Raising awareness about Prader-Willi Syndrome

One hundred-twenty men, women, children and their families gathered for the First Snowflake Ball to raise awareness and money for Prader-Willi Syndrome
Prader-Willi Syndrome Association of Ohio

PWSA of Ohio is a chapter of PWSA-USA and is a non-profit, tax-exempt organization dedicated to providing understanding and awareness of Prader-Willi syndrome, supporting affected persons and families, improving the quality of their lives, and encouraging research into the causes, management, and cure of Prader-Willi syndrome.

Submitted by
Pam Vogt, Board Member
Prader-Willi Syndrome of Ohio

Prader-Willi Syndrome of Ohio (PWS) held its First Snowflake Ball at Santangelos Party Center on January 24. President Steve Fetsko, Massillon Mayor Kathy Catazaro-Perry, and William Green, Superintendent of Stark County Board of DD welcomed over 120 attendees including 23 individuals with Prader-Willi Syndrome.

First Snowflake Ball raises awareness about Prader-Willi Syndrome

Prader-Willi Syndrome is a complex genetic disorder, chromosome 15, that typically causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behavior and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity. It is estimated that PWS occurs in one of 12,000-15,000 births and is considered a “rare” disorder.

Prader-Willi Syndrome of Ohio provides events and activities where the food is strictly monitored for the health and safety of their PWS individuals. This event was organized by Pam Vogt of Massillon. Pam is a Board Member of the PWS Ohio Chapter and mother of Kristi Vogt of Massillon who is diagnosed with PWS.

See more event photos at http://www.reradkephotography.com/
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Ohio Public Images Honors Baseball Director Bonnie McClellan, recently retired director of the Canton Challenger Baseball League, received the top Award of Excellence for an Individual/Organization at the Annual Ohio Public Images Awards luncheon on March 12 in Columbus. McClellan retired at the end of the 2014 baseball season after 24 years at the helm of the Canton Challenger League, which was created specifically for children ages 5-18 with developmental disabilities. See a video of all the Awards winners at http://publicimagesnetwork.org/?page_id=253.

Preschooler recognized for Personal Achievement Congratulations to 4-year-old Wesley Rash, who received the 2015 Personal Achievement Award at Thursday night’s The Arc of Ohio - Stark County Annual Awareness Dinner. The award is presented to an individual with developmental disabilities for outstanding personal achievement and self-advocacy. Wesley was born with arthrogryposis, which means that he has very limited strength and range of motion in his arms and hands. See Wesley in action on our video at https://www.youtube.com/watch?v=Nb5Bo1s3riU

The Art Of Community And More This year’s annual art collaboration with the Stark County District Library visually represented how each citizen in our community contributes their talents and abilities to make something beautiful. The art was made up of more than 1,400-4 x 4 inch paper squares, glued together to create a patchwork of color. Artists with disabilities also had work on display throughout the month at the Gallery 121 exhibit “Wonderfully Made” presented by Echoing U.

Special Olympians Charge the Court In celebration of 2015 Developmental Disabilities Awareness Month, Stark DD Special Olympics Men’s Basketball Red and Blues teams competed in an exhibition game during the halftime of the Canton Charge game on Friday, March 20. The teams had the crowd on their feet!
Centers for Medicaid and Medicare (CMS)

The new rule and why we care

The Direct Line

News from Director John Martin
Ohio Department of Developmental Disabilities

30 East Broad Street, 12th Floor
Columbus, Ohio 43215
DODD.Ohio.gov
800-617-6733

CMS Transition Plan: Employment and Day Services

In January 2014, the federal Centers for Medicare and Medicaid Services (CMS) released new requirements for Home and Community Based Services (HCBS) waivers administered by states. Essentially, the rule says that federal Medicaid funds no longer can be used to pay for waiver services in settings that isolate people, including institutions, and settings next to public institutions. This new rule applies to facility-based work and day services that are paid for using Medicaid HCBS waiver funds; it does not apply to Intermediate Care Facilities (ICF).

To keep this important federal funding, DODD is working to develop new service models that promote community employment and integrated day services. These new services will ensure that all individuals, regardless of where they choose to receive services, will have opportunities to be involved in community-based activities. The level of community participation will be based on each person’s service plan. Individuals will continue to have access to places during the day where they can receive assistance with personal care, medical needs, or respite. In addition, they will be able to receive the same level of support that they receive under the existing service models.

Individuals are asking for these new services – more people want to work in the community, and to participate in community activities. That’s why some organizations have consolidated their current operations – people are leaving those facility-based settings and spending more time working and participating in the community. It’s important to remember that none of these changes will occur overnight. In fact, DODD has asked CMS for ten years to make these changes so we can slowly and planfully make adjustments in consultation with families and stakeholders.

What does this mean for me?

This change may or may not affect your current setting, whether it is facility-based work or day services, or a disability-specific farm or apartment complex. While CMS has not ruled on any specific setting in Ohio, CMS has said that some settings will require heightened scrutiny, or an on-site review; this applies to settings that, on paper, look like they don’t meet the requirements of the rule when, in fact, they do. DODD will review each setting individually to determine whether or not it has the HCB setting characteristics required by the new CMS rule. If a specific setting does not meet those requirements, DODD will work with the provider to develop a plan to bring the setting into compliance. Our goal is to develop a plan that will minimize any disruption to the individuals receiving services.

Based on that, there are two ways this will affect you:

- You will have access to new and different services. As these new services are developed, you will have more options to help you get a job in the community, and participate in community activities.
- You may see some changes to your current setting. While these changes don’t necessarily mean you will have to change your setting or your provider, what you do during the day may change. Some providers will need to change how they offer services to meet the requirements of the new rule, and to be able to offer the new services once they are developed. It’s important to note that most providers report that they currently meet the requirements of the new rule, or can meet those requirements with minor changes.

How are you developing the new services?

We know there are people who are doing creative things in their local community. We also know that, on a bigger scale, we need more examples of some of these new service models. DODD will work to learn more about those things that are working well in local communities, and to come up with new ideas. That’s why DODD has asked CMS for ten years to make these changes.

Where can I learn more?

Online: Go to DODD.Ohio.gov/OurFuture for more information, including frequently asked questions, and a link to the Ohio’s updated Transition Plan. Email: Receive general news and information in your email inbox – sign up for Pipeline http://dodd.ohio.gov/pipeline/ By phone: Call the DODD Budget and Developmental Center Closure Hotline toll-free at 855-611-6446 (OHIO) or 614-728-5311

John R. Kasich, Governor

John L. Martin, Director
The Individual Service Plan is a plan authored by a Service and Support Administrator (SSA) in conjunction with an individual receiving services and their circle of support. It is required by rule and is the primary document to identify the services and supports someone receives as well as ensure the health and welfare of the person receiving services.

Recently, the SSA rule changed and there are new requirements for the ISP.

The ISP must be based on an assessment process that reviews Rights, Self-Determination, Physical/Emotional/Material Well-Being, Personal Development, Interpersonal Relationships and Social Inclusion. Stark DD has an assessment called the About Me For Me assessment that will be done annually and reviews these areas.

The rule also identifies that the ISP must be person-centered and focus on outcomes, what is important to a person, and what is important for a person.

The new ISP, which started on March 9, will focus on the individuals unique strengths, needs and wants.

What is important to a person is what makes them happy.
What is important for a person is what they and their team identify they need to keep them healthy and safe. Outcomes are a person’s goals and what dreams they want to reach for.

Stark DD’s new ISP will also identify support considerations and actions to help someone reach their goals. Support considerations is important information for others to know about the person to help serve them best. Actions are the steps others take to help a person reach their outcomes (goals).

The plan also has a cover page where a person can provide a picture they like. This could be their picture, their pet, a picture they drew, or a picture of their family. The cover page also has an area that identifies positives about the person.
The Stark County Board of Developmental Disabilities announced on January 27 that it will consolidate all of its adult workshop programs to two locations in Canton and Massillon by late 2015, and close the workshop program at the Whipple-Dale Centre in Canton. The decision is in keeping with the Board’s three-year strategic plan to transform its role and redistribute its resources in order to provide more support to those in need.

As part of the plan, Stark DD will relocate its Service and Support Administration staff from rented office space in North Canton to the Whipple-Dale Centre, a move that will result in annual savings of more than $130,000.

The decision to consolidate services supports the Board’s goal of moving as many individuals as possible to employment in the community, and recognizes the rights of individuals with disabilities to live and work in the community rather than in segregated environments. While the number of adults served has steadily increased, Stark DD Superintendent Bill Green said enrollment of individuals in the three workshops has declined by about 37 percent over the past four years.

The first of several family information meetings took place on April 9. During the meeting, Green outlined the new catchment areas which have helped determine where adults have been assigned to attend beginning in January 2016. From this meeting, families will receive correspondence about one-on-one meetings with their Service and Support Administrator to help them choose their day service provider.

### New catchment areas and bus schedules

Beginning in January 2016, both West Stark Center and Higgins will begin a two-shift schedule as the Whipple-Dale Centre has done since 2011.

**First Shift:** Adults will be picked up between 6:50 am & 7:50 am for first shift. Buses will arrive at Higgins and West Stark between 7:50 am and 8:15 am. At the end of the day, buses will load at Higgins and West Stark starting at 2:00 pm.

**Second Shift** Adults will be picked up between 8:20 am and 9:15 am. Buses will arrive at Higgins and West Stark between 9:00 am and 9:30 am. At the end of the day, buses will load at Higgins and West Stark at 3:05 pm.
New building assignments announced

Building assignments reflect strict catchment areas. As we go through the year, the plan is expected to evolve and change if and when people choose other providers. Therefore, people may be able to choose the building they would like to attend, but at the present time this is not possible.

West Stark Center 7891 Hills & Dales Rd. NE, Massillon

111 individuals would move from Whipple-Dale to West Stark
27 would move from Higgins to West Stark
113 would remain at West Stark

New West Stark Center Roster 2016
Projected average daily attendance 200
West Stark Capacity 195

Lester Higgins Adult Center 3041 Cleveland Ave. SW, Canton

68 would move from Whipple-Dale to Higgins
10 would move from West Stark to Higgins
56 would remain at Higgins

New Higgins Roster 2016
Projected average daily attendance 103
Higgins Capacity 131

Other strategies being considered

Just Imagine Gift Galley: Propose moving eight artists with two staff to a stand alone studio/retail shop in the Canton Art’s District. Artists working and interacting within the art community supports the goal of greater community integration, and the artists would become part of downtown economic development.

Seniors: Propose moving seniors, appropriate for community placement, into three community settings: Catholic Charities, JR Colman, and Sarah Care. Managers have already begun preliminary discussions and awaiting final proposals and costs. Seniors integrated with other non-disabled seniors sharing activities and supports and would be given additional opportunities to enrich their quality of life during aging years.

The Pallet Shop: Recommend closing the Pallet Shop by the end of 2015. Neither Higgins or WSC has the square footage to relocate the Pallet Shop. TWi has indicated they are not in a financial position to take over the wood operation.
Approximately 100 people attended a February 5 ceremony recognizing the 14 young adults with disabilities who completed the Project SEARCH program operated by Siffrin in 2014. This year’s ceremony, which was held at the Aultman Morrow House Auditorium, was the sixth annual for the program and celebrates the hard work and many successes of each participant.

Each of the Project SEARCH participants worked four, 11-week rotations within Aultman Hospital and other local businesses to learn applicable, tangible work skills. Seven of the 14 people have already found employment, while the others are in search for their next employment opportunity with the help and guidance of Siffrin Employment Support Professionals.

Connor Capeta, one of the 2014 Project SEARCH “graduates” spoke at the ceremony.

"Working at Aultman helped me prepare for a paying job by helping me learn how to better communicate."

He explained that learning how to be aware of people’s non-verbal communication through body language was one of the most useful skills he developed. Connor is currently employed at Canton Regency in the dish room. He said he enjoys his job because it keeps him busy. “Because I am a fast worker, I have been successful at my current job.”
Athletes bring home medals from State Basketball

The Stark DD Special Olympics Ladies and Mens Red Basketball teams competed in the State Tournament in Columbus on March 27-28.

Ladies Team:
Gold Medal in Division 2
Final game: 44-26 Stark DD Divas over Wood County Lady Wildcats
Head Coach- Jayme Riley; Asst Coach- Dan Contrucci

Men’s Red Team:
Bronze Medal in Division 2.
Final game: 66-46 Stark DD over Lucas County
Head Coach- Sandy Reed; Asst Coach- Katy Johnson

Do you know someone who is majoring in Special Education or a related field?

Stark DD and The Workshops Inc. will award a $1,000 scholarship through the Stark Community Foundation to a qualifying Stark County resident. Find information and the application in the link below. Application deadline is June 1, 2015.

Stark County Exceptional Olympics
May 8, 2015, 9 a.m. at Perry High School. Student athletes, elementary through high school from area districts, compete in both field and indoor style events.

Canton Challenger Baseball Opening Day
May 9, 2015, 9 a.m. at Barr Elementary School. Team sign up is still available at www.cantonchallenger.com. Regular league (ages 4-18, or 22 if still enrolled in high school) and Senior league (ages 16+).

Adult Social Night
May 28, 2015 from 7 p.m.- 9 p.m. at the St. George Serbian Center, 4667 Applegrove St., North Canton. Must be 18 years of age and over to attend.

5th Annual Autism & Exceptionalities Walk
May 2, 2015, 9 a.m. - 10:30 a.m. At Jackson High School Stadium. Walk and Vendor Fair. Sign up at http://jackson.stark.k12.oh.us/News. $6/person.

Beyond the Divide Kick-Off Celebration
May 16, 2015, 10 a.m. - 2 p.m. GentleBrook, 880 Sunnyside St., Hartville. Community celebration. Free.

Monthly Board Meeting
Stark County Board of Developmental Disabilities; May 16, 2015, 10:30 a.m. at 2950 Whipple Ave. NW.

Stark DD Early Childhood Graduation Ceremonies
May 28, 2015. Eastgate Early Childhood Center, 1 p.m. Taft Preschool Program, time to be announced.

Stark DD High School Commencement Ceremony
May 29, 2017, 7 p.m. at RS Southgate School.

Monthly Board Meeting
Stark County Board of Developmental Disabilities; June 27, 2015, 10:30 a.m. at 2950 Whipple Ave. NW.
The Stark County Board of Developmental Disabilities extends sincere condolences to the families of the following:

**John William (J.B.) Burchett**  
John, age 68, passed away on December 3, 2014. He received SSA services and previously attended the Board’s workshop program.

**Lori Ann Nobis**  
Lori, age 49, passed away on December 9, 2014. She received SSA services and previously worked at Whipple-Dale Centre.

**Edward “Ed” Havlatko**  
Ed, age 66, passed away on December 10, 2014. He received SSA services and formerly attended the Board day program.

**Vickie Jeanne Crabtree**  
Vickie, age 70, passed away on December 26, 2014. She received SSA services and previously worked at the Board workshops.

**John Edward Kistler**  
John, age 54, passed away on January 16, 2015. He received SSA services and previously attended the Board workshop program.

**John Anthony Mills, Jr.**  
John, age 78, passed away on January 19, 2015. He received SSA services and previously attended the Board workshop program.

**Clark Victor Barnard**  
Clark, age 57, passed away on February 14, 2015. He received SSA services and retired from the Board workshop program.

**John Norman Robinson**  
John, age 78, passed away on February 8, 2015. He received SSA services and worked at The Bridge. He previously attended the Board workshop program.

**Brenda Sue Kirk**  
Brenda, age 43, passed away on February 19, 2015. She received SSA services.

**Richard Lee Coulter**  
Richard, age 70, passed away on February 20, 2015. He received SSA services and attended PEAK.

**Thomas Leo Harbert**  
Tom, age 73, passed away on March 4, 2015. He received SSA services and worked at Cohen-Joliet Workshop and Whipple-Dale Centre.

**Diane Marie Massaro**  
Diane, age 60, passed away on March 11, 2015. She received SSA services.

**Michael Donald Shahan**  
Michael, age 33, passed away on March 14, 2015. He received SSA services.
Mission:
To be the support that connects individuals and families with the services they need.

The Art of Community:
All in the Family

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