

Children's Behavioral Health Services  
Provider Meeting  
June 14, 2010

Present:

Mike Parker (DHHS-CBHS)  
Jane Landry (Milestones Family Services)  
Nancy Givren (Community Counseling Center)  
Brian O'Leary (Back to Basics)  
Gary Grover (Back to Basics)  
Kelly Parnell (APS Healthcare)  
Terry Valente (Independence Association)  
Colleen Gilliam (Independence Association)  
Hannah Welch (Bridges of Maine)  
Erica Whiting (Port Resources)  
Melissa Ridlon (Providence Services Corp.)  
Karintha Haberstroh (Providence Services Corp.)  
Pat Proulx-Lough (Tri-County Mental Health Services)  
Michael Wentworth (Living Innovations)  
Ellen Martzial (Woodfords Family Services)  
Peggy Splaine (Providence)  
Nichole Hinton (Providence)  
Sarah Mehlhorn (Waban Projects)  
Jennifer Fullerton (Becket Family Services)  
Steve Tuck (Becket Family Services)  
Lonnie Leeman (Christopher Aaron Counseling)  
Hanna Sterzel (Affinity)  
Alison Patin (Affinity)  
Linda Higgins (Ethel's Tree of Life)  
Brett Webster (Bridges of Maine)  
Meg Hall (Spurwink Services)  
Durinda Chace (Spurwink Services)  
Carolyn Cheney (Pine Tree Society)  
Karen Backman (Casa, Inc.)  
Jim Pease (Casa, Inc.)  
Amy Mihill (MVRA)  
Sylvie Demers (CSI)  
Michael Damon (MBHA)  
Michelle Armstrong (DHHS-CBHS)  
Melissa Maurais (CAFÉ)  
John Regan (CAFÉ)  
Sally Hunt (DHHS-CBHS)  
Jana Colby (DHHS-CBHS)  
Roger Wentworth (Sweetser)  
Doug DuBois (Port Resources)  
Ellen Tims (DHHS-CBHS)

Elizabeth Sjulander (Saco River Health Services)  
Joyce Segee (Saco River Health Services)  
Terri Thompson (Connections for Kids)  
Brian Scanlon (DHHS-OACPD)  
Rachel Posner (DHHS-CBHS)

Thrive, GEAR, F.A.C.E.S.

“Together we can build a bridge” a public service message from Family Advisory Councils for Empowerment Statewide (F.A.C.E.S.) sponsored by G.E.A.R. Parent Network and Thrive System of Care

Lisa Preney is the social marketing director for Thrive, Maine’s current trauma-informed system of care <http://thriveinitiative.org/trauma-informed/> which is funded by a grant from the federal Substance Abuse and Mental Health Services Administration.

Lisa introduced presenters Joy Hodgson and Rebecca Williamson, both members of F.A.C.E.S. (<http://www.gearparentnetwork.com/faces/>), as well as Carol Tiernan, Director of G.E.A.R. (Gaining Empowerment Allows Results) the statewide parent network that sponsors F.A.C.E.S. The women distributed a F.A.C.E.S. informational flier and “What works Best” handout, which supplements the public service message.

In 2009 Joy and Rebecca were members of Thrive’s Family Committee, which produced the video. In November the committee merged with the local F.A.C.E.S. council. Families chose bridges to depict their hopes for bridging “the abyss” of differences and emotions with providers. They created the message to:

- raise awareness and help educate on “trauma informed” and “strength-based”;
- tell families “Help is available...you are not alone”
- get a more positive response from providers towards children’s behavioral issues
- help improve parent-provider communications related to service delivery

Each family chose a bridge in their town (E. Livermore, Dixfield, and Lewiston) to symbolize how isolated they felt when they first encountered a child-serving system. Families want help, but may not know how to get it or how to ask for what they need. The common interest and goal of families and providers is to help our children, but families often feel providers are not working with them. Building a bridge or being on the same bridge together means “providers are listening to us and not judging us. It means they see us as people they can also learn from and not as people they need to fix. It means our meetings are an exchange of experiences and a cultural learning opportunity.”

Families connected with each other, first through Thrive, now through F.A.C.E.S., and formed a strong, collective voice. At the end of the video, families are all together on a (neutral) bridge in Turner with a strength-based message for other families who can relate: “When you use your voice, you have a choice.”

In five months, the video has received 400 hits on the internet. F.A.C.E.S. members continue to present to CBHS regional meetings. We’ve presented to community

collaboratives, juvenile justice groups, an Adoptive and Foster Families Child Welfare Unit and Community Care, a statewide 65 M and N network of in-home support staff. The video is now part of new staff orientations at Community Care. We will continue to present to DHHS regional groups, and have been invited to present to Catholic Charities and the Healthy Families Network of early childhood providers in Brunswick. During May this video was broadcast to over 100,000 households in 34 Maine communities over Community Access TV and to over 300,000 households in FL, CA, NJ, MA, NM and MN. We expect these numbers to continue to increase and we are so excited.

- Provider would like to have the video available to show their team.
  - It is available online at <http://thriveinitiative.org/family-driven/together-we-can-build-a-bridge/> DVDs are available for training purposes through Thrive ([lprenney@tcmhs.org](mailto:lprenney@tcmhs.org)) and G.E.A.R. ([ctiernan@crisisandcounseling.org](mailto:ctiernan@crisisandcounseling.org))
- Comment: “We share these values, but when we are tired, or stressed, etc., it’s easy to fall back into old habits that might not be as strengths-based and family-focused.”
- Comment that the regulations that govern providers’ work also may cause frustration, and make implementing this perspective difficult.
- Comment: “Thanks. This is very innovative. We talk about collaboration & having a strengths-based, family focused perspective, but it’s important to train staff on this and reinforce the message.”
- Lisa Prenney: the video is only 1.5 minutes long, so the handout was designed to follow up on the message from the video. A companion document is being prepared to let families know “What works best...” for providers. If any providers in this room (or their staff) would like to contribute statements, please email [lprenney@tcmhs.org](mailto:lprenney@tcmhs.org) or call 782-5783 x1608. A review of all statements will be offered all contributors.
- #13 on the handout states: “What works best for me and my family is that you observe our family culture in our home, so you can better understand us.” Parent gave the example of a provider (from Child Protective Services) who interviewed her children at school, came to her home unannounced, spoke to her, then left abruptly when her children got off the bus. “He didn’t give us the opportunity to see me and my children at home, to see how we interact with each other. I really wanted that opportunity.”
- Parent said that when a child welfare worker in Ellsworth read #9, “...and understand our terror of you showing up...” it was interesting to hear that child welfare workers are sometimes nervous and afraid, too.
- Provider commented that he has heard from parents, “Just because I have a mental health diagnosis doesn’t mean I’m a bad parent.” Parents get blamed & shamed regularly.
  - NOTE: F.A.C.E.S. will review the suggested additional statement: “What works best for me and my family is that you believe I can be a ‘good’ parent even with a mental diagnosis myself.”
- Parent said a parent she knows has a card to give out when she’s in public, such as a grocery store, and her child is acting out, to people who are staring. The card explains what she is doing, for instance, calming the child with a special hold. G.E.A.R. has created cards to give parents who are dealing with their child’s behavioral problems.

The card has G.E.A.R. contact info on it and the statement: “It’s OK. You are not alone.”

- Especially when services are changing, and resources are tight, it’s important to keep communication open and clear. And when there’s a lot of stress, it’s especially hard for everyone to hear things.
- Parent said that the longer a child is bouncing off barriers between parents and providers, the more he falls behind.

Q: Where are G.E.A.R. support groups?

A: Go to: <http://www.gearparentnetwork.com/support/groups/> Click on the map to find the nearest group. Parents can also call 1-800-264-9224 (answered by a parent 24x7).

Q. Where are F.A.C.E.S. councils?

A: Portland, Lewiston, Bangor, Skowhegan and Rockland. As funding grows, the network will grow. For more information: <http://www.gearparentnetwork.com/faces/>

#### OACPD (Office of Adults with Cognitive & Physical Disabilities)

Brian Scanlon, Team Leader for Region 1, came to the meeting to provide information about transition to adult services.

Brian indicated that DHHS is systematically eradicating the term “mental retardation” from statute, regulation, and everywhere possible. That term has become offensive to the people we serve. In its place, we talk about Developmental Disabilities; we talk about Adult Developmental Services. We can predict, of course, that the terms will change again at some point in the future.

Brian asked some questions of the group:

- How many feel they need some additional basic information about how OACPD works?
- How may work for agencies that get the monthly OACPD newsletter?
  - This is a helpful way of getting information. Brian asked folks to sign up if they want further information. He will connect with people who want to learn more.

Millie Savage, who does intake for adult services in Region 1, wanted Brian to convey that the children’s case managers do a very good job preparing youth for transition. She also mentioned some school districts who don’t do as good a job as they might preparing youth for transition.

How things generally work: Brian’s office tries to identify anyone who is going to be in need of adult developmental services. Eligibility is as follows:

- Basic case management is available to individuals with a broad range of developmental diagnoses, which includes Aspergers and other autism spectrum disorders, as long as accompanied by Vineland showing functional impairment.

- Assistance with job coaching, day services, and residential services, requires a more restrictive eligibility which includes “mental retardation,” Autism, PDD-NOS, as long as accompanied by adaptive deficits. The Vineland needs to be signed off by a fully-licensed individual.
  - NOTE: The latest information available at CBHS about administration of the Vineland is as follows: *Qualifications to administer Vineland:*  
 Certification by full or active membership in a professional organization (APA, ASHA, AOTA, AERA, ACA, AMA, NASP, NAN, INS, CEC, AEA, AAA, EAA, NAEYC) that requires training or experience in a relevant area of assessment.  
 Or,  
 Masters level in Psychology, Education, OT, SLP, Social Work or a field closely related to the intended assessment, and formal training in the ethical administration, scoring and interpretation of clinical assessment.

A request was made from provider for explanation of acronyms. Brian indicated there might be a good topic for a future newsletter.

Brian indicated that the worry for most people is better services once the youth transitions to Adult Developmental Services. Many parents aren't clear about the division between children's and adult services. For those who anticipate requiring services from adult developmental services, virtually the only funding available is MaineCare. This includes Section 21, services for those who will need residential services and intensive in-home supports. Statewide expenditures for Section 21 is about \$280,000,000 with \$100,000 average per person. The waiver covering work support or community support (Section 29) averages significantly less per person. Both of these waivers are under considerable financial duress at present. The earliest you can get these services is age 18.

There is a question to clarify for future reference. The question is as follows: Can an adult get Section 17 (Community Support Services) and Section 29 (Community Support Benefits for Members with Mental Retardation and Autistic Disorder) simultaneously? Upon further research with Jeff Scott (Adult MR Case Worker Supervisor) and Earl Babcock (Social Services Program Supervisor), the answer to that question is yes, since they are not two waiver services. Section 17 (Community Support Services) is now found under MaineCare Section 65.

The financial distress the system is under is of extreme concern to families. The bulk of money being spent at present is for residential services, specifically for group homes. There's nothing wrong with these services, but they take up a disproportionate amount of spending, and the spending is growing at a rate that is not sustainable. The availability of Section 21 closed for about 2 years. It will open a bit in the coming year, but not enough to address the entire waitlist. There is a system for prioritizing the waitlist based on acuity. Youth who are aging out of the services they're currently in (such as youth who need to leave children's PNMI residential programs) are also a priority. This includes youth aging out of the Child Welfare system, which are in PNMI residential programs. There are also adults who have been cared for at home for a long time by caregivers who

are suddenly unable to care for them (e.g. elderly parents); and other families who for various reasons are no longer able to care for their disabled adult at home. Unfortunately, because all the needs can't be addressed, for some youth and families the situation significantly worsens before services are available.

Brian encouraged people to become "change agents" in reconfiguring the system in the future. Advocacy from outside the Department is important in influencing movement to innovative approaches in the future. Currently, a typical 3-person group home in a week uses 240 hours of staff. This is around \$300,000 for 3 people. Then add in job coaching, community support, or both for those 3 consumers. It's not that anyone working in the system is engaged in gross wastefulness, or is making a lot of money; it's that the system is configured in a way that is no longer sustainable. Services need to be reconfigured. An experimental approach has been tried in Region 1.

Brian commented that money could be saved by increasing the size of group homes, moving from 3 people to 4. But the larger the home gets, the more institutionalized it gets. This is a difficult challenge—how this might be done from the many practical points of view, while balancing the need to not move into the old institutional model? Brian says, "The institution is in our hearts." A 2-bed group home can feel like an institution; and a 4-5 bed home can feel very supportive and loving. There's a lot of disagreement on this. Some of the philosophical issues, and the practical issues, stem back to the closure of Pineland Center.

#### Discussion/questions:

- Healthcare reform has a provision for young adults to stay on their parents' health insurance until age 26. Is there a way a parallel to this could be achieved in the public sector, such as youth staying in children's services longer?
- Question about shared living, and changes that might occur in October.
  - Brian responded that there are enormous hurdles. There are changes being worked out. Brian feels confident that there will still be shared living, but the shape of it might change. Shared living is a viable option for many of the people the adult system serves. A challenge is that the system was originally designed for people with moderate needs, who could benefit from living in a family, which would promote community inclusion (basically a foster home model). Many families of young adults have a problem with this model, saying that the consumer already has a family, but instead needs a group home. There's a fear that the family providing shared living will supplant the consumer's family. Also, when the shared living model started, many consumers who would have been appropriate for the shared living model were in group homes, and their families were unwilling to try the newer model. There is also a fear that if the shared living family has a sudden change of circumstances, the consumer will experience a serious disruption. There are ways that the current shared living providers address these challenges.
- Is any money available, including grants, for creative residential alternatives, and ways to support families?
  - Brian is exploring grants at present.

- The website address that provides training/information on adult guardianship, etc is <http://www.maine.gov/dhhs/OACPDS/DS/Services/index.shtml>.

### Children's Waiver

After several years of not having a children's waiver, CBHS is in process of developing one. It will eventually be under MaineCare Section 32. The Commissioner hasn't signed off on this yet. It involves both a waiver (of Federal Medicaid regulations), which has been worked on with CMMS (the Centers for Medicaid and Medicare Services), as well as involving State regulations. The Department will be interested in talking to Maine vendors who might be interested in providing waiver services once it is implemented.

Question from provider about who would be served by the children's waiver. Without having seen the waiver itself or the draft regulations, some predictions about who might be qualified include children whose behavior needs very far exceed what can be done through RCS/Section 28; who are in and out of psychiatric hospitals because their behavior is so unsafe and unstable; whose behavioral needs so far exceed what can be addressed at home that they're currently in PNMI residential care; etc.

### RCS Section 28

This service has shifted from a support model to a treatment model. In the past, Section 24 was focused, at times, more on support than treatment. The new services is "managed" (managed care), to try to give people exactly what they need, but not more.

Bob talked about treatment plans. If the newly submitted plan looks like the previous year's plan, we will request more information. Goals and objectives should change. There is a limited amount of time in a child's life to help them achieve skills, and we need to maximize how we use these opportunities for growth. We may send out a request for more information, a letter that asks for the information in 8 state working days. We extend the authorization for 18 state working days when we send out the letter asking for more information, so the provider has time to get us the information, and we have time to read it when it comes in. In this new RCS/Section 28 process, CBHS has substantially more information to process, so we really need the information to come in time. When plans are revised, if there are substantial changes, new signatures are needed from the parents.

Also, please fill out forms completely. It may sound minor that CBHS pushes back when, for example, the zip code isn't included, but given the number of plans being processed; these simple pieces of missing information really slow things down. If there are a high number of hours in a plan, CBHS may ask whether a behavioral consultant might be helpful. Flex funding may be available for behavioral consults; please contact CBHS to ask if interested.

Embedding objectives: when you're addressing something like dining skills, the plans previously said we're working 10 minutes on one skill, 12 minutes on another skill, and 5

minutes on another skill. Instead, you can put down the amount of time for the meal, with objectives for skills being worked on during the meal. The other type of embedded objectives is the kinds that are being worked on all the time, such as speaking in full sentences, or making eye contact. These don't really need a separate objective. Think about the amount of time that realistically can be used for intensive training. The children are working intensively at school. How much time, when they leave school, is really available or appropriate for more skill acquisition? We also know that families have individual challenges. For example, a single parent, or a family with multiple children with disabilities, may not have the same time or energy for involvement in the plan. Spell this out.

Stranger awareness: children define "stranger" differently than adults do. And most of the time, we know that when children get molested, it's by someone they know rather than someone they don't know. Providers should consider this when developing objectives. Should the objective be about "stranger awareness" or would an objective around boundaries, safe touch, or the "Circles" program be more appropriate? Similarly, money management: there are a lot of objectives around making change. Might it be more helpful to distinguish between a \$1 bill and a \$10 bill, rather than focusing on change? Also, think about using ATM cards. The message here is to think about what is really the most practical thing to learn and what will help the child most as they move through life.

#### Questions:

- Smaller objectives & embedded objectives (eye contact, etc.)—instead of breaking these down in detail, would it be OK to submit a broad long-term goal that would encompass the smaller objectives?
  - It depends. You have to justify this. If you have a broader objective, you have to enumerate all the things being done in the larger period of time. Why 3 hours, not 2 hours or 1 hour? It is still important to break down the time. For hand washing, how much time? For mealtime, how much time—10 minutes, 30 minutes, an hour (it will vary according to child and family needs)?
- Brian talked about being encouraged about all of this discussion. This is consistent with how Adult Developmental services views the planning process. Consumers are facing global challenges, and need to gain skills. But if you make a list of every single thing the consumer needs to work on, it's discouraging and absurd; and focusing on only 1 or 2 things, or on something very global, also doesn't work. It makes more sense to what the person needs to work on and break down the skills within that. The consumers can only be lifelong learners if there is a very stable group of people working together on the plans over time. The work on Section 28 sounds seamless with this approach in adult services.

#### OTHER:

Tentative date for next Region 1 CBHS provider meeting is 9/13/10.

