

Collaborative Adventures

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Families' Voice and Choice – A Parent's Perspective

The concept of family voice and choice seems simple on the outside but is not so easy to implement in tough situations. Sometimes we need a little motivation to keep moving forward with challenging ideas. Who better to provide you with motivation than the families themselves? We hope that the stories and thoughts that follow inspire you to continue advocating for family voice and choice as it continues to take hold in systems of care. We are privileged to present families' feelings and opinions in their own words.

Family leaders describe family voice and choice as:

- Empowered
- Stronger
- More in charge and in control
- Nothing about us without us
- Hearing, listening and acknowledging
- Unity
- Understanding
- Power
- Knowledge
- Freedom

The best part of family voice and choice according to families is:

- I feel like I am more equal with the professional providers.
- I think having a voice for your feelings and opinions about things is more important to me than choice. I had a choice before in what services I wanted but I didn't have any say in it. Now I feel like I have the voice to say I don't think this is working and I feel like I am heard. I used to feel dismissed.
- Less intimidating to families who have dealt with child serving systems, law enforcement, etc.
- I was bombarded with professionals and institutions when my family was in crisis. I finally found a support group a year later and it really made a difference. I didn't feel like I was on trial. It was such a relief to find other parents that I could just talk to.
- The best part of this idea is that as parents of these children we have the power to open people's eyes and see how special our children are. Together with all of our understanding and knowledge we can now make a difference on how our children are accepted.

The most challenging aspect of family voice and choice is:

- It's really challenging to get other families on board with family voice and choice.
- Getting other families to be believers is really difficult.
- Knowing what professionals' job descriptions are and knowing they are not following them.
- I think it's sometimes hard when you have a choice to feel like you are making the right choice. You can't make a good choice without information and knowledge. Sometimes the only way to get that is to speak up and ask.
- On the surface there are some people who go along with it but when you get right down to it they don't believe parents are able to make the right choices.
- When you are first getting started having to convince professionals that I know what is going on and having the right to question the professionals.
- Helping the professionals understand that you are just trying to help not tell them what to do.
- Finding the right "tone" when talking with professionals.

- The challenge as always is that these kids are seen in society as "mentally challenged". Our job as parents is to help educate people on what this means. This scares society because they don't understand and are too dumb to ask.

Family voice and choice has changed many lives. Here are just a few examples of what families had to say.

- It's given me more of a purpose and an avenue to help others.
- It's shown my family the importance of community service.
- We are still trying to get the word out to the community. The ones who know about it support it.
- Working around a system of care, what I see at home is important too. It's made me feel it is okay to speak up. It gave me more confidence to speak up AND my son speaks up for himself too.
- This is our chance to speak out and tell our thoughts, a chance to help educate, and to show everyone how much our kids have to give. To me the most exciting part of this is our kids' voice. They know what works for them and what doesn't. It's past time for their voice to be heard.

In true wraparound fashion we asked families what their hopes and dreams are for family voice and choice in the next 5 years. These are truly inspirational.

- I hope that (family partners) will be involved in every intake and/or assessment appointment through wraparound and the department of children services so that families will feel more comfortable. For many families, when all these professionals come into their home they feel the professionals are there to snatch their kids. Having a family partner there helps families feel more comfortable knowing that we are just another mom or dad. Honestly, I don't want their kids – I have enough of my own.

~ Angie, HELP of Vigo Co.



- I am beginning a parent group so that parents can find support and not feel intimidated by professionals. Developing 1:1 relationships for parents to support other parents would be even more beneficial for parents.

~ Ellen, Huntington Co.



- That more people, especially mental health professionals and educators, allow voice and choice and BELIEVE in it. Also, that the people that work with families on a regular basis would understand some of the emotional ups and downs that the parents go through when you are raising a kid with emotional or behavior problems. If the facilitators understand that, they can do a lot for families to help them understand what family voice and choice means. Having strong support for family voice and choice from the community consortium is also important. Everyone who is involved in the system of care, both agencies and individuals, needs to understand family voice and choice and be able to convey that to the families.

~ Kathy, Visions of Hope

- My dream for the next 5 years is when a family moves to a new community with a special needs child, the community is proud and excited to let them know their involvement and knowledge of systems of care! Also to know our kids are accepted. People need to know that they didn't ask to be born with mental illness. Just like you don't ask to be sick. **My dream is that one day all of our children will be accepted by others. Thanks for asking my opinion.**

~ Kathy, United Families

Well said! Thank you to all the parents who work so hard everyday for their children and others. For more information about family voice and choice please visit the National Federation of Families website at <http://www.fcmh.org/> or contact the Choices TA Center at 1-888-543-9727, choicestac@choicesteam.org.

* Bruns, E. J., Walker, J. S., & The National Wraparound Initiative Advisory Group. (2008). Ten principles of the wraparound process. In E. J. Bruns & J. S. Walker (Eds.), *The resource guide to wraparound*. Portland, OR: National Wraparound Initiative, Research and Training Center for Family Support and Children's Mental Health.