The following is a fictional story: James and Terri inherited $100,000 and decided to pursue their dream and open a restaurant in the Phoenix area that catered to the many winter visitors who were present during the beautiful Arizona fall and winter seasons. James and Terri had just relocated from Texas six months earlier, but they had been studying about what it takes to open and operate a restaurant for many years. In some ways $100,000 seemed like a lot of money to work with, while in other ways it did not seem like much at all. But one thing was clear: they wanted to make sure to make the best use of the money because they knew this was their one shot at making their restaurant dream a reality.

James and Terri found themselves needing to make several critical decisions about their new restaurant and knew they needed some help. So, they pulled together a panel of people to ask questions about how to structure and run their new restaurant. This panel consisted of owners of other successful restaurants both locally and around the country, financial experts, interior decorators and designers, chefs, marketing strategists, and several of their friends and family whose opinions they trusted highly. James and Terri spent many hours meeting with the panel and making plans about the best types of food to serve, the best locations, the best type of décor, and the best type of marketing approach to attract the winter visitors and to make the business as welcoming and friendly as possible for their target audience. Everyone on the panel gave their advice about what would work best for the winter visitors and soon they had developed a plan, spent the money, and begun the construction process. The business had its grand opening the next May. It was a beautiful and trendy Sushi bar located in a very urban part of the city where there were few winter visitors. The restaurant featured a Karaoke stage, bright colors, and even had a shuffle board area. The name they chose for the restaurant was “Snowbird Sushi” and their slogan was “Every day is senior discount day at Snowbird Sushi.” By September, Snowbird Sushi was out of business.

Because they had chosen a less expensive part of town in which to open the restaurant, James and Terri had only spent $80,000 of their $100,000 on the restaurant. Rather than calling it quits completely, they decided to hire some people to help them figure out where they had gone wrong with Snowbird Sushi and to find out if there was any way to be successful in their goal of catering to winter visitors in the restaurant business. They were wondering where to turn for advice when a crazy idea came to Terri – they had designed all of the plans for Snowbird Sushi without involving the input of a single winter visitor. Instead, they had listened to the advice from everyone else about what winter visitors would like. This time they decided to spend their money getting input from winter visitors themselves, especially ones very familiar with the Phoenix area. It didn’t take long to begin to see all the areas they had made incorrect assumptions about what was needed to make a successful restaurant for winter visitors.
First of all, they learned that, despite the innovative approach, most of the winter visitors had no interest in trying to become part of the trendy Sushi eating crowd (creative idea, just one that wasn’t going to work) or in singing Karaoke. Second they realized there were much better places to put the restaurant than this part of the city because it was not the area where most of the winter visitors lived and most of them said they would not want to travel more than one mile to a restaurant, no matter how good it was. Third, many of the people they interviewed told them that it was patronizing to put bright ugly colors in the restaurant and to have a shuffle board area. While the designers thought they were catering to older folks, they were actually insulting them. And most of them didn’t like the slogan of “Every day is Senior Discount Day” for reasons you might imagine.

Terri and James also learned a lot about what would work well for the restaurant—they decided to locate it in part of the city where there was the greatest concentration of winter visitors. Even though the cost of space would be higher, they revenue gains of having a location where there were more winter visitors would far outweigh the extra costs. They decided to serve food cafeteria style and to offer some of the favorites from the hometowns of many of the winter visitors they spoke with. The interior decorator asked lots of questions to the winter visitors about preferences for color and design and made a plan based on this input rather than just guessing what winter visitors would like. And the group provided input about menu layout, marketing ideas, special incentives, and most of the new restaurant name: “Be Our Guest Café”. They decided to have the Grand Reopening in November (during the peak time of year for winter visitors) and to offer free shuttle service from some of the major retirement communities in the area. Within a year, Be Our Guest Café was one of the major restaurant hubs in the Valley for winter visitors.

As silly as the story sounds, many social service agencies around the country make the same mistakes when designing new programs or services as James and Terri made the first time around… they rely upon the opinions of others about what will be best for families rather than getting the information from families themselves. This is especially true with system reform. Input from families needs to be one of the key centerpieces of the system design process, not just an ancillary afterthought. And this is not just true because it is the right thing to do or because we need to be respectful to families (although these are both good reasons). It is true because families have the best answers about what is needed in a system that is set up to serve them. Can you imagine any other type of business getting started without relying heavily on the input of the audience being served? If you are building toys for kids, kids are the best experts about what they like. If you are producing soft drinks to sell in Mexico, you had better cater it to the tastes and preferences of people who live there.

It is true that accountants, consultants, doctors, administrators, and others bring their expertise to social service system design, but no only families know what families want and need in the system.

What does this mean for system reform? Here are some key points:
Include family members from the population being served in every stage of planning and design. Don’t just invite them to sporadic meetings, invite them to all of them.

Families should be paid for their input and expertise at a respectable rate, not a token rate.

Avoid the trap of asking for advice and then going off and making all the decisions without families.

Provide plenty of notice for family members for critical meetings and workgroups. It is not respectful to call the day before (especially when all the others attending the meeting were notified weeks in advance).

Use the family members present as experts and turn to them for input at each stage of development (as opposed to putting them in a corner of the room and never asking for their input).

Ask the family members what they need to feel comfortable at meetings – you never know what types of things may be intimidating or unwelcoming about the way your meetings are conducted. Once you receive this input, change the way you operate so that your meetings are more family friendly.

Do not allow individuals at the meetings to be patronizing toward family members (such as emphasizing that everyone there is a parent or family member and downplaying the value of what it means to be the parent or family member of a person with special needs).

Recruit the help of family members who are representative demographically of the population being served.

Develop a policy that every meeting at your agency (or in your community) where policy, reform, or other important items are being discussed, family members will represent at least 25% of the group.

Hire people who are parents or family members of children or adults with special needs to work at your agency in various capacities.

Invite the family members who help your agency to social functions like you do for employees (we have heard of some agencies having a planning meeting where they invited several parents and then asked the parent to leave at the end so they could have the agency luncheon).

Let a family member have the first word and the last at each meeting.

If you are a major player in an agency, community, or any other element of a social service system, avoid the mistakes made by Terri and James and rely upon the input of families every step of the way.