

Ohio Advocacy Updates

1/29/15

Some activities in Ohio over the last three months:

1. General Information

- o Ohio's transition plan draft will was posted on their website on 12/15/14. Public comment period ended 1/23/15. Six public informational meetings were held around the state. Also two public feedback meetings were held in Columbus. Public comment was accepted by email, voicemail, regular mail and at the two public feedback meetings.
- o Principals in Ohio's CMS transition planning are: John Martin (Director, Ohio Dept. of Developmental Disabilities), Greg Moody (Director, Governor's Office of Health Transformation) and John McCarthy (Director, Ohio Dept. of Medicaid)
- o Safe Haven Farms is located in Middletown (SW Ohio), between Cincinnati and Dayton. Bittersweet Farms is located in Whitehouse (NW Ohio), just south of Toledo. In addition to providing services at their own farm, Bittersweet is also the service provider at Safe Haven Farms. So we all worked closely together in our areas of the state and in Columbus (state capitol).
- o Advocacy Teams
 - Bittersweet Advocacy Team: Vicki Obee (Executive Director) and Jane Atwood (parent advocate)
 - Safe Haven Farms Advocacy Team: Denny Rogers (founding parent and Board President), Dr. Pam Lockwood (founding parent and Board VP), Gary Blevins (founding parent and Board member), Mike Odioso (parent advocate and attorney, prime legislative contact), Dan Norris (parent advocate and Disability Rights attorney)
 - Other families participated in one or two of the meetings

2. Meetings with Ohio State Representatives and Senators

- o Bittersweet advocates contacts:
 - Families contacted their state representatives
 - Talked with State Representative Barbara Sears (Bittersweet's district) several times
- o Safe Haven Farms advocates contacts:
 - Met with State Representative Lou Terhar (Odioso's district) on 12/19/14. He has a son with Aspergers! His wife was President of the Ohio Board of Education until 12/31/14.
 - Met with State Senator Bill Coley (Safe Haven's & many parents' district) on 12/29/14.
 - Met with State Representative Tim Derickson (Safe Haven's district) on 1/3/15.
 - Met with State Representative Margy Conditt (Rogers' district) on 1/8/15.
 - Met with State Senator Bill Seitz (Odioso's & Norris' district) on 1/12/15.
 - Met with State Representative Denise Driehaus (Democrat, Cincinnati district #31) on 1/23/15.
- o Outcomes:
 - All of the Representatives and Senators showed strong support for farm programs and for the rights of individuals and their guardians to choose where they want to live and be served.
 - Representative Conditt, on behalf of constituent Denny Rogers, filed a "Common Sense Initiative" petition with Lieutenant Governor's Office (Mary Taylor). This initiative requires acknowledgement and action by Lt. Gov. committee. Two Safe Haven Farms' parents also filed petitions.
 - Senator Seitz sent letter to Directors John Martin, Greg Moody and John McCarthy urging them to push back on CMS regarding farms and congregate settings.
 - Representatives Driehaus and Derickson issued joint letter of support for Safe Haven Farms to Directors Martin, Moody and McCarthy on 1/28/15.
 - Several Representatives and Senators said they would speak with the Directors and possibly Gov. Kasich.

3. Meetings with US Congress members and Senators

- Bittersweet advocate contacts:
 - Talked to Marcy Kaptur, their long-time US congresswoman, past supporter of their farm, and member of Congressional Autism Caucus. Since last re-districting, Marcy is no longer their representative.
 - Talked to US Congressman Bob Latta's office (Bittersweet's current rep)
 - Contacted Senator Sherrod Brown's office. He is the senior US senator (Democrat) from Ohio, resides in Cleveland area, and is also a member of the Congressional Autism Caucus. Someone from his staff visited Bittersweet.
- Safe Haven Farms advocates contacts
 - Met with member of Congressman Steve Chabot's staff in December
 - Met with a member of (Republican) Senator Rob Portman's staff at Safe Haven on 1/14/15 for tour and discussion. Also attending were Butler County DD Superintendent and two of her staff.
 - Contacted Speaker of the House John Boehner's local office (Safe Haven Farms' and Rogers' district), and got his endorsement of Latta/Kaptur letter.
- Outcomes
 - All of the Representatives and Senators staff's showed strong support for farm programs and for the rights of individuals and their guardians to choose where they want to live and be served.
 - Representatives Kaptur and Latta authored a letter from the Ohio federal delegation to CMS Secretary Sylvia Mathews Burwell in support of farms. The letter was issued on 1/26/15 with supporting signatures from 13 of 16 Ohio US Congress members: Marcy Kaptur, Robert Latta, Speaker John Boehner, Brad Wenstrup, Pat Tiberi, David Joyce, Bill Johnson, Jim Jordan, Steve Stivers, Bob Gibbs, James Renacci, Michael Turner, Steve Chabot and Ohio US Senator Rob Portman.
 - Senator Sherrod Brown's office is writing a letter to the Ohio DoDD.

4. Contacts with Ohio Department of Developmental Disabilities (DoDD)

- Bittersweet advocates contacts
 - Call from Director Martin to Vicki Obee (12/29/14)
 - Met with Disability Rights Ohio representatives on 1/22/15 at Bittersweet regarding DRO's threatened lawsuit against Ohio DoDD, and their perception that *"anyone with a choice would not want to live in a congregated setting"*.
- Safe Haven Farms advocates contacts
 - Ohio DD Director John Martin visited Safe Haven Farms on 7/9/14 with Lisa Guliano (Butler County DD Superintendent) for tour and discussion with parents and Bittersweet
 - Call from Director Martin to Denny Rogers 1/5/15 (result of call to Martin from Rep Terhar) – supportive, will work as our advocate, realizes farms are good option for some, etc.
 - Meeting in Columbus with Zachary Haughwout (Deputy Director Legislative Affairs and Communications for Ohio DoDD) on 1/5/15, and followup phone call on 1/8/15. He is hearing from Ohio politicians and echoed Director Martin's sentiments about the benefits of farm programs for some on the spectrum and their willingness to advocate for us.
 - Visit by Lisa Guliano (Butler County DD Superintendent) and two staff to Safe Haven Farms on 1/14/15. Very supportive of our approach.
 - Brief introduction with Lori Horvath (Deputy Director for DoDD Medicaid Services) on 1/10/15. Arranging a meeting.

5. Contacts with other public officials

- Safe Haven Farms parent advocate reached out Tom Strauss, with the local Cincinnati office of the Ohio Attorney General's Office, who has a son with autism. He is interested in discussing this issue, understanding how they can help and possibly getting us an audience with Mike DeWine, current Ohio AG. Advocate has been contacted by Mary Mertz, First Assistant AG for more information.

Tom is also working with another group in Cincinnati wanting to start an urban community that is stalled by CMS HCBS waiver issue.

6. Attendance at DoDD and other Meetings

- o Safe Haven advocates attended ARC/DRO meeting in Columbus on 11/19/14.
- o Bittersweet advocates attended similar ARC/DRO meeting in Toledo.
- o Safe Haven advocates attended state DoDD transition plan informational meeting in Columbus on 12/18/14.
- o Safe Haven advocates (and total of 14 parents) attended state DoDD transition plan informational meeting in Cincinnati on 1/10/15.
- o Safe Haven advocates attended transition plan public feedback meeting #1 in Columbus on 1/5/15.
- o Safe Haven and Bittersweet advocates attended transition plan public feedback meeting #2 in Columbus on 1/15/15.
- o All of the above meetings got very strong audience reaction against the effort to restrict congregate settings and farm communities. Many people from all over the state spoke passionately for the rights of individuals and families to choose the most appropriate settings for services, and the value of congregate settings for some people with disabilities. All also supported continuing to expand opportunities, but not at the expense of others.

7. Local Southwest Ohio Advocacy

- o Discussed issues with Impact Autism board of Cincinnati (Rogers is a member). They are supportive and subsequently joined the Coalition for Community Choice. They want to develop an urban community and are stopped due to concerns about CMS issue.
- o Safe Haven advocates met with leaders of RAAC - Regional Autism Advisory Council for SW Ohio (Rogers is a member) - to strategize on ways to address the issue, get the word out, and advocate for choice. In addition to RAAC leader, one attendee was on Hamilton County (Cincinnati) DD Board and leads the Harrison Ohio Community Network and two were affiliated with the Kelly O'Leary Center for Autism at Cincinnati Children's Hospital. RAAC is connected to over 500 organizations and individuals in SW Ohio, including four SW Ohio County DD Boards.
- o Safe Haven advocates coordinated with Autism Society of Greater Cincinnati - current president, past president and executive director all strongly support choice and farms, etc. They submitted a supportive letter during Ohio's public comment period.
- o Harrison, OH Community Network put out an action alert to their members. They are an organization on the west side of greater Cincinnati area working to develop opportunities for people with disabilities.
- o Leader of Harrison Community Network reached out to acquaintances in Autism Speaks for discussion: Shelley Hendrix, National Director, Grassroots Advocacy, Government and Angela Lello, Director of Housing and Community Living. Some good insights from them, supporting CCC position that this is a state battle, not a national one.
- o Stepping Stone Center is in Cincinnati suburb of Terrace Park where US Senator Rob Portman lives. He has been there several times and is a supporter of their programs. They reached out to us to discuss CMS & Employment First issues and joining our advocacy efforts.
- o Safe Haven advocates met with Butler County DD Superintendent Lisa Guliano to discuss concerns about protecting choice and right to live on a farm

8. Communications

- o Bittersweet parent advocate, Jane Atwood, started an on-line petition on 11/11/14 using change.org web site supporting choice and options like farm communities, congregated settings, etc. (<http://tinyurl.com/ohiodisabilitychoice>). **Currently has about 2,700 supporters.**
 - Jane was contacted by Disability Rights Ohio that resulted in a meeting at Bittersweet to define common ground.
- o Safe Haven held multiple meetings with their families and issued action alert to join the on-line petition, write letters to state in response to transition plan, attend meetings, etc.

- Most of the Safe Haven families submitted passionate letters as part of the public feedback period for the transition. In them, they told their family's stories and why the farm community best served their son or daughter's needs.
- Families, residents and leadership of Bittersweet traveled to Columbus, Ohio to give public testimony on the transition draft.
- Safe Haven's fall newsletter contained an article about "Building Community", highlighting all the people who come to the farm every year. It also contained an article "A Common Voice Supporting Choice", with discussion of the CMS issue, a position statement supporting farms and other intentional communities and choice, and link to the on-line petition. Distributed to 1100 people.
- Safe Haven sent an email to all members of ACAA (Agricultural Communities for Adults with Autism; www.ac-aa.org) with background on the issues, links to more information, etc. and encouraging them to get engaged in the discussions in their states. Bittersweet and Safe Haven Farms are both members of ACAA.
- Safe Haven sent a letter to all members of NARPAA (National Association of Residential Providers for Adults with Autism; www.narpaa.org) asking them to join CCC. Bittersweet and Safe Haven Farms are both members of NARPAA.
- Autism Society of Northwest Ohio issued a supportive action alert to their members and joined the Coalition for Community Choice.
- The Autism Society of Greater Cincinnati submitted a letter during the transition plan public comment period supporting choice.
- Bittersweet issued an action alert to their families.
- Vicki Obee of Bittersweet was interviewed on a TV talk show in Toledo.
- The Toledo Blade ran a front page story on Sunday, 11/9/14 on the issues
- The Columbus Dispatch ran article on 1/18/15 discussing parent comments at 1/15/15 public feedback meeting in Columbus:
<http://www.dispatch.com/content/stories/local/2015/01/18/families-fight-community-care-plan.html>
- Denny Rogers was interviewed by Farm World (a weekly newspaper published in Midwest). Reporter visited farm on 1/14/15 for tour and interview about the CMS issue. To be published soon.
- Safe Haven ordered "**Life is Better on a Farm**" T-shirts (slogan written over outline of the state of Ohio) from the Ohio Farm Bureau as part of their fundraising campaign. To use for Safe Haven farmer photos and video. See them at:
https://shirts.growwithfb.org/#_ga=1.72244563.1316776854.1365535774
- Safe Haven is working to develop a concept for an impactful video that could hopefully get widespread publicity for the cause!