As New York State continues to struggle with finite resources, and the OPWDD system of supports moves to more of a truly needs-based system, the concept of the non disability specific community as a support system has never been more important.

There are community resources that are disability specific, such as Special Olympics, STRIDE, Sports Are For Everyone, and these are all valuable resources. They provide a positive experience for individuals with peers with disabilities. And just as you and I often seek out others we share a commonality with, so do individuals with disabilities.

There are also times when we like to expand our horizons and find connections with others who are not just like we are, and individuals with disabilities are no different. This is where “generic” community resources become a real link for those connections. This can mean the local YMCA, a coffee shop, the corner deli, a ceramics class, a theater group, a faith community or any of a number of possibilities.

Wildwood has participated in a few different initiatives, which seek to provide enhanced opportunities for individuals to connect to their communities. Every Day Heroes has been one of these, where the tenant of becoming a “regular” can have real value. We know that making friends is not as simple as just meeting someone for the first time and forging an instant connection or relationship. However, through repeated exposure and familiarity, people have a greater chance to bond. By supporting individuals with disabilities to become regulars in the community venues of their choice, this can hopefully lead to some valued social connections.

Another project that we recently partnered with OPWDD on is The Faith Based Initiative. This involves supporting individuals who want to pursue their own spirituality and guiding them to have a more enhanced presence and role in the faith community of their choice. Rather than just attending services side by side with others, the focus is on finding opportunities to really be a part of their faith community. This could mean being a part of a choir, attending social events outside of services, helping with the children’s programming, or working on service projects.

Community mapping can be helpful in identifying potential locations and groups. It is done by putting the person at the center of the map and plotting out local community venues that fit in with their interest areas. From there, exploration can be done with the person to see what locations and groups they might like and wish to explore further.

These types of opportunities not only bring a valued social presence and sense of positive self-esteem for the person, but also seek to provide developing natural supports. If an individual with a disability makes a friend at ceramics class or at their faith community, perhaps that will lead to enhanced social opportunities between them. Perhaps they will offer to bring the person to class or service, thus creating less reliance on family or paid supports.

As these relationships evolve, they become seamless and are a win-win for all involved. Needs for social connectedness and, the often challenging transportation, can be met and lead to increased independence for the person.
Dear Friends...

Jason, my son, volunteered for a few hours a day at a popular deli in our community as part of his high school experience. Basically he was stocking shelves and helping to keep the place clean. Jason quickly decided that he wanted a real, paid job at the deli. Without letting me know, Jay rode his bike the three blocks to the deli, told them that he wanted to work for them and even let them know the days and hours that he'd like to work. Well, they hired him and he's been working there for the last 14 years.

Even more significant than the fact that Jason has become an integral member of their business operations and that he has become proficient in many aspects of the work, is the fact that he has become an important member of their extended community. The people who own and operate the deli, the merchants who provide goods and services to it and the community of people who frequent the shop, have become family to my son. He is included in all social events and warmly recognized and acknowledged. He attends their weddings and other gatherings. The staff and merchants put together a fabulous birthday party for Jay and the community of people look after my son on a daily basis.

It is almost impossible to describe the relief from worry and the happiness that it gives me, as a parent of a young adult who has special needs, to know that he is included in a community that treats him with care and respect and that will protect him from harm if it may come his way.

Jay has found what we all strive for—meaningful work and connectedness with people we admire and respect. I know my son is going to be okay when I'm busy with my own life because I know Jay has people.

Sincerely,

Brooke Zayle,
Parent
Tools and Strategies for Successful Community Inclusion

Michelle A. Brown, MSW

Inclusion requires time, energy and patience. There are a variety of ways to overcome the barriers to community participation. It can take months to help someone participate successfully in just the right activity. Time is always a factor. Record activities on a calendar. Organize the days tasks to include community inclusion.

Community inclusion will not occur without focused planning and effort. It’s important to make a plan, taking into consideration a variety of factors. Of course, we can’t predict everything, but we do know what makes the person we support uncomfortable and conversely, what makes them happy. By anticipating both the struggles and successes a person may encounter, we can be more prepared and able to provide support to both the person and the community.

People are being empowered to make more of their own choices, to speak up for themselves, to make choices and explore their dreams. Helping people to explore new activities and to risk with dignity is a must. Sometimes, fear can be an obstacle to inclusion. It can be scary to try something new. By encouraging people to take the first step, they gain confidence. At times, we as staff or family members can become overprotective. All of those “what if’s?” can prevent us from helping someone broaden their world in the community. We have fears too. “What if they’re not accepted?” “What if they have a problem?” None of us want to see the person we care for experience failure. However, this can be the greatest gift we can offer. Sometimes, by falling down, we learn the greatest lessons in life. It’s crucial to encourage people to experience new activities. With encouragement like, ”yes you can” or “give it a try” we can assist people to step outside their boundaries a bit. We know we’ll be there to support them, no matter what the outcome. The community can surprise us by offering acceptance and support in a variety of ways. It’s helpful to allow people to explore at their own pace and to capitalize upon those unexpected, wonderful interactions. Watch for this “magic.” It could be in the form of a welcoming smile, an offer to help in some way. Nuture these allies. Help people to give back to others and deepen their relationships- suggest they offer to buy a cup of coffee for their friend or to exchange holiday greeting cards.

How do I find out about different opportunities in the community? There are a variety of resources such as the internet, newspapers, radio or libraries. At the library, you may find Community Contacts Booklets (available in limited libraries) which are an amazing resource that documents community groups and activities, listing pertinent information including contacts and cost. See the Reference Desk at the library for this resource. Community bulletin boards at places like banks, Stewarts and grocery stores or even faith community bulletins are great places to check for opportunities. A great way to meet neighbors is at activities such as pancake breakfasts and spaghetti suppers that may be posted on these boards. Also, ask people you know. The theory of “6 degrees of separation” can lead you to any resource in the world.

Community integration, to be successful, requires us as staff or family members to give up our desire to control the process. Integration is a multi-path activity. We start with a plan, wanting to help someone to go from point A to point B. Rarely do any of us move in a straight line. We hit obstacles and road blocks. By working around them and allowing both the person and community to direct the process, many wonderful things can happen. People can make friends, explore new avenues you never thought of or gain skills and a sense of self. When inclusion is successful, we’ve seen people blossom, become happier people and have fewer behavioral issues. As participants have the opportunity to explore a variety of community activities, they have the opportunity to learn more about themselves, their likes and dislikes.

Financial obstacles present a challenge for some people. In those cases, we look for activities that require little or no money. Yes, they are out there. Scholarships are sometimes obtainable for certain activities or clubs. They may not be well advertised. Take a risk and ask if there is anything available. You may be surprised. At Wildwood, people may apply for the Randi Joan Anderson and Blackmore Scholarship funds as well.

Community Inclusion provides people with opportunities to grow, explore and participate in activities that give meaning and direction to our lives.
Shirley Davis and Her Community

Marie Awn Floyd
Director of Family Support Services

Shirley lives, mostly independently, in her own apartment with some support from Wildwood’s residential staff. She especially needs assistance getting to and from her medical appointments and also needs some help organizing her household responsibilities. Though she has some family nearby, she relies on a strong community of friends as her primary support.

That support, in Shirley’s case, comes from her church community. The church members act as a real community, looking out for each other and banding together to help members in need.

“We have become family over the years. If one of us gets sick, we have people who come and stay with us. We do whatever is needed, from making food to helping with household chores,” Shirley said.

Because Shirley doesn’t drive, she relies on church members often for transportation. It isn’t unusual for Shirley to get a lift, not just for church services, but to visit with friends after services and for shopping, sharing meals or even just to visit with someone who needs some company.

“My kids are too busy. They have their own lives, they’re working and they have their own kids and grandchildren,” Shirley said.

The support community that Shirley built became vital to her several years ago. Shirley suffered a heart attack and had an extended hospitalization. During that time she was seldom alone because once the church community knew she was in the hospital, a friend was bedside nearly around the clock. Shirley credits this type of caring with helping her to get back on her feet.

“It feels good because you know that people are really there for you and that they’re going to take care of you if there is trouble. I even had people come stay with me at home when I got out of the hospital because they didn’t want me to be alone,” Shirley said.

Shirley gives back as much as she receives. She regularly visits a friend from the church community who doesn’t have family at a nursing home, often bringing food and helping with personal care. She knows that’s how a community works and she appreciates how much people cared for her when she needed them.

2014 Front Door Orientations For Self-Advocates, Families and Professionals

OPWDD Front Door Orientation
Representatives from the Office for People with Developmental Disabilities will identify the necessary steps for individuals, and their families, seeking services and supports funded by OPWDD. Participants will hear about the process of eligibility and the various types of service options including self directed services.

Please choose from one of the following dates:
Friday, March 7, 2014
Monday, May 5, 2014
Monday, September 15, 2014
Wednesday, November 5, 2014

Time: 9:30am-11:30am
Where: Wildwood Programs Latham Office, Building 1
1190 Troy Schenectady Road, Latham, NY 12110
RSVP: Please call reception at 518-640-3300 to register
There is no charge for attendance.
Questions: Marie Floyd at mawnfloyd@wildwoodprograms.org and 518-640-3346
Consumer Directed Personal Assistance Program

Danielle Mazza, Medicaid Service Coordination

With so much attention recently focused on self-determined and self-directed services, one area under that umbrella that hasn’t received as much attention is the Consumer Directed Personal Assistance Program.

This program, funded by Medicaid, provides services to chronically ill or disabled individuals who have a medical need for help with activities of daily living or skilled nursing services. However, rather than being administered solely by an agency, it is self-directed by the individual receiving services or their designated representative.

This is not an OPWDD authorized service, but rather administered by the Department of Health through the local Social Services District.

As with other self directed services, the individual is truly in the driver’s seat, making decisions about who they will work with, how that person will work with them, and what the schedule will be. The individual, along with the help of their designated representative if needed, will recruit, hire, train and supervise their own staff. An agency, acting as a fiscal intermediary, would be partnered with to place staff on payroll. However, unlike self-directed options through the OPWDD system, hired caregivers under the CDPAP program can pass medications and assist with other more medically involved care due to an exemption in the Nurse Practice Act.

In order to qualify one must:

- Be Medicaid eligible;
- Be eligible for home care services, personal care services, or private duty nursing;
- Require some or total assistance with one or more: home care, personal care, or skilled nursing service;
- Have a stable medical condition; and
- Be self-directing or have a designated representative who is willing and competent to assume the roles and responsibilities that go with the program.

All referrals begin with the local social service district and must be authorized by the primary care physician. A nurse assessor reviews the information for eligibility and appropriateness for the program.

As this is not an OPWDD funded service, it is not provided by Wildwood, however this service can be paired with other OPWDD services, such as community habilitation, CSS or respite, to provide enhanced supports and services. For further information, contact your local services district long term or home care assessment office.
UNDERSTANDING FETAL ALCOHOL SPECTRUM DISORDERS
Presenters: Margo Singer M.P.A., FASD State Coordinator, NYS Office of Alcoholism & Substance Abuse Services, and Diane O’Connor, Mom to 9 children and 6 with an FASD Date: Wednesday, April 9, 2014, 9:30am-12noon
FASD refers to the wide range of physical, cognitive, and behavioral birth defects caused by maternal consumption of alcohol during pregnancy. This training session will provide an overview of FASD, including effects of prenatal alcohol exposure across the lifespan, diagnosis of FASD, strategies for prevention of secondary disabilities, and resources for both professionals and caregivers.

THE IMPACT OF SENSORY ISSUES ON LEARNING
Presenter: Jacquelyn Donahoe, MS OT
Date: Thursday, April 24, 2014, 9:30am-12noon
This presentation is designed to provide an in-depth understanding of the basics of the sensory system, what sensory dysfunction is and how it impacts life-long learning and coping skills. Also presented will be types of sensory issues and their impact on behavior. This is part 1 of a 2 part series on sensory diets and strategies for assisting individuals with sensory dysfunction. Please bring OT information with you if it addresses sensory issues. We will not have time to discuss specific individuals, but it will assist you in putting together a person’s profile. There will be time for questions and answers.

ANXIETY & AUTISM: THE MANIFESTATION OF ANXIETY IN INDIVIDUALS WITH AUTISM AND INTERVENTION STRATEGIES
Presenters: Marianne Simon, PsyD, and Kim Sumner, M. A.
Date: Friday, May 2, 2014 9:30am-11:30am
Marianne Simon, Wildwood Programs Psychologist, and Kim Sumner, Wildwood Programs In-Home Behavior Support Specialist, will discuss how children and adults with autism spectrum disorders often experience restrictive, ritualistic, and/or preservative behaviors that significantly impact their functioning at home, school, and the community. Frequently it is difficult to differentiate whether these symptoms represent a core feature of autism spectrum disorders or whether they constitute a comorbid anxiety disorder. This workshop will examine the prevalence of anxiety in both children and adults with autism. Symptom overlap between autism spectrum disorders and anxiety disorders will be explored, as well as a discussion of strategies/interventions that families or providers could utilize to address such issues.

AGING WITH DEVELOPMENTAL DISABILITIES
Presenters: Kari VanDenburgh, RN BSN, and Nancy Cummings, MBA
Date: Monday, May 12, 2014, 9:15am-11:30am
Kari VanDenburgh, Director of Nursing at Wildwood Programs, and Nancy Cummings, Program Director Alzheimer’s Resource Center of Albany Medical Center, will present an educational workshop on aging, dementia, and developmental disabilities. This program will provide an overview of the aging process and related health conditions experienced by persons with developmental disabilities. The event is designed to provide helpful information to families, direct support professionals, clinicians, program staff, and administrators concerned about adults with intellectual and developmental disabilities that are affected by Alzheimer’s disease and related dementias.

Participants will gain practical information on therapeutic activities, memory aids and environmental modifications as well as guidelines for communication and strategies to manage aggressive behaviors.

All workshops are held at Wildwood Programs’ Latham Office, 1190 Troy-Schenectady Rd., Latham, NY 12110
Registration is limited, Call 518-640-3300 within 1 week of program to register.
For more information contact Marie Awn Floyd at 518-640-3346 or mawnfloyd@wildwoodprograms.org
There is no charge for attendance