler health and development to give children the best possible start in life. The program is guided by the Ohio Department of Health and locally

administered by the Montgomery County FCFC through local providers. Participation in the program is entirely voluntary. Services include finding children through community screenings, community events, and outreach to the medical community; providing information and referral to families; conducting a home visit of newborn and mother; and ongoing services and service coordination for families of children at risk for, or with, a confirmed developmental delay or disability.

In 2006, 2,498 referrals to *Help Me Grow* were received, including over 730 from potential clients, family members, or friends, and 756 from community screenings and hospitals. *Help Me Grow* nurses made 1,258 home visits to check on the health and physical status of mothers and their newborns (most visited within the first two weeks of birth). In addition, on any given day, 1,313 Individualized Family Service Plans (ISFPs) were in place for children at risk for, or with, developmental delays/disabilities. The State of Ohio reviewed the Montgomery County *Help Me Grow* Program in June 2006 against 83 measures. Montgomery County received the highest rating of any urban county (95%), which demonstrates the high quality of services provided locally in our community.



#### CHILDREN RECEIVING ONGOING SERVICES

(DAILY COUNT AS OF 12/31/06)

■ Under 12 months (includes prenatal)   ■ 12 - 23 months   ■ 24 - 35 months

**AT RISK FOR DEVELOPMENTAL DELAY OR DISABILITY. TOTAL 715**



**SUSPECTED/DIAGNOSED DELAY OR DISABILITY. TOTAL 598**



#### IN 2006, HELP ME GROW SERVICES WERE PROVIDED BY:

##### CENTRAL INTAKE, REFERRAL AND ONGOING SERVICES:

Greater Dayton Area Hospital Association—  
Help Me Grow—Brighter Futures

##### NEWBORN HOME VISITS:

Brighter Futures  
Fidelity Health Care  
Kettering Medical Center—Precious Beginnings  
Home Care

##### DEVELOPMENTAL EVALUATIONS:

Montgomery County Board of MR/DD—  
PACE Program

Source: Ohio Department of Health Early Track

## HELP ME GROW SUCCESS STORIES

The work and impact of Help Me Grow is best explained through the stories of clients. Names have been changed.



### Newborn Home Visits

During a newborn home visit, *Help Me Grow* nurse Maria noticed an irregular heart sound when examining the newborn and reported this to the family's physician. The physician had the mother, Tamika, bring her daughter to his office. The newborn then was sent to Children's Medical Center for an additional evaluation, where a heart defect was discovered. Destiny had surgery and now is doing well.

### Family Support

*Help Me Grow* family support specialist Chris received a call from a Combined Health District nurse about Shana, a parent who lost a son with Down syndrome in her 23<sup>rd</sup> week of pregnancy. The family support specialist, who has a son with Down syndrome, took action when she found out that Shana had no financial resources for a headstone for the baby's grave. The family support specialist found a company to donate a headstone and she approached the Miami Valley Down Syndrome Association to pay for the engraving. Shana cried when Chris called her with the news. During the conversation, Chris found out that the Shana also has a two-year-old daughter with a congenital condition involving her jaw and a cleft palate. Breanne immediately was referred to *Help Me Grow* Ongoing Services. Shana was grateful that the family support specialist asked about her two-year-old daughter. She had been preoccupied with bed rest during her pregnancy, and then she suffered depression over the baby's death. The *Help Me Grow* family support specialist also attended the family's first service coordination visit.

### Ongoing Services

**Brandon** was introduced to *Help Me Grow* through a referral from the developmental clinic at Children's Medical Center. He was being tested for Pervasive Developmental Disorder (PDD), a behavioral disorder involving speech, communication, social interaction, and repetitive compulsive behavior. His mother, Emily, was overwhelmed with the information and all of the demands and said it seemed as if she had been given a box of puzzle pieces to sort through. Kathy, the *Help Me Grow* service coordinator, was able to provide the family with the tools and information needed to organize and understand the reports given to them and to develop a plan for services. The puzzle was beginning to come together into a clear picture. The family now is connected with MRDD PACE services, an infant mental health specialist, and a *Help Me Grow* parent mentor. The service coordinator facilitated meetings with all parties involved, including Brandon's daycare center. Brandon's mom said for the first time since Brandon's diagnosis, she was beginning to feel a sense of hope.

**Poverty**, domestic violence, and severe depression resulting from years of sexual abuse by a family member permeated Tiffany's life. Tiffany's *Help Me Grow* service coordinator, Allison, has become a mentor to the young mother. Tiffany has turned the corner in all

areas of her life. She feels proud of herself and plays with daughter, Nicole, every day after school. Tiffany smiles and laughs when she plays with her, and it's clear that Nicole loves her mommy. The service coordinator referred Tiffany to a GED program that has a daycare for her daughter. Tiffany plans to finish her GED, move to a new apartment, and wants to become a nurse. Nicole is developing at an age-appropriate level.

**Parents** Selena and Victor were referred to *Help Me Grow* when their son, Emanuel, was 32 months old. Emanuel had limited words and other concerns. After an evaluation of his needs, the evaluation team recommended a speech evaluation, consultation with a vision specialist, and referral to the developmental physician at the developmental clinic. Robin, the family's *Help Me Grow* service coordinator, also referred Emanuel to the MRDD PACE program for parent and child enrichment. The child has a speech delay, a prescription for glasses, and an appointment with the developmental clinic. Despite entering *Help Me Grow* only four months before their child's 3<sup>rd</sup> birthday, Selena and Victor are pleased with the resources and connections that have been made to prepare Emanuel for a successful transition and school experience at age three.