

PAL: Assessing and Improving Systems of Care

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Introduction

Who is PAL?

- A statewide organization of 4,000 families in Massachusetts whose children have mental health needs. Now that sounds like a lot, but there are about 1.5 million kids in the Commonwealth and according to the Surgeon General, 1 in 10 has a mental illness. And 2 of them are my sons.
- Whether they have been diagnosed or not, their parents often know or suspect that there is a reason why their child has outbursts or can't seem to focus on schoolwork or even cannot feel anything except anxiety or sadness or anguish.
- And once they decide to seek help, they discover that the system is like a grocery store in New England when a blizzard is predicted. There are gaps on the shelf where one item should be, another is backordered and still another has been moved to a display in the front where you would never think of looking for it.

So there we are, the families of these children. We all agree the system needs to change and we know we can't do it alone. And we have come to understand, that in order to be effective, we need to retain our unique voice as parents of children with mental health needs. We need to keep intact our perspective and our priorities.

As we all know, the legal definition of marriage has changed in Massachusetts over the last few weeks. And there has been a lot of discussion about how important and desirable marriage is. I don't really care today where you stand on this issue. But I am going to risk being a little politically incorrect here. What I want to tell you is that sometimes, a partnership is much better than a marriage. And that is especially true when you intend for your collaboration, your partnership, to effect systems change.

Since these presentations today are short, I can't give you the top ten reasons, like David Letterman would, why a partnership is better than a marriage, but I can give you five. So here they are:

Reason #5: You usually know what brought you together. It's not a mystery.

Reason #4: You don't have to stay together because of the children. Any offspring or products you create can go out into the world in a very short time.

Reason #3: A fear of intimacy is just fine. It's okay not to share everything.

Reason #2: Separate finances, checking accounts, and budgets are not a point of contention. In fact, they are preferable.

And the number one reason that a partnership is better than a marriage is:

It's okay to have other relationships that are just as important!

Having said all that, I want to briefly talk about our most successful partnership. Just as your first child teaches you how to parent, your first partnership teaches you how to partner.

For PAL, the first, and foremost, partnership has been with the Department of Mental Health. This collaboration has endured since the early 1990s and has helped PAL define its strengths and goals. We have brought the experiences of families to DMH and explained how important it is to have families involved in every aspect of care from planning to evaluation. We worked together to pass the mental health parity law and change the law requiring parents to voluntarily give up custody to get mental health treatment for their children from DSS. We have shown how fragmented services hurt our families and have worked together on local systems of care projects, such as MHSPY and Coordinate Family Focused Care. And we have worked together to get more funding for services in the communities where kids and families live. Some years with greater success than others.

When DMH or even Health and Human Services creates new policies, we bring individual stories showing the impact. These stories are sometimes about the parents who are trying to shop in that store just before a New England blizzard. They can point out where the shortages are and how hard it is to find certain items.

In exchange, we have learned that when making systems change, change takes a long time. As families, we begin by wanting things to be better for our children this year. As partners, we have learned that changing contracting, changing policy and even changing laws can take far longer. In order to do that, an organization needs someone who does what I do: collect the experiences of families and translate them into systems language.

Working together also creates a wonderful byproduct. We have often been very ambitious about what we want to accomplish. Large changes are not possible without a number of people and organizations working together. For us, these new organizations have frequently become partners for PAL in other endeavors.