

Family Voice Sampler: 3

Examples of partnering with families : SR

- His mother was concerned that his out of control behavior at home was not being adequately acknowledged as serious
- She was divorced from SR's father and there seemed to be an impenetrable wall in her ability to engage with her ex-husband for a plan they could agree on
- She was *given the dignity to be real* about her frustration and talked at length about her worry for SR.
- What had looked like anger and rage aimed at her ex-husband was voiced by her as fear of raising a child with significant mental health barriers all alone

Family Voice Sampler: 4

SR:

- At this meeting, although she began it very angry, SR's mother was "heard" more than she was "told"
- Listening to her own voice reflected, she realized she was locked into her fear and unable to move to the "what to do about it"
- It was such a revelation she began to seek her own support network through her private therapist and family support groups
- Her voice was respected, nurtured and encouraged; today she and SR's father are able to sit together, sharing Family Night activities and a mutual responsibility for his future

Family Voice Sampler: 5

- **Ownership:** CS, 10 yr., child welfare referral, great aunt's ownership of the plan held the team together through the storms of his severe illness, caregiver knew what she should and could not do
- **Building on Strengths:** AH, 16 yr., juvenile justice referral, Care Manager's strength-based lens gave providers and youth new perspective on his abilities, "set backs", could have been locked back up, instead took on leadership of his team

Family Voice Sampler: 6

- **Meeting the Need:** MJ, 14 yr., mental health referral, seemed to have just picked up more prescriptions with each hospitalization, crisis intervention kept her in the community, increased connections led to honor roll and vet school dreams
- **Shifting Perceptions:** LH, 12 yr., school referral, single parent a DMR client, demeaned and uncertain, girl embarrassed, isolated, increased positive peer opportunities for both mother and daughter allowed both to thrive and the child to stay in the home

Ownership

CS is an 11 year old child who lives with his widowed great aunt and holds a potpourri of diagnoses: ADHD, feature Aspergers, NVLD, anxiety Disorder, reactive detachment disorder and R/O mood disorder. His Care Manager sees overt severe anxiety disorder, significant social interaction impairments and impairments of his executive functioning. Explosive and unsafe behaviors at home and behavioral school struggles led CS's aunt to request voluntary services from the Department of Social Services. He had not adopted by his great aunt and many conversations initially focused on the reactive detachment disorder.

Prior provider involvement had been experienced by CS's aunt as folks looking at her family as lacking coping strategies and/or having "complex family dynamics", so that CS's need for a TEAM was a result of family deficits. However the Care Plan process understood that CS's need for a TEAM was a result of raising a child with significant mental illness.

This aunt was and is an intelligent, vocal leader in the Care Plan process for CS. The process's thoughtful consideration looked at what CS's family needed to raise a child with his needs. Worry, crisis and hospitalizations did not end but they were made bearable through education and support. CS's aunt owned the proposed plans that made sense to her individual family needs built on her and CS's strengths.

The family ownership of the plan held them together through the storms. When she wavered, the process locked its knees. When circumstances eroded her confidence, the TEAM stood strong with good counsel, unwavering commitment and genuine concern. She had such ownership of the process that when it needed revisiting, she lead the charge. She knew what she should and could not do.

She knew what made sense to her family and she became the heroine of the TEAM. She owns the plan and the TEAM supported her execution of the services and direction for CS.

Building on Strengths

AH was 16 years old when he was referred to our program by the Department of Youth Services upon release from a locked Juvenile residential facility. He had a number of infractions that resulted in his spending time in Juvenile facilities. AH had a long history of family and community struggles and his probation officer, school TEAM and other stakeholders did not hold much hope for his ability to integrate back into the community. His mother was a very vocal support for her son and also felt he would have to make an extraordinary shift, under great scrutiny, and was very concerned the pressure would be too great.

One of the first things that really stood out to his Care Manager was AH's impressive demeanor. He was very sweet, considerate and very likeable. It also was quite clear that his language abilities presented consistent with his records and he was functioning lower than expected in his expressive and receptive skills. This would often frustrate him and sometimes he would react impatiently and angrily to complex conversations. He was also depressed and quite sad. With multiple providers believing he was a bad kid...a portion of the work would need to be shifting some sets of beliefs.

His Care Manager came right out the gate capitalizing on all his (and his family's) strengths. She ensured that every meeting and every conversation was saturated with his multiple assets...starting with AH himself.

She was often alone in her building of a foundation anchored in his strengths. Bu it wasn't long before his meetings shifted from "Are you towing the line..." to ..."what do you think, AH?"

It was tough for AH's TEAM to stay this new course when he would be sent home from school, have run in's with police in the community, and, once, when he ran away for weeks. But his care manger was so committed to her belief in AH and his success that she held the TEAM through some disappointing turns.

She took events under her belt as part of the course and worked hard to bridge AH's struggles as momentary and reminded everyone (even AH) that the work towards his mission was not over!

His TEAM reluctantly began to also believe in AH. With needed interventions and providers in place, folks began to rally around him and champion small successes.

At a recent Care Planning Meeting, his Care Manager invited AH to lead the meeting. He began by welcoming and thanking everyone for coming and proceeded to check in with every TEAM member. "How am I doing?" was his question to all the attendees. He relished their remarks and proudly thanked them for their input. For probably the first time in his life, he had real ownership of a plan for himself. Services and intervention were not exacted on him or dictated by narrow agency practices; rather, the TEAM together developed an understanding of his complex presentation and worked together to develop a plan that met his needs built on his strengths. AH is doing well in school, at home and in the community, and is looking for job!

Meeting the Need

MJ was referred to our program along with her sister. MJ was struggling in school and had very difficult family interactions that would often be explosive and violent. She had had a series of hospitalizations and was on multiple medications. Along with her sister and her mother, MJ had developed a set of family interaction skills that consisted of yelling, provoking and reacting to each others stress and lack of communication skills.

MJ was a bright girl, depressed and stress reactive. She saw everyone else as a cause for her presentation and did not think she had a say in how her life could go. Her Care Manager quickly addressed a crisis plan that was proactive, putting multiple strategies and interventions in place to avoid the explosive behaviors that had landed her in the hospital time and time again.

Thoughtful consideration of her medications was an immediate need, as she seemed to have just collected new prescriptions with each hospital stay.

For MJ, one of the really successful interventions was community connections. MJ had been very disconnected from her school and community experiences, and longed for opportunities to shine. She joined a girl's community jazzercise class, and had a really invested teacher join her TEAM. This teacher stayed after school for months with MJ, helping her get caught up academically as she missed so much school with multiple hospitalizations. She began utilizing family coping strategies where she took herself out of any arguments while she cooled down and came back only when she could.

With a strong commitment from her teacher, she dedicated herself to school, and made new friends in her community jazzercise class. She eventually joined an after school club and began to talk about her love of animals.

Although her sister and mother continued to struggle, MJ had a strong support base in her providers and school. When the TEAM began to think about her transition to high school, MJ told the TEAM she wanted to go to an Agricultural School as a public school option. Because her attendance record from so many hospitalizations would be barrier (she had missed over forty eight days when she entered our program), the TEAM went to work providing glaring recommendations for her. She sailed through the interview process and was one of 11 students from her district accepted into the Agricultural High School that year.

She got up every morning at 5:30 to get the bus for the 45 minute ride and was not home until 4:30 in the afternoon. By the time she graduated from our program, she had made the merit roll in school and was talking about one day being a veterinarian.

Shifting Perceptions

LH was referred to our program from the local school department. She was struggling in school and held a DX of PTSD. Her single-parent mother was a DMR client and her school TEAM had little understanding of her mother's strengths and little interest in them. Her mother was often demeaned by staff and had little support from her overworked DMR case manager.

LH was entering adolescence and her school TEAM was very concerned that her mother did not have the sophistication to manage LH's social and adolescent needs for structure and therapeutic support. LH herself was somewhat embarrassed by her mother and would never invite friends over or go over other friends' houses.

When LH's mother felt belittled or blamed by her daughter's providers, she would not return calls or be very angry and yell. LH was aware that her mother had limitations and didn't always listen to the family rules. Her mother doubted every move she made on behalf of her daughter and lacked not only a clear set of expectations for LH, but the confidence to stand by any decision she made, even the smallest ones.

Her Care Manager worked hard to enlist LH's TEAM in a focus of skill building for her mother and building an alliance of support for her. LH's private therapist had a strong investment in her formulation that LH's mother would never be able to successfully parent LH and was very vocal at TEAM meetings about it. LH's mother would shut down, cry and become very angry.

It was very complex and until the TEAM was able to stand behind the possibility that through family support and parent skill building, LH could indeed remain at home with community and private services. The mother enrolled in a group for parents with cognitive impairments and was provided a parent support specialist.

The TEAM identified after school homework clubs and LH joined dance classes. They came to monthly Family Nights and met other families from their own town. LH's mother eventually graduated from her specialized parenting class with such impressive success that the DMR group leader asked her to mentor to some newer parents (a paid role at that!) LH herself has made tremendous growth in her understanding of her mother's limitations and strengths, as well as her need to respect family rules. She will soon be graduating and has many friends at school and in the community.

**Family Voice: From the Family
Coordinator Viewpoint**

Respect and understanding for the real life experiences of families with children that have mental health needs becomes the foundation for a successful system of care.

A measurement of progress for families is when they encounter mental health professionals that listen to their needs and build solutions using their strengths and the strengths of their child.

Receiving support through their community and educational systems assists families with the challenges they experience daily and gives them hope.

Summary

- Successful engagement of multiple challenged caregivers is a key outcome of the MHSPY model
- MHSPY relies on the active preferences of the family voice to facilitate engagement
- Engagement is a necessary step in creating partnerships for change

Discussion:

- Challenges in creating new models of parent/professional partnership
- Challenges in defining and sustaining new roles within family teams
- Multiple rewards of family, focused work in an intensively coordinated, multidimensional system of care

Contact Information:

Katherine E. Grimes, MD, MPH
Katherine_Grimes@hms.harvard.edu
617-204-1402

Lauri D. Medeiros, MHSPY Family
Coordinator
lauri_day-medeiros@nhp.org
781-321-4815

MHSPY
Families In Action