



# *Pipeline Quarterly*

*Summer 2014*

*Ohio Shared Living Opportunities Offer  
Family Home Relationships in the Community*



At home in Mahoning County are Sam, Mary Lou, and Susan Neva, with Regina, Lori, Debbie, and Kathy. See story on pages 6-7.

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## Living in their communities ...

The Ohio Department of Developmental Disabilities (DODD) is responsible for overseeing a statewide system of supports and services for more than 93,000 citizens with developmental disabilities and their families. We have learned from these individuals, their families, and friends, that many of the people served are ready for a greater level of independence than they currently have.

One of the Department's key initiatives is to encourage supports and services that offer new and better opportunities for living in the community, increasing independence, and maximizing resources.

We are exploring opportunities to access federal and state funds to support more community-based services and new or under-utilized options. An example of these efforts is a commitment to provide more information about the benefits of shared living as a service model.

Ramping up the state's efforts to utilize the shared living, or host home model of care, for Ohioans with developmental disabilities, we have partnered with the Ohio Provider Resource Association (OPRA) and with the Ohio Association of County Boards (OACB). Working together, we are discussing under-utilized residential

opportunities such as Adult Family Living or Adult Foster Care services. Offering community inclusion in a family setting, these shared living options fulfill a need and cost less to fund than some other residential settings.

OACB and OPRA have surveyed their respective members, and learned that DD professionals and people served have been reluctant to explore or discuss this residential option due to not fully understanding it, or due to a concern over the current terminology, Adult Foster Care. We heard, "Foster care is not something people feel comfortable with because the words conjure up a different scenario than what the reality is. Ohio shared living is a truly inclusive family home setting, not a short-term emergency kind of situation."

We also were encouraged to tell the stories of how this residential choice has worked for many individuals and families around the state, and so we share some of these stories in this issue of *Pipeline Quarterly*. As is often the case, information is the key to understanding, and understanding eases the path to change.



## Director's Message



DODD Director,  
*John L. Martin*

*“Home sharing is a flexible service model that is currently under-used. It is an important service option that should be considered when working with any individual who needs a stable family home in their community.”*

*-Director John Martin*

Welcome to our Summer 2014 *Pipeline Quarterly* feature publication, focusing on community-based living options for people with developmental disabilities. These options include services billed under Medicaid as Adult Foster Care or Adult Family Living, but are better described as shared living -- a way to provide and support residential relationships in a family home. We now will begin to refer to this option as Ohio shared living.

As we reached out to agency partners and stakeholders in Ohio's developmental disabilities community, we learned that this natural option was not often discussed during planning and discovery conversations with individuals in the system. It has been somewhat overlooked. A committee has been convened to address the need for more information, and to take a hard look at how Ohio shared living services are described in rule and statute, as well as how they are funded. We look forward to this process with the goal of helping more people build lives in their communities. (See more about the committee on page 10.)

## Marsha's Story...it all started in 2012

Marsha Mace resided at Gallipolis Developmental Center (GDC) from 1999 until 2011. Her support team knew she wanted to live in a smaller community environment, but her aggressive behaviors were working against her placement outside of GDC. Finally, in 2011, Marsha moved to a group home in Hocking County with two other former GDC residents, but it still wasn't what she was looking for.

After a second move to an apartment of her own with support from staff, Marsha's team thought perhaps this was the answer. Yet, Marsha wasn't thriving there. In 2012, Hocking County Board of DD Service and Support Administrator (SSA) Beth Hackney and Supervisor Matt Nobile told Marsha's Advocacy and Protective Services Inc. (APSI) guardian about a local home providing Adult Foster Care services, that had an opening after an individual who had lived with them for many years had passed away, and left a void in their lives.

*Beth explained that Bill Shepler and his family take care of only one person, and they make that person a part of their family.*

Beth and Matt felt that Marsha would benefit greatly from living in a family setting, so Marsha and Brittany Brown (APSI) met the Sheplers and toured their home. There was no hesitation on Marsha's part – she had finally found a home!

In 2012, Marsha moved into her own bedroom at the Shepler's. Kimberly Shepler, Bill's daughter, noted, "Marsha fit into our family easily. She was instantly comfortable in our home and had no problems acclimating to her surroundings. She has a bedroom decorated with her personal belongings. In addition to the clothing, bedding, and other things we purchased for her personally, we were able to work with the County Board and APSI to purchase a much-needed wheeled walker, and a wheelchair for long distances."

Over time, they also were able to purchase an iPad3 with Porloquo2Go software for Marsha's communication needs and she has since started vocalizing her wants and needs more effectively. The Shepler's also report,

***“ Former behaviors fueled by anger and frustration don't have a place in this busy family atmosphere. ”***

Trips to the zoo, movies, dining out, and attending church all keep Marsha active. Last year, the family took her on vacation with them to North Carolina and while there, they also visited Marsha's biological sister, whom she hadn't seen in ten years. Now the sisters speak on the phone almost daily.

Kim Shepler observed, "We are grateful to have met Marsha and have her in our family. She laughs freely, smiles often, has a wonderful sense of humor, and has brought some happiness back to our home. We look forward to many years ahead with Marsha and have planned a number of activities for her, including

*(cont. on p. 9)*



Marsha and her cat, Yum-Yum



... and her dog, Bo-Bo.

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## Family Advisory Council Spotlights Home Sharing

*Gaining strength and support from each other while sharing and learning is the hallmark of the DODD Family Advisory Council (FAC).*



The group's July meeting at the Columbus Developmental Center built on those strengths, and included information describing Ohio shared living services, billed under Medicaid as Adult Family Living or Adult Foster Care services, and debuted a video of one family's experience with this residential option. (See sidebar, p. 5)

Chris Kristanich, representing service provider Caregiver Homes, introduced real family stories illustrating Ohio shared living services as an option for individuals to experience community living as a member of a family home. Attending the meeting were caregivers Bonnie and Evelyn, and Jeff, an individual who lives with Evelyn's family.

Evelyn explained, "Home sharing is an under-valued option! With shared living, Jeff is a member of our family. He's a son to me – and I am mom to him." She added,

*"There's no visiting ... just living! Living as part of a natural family – with all the natural consequences."*

In describing the Department's focus on community-based services in long-range strategic planning, Director Martin observed, "There are no arbitrary lines in the sand as we explore what can improve our state-wide service system. We are exploring many ideas and approaches that may help us to improve the number of Ohioans living and working in community-based settings."

He added, "We know it is unrealistic to think that that there is one answer for everyone. Not 100 percent of the people we serve are going to be successful in the same kind of setting. Your input to us here at Family Advisory Council meetings always adds to that understanding, and we are grateful to you for your support."

Kristanich also noted that the flexibility and the value of shared living services in a family home setting is proven one family at a time, and that peer-to-peer conversations often provide the gateway to understanding. She explained, "We see it all the time. When a good match has been made, there's no better testimonial than that individual and that family connecting with others who also could make this approach work for them."

Evelyn agreed wholeheartedly and addressed the group stating, "Anyone who has room in their home and in their hearts should consider sharing their family home like this." Jeff was quick to add,

*"I was mess before I came to live with Evelyn and her family. Now I have a job -- work that I like -- and I eat right, take my meds, and have friends.*

*I love my family."*

(cont. on p. 5)

*Opening their hearts and homes. (l. to r.) Bonnie, Jeff, and Evelyn. Jeff says, "My life has never been better than it is now, with Evelyn and our family."*

*Bonnie also has opened her home to a young person who was in need of a stable family home. She says, "It has been good for both of us. Not always easy, but that's the way it is with any family."*

## Spotlight on Home Sharing *(cont. from p. 4)*

### Qualifying for Services

Kristanich also noted that overall, Caregiver Homes has seen good success with Structured Family Living, the agency’s program through which Evelyn’s family is served. To qualify, a person needing care must be eligible for Medicaid, benefit from 24-hour care and support, and require help with one or more daily personal care needs such as dressing, walking, and bathing.

Interested caregivers are screened to ensure that they are suited to making a full-time, around-the-clock care commitment. Screening includes a written application, telephone conversation, background check, in-person interview, and a home assessment to ensure that safety-related updates are in place.

Also speaking at the FAC meeting and discussing service models such as home sharing, DODD Deputy Director Patrick Stephan observed, “When we look at the new rules created by the Centers for Medicare and Medicaid Services (CMS), the themes of community integration are pretty consistent.” *(See sidebar)* He continued, “What all states are looking at is, ‘How can we make informed judgments about what an integrated setting is, and how can it be funded and supported in a given community?’ ”

Wrapping up the meeting, Family Advocate Peggy Martin expressed appreciation to each of the speakers and attendees, stating, “I see from the questions you have asked, and from the conversations I am hearing among you, that more people are open to shared living services than are currently taking advantage of them. Thank you for actively engaging with our speakers and with each other – that’s exactly what helps the system move forward with the needs of families in mind.”

*Family Advisory Council (FAC) meetings are open to anyone with a family member served by Ohio’s developmental disabilities system.*

Contact Peggy Martin at [Peggy.Martin@dodd.ohio.gov](mailto:Peggy.Martin@dodd.ohio.gov)

*Acknowledgments and thanks to Caregiver Homes for information contained in this article.*

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*Evelyn and Jeff’s story also has been featured in the OACB publication, DD Advocate.*

*See it at [www.ddadvocate.com](http://www.ddadvocate.com)*

### Looking Ahead

Working with other providers that serve individuals with developmental disabilities, Caregiver Homes is among those collaborating with DODD, OPRA, and OACB to build a comfort level with individuals and families who may be ready for the Adult Foster Care (AFC) service option, by clearly describing the value these opportunities offer.

AFC services are shared living services in family host homes, and will be more accurately described in the future as Ohio Shared Living services. When the Home and Community Based Services (HCBS) transition plan is submitted next year to the Centers for Medicare and Medicaid Services (CMS), and applicable waivers are amended, this language will begin to be more widely used.



A new video tells Jeff and Evelyn’s story at [www.caregiverhomes.com](http://www.caregiverhomes.com).

Visit the site for additional stories about people who have benefited from participating in shared living services.

## Service Numbers

Summary By Service Category			
Date Range: Between Jul 1, 2012 and Jun 30, 2013			
Service Category Description	Individuals Served	Units Delivered	Reimbursement Amount
Adult Foster Care	919	286,543	\$30,545,276.62
Adult Family Living	151	202,840	\$3,256,490.24
	<b>1,066</b>	<b>489,383</b>	<b>\$33,801,766.86</b>

Summary By Service Category			
Date Range: Between Jul 1, 2013 and Jun 30, 2014			
Service Category Description	Individuals Served	Units Delivered	Reimbursement Amount
Adult Foster Care	927	294,229	\$31,658,214.11
Adult Family Living	217	392,882	\$5,404,465.89
	<b>1,143</b>	<b>687,111</b>	<b>\$37,062,680.00</b>

*Number of individuals served, units of service, and provider reimbursement amounts are gradually improving.*

## Like One Big Extended Family

In Mahoning County, it is especially true that home sharing offers turning points for many lives. *Pipeline Quarterly* hit the road to meet several individuals and families who have benefited from home sharing experiences through service provider Turning Point Residential. The agency has matched many people who want to open their homes and care for someone with people who need a stable, caring home environment. In fact, after a day of visiting there, it appears that the entire Poland/Youngstown community is simply one big extended family.



*Above, l. to r.: Sam and Mary Lou Neva and their daughter Susan, housemate Regina, family home caregivers Lori and Debbie, and Kathy Phillips. Family dogs round out the photo. At right, Susan learns that she will soon be in Pipeline Quarterly!*

“It’s true,” said Kathy Phillips, owner of Turning Point. “We have more people who want to share their homes with someone we serve than we currently are able to match!” She added, “It has to be a good match, and sometimes even a family member who wants to become a shared living provider for a brother or sister with developmental disabilities is not the best match. It’s a tough call. But when you have the right people matched together in a community-based home setting, it’s extremely gratifying. I don’t know why more providers don’t look into this option for people in their communities.”

There are some challenges. One reason may be that it is sometimes less profitable for an agency to bill services under Adult Family Living or Adult Foster Care than it is with services under an Individual Options (I.O.) waiver. Phillips explained that the agency has to look at a person’s quality of life, and stability in the community. “For the person and for the host families, you have to look at that whole picture, not just the financial part.”

“Our lives have improved,” observed Debbie and Lori, who have welcomed Susan and Regina into their home. Susan Neva is living in Debbie and Lori’s home after

“Knowing that a person who had been lonely, or who had been not properly cared for when living elsewhere, is now in a loving family home is a wonderful feeling. We’ve learned that everyone involved wins in that environment.”

- Kathy Phillips



her elderly parents decided they could no longer care for their 63 year-old daughter in their home any longer.

“I’m 91,” said Mary Lou Neva. “It’s a hard thing to do in the beginning -- a hard decision. I felt like I was letting her down. It took me a while to feel comfortable with it, but I knew it was the right thing to do.”

She continued, “Kathy took time to talk with me about some options for Susan, and I trust her. Looking for a caring home for Susan away from us was the best next step. My husband, Sam, and I were delighted when we met Debbie and Lori, and Susan took a liking to them immediately.”

“In fact, shortly after Susan had started living there, she came to our house on the weekend, and on Sunday afternoon she got herself by the front door and indicated that she was ready to ‘go home’ now. Go home! Susan had learned that her new home was elsewhere. I’ll admit it made me feel bad at first, but I realized how good it was that she felt that way.”

- Mary Lou Neva, Susan’s Mom

(cont. on p. 7)

## Extended Family *(cont. from p. 6)*



*Anthony (left) and Jeff leave the house to grab a hot dog and soda on a beautiful day in Youngstown.*

Susan now has Lori and Debbie as caregivers, a new friend, Regina, to hang out with at home, and the companionship of the household's dogs, who clearly adore Susan and Regina. Mary Lou and Sam Neva now live in a downsized home, still nearby in the local community.

Lori and Debbie add, "We love caring for Susan and Regina, and they have added so much to our lives. The arrangement lets them be themselves, and lets us be us."

Another home shared in the community is owned by Anthony, who is caring for Jeff. Anthony, a young man in his 30s, has been a direct support professional for several years. He had made Jeff's acquaintance at the Mahoning County Board of DD adult services workshop. Jeff, who is in his 20s, was mostly withdrawn, and had some issues with aggression. Anthony quickly learned that with a little attention and care, Jeff's demeanor was quite different.

He also learned that Jeff's family life was less than ideal, especially after his mother passed away. "The family dynamic wasn't good," said Anthony. "I believed he would be safer with me." Qualifying as an independent provider, Anthony moved Jeff into

his small, neatly-kept home, and the two continued to bond and trust each other. The home sharing arrangement has worked well for more than two years, and Jeff is speaking more often. Anthony observed,

*"He's much calmer. Taking less meds. He's learned to respect personal space, and he knows I'll do what's in his best interest. I don't play games with him, you know -- I tell him the truth."*

Not only has Jeff grown in many ways during the time he has lived with Anthony, so has Anthony. He has now qualified as a small agency provider, and is working with other individuals who receive waiver services, as well as caring for Jeff in his home.

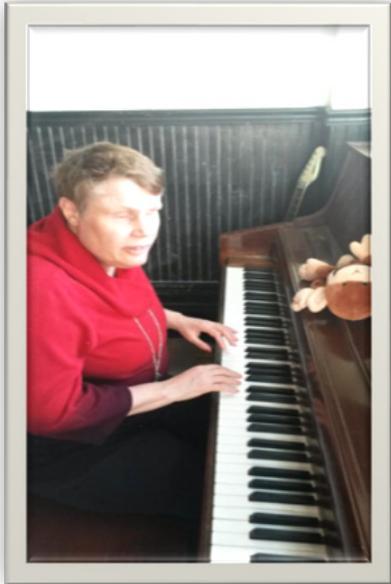


*"We take it one day at a time," said Anthony.*

Another long-time member of Mahoning County's extended family of people living in the community in a shared home setting is Ed, who lives with Ron. Ron and his wife, Gayle, had cared for several individuals in their home prior to Gayle's death a few years ago. Ron never hesitated in his decision to keep Ed safe and comfortable in his spacious home on a quiet, tree-lined street. Retired from the railroad business, Ron and Gayle had had other people live with them in a shared home setting for more than 30 years. "Maybe even before they had a name for it!" he said.

"We had Esther here for more than 20 years and she was a wonderful part of our lives. So was Jenny. They've both passed on. Now Ed is 72. Nine years ago when we first met him and talked about him living with us, we just 'clicked' right away. Kathy brought him over to the house, and the rest is history. He's like a brother to me, and good company with my wife gone. He continued, *(cont. on p. 9)*

## Back in Her Home Town



*Beth is sharing her musical talent in Jackson, Ohio, her home town, since returning there to live.*

“  
*The ache for home lives in all of us ... the safe place where we can go as we are and not be questioned.*”

*-Maya Angelou*



Beth Dunne had lived at Gallipolis Developmental Center (GDC) for approximately 12 years. According to her GDC support team, during that time, her desire grew to move to a home in the community. Last November, her wish came true and she moved back to her home town, Jackson, Ohio, and into a home established by Initial Independence providers.

This may not seem like big news, but for Beth, it was. Beth is in her fifties, is blind, and it had been a long time since her living quarters had changed. Beth also loves music, and not just listening to it, but playing music on the piano. Her only request regarding the move was that she hoped to have a piano available in her new home.

When she arrived to move into her new home there was a man tuning her very own piano. She was able to tell the man if she agreed with the tuning job, as her ears are especially good at detecting pitch. She asserted herself firmly, and the job was done well between them.

She wasted no time becoming known in the community. An arrangement was made with an establishment in Gallipolis, the Nybble Café, where she has played the piano for the enjoyment of all, fueled by an occasional free coffee and sweet treat.

Café customers learned that Beth will play songs upon request, as long as she already knows them. She plays by ear as she cannot see to read music, and according to her fans, “When she hears a song she likes, she will go over to the piano and play both the melody and the harmony. It is quite something to behold!”

Aside from making a name for herself at the piano, Beth’s friends report that she has made a smooth adjustment to her new home. One noted, “She has become a social butterfly, and on her own terms. Since moving back to her home town, Beth has made several new acquaintances and reconnected with old friends. She’s been attending dances, going out to dinner, playing music, shopping, and even hosting two house parties with some of her friends since moving in.”

Initial Independence staff Kris Frye and John McCombs say they are blessed to have Beth in their lives. They agree, “She has been an inspiration and a breath of fresh air! She lets us know exactly where she stands and how she feels.”

*Special thanks to Mary Holley and Kelly McGuire at GDC for information contained in this article.*

## Extended Family *(cont. from p. 7)*



Ron (left) visits with Ed while he reads in his favorite chair.

“If someone who had a person with DD in their family that needed a different living situation would ask me about home sharing, I’d say this:

“ *You have to click with that person. You have to care about their needs and interests. Family caregivers here in Mahoning County, we’re like a big extended family. We go to trainings together, keep up to date on rules, and talk about our good times and our challenges. We help each other with respite, too. We really are like a family.* ”

*Acknowledgments and thanks to Turning Point Residential for information contained in this article.  
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## What They’re Saying ...

Some common themes have been heard around the state as the subject of shared living or home sharing is discussed. The comments below include some key observations, and offer food for thought as we explore community-based residential options for Ohioans with developmental disabilities.

“ *We see it all the time. When a good match has been made, there’s no better testimonial than that individual and that family connecting with others who also could make this approach work for them.* ”  
- Christine Kristanich, Caregiver Homes

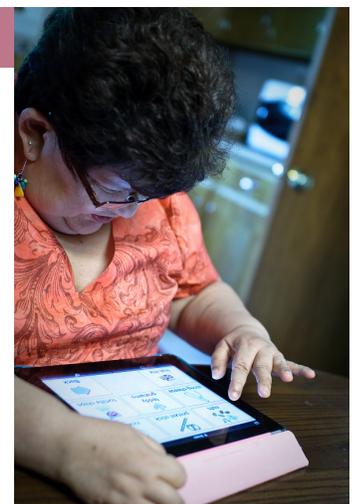
“ *There are no arbitrary lines in the sand as we explore what can improve our statewide service system. We are exploring many ideas and approaches that may help us to improve the number of Ohioans living and working in community-based settings.* ”  
- DODD Director John Martin

“ *I am sure there are other people who could be helping someone in their own community. I’d say, “Don’t be afraid to do this. Don’t be afraid to try and give a person a chance.* ”  
-Anthony, Mahoning County Caregiver

## Marsha’s Story *cont. from p. 3*

a trip to Disney World.” The Sheplers worked with Marsha’s support team to put a service plan in place for the coming year. With the new *imagine* plan, since Marsha has said she wanted to go to Disney World, the Sheplers started budgeting and actively planning for this. In fact, the trip was just taken, and Marsha loved every minute of it, according to all involved. They shared that her enthusiasm made everyone on the trip enjoy the vacation all the more.

Thanks to a caring family home in the community, Marsha has little time to reflect on frustrations or challenges of the past. And her support team couldn’t be more excited about her future, and the future for others who may be ready to explore different residential options, including Ohio shared living.



Improving her skills using an iPad3.

## Committee Has Shared Goals



*“We need to get relevant data to begin to build system change.”*

*-Jeff Davis, OPRA*

*“People have to be willing to meet certain standards in order to be providers we would recommend. REM mentors have to meet these standards.”*

*- Jo Spargo, REM Ohio*

A committee comprised of service providers throughout Ohio, as well as staff from agencies including DODD, OPRA, and OACB, has been meeting for several months to discuss the benefits of shared living options for individuals with developmental disabilities, and to brainstorm ways to improve understanding of this community-based option.

The group has pinpointed a disconnect between the perception of Adult Family Living and Adult Foster Care Services, and reality of what shared family homes actually offer. Acknowledging that the terminology is a turn-off and a deterrent to promoting the option, the committee is looking into ways to identify and describe the inherent benefits of shared family homes, not only for the individuals served, but also for the host families.

“It’s going to take that education piece for peoples’ thinking to turn the corner on this -- independent providers and agencies alike,” noted one service provider at a recent meeting. “We need to provide that education piece and be consistent about how that is done.”

The group currently is working on how staff at County Boards of DD and other service providers can more effectively connect individuals with families who are open to sharing their homes and family experiences with another person who may be in need of a stable, long-term residence.

*“This concept opens up opportunities for all of the agencies around the state to be able to do more.”*

*-Lori Stanfa, OACB*

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### The Mission of the Ohio Department of Developmental Disabilities

is continuous improvement of the quality of life for Ohio’s citizens with developmental disabilities and their families.

### Publication Notes

Published four times annually by the Ohio Department of Developmental Disabilities (DODD) Division of Legislative Affairs & Communications, *Pipeline Quarterly* focuses on people and topics of interest to the statewide developmental disabilities community, and supports the Administration’s core concepts and philosophy.

We thank all who have allowed us to work with them to prepare this issue, and who have contributed to its development.

Reader ideas, comments, and feedback are always welcomed. Please submit ideas and feedback to Editor Sherry Steinman, [sherry.steinman@dodd.ohio.gov](mailto:sherry.steinman@dodd.ohio.gov), or call 614-644-0262.

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